Congress of the United States

Washington, DC 20515

Join the Congressional Brain Injury Task Force

April 4, 2002

Dear Colleague,

We are writing to urge you to join us, along with other members of the Congressional Brain Injury Task Force and **55 organizations** in sending a letter to the Chairman and Ranking Member of the LHHS Subcommittee of the House Appropriations Committee, asking them to support increased funding for several programs funded through the Traumatic Brain Injury Act. We request the total amount of \$36.8 million in the FY 2003 Labor, Health and Human Services, and Education appropriations bill.

Traumatic Brain Injury (TBI) is the leading cause of death and disability in young Americans. Approximately 2 million Americans experience TBI each year. About half of these cases result in at least short-term disability, and 50,000 people die as a result of their injuries. Every year about 80,000 people sustain severe brain injuries leading to long term disability. An estimated 5.3 million Americans are living with long term, severe disability as a result of brain injury and as many as 6.5 million Americans are living with some form of permanent effects of mild and moderate brain injuries. The national cost is estimated at more than \$48 billion annually.

We are proud to share the endorsement of increased funding for the TBI act with the following 55 organizations which "represent major national and international groups devoted to furthering programs and research."

If you would like to sign on to the letter or have any questions please contact Ann Marie Benitez (Rep. Pascrell) 5-5751 or Alan Eisenberg (Rep. Greenwood) 5-4276.

Sincerely,

Rep. Jim Greenwood

co-Chair

Congressional Brain Injury

Task Force

Rep. Bill Pascrell, Jr.

Co-Chair

Congressional Brain Injury

Task Force

American Academy of Neurology; American Brain Injury Network; Coalition for American Trauma Care; International Brain Injury Association; National Association of Protection and Advocacy Services; National Association of State Head Injury Administrators; National Brain Injury Research, Treatment and Training Foundation; Brain Injury Association of Alabama; Brain Injury Association of Arizona; Brain Injury Association of Arkansas; Brain Injury Association of Colorado; Brain Injury Association of Connecticut; Brain Injury Association of Delaware; Brain Injury Association of Florida; Brain Injury Association of Georgia; Brain Injury Association of Hawaii; Brain Injury Association of Idaho; Brain Injury Association of Illinois; Brain Injury Association of Indiana; Brain Injury Association of Iowa; Brain Injury Association of Kansas; Brain Injury Association of Kentucky; Brain Injury Association of Maine; Brain Injury Association of Maryland; Brain Injury Association of Massachusetts; Brain Injury Association of Michigan; Brain Injury Association of Minnesota; Brain Injury Association of Mississippi; Brain Injury Association of Missouri; Brain Injury Association of Montana; Brain Injury Association of Nebraska; Brain Injury Association of New Hampshire; Brain Injury Association of New Jersey; Brain Injury Association of New Mexico; Brain Injury Association of New York; Brain Injury Association of North Carolina; Brain Injury Association of North Dakota; Brain Injury Association of Ohio; Brain Injury Association of Oklahoma; Brain Injury Association of Oregon; Brain Injury Association of Rhode Island; Brain Injury Association of South Carolina; Brain Injury Association of Tennessee; Brain Injury Association of Texas; Brain Injury Association of Utah; Brain Injury Association of Vermont ;Brain Injury Association of Virginia; Brain Injury Association of (Northern Virginia); Brain Injury Association of West Virginia; Brain Injury Association of Washington, Brain Injury Association of Wisconsin, Brain Injury Association of Wyoming, Brain Injury Association of E. Pennsylvania; Brain Injury Association of Washington DC; and Brain Injury Association of California.

The Honorable Ralph Regula
Chairman, Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
2358 Rayburn House Office Building
Washington, D.C. 20515-6024

Dear Chairman Regula:

The undersigned members of the Congressional Brain Injury Task Force and other Members of Congress urge you to include increased funding for several programs funded through the Traumatic Brain Injury Act of 1996 (P.L. 104-166) in the FY 2003 Labor, Health and Human Services, and Education appropriations bill to the total amount of \$36.8 million. These funds are sorely needed, and will help ensure that a greater percentage of the estimated 5.3 million Americans living with a disability as a result of a traumatic brain injury (TBI) have access to the services they need.

<u>The Health Resources and Services Administration (HRSA): State grants: \$9.8 million and Protection and Advocacy Services: \$5 million.</u>

- The Health Resources and Services Administration (HRSA) administers a state grant program for the purpose of carrying out planning, demonstration, and system capacity building projects to enhance access to health and related services for individuals with TBI and their families. To date, 45 states have been able to participate in this program, primarily at the planning level. HRSA has entered into contracts with nonprofit organizations to support the program and carry out goals that are national in scope. While Congress appropriated \$6 million for this program in FY 2002, a \$1 million increase over FY 2001, additional funding is needed to ensure that every state can participate. We are requesting \$9.8 million for the program in FY 2003, an increase of \$3.8 million over FY 2002. With these additional funds, all states with competitive proposals will be assured of funding, wherever that state may be in the development of a coordinated service delivery system, and allow HRSA to address the serious needs of emerging TBI populations such as Native American populations and individuals who are aging with TBI.
- The Children's Health Act of 2000 (P.L. 106-310) reauthorized the Traumatic Brain Injury Act to create a new state-based protection and advocacy (P&A) services program within HRSA. Congress included \$1.5 million for this new program in FY 2002. However, under the statute, grants may not be awarded for every state unless the appropriation exceeds \$2.7 million. Therefore, in order to ensure that each state has the resources necessary to conduct P&A services, we request that you include \$5 million for this program, which represents the full authorization for this program. This funding level will ensure that, in the implementation of a formula grant, each state is proportionately funded based on population.

CDC: Surveillance, Registries and National Education/ Public Awareness: \$7million

• The Centers for Disease Control and Prevention (CDC) also conducts TBI-related programs. CDC supports the collection, analysis, and reporting of data that show the magnitude and impact of TBI at state and national levels. CDC also promotes the use of data and data systems to increase awareness about TBI and to help people get services. The Children's Health Act of 2000 included a new authorization for CDC to develop a national program for TBI registries. CDC currently funds 12 states for statewide surveillance of TBI deaths and hospitalizations. CDC also funds a follow-up registry to document disability and other outcomes of TBI, including the need for services. In addition, CDC is charged with implementation of a national education and public awareness campaign. Since studies show that many people who have reported a TBI-related disability do not get the services they need, we feel it is important that individuals with TBI and their families have access to a "one stop" information center that can provide people with information on state-specific resources and services available to them. Due to CDC's increased responsibilities under the TBI Act, we request the current level of \$3 million (reflecting pre-reauthorization activities) increase by \$3 million; also, we request \$1 million for CDC to phase in this "one-stop" information resource center and 1-800 number for a total request for CDC of \$7million.

NIH: Basic Science, Applied Research & Cognitive Rehabilitation: \$15 million

- Finally, we need to continue to fund research to develop effective strategies to treat and eventually provide a cure for individuals with traumatic brain injury. The National Center for Medical Rehabilitation Research at the National Institutes of Health is in the process of launching a Cooperative Multi-Center Traumatic Brain Injury Clinical Trials Network. The primary scientific objective of the TBI Clinical Trials Network will be to identify which intervention variables result in improvements in long-term outcome for individuals with TBI. This program will be funded at \$5million annually.
- While the work that will be carried out by the TBI Clinical Trials Network is of critical importance, it is imperative that we continue to support research into the neurophysiology of TBI. The National Institute for Neurological Disorders and Stroke (NINDS) currently funds five research centers at \$1 million each. These five bench science research centers have now developed the laboratory models which will serve as the foundation for future research. Therefore, it is now time to augment the funding of these centers in order to intensify and accelerate and expand the research agenda. Therefore, we are requesting an additional \$1 million for each of these five centers, for a total funding level of \$10 million.

We thank you for your consideration of our requests. We are aware of the difficult task you face each year, as you must carefully consider a litany of funding requests. We believe these funds certainly represent money well spent and will help us better serve the needs of individuals with TBI and their families; a group currently very unserved and underserved at all levels of government.

Sincerely.