

The RFTS Mission: Changing the Future of Cerebral Palsy

Cerebral Palsy Facts

- **Cerebral Palsy is one of the most common developmental disabilities in the United States, affecting at least 800,000 children, adolescents and adults in America.** Cerebral Palsy is NOT a disease. It is not even a simple or single disorder but rather a broad range of disorders that disrupt a person's ability to move, sit, stand, walk, talk and use their hands. The severity of the movement disorder and the type of movement difficulties can vary greatly. Some patients have only mild difficulties with balance, walking and fine motor skills while patients at the other extreme are completely trapped in their own bodies, fighting rigid limbs, and unable to speak or swallow.
- **Most (75%) of individuals with Cerebral Palsy also have one or more additional developmental disabilities** including epilepsy, mental retardation, autism and visual impairments or blindness.
- **Individuals with cerebral palsy are at high risk for secondary complications such as muscle atrophy, joint contractures, bony deformities, fractures, and scoliosis and chronic pain.**
- **In the majority of cases (>80%) the cause of Cerebral Palsy is still unknown.** Cerebral Palsy results from an injury to the brain during development and this injury can occur during pregnancy, around the time of birth or anytime within the first two years of life. Major risk factors for cerebral palsy include prematurity and low birth weight. In some cases a clear cause such as meningitis, hemorrhage, infection or trauma can be identified. Contrary to popular belief, only a small percentage of Cerebral Palsy is caused by birth "asphyxia" (lack of oxygen at the time of birth).
- **There is currently no cure for Cerebral Palsy and in most cases, it is not preventable.** In over 50 years, treatments for Cerebral Palsy have not progressed much at all. In fact, today, there remains little consensus among medical professionals regarding what causes CP or how best to treat it. Why does one premature baby develop CP and another doesn't? Why are there so many cases of twins (including genetically identical twins) where one has CP and one doesn't or where each twin has a different type of CP, despite being exposed to the exact same conditions in-utero? Why do 800,000 or more Americans have CP, and yet we don't know much more about what causes it or how to prevent it than we did a half century ago?
- **Cerebral Palsy is INCREASING in this country.** Despite the introductions of modern prenatal testing, improved obstetric care, and newborn intensive care technologies, the prevalence of Cerebral Palsy is not declining, and appears to be increasing in many parts of the country. Although the national prevalence of CP is not known, recent estimates from the surveillance studies in Atlanta indicate that its prevalence is now 3 per 1,000 live births and on par with the prevalence rates for Autism. *In contrast, the prevalence of CP is significantly lower and is declining in other countries such as Sweden (1.9 per 1,000).*

- **Living with Cerebral Palsy is EXPENSIVE.** The economic impact of Cerebral Palsy is enormous. Most children and adults with Cerebral Palsy need long-term services or medical care. ***The average lifetime cost for just one person with cerebral palsy is estimated to be well over \$1,500,000 above and beyond the cost of living for an average U.S. citizen*** – including doctor visits, therapy, surgeries, prescriptions, hospital stays, durable medical equipment, prescription drugs, orthotic equipment, education/home/car modifications, and so on. A family's personal resources and private insurance shoulder a portion of the burden when possible, however federal and state governments in the form of Medicaid and other social services currently absorb much of this cost.

It is estimated that the lifetime care and medical costs for all people with cerebral palsy who were born in 2000 alone will total over \$13.5 billion. Investigating the cause of Cerebral Palsy will significantly reduce the cost – to society, the government and to the hundreds of thousands of families impacted across the U.S. – as ways to prevent CP are uncovered.

- **Cerebral Palsy research is severely under-funded.**
RFTS supports the CDC's efforts regarding birth defects and developmental disabilities. We also support the efforts of the "*Best Pharmaceuticals For Children Act*" and efforts by the NIH, especially research to understand brain development and injury. These efforts have resulted in new scientific interest in Cerebral Palsy and in new treatments to treat CP patients beyond drug therapies. However, research funding is severely limited for CP compared to the number of American children and adults impacted by it.

An analysis of CDC and NIH expenditures on diseases that affect a number of people similar to that affected by Cerebral Palsy shows a great disparity in spending. In fact, spending on some of these disorders, even those that affect far fewer people, is many times the amount allocated for Cerebral Palsy surveillance and research.

- **There is currently no national surveillance research for Cerebral Palsy.**
However, an infrastructure does exist through the Centers for Disease Control and Prevention (CDC), which have established major surveillance systems for Autism and Mental Retardation around the U.S.

The Centers for Disease Control and Prevention (CDC) reports the **prevalence of Cerebral Palsy in children is higher than childhood cancer, hearing and vision loss, spina bifida, hemophilia, fetal alcohol syndrome, cystic fibrosis – and similar to the prevalence of autistic disorder in 8-year-old children** – yet no comparable national surveillance study of Cerebral Palsy exists.

Summary of the Problem:

CP's prevalence is underestimated and underreported in the US, exacts a tremendous human toll of suffering, is severely under funded from a research perspective and places a staggering financial burden on our health care system.

RFTS: Parents Seeking A Solution:

We support national CP surveillance and epidemiological research in order to better understand how to prevent and identify causes of damage to the developing brain. In late 2004, a national group of committed parents and family members of children with Cerebral Palsy, concerned that little progress has been made to treat or cure CP, organized to form “*Reaching For The Stars. A Foundation Of Hope For Children With Cerebral Palsy*” (www.reachingforthestars.org), the only parent-led, national non-profit education and research foundation for pediatric Cerebral Palsy.

Through RFTS advocacy efforts of parents and caretakers uniting together, Cerebral Palsy is beginning to come to more national awareness. In fact, many national organizations have written letters stating their support of RFTS and our efforts regarding the need for the national CP surveillance and epidemiological research by the Centers of Disease Control and Prevention (CDC) including the *United Cerebral Palsy Education and Research Foundation, The Child Neurology Society and the American Academy of Cerebral Palsy and Developmental Medicine.*

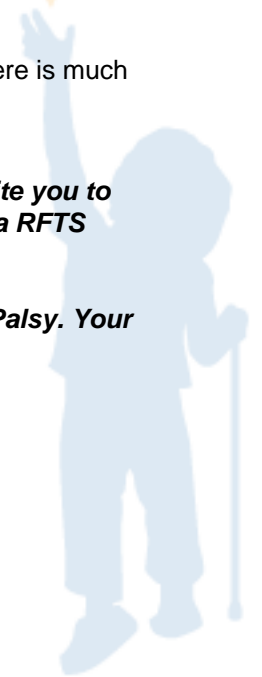
We want a cure for Cerebral Palsy. The only way this will happen is to better understand the risk factors for CP, what causes CP, if certain ethnic groups are more susceptible and why there are different clusters of prevalence and types of CP in different parts of the country and world. The only way to begin to answer these questions is through national CDC surveillance.

National surveillance and epidemiological research by the CDC will bolster basic science research efforts through the NIH, and assist scientists and the medical community to develop more effective strategies for the prevention and treatment of CP - much like the remarkable progress that has been made with Autism, Spina Bifida, Epilepsy and Cystic Fibrosis.

Cerebral Palsy is a complex problem leaving many feeling overwhelmed and hopeless. There is much that needs to be done and so many children that need help. But there is hope.

On behalf of the over 800,000 impacted children and families across the U.S., we invite you to join our efforts – whether it’s to join our mailing list, write a letter to Congress, start a RFTS chapter, help fundraise, or raise awareness in your community.

Please make a difference to change the future for children and adults with Cerebral Palsy. Your one voice will make a difference.



How to Contact Us

Please contact us and let us know what you think, ideas you may have, or if you would like to help. You may call, email or write to us. Thank you for helping to spread the word.

National Contact Information

RFTS, Inc.
3000 Old Alabama Road
Suite 119-300
Alpharetta, GA 30022
Phone: (770) 561-5950

Anna Marie Champion
achampion@reachingforthestars.org

Cynthia Gray
cgray@reachingforthestars.org

Illinois Chapter Contact Information

RFTS, Inc.
P.O. Box 113
Kenilworth, IL 60043

Melissa Siebert
msiebert@reachingforthestars.org

