

Past ALS Legislative Issues

The following are just a few of the accomplishments that have resulted from past advocacy efforts:

- The MODDERN Cures Act (H.R. 3116) is actively being discussed in legislation. This bill would accelerate the search for a treatment for ALS by encouraging research on treatments that have been set aside or abandoned in the lab, but hold promise as a successful treatment; remove barriers and provide incentives to develop new diagnostics and ensure timely and appropriate reimbursement for new tests and treatments to allow patients have access to the latest medical technology as soon as possible.
- In February 2013, the U.S. Food and Drug Administration (FDA) conducted its first-ever public hearing specific to ALS. Patients, caregivers, physicians and researchers addressed a panel of representatives from the FDA. The ALS Association and MDA partnered together to represent the ALS community at large and urged the FDA to partner with the community to help expedite the drug development and approval process and bring new treatments to patients as soon as possible. A variety of topics were discussed including: how people with ALS view benefit and risk; innovation and flexibility on clinical trial design; FDA engagement with investigators and industry leaders early and more frequent during the development process; the speed of the regulatory process; and FDA engagement with patients, organizations, including during the review process.
- In December 2011, the Veterans Administration officially established ALS as a service connected disease, meaning that military veterans with ALS now have access to the highest level of VA benefits without having to prove that their disease was caused by their service in the military. Studies funded by the DOD, the VA, the National Institute of Health and Harvard University discovered that veterans ranging from World War II to post-Vietnam are twice as likely to develop ALS than those who have never served in the military.
- For fiscal year 2011, Congress increased funding for the ALS Research Program (ALSRP) at the Department of Defense by \$500,000--bringing the total appropriated to \$8 million. The funding was included in the budget agreed to by Congress and the President and which was signed into law.

- In 2008, Congress mandated that the Agency for Toxic Substances and Disease Registry develop a national registry to gather and organize information about people living with ALS. The information collected by the National ALS Registry is being used to identify risk factors, estimate the number of people who have ALS at a specific point in time and help understand who gets ALS. The information may be used also to improve how the disease is managed and how standards of care are developed. To learn more about the National ALS Registry, click [here](#).
- The ALS Research Program was established by Congress in 2007 with an initial \$5 million appropriation and a mission to support preclinical therapy development for ALS. The research program has been funded every year since FY2009.
- The Social Security Administration included ALS on a list of conditions automatically qualified for expedited reviews, shortening review times to an average of just six to eight days.
- The Medicare-Prescription Drug Bill was enacted on December 8, 2003 which advocated optional drug benefits in which Medicare covers 95% of out-of-pocket drug costs above \$3,600 and provides even greater benefits to low-income individuals.
- Effective July 1, 2001, Congress waived the 24-month Medicare waiting period for those diagnosed with ALS.
- The Improving Access to Clinical Trials Act was passed, dictating that compensation of up to \$2,000 for participating in clinical trials can't be considered income in Social Security Supplemental Income (SSI) and Medicaid determinations. This enables people with ALS to participate in trials without putting their eligibility at risk.