Beating the Odds

I experienced the first symptoms of ALS in 1996. Here's how I've added life to my years.

BY CATHERINE G. WOLF, PH.D.

I first noticed *it* in April 1996, when I couldn't flex my left foot in modern dance class. I saw an orthopedist, who told me that a pinched nerve was unlikely the cause. By August, *it* was causing persistent pain in my left calf when I ran. I enrolled in an advanced swimming class that fall. I saw my local neurologist who assured me *it* was not amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease.

I had found a paragraph about ALS in the *Merck Manual* (the world's bestselling medical textbook) and was determined not to have *it*. I knew that Dr. Kevorkian had helped two patients afflicted with *it* commit suicide. From my research on the Web, and cheered on by my daughters, I convinced myself I had some kind of neuropathy or chronic Lyme disease instead.

ACCEPTANCE

September 1997: I had completed a series of monthly treatments with intravenous immunoglobulin (IVIg) for a possible motor neuropathy. But the physician at Columbia University in New York City specializing in neuropathy shook his head. The IVIg had failed to stop the increasing weakness in my leg, leading him to conclude I had "probable ALS."

"Do people die?" I asked. He looked away and said, "Sometimes." I started to cry, knowing that "sometimes" meant "always." How could I have this awful disease? I ate healthy and exercised. I was fit and thin and rarely sick.

The Columbia physician referred me to an ALS specialist. At first, I resisted the diagnosis and clung to the hope that I had something else. Anything but it. One year later—after second, third, and fourth opinions—I finally accepted the diagnosis I had most feared. ALS is fatal. Most people die within two to five years of diagnosis. A mere 10 percent survive more than 10 years.

PHOTOS COURTESY CATHERINE G. WOLF

Accepting the diagnosis was crucial: it enabled me to make several immediate decisions about my long-term health. Most importantly, I decided I was going to do whatever was necessary to make it into that 10 percent. My daughters, Laura and Erika, were just 18 and 22—far too young to say goodbye. I know some people make the decision to not use life-prolonging interventions, such as a feeding tube, bilevel positive airway pressure (BiPAP, a form of noninvasive breathing support), or a ventilator. Too often, it is for financial reasons. Medicare doesn't cover the cost of nurses or aides necessary to survive in the later stages of ALS. But I was determined to find a way.

> "I was determined to connect with others who had this disease. Not only to learn from them, but to **become an advocate**. I might be dying, but I was not going to go quietly."
>
> —CATHERINE G. WOLF

ADVOCACY

I was also determined to connect with others who had this disease. Not only to learn from them, but to become an advocate. I might be dying, but I was not going to go quietly. Perhaps having a sense of purpose would help me

FULL HOUSE Catherine Wolf surrounded by her immediate family, daughters (left to right) Erika and Laura, and (top left to right) husband, Joel Wolf, and sons-in-law, Tony Annunziata and Joel Port.

live and add years to my life. At least it would add life to my years.

My first opportunity to be an advocate came from my local Muscular Dystrophy Association (MDA) in Westchester, NY, in the summer of 1999. They asked me to be on their Labor Day telethon. My speech was starting to go, so this opportunity was in the nick of time. The staff filmed my daughters and husband. It was an emotional experience. The interviewers asked my daughters, "What is it like to take care of your mother, instead of the other way around?" My daughters reacted angrily, "She still takes care of us!" they said. In the next room, I sobbed quietly. Some of the questions they asked me pulled at my heartstrings. I cried, then collected myself, looked into the camera, and answered.

In the fall of 1999, I recorded my name, the names of family members, and a few standard greetings. Also two favorite family jokes: "What goes ha ha thunk?" Answer: a man laughing his head off. "What's green and hangs from trees?" Answer: giraffe snot. These recordings have survived at least three computers. I use them today in E-triloquist, a speech program that allows recorded phrases and also converts text to speech. Who says there's no fun in ALS?

Fast forward to May 2, 2001. After a bad night with the BiPAP, I found myself on my back in the emergency room of Columbia Presbyterian Hospital. I was faced with the decision of whether to have a tracheostomy, a procedure that would allow me to breathe with a ventilator. The question wasn't if; the question was whether this was the right time. As victims of car accidents flooded the ER, the ALS team tried to convince me it was the right time.

I remember the nurse practitioner, a longtime member of the team, said refusing to have a tracheostomy would be like writing "DNR"—Do Not Resuscitate—on my medical chart. I asked, "Will I be able to go to my daughter Erika's graduation in Boston early in June?" She said I would.

I had researched the changes that tracheostomy would bring, and I just wanted to delay them a few months. I knew I'd never be alone again because of the need to remove secretions from my lungs and the danger of mucous plugs that could kill me. My husband, Joel, held my hand and whispered, "It's really time." I decided: better six months early than six months late. Accepting the reality of your situation allows you to be more proactive. I took the biggest breath I could and said, "Yes."

The surgeon told my husband I'd be back with pneumonia within six months, as often happens to ALS patients on ventilators. Wisely, my husband didn't pass this forecast on to me for about five pneumonia-free years. Since my tracheostomy, I've experienced the joy of four grandchildren. Who knows, perhaps there will be more!

I worked for two-and-a-half years after my tracheostomy. But in December 2003, I realized I was too tired to continue my work in human-computer interaction at the IBM Thomas J. Watson Research Center in Yorktown Heights, NY. That's when I turned my energy to advocacy for ALS and other neurologic conditions.

SELF-EXPRESSION

Probably the first event was an article in the Westchester section of the *New York Times* about my political and ALS poetry in August 2005, with the ominous title "A Thing or Two to Say Before Dying." That got the attention of my local MDA chapter. I eagerly agreed to be on the organizing committee of their fundraiser, An Evening of Hope and Dreams. However, fundraising wasn't my strength. Perhaps the most enduring contribution was the poem I wrote, which has been used in subsequent fundraisers and by other chapters. Over the years, my family, friends, and other people have raised about $15,500 for the ALS Therapy Development Institute (**community.als.net/wolfmom**).

In a *Neurology Now* article on advocacy that I wrote (**bit.ly/1c3jNpa**), I discussed the different kinds of advocacy. Everyone is good at something. You should assess your skills, experience, and energy. Your advocacy could be as simple as sharing your experience with a journal or even your local newspaper. When I was threatened with the loss of the little nursing I had in 2005, I fought for full-time nursing with the help of a lawyer and won. I shared what I learned with the *MDA/ALS Newsmagazine* and *Neurology Now*. It turned out I had been denied without a review of the medical necessity in my particular case.

Now that online blogs are popular, I have my own occasional blog on **abcnews.go.com/blogs/health**. So when my drug insurance plan denied me a drug without review of medical necessity earlier in 2013, I knew just how to fight it and share my knowledge. I wrote about it in my blog (**abcn.ws/1gcp7YQ**). I figured if it had happened to me twice, it was a common cause of insurance denials.

I had always enjoyed writing. I found my niche in the world of advocacy by combining hard information and personal information in the form of storytelling. Just like I'm doing now.

I also have other skills from my 19 years at IBM as an experimental psychologist working in the field of human-computer interaction. I have been working with the brain-computer interface (BCI) project at the Wadsworth Center, part of the New York State Department of Health. I serve as a home user and the user-interface expert. I do it to advance the technology for others with movement disorders and myself. And, of course, I write about the field. (To read my article in *Neurology Now*, go to **bit.ly/1bt4PLn**.)

I have my down days, and I certainly wish I did not have ALS. By focusing on what I can still do, and not on what I've lost, I have a full life despite ALS. NN

FOR MORE INFORMATION

- For more about Catherine Wolf, see **en.wikipedia.org/wiki/Catherine_G._Wolf**
- For a collection of *Neurology Now* articles on ALS, go to **bit.ly/1fL98fW**
- For a collection of *Neurology Today* articles on ALS, go to **bit.ly/1ou9OvC**
- For a Patient Page on ALS from the American Academy of Neurology, go to **bit.ly/1l6BXZo**