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CEREBRAL
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FOUNDATION

Hope through research

CENTERS OF EXCELLENCE FOR CEREBRAL PALSY RESEARCH AND PREVENTION

**National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention (CDC)
US Public Health Service**

ISSUE: Need for in-depth clinical and applied research on preventing cerebral palsy, a leading cause of lifelong disability and for improved quality of life of children with disabilities due to cerebral palsy and other developmental disorders of the brain.

Cerebral palsy is a leading cause of chronic, lifelong disability caused by damage to the developing brain of the fetus or newborn infant. Everyday, 14 infants are born with cerebral palsy, making it the most common neurological disorder of the developing brain. Cerebral palsy is characterized by difficulty with walking and arm control and is often associated with impaired speech and swallowing. The per person increased medical costs are \$500,000. Annually, \$5 billion is spent for direct medical costs of the half million Americans with disabilities resulting from cerebral palsy. The impact of these life long disabilities on learning, employment and family life is immeasurable. The majority of adults with severe disabilities resulting from cerebral palsy are unemployed and receive direct federal benefits through the Supplemental Security Income program, estimated at an additional \$300,000 over the lifetime of the individual. In addition, such individuals can easily require \$20,000 to \$30,000 per year in non-medical support costs (such as personal care assistance, durable medical equipment, and expendable supplies).

Alarming, the number of new cases of cerebral palsy is increasing each year. The best answer to this growing problem is improved knowledge about the prevention of damage to the developing brain by identification of risk factors associated with the occurrence of cerebral palsy, and the development of methods of intervention to protect the developing brain from these factors.

In order to address this problem, a national network of Centers of Excellence for Cerebral Palsy Research and Prevention is required. \$6.5 million dollars needs to be appropriated to the National Center on Birth Defects and Disability, a unit of the Centers for Disease Control and Prevention (CDC), for grants to establish a coordinated network of six (6) Centers of Research Excellence and for the operation of a Cerebral Palsy Research National Coordination and Reporting Center. Each Center of Research Excellence should be a *regional focal point* for epidemiologic and for disability and prevention research on cerebral palsy and related neurodevelopmental disorders; also, a contract supported National Coordination and Reporting Center should provide expertise for the coordination and monitoring of cerebral palsy research, and for the reporting of scientific results to clinicians and for the public.

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This coordinated national effort will provide the impetus and activities necessary to focus national scientific attention on this growing problem of lifelong disability originating in infancy, and for dissemination of research findings rapidly to the community. Ultimately the impact of these Centers will reduce health care costs as well as reduce related costs to society of a lifetime of dependency of increasing numbers of Americans.

RECOMMENDATION: Appropriations report language should direct the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, to establish 6 regional Regional Centers of Excellence for Cerebral Palsy Research and Prevention and a Cerebral Palsy Research National Coordination and Reporting Center. The following report language is suggested:

The Committee has included \$6.5 million for the support of six regional Centers of Excellence for Cerebral Palsy Research and Prevention and for a Cerebral Palsy Research National Coordination and Reporting Center. The Committee recognizes the substantial health and related costs associated with cerebral palsy, which is a leading cause of lifelong disability and dependency originating in infancy. The Committee is concerned about the increasing incidence of cerebral palsy, and believes it is necessary to focus national scientific attention on this growing problem and to disseminate research findings rapidly to the community.

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