

January 15, 2016

Dear Members of Congress:

We are a group of US based cerebral palsy organizations and individuals representing a diverse group of community stakeholders which include; persons 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 2016 Federal budget. Further, we wish to extend our full support for continued language in the Federal budget that will strategically outline plans for furthering our understanding, prevention and treatment of CP, which broadly defined, involves circumstances leading to disturbances in early brain development.

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 CP only affects movement/motor control and function; however, as a developmental condition affecting a diversity of areas in the brain, CP may affect vision, hearing, speech, eating/digestion, learning, sensory processing, cognitive function, behavior, and may lead to other conditions such as epilepsy and chronic sleep disorders. Children and adults with CP often undergo orthopedic procedures to correct deformities and abnormal muscles and bones, yet still live with chronic pain and, as adults, often have a 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 to halt its impact on the lives of those who have it and prevent new cases from emerging. As of 2016, CP is still the most common cause of motor disability in children.

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

For reference, the current bill, S. 1695, Labor, Health and Human Services, Education and Related Agencies Appropriations Bill, 2016, includes the following language:

Page 68 - *Cerebral Palsy*.—The Committee encourages CDC to build on established surveillance and research methods to develop a robust research infrastructure focused on Cerebral Palsy across various geo- graphic U.S. regions.

Page 86 - Over 800,000 Americans are impacted by CP and it is the number one motor disability in children. Currently, there are no identified best practices at diagnosis or through the life span, no organized standards of care, no national CP registry, and few proven therapy protocols. The Committee urges NIH to work with scientists and stakeholders to develop a 5- year strategic plan for research on CP prevention, treatment, and cure through the lifespan with the goal of reducing the number of people impacted by CP overall, as well as improving the opportunity for recovery of those already diagnosed. The Committee urges NIH participation in work groups to develop a research registry of individuals with different forms of CP that could facilitate research related to the impact of diverse impairments and health issues on functioning, participation and well-being across the lifespan.

For the 2017 appropriations language we respectfully ask the Committee to ensure the CDC builds upon established surveillance, and promotes research applications by adding language requiring these activities and by providing \$1,000,000 in dedicated funding for this purpose.

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.

Sincerely,

*James Blackman*

James Blackman, MD, Medical Director, Cerebral Palsy Alliance Research Foundation US and Medical Consultant UCP

*Stephanie DeLuca*

Stephanie DeLuca, PhD, Head of The American Academy for Cerebral Palsy and Developmental Medicine's Advocacy Committee

*Lizette Dunay*

Lizette Dunay, Co-founder of Cure CP

*Richard Ellenson*

Richard Ellenson, CEO, The Cerebral Palsy Foundation

*Cynthia Frisina*

Cynthia Frisina, Founder and Executive Director, Reaching for the Stars—A Cerebral Palsy Foundation

*Paul Gross*

Paul Gross, Founder, The Cerebral Palsy Research Network

*Michele Shusterman*

Michele Shusterman, Founder and President, CP NOW