



March 21, 2019

Dear Members of Congress,

We are a North American collaborative of cerebral palsy organizations representing a diverse group of community stakeholders including individuals with cerebral palsy (CP), their families, caregivers, researchers, physicians and therapists. We would like to thank the members of Congress and their legislative assistants for supporting the CP community through the inclusion of appropriations language in the 2019 Federal budget. Further, we wish to extend our full support of continued language and *funding* in the 2020 Federal budget that will strategically outline plans for furthering our understanding, prevention and treatment of CP. Broadly defined, CP is caused by injury, disturbances, or damage to the developing brain that affects, but is not limited to, a person's ability to control their muscles, movement and posture.

There are over 800,000 Americans who have CP and many more family and community members who are impacted by the diagnosis. Many people mistakenly believe that CP only affects movement/motor control and function when actually a diversity of areas in the brain may have been affected. People who have CP may have problems with vision, hearing, speech, eating/digestion, learning, sensory processing, cognitive function, behavior as well as epilepsy and chronic sleep disorders. Children and adults with CP often undergo multiple orthopedic procedures to correct deformities and abnormal muscles and bones, yet still live with chronic pain and, as adults, often have reduced level of function and increasing pain as they age. Adults with CP have reduced mobility and are at higher risk for conditions like heart disease and diabetes. Despite the long history of this condition, it has continued to impact generations of Americans with little strategic planning or investment to halt its impact on the lives of those who have it and prevent new cases from emerging. As of 2019, CP is still the most common cause of motor disability in children and affects a large adult population as well.

With these facts in mind, we firmly stand behind the following proposed language addressing key strategic areas to advance knowledge and understanding of people with CP. These include:

1. **Population Surveillance** allowing us to more fully understand the American people impacted by CP and their families;

2. **NIH and CDC strategic planning to promote sound and robust scientific research** aimed at minimizing the impact of an early brain injury leading to CP on the life of the child and family; and
3. **Developing effective interventions** to increase participation and inclusion in life activities for people with CP across the life span.

2020 LHHS Appropriations Bill Report Language Recommendation:

In National Center on Birth Defects, Developmental Disabilities, Disability and Health:

Cerebral Palsy (CP) – 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 use existing resources, networks, data sets and systems in infant health to improve CP surveillance and develop better understanding of the mechanisms leading to earlier diagnosis and better outcomes. While the Hammersmith Infant Neurological Exam (HINE) for early detection of cerebral palsy has been developed and is being utilized by the CDC in other countries in response to the Zika virus, the standardized tools used for early detection are not being widely utilized in the US, and few providers are using these as standard of care. The Committee requests that CDC share early detection guidelines with pediatric providers and develop a US implementation plan. The Committee requests in the fiscal year 2021 CJ report on the cause, earlier diagnosis and treatment of CP across the lifespan.

In National Institute of Neurological Disorders and Stroke (NINDS):

Cerebral Palsy (CP) – The Committee commends NIH (NINDS) for implementing Funding Opportunity Announcements (FOAs) for clinical research supporting observational studies that are well suited for the study of Cerebral Palsy (CP). The Committee strongly encourages NIH to prioritize and implement additional FOA's to significantly strengthen, accelerate, and coordinate cerebral palsy research priorities across the lifespan identified in the five-year CP Strategic Plan. FOAs should target basic and translational discoveries, including genetics, regenerative medicine and mechanisms of neuroplasticity, as well as clinical studies aimed at early intervention, comparative effectiveness and functional outcomes in adults. The Committee also encourages, in conjunction with key stakeholders, that a follow-up workshop be held to further refine the specific opportunities that were identified in the NIH strategic plan with the objective of establishing CP-specific funding opportunities to address identified gaps. NICHD is also encouraged to coordinate with other agencies, including CDC, to support additional research on preventing, diagnosing and treating Cerebral Palsy.

We are deeply appreciative of the CDC and the NIH for their current efforts and are hopeful that the future holds their continued support and expansion of these initiatives to improve treatments and quality of life for people with CP across the lifespan.

Sincerely,

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Nadine Dehgan, CEO, Cerebral Palsy Alliance Research Foundation US

Richard Ellenson, CEO, Cerebral Palsy Foundation

Cynthia Frisina, Co-Founder, Reaching for the Stars - A Cerebral Palsy Foundation

Mary Gannotti, PhD, Chair of the Adolescent and Adult with Developmental Disabilities Special Interest Group, Member of the Research Committee, Member of the Academy Of Pediatric Physical Therapy Leadership Team

Paul Gross, Founder and Executive Director, Cerebral Palsy Research Network

Joline Brandenburg, MD, Interim Chair of the Pediatric Rehabilitation & Developmental Disabilities Community of the American Academy of Physical Medicine and Rehabilitation

Wendy Sullivan, Chair of the Community Council, American Academy for Cerebral Palsy and Developmental Medicine

Justin Ramsey, MD, Chair of the Advocacy Committee, American Academy for Cerebral Palsy and Developmental Medicine

Michele Shusterman, Founder and President, CP NOW