



Community of Hope

Celebrating loved ones with Lou Gehrig's Disease

Quick Stats about ALS & The ALS Association

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About ALS

- › A French neurologist named Jean-Martin Charcot first identified ALS in 1869, but the cause of the disease is not known.
- › ALS, or amyotrophic lateral sclerosis, is also referred to as Lou Gehrig's Disease after the New York Yankee who was diagnosed with the disease in 1939. He died from ALS on June 2, 1941 at the age of 37.
- › ALS is a neurodegenerative disease that affects the nerve cells in the brain and spinal cord, which eventually leads to muscle paralysis.
- › For unknown reasons, military veterans are twice as likely to be diagnosed with ALS than the general population.
- › Currently, there is no cure for ALS or any long-term effective treatments. There is only one FDA-approved drug, Rilutek, that expands a person with the disease's life by a few months.
- › Anyone can get ALS, but most commonly, the disease strikes people between the ages of 40 and 70, and as many as an estimated 30,000 Americans have the disease at any given time.
- › For reasons unknown, military veterans are approximately twice as likely as the general public to get ALS.
- › Approximately 5,600 people in the U.S. are diagnosed with ALS each year.
- › Every 90 minutes, someone in the U.S. will be diagnosed with ALS; every 90 minutes someone will die from the disease.
- › An estimated 10% of ALS is familial, or genetic, whereas 90% is sporadic or occurs randomly.

- › ALS affects a person's ability to eat, breathe, speak and move.
- › On average, a person with ALS will live two to five years following diagnosis of the disease.
- › About twenty percent of people with ALS live five years or more, and up to ten percent will survive more than ten years, and five percent will live 20 years.
- › There are people in whom ALS has stopped progressing and a small number of people in whom the symptoms of ALS have reversed.
- › In the advanced stage of the disease, the cost of caring for a person with ALS can cost more than \$250,000 annually.
- › Aside from Gehrig, other notables who have died from ALS include baseball Hall of Fame pitcher Jim "Catfish" Hunter; actor David Niven; jazz musician Charles Mingus; and New York Senator Jacob Javits. Today, athletes living with ALS include football players O.J. Brigance (Baltimore Ravens), Kevin Turner (New England Patriots; Philadelphia Eagles) and Steve Gleason (New Orleans Saints).

About The ALS Association

- › The ALS Association consists of 38 chapters and affiliates which provide comprehensive care and support to families living with ALS.
- › The ALS Association works in various capacities: We fund and support global research; advance public policy initiatives through working with various government entities; educate families coping with the disease thru care services; and educate the public about the disease through working with the media.

Chapter & Care Services Information

- › The services some of our chapters provide include support groups, patient education programs, physician referrals, equipment loan closets and respite care. In general, these services are free of charge for people with ALS and their families.
- › We have 34 Centers of Excellence and 38 ALS clinics across the U.S.
- › Our nationwide network of ALS Association Certified Centers of Excellence provide state-of-the-art, multi-disciplinary ALS care and services in a supportive atmosphere with an emphasis on hope and quality of life. To become certified as one of these centers of excellence, an ALS clinic must achieve national prominence, meet stringent clinical care standards, and pass a comprehensive site inspection.
- › Each month, our Care Services Department provides webinars on living with ALS. The department also publishes an online newsletter with expert advice on coping with the disease.

Research

- › To date, we have committed more than \$80 million in research toward finding treatments and a cure for ALS.
- › We fund basic to clinical research, and our TREAT ALS initiative (Translational Research Advancing Therapy for ALS™) strives to accelerate the clinical testing of compounds that show promise as treatments for the disease.
- › Some of our recent research findings involve the funding of two studies that found a genetic abnormality that, according to researchers, is the most common cause of amyotrophic lateral sclerosis (ALS) and frontotemporal dementia (FTD).
- › We have partnered with the Muscular Dystrophy Association to fund a clinical trial to test the effectiveness of a diaphragm pacing system in people with ALS. The device activates the diaphragm, supplementing breathing ability and possibly delaying diaphragm shrinkage (atrophy). Respiratory failure is the most common cause of death in people with Lou Gehrig's Disease.
- › We also work with NEALS (Northeast Amyotrophic Lateral Sclerosis Consortium) to provide information about clinical trials currently recruiting people living with ALS. (NEALS website: <http://www.alsconsortium.org>).
- › Clinical trials involve a scientist, or a group of scientists, who directly observe a person or people to gather data to answer a question about the safety or effectiveness of a certain medication or device.
- › Each month, our Research Department hosts a webinar with ALS experts in the U.S. and abroad who discuss scientific topics of interest to the ALS community.
- › The Research Department publishes updates to ALS-related research on the national website and also publishes a semi-annual publication, *Research ALS Today*.

Public Policy Efforts

- › Our organization's public policy efforts in Washington, D.C. have raised the profile of ALS at the White House, among members of Congress, and within federal agencies. These agencies include the National Institutes of Health, Centers for Medicare and Medicaid Services, Food and Drug Administration, Department of Defense, Department of Veterans Affairs, Social Security Administration, and Centers for Disease Control and Prevention.
- › A notable accomplishment of our Public Policy Department is the enactment of the ALS Registry Act to establish the first central database that will identify cases of ALS throughout the United States and collect comprehensive information about the disease never before collected on a nationwide scale. The registry, signed into law by President Bush on October 8,

2008, is administered by the Centers for Disease Control (CDC) Agency for Toxic Substance and Disease Registry (ATSDR) and is the single largest ALS research project ever created. The Registry will advance research and promote a better understanding of the disease and improved standards of care while potentially revealing clues about the causes of ALS.

- People with ALS began enrolling their information in the ALS Registry in 2010.
- Each May, ALS advocates from across the U.S., who work with our chapters, convene in Washington, D.C. for the National ALS Advocacy Day & Public Policy Conference. During this annual event, those living with Lou Gehrig's Disease and their families share their stories with Members of Congress.
- The conference is the single largest gathering of the ALS community and empowers people with ALS and their families with the ability to play an active role in advocating for a treatment and cure. This outreach to Members of Congress has helped to achieve many significant victories for people with ALS from waiving the 24-month Medicare waiting period for people with ALS to improving benefits for military veterans with the disease. The conference also helped lead to the establishment of the ALS Registry.
- ALS is the only disease for which Congress has waived the 24-month Medicare waiting period. The Association worked with Congress to waive this waiting period in 2001.
- Since Congress waived the Medicare waiting period, those with ALS have gained better access to important Medicare benefits.
- Since 1998, there has been a 500% increase in annual government funding for ALS research since 1998, the year The Association established the Public Policy Department based in Washington, D.C.
- Since the Public Policy Department's establishment, \$700 million in government funding has gone toward ALS research.

Events and Awareness

- Since 2000, we have hosted Walk to Defeat ALS® events in the spring and fall across the U.S. To date, The Walks have raised \$159 million. Monies from the Walks go toward local care services programs, research to find treatments and a cure for the disease, and federal, state and local public policy efforts.
- The Association has achieved expanded awareness of the disease and support of ALS issues through relationships with other organizations such as Major and Minor League Baseball teams. These teams work with our chapters for events such as "ALS Awareness Night."
- We have created public service announcements promoted in major markets across the U.S. for both ALS awareness and the Walk to Defeat ALS. Recent PSAs feature actor Jason Alexander of *Seinfeld* and baseball legend Tommy John. You can view the PSA on The Association's [You Tube Channel](#).