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March 13, 2006

U.S. Representative
The Honorable Jo Ann Emerson
2440 Rayburn House Office Building
Washington, DC 20515

Dear Congresswoman Emerson:

Thank you for your attention to the pressing research issues which face the nearly one million people in our country with cerebral palsy. My esteemed colleague, Janice Brunstrom, MD, Director of the renowned Cerebral Palsy Center in St. Louis, Missouri will be addressing the United States House of Representatives Committee on Appropriations on March 30, 2006. She is a remarkable clinician, researcher and advocate for individuals with cerebral palsy and for cerebral palsy research, and has the full support of the United Cerebral Palsy Research and Educational Foundation.

United Cerebral Palsy Research and Educational Foundation has worked since 1955 to cure and prevent brain damage leading to developmental disorders. Despite major research advances which we have supported, including identification of Rh Factor incompatibility, the Rubella Vaccine and identification and treatment of Kernicterus, the incidence of CP is increasing. One in 3 surviving low birth weight premature infants has cerebral palsy. Research has lead to earlier detection and research is leading to promising interventions to improve neurological outcomes. More and better research is required to provide the data to drive best evidenced based care. Cure is possible and better care is possible. Through research there is hope that adults with CP will live long productive healthful lives.

Despite the fact that CP is so common and there are many promising therapies, the resources currently available to the clinical and research communities is simply inadequate. Our non-profit Foundation and others attempt to fill this gap, but substantial Federal support is urgently needed.

The UCP Research and Educational Foundation joins with our colleagues at the RFTS Foundation and March of Dimes in supporting a program of national surveillance through the Centers for Disease Control and Prevention (CDC). UCP R&E Foundation asks that the Congress add CP to the CDC surveillance infrastructure that is already in place (since the CDC has in place major surveillance systems for Autism around the

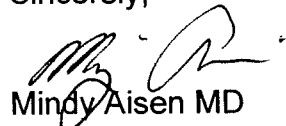
United States, we ask Congress to add CP surveillance and epidemiology to the program and that Congress allocate the resources necessary to ensure this happens in 2007). United Cerebral Palsy Research and Educational Foundation endorses the following draft reporting language for the Committee on Appropriations:

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.

Research is needed for prevention, cure and best care data for CP. A critical step for achieving this is to better understand the statistically associated risk and demographic factors.

Thank you for your consideration.

Sincerely,



Mindy Aisen MD
Director and CEO
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