# THE OFFICIAL PARENT'S SOURCEBOOK *on*

# CEREBRAL PALSY

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# Dedication

To the healthcare professionals dedicating their time and efforts to the study of cerebral palsy.

# Acknowledgements

The collective knowledge generated from academic and applied research summarized in various references has been critical in the creation of this sourcebook which is best viewed as a comprehensive compilation and collection of information prepared by various official agencies which directly or indirectly are dedicated to cerebral palsy. All of the *Official Parent's Sourcebooks* draw from various agencies and institutions associated with the United States Department of Health and Human Services, and in particular, the Office of the Secretary of Health and Human Services (OS), the Administration for Children and Families (ACF), the Administration on Aging (AOA), the Agency for Healthcare Research and Quality (AHRQ), the Agency for Toxic Substances and Disease Registry (ATSDR), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), the Healthcare Financing Administration (HCFA), the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), the institutions of the National Institutes of Health (NIH), the Program Support Center (PSC), and the Substance Abuse and Mental Health Services Administration (SAMHSA). In addition to these sources, information gathered from the National Library of Medicine, the United States Patent Office, the European Union, and their related organizations has been invaluable in the creation of this sourcebook. Some of the work represented was financially supported by the Research and Development Committee at INSEAD. This support is gratefully acknowledged. Finally, special thanks are owed to Tiffany LaRochelle for her excellent editorial support.

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# About ICON Health Publications

In addition to cerebral palsy, *Official Parent's Sourcebooks* are available for the following related topics:

- The Official Patient's Sourcebook on Asperger Syndrome
- The Official Patient's Sourcebook on Attention Deficit Hyperactivity Disorder
- The Official Patient's Sourcebook on Autism
- The Official Patient's Sourcebook on Dysgraphia
- The Official Patient's Sourcebook on Dyslexia
- The Official Patient's Sourcebook on Gerstmann
- The Official Patient's Sourcebook on Septo-optic Dysplasia

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# Table of Contents

# INTRODUCTION

## Overview

Dr. C. Everett Koop, former U.S. Surgeon General, once said, "The best prescription is knowledge."[1] The Agency for Healthcare Research and Quality (AHRQ) of the National Institutes of Health (NIH) echoes this view and recommends that all parents incorporate education into the treatment process. According to the AHRQ:

> Finding out more about your [child's] condition is a good place to start. By contacting groups that support your [child's] condition, visiting your local library, and searching on the Internet, you can find good information to help guide your decisions for your [child's] treatment. Some information may be hard to find—especially if you don't know where to look.[2]

As the AHRQ mentions, finding the right information is not an obvious task. Though many physicians and public officials had thought that the emergence of the Internet would do much to assist parents in obtaining reliable information, in March 2001 the National Institutes of Health issued the following warning:

> The number of Web sites offering health-related resources grows every day. Many sites provide valuable information, while others may have information that is unreliable or misleading.[3]

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[1] Quotation from http://www.drkoop.com.
[2] The Agency for Healthcare Research and Quality (AHRQ): http://www.ahcpr.gov/consumer/diaginfo.htm.
[3] From the NIH, National Cancer Institute (NCI): **http://cancertrials.nci.nih.gov/beyond/evaluating.html**.

Since the late 1990s, physicians have seen a general increase in parent Internet usage rates. Parents frequently enter their children's doctor's offices with printed Web pages of home remedies in the guise of latest medical research. This scenario is so common that doctors often spend more time dispelling misleading information than guiding children through sound therapies. *The Official Parent's Sourcebook on Cerebral Palsy* has been created for parents who have decided to make education and research an integral part of the treatment process. The pages that follow will tell you where and how to look for information covering virtually all topics related to cerebral palsy, from the essentials to the most advanced areas of research.

The title of this book includes the word "official." This reflects the fact that the sourcebook draws from public, academic, government, and peer-reviewed research. Selected readings from various agencies are reproduced to give you some of the latest official information available to date on cerebral palsy.

Given parents' increasing sophistication in using the Internet, abundant references to reliable Internet-based resources are provided throughout this sourcebook. Where possible, guidance is provided on how to obtain free-of-charge, primary research results as well as more detailed information via the Internet. E-book and electronic versions of this sourcebook are fully interactive with each of the Internet sites mentioned (clicking on a hyperlink automatically opens your browser to the site indicated). Hard copy users of this sourcebook can type cited Web addresses directly into their browsers to obtain access to the corresponding sites. Since we are working with ICON Health Publications, hard copy *Sourcebooks* are frequently updated and printed on demand to ensure that the information provided is current.

In addition to extensive references accessible via the Internet, every chapter presents a "Vocabulary Builder." Many health guides offer glossaries of technical or uncommon terms in an appendix. In editing this sourcebook, we have decided to place a smaller glossary within each chapter that covers terms used in that chapter. Given the technical nature of some chapters, you may need to revisit many sections. Building one's vocabulary of medical terms in such a gradual manner has been shown to improve the learning process.

We must emphasize that no sourcebook on cerebral palsy should affirm that a specific diagnostic procedure or treatment discussed in a research study, patent, or doctoral dissertation is "correct" or your child's best option. This sourcebook is no exception. Each child is unique. Deciding on appropriate

options is always up to parents in consultation with their children's physicians and healthcare providers.

## Organization

This sourcebook is organized into three parts. Part I explores basic techniques to researching cerebral palsy (e.g. finding guidelines on diagnosis, treatments, and prognosis), followed by a number of topics, including information on how to get in touch with organizations, associations, or other parent networks dedicated to cerebral palsy. It also gives you sources of information that can help you find a doctor in your local area specializing in treating cerebral palsy. Collectively, the material presented in Part I is a complete primer on basic research topics for cerebral palsy.

Part II moves on to advanced research dedicated to cerebral palsy. Part II is intended for those willing to invest many hours of hard work and study. It is here that we direct you to the latest scientific and applied research on cerebral palsy. When possible, contact names, links via the Internet, and summaries are provided. It is in Part II where the vocabulary process becomes important as authors publishing advanced research frequently use highly specialized language. In general, every attempt is made to recommend "free-to-use" options.

Part III provides appendices of useful background reading covering cerebral palsy or related disorders. The appendices are dedicated to more pragmatic issues facing parents. Accessing materials via medical libraries may be the only option for some parents, so a guide is provided for finding local medical libraries which are open to the public. Part III, therefore, focuses on advice that goes beyond the biological and scientific issues facing children with cerebral palsy and their families.

## Scope

While this sourcebook covers cerebral palsy, doctors, research publications, and specialists may refer to your child's condition using a variety of terms. Therefore, you should understand that cerebral palsy is often considered a synonym or a condition closely related to the following:

- Cerebral Diplegia
- Congenital Spastic Paralysis

- Congenital Static Encephalopathy
- Infantile Cerebral Paralysis
- Little Disease
- Little's Disease
- Palsy

In addition to synonyms and related conditions, physicians may refer to cerebral palsy using certain coding systems. The International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) is the most commonly used system of classification for the world's illnesses. Your physician may use this coding system as an administrative or tracking tool. The following classification is commonly used for cerebral palsy:[4]

- 343 infantile cerebral palsy
- 343.9 infantile cerebral palsy, unspecified
- 343.9 infantile cerebral palsy, unspeci-fied

For the purposes of this sourcebook, we have attempted to be as inclusive as possible, looking for official information for all of the synonyms relevant to cerebral palsy. You may find it useful to refer to synonyms when accessing databases or interacting with healthcare professionals and medical librarians.

## Moving Forward

Since the 1980s, the world has seen a proliferation of healthcare guides covering most illnesses. Some are written by parents, patients, or their family members. These generally take a layperson's approach to understanding and coping with an illness or disorder. They can be uplifting, encouraging, and highly supportive. Other guides are authored by physicians or other healthcare providers who have a more clinical outlook. Each of these two styles of guide has its purpose and can be quite useful.
As editors, we have chosen a third route. We have chosen to expose you to as many sources of official and peer-reviewed information as practical, for the purpose of educating you about basic and advanced knowledge as

[4] This list is based on the official version of the World Health Organization's 9th Revision, International Classification of Diseases (ICD-9). According to the National Technical Information Service, "ICD-9CM extensions, interpretations, modifications, addenda, or errata other than those approved by the U.S. Public Health Service and the Health Care Financing Administration are not to be considered official and should not be utilized. Continuous maintenance of the ICD-9-CM is the responsibility of the federal government."

recognized by medical science today. You can think of this sourcebook as your personal Internet age reference librarian.

Why "Internet age"? When their child has been diagnosed with cerebral palsy, parents will often log on to the Internet, type words into a search engine, and receive several Web site listings which are mostly irrelevant or redundant. Parents are left to wonder where the relevant information is, and how to obtain it. Since only the smallest fraction of information dealing with cerebral palsy is even indexed in search engines, a non-systematic approach often leads to frustration and disappointment. With this sourcebook, we hope to direct you to the information you need that you would not likely find using popular Web directories. Beyond Web listings, in many cases we will reproduce brief summaries or abstracts of available reference materials. These abstracts often contain distilled information on topics of discussion.

While we focus on the more scientific aspects of cerebral palsy, there is, of course, the emotional side to consider. Later in the sourcebook, we provide a chapter dedicated to helping you find parent groups and associations that can provide additional support beyond research produced by medical science. We hope that the choices we have made give you and your child the most options in moving forward. In this way, we wish you the best in your efforts to incorporate this educational approach into your child's treatment plan.

*The Editors*

# PART I: THE ESSENTIALS

## ABOUT PART I

Part I has been edited to give you access to what we feel are "the essentials" on cerebral palsy. The essentials typically include a definition or description of the condition, a discussion of who it affects, the signs or symptoms, tests or diagnostic procedures, and treatments for disease. Your child's doctor or healthcare provider may have already explained the essentials of cerebral palsy to you or even given you a pamphlet or brochure describing the condition. Now you are searching for more in-depth information. As editors, we have decided, nevertheless, to include a discussion on where to find essential information that can complement what the doctor has already told you. In this section we recommend a process, not a particular Web site or reference book. The process ensures that, as you search the Web, you gain background information in such a way as to maximize your understanding.

# CHAPTER 1. THE ESSENTIALS ON CEREBRAL PALSY: GUIDELINES

## Overview

Official agencies, as well as federally-funded institutions supported by national grants, frequently publish a variety of guidelines on cerebral palsy. These are typically called "Fact Sheets" or "Guidelines." They can take the form of a brochure, information kit, pamphlet, or flyer. Often they are only a few pages in length. The great advantage of guidelines over other sources is that they are often written with the parent in mind. Since new guidelines on cerebral palsy can appear at any moment and be published by a number of sources, the best approach to finding guidelines is to systematically scan the Internet-based services that post them.

### The National Institutes of Health (NIH)[5]

The National Institutes of Health (NIH) is the first place to search for relatively current guidelines and fact sheets on cerebral palsy. Originally founded in 1887, the NIH is one of the world's foremost medical research centers and the federal focal point for medical research in the United States. At any given time, the NIH supports some 35,000 research grants at universities, medical schools, and other research and training institutions, both nationally and internationally. The rosters of those who have conducted research or who have received NIH support over the years include the world's most illustrious scientists and physicians. Among them are 97 scientists who have won the Nobel Prize for achievement in medicine.

[5] Adapted from the NIH: **http://www.nih.gov/about/NIHoverview.html**.

There is no guarantee that any one Institute will have a guideline on a specific medical condition, though the National Institutes of Health collectively publish over 600 guidelines for both common and rare disorders. The best way to access NIH guidelines is via the Internet. Although the NIH is organized into many different Institutes and Offices, the following is a list of key Web sites where you are most likely to find NIH clinical guidelines and publications dealing with cerebral palsy and associated conditions:

- Office of the Director (OD); guidelines consolidated across agencies available at **http://www.nih.gov/health/consumer/conkey.htm**
- National Library of Medicine (NLM); extensive encyclopedia (A.D.A.M., Inc.) with guidelines available at **http://www.nlm.nih.gov/medlineplus/healthtopics.html**
- National Institute of Neurological Disorders and Stroke (NINDS); **http://www.ninds.nih.gov/health_and_medical/disorder_index.htm**

Among the above, the National Institute of Neurological Disorders and Stroke (NINDS) is particularly noteworthy. The mission of the NINDS is to reduce the burden of neurological disease—a burden borne by every age group, by every segment of society, by people all over the world.[6] To support this mission, the NINDS conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas. The following patient guideline was recently published by the NINDS on cerebral palsy.

## What Is Cerebral Palsy?[7]

In the 1860s, an English surgeon named William Little wrote the first medical descriptions of a puzzling disorder that struck children in the first years of life, causing stiff, spastic muscles in their legs and, to a lesser degree, their arms. These children had difficulty grasping objects, crawling, and walking. They did not get better as they grew up nor did they become worse. Their condition, which was called Little's disease for many years, is now known as spastic diplegia. It is just one of several disorders that affect

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[6] This paragraph has been adapted from the NINDS: **http://www.ninds.nih.gov/about_ninds/mission.htm**. "Adapted" signifies that a passage has been reproduced exactly or slightly edited for this book.

[7] Adapted from The National Institute of Neurological Disorders and Stroke (NINDS): **http://www.ninds.nih.gov/health_and_medical/pubs/cerebral_palsyhtr.htm**.

control of movement and are grouped together under the term cerebral palsy.

Because it seemed that many of these children were born following premature or complicated deliveries, Little suggested their condition resulted from a lack of oxygen during birth. This oxygen shortage damaged sensitive brain tissues controlling movement, he proposed. But in 1897, the famous psychiatrist Sigmund Freud disagreed. Noting that children with cerebral palsy often had other problems such as mental retardation, visual disturbances, and seizures, Freud suggested that the disorder might sometimes have roots earlier in life, during the brain's development in the womb. "Difficult birth, in certain cases," he wrote, "is merely a symptom of deeper effects that influence the development of the fetus."

Despite Freud's observation, the belief that birth complications cause most cases of cerebral palsy was widespread among physicians, families, and even medical researchers until very recently. In the 1980s, however, scientists analyzed extensive data from a government study of more than 35,000 births and were surprised to discover that such complications account for only a fraction of cases -- probably less than 10 percent. In most cases of cerebral palsy, no cause of the factors explored could be found. These findings from the NINDS perinatal study have profoundly altered medical theories about cerebral palsy and have spurred today's researchers to explore alternative causes.

At the same time, biomedical research has also led to significant changes in understanding, diagnosing, and treating persons with cerebral palsy. Risk factors not previously recognized have been identified, notably intrauterine exposure to infection and disorders of coagulation, and others are under investigation. Identification of infants with cerebral palsy very early in life gives youngsters the best opportunity to receive treatment for sensory disabilities and for prevention of contractures. Biomedical research has led to improved diagnostic techniques such as advanced brain imaging and modern gait analysis. Certain conditions known to cause cerebral palsy, such as rubella (German measles) and jaundice, can now be prevented or treated. Physical, psychological, and behavioral therapy that assist with such skills as movement and speech and foster social and emotional development can help children who have cerebral palsy to achieve and succeed. Medications, surgery, and braces can often improve nerve and muscle coordination, help treat associated medical problems, and either prevent or correct deformities.

Much of the research to improve medical understanding of cerebral palsy has been supported by the National Institute of Neurological Disorders and

Stroke (NINDS), one of the federal government's National Institutes of Health. The NINDS is America's leading supporter of biomedical research into cerebral palsy and other neurological disorders. Through this publication, the NINDS hopes to help the more than 4,500 American babies and infants diagnosed each year, their families, and others concerned about cerebral palsy benefit from these research results.

Cerebral palsy is an umbrella-like term used to describe a group of chronic disorders impairing control of movement that appear in the first few years of life and generally do not worsen over time. The term cerebral refers to the brain's two halves, or hemispheres, and palsy describes any disorder that impairs control of body movement. Thus, these disorders are not caused by problems in the muscles or nerves. Instead, faulty development or damage to motor areas in the brain disrupts the brain's ability to adequately control movement and posture.

Symptoms of cerebral palsy lie along a spectrum of varying severity. An individual with cerebral palsy may have difficulty with fine motor tasks, such as writing or cutting with scissors; experience trouble with maintaining balance and walking; or be affected by involuntary movements, such as uncontrollable writhing motion of the hands or drooling. The symptoms differ from one person to the next, and may even change over time in the individual. Some people with cerebral palsy are also affected by other medical disorders, including seizures or mental impairment. Contrary to common belief, however, cerebral palsy does not always cause profound handicap. While a child with severe cerebral palsy might be unable to walk and need extensive, lifelong care, a child with mild cerebral palsy might only be slightly awkward and require no special assistance. Cerebral palsy is not contagious nor is it usually inherited from one generation to the next. At this time, it cannot be cured, although scientific research continues to yield improved treatments and methods of prevention.

## How Many People Have This Disorder?

The United Cerebral Palsy Associations estimate that more than 500,000 Americans have cerebral palsy. Despite advances in preventing and treating certain causes of cerebral palsy, the number of children and adults it affects has remained essentially unchanged or perhaps risen slightly over the past 30 years. This is partly because more critically premature and frail infants are surviving through improved intensive care. Unfortunately, many of these infants have developmental problems of the nervous system or suffer

neurological damage. Research is under way to improve care for these infants, as in ongoing studies of technology to alleviate troubled breathing and trials of drugs to prevent bleeding in the brain before or soon after birth.

## What Are the Different Forms?

Spastic diplegia, the disorder first described by Dr. Little in the 1860s, is only one of several disorders called cerebral palsy. Today doctors classify cerebral palsy into four broad categories -- spastic, athetoid, ataxic, and mixed forms -- according to the type of movement disturbance.

### Spastic Cerebral Palsy

In this form of cerebral palsy, which affects 70 to 80 percent of patients, the muscles are stiffly and permanently contracted. Doctors will often describe which type of spastic cerebral palsy a patient has based on which limbs are affected. The names given to these types combine a Latin description of affected limbs with the term plegia or paresis, meaning paralyzed or weak. The four commonly diagnosed types of spastic cerebral palsy are illustrated in the figure.

When both legs are affected by spasticity, they may turn in and cross at the knees. As these individuals walk, their legs move awkwardly and stiffly and nearly touch at the knees. This causes a characteristic walking rhythm, known as the scissors gait.

Individuals with spastic hemiparesis may also experience hemiparetic tremors, in which uncontrollable shaking affects the limbs on one side of the body. If these tremors are severe, they can seriously impair movement.

### Athetoid or Dyskinetic Cerebral Palsy

This form of cerebral palsy is characterized by uncontrolled, slow, writhing movements. These abnormal movements usually affect the hands, feet, arms, or legs and, in some cases, the muscles of the face and tongue, causing grimacing or drooling. The movements often increase during periods of emotional stress and disappear during sleep. Patients may also have problems coordinating the muscle movements needed for speech, a condition known as dysarthria. Athetoid cerebral palsy affects about 10 to 20 percent of patients.

### Ataxic Cerebral Palsy

This rare form affects the sense of balance and depth perception. Affected persons often have poor coordination; walk unsteadily with a wide-based gait, placing their feet unusually far apart; and experience difficulty when attempting quick or precise movements, such as writing or buttoning a shirt. They may also have intention tremor. In this form of tremor, beginning a voluntary movement, such as reaching for a book, causes a trembling that affects the body part being used and that worsens as the individual gets nearer to the desired object. The ataxic form affects an estimated 5 to 10 percent of cerebral palsy patients.

Mixed forms. It is common for patients to have symptoms of more than one of the previous three forms. The most common mixed form includes spasticity and athetoid movements but other combinations are also possible.

## Medical Disorders Associated with Cerebral Palsy

Many individuals who have cerebral palsy have no associated medical disorders. However, disorders that involve the brain and impair its motor function can also cause seizures and impair an individual's intellectual development, attentiveness to the outside world, activity and behavior, and vision and hearing. Medical disorders associated with cerebral palsy include:

### Mental Impairment

About one-third of children who have cerebral palsy are mildly intellectually impaired, one-third are moderately or severely impaired, and the remaining third are intellectually normal. Mental impairment is even more common among children with spastic quadriplegia.

### Seizures or Epilepsy

As many as half of all children with cerebral palsy have seizures. During a seizure, the normal, orderly pattern of electrical activity in the brain is disrupted by uncontrolled bursts of electricity. When seizures recur without a direct trigger, such as fever, the condition is called epilepsy. In the person who has cerebral palsy and epilepsy, this disruption may be spread throughout the brain and cause varied symptoms all over the body -- as in

tonic-clonic seizures -- or may be confined to just one part of the brain and cause more specific symptoms -- as in partial seizures.

Tonic-clonic seizures generally cause patients to cry out and are followed by loss of consciousness, twitching of both legs and arms, convulsive body movements, and loss of bladder control.

Partial seizures are classified as simple or complex. In simple partial seizures, the individual has localized symptoms, such as muscle twitches, chewing movements, and numbness or tingling. In complex partial seizures, the individual may hallucinate, stagger, perform automatic and purposeless movements, or experience impaired consciousness or confusion.

### Growth Problems

A syndrome called failure to thrive is common in children with moderate-to-severe cerebral palsy, especially those with spastic quadriparesis. Failure to thrive is a general term physicians use to describe children who seem to lag behind in growth and development despite having enough food. In babies, this lag usually takes the form of too little weight gain; in young children, it can appear as abnormal shortness; in teenagers, it may appear as a combination of shortness and lack of sexual development. Failure to thrive probably has several causes, including, in particular, poor nutrition and damage to the brain centers controlling growth and development. In addition, the muscles and limbs affected by cerebral palsy tend to be smaller than normal. This is especially noticeable in some patients with spastic hemiplegia, because limbs on the affected side of the body may not grow as quickly or as large as those on the more normal side. This condition usually affects the hand and foot most severely. Since the involved foot in hemiplegia is often smaller than the unaffected foot even among patients who walk, this size difference is probably not due to lack of use. Scientists believe the problem is more likely to result from disruption of the complex process responsible for normal body growth.

### Impaired Vision or Hearing

A large number of children with cerebral palsy have strabismus, a condition in which the eyes are not aligned because of differences in the left and right eye muscles. In an adult, this condition causes double vision. In children, however, the brain often adapts to the condition by ignoring signals from one of the misaligned eyes. Untreated, this can lead to very poor vision in

one eye and can interfere with certain visual skills, such as judging distance. In some cases, physicians may recommend surgery to correct strabismus. Children with hemiparesis may have hemianopia, which is defective vision or blindness that impairs the normal field of vision of one eye. For example, when hemianopia affects the right eye, a child looking straight ahead might have perfect vision except on the far right. In homonymous hemianopia, the impairment affects the same part of the visual field of both eyes. Impaired hearing is also more frequent among those with cerebral palsy than in the general population.

### Abnormal Sensation and Perception

Some children with cerebral palsy have impaired ability to feel simple sensations like touch and pain. They may also have stereognosia, or difficulty perceiving and identifying objects using the sense of touch. A child with stereognosia, for example, would have trouble identifying a hard ball, sponge, or other object placed in his hand without looking at the object.

## What Causes Cerebral Palsy?

Cerebral palsy is not one disease with a single cause, like chicken pox or measles. It is a group of disorders with similar problems in control of movement, but probably with different causes. When physicians try to uncover the cause of cerebral palsy in an individual child, they look at the form of cerebral palsy, the mother's and child's medical history, and onset of the disorder.

In the United States, about 10 to 20 percent of children who have cerebral palsy acquire the disorder after birth. (The figures are higher in underdeveloped countries.) Acquired cerebral palsy results from brain damage in the first few months or years of life and can follow brain infections, such as bacterial meningitis or viral encephalitis, or results from head injury -- most often from a motor vehicle accident, a fall, or child abuse.

Congenital cerebral palsy, on the other hand, is present at birth, although it may not be detected for months. In most cases, the cause of congenital cerebral palsy is unknown. Thanks to research, however, scientists have pinpointed some specific events during pregnancy or around the time of birth that can damage motor centers in the developing brain. Some of these causes of congenital cerebral palsy include:

### Infections during Pregnancy

German measles, or rubella, is caused by a virus that can infect pregnant women and, therefore, the fetus in the uterus, to cause damage to the developing nervous system. Other infections that can cause brain injury in the developing fetus include cytomegalovirus and toxoplasmosis. There is relatively recent evidence that placental and perhaps other maternal infection can be associated with cerebral palsy.

### Jaundice in the Infant

Bile pigments, compounds that are normally found in small amounts in the bloodstream, are produced when blood cells are destroyed. When many blood cells are destroyed in a short time, as in the condition called Rh incompatibility (see below), the yellow-colored pigments can build up and cause jaundice. Severe, untreated jaundice can damage brain cells.

### Rh Incompatibility

In this blood condition, the mother's body produces immune cells called antibodies that destroy the fetus's blood cells, leading to a form of jaundice in the newborn.

### Oxygen Shortage to the Brain or Trauma to the Head during Labor and Delivery

The newborn infant's blood is specially equipped to compensate for low levels of oxygen, and asphyxia (lack of oxygen caused by interruption in breathing or poor oxygen supply) is common in babies during the stresses of labor and delivery. But if asphyxia severely lowers the supply of oxygen to the infant's brain for lengthy periods, the child may develop brain damage called hypoxic-ischemic encephalopathy. A significant proportion of babies with this type of brain damage die, and others may develop cerebral palsy, which is then often accompanied by mental impairment and seizures.

In the past, physicians and scientists attributed most cases of cerebral palsy to asphyxia or other complications during birth if they could not identify another cause. However, extensive research by NINDS scientists and others has shown that very few babies who experience asphyxia during birth develop encephalopathy soon after birth. Research also shows that a large

proportion of babies who experience asphyxia do not grow up to have cerebral palsy or other neurological disorders. Birth complications including asphyxia are now estimated to account for about 6 percent of congenital cerebral palsy cases.

### Stroke

Coagulation disorders in mothers or infants can produce stroke in the fetus or newborn baby. Bleeding in the brain has several causes -- including broken blood vessels in the brain, clogged blood vessels, or abnormal blood cells -- and is one form of stroke. Although strokes are better known for their effects on older adults, they can also occur in the fetus during pregnancy or the newborn around the time of birth, damaging brain tissue and causing neurological problems. Ongoing research is testing potential treatments that may one day help prevent stroke in fetuses and newborns.

## What Are the Risk Factors?

Research scientists have examined thousands of expectant mothers, followed them through childbirth, and monitored their children's early neurological development. As a result, they have uncovered certain characteristics, called risk factors, that increase the possibility that a child will later be diagnosed with cerebral palsy:

- Breech presentation. Babies with cerebral palsy are more likely to present feet first, instead of head first, at the beginning of labor.
- Complicated labor and delivery. Vascular or respiratory problems of the baby during labor and delivery may sometimes be the first sign that a baby has suffered brain damage or that a baby's brain has not developed normally. Such complications can cause permanent brain damage.
- Low Apgar score. The Apgar score (named for anesthesiologist Virginia Apgar) is a numbered rating that reflects a newborn's condition. To determine an Apgar score, doctors periodically check the baby's heart rate, breathing, muscle tone, reflexes, and skin color in the first minutes after birth. They then assign points; the higher the score, the more normal the baby's condition. A low score at 10-20 minutes after delivery is often considered an important sign of potential problems.
- Low birthweight and premature birth. The risk of cerebral palsy is higher among babies who weigh less than 2500 grams (5 lbs., 7 1/2 oz.) at birth

and among babies who are born less than 37 weeks into pregnancy. This risk increases as birthweight falls.

- Multiple births. Twins, triplets, and other multiple births are linked to an increased risk of cerebral palsy.
- Nervous system malformations. Some babies born with cerebral palsy have visible signs of nervous system malformation, such as an abnormally small head (microcephaly). This suggests that problems occurred in the development of the nervous system while the baby was in the womb.
- Maternal bleeding or severe proteinuria late in pregnancy. Vaginal bleeding during the sixth to ninth months of pregnancy and severe proteinuria (the presence of excess proteins in the urine) are linked to a higher risk of having a baby with cerebral palsy.
- Maternal hyperthyroidism, mental retardation, or seizures. Mothers with any of these conditions are slightly more likely to have a child with cerebral palsy.
- Seizures in the newborn. An infant who has seizures faces a higher risk of being diagnosed, later in childhood, with cerebral palsy.

Knowing these warning signs helps doctors keep a close eye on children who face a higher risk for long-term problems in the nervous system. However, parents should not become too alarmed if their child has one or more of these factors. Most such children do not have and do not develop cerebral palsy.

## Can Cerebral Palsy Be Prevented?

Several of the causes of cerebral palsy that have been identified through research are preventable or treatable:

- Head injury can be prevented by regular use of child safety seats when driving in a car and helmets during bicycle rides, and elimination of child abuse. In addition, common sense measures around the household -- like close supervision during bathing and keeping poisons out of reach -- can reduce the risk of accidental injury.
- Jaundice of newborn infants can be treated with phototherapy. In phototherapy, babies are exposed to special blue lights that break down bile pigments, preventing them from building up and threatening the brain. In the few cases in which this treatment is not enough, physicians can correct the condition with a special form of blood transfusion.

- Rh incompatibility is easily identified by a simple blood test routinely performed on expectant mothers and, if indicated, expectant fathers. This incompatibility in blood types does not usually cause problems during a woman's first pregnancy, since the mother's body generally does not produce the unwanted antibodies until after delivery. In most cases, a special serum given after each childbirth can prevent the unwanted production of antibodies. In unusual cases, such as when a pregnant woman develops the antibodies during her first pregnancy or antibody production is not prevented, doctors can help minimize problems by closely watching the developing baby and, when needed, performing a transfusion to the baby while in the womb or an exchange transfusion (in which a large volume of the baby's blood is removed and replaced) after birth.
- Rubella, or German measles, can be prevented if women are vaccinated against this disease before becoming pregnant.

In addition, it is always good to work toward a healthy pregnancy through regular prenatal care and good nutrition and by eliminating smoking, alcohol consumption, and drug abuse. Despite the best efforts of parents and physicians, however, children will still be born with cerebral palsy. Since in most cases the cause of cerebral palsy is unknown, little can currently be done to prevent it. As investigators learn more about the causes of cerebral palsy through basic and clinical research, doctors and parents will be better equipped to help prevent this disorder.

## What Are the Early Signs?

Early signs of cerebral palsy usually appear before 3 years of age, and parents are often the first to suspect that their infant is not developing motor skills normally. Infants with cerebral palsy are frequently slow to reach developmental milestones, such as learning to roll over, sit, crawl, smile, or walk. This is sometimes called developmental delay.

Some affected children have abnormal muscle tone. Decreased muscle tone is called hypotonia; the baby may seem flaccid and relaxed, even floppy. Increased muscle tone is called hypertonia, and the baby may seem stiff or rigid. In some cases, the baby has an early period of hypotonia that progresses to hypertonia after the first 2 to 3 months of life. Affected children may also have unusual posture or favor one side of their body.

Parents who are concerned about their baby's development for any reason should contact their physician, who can help distinguish normal variation in development from a developmental disorder.

## How Is Cerebral Palsy Diagnosed?

Doctors diagnose cerebral palsy by testing an infant's motor skills and looking carefully at the infant's medical history. In addition to checking for those symptoms described above -- slow development, abnormal muscle tone, and unusual posture -- a physician also tests the infant's reflexes and looks for early development of hand preference.

Reflexes are movements that the body makes automatically in response to a specific cue. For example, if a newborn baby is held on its back and tilted so the legs are above its head, the baby will automatically extend its arms in a gesture, called the Moro reflex, that looks like an embrace. Babies normally lose this reflex after they reach 6 months, but those with cerebral palsy may retain it for abnormally long periods. This is just one of several reflexes that a physician can check.

Doctors can also look for hand preference -- a tendency to use either the right or left hand more often. When the doctor holds an object in front and to the side of the infant, an infant with hand preference will use the favored hand to reach for the object, even when it is held closer to the opposite hand. During the first 12 months of life, babies do not usually show hand preference. But infants with spastic hemiplegia, in particular, may develop a preference much earlier, since the hand on the unaffected side of their body is stronger and more useful.

The next step in diagnosing cerebral palsy is to rule out other disorders that can cause movement problems. Most important, doctors must determine that the child's condition is not getting worse. Although its symptoms may change over time, cerebral palsy by definition is not progressive. If a child is continuously losing motor skills, the problem more likely springs from elsewhere -- including genetic diseases, muscle diseases, disorders of metabolism, or tumors in the nervous system. The child's medical history, special diagnostic tests, and, in some cases, repeated check-ups can help confirm that other disorders are not at fault.

The doctor may also order specialized tests to learn more about the possible cause of cerebral palsy. One such test is computed tomography, or CT, a

sophisticated imaging technique that uses X rays and a computer to create an anatomical picture of the brain's tissues and structures. A CT scan may reveal brain areas that are underdeveloped, abnormal cysts (sacs that are often filled with liquid) in the brain, or other physical problems. With the information from CT scans, doctors may be better equipped to judge the long-term outlook for an affected child.

Magnetic resonance imaging, or MRI, is a relatively new brain imaging technique that is rapidly gaining widespread use for identifying brain disorders. This technique uses a magnetic field and radio waves, rather than X rays. MRI gives better pictures of structures or abnormal areas located near bone than CT.

A third test that can expose problems in brain tissues is ultrasonography. This technique bounces sound waves off the brain and uses the pattern of echoes to form a picture, or sonogram, of its structures. Ultrasonography can be used in infants before the bones of the skull harden and close. Although it is less precise than CT and MRI scanning, this technique can detect cysts and structures in the brain, is less expensive, and does not require long periods of immobility.

Finally, physicians may want to look for other conditions that are linked to cerebral palsy, including seizure disorders, mental impairment, and vision or hearing problems.

When the doctor suspects a seizure disorder, an electroencephalogram, or EEG, may be ordered. An EEG uses special patches called electrodes placed on the scalp to record the natural electrical currents inside the brain. This recording can help the doctor see telltale patterns in the brain's electrical activity that suggest a seizure disorder.

Intelligence tests are often used to determine if a child with cerebral palsy is mentally impaired. Sometimes, however, a child's intelligence may be underestimated because problems with movement, sensation, or speech due to cerebral palsy make it difficult for him or her to perform well on these tests.

If problems with vision are suspected, the doctor may refer the patient to an ophthalmologist for examination; if hearing impairment seems likely, an otologist may be called in.

Identifying these accompanying conditions is important and is becoming more accurate as ongoing research yields advances that make diagnosis

easier. Many of these conditions can then be addressed through specific treatments, improving the long-term outlook for those with cerebral palsy.

## How Is Cerebral Palsy Managed?

Cerebral palsy can not be cured, but treatment can often improve a child's capabilities. In fact, progress due to medical research now means that many patients can enjoy near-normal lives if their neurological problems are properly managed. There is no standard therapy that works for all patients. Instead, the physician must work with a team of health care professionals first to identify a child's unique needs and impairments and then to create an individual treatment plan that addresses them.

Some approaches that can be included in this plan are drugs to control seizures and muscle spasms, special braces to compensate for muscle imbalance, surgery, mechanical aids to help overcome impairments, counseling for emotional and psychological needs, and physical, occupational, speech, and behavioral therapy. In general, the earlier treatment begins, the better chance a child has of overcoming developmental disabilities or learning new ways to accomplish difficult tasks.

The members of the treatment team for a child with cerebral palsy should be knowledgeable professionals with a wide range of specialties. A typical treatment team might include:

- A physician, such as a pediatrician, a pediatric neurologist, or a pediatric physiatrist, trained to help developmentally disabled children. This physician, often the leader of the treatment team, works to synthesize the professional advice of all team members into a comprehensive treatment plan, implements treatments, and follows the patient's progress over a number of years.
- An orthopedist, a surgeon who specializes in treating the bones, muscles, tendons, and other parts of the body's skeletal system. An orthopedist might be called on to predict, diagnose, or treat muscle problems associated with cerebral palsy.
- A physical therapist, who designs and implements special exercise programs to improve movement and strength.
- An occupational therapist, who can help patients learn skills for day-to-day living, school, and work.
- A speech and language pathologist, who specializes in diagnosing and treating communication problems.

- A social worker, who can help patients and their families locate community assistance and education programs.
- A psychologist, who helps patients and their families cope with the special stresses and demands of cerebral palsy. In some cases, psychologists may also oversee therapy to modify unhelpful or destructive behaviors or habits.
- An educator, who may play an especially important role when mental impairment or learning disabilities present a challenge to education.

Individuals who have cerebral palsy and their family or caregivers are also key members of the treatment team, and they should be intimately involved in all steps of planning, making decisions, and applying treatments. Studies have shown that family support and personal determination are two of the most important predictors of which individuals who have cerebral palsy will achieve long-term goals.

Too often, however, physicians and parents may focus primarily on an individual symptom -- especially the inability to walk. While mastering specific skills is an important focus of treatment on a day-to-day basis, the ultimate goal is to help individuals grow to adulthood and have maximum independence in society. In the words of one physician, "After all, the real point of walking is to get from point A to point B. Even if a child needs a wheelchair, what's important is that they're able to achieve this goal."

## What Specific Treatments Are Available?

### Physical, Behavioral, and Other Therapies

Therapy--whether for movement, speech, or practical tasks--is a cornerstone of cerebral palsy treatment. The skills a 2-year-old needs to explore the world are very different from those that a child needs in the classroom or a young adult needs to become independent. Cerebral palsy therapy should be tailored to reflect these changing demands.

Physical therapy usually begins in the first few years of life, soon after the diagnosis is made. Physical therapy programs use specific sets of exercises to work toward two important goals: preventing the weakening or deterioration of muscles that can follow lack of use (called disuse atrophy) and avoiding contracture, in which muscles become fixed in a rigid, abnormal position.

Contracture is one of the most common and serious complications of cerebral palsy. Normally, a child whose bones are growing stretches the body's muscles and tendons through running and walking and other daily activities. This ensures that muscles will grow at the same rate. But in children with cerebral palsy, spasticity prevents this stretching and, as a result, muscles do not grow fast enough to keep up with lengthening bones. The resulting contracture can disrupt balance and trigger loss of previous abilities. Physical therapy alone, or in combination with special braces (sometimes called orthotic devices), works to prevent this complication by stretching spastic muscles. For example, if a child has spastic hamstrings (tendons located behind the knee), the therapist and parents should encourage the child to sit with the legs extended to stretch them.

A third goal of some physical therapy programs is to improve the child's motor development. A widespread program of physical therapy that works toward this goal is the Bobath technique, named for a husband and wife team who pioneered this approach in England. This program is based on the idea that the primitive reflexes retained by many children with cerebral palsy present major roadblocks to learning voluntary control. A therapist using the Bobath technique tries to counteract these reflexes by positioning the child in an opposing movement. So, for example, if a child with cerebral palsy normally keeps his arm flexed, the therapist would repeatedly extend it.

A second such approach to physical therapy is "patterning," which is based on the principle that motor skills should be taught in more or less the same sequence that they develop normally. In this controversial approach, the therapist guides the child with movement problems along the path of normal motor development. For example, the child is first taught elementary movements like pulling himself to a standing position and crawling before he is taught to walk -- regardless of his age. Some experts and organizations, including the American Academy of Pediatrics, have expressed strong reservations about the patterning approach, because studies have not documented its value.

Physical therapy is usually just one element of an infant development program that also includes efforts to provide a varied and stimulating environment. Like all children, the child with cerebral palsy needs new experiences and interactions with the world around him in order to learn. Stimulation programs can bring this valuable experience to the child who is physically unable to explore.

As the child with cerebral palsy approaches school age, the emphasis of therapy shifts away from early motor development. Efforts now focus on preparing the child for the classroom, helping the child master activities of daily living, and maximizing the child's ability to communicate.

Physical therapy can now help the child with cerebral palsy prepare for the classroom by improving his or her ability to sit, move independently or in a wheelchair, or perform precise tasks, such as writing. In occupational therapy, the therapist works with the child to develop such skills as feeding, dressing, or using the bathroom. This can help reduce demands on caregivers and boost self-reliance and self-esteem. For the many children who have difficulty communicating, speech therapy works to identify specific difficulties and overcome them through a program of exercises. For example, if a child has difficulty saying words that begin with "b," the therapist may suggest daily practice with a list of "b" words, increasing their difficulty as each list is mastered. Speech therapy can also work to help the child learn to use special communication devices, such as a computer with voice synthesizers.

Behavioral therapy provides yet another avenue to increase a child's abilities. This therapy, which uses psychological theory and techniques, can complement physical, speech, or occupational therapy. For example, behavioral therapy might include hiding a toy inside a box to reward a child for learning to reach into the box with his weaker hand. Likewise, a child learning to say his "b" words might be given a balloon for mastering the word. In other cases, therapists may try to discourage unhelpful or destructive behaviors, such as hair-pulling or biting, by selectively presenting a child with rewards and praise during other, more positive activities.

As a child with cerebral palsy grows older, the need for and types of therapy and other support services will continue to change. Continuing physical therapy addresses movement problems and is supplemented by vocational training, recreation and leisure programs, and special education when necessary. Counseling for emotional and psychological challenges may be needed at any age, but is often most critical during adolescence. Depending on their physical and intellectual abilities, adults may need attendant care, living accommodations, transportation, or employment opportunities.

Regardless of the patient's age and which forms of therapy are used, treatment does not end when the patient leaves the office or treatment center. In fact, most of the work is often done at home. The therapist functions as a coach, providing parents and patients with the strategy and

drills that can help improve performance at home, at school, and in the world. As research continues, doctors and parents can expect new forms of therapy and better information about which forms of therapy are most effective for individuals with cerebral palsy.

### Drug Therapy

Physicians usually prescribe drugs for those who have seizures associated with cerebral palsy, and these medications are very effective in preventing seizures in many patients. In general, the drugs given to individual patients are chosen based on the type of seizures, since no one drug controls all types. However, different people with the same type of seizure may do better on different drugs, and some individuals may need a combination of two or more drugs to achieve good seizure control.

Drugs are also sometimes used to control spasticity, particularly following surgery. The three medications that are used most often are diazepam, which acts as a general relaxant of the brain and body; baclofen, which blocks signals sent from the spinal cord to contract the muscles; and dantrolene, which interferes with the process of muscle contraction. Given by mouth, these drugs can reduce spasticity for short periods, but their value for long-term control of spasticity has not been clearly demonstrated. They may also trigger significant side effects, such as drowsiness, and their long-term effects on the developing nervous system are largely unknown. One possible solution to avoid such side effects may lie in current research to explore new routes for delivering these drugs.

Patients with athetoid cerebral palsy may sometimes be given drugs that help reduce abnormal movements. Most often, the prescribed drug belongs to a group of chemicals called anticholinergics that work by reducing the activity of acetylcholine. Acetylcholine is a chemical messenger that helps some brain cells communicate and that triggers muscle contraction. Anticholinergic drugs include trihexyphenidyl, benztropine, and procyclidine hydrochloride.

Occasionally, physicians may use alcohol “washes” -- or injections of alcohol into a muscle -- to reduce spasticity for a short period. This technique is most often used when physicians want to correct a developing contracture. Injecting alcohol into a muscle that is too short weakens the muscle for several weeks and gives physicians time to work on lengthening the muscle through bracing, therapy, or casts. In some cases, if the contracture is detected early enough, this technique may avert the need for surgery.

## Surgery

Surgery is often recommended when contractures are severe enough to cause movement problems. In the operating room, surgeons can lengthen muscles and tendons that are proportionately too short. First, however, they must determine the exact muscles at fault, since lengthening the wrong muscle could make the problem worse.

Finding problem muscles that need correction can be a difficult task. To walk two strides with a normal gait, it takes more than 30 major muscles working at exactly the right time and exactly the right force. A problem in any one muscle can cause abnormal gait. Furthermore, the natural adjustments the body makes to compensate for muscle problems can be misleading. A new tool that enables doctors to spot gait abnormalities, pinpoint problem muscles, and separate real problems from compensation is called gait analysis. Gait analysis combines cameras that record the patient while walking, computers that analyze each portion of the patient's gait, force plates that detect when feet touch the ground, and a special recording technique that detects muscle activity (known as electromyography). Using these data, doctors are better equipped to intervene and correct significant problems. They can also use gait analysis to check surgical results.

Because lengthening a muscle makes it weaker, surgery for contractures is usually followed by months of recovery. For this reason, doctors try to fix all of the affected muscles at once when it is possible or, if more than one surgical procedure is unavoidable, they may try to schedule operations close together.

A second surgical technique, known as selective dorsal root rhizotomy, aims to reduce spasticity in the legs by reducing the amount of stimulation that reaches leg muscles via nerves. In the procedure, doctors try to locate and selectively sever overactivated nerves controlling leg muscles. Although there is scientific controversy over how selective this technique actually is, recent research results suggest it can reduce spasticity in some patients, particularly those who have spastic diplegia. Ongoing research is evaluating this surgery's effectiveness.

Experimental surgical techniques include chronic cerebellar stimulation and stereotaxic thalamotomy. In chronic cerebellar stimulation, electrodes are implanted on the surface of the cerebellum -- the part of the brain responsible for coordinating movement -- and are used to stimulate certain cerebellar nerves. While it was hoped that this technique would decrease spasticity and improve motor function, results of this invasive procedure

have been mixed. Some studies have reported improvements in spasticity and function, others have not.

Stereotaxic thalamotomy involves precise cutting of parts of the thalamus, which serves as the brain's relay station for messages from the muscles and sensory organs. This has been shown effective only for reducing hemiparetic tremors (see glossary).

### Mechanical aids

Whether they are as humble as velcro shoes or as advanced as computerized communication devices, special machines and gadgets in the home, school, and workplace can help the child or adult with cerebral palsy overcome limitations.

The computer is probably the most dramatic example of a new device that can make a difference in the lives of those with cerebral palsy. For example, a child who is unable to speak or write but can make head movements may be able to learn to control a computer using a special light pointer that attaches to a headband. Equipped with a computer and voice synthesizer, this child could communicate with others. In other cases, technology has led to new versions of old devices, such as the traditional wheelchair and its modern offspring that runs on electricity.

Many such devices are products of engineering research supported by private foundations and other groups.

## What Other Major Problems Are Associated with Cerebral Palsy?

Poor control of the muscles of the throat, mouth and tongue sometimes leads to drooling. Drooling can cause severe skin irritation and, because it is socially unacceptable, can lead to further isolation of affected children from their peers. Although numerous treatments for drooling have been tested over the years, there is no one treatment that always helps. Drugs called anticholinergics can reduce the flow of saliva but may cause significant side effects, such as mouth dryness and poor digestion. Surgery, while sometimes effective, carries the risk of complications, including worsening of swallowing problems. Some patients benefit from a technique called biofeedback that can tell them when they are drooling or having difficulty

controlling muscles that close the mouth. This kind of therapy is most likely to work if the patient has a mental age of more than 2 or 3 years, is motivated to control drooling, and understands that drooling is not socially acceptable.

Difficulty with eating and swallowing -- also triggered by motor problems in the mouth -- can cause poor nutrition. Poor nutrition, in turn, may make the individual more vulnerable to infections and cause or aggravate "failure to thrive" -- a lag in growth and development that is common among those with cerebral palsy. To make swallowing easier, the caregiver may want to prepare semisolid food, such as strained vegetables and fruits. Proper position, such as sitting up while eating or drinking and extending the individual's neck away from the body to reduce the risk of choking, is also helpful. In severe cases of swallowing problems and malnutrition, physicians may recommend tube feeding, in which a tube delivers food and nutrients down the throat and into the stomach, or gastrostomy, in which a surgical opening allows a tube to be placed directly into the stomach.

A common complication is incontinence, caused by faulty control over the muscles that keep the bladder closed. Incontinence can take the form of bed-wetting (also known as enuresis), uncontrolled urination during physical activities (or stress incontinence), or slow leaking of urine from the bladder. Possible medical treatments for incontinence include special exercises, biofeedback, prescription drugs, surgery, or surgically implanted devices to replace or aid muscles. Specially designed undergarments are also available.

## What Research Is Being Done?

Investigators from many arenas of medicine and health are using their expertise to help improve treatment and prevention of cerebral palsy. Much of their work is supported through the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Child Health and Human Development, other agencies within the Federal Government, nonprofit groups such as the United Cerebral Palsy Research Foundation, and private institutions.

The ultimate hope for overcoming cerebral palsy lies with prevention. In order to prevent cerebral palsy, however, scientists must first understand the complex process of normal brain development and what can make this process go awry.

Between early pregnancy and the first months of life, one cell divides to form first a handful of cells, and then hundreds, millions, and, eventually, billions of cells. Some of these cells specialize to become brain cells. These brain cells specialize into different types and migrate to their appropriate site in the brain. They send out branches to form crucial connections with other brain cells. Ultimately, the most complex entity known to us is created: a human brain with its billions of interconnected neurons.

Mounting evidence is pointing investigators toward this intricate process in the womb for clues about cerebral palsy. For example, a group of researchers has recently observed that more than one-third of children who have cerebral palsy also have missing enamel on certain teeth. This tooth defect can be traced to problems in the early months of fetal development, suggesting that a disruption at this period in development might be linked both to this tooth defect and to cerebral palsy.

As a result of this and other research, many scientists now believe that a significant number of children develop cerebral palsy because of mishaps early in brain development. They are examining how brain cells specialize, how they know where to migrate, how they form the right connections -- and they are looking for preventable factors that can disrupt this process before or after birth.

Scientists are also scrutinizing other events -- such as bleeding in the brain, seizures, and breathing and circulation problems -- that threaten the brain of the newborn baby. Through this research, they hope to learn how these hazards can damage the newborn's brain and to develop new methods for prevention.

Some newborn infants, for example, have life-threatening problems with breathing and blood circulation. A recently introduced treatment to help these infants is extracorporeal membrane oxygenation, in which blood is routed from the patient to a special machine that takes over the lungs' task of removing carbon dioxide and adding oxygen. Although this technique can dramatically help many such infants, some scientists have observed that a substantial fraction of treated children later experience long-term neurological problems, including developmental delay and cerebral palsy. Investigators are studying infants through pregnancy, delivery, birth, and infancy, and are tracking those who undergo this treatment. By observing them at all stages of development, scientists can learn whether their problems developed before birth, result from the same breathing problems that made them candidates for the treatment, or spring from errors in the treatment itself. Once this is determined, they may be able to correct any

existing problems or develop new treatment methods to prevent brain damage.

Other scientists are exploring how brain insults like hypoxic-ischemic encephalopathy (brain damage from a shortage of oxygen or blood flow), bleeding in the brain, and seizures can cause the abnormal release of brain chemicals and trigger brain damage. For example, research has shown that bleeding in the brain unleashes dangerously high amounts of a brain chemical called glutamate. While glutamate is normally used in the brain for communication, too much glutamate overstimulates the brain's cells and causes a cycle of destruction. Scientists are now looking closely at glutamate to detect how its release harms brain tissue and spreads the damage from stroke. By learning how such brain chemicals that normally help us function can hurt the brain, scientists may be equipped to develop new drugs that block their harmful effects.

In related research, some investigators are already conducting studies to learn if certain drugs can help prevent neonatal stroke. Several of these drugs seem promising because they appear to reduce the excess production of potentially dangerous chemicals in the brain and may help control brain blood flow and volume. Earlier research has linked sudden changes in blood flow and volume to stroke in the newborn.

Low birthweight itself is also the subject of extensive research. In spite of improvements in health care for some pregnant women, the incidence of low birth-weight babies born each year in the United States remains at about 7 1/2 percent. Some scientists currently investigating this serious health problem are working to understand how infections, hormonal problems, and genetic factors may increase a woman's chances of giving birth prematurely. They are also conducting more applied research that could yield: 1) new drugs that can safely delay labor, 2) new devices to further improve medical care for premature infants, and 3) new insight into how smoking and alcohol consumption can disrupt fetal development.

While this research offers hope for preventing cerebral palsy in the future, ongoing research to improve treatment brightens the outlook for those who must face the challenges of cerebral palsy today. An important thrust of such research is the evaluation of treatments already in use so that physicians and parents have the information they need to choose the best therapy. A good example of this effort is an ongoing NINDS-supported study that promises to yield new information about which patients are most likely to benefit from selective dorsal root rhizotomy, a recently introduced surgery that is becoming increasingly in demand for reduction of spasticity.

Similarly, although physical therapy programs are a popular and widespread approach to managing cerebral palsy, little scientific evidence exists to help physicians, other health professionals, and parents determine how well physical therapy works or to choose the best approach among many. Current research on cerebral palsy aims to provide this information through careful studies that compare the abilities of children who have had physical and other therapy with those who have not.

As part of this effort, scientists are working to create new measures to judge the effectiveness of treatment, as in ongoing research to precisely identify the specific brain areas responsible for movement may yield one such approach. Using magnetic pulses, researchers can locate brain areas that control specific actions, such as raising an arm or lifting a leg, and construct detailed maps. By comparing charts made before and after therapy among children who have cerebral palsy, researchers may gain new insights into how therapy affects the brain's organization and new data about its effectiveness.

Investigators are also working to develop new drugs -- and new ways of using existing drugs -- to help relieve cerebral palsy's symptoms. In one such set of studies, early research results suggest that doctors may improve the effectiveness of the anti-spasticity drug called baclofen by giving the drug through spinal injections, rather than by mouth. In addition, scientists are also exploring the use of tiny implanted pumps that deliver a constant supply of anti-spasticity drugs into the fluid around the spinal cord, in the hope of improving these drugs' effectiveness and reducing side effects, such as drowsiness.

Other experimental drug development efforts are exploring the use of minute amounts of the familiar toxin called botulinum. Ingested in large amounts, this toxin is responsible for botulism poisoning, in which the body's muscles become paralyzed. Injected in tiny amounts, however, this toxin has shown early promise in reducing spasticity in specific muscles.

A large research effort is also directed at producing more effective, nontoxic drugs to control seizures. Through its Antiepileptic Drug Development Program, the NINDS screens new compounds developed by industrial and university laboratories around the world for toxicity and anticonvulsant activity and coordinates clinical studies of efficacy and safety. To date, this program has screened more than 13,000 compounds and, as a result, five new antiepileptic drugs -- carbamazepine, clonazepam, valproate, clorazepate, and felbamate -- have been approved for marketing. A new project within the program is exploring how the structure of a given antiseizure medication relates to its effectiveness. If successful, this project

may enable scientists to design better antiseizure medications more quickly and cheaply.

As researchers continue to explore new treatments for cerebral palsy and to expand our knowledge of brain development, we can expect significant medical advances to prevent cerebral palsy and many other disorders that strike in early life.

## Research Update: June 2000

### Magnesium Sulfate and Decreased Risk of Cerebral Palsy

Research conducted and supported by the National Institute of Neurological Disorders and Stroke (NINDS) continuously seeks to uncover new clues about cerebral palsy (CP). Investigators from the NINDS and the California Birth Defects Monitoring Program (CBDMP) presented data suggesting that very low birthweight babies have a decreased incidence of CP when their mothers are treated with magnesium sulfate soon before giving birth. The results of this study, which were based on observations of a group of children born in four Northern California counties, were published in the February 1995 issue of Pediatrics.[8]

Low birthweight babies are 100 times more likely to develop CP than normal birthweight infants. If further research confirms the study's findings, use of magnesium sulfate may prevent 25 percent of the cases of CP in the approximately 52,000 low birthweight babies born each year in the United States.

Magnesium is a natural compound that is responsible for numerous chemical processes within the body and brain. Obstetricians in the United States often administer magnesium sulfate, an inexpensive form of the compound, to pregnant women to prevent preterm labor and high blood pressure brought on by pregnancy. The drug, administered intravenously in the hospital, is considered safe when given under medical supervision.

Scientists speculate that magnesium may play a role in brain development and possibly prevent bleeding inside the brains of preterm infants. Previous research has shown that magnesium may protect against brain bleeding in

[8] Nelson KB, and Grether JK. Can magnesium sulfate reduce the risk of cerebral palsy in very low birthweight infants? Pediatrics, February 1995, vol. 95, no. 2, page 263.

very premature infants. Animal studies have demonstrated that magnesium given after a traumatic brain injury can reduce the severity of brain damage.

Despite these encouraging research findings, pregnant women should not change their magnesium intake because the effects of high doses have not yet been studied and the possible risks and benefits are not known.

Researchers caution that more research will be required to establish a definitive relationship between the drug and prevention of the disorder. Clinical trials now underway, one of them a collaboration between the NINDS and the National Institute of Child Health and Human Development, are evaluating magnesium for the prevention of cerebral palsy in prematurely born babies.

## Where Can I Find More Information?

The NINDS is the Federal Government's leading supporter of biomedical research on brain and nervous system disorders, including cerebral palsy. The NINDS conducts research in its own laboratories at the National Institutes of Health in Bethesda, MD, and supports research at institutions worldwide. The Institute also sponsors an active public information program. Other NINDS publications that may be of interest to those concerned about cerebral palsy include "Seizures and Epilepsy: Hope Through Research" and "The Dystonias." The Institute's address and phone number, as well as information on other organizations that offer various services to those affected by cerebral palsy, are provided in the information resources section at the end of this brochure.

### Information Resources

For information on other neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

**BRAIN**
P.O. Box 5801
Bethesda, MD 20824
800-352-9424
**www.ninds.nih.gov**

In addition, a number of private organizations offer a variety of services and information that can help those affected by cerebral palsy. They include:

**Epilepsy Foundation**
4351 Garden City Drive, Suite 500
Landover, MD 20785-2267
301-459-3700
800-EFA-1000 (332-1000)
301-577-2684 (fax)
postmaster@efa.org
**www.epilepsyfoundation.org**
This foundation sponsors programs for patient and public education, legal and government affairs, and employment training and placement. The foundation also supports research, maintains the National Epilepsy Library (800-EFA-4050), publishes a variety of patient/family and professional education materials, and sponsors affiliates.

**March of Dimes Birth Defects Foundation**
1275 Mamaroneck Avenue
White Plains, NY 10605
914-428-7100
888-MODIMES (663-4637)
914-428-8203 (fax)
resourcecenter@modimes.org
**www.modimes.org**
This foundation funds research, medical services, public education, and genetic counseling. Resources include fact sheets, brochures, educational kits, and audiovisual materials.

**National Easter Seal Society/Easter Seals**
230 West Monroe Street
Suite 1800
Chicago, IL 60606-4802
312-726-6200
800-221-6827
312-726-1494 (fax)
info@easterseals.org
**www.easter-seals.org**
This organization includes state and local affiliates and operates facilities and programs across the country. They offer a range of rehabilitation services, research and public education programs, and assistive technology services. Their programs also include therapy, counseling, training, social clubs, camping, transportation, and referrals. In addition,

the society sponsors a grants program for research on disabling conditions and rehabilitation, provides low-cost booklets and pamphlets to the public, and publishes a bimonthly journal.

**United Cerebral Palsy Associations, Inc. and**
The United Cerebral Palsy Research and Educational Foundation
1660 L Street, NW, Suite 700
Washington, DC 20036
202-776-0406
800-USA-5UCP (872-5827)
202-776-0414 (fax)
webmaster@ucp.org
**www.ucpa.org**
This coalition of associations provide family support, legislative advocacy, public information and education, and training, specifically for issues of importance to those who have cerebral palsy. It also publishes newsletters and various brochures and pamphlets. The UCP Research and Educational Foundation supports research to prevent cerebral palsy and develop therapies to improve the quality of life for those affected by this disorder.

**Children's Hemiplegia and Stroke Association (CHASA)**
4101 West Green Oaks Blvd.
PMB #149
Arlington, TX 76016
817-492-4325
info@chasa.org
**www.hemikids.org**

## More Guideline Sources

The guideline above on cerebral palsy is only one example of the kind of material that you can find online and free of charge. The remainder of this chapter will direct you to other sources which either publish or can help you find additional guidelines on topics related to cerebral palsy. Many of the guidelines listed below address topics that may be of particular relevance to your child's specific situation, while certain guidelines will apply to only some children with cerebral palsy. Due to space limitations these sources are listed in a concise manner. Do not hesitate to consult the following sources by either using the Internet hyperlink provided, or, in cases where the contact information is provided, contacting the publisher or author directly.

### Topic Pages: MEDLINEplus

For parents wishing to go beyond guidelines published by specific Institutes of the NIH, the National Library of Medicine has created a vast and parent-oriented healthcare information portal called MEDLINEplus. Within this Internet-based system are "health topic pages." You can think of a health topic page as a guide to patient guides. To access this system, log on to **http://www.nlm.nih.gov/medlineplus/healthtopics.html**. From there you can either search using the alphabetical index or browse by broad topic areas.

If you do not find topics of interest when browsing health topic pages, then you can choose to use the advanced search utility of MEDLINEplus at **http://www.nlm.nih.gov/medlineplus/advancedsearch.html**. This utility is similar to the NIH Search Utility, with the exception that it only includes material linked within the MEDLINEplus system (mostly parent-oriented information). It also has the disadvantage of generating unstructured results. We recommend, therefore, that you use this method only if you have a very targeted search.

### The Combined Health Information Database (CHID)

CHID Online is a reference tool that maintains a database directory of thousands of journal articles and educational guidelines on cerebral palsy and related conditions. One of the advantages of CHID over other sources is that it offers summaries that describe the guidelines available, including contact information and pricing. CHID's general Web site is **http://chid.nih.gov/**. To search this database, go to **http://chid.nih.gov/detail/detail.html**. In particular, you can use the advanced search options to look up pamphlets, reports, brochures, and information kits. The following was recently posted in this archive:

- **About Cerebral Palsy**

  Source: South Deerfield, MA: Channing L. Bete Company, Inc. 1997. 16 p.

  Contact: Available from Channing L. Bete Company, Inc. 200 State Road, South Deerfield, MA 01373-0200. (800) 628-7733; Fax (800) 499-6464; http://www.channing.bete.com. Price: $1.25 each for 1-24 copies; bulk rates available. Item Number 39503A-5-96.

  Summary: This booklet describes cerebral palsy, a group of brain disorders that affects movement. Cerebral palsy (CP) results from brain damage that occurs before, during, or shortly after birth. CP affects

muscle tone and coordination and can be mild or severe. This booklet describes the challenges faced by a person with CP, including physical, mental, and social challenges. The booklet reviews the causes and effects of CP; other conditions that often appear with CP; diagnostic considerations; classification of the types of CP (spastic, athetoid, ataxic, and mixed); therapy for CP (physical, occupational, speech and language); other methods for managing CP (orthotic devices, medications, surgery); use of specialized equipment for communication, learning, mobility, and daily living; special programs for people with CP, including early intervention programs, special education, and school-age programs; and legislation that regulates these special programs. The booklet concludes with a brief section of the answers to questions commonly asked by parents of a child recently diagnosed with CP. The toll-free telephone numbers of three resource organizations are also provided. The booklet is illustrated with simple line drawings of families and children in a variety of everyday settings; simple anatomical drawings are included in the sections about the physiology of CP.

- **Cerebral palsy: Guidelines for care for children with special health care needs**

  Source: Minneapolis, MN: Services for Children with Handicaps, Minnesota Department of Health. 1993. 52 pp.

  Contact: Available from Minnesota Children with Special Health Care Needs, 717 Delaware Street, S.E., Box 9441, Minneapolis, MN 55440. Telephone: (612) 623-5150 or (800) 728-5420. Available at no charge.

  Summary: This publication was developed for families and health professionals caring for children with cerebral palsy. The guidelines are aimed at helping families coordinate the health care needed for the optimal growth and development of their child. General information concerning cerebral palsy is provided along with an overview of the family-centered health care team approach to treating a child or adolescent with this condition. The publication also outlines the child's needs at various stages of his or her life in terms of health care, development, school, and child care. A glossary and list of resources are also included.

- **Phelps Cerebral Palsy Treatment Center**

  Source: Baltimore, MD: Kennedy Krieger Institute. [6 p.].

  Contact: Available from Kennedy Krieger Institute. 707 North Broadway, Baltimore, MD 21205. (800) 873-3377 or (410) 550-9000; FAX (410) 550-9498; TTY (410) 550-9806. Price: Free.

Summary: This brochure describes the services offered by the Phelps Cerebral Palsy Treatment Center. Specialized programs are discussed in the areas of developmental pediatrics, pediatric orthopedics, rhizotomy, physical therapy, occupational therapy, orthotics, assistive technology, communication sciences, and gastroenterology and nutrition.

### The National Guideline Clearinghouse™

The National Guideline Clearinghouse™ offers hundreds of evidence-based clinical practice guidelines published in the United States and other countries. You can search their site located at **http://www.guideline.gov** by using the keyword "cerebral palsy" or synonyms.

### Healthfinder™

Healthfinder™ is an additional source sponsored by the U.S. Department of Health and Human Services which offers links to hundreds of other sites that contain healthcare information. This Web site is located at **http://www.healthfinder.gov**. Again, keyword searches can be used to find guidelines. The following was recently found in this database:

- **Cerebral Palsy**

  Summary: This fact sheet defines cerebral palsy and discusses is incidence, symptoms, characteristics, diagnosis, and treatment.

  Source: National Information Center for Children and Youth with Disabilities, U.S. Department of Education

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=3406

- **Cerebral Palsy Among Children**

  Summary: This online brochure presents a synopsis of CP-related surveillance and research activities.

  Source: Office on Disability and Health, National Center on Birth Defects and Developmental Disabilities

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=4850

- **Cerebral Palsy Information**

  Summary: A general overview of cerebral palsy that includes a description and information about treatment, prognosis and research.

  Source: National Institute of Neurological Disorders and Stroke, National Institutes of Health

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=2078

- **Cerebral Palsy Risks and Pregnancy**

  Summary: This brochure describes the National Institute of Neurological Disorders and Stroke's (NINDS) conduct and support of research aimed at preventing CP.

  Source: National Institutes of Health, U.S. Department of Health and Human Services

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=4851

- **Cerebral Palsy: Advocacy in Action**

  Summary: Visit this site if you will like information on how to make a difference in the lives of people with disabilities but are not quite sure how to go about it.

  Source: United Cerebral Palsy Associations

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=2431

- **Cerebral Palsy: Hope Through Research**

  Summary: This NINDS page describes the causes, risk factors, signs, diagnosis, management, and treatment of cerebral palsy. A glossary and information resources are included.

  Source: National Institute of Neurological Disorders and Stroke, National Institutes of Health

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=6332

- **When Your Child Has Cerebral Palsy**

  Summary: Information and guidance for parents of children with cerebral palsy.

  Source: Nemours Foundation

  http://www.healthfinder.gov/scripts/recordpass.asp?RecordType=0&RecordID=4853

### The NIH Search Utility

After browsing the references listed at the beginning of this chapter, you may want to explore the NIH Search Utility. This allows you to search for documents on over 100 selected Web sites that comprise the NIH-WEB-SPACE. Each of these servers is "crawled" and indexed on an ongoing basis. Your search will produce a list of various documents, all of which will relate in some way to cerebral palsy. The drawbacks of this approach are that the information is not organized by theme and that the references are often a mix of information for professionals and parents. Nevertheless, a large number of the listed Web sites provide useful background information. We can only recommend this route, therefore, for relatively rare or specific disorders, or when using highly targeted searches. To use the NIH search utility, visit the following Web page: **http://search.nih.gov/index.html**.

### Additional Web Sources

A number of Web sites that often link to government sites are available to the public. These can also point you in the direction of essential information. The following is a representative sample:

- AOL: **http://search.aol.com/cat.adp?id=168&layer=&from=subcats**
- drkoop.com®: **http://www.drkoop.com/conditions/ency/index.html**
- Family Village: **http://www.familyvillage.wisc.edu/specific.htm**
- Google: **http://directory.google.com/Top/Health/Conditions_and_Diseases/**
- Med Help International: **http://www.medhelp.org/HealthTopics/A.html**
- Open Directory Project: **http://dmoz.org/Health/Conditions_and_Diseases/**
- Yahoo.com: **http://dir.yahoo.com/Health/Diseases_and_Conditions/**
- WebMD®Health: **http://my.webmd.com/health_topics**

## Vocabulary Builder

The material in this chapter may have contained a number of unfamiliar words. The following Vocabulary Builder introduces you to terms used in this chapter that have not been covered in the previous chapter:

**Accommodation:** Adjustment, especially that of the eye for various distances. [EU]

**Acetylcholine:** A neurotransmitter. Acetylcholine in vertebrates is the major transmitter at neuromuscular junctions, autonomic ganglia, parasympathetic effector junctions, a subset of sympathetic effector junctions, and at many sites in the central nervous system. It is generally not used as an administered drug because it is broken down very rapidly by cholinesterases, but it is useful in some ophthalmological applications. [NIH]

**Adolescence:** The period of life beginning with the appearance of secondary sex characteristics and terminating with the cessation of somatic growth. The years usually referred to as adolescence lie between 13 and 18 years of age. [NIH]

**Anatomical:** Pertaining to anatomy, or to the structure of the organism. [EU]

**Antibody:** An immunoglobulin molecule that has a specific amino acid sequence by virtue of which it interacts only with the antigen that induced its synthesis in cells of the lymphoid series (especially plasma cells), or with antigen closely related to it. Antibodies are classified according to their ode of action as agglutinins, bacteriolysins, haemolysins, opsonins, precipitins, etc. [EU]

**Anticholinergic:** An agent that blocks the parasympathetic nerves. Called also parasympatholytic. [EU]

**Anticonvulsant:** An agent that prevents or relieves convulsions. [EU]

**Antiepileptic:** An agent that combats epilepsy. [EU]

**Asphyxia:** A pathological condition caused by lack of oxygen, manifested in impending or actual cessation of life. [NIH]

**Atrophy:** A wasting away; a diminution in the size of a cell, tissue, organ, or part. [EU]

**Benztropine:** A centrally active muscarinic antagonist that has been used in the symptomatic treatment of parkinson disease. Benztropine also inhibits the uptake of dopamine. [NIH]

**Bile:** An emulsifying agent produced in the liver and secreted into the duodenum. Its composition includes bile acids and salts, cholesterol, and electrolytes. It aids digestion of fats in the duodenum. [NIH]

**Carbamazepine:** An anticonvulsant used to control grand mal and psychomotor or focal seizures. Its mode of action is not fully understood, but some of its actions resemble those of phenytoin; although there is little chemical resemblance between the two compounds, their three-dimensional structure is similar. [NIH]

**Carcinoma:** A malignant new growth made up of epithelial cells tending to infiltrate the surrounding tissues and give rise to metastases. [EU]

**Cardiotocography:** Monitoring of fetal heart frequency before birth in order to assess impending prematurity in relation to the pattern or intensity of antepartum uterine contraction. [NIH]

**Cerebellar:** Pertaining to the cerebellum. [EU]

**Cerebellum:** Part of the metencephalon that lies in the posterior cranial fossa behind the brain stem. It is concerned with the coordination of movement. [NIH]

**Cerebral:** Of or pertaining of the cerebrum or the brain. [EU]

**Chronic:** Persisting over a long period of time. [EU]

**Clonazepam:** An anticonvulsant used for several types of seizures, including myotonic or atonic seizures, photosensitive epilepsy, and absence seizures, although tolerance may develop. It is seldom effective in generalized tonic-clonic or partial seizures. The mechanism of action appears to involve the enhancement of gaba receptor responses. [NIH]

**Clonic:** Pertaining to or of the nature of clonus. [EU]

**Coagulation:** 1. the process of clot formation. 2. in colloid chemistry, the solidification of a sol into a gelatinous mass; an alteration of a disperse phase or of a dissolved solid which causes the separation of the system into a liquid phase and an insoluble mass called the clot or curd. Coagulation is usually irreversible. 3. in surgery, the disruption of tissue by physical means to form an amorphous residuum, as in electrocoagulation and photocoagulation. [EU]

**Confusion:** Disturbed orientation in regard to time, place, or person, sometimes accompanied by disordered consciousness. [EU]

**Consciousness:** Sense of awareness of self and of the environment. [NIH]

**Contracture:** A condition of fixed high resistance to passive stretch of a muscle, resulting from fibrosis of the tissues supporting the muscles or the joints, or from disorders of the muscle fibres. [EU]

**Cyst:** Any closed cavity or sac; normal or abnormal, lined by epithelium, and especially one that contains a liquid or semisolid material. [EU]

**Cytomegalovirus:** A genus of the family herpesviridae, subfamily betaherpesvirinae, infecting the salivary glands, liver, spleen, lungs, eyes, and other organs, in which they produce characteristically enlarged cells

with intranuclear inclusions. Infection with Cytomegalovirus is also seen as an opportunistic infection in AIDS. [NIH]

**Dantrolene:** Skeletal muscle relaxant that acts by interfering with excitation-contraction coupling in the muscle fiber. It is used in spasticity and other neuromuscular abnormalities. Although the mechanism of action is probably not central, dantrolene is usually grouped with the central muscle relaxants. [NIH]

**Digestion:** The process of breakdown of food for metabolism and use by the body. [NIH]

**Dorsal:** 1. pertaining to the back or to any dorsum. 2. denoting a position more toward the back surface than some other object of reference; same as posterior in human anatomy; superior in the anatomy of quadrupeds. [EU]

**Dysarthria:** Imperfect articulation of speech due to disturbances of muscular control which result from damage to the central or peripheral nervous system. [EU]

**Dystonia:** Disordered tonicity of muscle. [EU]

**Dystrophy:** Any disorder arising from defective or faulty nutrition, especially the muscular dystrophies. [EU]

**Electromyography:** Recording of the changes in electric potential of muscle by means of surface or needle electrodes. [NIH]

**Encephalitis:** Inflammation of the brain. [EU]

**Encephalopathy:** Any degenerative disease of the brain. [EU]

**Endocrinology:** A subspecialty of internal medicine concerned with the metabolism, physiology, and disorders of the endocrine system. [NIH]

**Enuresis:** Involuntary discharge of urine after the age at which urinary control should have been achieved; often used alone with specific reference to involuntary discharge of urine occurring during sleep at night (bed-wetting, nocturnal enuresis). [EU]

**Extracorporeal:** Situated or occurring outside the body. [EU]

**Gait:** Manner or style of walking. [NIH]

**Gastrostomy:** Creation of an artificial external opening into the stomach for nutritional support or gastrointestinal compression. [NIH]

**Hemiplegia:** Paralysis of one side of the body. [EU]

**Hyperthyroidism:** 1. excessive functional activity of the thyroid gland. 2. the abnormal condition resulting from hyperthyroidism marked by increased metabolic rate, enlargement of the thyroid gland, rapid heart rate, high blood pressure, and various secondary symptoms. [EU]

**Hypertonia:** Or hypertony n, pl. hypertonias or hypertonies : hypertonicity. n. Pathology: increased rigidity, tension and spasticity of the muscles. [EU]

**Hypotonia:** A condition of diminished tone of the skeletal muscles; diminished resistance of muscles to passive stretching. [EU]

**Immunization:** The induction of immunity. [EU]

**Incontinence:** Inability to control excretory functions, as defecation (faecal i.) or urination (urinary i.). [EU]

**Invasive:** 1. having the quality of invasiveness. 2. involving puncture or incision of the skin or insertion of an instrument or foreign material into the body; said of diagnostic techniques. [EU]

**Jaundice:** A clinical manifestation of hyperbilirubinemia, consisting of deposition of bile pigments in the skin, resulting in a yellowish staining of the skin and mucous membranes. [NIH]

**Malformation:** A morphologic defect resulting from an intrinsically abnormal developmental process. [EU]

**Membrane:** A thin layer of tissue which covers a surface, lines a cavity or divides a space or organ. [EU]

**Meningitis:** Inflammation of the meninges. When it affects the dura mater, the disease is termed pachymeningitis; when the arachnoid and pia mater are involved, it is called leptomeningitis, or meningitis proper. [EU]

**Mental:** Pertaining to the mind; psychic. 2. (L. mentum chin) pertaining to the chin. [EU]

**Neonatal:** Pertaining to the first four weeks after birth. [EU]

**Neurology:** A medical specialty concerned with the study of the structures, functions, and diseases of the nervous system. [NIH]

**Neurons:** The basic cellular units of nervous tissue. Each neuron consists of a body, an axon, and dendrites. Their purpose is to receive, conduct, and transmit impulses in the nervous system. [NIH]

**Orthopedics:** A surgical specialty which utilizes medical, surgical, and physical methods to treat and correct deformities, diseases, and injuries to the skeletal system, its articulations, and associated structures. [NIH]

**Oxygenation:** The process of supplying, treating, or mixing with oxygen. No:1245 - oxygenation the process of supplying, treating, or mixing with oxygen. [EU]

**Paresis:** Slight or incomplete paralysis. [EU]

**Pediatrics:** A medical specialty concerned with maintaining health and providing medical care to children from birth to adolescence. [NIH]

**Perinatal:** Pertaining to or occurring in the period shortly before and after birth; variously defined as beginning with completion of the twentieth to twenty-eighth week of gestation and ending 7 to 28 days after birth. [EU]

**Phototherapy:** Treatment of disease by exposure to light, especially by variously concentrated light rays or specific wavelengths. [NIH]

**Pigments:** Any normal or abnormal coloring matter in plants, animals, or micro-organisms. [NIH]

**Poisoning:** A condition or physical state produced by the ingestion, injection or inhalation of, or exposure to a deleterious agent. [NIH]

**Prenatal:** Existing or occurring before birth, with reference to the fetus. [EU]

**Procyclidine:** A muscarinic antagonist that crosses the blood-brain barrier and is used in the treatment of drug-induced extrapyramidal disorders and in parkinsonism. [NIH]

**Progressive:** Advancing; going forward; going from bad to worse; increasing in scope or severity. [EU]

**Proteins:** Polymers of amino acids linked by peptide bonds. The specific sequence of amino acids determines the shape and function of the protein. [NIH]

**Pulse:** The rhythmical expansion and contraction of an artery produced by waves of pressure caused by the ejection of blood from the left ventricle of the heart as it contracts. [NIH]

**Quadriplegia:** Severe or complete loss of motor function in all four limbs which may result from brain diseases; spinal cord diseases; peripheral nervous system diseases; neuromuscular diseases; or rarely muscular diseases. The locked-in syndrome is characterized by quadriplegia in combination with cranial muscle paralysis. Consciousness is spared and the only retained voluntary motor activity may be limited eye movements. This condition is usually caused by a lesion in the upper brain stem which injures the descending cortico-spinal and cortico-bulbar tracts. [NIH]

**Radiology:** A specialty concerned with the use of x-ray and other forms of radiant energy in the diagnosis and treatment of disease. [NIH]

**Relaxant:** 1. lessening or reducing tension. 2. an agent that lessens tension. [EU]

**Rubella:** An acute, usually benign, infectious disease caused by a togavirus and most often affecting children and nonimmune young adults, in which the virus enters the respiratory tract via droplet nuclei and spreads to the lymphatic system. It is characterized by a slight cold, sore throat, and fever, followed by enlargement of the postauricular, suboccipital, and cervical lymph nodes, and the appearances of a fine pink rash that begins on the head and spreads to become generalized. Called also German measles, roetln, röteln, and three-day measles, and rubeola in French and Spanish. [EU]

**Saliva:** The clear, viscous fluid secreted by the salivary glands and mucous glands of the mouth. It contains mucins, water, organic salts, and ptylin. [NIH]

**Seizures:** Clinical or subclinical disturbances of cortical function due to a sudden, abnormal, excessive, and disorganized discharge of brain cells. Clinical manifestations include abnormal motor, sensory and psychic phenomena. Recurrent seizures are usually referred to as epilepsy or "seizure disorder." [NIH]

**Serum:** The clear portion of any body fluid; the clear fluid moistening serous membranes. 2. blood serum; the clear liquid that separates from blood on clotting. 3. immune serum; blood serum from an immunized animal used for passive immunization; an antiserum; antitoxin, or antivenin. [EU]

**Skull:** The skeleton of the head including the bones of the face and the bones enclosing the brain. [NIH]

**Spastic:** 1. of the nature of or characterized by spasms. 2. hypertonic, so that the muscles are stiff and the movements awkward. 3. a person exhibiting spasticity, such as occurs in spastic paralysis or in cerebral palsy. [EU]

**Spasticity:** A state of hypertonicity, or increase over the normal tone of a muscle, with heightened deep tendon reflexes. [EU]

**Spectrum:** A charted band of wavelengths of electromagnetic vibrations obtained by refraction and diffraction. By extension, a measurable range of activity, such as the range of bacteria affected by an antibiotic (antibacterial s.) or the complete range of manifestations of a disease. [EU]

**Stomach:** An organ of digestion situated in the left upper quadrant of the abdomen between the termination of the esophagus and the beginning of the duodenum. [NIH]

**Strabismus:** Deviation of the eye which the patient cannot overcome. The visual axes assume a position relative to each other different from that required by the physiological conditions. The various forms of strabismus are spoken of as tropias, their direction being indicated by the appropriate prefix, as cyclo tropia, esotropia, exotropia, hypertropia, and hypotropia. Called also cast, heterotropia, manifest deviation, and squint. [EU]

**Thalamus:** Either of two large, ovoid masses, consisting chiefly of grey substance, situated one on each side of and forming part of the lateral wall of the third ventricle. It is divided into two major parts : dorsal and ventral, each of which contains many nuclei. [EU]

**Tomography:** The recording of internal body images at a predetermined plane by means of the tomograph; called also body section roentgenography. [EU]

**Tone:** 1. the normal degree of vigour and tension; in muscle, the resistance to passive elongation or stretch; tonus. 2. a particular quality of sound or of voice. 3. to make permanent, or to change, the colour of silver stain by chemical treatment, usually with a heavy metal. [EU]

**Tonic:** 1. producing and restoring the normal tone. 2. characterized by continuous tension. 3. a term formerly used for a class of medicinal preparations believed to have the power of restoring normal tone to tissue. [EU]

**Toxicity:** The quality of being poisonous, especially the degree of virulence of a toxic microbe or of a poison. [EU]

**Toxin:** A poison; frequently used to refer specifically to a protein produced by some higher plants, certain animals, and pathogenic bacteria, which is highly toxic for other living organisms. Such substances are differentiated from the simple chemical poisons and the vegetable alkaloids by their high molecular weight and antigenicity. [EU]

**Toxoplasmosis:** An acute or chronic, widespread disease of animals and humans caused by the obligate intracellular protozoon Toxoplasma gondii, transmitted by oocysts containing the pathogen in the feces of cats (the definitive host), usually by contaminated soil, direct exposure to infected feces, tissue cysts in infected meat, or tachyzoites (proliferating forms) in blood. [EU]

**Transfusion:** The introduction of whole blood or blood component directly into the blood stream. [EU]

**Tremor:** An involuntary trembling or quivering. [EU]

**Trihexyphenidyl:** A centrally acting muscarinic antagonist used in the treatment of parkinsonism and drug-induced extrapyramidal movement disorders and as an antispasmodic. [NIH]

**Ultrasonography:** The visualization of deep structures of the body by recording the reflections of echoes of pulses of ultrasonic waves directed into the tissues. Use of ultrasound for imaging or diagnostic purposes employs frequencies ranging from 1.6 to 10 megahertz. [NIH]

**Uterus:** The hollow muscular organ in female mammals in which the fertilized ovum normally becomes embedded and in which the developing embryo and fetus is nourished. In the nongravid human, it is a pear-shaped structure; about 3 inches in length, consisting of a body, fundus, isthmus, and cervix. Its cavity opens into the vagina below, and into the uterine tube on either side at the cornu. It is supported by direct attachment to the vagina and by indirect attachment to various other nearby pelvic structures. Called also metra. [EU]

**Vaginal:** 1. of the nature of a sheath; ensheathing. 2. pertaining to the vagina. 3. pertaining to the tunica vaginalis testis. [EU]

**Vascular:** Pertaining to blood vessels or indicative of a copious blood supply. [EU]

# CHAPTER 2. SEEKING GUIDANCE

## Overview

Some parents are comforted by the knowledge that a number of organizations dedicate their resources to helping people with cerebral palsy. These associations can become invaluable sources of information and advice. Many associations offer parent support, financial assistance, and other important services. Furthermore, healthcare research has shown that support groups often help people to better cope with their conditions.[9] In addition to support groups, your child's physician can be a valuable source of guidance and support.

In this chapter, we direct you to resources that can help you find parent organizations and medical specialists. We begin by describing how to find associations and parent groups that can help you better understand and cope with your child's condition. The chapter ends with a discussion on how to find a doctor that is right for your child.

## Associations and Cerebral Palsy

In addition to associations or groups that your child's doctor might recommend, we suggest that you consider the following list (if there is a fee for an association, you may want to check with your child's insurance provider to find out if the cost will be covered):

[9] Churches, synagogues, and other houses of worship might also have groups that can offer you the social support you need.

- **California Developmental Disabilities NETLINK**

  Address: California Developmental Disabilities NETLINK Web Site on the Internet,

  Telephone: (813) 281-0300 Toll-free: (800) 237-5055

  Email: Oraynor@mednet.ucla.edu

  Web Site: http://www.npi.ucla.edu/uap/cddn/

  Background: California Developmental Disabilities NETLINK, a project of the University Affiliated Programs (UAP) at the University of California, Los Angeles (UCLA), offers a web site on the Internet that provides information about services and programs for children and adults with developmental disabilities in California. The California Developmental Disabilities NETLINK is funded by the State Council on Developmental Disabilities Program Development Fund Cycle XIX and the UCLA UAP. The mission of the UCLA UPA is to ensure that individuals with developmental disabilities and their families have access to services, support systems, and opportunities that promote independence, productivity, and inclusion in the community. The UCLA UAP is an interdisciplinary training, technical assistance, and information dissemination program. The California Developmental Disabilities NETLINK web site enables online visitors to search for information about services and programs in the following areas: assistive technology, housing and residential services, family support, employment and vocational training, special education, recreation, transportation, and public assistance. Currently, the site contains information from a survey on over 800 organizations and programs identified across California. The site's 'links page' provides dynamic linkage to web sites and online services provided by organizations and agencies in California as well as national resources. The site's listing of state resources includes the State Council on Developmental Disabilities, Protection and Advocacy, Area Boards, Regional Centers, and University Affiliated Programs in California.

  Relevant area(s) of interest: Autism, Cerebral Palsy

- **Challenge Air For Kids and Friends**

  Address: Challenge Air For Kids and Friends Love Field North Concourse, 8008 Cedar Springs Road, Suite N106 LB24, Dallas, TX 75235

  Telephone: (214) 351-3353 Toll-free: (800) 221-6827

  Fax: (214) 351-4565

  Email: lharris@cyberramp.net

Web Site: http://www.challengeair.com

Background: Challenge Air for Kids and Friends is a national nonprofit organization dedicated to providing motivational, occupational, recreational, and educational therapy to disabled, disadvantaged, and seriously ill children through the experience of flight with a disabled pilot free of charge. Challenge Air was established in 1993 by a pilot who lost the use of his legs when his plane crashed while returning from a combat mission over Vietnam. The purpose of the flights is to provide enjoyable experiences and to demonstrate that the human spirit can prevail over any physical or mental obstacle. Challenge Air organizes day long events that allow groups of children to enjoy motivational flights, food, and other fun. Events have include handicapped athletic groups, therapy programs, social service organizations, and more. A typical Challenge Air fly day serves more than 150 children and their families. Each program is underwritten by individual, corporate, and philanthropic donations. Challenge Air has flown over 4,000 children in 15 states as well as Canada. Challenge Air has several materials available including brochures, pamphlets, videos, and a newsletter. Challenge Air also has a web site at http://www.challengeair.com.

Relevant area(s) of interest: Cerebral Palsy

- **Cincinnati Center for Developmental Disorders**

  Address: Cincinnati Center for Developmental Disorders Pavilion Building, 3333 Burnet Avenue, Cincinnai, OH 45229-3039

  Telephone: (513) 636-4688 Toll-free: (800) 736-2216

  Fax: (513) 636-7361

  Web Site: http://www.chmcc.org

  Background: Established in 1957, the Cincinnati Center for Developmental Disorders is dedicated to facilitating the empowerment and maximizing the skills of individuals with developmental disabilities and other chronic handicapping conditions to help them recognize their own value, become self-advocates, attain full inclusion, and achieve equal partnership as participating and contributing members of the community. The Center, which serves approximately 9,000 individuals each year, is committed to providing comprehensive, interdisciplinary services for each child and adult. Pediatricians trained in developmental disorders, speech and hearing specialists, psychologists, special educators, occupational therapists, and other professionals work together with an affected individual's family to create customized plans to meet an affected individual's special needs. The Center provides a range of services including a complete evaluation that lays the groundwork for a

unique plan of care as well as specialized services that provide families with complete programs of evaluation, treatment, and support for specific problems such as autism, behavioral problems, cerebral palsy, craniofacial abnormalities such as cleft lip and palate, Down Syndrome, myelomeningocele, neurofibromatosis, Rubinstein-Taybi Syndrome, and Williams Syndrome. The Center also provides classroom therapy to help parents and community classroom teachers learn how to manage a child's behavior and communication problems as well as family support services that offer a wide range of resources ranging from special toy libraries and parent discussion groups to information and referral services. Adult services are also provided to help ease the transition to adult life in such areas as health care, housing, work, and other issues. The Center also serves the larger community through its outreach program, which provides training and technical assistance to teachers, social workers, and health care professionals so that individuals with disabilities may receive support within their communities and be included as fully participating members. In addition, the Center's ongoing research into the cause and treatment of various disabilities such as autism, Down Syndrome, and spina bifida enables the Center to look for new, effective methods in treating and caring for individuals with developmental disorders. The Center also offers a variety of materials including brochures, pamphlets, reports, and a regular newsletter.

Relevant area(s) of interest: Autism, Cerebral Palsy

- **Dana Alliance for Brain Initiatives**

  Address: Dana Alliance for Brain Initiatives 745 Fifth Avenue, Suite 700, New York, NY 10151

  Telephone: (212) 223-4040 Toll-free: (800) 221-6827

  Fax: (212) 593-7623

  Email: danainfo@danany.dana.org

  Web Site: http://www.dana.org

  Background: The Dana Alliance for Brain Initiatives, a nonprofit organization supported by the Charles A. Dana Foundation, was established as an alliance of neuroscientists dedicated to providing information and promoting understanding concerning the personal and public benefits of brain research. (The Charles A. Dana Foundation is a private philanthropic foundation with grant programs in health and education.) Established in 1993, the Dana Alliance for Brain Initiatives currently consists of more than 175 neuroscientists. Alliance members have set 10 main objectives in brain research that are considered obtainable by the Year 2000. These objectives include the identification of

the genes that are defective in familial Alzheimer's and Huntington's diseases; identification of genes responsible for hereditary forms of manic- depressive illness; and development of new drugs and other measures to alleviate the effects of multiple sclerosis, Alzheimer's disease, Parkinson's disease, motor neuron disease such as Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's disease), and epilepsy. Many of the 10 objectives have been met, and significant progress is being made on all 10 objectives. According to the Alliance, approximately one in five Americans is affected by a brain disease or disorder, ranging from learning disabilities to Parkinson's Disease from epilepsy to spinal cord injuries. The Dana Alliance for Brain Initiatives is dedicated to answering questions concerning brain-related research and providing information concerning new developments. The Alliance offers a variety of periodicals, newsletters, reports, reference works, and books. The Dana Alliance and the Dana Foundation also have a web site on the Internet that provides information on current activities and services, describes the Dana Alliance's objectives, offers information concerning available publications, and provides comprehensive dynamic linkage through the Dana BrainWeb. The Dana BrainWeb recommends several Internet sites as helpful resources for individuals concerned about brain diseases and disorders. The Dana Foundation and Alliance web site is located at http://www.dana.org.

Relevant area(s) of interest: Autism, Cerebral Palsy

- **Disabled Sports USA**

  Address: Disabled Sports USA 451 Hungerford Drive, Suite 100, Rockville, MD 20850

  Telephone: (301) 217-0960 Toll-free: (800) 221-6827

  Fax: (301) 217-0968

  Email: dsusa@dsusa.org

  Web Site: http://www.dsusa.org/~dsusa/dsusa.html

  Background: Disabled Sports USA (DS/USA) is a not-for-profit organization dedicated to ensuring that disabled people have access to sports, recreation, and physical education programs from preschool through college to elite sports levels. Established in 1967 by disabled Vietnam veterans, DS/USA serves people with physical disabilities that restrict mobility, including amputations, weakness or paralysis of both legs (paraplegia), paralysis of all four limbs (quadriplegia), cerebral palsy, head injury, multiple sclerosis, muscular dystrophy, spina bifida, stroke, and visual impairment. DS/USA consists of more than 60,000 members and 80 chapters around the United States. Educational

materials include a general information packet, a newsletter entitled 'Disabled Sports USA Update,' and a sports magazine entitled 'Challenge.' Program activities include sporting activities and events, patient education (e.g., workshops), and patient networking. DS/USA maintains a web site at http://www.dsusa.org/~dsusa/dsusa.html.

- **Easter Seals National Headquarters**

  Address: Easter Seals National Headquarters 230 West Monroe Street, Suite 1800, Chicago, IL 60606-4802

  Telephone: (312) 726-6200 Toll-free: (800) 221-6827

  Fax: (312) 726-1494

  Email: info@easter-seals.org

  Web Site: http://www.easter-seals.org

  Background: The National Easter Seal Society, Inc. is a voluntary nonprofit service organization established in 1919 to serve the needs of children and adults with disabilities and to help them achieve independence. Easter Seals currently consists of a nationwide network of 105 affiliate societies that operates approximately 400 centers throughout the United States and Puerto Rico. The Society provides rehabilitation services; technological assistance; and disability prevention, advocacy and public education programs. Among its programs and services are the provision of physical, occupational, and speech therapy for children and adults; screening programs to identify vision, speech, and hearing problems, scoliosis, and other disabling conditions; and daycare programs for children with disabilities and their non-disabled peers that foster early acceptance of persons with disabilities. In addition, Easter Seals operates parent resource centers with adaptive toys and play therapy programs for young children; offers educational evaluation services; offers job evaluation, training, and placement for people with disabilities; provides loans of such equipment as braces, crutches, wheelchairs, and hearing aids; provides medical treatment and prosthetic care; and offers head trauma programs for children and adults. The National Easter Seal Society maintains a web site at http://www.seals.com.

  Relevant area(s) of interest: Cerebral Palsy

- **Hydrocephalus Support Group, Inc**

  Address:

  Telephone: (636) 532-8228 Toll-free: (800) 221-6827

Fax: (636) 995-4108

Email: hydrobuff@postnet.com

Background: The Hydrocephalus Support Group, Inc. (HSG) is an international nonprofit self-help organization dedicated to providing information, assistance, and support to individuals affected by hydrocephalus and their family members. Hydrocephalus is a condition characterized by inhibition of the normal flow of cerebrospinal fluid (CSF) and abnormal widening (dilatation) of the cerebral spaces of the brain (ventricles), causing accumulation of CSF in the skull and potentially increased pressure on brain tissue. Founded in 1986 and currently consisting of 1,000 members, HSG provides patient referrals, engages in patient advocacy, offers networking services, promotes research, and conducts meetings with speakers who discuss all aspects of hydrocephalus and related conditions. HSG also has a library of over 150 articles and tapes concerning hydrocephalus and provides pamphlets, brochures, and a quarterly newsletter.

Relevant area(s) of interest: Cerebral Palsy

- **IVH Parents**

  Address: IVH Parents P.O. Box 56-1111, Miami, FL 33256-1111

  Telephone: (305) 232-0381 Toll-free: (888) 663-4637

  Fax: (305) 232-9890

  Email: 72167.633@compuserve.com

  Background: IVH Parents is a voluntary not-for-profit self-help organization dedicated to sharing information concerning intraventricular hemorrhages (IVHs) of the brain, providing support to affected individuals and their families, and conducting ongoing follow-up. Established in 1984, the group consists of parents as well as professionals who work with affected children including physicians from several specialties, therapists, nurses, researchers, and teachers. Intraventricular hemorrhage of the brain, or bleeding into the brain's cerebrum, can occur after a premature birth or due to a traumatic full-term birth. Intraventricular hemorrhage may result in cerebral palsy, hydrocephalus, sensory loss, seizures, mental retardation, or multiple disabilities. IVH Parents enables families with affected children to network with one another in order to exchange information and mutual support. The organization also has a registry of children with IVH, provides a directory of members, and publishes a regular newsletter for parents and professionals.

- **March of Dimes Birth Defects Foundation**

  Address: March of Dimes Birth Defects Foundation 1275 Mamaroneck Avenue, White Plains, NY 10605

  Telephone: (914) 428-7100 Toll-free: (888) 663-4637

  Fax: (914) 997-4763

  Email: resourcecenter@modimes.org

  Web Site: http://www.modimes.org

  Background: The March of Dimes Birth Defects Foundation is a national not-for- profit organization that was established in 1938. The mission of the Foundation is to improve the health of babies by preventing birth defects and infant mortality. Through the Campaign for Healthier Babies, the March of Dimes funds programs of research, community services, education, and advocacy. Educational programs that seek to prevent birth defects are important to the Foundation and to that end it produces a wide variety of printed informational materials and videos. The March of Dimes public health educational materials provide information encouraging health- enhancing behaviors that lead to a healthy pregnancy and a healthy baby.

  Relevant area(s) of interest: Autism, Cerebral Palsy, Dyslexia

- **Munroe-Meyer Institute for Genetics and Rehabilitation**

  Address: Munroe-Meyer Institute for Genetics and Rehabilitation 985430 Nebraska Medical Center, Omaha, NE 68198-5430

  Telephone: (402) 559-6800 Toll-free: (800) 656-3937

  Fax: (402) 559-6688

  Email: gbschaef@unmc.edu

  Web Site: http://www.unmc.edu/mrimedia/meyertes.html

  Background: The Munroe-Meyer Institute for Genetics and Rehabilitation (MMI), a not-for-profit University Affiliated Program, is a clinical and rehabilitation facility and genetics center that is part of the University of Nebraska Medical Center. Established in 1954, the Institute is dedicated to offering the services of professionals trained in research, education, and patient care to support individuals with developmental disabilities and their families. MMI provides a learning environment for students preparing to enter the fields of disability and health care, particularly professionals who will provide services for children and adults with special health care needs and their families. The Institute provides comprehensive interdisciplinary clinical and laboratory genetics services, genetic counseling, professional education, patient education, and

support groups. The Institute's educational materials include several guidebooks for parents of children affected by particular disorders or disabilities such as Sotos Syndrome, Trisomy 13, Trisomy 18, and Wolf-Hirschhorn Syndrome. (Sotos Syndrome is a rare genetic disorder characterized by excessive growth while the latter disorders are rare chromosomal disorders characterized by a variety of abnormalities.) MMI also has a web site at http://www.umc.edu/mrimedia/meyertes.html.

Relevant area(s) of interest: Cerebral Palsy

- **National Institute for Rehabilitation Engineering**

  Address: National Institute for Rehabilitation Engineering P.O. Box T, Hewitt, NJ 07421

  Telephone: (973) 853-6585 Toll-free: (800) 736-2216

  Email: nire@theoffice.net

  Web Site: http://nire@TheOffice.net

  Background: The National Institute for Rehabilitation Engineering (NIRE) is a voluntary organization dedicated to providing assistive technology information, counseling, referrals, information, and user training. NIRE also custom designs and custom builds assistive devices and systems when commercial products are not adequate. NIRE's services and expertise assist people with any types of functional disabilities, individually and in various combinations. People of all ages are helped with special attention to those with severe and/or multiple handicaps. Established in 1967, the Institute is an onsite technology training organization and research and development facility. Its staff designs custom-made devices for handicapped persons who are trial-fitted, trained, counseled, and evaluated in the field. Such devices include special field-expander glasses for monocular vision, loss of one half the field vision in both eyes (hemianopsia), and tunnel vision; low vision cataract glasses; night vision aids; and macular degeneration glasses. Conventional vision, hearing, and other services are provided for persons otherwise handicapped. In addition, electronic speech aids are available, and aids for the totally deaf and special visual aids for deaf people with impaired vision are also provided by the Institute. The organization supplies specifically designed mobility aids for individuals with cerebral palsy, paralysis, or paralysis of all four limbs (quadriplegia). The Institute also provides self-care aids, communication aids, and occupational aids. In addition, NIRE provides computers and specially modified computer programs with educational and employment applications for handicapped individuals; provides driver assessment and/or training for persons with a wide range of disabilities; offers technical assistance to

handicapped persons trying to set up their own businesses; and coordinates outreach programs that provide most of these services and aids in clients' own local areas such as schools, clinics, homes, and places of employment. The Institute supports the Swedish and Norwegian languages in both spoken and written form, and the French, Spanish, German, and Italian languages in written form only.

- **New Directions for People with Disabilities, Inc**

  Address: New Directions for People with Disabilities, Inc. 5276 Hollister Avenue, Suite 207, Santa Barbara, CA 93111

  Telephone: (805) 967-2841 Toll-free: (800) 221-6827

  Fax: (805) 964-7344

  Email: NewDirec@silcom.com

  Background: New Directions for People with Disabilities, Inc., a not-for-profit organization established in 1985, is dedicated to providing local, national, and international travel and foreign exchange programs for people with disabilities. The purpose of the programs is to promote the understanding, acceptance, and appreciation of people with disabilities as important and contributing members of our society as well as to promote a sense of accomplishment, belonging, and self-worth for participants by providing a wide range of challenging activities. Such activities include skiing, river rafting, biking tours, and hot air ballooning. The Tour Guides/Chaperones are special educational instructors, recreation therapists, residential counselors, nurses, nurses' aides, vocational and independent living skill counselors, and other professional staff who have been trained to work with people with disabilities. Each year, New Directions serves over 350 children, adults, and seniors who have developmental, emotional, and physical disabilities such as cerebral palsy, Down Syndrome, autism, schizophrenia, blindness, hearing impairment, and mental retardation. Participants live in state hospitals, board and care homes, residential treatment centers, and nursing homes. Most have not previously had a vacation, and many have not been away from their facilities or treatment centers for 10 or more years. New Directions annually sponsors trips in the United States and abroad to locations including Hawaii, Washington D.C., New York City, Las Vegas, Disneyland, the Grand Canyon, Australia, Ireland, Japan, and Mexico.

  Relevant area(s) of interest: Autism, Cerebral Palsy

- **Ontario Federation for Cerebral Palsy**

  Address: Ontario Federation for Cerebral Palsy 1630 Lawrence Avenue West, Suite 104, Toronto, M6L 1C5, Canada

  Telephone: (416) 244-9686 Toll-free: (800) 656-3937

  Fax: (416) 244-6543

  Email: ofcp@ofcp.on.ca

  Web Site: http://www.ofcp.on.ca

  Background: The Ontario Federation for Cerebral Palsy (OFCP), a voluntary, non- profit, charitable organization is dedicated to working with and for people with cerebral palsy and other disabilities. The Federation is also committed to initiating programs, personal attendant care services, and facilities; promoting public and professional awareness and education; offering family support groups; and promoting and supporting research. Cerebral palsy, a nonprogressive motor disorder thought to be due to a prenatal brain defect or brain injury during birth, is characterized by spastic paralysis, impaired control of voluntary movements (ataxia), seizures, and/or mental retardation. Established in 1947 and consisting of 50 member groups, OFCP offers a variety of programs and services including several annual conferences, workshops and seminars, consumer peer support, and publication and distribution of printed and audiovisual materials on cerebral palsy and related issues. The Federation also developed the International Cerebral Palsy Registry to help parents of affected children as well as adults with cerebral palsy make direct contact with others to support one another and share information and strategies in their pursuit to become empowered and self- directed. OFCP also offers information packets developed for parents, grandparents, adolescents, young adults, teachers, and other professionals; provides a reference library for parents and professionals; and assists in the development of regional member groups and community support programs. In addition, OFCP has developed a 'Service Information Database for People With Disabilities Program' (SIDD), offering current comprehensive disability-specific information on a variety of service needs in a user-friendly computer format for people of all ages with all types of physical and developmental disabilities. The Federation offers a variety of educational materials including booklets, pamphlets, videos, self-help guides, information packets, and a regular newsletter entitled 'Participaper.' OFCP also has a web site on the Internet at http://www.connection.com/ofcp/.

  Relevant area(s) of interest: Cerebral Diplegia, Cerebral Palsy, Infantile Cerebral Paralysis, Little Disease

- **Roeher Institute**

  Address: Roeher Institute Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, M3J 1P3, Canada

  Telephone: (416) 661-9611 Toll-free: (800) 856-2207

  Fax: (416) 661-5701

  Email: info@roeher.ca

  Web Site: http://www.roeher.ca

  Background: The Roeher Institute, located in Ontario, Canada, is a nonprofit organization dedicated to the study of public policy affecting people with intellectual impairments and other disabilities. Established in 1957, the Institute has an extensive national and international network and acts as a clearinghouse for information about disability issues around the world. The Institute's services include reference and referral information; customized responses to information requests; a generation of bibliographies on specific topics; and the development of customized information packages. The Roeher Institute's goals are to examine and understand issues that affect individuals with an intellectual impairment and other disabilities; to act as a center for the exchange of ideas and to encourage new ways of thinking about persons with an intellectual impairment and other disabilities; and to provide insight into the social policy, programs, laws, and other features of Canadian society that affect the capacity of people with an intellectual impairment and other disabilities to exercise their rights and fully participate in society. Educational materials include a pamphlet entitled 'An International Information Centre of Disability at The Roeher Institute,' a catalog that lists resource books, and a booklet entitled 'Issues and Resources.' The Institute supports research, encourages educational activities, and provides appropriate referrals. The Roeher Institute can be reached at its web site on the Internet at http://www.roeher.ca.

  Relevant area(s) of interest: Autism, Cerebral Palsy

- **Shriners Hospitals for Children**

  Address: Shriners Hospitals for Children P.O. Box 31356, Tampa, FL 33613-3356

  Telephone: (813) 281-0300 Toll-free: (800) 237-5055

  Fax: (813) 281-8496

  Web Site: http://www.shrinershq.org

  Background: The Shriners Hospital for Children and the Shriners Burn Institutes are a network of pediatric hospitals that provide no-cost

medical care to children with orthopedic problems or burn injuries. Shriners Hospital conducts research on orthopedic treatment and burn care and trains healthcare professionals in the treatment of orthopedic disabilities and burn injuries. Established in 1922, the hospitals are substantially funded through the Shriners Hospital for Children endowment fund. The hospitals treat children with a variety of diseases including (but not limited to) scoliosis, osteogenesis imperfecta, Legg Calve Perthes, and others. Burns and spinal injuries are also treated. Shriners Hospital consists of 23 chapters and offers educational materials such as 'Between Us' magazine, '20 Questions,' and 'The Story of Shriners Hospitals.' In addition, the organization assists in training physicians and other medical professionals in the treatment of orthopedic disabilities and burn injuries. The Shriners also operate a World Wide Web site at http://www.shrinershq.org.

Relevant area(s) of interest: Cerebral Palsy

- **Twin Hope (Twin-Twin Transfusion Syndrome)**

  Address: Twin Hope (Twin-Twin Transfusion Syndrome) 2592 West 14th Street, Cleveland, OH 44113

  Telephone: (216) 228-8887 Toll-free: (800) 221-6827

  Email: twinhope@mail.ohio.net

  Web Site: http://www.twinhope.com

  Background: Twin Hope is an international not-for-profit organization dedicated to providing information and support to parents of children with Twin- Twin Transfusion Syndrome and other related disorders that may affect twins (including Cerebral Palsy and Conjoined Twinning). During the development of identical twins, there are often blood vessels in the fetuses' shared placenta that connect their blood circulations (placental anastomoses). In cases of Twin-Twin Transfusion Syndrome, the blood begins to flow unevenly, with one fetal twin receiving too much blood (recipient) and one receiving too little (donor). The recipient twin may experience heart failure due to continual strain on its heart and blood vessels. The donor twin, on the other hand, may experience life-threatening anemia due to its inadequate supply of blood. In some cases, both twins may receive an inadequate supply of oxygen during pregnancy or due to early delivery; as a result, brain damage may occur, potentially causing Cerebral Palsy. Twin Hope is committed to promoting awareness of TTTS and other related disorders among the medical community and the general public; engaging in patient advocacy; and promoting research. Established in 1994, Twin Hope also provides networking services for affected families, has a registry,

conducts presentations, and offers a variety of educational materials. Such materials include a biannual newsletter entitled 'TwinLines,' a Family Support Guide, brochures, articles, multiple birth loss information, a Medical Professional Resource Manual, and other publications.

Relevant area(s) of interest: Cerebral Palsy

- **United Cerebral Palsy Association**

  Address: United Cerebral Palsy Association 1660 L Street NW, Suite 700, Washington, D.C. 20036-5602

  Telephone: (202) 776-0406 Toll-free: (800) 872-5827

  Fax: (202) 776-0414

  Email: ucpanatl@ucpa.org

  Web Site: http://www.ucpa.org

  Background: The United Cerebral Palsy Association is a national not-for-profit self-help organization dedicated to providing information and support to individuals with Cerebral Palsy and their families. Cerebral Palsy is a neurological movement disorder characterized by lack of muscle control and impairment in the coordination of movement. Established in 1949, the United Cerebral Palsy Association supports its more than 160 local affiliates; these affiliates provide a variety of programs and services for affected families, including support groups. The United Cerebral Palsy Association offers several educational and support materials including a quarterly magazine, regular newsletters, and research reports. In addition, the Association conducts regular forums on America On-Line.

  Relevant area(s) of interest: Cerebral Palsy

- **WE MOVE (Worldwide Education and Awareness for Movement Disorders)**

  Address: WE MOVE (Worldwide Education and Awareness for Movement Disorders) Mt. Sinai Medical Center, One Gustave L. Levy Place Box 1052, New York, NY 10029

  Telephone: (212) 241-8567 Toll-free: (800) 437-6682

  Fax: (212) 987-7363

  Email: wemove@wemove.org

  Web Site: http://www.wemove.org

Background: WE MOVE (Worldwide Education and Awareness for Movement Disorders) is an international educational program endorsed by the Movement Disorder Society. It is dedicated to promoting awareness of neurological movement disorders for the purpose of early diagnosis, appropriate treatment, and patient support. The primary focus of the program is to educate the health care community about movement disorders. To that end, the organization sponsors education programs and produces teaching materials designed for medical professionals including neurologists, family practitioners, physical therapists, speech pathologists, and other health care workers. WE MOVE serves as a communication link between physicians, affected individuals, and support groups around the world. The program also publishes the 'International Guide to Patient Support Organizations' and a brochure entitled 'Educator's Resource Materials.' In addition to their primary site, the organization maintains a web site at http://www.mssm.edu/neurology/html/wemove.html.

Relevant area(s) of interest: Cerebral Palsy

## Finding More Associations

There are a number of directories that list additional medical associations that you may find useful. While not all of these directories will provide different information than what is listed above, by consulting all of them, you will have nearly exhausted all sources for parent associations.

### The National Health Information Center (NHIC)

The National Health Information Center (NHIC) offers a free referral service to help people find organizations that provide information about cerebral palsy. For more information, see the NHIC's Web site at **http://www.health.gov/NHIC/** or contact an information specialist by calling 1-800-336-4797.

### DIRLINE

A comprehensive source of information on associations is the DIRLINE database maintained by the National Library of Medicine. The database comprises some 10,000 records of organizations, research centers, and government institutes and associations which primarily focus on health and biomedicine. DIRLINE is available via the Internet at the following Web site:

**http://dirline.nlm.nih.gov**. Simply type in "cerebral palsy" (or a synonym) or the name of a topic, and the site will list information contained in the database on all relevant organizations.

### The Combined Health Information Database

Another comprehensive source of information on healthcare associations is the Combined Health Information Database. Using the "Detailed Search" option, you will need to limit your search to "Organizations" and "cerebral palsy". Type the following hyperlink into your Web browser: **http://chid.nih.gov/detail/detail.html**. To find associations, use the drop boxes at the bottom of the search page where "You may refine your search by." For publication date, select "All Years." Then, select your preferred language and the format option "Organization Resource Sheet." By making these selections and typing in "cerebral palsy" (or synonyms) into the "For these words:" box, you will only receive results on organizations dealing with cerebral palsy. You should check back periodically with this database since it is updated every 3 months.

### The National Organization for Rare Disorders, Inc.

The National Organization for Rare Disorders, Inc. has prepared a Web site that provides, at no charge, lists of associations organized by specific medical conditions. You can access this database at the following Web site: **http://www.rarediseases.org/cgi-bin/nord/searchpage**. Select the option called "Organizational Database (ODB)" and type "cerebral palsy" (or a synonym) in the search box.

### Online Support Groups

In addition to support groups, commercial Internet service providers offer forums and chat rooms to discuss different illnesses and conditions. WebMD®, for example, offers such a service at their Web site: **http://boards.webmd.com/roundtable**. These online communities can help you connect with a network of people whose concerns are similar to yours. Online support groups are places where people can talk informally. If you read about a novel approach, consult with your child's doctor or other healthcare providers, as the treatments or discoveries you hear about may not be scientifically proven to be safe and effective.

## Finding Doctors

All parents must go through the process of selecting a physician for their children with cerebral palsy. While this process will vary, the Agency for Healthcare Research and Quality makes a number of suggestions, including the following:[10]

- If your child is in a managed care plan, check the plan's list of doctors first.
- Ask doctors or other health professionals who work with doctors, such as hospital nurses, for referrals.
- Call a hospital's doctor referral service, but keep in mind that these services usually refer you to doctors on staff at that particular hospital. The services do not have information on the quality of care that these doctors provide.
- Some local medical societies offer lists of member doctors. Again, these lists do not have information on the quality of care that these doctors provide.

Additional steps you can take to locate doctors include the following:

- Check with the associations listed earlier in this chapter.
- Information on doctors in some states is available on the Internet at **http://www.docboard.org**. This Web site is run by "Administrators in Medicine," a group of state medical board directors.
- The American Board of Medical Specialties can tell you if your child's doctor is board certified. "Certified" means that the doctor has completed a training program in a specialty and has passed an exam, or "board," to assess his or her knowledge, skills, and experience to provide quality patient care in that specialty. Primary care doctors may also be certified as specialists. The AMBS Web site is located at **http://www.abms.org/newsearch.asp**.[11] You can also contact the ABMS by phone at 1-866-ASK-ABMS.
- You can call the American Medical Association (AMA) at 800-665-2882 for information on training, specialties, and board certification for many licensed doctors in the United States. This information also can be found in "Physician Select" at the AMA's Web site: **http://www.ama-assn.org/aps/amahg.htm**.

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[10] This section is adapted from the AHRQ: www.ahrq.gov/consumer/qntascii/qntdr.htm.
[11] While board certification is a good measure of a doctor's knowledge, it is possible to receive quality care from doctors who are not board certified.

If the previous sources did not meet your needs, you may want to log on to the Web site of the National Organization for Rare Disorders (NORD) at **http://www.rarediseases.org/**. NORD maintains a database of doctors with expertise in various rare medical conditions. The Metabolic Information Network (MIN), 800-945-2188, also maintains a database of physicians with expertise in various metabolic diseases.

## Finding a Neurologist

The American Academy of Neurology allows you to search for member neurologists by name or location. To use this service, go to **http://www.aan.com/**, select "Find a Neurologist" from the toolbar. Enter your search criteria, and click "Search." To find out more information on a particular neurologist, click on the physician's name.
If the previous sources did not meet your needs, you may want to log on to the Web site of the National Organization for Rare Disorders (NORD) at **http://www.rarediseases.org/**. NORD maintains a database of doctors with expertise in various rare diseases. The Metabolic Information Network (MIN), 800-945-2188, also maintains a database of physicians with expertise in various metabolic diseases.

## Selecting Your Doctor[12]

When you have compiled a list of prospective doctors, call each of their offices. First, ask if the doctor accepts your child's health insurance plan and if he or she is taking new patients. If the doctor is not covered by your child's plan, ask yourself if you are prepared to pay the extra costs. The next step is to schedule a visit with your first choice. During the first visit you will have the opportunity to evaluate your child's doctor and to find out if your child feels comfortable with him or her.

[12] This section has been adapted from the AHRQ: www.ahrq.gov/consumer/qntascii/qntdr.htm.

## Working with Your Child's Doctor[13]

Research has shown that parents who have good relationships with their children's doctors tend to be more satisfied with their children's care. Here are some tips to help you and your child's doctor become partners:

- You know important things about your child's symptoms and health history. Tell the doctor what you think he or she needs to know.
- Always bring any medications your child is currently taking with you to the appointment, or you can bring a list of your child's medications including dosage and frequency information. Talk about any allergies or reactions your child has had to medications.
- Tell your doctor about any natural or alternative medicines your child is taking.
- Bring other medical information, such as x-ray films, test results, and medical records.
- Ask questions. If you don't, the doctor will assume that you understood everything that was said.
- Write down your questions before the doctor's visit. List the most important ones first to make sure that they are addressed.
- Ask the doctor to draw pictures if you think that this will help you and your child understand.
- Take notes. Some doctors do not mind if you bring a tape recorder to help you remember things, but always ask first.
- Take information home. Ask for written instructions. Your child's doctor may also have brochures and audio and videotapes on cerebral palsy.

By following these steps, you will enhance the relationship you and your child have with the physician.

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[13] This section has been adapted from the AHRQ: www.ahrq.gov/consumer/qntascii/qntdr.htm.

## Broader Health-Related Resources

In addition to the references above, the NIH has set up guidance Web sites that can help parents find healthcare professionals. These include:[14]

- Caregivers:
  **http://www.nlm.nih.gov/medlineplus/caregivers.html**
- Choosing a Doctor or Healthcare Service:
  **http://www.nlm.nih.gov/medlineplus/choosingadoctororhealthcareservice.html**
- Hospitals and Health Facilities:
  **http://www.nlm.nih.gov/medlineplus/healthfacilities.html**

## Vocabulary Builder

The following vocabulary builder provides definitions of words used in this chapter that have not been defined in previous chapters:

**Anemia:** A reduction in the number of circulating erythrocytes or in the quantity of hemoglobin. [NIH]

**Ataxia:** Failure of muscular coordination; irregularity of muscular action. [EU]

**Cataract:** An opacity, partial or complete, of one or both eyes, on or in the lens or capsule, especially an opacity impairing vision or causing blindness. The many kinds of cataract are classified by their morphology (size, shape, location) or etiology (cause and time of occurrence). [EU]

**Cerebrospinal:** Pertaining to the brain and spinal cord. [EU]

**Chromosomal:** Pertaining to chromosomes. [EU]

**Dilatation:** The condition, as of an orifice or tubular structure, of being dilated or stretched beyond the normal dimensions. [EU]

**Hemorrhage:** Bleeding or escape of blood from a vessel. [NIH]

**Hydrocephalus:** A condition marked by dilatation of the cerebral ventricles, most often occurring secondarily to obstruction of the cerebrospinal fluid pathways, and accompanied by an accumulation of cerebrospinal fluid within the skull; the fluid is usually under increased pressure, but occasionally may be normal or nearly so. It is typically characterized by enlargement of the head, prominence of the forehead, brain atrophy, mental

[14] You can access this information at:
http://www.nlm.nih.gov/medlineplus/healthsystem.html.

deterioration, and convulsions; may be congenital or acquired; and may be of sudden onset (acute h.) or be slowly progressive (chronic or primary b.). [EU]

**Infantile:** Pertaining to an infant or to infancy. [EU]

**Lip:** Either of the two fleshy, full-blooded margins of the mouth. [NIH]

**Manic:** Affected with mania. [EU]

**Osteogenesis:** The histogenesis of bone including ossification. It occurs continuously but particularly in the embryo and child and during fracture repair. [NIH]

**Paralysis:** Loss or impairment of motor function in a part due to lesion of the neural or muscular mechanism; also by analogy, impairment of sensory function (sensory paralysis). In addition to the types named below, paralysis is further distinguished as traumatic, syphilitic, toxic, etc., according to its cause; or as obturator, ulnar, etc., according to the nerve part, or muscle specially affected. [EU]

**Paraplegia:** Paralysis of the legs and lower part of the body. [EU]

**Schizophrenia:** A severe emotional disorder of psychotic depth characteristically marked by a retreat from reality with delusion formation, hallucinations, emotional disharmony, and regressive behavior. [NIH]

**Sclerosis:** A induration, or hardening; especially hardening of a part from inflammation and in diseases of the interstitial substance. The term is used chiefly for such a hardening of the nervous system due to hyperplasia of the connective tissue or to designate hardening of the blood vessels. [EU]

**Trisomy:** The possession of a third chromosome of any one type in an otherwise diploid cell. [NIH]

# CHAPTER 3. CLINICAL TRIALS AND CEREBRAL PALSY

## Overview

Very few medical conditions have a single treatment. The basic treatment guidelines that your child's physician has discussed with you, or those that you have found using the techniques discussed in Chapter 1, may provide you with all that you will require. For some patients, current treatments can be enhanced with new or innovative techniques currently under investigation. In this chapter, we will describe how clinical trials work and show you how to keep informed of trials concerning cerebral palsy.

### What Is a Clinical Trial?[15]

Clinical trials involve the participation of people in medical research. Most medical research begins with studies in test tubes and on animals. Treatments that show promise in these early studies may then be tried with people. The only sure way to find out whether a new treatment is safe, effective, and better than other treatments for cerebral palsy is to try it on patients in a clinical trial.

[15] The discussion in this chapter has been adapted from the NIH and the NEI: www.nei.nih.gov/netrials/ctivr.htm.

### What Kinds of Clinical Trials Are There?

Clinical trials are carried out in three phases:

- **Phase I.** Researchers first conduct Phase I trials with small numbers of patients and healthy volunteers. If the new treatment is a medication, researchers also try to determine how much of it can be given safely.
- **Phase II.** Researchers conduct Phase II trials in small numbers of patients to find out the effect of a new treatment on cerebral palsy.
- **Phase III.** Finally, researchers conduct Phase III trials to find out how new treatments for cerebral palsy compare with standard treatments already being used. Phase III trials also help to determine if new treatments have any side effects. These trials--which may involve hundreds, perhaps thousands, of people--can also compare new treatments with no treatment.

### How Is a Clinical Trial Conducted?

Various organizations support clinical trials at medical centers, hospitals, universities, and doctors' offices across the United States. The "principal investigator" is the researcher in charge of the study at each facility participating in the clinical trial. Most clinical trial researchers are medical doctors, academic researchers, and specialists. The "clinic coordinator" knows all about how the study works and makes all the arrangements for your child's visits.

All doctors and researchers who take part in the study on cerebral palsy carefully follow a detailed treatment plan called a protocol. This plan fully explains how the doctors will treat your child in the study. The "protocol" ensures that all patients are treated in the same way, no matter where they receive care.

Clinical trials are controlled. This means that researchers compare the effects of the new treatment with those of the standard treatment. In some cases, when no standard treatment exists, the new treatment is compared with no treatment. Patients who receive the new treatment are in the treatment group. Patients who receive a standard treatment or no treatment are in the "control" group. In some clinical trials, patients in the treatment group get a new medication while those in the control group get a placebo. A placebo is a harmless substance, a "dummy" pill, that has no effect on cerebral palsy. In other clinical trials, where a new surgery or device (not a medicine) is being tested, patients in the control group may receive a "sham treatment." This

treatment, like a placebo, has no effect on cerebral palsy and will not harm your child.

Researchers assign patients "randomly" to the treatment or control group. This is like flipping a coin to decide which patients are in each group. If you choose to have your child participate in a clinical trial, you will not know which group he or she will be appointed to. The chance of any patient getting the new treatment is about 50 percent. You cannot request that your child receive the new treatment instead of the placebo or "sham" treatment. Often, you will not know until the study is over whether your child has been in the treatment group or the control group. This is called a "masked" study. In some trials, neither doctors nor patients know who is getting which treatment. This is called a "double masked" study. These types of trials help to ensure that the perceptions of the participants or doctors will not affect the study results.

### Natural History Studies

Unlike clinical trials in which patient volunteers may receive new treatments, natural history studies provide important information to researchers on how cerebral palsy develops over time. A natural history study follows patient volunteers to see how factors such as age, sex, race, or family history might make some people more or less at risk for cerebral palsy. A natural history study may also tell researchers if diet, lifestyle, or occupation affects how a medical condition develops and progresses. Results from these studies provide information that helps answer questions such as: How fast will a medical condition usually progress? How bad will the condition become? Will treatment be needed?

### What Is Expected of Your Child in a Clinical Trial?

Not everyone can take part in a clinical trial for a specific medical condition. Each study enrolls patients with certain features or eligibility criteria. These criteria may include the type and stage of the condition, as well as, the age and previous treatment history of the patient. You or your child's doctor can contact the sponsoring organization to find out more about specific clinical trials and their eligibility criteria. If you would like your child to participate in a clinical trial, your child's doctor must contact one of the trial's investigators and provide details about his or her diagnosis and medical history.

When participating in a clinical trial, your child may be required to have a number of medical tests. Your child may also need to take medications and/or undergo surgery. Depending upon the treatment and the examination procedure, your child may be required to receive inpatient hospital care. He or she may have to return to the medical facility for follow-up examinations. These exams help find out how well the treatment is working. Follow-up studies can take months or years. However, the success of the clinical trial often depends on learning what happens to patients over a long period of time. Only patients who continue to return for follow-up examinations can provide this important long-term information.

## Recent Trials on Cerebral Palsy

The National Institutes of Health and other organizations sponsor trials on various medical conditions. Because funding for research goes to the medical areas that show promising research opportunities, it is not possible for the NIH or others to sponsor clinical trials for every medical condition at all times. The following lists recent trials dedicated to cerebral palsy.[16] If the trial listed by the NIH is still recruiting, your child may be eligible. If it is no longer recruiting or has been completed, then you can contact the sponsors to learn more about the study and, if published, the results. Further information on the trial is available at the Web site indicated. Please note that some trials may no longer be recruiting patients or are otherwise closed. Before contacting sponsors of a clinical trial, consult with your child's physician who can help you determine if your child might benefit from participation.

- **BEAM Trial**

  Condition(s): Cerebral Palsy; Intraventricular hemorrhage; Periventricular Leukomalacia; Pulmonary Edema; Abruptio Placentae

  Study Status: This study is currently recruiting patients.

  Sponsor(s): National Institute of Child Health and Human Development (NICHD); National Institute of Neurological Disorders and Stroke (NINDS)

  Purpose - Excerpt: As many more premature infants survive, the numbers of these infants with health problems also has increased. The rate of cerebral palsy in extremely premature infants is approximately 20%. Magnesium sulfate, the most commonly used drug in the US used to stop premature labor may prevent CP. This trial tests whether magnesium sulfate given to a woman in labor with a premature fetus (24

[16] These are listed at www.ClinicalTrials.gov.

to 31 weeks out of 40) will reduce the rate of death or moderate to severe CP in the children at 2 years. The children receive ultrasounds of their brains as infants and attend three follow-up visits over two years to assess their health and development.

Phase(s): Phase III

Study Type: Interventional

Contact(s): see Web site below

Web Site:
http://clinicaltrials.gov/ct/gui/show/NCT00014989;jsessionid=D72559471452978678233 2E3E2333239

- **Eye-Hand Coordination in Children with Spastic Diplegia**

  Study Status: This study is currently recruiting patients.

  Sponsor(s): National Institute of Neurological Disorders and Stroke (NINDS)

  Purpose - Excerpt: This study will examine how the brain controls eye-hand coordination (visuomotor skills) in children with spastic diplegia and will determine whether impairment of this skill is related to the learning difficulties in school that some of these children experience. Spastic diplegia is a form of cerebral palsy that affects the legs more than the hands. The brain injury causing the leg problem in this disease may also cause difficulty with eye-hand coordination. Healthy normal volunteers and children with spastic diplegia between 6 and 12 years of age may be eligible for this study. Candidates will be screened with a review of medical and school records, psychological testing, neurological and physical examinations, and assessment of muscle function in the arms and legs. Participants may undergo one or more of the following procedures: Neuropsychological testing (1 to 2 hours) - involves sitting at a computer and answering questions, such as whether the letters on the screen make up a real word. Magnetic resonance imaging (MRI) (45 minutes) - uses a strong magnetic field and radio waves to provide images of the brain. The child lies on a table in a narrow cylindrical machine while the scans are obtained. Both the child and parent wear earplugs to muffle the loud noise the radio waves make while the images are formed. Electroencephalography (EEG) and electromyography (EMG) (1 to 2 hours) - EEG uses electrodes to record the electrical activity of the brain. The electrodes are in a special cap that is worn on the head during the procedure. EMG records electrical activity from muscles. Electrodes are placed on the skin over certain muscles. During the test, the child makes simple repetitive movements, such as finger tapping. The cap and the electrodes on the skin are removed at the end of the test.

Study Type: Observational

Contact(s): Maryland; National Institute of Neurological Disorders and Stroke (NINDS), 9000 Rockville Pike Bethesda, Maryland, 20892, United States; Recruiting; Patient Recruitment and Public Liaison Office 1-800-411-1222 prpl@mail.cc.nih.gov; TTY 1-866-411-1010

Web Site:
http://clinicaltrials.gov/ct/gui/show/NCT00024791;jsessionid=D72559471452978678233 2E3E2333239

- **Study of Tongue Pressures**

  Condition(s): Deglutition Disorder; Healthy

  Study Status: This study is currently recruiting patients.

  Sponsor(s): Warren G Magnuson Clinical Center (CC)

  Purpose - Excerpt: This study will examine tongue strength and endurance, how the tongue applies pressure during swallowing, and how the chin muscles react during swallowing in healthy volunteers and in patients with dysphagia (difficulty swallowing). The information from this study may be helpful in developing better treatments for people with swallowing problems. Healthy volunteers who have no history of speech, swallowing or breathing problems and patients who have difficulty swallowing because of a neurologic disorder, musculoskeletal disease or head and neck cancer that caused tongue weakness and dysphagia may be eligible for this study. Such medical conditions may include stroke, Parkinson's disease, multiple sclerosis corticobasal degeneration, progressive supranuclear palsy, Gaucher's disease, leukodystrophy, cerebral palsy, myositis, or mouth, throat or neck cancer. Volunteers who have not participated in a NIH protocol for 1 year will be screened with a brief medical history and physical examination. Dysphagic patients not currently enrolled in a NIH protocol will also have a brief medical history and physical examination. In addition, they will have a modified barium swallow to determine the nature and degree of their swallowing difficulty. Participants will have a 15-minute examination of movements of their tongue, lips and jaw and will fill out a questionnaire about their swallowing ability. They will then begin the tongue pressure test. To monitor and record tongue pressure, a thin rubber strip with air-filled pressure bulbs will be attached to the roof of the mouth with dental adhesive. The pressure bulbs are connected to an external pressure-reading device. In addition, a small plastic pad with adhesive backing will be placed under the chin. Electrodes (wires) attached to the pad record chin muscle activities. With the pressure bulbs and chin electrodes in place, the patient will perform tongue pressure tasks to test tongue

strength, how long the patient can maintain a certain tongue pressure, and how fast tongue pressure drops. The tasks include saliva swallows, water swallows and cup-drinking.

Study Type: Observational

Contact(s): Maryland; Warren G. Magnuson Clinical Center (CC), 9000 Rockville Pike Bethesda, Maryland, 20892, United States; Recruiting; Patient Recruitment and Public Liaison Office 1-800-411-1222 prpl@mail.cc.nih.gov; TTY 1-866-411-1010

Web Site:
http://clinicaltrials.gov/ct/gui/show/NCT00013832;jsessionid=D72559471452978678233 2E3E2333239

- **Heel Cord Surgery for Cerebral Palsy**

  Condition(s): Cerebral Palsy

  Study Status: This study is no longer recruiting patients.

  Sponsor(s): National Institute of Child Health and Human Development (NICHD)

  Purpose - Excerpt: Toe walking is the most common problem in children with cerebral palsy (CP). This study compares the effectiveness of three surgical techniques commonly used to correct this problem. Ankle movement, walking and other tests of disability will be examined before and 12 months after surgery.

  Phase(s): Phase I

  Study Type: Interventional

  Contact(s): Missouri; Jack R. Engsberg, Ph.D., St. Louis, Missouri, 63108, United States; Jack R Engsberg, PhD 314-454-8288 jre6264@BJCMail.carenet.org

  Web Site:
  http://clinicaltrials.gov/ct/gui/show/NCT00009607;jsessionid=D72559471452978678233 2E3E2333239

- **Prospective Studies of the Use of Self Hypnosis, Acupuncture and Osteopathic Manipulation on Muscle Tension in Children with Spastic Cerebral Palsy**

  Condition(s): Spastic Cerebral Palsy

  Study Status: This study is not yet open for patient recruitment.

  Sponsor(s): National Center for Complementary and Alternative Medicine (NCCAM)

Purpose - Excerpt: We propose to identify patients and families for inclusion in pilot studies of the three modalities. Patients and their families will be asked to participate in these studies. Our research group has done some preliminary work with the modality of hypnotherapy, but has no experience to date with the other two modalities. The idea to try relaxation techniques was generated by the observation that there is great variation in the degree to spasticity at different times in the same patient with CP. When queried, mothers responded that they were able to get their child to relax and decrease the tension in their muscles by stroking, talking softly, and/or by playing certain types of music. The availability of hypnosis and training in self-hypnosis was presented to several families of our patients. Their understanding and acceptance of this alternate therapy was gratifying. The results of this therapy have been promising and have encouraged us to proceed with this modality and to consider making other nonconventional modalities available to our patients. We hypothesize that at least one of the three modalities will be accepted readily by patients with CP and their families, and with their acceptance compliance with the method chosen will be at levels of 80 percent or more.

Phase(s): Phase II

Study Type: Interventional

Contact(s): Burris Duncan 1-520-656-6102; Arizona; University of Arizona, Tucson, Arizona, 85724-5035, United States. Study chairs or principal investigators: Burris Duncan, Principal Investigator; University of Arizona

Web Site:
http://clinicaltrials.gov/ct/gui/show/NCT00011024;jsessionid=D72559471452978678233 2E3E2333239

## Benefits and Risks[17]

### What Are the Benefits of Participating in a Clinical Trial?

If you are considering a clinical trial, it is important to realize that your child's participation can bring many benefits:

- A new treatment could be more effective than the current treatment for cerebral palsy. Although only half of the participants in a clinical trial receive the experimental treatment, if the new treatment is proved to be more effective and safer than the current treatment, then those patients who did not receive the new treatment during the clinical trial may be among the first to benefit from it when the study is over.
- If the treatment is effective, then it may improve your child's health.
- Clinical trial patients receive the highest quality of medical care. Experts watch them closely during the study and may continue to follow them after the study is over.
- People who take part in trials contribute to scientific discoveries that may help others with cerebral palsy. In cases where certain medical conditions run in families, your child's participation may lead to better care or prevention for you and other family members.

### The Informed Consent

Once you agree to have your child take part in a clinical trial, you will be asked to sign an "informed consent." This document explains a clinical trial's risks and benefits, the researcher's expectations of you and your child, and your child's rights as a patient.

### What Are the Risks?

Clinical trials may involve risks as well as benefits. Whether or not a new treatment will work cannot be known ahead of time. There is always a chance that a new treatment may not work better than a standard treatment. There is also the possibility that it may be harmful. The treatment your child

[17] This section has been adapted from ClinicalTrials.gov, a service of the National Institutes of Health: http://www.clinicaltrials.gov/ct/gui/c/a1r/info/whatis?JServSessionIdzone_ct=9jmun6f291.

receives may cause side effects that are serious enough to require medical attention.

### How Is Your Child's Safety Protected?

Clinical trials can raise fears of the unknown. Understanding the safeguards that protect your child can ease some of these fears. Before a clinical trial begins, researchers must get approval from their hospital's Institutional Review Board (IRB), an advisory group that makes sure a clinical trial is designed to protect your child's safety. During a clinical trial, doctors will closely watch your child to see if the treatment is working and if he or she is experiencing any side effects. All the results are carefully recorded and reviewed. In many cases, experts from the Data and Safety Monitoring Committee carefully monitor each clinical trial and can recommend that a study be stopped at any time. Your child will only be asked to participate in a clinical trial as a volunteer with your informed consent.

### What Are Your Child's Rights in a Clinical Trial?

If your child is eligible for a clinical trial, you will be given information to help you decide whether or not you want him or her to participate. You and your child have the right to:

- Information on all known risks and benefits of the treatments in the study.
- Know how the researchers plan to carry out the study, for how long, and where.
- Know what is expected of your child.
- Know any costs involved for you or your child's insurance provider.
- Know before any of your child's medical or personal information is shared with other researchers involved in the clinical trial.
- Talk openly with doctors and ask any questions.

After your child joins a clinical trial, you and your child have the right to:

- Leave the study at any time. Participation is strictly voluntary.
- Receive any new information about the new treatment.
- Continue to ask questions and get answers.
- Maintain your child's privacy. Your child's name will not appear in any reports based on the study.

- Know whether your child participated in the treatment group or the control group (once the study has been completed).

### What about Costs?

In some clinical trials, the research facility pays for treatment costs and other associated expenses. You or your child's insurance provider may have to pay for costs that are considered standard care. These things may include inpatient hospital care, laboratory and other tests, and medical procedures. You also may need to pay for travel between your home and the clinic. You should find out about costs before committing your child to participation in the trial. If your child has health insurance, find out exactly what it will cover. If your child does not have health insurance, or if your child's insurance policy will not cover care, talk to the clinic staff about other options for covering the costs.

### What Questions Should You Ask before Your Child Participates in a Clinical Trial?

Questions you should ask when deciding whether or not to enroll your child in a clinical trial include the following:

- What is the purpose of the clinical trial?
- What are the standard treatments for cerebral palsy? Why do researchers think the new treatment may be better? What is likely to happen to my child with or without the new treatment?
- What tests and treatments will my child need? Will my child need surgery? Medication? Hospitalization?
- How long will the treatment last? How often will my child have to come back for follow-up exams?
- What are the treatment's possible benefits to my child's condition? What are the short- and long-term risks? What are the possible side effects?
- Will the treatment be uncomfortable? Will it make my child sick? If so, for how long?
- How will my child's health be monitored?
- Where will my child need to go for the clinical trial?
- How much will it cost to participate in the study? What costs are covered by the study? How much will my child's health insurance cover?
- Who will be in charge of my child's care?

- Will taking part in the study affect my child's daily life?
- How does my child feel about taking part in a clinical trial? Will other family members benefit from my child's contributions to new medical knowledge?

## Keeping Current on Clinical Trials

Various government agencies maintain databases on trials. The U.S. National Institutes of Health, through the National Library of Medicine, has developed ClinicalTrials.gov to provide the public and physicians with current information about clinical research across the broadest number of medical conditions.

The site was launched in February 2000 and currently contains approximately 5,700 clinical studies in over 59,000 locations worldwide, with most studies being conducted in the United States. ClinicalTrials.gov receives about 2 million hits per month and hosts approximately 5,400 visitors daily. To access this database, simply go to their Web site (**www.clinicaltrials.gov**) and search by "cerebral palsy" (or synonyms).

While ClinicalTrials.gov is the most comprehensive listing of NIH-supported clinical trials available, not all trials are in the database. The database is updated regularly, so clinical trials are continually being added. The following is a list of specialty databases affiliated with the National Institutes of Health that offer additional information on trials:

- For clinical studies at the Warren Grant Magnuson Clinical Center located in Bethesda, Maryland, visit their Web site: **http://clinicalstudies.info.nih.gov/**
- For clinical studies conducted at the Bayview Campus in Baltimore, Maryland, visit their Web site: **http://www.jhbmc.jhu.edu/studies/index.html**
- For trials on neurological disorders and stroke, visit and search the Web site sponsored by the National Institute of Neurological Disorders and Stroke of the NIH: **http://www.ninds.nih.gov/funding/funding_opportunities.htm#Clinical_Trials**

## General References

The following references describe clinical trials and experimental medical research. They have been selected to ensure that they are likely to be available from your local or online bookseller or university medical library. These references are usually written for healthcare professionals, so you may consider consulting with a librarian or bookseller who might recommend a particular reference. The following includes some of the most readily available references (sorted alphabetically by title; hyperlinks provide rankings, information and reviews at Amazon.com):

- **A Guide to Patient Recruitment : Today's Best Practices & Proven Strategies** by Diana L. Anderson; Paperback - 350 pages (2001), CenterWatch, Inc.; ISBN: 1930624115; **http://www.amazon.com/exec/obidos/ASIN/1930624115/icongroupinterna**
- **A Step-By-Step Guide to Clinical Trials** by Marilyn Mulay, R.N., M.S., OCN; Spiral-bound - 143 pages Spiral edition (2001), Jones & Bartlett Pub; ISBN: 0763715697; **http://www.amazon.com/exec/obidos/ASIN/0763715697/icongroupinterna**
- **The CenterWatch Directory of Drugs in Clinical Trials** by CenterWatch; Paperback - 656 pages (2000), CenterWatch, Inc.; ISBN: 0967302935; **http://www.amazon.com/exec/obidos/ASIN/0967302935/icongroupinterna**
- **The Complete Guide to Informed Consent in Clinical Trials** by Terry Hartnett (Editor); Paperback - 164 pages (2000), PharmSource Information Services, Inc.; ISBN: 0970153309; **http://www.amazon.com/exec/obidos/ASIN/0970153309/icongroupinterna**
- **Dictionary for Clinical Trials** by Simon Day; Paperback - 228 pages (1999), John Wiley & Sons; ISBN: 0471985961; **http://www.amazon.com/exec/obidos/ASIN/0471985961/icongroupinterna**
- **Extending Medicare Reimbursement in Clinical Trials** by Institute of Medicine Staff (Editor), et al; Paperback 1st edition (2000), National Academy Press; ISBN: 0309068886; **http://www.amazon.com/exec/obidos/ASIN/0309068886/icongroupinterna**
- **Handbook of Clinical Trials** by Marcus Flather (Editor); Paperback (2001), Remedica Pub Ltd; ISBN: 1901346293; **http://www.amazon.com/exec/obidos/ASIN/1901346293/icongroupinterna**

## Vocabulary Builder

The following vocabulary builder gives definitions of words used in this chapter that have not been defined in previous chapters:

**Ankle:** That part of the lower limb directly above the foot. [NIH]

**Barium:** An element of the alkaline earth group of metals. It has an atomic symbol Ba, atomic number 56, and atomic weight 138. All of its acid-soluble salts are poisonous. [NIH]

**Dysphagia:** Difficulty in swallowing. [EU]

**Edema:** Excessive amount of watery fluid accumulated in the intercellular spaces, most commonly present in subcutaneous tissue. [NIH]

**Electroencephalography:** The recording of the electric currents developed in the brain, by means of electrodes applied to the scalp, to the surface of the brain (intracranial e.) or placed within the substance of the brain (depth e.). [EU]

**Myositis:** Inflammation of a voluntary muscle. [EU]

**Prophylaxis:** The prevention of disease; preventive treatment. [EU]

**Pulmonary:** Pertaining to the lungs. [EU]

# PART II: ADDITIONAL RESOURCES AND ADVANCED MATERIAL

## ABOUT PART II

In Part II, we introduce you to additional resources and advanced research on cerebral palsy. All too often, parents who conduct their own research are overwhelmed by the difficulty in finding and organizing information. The purpose of the following chapters is to provide you an organized and structured format to help you find additional information resources on cerebral palsy. In Part II, as in Part I, our objective is not to interpret the latest advances on cerebral palsy or render an opinion. Rather, our goal is to give you access to original research and to increase your awareness of sources you may not have already considered. In this way, you will come across the advanced materials often referred to in pamphlets, books, or other general works. Once again, some of this material is technical in nature, so consultation with a professional familiar with cerebral palsy is suggested.

# CHAPTER 4. STUDIES ON CEREBRAL PALSY

## Overview

Every year, academic studies are published on cerebral palsy or related conditions. Broadly speaking, there are two types of studies. The first are peer reviewed. Generally, the content of these studies has been reviewed by scientists or physicians. Peer-reviewed studies are typically published in scientific journals and are usually available at medical libraries. The second type of studies is non-peer reviewed. These works include summary articles that do not use or report scientific results. These often appear in the popular press, newsletters, or similar periodicals.

In this chapter, we will show you how to locate peer-reviewed references and studies on cerebral palsy. We will begin by discussing research that has been summarized and is free to view by the public via the Internet. We then show you how to generate a bibliography on cerebral palsy and teach you how to keep current on new studies as they are published or undertaken by the scientific community.

## The Combined Health Information Database

The Combined Health Information Database summarizes studies across numerous federal agencies. To limit your investigation to research studies and cerebral palsy, you will need to use the advanced search options. First, go to **http://chid.nih.gov/index.html**. From there, select the "Detailed Search" option (or go directly to that page with the following hyperlink: **http://chid.nih.gov/detail/detail.html**). The trick in extracting studies is found in the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer, and the

format option "Journal Article." At the top of the search form, select the number of records you would like to see (we recommend 100) and check the box to display "whole records." We recommend that you type in "cerebral palsy" (or synonyms) into the "For these words:" box. Consider using the option "anywhere in record" to make your search as broad as possible. If you want to limit the search to only a particular field, such as the title of the journal, then select this option in the "Search in these fields" drop box. The following is a sample of what you can expect from this type of search:

- **Epilepsy in Patients With Spastic Cerebral Palsy: Correlation With MRI Findings at 5 Years of Age**

  Source: Brain and Development. 21(8):540-543, December 1999.

  Summary: Researchers examined the relationship between epilepsy in the first 5 years of life and the type of brain lesion in patients with spastic cerebral palsy (CP), as visualized by magnetic resonance imaging (MRI). They studied 152 patients with spastic CP who had been under the care of the Department of Pediatrics, Anjo Kosei Hospital and Daini-Aoitari Gakuen Aichi Prefectural Hospital and Rehabilitation Center for Disabled Children, Aichi, Japan, from 1993 through 1994. Patients had had brain MRI scans and had been followed up to more than 5 years of age. The patients were diagnosed with epilepsy if and when they had had at least two unprovoked seizures. MRI was performed when the patients were an average of 3.3 years old. MRI-visualized brain lesions were found in 130 patients. Fourteen had lesions characterized as a congenital anomaly, and 116 had lesions characterized as a perinatal injury. The patients with perinatal injury were subdivided into two groups: (1) Those with preterm injury alone (group P), and (2) those with term type injury with or without preterm injury (group T). Group P of the perinatal injury group contained 89 patients, and group T contained 27 patients. The median age at last followup was 109 months in patients with congenital anomalies, and 90 months in those with perinatal injury. Epilepsy developed in 7 (50 percent) of the 14 patients with a congenital anomaly, and in 30 (26 percent) of the 116 with perinatal injury. The initial seizure type was infantile spasms (IS) in half and partial seizures in a third of the patients with epilepsy in both groups. Seizure onset occurred within the first 12 months of life in 66 percent of the patients with congenital anomaly, and in 43 percent of those with perinatal injury. Patients in the congenital anomaly group had a significantly earlier onset of seizure activity than those in the perinatal injury group. Of patients in the perinatal injury group, group T patients showed a higher incidence and later onset of epilepsy than those in group P, 52 versus 18 percent, respectively, within the first 5 years of life. Researchers concluded that the proportion of

patients with epilepsy and the time course of the development of epilepsy differ with the type of brain lesions, visualizable by MRI. Further studies using larger numbers of patients are necessary to determine exactly the relationship between childhood epilepsy and the type of brain lesions. 3 figures, 1 table, 10 references.

- **Characteristics and Prognosis of Epilepsy in Children with Cerebral Palsy**

  Source: Journal of Child Neurology. 14(5):289-294, May 1999.

  Summary: Researchers conducted a prospective study to describe the characteristics of epilepsy in patients with cerebral palsy and to find the relapse rate due to discontinuation of antiepileptic drugs (AED's) after a 3-year seizure-free period. The researchers followed (1) 178 consecutive children with epilepsy and cerebral palsy for 5 years after the onset of seizures, and (2) 150 consecutive patients with epilepsy without cerebral palsy for 5 years. They assessed epilepsy outcome according to the patients' status at their last followup visit. The groups were compared regarding (1) sex, (2) age at onset of seizures, (3) epilepsy and seizure types, (4) presence of neonatal seizures or status epilepticus, (5) frequency of seizures, (6) need for monotherapy or polytherapy, (7) electroencephalography findings, (8) computed tomography or magnetic resonance imaging findings, (9) presence of other impairments, and (10) recurrence rate after AED discontinuation. Results showed that (1) the overall prevalence of epilepsy in the children with cerebral palsy was 36.1 percent; (2) patients with atonic-diplegic, dystonic, tetraplegic, and hemiplegic cerebral palsy had higher prevalences of epilepsy; (3) 134 (75.3 percent) of 178 children with cerebral palsy could discontinue AED's successfully after a 3-year seizure-free period; (4) 116 (86.6 percent) of these children had no relapse of seizures during the followup period, resulting in a relapse rate of 13.4 percent; (5) 44 children (24.7 percent) with cerebral palsy were still having seizures or were seizure free for less than 3 years at followup; and (6) 121 children (80.7 percent) in the control group were seizure free after 3 years, while the relapse rate was 4.7 percent. The researchers conclude that epilepsy is a major prognostic factor regarding the presence of mental retardation and the motor development of children with cerebral palsy. 2 figures, 5 tables, 38 references.

- **Tooth Wear in Children: An Investigation of Etiological Factors in Children with Cerebral Palsy and Gastroesophageal Reflux**

  Source: Journal of Dentistry for Children. 65(6): 484-486. November-December 1998.

Contact: Available from American Society of Dentistry for Children. John Hancock Center, 875 North Michigan Avenue, Suite 4040, Chicago, IL 60611-1901. (312) 943-1244.

Summary: This article reports on a study undertaken to establish the prevalence and distribution of tooth wear in different groups of children attending a children's hospital and to assess the possible influence of gastroesophageal reflux, dietary factors, and parafunctional activity. Fifty one children were included; they were examined clinically and all surfaces of all teeth were scored on a tooth wear index. The children were classified in one of three groups: no or only mild erosion; moderate erosion; or severe erosion. Following the clinical examination, a structured interview was undertaken and an extensive questionnaire was completed (including medical history, medication, gastroesophageal reflux, feeding and drinking habits, parafunctional activity, and toothbrushing procedures). Of the 51 children examined, 21 had cerebral palsy. The other 30 children had a wide range of medical problems, many with congenital cardiac conditions, renal and liver transplants, or who were in remission from leukemia. The results showed that tooth wear was related to whether the children had gastroesophageal reflux, not to whether they had cerebral palsy. This appeared to be much more important than parafunctional activity or any of the dietary influences. In addition, there may be a relationship between the consumption of acidic foods and drinks and regurgitation associated with gastroesophageal reflux. Nevertheless, much gastroesophageal reflux is due to the incompetence of the gastroesophageal sphincter, which may occur as a primary disorder or a secondary neuromuscular problem (such as occurs in cerebral palsy). 3 tables. 10 references.

- **Dental Hygiene Care for the Patient with Cerebral Palsy**

  Source: Access. 10(6): 34-37. July 1995.

  Contact: Available from American Dental Hygienists' Association (ADHA). 444 North Michigan Avenue, Chicago, IL 60611. (800) 243-2342 or (312) 440-8900; Fax (312) 440-8929; E-mail: adha@ix.netcom.com; http://www.adha.org.

  Summary: This article was written to familiarize dental hygienists with dental hygiene care for patients with cerebral palsy. The author introduces the topic with a review of cerebral palsy, its symptoms, and associated movement disorders. The next section of the article addresses oral health care considerations. It covers such topics as dealing with patient movement during treatment, reducing stress associated with the dental visit, the use of restraints to keep the head positioned for adequate visualization, the use of desensitization and relaxation techniques, using

mouth props, and problems with delayed swallowing. Other topics covered include oral health care needs of patients with cerebral palsy and planning dental hygiene services. The author concludes that working with patients with cerebral palsy can be a challenging and rewarding experience. 3 figures. 5 references.

- **Dental Health of Children with Cerebral Palsy Following Sialodochoplasty**

  Source: SCD. Special Care in Dentistry. 15(6): 234-238. November-December 1995.

  Summary: This article reports on a study that investigated 19 children with cerebral palsy (CP) following sialodochoplasty (surgery group) and 75 children with CP treated nonsurgically (control group). Sialodochoplasties include major salivary gland excision, parasympathetic nerve section, duct ligation, and duct re-routing. Saliva buffering capacity and bacterial counts were assessed. The surgical group had significantly more dental caries when compared with the control group. Although no caries predictors were identified, alterations to the caries-protective role of saliva are considered the likely cause. The authors stress that children who undergo this procedure should receive intensive pre-and postsurgical preventive dental therapy. 3 tables. 23 references. (AA-M).

- **Plaque Removing Efficacy of Individually Modified Toothbrushes in Cerebral Palsy Children**

  Source: Journal of Dentistry for Children. 62(4): 279-282. July-August 1995.

  Summary: This article reports on a study of the plaque-removing efficacy of individually-modified toothbrushes used by children with cerebral palsy (CP). Ten children with CP, aged twelve to fourteen years, were selected; three were ataxic athetoids; three were spastic diplegics; three, spastic quadriplegics; and one, spastic athetoid. A horizontal, scrubbing technique was demonstrated to these children. They were given standard toothbrushes, similar to the ones they were using at home, and asked to brush without parental help for a period of seven days. The brushing sessions were supervised daily, after which the plaque was disclosed and the index score recorded. The standard toothbrush was then individually modified, with the help of an occupational therapist: various attachments were made in accordance with the physical disabilities of the individual. The brushing sessions were supervised daily for another period of seven days; the plaque score was determined after this period. Unsupervised brushing sessions followed, concluded by another measurement of

plaque levels. The results of toothbrushing with individually modified toothbrushes in this population showed a marked reduction in plaque levels, under supervision as well as during home use. 2 figures. 2 tables. 17 references.

- **Implant-Stabilized Complete Mandibular Denture for a Patient with Cerebral Palsy**

  Source: Dental Update. 22(1): 23-26. January-February 1995.

  Summary: People with cerebral palsy (CP) often have difficulty in chewing, speaking, and swallowing because of the involuntary muscle spasms caused by CP. This problem also makes it very difficult or even impossible for them to wear complete mandibular dentures. This article describes a person with CP who was successfully fitted with a complete lower denture stabilized by osseointegrated implants. The author first provides a brief overview of CP, including how it is classified. The case report describes a 64-year-old edentulous woman with cerebral palsy who was having difficulty retaining her complete lower denture. The problems related to her CP included involuntary movements of the mandible, tongue, and lips. The author reports that the patient also had major problems in controlling her legs and to a lesser extent her arms. The author describes the care given and the followup; the patient was provided with the Astra overdenture system with magnetic retention of the denture. At initial review, the patient's speech had improved, she was eating with enjoyment, and she experienced no discomfort or other problems. The lower denture needed some additional shaping to support wide mouth opening when the patient was excited. The choice of magnets demanded precise alignment of the implant fixtures and produced easier insertion and removal than that created by stud anchorage. The simple flat surface of the keeper is easily cleaned by the caregiver. 5 figures. 4 references. (AA-M).

- **Study of the Barriers to Dental Care in a Sample of Patients with Cerebral Palsy**

  Source: Community Dental Health. 10(1): 57-64. March 1993.

  Summary: This article reports on a study that examined the potential barriers to dental care for a selected sample of 57 adults in England with cerebral palsy. The majority (60 percent) were regular dental attenders and they received dental care in general dental practice and community dental practice in almost equal numbers. Those with mobility or communication difficulties were significantly more likely to attend the community or hospital dental services. Their most common perceived barriers to dental care were fear, the need to be accompanied, and

negative attitudes; cost was rarely a stated barrier. A dislike of dental treatment was significantly related to irregular attendance, but neither anxiety nor the need to be accompanied were significantly related to attendance pattern. 6 tables. 25 references. (AA-M).

- **Prevalence of Developmental Enamel Defects in Children with Cerebral Palsy**

  Source: Journal of Oral Pathology and Medicine. 21(6): 241-244. July 1992.

  Summary: This article reports on a study in which enamel defects observed in the primary anterior teeth of 123 children with congenital cerebral palsy (CP) born 1983 through 1985 were categorized, using an adaptation of the Developmental Defects of Enamel Index. Nineteen children (15 percent) had crowns or loss of tooth substance (LTS) due to attrition. Missing enamel (ME), including horizontal groove, was observed in 39 children (32 percent). Twenty-four children without ME (20 percent) had enamel pits, vertical grooves, or colored enamel opacities. Forty-one (33 percent) had clinically normal enamel. ME children did not differ significantly from those with normal enamel with respect to race, sex, singleton versus twin, severity or type of CP, or presence of dysmorphic features. ME children more often had shorter gestational ages than children with normal enamel. More ME children, even those who were not low in birth weight, were reported by parents to have required neonatal intensive care. 3 figures. 1 table. 8 references. (AA).

- **Predictors of Low and Very Low Birth Weight and the Relation of These to Cerebral Palsy**

  Source: Journal of the American Medical Association (JAMA). 254(11):1473-1479, September 20, 1985.

  Summary: In a large prospective study, we investigated predictors of moderately low (1,501 g to 2,500 g) and very low (less than 1,501 g) birth weight. Maternal age, height, and socioeconomic status, related to moderately low birth weight on univariate analysis, were not on multivariate analysis significant predictors for either low-birth-weight outcome. The leading predictors of very low birth weight were low weight (less than 2,000 g) of last live birth, fetal malformation, nonwhite race, early vaginal bleeding, cigarette smoking, and chorionitis. Some of these were also predictors of moderately low birth weight. About 20 percent of births under 1,501 g could be attributed to chorionitis, a characteristic of less than 3 percent of the births. Of the major predictors of low birth weight, only prolonged rupture of membranes, chorionitis, and congenital malformations contributed to the risk of cerebral palsy

beyond their contribution to the risk of low birth weight. 8 tables, 21 references.

## Federally-Funded Research on Cerebral Palsy

The U.S. Government supports a variety of research studies relating to cerebral palsy and associated conditions. These studies are tracked by the Office of Extramural Research at the National Institutes of Health.[18] CRISP (Computerized Retrieval of Information on Scientific Projects) is a searchable database of federally-funded biomedical research projects conducted at universities, hospitals, and other institutions. Visit the CRISP Web site at **http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket**. You can perform targeted searches by various criteria including geography, date, as well as topics related to cerebral palsy and related conditions.

For most of the studies, the agencies reporting into CRISP provide summaries or abstracts. As opposed to clinical trial research using patients, many federally-funded studies use animals or simulated models to explore cerebral palsy and related conditions. In some cases, therefore, it may be difficult to understand how some basic or fundamental research could eventually translate into medical practice. The following sample is typical of the type of information found when searching the CRISP database for cerebral palsy:

- **Project Title: Arm Kinematics in Hyperkinetic Cerebral Palsy**

  Principal Investigator & Institution: Sanger, Terence D.; Neurology & Neurological Scis; Stanford University Stanford, Ca 94305

  Timing: Fiscal Year 2001; Project Start 5-JUL-2001; Project End 0-JUN-2006

  Summary: (provided by applicant): The purpose of this research career development proposal is to extend Dr. Sanger's training beyond his current theoretical background into clinicallyoriented research on children with movement disorders. Dr. Sanger's past research has focused on computational models of movement and motor learning. This research plan proposes to apply this background in a clinical research

[18] Healthcare projects are funded by the National Institutes of Health (NIH), Substance Abuse and Mental Health Services (SAMHSA), Health Resources and Services Administration (HRSA), Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDCP), Agency for Healthcare Research and Quality (AHRQ), and Office of Assistant Secretary of Health (OASH).

setting by performing a quantitative investigation of increased upperextremity movement in children with hyperkinetic cerebral palsy (CP). It is not known whether abnormal movements result from random noise, decreased ability to modulate the amplitude of movements, or inappropriate planning of motor sequences. This proposal suggests two related hypotheses: (1) Hyperkinetic CP is a result of a restriction in the variability of motor commands such that desired smooth movements are not available, and (2) Progression of abnormal movements over time is reflected by an increasing restriction in the variability of motor commands and worsening energetic efficiency. To test these hypotheses, position sensors and surface electomyographic (EMG) recordings of reaching movements will be made at 6 month intervals in children of different ages with hyperkinetic CP. Kinematic and EMG data will be analyzed to determine energy expenditure, variability of the set of kinematic patterns, and total information content of movement. If the hypotheses are correct, then we expect progression of symptoms in dyskinetic CP to be reflected in decreasing dimensionality, information content, and energy efficiency of the patterns of movements. The results of this study may allow early identification of children at risk for hyperkinetic CP as well as prediction of the progression and ultimate severity of symptoms. Dr. Andriacchi, Dr. Mobley, and Dr. Hlatky will serve as mentors for Dr. Sanger's work on this project. Dr. Andriacchi will provide instruction on the measurement of kinematics and energetics in children, Dr. Mobley will provide instruction on the clinical evaluation of children with movement disorders, and Dr. Hlatky will guide the design and implementation of clinical trials and outcome measure validation. The proposal includes coursework in cellular and molecular neurobiology and in the design of clinical research studies.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Botulinum Toxin for Spasticity in Cerebral Palsy**

  Principal Investigator & Institution: Hays, Ross; University of Washington Seattle, Wa 98195

  Timing: Fiscal Year 2000

  Summary: The study will evaluate the effectiveness of Botulinum Toxin (BTX) in reducing spasticity and improving function and mobility in children with spastic diplegia, a common form of Cerebral Palsy (CP). We will measure the effects of the intervention across the five domains of science related to disability: pathophysiology, impairment, functional limitation, disability and societal limitation. The design is a prospective, randomized, double-masked clinical trial with a six-month evaluation period. Forty (40) children ages 4-12 years will be recruited and

randomized into two groups. Group A will receive BTX. Group B will receive a placebo. Outcomes will be assessed in a masked evaluation at baseline, 3 weeks, 8 weeks, 12 weeks, and 24 weeks. Group B subjects will have the opportunity to receive BTX treatment after 24 weeks.

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- **Project Title: Dynamic Balance Control in Children with Cerebral Palsy**

  Principal Investigator & Institution: Woollacott, Marjorie H.; Professor; Institute of Neuroscience; University of Oregon Eugene, or 97403

  Timing: Fiscal Year 2000; Project Start 1-MAY-1999; Project End 0-APR-2003

  Summary: (adapted from applicant's abstract) The long-term objective of this research is to understand constraints on balance control in the child with cerebral palsy during both static and dynamic tasks. Aims of the project are to determine the limitation of balance abilities in children with cerebral palsy when balance is disturbed with varying magnitudes, to determine the contributions of muscular and non-muscular forces to balance control, and to determine the contributions of training to the emergence of efficient balance strategies. Electromyography, kinematic, and kinetic recordings will be obtained during stance perturbations. The data will serve as a basis for designing intervention strategies that are appropriate to the children's specific balance constraints.

  Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Effects of Postural Support in Cerebral Palsy**

  Principal Investigator & Institution: Kamm, Kathi L.; Occupational Therapy; University of Wisconsin Milwaukee Box 413 Milwaukee, Wi 53201

  Timing: Fiscal Year 2000; Project Start 7-SEP-2000; Project End 0-JUN-2002

  Summary: (Adapted from Applicant's Description): The purpose of this proposal is to examine the effects of postural support on reach coordination in twenty 3-5 year-old children with cerebral palsy, spastic quadruparesis type. These children, if they lack functional sitting skills at the time of entering formal educational programs, are typically positioned in a custom seating system (generically referred to as Assistive Seating Devices or ASDs) for trunk support. This approach is based on the long held developmental assumption that proximal stability is a necessary precursor to distal mobility. Thus, providing proximal trunk support to decrease unintentional movement should free up the arms for self-care, prewriting and communication skills. Numerous studies have

been conducted to test this reasoning without any clear demonstration that providing external postural support improves fine motor function. This design of this study is based on more recent theories of motor development that focus more on active movement strategies as a source of organization in movement. Furthermore, this newer perspective and more recent evidence suggests that even the earliest attempts to sit and reach display coordination between proximal and distal segments when actively engaged in a task. Therefore, active strategies for function are influencing the development of skilled synergies. Theoretical models for prescribing ASDs are based in reflex and neuromaturational theories without reference to active strategies. The pragmatics of clinical practice, however, are more inclusive and frequently incorporate the child's functional strategies. This study addresses two needs in this area: first, to provide the descriptive base for the purpose of establishing a taxonomy of active strategies for sitting and reaching these children use, and, second, to describe and test specific hypotheses about the effects of increasing postural support on trunk and hand coordination during reaching. This study examines reaching and posture in four support contexts to describe the range of active strategies available to these children. Detailed behavioral and kinematic descriptions will provide a descriptive base for clinical reasoning in conjunction with statistical analyses to test assumptions about proximal and distal motor control.

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- **Project Title: Intraoperative Measurement in Cerebral Palsy Surgery**

  Principal Investigator & Institution: Lieber, Richard L.; Professor of Orthopaedics and Bioenginee; Orthopaedics; University of California San Diego 9500 Gilman Dr San Diego, Ca 92093

  Timing: Fiscal Year 2000; Project Start 1-JUL-1999; Project End 0-JUN-2004

  Summary: (adapted from Investigator's abstract) The intent of this proposal is to develop a surgical tool that can be used to study surgery performed on patients with cerebral palsy (CP) and to study the mechanical and biological properties of spastic skeletal muscle. CP is a neuromuscular disorder that can result in joint contractures that require surgical correction. Surgical procedures used include tendon lengthenings and tendon transfers. While a great deal of progress has been made creating procedures that improve function, comparatively little attention has been directed toward objectively evaluating such procedures. In order to critically differentiate between the various surgical procedures available to correct ankle deformities, it is suggested that an understanding of the effects of the surgery on muscle must be

defined and functional differences between procedures (if any) documented. The investigators also propose quantitative studies of the passive mechanical properties of spastic skeletal muscle to determine the relationship between passive tension (easily measured intraoperatively) and optimal sarcomere length (measured with a laser diffraction tool). They thus propose development and testing of an intraoperative laser diffraction device for sarcomere length measurement that allows muscle properties to be defined during surgical tendon lengthening, such as is commonly performed on patients with CP. In the first phase of the study, a user-friendly intraoperative laser diffraction device will be fabricated based on a design which has been used for over 15 years in this laboratory. This device will then be used in a prospective clinical study which compares two methods for equinus deformity correction: tendoachilles lengthening (TAL) and gastrocnemius-soleus recession (GSR, "Strayer" procedure). Intraoperative laser diffraction will be used during surgical correction as an objective measure of the biomechanical effects of the surgery. Functional differences (if any) between the TAL and GSR procedures will be evaluated by comparing kinetic and kinematic analysis of normal gait in these subjects before and after surgery. They will also completely characterize the spastic muscle in terms of the titin isoforms expressed and determine the degree to which these isoforms affect passive mechanical properties. Muscle fibers will be typed based on the myosin heavy chain expressed. These data, in conjunction with intraoperative sarcomere lengths will be integrated into a biomechanical model that includes muscle, tendon and joint properties and can be used to predict joint function given muscle properties. The goal is to gain understanding of the immediate intraoperative and functional postoperative effects of these very common surgical procedures. In addition, these data will be relevant to management of other disorders such as stroke, head injury and spinal cord injury, where surgical tendon transfers are performed.

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- **Project Title: Management of Chronic Pain in Individuals with Cerebral Palsy**

  Principal Investigator & Institution: Engel, Joyce M.; University of Washington Seattle, Wa 98195

  Timing: Fiscal Year 2000

  Summary: The long-term objectives of Project II are to increase our understanding of the nature and scope of the chronic pain problems associated with cerebral palsy and to develop and test interventions designed to address these problems. The specific aims of Project II are: (1)

to ascertain the frequency and characteristics of chronic pain problems experienced by persons with cerebral palsy: and (2) to examine the associations between pain coping responses and subsequent pain and functioning in individuals with cerebral palsy. To accomplish Aim 1, interviews will be performed with a large group of individuals with CP in the Puget Sound area. Interview data will be used to describe the frequency and severity of chronic pain in these individuals. To accomplish Aim 2, 30 individuals who report having chronic pain associated with cerebral palsy will be interviewed in depth, every three months for 1.5 years, concerning the nature of their pain, coping strategies employed to manage pain, and adjustment to chronic pain. Findings from this study will dramatically increase our understanding of the nature and scope of the chronic pain problems that individuals with cerebral palsy experience.

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- **Project Title: North American Growth in Cerebral Palsy Project**

  Principal Investigator & Institution: Stevenson, Richard D.; Associate Professor of Pediatrics; Pediatrics; University of Virginia Charlottesville Box 400195 Charlottesville, Va 22904

  Timing: Fiscal Year 2000; Project Start 7-SEP-1997; Project End 1-AUG-2002

  Summary: Normal growth in children is generally accepted as a marker for health, while abnormal growth is a marker that the child may be ill or malnourished or that something may be awry in the child's environment. Children with cerebral palsy (CP) frequently grow poorly. However, normal growth patterns for children with CP have not been established, so it is often difficult to discriminate children with CP who are healthy from those who are ill. The North American Growth in Cerebral Palsy Project (NAGCePP) was developed to address the lack of data regarding growth and nutritional status in children with Cerebral Palsy. The specific aims of this proposal are: A. To refine a clinical protocol and methodology for the comprehensive study of growth and nutritional status in children with CP B. To develop a well-equipped, multicenter network for the comprehensive study of growth and nutritional status in children with CP and to demonstrate the feasibility of this network C. To collect pilot data of growth in a representative, population- based sample of children with CP in five geographic areas in North America D. To complete collection of data of a representative, population- based sample of children with CP in order to describe expected growth patterns NAGCePP will consist of a multicenter core study coupled with one or more nested studies. The core study is to be anthropometric study of

growth in a population-based, random sample of children with CP to which all centers will contribute data. Additionally, individual centers will have ongoing nested studies utilizing small subsamples to which only that individually site (or a few sites) contributes data. These nested studies will address more specific questions related to growth, nutritional status, and their effects on functional status and quality of life. This proposal requests funds for the multicenter core study and for the first nested study, which will be performed at the main study and for the first nested study, which will be performed at the main study site. This proposal aims to contribute information toward the understanding of normal growth and nutritional status in children with cerebral palsy. An understanding of normal growth in these children is a prerequisite to understanding the relationship between growth, nutritional status, functional abilities and health-related quality of life

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- **Project Title: North American Growth in Cerebral Palsy--Pilot Dexa Project**

  Principal Investigator & Institution: Stallings, Virginia; Children's Hospital of Philadelphia 34Th St and Civic Ctr Blvd Philadelphia, Pa 19104

  Timing: Fiscal Year 2000

  Summary: The North American Growth in Cerebral Palsy Project (NAGCePP) was developed as a multi-center (4 sites within the United States and 2 sites in Canada) study of growth in cerebral palsy. The identified long-term goals and specific hypotheses for study were delineated into three phases of the project: Phase I: protocol development; Phase II: pilot/feasibility study and Phase III: the formal project: development of growth charts. We have just completed Phase II of the core part of this project, and have submitted abstracts to upcoming meetings based on this pilot anthropological data. The core study was an anthropometric study of growth in a population-based sample of children with CP to which all centers have contributed data. Additionally, individual centers have participated in ongoing nested studies utilizing small sub-samples to which only that individual site (or a few sites) have contributed data. These nested studies have addressed more specific questions related to growth, nutritional status, and their effects on functional status and quality of life. This proposal addresses the nested pilot study of bone mineral density that was initiated at our geographical region (Philadelphia). The specific aims of the Bone Density Nested Study were as follows: 1. To collect pilot data on bone density in a representative, population-based sample of children with CP in two

geographic areas in North America. 2. To collect data on risk factors for bone fracture at baseline (e.g. calcium intake, body size, markers of bone mineral metabolism, medications and level of mobility) 3. To collect longitudinal data (by follow-up phone call) on fracture incidence. 4. To compare the results of bone mineral density at the distal femur from children with Cerebral Palsy to healthy children without Cerebral Palsy.

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- **Project Title: Optimizing Muscle Function in Cerebral Palsy**

  Principal Investigator & Institution: Damiano, Diane L.; Associate Professor; Barnes-Jewish Hospital 216 S Kingshighway Blvd St. Louis, Mo 63110

  Timing: Fiscal Year 2000; Project Start 1-SEP-1997; Project End 1-AUG-2002

  Summary: Cerebral palsy (CP) is the most prevalent physical disability occurring in childhood, for which no cure is available. All current treatments such a surgery and physical therapy aim solely to alleviate the peripheral effects of this central nervous system disorder, often with limited and inconsistent success. A prevalent clinical system that has long been recognized, but rarely addressed therapeutically in this population is muscle weakness. While strength training is routinely used in the adult orthopaedic population and in athletes to increase force production or alter muscle imbalance, this type of intervention is grossly under- utilized in pediatric rehabilitation, and in particular children with CP. No evidence exists to support the clinical prejudice against strength training and testing in cerebral palsy. In fact, research findings are accumulating toe the contrary, demonstrating that individuals with CP are indeed weak, the degree of weakness has a direct relationship to motor performance, and strengthening programs can produce positive functional outcomes. However, the neurophysiological and biomechanical bases of weakness in CP remain poorly understood. An additional concern is that the two major surgical interventions in ambulatory children with spastic diplegia, muscle-tendon lengthening (orthopaedic surgery) and selective dorsal rhizotomy (neurosurgery), often serve to exacerbate or unmask the symptom of weakness, which can be problematic in children who are already weak. The ultimate goal of this project is to improve motor outcomes in CP by first exploring the mechanisms that lead to diminished force production and defining the relative role of weakness in the functional motor deficit in spastic CP. This will be accomplished by isokinetic and electromyographic evaluation to examine voluntary and involuntary muscle responses in children with CP at the knee and ankle joint throughout the range of

motion and at different movement speeds. Muscle performance will then be related to validated pediatric measures of functional status and disability. Lastly, the interaction of strength with surgical interventions will be determined by quantifying the effects of orthopaedic and neurosurgery on strength and functional measures, and assessing whether the addition of a strengthening program enhances surgical outcomes. Strength is an essential component of normal motor control that is deficient in CP, but can be altered through training. Continued research, as proposed here, needs to be conducted to verify and solidify the role of strengthening in the rehabilitation of children with CP.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: New Approach to Detect CP and Brain Injury by Term Age**

  Principal Investigator & Institution: Ariagno, Ronald L.; Professor of Pediatrics; Pediatrics; Stanford University Stanford, Ca 94305

  Timing: Fiscal Year 2001; Project Start 0-APR-2001; Project End 1-MAR-2004

  Summary: (provided by applicant): There have been significant advances in medical technology and care for critically ill neonates over the last 3 decades. Survival of very low birth weight infants (VLBW), at a significant national health cost and family hardship, is now a reality. Furthermore, the number of VLBW preterm infants has begun to increase due to advances in the science of fertility and increasing maternal age. The long term neurological morbidity for these lowest weight and gestational age infants is increased. The incidence of handicap in this population has changed little over the past decades. VLBW preterm infants constitute 25% of all children with cerebral palsy (CP). Currently, we lack diagnostic techniques to identify brain injury such as CP early (i.e., around corrected term age). Although the brain injury is present from early neonatal period, it takes 1-2 years before the disease is neurologically manifested. Thus, our ability to learn more about causes, prevention, and treatment is currently very limited. This proposal utilizes state-of-the-art MRI technology to predict those preterm infants who will develop CP. This innovative proposal concerns a timely pediatric problem of critical importance to pediatricians, neonatologists, pediatric neurologists, radiologists and MR physicists. Using quantitative MRI, EEG, and neurobehavioral tests we hope to be able to identify infants at risk for CP as early as 37 weeks post conceptional age. The collaboration between neonatal, neurological, and neuroimaging expertise is integral for an advance in our knowledge of detecting neonatal neurobiological pathology prior to 1-2 years of age. It is essential to discover a new

approach to identify brain injury early, before it will be possible to effectively investigate interventions that can improve neurological outcome of these high risk very premature infants.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Quantify Spasticity/ Biomechanical Influence On Function**

  Principal Investigator & Institution: Granata, Kevin P.; Assistant Professor; University of Virginia Charlottesville Box 400195 Charlottesville, Va 22904

  Timing: Fiscal Year 2000; Project Start 8-SEP-2000; Project End 0-JUN-2005

  Summary: Spastic muscle behavior results from neuromuscular injury or illness of the central nervous system and limits motor control and functional performance thereby contributing to disability. Unfortunately, treatment outcomes are limited because spasticity is poorly quantified and the relation between spasticity and dysfunction is poorly understood. We hypothesize 1) existing clinical spasticity assays, specifically the Ashworth test which is the primary indicator for treatment, qualitatively describes only a sub-set of the multiple dimensions of spasticity, and 2) functional constraints can be predicted from quantitatively measures of spasticity. Spasticity of individual patients with cerebral palsy will be quantitatively measures of spasticity. Spasticity of individual patients with cerebral palsy will be quantitatively measured in terms of the threshold joint angle at which spastic activation is initiated, the velocity- dependence of this threshold angle, and the post-threshold response severity. These three dimensions of spasticity will be computed from resistance force and myoelectric activity during passive isokinetic knee flexion and extension. Results will be compared with each patient's Ashworth score of the knee to determine which dimensions of spasticity the Ashworth test records. Kinematics of walking (knee joint angle and angular velocity) will be recorded to illustrate the function in these patients is achieved predominantly using sub-threshold motion patterns. Gross Motor Function Measures (GMFM) scores will be compared to the magnitude of the subthreshold region of motion demonstrating that functional limitation is related to the severity of the kinematic restrictions imposed by the spastic activation threshold. Results will provide a quantifiable measure of spasticity and improve our understanding of existing clinical assays and functional limitations associated with spasticity. These will contribute to improve clinical outcomes by developing predictive tools for clinical assessment, patient characterization and treatment evaluation. These efforts will also

establish the preliminary components of a multi-disciplinary center of excellence for the clinical/biomechanical quantification and characterization of spasticity.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

- **Project Title: Spasticity and Strength as Indicators for Rhizotomy**

  Principal Investigator & Institution: Engsberg, Jack R.; Director; Barnes-Jewish Hospital 216 S Kingshighway Blvd St. Louis, Mo 63110

  Timing: Fiscal Year 2000; Project Start 5-AUG-1997; Project End 1-JUL-2002

  Summary: (Adapted from the Applicant's Abstract): The long term goal is to improve function in children with cerebral palsy (CP). A selective dorsal rhizotomy (SDR) is performed to improve function by minimizing spasticity. A contraindication and limitation of the SDR is muscle weakness. Muscle weakness is related to reduced function. Thus, determining the degree of spasticity and strength/weakness in a child is a key consideration in the SDR selection process. Objective measures to assess spasticity and strength are not presently used in the process. In this study, objective measures to quantify spasticity and strength will be utilized to determine relationships between pre-surgery spasticity and strength and post-surgery functional measures. Based upon these relationships, an objective clinical tool to improve the selection of SDR candidates will be developed. In addition, comparisons of the measures among 4 different groups of children (n=40/group) will be made, those: 1) undergoing a SDR (SDR group), 2) undergoing physical therapy (PT) identical to the SDR group (PT group), 3) undergoing no change in current intervention (CP controls) and 4) having able bodies (AB controls). Specific Aim 1: Evaluate the importance of pre-surgery spasticity and strength as predictors of functional change due to SDR. Children from the SDR group will be tested on a dynamometer for spasticity and strength, evaluated using the Gross Motor Function Measure, have a gait analysis performed and answer a disability questionnaire. These assessments will be made 6 weeks and again 2 days prior to surgery, and at 8 and 20 months post surgery. Stepwise multiple regression with repeated measures will test the hypothesis that composite pre-surgery spasticity and strength from the ankles, knees, and hips in the SDR group will predict functional changes as a result of the SDR. Specific Aim 2: Compare impairment and functional measures among the SDR group, PT group and CP controls. The same assessments and testing sequence as the SDR group will be followed for these groups, but no surgery will be performed. ANOVA and ANCOVA will test the null hypotheses that the 3 CP groups will not change in impairment and

function over all sessions and will not be different from one another. Specific Aim 3: Compare impairment and functional measures from 3 CP groups with those from AB controls. The children with able bodies will be assessed for spasticity, strength, and gait. ANOVA will test the null hypothesis that the CP groups will not be significantly different from the AB controls across all sessions. Descriptive statistics will describe the extent of differences from AP controls. The intent is that this investigation will improve the current methods for selecting SDR patients, thereby improving patient outcomes and reducing costs. It will also compare the efficacy of 3 modes of treatment for CP: SDR with intensive PT, intensive PT without SDR, and standard intervention.

Website: http://commons.cit.nih.gov/crisp3/CRISP.Generate_Ticket

## E-Journals: PubMed Central[19]

PubMed Central (PMC) is a digital archive of life sciences journal literature developed and managed by the National Center for Biotechnology Information (NCBI) at the U.S. National Library of Medicine (NLM).[20] Access to this growing archive of e-journals is free and unrestricted.[21] To search, go to **http://www.pubmedcentral.nih.gov/index.html#search**, and type "cerebral palsy" (or synonyms) into the search box. This search gives you access to full-text articles. The following is a sample of items found for cerebral palsy in the PubMed Central database:

- **Randomised trial of early diet in preterm babies and later intelligence quotient** by A Lucas, R Morley, and T J Cole; 1998 November 28
  http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=28727
- **The adverse neuro-developmental effects of postnatal steroids in the preterm infant: a systematic review of RCTs** by Keith J. Barrington; 2001
  http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=29104

[19] Adapted from the National Library of Medicine:
http://www.pubmedcentral.nih.gov/about/intro.html.

[20] With PubMed Central, NCBI is taking the lead in preservation and maintenance of open access to electronic literature, just as NLM has done for decades with printed biomedical literature. PubMed Central aims to become a world-class library of the digital age.

[21] The value of PubMed Central, in addition to its role as an archive, lies the availability of data from diverse sources stored in a common format in a single repository. Many journals already have online publishing operations, and there is a growing tendency to publish material online only, to the exclusion of print.

## The National Library of Medicine: PubMed

One of the quickest and most comprehensive ways to find academic studies in both English and other languages is to use PubMed, maintained by the National Library of Medicine. The advantage of PubMed over previously mentioned sources is that it covers a greater number of domestic and foreign references. It is also free to the public.[22] If the publisher has a Web site that offers full text of its journals, PubMed will provide links to that site, as well as to sites offering other related data. User registration, a subscription fee, or some other type of fee may be required to access the full text of articles in some journals.

To generate your own bibliography of studies dealing with cerebral palsy, simply go to the PubMed Web site at **www.ncbi.nlm.nih.gov/pubmed**. Type "cerebral palsy" (or synonyms) into the search box, and click "Go." The following is the type of output you can expect from PubMed for "cerebral palsy" (hyperlinks lead to article summaries):

- **Outcomes after selective dorsal rhizotomy for spastic cerebral palsy.**
  Author(s): Steinbok P.
  Source: Child's Nervous System: Chns: Official Journal of the International Society for Pediatric Neurosurgery. 2001 January; 17(1-2): 1-18. Review.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11219613&dopt=Abstract

- **Problems of communication between parents and staff in the treatment and management of children with cerebral palsy.**
  Author(s): Bobath B, Finnie NR.
  Source: Developmental Medicine and Child Neurology. 1970 October; 12(5): 629-35. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=5477946&dopt=Abstract

- **Prompt pressure applied to peculiar points in the treatment of spasmodic infantile cerebral palsy--a report of 318 cases.**
  Author(s): Lu W.

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[22] PubMed was developed by the National Center for Biotechnology Information (NCBI) at the National Library of Medicine (NLM) at the National Institutes of Health (NIH). The PubMed database was developed in conjunction with publishers of biomedical literature as a search tool for accessing literature citations and linking to full-text journal articles at Web sites of participating publishers. Publishers that participate in PubMed supply NLM with their citations electronically prior to or at the time of publication.

Source: J Tradit Chin Med. 1994 September; 14(3): 180-4.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7799650&dopt=Abstract

- **Reducing spasticity to control muscle contracture of children with cerebral palsy.**
  Author(s): Nash J, Neilson PD, O'Dwyer NJ.
  Source: Developmental Medicine and Child Neurology. 1989 August; 31(4): 471-80.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=2806733&dopt=Abstract

- **Reduction of spasticity in cerebral palsy using feedback of the tonic stretch reflex: a controlled study.**
  Author(s): O'Dwyer N, Neilson P, Nash J.
  Source: Developmental Medicine and Child Neurology. 1994 September; 36(9): 770-86.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7926328&dopt=Abstract

- **Relaxation in cerebral palsy.**
  Author(s): O'Donoghue P.
  Source: Developmental Medicine and Child Neurology. 1988 February; 30(1): 115-7. Review. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3286337&dopt=Abstract

- **Selection of children with cerebral palsy for conductive education and the characteristics of children judged suitable and unsuitable.**
  Author(s): Bairstow P, Cochrane R, Rusk I.
  Source: Developmental Medicine and Child Neurology. 1991 November; 33(11): 984-92.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1835944&dopt=Abstract

- **Self-regulation of spasm and spasticity in cerebral palsy.**
  Author(s): Neilson PD, McCaughey J.
  Source: Journal of Neurology, Neurosurgery, and Psychiatry. 1982 April; 45(4): 320-30.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7077341&dopt=Abstract

- **Sensory feedback for head control in cerebral palsy.**
  Author(s): Leiper CI, Miller A, Lang J, Herman R.
  Source: Physical Therapy. 1981 April; 61(4): 512-8.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7208633&dopt=Abstract

- **Startle reflex habituation in children with cerebral palsy.**
  Author(s): Goldberg J, Anderson DE, Wilder S.
  Source: Percept Mot Skills. 1979 June; 48(3 Pt 2): 1135-9.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=492882&dopt=Abstract

- **Surgical treatment of spasticity in cerebral palsy.**
  Author(s): Fasano VA, Broggi G, Barolat-Romana G, Sguazzi A.
  Source: Childs Brain. 1978; 4(5): 289-305.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=657884&dopt=Abstract

- **The effect of quadriceps femoris muscle strengthening exercises on spasticity in children with cerebral palsy.**
  Author(s): Fowler EG, Ho TW, Nwigwe AI, Dorey FJ.
  Source: Physical Therapy. 2001 June; 81(6): 1215-23.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11380277&dopt=Abstract

- **The effects of auditorally augmented feedback on the eye-hand coordination of students with cerebral palsy.**
  Author(s): Talbot ML, Junkala J.
  Source: Am J Occup Ther. 1981 August; 35(8): 525-8.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7025642&dopt=Abstract

- **The integrity of visual-proprioceptive mapping in cerebral palsy.**
  Author(s): Wann JP.
  Source: Neuropsychologia. 1991; 29(11): 1095-106.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1775227&dopt=Abstract

- **The normal postural reflex mechanism and its deviation in children with cerebral palsy.**
  Author(s): Bobath K.

Source: Physiotherapy. 1971 November 10; 57(11): 515-25. No Abstract Available.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=5139031&dopt=Abstract

- **The very early treatment of cerebral palsy.**
  Author(s): Bobath B.
  Source: Developmental Medicine and Child Neurology. 1967 August; 9(4): 373-90. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=6035999&dopt=Abstract

- **Treatment of cerebral palsy in the severely subnormal.**
  Author(s): Campbell ED, Green EA.
  Source: Rheumatol Phys Med. 1970 November; 10(8): 416-20. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=5484946&dopt=Abstract

- **Use of dohsa-hou, a Japanese psychorehabilitative program, to guide motor activity of young adults with cerebral palsy.**
  Author(s): Dadkhah A.
  Source: Percept Mot Skills. 1998 February; 86(1): 243-9.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9530741&dopt=Abstract

- **Voluntary control of heart rate by external feedback in normal children and children with infantile cerebral palsy.**
  Author(s): Bogdanov OV, Smetankin AA, Inin YS, Khakhan YV.
  Source: Hum Physiol. 1983 September-October; 9(5): 319-22. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=6678783&dopt=Abstract

- **Letter: The fate of patients with Little's disease.**
  Author(s): Bobath K.
  Source: Developmental Medicine and Child Neurology. 1976 June; 18(3): 398. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=939355&dopt=Abstract

## Vocabulary Builder

**Amitriptyline:** Tricyclic antidepressant with anticholinergic and sedative properties. It appears to prevent the re-uptake of norepinephrine and serotonin at nerve terminals, thus potentiating the action of these neurotransmitters. Amitriptyline also appears to antaganize cholinergic and alpha-1 adrenergic responses to bioactive amines. [NIH]

**Anxiety:** The unpleasant emotional state consisting of psychophysiological responses to anticipation of unreal or imagined danger, ostensibly resulting from unrecognized intrapsychic conflict. Physiological concomitants include increased heart rate, altered respiration rate, sweating, trembling, weakness, and fatigue; psychological concomitants include feelings of impending danger, powerlessness, apprehension, and tension. [EU]

**Assay:** Determination of the amount of a particular constituent of a mixture, or of the biological or pharmacological potency of a drug. [EU]

**Cardiac:** Pertaining to the heart. [EU]

**Cutaneous:** Pertaining to the skin; dermal; dermic. [EU]

**Dentures:** An appliance used as an artificial or prosthetic replacement for missing teeth and adjacent tissues. It does not include crowns, dental abutments, nor tooth, artificial. [NIH]

**Desensitization:** The prevention or reduction of immediate hypersensitivity reactions by administration of graded doses of allergen; called also hyposensitization and immunotherapy. [EU]

**Distal:** Remote; farther from any point of reference; opposed to proximal. In dentistry, used to designate a position on the dental arch farther from the median line of the jaw. [EU]

**Energetic:** Exhibiting energy : strenuous; operating with force, vigour, or effect. [EU]

**Femur:** The longest and largest bone of the skeleton, it is situated between the hip and the knee. [NIH]

**Flexion:** In gynaecology, a displacement of the uterus in which the organ is bent so far forward or backward that an acute angle forms between the fundus and the cervix. [EU]

**Hyperbaric:** Characterized by greater than normal pressure or weight; applied to gases under greater than atmospheric pressure, as hyperbaric oxygen, or to a solution of greater specific gravity than another taken as a standard of reference. [EU]

**Incompetence:** Physical or mental inadequacy or insufficiency. [EU]

**Lesion:** Any pathological or traumatic discontinuity of tissue or loss of

function of a part. [EU]

**Ligation:** Application of a ligature to tie a vessel or strangulate a part. [NIH]

**Mandible:** The largest and strongest bone of the face constituting the lower jaw. It supports the lower teeth. [NIH]

**Membranes:** Thin layers of tissue which cover parts of the body, separate adjacent cavities, or connect adjacent structures. [NIH]

**Mentors:** Senior professionals who provide guidance, direction and support to those persons desirous of improvement in academic positions, administrative positions or other career development situations. [NIH]

**Molecular:** Of, pertaining to, or composed of molecules : a very small mass of matter. [EU]

**Monotherapy:** A therapy which uses only one drug. [EU]

**Myosin:** Chief protein in muscle and the main constituent of the thick filaments of muscle fibers. In conjunction with actin, it is responsible for the contraction and relaxation of muscles. [NIH]

**Neural:** 1. pertaining to a nerve or to the nerves. 2. situated in the region of the spinal axis, as the neutral arch. [EU]

**Neuromuscular:** Pertaining to muscles and nerves. [EU]

**Neurosurgery:** A surgical specialty concerned with the treatment of diseases and disorders of the brain, spinal cord, and peripheral and sympathetic nervous system. [NIH]

**Orofacial:** Of or relating to the mouth and face. [EU]

**Orthopaedic:** Pertaining to the correction of deformities of the musculoskeletal system; pertaining to orthopaedics. [EU]

**Polytherapy:** A therapy which uses more than one drug. [EU]

**Postnatal:** Occurring after birth, with reference to the newborn. [EU]

**Postoperative:** Occurring after a surgical operation. [EU]

**Postural:** Pertaining to posture or position. [EU]

**Precursor:** Something that precedes. In biological processes, a substance from which another, usually more active or mature substance is formed. In clinical medicine, a sign or symptom that heralds another. [EU]

**Prejudice:** A preconceived judgment made without adequate evidence and not easily alterable by presentation of contrary evidence. [NIH]

**Prevalence:** The total number of cases of a given disease in a specified population at a designated time. It is differentiated from incidence, which refers to the number of new cases in the population at a given time. [NIH]

**Proximal:** Nearest; closer to any point of reference; opposed to distal. [EU]

**Psychiatry:** The medical science that deals with the origin, diagnosis, prevention, and treatment of mental disorders. [NIH]

**Recurrence:** The return of a sign, symptom, or disease after a remission. [NIH]

**Reflux:** A backward or return flow. [EU]

**Regurgitation:** A backward flowing, as the casting up of undigested food, or the backward flowing of blood into the heart, or between the chambers of the heart when a valve is incompetent. [EU]

**Remission:** A diminution or abatement of the symptoms of a disease; also the period during which such diminution occurs. [EU]

**Spasmodic:** Of the nature of a spasm. [EU]

**Sphincter:** A ringlike band of muscle fibres that constricts a passage or closes a natural orifice; called also musculus sphincter. [EU]

**Systemic:** Pertaining to or affecting the body as a whole. [EU]

# CHAPTER 5. PATENTS ON CEREBRAL PALSY

## Overview

You can learn about innovations relating to cerebral palsy by reading recent patents and patent applications. Patents can be physical innovations (e.g. chemicals, pharmaceuticals, medical equipment) or processes (e.g. treatments or diagnostic procedures). The United States Patent and Trademark Office defines a patent as a grant of a property right to the inventor, issued by the Patent and Trademark Office.[23] Patents, therefore, are intellectual property. For the United States, the term of a new patent is 20 years from the date when the patent application was filed. If the inventor wishes to receive economic benefits, it is likely that the invention will become commercially available within 20 years of the initial filing. It is important to understand, therefore, that an inventor's patent does not indicate that a product or service is or will be commercially available. The patent implies only that the inventor has "the right to exclude others from making, using, offering for sale, or selling" the invention in the United States. While this relates to U.S. patents, similar rules govern foreign patents.

In this chapter, we show you how to locate information on patents and their inventors. If you find a patent that is particularly interesting to you, contact the inventor or the assignee for further information.

[23]Adapted from The U. S. Patent and Trademark Office: **http://www.uspto.gov/web/offices/pac/doc/general/whatis.htm**.

## Patents on Cerebral Palsy

By performing a patent search focusing on cerebral palsy, you can obtain information such as the title of the invention, the names of the inventor(s), the assignee(s) or the company that owns or controls the patent, a short abstract that summarizes the patent, and a few excerpts from the description of the patent. The abstract of a patent tends to be more technical in nature, while the description is often written for the public. Full patent descriptions contain much more information than is presented here (e.g. claims, references, figures, diagrams, etc.). We will tell you how to obtain this information later in the chapter. The following is an example of the type of information that you can expect to obtain from a patent search on cerebral palsy:

- **Transcranial stimulation for the treatment of cerebral palsy**

  Inventor(s): Liss; Saul (Glen Rock, NJ), Liss; Bernard (Glen Rock, NJ)

  Assignee(s): Pain Suppression Labs, Inc. (Elmwood Park, NJ)

  Patent Number: 4,844,075

  Date filed: May 7, 1986

  Abstract: Cerebral palsy treatment apparatus and methodology employs a transcutaneous electronic wave to suppress pain and increase motor function. A first positive contact electrode is placed at the right side of the cranium, and a second negative contact electrode is placed at the left side of the cranium of the head. An electronic current wave comprising relatively high frequency pulses with a low frequency amplitude modulation is then applied between the first to the second electrodes.

  Excerpt(s): This invention relates to electronic pain suppression and spasticity reduction apparatus and methodology and, more specifically, to cerebral palsy treatment apparatus and procedure for treating symptoms incident to the disease. ... Apparatus for electronic treatment of patients with cerebral palsy is known. See U.S. Pat. No. 4,559,998. ... It is an object of the present invention to provide improved cerebral palsy treatment methodology; and more specifically, to treat patients of cerebral palsy by means of electronic transcranial stimulation in a safe, efficient and rapid manner to increase motor function and alleviate the pain and discomfort associated with the disease.

  Web site: http://www.delphion.com/details?pn=US04844075__

- **Cerebral palsy treatment apparatus and methodology**

  Inventor(s): Liss; Saul (Glen Rock, NJ), Liss; Bernard (Glen Rock, NJ)

  Assignee(s): Pain Suppression Labs (Elmwood Park, NJ)

  Patent Number: 4,559,948

  Date filed: August 7, 1984

  Abstract: Cerebral palsy treatment apparatus and methodology employs a transcutaneous electronic wave to suppress pain and increase motor function. A first positive contact electrode is placed at the frontalis, and a second negative contact electrode is placed at the occiput of the head. Alternatively, the first positive contact electrode is placed at the cervical spinous process and the second negative contact electrode is placed at each affected muscle. An electronic current wave comprising relatively high frequency pulses with a low frequency amplitude modulation is then applied between the first to the second electrodes.

  Excerpt(s): This invention relates to electronic pain suppression apparatus and methodology and, more specifically, to cerebral palsy treatment apparatus and procedure for treating symptoms incident to the disease. ... It is an object of the present invention to provide improved cerebral palsy treatment apparatus and methodology. ... More specifically, an object of the present invention is the electronic treatment of cerebral palsy in a safe, efficient and rapid manner to increase motor function and alleviate the pain and discomfort associated with the disease.

  Web site: http://www.delphion.com/details?pn=US04559948__

- **Cerebral palsy arm and hand brace**

  Inventor(s): Terry; Thomas E. (204 E. Athey R.R. #1, Farber, MO 63345), Hoyt, Sr.; Laurance J. (R.R. #2, Laddonia, MO 63352)

  Assignee(s): none reported

  Patent Number: 4,237,873

  Date filed: December 11, 1978

  Abstract: An arm and hand brace for persons afflicted with the neuro-muscular tremors of cerebral palsy; a bracing device framing the shoulders, upper arm, forearm and hand which, in application, damps and controls involuntary neuro-muscular spasms and permits the performance of controlled, willed actions of these members by cerebral palsy victims; an articulated frame comprised of a support, a train of

linked arms, a sleeve clasping the hand, wrist and forearm, a series of double and single element joints and a piston-piston rod extension-retraction system, all for establishing and maintaining control of gross and fine arm and hand movements in the cerebral palsy patient.

Excerpt(s): The literature of cerebral palsy is voluminous. The instant invention is directed to certain specific problems arising out of certain manifestations of certain forms of cerebral palsy. ... Five types are generally recognized in cerebral palsy, with varying degrees and types of motor involvement: spastic, dyskinetic (including athethoid), ataxic, mixed and flaccid. The American Academy of Cerebral Palsy recognizes seven types: spastic, athetotic (tension, non-tension, dystonia and tremor athetosis), rigidity, ataxic, tremor, atonic and mixed. Speaking descriptively, the spastic type, comprising some 65% of the cerebral palsied, typically involves stiffness of musculature, with motions of the extremities made slowly and with great effort. Thus, when the afflicted person attempts to bend the joints, the opposing muscles contract, blocking the patient's efforts. In the athetoid type, typically comprising 30% of the afflicted, the individual moves his body or parts of his body even when he does not wish to. The body and extremities may be in constant motion. The individual may have difficulty in controlling and directing his movements. Phelps recognizes nine types of athetoids. These include rotary, dystonic, tremor-like, shudder-like, flail, non-tension, hemi-athetoid and emotional release athetosis. ... In therapy of cerebral palsy conditions, rests, body braces, special chairs and tables, corsets and other devices may be used to control those motions which use up much of the energy of cerebral palsied individuals. Motion training may also use such devices.

Web site: http://www.delphion.com/details?pn=US04237873__

- **Therapeutic chair for cerebral palsy child**

  Inventor(s): Urban; Frank K. (2455 N. Star, Columbus, OH 43215)

  Assignee(s): none reported

  Patent Number: 4,145,083

  Date filed: June 17, 1977

  Abstract: A therapeutic chair is provided having angularly displaceable seat bottom and seat back positioned on a supporting base for pivotable movement relative thereto. The seat bottom and seat back include longitudinally extending sidewalls having inwardly facing surfaces which may be selectively displaced inwardly to effectively provide support for the occupant of the chair. Selective displacement of the inner

sidewall surfaces is achieved through incorporation of selectively inflatable air cells which are restrained against the respective side walls. These cells are inflated to expand inwardly and provide the proper size adjustment and support of the occupant in maintaining the desired body position for comfort and avoidance of the involuntary extensor thrust positioning. Background of the Invention: The therapeutic chair of this invention is directed primarily to the assistance and aid of a spastic cerebral palsied child to improve the stability of such a child in maintenance of a sitting position and thereby permit the child more useful movement and development of hand activities and operations. Another important objective of the therapeutic chair of this invention, is to better enable the child to avoid the extensor thrust positioning that may involuntarily occur when the child is placed or inadvertently moves into an improper or inappropriate position.It has been found that the extensor thrust positioning may readily occur when a child contacts a stable object or support such as the floor or a foot rest on a chair structure with his feet. The result of this thrust positioning is that the child's body assumes a relatively contorted position and this position is then maintained unless attendant assistance is obtained for again moving the child to the normal sitting position. Another disadvantage of known structures for assisting children having spastic cerebral palsy is the relative inability of such chairs and other devices or appliances to readily maintain the upper trunk of the child's body in an upright and generally vertically disposed position and resisting lateral movement. Also such previously provided appliances and chairs generally do not provide an adequate support for the head which may involuntarily move in a lateral direction to an extent where the child is incapable by himself or return head movement to a more normal position. Absent the necessary side support, cerebral-palsied children are unable to attempt simultaneous hand movement since one hand is generally used for support and eye-hand movement coordination training is substantially impaired. Summary of the Invention: A therapeutic chair is provided by this invention which has been found not only capable of readily providing the necessary support in maintaining a spastic cerebral palsy child in a preferred sitting position, but is also capable of substantially eliminating the involuntary extensoir thrust positioning that can otherwise occur. The chair structure in accordance with this invention includes a seat bottom and seat back which are provided with lateral side walls that serve to maintain a child's upright and generally longitudinally aligned body and trunk position. The seat bottom and seat back are preferably pivotably mounted on a supporting base to permit relative angular positioning of both seat bottom and back to a preferred angular position for optimum support of the child's trunk and legs in a comfortable and more adaptive

position for enabling the child to function in effecting use of it's hands and arms as well as maintenance of the head in a position where activities in the surrounding area may be more readily and naturally observed.In order that the chair structure will be properly adaptive to a specific child, the side walls of both the seat bottom and seat back are formed with inner surface portions which are relatively displaceable in inwardly directed relationship to the chair's structure. This achievement of inward displacement of the inner sidewall surface is obtained through incorporation of selectively inflatable air cells carried and supported in adjacent relationship to each of the side walls. These selectively inflatable air cells may be inflated to a desired degree necessary to attain the particular size as to lateral spacing in either the seat bottom or seat back to properly engage and support the child thus positioned in the chair. The vertical height of the seat back is of an extent to assure that support is also provided for the head and is able to restrict the extreme lateral displacement which may inadvertently occur without such support.Relative pivoting movement of the seat back to the seat bottom enables one to angularly position these two components to best suppport the cerebral-palsied child. Also, the seat back and seat bottom may be angularly positioned with respect to a supporting base such that the seat bottom will be inclined upwardly from a rear supporting pivot and is of a length such that, when thus upwardly inclined, the child's feet will be incapable of contacting any rigid supporting surface which may tend to trigger the extensor thrust positioning.These and other objects and advantages of this invention will be readily apparent from the following detailed description of an illustrative embodiment thereof and the accompanying drawings.

Excerpt(s): Attachment of the seat back 12 is accomplished in substantially the same manner as that of the seat bottom with respect to the supporting base 10. As indicated, the side plates 40 of the respective side walls for the seat back project into interleaved relationship between the adjacent portions of the seat bottom and the upstanding walls 15 of the supporting base. Accordingly, the shank of the bolt forming the pivot structure 13 projects through an aperture formed in the side plate 40. Consequently, tightening of the bolt of this pivot structure 13 will frictionally secure the seat back 12 in proper relationship with respect to the seat bottom 11. This pivotable relationship and interconnection of the seat bottom and seat back enables the angular relationship to be properly adjusted to best accommodate a specific child as determined by the extent of the cerebral palsy condition. In some instances, this angular relationship is preferably less than 90.degree. and may be of the order of 75.degree.-80.degree.. This has been found advantageous in proper support of the child to provide the necessary comfort and to minimize the

possibility of the inadvertent extensior thrust positioning that can otherwise occur. However, it will be seen that the seat back may be angularly inclined to a position that is at a greater than 90.degree. angle with respect to the seat bottom. Consequently, the seat structure may be readily positioned in an optimum preferred configuration for any specific case. The structure may be positioned with the seat bottom upwardly inclined from its pivot point through the adjustable, slotted bracket 32 and the seat back may be independently positioned with respect to the seat bottom. Additional to the angular support of the seat bottom and seat back in a desired position, the providing of selectively inflatable air cells 27 and 45 in the respective side walls enables the chair to be further adjusted to better accommodate a particular occupant. Inflation of the air cells to a desired degree not only changes the spacing between the side walls for size adjustment but the degree of inflation further provides either a more rigid or more pliable or cushioned side wall. Arrangement of the air cells in longitudinally extending relationship to the respective side walls results in continuous adjustable support with respect to each side wall surface and thus better enable the chair structure to be adapted to a particular occupant.

Web site: http://www.delphion.com/details?pn=US04145083__

- **Simplified adjustable chair for children with cerebral palsy**

  Inventor(s): Studebaker; Gary Weldon (9340 Buell St., Downey, CA 90241)

  Assignee(s): none reported

  Patent Number: 3,992,057

  Date filed: February 3, 1975

  Abstract: A chair, especially useful for children with cerebral palsy, which has a board-type backrest integral with a board-type seat which are mounted on suitable legs that have adjustment means to adjust the height of the seat. The backrest is provided with a chest strap for strapping a child's chest erect. Means are provided for moving the chest strap vertically along the backrest. Arm rests are adjustably fastened to the backrest to be adjusted in and out, and up and down. The seat is provided with a post to inhibit leg adduction and is movable towards and away from the backrest.

  Excerpt(s): This invention relates to medical or invalid chairs and, more specifically, to a simplified economical chair suitable to accommodate children with cerebral palsy and helping the child develop more normally. ... Ordinary or conventional chairs are not adequate to assist

and satisfy the special needs of children with cerebral palsy. However, in the past, adjustable chairs have been developed to support cerebral palsied children. These chairs were developed to provide a more comfortable rest for the child instead of trying to rehabilitate the child by developing his muscles to support himself. For example, U.S. Pat. No. 3,761,126 is such a chair of the prior art. This chair, besides being expensive, is complicated to use.

Web site: http://www.delphion.com/details?pn=US03992057__

## Patent Applications on Cerebral Palsy

As of December 2000, U.S. patent applications are open to public viewing.[24] Applications are patent requests which have yet to be granted (the process to achieve a patent can take several years). The following patent applications have been filed since December 2000 relating to cerebral palsy:

- **Method and compositions for the treatment of cerebral palsy**

  Inventor(s): Graham, Herbert Kerr ;  (Lisburn, GB)

  Correspondence: Frank J. Uxa; Stout, Uxa, Buyan & Mullins, LLP; Suite 300; 4 Venture; Irvine; CA; 92618; US

  Patent Application Number: 20010046962

  Date filed: July 6, 2001

  Abstract: The invention provides for the use of a presynaptic neurotoxin (for example a bacterial neurotoxin such as botulinum toxin A) for the manufacture of a medicament for the treatment of cerebral palsy in juvenile patients. The juvenile patients are preferably juveniles of up to 6 years in age.

  Excerpt(s): The present invention relates to the treatment of cerebral palsy in a juvenile patient and in particular to the promotion of normal muscle growth in a juvenile patient suffering from dynamic contractures caused by cerebral palsy. ... Cerebral palsy is a collective name given to a range of conditions caused by brain injury caused at or around the time of birth, or in the first year of an infant's life. The brain injury may be caused, for example, by trauma during delivery. It may also arise through such causes as trauma due to road traffic accidents or meningitis during the first year of life. It has been found that there is an increased risk of cerebral palsy in prematurely born babies and, as a result of the improvements in technology which enable premature babies to be kept

[24] This has been a common practice outside the United States prior to December 2000.

alive from a much earlier age, the incidence of cerebral palsy in many countries is actually increasing rather than falling. ... Although the brain injury causing cerebral palsy is a non-progressive injury, its effects may change as the sufferer grows older. The largest group of sufferers from cerebral palsy suffer from spastic cerebral palsy. Spastic cerebral palsy is characterised by dynamic contractures of the muscles which impair or inhibit completely the sufferer's ability to use his or her muscles. Moreover, muscle growth is impaired such that the longitudinal muscles become shorter relative to their associated bones as the infant grows older. Where the leg muscles are affected, the mobility of the sufferer can be severely reduced. Conventional attempts to cure this defect and to restore a measure of normal mobility typically have involved surgical intervention to alter the lengths of the tendons once the stage has been reached at which the knee joint can no longer be straightened or the sufferer can only walk on tiptoe.

Web site: http://appft1.uspto.gov/netahtml/PTO/search-bool.html

## Keeping Current

In order to stay informed about patents and patent applications dealing with cerebral palsy, you can access the U.S. Patent Office archive via the Internet at no cost to you. This archive is available at the following Web address: **http://www.uspto.gov/main/patents.htm**. Under "Services," click on "Search Patents." You will see two broad options: (1) Patent Grants, and (2) Patent Applications. To see a list of granted patents, perform the following steps: Under "Patent Grants," click "Quick Search." Then, type "cerebral palsy" (or synonyms) into the "Term 1" box. After clicking on the search button, scroll down to see the various patents which have been granted to date on cerebral palsy. You can also use this procedure to view pending patent applications concerning cerebral palsy. Simply go back to the following Web address: **http://www.uspto.gov/main/patents.htm**. Under "Services," click on "Search Patents." Select "Quick Search" under "Patent Applications." Then proceed with the steps listed above.

## Vocabulary Builder

**Athetosis:** A derangement marked by ceaseless occurrence of slow, sinuous, writhing movements, especially severe in the hands, and performed involuntarily; it may occur after hemiplegia, and is then known as posthemiplegic chorea. Called also mobile spasm. [EU]

**Cervical:** Pertaining to the neck, or to the neck of any organ or structure. [EU]

**Medicament:** A medicinal substance or agent. [EU]

**Musculature:** The muscular apparatus of the body, or of any part of it. [EU]

**Presynaptic:** Situated proximal to a synapse, or occurring before the synapse is crossed. [EU]

**Retraction:** 1. the act of drawing back; the condition of being drawn back. 2. distal movement of teeth, usually accomplished with an orthodontic appliance. [EU]

**Rigidity:** Stiffness or inflexibility, chiefly that which is abnormal or morbid; rigor. [EU]

**Transcutaneous:** Transdermal. [EU]

**Transdermal:** Entering through the dermis, or skin, as in administration of a drug applied to the skin in ointment or patch form. [EU]

# CHAPTER 6. BOOKS ON CEREBRAL PALSY

## Overview

This chapter provides bibliographic book references relating to cerebral palsy. You have many options to locate books on cerebral palsy. The simplest method is to go to your local bookseller and inquire about titles that they have in stock or can special order for you. Some parents, however, prefer online sources (e.g. **www.amazon.com** and **www.bn.com**). In addition to online booksellers, excellent sources for book titles on cerebral palsy include the Combined Health Information Database and the National Library of Medicine. Once you have found a title that interests you, visit your local public or medical library to see if it is available for loan.

## Book Summaries: Federal Agencies

The Combined Health Information Database collects various book abstracts from a variety of healthcare institutions and federal agencies. To access these summaries, go to **http://chid.nih.gov/detail/detail.html**. You will need to use the "Detailed Search" option. To find book summaries, use the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer. For the format option, select "Monograph/Book." Now type "cerebral palsy" (or synonyms) into the "For these words:" box. You will only receive results on books. You should check back periodically with this database which is updated every 3 months. The following is a typical result when searching for books on cerebral palsy:

- **Cerebral Palsy. 2nd ed**

  Source: Austin, TX: Pro-Ed. 1996. 189 p.

Contact: Available from Pro-Ed. 8700 Shoal Creek Boulevard, Austin, TX 78757-6897. (800) 897-3202 or (512) 451-3246; Fax (512) 451-8542. Price: $26.00 plus shipping and handling. ISBN: 089796270.

Summary: This book, one of a series in communicative disorders, discusses a cluster of developmental motor speech disorders that are found in persons with cerebral palsy. The author presents and discusses clinical problems that are typically found in speech language therapy settings. The first chapter describes various developmental problems facing children with cerebral palsy and summarizes their medical, social, communicative, and educational implications. Chapter Two discusses the role of the multidisciplinary professional team ordinarily required to deal with the problems of individuals with cerebral palsy. It also summarizes the impact federal legislation has had on resources and programs for children with severe disabilities at various age levels. Chapter Three describes the communication problems commonly encountered and their neurolinguistic and neuromotor components. The author details the general communication characteristics of these children and discusses in detail a number of speech and hearing problems frequently present in this population. Chapter Four describes assessment problems and procedures. Specific procedures are recommended for assessing language, voice, articulation, hearing, and related neuromotor systems. One section covers procedures for determining the need for augmentative or alternative communication systems. The final chapter addresses current issues and procedures in communication intervention. The author emphasizes use of an indirect physiological and social readiness program designed to meet the unique needs of each child, accompanied by direct intervention procedures for any problems in language, voice, articulation, and hearing. A subject index concludes the volume. 171 references. (AA-M).

- **Promoting the Development of Young Children with Cerebral Palsy: A Guide for Mid-Level Rehabilitation Workers**

  Source: Albany, NY: World Health Organization (WHO). 1993. 87 p.

  Contact: Available from World Health Organization (WHO). Publications Center, 49 Sheridan Avenue, Albany, NY 12210. (518) 436-9686. Price: $10.80 plus shipping and handling.

  Summary: This manual from the World Health Organization (WHO) is designed for midlevel rehabilitation workers who work with children who have cerebral palsy and their families, and with other rehabilitation or health workers. The manual includes information on early detection of cerebral palsy and assessment of the child's development. Training suggestions are given for promoting mobility, self-help, and

communication skills. Communication problems related to cerebral palsy include hearing loss and problems with eating and speaking because of a reduced ability to control the muscles of the tongue, lips, and throat. The chapter on communication outlines some of these problems and presents recommendations for addressing them. One section describes alternative ways of communicating, including asking yes or no questions, using picture boards, and using sign language.

- **Children with cerebral palsy: A parents' guide**

  Source: Bethesda, MD: Woodbine House. 1991. 434 pp.

  Contact: Available from Woodbine House, 6510 Bells Mill Road, Bethesda, MD 20817. Telephone: (800) 843-7323 or (301) 897-3570 / fax: (301) 897- 5838. $14.95.

  Summary: This book provides parents who have a child with cerebral palsy a guide to help their children by providing information and support. Topics covered include information about cerebral palsy, adjusting to the child's diagnosis, medical concerns and treatment, daily care, family life, self-esteem, the child's development, various types of therapy, early intervention and special education, legal rights, and advocacy. The book includes a glossary, a bibliography, a list of suppliers of special equipment, and national and state resource organizations.

## Book Summaries: Online Booksellers

Commercial Internet-based booksellers, such as Amazon.com and Barnes & Noble.com, offer summaries which have been supplied by each title's publisher. Some summaries also include customer reviews. Your local bookseller may have access to in-house and commercial databases that index all published books (e.g. Books in Print®). The following have been recently listed with online booksellers as relating to cerebral palsy (sorted alphabetically by title; follow the hyperlink to view more details at Amazon.com):

- **Children With Cerebral Palsy: A Parents' Guide** by Elaine Geralis (Editor) (1998); ISBN: 0933149824
  http://www.amazon.com/exec/obidos/ASIN/0933149824/iconinterna

- **Handling the Young Child With Cerebral Palsy at Home** by Nancie R. Finnie, J. Bavin, M. Bax, Marian Browne, Mary Gardner, Nancy Finnie (1997); ISBN: 0750605790
  http://www.amazon.com/exec/obidos/ASIN/0750605790/ iconinterna

## The National Library of Medicine Book Index

The National Library of Medicine at the National Institutes of Health has a massive database of books published on healthcare and biomedicine. Go to the following Internet site, **http://locatorplus.gov/**, and then select "Search LOCATORplus." Once you are in the search area, simply type "cerebral palsy" (or synonyms) into the search box, and select "books only." From there, results can be sorted by publication date, author, or relevance. The following was recently catalogued by the National Library of Medicine:[25]

- **Cerebral palsies: causes, consequences, and management.** Author: [edited by] Geoffrey Miller, Gary D. Clark; Year: 1998
- **Cerebral palsy: the child and young person.** Author: edited by Lesley Cogher, Elizabeth Savage, and Michael F. Smith; Year: 1992
- **Cerebral palsy at the turn of the millennium: the presentations from the 5th International Congress on the Cerebral Palsy: Bled, Slovenia, June 7-10, 2001.** Author: editor: Milivoj Velickovic Perat; Year: 2001
- **Cerebral palsy.** Author: Merlin J. Mecham; Year: 2002
- **Cerebral palsy.** Author: Susan Dudley Gold; Year: 2001
- **Children with cerebral palsy: a functional approach to physical therapy.** Author: Marjolijn Ketelaar; Year: 1999
- **Computerized gait analysis in the rehabilitation of children with cerebral palsy and spina bifida.** Author: Jo-Anne Tomie and David Hailey; Year: 1997
- **Dorsal rhizotomy for spasticity.** Author: B. Johnson ... [et al.]; Year: 1996

[25] In addition to LOCATORPlus, in collaboration with authors and publishers, the National Center for Biotechnology Information (NCBI) is adapting biomedical books for the Web. The books may be accessed in two ways: (1) by searching directly using any search term or phrase (in the same way as the bibliographic database PubMed), or (2) by following the links to PubMed abstracts. Each PubMed abstract has a "Books" button that displays a facsimile of the abstract in which some phrases are hypertext links. These phrases are also found in the books available at NCBI. Click on hyperlinked results in the list of books in which the phrase is found. Currently, the majority of the links are between the books and PubMed. In the future, more links will be created between the books and other types of information, such as gene and protein sequences and macromolecular structures. See **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Books.**

- **Early diagnosis and interventional therapy in cerebral palsy: an interdisciplinary age-focused approach.** Author: edited by Alfred L. Scherzer; Year: 2001
- **Moving ahead: a training manual for children with motor disorders.** Author: Joan O'Connor, Elsie Yu; illustrations by Lin Guohui; Year: 1998
- **Pediatric balance program.** Author: Sieglinde Martin; illustrations by P. Jason Sauer; Year: 1998
- **Posture and movement of the child with cerebral palsy.** Author: Marcia Stamer; illustrations by Delilah R. Cohn, Kathy Jung, and Diane L. Nelson; Year: 2000

## Chapters on Cerebral Palsy

Frequently, cerebral palsy will be discussed within a book, perhaps within a specific chapter. In order to find chapters that are specifically dealing with cerebral palsy, an excellent source of abstracts is the Combined Health Information Database. You will need to limit your search to book chapters and cerebral palsy using the "Detailed Search" option. Go directly to the following hyperlink: **http://chid.nih.gov/detail/detail.html**. To find book chapters, use the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer, and the format option "Book Chapter." By making these selections and typing in "cerebral palsy" (or synonyms) into the "For these words:" box, you will only receive results on chapters in books. The following is a typical result when searching for book chapters on cerebral palsy:

- **Child with More than One Disability**

  Source: in Cornett, R.O. and Daisey, M.E. Cued Speech Resource Book for Parents of Deaf Children. 2nd ed. Cleveland, OH: National Cued Speech Association. 2001. p. 537-562.

  Contact: Available from National Cued Speech Association. 23970 Hermitage Road, Cleveland, OH 44122-4008. Voice/TTY (800) 459-3529 or (216) 292-6213. E-mail: cuedspdisc@aol.com. Price: $37.50 for members; $39.50 for nonmembers, plus shipping and handling. ISBN: 0963316419.

  Summary: Hearing impairment often occurs concurrently with one or more other disabling conditions that may impede communication or learning, such as memory problems, mental retardation, aphasia (lack of language comprehension), dyslexia, dysarthria (motor speech disorders), cerebral palsy, Usher syndrome (a cause of deaf blindness), and others. This chapter on children with more than one disability is from a book

that offers an overview of cued speech, the use of hand cues with speech that permits the deaf child to learn the English language. The book includes information and advice for parents who have decided to use Cued Speech with a child who is deaf or hard of hearing, or are considering doing so. The authors discuss specific overlying conditions, including minor or correctable conditions, cerebral palsy, memory problems, aphasia, apraxia (difficulty in expressive language), dyslexia, deaf blindness, and nonspecific learning disability. The chapter then offers case histories of children who have at least one other learning problem in addition to hearing impairment. Two case histories, while not featuring additional learning problems, tell of children whose early years were so dominated by health problems that there appeared to be little hope for normal development of language, communication, or reading.

- **Pediatric Phonatory Disorders**

  Source: in Andrews, M.L. Manual of Voice Treatment: Pediatrics Through Geriatrics. 2nd ed. San Diego, CA: Singular Publishing Group, Inc. 1999. p. 151-217.

  Contact: Available from Singular Publishing Group, Inc. 401 West 'A' Street, Suite 325, San Diego, CA 92101-7904. (800) 521-8545 or (619) 238-6777. Fax (800) 774-8398 or (619) 238-6789. E-mail: singpub@singpub.com. Website: www.singpub.com. Price: $55.00 plus shipping and handling. ISBN: 1565939880.

  Summary: This chapter on pediatric phonatory disorders is from a resource book for clinicians and clinicians in training who are treating patients with voice disorders. The chapter offers five sections: preschool children, school age children, pediatric voice problems associated with other conditions (hearing impairment, cerebral palsy, craniofacial dysmorphology, nasal obstruction, obstructive sleep apnea syndrome, trauma, lesions), the voice at puberty, and the treatment of resonance disorders. The chapter discusses the physiologic systems relevant to voice production from a developmental perspective. To emphasize the importance of complete case history information, the relevance of the possible effects on voice of infant airway obstruction and medical and surgical treatments to alleviate it are reviewed. Other topics include the reasons for tracheotomy and possible complications and sequelae of this surgery; the common symptoms of vocal disruption in school age children; hyperfunctional and hypofunctional patterns associated with respiration, phonation, resonance, and psychodynamics; and the importance of explaining the effects of specific voice disorders in children to their parents, teachers, and allied health professionals. 9 figures. 3 tables.

- **Speech and Voice Specific Neurologic Disorders**

  Source: in Vogel, D.; Carter, J.E.; Carter, P.B. Effects of Drugs on Communication Disorders. 2nd ed. San Diego, CA: Singular Publishing Group, Inc. 1999. p. 39-101.

  Contact: Available from Singular Publishing Group, Inc. 401 West 'A' Street, Suite 325, San Diego, CA 92101-7904. (800) 347-7707. Fax (800) 774-8398. E-mail: info@delmar.com. Website: www.singpub.com. Price: $49.95 plus shipping and handling. ISBN: 1565939964.

  Summary: This chapter on speech and voice specific neurologic disorders is from a handbook that gives communication specialists information about prescription drugs and their use with patients who suffer neurogenic or psychogenic communication disorders. The book was designed for communication specialists who work in medical centers, rehabilitation clinics, private practice, public schools, or any setting in which drug therapy may influence a client's communication. This chapter covers neurologic disorders that may affect speech and voice production. For each disorder, the authors provide a definition and cause; discuss the general features, symptoms, and signs; describe the features, symptoms, and signs of communication impairment associated with each disorder; list pharmacologic (drug) treatment for each disorder; and discuss the influence that drug treatment may have on communication. Each section also lists references for additional information. Disorders covered include Parkinson's disease, myasthenia gravis, amyotrophic lateral sclerosis (ALS), multiple sclerosis, Wilson's disease, cerebral palsy, Huntington's disease, and Tourette's syndrome. 4 tables. 63 references.

- **Promoting Function: Communication and Feeding**

  Source: in Dormans, J.P. and Pellegrino, L., eds. Caring for Children with Cerebral Palsy: A Team Approach. Baltimore, MD: Paul H. Brookes Publishing Company. 1998. p. 347-370.

  Contact: Available from Paul H. Brookes Publishing Company. P.O. Box 10624, Baltimore, MD 21285-0624. (800) 638-3775. Fax (410) 337-8539. E-mail: custserv@pbrookes.com. Website: www.brookespublishing.com. Price: $38.95 plus shipping and handling. ISBN: 155766322X.

  Summary: The use of speech and language for communicating, learning, and regulating behavior is a critical developmental task and forms the basis for all social interactions. Children with cerebral palsy have significant neuromotor impairments that frequently affect their oral motor system and, as a result, also affect their development of speech, language, and feeding skills. In this chapter, from a book on the team approach to caring for children with cerebral palsy, basic aspects of

assessment and treatment of communication and feeding problems are reviewed and an illustrative case example is provided. Speech, language, and communication topics covered include drooling (sialorrhea), dysarthria (movement disorders of neurological origin that can affect speech production), respiration, phonation (the generation of sound), resonation, articulation, speech therapy, language assessment, and language therapy. Because each child with cerebral palsy presents a unique profile of motor, cognitive, socioemotional, linguistic, and familial characteristics, comprehensive evaluation of the child must occur (and should be ongoing during treatment phases) before goals are established. For some children, conventional forms of communication and traditional forms of therapy will suffice to produce satisfactory outcomes; for other children, alternative methods of feeding and communication must be employed. 1 table. 33 references.

- **Messaging: Vocabulary, Small Talk, and Storytelling**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 13-37.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website: www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

  Summary: This chapter on messaging is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services for people with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). The authors discuss various aspects of the initial vocabulary selection process in this chapter and emphasize that vocabulary selection also involves the ongoing process of vocabulary maintenance. Topics include factors that influence AAC message selection, the messages of conversation, greetings, small talk, storytelling, procedural descriptions, content specific conversations, wrap up remarks and farewell statements, vocabulary needs for different communication modes and contexts (e.g., spoken and written communication, school talk and home talk, age variables, gender variables), vocabulary needs of people with different communication capabilities, and vocabulary resources. The chapter includes sidebars that offer relevant quotes from the literature and that pose questions for readers to consider while reading the chapter. 5 tables.

- **Symbols and Rate Enhancement**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 39-88.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website: www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

  Summary: The ability to represent messages and concepts in alternative ways, including symbols, is a central communication skill, especially for people who cannot read or write. This chapter on symbols and rate enhancement is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services for individuals with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). The authors of the chapter review many of the most commonly used types of symbols and discuss their usefulness for various people. Topics include an overview of symbols, gestures and vocalizations (unaided symbols), gestural codes (Amer-Ind and the Tadoma Method), manual sign systems, considerations for use of sign language (intelligibility, motoric complexity, and combining signs and speech), types of manual sign systems, aided symbols (the use of tangible symbols, such as read objects, miniature objects, etc.), aided symbols that use representation (photographs, line drawings, pictograms), aided symbols that use abstract symbol systems (orthography, Yerkish Lexigram, Braille), combined symbol systems, rate enhancement techniques, message retrieval and learnability, and rate enhancement research. The chapter includes sidebars that offer relevant quotes from the literature, that share stories from the authors' experiences, and that pose questions for readers to consider while reading the chapter. 14 figures. 2 tables.

- **Alternative Access**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 89-121.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website:

www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

Summary: Communication is based on the selection of one or more types of symbols used alone or in combination to express messages. People who are unable to speak or write through traditional means need alternative strategies in order to communicate. This chapter on alternative access is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services for people with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). The authors of the chapter cover the components of the selection set, the physical characteristics of selection set displays, types of displays, selection techniques (how the AAC system user selects or identifies items from the selection set), feedback (activation feedback and message feedback), research on alternative access, and message output and input. The chapter includes sidebars that offer relevant quotes from the literature, that share stories from the authors' experiences, and that pose questions for readers to consider while reading the chapter. 12 figures.

- **AAC Issues for People with Developmental Disabilities**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 245-264.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website: www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

  Summary: This chapter on AAC issues for people with developmental disabilities is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services for people with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). This chapter serves as an introduction to the part of the text that addresses the communication needs of people who are acquiring communication and language skills for the first time. These people have disabilities that were either present since birth or before the age of 18 and that affect one or more aspects of development (physical, sensory, cognitive). AAC techniques are used quite routinely with people who

experience developmental disabilities, including cerebral palsy, cognitive disability (i.e., mental retardation), autism and the associated spectrum disorders, and developmental apraxia of speech. In this chapter, each of these impairments is defined and explained briefly in terms of its description, prevalence, and major characteristics. An overview of the AAC issues most pertinent to each impairment is provided. The chapter includes sidebars that offer relevant quotes from the literature, that share stories from the authors' experiences, and that pose questions for readers to consider while reading the chapter. 2 tables.

- **AAC Strategies for Beginning Communicators: Building Opportunities and Nonsymbolic Communication**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 265-294.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website: www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

  Summary: Beginning communicators are people in different age ranges who rely primarily on nonsymbolic modes of communication (gestures, vocalizations, eye gaze, body language), who do not demonstrative communication intentionality, who are learning to use aided or unaided symbols to represent basic messages, and who use nonelectronic communication displays or simple technology. This chapter on the use of AAC strategies for beginning communicators is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services for people with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). The authors of the chapter discuss interventions for beginning communicators that are related to opportunity barriers and nonsymbolic communication. The authors stress that, regardless of their ages or the etiologies (causes) of their communication impairments, beginning communicators require support to learn that through communication they can have a positive impact on their environments and the people around them. Topics include opportunities for different age groups, nonsymbolic communication interventions, the relationship between communication and challenging behaviors, sensitizing facilitators, responding to spontaneous signals, building a communication foundation, parent

training programs, scripted routines, a movement based approach, and the use of gesture dictionaries. The chapter includes sidebars that offer relevant quotes from the literature, that share stories from the authors' experiences, and that pose questions for readers to consider while reading the chapter. 2 figures. 5 tables.

- **AAC Strategies for Beginning Communicators: Symbolic Approaches to Communication**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 295-329.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website: www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

  Summary: Beginning communicators are people in different age ranges who rely primarily on nonsymbolic modes of communication (gestures, vocalizations, eye gaze, body language), who do not demonstrate communication intentionality, who are learning to use aided or unaided symbols to represent basic messages, and who use nonelectronic communication displays or simple technology. This chapter on the use of AAC strategies for beginning communicators is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services for people with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). The authors of the chapter focus on interventions for beginning communicators that use symbolic communication. The authors describe some of the most common techniques for teaching functional communication skills using symbols. The authors begin by discussing some of the issues for consideration when choosing aided and unaided symbols and then describe a range of instructional approaches that have been reported in the AAC literature. Specific topics include calendar and schedule systems, talking switch techniques, teaching basic choice making and requesting, picture exchange communication system, general case instruction, teaching basic rejecting, the relationship of rejecting to challenging behaviors, teaching basic conversational skills, dual communication boards, and facilitated communication. The chapter includes sidebars that offer relevant quotes from the literature, that share

stories from the authors' experiences, and that pose questions for readers to consider while reading the chapter. 2 figures. 8 tables.

- **Language Learning and Development**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 331-354.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website: www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

  Summary: This chapter on language learning and development is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services for people with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). The authors of the chapter describe and summarize the current knowledge of AAC language learning and development, and discuss the implications of this knowledge for clinical practice, especially with regard to children and adolescents who use AAC. Topics include speech acts, pragmatics, phonology, semantics, morphology, syntax, graphic symbols and language, interventions to support language learning and development, and instructional strategies and language learning. The chapter includes sidebars that offer relevant quotes from the literature, that share stories from the authors' experiences, and that pose questions for readers to consider while reading the chapter. 4 figures. 1 table.

- **Literacy Development of AAC Users**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 355-390.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website: www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

  Summary: This chapter on the literacy development of AAC users is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services

for people with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). The authors of the chapter review literacy development from preschool through the school years and present special instructional and technical considerations for individuals with impairments that affect literacy. Topics include determining who requires AAC support for literacy, the impact of primary motor impairments, handwriting or other fine motor impairments, specific language impairment, learning disabilities, cognitive impairments, visual impairments, emergent literacy and literacy development, the relationship between language knowledge and literacy learning, augmented reading and writing, symbolization and literacy learning, the classroom literacy experiences of AAC users, the participation of AAC users in literacy instruction, and technology supported writing. The chapter includes sidebars that offer relevant quotes from the literature, that share stories from the authors' experiences, and that pose questions for readers to consider while reading the chapter. 5 figures. 1 table.

- **Educational Inclusion of AAC Users**

  Source: in Beukelman, D.R. and Mirenda, P. Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co. 1998. p. 391-424.

  Contact: Available from Paul H. Brookes Publishing Co. P.O. Box 10624, Baltimore, MD 21285. (800) 638-3775. Fax (410) 337-8539. Website: www.brookespublishing.com. Price: $59.95 plus shipping and handling. ISBN: 1557663335.

  Summary: This chapter on the educational inclusion of AAC users is from a textbook that promotes a comprehensive approach to designing and providing augmentative and alternative communication (AAC) services for people with a full range of congenital (present at birth) and acquired communication disorders, including those associated with cerebral palsy, autism, aphasia, and traumatic brain injury (TBI). The authors of the chapter stress that because participation in the general classroom requires many kinds of extensive communication, effective augmentative and alternative (AAC) systems that are age and context appropriate serve as critical tools for academic success. The authors present a framework for delivering inclusive communication and educational services within general classrooms to children who require AAC systems across the ability range. The authors emphasize that as placement of students with severe communication disorders in general

classrooms becomes more common, there is a critical need for policies, practices, and strategies to replace the prevailing 'management by exception' approach. The chapter concludes with a section discussing collaborative teaming and consensus building. The chapter includes sidebars that offer relevant quotes from the literature, that share stories from the authors' experiences, and that pose questions for readers to consider while reading the chapter. 2 figures. 8 tables.

- **Introduction to Augmentative and Alternative Communication**

  Source: in Glennen, S.L.; DeCostes, D.C., eds. Handbook of Augmentative and Alternative Communication. San Diego, CA: Singular Publishing Group, Inc. 1997. p. 3-19.

  Contact: Available from Singular Publishing Group, Inc. 401 West 'A' Street, Suite 325, San Diego, CA 92101-7904. (800) 521-8545 or (619) 238-6777. Fax (800) 774-8398 or (619) 238-6789. E-mail: singpub@singpub.com. Website: www.singpub.com. Price: $65.00 plus shipping and handling. ISBN: 1565936841.

  Summary: This chapter, which introduces augmentative and alternative communication (AAC) systems, is from a graduate-level textbook on AAC. The author provides an historical perspective for the field, while simultaneously introducing basic terminology. The chapter begins with a description of the real-life of an AAC user with cerebral palsy; 'Bill' was born in 1957 and grew up with many benefits of AAC-like technology. The chapter concludes by comparing this experience with a real-life description of an AAC user ('Susan') who is graduating from high school in the mid-1990's. The author also outlines the roles and responsibilities for AAC professionals. One section considers the impact of legislation, including the Americans With Disabilities Act (ADA), on AAC and its development. 2 tables. 61 references. (AA-M).

## Directories

In addition to the references and resources discussed earlier in this chapter, a number of directories relating to cerebral palsy have been published that consolidate information across various sources. These too might be useful in gaining access to additional guidance on cerebral palsy. The Combined Health Information Database lists the following, which you may wish to consult in your local medical library:[26]

- **Complete Directory for People with Chronic Illness. 4th ed**

  Source: Lakeville, CT: Grey House Publishing, Inc. 2000. 1009 p.

  Contact: Available from Grey House Publishing, Inc. Pocket Knife Square, Lakeville, CT 06039. (860) 435-0868. Fax (860) 435-0867. Price: $165.00. ISBN: 0939300931.

  Summary: This directory provides a comprehensive overview of the support services and information resources available for people with any of 80 specific chronic illnesses. It presents information on various organizations, educational materials, publications, and databases. A chapter is devoted to each chronic illness and includes a brief description of it. The sections related to kidney and urologic diseases include: AIDS, Alzheimer's disease, cancer, cerebral palsy, diabetes, hypertension, impotence, incontinence, infertility, kidney disease, multiple sclerosis, sexually transmitted diseases, spina bifida, stroke, and substance abuse. The description of each disease is followed by subchapters that identify national and State associations and agencies, libraries, research centers, reference books, children's books, magazines, newsletters, pamphlets, videotapes and films, support groups and hotlines, and websites. In addition, the directory includes a chapter on death and bereavement, as well as a chapter on Wish Foundations for terminally and chronically ill children.

- **Sports, Anyone?**

  Source: Alexandria, VA, Orthotics and Prosthetics National Office, 17 p., September 1994.

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[26] You will need to limit your search to "Directories" and cerebral palsy using the "Detailed Search" option. Go directly to the following hyperlink: **http://chid.nih.gov/detail/detail.html**. To find directories, use the drop boxes at the bottom of the search page where "You may refine your search by". For publication date, select "All Years", select language and the format option "Directory". By making these selections and typing in "cerebral palsy" (or synonyms) into the "For these words:" box, you will only receive results on directories dealing with cerebral palsy. You should check back periodically with this database as it is updated every three months.

Contact: Orthotics and Prosthetics National Office, 1650 King Street, Suite 500, Alexandria, VA 22314. (703) 836-7114.

Summary: Sports, Anyone? gives detailed information on organizations that offer physical activities programs for individuals with disabilities. The National Handicapped Sports (NHS) and other U.S. Olympic Committee Disabled Sports Organizations offer training programs and conduct competitions that can give the disabled person the opportunity to compete in the Paralympic Games, which immediately follow the Olympics. Disabled Sports Organizations listed in the directory include the American Athletic Association of the Deaf (AAAD), the Dwarf Athletic Association of America (DAAA), the National Amputee Golf Association (NAGA), National Handicapped Sports (NHS), the United States Association of Blind Athletes (USABA), the United States Cerebral Palsy Athletic Association (USCPAA), the United States Les Autres Sports Association (USLASA) (which includes persons with such physical impairments as multiple sclerosis, muscular dystrophy, osteogenesis imperfecta, and other lesser-known disabilities), and Wheelchair Sports USA. Each entry includes address, telephone, and contact person information, eligibility criteria, a brief description of the organization, and the types of activities offered. The directory concludes with two inspirational essays, Rising to the Top and Essentials of Activity, which were written by disabled athletes, and provides information about the 1996 Paralympic Games in Atlanta, Georgia.

- **Nutrition resource guide for children with special health care needs**

  Source: Boston, MA: Massachusetts Department of Public Health. 1990. 27 pp.

  Contact: Available from Cynthia Taft Bayerl, R.D., M.S., Massachusetts Department of Public Health, Nutrition Services for Children with Special Health Care Needs, 150 Tremont Street, Fourth floor, Boston, MA 02111. Telephone: (617) 727-5822 or (617) 727-9283. Available at no charge.

  Summary: This reference guide is designed to help those interested in finding nutrition counseling and education for children with special health care needs in Massachusetts. The guide provides a list of names and addresses of counseling services, other support services, food assistance programs which provide food at reduced or no cost, special needs publications, general nutrition information, professional organizations, and related department of public health programs. A special needs publications list provides information on PKU, cerebral palsy, cleft lip and palate, spina bifida, and developmental disabilities. A

list of books for parents, caregivers, and professionals is included. [Funded by the Maternal and Child Health Bureau].

## General Home References

In addition to references for cerebral palsy, you may want a general home medical guide that spans all aspects of home healthcare. The following list is a recent sample of such guides (sorted alphabetically by title; hyperlinks provide rankings, information, and reviews at Amazon.com):

- **Adams & Victor's Principles Of Neurology** by Maurice Victor, et al; Hardcover - 1692 pages; 7th edition (December 19, 2000), McGraw-Hill Professional Publishing; ISBN: 0070674973; **http://www.amazon.com/exec/obidos/ASIN/0070674973/icongroupinterna**
- **American Academy of Pediatrics Guide to Your Child's Symptoms : The Official, Complete Home Reference, Birth Through Adolescence** by Donald Schiff (Editor), et al; Paperback - 256 pages (January 1997), Villard Books; ISBN: 0375752579; **http://www.amazon.com/exec/obidos/ASIN/0375752579/icongroupinterna**
- **The Children's Hospital Guide to Your Child's Health and Development** by Alan D. Woolf (Editor), et al; Hardcover - 796 pages, 1st edition (January 15, 2001), Perseus Books; ISBN: 073820241X; **http://www.amazon.com/exec/obidos/ASIN/073820241X/icongroupinterna**
- **Clinical Neuroanatomy Made Ridiculously Simple (MedMaster Series, 2000 Edition)** by Stephen Goldberg; Paperback: 97 pages; 2nd edition (February 15, 2000), Medmaster; ISBN: 0940780461; **http://www.amazon.com/exec/obidos/ASIN/0940780461/icongroupinterna**
- **Helping Your Child in the Hospital: A Practical Guide for Parents** by Nancy Keene, Rachel Prentice; Paperback - 176 pages, 3rd edition (April 15, 2002), O'Reilly & Associates; ISBN: 0596500114; **http://www.amazon.com/exec/obidos/ASIN/0596500114/icongroupinterna**
- **It's Not a Tumor!: The Patient's Guide to Common Neurological Problems** by Robert Wiedemeyer; Paperback: (January 1996), Boxweed Pub; ISBN: 0964740796; **http://www.amazon.com/exec/obidos/ASIN/0964740796/icongroupinterna**
- **Medical Emergencies & Childhood Illnesses: Includes Your Child's Personal Health Journal (Parent Smart)** by Penny A. Shore, William Sears (Contributor); Paperback - 115 pages (February 2002), Parent Kit

Corporation; ISBN: 1896833187;
**http://www.amazon.com/exec/obidos/ASIN/1896833187/icongroupinterna**

- **Neurology for the Non-Neurologist** by William J. Weiner (Editor), Christopher G. Goetz (Editor); Paperback (May 1999), Lippincott, Williams & Wilkins Publishers; ISBN: 0781717078;
**http://www.amazon.com/exec/obidos/ASIN/0781717078/icongroupinterna**
- **Taking Care of Your Child: A Parent's Guide to Complete Medical Care** by Robert H. Pantell, M.D., et al; Paperback - 524 pages, 6th edition (March 5, 2002), Perseus Press; ISBN: 0738206016;
**http://www.amazon.com/exec/obidos/ASIN/0738206016/icongroupinterna**

## Vocabulary Builder

**Alopecia:** Baldness; absence of the hair from skin areas where it normally is present. [EU]

**Aphasia:** Defect or loss of the power of expression by speech, writing, or signs, or of comprehending spoken or written language, due to injury or disease of the brain centres. [EU]

**Apnea:** A transient absence of spontaneous respiration. [NIH]

**Bereavement:** Refers to the whole process of grieving and mourning and is associated with a deep sense of loss and sadness. [NIH]

**Cardiovascular:** Pertaining to the heart and blood vessels. [EU]

**Cues:** Signals for an action; that specific portion of a perceptual field or pattern of stimuli to which a subject has learned to respond. [NIH]

**Dermatology:** A medical specialty concerned with the skin, its structure, functions, diseases, and treatment. [NIH]

**Fibrosis:** The formation of fibrous tissue; fibroid or fibrous degeneration [EU]

**Gestures:** Movement of a part of the body for the purpose of communication. [NIH]

**Hypertension:** Persistently high arterial blood pressure. Various criteria for its threshold have been suggested, ranging from 140 mm. Hg systolic and 90 mm. Hg diastolic to as high as 200 mm. Hg systolic and 110 mm. Hg diastolic. Hypertension may have no known cause (essential or idiopathic h.) or be associated with other primary diseases (secondary h.). [EU]

**Impotence:** The inability to perform sexual intercourse. [NIH]

**Infertility:** The diminished or absent ability to conceive or produce an offspring while sterility is the complete inability to conceive or produce an offspring. [NIH]

**Lupus:** A form of cutaneous tuberculosis. It is seen predominantly in women and typically involves the nasal, buccal, and conjunctival mucosa. [NIH]

**Myasthenia:** Muscular debility; any constitutional anomaly of muscle. [EU]

**Neuroanatomy:** Study of the anatomy of the nervous system as a specialty or discipline. [NIH]

**Phonation:** The process of producing vocal sounds by means of vocal cords vibrating in an expiratory blast of air. [NIH]

**Podiatry:** A specialty concerned with the diagnosis and treatment of foot disorders and injuries and anatomic defects of the foot. [NIH]

**Prostate:** A gland in males that surrounds the neck of the bladder and the urethra. It secretes a substance that liquifies coagulated semen. It is situated in the pelvic cavity behind the lower part of the pubic symphysis, above the deep layer of the triangular ligament, and rests upon the rectum. [NIH]

**Psychogenic:** Produced or caused by psychic or mental factors rather than organic factors. [EU]

**Puberty:** The period during which the secondary sex characteristics begin to develop and the capability of sexual reproduction is attained. [EU]

**Semantics:** The relationships between symbols and their meanings. [NIH]

**Sialorrhea:** Increased salivary flow. [NIH]

**Tracheotomy:** Surgical incision of the trachea. [NIH]

**Withdrawal:** 1. a pathological retreat from interpersonal contact and social involvement, as may occur in schizophrenia, depression, or schizoid avoidant and schizotypal personality disorders. 2. (DSM III-R) a substance-specific organic brain syndrome that follows the cessation of use or reduction in intake of a psychoactive substance that had been regularly used to induce a state of intoxication. [EU]

# CHAPTER 7. MULTIMEDIA ON CEREBRAL PALSY

## Overview

Information on cerebral palsy can come in a variety of formats. Among multimedia sources, video productions, slides, audiotapes, and computer databases are often available. In this chapter, we show you how to keep current on multimedia sources of information on cerebral palsy. We start with sources that have been summarized by federal agencies, and then show you how to find bibliographic information catalogued by the National Library of Medicine. If you see an interesting item, visit your local medical library to check on the availability of the title.

## Video Recordings

Most medical conditions do not have a video dedicated to them. If they do, they are often rather technical in nature. An excellent source of multimedia information on cerebral palsy is the Combined Health Information Database. You will need to limit your search to "video recording" and "cerebral palsy" using the "Detailed Search" option. Go directly to the following hyperlink: **http://chid.nih.gov/detail/detail.html**. To find video productions, use the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer, and the format option "Videorecording (videotape, videocassette, etc.)." By making these selections and typing "cerebral palsy" (or synonyms) into the "For these words:" box, you will only receive results on video productions. The following is a typical result when searching for video recordings on cerebral palsy:

- **Enable: People with Disabilities and Computers**

  Source: Redmond, WA: Microsoft Corporation. 1999. (videocassette).

Contact: Available from Microsoft Corporation. One Microsoft Way, Redmond, WA 98052-6399. (800) 573-2256. TTY (800) 736-1123. Website: www.microsoft.com/enable/productions. Price: Single copy free.

Summary: With the help of the personal computer, people with disabilities are working, creating, communicating, and juggling the activities of life. In this videotape program, the Flying Karamazov Brothers introduce viewers to people who are using the personal computer and other technologies to allow them to get back into the rhythm of life. The program begins by discussing how complicated everyone's life has become, then addresses some of the issues that arise when a disability is present. The program emphasizes the role of the computer as a way to empower people and to give them access to what they need, no matter what their disability. The program features interviews with a variety of people, including a person in a wheelchair and on a respirator who uses the computer for his business; a man who was paralyzed on one side by a stroke who uses the computer for enrichment and for keeping in touch with family and friends through e-mail; a young blind woman who uses her computer, a Braille'n'Speak program, and a Braille printer; a young hearing impaired woman who uses a computer and notetaker in the university classroom; a man who is in a wheelchair and uses the Internet to run a support network for people with quadraplegia; an older man with cerebral palsy who uses a variety of high and lower tech augmentative and alternative communication devices to communicate; and a deaf blind university student who uses a personal computer and a Braille display to communicate with others. The program features a suppertime gathering of the Karamazov Brothers and a group of people with different disabilities; the group discusses some of the joys and frustrations of coping with a disability and demonstrate some of the ways people can communicate (including sign language). The program also offers numerous inspirational quotes between scenes, stressing the resiliency of the human spirit and the role of the computer in helping all people to achieve their potential.

- **Speech to Speech: Telephone Access for People With Speech Disabilities**

  Source: Verona, WI: Attainment Company, Inc. 1999. (videorecording).

  Contact: Available from Attainment Company, Inc. P.O. Box 930160, Verona, WI 53593-0160. (800) 327-4269 or (608) 845-7880. Fax (800) 942-3865 or (608) 845-8040. Website: www.attainmentcompany.com. Price: $29.00 plus shipping and handling. ISBN: 1578610370.

  Summary: This videotape program describes the Speech to Speech program, which provides telephone access for people with speech

disabilities. Dr. Bob Segalman began a one man crusade to establish a Speech to Speech telephone service in California during the 1990s. His efforts have benefited all people with speech disabilities, eventually giving access to the telephone like never before. In 1998, the FCC mandated that all states initiate a Speech to Speech service within two years. Speech to Speech works in a similar fashion to telecommunications relay services: a communications assistant (CA) revoices everything the caller says. The program first demonstrates the frustration of everyday telephone activities for people with speech disorders: Dr. Segalman, who has cerebral palsy and speaks in a whispered voice, demonstrates the difficulties of ordering a pizza over the telephone. The program then features Dr. Raymond Kent and Jamie Murray Branch who describe how Speech to Speech works, who can use it, and when it is used. Other topics covered include the issue of confidentiality, difficulties with telephone communication in general (even for those people without speech disorders), and the indications for this type of assistive service. The program then shows Dr. Segalman happily ordering a pizza with the help of a Speech to Speech CA.

- **Determining Goals, Needs and Basic Skills**

  Source: Sacramento, CA: California State University, Sacramento. 1992. (videocassette, guide).

  Contact: Available from Imaginart Communication Products. 307 Arizona Street, Bisbee, AZ 85603. (800) 828-1376; Fax (602) 432-5134. E-mail: imaginart@aol.com. Price: $89.00 plus shipping and handling; $479.00 for series of 6 videos. Item Number 4051K.

  Summary: This videotape on determining goals, needs, and basic skills is one of six training tapes on augmentative communication (AC). This module is concerned with referrals and screening for AC. Two clients, a 25-month-old child with cerebral palsy and a 16-year-old young woman with cerebral palsy, are shown as examples. They differ considerably in their physical, cognitive, and language skills and needs. These differences are discussed and a variety of approaches to screening and needs assessment are demonstrated. The video covers parent interviews and the observations of clients. The accompanying guide describes the content of the videotape, poses some questions relating to the information presented, and provides detailed answers to those questions. (AA-M).

- **Oral Care Management of Persons with Movement Disorders**

  Source: Seattle, WA: Dental Education in Care of Persons with Disabilities (DECOD), University of Washington. 1997. (videocassette).

Contact: Available from Dental Education in Care of Persons with Disabilities (DECOD). Continuing Dental Education, Box 357137, University of Washington, Seattle, WA 98195-6370. (206) 543-5448. Fax (206) 685-3164. Price: $95.00 plus shipping and handling.

Summary: For persons with movement disorders, maintaining oral health can make a significant difference in their quality of life. Yet, the provision of oral health care to persons with such conditions can be a challenge for the patient, the caregiver, and the dental professional. This videotape is designed for audiences who wish to learn more about oral home care as well as for those treating patients with unanticipated or uncontrolled movements in the dental office setting. Filmed in dental clinic settings with actual patients, the program covers oral care for persons with an array of neuromotor dysfunctions, including cerebral palsy, multiple sclerosis, amyotrophic lateral sclerosis, spinal cord injury, Parkinson's disease, and chronic mental illness. The program addresses issues in communication, positioning, control of pain and anxiety, primitive reflexes, airway protection, stabilization of the head, bruxism, oral hygiene, and use of oral chemotherapeutic agents and adaptive aides. In each of these areas, effective management techniques are demonstrated. The program also offers practical instruction in methods of preventive oral care for persons with self-care ability as well as those dependent on caregivers. (AA-M).

- **Dental Care for Individuals with Cerebral Palsy**

  Source: Indianapolis, IN: United Cerebral Palsy Association of Greater Indiana, Inc. 199x. (videocassette).

  Contact: Available from United Cerebral Palsy Association of Greater Indiana, Inc. 615 North Alabama Street, Room 322, Indianapolis, IN 46204. (317) 632-3561. Price: $30.00 each; free for Indiana residents.

  Summary: This videotape program provides parents with information about dental care and oral hygiene for children with cerebral palsy (CP). Narrated by Dr. Brian Sanders, DDS, the program reviews the dental conditions associated with CP and explains how parents can improve the quality of home and dental care provided to children with CP. The program stresses that it can be difficult to find time for proper dental care, that children with CP can be 'orally defensive', and that some of the related medical care (drugs and special diets) can be risk factors for increased oral health problems in these children. The program then reviews common questions that parents may have, providing basic answers to those questions. Topics include finding a dentist who will treat the child with CP, the child's first visit to the dentist, bottle-feeding concerns, managing special diets (especially those that are high in

sugars), caries rate and gingival (gum) problems, preparing the child for a dental visit, handling dental visits that do not go well, toothbrushing techniques (including managing the increased gag reflex in these children), the use of mouth props and or restraints for dental care, braces, toothgrinding (bruxism), mouthguards, seizures, and falls or trauma to the mouth and face. The video depicts children with CP at the dental office and at home, experiencing toothbrushing or dental examinations.

## Bibliography: Multimedia on Cerebral Palsy

The National Library of Medicine is a rich source of information on healthcare-related multimedia productions including slides, computer software, and databases. To access the multimedia database, go to the following Web site: **http;//locatorplus.gov/**. Select "Search LOCATORplus." Once in the search area, simply type in cerebral palsy (or synonyms). Then, in the option box provided below the search box, select "Audiovisuals and Computer Files." From there, you can choose to sort results by publication date, author, or relevance. The following multimedia has been indexed on cerebral palsy. For more information, follow the hyperlink indicated:

- **Adolescent neuromotor assessment and treatment planning: cerebral palsy, athetosis.** Source: a Whiteford-Cohen production; Year: 1987; Format: Videorecording; Baltimore, MD: Distributed by Video Press, University of Maryland, c1987
- **Alexis, accessibility in the small community.** Source: a presentation of the IATP, Illinois Assistive Technology Project; produced in the facilities of the Biomedical Communications Center for Educational Television, Southern IllinoisUniversity; Year: 1992; Format: Videorecording; [Springfield, Ill.]: The Project, [1992]
- **Case studies in child development, David.** Source: [presented by] the Child Development Clinic, University of Arizona; Year: 1982; Format: Videorecording; Tucson, Ariz.: The University, c1982
- **Cerebral palsy: methods of ambulation.** Source: produced by the New York State Association for Crippled Children, Inc. (the Easter Seal Agency), an affiliate of the National Society for Crippled Children and Adults, Inc.; a Medicolor film produ; Year: 1951; Format: Motion picture; United States: The Association, [1951]
- **Cerebral palsy is not necessary.** Source: [presented by] Maxi-Move Foundation; Year: 1999; Format: Videorecording; [Lithicum, MD]: The Foundation, c1999

- **Developmental components of eye-hand coordination in the child with special needs: strategies for assessment and intervention.** Source: produced by Rhoda P. Erhardt; Year: 1996; Format: Videorecording; Maplewood, MN: Erhardt Developmental Products, c1996
- **Extra-articular subtalar arthrodesis in the cerebral palsy patient by the Grice technique.** Source: by Frank H. Bassett III, James A. Pressly, Lenox D. Baker; Year: 1973; Format: Slide; [Chicago, Ill.]: American Academy of Orthopaedic Surgeons, [1973]
- **Flexor slide operation for severe flexion contraction of the wrist and fingers.** Year: 1984; Format: Videorecording; [Chicago, Ill.]: American Academy of Orthopaedic Surgeons, [1984]
- **Four year follow-up, Autumn : neuromotor assessment and treatment planning: cerebral palsy, spastic quadriplegia.** Source: a Whiteford-Cohen production; Year: 1987; Format: Videorecording; Baltimore, MD: Distributed by Video Press, University of Maryland, c1987
- **Four year follow-up, Ellen: neuromotor assessment and treatment planning: cerebral palsy, athetosis.** Source: a Whiteford-Cohen production; Year: 1987; Format: Videorecording; Baltimore, MD: Distributed by Video Press, University of Maryland, c1987
- **Home dental care for children and young adults with cerebral palsy and spinal cord injuries.** Source: the University of Michigan; Year: 1983; Format: Videorecording; [Ann Arbor, Mich.]: The University, c1983
- **Locomotor prognosis in cerebral palsy.** Source: presented as an educational service to the medical profession by CIBA Pharmaceutical Company; Year: 1977; Format: Videorecording; [Chicago, Ill.]: American Academy of Orthopaedic Surgeons, [1977]
- **Management of cerebral palsy: a neuro-developmental approach.** Source: an AREN production; produced at the facilities of WQED/Pittsburgh by QED Enterprises; Year: 1986; Format: Videorecording; [Pittsburgh, Pa.]: American Rehabilitation Educational Network, c1986
- **Medical aspects of disabilities. Cerebral palsy and epilepsy.** Year: 1996; Format: Videorecording; [Logan, Utah]: Vocational Rehabilitation Distance Learning Project, Utah State University; [Stillwater, Okla.]: National Clearinghouse of Rehabilitation Training Materials [distributor], c1996
- **Occupational therapy.** Source: [presented by] the Council on Physical Therapy of the American Medical Association; Year: 1938; Format: Motion picture; [United States]: The Association, [1938]

- **Orthopaedic management of cerebral palsy.** Source: [American Academy of Orthopaedic Surgeons]; Year: 1972; Format: Slide; [Chicago, Ill.]: The Academy, [1972]
- **Overview and update of musculoskeletal management.** Source: Marshfield Clinic, Saint Joseph's Hospital; a presentation of the Marshfield Video Network; Year: 1999; Format: Videorecording; Marshfield, WI: The Network, c1999
- **Premedication for reconstructive dentistry of the adult cerebral palsy patient: a technique for dental office management.** Source: by Niels Bjorn Jorgensen and Charles T. Hurley; from the School of Dentistry, College of Medical Evangelists; Year: 1957; Format: Motion picture; Loma Linda, Calif.: The School, [1957]
- **Pre-speech evaluation of a cerebral palsied child (Kelly).** Source: a Waisman Center Communications Services production; Year: 1975; Format: Videorecording; Milwaukee, Wis.: C.P. Project, Demmer-Kiwanis Children's Div., Curative Workshop of Milwaukee, [1975?]
- **Principles of pathologic gait in cerebral palsy.** Source: from the Motion Analysis Laboratory of Gillette Children's Hospital; Year: 1995; Format: Electronic resource; St. Paul, Minn.: Gillette Children's Hospital, c1995
- **Programming the dysfunctional brain: discover options for the treatment of cerebral palsy & traumatic brain injury.** Source: Successful Images, Inc. & Institute of Human Development, Inc; Year: 2000; Format: Videorecording; Ft. Lauderdale, FL: Successful Images, c2000
- **Rachael, being five.** Source: a Whiteford-Cohen production for University of Maryland at Baltimore, Dept. of Physical Therapy; Year: 1985; Format: Videorecording; Baltimore, MD: Video Services, Dept. of Physical Therapy, School of Medicine, University of Maryland at Baltimore, c1985
- **Rachael's team.** Source: producers, Susan Hadary Cohen, William A. Whiteford; a Whiteford Cohen production for the Univ. of Maryland at Baltimore, Dept. of Physical Therapy; Year: 1986; Format: Videorecording; Baltimore, Md.: Video Services, Dept. of Physical Therapy, School of Medicine, University of Maryland, c1986
- **Rehabilitation & management of disabled young adults.** Source: a joint production of ... Audio Visual Center and Staff Education; Year: 1991; Format: Videorecording; [Oakland, Calif.]: Kaiser Foundation Health Plan, c1991
- **Self-feeding in the child with special needs.** Source: produced by Rhoda P. Erhardt; Year: 1995; Format: Videorecording; Maplewood, MN: Erhardt Developmental Products, c1995

- **Spinal nerve surgery.** Source: a presentation of Films for the Humanities & Sciences; produced for the Learning Channel by Advanced Medical Productions, Inc; Year: 1997; Format: Videorecording; Princeton, N.J.: Films for the Humanities ; Sciences, c1997
- **Surgery of the foot & knee in cerebral palsy.** Source: the American Academy of Orthopaedic Surgeons; Year: 1970; Format: Slide; [Chicago, Ill.]: The Academy, [1970]
- **Surgical treatment of spastic hip flexion gait patterns.** Source: presented as an educational service to the medical profession by CIBA Pharmaceutical Company; Year: 1976; Format: Videorecording; [Chicago, Ill.]: American Academy of Orthopaedic Surgeons, c1976
- **Value of physical therapy in treatment of cerebral palsy.** Source: [presented by] Marshfield Video Network, in cooperation with Marshfield Clinic, St. Joseph's Hospital, and Marshfield Medical Research Foundation; Year: 1988; Format: Videorecording; Marshfield, WI: The Network, [1988]
- **Year of birth.** Source: [presented by] the National Institute of Neurological Diseases and Blindness in association with Brown University; a Norwood Studios, Inc. production; Year: 1964; Format: Motion picture; Washington, D.C.: The Studios, [1964]

## Vocabulary Builder

**Bruxism:** A disorder characterized by grinding and clenching of the teeth. [NIH]

**Curative:** Tending to overcome disease and promote recovery. [EU]

**Pathologic:** 1. indicative of or caused by a morbid condition. 2. pertaining to pathology (= branch of medicine that treats the essential nature of the disease, especially the structural and functional changes in tissues and organs of the body caused by the disease). [EU]

**Stabilization:** The creation of a stable state. [EU]

**Telecommunications:** Transmission of information over distances via electronic means. [NIH]

# CHAPTER 8. PERIODICALS AND NEWS ON CEREBRAL PALSY

## Overview

Keeping up on the news relating to cerebral palsy can be challenging. Subscribing to targeted periodicals can be an effective way to stay abreast of recent developments on cerebral palsy. Periodicals include newsletters, magazines, and academic journals.

In this chapter, we suggest a number of news sources and present various periodicals that cover cerebral palsy beyond and including those which are published by parent associations mentioned earlier. We will first focus on news services, and then on periodicals. News services, press releases, and newsletters generally use more accessible language, so if you do chose to subscribe to one of the more technical periodicals, make sure that it uses language you can easily follow.

## News Services & Press Releases

Well before articles show up in newsletters or the popular press, they may appear in the form of a press release or a public relations announcement. One of the simplest ways of tracking press releases on cerebral palsy is to search the news wires. News wires are used by professional journalists, and have existed since the invention of the telegraph. Today, there are several major "wires" that are used by companies, universities, and other organizations to announce new medical breakthroughs. In the following sample of sources, we will briefly describe how to access each service. These services only post recent news intended for public viewing.

### PR Newswire

Perhaps the broadest of the wires is PR Newswire Association, Inc. To access this archive, simply go to **http://www.prnewswire.com**. Below the search box, select the option "The last 30 days." In the search box, type "cerebral palsy" or synonyms. The search results are shown by order of relevance. When reading these press releases, do not forget that the sponsor of the release may be a company or organization that is trying to sell a particular product or therapy. Their views, therefore, may be biased.

### Reuters

The Reuters' Medical News database can be very useful in exploring news archives relating to cerebral palsy. While some of the listed articles are free to view, others can be purchased for a nominal fee. To access this archive, go to **http://www.reutershealth.com/frame2/arch.html** and search by "cerebral palsy" (or synonyms). The following was recently listed in this archive for cerebral palsy:

- **Magnesium Sulfate Used To Prevent Preterm Labor Or Preeclampsia May Protect Against Cerebral Palsy In The Infant**
  Source: Reuters Medical News
  Date: February 09, 1995
  http://www.reuters.gov/archive/1995/02/09/professional/links/19950209clin002.html
- **Preterm infants' early movements can predict cerebral palsy**
  Source: Reuters Medical News
  Date: May 15, 2002
  http://www.reuters.gov/archive/2002/05/15/professional/links/20020515clin005.html
- **Babies' early movements can predict cerebral palsy**
  Source: Reuters Health eLine
  Date: May 15, 2002
  http://www.reuters.gov/archive/2002/05/15/eline/links/20020515elin014.html
- **Teens with cerebral palsy need specialized drug education**
  Source: Reuters Medical News
  Date: September 22, 2000
  http://www.reuters.gov/archive/2000/09/22/professional/links/20000922publ003.html

- **Horseback riding may help children with cerebral palsy**
  Source: Reuters Health eLine
  Date: September 22, 2000
  http://www.reuters.gov/archive/2000/09/22/eline/links/20000922elin036.html
- **Horseback riding beneficial for children with cerebral palsy**
  Source: Reuters Medical News
  Date: September 22, 2000
  http://www.reuters.gov/archive/2000/09/22/professional/links/20000922clin026.html
- **Electrodes Used To Treat Cerebral Palsy**
  Source: Reuters Health eLine
  Date: December 23, 1997
  http://www.reuters.gov/archive/1997/12/23/eline/links/19971223elin003.html
- **Meconium-Stained Amniotic Fluid Risk Factor For Cerebral Palsy In Preterm Infants**
  Source: Reuters Medical News
  Date: October 29, 1997
  http://www.reuters.gov/archive/1997/10/29/professional/links/19971029epid001.html
- **Maternal Infection A Risk Factor For Cerebral Palsy**
  Source: Reuters Medical News
  Date: July 16, 1997
  http://www.reuters.gov/archive/1997/07/16/professional/links/19970716clin004.html
- **Cerebral Palsy Linked to Infection**
  Source: Reuters Health eLine
  Date: July 15, 1997
  http://www.reuters.gov/archive/1997/07/15/eline/links/19970715elin004.html
- **Magnesium Sulfate Exposure In Utero Might Reduce Risk Of Cerebral Palsy In VLBW Infants**
  Source: Reuters Medical News
  Date: December 11, 1996
  http://www.reuters.gov/archive/1996/12/11/professional/links/19961211clin003.html

- **Drug May Prevent Cerebral Palsy**
  Source: Reuters Health eLine
  Date: December 10, 1996
  http://www.reuters.gov/archive/1996/12/10/eline/links/19961210elin004.html
- **Electronic Fetal Monitoring: A Low Specificity For Cerebral Palsy**
  Source: Reuters Medical News
  Date: March 07, 1996
  http://www.reuters.gov/archive/1996/03/07/professional/links/19960307clin001.html
- **Cerebral Palsy With Epilepsy: Management Strategy For Children**
  Source: Reuters Medical News
  Date: February 14, 1996
  http://www.reuters.gov/archive/1996/02/14/professional/links/19960214clin002.html
- **Chorioamnionitis Linked To Cerebral Palsy In Premature Infants**
  Source: Reuters Medical News
  Date: December 01, 1995
  http://www.reuters.gov/archive/1995/12/01/professional/links/19951201clin007.html

### The NIH

Within MEDLINEplus, the NIH has made an agreement with the New York Times Syndicate, the AP News Service, and Reuters to deliver news that can be browsed by the public. Search news releases at **http://www.nlm.nih.gov/medlineplus/alphanews_a.html.** MEDLINEplus allows you to browse across an alphabetical index. Or you can search by date at **http://www.nlm.nih.gov/medlineplus/newsbydate.html**. Often, news items are indexed by MEDLINEplus within their search engine. The following was recently indexed as relating to cerebral palsy:

- Increase in Low Birthweight Babies Seen in US
  http://www.nlm.nih.gov/medlineplus/news/fullstory_8803.html

### Business Wire

Business Wire is similar to PR Newswire. To access this archive, simply go to **http://www.businesswire.com**. You can scan the news by industry category or company name.

### Internet Wire

Internet Wire is more focused on technology than the other wires. To access this site, go to **http://www.internetwire.com** and use the "Search Archive" option. Type in "cerebral palsy" (or synonyms). As this service is oriented to technology, you may wish to search for press releases covering diagnostic procedures or tests that you may have read about.

### Search Engines

Free-to-view news can also be found in the news section of your favorite search engines (see the health news page at Yahoo: **http://dir.yahoo.com/Health/News_and_Media/,** or use this Web site's general news search page **http://news.yahoo.com/.** Type in "cerebral palsy" (or synonyms). If you know the name of a company that is relevant to cerebral palsy, you can go to any stock trading Web site (such as **www.etrade.com**) and search for the company name there. News items across various news sources are reported on indicated hyperlinks.

### BBC

Covering news from a more European perspective, the British Broadcasting Corporation (BBC) allows the public free access to their news archive located at **http://www.bbc.co.uk/**. Search by "cerebral palsy" (or synonyms).

## Academic Periodicals covering Cerebral Palsy

Academic periodicals can be a highly technical yet valuable source of information on cerebral palsy. We have compiled the following list of periodicals known to publish articles relating to cerebral palsy and which are currently indexed within the National Library of Medicine's PubMed database (follow hyperlinks to view more information, summaries, etc., for each). In addition to these sources, to keep current on articles written on cerebral palsy published by any of the periodicals listed below, you can simply follow the hyperlink indicated or go to the following Web site: **www.ncbi.nlm.nih.gov/pubmed**. Type the periodical's name into the search box to find the latest studies published.

If you want complete details about the historical contents of a periodical, you can also visit **http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi**. Here, type

in the name of the journal or its abbreviation, and you will receive an index of published articles. At **http://locatorplus.gov/** you can retrieve more indexing information on medical periodicals (e.g. the name of the publisher). Select the button "Search LOCATORplus." Then type in the name of the journal and select the advanced search option "Journal Title Search." The following is a sample of periodicals which publish articles on cerebral palsy:

- **Archives of Physical Medicine and Rehabilitation. (Arch Phys Med Rehabil)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Archives+of+Physical+Medicine+and+Rehabilitation&dispmax=20&dispstart=0

- **Brain & Development. (Brain Dev)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Brain+&+Development&dispmax=20&dispstart=0

- **Child's Nervous System : Chns : Official Journal of the International Society for Pediatric Neurosurgery. (Childs Nerv Syst)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Child's+Nervous+System+:+Chns+:+Official+Journal+of+the+International+Society+for+Pediatric+Neurosurgery&dispmax=20&dispstart=0

- **Developmental Medicine and Child Neurology. (Dev Med Child Neurol)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Developmental+Medicine+and+Child+Neurology&dispmax=20&dispstart=0

- **European Journal of Neurology : the Official Journal of the European Federation of Neurological Societies. (Eur J Neurol)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=European+Journal+of+Neurology+:+the+Official+Journal+of+the+European+Federation+of+Neurological+Societies&dispmax=20&dispstart=0

- **Gait & Posture. (Gait Posture)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Gait+&+Posture&dispmax=20&dispstart=0

- **Journal of Behavioral Medicine. (J Behav Med)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Journal+of+Behavioral+Medicine&dispmax=20&dispstart=0

- **Journal of Neurology, Neurosurgery, and Psychiatry. (J Neurol Neurosurg Psychiatry)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Journal+of+Neurology,+Neurosurgery,+and+Psychiatry&dispmax=20&dispstart=0

- **Journal of Paediatrics and Child Health. (J Paediatr Child Health)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Journal+of+Paediatrics+and+Child+Health&dispmax=20&dispstart=0

- **Muscle & Nerve. (Muscle Nerve)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Muscle+&+Nerve&dispmax=20&dispstart=0

- **Pediatric Annals. (Pediatr Ann)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Pediatric+Annals&dispmax=20&dispstart=0

- **Physical Therapy. (Phys Ther)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=Physical+Therapy&dispmax=20&dispstart=0

- **South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde. (S Afr Med J)**
  http://www.ncbi.nlm.nih.gov/entrez/jrbrowser.cgi?field=0&regexp=South+African+Medical+Journal.+Suid-Afrikaanse+Tydskrif+Vir+Geneeskunde&dispmax=20&dispstart=0

## Vocabulary Builder

**Fissure:** Any cleft or groove, normal or otherwise; especially a deep fold in the cerebral cortex which involves the entire thickness of the brain wall. [EU]

**Preeclampsia:** A toxaemia of late pregnancy characterized by hypertension, edema, and proteinuria, when convulsions and coma are associated, it is called eclampsia. [EU]

**Torticollis:** Wryneck; a contracted state of the cervical muscles, producing twisting of the neck and an unnatural position of the head. [EU]

# CHAPTER 9. PHYSICIAN GUIDELINES AND DATABASES

## Overview

Doctors and medical researchers rely on a number of information sources to help children with cerebral palsy. Many will subscribe to journals or newsletters published by their professional associations or refer to specialized textbooks or clinical guides published for the medical profession. In this chapter, we focus on databases and Internet-based guidelines created or written for this professional audience.

## NIH Guidelines

For the more common medical conditions, the National Institutes of Health publish guidelines that are frequently consulted by physicians. Publications are typically written by one or more of the various NIH Institutes. For physician guidelines, commonly referred to as "clinical" or "professional" guidelines, you can visit the following Institutes:

- Office of the Director (OD); guidelines consolidated across agencies available at **http://www.nih.gov/health/consumer/conkey.htm**
- National Institute of General Medical Sciences (NIGMS); fact sheets available at **http://www.nigms.nih.gov/news/facts/**
- National Library of Medicine (NLM); extensive encyclopedia (A.D.A.M., Inc.) with guidelines: **http://www.nlm.nih.gov/medlineplus/healthtopics.html**
- National Institute of Neurological Disorders and Stroke (NINDS); neurological disorder information pages available at **http://www.ninds.nih.gov/health_and_medical/disorder_index.htm**

## NIH Databases

In addition to the various Institutes of Health that publish professional guidelines, the NIH has designed a number of databases for professionals.[27] Physician-oriented resources provide a wide variety of information related to the biomedical and health sciences, both past and present. The format of these resources varies. Searchable databases, bibliographic citations, full text articles (when available), archival collections, and images are all available. The following are referenced by the National Library of Medicine:[28]

- **Bioethics:** Access to published literature on the ethical, legal and public policy issues surrounding healthcare and biomedical research. This information is provided in conjunction with the Kennedy Institute of Ethics located at Georgetown University, Washington, D.C.: **http://www.nlm.nih.gov/databases/databases_bioethics.html**
- **HIV/AIDS Resources:** Describes various links and databases dedicated to HIV/AIDS research: **http://www.nlm.nih.gov/pubs/factsheets/aidsinfs.html**
- **NLM Online Exhibitions:** Describes "Exhibitions in the History of Medicine": **http://www.nlm.nih.gov/exhibition/exhibition.html**. Additional resources for historical scholarship in medicine: **http://www.nlm.nih.gov/hmd/hmd.html**
- **Biotechnology Information:** Access to public databases. The National Center for Biotechnology Information conducts research in computational biology, develops software tools for analyzing genome data, and disseminates biomedical information for the better understanding of molecular processes affecting human health and disease: **http://www.ncbi.nlm.nih.gov/**
- **Population Information:** The National Library of Medicine provides access to worldwide coverage of population, family planning, and related health issues, including family planning technology and programs, fertility, and population law and policy: **http://www.nlm.nih.gov/databases/databases_population.html**
- **Cancer Information:** Access to caner-oriented databases: **http://www.nlm.nih.gov/databases/databases_cancer.html**

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[27] Remember, for the general public, the National Library of Medicine recommends the databases referenced in MEDLINE*plus* (**http://medlineplus.gov/** or **http://www.nlm.nih.gov/medlineplus/databases.html**).

[28] See http://www.nlm.nih.gov/databases/databases.html.

- **Profiles in Science:** Offering the archival collections of prominent twentieth-century biomedical scientists to the public through modern digital technology: **http://www.profiles.nlm.nih.gov/**
- **Chemical Information:** Provides links to various chemical databases and references: **http://sis.nlm.nih.gov/Chem/ChemMain.html**
- **Clinical Alerts:** Reports the release of findings from the NIH-funded clinical trials where such release could significantly affect morbidity and mortality: **http://www.nlm.nih.gov/databases/alerts/clinical_alerts.html**
- **Space Life Sciences:** Provides links and information to space-based research (including NASA): **http://www.nlm.nih.gov/databases/databases_space.html**
- **MEDLINE:** Bibliographic database covering the fields of medicine, nursing, dentistry, veterinary medicine, the healthcare system, and the pre-clinical sciences: **http://www.nlm.nih.gov/databases/databases_medline.html**
- **Toxicology and Environmental Health Information (TOXNET):** Databases covering toxicology and environmental health: **http://sis.nlm.nih.gov/Tox/ToxMain.html**
- **Visible Human Interface:** Anatomically detailed, three-dimensional representations of normal male and female human bodies: **http://www.nlm.nih.gov/research/visible/visible_human.html**

While all of the above references may be of interest to physicians who study and treat cerebral palsy, the following are particularly noteworthy.

### The Combined Health Information Database

A comprehensive source of information on clinical guidelines written for professionals is the Combined Health Information Database. You will need to limit your search to "Brochure/Pamphlet," "Fact Sheet," or "Information Package" and cerebral palsy using the "Detailed Search" option. Go directly to the following hyperlink: **http://chid.nih.gov/detail/detail.html**. To find associations, use the drop boxes at the bottom of the search page where "You may refine your search by." For the publication date, select "All Years," select your preferred language, and the format option "Fact Sheet." By making these selections and typing "cerebral palsy" (or synonyms) into the "For these words:" box above, you will only receive results on fact sheets dealing with cerebral palsy. The following is a sample result:

- **Demonstrating cost-effectiveness of nutrition services for children with special health care needs: A national network**

  Source: Arlington, VA: National Center for Education in Maternal and Child Health; Los Angeles, CA: Center for Child Development and Developmental Disabilities, University of Southern California. 1999. 67 pp.

  Contact: Available from National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536. Telephone: (703) 356-1964 or (888) 434-4MCH / fax: (703) 821-2098 / e-mail: nmchc@circsol.com. Available at no charge.

  Summary: This report summarizes a literature review and a field survey related to the cost-effectiveness of nutrition services for children with special health care needs (CSHCN). The literature review concentrates on cystic fibrosis, cerebral palsy, and failure to thrive. It includes an overview of each illness and the outcome indicators cited in the literature. The survey analysis results are presented by agency setting (i.e., clinical, public health, or university setting) and by federal region. A report on the expert panel convened to identify nutrition indicators for CSHCN, a description of workshop participant projects, and a list of workshop participants are included. The report was prepared for the Maternal and Child Health Interorganizational Nutrition Group (MCHING). [Funded by the Maternal and Child Health Bureau].

- **Healthy from the start: Why America needs a better system to track and understand birth defects and the environment**

  Source: Baltimore, MD: Pew Environmental Health Commission. [1999]. 86 pp.

Contact: Available from Pew Environmental Health Commission, Johns Hopkins School of Public Health, 111 Market Street, Suite 850, Baltimore, MD 21202. Available from the Web site at no charge.

Summary: This report examines the need for a comprehensive, modern tracking system to identify environmental and other preventable factors that contribute to birth defects and other disabilities and preventable diseases. The first section of the report discusses the connection between environmental exposures and birth defects, preterm and low birthweight, cerebral palsy, mental retardation and autism. The second section analyzes existing information from the National Center for Health Statistics and state birth defects registries to understand the rates and time trends of infant mortality, low birthweight, preterm birth, and birth defects and the geographic variability of birth defects in the United States. The third section of the report examines the adequacy, comprehensiveness, and quality of state birth defects surveillance systems.

- **Epidemiology of Problems Leading to Communicative Disorders**

  Source: in Billeaud, F.P. Communication Disorders in Infants and Toddlers: Assessment and Intervention. Woburn, MA: Butterworth-Heinemann. 1993. p. 8-18.

  Contact: Available from Butterworth-Heinemann, 225 Wildwood Avenue, Unit B, Woburn, MA 01801-2041. (617) 928-2500; Fax (617) 933-6333. Price: $35.00 plus shipping and handling. ISBN: 1563720361.

  Summary: This chapter, from a book on communication disorders in infants and children, discusses the epidemiology of problems leading to communicative disorders. The introductory section provides a statistical overview of the types of problems, including chromosomal anomalies, prenatal drug exposure, fetal alcohol syndrome, cerebral palsy, hearing impairment, autism, premature birth, and regulatory disorders of infancy. Other topics covered include the identification of handicaps, including both high-visibility and low-visibility communication disorders; some reasons for delayed intervention; the importance of early intervention and how to achieve it; intervention for children with obvious problems; and intervention for children with less obvious conditions, such as hearing impairment and atypical language development. The author concludes with a brief discussion of the cost-effectiveness of providing early intervention services for children.

- **Augmentative Communication: Consumers**

  Source: Rockville, MD: American Speech-Language-Hearing Association (ASHA). 199x. 36 p.

  Contact: Available from American Speech-Language-Hearing Association (ASHA). Product Sales, 10801 Rockville Pike, Rockville, MD 20852. (888) 498-6699. TTY (301) 897-0157. Website: www.asha.org. Price: $1.50 per booklet. Item Number 0210251.

  Summary: This consumer information booklet describes the use of augmentative communication for people who can hear but have little or no usable speech. Such severe communication disabilities can result from severe language delay, cerebral palsy, mental retardation, autism, traumatic brain injury (TBI), or stroke. In addition, a variety of specific neuromuscular disorders, such as amyotrophic lateral sclerosis (ALS), dystonia, Huntington's disease, multiple sclerosis, and muscular dystrophy can also cause severe speech problems. Augmentative communication is defined as any method other than speech, to send a message from one person to another. Techniques of augmentative communication range from specialized gestures and sign language to communication aids such as sign boards to highly specialized computer-based techniques. The booklet emphasizes the implementation of an effective augmentative communication system, regardless of level of sophistication, requires a detailed multidisciplinary assessment, training for the user(s), and regular re-evaluation. The booklet outlines the roles of members of the patient care team, including the speech language pathologist, the occupational therapist, the physical therapist, physicians, the educator, social worker, psychologist, rehabilitation engineer, computer programmer, vocational counselor, audiologist, orthotist, and manufacturers or distributors of communication devices. The author encourages readers to become active partners in their own care or the care of their children with communication disorders. The booklet includes a resource list of professional and consumer groups concerned with augmentative communication. An appendix provides a glossary of some of the terms used in augmentative communication. The booklet is illustrated with black and white photographs.

- **Augmentative Communication for General Public**

  Source: Rockville, MD: American Speech-Language-Hearing Association (ASHA). 1987. 20 p.

  Contact: Available from American Speech-Language-Hearing Association (ASHA). Product Sales, 10801 Rockville Pike, Rockville, MD

20852. (888) 498-6699. TTY (301) 897-0157. Website: www.asha.org. Price: $1.50 each; $6.00 for set of four.

Summary: This booklet introduces augmentative communication, a method of communication that uses a variety of techniques, from simple headshaking, gestures and pointing, to sign language, communication boards, and computers. The booklet describes how augmentative communication can promote social interaction, personal growth and independence; facilitate speech and language development; help students with severe speech and language impairments participate in the classroom; and enhance vocational opportunities. The booklet then describes how augmentative communication is taught and utilized. The next section describes how readers can help facilitate augmentative communication by locating resources, getting an evaluation, obtaining funds to purchase a communication aid, and becoming a communication partner. The booklet concludes with a list of communication tips and a directory of resource organizations and manufacturers. Throughout the booklet, the stories of two people with communication disorders (a child with cerebral palsy, and a 47-year-old woman who had a stroke) are presented, including how they learned to use augmentative communication and its impact on their lives. 4 figures.

- **Dental Services for Children and Adults with Developmental Disabilities**

  Source: New York, NY: United Cerebral Palsy of New York City. 199x. 2 p.

  Contact: Available from United Cerebral Palsy of New York City, Inc. 122 East 23rd Street, 2nd floor, New York, NY 10010. (212) 677-7400, ext. 306. Price: Single copy free.

  Summary: This brochure, presented in an oversized-bookmark format, briefly summarizes the services available at the Dental Services Diagnostic and Treatment Clinic of the United Cerebral Palsy of New York City. Services available include complete exam, cleanings, fillings, simple extractions, sealants, x-rays, fluoride treatment, oral hygiene instruction, and nutritional counseling. The verso of the bookmark lists the clinic schedule, the clinical staff, and information about fee reimbursement and transportation.

### The NLM Gateway[29]

The NLM (National Library of Medicine) Gateway is a Web-based system that lets users search simultaneously in multiple retrieval systems at the U.S. National Library of Medicine (NLM). It allows users of NLM services to initiate searches from one Web interface, providing "one-stop searching" for many of NLM's information resources or databases.[30] One target audience for the Gateway is the Internet user who is new to NLM's online resources and does not know what information is available or how best to search for it. This audience may include physicians and other healthcare providers, researchers, librarians, students, and, increasingly, parents and the public.[31] To use the NLM Gateway, simply go to the search site at **http://gateway.nlm.nih.gov/gw/Cmd**. Type "cerebral palsy" (or synonyms) into the search box and click "Search." The results will be presented in a tabular form, indicating the number of references in each database category.

**Results Summary**

| Category | Items Found |
|---|---|
| Journal Articles | 346318 |
| Books / Periodicals / Audio Visual | 2566 |
| Consumer Health | 294 |
| Meeting Abstracts | 3093 |
| Other Collections | 100 |
| Total | 352371 |

[29] Adapted from NLM: **http://gateway.nlm.nih.gov/gw/Cmd?Overview.x**.

[30] The NLM Gateway is currently being developed by the Lister Hill National Center for Biomedical Communications (LHNCBC) at the National Library of Medicine (NLM) of the National Institutes of Health (NIH).

[31] Other users may find the Gateway useful for an overall search of NLM's information resources. Some searchers may locate what they need immediately, while others will utilize the Gateway as an adjunct tool to other NLM search services such as PubMed® and MEDLINEplus®. The Gateway connects users with multiple NLM retrieval systems while also providing a search interface for its own collections. These collections include various types of information that do not logically belong in PubMed, LOCATORplus, or other established NLM retrieval systems (e.g., meeting announcements and pre-1966 journal citations). The Gateway will provide access to the information found in an increasing number of NLM retrieval systems in several phases.

### HSTAT[32]

HSTAT is a free, Web-based resource that provides access to full-text documents used in healthcare decision-making.[33] HSTAT's audience includes healthcare providers, health service researchers, policy makers, insurance companies, consumers, and the information professionals who serve these groups. HSTAT provides access to a wide variety of publications, including clinical practice guidelines, quick-reference guides for clinicians, consumer health brochures, evidence reports and technology assessments from the Agency for Healthcare Research and Quality (AHRQ), as well as AHRQ's Put Prevention Into Practice.[34] Simply search by "cerebral palsy" (or synonyms) at the following Web site: **http://text.nlm.nih.gov**.

### Coffee Break: Tutorials for Biologists[35]

Some parents may wish to have access to a general healthcare site that takes a scientific view of the news and covers recent breakthroughs in biology that may one day assist physicians in developing treatments. To this end, we recommend "Coffee Break," a collection of short reports on recent biological discoveries. Each report incorporates interactive tutorials that demonstrate how bioinformatics tools are used as a part of the research process. Currently, all Coffee Breaks are written by NCBI staff.[36] Each report is about 400 words and is usually based on a discovery reported in one or more articles from recently published, peer-reviewed literature.[37] This site has new

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[32] Adapted from HSTAT: http://www.nlm.nih.gov/pubs/factsheets/hstat.html.

[33] The HSTAT URL is **http://hstat.nlm.nih.gov/**.

[34] Other important documents in HSTAT include: the National Institutes of Health (NIH) Consensus Conference Reports and Technology Assessment Reports; the HIV/AIDS Treatment Information Service (ATIS) resource documents; the Substance Abuse and Mental Health Services Administration's Center for Substance Abuse Treatment (SAMHSA/CSAT) Treatment Improvement Protocols (TIP) and Center for Substance Abuse Prevention (SAMHSA/CSAP) Prevention Enhancement Protocols System (PEPS); the Public Health Service (PHS) Preventive Services Task Force's *Guide to Clinical Preventive Services*; the independent, nonfederal Task Force on Community Services *Guide to Community Preventive Services*; and the Health Technology Advisory Committee (HTAC) of the Minnesota Health Care Commission (MHCC) health technology evaluations.

[35] Adapted from http://www.ncbi.nlm.nih.gov/Coffeebreak/Archive/FAQ.html.

[36] The figure that accompanies each article is frequently supplied by an expert external to NCBI, in which case the source of the figure is cited. The result is an interactive tutorial that tells a biological story.

[37] After a brief introduction that sets the work described into a broader context, the report focuses on how a molecular understanding can provide explanations of observed biology and lead to therapies for diseases. Each vignette is accompanied by a figure and hypertext links that lead to a series of pages that interactively show how NCBI tools and resources are used in the research process.

articles every few weeks, so it can be considered an online magazine of sorts, and intended for general background information. Access the Coffee Break Web site at **http://www.ncbi.nlm.nih.gov/Coffeebreak/**.

## Other Commercial Databases

In addition to resources maintained by official agencies, other databases exist that are commercial ventures addressing medical professionals. Here are a few examples that may interest you:

- **CliniWeb International:** Index and table of contents to selected clinical information on the Internet; see **http://www.ohsu.edu/cliniweb/**.
- **Image Engine:** Multimedia electronic medical record system that integrates a wide range of digitized clinical images with textual data stored in the University of Pittsburgh Medical Center's MARS electronic medical record system; see the following Web site: **http://www.cml.upmc.edu/cml/imageengine/imageEngine.html**.
- **Medical World Search:** Searches full text from thousands of selected medical sites on the Internet; see **http://www.mwsearch.com/**.
- **MedWeaver:** Prototype system that allows users to search differential diagnoses for any list of signs and symptoms, to search medical literature, and to explore relevant Web sites; see **http://www.med.virginia.edu/~wmd4n/medweaver.html**.
- **Metaphrase:** Middleware component intended for use by both caregivers and medical records personnel. It converts the informal language generally used by caregivers into terms from formal, controlled vocabularies; see the following Web site: **http://www.lexical.com/Metaphrase.html**.

## The Genome Project and Cerebral Palsy

With all the discussion in the press about the Human Genome Project, it is only natural that physicians, researchers, and parents want to know about how human genes relate to cerebral palsy. In the following section, we will discuss databases and references used by physicians and scientists who work in this area.

### Online Mendelian Inheritance in Man (OMIM)

The Online Mendelian Inheritance in Man (OMIM) database is a catalog of human genes and genetic disorders authored and edited by Dr. Victor A. McKusick and his colleagues at Johns Hopkins and elsewhere. OMIM was developed for the World Wide Web by the National Center for Biotechnology Information (NCBI).[38] The database contains textual information, pictures, and reference information. It also contains copious links to NCBI's Entrez database of MEDLINE articles and sequence information.

Go to **http://www.ncbi.nlm.nih.gov/Omim/searchomim.html** to search the database. Type "cerebral palsy" (or synonyms) in the search box, and click "Submit Search." If too many results appear, you can narrow the search by adding the word "clinical." Each report will have additional links to related research and databases. By following these links, especially the link titled "Database Links," you will be exposed to numerous specialized databases that are largely used by the scientific community. These databases are overly technical and seldom used by the general public, but offer an abundance of information. The following is an example of the results you can obtain from the OMIM for cerebral palsy:

- **Cerebral Palsy, Ataxic, Autosomal Recessive**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?605388
- **Spastic Cerebral Palsy, Symmetric, Autosomal Recessive**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?603513
- **Supranuclear Palsy, Progressive**
  Web site: http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?601104

### Genes and Disease (NCBI - Map)

The Genes and Disease database is produced by the National Center for Biotechnology Information of the National Library of Medicine at the

[38] Adapted from **http://www.ncbi.nlm.nih.gov/**. Established in 1988 as a national resource for molecular biology information, NCBI creates public databases, conducts research in computational biology, develops software tools for analyzing genome data, and disseminates biomedical information--all for the better understanding of molecular processes affecting human health and disease.

National Institutes of Health. This Web site categorizes each disorder by the system of the body associated with it. Go to **http://www.ncbi.nlm.nih.gov/disease/**, and browse the system pages to have a full view of important conditions linked to human genes. Since this site is regularly updated, you may wish to re-visit it from time to time. The following systems and associated disorders are addressed:

- **Muscle and Bone:** Movement and growth.
  Examples: Duchenne muscular dystrophy, Ellis-van Creveld syndrome, Marfan syndrome, myotonic dystrophy, spinal muscular atrophy.
  Web site: **http://www.ncbi.nlm.nih.gov/disease/Muscle.html**
- **Nervous System:** Mind and body.
  Examples: Alzheimer disease, Amyotrophic lateral sclerosis, Angelman syndrome, Charcot-Marie-Tooth disease, epilepsy, essential tremor, Fragile X syndrome, Friedreich's ataxia, Huntington disease, Niemann-Pick disease, Parkinson disease, Prader-Willi syndrome, Rett syndrome, Spinocerebellar atrophy, Williams syndrome.
  Web site: **http://www.ncbi.nlm.nih.gov/disease/Brain.html**
- **Signals:** Cellular messages.
  Examples: Ataxia telangiectasia, Baldness, Cockayne syndrome, Glaucoma, SRY: sex determination, Tuberous sclerosis, Waardenburg syndrome, Werner syndrome.
  Web site: **http://www.ncbi.nlm.nih.gov/disease/Signals.html**

### Entrez

*Entrez* is a search and retrieval system that integrates several linked databases at the National Center for Biotechnology Information (NCBI). These databases include nucleotide sequences, protein sequences, macromolecular structures, whole genomes, and MEDLINE through PubMed. Entrez provides access to the following databases:

- **PubMed:** Biomedical literature (PubMed),
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed**
- **Nucleotide Sequence Database (Genbank):**
  Web site:
  **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Nucleotide**
- **Protein Sequence Database:**
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Protein**
- **Structure:** Three-dimensional macromolecular structures,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Structure**

- **Genome:** Complete genome assemblies,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Genome**
- **PopSet:** Population study data sets,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Popset**
- **OMIM:** Online Mendelian Inheritance in Man,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM**
- **Taxonomy:** Organisms in GenBank,
  Web site:
  **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Taxonomy**
- **Books:** Online books,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=books**
- **ProbeSet:** Gene Expression Omnibus (GEO),
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=geo**
- **3D Domains:** Domains from Entrez Structure,
  Web site: **http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=geo**
- **NCBI's Protein Sequence Information Survey Results:**
  Web site: **http://www.ncbi.nlm.nih.gov/About/proteinsurvey/**

To access the Entrez system at the National Center for Biotechnology Information, go to **http://www.ncbi.nlm.nih.gov/entrez/**, and then select the database that you would like to search. The databases available are listed in the drop box next to "Search." In the box next to "for," enter "cerebral palsy" (or synonyms) and click "Go."

### Jablonski's Multiple Congenital Anomaly/Mental Retardation (MCA/MR) Syndromes Database[39]

This online resource can be quite useful. It has been developed to facilitate the identification and differentiation of syndromic entities. Special attention is given to the type of information that is usually limited or completely omitted in existing reference sources due to space limitations of the printed form.

At the following Web site you can also search across syndromes using an index: **http://www.nlm.nih.gov/mesh/jablonski/syndrome_toc/toc_a.html.** You can search by keywords at this Web site: **http://www.nlm.nih.gov/mesh/jablonski/syndrome_db.html**.

[39] Adapted from the National Library of Medicine:
http://www.nlm.nih.gov/mesh/jablonski/about_syndrome.html.

### The Genome Database[40]

Established at Johns Hopkins University in Baltimore, Maryland in 1990, the Genome Database (GDB) is the official central repository for genomic mapping data resulting from the Human Genome Initiative. In the spring of 1999, the Bioinformatics Supercomputing Centre (BiSC) at the Hospital for Sick Children in Toronto, Ontario assumed the management of GDB. The Human Genome Initiative is a worldwide research effort focusing on structural analysis of human DNA to determine the location and sequence of the estimated 100,000 human genes. In support of this project, GDB stores and curates data generated by researchers worldwide who are engaged in the mapping effort of the Human Genome Project (HGP). GDB's mission is to provide scientists with an encyclopedia of the human genome which is continually revised and updated to reflect the current state of scientific knowledge. Although GDB has historically focused on gene mapping, its focus will broaden as the Genome Project moves from mapping to sequence, and finally, to functional analysis.

To access the GDB, simply go to the following hyperlink: **http://www.gdb.org/**. Search "All Biological Data" by "Keyword." Type "cerebral palsy" (or synonyms) into the search box, and review the results. If more than one word is used in the search box, then separate each one with the word "and" or "or" (using "or" might be useful when using synonyms). This database is extremely technical as it was created for specialists. The articles are the results which are the most accessible to non-professionals and often listed under the heading "Citations." The contact names are also accessible to non-professionals.

## Specialized References

The following books are specialized references written for professionals interested in cerebral palsy (sorted alphabetically by title; hyperlinks provide rankings, information, and reviews at Amazon.com):

- **Atlas of Pediatric Physical Diagnosis** by Basil J. Zitelli, Holly W. Davis (Editor); Hardcover, 3rd edition (March 1997), Mosby-Year Book; ISBN: 0815199309; **http://www.amazon.com/exec/obidos/ASIN/0815199309/icongroupinterna**
- **The 5-Minute Pediatric Consult** by M. William Schwartz (Editor); Hardcover - 1050 pages, 2nd edition (January 15, 2000), Lippincott,

[40] Adapted from the Genome Database: http://gdbwww.gdb.org/gdb/aboutGDB.html#mission.

Williams & Wilkins; ISBN: 0683307444;
**http://www.amazon.com/exec/obidos/ASIN/0683307444/icongroupinterna**

- **The Behavioral Neurology of White Matter** by Christopher M. Filley; Paperback - 279 pages; 1st edition (September 15, 2001), Oxford University Press; ISBN: 019513561X;
**http://www.amazon.com/exec/obidos/ASIN/019513561X/icongroupinterna**
- **The Cerebellum and Its Disorders** by Mario-Ubaldo Manto, Massimo Pandolfo; Hardcover - 1st edition (January 2002), Cambridge University Press; ISBN: 0521771560;
**http://www.amazon.com/exec/obidos/ASIN/0521771560/icongroupinterna**
- **Clinical Neurology** by David A. Greenberg, et al; Paperback - 390 pages; 5th edition (February 9, 2002), Appleton & Lange; ISBN: 0071375430;
**http://www.amazon.com/exec/obidos/ASIN/0071375430/icongroupinterna**
- **Clinical Neurology for Psychiatrists** by David M. Kaufman; Hardcover - 670 pages, 5th edition (January 15, 2001), W. B. Saunders Co.; ISBN: 0721689957;
**http://www.amazon.com/exec/obidos/ASIN/0721689957/icongroupinterna**
- **Comprehensive Neurology** by Roger N. Rosenberg (Editor), David E. Pleasure (Editor); 1280 pages, 2nd edition (April 1998), Wiley-Liss; ISBN: 0471169587;
**http://www.amazon.com/exec/obidos/ASIN/0471169587/icongroupinterna**
- **Emergent and Urgent Neurology** by William J. Weiner (Editor), Lisa M. Shulman (Editor); Hardcover - 571 pages; 2nd edition (January 15, 1999), Lippincott, Williams & Wilkins Publishers; ISBN: 0397518579;
**http://www.amazon.com/exec/obidos/ASIN/0397518579/icongroupinterna**
- **Nelson Textbook of Pediatrics** by Richard E. Behrman (Editor), et al; Hardcover - 2414 pages, 16th edition (January 15, 2000), W B Saunders Co; ISBN: 0721677673;
**http://www.amazon.com/exec/obidos/ASIN/0721677673/icongroupinterna**
- **Neurology in Clinical Practice: Volume I: Principles of Diagnosis and Management, Volume II: The Neurological Disorders (2-Volume Set, Includes a 12-Month Subscription to the Online Edition)** by W. G. Bradley, et al; Hardcover **-** 2413 pages, 3rd edition, Vol 1-2 (January 15, 2000), Butterworth-Heinemann; ISBN: 0750699736;
**http://www.amazon.com/exec/obidos/ASIN/0750699736/icongroupinterna**
- **Neuroscience: Exploring the Brain** by Mark F. Bear, et al; Hardcover - 855 pages, 2nd edition (January 15, 2001), Lippincott, Williams & Wilkins Publishers; ISBN: 0683305964;
**http://www.amazon.com/exec/obidos/ASIN/0683305964/icongroupinterna**

- **Office Practice of Neurology** by Martain A. Samuels, Steven F. Feske; Hardcover, Churchill Livingstone; ISBN: 0443065578; **http://www.amazon.com/exec/obidos/ASIN/0443065578/icongroupinterna**
- **Patient-Based Approaches to Cognitive Neuroscience** by Martha J. Farah (Editor), Todd E. Feinberg (Editor); Paperback - 425 pages (April 3, 2000), MIT Press; ISBN: 0262561239; **http://www.amazon.com/exec/obidos/ASIN/0262561239/icongroupinterna**
- **Principles of Neural Science** by Eric R. Kandel (Editor), et al; Hardcover - 1414 pages, 4th edition (January 5, 2000), McGraw-Hill Professional Publishing; ISBN: 0838577016; **http://www.amazon.com/exec/obidos/ASIN/0838577016/icongroupinterna**
- **Review Manual for Neurology in Clinical Practice** by Karl E. Misulis, et al; Paperback, Butterworth-Heinemann Medical; ISBN: 0750671920; **http://www.amazon.com/exec/obidos/ASIN/0750671920/icongroupinterna**

## Vocabulary Builder

**Atypical:** Irregular; not conformable to the type; in microbiology, applied specifically to strains of unusual type. [EU]

**Extraction:** The process or act of pulling or drawing out. [EU]

**Registries:** The systems and processes involved in the establishment, support, management, and operation of registers, e.g., disease registers. [NIH]

# CHAPTER 10. DISSERTATIONS ON CEREBRAL PALSY

## Overview

University researchers are active in studying almost all known medical conditions. The result of research is often published in the form of Doctoral or Master's dissertations. You should understand, therefore, that applied diagnostic procedures and/or therapies can take many years to develop after the thesis that proposed the new technique or approach was written.

In this chapter, we will give you a bibliography on recent dissertations relating to cerebral palsy. You can read about these in more detail using the Internet or your local medical library. We will also provide you with information on how to use the Internet to stay current on dissertations.

## Dissertations on Cerebral Palsy

*ProQuest Digital Dissertations* is the largest archive of academic dissertations available. From this archive, we have compiled the following list covering dissertations devoted to cerebral palsy. You will see that the information provided includes the dissertation's title, its author, and the author's institution. To read more about the following, simply use the Internet address indicated. The following covers recent dissertations dealing with cerebral palsy:

- **A Behavioral Analysis of Interactions between Physical Therapists and Children with Cerebral Palsy during Treatment** by Carter, Russell E., Edd from Northern Illinois University, 1989, 194 pages
  http://wwwlib.umi.com/dissertations/fullcit/9000516

- **A Comparison of the Effect of Standard Wheelchair Seating and Adaptive Seating on the Speech Intelligibility of Children Who Have Cerebral Palsy (severely, Physically Handicapped, Adaptive Equipment, Technology)** by Smith, Pamela Dianne, Edd from The University of Alabama, 1985, 156 pages
  http://wwwlib.umi.com/dissertations/fullcit/8611968
- **A Game of Cat and Mouse: the Bullying and Teasing Experiences of Children with Cerebral Palsy** by Tentoglou, Nikie; Msw from University of Toronto (canada), 2001, 76 pages
  http://wwwlib.umi.com/dissertations/fullcit/MQ63230
- **A Microcomputer-based Education and Communication System for Children with Cerebral Palsy** by Fowler, Jeffrey Ronald, Phd from Council for National Academic Awards (united Kingdom), 1988, 308 pages
  http://wwwlib.umi.com/dissertations/fullcit/DX83952
- **A Programmed Approach to the Instruction of Volunteers in the Perceptuo-motor Training of Pre-school Children with Cerebral Palsy.** by Affleck, James Quinn, Edd from Columbia University, 1968, 154 pages
  http://wwwlib.umi.com/dissertations/fullcit/6900656
- **A Study on the Interaction of Cerebral Palsy and Group Process** by French, Maria Soledad, Phd from University of Southern California, 1986
  http://wwwlib.umi.com/dissertations/fullcit/f1015733
- **Achievement Motivation a Follow-up Study of Cerebral Palsy in Northern Alberta** by Ruth, Jean; Advdeg from University of Alberta (canada), 1970
  http://wwwlib.umi.com/dissertations/fullcit/NK06755
- **Adaptive Behavior Assessment of Adults with Developmental Disabilities, Primarily Those with Cerebral Palsy** by Kagedan, Steven Meir, Edd from Columbia University Teachers College, 1992, 106 pages
  http://wwwlib.umi.com/dissertations/fullcit/9228487
- **An Exploratory Case Study of the Experiences of Preschool Children with Spastic Cerebral Palsy in Hydrotherapy** by Appleby, Jennifer; Msc from The University of Regina (canada), 2001, 102 pages
  http://wwwlib.umi.com/dissertations/fullcit/MQ60217
- **An Investigation into Certain Aspects of Visual and Visual-motor Perception in Children with Cerebral Palsy** by Delany, Frances Imelda, Phd from Fordham University, 1967, 165 pages
  http://wwwlib.umi.com/dissertations/fullcit/6711487

## Keeping Current

As previously mentioned, an effective way to stay current on dissertations dedicated to cerebral palsy is to use the database called *ProQuest Digital Dissertations* via the Internet, located at the following Web address: **http;//wwwlib.umi.com/dissertations.** The site allows you to freely access the last two years of citations and abstracts. Ask your medical librarian if the library has full and unlimited access to this database. From the library, you should be able to do more complete searches than with the limited 2-year access available to the general public.

# PART III. APPENDICES

## ABOUT PART III

Part III is a collection of appendices on general medical topics relating to cerebral palsy and related conditions.

# APPENDIX A. RESEARCHING YOUR CHILD'S MEDICATIONS

## Overview

There are a number of sources available on new or existing medications which could be prescribed to treat cerebral palsy. While a number of hard copy or CD-Rom resources are available to parents and physicians for research purposes, a more flexible method is to use Internet-based databases. In this chapter, we will begin with a general overview of medications. We will then proceed to outline official recommendations on how you should view your child's medications. You may also want to research medications that your child is currently taking for other conditions as they may interact with medications for cerebral palsy. Research can give you information on the side effects, interactions, and limitations of prescription drugs used in the treatment of cerebral palsy. Broadly speaking, there are two sources of information on approved medications: public sources and private sources. We will emphasize free-to-use public sources.

## Your Child's Medications: The Basics[41]

The Agency for Health Care Research and Quality has published extremely useful guidelines on the medication aspects of cerebral palsy. Giving your child medication can involve many steps and decisions each day. The AHCRQ recommends that parents take part in treatment decisions. Do not be afraid to ask questions and talk about your concerns. By taking a moment to ask questions, your child may be spared from possible problems. Here are some points to cover each time a new medicine is prescribed**:**

- Ask about all parts of your child's treatment, including diet changes, exercise, and medicines.
- Ask about the risks and benefits of each medicine or other treatment your child might receive.
- Ask how often you or your child's doctor will check for side effects from a given medication.

Do not hesitate to tell the doctor about preferences you have for your child's medicines. You may want your child to have a medicine with the fewest side effects, or the fewest doses to take each day. You may care most about cost. Or, you may want the medicine the doctor believes will work the best. Sharing your concerns will help the doctor select the best treatment for your child.

Do not be afraid to "bother" the doctor with your questions about medications for cerebral palsy. You can also talk to a nurse or a pharmacist. They can help you better understand your child's treatment plan. Talking over your child's options with someone you trust can help you make better choices. Specifically, ask the doctor the following:

- The name of the medicine and what it is supposed to do.
- How and when to give your child the medicine, how much, and for how long.
- What food, drinks, other medicines, or activities your child should avoid while taking the medicine.
- What side effects your child may experience, and what to do if they occur.
- If there are any refills, and how often.
- About any terms or directions you do not understand.
- What to do if your child misses a dose.

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[41] This section is adapted from AHCRQ: **http://www.ahcpr.gov/consumer/ncpiebro.htm**.

- If there is written information you can take home (most pharmacies have information sheets on prescription medicines; some even offer large-print or Spanish versions).

Do not forget to tell the doctor about all the medicines your child is currently taking (not just those for cerebral palsy). This includes prescription medicines and the medicines that you buy over the counter. When talking to the doctor, you may wish to prepare a list of medicines your child is currently taking including why and in what forms. Be sure to include the following information for each:

- Name of medicine
- Reason taken
- Dosage
- Time(s) of day

Also include any over-the-counter medicines, such as:

- Laxatives
- Diet pills
- Vitamins
- Cold medicine
- Aspirin or other pain, headache, or fever medicine
- Cough medicine
- Allergy relief medicine
- Antacids
- Sleeping pills
- Others (include names)

## Learning More about Your Child's Medications

Because of historical investments by various organizations and the emergence of the Internet, it has become rather simple to learn about the medications the doctor has recommended for cerebral palsy. One such source is the United States Pharmacopeia. In 1820, eleven physicians met in Washington, D.C. to establish the first compendium of standard drugs for the United States. They called this compendium the "U.S. Pharmacopeia (USP)." Today, the USP is a non-profit organization consisting of 800 volunteer scientists, eleven elected officials, and 400 representatives of state

associations and colleges of medicine and pharmacy. The USP is located in Rockville, Maryland, and its home page is located at **www.usp.org**. The USP currently provides standards for over 3,700 medications. The resulting USP DI® Advice for the Patient® can be accessed through the National Library of Medicine of the National Institutes of Health. The database is partially derived from lists of federally approved medications in the Food and Drug Administration's (FDA) Drug Approvals database.[42]

While the FDA database is rather large and difficult to navigate, the Phamacopeia is both user-friendly and free to use. It covers more than 9,000 prescription and over-the-counter medications. To access this database, simply type the following hyperlink into your Web browser: **http://www.nlm.nih.gov/medlineplus/druginformation.html**. To view examples of a given medication (brand names, category, description, preparation, proper use, precautions, side effects, etc.), simply follow the hyperlinks indicated within the United States Pharmacopoeia (USP). It is important to read the disclaimer by the USP (**http://www.nlm.nih.gov/medlineplus/drugdisclaimer.html**) before using the information provided.

Of course, we as editors cannot be certain as to what medications your child is taking. Therefore, we have compiled a list of medications associated with the treatment of cerebral palsy. Once again, due to space limitations, we only list a sample of medications and provide hyperlinks to ample documentation (e.g. typical dosage, side effects, drug-interaction risks, etc.). The following drugs have been mentioned in the Pharmacopeia and other sources as being potentially applicable to cerebral palsy:

**Amantadine**

- **Systemic - U.S. Brands:** Symmetrel
  http://www.nlm.nih.gov/medlineplus/druginfo/amantadinesystemic202024.html

**Baclofen**

- **Systemic - U.S. Brands:** Lioresal
  http://www.nlm.nih.gov/medlineplus/druginfo/baclofensystemic202080.html

[42] Though cumbersome, the FDA database can be freely browsed at the following site: **www.fda.gov/cder/da/da.htm**.

**Botulinum Toxin Type A**

- **Parenteral-Local - U.S.** Brands: Botox
  http://www.nlm.nih.gov/medlineplus/druginfo/botulinumtoxintypeaparenterall202608.html

**Dantrolene**

- **Systemic - U.S. Brands:** Dantrium
  http://www.nlm.nih.gov/medlineplus/druginfo/dantrolenesystemic202181.html

**Entacapone**

- **Systemic - U.S. Brands:** Comtan
  http://www.nlm.nih.gov/medlineplus/druginfo/entacaponesystemic500103.html

**Levodopa**

- **Systemic - U.S. Brands:** Atamet; Larodopa; Sinemet; Sinemet CR
  http://www.nlm.nih.gov/medlineplus/druginfo/levodopasystemic202326.html

**Selegiline**

- **Systemic - U.S. Brands:** Carbex; Eldepryl
  http://www.nlm.nih.gov/medlineplus/druginfo/selegilinesystemic202519.html

## Commercial Databases

In addition to the medications listed in the USP above, a number of commercial sites are available by subscription to physicians and their institutions. You may be able to access these sources from your local medical library or your child's doctor's office.

### Reuters Health Drug Database

The Reuters Health Drug Database can be searched by keyword at the hyperlink: **http://www.reutershealth.com/frame2/drug.html**. The following medications are listed in the Reuters' database as associated with cerebral palsy (including those with contraindications):[43]

[43] Adapted from *A to Z Drug Facts* by Facts and Comparisons.

- **Baclofen**
  http://www.reutershealth.com/atoz/html/Baclofen.htm
- **Dantrolene Sodium**
  http://www.reutershealth.com/atoz/html/Dantrolene_Sodium.htm

#### Mosby's GenRx

Mosby's GenRx database (also available on CD-Rom and book format) covers 45,000 drug products including generics and international brands. It provides information on prescribing and drug interactions. Information can be obtained at **http://www.genrx.com/Mosby/PhyGenRx/group.html**.

#### Physicians Desk Reference

The Physicians Desk Reference database (also available in CD-Rom and book format) is a full-text drug database. The database is searchable by brand name, generic name or by indication. It features multiple drug interactions reports. Information can be obtained at the following hyperlink: **http://physician.pdr.net/physician/templates/en/acl/psuser_t.htm**.

#### Other Web Sites

A number of additional Web sites discuss drug information. As an example, you may like to look at **www.drugs.com** which reproduces the information in the Pharmacopeia as well as commercial information. You may also want to consider the Web site of the Medical Letter, Inc. which allows users to download articles on various drugs and therapeutics for a nominal fee: **http://www.medletter.com/**.

## Contraindications and Interactions (Hidden Dangers)

Some of the medications mentioned in the previous discussions can be problematic for children with cerebral palsy--not because they are used in the treatment process, but because of contraindications, or side effects. Medications with contraindications are those that could react with drugs used to treat cerebral palsy or potentially create deleterious side effects in patients with cerebral palsy. You should ask the physician about any

contraindications, especially as these might apply to other medications that your child may be taking for common ailments.

Drug-drug interactions occur when two or more drugs react with each other. This drug-drug interaction may cause your child to experience an unexpected side effect. Drug interactions may make medications less effective, cause unexpected side effects, or increase the action of a particular drug. Some drug interactions can even be harmful to your child.

Be sure to read the label every time you give your child a nonprescription or prescription drug, and take the time to learn about drug interactions. These precautions may be critical to your child's health. You can reduce the risk of potentially harmful drug interactions and side effects with a little bit of knowledge and common sense.

Drug labels contain important information about ingredients, uses, warnings, and directions which you should take the time to read and understand. Labels also include warnings about possible drug interactions. Further, drug labels may change as new information becomes avaiable. This is why it's especially important to read the label every time you give your child a medication. When the doctor prescribes a new drug, discuss all over-the-counter and prescription medications, dietary supplements, vitamins, botanicals, minerals and herbals your child takes. Ask your pharmacist for the package insert for each drug prescribed. The package insert provides more information about potential drug interactions.

## A Final Warning

At some point, you may hear of alternative medications from friends, relatives, or in the news media. Advertisements may suggest that certain alternative drugs can produce positive results for cerebral palsy. Exercise caution--some of these drugs may have fraudulent claims, and others may actually hurt your child. The Food and Drug Administration (FDA) is the official U.S. agency charged with discovering which medications are likely to improve the health of patients with cerebral palsy. The FDA warns to watch out for[44]:

- Secret formulas (real scientists share what they know)

[44] This section has been adapted from http://www.fda.gov/opacom/lowlit/medfraud.html.

- Amazing breakthroughs or miracle cures (real breakthroughs don't happen very often; when they do, real scientists do not call them amazing or miracles)
- Quick, painless, or guaranteed cures
- If it sounds too good to be true, it probably isn't true.

If you have any questions about any kind of medical treatment, the FDA may have an office near you. Look for their number in the blue pages of the phone book. You can also contact the FDA through its toll-free number, 1-888-INFO-FDA (1-888-463-6332), or on the World Wide Web at **www.fda.gov**.

## General References

In addition to the resources provided earlier in this chapter, the following general references describe medications (sorted alphabetically by title; hyperlinks provide rankings, information and reviews at Amazon.com):

- **Current Therapy in Neurologic Disease** by Richard T. Johnson, et al; Hardcover **-** 457 pages, 6th edition (January 15, 2002), Mosby-Year Book; ISBN: 0323014720; **http://www.amazon.com/exec/obidos/ASIN/0323014720/icongroupinterna**
- **Emerging Pharmacological Tools in Clinical Neurology** by MedPanel Inc. (Author); Digital - 66 pages, MarketResearch.com; ISBN: B00005RBN8; **http://www.amazon.com/exec/obidos/ASIN/B00005RBN8/icongroupinterna**
- **Goodman & Gilman's The Pharmacological Basis of Therapeutics by** Joel G. Hardman (Editor), Lee E. Limbird; Hardcover - 1825 pages, 10th edition (August 13, 2001), McGraw-Hill Professional Publishing; ISBN: 0071354697; **http://www.amazon.com/exec/obidos/ASIN/0071354697/icongroupinterna**
- **Neurology and General Medicine** by Michael J. Aminoff (Editor), Hardcover - 992 pages, 3rd edition (March 15, 2001), Churchill Livingstone; ISBN: 0443065713; **http://www.amazon.com/exec/obidos/ASIN/0443065713/icongroupinterna**
- **Neurology and Medicine** by Hughes Perkins; Hardcover - 415 pages, 1st edition (December 15, 1999), B. M. J. Books; ISBN: 0727912240; **http://www.amazon.com/exec/obidos/ASIN/0727912240/icongroupinterna**
- **Pharmacological Management of Neurological and Psychiatric Disorders** by S. J. Enna (Editor), et al; Hardcover - 736 pages, 1st edition, McGraw-

Hill Professional Publishing; ISBN: 0070217645;
**http://www.amazon.com/exec/obidos/ASIN/0070217645/icongroupinterna**

## Vocabulary Builder

The following vocabulary builder gives definitions of words used in this chapter that have not been defined in previous chapters:

**Amantadine:** An antiviral that is used in the prophylactic or symptomatic treatment of influenza A. It is also used as an antiparkinsonian agent, to treat extrapyramidal reactions, and for postherpetic neuralgia. The mechanisms of its effects in movement disorders are not well understood but probably reflect an increase in synthesis and release of dopamine, with perhaps some inhibition of dopamine uptake. [NIH]

**Botulinum Toxin Type A:** A neurotoxin produced by Clostridium botulinum. When consumed in contaminated food it can cause paralysis and death. In its purified form, it has been used in the treatment of blepharospasm and strabismus. [NIH]

**Levodopa:** The naturally occurring form of dopa and the immediate precursor of dopamine. Unlike dopamine itself, it can be taken orally and crosses the blood-brain barrier. It is rapidly taken up by dopaminergic neurons and converted to dopamine. It is used for the treatment of parkinsonism and is usually given with agents that inhibit its conversion to dopamine outside of the central nervous system. [NIH]

**Parenteral:** Not through the alimentary canal but rather by injection through some other route, as subcutaneous, intramuscular, intraorbital, intracapsular, intraspinal, intrasternal, intravenous, etc. [EU]

**Psychiatric:** Pertaining to or within the purview of psychiatry. [EU]

# APPENDIX B. RESEARCHING ALTERNATIVE MEDICINE

## Overview

Complementary and alternative medicine (CAM) is one of the most contentious aspects of modern medical practice. You may have heard of these treatments on the radio or on television. Maybe you have seen articles written about these treatments in magazines, newspapers, or books. Perhaps your child's doctor or your friends have mentioned alternatives.

In this chapter, we will begin by giving you a broad perspective on complementary and alternative therapies. Next, we will introduce you to official information sources on CAM relating to cerebral palsy. Finally, at the conclusion of this chapter, we will provide a list of readings on cerebral palsy from various authors. We will begin, however, with the National Center for Complementary and Alternative Medicine's (NCCAM) overview of complementary and alternative medicine.

## What Is CAM?[45]

Complementary and alternative medicine (CAM) covers a broad range of healing philosophies, approaches, and therapies. Generally, it is defined as those treatments and healthcare practices which are not taught in medical schools, used in hospitals, or reimbursed by medical insurance companies. Many CAM therapies are termed "holistic," which generally means that the healthcare practitioner considers the whole person, including physical, mental, emotional, and spiritual health. Some of these therapies are also known as "preventive," which means that the practitioner educates and treats the person to prevent health problems from arising, rather than treating symptoms after problems have occurred.

People use CAM treatments and therapies in a variety of ways. Therapies are used alone (often referred to as alternative), in combination with other alternative therapies, or in addition to conventional treatment (sometimes referred to as complementary). Complementary and alternative medicine, or "integrative medicine," includes a broad range of healing philosophies, approaches, and therapies. Some approaches are consistent with physiological principles of Western medicine, while others constitute healing systems with non-Western origins. While some therapies are far outside the realm of accepted Western medical theory and practice, others are becoming established in mainstream medicine.

Complementary and alternative therapies are used in an effort to prevent illness, reduce stress, prevent or reduce side effects and symptoms, or control or cure disease. Some commonly used methods of complementary or alternative therapy include mind/body control interventions such as visualization and relaxation, manual healing including acupressure and massage, homeopathy, vitamins or herbal products, and acupuncture.

## What Are the Domains of Alternative Medicine?[46]

The list of CAM practices changes continually. The reason being is that these new practices and therapies are often proved to be safe and effective, and therefore become generally accepted as "mainstream" healthcare practices. Today, CAM practices may be grouped within five major domains: (1) alternative medical systems, (2) mind-body interventions, (3) biologically-based treatments, (4) manipulative and body-based methods, and (5) energy

[45] Adapted from the NCCAM: **http://nccam.nih.gov/nccam/fcp/faq/index.html#what-is**.
[46] Adapted from the NCCAM: http://nccam.nih.gov/nccam/fcp/classify/index.html.

therapies. The individual systems and treatments comprising these categories are too numerous to list in this sourcebook. Thus, only limited examples are provided within each.

### Alternative Medical Systems

Alternative medical systems involve complete systems of theory and practice that have evolved independent of, and often prior to, conventional biomedical approaches. Many are traditional systems of medicine that are practiced by individual cultures throughout the world, including a number of venerable Asian approaches.

Traditional oriental medicine emphasizes the balance or disturbances of qi (pronounced chi) or vital energy in health and illness, respectively. Traditional oriental medicine consists of a group of techniques and methods including acupuncture, herbal medicine, oriental massage, and qi gong (a form of energy therapy). Acupuncture involves stimulating specific anatomic points in the body for therapeutic purposes, usually by puncturing the skin with a thin needle.

Ayurveda is India's traditional system of medicine. Ayurvedic medicine (meaning "science of life") is a comprehensive system of medicine that places equal emphasis on body, mind, and spirit. Ayurveda strives to restore the innate harmony of the individual. Some of the primary Ayurvedic treatments include diet, exercise, meditation, herbs, massage, exposure to sunlight, and controlled breathing.

Other traditional healing systems have been developed by the world's indigenous populations. These populations include Native American, Aboriginal, African, Middle Eastern, Tibetan, and Central and South American cultures. Homeopathy and naturopathy are also examples of complete alternative medicine systems.

Homeopathic medicine is an unconventional Western system that is based on the principle that "like cures like," i.e., that the same substance that in large doses produces the symptoms of an illness, in very minute doses cures it. Homeopathic health practitioners believe that the more dilute the remedy, the greater its potency. Therefore, they use small doses of specially prepared plant extracts and minerals to stimulate the body's defense mechanisms and healing processes in order to treat illness.

Naturopathic medicine is based on the theory that a medical condition is the manifestation of alterations in the processes by which the body naturally heals itself and emphasizes health restoration rather than treatment for the condition itself. Naturopathic physicians employ an array of healing practices, including the following: diet and clinical nutrition, homeopathy, acupuncture, herbal medicine, hydrotherapy (the use of water in a range of temperatures and methods of applications), spinal and soft-tissue manipulation, physical therapies (such as those involving electrical currents, ultrasound, and light), therapeutic counseling, and pharmacology.

### Mind-Body Interventions

Mind-body interventions employ a variety of techniques designed to facilitate the mind's capacity to affect bodily function and symptoms. Only a select group of mind-body interventions having well-documented theoretical foundations are considered CAM. For example, patient education and cognitive-behavioral approaches are now considered "mainstream." On the other hand, complementary and alternative medicine includes meditation, certain uses of hypnosis, dance, music, and art therapy, as well as prayer and mental healing.

### Biological-Based Therapies

This category of CAM includes natural and biological-based practices, interventions, and products, many of which overlap with conventional medicine's use of dietary supplements. This category includes herbal, special dietary, orthomolecular, and individual biological therapies.

Herbal therapy employs an individual herb or a mixture of herbs for healing purposes. An herb is a plant or plant part that produces and contains chemical substances that act upon the body. Special diet therapies, such as those proposed by Drs. Atkins, Ornish, Pritikin, and Weil, are believed to prevent and/or control illness as well as promote health. Orthomolecular therapies aim to treat medical conditions with varying concentrations of chemicals such as magnesium, melatonin, and mega-doses of vitamins. Biological therapies include, for example, the use of laetrile and shark cartilage to treat cancer and the use of bee pollen to treat autoimmune and inflammatory conditions.

### Manipulative and Body-Based Methods

This category includes methods that are based on manipulation and/or movement of the body. For example, chiropractors focus on the relationship between structure and function, primarily pertaining to the spine, and how that relationship affects the preservation and restoration of health. Chiropractors use manipulative therapy as an integral treatment tool.

In contrast, osteopaths place particular emphasis on the musculoskeletal system and practice osteopathic manipulation. Osteopaths believe that all of the body's systems work together and that disturbances in one system may have an impact upon function elsewhere in the body. Massage therapists manipulate the soft tissues of the body to normalize those tissues.

### Energy Therapies

Energy therapies focus on energy fields originating within the body (biofields) or those from other sources (electromagnetic fields). Biofield therapies are intended to affect energy fields (the existence of which is not yet experimentally proven) that surround and penetrate the human body. Some forms of energy therapy manipulate biofields by applying pressure and/or manipulating the body by placing the hands in or through these fields. Examples include Qi gong, Reiki and Therapeutic Touch.

Qi gong is a component of traditional oriental medicine that combines movement, meditation, and regulation of breathing to enhance the flow of vital energy (qi) in the body, improve blood circulation, and enhance immune function. Reiki, the Japanese word representing Universal Life Energy, is based on the belief that, by channeling spiritual energy through the practitioner, the spirit is healed and, in turn, heals the physical body. Therapeutic Touch is derived from the ancient technique of "laying-on of hands." It is based on the premises that the therapist's healing force affects recovery and that healing is promoted when the body's energies are in balance. By passing their hands over the patient, these healers identify energy imbalances.

Bioelectromagnetic-based therapies involve the unconventional use of electromagnetic fields to treat illnesses or manage pain. These therapies are often used to treat asthma, cancer, and migraine headaches. Types of electromagnetic fields which are manipulated in these therapies include pulsed fields, magnetic fields, and alternating current or direct current fields.

## Can Alternatives Affect My Child's Treatment?

A critical issue in pursuing complementary alternatives mentioned thus far is the risk that these might have undesirable interactions with your child's medical treatment. It becomes all the more important to speak with the doctor who can offer advice on the use of alternatives. Official sources confirm this view. Though written for women, we find that the National Women's Health Information Center's advice on pursuing alternative medicine is appropriate for everyone.[47]

### Is It Okay to Want Both Traditional and Alternative or Complementary Medicine?

Should you wish to explore non-traditional types of treatment, be sure to discuss all issues concerning treatments and therapies with your child's healthcare provider, whether a physician or practitioner of complementary and alternative medicine. Competent healthcare management requires that the practitioner know of all conventional and alternative therapies that your child is taking.

The decision to use complementary and alternative treatments is an important one. Consider before selecting an alternative therapy, the safety and effectiveness of the therapy or treatment, the expertise and qualifications of the healthcare practitioner, and the quality of delivery. These topics should be considered when selecting any practitioner or therapy.

## Finding CAM References on Cerebral Palsy

Having read the previous discussion, you may be wondering which complementary or alternative treatments might be appropriate for cerebral palsy. For the remainder of this chapter, we will direct you to a number of official sources which can assist you in researching studies and publications. Some of these articles are rather technical, so some patience may be required.

### National Center for Complementary and Alternative Medicine

The National Center for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health (**http://nccam.nih.gov**) has

[47] Adapted from **http://www.4woman.gov/faq/alternative.htm**.

created a link to the National Library of Medicine's databases to allow parents to search for articles that specifically relate to cerebral palsy and complementary medicine. To search the database, go to the following Web site: **www.nlm.nih.gov/nccam/camonpubmed.html**. Select "CAM on PubMed." Enter "cerebral palsy" (or synonyms) into the search box. Click "Go." The following references provide information on particular aspects of complementary and alternative medicine (CAM) that are related to cerebral palsy:

- **"A special kind of magic": changes in family dynamics arising from parent participation in a conductive education program for children with cerebral palsy.**
  Author(s): Cooper D.
  Source: Community Health Stud. 1986; 10(3): 294-306. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3802766&dopt=Abstract

- **"Whole body" mobility after one year of intraoral appliance therapy in children with cerebral palsy and moderate eating impairment.**
  Author(s): Gisel EG, Schwartz S, Petryk A, Clarke D, Haberfellner H.
  Source: Dysphagia. 2000 Fall; 15(4): 226-35.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11014886&dopt=Abstract

- **A clinical study on acupuncture treatment of pediatric cerebral palsy.**
  Author(s): Shi B, Bu H, Lin L.
  Source: J Tradit Chin Med. 1992 March; 12(1): 45-51. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1597999&dopt=Abstract

- **A parent group for the Hispanic parents of children with severe cerebral palsy.**
  Author(s): Pilon BH, Smith KA.
  Source: Child Health Care. 1985 Fall; 14(2): 96-102.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10274043&dopt=Abstract

- **A pilot evaluation of conductive education-based intervention for children with cerebral palsy: the Tongala project.**
  Author(s): Coleman GJ, King JA, Reddihough DS.

Source: Journal of Paediatrics and Child Health. 1995 October; 31(5): 412-7.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8554861&dopt=Abstract

- **Acoustic and electrical activities during voluntary isometric contraction of biceps brachii muscles in patients with spastic cerebral palsy.**
  Author(s): Bodor M.
  Source: Muscle & Nerve. 1997 June; 20(6): 764-5. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9149089&dopt=Abstract

- **Acupuncture for the relief of painful muscle spasms in dystonic cerebral palsy.**
  Author(s): Sanner C, Sundequist U.
  Source: Developmental Medicine and Child Neurology. 1981 August; 23(4): 544-5. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7274598&dopt=Abstract

- **Augmented feedback training of motor control in cerebral palsy.**
  Author(s): Harrison A.
  Source: Developmental Medicine and Child Neurology. 1977 February; 19(1): 75-8. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=844671&dopt=Abstract

- **Biofeedback techniques and behaviour modification in the conservative remediation of drooling by children with cerebral palsy.**
  Author(s): Koheil R, Sochaniwskyj AE, Bablich K, Kenny DJ, Milner M.
  Source: Developmental Medicine and Child Neurology. 1987 February; 29(1): 19-26.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3556797&dopt=Abstract

- **Biofeedback therapy to achieve symmetrical gait in children with hemiplegic cerebral palsy: long-term efficacy.**
  Author(s): Seeger BR, Caudrey DJ.

Source: Archives of Physical Medicine and Rehabilitation. 1983 April; 64(4): 160-2.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=6838342&dopt=Abstract

- **Can children with spastic cerebral palsy use self-hypnosis to reduce muscle tone? a preliminary study.**
  Author(s): Mauersberger K, Artz K, Duncan B, Gurgevich S.
  Source: Integr. Med. 2000 March 21; 2(2): 93-96.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10882882&dopt=Abstract

- **Cerebral palsy: a clinical approach.**
  Author(s): Lord J.
  Source: Archives of Physical Medicine and Rehabilitation. 1984 September; 65(9): 542-8.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=6477089&dopt=Abstract

- **Controversial therapies in the management of cerebral palsy.**
  Author(s): Matthews DJ.
  Source: Pediatric Annals. 1988 December; 17(12): 762-4. Review. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3068619&dopt=Abstract

- **Desensitization of the gag reflex in an adult with cerebral palsy: a case report.**
  Author(s): Reid JA, King PL, Kilpatrick NM.
  Source: Spec Care Dentist. 2000 March-April; 20(2): 56-60.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11203879&dopt=Abstract

- **Effect of an equine-movement therapy program on gait, energy expenditure, and motor function in children with spastic cerebral palsy: a pilot study.**
  Author(s): McGibbon NH, Andrade CK, Widener G, Cintas HL.
  Source: Developmental Medicine and Child Neurology. 1998 November; 40(11): 754-62.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9881805&dopt=Abstract

- **Effects of a movement and swimming program on vital capacity and water orientation skills of children with cerebral palsy.**
  Author(s): Hutzler Y, Chacham A, Bergman U, Szeinberg A.
  Source: Developmental Medicine and Child Neurology. 1998 March; 40(3): 176-81.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9566654&dopt=Abstract

- **Effects of electromyographic feedback training on motor control in spastic cerebral palsy.**
  Author(s): Skrotzky K, Gallenstein JS, Osternig LR.
  Source: Physical Therapy. 1978 May; 58(5): 547-52.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=643933&dopt=Abstract

- **Effects of hyperbaric oxygen therapy on children with spastic diplegic cerebral palsy: a pilot project.**
  Author(s): Montgomery D, Goldberg J, Amar M, Lacroix V, Lecomte J, Lambert J, Vanasse M, Marois P.
  Source: Undersea Hyperb Med. 1999 Winter; 26(4): 235-42.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10642070&dopt=Abstract

- **Effects of Johnstone pressure splints combined with neurodevelopmental therapy on spasticity and cutaneous sensory inputs in spastic cerebral palsy.**
  Author(s): Kerem M, Livanelioglu A, Topcu M.
  Source: Developmental Medicine and Child Neurology. 2001 May; 43(5): 307-13.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11368483&dopt=Abstract

- **Effects of respiratory exercises on the vital capacity and forced expiratory volume in children with cerebral palsy.**
  Author(s): Rothman JG.
  Source: Physical Therapy. 1978 April; 58(4): 421-5.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=635021&dopt=Abstract

- **Effects of upper-extremity weight-bearing on hand-opening and prehension patterns in children with cerebral palsy.**
  Author(s): Chakerian DL, Larson MA.

Source: Developmental Medicine and Child Neurology. 1993 March; 35(3): 216-29.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8462755&dopt=Abstract

- **Efficacy of programmes based on Conductive Education for young children with cerebral palsy.**
  Author(s): Reddihough DS, King J, Coleman G, Catanese T.
  Source: Developmental Medicine and Child Neurology. 1998 November; 40(11): 763-70.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9881806&dopt=Abstract

- **EMG biofeedback training for a mentally retarded individual with cerebral palsy.**
  Author(s): Asato H, Twiggs DG, Ellison S.
  Source: Physical Therapy. 1981 October; 61(10): 1447-51.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7280026&dopt=Abstract

- **Evaluation of biofeedback seat insert for improving active sitting posture in children with cerebral palsy. A clinical report.**
  Author(s): Bertoti DB, Gross AL.
  Source: Physical Therapy. 1988 July; 68(7): 1109-13.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=3387467&dopt=Abstract

- **Evaluation of the functional effects of a course of Bobath therapy in children with cerebral palsy: a preliminary study.**
  Author(s): Knox V, Evans AL.
  Source: Developmental Medicine and Child Neurology. 2002 July; 44(7): 447-60.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12162382&dopt=Abstract

- **Experimental analysis of EMG feedback in treating cerebral palsy.**
  Author(s): Cataldo MF, Bird BL, Cunningham CE.
  Source: Journal of Behavioral Medicine. 1978 September; 1(3): 311-22.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=755864&dopt=Abstract

- **Feedback of triceps surae EMG in gait of children with cerebral palsy: a controlled study.**
  Author(s): Colborne GR, Wright FV, Naumann S.
  Source: Archives of Physical Medicine and Rehabilitation. 1994 January; 75(1): 40-5.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8291961&dopt=Abstract

- **Frontal EMG-biofeedback training of athetoid cerebral palsy patients: a report of six cases.**
  Author(s): Finley WW, Niman C, Standley J, Ender P.
  Source: Biofeedback Self Regul. 1976 June; 1(2): 169-82.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=990347&dopt=Abstract

- **Functional evaluation of Rolfing in cerebral palsy.**
  Author(s): Perry J, Jones MH, Thomas L.
  Source: Developmental Medicine and Child Neurology. 1981 December; 23(6): 717-29.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7319140&dopt=Abstract

- **Functional outcomes of orofacial myofunctional therapy in children with cerebral palsy.**
  Author(s): Ray J.
  Source: Int J Orofacial Myology. 2001 November; 27: 5-17.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11892371&dopt=Abstract

- **Functional recovery in hemiplegic cerebral palsy: ipsilateral electromyographic responses to focal transcranial magnetic stimulation.**
  Author(s): Nezu A, Kimura S, Takeshita S, Tanaka M.
  Source: Brain & Development. 1999 April; 21(3): 162-5.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10372901&dopt=Abstract

- **Hyperbaric oxygen for children with cerebral palsy: a randomised multicentre trial. HBO-CP Research Group.**
  Author(s): Collet JP, Vanasse M, Marois P, Amar M, Goldberg J, Lambert J, Lassonde M, Hardy P, Fortin J, Tremblay SD, Montgomery D, Lacroix J, Robinson A, Majnemer A.

Source: Lancet. 2001 February 24; 357(9256): 582-6.
http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11558483&dopt=Abstract

- **Hyperbaric oxygen therapy for cerebral palsy: two complications of treatment.**
  Author(s): Nuthall G, Seear M, Lepawsky M, Wensley D, Skippen P, Hukin J.
  Source: Pediatrics. 2000 December; 106(6): E80.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11099623&dopt=Abstract

- **Hyperbaric oxygen therapy for children with cerebral palsy.**
  Author(s): van Bever Donker SC.
  Source: South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde. 2001 November; 91(11): 909. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11847909&dopt=Abstract

- **Hyperbaric oxygen therapy for children with cerebral palsy.**
  Author(s): Cronje F.
  Source: South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde. 2001 August; 91(8): 615-6. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11584767&dopt=Abstract

- **Hyperbaric oxygen therapy for children with cerebral palsy.**
  Author(s): van Bever Donker SC.
  Source: South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde. 1999 April; 89(4): 360-1. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10341811&dopt=Abstract

- **Hyperbaric oxygen therapy for children with cerebral palsy.**
  Author(s): Cronje F.
  Source: South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde. 1999 April; 89(4): 359-60; Discussion 361. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10341810&dopt=Abstract

- **Hyperbaric oxygen therapy for children with cerebral palsy.**
  Author(s): Venter A, Leary M, Schoeman J, Jacklin L, Rodda J, Adnams C, Lippert MM.
  Source: South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde. 1998 November; 88(11): 1362-3. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9861934&dopt=Abstract

- **Hyperbaric oxygen therapy in cerebral palsy.**
  Author(s): Bischof F.
  Source: South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde. 2001 March; 91(3): 182. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11291406&dopt=Abstract

- **Hyperbaric oxygenation for cerebral palsy.**
  Author(s): Heuser G, Uszler JM.
  Source: Lancet. 2001 June 23; 357(9273): 2053-4. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11441858&dopt=Abstract

- **Hyperbaric oxygenation for cerebral palsy.**
  Author(s): James PB.
  Source: Lancet. 2001 June 23; 357(9273): 2052-3. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11441856&dopt=Abstract

- **Improved ankle function in children with cerebral palsy after computer-assisted motor learning.**
  Author(s): Toner LV, Cook K, Elder GC.
  Source: Developmental Medicine and Child Neurology. 1998 December; 40(12): 829-35.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9881679&dopt=Abstract

- **Influence of artificial saddle riding on postural stability in children with cerebral palsy.**
  Author(s): Kuczynski M, Slonka K.
  Source: Gait & Posture. 1999 October; 10(2): 154-60.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10502649&dopt=Abstract

- **Management of upper limb dysfunction in children with cerebral palsy: a systematic review.**
  Author(s): Boyd RN, Morris ME, Graham HK.
  Source: European Journal of Neurology : the Official Journal of the European Federation of Neurological Societies. 2001 November; 8 Suppl 5: 150-66.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11851744&dopt=Abstract

- **Massage for children with cerebral palsy.**
  Author(s): Stewart K.
  Source: Nurs Times. 2000 January 6-12; 96(1): 50-1. Review. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11188625&dopt=Abstract

- **Motor development, its effect on general development, and application to the treatment of cerebral palsy.**
  Author(s): Bobath B.
  Source: Physiotherapy. 1971 November 10; 57(11): 526-32. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=5139032&dopt=Abstract

- **Motor skill learning in cerebral palsy: movement, action and computer-enhanced therapy.**
  Author(s): Wann JP, Turnbull JD.
  Source: Baillieres Clin Neurol. 1993 April; 2(1): 15-28. Review.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8143070&dopt=Abstract

- **Neuropsychological effects of hyperbaric oxygen therapy in cerebral palsy.**
  Author(s): Hardy P, Collet JP, Goldberg J, Ducruet T, Vanasse M, Lambert J, Marois P, Amar M, Montgomery DL, Lecomte JM, Johnston KM, Lassonde M.
  Source: Developmental Medicine and Child Neurology. 2002 July; 44(7): 436-46.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12162381&dopt=Abstract

- **New homeopathic medication in rehabilitation of cerebral palsy and mental retardation.**
  Author(s): Oswal GD.
  Source: Nurs J India. 1996 November; 87(11): 242-4, 261-4. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9096487&dopt=Abstract

- **Nursing the child with cerebral palsy.**
  Author(s): Bobath K.
  Source: Nurs Mirror Midwives J. 1972 September 29; 135(13): 20-3. No Abstract Available.
  http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=4484803&dopt=Abstract

## Additional Web Resources

A number of additional Web sites offer encyclopedic information covering CAM and related topics. The following is a representative sample:

- Alternative Medicine Foundation, Inc.: **http://www.herbmed.org/**
- AOL: **http://search.aol.com/cat.adp?id=169&layer=&from=subcats**
- Chinese Medicine: **http://www.newcenturynutrition.com/**
- drkoop.com®: **http://www.drkoop.com/InteractiveMedicine/IndexC.html**
- Family Village: **http://www.familyvillage.wisc.edu/med_altn.htm**
- Google: **http://directory.google.com/Top/Health/Alternative/**
- Healthnotes: **http://www.thedacare.org/healthnotes/**
- Open Directory Project: **http://dmoz.org/Health/Alternative/**
- TPN.com: **http://www.tnp.com/**
- Yahoo.com: **http://dir.yahoo.com/Health/Alternative_Medicine/**
- WebMD®Health: **http://my.webmd.com/drugs_and_herbs**
- WellNet: **http://www.wellnet.ca/herbsa-c.htm**
- WholeHealthMD.com: **http://www.wholehealthmd.com/reflib/0,1529,,00.html**

The following is a specific Web list relating to Cerebral Palsy; please note that any particular subject below may indicate either a therapeutic use, or a contraindication (potential danger), and does not reflect an official recommendation:

- **General Overview**

  **Bell's Palsy**
  Source: Healthnotes, Inc.; www.healthnotes.com
  Hyperlink:
  http://www.thedacare.org/healthnotes/Concern/Bells_Palsy.htm

  **Dysphagia**
  Source: Integrative Medicine Communications;
  www.onemedicine.com
  Hyperlink:
  http://www.drkoop.com/interactivemedicine/ConsConditions/Dysphagiacc.html

  **Lyme Disease**
  Source: Integrative Medicine Communications;
  www.onemedicine.com
  Hyperlink:
  http://www.drkoop.com/interactivemedicine/ConsConditions/LymeDiseasecc.html

  **Swallowing, Difficulty**
  Source: Integrative Medicine Communications;
  www.onemedicine.com
  Hyperlink:
  http://www.drkoop.com/interactivemedicine/ConsConditions/Dysphagiacc.html

- **Alternative Therapy**

  **Facilitated communication**
  Alternative names: FC Facilitated Communication therapy facilitated communication training [FCT]
  Source: The Canoe version of A Dictionary of Alternative-Medicine Methods, by Priorities for Health editor Jack Raso, M.S., R.D.
  Hyperlink: http://www.canoe.ca/AltmedDictionary/f.html

**Feldenkrais**
Source: WholeHealthMD.com, LLC.; www.wholehealthmd.com
Hyperlink:
http://www.wholehealthmd.com/refshelf/substances_view/0,1525,695,00.html

- **Chinese Medicine**

**Fufang Qianzheng Gao**
Alternative names: Compound Qianzheng Plaster
Source: Pharmacopoeia Commission of the Ministry of Health, People's Republic of China
Hyperlink: http://www.newcenturynutrition.com/cgi-local/patent_herbs_db/db.cgi?db=default&Chinese=Fufang%20Qianzheng%20Gao&mh=10&sb=---&view_records=View+Records

- **Homeopathy**

**Aconitum napellus**
Source: Healthnotes, Inc.; www.healthnotes.com
Hyperlink:
http://www.thedacare.org/healthnotes/Homeo_Homeoix/Aconitum_napellus.htm

**Cadmium sulphuricum**
Source: Healthnotes, Inc.; www.healthnotes.com
Hyperlink:
http://www.thedacare.org/healthnotes/Homeo_Homeoix/Cadmium_sulphuricum.htm

**Causticum**
Source: Healthnotes, Inc.; www.healthnotes.com
Hyperlink:
http://www.thedacare.org/healthnotes/Homeo_Homeoix/Causticum.htm

**Dulcamara**
Source: Healthnotes, Inc.; www.healthnotes.com
Hyperlink:
http://www.thedacare.org/healthnotes/Homeo_Homeoix/Dulcamara.htm

**Platinum metallicum**
Source: Healthnotes, Inc.; www.healthnotes.com
Hyperlink:
http://www.thedacare.org/healthnotes/Homeo_Homeoix/Platinum_metallicum.htm

- **Herbs and Supplements**

**Melatonin**
Source: Integrative Medicine Communications;
www.onemedicine.com
Hyperlink:
http://www.drkoop.com/interactivemedicine/ConsSupplements/Melatonincs.html

**Ruta**
Alternative names: Rue; Ruta graveolens L.
Source: Alternative Medicine Foundation, Inc.;
www.amfoundation.org
Hyperlink: http://www.herbmed.org/

## General References

A good place to find general background information on CAM is the National Library of Medicine. It has prepared within the MEDLINEplus system an information topic page dedicated to complementary and alternative medicine. To access this page, go to the MEDLINEplus site at: **www.nlm.nih.gov/medlineplus/alternativemedicine.html.** This Web site provides a general overview of various topics and can lead to a number of general sources. The following additional references describe, in broad terms, alternative and complementary medicine (sorted alphabetically by title; hyperlinks provide rankings, information, and reviews at Amazon.com):

- **Alternative and Complementary Treatment in Neurologic Illness** by Michael I. Weintraub (Editor); Paperback - 288 pages (March 23, 2001), Churchill Livingstone; ISBN: 0443065586;
**http://www.amazon.com/exec/obidos/ASIN/0443065586/icongroupinterna**
- **Healthy Child, Whole Child: Integrating the Best of Conventional and Alternative Medicine to Keep Your Kids Healthy** by Stuart H. Ditchek, M.D. and Russell H. Greenfield; Paperback - 464 pages (June 2002), Harper

Resource; ISBN: 0062737465;
**http://www.amazon.com/exec/obidos/ASIN/0062737465/icongroupinterna**

- **Radical Healing: Integrating the World's Great Therapeutic Traditions to Create a New Transformative Medicine** by Rudolph Ballentine, M.D., Linda Funk (Illustrator); Paperback - 612 pages; Reprint edition (March 14, 2000), Three Rivers Press; ISBN: 0609804847;
**http://www.amazon.com/exec/obidos/ASIN/0609804847/icongroupinterna**
- **The Review of Natural Products** by Facts and Comparisons (Editor); Cd-Rom edition (January 2002), Facts & Comparisons; ISBN: 1574391453;
**http://www.amazon.com/exec/obidos/ASIN/1574391453/icongroupinterna**

For additional information on complementary and alternative medicine, ask your child's doctor or write to:

National Institutes of Health
National Center for Complementary and Alternative Medicine Clearinghouse
P. O. Box 8218
Silver Spring, MD 20907-8218

The following is a specific Web site relating to Cerebral Palsy; please note that the particular subject below may indicate either a therapeutic use, or a contraindication (potential danger), and does not reflect an official recommendation:

- **Vitamins**

**Vitamin B12**
Source: Healthnotes, Inc.; www.healthnotes.com
Hyperlink:
http://www.thedacare.org/healthnotes/Supp/Vitamin_B12.htm

# APPENDIX C. FINDING MEDICAL LIBRARIES

## Overview

At a medical library you can find medical texts and reference books, consumer health publications, specialty newspapers and magazines, as well as medical journals. In this Appendix, we show you how to quickly find a medical library in your area.

## Preparation

Before going to the library, highlight the references mentioned in this sourcebook that you find interesting. Focus on those items that are not available via the Internet, and ask the reference librarian for help with your search. He or she may know of additional resources that could be helpful to you. Most importantly, your local public library and medical libraries have Interlibrary Loan programs with the National Library of Medicine (NLM), one of the largest medical collections in the world. According to the NLM, most of the literature in the general and historical collections of the National Library of Medicine is available on interlibrary loan to any library. NLM's interlibrary loan services are only available to libraries. If you would like to access NLM medical literature, then visit a library in your area that can request the publications for you.[48]

[48] Adapted from the NLM: http://www.nlm.nih.gov/psd/cas/interlibrary.html.

## Finding a Local Medical Library

The quickest method to locate medical libraries is to use the Internet-based directory published by the National Network of Libraries of Medicine (NN/LM). This network includes 4626 members and affiliates that provide many services to librarians, health professionals, and the public. To find a library in your area, simply visit **http://nnlm.gov/members/adv.html** or call 1-800-338-7657.

## Medical Libraries Open to the Public

In addition to the NN/LM, the National Library of Medicine (NLM) lists a number of libraries that are generally open to the public and have reference facilities. The following is the NLM's list plus hyperlinks to each library Web site. These Web pages can provide information on hours of operation and other restrictions. The list below is a small sample of libraries recommended by the National Library of Medicine (sorted alphabetically by name of the U.S. state or Canadian province where the library is located):[49]

- **Alabama:** Health InfoNet of Jefferson County (Jefferson County Library Cooperative, Lister Hill Library of the Health Sciences), **http://www.uab.edu/infonet/**
- **Alabama:** Richard M. Scrushy Library (American Sports Medicine Institute), **http://www.asmi.org/LIBRARY.HTM**
- **Arizona:** Samaritan Regional Medical Center: The Learning Center (Samaritan Health System, Phoenix, Arizona), **http://www.samaritan.edu/library/bannerlibs.htm**
- **California:** Kris Kelly Health Information Center (St. Joseph Health System), **http://www.humboldt1.com/~kkhic/index.html**
- **California:** Community Health Library of Los Gatos (Community Health Library of Los Gatos), **http://www.healthlib.org/orgresources.html**
- **California:** Consumer Health Program and Services (CHIPS) (County of Los Angeles Public Library, Los Angeles County Harbor-UCLA Medical Center Library) - Carson, CA, **http://www.colapublib.org/services/chips.html**
- **California:** Gateway Health Library (Sutter Gould Medical Foundation)
- **California:** Health Library (Stanford University Medical Center), **http://www-med.stanford.edu/healthlibrary/**

[49] Abstracted from **http://www.nlm.nih.gov/medlineplus/libraries.html**.

- **California:** Patient Education Resource Center - Health Information and Resources (University of California, San Francisco), **http://sfghdean.ucsf.edu/barnett/PERC/default.asp**
- **California:** Redwood Health Library (Petaluma Health Care District), **http://www.phcd.org/rdwdlib.html**
- **California:** San José PlaneTree Health Library, **http://planetreesanjose.org/**
- **California:** Sutter Resource Library (Sutter Hospitals Foundation), **http://go.sutterhealth.org/comm/resc-library/sac-resources.html**
- **California:** University of California, Davis. Health Sciences Libraries
- **California:** ValleyCare Health Library & Ryan Comer Cancer Resource Center (ValleyCare Health System), **http://www.valleycare.com/library.html**
- **California:** Washington Community Health Resource Library (Washington Community Health Resource Library), **http://www.healthlibrary.org/**
- **Colorado:** William V. Gervasini Memorial Library (Exempla Healthcare), **http://www.exempla.org/conslib.htm**
- **Connecticut:** Hartford Hospital Health Science Libraries (Hartford Hospital), **http://www.harthosp.org/library/**
- **Connecticut:** Healthnet: Connecticut Consumer Health Information Center (University of Connecticut Health Center, Lyman Maynard Stowe Library), **http://library.uchc.edu/departm/hnet/**
- **Connecticut:** Waterbury Hospital Health Center Library (Waterbury Hospital), **http://www.waterburyhospital.com/library/consumer.shtml**
- **Delaware:** Consumer Health Library (Christiana Care Health System, Eugene du Pont Preventive Medicine & Rehabilitation Institute), **http://www.christianacare.org/health_guide/health_guide_pmri_health_info.cfm**
- **Delaware:** Lewis B. Flinn Library (Delaware Academy of Medicine), **http://www.delamed.org/chls.html**
- **Georgia:** Family Resource Library (Medical College of Georgia), **http://cmc.mcg.edu/kids_families/fam_resources/fam_res_lib/frl.htm**
- **Georgia:** Health Resource Center (Medical Center of Central Georgia), **http://www.mccg.org/hrc/hrchome.asp**
- **Hawaii:** Hawaii Medical Library: Consumer Health Information Service (Hawaii Medical Library), **http://hml.org/CHIS/**

- **Idaho:** DeArmond Consumer Health Library (Kootenai Medical Center), **http://www.nicon.org/DeArmond/index.htm**
- **Illinois:** Health Learning Center of Northwestern Memorial Hospital (Northwestern Memorial Hospital, Health Learning Center), **http://www.nmh.org/health_info/hlc.html**
- **Illinois:** Medical Library (OSF Saint Francis Medical Center), **http://www.osfsaintfrancis.org/general/library/**
- **Kentucky:** Medical Library - Services for Patients, Families, Students & the Public (Central Baptist Hospital), **http://www.centralbap.com/education/community/library.htm**
- **Kentucky:** University of Kentucky - Health Information Library (University of Kentucky, Chandler Medical Center, Health Information Library), **http://www.mc.uky.edu/PatientEd/**
- **Louisiana:** Alton Ochsner Medical Foundation Library (Alton Ochsner Medical Foundation), **http://www.ochsner.org/library/**
- **Louisiana:** Louisiana State University Health Sciences Center Medical Library-Shreveport, **http://lib-sh.lsuhsc.edu/**
- **Maine:** Franklin Memorial Hospital Medical Library (Franklin Memorial Hospital), **http://www.fchn.org/fmh/lib.htm**
- **Maine:** Gerrish-True Health Sciences Library (Central Maine Medical Center), **http://www.cmmc.org/library/library.html**
- **Maine:** Hadley Parrot Health Science Library (Eastern Maine Healthcare), **http://www.emh.org/hll/hpl/guide.htm**
- **Maine:** Maine Medical Center Library (Maine Medical Center), **http://www.mmc.org/library/**
- **Maine:** Parkview Hospital, **http://www.parkviewhospital.org/communit.htm#Library**
- **Maine:** Southern Maine Medical Center Health Sciences Library (Southern Maine Medical Center), **http://www.smmc.org/services/service.php3?choice=10**
- **Maine:** Stephens Memorial Hospital Health Information Library (Western Maine Health), **http://www.wmhcc.com/hil_frame.html**
- **Manitoba, Canada:** Consumer & Patient Health Information Service (University of Manitoba Libraries), **http://www.umanitoba.ca/libraries/units/health/reference/chis.html**
- **Manitoba, Canada:** J.W. Crane Memorial Library (Deer Lodge Centre), **http://www.deerlodge.mb.ca/library/libraryservices.shtml**

- **Maryland:** Health Information Center at the Wheaton Regional Library (Montgomery County, Md., Dept. of Public Libraries, Wheaton Regional Library), **http://www.mont.lib.md.us/healthinfo/hic.asp**
- **Massachusetts:** Baystate Medical Center Library (Baystate Health System), **http://www.baystatehealth.com/1024/**
- **Massachusetts:** Boston University Medical Center Alumni Medical Library (Boston University Medical Center), **http://med-libwww.bu.edu/library/lib.html**
- **Massachusetts:** Lowell General Hospital Health Sciences Library (Lowell General Hospital), **http://www.lowellgeneral.org/library/HomePageLinks/WWW.htm**
- **Massachusetts:** Paul E. Woodard Health Sciences Library (New England Baptist Hospital), **http://www.nebh.org/health_lib.asp**
- **Massachusetts:** St. Luke's Hospital Health Sciences Library (St. Luke's Hospital), **http://www.southcoast.org/library/**
- **Massachusetts:** Treadwell Library Consumer Health Reference Center (Massachusetts General Hospital), **http://www.mgh.harvard.edu/library/chrcindex.html**
- **Massachusetts:** UMass HealthNet (University of Massachusetts Medical School), **http://healthnet.umassmed.edu/**
- **Michigan:** Botsford General Hospital Library - Consumer Health (Botsford General Hospital, Library & Internet Services), **http://www.botsfordlibrary.org/consumer.htm**
- **Michigan:** Helen DeRoy Medical Library (Providence Hospital and Medical Centers), **http://www.providence-hospital.org/library/**
- **Michigan:** Marquette General Hospital - Consumer Health Library (Marquette General Hospital, Health Information Center), **http://www.mgh.org/center.html**
- **Michigan:** Patient Education Resouce Center - University of Michigan Cancer Center (University of Michigan Comprehensive Cancer Center), **http://www.cancer.med.umich.edu/learn/leares.htm**
- **Michigan:** Sladen Library & Center for Health Information Resources - Consumer Health Information, **http://www.sladen.hfhs.org/library/consumer/index.html**
- **Montana:** Center for Health Information (St. Patrick Hospital and Health Sciences Center), **http://www.saintpatrick.org/chi/librarydetail.php3?ID=41**

- **National:** Consumer Health Library Directory (Medical Library Association, Consumer and Patient Health Information Section), **http://caphis.mlanet.org/directory/index.html**
- **National:** National Network of Libraries of Medicine (National Library of Medicine) - provides library services for health professionals in the United States who do not have access to a medical library, **http://nnlm.gov/**
- **National:** NN/LM List of Libraries Serving the Public (National Network of Libraries of Medicine), **http://nnlm.gov/members/**
- **Nevada:** Health Science Library, West Charleston Library (Las Vegas Clark County Library District), **http://www.lvccld.org/special_collections/medical/index.htm**
- **New Hampshire:** Dartmouth Biomedical Libraries (Dartmouth College Library), **http://www.dartmouth.edu/~biomed/resources.htmld/conshealth.htmld/**
- **New Jersey:** Consumer Health Library (Rahway Hospital), **http://www.rahwayhospital.com/library.htm**
- **New Jersey:** Dr. Walter Phillips Health Sciences Library (Englewood Hospital and Medical Center), **http://www.englewoodhospital.com/links/index.htm**
- **New Jersey:** Meland Foundation (Englewood Hospital and Medical Center), **http://www.geocities.com/ResearchTriangle/9360/**
- **New York:** Choices in Health Information (New York Public Library) - NLM Consumer Pilot Project participant, **http://www.nypl.org/branch/health/links.html**
- **New York:** Health Information Center (Upstate Medical University, State University of New York), **http://www.upstate.edu/library/hic/**
- **New York:** Health Sciences Library (Long Island Jewish Medical Center), **http://www.lij.edu/library/library.html**
- **New York:** ViaHealth Medical Library (Rochester General Hospital), **http://www.nyam.org/library/**
- **Ohio:** Consumer Health Library (Akron General Medical Center, Medical & Consumer Health Library), **http://www.akrongeneral.org/hwlibrary.htm**
- **Oklahoma:** Saint Francis Health System Patient/Family Resource Center (Saint Francis Health System), **http://www.sfh-tulsa.com/patientfamilycenter/default.asp**

- **Oregon:** Planetree Health Resource Center (Mid-Columbia Medical Center), **http://www.mcmc.net/phrc/**
- **Pennsylvania:** Community Health Information Library (Milton S. Hershey Medical Center), **http://www.hmc.psu.edu/commhealth/**
- **Pennsylvania:** Community Health Resource Library (Geisinger Medical Center), **http://www.geisinger.edu/education/commlib.shtml**
- **Pennsylvania:** HealthInfo Library (Moses Taylor Hospital), **http://www.mth.org/healthwellness.html**
- **Pennsylvania:** Hopwood Library (University of Pittsburgh, Health Sciences Library System), **http://www.hsls.pitt.edu/chi/hhrcinfo.html**
- **Pennsylvania:** Koop Community Health Information Center (College of Physicians of Philadelphia), **http://www.collphyphil.org/kooppg1.shtml**
- **Pennsylvania:** Learning Resources Center - Medical Library (Susquehanna Health System), **http://www.shscares.org/services/lrc/index.asp**
- **Pennsylvania:** Medical Library (UPMC Health System), **http://www.upmc.edu/passavant/library.htm**
- **Quebec, Canada:** Medical Library (Montreal General Hospital), **http://ww2.mcgill.ca/mghlib/**
- **South Dakota:** Rapid City Regional Hospital - Health Information Center (Rapid City Regional Hospital, Health Information Center), **http://www.rcrh.org/education/LibraryResourcesConsumers.htm**
- **Texas:** Houston HealthWays (Houston Academy of Medicine-Texas Medical Center Library), **http://hhw.library.tmc.edu/**
- **Texas:** Matustik Family Resource Center (Cook Children's Health Care System), **http://www.cookchildrens.com/Matustik_Library.html**
- **Washington:** Community Health Library (Kittitas Valley Community Hospital), **http://www.kvch.com/**
- **Washington:** Southwest Washington Medical Center Library (Southwest Washington Medical Center), **http://www.swmedctr.com/Home/**

# APPENDIX D. YOUR CHILD'S RIGHTS AND INSURANCE

## Overview

Parents face a series of issues related more to the healthcare industry than to their children's medical conditions. This appendix covers two important topics in this regard: your responsibilities and your child's rights as a patient, and how to get the most out of your child's medical insurance plan.

## Your Child's Rights as a Patient

The President's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry has created the following summary of your child's rights as a patient.[50]

### Information Disclosure

Consumers have the right to receive accurate, easily understood information. Some consumers require assistance in making informed decisions about health plans, health professionals, and healthcare facilities. Such information includes:

- ***Health plans.*** Covered benefits, cost-sharing, and procedures for resolving complaints, licensure, certification, and accreditation status, comparable measures of quality and consumer satisfaction, provider network composition, the procedures that govern access to specialists and emergency services, and care management information.

[50]Adapted from Consumer Bill of Rights and Responsibilities: **http://www.hcqualitycommission.gov/press/cbor.html#head1**.

- ***Health professionals.*** Education, board certification, and recertification, years of practice, experience performing certain procedures, and comparable measures of quality and consumer satisfaction.
- ***Healthcare facilities.*** Experience in performing certain procedures and services, accreditation status, comparable measures of quality, worker, and consumer satisfaction, and procedures for resolving complaints.
- ***Consumer assistance programs.*** Programs must be carefully structured to promote consumer confidence and to work cooperatively with health plans, providers, payers, and regulators. Desirable characteristics of such programs are sponsorship that ensures accountability to the interests of consumers and stable, adequate funding.

### Choice of Providers and Plans

Consumers have the right to a choice of healthcare providers that is sufficient to ensure access to appropriate high-quality healthcare. To ensure such choice, the Commission recommends the following:

- ***Provider network adequacy.*** All health plan networks should provide access to sufficient numbers and types of providers to assure that all covered services will be accessible without unreasonable delay -- including access to emergency services 24 hours a day and 7 days a week. If a health plan has an insufficient number or type of providers to provide a covered benefit with the appropriate degree of specialization, the plan should ensure that the consumer obtains the benefit outside the network at no greater cost than if the benefit were obtained from participating providers.
- ***Access to specialists.*** Consumers with complex or serious medical conditions who require frequent specialty care should have direct access to a qualified specialist of their choice within a plan's network of providers. Authorizations, when required, should be for an adequate number of direct access visits under an approved treatment plan.
- ***Transitional care.*** Consumers who are undergoing a course of treatment for a chronic or disabling condition at the time they involuntarily change health plans or at a time when a provider is terminated by a plan for other than cause should be able to continue seeing their current specialty providers for up to 90 days to allow for transition of care.
- ***Choice of health plans.*** Public and private group purchasers should, wherever feasible, offer consumers a choice of high-quality health insurance plans.

### Access to Emergency Services

Consumers have the right to access emergency healthcare services when and where the need arises. Health plans should provide payment when a consumer presents to an emergency department with acute symptoms of sufficient severity--including severe pain--such that a "prudent layperson" could reasonably expect the absence of medical attention to result in placing that consumer's health in serious jeopardy, serious impairment to bodily functions, or serious dysfunction of any bodily organ or part.

### Participation in Treatment Decisions

Consumers have the right and responsibility to fully participate in all decisions related to their healthcare. Consumers who are unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators. Physicians and other health professionals should:

- Provide parents with sufficient information and opportunity to decide among treatment options consistent with the informed consent process.
- Discuss all treatment options with a parent in a culturally competent manner, including the option of no treatment at all.
- Ensure that persons with disabilities have effective communications with members of the health system in making such decisions.
- Discuss all current treatments a consumer may be undergoing.
- Discuss all risks, benefits, and consequences to treatment or nontreatment.
- Give parents the opportunity to refuse treatment for their children and to express preferences about future treatment decisions.
- Discuss the use of advance directives -- both living wills and durable powers of attorney for healthcare -- with parents.
- Abide by the decisions made by parents consistent with the informed consent process.

Health plans, health providers, and healthcare facilities should:

- Disclose to consumers factors -- such as methods of compensation, ownership of or interest in healthcare facilities, or matters of conscience -- that could influence advice or treatment decisions.
- Assure that provider contracts do not contain any so-called "gag clauses" or other contractual mechanisms that restrict healthcare providers' ability to communicate with and advise parents about medically necessary treatment options for their children.
- Be prohibited from penalizing or seeking retribution against healthcare professionals or other health workers for advocating on behalf of their patients.

### Respect and Nondiscrimination

Consumers have the right to considerate, respectful care from all members of the healthcare industry at all times and under all circumstances. An environment of mutual respect is essential to maintain a quality healthcare system. To assure that right, the Commission recommends the following:

- Consumers must not be discriminated against in the delivery of healthcare services consistent with the benefits covered in their policy, or as required by law, based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.
- Consumers eligible for coverage under the terms and conditions of a health plan or program, or as required by law, must not be discriminated against in marketing and enrollment practices based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.

### Confidentiality of Health Information

Consumers have the right to communicate with healthcare providers in confidence and to have the confidentiality of their individually identifiable healthcare information protected. Consumers also have the right to review and copy their own medical records and request amendments to their records.

### Complaints and Appeals

Consumers have the right to a fair and efficient process for resolving differences with their health plans, healthcare providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review. A free copy of the Patient's Bill of Rights is available from the American Hospital Association.[51]

## Parent Responsibilities

To underscore the importance of finance in modern healthcare as well as your responsibility for the financial aspects of your child's care, the President's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry has proposed that parents understand the following "Consumer Responsibilities."[52] In a healthcare system that protects consumers' rights, it is reasonable to expect and encourage consumers to assume certain responsibilities. Greater involvement by parents in their children's care increases the likelihood of achieving the best outcome and helps support a quality-oriented, cost-conscious environment. Such responsibilities include:

- Take responsibility for maximizing your child's healthy habits.
- Work collaboratively with healthcare providers in developing and carrying out your child's agreed-upon treatment plans.
- Disclose relevant information and clearly communicate wants and needs.
- Use the insurance company's internal complaint and appeal processes to address your concerns.
- Recognize the reality of risks, the limits of the medical science, and the human fallibility of the healthcare professional.
- Be aware of a healthcare provider's obligation to be reasonably efficient and equitable in providing care to the community.
- Become knowledgeable about health plan coverage and options (when available) including all covered benefits, limitations, and exclusions, rules regarding use of network providers, coverage and referral rules,

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[51] To order your free copy of the Patient's Bill of Rights, telephone 312-422-3000 or visit the American Hospital Association's Web site: http://www.aha.org. Click on "Resource Center," go to "Search" at bottom of page, and then type in "Patient's Bill of Rights." The Patient's Bill of Rights is also available from Fax on Demand, at 312-422-2020, document number 471124.

[52] Adapted from http://www.hcqualitycommission.gov/press/cbor.html#head1.

appropriate processes to secure additional information, and the process to appeal coverage decisions.

- Make a good-faith effort to meet financial obligations.
- Abide by administrative and operational procedures of health plans, healthcare providers, and Government health benefit programs.

## Choosing an Insurance Plan

There are a number of official government agencies that help consumers understand their healthcare insurance choices.[53] The U.S. Department of Labor, in particular, recommends ten ways to make your health benefits choices work best for your family.[54]

**1. Your options are important.** There are many different types of health benefit plans. Find out which one your employer offers, then check out the plan, or plans, offered. Your employer's human resource office, the health plan administrator, or your union can provide information to help you match your family's needs and preferences with the available plans. The more information you have, the better your healthcare decisions will be.

**2. Reviewing the benefits available.** Do the plans offered cover preventive care, well-baby care, vision or dental care? Are there deductibles? Answers to these questions can help determine the out-of-pocket expenses you may face. Cheapest may not always be best. Your goal is high quality health benefits.

**3. Look for quality.** The quality of healthcare services varies, but quality can be measured. You should consider the quality of healthcare in deciding among the healthcare plans or options available to your family. Not all health plans, doctors, hospitals and other providers give the highest quality care. Fortunately, there is quality information you can use right now to help you compare your healthcare choices. Find out how you can measure quality. Consult the U.S. Department of Health and Human Services publication "Your Guide to Choosing Quality Health Care" on the Internet at **www.ahcpr.gov/consumer**.

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[53] More information about quality across programs is provided at the following AHRQ Web site:
**http://www.ahrq.gov/consumer/qntascii/qnthplan.htm**.

[54] Adapted from the Department of Labor:
**http://www.dol.gov/dol/pwba/public/pubs/health/top10-text.html**.

**4. Your plan's summary plan description (SPD) provides a wealth of information.** Your health plan administrator can provide you with a copy of your plan's SPD. It outlines your family's benefits and your legal rights under the Employee Retirement Income Security Act (ERISA), the federal law that protects your family's health benefits. It should contain information about the coverage of dependents, what services will require a co-pay, and the circumstances under which your employer can change or terminate a health benefits plan. Save the SPD and all other health plan brochures and documents, along with memos or correspondence from your employer relating to health benefits.

**5. Assess your benefit coverage as your family status changes.** Marriage, divorce, childbirth or adoption, and the death of a spouse are all life events that may signal a need to change your health benefits. You, your spouse and dependent children may be eligible for a special enrollment period under provisions of the Health Insurance Portability and Accountability Act (HIPAA). Even without life-changing events, the information provided by your employer should tell you how you can change benefits or switch plans, if more than one plan is offered. If your spouse's employer also offers a health benefits package, consider coordinating both plans for maximum coverage.

**6. Changing jobs and other life events can affect your family's health benefits.** Under the Consolidated Omnibus Budget Reconciliation Act (COBRA), you, your covered spouse, and your dependent children may be eligible to purchase extended health coverage under your employer's plan if you lose your job, change employers, get divorced, or upon occurrence of certain other events. Coverage can range from 18 to 36 months depending on your situation. COBRA applies to most employers with 20 or more workers and requires your plan to notify you of your rights. Most plans require eligible individuals to make their COBRA election within 60 days of the plan's notice. Be sure to follow up with your plan sponsor if you don't receive notice, and make sure you respond within the allotted time.

**7. HIPAA can also help if you are changing jobs, particularly if you have a medical condition.** HIPAA generally limits pre-existing condition exclusions to a maximum of 12 months (18 months for late enrollees). HIPAA also requires this maximum period to be reduced by the length of time you had prior "creditable coverage." You should receive a certificate documenting your prior creditable coverage from your old plan when coverage ends.

**8. Plan for retirement.** Before you retire, find out what health benefits, if any, extend to you and your spouse during your retirement years. Consult with

your employer's human resources office, your union, the plan administrator, and check your SPD. Make sure there is no conflicting information among these sources about the benefits your family will receive or the circumstances under which they can change or be eliminated. With this information in hand, you can make other important choices, like finding out if you are eligible for Medicare and Medigap insurance coverage.

**9. Know how to file an appeal if a health benefits claim is denied.** Understand how your plan handles grievances and where to make appeals of the plan's decisions. Keep records and copies of correspondence. Check your health benefits package and your SPD to determine who is responsible for handling problems with benefit claims. Contact PWBA for customer service assistance if you are unable to obtain a response to your complaint.

**10. You can take steps to improve the quality of the healthcare and the health benefits your family receives.** Look for and use things like Quality Reports and Accreditation Reports whenever you can. Quality reports may contain consumer ratings -- how satisfied consumers are with the doctors in their plan, for instance-- and clinical performance measures -- how well a healthcare organization prevents and treats illness. Accreditation reports provide information on how accredited organizations meet national standards, and often include clinical performance measures. Look for these quality measures whenever possible. Consult "Your Guide to Choosing Quality Health Care" on the Internet at **www.ahcpr.gov/consumer**.

## Medicaid

Illness strikes both rich and poor families. For low-income families, Medicaid is available to defer the costs of treatment. In the following pages, you will learn the basics about Medicaid as well as useful contact information on how to find more in-depth information.

Medicaid is a joint federal and state program that helps pay medical costs for some people with low incomes and limited resources. Medicaid programs vary from state to state. You can find more information about Medicaid on the HCFA.gov Web site at **http://www.hcfa.gov/medicaid/medicaid.htm**.

## NORD's Medication Assistance Programs

Finally, the National Organization for Rare Disorders, Inc. (NORD) administers medication programs sponsored by humanitarian-minded

pharmaceutical and biotechnology companies to help uninsured or under-insured individuals secure life-saving or life-sustaining drugs.[55] NORD programs ensure that certain vital drugs are available "to those families whose income is too high to qualify for Medicaid but too low to pay for their prescribed medications." The program has standards for fairness, equity, and unbiased eligibility. It currently covers some 14 programs for nine pharmaceutical companies. NORD also offers early access programs for investigational new drugs (IND) under the approved "Treatment INDs" programs of the Food and Drug Administration (FDA). In these programs, a limited number of individuals can receive investigational drugs that have yet to be approved by the FDA. These programs are generally designed for rare medical conditions. For more information, visit **www.rarediseases.org**.

## Additional Resources

In addition to the references already listed in this chapter, you may need more information on health insurance, hospitals, or the healthcare system in general. The NIH has set up an excellent guidance Web site that addresses these and other issues. Topics include:[56]

- Health Insurance: **http://www.nlm.nih.gov/medlineplus/healthinsurance.html**
- Health Statistics: **http://www.nlm.nih.gov/medlineplus/healthstatistics.html**
- HMO and Managed Care: **http://www.nlm.nih.gov/medlineplus/managedcare.html**
- Hospice Care: **http://www.nlm.nih.gov/medlineplus/hospicecare.html**
- Medicaid: **http://www.nlm.nih.gov/medlineplus/medicaid.html**
- Medicare: **http://www.nlm.nih.gov/medlineplus/medicare.html**
- Nursing Homes and Long-term Care: **http://www.nlm.nih.gov/medlineplus/nursinghomes.html**
- Patient's Rights, Confidentiality, Informed Consent, Ombudsman Programs, Privacy and Patient Issues: **http://www.nlm.nih.gov/medlineplus/patientissues.html**
- Veteran's Health, Persian Gulf War, Gulf War Syndrome, Agent Orange: **http://www.nlm.nih.gov/medlineplus/veteranshealth.html**

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[55] Adapted from NORD: **http://www.rarediseases.org/cgi-bin/nord/progserv#patient?id=rPIzL9oD&mv_pc=30**.

[56] You can access this information at: **http://www.nlm.nih.gov/medlineplus/healthsystem.html**.

## Vocabulary Builder

**Cadmium:** An element with atomic symbol Cd, atomic number 48, and atomic weight 114. It is a metal and ingestion will lead to cadmium poisoning. [NIH]

# ONLINE GLOSSARIES

The Internet provides access to a number of free-to-use medical dictionaries and glossaries. The National Library of Medicine has compiled the following list of online dictionaries:

- ADAM Medical Encyclopedia (A.D.A.M., Inc.), comprehensive medical reference: **http://www.nlm.nih.gov/medlineplus/encyclopedia.html**
- MedicineNet.com Medical Dictionary (MedicineNet, Inc.): **http://www.medterms.com/Script/Main/hp.asp**
- Merriam-Webster Medical Dictionary (Inteli-Health, Inc.): **http://www.intelihealth.com/IH/**
- Multilingual Glossary of Technical and Popular Medical Terms in Eight European Languages (European Commission) - Danish, Dutch, English, French, German, Italian, Portuguese, and Spanish: **http://allserv.rug.ac.be/~rvdstich/eugloss/welcome.html**
- On-line Medical Dictionary (CancerWEB): **http://www.graylab.ac.uk/omd/**
- Technology Glossary (National Library of Medicine) - Health Care Technology: **http://www.nlm.nih.gov/nichsr/ta101/ta10108.htm**
- Terms and Definitions (Office of Rare Diseases): **http://rarediseases.info.nih.gov/ord/glossary_a-e.html**

Beyond these, MEDLINEplus contains a very user-friendly encyclopedia covering every aspect of medicine (licensed from A.D.A.M., Inc.). The ADAM Medical Encyclopedia Web site address is **http://www.nlm.nih.gov/medlineplus/encyclopedia.html**. ADAM is also available on commercial Web sites such as drkoop.com (**http://www.drkoop.com/**) and Web MD (**http://my.webmd.com/adam/asset/adam_disease_articles/a_to_z/a)**. Topics of interest can be researched by using keywords before continuing elsewhere, as these basic definitions and concepts will be useful in more advanced areas of research. You may choose to print various pages specifically relating to cerebral palsy and keep them on file. The NIH, in particular, suggests that parents of children with cerebral palsy visit the following Web sites in the ADAM Medical Encyclopedia:

- **Basic Guidelines for Cerebral Palsy**

  **Cerebral palsy**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/000716.htm

  **Cerebral palsy - resources**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/002167.htm

- **Signs & Symptoms for Cerebral Palsy**

  **Contractures**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003185.htm

  **Dysarthria**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003204.htm

  **Hypotonia**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003298.htm

  **Hypoxia**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003215.htm

  **Infantile reflexes**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003292.htm

  **Limited range of motion**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003173.htm

  **Loss of coordination**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003198.htm

**Loss of movement**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003190.htm

**Motormental retardation**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003313.htm

**Muscle**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003193.htm

**Muscle contractions**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003193.htm

**Paralysis**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003190.htm

**Peg teeth**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003064.htm

**Seizures**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003200.htm

**Spasticity**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003297.htm

**Stress**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003211.htm

**Unsteady gait**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/003199.htm

- **Diagnostics and Tests for Cerebral Palsy**

  **ANA**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003535.htm

  **CT**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003330.htm

  **CT scan of the head**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003786.htm

  **EEG**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003931.htm

  **MRI**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003335.htm

  **MRI of the head**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/003791.htm

- **Background Topics for Cerebral Palsy**

  **Cerebral palsy - support group**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/002167.htm

  **Head injury**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/000028.htm

  **Incidence**
  Web site:
  http://www.nlm.nih.gov/medlineplus/ency/article/002387.htm

**Irregular breathing**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/000007.htm

**Support group**
Web site:
http://www.nlm.nih.gov/medlineplus/ency/article/002150.htm

## Online Dictionary Directories

The following are additional online directories compiled by the National Library of Medicine, including a number of specialized medical dictionaries and glossaries:

- Medical Dictionaries: Medical & Biological (World Health Organization): **http://www.who.int/hlt/virtuallibrary/English/diction.htm#Medical**
- MEL-Michigan Electronic Library List of Online Health and Medical Dictionaries (Michigan Electronic Library): **http://mel.lib.mi.us/health/health-dictionaries.html**
- Patient Education: Glossaries (DMOZ Open Directory Project): **http://dmoz.org/Health/Education/Patient_Education/Glossaries/**
- Web of Online Dictionaries (Bucknell University): **http://www.yourdictionary.com/diction5.html#medicine**

# CEREBRAL PALSY GLOSSARY

The following is a complete glossary of terms used in this sourcebook. The definitions are derived from official public sources including the National Institutes of Health [NIH] and the European Union [EU]. After this glossary, we list a number of additional hardbound and electronic glossaries and dictionaries that you may wish to consult.

**Accommodation:** Adjustment, especially that of the eye for various distances. [EU]

**Acetylcholine:** A neurotransmitter. Acetylcholine in vertebrates is the major transmitter at neuromuscular junctions, autonomic ganglia, parasympathetic effector junctions, a subset of sympathetic effector junctions, and at many sites in the central nervous system. It is generally not used as an administered drug because it is broken down very rapidly by cholinesterases, but it is useful in some ophthalmological applications. [NIH]

**Adolescence:** The period of life beginning with the appearance of secondary sex characteristics and terminating with the cessation of somatic growth. The years usually referred to as adolescence lie between 13 and 18 years of age. [NIH]

**Alopecia:** Baldness; absence of the hair from skin areas where it normally is present. [EU]

**Amantadine:** An antiviral that is used in the prophylactic or symptomatic treatment of influenza A. It is also used as an antiparkinsonian agent, to treat extrapyramidal reactions, and for postherpetic neuralgia. The mechanisms of its effects in movement disorders are not well understood but probably reflect an increase in synthesis and release of dopamine, with perhaps some inhibition of dopamine uptake. [NIH]

**Amitriptyline:** Tricyclic antidepressant with anticholinergic and sedative properties. It appears to prevent the re-uptake of norepinephrine and serotonin at nerve terminals, thus potentiating the action of these neurotransmitters. Amitriptyline also appears to antaganize cholinergic and alpha-1 adrenergic responses to bioactive amines. [NIH]

**Anatomical:** Pertaining to anatomy, or to the structure of the organism. [EU]

**Anemia:** A reduction in the number of circulating erythrocytes or in the quantity of hemoglobin. [NIH]

**Ankle:** That part of the lower limb directly above the foot. [NIH]

**Antibody:** An immunoglobulin molecule that has a specific amino acid sequence by virtue of which it interacts only with the antigen that induced

its synthesis in cells of the lymphoid series (especially plasma cells), or with antigen closely related to it. Antibodies are classified according to their ode of action as agglutinins, bacteriolysins, haemolysins, opsonins, precipitins, etc. [EU]

**Anticholinergic:** An agent that blocks the parasympathetic nerves. Called also parasympatholytic. [EU]

**Anticonvulsant:** An agent that prevents or relieves convulsions. [EU]

**Antiepileptic:** An agent that combats epilepsy. [EU]

**Anxiety:** The unpleasant emotional state consisting of psychophysiological responses to anticipation of unreal or imagined danger, ostensibly resulting from unrecognized intrapsychic conflict. Physiological concomitants include increased heart rate, altered respiration rate, sweating, trembling, weakness, and fatigue; psychological concomitants include feelings of impending danger, powerlessness, apprehension, and tension. [EU]

**Aphasia:** Defect or loss of the power of expression by speech, writing, or signs, or of comprehending spoken or written language, due to injury or disease of the brain centres. [EU]

**Apnea:** A transient absence of spontaneous respiration. [NIH]

**Asphyxia:** A pathological condition caused by lack of oxygen, manifested in impending or actual cessation of life. [NIH]

**Assay:** Determination of the amount of a particular constituent of a mixture, or of the biological or pharmacological potency of a drug. [EU]

**Ataxia:** Failure of muscular coordination; irregularity of muscular action. [EU]

**Athetosis:** A derangement marked by ceaseless occurrence of slow, sinuous, writhing movements, especially severe in the hands, and performed involuntarily; it may occur after hemiplegia, and is then known as posthemiplegic chorea. Called also mobile spasm. [EU]

**Atrophy:** A wasting away; a diminution in the size of a cell, tissue, organ, or part. [EU]

**Atypical:** Irregular; not conformable to the type; in microbiology, applied specifically to strains of unusual type. [EU]

**Barium:** An element of the alkaline earth group of metals. It has an atomic symbol Ba, atomic number 56, and atomic weight 138. All of its acid-soluble salts are poisonous. [NIH]

**Benztropine:** A centrally active muscarinic antagonist that has been used in the symptomatic treatment of parkinson disease. Benztropine also inhibits the uptake of dopamine. [NIH]

**Bereavement:** Refers to the whole process of grieving and mourning and is

associated with a deep sense of loss and sadness. [NIH]

**Bile:** An emulsifying agent produced in the liver and secreted into the duodenum. Its composition includes bile acids and salts, cholesterol, and electrolytes. It aids digestion of fats in the duodenum. [NIH]

**Botulinum Toxin Type A:** A neurotoxin produced by Clostridium botulinum. When consumed in contaminated food it can cause paralysis and death. In its purified form, it has been used in the treatment of blepharospasm and strabismus. [NIH]

**Bruxism:** A disorder characterized by grinding and clenching of the teeth. [NIH]

**Cadmium:** An element with atomic symbol Cd, atomic number 48, and atomic weight 114. It is a metal and ingestion will lead to cadmium poisoning. [NIH]

**Carbamazepine:** An anticonvulsant used to control grand mal and psychomotor or focal seizures. Its mode of action is not fully understood, but some of its actions resemble those of phenytoin; although there is little chemical resemblance between the two compounds, their three-dimensional structure is similar. [NIH]

**Carcinoma:** A malignant new growth made up of epithelial cells tending to infiltrate the surrounding tissues and give rise to metastases. [EU]

**Cardiac:** Pertaining to the heart. [EU]

**Cardiotocography:** Monitoring of fetal heart frequency before birth in order to assess impending prematurity in relation to the pattern or intensity of antepartum uterine contraction. [NIH]

**Cardiovascular:** Pertaining to the heart and blood vessels. [EU]

**Cataract:** An opacity, partial or complete, of one or both eyes, on or in the lens or capsule, especially an opacity impairing vision or causing blindness. The many kinds of cataract are classified by their morphology (size, shape, location) or etiology (cause and time of occurrence). [EU]

**Cerebellar:** Pertaining to the cerebellum. [EU]

**Cerebellum:** Part of the metencephalon that lies in the posterior cranial fossa behind the brain stem. It is concerned with the coordination of movement. [NIH]

**Cerebrospinal:** Pertaining to the brain and spinal cord. [EU]

**Cervical:** Pertaining to the neck, or to the neck of any organ or structure. [EU]

**Chromosomal:** Pertaining to chromosomes. [EU]

**Chronic:** Persisting over a long period of time. [EU]

**Clonazepam:** An anticonvulsant used for several types of seizures, including myotonic or atonic seizures, photosensitive epilepsy, and absence

seizures, although tolerance may develop. It is seldom effective in generalized tonic-clonic or partial seizures. The mechanism of action appears to involve the enhancement of gaba receptor responses. [NIH]

**Clonic:** Pertaining to or of the nature of clonus. [EU]

**Coagulation:** 1. the process of clot formation. 2. in colloid chemistry, the solidification of a sol into a gelatinous mass; an alteration of a disperse phase or of a dissolved solid which causes the separation of the system into a liquid phase and an insoluble mass called the clot or curd. Coagulation is usually irreversible. 3. in surgery, the disruption of tissue by physical means to form an amorphous residuum, as in electrocoagulation and photocoagulation. [EU]

**Confusion:** Disturbed orientation in regard to time, place, or person, sometimes accompanied by disordered consciousness. [EU]

**Consciousness:** Sense of awareness of self and of the environment. [NIH]

**Contracture:** A condition of fixed high resistance to passive stretch of a muscle, resulting from fibrosis of the tissues supporting the muscles or the joints, or from disorders of the muscle fibres. [EU]

**Cues:** Signals for an action; that specific portion of a perceptual field or pattern of stimuli to which a subject has learned to respond. [NIH]

**Curative:** Tending to overcome disease and promote recovery. [EU]

**Cutaneous:** Pertaining to the skin; dermal; dermic. [EU]

**Cyst:** Any closed cavity or sac; normal or abnormal, lined by epithelium, and especially one that contains a liquid or semisolid material. [EU]

**Cytomegalovirus:** A genus of the family herpesviridae, subfamily betaherpesvirinae, infecting the salivary glands, liver, spleen, lungs, eyes, and other organs, in which they produce characteristically enlarged cells with intranuclear inclusions. Infection with Cytomegalovirus is also seen as an opportunistic infection in AIDS. [NIH]

**Dantrolene:** Skeletal muscle relaxant that acts by interfering with excitation-contraction coupling in the muscle fiber. It is used in spasticity and other neuromuscular abnormalities. Although the mechanism of action is probably not central, dantrolene is usually grouped with the central muscle relaxants. [NIH]

**Dentures:** An appliance used as an artificial or prosthetic replacement for missing teeth and adjacent tissues. It does not include crowns, dental abutments, nor tooth, artificial. [NIH]

**Dermatology:** A medical specialty concerned with the skin, its structure, functions, diseases, and treatment. [NIH]

**Desensitization:** The prevention or reduction of immediate hypersensitivity reactions by administration of graded doses of allergen; called also hyposensitization and immunotherapy. [EU]

**Digestion:** The process of breakdown of food for metabolism and use by the body. [NIH]

**Dilatation:** The condition, as of an orifice or tubular structure, of being dilated or stretched beyond the normal dimensions. [EU]

**Distal:** Remote; farther from any point of reference; opposed to proximal. In dentistry, used to designate a position on the dental arch farther from the median line of the jaw. [EU]

**Dorsal:** 1. pertaining to the back or to any dorsum. 2. denoting a position more toward the back surface than some other object of reference; same as posterior in human anatomy; superior in the anatomy of quadrupeds. [EU]

**Dysarthria:** Imperfect articulation of speech due to disturbances of muscular control which result from damage to the central or peripheral nervous system. [EU]

**Dysphagia:** Difficulty in swallowing. [EU]

**Dystonia:** Disordered tonicity of muscle. [EU]

**Dystrophy:** Any disorder arising from defective or faulty nutrition, especially the muscular dystrophies. [EU]

**Edema:** Excessive amount of watery fluid accumulated in the intercellular spaces, most commonly present in subcutaneous tissue. [NIH]

**Electroencephalography:** The recording of the electric currents developed in the brain, by means of electrodes applied to the scalp, to the surface of the brain (intracranial e.) or placed within the substance of the brain (depth e.). [EU]

**Electromyography:** Recording of the changes in electric potential of muscle by means of surface or needle electrodes. [NIH]

**Encephalitis:** Inflammation of the brain. [EU]

**Encephalopathy:** Any degenerative disease of the brain. [EU]

**Endocrinology:** A subspecialty of internal medicine concerned with the metabolism, physiology, and disorders of the endocrine system. [NIH]

**Energetic:** Exhibiting energy : strenuous; operating with force, vigour, or effect. [EU]

**Enuresis:** Involuntary discharge of urine after the age at which urinary control should have been achieved; often used alone with specific reference to involuntary discharge of urine occurring during sleep at night (bed-wetting, nocturnal enuresis). [EU]

**Extracorporeal:** Situated or occurring outside the body. [EU]

**Extraction:** The process or act of pulling or drawing out. [EU]

**Femur:** The longest and largest bone of the skeleton, it is situated between

the hip and the knee. [NIH]

**Fibrosis:** The formation of fibrous tissue; fibroid or fibrous degeneration [EU]

**Fissure:** Any cleft or groove, normal or otherwise; especially a deep fold in the cerebral cortex which involves the entire thickness of the brain wall. [EU]

**Flaccid:** Weak, lax and soft. [EU]

**Flexion:** In gynaecology, a displacement of the uterus in which the organ is bent so far forward or backward that an acute angle forms between the fundus and the cervix. [EU]

**Gait:** Manner or style of walking. [NIH]

**Gastrostomy:** Creation of an artificial external opening into the stomach for nutritional support or gastrointestinal compression. [NIH]

**Gestures:** Movement of a part of the body for the purpose of communication. [NIH]

**Hemiplegia:** Paralysis of one side of the body. [EU]

**Hemorrhage:** Bleeding or escape of blood from a vessel. [NIH]

**Hormonal:** Pertaining to or of the nature of a hormone. [EU]

**Hydrocephalus:** A condition marked by dilatation of the cerebral ventricles, most often occurring secondarily to obstruction of the cerebrospinal fluid pathways, and accompanied by an accumulation of cerebrospinal fluid within the skull; the fluid is usually under increased pressure, but occasionally may be normal or nearly so. It is typically characterized by enlargement of the head, prominence of the forehead, brain atrophy, mental deterioration, and convulsions; may be congenital or acquired; and may be of sudden onset (acute h.) or be slowly progressive (chronic or primary b.). [EU]

**Hyperbaric:** Characterized by greater than normal pressure or weight; applied to gases under greater than atmospheric pressure, as hyperbaric oxygen, or to a solution of greater specific gravity than another taken as a standard of reference. [EU]

**Hypertension:** Persistently high arterial blood pressure. Various criteria for its threshold have been suggested, ranging from 140 mm. Hg systolic and 90 mm. Hg diastolic to as high as 200 mm. Hg systolic and 110 mm. Hg diastolic. Hypertension may have no known cause (essential or idiopathic h.) or be associated with other primary diseases (secondary h.). [EU]

**Hyperthyroidism:** 1. excessive functional activity of the thyroid gland. 2. the abnormal condition resulting from hyperthyroidism marked by increased metabolic rate, enlargement of the thyroid gland, rapid heart rate, high blood pressure, and various secondary symptoms. [EU]

**Hypertonia:** Or hypertony n, pl. hypertonias or hypertonies : hypertonicity.

n. Pathology: increased rigidity, tension and spasticity of the muscles. [EU]

**Hypotonia:** A condition of diminished tone of the skeletal muscles; diminished resistance of muscles to passive stretching. [EU]

**Hypoxia:** Reduction of oxygen supply to tissue below physiological levels despite adequate perfusion of the tissue by blood. [EU]

**Immunization:** The induction of immunity. [EU]

**Impotence:** The inability to perform sexual intercourse. [NIH]

**Incompetence:** Physical or mental inadequacy or insufficiency. [EU]

**Incontinence:** Inability to control excretory functions, as defecation (faecal i.) or urination (urinary i.). [EU]

**Infantile:** Pertaining to an infant or to infancy. [EU]

**Infertility:** The diminished or absent ability to conceive or produce an offspring while sterility is the complete inability to conceive or produce an offspring. [NIH]

**Intestinal:** Pertaining to the intestine. [EU]

**Invasive:** 1. having the quality of invasiveness. 2. involving puncture or incision of the skin or insertion of an instrument or foreign material into the body; said of diagnostic techniques. [EU]

**Jaundice:** A clinical manifestation of hyperbilirubinemia, consisting of deposition of bile pigments in the skin, resulting in a yellowish staining of the skin and mucous membranes. [NIH]

**Lesion:** Any pathological or traumatic discontinuity of tissue or loss of function of a part. [EU]

**Levodopa:** The naturally occurring form of dopa and the immediate precursor of dopamine. Unlike dopamine itself, it can be taken orally and crosses the blood-brain barrier. It is rapidly taken up by dopaminergic neurons and converted to dopamine. It is used for the treatment of parkinsonism and is usually given with agents that inhibit its conversion to dopamine outside of the central nervous system. [NIH]

**Ligation:** Application of a ligature to tie a vessel or strangulate a part. [NIH]

**Lip:** Either of the two fleshy, full-blooded margins of the mouth. [NIH]

**Lupus:** A form of cutaneous tuberculosis. It is seen predominantly in women and typically involves the nasal, buccal, and conjunctival mucosa. [NIH]

**Malformation:** A morphologic defect resulting from an intrinsically abnormal developmental process. [EU]

**Mandible:** The largest and strongest bone of the face constituting the lower jaw. It supports the lower teeth. [NIH]

**Medicament:** A medicinal substance or agent. [EU]

**Membrane:** A thin layer of tissue which covers a surface, lines a cavity or divides a space or organ. [EU]

**Meningitis:** Inflammation of the meninges. When it affects the dura mater, the disease is termed pachymeningitis; when the arachnoid and pia mater are involved, it is called leptomeningitis, or meningitis proper. [EU]

**Mental:** Pertaining to the mind; psychic. 2. (L. mentum chin) pertaining to the chin. [EU]

**Mentors:** Senior professionals who provide guidance, direction and support to those persons desirous of improvement in academic positions, administrative positions or other career development situations. [NIH]

**Molecular:** Of, pertaining to, or composed of molecules : a very small mass of matter. [EU]

**Monotherapy:** A therapy which uses only one drug. [EU]

**Musculature:** The muscular apparatus of the body, or of any part of it. [EU]

**Myasthenia:** Muscular debility; any constitutional anomaly of muscle. [EU]

**Myosin:** Chief protein in muscle and the main constituent of the thick filaments of muscle fibers. In conjunction with actin, it is responsible for the contraction and relaxation of muscles. [NIH]

**Myositis:** Inflammation of a voluntary muscle. [EU]

**Neonatal:** Pertaining to the first four weeks after birth. [EU]

**Neural:** 1. pertaining to a nerve or to the nerves. 2. situated in the region of the spinal axis, as the neutral arch. [EU]

**Neuroanatomy:** Study of the anatomy of the nervous system as a specialty or discipline. [NIH]

**Neurology:** A medical specialty concerned with the study of the structures, functions, and diseases of the nervous system. [NIH]

**Neuromuscular:** Pertaining to muscles and nerves. [EU]

**Neurons:** The basic cellular units of nervous tissue. Each neuron consists of a body, an axon, and dendrites. Their purpose is to receive, conduct, and transmit impulses in the nervous system. [NIH]

**Neurosurgery:** A surgical specialty concerned with the treatment of diseases and disorders of the brain, spinal cord, and peripheral and sympathetic nervous system. [NIH]

**Orofacial:** Of or relating to the mouth and face. [EU]

**Orthopaedic:** Pertaining to the correction of deformities of the musculoskeletal system; pertaining to orthopaedics. [EU]

**Orthopedics:** A surgical specialty which utilizes medical, surgical, and

physical methods to treat and correct deformities, diseases, and injuries to the skeletal system, its articulations, and associated structures. [NIH]

**Osteogenesis:** The histogenesis of bone including ossification. It occurs continuously but particularly in the embryo and child and during fracture repair. [NIH]

**Oxygenation:** The process of supplying, treating, or mixing with oxygen. No:1245 - oxygenation the process of supplying, treating, or mixing with oxygen. [EU]

**Paediatric:** Of or relating to the care and medical treatment of children; belonging to or concerned with paediatrics. [EU]

**Paralysis:** Loss or impairment of motor function in a part due to lesion of the neural or muscular mechanism; also by analogy, impairment of sensory function (sensory paralysis). In addition to the types named below, paralysis is further distinguished as traumatic, syphilitic, toxic, etc., according to its cause; or as obturator, ulnar, etc., according to the nerve part, or muscle specially affected. [EU]

**Paraplegia:** Paralysis of the legs and lower part of the body. [EU]

**Parenteral:** Not through the alimentary canal but rather by injection through some other route, as subcutaneous, intramuscular, intraorbital, intracapsular, intraspinal, intrasternal, intravenous, etc. [EU]

**Paresis:** Slight or incomplete paralysis. [EU]

**Pathologic:** 1. indicative of or caused by a morbid condition. 2. pertaining to pathology (= branch of medicine that treats the essential nature of the disease, especially the structural and functional changes in tissues and organs of the body caused by the disease). [EU]

**Pediatrics:** A medical specialty concerned with maintaining health and providing medical care to children from birth to adolescence. [NIH]

**Perinatal:** Pertaining to or occurring in the period shortly before and after birth; variously defined as beginning with completion of the twentieth to twenty-eighth week of gestation and ending 7 to 28 days after birth. [EU]

**Phonation:** The process of producing vocal sounds by means of vocal cords vibrating in an expiratory blast of air. [NIH]

**Phototherapy:** Treatment of disease by exposure to light, especially by variously concentrated light rays or specific wavelengths. [NIH]

**Pigments:** Any normal or abnormal coloring matter in plants, animals, or micro-organisms. [NIH]

**Podiatry:** A specialty concerned with the diagnosis and treatment of foot disorders and injuries and anatomic defects of the foot. [NIH]

**Poisoning:** A condition or physical state produced by the ingestion,

injection or inhalation of, or exposure to a deleterious agent. [NIH]

**Polytherapy:** A therapy which uses more than one drug. [EU]

**Postnatal:** Occurring after birth, with reference to the newborn. [EU]

**Postoperative:** Occurring after a surgical operation. [EU]

**Postural:** Pertaining to posture or position. [EU]

**Precursor:** Something that precedes. In biological processes, a substance from which another, usually more active or mature substance is formed. In clinical medicine, a sign or symptom that heralds another. [EU]

**Preeclampsia:** A toxaemia of late pregnancy characterized by hypertension, edema, and proteinuria, when convulsions and coma are associated, it is called eclampsia. [EU]

**Prejudice:** A preconceived judgment made without adequate evidence and not easily alterable by presentation of contrary evidence. [NIH]

**Prenatal:** Existing or occurring before birth, with reference to the fetus. [EU]

**Presynaptic:** Situated proximal to a synapse, or occurring before the synapse is crossed. [EU]

**Prevalence:** The total number of cases of a given disease in a specified population at a designated time. It is differentiated from incidence, which refers to the number of new cases in the population at a given time. [NIH]

**Procyclidine:** A muscarinic antagonist that crosses the blood-brain barrier and is used in the treatment of drug-induced extrapyramidal disorders and in parkinsonism. [NIH]

**Progressive:** Advancing; going forward; going from bad to worse; increasing in scope or severity. [EU]

**Prophylaxis:** The prevention of disease; preventive treatment. [EU]

**Prostate:** A gland in males that surrounds the neck of the bladder and the urethra. It secretes a substance that liquifies coagulated semen. It is situated in the pelvic cavity behind the lower part of the pubic symphysis, above the deep layer of the triangular ligament, and rests upon the rectum. [NIH]

**Proteins:** Polymers of amino acids linked by peptide bonds. The specific sequence of amino acids determines the shape and function of the protein. [NIH]

**Proximal:** Nearest; closer to any point of reference; opposed to distal. [EU]

**Psychiatric:** Pertaining to or within the purview of psychiatry. [EU]

**Psychiatry:** The medical science that deals with the origin, diagnosis, prevention, and treatment of mental disorders. [NIH]

**Psychogenic:** Produced or caused by psychic or mental factors rather than organic factors. [EU]

**Puberty:** The period during which the secondary sex characteristics begin to develop and the capability of sexual reproduction is attained. [EU]

**Pulmonary:** Pertaining to the lungs. [EU]

**Pulse:** The rhythmical expansion and contraction of an artery produced by waves of pressure caused by the ejection of blood from the left ventricle of the heart as it contracts. [NIH]

**Quadriplegia:** Severe or complete loss of motor function in all four limbs which may result from brain diseases; spinal cord diseases; peripheral nervous system diseases; neuromuscular diseases; or rarely muscular diseases. The locked-in syndrome is characterized by quadriplegia in combination with cranial muscle paralysis. Consciousness is spared and the only retained voluntary motor activity may be limited eye movements. This condition is usually caused by a lesion in the upper brain stem which injures the descending cortico-spinal and cortico-bulbar tracts. [NIH]

**Radiology:** A specialty concerned with the use of x-ray and other forms of radiant energy in the diagnosis and treatment of disease. [NIH]

**Recurrence:** The return of a sign, symptom, or disease after a remission. [NIH]

**Reflux:** A backward or return flow. [EU]

**Registries:** The systems and processes involved in the establishment, support, management, and operation of registers, e.g., disease registers. [NIH]

**Regurgitation:** A backward flowing, as the casting up of undigested food, or the backward flowing of blood into the heart, or between the chambers of the heart when a valve is incompetent. [EU]

**Relaxant:** 1. lessening or reducing tension. 2. an agent that lessens tension. [EU]

**Remission:** A diminution or abatement of the symptoms of a disease; also the period during which such diminution occurs. [EU]

**Retraction:** 1. the act of drawing back; the condition of being drawn back. 2. distal movement of teeth, usually accomplished with an orthodontic appliance. [EU]

**Rigidity:** Stiffness or inflexibility, chiefly that which is abnormal or morbid; rigor. [EU]

**Rubella:** An acute, usually benign, infectious disease caused by a togavirus and most often affecting children and nonimmune young adults, in which the virus enters the respiratory tract via droplet nuclei and spreads to the lymphatic system. It is characterized by a slight cold, sore throat, and fever, followed by enlargement of the postauricular, suboccipital, and cervical lymph nodes, and the appearances of a fine pink rash that begins on the head and spreads to become generalized. Called also German measles, roetln, röteln, and three-day measles, and rubeola in French and Spanish. [EU]

**Saliva:** The clear, viscous fluid secreted by the salivary glands and mucous glands of the mouth. It contains mucins, water, organic salts, and ptylin. [NIH]

**Schizophrenia:** A severe emotional disorder of psychotic depth characteristically marked by a retreat from reality with delusion formation, hallucinations, emotional disharmony, and regressive behavior. [NIH]

**Sclerosis:** A induration, or hardening; especially hardening of a part from inflammation and in diseases of the interstitial substance. The term is used chiefly for such a hardening of the nervous system due to hyperplasia of the connective tissue or to designate hardening of the blood vessels. [EU]

**Seizures:** Clinical or subclinical disturbances of cortical function due to a sudden, abnormal, excessive, and disorganized discharge of brain cells. Clinical manifestations include abnormal motor, sensory and psychic phenomena. Recurrent seizures are usually referred to as epilepsy or "seizure disorder." [NIH]

**Semantics:** The relationships between symbols and their meanings. [NIH]

**Serum:** The clear portion of any body fluid; the clear fluid moistening serous membranes. 2. blood serum; the clear liquid that separates from blood on clotting. 3. immune serum; blood serum from an immunized animal used for passive immunization; an antiserum; antitoxin, or antivenin. [EU]

**Sialorrhea:** Increased salivary flow. [NIH]

**Skeletal:** Pertaining to the skeleton. [EU]

**Skull:** The skeleton of the head including the bones of the face and the bones enclosing the brain. [NIH]

**Spasmodic:** Of the nature of a spasm. [EU]

**Spastic:** 1. of the nature of or characterized by spasms. 2. hypertonic, so that the muscles are stiff and the movements awkward. 3. a person exhibiting spasticity, such as occurs in spastic paralysis or in cerebral palsy. [EU]

**Spasticity:** A state of hypertonicity, or increase over the normal tone of a muscle, with heightened deep tendon reflexes. [EU]

**Spectrum:** A charted band of wavelengths of electromagnetic vibrations obtained by refraction and diffraction. By extension, a measurable range of activity, such as the range of bacteria affected by an antibiotic (antibacterial s.) or the complete range of manifestations of a disease. [EU]

**Sphincter:** A ringlike band of muscle fibres that constricts a passage or closes a natural orifice; called also musculus sphincter. [EU]

**Stabilization:** The creation of a stable state. [EU]

**Stomach:** An organ of digestion situated in the left upper quadrant of the abdomen between the termination of the esophagus and the beginning of the duodenum. [NIH]

**Strabismus:** Deviation of the eye which the patient cannot overcome. The visual axes assume a position relative to each other different from that required by the physiological conditions. The various forms of strabismus are spoken of as tropias, their direction being indicated by the appropriate prefix, as cyclo tropia, esotropia, exotropia, hypertropia, and hypotropia. Called also cast, heterotropia, manifest deviation, and squint. [EU]

**Systemic:** Pertaining to or affecting the body as a whole. [EU]

**Telecommunications:** Transmission of information over distances via electronic means. [NIH]

**Testicular:** Pertaining to a testis. [EU]

**Thalamus:** Either of two large, ovoid masses, consisting chiefly of grey substance, situated one on each side of and forming part of the lateral wall of the third ventricle. It is divided into two major parts : dorsal and ventral, each of which contains many nuclei. [EU]

**Tomography:** The recording of internal body images at a predetermined plane by means of the tomograph; called also body section roentgenography. [EU]

**Tone:** 1. the normal degree of vigour and tension; in muscle, the resistance to passive elongation or stretch; tonus. 2. a particular quality of sound or of voice. 3. to make permanent, or to change, the colour of silver stain by chemical treatment, usually with a heavy metal. [EU]

**Tonic:** 1. producing and restoring the normal tone. 2. characterized by continuous tension. 3. a term formerly used for a class of medicinal preparations believed to have the power of restoring normal tone to tissue. [EU]

**Torticollis:** Wryneck; a contracted state of the cervical muscles, producing twisting of the neck and an unnatural position of the head. [EU]

**Toxicity:** The quality of being poisonous, especially the degree of virulence of a toxic microbe or of a poison. [EU]

**Toxin:** A poison; frequently used to refer specifically to a protein produced by some higher plants, certain animals, and pathogenic bacteria, which is highly toxic for other living organisms. Such substances are differentiated from the simple chemical poisons and the vegetable alkaloids by their high molecular weight and antigenicity. [EU]

**Toxoplasmosis:** An acute or chronic, widespread disease of animals and humans caused by the obligate intracellular protozoon Toxoplasma gondii, transmitted by oocysts containing the pathogen in the feces of cats (the definitive host), usually by contaminated soil, direct exposure to infected feces, tissue cysts in infected meat, or tachyzoites (proliferating forms) in blood. [EU]

**Tracheotomy:** Surgical incision of the trachea. [NIH]

**Transcutaneous:** Transdermal. [EU]

**Transdermal:** Entering through the dermis, or skin, as in administration of a drug applied to the skin in ointment or patch form. [EU]

**Transfusion:** The introduction of whole blood or blood component directly into the blood stream. [EU]

**Tremor:** An involuntary trembling or quivering. [EU]

**Trihexyphenidyl:** A centrally acting muscarinic antagonist used in the treatment of parkinsonism and drug-induced extrapyramidal movement disorders and as an antispasmodic. [NIH]

**Trisomy:** The possession of a third chromosome of any one type in an otherwise diploid cell. [NIH]

**Ultrasonography:** The visualization of deep structures of the body by recording the reflections of echoes of pulses of ultrasonic waves directed into the tissues. Use of ultrasound for imaging or diagnostic purposes employs frequencies ranging from 1.6 to 10 megahertz. [NIH]

**Uterus:** The hollow muscular organ in female mammals in which the fertilized ovum normally becomes embedded and in which the developing embryo and fetus is nourished. In the nongravid human, it is a pear-shaped structure; about 3 inches in length, consisting of a body, fundus, isthmus, and cervix. Its cavity opens into the vagina below, and into the uterine tube on either side at the cornu. It is supported by direct attachment to the vagina and by indirect attachment to various other nearby pelvic structures. Called also metra. [EU]

**Vaginal:** 1. of the nature of a sheath; ensheathing. 2. pertaining to the vagina. 3. pertaining to the tunica vaginalis testis. [EU]

**Vascular:** Pertaining to blood vessels or indicative of a copious blood supply. [EU]

**Viral:** Pertaining to, caused by, or of the nature of virus. [EU]

**Withdrawal:** 1. a pathological retreat from interpersonal contact and social involvement, as may occur in schizophrenia, depression, or schizoid avoidant and schizotypal personality disorders. 2. (DSM III-R) a substance-specific organic brain syndrome that follows the cessation of use or reduction in intake of a psychoactive substance that had been regularly used to induce a state of intoxication. [EU]

## General Dictionaries and Glossaries

While the above glossary is essentially complete, the dictionaries listed here cover virtually all aspects of medicine, from basic words and phrases to more advanced terms (sorted alphabetically by title; hyperlinks provide rankings, information and reviews at Amazon.com):

- **Dictionary of Medical Acronymns & Abbreviations** by Stanley Jablonski (Editor), Paperback, 4th edition (2001), Lippincott Williams & Wilkins Publishers, ISBN: 1560534605, **http://www.amazon.com/exec/obidos/ASIN/1560534605/icongroupinterna**
- **Dictionary of Medical Terms : For the Nonmedical Person (Dictionary of Medical Terms for the Nonmedical Person, Ed 4)** by Mikel A. Rothenberg, M.D, et al, Paperback - 544 pages, 4th edition (2000), Barrons Educational Series, ISBN: 0764112015, **http://www.amazon.com/exec/obidos/ASIN/0764112015/icongroupinterna**
- **A Dictionary of the History of Medicine** by A. Sebastian, CD-Rom edition (2001), CRC Press-Parthenon Publishers, ISBN: 185070368X, **http://www.amazon.com/exec/obidos/ASIN/185070368X/icongroupinterna**
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# INDEX


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