



St. Louis Regional Chapter

THE FIGHT AGAINST ALS

For more information, donate to fight ALS, or ask for assistance:

Visit www.alsa-stl.org

Did you know **Compassionate Nursing Services, LLC** helps to find a cure for ALS and improve the quality of life for ALS patients and their family caregivers each day. You too, can become involved and make a difference in the lives of those living with ALS.

What is ALS? ALS is considered one of the most devastating neurological disorders, as there is no known cause or cure. It was first detected in 1869 and gained notoriety after Legendary Yankees First Baseman, Lou Gehrig, retired from baseball in 1939, after being diagnosed with ALS, Amyotrophic Lateral Sclerosis - a fatal progressive neurodegenerative disease that causes fatigue, loss of stamina and muscle mass, and eventually paralysis.

In ALS, the progressive weakness that develops is due to selective death of motor neurons, the nerve cells that carry messages telling muscles to move. Since motor neurons are unique cells and the longest in the body, all muscle groups are affected. The patient slowly loses the ability to use his/her limbs, to speak and swallow, and ultimately, the ability to breathe due to atrophy of the diaphragm muscle.

Most commonly, ALS strikes people between the ages of 40 and 70 and as many as 30,000 Americans have the disease at any given time. Familial ALS represents between 5 to 10 percent of all diagnosed cases. The rest arise spontaneously and mysteriously, making seemingly random attacks on previously healthy adults. Veterans are reported to be diagnosed with ALS nearly twice as often as those with no history of military service, regardless of where or when they served in the military.

Who leads the Fight? Established in 1987, The ALS Association is the only non-profit organization fighting on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

Research: The ALS Association (ALSA) directs the most comprehensive, global ALS research program ever organized and is currently overseeing approximately 100 different research projects into all aspects of ALS. During the past decade, The Association has committed \$56 million toward ALS research. Each dollar has gone directly to investigators doing the research. The ALS Association's research enterprise is recognized in the ALS community for its scope and diversity. The Association has research projects covering every hypothesis that now exists about the pathogenesis of this disease. ALSA's Clinical Management Research Program focuses on managing the care of people with ALS in such areas as nutrition, respiration, mobility and psychosocial needs.

Advocacy: ALSA's network plays a lead role in advocacy for increased public and private support of ALS research and public policy initiatives that responds to the needs of people with ALS. The Association's advocacy efforts have generated more than \$365 million for ALS research over the past 10 years. Among the signature accomplishments of our Advocacy and Public Policy Department are: Better guidelines for Medicare and Social Security Benefits for patients; 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 for research; and Veterans' eligibility for service connected benefits for those diagnosed with ALS.

Patient and Community Services: The ALS Association helps patients and families through its nationwide chapter network and multi-disciplinary clinic ALS Certified Centers of Excellence.

Local Services: The ALS Association, St. Louis Regional Chapter, has local offices in St. Louis and Sikeston, Missouri as well as Peoria, Illinois serving over 350 patients each and every day throughout Eastern Missouri and Central and Southern Illinois. The Chapter provides 28 in-home services at NO COST to families struggling with ALS. It branches out to every part of a life that is affected by ALS, because ALS affects every part of a person's life.

These programs greatly improve accessibility to in-home healthcare for ALS patients and help extend their lives longer than the current two to five year timeframe. Services provided include respite care, case management counseling, spiritual and end-of-life therapy, durable medical equipment, communication device and assistive technology loan closets, Physical, Occupational, and Speech Therapy sessions, nutritional supplement, children's grief counseling, and home visits by case managers. These case managers help patients and families cope with the ever-changing symptoms, navigate through the healthcare system, and maximize a person's functional capability. Most options are not provided for ALS patients through the traditional insurance coverage. The chapter helps offset the estimated \$250,000 that it costs a family to live and fight ALS.

How Can YOU Join Compassionate Nursing Services, LLC To Fight ALS: The chapter has many opportunities to make a difference in the lives of ALS patients. These programs include: County Ambassadors: to help educate the rural healthcare network and general public; Extra Hands Volunteers: to provide non-medical assistance in the homes of ALS patient; or Walk Teams in the ALS Walk to Defeat ALS fundraising events held each year throughout the service area.