Chairman Kingston, and Distinguished Members of the Committee:

Thank you for allowing us to speak on *National Cerebral Palsy Awareness Day* on behalf of the more than 800,000 Americans and 17,000,000 people worldwide with Cerebral Palsy. My name is Cynthia Frisina and I am the mother of a daughter with Cerebral Palsy. I am also the Executive Director of *"Reaching for the Stars. A Foundation of Hope for Children with Cerebral Palsy"*, the largest pediatric Cerebral Palsy nonprofit foundation in the world led by parent volunteers. With me is Dr. Lisa Thornton, Executive Board member of "*Reaching for the Stars*" and the *American Academy for Cerebral Palsy and Developmental Medicine*.

Today we ask Congress to take all steps necessary to establish a two-prong National Cerebral Palsy Research Initiative.

1. Allocate $10 million in dedicated federal funding for CDC to conduct research into the causation and prevalence of Cerebral Palsy leveraging existing research infrastructure.
2. Allocate $30MM for high priority NIH funding for translational CP research.

Cerebral Palsy (CP), the most common motor disability in childhood, is a devastating group of disorders, disrupting a person's ability to move, sit, stand, walk, talk and use their hands. CP is caused by a non-progressive injury to the developing brain and the severity can vary: Some patients have only mild difficulties with balance, walking and fine motor skills, while others are completely trapped in their own bodies, fighting rigid limbs, and unable to speak or swallow. *75% of people with CP have additional conditions,* including epilepsy, autism, hearing and vision impairments, communication problems, and chronic pain. More than 10,000 babies are diagnosed with Cerebral Palsy each year. In most cases, the specific cause is unknown. There is currently no known cure.

The reason I am here today began 13 years ago when my daughter, Cathryn was born three months early, weighing 3 pounds and fighting for life. After a month-long stay in the NICU, we hoped she was out of the woods, but I knew something was wrong. Cathryn wasn't hitting basic milestones. She was floppy, then stiff, and held her head to one side. She choked when drinking and fisted her hands oddly. When a neurologist finally diagnosed Cathryn with CP at 11 months of age, we had no answers to even the simplest questions of whether she would be able to walk or talk. We were told to wait and hope for the best. *Like the majority of others who receive a CP diagnosis, the cause of Cathryn's Cerebral Palsy remains unknown*.

Cathryn's care in the *Neonatal Intensive Care Unit* (NICU) cost well over $100,000, yet post discharge, there was no treatment protocol or plan to help her reach her potential. Unfortunately, our experience is still all too common, and typical NICU costs are even higher today.

After an exhausting search for answers and finding very little regarding early treatments for children with CP, we launched *Reaching for the Stars* in 2005 - the first parent-led voice of children with Cerebral Palsy focusing on advocacy, research and education. Thousands of families across the U.S. and into Canada, Australia and Asia are part of our growing CP community. We have an outstanding international Medical Advisory Board to advise us.

Over the years, our treatment search has taken us all over the country with no two opinions the same regarding surgeries, medications, devices, various therapies etc. Cathryn's story highlights the current reality that there is <u>no consensus of "Best Practices" for a person with CP – at diagnosis, or through their life span. Cerebral Palsy does not have organized standards of care or proven therapy protocols. Until just recently, there has been little talk of recovery, let alone a cure for CP.</u>

Despite the number of Americans impacted by Cerebral Palsy, there is ZERO dedicated public research funding for it at NIH or CDC. There is no federal strategy to address the #1 motor disability in children - affecting a large adult population as well. We ask you to contrast the NIH research funding for Adult Stroke with that of Cerebral Palsy. There are approximately 795,000 new Adult Stroke cases each year. In 2013, Stroke received $282,000,000 in NIH research funding - *equating close to* $24,000 per new adult stroke case. In contrast, more than 10,000 babies each year are diagnosed with CP. $18,000,000 in NIH grant-initiated CP research in 2013 *equates to less than $1,800 per new baby diagnosed*. This was less than one tenth the funding for Adult Stroke, even though most children with CP are expected to live a normal lifespan.

Human brain neuroplasticity is now an accepted scientific fact that has revolutionized the care of adults with a wide variety of brain injuries and diseases. If we compare the care of an adult with a stroke involving one side of the body, to a child with hemiplegic Cerebral Palsy involving one side of the body, there is a world of difference in the available treatments and hope for recovery. *It is illogical to think that older injured brains can improve, but baby brains cannot.*

It is estimated that <u>lifetime care and medical costs for all Americans with CP exceeds $1.5MM per person more than someone who does not have CP</u> causing financial devastation in the struggle to afford care and treatment not covered by insurance. Government programs, like Medicaid, bear much of this cost**. Lifetime care costs for those born with CP in 2000 will total over $11.5 billion.** Investing in CP research funding, with the goal of preventing and minimizing the impact of CP, would dramatically reduce the staggering costs and human suffering. In the age of human neuroplasticity, *continuing the status quo is no longer an acceptable course of action.*

Mr. Chairman, thank you and the Subcommittee, for your leadership in supporting the CDC’s research into birth defects and developmental disabilities, which includes local surveillance of CP in four sites as part of the *ADDM Network.* We also thank the committee for your ongoing support of NIH research into brain development and injury, including the new *Brain Initiative*, and hope it will include the brains of people with Cerebral Palsy as well.

Thirteen years after Cathryn was discharged from the NICU babies with brain injuries in most cases, are shockingly STILL being discharged with little more than a *“wait and see”* attitude - despite recognition of the importance of the first few years of every baby’s life when the brain grows rapidly with exuberant neuroplasticity and realistic hope for significant recovery. Children like Cathryn lose valuable therapeutic time with the usual delay in CP diagnosis. Many children are not diagnosed until age 2 or 3, or even later. Knowing what we now know about neuroplasticity, it is tragic there is not an aggressive protocol in place from the minute a brain injury in a baby or toddler is suspected. There should be.

The wonderful research focused on adult brain disorders is not being effectively translated to benefit the most precious resource we have - our children. There is incredible financial and societal cost that could be saved by shifting our approach to cross-disciplinary translational CP research. There are many research areas where we don’t need to “rediscover the wheel”. One example is *Constraint Induced Movement Therapy* (CIMT) introduced and tested successfully in adults with stroke over 30 years ago, and proven to be successful in children as well. This is just one treatment modality that works in both children and adults, yet there is no widespread use or availability of it to U.S. children with CP. Further research is needed to determine which treatments, or combination of treatments, offer the best hope for improvement and recovery, and to translate treatments and technologies known to work for adult brains to children with CP.

Two weeks ago, *Reaching for* the *Stars* launched a *national petition to regarding the need for federally funded Cerebral Palsy research*. http://www.change.org/petitions/us-senate-and-us-house-of-representatives-appropriate-dedicated-funding-for-cerebral-palsy-prevention-treatment-and-cure-research In that short amount of time, *5,000 Americans have signed this petition*! Our community is coming together because it is incomprehensible that so many basic questions have not been answered about a disorder that impairs movement in more children than any other.

There are many examples of what can happen when government resources and ingenuity meet: sending a man to the moon, changing HIV from a death sentence to managed chronic disease. People with Cerebral Palsy deserve nothing less than our best efforts.

Mr. Chairman and members of the Subcommittee, we thank you very much for the opportunity to speak to you today, and for your time and attention to this urgent matter. Dr. Thornton and I would be happy to provide any additional information and answer questions.

For more information please visit www.reachingforthestars.org Our mission is the Prevention, Treatment and Cure of Cerebral Palsy.

CDC Disorders	**U.S. Population**	**2013 Budget**
Fetal Alcohol Syndrome	0.2 - 1.5 per 1000	$10,168,000
Spina Bifida	1 in 1400	$5,939,000
Autism/ASD	1 in 88 children	$21,665,000
Thallasemia	Less than 1,000 in U.S.	$1,863,000
Cerebral Palsy	1 in 323	$0

An investment of $10MM in CDC’s Developmental Disabilities (DD) activities will allow CDC to build on established surveillance and research methods to develop a robust research infrastructure focused on CP across various geographic U.S. regions. Infrastructure of this type holds promise for answering questions about the causes of CP and for identifying opportunities for prevention. The U.S. lags behind other countries like Australia, most of Europe, and the Scandinavian countries in CP research funding translating to improved early diagnosis and care *(Source: Hagberg et al: CP Alliance).*