



# **CEREBRAL PALSY**

## A MESSAGE OF HOPE FOR ILLINOIS FAMILIES

A WHITE PAPER PRESENTED BY

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# WHAT YOU NEED TO KNOW AFTER YOUR BABY RECEIVES A DIAGNOSIS OF CEREBRAL PALSY

A white paper presented by the medical malpractice trial lawyers of  
Cirignani, Heller & Harman, LLP

A diagnosis of cerebral palsy means a significant change for your family. You probably want to find out as much as you can about the condition to answer the following questions:

*What will the diagnosis mean for your child's future?*

*How severe are your child's symptoms?*

*Why did this happen to your child?*

**We want you to know there is hope.** In our white paper, you will learn more about the condition, its causes and its symptoms. We have also compiled a checklist for raising a child with cerebral palsy, which may include legal action as part of advocating for your child's best interests. At the end of the white paper, you will find a list of groups and associations that may be able to provide you with additional resources to help your child.

# THERAPY AND TECHNOLOGY EXPAND OPPORTUNITIES

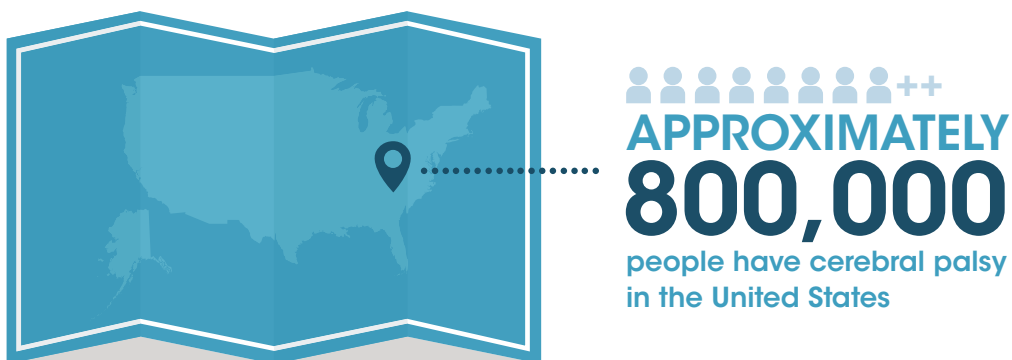
Many people with cerebral palsy live typical lives and go to school, have fulfilling careers, get married, have children and maintain their own homes. As your child grows, he or she can develop the skills and abilities needed to be as independent as possible through physical, occupational and speech therapy.

Modern technology has opened up new ways for children with cerebral palsy to keep pace with their peers in terms of social, emotional and cognitive development. For example, specialized computers can provide a voice for children who cannot speak, while powered wheelchairs provide independent mobility for those who cannot walk. Meanwhile, anti-discrimination laws help to level the playing field for people with cerebral palsy and other disabilities.

Today, kids with cerebral palsy routinely attend school in mainstream classrooms with the help of a caregiver. The expanded treatment and mobility options now available offer a better opportunity for a satisfying and productive life than in past decades, when institutional care was the norm. As you learn about your child's needs and begin preparing him or her for school, you are likely to discover supportive communities that will rally around you and help you along. The resource list at the end of this white paper is a good starting point to help you identify some of the communities and organizations that provide support and advocacy for children with cerebral palsy and their families.

# WHAT IS CEREBRAL PALSY?

Cerebral palsy is the most common childhood disability affecting motor skills. According to the United Cerebral Palsy Foundation, almost 800,000 children and adults live with cerebral palsy in the United States. Each year, approximately 10,000 babies are born with the condition, or approximately three of every 1,000 births.

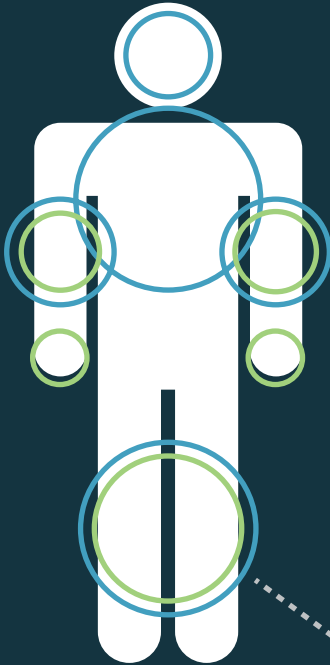


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*Cerebral* refers to the brain and *palsy* means a problem using muscles. The term describes a group of disorders caused when the pathways of communication within the brain are damaged. Thus, cerebral palsy is the result of some form of early brain injury and can occur both before and after birth while the brain is still developing.

Although cerebral palsy primarily affects muscle function, it can sometimes cause mental or cognitive impairments as well. For example, conditions such as autism, attention deficit hyperactivity disorder (ADHD) and learning disabilities are sometimes associated with cerebral palsy. However, mental impairments that occur on their own, without physical disabilities, are unlikely to be the result of cerebral palsy.

## THERE ARE THREE MAIN TYPES OF **CEREBRAL PALSY**



### ● **SPASTIC CEREBRAL PALSY**

The word spastic refers to stiff muscles that are permanently contracted. This can affect different parts of the body. Spastic diplegia mostly affects the legs, while spastic quadriplegia affects all the limbs, the torso and the face.

### ● **DYSKINETIC CEREBRAL PALSY**

Includes problems with moving hands, arms and legs, along with slower movements or sometimes rapid and jerky movements



### ● **ATAXIC CEREBRAL PALSY**

Characterized by a lack of balance and poor coordination

Some children can have a combination of more than one type of cerebral palsy. Learning the medical terminology for your child's condition is the first step to better understanding its severity.

# WHAT CAUSES THE CONDITION?

A lack of oxygen (asphyxia) to the brain during labor or just after birth is one cause of cerebral palsy. Symptoms of birth asphyxia are not always obvious, but may include:



**An abnormal fetal heart rate along with a low pH level (indicating there is too much acid in the blood) at the time of delivery**




**A low heart rate, pale skin color, gasping or weak breathing at birth**

However, oxygen deprivation at birth does not always result in cerebral palsy. Some babies who experience substantial hypoxia do not suffer any identifiable brain injury at all.


## OTHER CAUSES OF CEREBRAL PALSY INCLUDE:




**Genetic abnormalities** – Hereditary disorders or genetic abnormalities may affect the way the brain develops.



**Fetal stroke** – During pregnancy, fetal brain development may be disrupted by an interruption of blood flow or bleeding into the brain.



**Head injuries** – A baby's brain may be injured as a result of head trauma after birth, for instance, due to a car accident or fall.



**Infections** – If the mother develops an infection during pregnancy, it can sometimes damage the infant's delicate brain tissues. Similarly, certain infections such as bacterial meningitis and viral encephalitis can occur after birth, causing inflammation in or around a young child's developing brain.

Sometimes, signs of cerebral palsy may not be recognizable until a baby fails to reach certain developmental milestones.



## SIGNS SOMETHING MIGHT BE WRONG

Because children develop at their own pace, reaching a milestone later than expected does not necessarily mean a child has cerebral palsy; it only indicates there is a possibility. Doctors will look for other signs like stiff or loose limbs and may suggest radiological tests such as MRIs, CT scans and cranial ultrasound.

No two children with cerebral palsy are affected in exactly the same way, and doctors generally cannot predict exactly how the condition will affect your child. In less severe cases, a cerebral palsy diagnosis might have only a small effect on a child's ability to engage in everyday activities. In the most serious cases, a child might need special equipment to walk or may not walk at all. Some children may need lifelong care, while others will be able to live independently once they reach adulthood.

You may wonder about the day-to-day complications that a child with cerebral palsy will face. In addition to pain and possible mental impairment, the most common complications of cerebral palsy include:

-  **DIFFICULTY WALKING AND TALKING**
-  **POOR MOTOR SKILLS THAT AFFECT ACTIVITIES LIKE WRITING OR CUTTING WITH SCISSORS**
-  **SLEEP DISORDERS**
-  **IMPAIRED VISION OR HEARING**
-  **EPILEPSY**
-  **BEHAVIOR DISORDERS**
-  **BLADDER CONTROL ISSUES**

It may take until your child is 2 or 3 years old to fully understand the extent of his or her disabilities. As your child's needs become clearer, physical, occupational and speech therapy along with special education can address those needs and lead to improvements in key areas.



# RAISING A CHILD WITH CEREBRAL PALSY

You may wonder how to move forward in raising and advocating for your child. As a parent, you expect to help your child navigate challenging moments and celebrate his or her accomplishments. A diagnosis of cerebral palsy is an additional hurdle, but does not change this. At first, it can seem intimidating, but the more you can learn about your child’s condition and make connections with others who understand cerebral palsy, the more confident you will feel as an advocate for your child. Here is a checklist with four steps to get you started.



## 1. Keep Medical Records and Develop a Care Plan

When you have worries about your child’s development, the first step is to speak with a pediatrician. Follow-up conversations may be required, especially if you notice your baby’s condition seems to be worsening. Keep your child’s medical records so you understand his or her diagnosis and can advocate for the appropriate medical care.

Developing a care plan with your child’s pediatrician will often involve assembling a team of care professionals. The team may include:



An orthopedic physician

*Consult on muscle or bone problems*



A physical therapist

*Design exercise programs to strengthen muscles*



An occupational therapist

*Assist in learning daily living skills*



A speech therapist

*Aid your child in communication*



Early intervention is the best way to improve your child's quality of life, so it is important to take action right away when you notice unusual behavior or lack of muscle control. The sooner you start, the more you can do for your child.



## **2. Research Insurance and Financial Support Options**

The lifetime medical care costs for a child with cerebral palsy can be staggering. A good insurance policy will cover many of those costs, but you will need to research the potential out-of-pocket costs, coverage limits and available network of medical providers.

Government aid may also be available to help you make sure your child's needs are met. To ensure you are taking advantage of all of the resources available to you, it is a good idea to find out about any aid and services available from your state, the federal government and nonprofit organizations.



### **3. Find Support Groups and Start Building Your Network**

There are many support groups across the country for parents raising children with cerebral palsy. Other families in similar circumstances can be an excellent resource and are often able to answer your questions based on their own experience. It is important to know you are not alone. Others have successfully navigated the challenges your family faces.

Cerebral palsy support groups may offer suggestions about local educational and social services, as well as the types of therapies that have worked for them. It is important to form a strong supportive network for you and your child. The support of family, friends and your community can help bridge the gaps — especially in those moments when you feel “stretched thin.” Take some time to review the list of resources at the end of this paper; they are a great starting place to develop your own support network.



### **4. Take Legal Action**

Cerebral palsy is not always caused by medical negligence. There are many cases in which the cause may be genetics, an infection or simply unknown.

To determine whether your child’s cerebral palsy was caused by a medical mistake, speak with a medical malpractice attorney. An experienced attorney can start a thorough investigation and review of your child’s medical records, with the assistance of medical experts who understand the standard of care involved and can determine whether that standard was met.



Medical mistakes that lead to cerebral palsy often relate to timing or a failure to call in a specialist when one is needed. During delivery, a delay in responding to signs of fetal distress or a failure to properly monitor the administration of the labor-inducing drug Pitocin can result in harm to the infant. Mistakes that occur after birth can also constitute medical negligence. This may occur, for example, when a dangerous condition such as bacterial meningitis is overlooked or misdiagnosed and leads to cerebral palsy.

When a child is diagnosed with cerebral palsy, it can be an overwhelming experience. You may wonder about your ability to provide for your child and to ensure he or she is well-cared for in the years to come.

If medical negligence contributed to your child's brain injury, there may be financial resources available through the civil legal system to help set your mind at ease and plan for your child's future. Medical costs are estimated based on a life-care plan that accounts for specialists, therapy, personal attendants, hospital bills, surgery, medicine and equipment to help your child function as well as possible throughout his or her life. Monetary damages may also be available to help offset your child's lost or reduced opportunity to earn wages and to compensate for pain and suffering.

# ADVOCATING FOR YOUR CHILD

You set the tone for your child's treatment in medical, educational and extracurricular settings. While similar in many ways to typical parenting, being the parent of a child with cerebral palsy can be more complex and demanding.

At first, it may be hard to tell what will or will not work for you and your family, and there will most likely be some trial and error involved. Over time, however, you will discover which therapies and treatments work best for your child, and this will guide you in finding ways to improve his or her care and opportunities.

**Remember you are your child's most important advocate.** No one knows your child better than you do, and no one is in a better position to make final decisions about his or her care. This is especially important to keep in mind when working with your child's health care providers to develop a care plan. Be sure to speak up and ask clarifying questions.

It is also important you take time to consider your schedule, flexibility and financial resources when implementing a plan to meet your child's special needs and you are prepared for those needs to change over time. As you monitor your child's schedule and the effectiveness of different therapies, you may find some things work better than others. As an advocate for your child, you need to speak up when concerns arise. Your insights and observations may help open new possibilities for your child.



You may never have expected to find yourself in the position of advocate, but the efforts you make on behalf of your child, your family and others can help improve the lives of kids with cerebral palsy and those who love them.

# A FINAL MESSAGE OF HOPE FOR PARENTS OF KIDS WITH CEREBRAL PALSY

Currently there is no cure for cerebral palsy, but this has not stopped parents from helping their children maximize their potential. They are constantly finding new ways to help their children beat the odds. By embracing technology and advances in therapy, many of their children are engaging in hobbies, playing sports, holding jobs and achieving many other exciting goals. Even with some of the most severe cases of cerebral palsy, parents are helping their children reach their potential and, in some cases, exceed the initial assessments of their doctors.

Embracing their role as advocates, parents discover they can do more than just meet their child's basic needs; they help them achieve greater independence and a better quality of life. These advocate parents have helped enact laws that prevent discrimination and provide for greater accessibility to jobs and housing. Consequently, this work on behalf of their children has paved the way for them and other children with cerebral palsy to have lifelong opportunities and greater inclusion in their communities. They are giving their children the best opportunities for a successful, happy life.



# ORGANIZATIONS THAT CAN PROVIDE MORE RESOURCES:

## **United Cerebral Palsy (UCP)**

1825 K St. NW  
Suite 600  
Washington, DC 20006  
info@ucp.org  
www.ucp.org  
Tel: 202-776-0406  
800-USA-5UCP(872-5827)  
Fax: 202-776-0414

## **Reaching for the Stars**

3000 Old Alabama Road  
Suite 119 – 300  
Alpharetta, GA 30022  
info@reachingforthestars.org  
http://reachingforthestars.org  
Tel: 855-240-7387

## **Pedal-with-Pete Foundation [for Research on Cerebral Palsy]**

P.O. Box 1233  
Worthington, OH 43085  
pwp@pedal-with-pete.org  
www.pedal-with-pete.org  
Tel: 614-527-0202  
Fax: 330-673-1240

## **March of Dimes**

1275 Mamaroneck Avenue  
White Plains, NY 10605  
askus@marchofdimes.com  
www.marchofdimes.com  
Tel: 914-997-4488  
888-MODIMES (663-4637)  
Fax: 914-428-8203

## **Pathways Awareness**

150 N. Michigan Avenue  
Suite 2100  
Chicago, IL 60601  
friends@pathwaysawareness.org  
www.pathwaysawareness.org  
Tel: 800-955-CHILD (2445)  
Fax: 312-893-6621

## **National Institute of Child Health and Human Development (NICHD)**

National Institutes of Health,  
DHHS  
31 Center Drive, Room 2A32  
MSC 2425  
Bethesda, MD 20892-2425  
www.nichd.nih.gov  
Tel: 301-496-5133  
Fax: 301-496-7101

## **Children's Neurobiological Solutions (CNS) Foundation**

1223 Wilshire Blvd., Suite 937  
Santa Monica, CA 90403  
info@cnsfoundation.org  
www.cnsfoundation.org  
Tel: (310) 889-8611

## **Easter Seals**

233 South Wacker Drive  
Suite 2400  
Chicago, IL 60606  
info@easterseals.com  
www.easterseals.com  
Tel: 312-726-6200 800-221-6827  
Fax: 312-726-1494

## **Cerebral Palsy International Research Foundation**

445 Park Avenue  
9th Floor  
New York, NY 10022  
cpirf@cpirf.org  
www.cpirf.org  
Tel: 212-836-4756

## **Children's Hemiplegia and Stroke Asscn. (CHASA)**

4101 West Green Oaks Blvd.  
Suite 305  
PMB 149  
Arlington, TX 76016  
info437@chasa.org  
www.chasa.org  
Tel: 817-492-4325

# SOURCES

<sup>1</sup> Centers for Disease Control and Prevention: Cerebral Palsy. <http://www.cdc.gov/ncbddd/cp/features/vt> (page last updated October 2013).

<sup>2</sup> United Cerebral Palsy, Each of Us Remembers, Parents of Children With Cerebral Palsy Answer Your Questions, 2013.

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