Hundreds of people with ALS, their families and caregivers joined together May 11-13 in Washington, D.C., for the 2008 National ALS Advocacy Day and Public Policy Conference. While together, we also held the fifth annual candlelight vigil for ALS awareness.

Although a torrential rainstorm pounded us on the drive down, it did not dampen our determination to connect over our experiences with ALS. Each year the conference seeks to garner support for treatment and a cure for the deadly illness.

It was my first foray into the milieu of legislative lobbying. While there, I joined others speaking with several legislative staffers and U.S. Rep. Jason Altmire on the subject.

Although it affects a handful of people at any one time, amyotrophic lateral sclerosis kills almost without exception. It can attack anyone, young or old. What’s more, before death ALS completely debilitates its victim and drags family members and caregivers along a seemingly endless corridor of despair. The ALS Association is the only national nonprofit health organization dedicated solely to the fight against ALS. The association helps advocate for research, provides patient and community services, informs the public and supports affected families.

The local Western PA-West Virginia Chapter was founded in 1982. Through it patients can borrow helpful equipment and receive grant assistance and respite care. The chapter also helps pay for communication devices and provides transportation. Chapter workers partner with local hospitals' multidisciplinary ALS clinics. All of its services are paid via donations and the proceeds from the annual Walk to Defeat ALS fund-raising event. The next Walk to Defeat ALS will be on Sept. 13 at the Pittsburgh Zoo. For more information go to [www.cure4als.org](http://www.cure4als.org).

Michael Bernarding, 29, is the executive director of the local ALS Association chapter, based in Millvale. The native Pittsburgher recently talked about his organization and ALS. His remarks on the Washington trip were made beforehand.

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Q. How long have you been the executive director of the local chapter?
A. I have been serving as executive director for 4½ years. I volunteered with the chapter and served on the board for two years prior to assuming my current position. The chapter’s service region spans the 31 western counties of Pennsylvania and the entire state of West Virginia.

Q. How many people in the chapter coverage area have Lou Gehrig’s disease?
A. Based on population statistics, we estimate that there are nearly 400 people living with ALS at any given time in our service area. Fifteen new cases are diagnosed each day and, sadly, 15 people succumb to the disease each day. ALS actually occurs more frequently than multiple sclerosis, however the life expectancy of those living with ALS is brief. ALS remains a fatal disease. ALS can strike anyone and occurs with no racial, ethnic or socioeconomic boundaries.

Q. Has ALS touched your life?
A. My mother had a potential diagnosis of ALS almost seven years ago. Even though her symptoms mimicked ALS, fortunately for her, she ended up not having ALS.
I started volunteering with the chapter around that time and my passion for the mission has continuously grown. It is heart-wrenching to watch people with ALS and their families go through this. It is the hope that, one day very soon, nobody else will have to experience ALS that keeps us all -- staff and volunteers -- going.

Q. Why is ALS still an unknown entity 70 years after Lou Gehrig’s death?
A. Many in the general public still do not know much about ALS, but The ALS Association is working fervently to change that. We recently have recently developed new media and public awareness campaigns. Also, actress Angela Lansbury joined in on the fight by starring in our new public service campaign, "Cure ALS." Commercials began airing across the nation this month in an effort to raise awareness of ALS and all that The ALS Association is doing to fight ALS on every front.

Q. What are the current theories behind the causes of ALS?
A. In short, we just do not yet know what causes ALS. The biological mechanisms of ALS are only partially understood. Discovering the cause is the focus of much research. We are confident that the discovery of a cause will lead to the cure. We know that environmental factors probably do play a role, since research has shown that those who serve in the military are nearly twice as likely to develop ALS.

Q. Are there any effective treatments on the horizon?
A. The ALS Association launched a program called TREAT ALS, which stands for Translational Research Advancing Therapy for ALS. The sole purpose is to accelerate clinical testing of drugs that show promise in treating ALS. There are many drugs in clinical trials under way right now. An entire list can be found on our Web site, www.cure4als.org. In January, we held a conference that brought together research scientists, neurologists, government officials, and drug company CEOs as part of our TREAT ALS program. It is our firm belief that collaboration among diverse groups is the best way to advance drug discovery and development. Stem cell therapy does have great promise for ALS, although more research needs to be done. A local biotech company, Knopp Neurosciences, is in the process of clinically developing a compound that has shown promise for treating ALS.

Q. Is the government funding much research? What needs to be done?
A. Since the association established an advocacy department in Washington, we have been able to significantly expand funding for ALS research from approximately $15 million per year in 1998 to more than $60 million in 2007 alone. However, much more needs to be done. We need to support our men and women in the military, who are at twice the risk of the disease, by continuing funding for the ALS Research Program at the Department of Defense. And we need to continue and expand funding for the ALS registry at the CDC. This funding will enable us to expand the registry projects under way and advance the search for biomarkers, causes of ALS and new treatments.

Q. What do you hope to accomplish each year at the national conference in Washington, D.C.?
A. We want to give members of Congress a better understanding of the true nature of this disease -- that it's a family disease
impacting both patients and their loved ones, that it does not discriminate and can strike anyone at any time, regardless of their age, gender or race, that it strikes military veterans at twice the rate as the general public, and that there currently is no effective treatment.

We want to let them know exactly why they should join our fight for a treatment and cure not only this year, but next year and beyond. From a chapter perspective, we also look forward to learning the latest advocacy strategies, how we can continue to deliver our message to Congress throughout the year, and how we can develop relationships with members of Congress and partner with them on the many issues that impact people with ALS and their families.

Another important goal of Advocacy Day -- and our advocacy program -- is to demonstrate to the ALS community that there is something we can do to fight back against this disease ... that we can make a difference through advocacy.

Having joined the fight, I will be going to Harrisburg with the ALS Association this month and urging legislators to give the two Pennsylvania ALS Association chapters line-item status in the state budget.

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Correction/Clarification: (Published June 12, 2008) Linda Talmon was misidentified in the caption of a photo accompanying this story as originally published June 11, 2008 about the local chapter of the ALS Foundation and its efforts to expand funding for research on amyotrophic lateral sclerosis.

M. Tinsley-Crabb can be reached at health@post-gazette.com.