Each morning a Coraopolis man I know tenderly places his fingertips on the eyelids of his wife and gently pulls them open. She hasn't the strength any more to open her own eyes. She has had amyotrophic lateral sclerosis, or ALS, for 5½ years. The disease has progressed to the point where her entire body is affected. This once-vital woman lies completely still now, breathing through a slit in her throat. Her meals are a liquid substance that is drained directly into her stomach from an IV drip bag hooked to a feeding tube.

This is ALS. It is an unforgiving, relentless, diabolical illness that steals all vitality, all strength, all ability to enjoy even the simplest things of life. And then, of course, you die.

With that in mind, I cannot fathom the thinking of our federal and state legislators. These men and women of flesh -- just like those of us with ALS -- torpedoed legislation that could have aided people and families facing this insidious disease.

This spring, my husband, several others from the local chapter of the ALS Association and I went to Washington, D.C., to implore legislators to continue supporting the National ALS Registry Act, which had already passed the House last year. The bill would have appropriated $5 million to fund the collection of data on every person diagnosed with ALS and to house that information at the Centers for Disease Control and Prevention.

Scientists believe that sifting through environmental factors, lifestyle, physical traits, genetics and other variables that ALS patients present could lead to a cause and, ultimately, a cure for the malady also called Lou Gehrig's disease. The legislation would also have provided $5 million to continue studying why it seems that armed service veterans contract ALS more often.

At the state level we again looked to our elected officials for $800,000 in funding to ensure that those nearly 1,000 Pennsylvanians already struggling with ALS received much-needed and expensive patient services associated with the illness. That would include wheelchairs, assistive speech devices, nurse visits and so on. It is estimated that it costs the family of an ALS patient upwards of $200,000 to care for him or her.

Part of the problem at the federal level was that Sen. Harry Reid, D-Nevada, the bill's original sponsor, rolled the Registry Act into a huge omnibus spending package in hopes of skirting a kibosh that Sen. Tom Coburn, R-Okla., had placed on it last year when it was quashed as Senate Bill 1382.

The spending package included, among other things, bills to: fund stem cell, stroke and spinal cord paralysis research; protect homeless and runaway children; and expand the Department of Justice's ability to investigate child pornography.

It also authorizes: funds to aid the Museum of the History of Polish Jews; the Smithsonian Institution to construct a greenhouse to preserve its orchid collection; 10 years of funding for the Washington, D.C. Metropolitan Area Transit Authority; and amendments to the Lacey Act Amendments of 1981 to add nonhuman primates to the definition of "prohibited wildlife species," to stop the sale of animals in interstate or foreign commerce.

So, one would guess that Mr. Reid knew he'd face some opposition. He got it.

Forty of 48 Republicans decided to keep the legislation off the floor, which by then was called the Advancing America's Priorities Act. John McCain and five other Republicans abstained.

Forty-seven Democrats -- Hillary Rodham Clinton and Barack Obama abstained -- approved the package. Three Republicans -- John Warner of Virginia, Norm Coleman of Minnesota and Gordon Smith of Oregon -- and the two independents joined them.
Thus the measure fell short of the 60 needed to put it up for a floor vote. Now it's back to the drawing board for another year or two while more people with ALS die. Life expectancy after diagnosis is roughly two to seven years. A Canonsburg friend of mine lost his son, a 49-year-old father of two, last week. He lived about 20 months.

Among the 40 nays was Sen. Arlen Specter. Perhaps when he marched lock step he did not consider what it's like to suffer with a deadly illness. But how can that be, when he was diagnosed with Hodgkin's disease in 2005? And did he some how forget having brain and heart surgery in the 1990s? What's more, his lymphoma reemerged this spring. Surely the 78-year-old again felt the uncertainty and watched helplessly as his loved ones squirmed under the fear of losing him.

I won't know what he thought, however. He did not respond to my request for an interview.

Fact is, some 300 Americans die of cancer each day. Consequently, there is more research and more money swirling around cancer than ALS, which claims just 5,000 Americans annually, or 14 daily. But does that then sanction the unchallenged deaths of ALS victims? Which life is more precious, the cancer-afflicted life or the ALS-shortened life? And who decides? The moneyed research corporations?

As for Harrisburg, when we went there seeking the modest sum of $800,000 to undergird the work of the ALS Association, we left believing that it would at least be seriously considered. Wrong. The request never even made it to debate.

We visited a half-dozen legislators including William DeWeese and Frank Dermody, had impromptu meetings with House Speaker Dennis O'Brien and the governor's chief of staff Gregory Fajt, and met an assistant to Sen. Jane Orie.

One of their own, Rep. Bryan Cutler, R-Lancaster, even took up the cause. During our time at the capitol in June, he pleaded on the House floor for support. Both of his parents fell to ALS.

Our and his efforts came to naught. Days after we were back in Pittsburgh we learned that Mr. DeWeese and the Democrats were under a cloud because of "Bonusgate." A grand jury was looking at whether state employees, mainly within the House Democratic caucus, illegally received taxpayer-funded salary bonuses as a reward for campaign work.

Subsequently, Deputy Speaker of the House Rep. Josh Shapiro, and Mr. Cutler's ally in seeking help for ALS victims, called for Mr. DeWeese, who was not indicted, to step away from caucus leadership.

Looks like the 2009 state budget may have been too tight for ALS patients, but there seems to have been money to spend elsewhere.

The annual walk to raise money for the ALS Foundation is Saturday at the Pittsburgh Zoo and PPG Aquarium. Registration starts at 7:30 a.m., walk starts 9 a.m. To sign up or contribute online, see www.cure4als.org.

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