



**Written Testimony of the ALS Association on H.R. 6001 – The Veterans with ALS Reporting Act
United States House of Representatives
Veterans Affairs Committee, Subcommittee on Health
Legislative Hearing
January 13, 2026**

On behalf of the more than 30,000 Americans living with amyotrophic lateral sclerosis (ALS) and their caregivers that we serve, The ALS Association thanks you for this opportunity to share our views on H.R. 6001, the *Veterans with ALS Reporting Act*. In addition, we would like to thank the co-chairs of the Congressional ALS Caucus for their leadership in the fight to make ALS a livable disease while we develop a cure for this devastating disease.

The ALS Association is the largest philanthropic funder of ALS research around the world. The Association funds global research collaborations, supports people living with ALS and their loved ones in their communities, and advocates for better public policies for people with ALS. The ALS Association builds hope and enhances quality of life while urgently searching for new treatments and a cure. For more information about The ALS Association, visit our website at www.als.org.

ALS, sometimes called Lou Gehrig's disease, is a rapidly progressive and always fatal neurological disease that attacks the nerve cells responsible for controlling voluntary muscles. The life expectancy of a person with ALS averages about two to five years from the time of diagnosis. The cause of ALS is not known and there is no cure. Annual costs associated with ALS, both direct for medical care and indirect costs like lost income, are over \$1 billion in the US.

For military veterans, the reality is even more sobering. Decades of research have confirmed that veterans, whether they serve in times of war or peace, are at significantly greater risk of developing ALS compared to their civilian counterparts. Because of ALS's connection to military service, the Department of Veterans Affairs has recognized ALS as a service-connected disease and assigns a 100% disability rating upon diagnosis. While this link is recognized, the causes and ways to protect military personnel defending our freedoms are still unclear.

H.R. 6001, the *Veterans with ALS Reporting Act*, represents an urgent opportunity for Congress to support our veterans living with ALS and their loved ones. This bill is no- to low-cost for the Veterans Administration (VA). Even though the VA provides excellent care for our veterans living with ALS and their caregivers through their ALS System of Care, there are gaps in care that need to be addressed for this vulnerable population. H.R. 6001 aims to find those gaps.

H.R. 6001 requires the Secretary of Veterans Affairs, in consultation with the Director of the Centers for Disease Control and Prevention, to submit a report to Congress on the incidence and prevalence of ALS in veterans. The report must include:

1. An assessment of ALS incidence and prevalence in veterans.
2. A description of resources and support provided to veterans with ALS.
3. Identification of any deficiencies in those resources and support.
4. A strategy to develop and test risk reduction strategies for ALS.
5. A pathway for veterans receiving ALS care within VA clinics to participate in clinical trials and research.
6. Recommendations for further legislative action to address the challenge of ALS among our military and veterans.
7. Ongoing tracking of ALS prevalence in veterans using the CDC's National ALS Registry and Biorepository, with updates to Congress every three year.

This bill serves not only as a report, but also as essential support for veterans living with ALS and their families. It represents a commitment to actively pursue solutions that address this serious disease, reinforcing efforts to promote the health and readiness of the military community.

We appreciate the Committee's consideration of H.R. 6001, the *Veterans with ALS Reporting Act*. The ALS Association strongly endorses this legislation and urges swift advancement of this bill. Veterans living with ALS do not have the luxury of time. This bill is a key step toward ensuring veterans receive the protection, information, and care they deserve.