

NATIONAL ALS REGISTRY

Issue:

The ALS Association urges Congress to appropriate \$10 million in FY 2014 to continue the National ALS Registry at the Centers for Disease Control and Prevention (CDC). This is an authorized program request, not an earmark.

Congressional and CDC Activity:

- On October 8, 2008, the President signed into law the ALS Registry Act (Public Law 110-373), legislation that passed the Senate by unanimous consent and the House by a 415-2 vote. The law authorizes CDC to establish a national ALS patient registry.
- Congress has provided more than \$33 million over eight years to support the design and implementation of the National ALS Registry and the Registry has consistently been included in the President's budget request to Congress. The CDC fully implemented the ALS Registry in October 2010 (www.cdc.gov/ALS).

Appropriations Needed to Continue the ALS Registry

- The Registry may close without continued funding, wasting more than \$33 million that Congress already has appropriated for this critical research project. Without funding, the Registry cannot achieve the goals Congress set when it passed the ALS Registry Act, which include identifying cases of ALS throughout the country and advancing the search for the cause, treatment and cure for ALS.
- Reducing or eliminating funding in FY 2014 could prevent the Registry from identifying cases of ALS in all 50 states and significantly limit the ability of the Registry to drive ALS research and improve standards of care.
- Funding is needed in FY 2014 to continue the Registry, including to coordinate federal efforts, help people enroll in the Registry and conduct outreach activities to identify cases in every state, in rural and urban underserved areas and in minority populations. Funding also is needed to enable the Registry to collect additional information about the disease, such as information about head trauma, and to establish a biorepository that would collect critical DNA and tissue samples. Moreover, continued funding will help drive enrollment in clinical trials and link this powerful tool to epidemiologic studies and research into biomarkers and risk factors, all of which can lead to the discovery of the cause and treatment for ALS.

Need for the ALS Registry

- The National ALS Registry will help to determine causes of ALS and significantly enhance the nation's efforts to find a treatment and cure for ALS, a disease for which there currently is no effective treatment and the average lifespan is just two to five years following diagnosis.
- In addition to collecting data on the incidence and prevalence of ALS, the Registry is gathering data on environmental and occupational factors that may be associated with the disease; the age, race and ethnicity of individuals with ALS; family history; military service; and other information that is vital to ALS research.
- The Registry will help to streamline current research, avoid duplication and improve efficiency by ensuring collaboration among existing projects as well as efforts underway at other federal agencies such as the National Institutes of Health and the Department of Veterans Affairs.
- The National ALS Registry is an integral part of the scientific community's goal to learn what causes ALS and how it can be effectively diagnosed, treated, and cured.

Please join your constituents in the fight against ALS by **sending a letter requesting the Appropriations Committee provide \$10 million for the National ALS Registry in FY 2014.** A sample letter is available here:

<http://capwiz.com/alsa/forpolicymakers/>.



DOD RESEARCH FUNDING

Issue:

The ALS Association urges Congress to appropriate \$10 million in FY 2014 to continue the ALS Research Program (ALSRP) at the Department of Defense. This is a program request, not an earmark.

Key Facts:

- Over six years, Congress has appropriated a total of \$39.4 million for the ALSRP, including \$7.5 million in FY 2013.
- Funding for the ALSRP is part of the DOD's Congressionally Directed Medical Research Programs and is initiated solely by Congress. As a Congressionally directed program, it is not included in the President's annual budget request. However, funding for the ALSRP is not an earmark; the program supports researchers nationwide via competitive grants.
- The ALSRP is the only ALS-specific research program at the DOD and was created to find a treatment for ALS, a disease for which there is no effective treatment. Unlike other federal research efforts, which focus on basic science, the ALSRP advances translational research and fills a gap in the drug development pipeline in which limited funding prevents promising treatments from reaching patients. The ALSRP also supports the best science as projects are peer reviewed and awarded on a competitive grant basis to researchers nationwide. Importantly, the program is a partnership between the DOD, VA, NIH and the private sector to avoid duplication and ensure that scarce resources are provided to the most promising projects across the country.

Military Relevance:

- Studies funded by the DOD, the VA and the NIH found that veterans of the 1991 Gulf War are twice as likely to develop ALS as those not deployed to the Gulf. However, researchers at Harvard University found in 2005 and 2009 studies that military veterans from other eras, ranging from before World War II to post Vietnam, also are nearly twice as likely to develop ALS as those who have never served in the military.
- In 2008, the Department of Veterans Affairs acknowledged the link between ALS and military service by implementing regulations to establish a presumption of service connection for ALS. Under the regulation, the VA presumes that the development of ALS was aggravated by or incurred during a veteran's service in the military. In December 2011, the VA updated those regulations to provide that veterans with ALS automatically receive a minimum 100% disability rating, enabling them to access benefits they need as soon as possible.
- The ALS Association has developed a report, "ALS in the Military," that summarizes the studies that have been conducted. The paper can be found at http://www.alsa.org/assets/pdfs/advocacy/als_military_paper.pdf.

Appropriations Needed to Continue ALS Research:

- The only ALS specific research program at DOD will be eliminated if funding is not appropriated for FY 2014. Moreover, Congress will eliminate a program designed to find a treatment for a disease that is directly related to military service at a time when the needs of our servicemen and women returning from Iraq and Afghanistan may be greatest.
- Funding for the ALSRP already has been reduced as funding was cut 20% in FY 2012. The current funding level only is expected to fund approximately five of the more than 100 grant requests expected this year. As a result, more than 95% of projects will not receive funding.
- Increased funding in FY 2014 is urgently needed to discover a treatment that can save or extend the lives of our military heroes who each day risk their own lives in defense of this country. In addition, increased funding may help us learn what about military service causes ALS and how it can be prevented.

Please support our nation's military heroes by **sending a letter requesting the Appropriations Committee provide \$10 million for the ALSRP in FY 2014.** A sample letter is available here: <http://capwiz.com/alsa/forpolicymakers/>. Together, we can find a treatment and cure for Lou Gehrig's Disease.

