



The Urgent Need to Support ALS Programs in Pennsylvania

Overview:

At any given time, over 1,000 Pennsylvanians are living with Amyotrophic Lateral Sclerosis (ALS), also referred to as "Lou Gehrig's Disease." ALS is a fatal, progressive, neurodegenerative disease with no known cure. In Pennsylvania, almost all patient care services available to people living with ALS and their families are provided free of charge through The ALS Association's Greater Philadelphia and Western PA Chapters. With an increased awareness of ALS and The ALS Association, more patient families than ever before are looking for these vital services such as treatment at an ALS clinic, van transportation, Assistive Technology and in-home care. Due to The ALS Association's efficient and effective use of funding in previous budgets, the Pennsylvania legislature approved a \$350,000 line item for ALS patient care in 2014. Both the House and Senate 2015-16 budgets had increases for this vital line item, but this line item has not yet been passed in a final budget. Maintaining funding for ALS patients in Pennsylvania is not only critical to their well-being but is also a cost-effective measure that saves the state significant funds on an annual basis.

Why this line item funding must continue:

- The ALS Association provides direct in-home care services, which allow people with ALS to stay in their homes longer instead of living in costly long term care facilities. In Pennsylvania, the annual market value of the services family caregivers provide for "free" is estimated to be \$13.4 billion.¹
- The Chapters provide financial support to purchase, or directly loan, necessary medical equipment to patients and their families. The average cost savings generated from The Association's equipment loan program is approximately \$470.95 per person per year.²
- ALS is considered a service connected disease as military members are twice as likely to be diagnosed with ALS as the general population. Pennsylvania has the fourth largest population of military personnel and veterans in the country, totaling over 939,000.³
- State funding has made it possible for The ALS Association to provide patients with wheelchair ramps in and out of their homes, stair glides, lift chairs, bathroom modifications, adjustments to door handles, and electronic wheelchairs. The ALS Association, through state support and improved fundraising, has increased the amount of home ramping and modifications it is able to provide in Pennsylvania, making it easier for people with ALS to stay in their homes.
- Persons with ALS lose their ability to speak, which can also make it difficult for them to receive the proper care and support. The ALS Association provides speech-generating devices to those living with ALS who lose their ability to communicate. This not only improves quality of life, but also allows many persons with ALS to continue working and contributing to the tax base of the state.
- The ALS Association Chapters operate Multidisciplinary Clinics throughout Pennsylvania to serve over 1,000 people with ALS each year. ALS patients who receive their care at a multidisciplinary clinic, where they can see up to 12 specialists in a single visit, have a better prognosis than patients attending a general clinic.⁴ Patients who are healthier are able to remain in their homes longer and out of assisted-care facilities longer, saving the state as much as \$91,954 per person per year.⁵

¹ National Family Caregivers Association. <http://www.caregiveraction.org/statistics/>

² ALS Association Western Pennsylvania Chapter conducted analysis of most frequently requested loan items. Study data is available upon request.

³ http://www.va.gov/vetdata/veteran_population.asp

⁴ Traynor, Alexander, Corr, Frost, Hardiman "Effects of a multidisciplinary ALS clinic on ALS." Journal of Neurology, Neurosurgery, and Psychiatry 2003; 74:1258-1261

⁵ PHCA, "PA Long-Term Care Statistics" <http://www.phca.org/research/long-term-care-statistics.htm> Retrieved December 28, 2011.