

Hon. Tom Corbett
225 Main Capitol Building
Harrisburg, PA 17120

Dear Governor Corbett:

On behalf of The ALS Association and the more than 900 Pennsylvania patients and families living with Lou Gehrig 's Disease (or ALS), I urge you to continue to support and strengthen ALS patient care in your upcoming budget proposal for 2014/2015.

ALS is one of the most devastating medical diagnoses that a person can face. ALS is a fatal neurodegenerative disease that robs a person of their ability to control the voluntary muscles in their body. The onset of ALS is different for each person but symptoms may include muscle weakness or impairment in the hands, arms, or legs and difficulty in speaking, breathing and swallowing. This degeneration occurs methodically, painfully and relentlessly until the victim loses his or her ability to move, eat, blink and breathe. People with ALS typically live 2 to 5 years after diagnosis and in Pennsylvania, it has afflicted people from ages 18 to 95. ALS is a grueling and torturous death sentence. Eventually everyone with ALS dies because they can no longer breathe.

A diagnosis of ALS can be the loneliest feeling in the world. However, for those who utilize ALS Association services and multidisciplinary clinics, that is not the case. So many people rely, both financially and emotionally, on their support, **including military veterans, who are twice as likely to develop the disease.** The ALS Association is meticulous in the stewardship of state funding. Studies show that an average family caring for a patient with advanced ALS can easily face medical costs in excess of \$250,000 a year. An increase of state funding to \$500,000 in 2014/15 would help to greatly ease that cost burden to our families, state-funded agencies and insurance companies.

In 2013, with the support of Representative Bryan Cutler, Chairman Bill Adolph, Majority Leader Pileggi, and allies from across the state, the Pennsylvania legislature approved a \$350,000 line item in the state budget. This funding is critical to establishing a baseline of support for ALS patient services including clinics in Philadelphia, Pittsburgh, Hershey, Allentown, Johnstown, and Danville.

In order to sustain and improve the services for families facing this devastating disease, I am asking you to propose increasing funding to \$500,000 in the next budget, which can save millions of dollars in the state budget while providing families with ALS the compassionate care and support they need in the face of this terrible disease.

A group of us will be in Harrisburg next spring to discuss state funding for ALS patient care. We would like to meet with you before your next budget proposal so you can hear the stories of those living with ALS first hand and so we can demonstrate the value of The ALS Association in Pennsylvania. Thank you for listening to ALS families. We look forward to being partners in quality care as we work to end ALS.

Sincerely Your PA Constituent,

NAME _____

ADDRESS _____
