

The Need For National Cerebral Palsy Surveillance - Testimony before the House Subcommittee on Labor, Health and Human Services, Education, and Related Agencies - Committee on Appropriations

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Mr. Chairman and Members of the Committee:

Thank you for allowing me to speak to you today on behalf of the more than three-quarters of a million Americans with Cerebral Palsy, and their families. My name is Dr. Janice Brunstrom, or “Dr. Jan” as my patients and their parents call me. Together with the thousands of parents affiliated with “Reaching For The Stars. A Foundation Of Hope For Children With Cerebral Palsy” (www.reachingforthestars.org), I ask you to help us change the course of the future for children, adolescents and adults with Cerebral Palsy from one of uncertainty to one of Hope.

You can do this by urging and funding the CDC to establish a national CP surveillance program that will provide crucial insights into this group of disorders, yield improved treatments, help prevent secondary complications and bolster the research efforts at the NIH so that we may someday prevent and even cure Cerebral Palsy.

My expertise in Cerebral Palsy is both professional and personal. I am a pediatric neurologist, an Assistant Professor of Neurology, Pediatrics and Cell Biology for the Washington University School of Medicine and Director of the Pediatric Neurology Cerebral Palsy Center for St. Louis Children’s Hospital. *Our CP Center enrolled its first patient on June 1st 1998 and now helps an estimated 2,000 children from across the United States and around the world to become more independent and productive members of society and to participate fully in all aspects of life.* I am an NIH funded neuroscientist investigating mechanisms of prenatal brain development. I am a clinical research scientist developing and testing new treatment strategies for children with cerebral palsy. I am a mother and I am a woman with Cerebral Palsy.

My cerebral palsy is due to complications associated with prematurity and low birth weight. I was born three months prematurely (29 weeks gestation) weighing about 3 pounds. 43 years ago my parents were told I would not survive. The experts also predicted I would never walk or talk and that I would have mental retardation. Thankfully, by the grace of God, the experts were wrong.

Unfortunately in the four decades since my birth, 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. There is no cure. Why does one premature baby develop CP and another doesn’t? Why do I see many cases of twins (including genetically identical twins) where one has CP and one doesn’t? Or each twin has a different type of CP, despite being exposed to the exact same conditions in utero? **Why do more than 800,000 Americans have CP, and yet we don’t know much more about what causes it or how to prevent it than we did the day I was born?**

CP 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, 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.

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 Americans with CP 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: Mr. Chairman, I would be remiss if I did not thank you and the Subcommittee for your leadership in supporting the CDC's efforts regarding birth defects and developmental disabilities, which has included local surveillance in Atlanta for Cerebral Palsy. I also thank the committee for your ongoing support of the NIH, especially research to understand brain development and injury. However, I must raise the point that research funding is severely limited for CP compared to the number of American children and adults impacted by it.

Disease/Condition	# US Citizens Affected	NIH Funding 2005
Muscular Dystrophy	250,000	\$40,000,000
Cooley's Anemia	518 in 1993	\$42,000,000
Multiple Sclerosis	400,000	\$110,000,000
Childhood Leukemia	1 in 29,000	\$60,000,000
Cystic Fibrosis	30,000	\$89,000,000
West Nile Virus	15,000 since 1999	\$43,000,000
Cerebral Palsy	800,000	\$23,000,000

** Source: NIH 2005

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 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 spectrum disorder in 8-year-old children** – yet no comparable national surveillance study of Cerebral Palsy exists.

Disease/Condition	# US Citizens Affected	CDC Funding 2005
Spina Bifida	70,000	\$5,104,000
Hemophilia	17,000	\$21,380,000
West Nile Virus	15,000 since 1999	\$40,446,000
Fetal Alcohol Syndrome	.8 per 1000 live births	\$12,598,000
Chronic Fatigue Syndrome (base funding)	500,000	\$6,822,000
Cerebral Palsy	800,000	\$0

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.

PARENTS SEEKING A SOLUTION:

We support national CP surveillance 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 virtually no progress has been made to treat or cure CP in the last 50 years and that there is no national CP surveillance and epidemiological research being conducted, organized to form "*Reaching For The Stars. A*

Foundation Of Hope For Children With Cerebral Palsy” (www.reachingforthestars.org). I am a medical advisor to their board.

Through these grassroots advocacy efforts, the issue of Cerebral Palsy is beginning to come to more national awareness. In fact, many national organizations have written letters stating their support for the need for the national CP surveillance and epidemiological research we are recommending, as well as supporting our recommended report language, including the *United Cerebral Palsy Education and Research Foundation, The Child Neurology Society and the American Academy of Cerebral Palsy and Developmental Medicine.*

****THERE IS HOPE WITH YOUR HELP! THERE IS SOMETHING YOU CAN DO****

We are asking Congress to add Cerebral Palsy to the CDC-funded surveillance infrastructure that is already in place.

- The Centers for Disease Control and Prevention (CDC) has established major surveillance systems for Autism and Mental Retardation around the U.S.

We ask Congress to take all steps necessary to request that the CDC establish Cerebral Palsy surveillance and epidemiology sites throughout the US and that Congress allocate \$10,000,000 to ensure that this happens in 2007.

- \$10MM will fund approximately 10 sites across the country and should be based both upon methodology developed in Atlanta via the CDC's studies in the MADDs and the MADDSP surveillance systems for Cerebral Palsy, and also based upon methods that should be developed to include both sophisticated imaging, genetics and clinical evaluations.
- The CDC should build upon the infrastructure already established for Autism and **establish surveillance/epidemiology/clinical research centers for Cerebral Palsy.**

CONCLUSION

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.

Basic 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 so much that needs to be done and so many children that need help. **But it doesn't need to be hopeless.** At our Cerebral Palsy Center we work with many, many children who are challenging the dogma and beating the odds every day. They are working very hard and they are learning to do the impossible -- like walk and talk. They are using computer technology and voice activated software to gain access to classrooms and enter a world once “off limits” to them. They are playing sports, having fun and living life.

These children are learning to dream big dreams for their future and some aspire to become doctors, teachers, parents and Congressional leaders! My first step in helping them was to change

their perception about themselves and to teach them to **stop listening to “can’t and “never”** and to start saying **“I’ll try.”**

I believe we CAN change the future for these children if we all work together and do our part. I believe we CAN cure these disorders someday.

On behalf of the over 800,000 impacted children and families across the country, I am asking for your support to ensure the CDC establishes a national Cerebral Palsy Surveillance Program to change the future for children and adults with these disorders.

Mr. Chairman and members of the subcommittee, I thank you so very much for the opportunity to speak to you today and for your time and attention to this urgent matter.

Dr. Jan

For more information please visit www.reachingforthestars.org

RFTS, Inc. is a world-class research foundation started by, and for, the parents of children with Cerebral Palsy centered on the belief that leading-edge pediatric research can lead to prevention and new treatments of CP while delivering measurable improvements in the lives of impacted children and their families.

Launched in 2004, RFTS, Inc. is a tax-exempt, national non profit organization, committed to driving research to serve the needs of children with Cerebral Palsy and those parents and care givers involved in their care.