



CHILD NEUROLOGY SOCIETY

March 16, 2006

The Honorable Ralph Regula
2306 Rayburn Building
Washington, DC 20515

Viquar_ahmad@mail.house.gov

Dear Congressman Regula:

Thank you very much for your efforts to address the need for further studies in the care of individuals with Cerebral Palsy. As you know this is an area that has not been adequately studied and yet affects the lives of almost 800,000 children and adults in the United States. Cerebral Palsy is one of the most common developmental disabilities in the United States. Furthermore, individuals with cerebral palsy often have other developmental disabilities, including epilepsy, mental retardation, autism and visual impairments or blindness. Despite the introductions of modern prenatal testing, improved obstetric care, and newborn intensive care technologies, the prevalence of Cerebral Palsy is not reducing. There is currently no national surveillance for Cerebral Palsy. However, an infrastructure does exist through the Centers for Disease Control and Prevention (CDC) which has established major surveillance systems for Autism and Mental Retardation around the U.S.

Fortunately the issue of Cerebral Palsy is beginning to come to more national awareness. Janice Brunstrom MD, Director of the Pediatric Neurology Cerebral Palsy Center in St. Louis, Missouri and member of the Child Neurology Society will be addressing the United States House of Representatives Committee on Appropriations on March 30, 2006. She is an internationally recognized expert in the management of children with cerebral palsy, an NIH-funded researcher who is investigating factors that may cause CP and is directing clinical trials of treatments for CP. Dr Brunstrom has been a tireless advocate for individuals with cerebral palsy. She brings personal experience as an individual with cerebral palsy to the forefront to increase awareness of the capabilities of affected individuals as well as to point out the many areas of clinical care and research

that needs to be addressed.

We at the Child Neurology Society support national CP surveillance as a crucial step in order to better understand how to identify and prevent causes of damage to the developing brain and to improve our ability recognize and treat the multiple needs of these children.

The Child Neurology Society is the national organization that represents approximately 1000 Child Neurologists in the United States. Child Neurologists are the experts who have specialized interest and training in disorders of the central and peripheral nervous system. Thus their areas of expertise include cerebral palsy, movement disorders, seizures, developmental delay, mental retardation, autism, and nerve and muscle disorders to name just a few.

The National Child Neurology Society joins Reaching for the Stars (RFTS), the United Cerebral Palsy Research and Education Foundation (UCP) and the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) in asking Congress to add cerebral palsy to the CDC surveillance 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.

We at the Child Neurology Society would like to offer our strongest support for their and your efforts on behalf of children with CP.

Sincerely,



Ann Henderson Tilton, MD
President Child Neurology Society