

# Improved Public Health Outcomes for Cerebral Palsy FY 2022

## FY 2022 LHHS Appropriations Draft Report Language

### CDC

Cerebral Palsy is the most common, lifelong motor disability caused by an early developmental brain injury. The mechanism of injury underlying CP is still not well-understood; therefore, the Committee encourages NCBDDD to explore cross-divisional funding opportunities, networks, data sets and systems to accelerate data-driven public health research to improve CP surveillance and develop better understanding of the mechanisms leading to earlier diagnosis and better outcomes to reduce the public health burden of CP. Private partnerships in select US NICU's representing 10% of high-risk infants have reduced the age of cerebral palsy diagnosis from 19.5 months to 9.5 months by creating rigorous training and systems approach. Additionally, these methodologies have been utilized by CDC in other countries in response to the Zika virus. Therefore, the Committee requests \$5,000,000 for additional US high risk infant follow up sites to reduce the age of cerebral palsy detection and diagnosis, as well as the addition of cerebral palsy to the existing surveillance sites across the Autism and Developmental Disabilities Monitoring (ADDM) network. Additionally, the committee encourages the CDC to conduct an updated study from the 2003 report on the healthcare and societal costs of CP in the US.

### NIH

The Committee commends NIH (NINDS & NICHD) for supporting research on mechanisms leading to CP, health outcomes for those affected, biomarkers that may aid in diagnosis or treatment selection, and interventions for treatment and prevention of CP. The Committee strongly encourages NIH to prioritize and establish a dedicated CP Funding Opportunity Announcement (FOA) to significantly strengthen, accelerate, and coordinate cerebral palsy research priorities across the lifespan identified in the 2017 NINDS/NICHD Strategic Plan for CP Research. This CP FOA should target basic and translational discoveries, including neuroprotective, regenerative medicine and mechanisms of neuroplasticity, as well as implementation and clinical studies aimed at early detection and intervention, comparative effectiveness and functional outcomes. 2022 will be five years since the last CP Strategic Planning workshop, therefore the Committee encourages that a follow-up workshop be held in 2022 in conjunction with key stakeholders. The purpose of this workshop will be to provide updates on promising research performed to date with the goal to further refine the specific opportunities that were identified in the 5-year NIH strategic plan including early detection and intervention. NICHD is also encouraged to consider a neuroplasticity workshop and research opportunities focusing on the motor and health benefits of physical activity for patients with cerebral palsy through the lifespan.

CDC Funded Disorders	U.S. Population	2020 CDC Budget
Fetal Alcohol Syndrome	0.2 - 1.5 per 1,000 children	\$11,000,000
Spina Bifida	1 in 2,758	\$6,000,000
Autism/ASD	1 in 54 children	\$23,100,000
Thalassemia	Fewer than 1,000 cases in U.S.	\$2,100,000
Fragile X	1 in 11,000 females	\$2,000,000
Hemophilia	1 in 5,000 males	\$8,600,000
<b>Cerebral Palsy</b>	<b>1 in 345 children</b>	<b>\$0</b>

## Why we need this funding and focus now

**With dedicated federal research funding and focus, we can make strides toward determining causation, improving early detection and identifying the most effective treatments for cerebral palsy (CP) resulting in improved outcomes.**

### **CP is the most common motor disability in children,**

affecting more than 1,000,000 Americans, 1 in 345 children, and over 17,000,000 people worldwide. More than 10,000 U.S. babies are diagnosed with Cerebral Palsy each year.

### **Despite the incidence and prevalence of CP going down**

in other countries like Australia and Sweden through earlier detection and intervention, those established tools are not being implemented widely in the US due to lack of research focus and support.



### **NO dedicated funding exists for Cerebral Palsy,**

despite the fact it is the most common lifelong motor disability affecting more people than Spina Bifida, Muscular Dystrophy, Downs Syndrome, Parkinson's disease, childhood cancer, hearing and vision loss, Hemophilia, Fetal Alcohol Syndrome or Cystic fibrosis. Research registries have been established for many of these disorders but not for Cerebral Palsy.\*

### **CP is a broad group of disorders disrupting a person's ability to move, sit, stand, walk, talk and use their hands.**

The severity and type of the movement disorder and difficulties 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 individuals with CP also have one or more additional developmental disabilities,**

including epilepsy, intellectual disability, communication problems, learning and attention disorders, chronic pain, autism, hearing disorders, and visual impairments or blindness.

### **Currently, there is no known cure for CP, and in most cases, (based on current scientific knowledge) it is currently not preventable.**

Today, medical experts and researchers agree that the critical mechanisms leading to CP are still not well understood or researched. Best practice guidelines are evolving. Despite advances in genetics, obstetrics and neonatology, we STILL do not understand much more about the underlying causes or prevention of CP than we did half a century ago.

### **In more than 80% of CP cases, the cause is still unknown.**

CP results from an injury to the brain during development, which can occur during pregnancy, around the time of birth or anytime within the first two years of life. Contrary to popular belief, only a small percentage of CP is caused birth "asphyxia" (lack of oxygen to the brain and time or birth).

### **Children with CP in the U.S. are more likely to die from the flu and related viruses (including COVID-19) than children without neurologic disorders.\*\***

\*Source: CDC, National Institute of Neurological Disorders & Stroke (NINDS/NIH)

\*\*Source: Pediatrics 2012. Pandemic Influenza Neurologic Disorders Among Pediatric Deaths



## The prevalence of CP is NOT decreasing in the United States.

**Despite advances in prenatal and neonatal care, CDC indicates the prevalence of CP is as high as 3.6 per 1,000 U.S. 8 year- olds.**

In contrast, the prevalence of CP is significantly lower, and is declining, in other countries such as Australia (1.4 live births) and Sweden (1.9 per 1,000 live births) due to better management of high-risk pregnancies, improvements in neonatal intensive care, earlier detection and intervention standards of care that are not being implemented in the U.S.

**Currently, there is no consensus of “Best Practices” for a person with Cerebral Palsy at time of diagnosis or through the life span.**

There are not organized standards of care or proven therapy protocols widely available like there are for adults who have a stroke, for example. Human brain neuroplasticity is now an accepted scientific fact revolutionizing the care of adults with a wide variety of brain injuries and diseases. It is illogical to think that older, injured brains can improve, but baby brains cannot.



**When Cerebral Palsy isn't diagnosed until later in life, children and families often face significant and unnecessary challenges that could be prevented.**



**The financial burden of Cerebral Palsy on families and the healthcare system is exceedingly high.**

**It is estimated that the lifetime care and medical costs for all people with Cerebral Palsy who were born in 2000 alone will total more than \$13.5 billion. The loss of productivity, lost wages of the individual with CP and their family members top \$35 billion.**

Investing in Cerebral Palsy research funding, with the goal of preventing and minimizing the impact of CP, would dramatically reduce these staggering costs and human suffering.

**Living with CP is expensive.**

Most children and adults with CP need long-term medical care. The average lifetime additional direct cost for just one person with CP is estimated to be over \$1.5 million more than someone who does not have CP - causing financial devastation in the struggle to afford treatment not covered by insurance. Federal and state governments in the form of Medicaid and other social services currently absorb much of this cost.

Since 2007, the CP community has increased focus on the need for federally funded Cerebral Palsy research.

Our community has come together to request answers to so many basic questions about a disorder and public health issue that impairs movement in more children than any other, and yet is not a federal research priority.



## About the Cerebral Palsy Foundation

Our mission is to be a catalyst for creating positive change for people with cerebral palsy.

People with cerebral palsy rarely get the interventions and supports they need at the moments they need them. The Cerebral Palsy Foundation is the largest cerebral palsy 501(c)3 tax-exempt organization that defines and addresses Moments of Impact – the times at which interventions and insights, if properly implemented, have the power to change lives. We work to better understand how to effect change and implement it. We bring together many of the most prestigious medical institutions in the US, as well as innovative thinkers in diverse areas such as technology and media, in order to accelerate the development of critical advances.



YourCPF.org | CPResource.org

Facebook: @CerebralPalsyFoundation

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