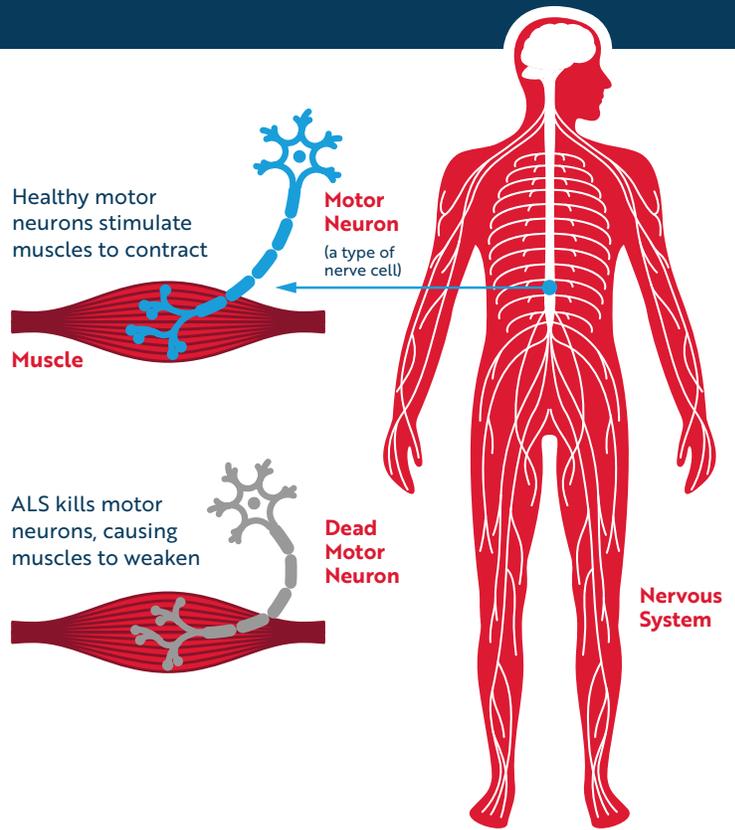


ALS IS A PROGRESSIVE NEURODEGENERATIVE DISEASE THAT AFFECTS NERVE CELLS IN THE BRAIN AND SPINAL CORD.

ALS usually strikes people between the ages of 40 and 70, but it can strike anyone at any time. There are more than 16,500 Americans living with ALS.

Although there is not yet a cure or treatment that halts ALS, scientists we fund through our global research program have made significant progress in understanding what causes ALS. But their work is not done. Together, we work toward a cure.



FACTS ABOUT ALS

5,000+ people are diagnosed per year

10% of cases are inherited through a mutated gene

2-5 YEARS is the average life expectancy

90% of cases occur without family history

Every **90 MINUTES** someone is diagnosed and someone passes away

\$250,000 is the estimated out-of-pocket cost for caring for a person with ALS

Only 4 DRUGS are currently approved by the U.S. FDA to treat ALS (Riluzole, Nuedexta, Radicava, and Tigtulik)

\$2 BILLION is the estimated cost to develop a drug to slow or stop the progression of ALS

There is **NO CURE** for ALS



SYMPTOMS

Progressive loss of muscle control

- ALS gradually prohibits the ability to:
 - Speak
 - Grasp objects
 - Swallow
 - Move
 - Walk
 - Breathe



DIAGNOSIS

Difficult to diagnose

- ALS is often diagnosed by ruling out other diseases, which may take months or years



MILITARY

Veterans are more likely to get ALS

- ALS affects veterans who served in peacetime and war
- ALS impacts veterans, regardless of the branch of service or the war they served in

We bring together the ALS community to speak with one voice to increase awareness, advocate for research funding and improved access to healthcare, and educate legislature at a federal level, impacting thousands of people with ALS and their families. Our 39 chapters and over 16,000 ALS Advocates are essential to our success. This advances our mission 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.

Here are 2018's BIGGEST successes in ALS advocacy!

\$10M
NATIONAL ALS
REGISTRY

Led the charge to **secure \$10 million in appropriations** for the National ALS Registry at Centers for Disease Control and Prevention to identify genetic and environmental factors for ALS, provide support to researchers to find treatments and a cure, and promote access to clinical trials.



Spearheaded the effort to pass bipartisan ALS Disability Insurance Access Act to waive 5-month wait for people living with ALS. As of October 2018, 154 Representatives and 34 Senators support it.

\$10
MILLION

Successfully protected the ALS Research Program at the Department of Defense (DOD), resulting in \$10 million in appropriations and ensuring its place at the DOD.



Continue to play a key role in **ensuring people with ALS have access to wheelchairs, speech-generating devices, and other complex technology** through legislative and regulatory pressure.

NIH
\$39.1B

Joined with other leading patient organizations to secure \$39.1 billion in funding for **the National Institutes of Health (NIH)** for FY2019. In 2018, NIH spent \$83 million in FY2018 on ALS research.



Joined with other leading patient organizations in the fight to **preserve protections for pre-existing conditions for people with ALS** under Medicare, Medicaid, private insurance, and all insurance plans.



Continued leadership on **ensuring patient voice in the FDA's Draft Guidance on ALS Drug Development** by hosting a public forum that provided the FDA with targeted feedback and information from people with ALS, caregivers, and stakeholders.

500
MEETINGS
6 ACTION
ALERTS

Supported nearly **500 meetings with Members of Congress** at the Advocacy Fly-In and National ALS Advocacy Conference. **Empowered more than 16,000 ALS Advocates** with six action alerts – resulting in nearly **4,700 advocacy messages** to Congress.



Advocated with Centers for Medicare and Medicaid Services to **remove barriers to Medicare home health for people living with ALS** and initiated a multi-year effort to influence Congress and federal officials.

Our nationwide chapters carry out our mission at both the state and community level and many have achieved successes in securing state-level services and support. Together, we provide an array of services to people living with ALS and their caregivers, work with our national network of ALS Certified Centers of Excellence, and support global ALS research efforts.