



american academy for cerebral
palsy and developmental medicine

March 16, 2006

Congressman Ralph Regula
Labor, Health and Human Services and Education Appropriations Subcommittee
2306 Rayburn Building
Washington, D.C. 20515

Dear Congressman Regula,

Thank you for your attention to the need for more research efforts dedicated towards improving the lives of individuals with Cerebral Palsy. We especially thank you for being willing to listen and respond to individuals from the Reaching for the Stars Foundation, including Dr. Janice Brunstrom, who met with you recently. We at the American Academy for Cerebral Palsy and Developmental Medicine (AACPDm) would like to offer our strongest support for their and your efforts on behalf of children with Cerebral Palsy.

Cerebral Palsy is the most common physical disability originating in childhood (2.2/1000 live births), but no cure exists or is imminent. Further, scientific evidence for many of the treatments that are currently available is lacking and the low priority at the federal level given to research in this area is limiting the development of new and more promising treatment strategies for these individuals. Consequently, these individuals often fail to reach their full potential to lead fulfilling lives and maximally contribute to society. It is also difficult to attract the best clinicians and researchers to cerebral palsy because of the limited research and clinical funding available. This situation needs to change drastically and we believe that only major policy decisions and initiatives at the federal level can make this possible.

Dr. Brunstrom, a member of the AACPDm and Director of the Pediatric Neurology Cerebral Palsy Center in St. Louis, Missouri will be addressing the United States House of Representatives Committee on Appropriations on March 30, 2006. As an individual with Cerebral Palsy, she is an inspiration not only to her patients and their families, but also, to her colleagues. She has done much to transform attitudes and clinical management of Cerebral Palsy. In addition to being an internationally recognized expert in the management of children with Cerebral Palsy, she is an NIH-funded researcher who is investigating factors that may cause Cerebral Palsy and who is directing clinical trials of treatments for Cerebral Palsy. She is an outspoken advocate for these children and for the pressing need for increased research efforts in the basic science, clinical and epidemiological arenas, so that we can better understand and treat these children and someday find a cure for these disorders.

The American Academy for Cerebral Palsy and Developmental Medicine, a professional society, founded in 1947, is comprised of over 1100 members whose mission is to "promote interdisciplinary professional education and research in Cerebral Palsy and other developmental



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disabilities" (Mission statement) thus " leading the way to optimal quality of life" for these children (Vision statement). In addition to promoting research and offering multiple educational activities throughout the year, we conduct an exceptional annual scientific meeting each year that attracts almost 800 attendees. Our society is also an official sponsor of the major journal in the field, namely, *Developmental Medicine and Child Neurology*. Our members include clinicians and scientists in academic medical centers, private hospitals, and community-based practice settings. For more information, please refer to our website www.aacpdm.org.

Dr. Brunstrom and the RFTS foundation have the full support of the AACPDm. Dr. Brunstrom and several other members of our Academy who are leading researchers and clinicians throughout the USA and Canada working to improve the lives of individuals with Cerebral Palsy also serve on the RFTS Advisory Board. Additionally, several AACPDm members also serve on the Scientific Board of the United Cerebral Palsy Research and Education Foundation.

We join Dr. Brunstrom and the RFTS foundation in asking Congress to ask the CDC to add Cerebral Palsy surveillance to the national infrastructure that is already in place for Autism and we endorse the following draft reporting language for the Committee on Appropriations:

The Labor Health and Human Services subcommittee recommends that the Committee on Appropriations urge the CDC to establish Cerebral Palsy surveillance and epidemiology sites throughout the United States based on methodology developed in the Metropolitan Atlanta Developmental Disabilities Study (MADDs) and the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), and also based on methodology that should be developed to include sophisticated imaging techniques, genetics and clinical evaluations. The Committee should request that the CDC build upon the infrastructure established for the seventeen Autism, Developmental Disability Monitoring (ADDM) sites and the six Centers for Autism, Developmental Disability Research and Epidemiology (CADDRE) sites and establish surveillance/ epidemiology/ clinical research centers for Cerebral Palsy as was done for Autism.

Thank you for your support and consideration.

Sincerely,

A handwritten signature in black ink that reads "Barry S. Russman". The signature is written in a cursive, flowing style.

Barry S. Russman, MD
President of AACPDm
555 East Wells, Suite 1100
Milwaukee, WI 53202
Phone: 414.918.3014
Fax: 414.276.2146
Email: tburr@aacpdm.org

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