



## 2019 Public Policy Priorities

### New Congress

#### Educate, Advocate, Mobilize

The ALS Association will focus on educating, advocating and mobilizing all members of Congress in a bipartisan fashion to achieve the mission of The ALS Association:

*To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.*

### Lead Initiatives

#### 1. Waive the Five-Month Waiting Period for Social Security

The ALS Disability Insurance Access Act, to be introduced in the 116th Congress, will eliminate the five-month waiting period for Social Security Disability Insurance (SSDI). Under current law, people with ALS who qualify for SSDI must wait five months before receiving SSDI and access to Medicare. The legislation would eliminate the five-month waiting period for people with ALS.

#### 2. Preserve and Increase Federal Resources for ALS Research

##### ▪ Department of Defense

Provide at least a \$20 million appropriation to continue the ALS Research Program (ALSRP) at the Department of Defense (DOD). Research has repeatedly demonstrated that military veterans, regardless of branch or era of service, are approximately twice as likely to die from ALS than civilians. The ALSRP funded as a part of the Congressional Directed Medical Research Program at DOD, provides competitive grants that are an essential component of efforts to identify treatments and a cure for ALS.

##### ▪ National ALS Registry

Provide a \$10 million appropriation to continue the National ALS Registry and Biorepository at the Centers for Disease Control and Prevention. The Registry collects and analyzes data and directs a Bio Repository. It works in close collaboration with the Centers for Medicare and Medicaid Services, the Veteran's Administration, the Department of Defense ALS research program and the National Institutes of Health (NIH). It is a critical driver of the search to find treatments and a cure

because it connects researchers conducting clinical trials with people living with ALS and funds its own important research.

- **National Institutes of Health**

Continue ALS Research at the National Institute for Neurological Disorders and Stroke and other Institutes at the National Institutes of Health (NIH). In FY19, NIH spent approximately \$83million for ALS research, with National Institute of Neurological Disorders and Stroke (NINDS) making the largest investment and four other NIH Institutes contributing the balance. The ALS Association will work in collaboration with other national organizations to advocate for \$41.6 billion in funding for the NIH in 2019 (a \$2.5 billion increase over 2018) so that NIH can maintain and increase this level of commitment to ALS research.

**3. Access to Home Health Services**

Achievable policy solutions are needed to improve access to home health services for people living with ALS. Federal government concerns about waste, fraud, and abuse of Medicare home health benefits for all seniors and misunderstandings about the scope of the benefit have significantly limited access for people living with ALS. In 2019, The ALS Association will continue to educate and advocate with the Administration and Congress on the home health needs of people with ALS as well as identify achievable ways to remove barriers through regulatory and legislative action.

**4. Represent People Living with ALS on Access to Health Care and Medications**

It is anticipated that both legislative and administrative proposal will be introduced that will impact access to health care and medications. The ALS Association will closely monitor and work with other patient advocacy groups to examine emerging proposals to determine their impact on people with ALS and their families.