My husband, Brad, and I went to Harrisburg in June, along with the local ALS Association director and others, in support of the two association chapters in Pennsylvania.

Whatever the outcome, we wanted to represent the Western Pennsylvania and West Virginia chapter, based in Millvale, and the Greater Philadelphia chapter. They help about 800 Pennsylvanians, including me, who live with amyotrophic lateral sclerosis, also known as Lou Gehrig's disease.

For those who may not know, ALS is a disease that kills the motor neurons. In fact, in Europe ALS is called motor neuron disease or MND. No one knows the cause. As yet, there is no cure. The outcome for those with ALS is almost always fatal. Why? Because eventually ALS kills all the neurons that signal movement in voluntary muscles, including the diaphragm. In time, the diaphragm ceases; the lungs cannot move air and the ALS patient cannot breathe. Unless he or she is hooked up to a ventilator, death follows. The average life expectancy is two to seven years.

Those are the ugly facts of ALS.

With that in mind, along with the fact that state legislators faced a June 30 budget deadline, we found ourselves under the State Capitol dome, traipsing down halls and chatting with politicos on the 16th.

Seven of us from Pittsburgh lobbied lawmakers for $800,000 to help ALS patients here and in the Philly area. The money is to cover patient services. The hope was either to get the money by achieving line-item status for the association or by piggybacking the request onto another bill.

It turned out to be a losing battle -- for now. We received an update from Michael Bernarding, executive director of the local ALS Association chapter on July 8 that the state budget was passed and signed by the governor.

"Unfortunately, the final budget did not include a line item for ALS," Mr. Bernarding wrote in an e-mail.

The need for funding doesn't go away.

Patient services includes things like special computers that simulate speech, wheelchairs, other equipment, transportation and nurse visits. Living with this ailment is extremely expensive. As the ALS patient loses function, he or she needs machines and caregivers to take over. A power wheelchair can cost up to $30,000. A speaking device can be nearly $9,000.

Mr. Bernarding said an ALS patient's family can spend up to $250,000 annually to maintain quality of life for that person.
He's got plans to keep up the effort for public money. In his e-mail to ALS advocates last week, he wrote:

"You did a great job reaching out to our elected officials and they are now very aware of the ALS community in Pennsylvania! We are now working with our legislative champions on a new plan to try to secure funding this year from each of the caucuses and that process will take time." He encouraged supporters to join a writing campaign, telling media outlets of their disappointment in the governor and legislature.

I'm certain that during our visit to Harrisburg we made an impact on some lawmakers. One in particular was freshman representative Bryan Cutler, R-Lancaster.

Although ALS is considered a rare disease, both of Mr. Cutler's parents succumbed to it when he was just entering adulthood. His mother contracted ALS when he was just 15. She lived for about seven years and died at 47. A year after his mom's diagnosis his father developed bulbar ALS, the most aggressive form. He died at 40.

In reality ALS seems more rare than it is because the number of those living with it stays around 30,000 in the United States. The number, however, simply indicates another miserable fact about ALS: For every new diagnosis, there is one death. Thus, the number of sufferers never grows or declines.

Since I came down with this scourge I have been shocked that most everyone who learns of my plight tells me an ALS story about an acquaintance, a friend, a relative, a parent or sibling who has it or has died from it. I had assumed most would know little about such an infrequently occurring malady. I was wrong.

Sadly, Mr. Cutler knows more about ALS than anyone should. The experience has spurred him to try to bring about a change, though. Since he was elected in 2006, he and Rep. Josh Shapiro, D-Montgomery County, have pushed their colleagues to recognize the need to financially support the work of the ALS Association.

To reinforce the urgency, the day we were there Mr. Cutler told the afternoon session in House chambers the story of his parents and introduced four ALS patients -- Michael Sullivan of McKees Rocks, two men from the Philadelphia area and me -- on the House floor. At that, the entire assembly of legislators stood beneath the glowing crystal chandeliers in that immense gilded hall and applauded us for several seconds.

We visited several lawmakers' offices. Most of the time we spoke with attentive aides. We also caught busy legislators in the hall. At those times we were blessed to have Anne Lewis with us. Mrs. Lewis' late husband, Ed, was a well-known Pittsburgh developer, whose family founded, built and owns One Oxford Centre, Downtown.

In 2004, ALS killed her 35-year-old stepson.

Unassuming and kindly, Mrs. Lewis pushed my wheelchair the whole day. Still, however unpretentious, she's on first-name terms with Sen. Jane Clare Orie, R-McCandless, the majority whip, who has been supportive of Mrs. Lewis' work for the ALS Association.


Misters Dermody, DeWeese and Fajt talked with us for quite some time in the governor's reception room. They listened to us promote the $800,000 allotment and to my computer voice speak briefly of living with ALS and about how it can strike anyone.

In the end, Mr. Fajt left us saying: "I hear you; I get you."

We can only hope they take on our cause.

We drove through a deluge to carry out a similar mission in Washington, D.C., on ALS Advocacy Day, May 11.

There the goal was three-pronged. First, to nudge legislators, specifically senators, toward passing the ALS Registry Act and to provide $5 million to cover the Centers for Disease Control and Prevention's work of collecting data on every ALS patient in the nation.

Second, to secure another $5 million to continue supporting a research program at the Department of Defense aimed at putting
ALS on the list of diseases that VA hospitals may treat. Armed forces vets are twice as likely to contract ALS.

Third, to garner funding for long-term care services for ALS patients via the Lifespan Respite Care Act.

The Registry Act cleared the House last year. Since May, 77 cosponsors of the bill in the Senate have stepped forward. The research project is in its second year. Since our May visit, Sens. Bob Casey, D-Pa., and Elizabeth Dole, R-N.C., have been talking up the appropriation among their colleagues.

Correction/clarification (published July 17, 2008) -- This column about amyotrophic lateral sclerosis or ALS mistakenly said Pennsylvania tax dollars could go to West Virginia patients of the disease. That is not the case, according to local Western Pennsylvania and West Virginia ALS Association officials.

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