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**Cerebral Palsy Foundation**  
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**Chairman Aderholt, Ranking Member DeLauro, and Distinguished Members of the Committee:**

Thank you for allowing me to speak during *National Cerebral Palsy Awareness Month 2023* on behalf of the more than 1,000,000 Americans and 17,000,000+ people worldwide living with Cerebral Palsy (CP). My name is Michael Kutcher, and I was born with Cerebral Palsy. I am also an advocate for the Cerebral Palsy Foundation, the largest cerebral palsy nonprofit organization in the US, as well as a businessperson, father, and public speaker. With me is Cynthia Frisina, senior vice president of the Cerebral Palsy Foundation, a mother of a daughter with CP and the creator of National Cerebral Palsy Awareness Month, and Day which is March 25<sup>th</sup>.

Today we ask Congress to take all steps necessary to establish baseline federal cerebral palsy research investment and a National Cerebral Palsy Research Initiative. We thank the Committee for the \$2 million re-establishing cerebral palsy surveillance in at least two sites of the existing Centers for Disease Control and Prevention Autism & Developmental Disabilities Network (ADDM). This funding will help better understand the prevalence of CP and restore the intent of the ADDM Network to track major developmental disorders. We request continuing support for this vital public health initiative. We also request the Committee direct \$2 million to the Centers for Disease Control and Prevention to establish a Cerebral Palsy Research program focused on the diagnosis, treatment, prevention, health care and societal costs of CP, and track the number of people diagnosed with CP in the United States across the lifespan. In addition, we also request National Institutes of Health (NIH) to continue to prioritize and invest in research on cerebral palsy (CP) including the establishment of a Cerebral Palsy Notice of Special Interest (NOSI) to significantly strengthen and accelerate CP research priorities across the lifespan. While some progress has been made in the understanding of CP over the last forty years, large gaps remain that must be addressed to improve outcomes and treatment for the CP population and their families.



Cerebral Palsy (CP), the most common lifelong physical disability of all, is a devastating group of disorders, disrupting a person's ability to move, sit, stand, walk, talk and use their hands. Despite the large number of Americans impacted by cerebral palsy, and the number of years the cerebral palsy community has advocated for federal research, the dollar amount of dedicated federal funding has remained sadly zero.

I'd like to emphasize that despite the 1,000,000 plus Americans impacted by Cerebral Palsy, there is currently ZERO dedicated public research funding for it at NIH or CDC. There is currently no existing federal strategy to address the most prevalent lifelong physical disability. We request your support in changing this.

CP is caused by a non-progressive early injury to the developing brain and the severity can vary widely. More than 10,000 babies are diagnosed with Cerebral Palsy each year. In most cases the specific cause is unknown. Some people with cerebral palsy like me have difficulties with balance, walking and fine motor skills, while others are fighting uncontrollable movements, rigid limbs, and are 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.

The reason I am here today began 45 years ago when I was born as a smaller, unexpected twin of my brother, actor Christopher "Ashton" Kutcher. My mother didn't know she was having twins until our arrival. I was tiny and fighting for life. As a baby and toddler, I missed many developmental milestones struggling with motor skills, vision, hearing and using my hands. When I was finally diagnosed with Cerebral Palsy close to kindergarten age, I had missed a key window of opportunity for early intervention. We were told to wait and hope for the best. *Like the majority of others who have received a CP diagnosis, the cause of my Cerebral Palsy remains unknown.* 45 years later a late diagnosis and few answers is still sadly the case for many families.

My story, and hundreds of thousands more like it, highlights the current reality that, even in 2023, there is no consensus of "Best Practices" for a person with CP – at diagnosis, or through their life span. High risk 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 exists. 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.

It is estimated that lifetime care and medical costs for all Americans with CP exceeds \$1.5MM per person more than someone who does not have CP - 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 alone will total over \$12.5 billion. Investing in CP research funding, with the goal of preventing and minimizing the impact of CP, would dramatically reduce the staggering costs and lifelong human suffering.

Of note, the U.S. lags behind other countries like Australia and most of Europe in CP research funding translating to improved early diagnosis and care (*Source: Hagberg et al: CP Alliance*).

Some risk factors for cerebral palsy include maternal infection, perinatal stroke, preterm birth, multiple births, lack of oxygen, and genetic factors. But for almost half of babies with cerebral palsy, no direct risk factors have yet been identified.

What we do know is that the brain injury does not progress in CP. And with the right treatment, function can improve for people. In reality, being able to move is absolutely critical to all of baby learning and it has a lifelong impact. That's why the earlier treatment can begin the better the long-term outcome.

Cerebral palsy has a profound lifetime consequence for a child's ability to participate in family life, their community, access educational and get a job. A baby with CP becomes an adult with CP, which is why research across the lifespan is so critically important.

Right now, because of lack of research funding, there's really no consensus for best healthcare practices and treatments for CP throughout the lifespan.

We can't let this continue to happen to other children and adults with CP.



And the great thing is - we don't have to. Please wipe the image you may have had in the past of what cerebral palsy was and know that change IS possible. If we invest in research that will lead to better outcomes, there are now tools to help detect cerebral palsy and its consequences as early as possible. Outcomes CAN be improved. Lifelong healthcare costs for 10,000 babies each year CAN be reduced. Quality of life for more than 1,000,000 Americans and their families WILL be better.

We're so fortunate to live in the US with some of the best researchers and healthcare professionals. We can easily improve outcomes for people with CP, the way others across the world have done, and our country has done with other disorders and diseases, by investing in research.

But honestly, this is not going to happen in the US unless the right kind of research is funded to help researchers translate the best and newest findings into healthcare practice for lasting change. Without funding, it could take 20 years between when a new treatment is being discovered and then it's being used regularly into practice. We know this from other conditions, and we know it about Cerebral Palsy. People with cerebral palsy have already been waiting too long for a meaningful improvement in their treatments and their quality of care.

It's important to know that researchers are starting to design new interventions for cerebral palsy. Some of these starting within months of a baby's birth. And these interventions will change how an adult with CP will use their hands, walk, talk, see, hear, and have a fighting chance to make their own difference in the world.

It's been very difficult as an adult with the most common, lifelong physical disability of all to understand why there hasn't been more federal research support, and frankly interest, that would lead to better treatments, standards of care and understanding of cerebral palsy across the lifespan. Why has this condition been so overlooked when it comes to research and healthcare innovation? Now that I'm an adult, I've discovered another obstacle. There are very few doctors who understand adults with cerebral palsy, and they do not have protocols in place to treat our issues and special considerations. In fact, many adults with cerebral palsy resort to seeking care at children's hospitals, if at all.



Currently, there are very few research studies or clinical trials for adults with cerebral palsy. This needs to change.

Mr. Chairman, Ranking Member DeLauro, thank you and the Subcommittee, for your leadership in supporting the CDC's research into birth defects and developmental disabilities and for allowing me to testify today. We also thank the Committee for your ongoing support of NIH research into brain development and injury.

I hope to see in my lifetime, more research treatments and better quality of life for people with cerebral palsy. I don't want another generation of children to unnecessarily have to go through late diagnosis, delayed treatment, and an uncertain future. All because basic research isn't being funded and conducted, and too few doctors are familiar with cerebral palsy. On behalf of the Cerebral Palsy Foundation and the cerebral palsy community, I respectfully ask you to dedicate funding for cerebral palsy research. Your support will improve more than 1,000,000 American lives. Thank you for your support and attention to this urgent public health issue.

Cynthia Frisina and I would be happy to provide any additional information and answer any questions. Please email [Cynthia.Frisina@yourcpf.org](mailto:Cynthia.Frisina@yourcpf.org).

CDC Funded Disorders	U.S. Population	FY 2022 CDC Budget
Autism/ASD	1 in 44	\$23,100,000
Fetal Alcohol Syndrome	1 in 1,000	\$11,000,000
Hemophilia	1 in 5,000 males	\$8,600,000
Spina Bifida	1 in 2,500	\$7,500,000
Congenital Heart	40,000 babies each year	\$7,250,000
Cooley's Anemia	Fewer than 1,000 cases	\$2,100,000
Fragile X	1 in 11,000 females	\$2,000,000
<b>Cerebral Palsy</b>	<b>1 in 345 children</b>	<b>\$0</b>