Join the Fight against Lou Gehrig's Disease
Support Continued Funding for the National ALS Registry

This is a Programmatic Request

Deadline to Sign-April 1, 2009

Dear Colleague:

Please join us in the fight against Lou Gehrig's Disease (Amyotrophic Lateral Sclerosis, ALS) by supporting continued funding for the national ALS patient registry during the FY 2010 appropriations process.

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's Disease, is a fatal, progressive neurodegenerative disease that affects motor nerve cells in the brain and spinal cord. Approximately 5,600 people in the U.S. are diagnosed with ALS each year, and it is estimated that as many as 30,000 Americans have the disease at any given time. The average life expectancy for a person with ALS is 2 to 5 years from the time of diagnosis. It has been more than 140 years since ALS was first identified as a disease, but we still do not know what causes the disease, how it can be effectively treated or cured, or why it strikes military veterans at twice the rate as the general public.

In 2008, Congress passed and the President signed into law the ALS Registry Act (P.L. 110-373), which authorizes the Centers for Disease Control and Prevention (CDC) to establish a national ALS patient registry. Congress also supported the registry through the appropriations process, providing funding for registry projects in each of the past four fiscal years, including $5 million as part of the FY 2009 Omnibus Appropriations Act. **We hope you will join us in supporting a $5 million appropriation for the CDC in FY 2010 to continue this vital project.** This is a programmatic request that would help arm our nation's scientists with the information they need to advance research and find a treatment for this devastating disease.

Thanks to previous Congressional appropriations, the CDC has initiated several projects that are building the foundations of the ALS registry, determining the most effective ways to identify ALS cases, share information and avoid duplication. However, continued funding is needed in FY 2010 to enable the CDC to implement the ALS Registry Act and meet reporting and progress deadlines set by Congress. Funding will also ensure the CDC can collect vital information on a broader scale and explore opportunities for the registry to facilitate public health initiatives, epidemiologic studies, and research into biomarkers, risk factors, and clinical studies to identify new treatments for the disease.

Together, we can find a treatment and cure by continuing funding for the national ALS registry. Please join us in signing the attached letter to the Subcommittee on Labor, HHS & Education.

If you would like to sign the letter or have further questions, please contact Emily Gibbons with Rep. Eliot Engel at 5-2464 Tessie Abraham with Rep. Lee Terry at 5-4155. The deadline for signing the letter is COB April 1, 2009.

Sincerely,

Eliot L. Engel
MEMBER OF CONGRESS

Lee Terry
MEMBER OF CONGRESS

The Honorable David Obey
Chairman
Subcommittee on Labor, HHS & Education
Committee on Appropriations
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Todd Tiahrt
Ranking Member
Subcommittee on Labor, HHS & Education
Committee on Appropriations
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Obey and Ranking Member Tiahrt:

We are writing to respectfully request that during consideration of the FY 2010 Labor/HHS Appropriations Act, the Subcommittee include $5 million in funding for the Centers for Disease Control and Prevention (CDC) to continue the ALS patient registry. This is a programmatic request, and not an earmark, that would build upon previous Congressional appropriations and enable the CDC to continue vital work underway to combat, prevent, and find a treatment for Lou Gehrig's Disease.

Lou Gehrig's Disease (Amyotrophic Lateral Sclerosis, ALS) is a particularly cruel disease that destroys a person's ability to control muscle movement. As the disease progresses, its victims become trapped inside a body they no longer can control; unable to walk, talk, breathe or even blink an eye. There is no effective treatment for ALS, no known cause and no cure. Military veterans are approximately twice as likely to die from ALS as those who have not served in the military; although the disease can strike anyone, regardless of their age, gender, race or nationality. And it is always fatal – in an average of two to five years following diagnosis.

Congress has expressed strong support for the ALS registry at CDC. In 2008, the House passed authorization legislation, the ALS Registry Act, by an overwhelming 415-2 vote and the President signed the bill into law (P.L. 110-373) on October 8, 2008. Moreover, Congress also has supported the ALS registry through the appropriations process by providing vital funding in each of the past four fiscal years, including $5 million for the registry as part of the FY 2009 Omnibus Appropriations Act.

Current appropriations have enabled the CDC and Agency for Toxic Substances and Disease Registry (ATSDR) to launch projects that are evaluating the most effective and efficient ways to identify cases of ALS and to share information. Funding is needed in FY 2010 to build upon these projects and enable the CDC to implement the ALS Registry Act, and meet reporting and progress deadlines set by Congress. In addition, this funding will allow CDC to collect information on a broader scale and explore opportunities for the registry to facilitate public health initiatives, epidemiologic studies, and research into biomarkers, risk factors, and clinical studies that identify new treatments for the disease.

We urge you to support this programmatic request and include $5 million in the FY 2010 LHHS Appropriations Act to continue the national ALS patient registry. We look forward to working with you and the Subcommittee on this important issue. Thank you for your consideration.

Sincerely,

Eliot L. Engel
MEMBER OF CONGRESS

Lee Terry
MEMBER OF CONGRESS