

What Is ALS?

ALS was first identified in 1869, but it wasn't until 1939 that baseball great Lou Gehrig brought national and international attention to the disease. Still commonly known as Lou Gehrig's Disease, ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord.

ALS destroys a person's ability to control muscle movement. As the disease progresses, it takes away a person's ability to move, speak, and eventually breathe.

Average life expectancy for a person with ALS is just two to five years from diagnosis. However, recent studies, many funded by The ALS Association, are providing much hope for new treatments and a cure for ALS. While the disease can strike anyone regardless of age, gender, race, or nationality, studies have found that military veterans are approximately twice as likely to develop ALS as the general public.



Progress in Advocacy

Each year, ALS advocates meet with local, state, and federal policymakers to review issues that impact the ALS community. Their outreach produces progress that is improving lives right now, including:

- More than \$1 million annually in combined state funding for ALS care services in Pennsylvania, New Jersey, and Delaware.
- Establishment of the ALS Research Project at the Department of Defense (ALSRP) and support for \$46.1 Billion in funding from The National Institutes of Health (NIH) that ultimately helps ALS research.
- Funding for the National ALS Registry, which connects researchers with valuable data from thousands of people with ALS and helps support clinical trials.
- Recognition of ALS as a military service-connected disease.
- Reducing the 24-month waiting period that people with ALS had to endure before receiving Medicare benefits.
- Enactment of the Steve Gleason Enduring Voices Act that ensures access to voice-generating devices.
- Passed The ALS Disability Insurance Access Act, which eliminates the waiting period for people with ALS to access Social Security Disability Insurance.

How You Can Help

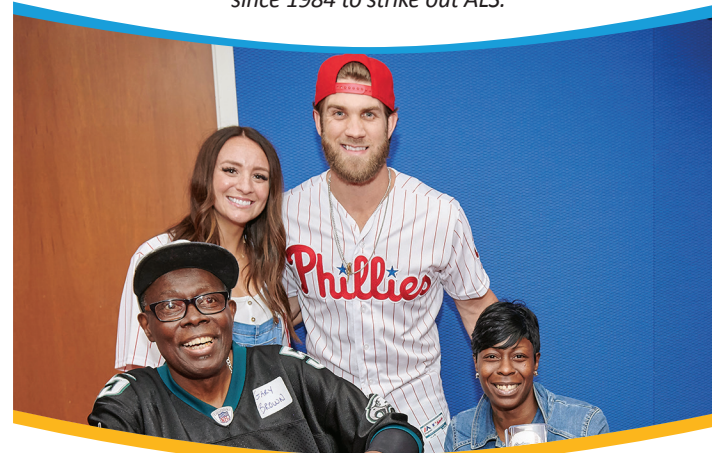
There are many ways you can support the fight against ALS – from joining a local Walk to Defeat ALS®, creating your own fundraiser, participating in advocacy efforts, or volunteering for one of the Chapter's programs or events. Additionally, there are many meaningful giving opportunities that help support our work.

About The ALS Association Greater Philadelphia Chapter

For more than 40 years, the Greater Philadelphia Chapter has worked to improve the quality of life for people with ALS by supporting critical ALS research, providing care and services to patients and their families, and promoting legislation that fosters ways to better manage, and eventually end, this devastating disease.

Since 1977, the Greater Philadelphia Chapter has served 1,200 people each year over a broad service area covering eastern and central Pennsylvania, southern and central New Jersey, and all of Delaware.

The Greater Philadelphia Chapter is honored to be the principal charity of the Philadelphia Phillies. Through this special partnership, the Phillies have raised over \$19 million since 1984 to strike out ALS.



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Fighting ALS on All Fronts

Whatever It Takes



ALS Greater
ASSOCIATION Philadelphia
Chapter

Progress in Research

The ALS Association Greater Philadelphia Chapter helps fund ALS research efforts that are leading to promising and significant advances.

Through generous donations and effective advocacy, The ALS Association has supported groundbreaking initiatives such as:

- Discovery of new genes that contribute to ALS. Knowledge of these genes allows scientists to target them for therapy, increasing the likelihood of finding a new treatment.
- Development of antisense drugs that target two of the most common ALS genes. Trials of these drugs are ongoing and aim to slow or stop disease progression. There are currently four drugs approved by the U.S. FDA to treat ALS.
- Development of cutting-edge voice technology that gives people with ALS the ability to communicate with their own voice, even after they can no longer speak.
- Advancements in wearable sensor and Brain Computer Interface technology.
- Establishment of global collaborations that target new therapies, expedite clinical trials, and make RNA and DNA sequencing data available to the entire ALS research community.

Moreover, The ALS Association, in partnership with the Northeast ALS Consortium (NEALS), provides the most accurate and up-to-date information on federally and privately funded clinical studies focusing on ALS.

ALS Treatment Centers

The Greater Philadelphia Chapter supports eight distinguished ALS Treatment Centers. These facilities deliver clinical excellence to patients and their families through a compassionate, comprehensive, interdisciplinary approach.

Southeastern PA

- The Jefferson Weinberg ALS Association Certified Center of Excellence at Thomas Jefferson University Hospital
- The ALS VA Clinic at Corporal Michael J. Crescenz VA Medical Center

South Central PA

- The ALS Association Certified Center of Excellence at Penn State Health M.S. Hershey Medical Center

North Central PA

- The ALS Association Recognized Treatment Center at Lehigh Valley Hospital
- The ALS Association Recognized Treatment Center at Geisinger Bloomsburg Hospital
- The ALS Clinic at Geisinger Wyoming Valley Medical Center

Central/Southern NJ

- Hackensack Meridian Health ALS Association Recognized Center at Jersey Shore University Medical Center

Delaware

- The TidalHealth Peninsula Regional Medical Center ALS Clinic



Progress in Care — The Arthur and Lea Powell ALS Care Services Program

ALS not only impacts health, but also quality of life, and often financial security. The Greater Philadelphia Chapter provides vital programs that help individuals with ALS and their families face the rigors of this disease with strength and confidence.

The Arthur and Lea Powell ALS Care Services Program provides patient and caregiver education, support, and recreational activities, as well as:

- **The Howard I. Abrams In-Home Care Program** which helps families with the costs of paying for a caregiver to assist them in their home.
- **The Mike Kilpatric ALS Transportation Program** which provides free transportation to medical appointments in a van accommodating ALS patients.
- **The Visiting Volunteer Program** which offers friendship and visits from those who truly understand how ALS impacts daily living.
- **The Marjorie Shimer Durable Medical Equipment Loan Program** which provides equipment, at no charge, to those who are not covered by health insurance or have high out-of-pocket deductibles. This can include transport/companion wheelchairs, power wheelchairs, and shower chairs.
- **The Chapter Accessibility Program** which installs ramping and stair glides in the homes of people with ALS who have limited or no means to purchase such items for themselves. The Chapter also offers free virtual home assessments for modifications and safety.
- **The Scott A. Mackler, MD, PhD, Assistive Technology Program** which provides assistive technology support and items such as speech generation devices and computers with voice output.