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Reducing the burden of neurological disease...

Cerebral Palsy: Hope Through Research

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Parálisis Cerebral: Esperanza en la Investigación

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Introduction

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, in their arms. These children had difficulty grasping objects, crawling, and walking. Unlike most other diseases that affect the brain, this condition didn't get worse as the children grew older. Instead, their disabilities stayed relatively the same.

The disorder, which was called Little's disease for many years, is now known as *spastic diplegia*. It is one of a group of disorders that affect the control of movement and are gathered under the umbrella term of "cerebral palsy."

Because it seemed that many of Little's patients were born following premature or complicated deliveries, the doctor suggested their condition was the result of oxygen deprivation during birth, which damaged sensitive brain tissues controlling movement. But in 1897, the famous psychiatrist Sigmund Freud disagreed. Noting that children with cerebral palsy often had other neurological problems such as mental retardation, visual disturbances, and seizures, Freud suggested that the disorder might 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."

In spite of Freud's observation, for many decades the belief that birth complications caused most cases of

cerebral palsy was widespread among physicians, families, and even medical researchers. In the 1980s, however, scientists funded by the National Institute of Neurological Disorders and Stroke (NINDS) analyzed extensive data from more than 35,000 newborns and their mothers, and discovered that complications during birth and labor accounted for only a fraction of the infants born with cerebral palsy — probably less than 10 percent. In most cases, they could find no single, obvious cause.

This finding challenged the accepted medical theory about the cause of cerebral palsy. It also stimulated researchers to search for other factors before, during, and after birth that were associated with the disorder.

Advances in imaging technology, such as magnetic resonance imaging (MRI), have given researchers a way to look into the brains of infants and children with cerebral palsy and discover unique structural malformations and areas of damage. Basic science studies have identified genetic mutations and deletions associated with the abnormal development of the fetal brain. These discoveries offer provocative clues about what could be going wrong during brain development to cause the abnormalities that lead to cerebral palsy.

Much of this new understanding about what causes cerebral palsy is the result of research spanning the past two decades that has been sponsored by the NINDS, the federal government's leading supporter of neurological research. These findings from NINDS research have:

- identified new causes and risk factors for cerebral palsy;
- increased our understanding of how and why brain damage at critical stages of fetal development causes cerebral palsy;
- refined surgical techniques to correct abnormalities in muscle and bone;
- discovered new drugs to control stiff and spastic muscles and developed more precise methods to deliver them; and
- tested the effectiveness of therapies used to treat cerebral palsy to discover which methods work best.

This brochure describes what cerebral palsy is, its causes, its treatments, and how it might possibly be prevented. Medical terms in *italics* are defined in the glossary at the back of the booklet.

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What is Cerebral Palsy?

Doctors use the term cerebral palsy to refer to any one of a number of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination but aren't progressive, in other words, they don't get worse over time. The term *cerebral* refers to the two halves or hemispheres of the brain, in this case to the motor area of the brain's outer layer (called the cerebral cortex), the part of the brain that directs muscle movement; *palsy* refers to the loss or impairment of motor function.

Even though cerebral palsy affects muscle movement, it isn't caused by problems in the muscles or nerves. It is caused by abnormalities inside the brain that disrupt the brain's ability to control movement and posture.

In some cases of cerebral palsy, the cerebral motor cortex hasn't developed normally during fetal growth. In others, the damage is a result of injury to the brain either before, during, or after birth. In either case, the damage is not repairable and the disabilities that result are permanent.

Children with cerebral palsy exhibit a wide variety of symptoms, including:

- lack of muscle coordination when performing voluntary movements (*ataxia*);
- stiff or tight muscles and exaggerated reflexes (*spasticity*);
- walking with one foot or leg dragging;
- walking on the toes, a crouched gait, or a "scissored" gait;

- variations in muscle tone, either too stiff or too floppy;
- excessive drooling or difficulties swallowing or speaking;
- shaking (*tremor*) or random involuntary movements; and
- difficulty with precise motions, such as writing or buttoning a shirt.

The symptoms of cerebral palsy differ in type and severity from one person to the next, and may even change in an individual over time. Some people with cerebral palsy also have other medical disorders, including mental retardation, seizures, impaired vision or hearing, and abnormal physical sensations or perceptions.

Cerebral palsy doesn't always cause profound disabilities. While one child with severe cerebral palsy might be unable to walk and need extensive, lifelong care, another with mild cerebral palsy might be only slightly awkward and require no special assistance.

Cerebral palsy isn't a disease. It isn't contagious and it can't be passed from one generation to the next. There is no cure for cerebral palsy, but supportive treatments, medications, and surgery can help many individuals improve their motor skills and ability to communicate with the world.

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How Many People Have Cerebral Palsy?

The United Cerebral Palsy (UCP) Foundation estimates that nearly 800,000 children and adults in the United States are living with one or more of the symptoms of cerebral palsy. According to the federal government's Centers for Disease Control and Prevention, each year about 10,000 babies born in the United States will develop cerebral palsy.

Despite advances in preventing and treating certain causes of cerebral palsy, the percentage of babies who develop the condition has remained the same over the past 30 years. Improved care in neonatal intensive-care units has resulted in higher survival rates for very low birthweight babies. Many of these infants will have developmental defects in their nervous systems or suffer brain damage that will cause the characteristic symptoms of cerebral palsy.

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What Are the Early Signs?

The early signs of cerebral palsy usually appear before a child reaches 3 years of age. Parents are often the first to suspect that their baby's motor skills aren't developing normally. Infants with cerebral palsy frequently have *developmental delay*, in which they are slow to reach developmental milestones such as learning to roll over, sit, crawl, smile, or walk. Some infants with cerebral palsy have abnormal muscle tone as infants. Decreased muscle tone (*hypotonia*) can make them appear relaxed, even floppy. Increased muscle tone (*hypertonia)* can make them seem stiff or rigid. In some cases, an early period of hypotonia will progress to hypertonia after the first 2 to 3 months of life. Children with cerebral palsy may also have unusual posture or favor one side of the body when they move.

Parents who are concerned about their baby's development for any reason should contact their pediatrician. A doctor can determine the difference between a normal lag in development and a delay that could indicate cerebral palsy.

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What Causes Cerebral Palsy?

The majority of children with cerebral palsy are born with it, although it may not be detected until months or years later. This is called *congenital cerebral palsy*. In the past, if doctors couldn't identify another cause, they attributed most cases of congenital cerebral palsy to problems or complications during labor that caused *asphyxia* (a lack of oxygen) during birth. However, extensive research by NINDS scientists and others has shown that few babies who experience asphyxia during birth grow up to have cerebral palsy or any other neurological disorder. Birth complications, including asphyxia, are now estimated to account for

only 5 to 10 percent of the babies born with congenital cerebral palsy.

A small number of children have *acquired cerebral palsy*, which means the disorder begins after birth. In these cases, doctors can often pinpoint a specific reason for the problem, such as brain damage in the first few months or years of life, brain infections such as bacterial meningitis or viral encephalitis, or head injury from a motor vehicle accident, a fall, or child abuse.

What causes the remaining 90 to 95 percent? Research has given us a bigger and more accurate picture of the kinds of events that can happen during early fetal development, or just before, during, or after birth, that cause the particular types of brain damage that will result in congenital cerebral palsy. There are multiple reasons why cerebral palsy happens – as the result of genetic abnormalities, maternal infections or fevers, or fetal injury, for example. But in all cases the disorder is the result of four types of brain damage that cause its characteristic symptoms:

Damage to the white matter of the brain (*periventricular leukomalacia* [PVL]). The white matter of the brain is responsible for transmitting signals inside the brain and to the rest of the body. PVL describes a type of damage that looks like tiny holes in the white matter of an infant's brain. These gaps in brain tissue interfere with the normal transmission of signals. There are a number of events that can cause PVL, including maternal or fetal infection. Researchers have also identified a period of *selective vulnerability* in the developing fetal brain, a period of time between 26 and 34 weeks of *gestation*, in which periventricular white matter is particularly sensitive to insults and injury.

Abnormal development of the brain (*cerebral dysgenesis*). Any interruption of the normal process of brain growth during fetal development can cause brain malformations that interfere with the transmission of brain signals. The fetal brain is particularly vulnerable during the first 20 weeks of development. Mutations in the genes that control brain development during this early period can keep the brain from developing normally. Infections, fevers, trauma, or other conditions that cause unhealthy conditions in the womb also put an unborn baby's nervous system at risk.

Bleeding in the brain (*intracranial hemorrhage*). Intracranial hemorrhage describes bleeding inside the brain caused by blocked or broken blood vessels. A common cause of this kind of damage is fetal stroke. Some babies suffer a stroke while still in the womb because of blood clots in the *placenta* that block blood flow. Other types of fetal stroke are caused by malformed or weak blood vessels in the brain or by blood-clotting abnormalities. Maternal high blood pressure (hypertension) is a common medical disorder during pregnancy that has been known to cause fetal stroke. Maternal infection, especially *pelvic inflammatory disease*, has also been shown to increase the risk of fetal stroke.

Brain damage caused by a lack of oxygen in the brain (*hypoxic-ischemic encephalopathy* or *intrapartum asphyxia*). Asphyxia, a lack of oxygen in the brain caused by an interruption in breathing or poor oxygen supply, is common in babies due to the stress of labor and delivery. But even though a newborn's blood is equipped to compensate for short-term low levels of oxygen, if the supply of oxygen is cut off or reduced for lengthy periods, an infant can develop a type of brain damage called hypoxic-ischemic encephalopathy, which destroys tissue in the cerebral motor cortex and other areas of the brain. This kind of damage can also be caused by severe maternal low blood pressure, rupture of the uterus, detachment of the placenta, or problems involving the umbilical cord.

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What are the Risk Factors?

Just as there are particular types of brain damage that cause cerebral palsy, there are also certain medical conditions or events that can happen during pregnancy and delivery that will increase a baby's risk of being born with cerebral palsy. Research scientists have examined thousands of expectant mothers, followed them through childbirth, and monitored their children's early neurological development to establish these risk factors. If a mother or her baby has any of these risk factors, it doesn't mean that cerebral palsy is inevitable, but it does increase the chance for the kinds of brain damage that cause it.

Low birthweight and premature birth. The risk of cerebral palsy is higher among babies who weigh less than 5 ½ pounds at birth or are born less than 37 weeks into pregnancy. The risk increases as birthweight falls or weeks of gestation shorten. Intensive care for premature infants has improved dramatically over the course of the past 30 years. Babies born extremely early are surviving, but with medical problems that can put them at risk for cerebral palsy. Although normal- or heavier-weight babies are at relatively low

individual risk for cerebral palsy, term or near-term babies still make up half of the infants born with the condition.

Multiple births. Twins, triplets, and other multiple births -- even those born at term -- are linked to an increased risk of cerebral palsy. The death of a baby's twin or triplet further increases the risk.

Infections during pregnancy. Infectious diseases caused by viruses, such as toxoplasmosis, *rubella* (German measles), cytomegalovirus, and herpes, can infect the womb and placenta. Researchers currently think that maternal infection leads to elevated levels of immune system cells called *cytokines* that circulate in the brain and blood of the fetus. Cytokines respond to infection by triggering inflammation. Inflammation may then go on to cause central nervous system damage in an unborn baby. Maternal fever during pregnancy or delivery can also set off this kind of inflammatory response.

Blood type incompatibility. *Rh incompatibility* is a condition that develops when a mother's Rh blood type (either positive or negative) is different from the blood type of her baby. Because blood cells from the baby and mother mix during pregnancy, if a mother is negative and her baby positive, for example, the mother's system won't tolerate the presence of Rh-positive red blood cells. Her body will begin to make antibodies that will attack and kill her baby's blood cells. Rh incompatibility is routinely tested for and treated in the United States , but conditions in other countries continue to keep blood type incompatibility a risk factor for cerebral palsy.

Exposure to toxic substances. Mothers who have been exposed to toxic substances during pregnancy, such as methyl mercury, are at a heightened risk of having a baby with cerebral palsy.

Mothers with thyroid abnormalities, mental retardation, or seizures. Mothers with any of these conditions are slightly more likely to have a child with cerebral palsy.

There are also medical conditions during labor and delivery, and immediately after delivery, that act as warning signs for an increased risk of cerebral palsy. Knowing these warning signs helps doctors keep a close eye on children who face a higher risk. However, parents shouldn't become too alarmed if their baby has one or more of these conditions at birth. Most of these children will not develop cerebral palsy. Warning signs include:

Breech presentation. Babies with cerebral palsy are more likely to be in a breech position (feet first) instead of head first at the beginning of labor.

Complicated labor and delivery. A baby who has vascular or respiratory problems during labor and delivery may already have suffered brain damage or abnormalities.

Small for gestational age. Babies born smaller than normal for their gestational age are at risk for cerebral palsy because of factors that kept them from growing naturally in the womb.

Low *Apgar score*. The Apgar score is a numbered rating that reflects a newborn's condition. To determine an Apgar score, doctors periodically check a baby's heart rate, breathing, muscle tone, reflexes, and skin color during the first minutes after birth. They then assign points; the higher the score, the more normal a baby's condition. A low score at 10-20 minutes after delivery is often considered an important sign of potential problems such as cerebral palsy.

Jaundice. More than 50 percent of newborns develop jaundice after birth when *bilirubin*, a substance normally found in bile, builds up faster than their livers can break it down and pass it from the body. Severe, untreated jaundice can cause a neurological condition known as *kernicterus,* which kills brain cells and can cause deafness and cerebral palsy.

Seizures. An infant who has seizures faces a higher risk of being diagnosed later in childhood with cerebral palsy.

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Can Cerebral Palsy Be Prevented?

Cerebral palsy related to genetic abnormalities is not preventable, but a few of the risk factors for congenital cerebral palsy can be managed or avoided. For example, rubella, or German measles, is preventable if women are vaccinated against the disease before becoming pregnant. Rh incompatibilities

can also be managed early in pregnancy. But there are still risk factors that can't be controlled or avoided in spite of medical intervention.

For example, the use of electronic fetal monitoring machines to keep track of an unborn baby's heartbeat during labor, and the use of emergency cesarean section surgery when there are significant signs of fetal distress, haven't lowered the numbers of babies born with cerebral palsy. Interventions to treat other prenatal causes of cerebral palsy, such as therapies to prevent prenatal stroke or antibiotics to cure *intrauterine infections*, are either difficult to administer or haven't yet been proven to lower the risk of cerebral palsy in vulnerable infants.

Fortunately, acquired cerebral palsy, often due to head injury, is preventable using common safety tactics, such as using car seats for infants and toddlers, and making sure young children wear helmets when they ride bicycles. In addition, common sense measures around the household, such as supervising babies and young children closely when they bathe, can reduce the risk of accidental injury.

Despite the best efforts of parents and physicians, however, children will still be born with cerebral palsy. Since in many cases the cause or causes of cerebral palsy aren't fully known, 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 know more about how to prevent this disorder.

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What Are the Different Forms?

The specific forms of cerebral palsy are determined by the extent, type, and location of a child's abnormalities. Doctors classify cerebral palsy according to the type of movement disorder involved -- *spastic* (stiff muscles), *athetoid* (writhing movements), or *ataxic* (poor balance and coordination) -- plus any additional symptoms. Doctors will often describe the type of cerebral palsy a child has based on which limbs are affected. The names of the most common forms of cerebral palsy use Latin terms to describe the location or number of affected limbs, combined with the words for weakened *(paresis)* or paralyzed (*plegia)*. For example, *hemiparesis* (*hemi* = half) indicates that only one side of the body is weakened. *Quadriplegia* (*quad* = four) means all four limbs are paralyzed.

Spastic hemiplegia/hemiparesis. This type of cerebral palsy typically affects the arm and hand on one side of the body, but it can also include the leg. Children with spastic hemiplegia generally walk later and on tip-toe because of tight heel tendons. The arm and leg of the affected side are frequently shorter and thinner. Some children will develop an abnormal curvature of the spine (*scoliosis*). Depending on the location of the brain damage, a child with spastic hemiplegia may also have seizures. Speech will be delayed and, at best, may be competent, but intelligence is usually normal.

Spastic diplegia/diparesis. In this type of cerebral palsy, muscle stiffness is predominantly in the legs and less severely affects the arms and face, although the hands may be clumsy. Tendon reflexes are hyperactive. Toes point up. Tightness in certain leg muscles makes the legs move like the arms of a scissor. Children with this kind of cerebral palsy may require a walker or leg braces. Intelligence and language skills are usually normal.

Spastic quadriplegia/quadriparesis. This is the most severe form of cerebral palsy, often associated with moderate-to-severe mental retardation. It is caused by widespread damage to the brain or significant brain malformations. Children will often have severe stiffness in their limbs but a floppy neck. They are rarely able to walk. Speaking and being understood are difficult. Seizures can be frequent and hard to control.

***Dyskinetic* cerebral palsy (also includes athetoid, *choreoathetoid*, and *dystonic* cerebral palsies).** This type of cerebral palsy is characterized by slow and uncontrollable writhing movements of the hands, feet, arms, or legs. In some children, hyperactivity in the muscles of the face and tongue makes them grimace or drool. They find it difficult to sit straight or walk. Children may also have problems coordinating the muscle movements required for speaking. Intelligence is rarely affected in these forms of cerebral palsy.

Ataxic cerebral palsy. This rare type of cerebral palsy affects balance and depth perception. Children will often have poor coordination and walk unsteadily with a wide-based gait, placing their feet unusually far apart. They have difficulty with quick or precise movements, such as writing or buttoning a shirt. They may

also have intention tremor, in which a voluntary movement, such as reaching for a book, is accompanied by trembling that gets worse the closer their hand gets to the object.

Mixed types. It is common for children to have symptoms that don't correspond to any single type of cerebral palsy. Their symptoms are a mix of types. For example, a child with mixed cerebral palsy may have some muscles that are too tight and others that are too relaxed, creating a mix of stiffness and floppiness.

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What Other Conditions Are Associated With Cerebral Palsy?

Many individuals with cerebral palsy have no additional medical disorders. However, because cerebral palsy involves the brain and the brain controls so many of the body's functions, cerebral palsy can also cause seizures, impair intellectual development, and affect vision, hearing, and behavior. Coping with these disabilities may be even more of a challenge than coping with the motor impairments of cerebral palsy.

These additional medical conditions include:

Mental retardation. Two-thirds of individuals with cerebral palsy will be intellectually impaired. Mental impairment is more common among those with spastic quadriplegia than in those with other types of cerebral palsy, and children who have epilepsy and an abnormal *electroencephalogram* (EEG) or MRI are also more likely to have mental retardation.

Seizure disorder. As many as half of all children with cerebral palsy have seizures. Seizures can take the form of the classic convulsions of *tonic-clonic seizures* or the less obvious *focal (partial) seizures*, in which the only symptoms may be muscle twitches or mental confusion.

Delayed growth and development. 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 doctors use to describe children who lag behind in growth and development. In babies this lag usually takes the form of too little weight gain. In young children it can appear as abnormal shortness, and in teenagers it may appear as a combination of shortness and lack of sexual development.

In addition, the muscles and limbs affected by cerebral palsy tend to be smaller than normal. This is especially noticeable in children with spastic hemiplegia because limbs on the affected side of the body may not grow as quickly or as long as those on the normal side.

Spinal deformities. Deformities of the spine -- curvature (scoliosis), humpback (*kyphosis*), and saddle back (*lordosis*) -- are associated with cerebral palsy. Spinal deformities can make sitting, standing, and walking difficult and cause chronic back pain.

Impaired vision, hearing, or speech. A large number of children with cerebral palsy have *strabismus*, commonly called "cross eyes," in which the eyes are misaligned because of differences between the left and right eye muscles. In an adult, strabismus causes double vision. In children, the brain adapts to the condition by ignoring signals from one of the misaligned eyes. Untreated, this can lead to poor vision in one eye and can interfere with the ability to judge distance. In some cases, doctors will recommend surgery to realign the muscles.

Children with hemiparesis may have *hemianopia*, which is defective vision or blindness that blurs the normal field of vision in one eye. In *homonymous* hemianopia, the impairment affects the same part of the visual field in both eyes.

Impaired hearing is also more frequent among those with cerebral palsy than in the general population. Speech and language disorders, such as difficulty forming words and speaking clearly, are present in more than a third of those with cerebral palsy.

Drooling. Some individuals with cerebral palsy drool because they have poor control of the muscles of the throat, mouth, and tongue. Drooling can cause severe skin irritation. Because it is socially unacceptable, drooling may also isolate children from their peers.

Incontinence. A common complication of cerebral palsy is incontinence, caused by poor control of the

muscles that keep the bladder closed. Incontinence can take the form of bed-wetting, uncontrolled urination during physical activities, or slow leaking of urine throughout the day.

Abnormal sensations and perceptions. Some children with cerebral palsy have difficulty feeling simple sensations, such as touch. They may have *stereognosia*, which makes it difficult to perceive and identify objects using only the sense of touch. A child with stereognosia, for example, would have trouble closing his eyes and sensing the difference between a hard ball or a sponge ball placed in his hand.

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How Does a Doctor Diagnose Cerebral Palsy?

Early signs of cerebral palsy may be present from birth. Most children with cerebral palsy are diagnosed during the first 2 years of life. But if a child's symptoms are mild, it can be difficult for a doctor to make a reliable diagnosis before the age of 4 or 5. Nevertheless, if a doctor suspects cerebral palsy, he or she will most likely schedule an appointment to observe the child and talk to the parents about their child's physical and behavioral development.

Doctors diagnose cerebral palsy by evaluating a child's motor skills and taking a careful and thorough look at their medical history. In addition to checking for the most characteristic symptoms -- slow development, abnormal muscle tone, and unusual posture -- a doctor also has to rule out other disorders that could cause similar symptoms. Most important, a doctor has to determine that the child's condition is not getting worse. Although symptoms may change over time, cerebral palsy by definition is not progressive. If a child is continuously losing motor skills, the problem more likely begins elsewhere – such as a genetic or muscle disease, metabolism disorder, or tumors in the nervous system. A comprehensive medical history, special diagnostic tests, and, in some cases, repeated check-ups can help confirm that other disorders are not at fault.

Additional tests are often used to rule out other movement disorders that could cause the same symptoms as cerebral palsy. Neuroimaging techniques that allow doctors to look into the brain (such as an MRI scan) can detect abnormalities that indicate a potentially treatable movement disorder. If it is cerebral palsy, an MRI scan can also show a doctor the location and type of brain damage.

Neuroimaging methods include:

- **Cranial *ultrasound.*** This test is used for high-risk premature infants because it is the least intrusive of the imaging techniques, although it is not as successful as the two methods described below at capturing subtle changes in white matter – the type of brain tissue that is damaged in cerebral palsy.
- ***Computed tomography (CT) scan.*** This technique creates images that show the structure of the brain and the areas of damage.
- ***Magnetic resonance imaging (MRI) scan.*** This test uses a computer, a magnetic field, and radio waves to create an anatomical picture of the brain's tissues and structures. Doctors prefer MRI imaging because it offers finer levels of detail.

On rare occasions, metabolic disorders can masquerade as cerebral palsy and some children will require additional tests to rule them out. Most of the childhood metabolic disorders have characteristic brain abnormalities or malformations that will show up in an MRI.

Other types of disorders can also be mistaken for cerebral palsy. For example, coagulation disorders (which prevent blood from clotting) can cause prenatal or perinatal strokes that damage the brain and cause symptoms characteristic of cerebral palsy. Because stroke is so often the cause of hemiplegic cerebral palsy, a doctor may find it necessary to perform diagnostic testing on children with this kind of cerebral palsy to rule out the presence of a coagulation disorder. If left undiagnosed, coagulation disorders can cause additional strokes and more extensive brain damage.

To confirm a diagnosis of cerebral palsy, a doctor may refer a child to additional doctors with specialized knowledge and training, such as a child neurologist, developmental pediatrician, ophthalmologist (eye doctor), or otologist (ear doctor). Additional observations help a doctor make a more accurate diagnosis and begin to develop a specific plan for treatment.

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How is Cerebral Palsy Managed?

Cerebral palsy can't be cured, but treatment will often improve a child's capabilities. Many children go on to enjoy near-normal adult lives if their disabilities are properly managed. In general, the earlier treatment begins, the better chance children have of overcoming developmental disabilities or learning new ways to accomplish the tasks that challenge them.

There is no standard therapy that works for every individual with cerebral palsy. Once the diagnosis is made, and the type of cerebral palsy is determined, a team of health care professionals will work with a child and his or her parents to identify specific impairments and needs, and then develop an appropriate plan to tackle the core disabilities that affect the child's quality of life.

A comprehensive management plan will pull in a combination of health professionals with expertise in the following:

physical therapy to improve walking and gait, stretch spastic muscles, and prevent deformities;

occupational therapy to develop compensating tactics for everyday activities such as dressing, going to school, and participating in day-to-day activities;

speech therapy to address swallowing disorders, speech impediments, and other obstacles to communication;

counseling and behavioral therapy to address emotional and psychological needs and help children cope emotionally with their disabilities;

drugs to control seizures, relax muscle spasms, and alleviate pain;

surgery to correct anatomical abnormalities or release tight muscles;

braces and other orthotic devices to compensate for muscle imbalance, improve posture and walking, and increase independent mobility;

mechanical aids such as wheelchairs and rolling walkers for individuals who are not independently mobile; and

communication aids such as computers, voice synthesizers, or symbol boards to allow severely impaired individuals to communicate with others.

Doctors use tests and evaluation scales to determine a child's level of disability, and then make decisions about the types of treatments and the best timing and strategy for interventions. Early intervention programs typically provide all the required therapies within a single treatment center. Centers also focus on parents' needs, often offering support groups, babysitting services, and *respite care*.

The members of the treatment team for a child with cerebral palsy will most likely include the following:

A **physician**, such as a pediatrician, pediatric neurologist, or pediatric physiatrist, who is trained to help developmentally disabled children. This doctor, who often acts as the leader of the treatment team, integrates the professional advice of all team members into a comprehensive treatment plan, makes sure the plan is implemented properly, and follows the child's progress over a number of years.

An **orthopedist**, a surgeon who specializes in treating the bones, muscles, tendons, and other parts of the skeletal system. An orthopedist is often brought in to diagnose and treat muscle problems associated with cerebral palsy.

A **physical therapist**, who designs and puts into practice special exercise programs to improve strength and functional mobility.

An **occupational therapist,** who teaches the skills necessary for day-to-day living, school, and work.

A **speech and language pathologist,** who specializes in diagnosing and treating disabilities relating to

difficulties with swallowing and communication.

A **social worker,** who helps individuals and their families locate community assistance and education programs.

A **psychologist,** who helps individuals 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.

An **educator,** who may play an especially important role when mental retardation or learning disabilities present a challenge to education.

Regardless of age or the types of therapy that are used, treatment doesn't end when an individual with cerebral palsy leaves the treatment center. Most of the work is done at home. Members of the treatment team often act as coaches, giving parents and children techniques and strategies to practice at home. Studies have shown that family support and personal determination are two of the most important factors in helping individuals with cerebral palsy reach their long-term goals.

While mastering specific skills is an important focus of treatment on a day-to-day basis, the ultimate goal is to help children grow into adulthood with as much independence as possible.

As a child with cerebral palsy grows older, the need for therapy and the kinds of therapies required, as well as support services, will likely change. 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 help finding attendants to care for them, a place to live, a job, and a way to get to their place of employment.

Addressing the needs of parents and caregivers is also an important component of the treatment plan. The well-being of an individual with cerebral palsy depends upon the strength and well-being of his or her family. For parents to accept a child's disabilities and come to grips with the extent of their caregiving responsibilities will take time and support from health care professionals. Family-centered programs in hospitals and clinics and community-based organizations usually work together with families to help them make well-informed decisions about the services they need. They also coordinate services to get the most out of treatment.

A good program will encourage the open exchange of information, offer respectful and supportive care, encourage partnerships between parents and the health care professionals they work with, and acknowledge that although medical specialists may be the experts, it's parents who know their children best.

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What Specific Treatments Are Available?

Physical therapy, usually begun in the first few years of life or soon after the diagnosis is made, is a cornerstone of cerebral palsy treatment. Physical therapy programs use specific sets of exercises and activities to work toward two important goals: preventing weakening or deterioration in the muscles that aren't being used (*disuse atrophy*), and keeping muscles from becoming fixed in a rigid, abnormal position (*contracture*).

Resistive exercise programs (also called strength training) and other types of exercise are often used to increase muscle performance, especially in children and adolescents with mild cerebral palsy. Daily bouts of exercise keep muscles that aren't normally used moving and active and less prone to wasting away. Exercise also reduces the risk of contracture, one of the most common and serious complications of cerebral palsy.

Normally growing children stretch their muscles and tendons as they run, walk, and move through their daily activities. This insures that their muscles grow at the same rate as their bones. But in children with cerebral palsy, spasticity prevents muscles from stretching. As a result, their muscles don't grow fast enough to keep up with their lengthening bones. The muscle contracture that results can set back the gains in function they've made. Physical therapy alone or in combination with special braces (called *orthotic devices*) helps prevent contracture by stretching spastic muscles.

Occupational therapy. This kind of therapy focuses on optimizing upper body function, improving posture, and making the most of a child's mobility. An occupational therapist helps a child master the basic activities of daily living, such as eating, dressing, and using the bathroom alone. Fostering this kind of independence boosts self-reliance and self-esteem, and also helps reduce demands on parents and caregivers.

Recreational therapies. Recreational therapies, such as therapeutic horseback riding (also called hippotherapy), are sometimes used with mildly impaired children to improve gross motor skills. Parents of children who participate in recreational therapies usually notice an improvement in their child's speech, self-esteem, and emotional well-being.

Controversial physical therapies. "Patterning" is a physical therapy based on the principle that children with cerebral palsy should be taught motor skills in the same sequence in which they develop in normal children. In this controversial approach, the therapist begins by teaching a child elementary movements such as crawling -- regardless of age – before moving on to walking skills. 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.

Experts have similar reservations about the Bobath technique (which is also called "neurodevelopmental treatment"), named for a husband and wife team who pioneered the approach in England . In this form of physical therapy, instructors inhibit abnormal patterns of movement and encourage more normal movements.

The Bobath technique has had a widespread influence on the core physical therapies of cerebral palsy treatment, but there is no evidence that the technique improves motor control. The American Academy of Cerebral Palsy and Developmental Medicine reviewed studies that measured the impact of neurodevelopmental treatment and concluded that there was no strong evidence supporting its effectiveness for children with cerebral palsy.

Conductive education, developed in Hungary in the 1940s, is another physical therapy that at one time appeared to hold promise. Conductive education instructors attempt to improve a child's motor abilities by combining rhythmic activities, such as singing and clapping, with physical maneuvers on special equipment. The therapy, however, has not been able to produce consistent or significant improvements in study groups.

Speech and language therapy. About 20 percent of children with cerebral palsy are unable to produce intelligible speech. They also experience challenges in other areas of communication, such as hand gestures and facial expressions, and they have difficulty participating in the basic give and take of a normal conversation. These challenges will last throughout their lives.

Speech and language therapists (also known as speech therapists or speech-language pathologists) observe, diagnose, and treat the communication disorders associated with cerebral palsy. They use a program of exercises to teach children how to overcome specific communication difficulties.

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. Other kinds of exercises help children master the social skills involved in communicating by teaching them to keep their head up, maintain eye contact, and repeat themselves when they are misunderstood.

Speech therapists can also help children with severe disabilities learn how to use special communication devices, such as a computer with a voice synthesizer, or a special board covered with symbols of everyday objects and activities to which a child can point to indicate his or her wishes.

Speech interventions often use a child's family members and friends to reinforce the lessons learned in a therapeutic setting. This kind of indirect therapy encourages people who are in close daily contact with a child to create opportunities for him or her to use their new skills in conversation.

Treatments for problems with eating and drooling are often necessary when children with cerebral palsy have difficulty eating and drinking because they have little control over the muscles that move their mouth, jaw, and tongue. They are also at risk for breathing food or fluid into the lungs. Some children develop *gastroesophageal reflux disease* (GERD, commonly called heartburn) in which a weak diaphragm

can't keep stomach acids from spilling into the esophagus. The irritation of the acid can cause bleeding and pain.

Individuals with cerebral palsy are also at risk for malnutrition, recurrent lung infections, and progressive lung disease. The individuals most at risk for these problems are those with spastic quadriplegia.

Initially, children should be evaluated for their swallowing ability, which is usually done with a modified barium swallow study. Recommendations regarding diet modifications will be derived from the results of this study.

In severe cases where swallowing problems are causing malnutrition, a doctor 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.

Although numerous treatments for drooling have been tested over the years, there is no one treatment that helps reliably. *Anticholinergic drugs* – such as glycopyrolate -- can reduce the flow of saliva but may cause unpleasant side effects, such as dry mouth, constipation, and urinary retention. Surgery, while sometimes effective, carries the risk of complications. Some children benefit from biofeedback techniques that help them recognize more quickly when their mouths fall open and they begin to drool. Intraoral devices (devices that fit into the mouth) that encourage better tongue positioning and swallowing are still being evaluated, but appear to reduce drooling for some children.

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Drug Treatments

Oral medications such as diazepam, baclofen, dantrolene sodium, and tizanidine are usually used as the first line of treatment to relax stiff, contracted, or overactive muscles. These drugs are easy to use, except that dosages high enough to be effective often have side effects, among them drowsiness, upset stomach, high blood pressure, and possible liver damage with long-term use. Oral medications are most appropriate for children who need only mild reduction in muscle tone or who have widespread spasticity.

Doctors also sometimes use alcohol "washes" -- injections of alcohol into muscles -- to reduce spasticity. The benefits last from a few months to 2 years or more, but the adverse effects include a significant risk of pain or numbness, and the procedure requires a high degree of skill to target the nerve.

The availability of new and more precise methods to deliver antispasmodic medications is moving treatment for spasticity toward *chemodenervation*, in which injected drugs are used to target and relax muscles.

Botulinum toxin **(BT-A)**, injected locally, has become a standard treatment for overactive muscles in children with spastic movement disorders such as cerebral palsy. BT-A relaxes contracted muscles by keeping nerve cells from over-activating muscle. Although BT-A is not approved by the Food and Drug Administration (FDA) for treating cerebral palsy, since the 1990s doctors have been using it *off-label* to relax spastic muscles. A number of studies have shown that it reduces spasticity and increases the range of motion of the muscles it targets.

The relaxing effect of a BT-A injection lasts approximately 3 months. Undesirable side effects are mild and short-lived, consisting of pain upon injection and occasionally mild flu-like symptoms. BT-A injections are most effective when followed by a stretching program including physical therapy and splinting. BT-A injections work best for children who have some control over their motor movements and have a limited number of muscles to treat, none of which is fixed or rigid.

Because BT-A does not have FDA approval to treat spasticity in children, parents and caregivers should make sure that the doctor giving the injection is trained in the procedure and has experience using it in children.

Intrathecal baclofen therapy uses an implantable pump to deliver baclofen, a muscle relaxant, into the fluid surrounding the spinal cord. Baclofen works by decreasing the excitability of nerve cells in the spinal cord, which then reduces muscle spasticity throughout the body. Because it is delivered directly into the nervous system, the intrathecal dose of baclofen can be as low as one one-hundredth of the oral dose. Studies have shown it reduces spasticity and pain and improves sleep.

The pump is the size of a hockey puck and is implanted in the abdomen. It contains a refillable reservoir connected to an alarm that beeps when the reservoir is low. The pump is programmable with an electronic *telemetry wand*. The program can be adjusted if muscle tone is worse at certain times of the day or night.

The baclofen pump carries a small but significant risk of serious complications if it fails or is programmed incorrectly, if the catheter becomes twisted or kinked, or if the insertion site becomes infected. Undesirable, but infrequent, side effects include overrelaxation of the muscles, sleepiness, headache, nausea, vomiting, dizziness, and constipation.

As a muscle-relaxing therapy, the baclofen pump is most appropriate for individuals with chronic, severe stiffness or uncontrolled muscle movement throughout the body. Doctors have successfully implanted the pump in children as young as 3 years of age.

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Surgery

Orthopedic surgery is often recommended when spasticity and stiffness are severe enough to make walking and moving about difficult or painful. For many people with cerebral palsy, improving the appearance of how they walk – their gait – is also important. A more upright gait with smoother transitions and foot placements is the primary goal for many children and young adults.

In the operating room, surgeons can lengthen muscles and tendons that are proportionately too short. But first, they have to determine the specific muscles responsible for the gait abnormalities. Finding these muscles can be difficult. It takes more than 30 major muscles working at the right time using the right amount of force to walk two strides with a normal gait. A problem with any of those muscles can cause an abnormal gait.

In addition, because the body makes natural adjustments to compensate for muscle imbalances, these adjustments could appear to be the problem, instead of a compensation. In the past, doctors relied on clinical examination, observation of the gait, and the measurement of motion and spasticity to determine the muscles involved. Now, doctors have a diagnostic technique known as *gait analysis*.

Gait analysis uses cameras that record how an individual walks, force plates that detect when and where feet touch the ground, a special recording technique that detects muscle activity (known as *electromyography*), and a computer program that gathers and analyzes the data to identify the problem muscles. Using gait analysis, doctors can precisely locate which muscles would benefit from surgery and how much improvement in gait can be expected.

The timing of orthopedic surgery has also changed in recent years. Previously, orthopedic surgeons preferred to perform all of the necessary surgeries a child needed at the same time, usually between the ages of 7 and 10. Because of the length of time spent in recovery, which was generally several months, doing them all at once shortened the amount of time a child spent in bed. Now most of the surgical procedures can be done on an outpatient basis or with a short inpatient stay. Children usually return to their normal lifestyle within a week.

Consequently, doctors think it is much better to stagger surgeries and perform them at times appropriate to a child's age and level of motor development. For example, spasticity in the upper leg muscles (the adductors), which causes a "scissor pattern" walk, is a major obstacle to normal gait. The optimal age to correct this spasticity with adduction release surgery is 2 to 4 years of age. On the other hand, the best time to perform surgery to lengthen the hamstrings or Achilles tendon is 7 to 8 years of age. If adduction release surgery is delayed so that it can be performed at the same time as hamstring lengthening, the child will have learned to compensate for spasticity in the adductors. By the time the hamstring surgery is performed, the child's abnormal gait pattern could be so ingrained that it might not be easily corrected.

With shorter recovery times and new, less invasive surgical techniques, doctors can schedule surgeries at times that take advantage of a child's age and developmental abilities for the best possible result.

Selective dorsal rhizotomy (SDR) is a surgical procedure recommended only for cases of severe spasticity when all of the more conservative treatments – physical therapy, oral medications, and intrathecal baclofen -- have failed to reduce spasticity or chronic pain. In the procedure, a surgeon locates

and selectively severs overactivated nerves at the base of the spinal column.

Because it reduces the amount of stimulation that reaches muscles via the nerves, SDR is most commonly used to relax muscles and decrease chronic pain in one or both of the lower or upper limbs. It is also sometimes used to correct an overactive bladder. Potential side effects include sensory loss, numbness, or uncomfortable sensations in limb areas once supplied by the severed nerve.

Even though the use of microsurgery techniques has refined the practice of SDR surgery, there is still controversy about how selective SDR actually is. Some doctors have concerns since it is invasive and irreversible and may only achieve small improvements in function. Although recent research has shown that combining SDR with physical therapy reduces spasticity in some children, particularly those with spastic diplegia, whether or not it improves gait or function has still not been proven. Ongoing research continues to look at this surgery's effectiveness.

Spinal cord stimulation was developed in the 1980s to treat spinal cord injury and other neurological conditions involving motor neurons. An implanted electrode selectively stimulates nerves at the base of the spinal cord to inhibit and decrease nerve activity. The effectiveness of spinal cord stimulation for the treatment of cerebral palsy has yet to be proven in clinical studies. It is considered a treatment alternative only when other conservative or surgical treatments have been unsuccessful at relaxing muscles or relieving pain.

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Orthotic Devices

Orthotic devices – such as braces and splints – use external force to correct muscle abnormalities. The technology of orthotics has advanced over the past 30 years from metal rods that hooked up to bulky orthopedic shoes, to appliances that are individually molded from high-temperature plastics for a precise fit. Ankle-foot orthoses are frequently prescribed for children with spastic diplegia to prevent muscle contracture and to improve gait. Splints are also used to correct spasticity in the hand muscles.

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Assistive Technology

Devices that help individuals move about more easily and communicate successfully at home, at school, or in the workplace can help a child or adult with cerebral palsy overcome physical and communication limitations. There are a number of devices that help individuals stand straight and walk, such as postural support or seating systems, open-front walkers, quadrupedal canes (lightweight metal canes with four feet), and gait poles. Electric wheelchairs let more severely impaired adults and children move about successfully.

The computer is probably the most dramatic example of a communication device that can make a big difference in the lives of people with cerebral palsy. Equipped with a computer and voice synthesizer, a child or adult with cerebral palsy can communicate successfully with others. For example, a child who is unable to speak or write but can make head movements may be able to control a computer using a special light pointer that attaches to a headband.

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Alternative Therapies

Therapeutic (subthreshold) electrical stimulation, also called neuromuscular electrical stimulation (NES), pulses electricity into the motor nerves to stimulate contraction in selective muscle groups. Many studies have demonstrated that NES appears to increase range of motion and muscular strength.

Threshold electrical stimulation, which involves the application of electrical stimulation at an intensity too low to stimulate muscle contraction, is a controversial therapy. Studies have not been able to demonstrate its effectiveness or any significant improvement with its use.

Hyperbaric oxygen therapy. Some children have cerebral palsy as the result of brain damage from oxygen deprivation. Proponents of hyperbaric oxygen therapy propose that the brain tissue surrounding the damaged area can be "awakened" by forcing high concentrations of oxygen into the body under greater than atmospheric pressure.

A recent study compared a group of children who received no hyperbaric treatment to a group that received 40 treatments over 8 weeks. On every measure of function (gross motor, cognitive, communication, and memory) at the end of 2 months of treatment and after a further 3 months of follow up, the two groups were identical in outcome. There was no added benefit from hyperbaric oxygen therapy.

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Are There Treatments for Other Conditions Associated with Cerebral Palsy?

Epilepsy. Twenty to 40 percent of children with mental retardation and cerebral palsy also have epilepsy. Doctors usually prescribe medications to control seizures. The classic medications for this purpose are phenobarbital, phenytoin, carbamazepine, and valproate. Although these drugs generally are effective in controlling seizures, their use is hampered by harmful or unpleasant side effects.

Treatment for epilepsy has advanced significantly with the development of new medications that have fewer side effects. These drugs include felbamate, gabapentin, lamotrigine, levetiracetam, oxcarbazepine, tiagabine, topiramate, vigabatrin, and zonisamide.

In general, drugs are prescribed based on the type of seizures an individual experiences, since no one drug controls all types. Some individuals may need a combination of two or more drugs to achieve good seizure control.

Incontinence. Medical treatments for incontinence include special exercises, biofeedback, prescription drugs, surgery, or surgically implanted devices to replace or aid muscles. Specially designed absorbent undergarments can also be used to protect against accidental leaks.

Osteopenia. Children with cerebral palsy who aren't able to walk risk developing poor bone density (osteopenia), which makes them more likely to break bones. In a study of older Americans funded by the National Institutes of Health (NIH), a family of drugs called *bisphosphonates*, which was recently approved by the FDA to treat mineral loss in elderly patients, also appeared to increase bone mineral density. Doctors may choose to selectively prescribe the drug off-label to children to prevent osteopenia.

Pain. Pain can be a problem for people with cerebral palsy due to spastic muscles and the stress and strain on parts of the body that are compensating for muscle abnormalities. Some individuals may also have frequent and irregular muscle spasms that can't be predicted or medicated in advance.

Doctors often prescribe diazepam to reduce the pain associated with muscle spasms, but it's not known exactly how the drug works to interfere with pain signals. The drug gabapentin has been used successfully to decrease the severity and frequency of painful spasms. BT-A injections have also been shown to decrease spasticity and pain, and are commonly given under anesthesia to avoid the pain associated with the injections. Intrathecal baclofen has shown good results in reducing pain, but its delivery is invasive, time intensive, and expensive.

Some children and adults have been able to decrease pain by using noninvasive and drug-free interventions such as distraction, relaxation training, biofeedback, and therapeutic massage.

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Do Adults with Cerebral Palsy Face Special Health Challenges?

Before the mid-twentieth century, few children with cerebral palsy survived to adulthood. Now, because of improvements in medical care, rehabilitation, and assistive technologies, 65 to 90 percent of children with cerebral palsy live into their adult years. This increase in life expectancy is often accompanied by a rise in medical and functional problems – some of them beginning at a relatively early age – including the following:

Premature aging. The majority of individuals with cerebral palsy will experience some form of premature aging by the time they reach their 40s because of the extra stress and strain the disease puts upon their bodies. The developmental delays that often accompany cerebral palsy keep some organ systems from developing to their full capacity and level of performance. As a consequence, organ systems such as the cardiovascular system (the heart, veins, and arteries) and pulmonary system (lungs) have to work harder and they age prematurely.

Functional issues at work. The day-to-day challenges of the workplace are likely to increase as an employed individual with cerebral palsy reaches middle age. Some individuals will be able to continue working with accommodations such as an adjusted work schedule, assistive equipment, or frequent rest periods. Early retirement may be necessary for others.

Depression. Mental health issues can also be of concern as someone with cerebral palsy grows older. The rate of depression is three to four times higher in people with disabilities such as cerebral palsy. It appears to be related not so much to the severity of their disabilities, but to how well they cope with them. The amount of emotional support someone has, how successful they are at coping with disappointment and stress, and whether or not they have an optimistic outlook about the future all have a significant impact on mental health.

Post-impairment syndrome. Most adults with cerebral palsy experience what is called *post-impairment syndrome*, a combination of pain, fatigue, and weakness due to muscle abnormalities, bone deformities, *overuse syndromes* (sometimes also called repetitive motion injuries), and arthritis. Fatigue is often a challenge, since individuals with cerebral palsy use three to five times the amount of energy that able-bodied people use when they walk and move about.

Osteoarthritis and degenerative arthritis. Musculoskeletal abnormalities that may not produce discomfort during childhood can cause pain in adulthood. For example, the abnormal relationships between joint surfaces and excessive joint compression can lead to the early development of painful osteoarthritis and degenerative arthritis. Individuals with cerebral palsy also have limited strength and restricted patterns of movement, which puts them at risk for overuse syndromes and *nerve entrapments*.

Pain. Issues related to pain often go unrecognized by health care providers since individuals with cerebral palsy may not be able to describe the extent or location of their pain. Pain can be acute or chronic, and is experienced most commonly in the hips, knees, ankles, and the upper and lower back. Individuals with spastic cerebral palsy have an increased number of painful sites and worse pain than those with other types of cerebral palsy. The best treatment for pain due to musculoskeletal abnormalities is preventive – correcting skeletal and muscle abnormalities early in life to avoid the progressive accumulation of stress and strain that causes pain. Dislocated hips, which are particularly likely to cause pain, can be surgically repaired. If it is managed properly, pain does not have to become a chronic condition.

Other medical conditions. Adults have higher than normal rates of other medical conditions secondary to their cerebral palsy, such as hypertension, incontinence, bladder dysfunction, and swallowing difficulties. Curvature of the spine (scoliosis) is likely to progress after puberty, when bones have matured into their final shape and size. People with cerebral palsy also have a higher incidence of bone fractures, occurring most frequently during physical therapy sessions. A combination of mouth breathing, poor hygiene, and abnormalities in tooth enamel increase the risk of cavities and periodontal disease. Twenty-five percent to 39 percent of adults with cerebral palsy have vision problems; eight to 18 percent have hearing problems.

Because of their unique medical situations, adults with cerebral palsy benefit from regular visits to their doctor and ongoing evaluation of their physical status. It is important to evaluate physical complaints to make sure they are not the result of underlying conditions. For example, adults with cerebral palsy are likely to experience fatigue, but fatigue can also be due to undiagnosed medical problems that could be treated and reversed.

Because many individuals with cerebral palsy outlive their primary caregiver, the issue of long-term care and support should be taken into account and planned for.

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What Research Is Being Done?

Investigators from many fields of medicine and health are using their expertise to help improve the treatment and diagnosis of cerebral palsy. Much of their work is supported through the NINDS, the National Institute of Child Health and Human Development (NICHD), other agencies within the federal government, nonprofit groups such as the United Cerebral Palsy Research and Educational Foundation, and other private institutions.

The ultimate hope for curing cerebral palsy rests with prevention. In order to prevent cerebral palsy, however, scientists have to understand normal fetal brain development so that they can understand what

happens when a baby's brain develops abnormally.

Between conception and the birth of a baby, one cell divides to form a handful of cells, and then hundreds, millions, and, eventually, billions of cells. Some of these cells specialize to become brain cells, and then specialize even further into particular types of neurons that travel to their appropriate place in the brain (a process that scientists call *neuronal migration*). Once they are in the right place, they establish connections with other brain cells. This is how the brain develops and becomes able to communicate with the rest of the body -- through overlapping neural circuits made up of billions of interconnected and interdependent neurons.

Many scientists now think that a significant number of children develop cerebral palsy because of mishaps early in **brain development**. They are examining how brain cells specialize and form the right connections, and they are looking for ways to prevent the factors that disrupt the normal processes of brain development.

Genetic defects are sometimes responsible for the brain malformations and abnormalities that cause cerebral palsy. Scientists funded by the NINDS are searching for the genes responsible for these abnormalities by collecting DNA samples from people with cerebral palsy and their families and using genetic screening techniques to discover linkages between individual genes and specific types of abnormality – primarily those associated with abnormal neuronal migration.

Scientists are scrutinizing events in newborn babies' brains, such as bleeding, epileptic seizures, and breathing and circulation problems, which can cause the **abnormal release of chemicals** that trigger the kind of damage that causes cerebral palsy. For example, research has shown that bleeding in the brain unleashes dangerously high amounts of a brain chemical called glutamate. Although glutamate is necessary in the brain to help neurons communicate, too much glutamate overexcites and kills neurons. Scientists are now looking closely at glutamate to detect how its release harms brain tissue. By learning how brain chemicals that are normally helpful become dangerously toxic, scientists will have opportunities to develop new drugs to block their harmful effects.

Scientists funded by the NINDS are also investigating whether **substances in the brain that protect neurons from damage**, called *neurotrophins*, could be used to prevent brain damage as a result of stroke or oxygen deprivation. Understanding how these *neuroprotective* substances act would allow scientists to develop synthetic neurotrophins that could be given immediately after injury to prevent neuron death and damage.

The relationship between **uterine infections during pregnancy** and the risk of cerebral palsy continues to be studied by researchers funded by the NIH. There is evidence that uterine infections trigger inflammation and the production of immune system cells called cytokines, which can pass into an unborn baby's brain and interrupt normal development. By understanding what cytokines do in the fetal brain and the type of damage these immune system cells cause, researchers have the potential to develop medications that could be given to mothers with uterine infections to prevent brain damage in their unborn children.

Approximately 10 percent of newborns are born prematurely, and of those babies, more than 10 percent will have **brain injuries** that will lead to cerebral palsy and other brain-based disabilities. A particular type of damage to the white matter of the brain, called periventricular leukomalacia (PVL), is the predominant form of brain injury in premature infants. NINDS-sponsored researchers studying PVL are looking for new strategies to prevent this kind of damage by developing safe, nontoxic therapies delivered to at-risk mothers to protect their unborn babies.

Although congenital cerebral palsy is a condition that is present at birth, a year or two can pass before any disabilities are noticed. Researchers have shown that the earlier rehabilitative treatment begins, the better the outcome for children with cerebral palsy. But an **early diagnosis** is hampered by the lack of diagnostic techniques to identify brain damage or abnormalities in infants.

Research funded by the NINDS is using imaging techniques, devices that measure electrical activity in the brain, and neurobehavioral tests to predict those preterm infants who will develop cerebral palsy. If these screening techniques are successful, doctors will be able to identify infants at risk for cerebral palsy before they are born.

Noninvasive methods to record the brain activity of unborn babies in the womb and to identify those with brain damage or abnormalities would also be a valuable addition to the diagnostic tool kit. Another NINDS-

funded study focuses on the development of fetal magnetoencephalography (fMEG) – a technology that would allow doctors to look for abnormalities in fetal brain activity.

Epidemiological studies – studies that look at the distribution and causes of disease among people -- help scientists understand **risk factors** and outcomes for particular diseases and medical conditions. Researchers have established that preterm birth (when a baby is born before 32 weeks' gestation) is the highest risk factor for cerebral palsy. Consequently, the increasing rate of premature births in the United States puts more babies at risk. A large, long-term study funded by the NIH is following a group of more than 400 mothers and their infants born between 24 and 31 weeks' gestation. They are looking for relationships between preterm birth, maternal uterine infection, fetal exposure to infection, and short-term and long-term health and neurological outcomes. The researchers are hoping to discover environmental or lifestyle factors, or particular characteristics of mothers, which might protect preterm babies from neurological disabilities.

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 valid information to help them 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 rhizotomy, a surgical technique that is increasingly being used to reduce spasticity (see Surgery).

Similarly, although physical therapy programs are used almost universally to rehabilitate children with cerebral palsy, there are no definitive studies to indicate which techniques work best. For example, constraint-induced therapy (CIT) is a type of physical therapy that has been used successfully with adult stroke survivors and individuals who have traumatic brain injury and are left with a weak or disabled arm on one side of the body. The therapy involves restraining the stronger arm in a cast and forcing the weaker arm to perform 6 hours of intensive "shaping" activities every day over the course of 3 weeks. The researchers who conducted the clinical trials in adult stroke survivors realized CIT's potential for strengthening children's arms weakened by cerebral palsy.

In a randomized, controlled study of children with cerebral palsy funded by the NIH, researchers put one group of children through conventional physical therapy and another group through 21 consecutive days of CIT. Researchers looked for evidence of improvement in the movement and function of the disabled arm, whether the improvement lasted after the end of treatment, and if it was associated with significant gains in other areas, such as trunk control, mobility, communication, and self-help skills.

Children receiving CIT outperformed the children receiving conventional physical therapy across all measures of success, including how well they could move their arms after therapy and their ability to do new tasks during the study and then at home with their families. Six months later they still had better control of their arm. The results from this study are the first to prove the benefits of a physical therapy. Additional research to determine the optimal length and intensity of CIT will allow doctors to add this therapy to the cerebral palsy treatment toolbox.

Studies have shown that **functional electrical stimulation** is an effective way to target and strengthen spastic muscles, but the method of delivering the electrical pulses requires expensive, bulky devices implanted by a surgeon, or skin surface stimulation applied by a trained therapist. NINDS-funded researchers have developed a high-tech method that does away with the bulky apparatus and lead wires by using a hypodermic needle to inject microscopic wireless devices into specific muscles or nerves. The devices are powered by a telemetry wand that can direct the number and strength of their pulses by remote control. The device has been used to activate and strengthen muscles in the hand, shoulder, and ankle in people with cerebral palsy as well as in stroke survivors.

As researchers continue to explore new treatments for cerebral palsy and to expand our knowledge of brain development, we can expect significant improvements in the care of children with cerebral palsy and many other disorders that strike in early life.

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Where can I get more information?

For more information on 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
http://www.ninds.nih.gov

Information also is available from the following organizations:

United Cerebral Palsy (UCP)
1660 L Street, NW
Suite 700
Washington, DC 20036
national@ucp.org
http://www.ucp.org
Tel: 202-776-0406 800-USA-5UCP (872-5827)
Fax: 202-776-0414
Works to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities, through our commitment to the principles of independence, inclusion and self-determination.

Pathways Awareness
150 N. Michigan Avenue
Suite 2100
Chicago, IL 60601
friends@pathwaysawareness.org
http://www.pathwaysawareness.org
Tel: 800-955-CHILD (2445)
Fax: 312-893-6621
National non-profit organization trusted to assure the best for all babies' physical development by raising awareness about the gift of early detection, the promise of early therapy, and the benefits of tummy time. Trusted to assure the best for all babies physical development.

March of Dimes
1275 Mamaroneck Avenue
White Plains, NY 10605
askus@marchofdimes.com
http://www.marchofdimes.com
Tel: 914-997-4488 888-MODIMES (663-4637)
Fax: 914-428-8203
Works to improve the health of babies by preventing birth defects and infant mortality through programs of research, community services, education, and advocacy.

Easter Seals
233 South Wacker Drive
Suite 2400
Chicago, IL 60606
info@easterseals.com
http://www.easterseals.com
Tel: 312-726-6200 800-221-6827
Fax: 312-726-1494
Provides services to help children and adults with disabilities and/or special needs as well as support to their families. Supports the National AgrAbility Project, a program for farmers, ranchers, and farm workers with disabilities.

Children's Neurobiological Solutions (CNS) Foundation
909 E. 1st Street
#12
Long Beach, CA 90802
info@cnsfoundation.org
http://www.cnsfoundation.org
Tel: 866-CNS-5580 (267-5580) 562- 331-0642
National, non-profit organization whose mission is to accelerate the development of brain repair therapies and cures by supporting cutting-edge collaborative research on brain damage due to childhood illness, injury, or any other cause. Provides information and resources for families and health care providers.

Children's Hemiplegia and Stroke Assocn. (CHASA)
4101 West Green Oaks Blvd., Ste. 305
PMB 149
Arlington, TX 76016
info437@chasa.org
http://www.chasa.org
Tel: 817-492-4325
CHASA is a 501(c)(3) nonprofit organization dedicated to improving the lives of children and families affected by pediatric stroke and other causes of hemiplegia. Offers national family retreat, local family events and seminars, online support group, websites, fact sheets, clinical study information, and pediatric stroke awareness campaigns.

Cerebral Palsy International Research Foundation
1025 Connecticut Avenue
Suite 701
Washington, DC 20036
nmaher@cpirf.org
http://www.cpirf.org
Tel: 202-496-5060
Provides grants for research and training on causes and prevention of cerebral palsy and on improving the quality of life of persons with cerebral palsy.

Pedal with Pete [For Research on Cerebral Palsy]
P.O. Box 274
Kent, OH 44240
petezeid@aol.com
http://www.pedalwithpete.com
Tel: 800-304-PETE (7383)
Fax: 330-673-1240
Nonprofit organization dedicated to raising money for research to improve the quality of life for those with cerebral palsy. Aim is to help in the fight for the prevention, treatment and cure of cerebral palsy.

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Glossary

acquired cerebral palsy — cerebral palsy that occurs as a result of injury to the brain after birth or during early childhood.

Apgar score — a numbered scoring system doctors use to assess a baby's physical state at the time of birth.

anticholinergic drugs — a family of drugs that inhibit parasympathetic neural activity by blocking the neurotransmitter acetylcholine.

asphyxia — a lack of oxygen due to trouble with breathing or poor oxygen supply in the air.

ataxia (ataxic) — the loss of muscle control.

athetoid — making slow, sinuous, involuntary, writhing movements, especially with the hands.

bilirubin — a bile pigment produced by the liver of the human body as a byproduct of digestion.

bisphosphonates — a family of drugs that strengthen bones and reduce the risk of bone fracture in elderly adults.

botulinum toxin — a drug commonly used to relax spastic muscles; it blocks the release of acetylcholine, a neurotransmitter that energizes muscle tissue.

cerebral — relating to the two hemispheres of the human brain.

cerebral dysgenesis — defective brain development.

chemodenervation — a treatment that relaxes spastic muscles by interrupting nerve impulse pathways via a drug, such as botulinum toxin, which prevents communication between neurons and muscle tissue.

choreoathetoid — a condition characterized by aimless muscle movements and involuntary motions.

computed tomography (CT) scan — an imaging technique that uses X-rays and a computer to create a picture of the brain's tissues and structures.

congenital cerebral palsy — cerebral palsy that is present at birth from causes that have occurred during fetal development.

contracture — a condition in which muscles become fixed in a rigid, abnormal position, which causes distortion or deformity.

cytokines — messenger cells that play a role in the inflammatory response to infection.

developmental delay — behind schedule in reaching the milestones of early childhood development.

disuse atrophy — muscle wasting caused by the inability to flex and exercise muscles.

dyskinetic — the impairment of the ability to perform voluntary movements, which results in awkward or incomplete movements.

dystonia **(dystonic)** a condition of abnormal muscle tone.

electroencephalogram (EEG) — a technique for recording the pattern of electrical currents inside the brain.

electromyography — a special recording technique that detects muscle activity.

failure to thrive — a condition characterized by a lag in physical growth and development.

focal (partial) seizure — a brief and temporary alteration in movement, sensation, or autonomic nerve function caused by abnormal electrical activity in a localized area of the brain.

gait analysis — a technique that uses cameras, force plates, electromyography, and computer analysis to objectively measure an individual's pattern of walking.

gastroesophageal reflux disease (GERD) — also known as heartburn, which happens when stomach acids back up into the esophagus.

gastrostomy — a surgical procedure that creates an artificial opening in the stomach for the insertion of a feeding tube.

gestation — the period of fetal development from the time of conception until birth.

hemianopia — defective vision or blindness that impairs half of the normal field of vision.

hemiparesis — paralysis affecting only one side of the body.

homonymous — having the same description, name, or term.

hypertonia — increased muscle tone.

hypotonia — decreased muscle tone.

hypoxic-ischemic encephalopathy — brain damage caused by poor blood flow or insufficient oxygen supply to the brain.

intracranial hemorrhage — bleeding in the brain.

intrapartum asphyxia — the reduction or total stoppage of oxygen circulating in a baby's brain during labor and delivery.

intrathecal baclofen — baclofen that is injected into the cerebrospinal fluid of the spinal cord to reduce spasticity.

intrauterine infection — infection of the uterus, ovaries, or fallopian tubes (see ***pelvic inflammatory disease*** for a more detailed explanation).

jaundice — a blood disorder caused by the abnormal buildup of bilirubin in the bloodstream.

kernicterus — a neurological syndrome caused by deposition of bilirubin into brain tissues. Kernicterus develops in extremely jaundiced infants, especially those with severe Rh incompatibility.

kyphosis — a humpback-like outward curvature of the upper spine.

lordosis — an increased inward curvature of the lower spine.

magnetic resonance imaging (MRI) — an imaging technique that uses radio waves, magnetic fields, and computer analysis to create a picture of body tissues and structures.

nerve entrapment — repeated or prolonged pressure on a nerve root or peripheral nerve.

neuronal migration — the process in the developing brain in which neurons migrate from where they are born to where they settle into neural circuits. Neuronal migration, which occurs as early as the second month of gestation, is controlled in the brain by chemical guides and signals.

neuroprotective — describes substances that protect nervous system cells from damage or death.

neurotrophins — a family of molecules that encourage survival of nervous system cells.

off-label drugs — drugs prescribed to treat conditions other than those that have been approved by the Food and Drug Administration.

orthotic devices — special devices, such as splints or braces, used to treat posture problems involving the muscles, ligaments, or bones.

osteopenia — reduced density and mass of the bones.

overuse syndrome (also called repetitive strain injury) — a condition in which repetitive movements or

constrained posture cause nerve and muscle damage, which results in discomfort or persistent pain in muscles, tendons, and other soft tissues. This can happen in various parts of the body, but is most likely to happen in the arms, legs, or hands.

palsy — paralysis, or the lack of control over voluntary movement.

-paresis or ***-plegia*** — weakness or paralysis. In cerebral palsy, these terms are typically combined with other phrases that describe the distribution of paralysis and weakness; for example, quadriplegia means paralysis of all four limbs.

pelvic inflammatory disease (**PID**, also sometimes called *pelvic infection* or *intrauterine infection*) — an infection of the upper genital tract (the uterus, ovaries, and fallopian tubes) caused by sexually transmitted infectious microorganisms. Symptoms of PID include fever, foul-smelling vaginal discharge, abdominal pain and pain during intercourse, and vaginal bleeding. Many different organisms can cause PID, but most cases are associated with gonorrhea and chlamydia.

periventricular leukomalacia (PVL) — "peri" means near; "ventricular" refers to the ventricles or fluid spaces of the brain; and "leukomalacia" refers to softening of the white matter of the brain. PVL is a condition in which the cells that make up white matter die near the ventricles. Under a microscope, the tissue looks soft and sponge-like.

placenta — an organ that joins a mother with her unborn baby and provides nourishment and sustenance.

post-impairment syndrome — a combination of pain, fatigue, and weakness due to muscle abnormalities, bone deformities, overuse syndromes, or arthritis.

quadriplegia — paralysis of both the arms and legs.

respite care — rest or relief from caretaking obligations.

Rh incompatibility — a blood condition in which antibodies in a pregnant woman's blood attack fetal blood cells and impair an unborn baby's supply of oxygen and nutrients.

rubella — (also known as German measles) a viral infection that can damage the nervous system of an unborn baby if a mother contracts the disease during pregnancy.

scoliosis — a disease of the spine in which the spinal column tilts or curves to one side of the body.

selective dorsal rhizotomy — a surgical procedure in which selected nerves are severed to reduce spasticity in the legs.

selective vulnerability — a term that describes why some neurons are more vulnerable than others to particular diseases or conditions. For example, motor neurons are selectively vulnerable to the loss or reduction in levels of the neurotransmitter dopamine, which results in the weakness and paralysis of amyotrophic lateral sclerosis (ALS, commonly called Lou Gehrig's disease).

spastic (or ***spasticity***) — describes stiff muscles and awkward movements.

spastic diplegia (or ***diparesis***) — a form of cerebral palsy in which spasticity affects both legs, but the arms are relatively or completely spared.

spastic hemiplegia (or ***hemiparesis***) — a form of cerebral palsy in which spasticity affects an arm and leg on one side of the body.

spastic quadriplegia (or ***quadriparesis***) — a form of cerebral palsy in which all four limbs are paralyzed or weakened equally.

stereognosia — difficulty perceiving and identifying objects using the sense of touch.

strabismus — misalignment of the eyes, also known as cross eyes.

telemetry wand — a hand-held device that acts as a remote control, directing the dosing level of a drug

via a pump implanted beneath the skin.

tonic-clonic seizure — a type of seizure that results in loss of consciousness, generalized convulsions, loss of bladder control, and tongue biting followed by confusion and lethargy when the convulsions end.

tremor — an involuntary trembling or quivering.

ultrasound — a technique that bounces sound waves off tissue and bone and uses the pattern of echoes to form an image, called a sonogram.

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"Cerebral Palsy: Hope Through Research," NINDS. Publication date December 2009.

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See a list of all NINDS Disorders

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