



# The Benefit of Supporting ALS Programs in Pennsylvania

## Overview:

At any given time, over 900 Pennsylvanians are living with ALS. ALS, Amyotrophic Lateral Sclerosis, also referred to as “Lou Gehrig’s Disease,” is a fatal, progressive, neurodegenerative disease with no known cure. In Pennsylvania, the majority of support services available to people living with ALS and their families are made available through The ALS Association’s Greater Philadelphia and Western PA Chapters.

## Addressing ALS in Pennsylvania:

For FY '10-'11, the General Assembly allocated \$325,000 for ALS patient services and The ALS Association Chapters in Pennsylvania were able to provide a significant number of services to Pennsylvania constituents and healthcare professionals as a result of this funding. As a result of The ALS Association’s efficient use of that money to directly benefit patients, the legislature in 2012 approved a \$300,000 line item for ALS patient care. An allocation of \$900,000 would allow The ALS Association to not only sustain, but also grow, patient services and resources throughout the state, at a rate of just \$1,000 per person with ALS in the state. With an understanding for the many budget constraints facing the Commonwealth, The ALS Association is looking to maintain our \$300,000 line item and hopefully boost it to \$500,000. Maintaining critical funding for ALS patients in Pennsylvania is not only a good thing to do but a cost-effective measure that can save the state significant funds in the long run.

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## Providing Effective and Efficient Services:

Through donor, grant, and state funding, The ALS Association chapters of Pennsylvania are able to provide a number of important services and service referrals to ALS patients that allow them to maintain a high quality-of-life, including the opportunity to remain active in the workplace for as long as possible, delaying the onset of loss of earnings for the patient.

### Services include:

- **Medical and mobility equipment assistance programs.** 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.<sup>1</sup>
  - The ALS Association also provides \$250 equipment grants to enable ALS patients and their families to purchase long-term equipment not otherwise covered by insurance.These programs help to decrease the burden on the health care systems to provide support equipment and ensure that patients who lack adequate insurance coverage receive the services they need.
  
- **Speech-generating device acquisition and loan programs.** Speech-generating devices are vital for ALS patients who are losing their ability to communicate. These devices can cost from approximately \$5,300 to over \$21,200. The ALS Association works with patients to support speech continuation through two programs:
  - 80/20 program: The ALS Association helps patients with limited or no health insurance coverage by providing up to \$2,000 in a one time grant to purchase a speech device.
  - Loan program: the loan program helps patients and the healthcare system in two ways:
    - Medically appropriate devices – the loan program allows patients to test which speech device works best for their needs, saving health insurers from providing a

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<sup>1</sup> ALS Association Western Pennsylvania Chapter conducted analysis of most frequently requested loan items. Study data is available upon request.



## **Strengthening Pennsylvania's Healthcare System:**

Studies have shown that one of the keys to reducing the economic costs associated with ALS is education of the health care community.<sup>4</sup> The ALS Association works collaboratively with healthcare professional and health-related social service providers throughout the state to strengthen provider knowledge and resources to provide effective care for ALS patients.

### **Services include:**

- **Establishment and sponsorship of multidisciplinary clinics (MDCs).** MDCs are regularly scheduled programs that bring healthcare providers and equipment providers to a central location for the medical equivalent of an “all-inclusive” experience for patients.
  - ALS patients who receive their care at a multidisciplinary clinic have a better prognosis than patients attending a general clinic.<sup>5</sup> 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.**<sup>6</sup>
  - Multidisciplinary clinics help to reduce transportation costs for patients and public transit providers, and effectively allocate healthcare provider time, and resources.
  - MDCs also allow caregivers to spend less time away from work and other family obligations, rather than going to appointments one at a time throughout the month, often in different locations.
  - The ALS Association and its healthcare partners currently operate six MDCs in Pennsylvania. Previous state funding allowed us to expand MDC services, particularly at our Pittsburgh clinic. Without continued support, these programs face a reduction in services or closings, necessitating patients to travel to multiple doctors, and increasing the strain on both Chapter and state-funded transportation programs.
  
- **In-service trainings for healthcare professionals and site-visits**
  - When an underserved or rural community lacks healthcare providers and cannot provide necessary care, patients may have to travel over 200 miles to reach facilities that can meet their needs.
  - The ALS Association staff also work with healthcare providers to conduct in-home site visits. While these visits are important for all ALS patients, site-visits can be of critical importance for patients in rural parts of the state who are not able to travel to their primary ALS treatment sites on a regular basis.

## **Supporting Caregivers:**

Caregivers are incredibly important in the life of ALS patients. Primary caregivers for patients in Pennsylvania tend to be a family member; most often a spouse.

- Nationally, on average, 87.9% of ALS patients and other patients with neurotrauma are cared for in private homes.<sup>7</sup>
- Caregiving families have median incomes that are more than 15% lower than non-caregiving families.<sup>8</sup>

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<sup>4</sup> Klein and Forshew. “The Economic Impact of ALS.” *NEUROLOGY* 1996;47(Suppl 2):126S-129S

<sup>5</sup> Traynor, Alexander, Corr, Frost, Hardiman “Effects of a multidisciplinary ALS clinic on ALS.” *Journal of Neurology, Neurosurgery, and Psychiatry* 2003; 74:1258-1261

<sup>6</sup> PHCA, “PA Long-Term Care Statistics” <http://www.phca.org/research/long-term-care-statistics.htm> Retrieved December 28, 2011.

<sup>7</sup> Christopher and Dana Reeve Foundation. “Paralysis Resource Center.” [http://www.christopherreeve.org/site/c.mtKZKgMwKwG/b.5193227/k.AFB/Costs\\_of\\_Living\\_with\\_Spinal\\_Cord\\_Injury.htm](http://www.christopherreeve.org/site/c.mtKZKgMwKwG/b.5193227/k.AFB/Costs_of_Living_with_Spinal_Cord_Injury.htm) Retrieved October 27, 2009.

<sup>8</sup> National Family Caregivers Association. “Caregiving Statistics.” [http://www.nfcares.org/who\\_are\\_family\\_caregivers/care\\_giving\\_statistics.cfm#2](http://www.nfcares.org/who_are_family_caregivers/care_giving_statistics.cfm#2) Retrieved December 30, 2011.

- The ALS Association's Respite Care and In-Home Care programs, which assist with the costs of the home health aides to allow caregivers to remain in the workplace, prevent or diminish loss in wages to the caregiver.
- These programs also allow caregivers to continue to provide workplace-sponsored medical insurance for family members, keeping ALS patients off of Medicaid and state assistance programs.
- Nationally, the value of the services family caregivers provide for "free" is estimated to be \$306 billion a year. That is almost twice as much as is actually spent on homecare and nursing home services combined (\$158 billion).<sup>9</sup>
- **In Pennsylvania, the value of the services family caregivers provide for "free" is estimated to be \$13.4 billion a year.**<sup>10</sup>

### **Educating the Public about ALS:**

The ALS Association works to educate members of the public about ALS and how they can support others whose lives are affected by the disease. The ALS Association provides community education by:

- Participating in community health fairs;
- Maintaining educational information on its chapter's websites, which are cited by the Pennsylvania Department of Health's website for information on ALS;
- Publishing newsletters and participating in other community events on a regular basis.

### **Continuing the Fight:**

The ALS Association provides important programs and services that help to defray costs and the need for patients to receive services from state programs. Investing in essential programs for ALS patients and their caregivers, healthcare provider education, and community education creates economic and social benefits for the state and helps to meet the needs of families impacted by ALS. An allocation of \$900,000 would allow The ALS Association to not only sustain, but also grow, patient services and resources throughout the state. Understanding that financial resources are limited, an allocation of \$600,000 would allow the ALS Community to continue to receive a high level of support and care. Maintaining critical funding for ALS patients in Pennsylvania is not only a good thing to do but a cost-effective measure that can save the state significant funds in the long run. Please reinstate funding for these vital services. A small investment yields significant cost savings to the state, allows the Department of Health to operate even more efficiently, and improves the lives of hundreds of ALS patients throughout Pennsylvania.

This year, with funding tighter than ever, ALS patients and their families need your help to reinstate financial support for these vital services. It is a win/win for families living with ALS and for our state budget. Please join the fight against ALS by increasing the ALS line item to \$900,000 in the state budget to support ALS patients and their families in Pennsylvania.

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<sup>9</sup> Arno, Peter S., "Economic Value of Informal Caregiving," presented at the Care Coordination and the Caregiving Forum, Dept. of Veterans Affairs, NIH, Bethesda, MD, January 25-27, 2006.

<sup>10</sup> National Family Caregivers Association. "State Caregiving Database."  
[http://www.nfcares.org/pdfs/State\\_Caregiving\\_Databystate2006.pdf](http://www.nfcares.org/pdfs/State_Caregiving_Databystate2006.pdf)