



April 11, 2018

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 2018 Federal budget. Further, we wish to extend our full support of continued language and *funding* in the 2019 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 2018, 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.

For reference, the current Labor, Health and Human Services, Education and Related Agencies Appropriations Bill, 2018, includes the following language:

In CDC - pg. 69

Cerebral Palsy [CP].—The Committee encourages CDC to build upon existing surveillance and research applications of CP surveillance within the established 11 Autism and Developmental Disabilities Monitoring Network surveillance sites. The Committee recognizes and supports CDC's efforts to include CP surveillance in three existing sites and encourage CDC to expand this effort within current resources to additional sites allowing for a more nationally representative sample.

In NINDS - pg. 91

Cerebral Palsy [CP].—The Committee commends NINDS for developing the CP 5-year Strategic Plan and urges NINDS to implement Funding Opportunity Announcements in support of the top priorities and increase its CP research efforts for prevention, treatment, and cure through the lifespan. The Committee encourages funding for basic and translational research (including regenerative medicine) for improved outcomes for patients with CP, and recommends collaboration with the research and advocacy community. Furthermore, the Committee recommends that NIH form a transNIH working group of program officers who manage their Institute's CP portfolio and that this group regularly interact with CP patient advocacy groups.

2019 LHHS Appropriations Bill Report Language Recommendation:

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

Cerebral Palsy (CP) – Over 800,000 Americans are impacted by Cerebral Palsy (CP), and it is the number one motor disability in children, affecting 1 in 323 live births. CDC is the lead federal agency for conducting population based research and currently, there is no such large-scale research on CP at CDC despite the prevalence and incidence. The Committee urges CDC to work with scientists and stakeholders to have a Strategic Planning meeting in 2019 to develop a Scientific Agenda to enhance the current CP surveillance. The Committee requests specific recommendations of data sets (including EMR, surveys, claims) that will answer the questions around the cause, prevalence and treatment of CP.

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

Cerebral Palsy (CP) – The Committee commends NINDS for developing the Cerebral Palsy 5-year Strategic Plan and urges NINDS to implement Funding Opportunity Announcements in support of the top priorities and increase its CP research efforts for prevention, treatment, and cure through the life span. The Committee encourages funding for basic, translational and implementation research (including regenerative medicine and genomic research) for understanding mechanisms underlying CP and improving outcomes for patients with CP, and recommends collaboration with the research and advocacy community, including public-private partnerships that can accelerate clinical research in CP. Furthermore, the Committee recommends that NIH form a trans-NIH working group of program officers who manage their Institute’s CP portfolio and that this group regularly interact with CP patient advocacy groups.

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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