Utilizing state resources on behalf of families with ALS in Pennsylvania

The $350,000 funding provided through a line item in the Pennsylvania state budget in FY 2014 for ALS care services was directed to provide the most positive outcomes for people living with ALS and their families. This financial support was used by The ALS Association Greater Philadelphia and Western Pennsylvania Chapters, who collectively serve over 1,000 people with Lou Gehrig's disease in our state.

The most immediate and substantial impact from the line item was through the support of Multidisciplinary Clinics at Pennsylvania Hospital, Hershey Medical Center, Allegheny General Hospital, and John P. Murtha Neuroscience and Pain Institute. These clinics allow people with ALS to see up to a dozen specialists in one visit, including a neurologist, a nurse, social worker, physical, occupational, and speech therapists, and dietician. Multiple studies confirm that ALS patients who receive care at MDC's have a better prognosis than those who do not. Funding from the ALS care services line item contributed to 477 patients utilizing these MDC's, which in turn helped contribute to over $43,917,120 in savings for the state budget, based on data through the Pennsylvania Health Care Association (PHCA). People as old as 95 and as young as 20 use these clinic services, joined by their family caregiver, to not only get the best in quality care, but to learn how to use more services, equipment, and techniques to maintain a higher quality of life in their own home.

The care provided through the ALS line item does not stop once they make it home. The ALS Association provides upwards of 12,000 hours of in-home care to people with ALS in Pennsylvania each year. The funding provided through the budget line item directly supported 3,051 hours of in-home care, nearly 24% of our total in-home care needs. This care not only contributed to patient staying home and out of expensive long term care facilities, but also directly helped support the jobs of caregivers in Pennsylvania, providing an additional economic benefit.

People with ALS continue to need specialized care services outside of the clinic setting and The ALS Association is proud to be able to provide them with a variety of medical equipment devices, from wheelchairs to speech technology and to shower chairs, all to make their lives easier and ensure they can stay closer to their loved ones at home. Many of these devices can be used more than once, meaning just one device can more than quadruple its positive impact here in Pennsylvania.

The impact of the line item funding for ALS care services is great, yet the need is even greater. There are over 1,000 people living with ALS in Pennsylvania and the disease does not discriminate by age, gender, race, region, or socioeconomic status. ALS is always fatal, usually within just 2 to 5 years, and so the need for quality care is always urgent. The ALS Association is committed to using every last penny efficiently to provide compassionate care and support for every person with Lou Gehrig's Disease to the best of our ability. Because the size and structure of The ALS Association allows its healthcare professionals to deliver necessary services more quickly than typical government programs.

Governor Corbett's budget continues the ALS patient services line item at $350,000. It is critical that the legislature at a minimum maintain this funding in the final budget with an eye towards increasing it to $500,000, which would be just $500 per person with ALS in the state, a modest amount given the substantial impact on ALS families who depend on these services every day.