



April 30, 2021

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 cerebral palsy community through the inclusion of appropriations language in the 2022 Federal budget. Further, we wish to extend our full support of continued language and *funding* in the 2022 Federal budget that will strategically outline plans for furthering our understanding, prevention and treatment of cerebral palsy. Broadly defined, cerebral palsy 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 1,000,000 Americans who have cerebral palsy and many more family and community members who are impacted by the diagnosis. Many people mistakenly believe that cerebral palsy only affects movement/motor control and function when actually a diversity of areas in the brain may have been affected. People who have cerebral palsy 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 cerebral palsy 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 cerebral palsy 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 2021, cerebral palsy is still the most common lifelong cause of motor disability.

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 American people impacted by cerebral palsy and their families - both nationally and by state.

2. **CDC and NIH strategic planning to promote sound and robust scientific research** aimed at understanding causation, improving early diagnosis and outcomes, therefore minimizing the impact and cost of cerebral palsy on the life of the individual and family/caregivers.
3. **Developing effective interventions** to improve health and quality of life for people with cerebral palsy across the lifespan.

2022 LHHS Appropriations Bill Report Language Recommendation:

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

Cerebral Palsy (CP) is the most common, lifelong motor disability caused by an early developmental brain injury. The mechanism of injury underlying Cerebral Palsy 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 Cerebral Palsy surveillance and develop better understanding of the mechanisms leading to earlier diagnosis and better outcomes to reduce the public health burden of Cerebral Palsy. 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 Cerebral Palsy in the US.

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

The Committee commends NIH (NINDS & NICHD) for supporting research on mechanisms leading to Cerebral Palsy, health outcomes for those affected, biomarkers that may aid in diagnosis or treatment selection, and interventions for treatment and prevention of Cerebral Palsy. The Committee strongly encourages NIH to prioritize and establish a dedicated Cerebral Palsy 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 Cerebral Palsy research. This Cerebral Palsy 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 Cerebral Palsy 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.

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 cerebral palsy across the lifespan.

Sincerely,
Cerebral Palsy Collaborative

DocuSigned by:



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Rachel Byrne, Executive Director, Cerebral Palsy Foundation

DocuSigned by:



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Armando Contreras, President and CEO, United Cerebral Palsy

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Nick Farmer, Board President, Pedal with Pete Foundation

DocuSigned by:



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Carl D. Gelfius, MD, FAAPM&R, Health Policy and Legislation Committee, American Academy of Physical Medicine and Rehabilitation

DocuSigned by:



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Mary Gannotti, PhD, American Academy of Pediatric Physical Therapy

DocuSigned by:



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Paul Gross, Executive Director Cerebral Palsy Research Network/CPNOW Foundation

DocuSigned by:
Chris Olver
EE884B7592984C4...

Chris Olver, Executive Director, Cerebral Palsy Alliance Research Foundation

DocuSigned by:
Susan Sienko
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Susan Sienko, PhD, President, American Academy for Cerebral Palsy and
Developmental Medicine