



# Join the Cause

How to become an advocate for yourself and others. BY CATHERINE G. WOLF, PH.D.

I have had amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, for 15 years. Most people with neurologic diseases feel better when they are *doing* something about their situation. I certainly feel better when I am involved in advocacy. It gives me a sense of purpose.

Advocacy means active support for a cause. Whether you're newly diagnosed and relatively unimpeded by your condition or a veteran of your disease with many useful tips to share, you can take action.

You may be thinking, "I don't have the energy or personality for advocacy." Keep in mind that advocacy takes many forms, large and small. For example, after successfully appealing an insurance company's denial of benefits, I shared what I learned with *MDA/ALS Newsmagazine*, published by the Muscular Dystrophy Association (MDA; [mdausa.org](http://mdausa.org)). This was a relatively easy but powerful form of advocacy that raised awareness of the disease and helped other people fight for their rights.

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## EVERYONE IS GOOD AT SOMETHING

When contemplating how to get involved, assess your skills. Are you a bookkeeper? Then perhaps you can volunteer to keep the books for a fundraiser or help a fellow patient organize her finances. Are you a small business owner or a manager? You probably have the skills to organize your own event. Everyone is good at something.

In my case, I had spent many years in computer software design when I was diagnosed. My job as a "usability expert" was to make sure the software we produced was user-friendly for everyone. So when I encountered programs made by my company that were difficult for me to use, I suggested ways to improve them for other people with disabilities. I also made suggestions for improving the assistive technology I used on the job. (Assistive technology is software or hardware that makes it

easier for people with disabilities to accomplish a task—everything from wheelchairs to hearing aids to computer programs for people who have limited mobility.)

Most recently, I have been participating in research on brain-computer interfaces. (For more on brain-computer interfaces, see "Wave of the Future" in the Nov/Dec 2007 issue of *Neurology Now*, available online at <http://bit.ly/oM7Ajk>.) Brain-computer interfaces help people with no movement communicate and control their environment. I am a usability expert and home tester for a lab.

When the opportunity arose to demonstrate the brain-computer interface on CNN and for the American Museum of Natural History, I took a deep breath and let them film me. (To watch the video, go to <http://bit.ly/WolfBCI>.)

Sometimes neurologic disorders can wake up talents people didn't know they had. In my case, it was poetry. I started writing poems about my reaction to ALS and sending them to friends. One friend with connections finagled an article about my poetry into my county's section of *The New York Times*. I'm sure that article helped raise awareness of ALS. An article

in the May/June 2006 issue of *Neurology Now* included some of my ALS poetry. The neurologist who wrote it said my poems gave her a new appreciation of the patient's perspective. I use these examples from my life not to toot my own horn but to show that even one person can make a difference.

## ADVOCATING FOR A FELLOW PATIENT

Since I am a 15-year veteran of ALS, I have had to cope with increasing disabilities. During this time, I have helped other people find services and manage the symptoms of ALS—everything from how to alleviate constipation to talking to children about the disease. I have done one-on-one advocacy mostly by e-mail, but opportunities for advocacy can also be found on the many Web sites devoted to people with specific neurologic diseases. For example, PatientsLikeMe

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—JANICE KROGER

([patientslikeme.com](http://patientslikeme.com)) has forums devoted to people living with ALS, MS, Parkinson’s disease, Lyme disease, and epilepsy. Facebook also has groups for specific neurologic disorders, and *Neurology Now* has active Facebook and Twitter pages.

If you are newly diagnosed, you may have the energy and voice to help a more advanced patient. For example, you might organize a Share the Care team—a network of neighbors and friends that helps with everyday tasks—for someone in your local support group.

Janice Kroger, of southeast central Indiana, has an inherited form of Parkinson’s disease (in most cases, Parkinson’s disease is not hereditary). Diagnosed in 1995, she was forced to retire in 2006, but then she started educating people about her condition. Kroger has presented programs at support groups to educate people with Parkinson’s disease and their families and has talked about the disease to high school students.

Kroger’s advice to would-be advocates: “The first thing one must do is accept the diagnosis and be at peace with it. Then talk about your disease to anyone who will listen. Be prepared to be ‘tuned out’ by friends and relatives. It is not the most pleasant subject for conversation, and it can be difficult for others to know how to respond.”

### CAUSE ADVOCACY

Debra Quinn lives in rural Wellsville, NY. She watched her grandmother, father, great-aunt, aunt, and little sister die of familial ALS, which affects 5 percent to 10 percent of those with ALS. When Quinn was diagnosed with familial ALS in 2009, she started speaking out about the disease. She went to Washington, D.C., in May 2011 to educate lawmakers about this inherited form of ALS. Family members have a 50-percent chance of inheriting the disease. “Teaching the general

public that familial ALS happens again and again and again really drums home the challenges that we face,” Quinn says. She and a few supporters founded a local organization, Hearts for ALS NY ([heartsforalsny.org](http://heartsforalsny.org)) to assist patients, families, and caregivers. For her advocacy efforts, Quinn was awarded the New York State Senate Liberty Medal.

Advocating for a specific cause can be as easy as forwarding an e-mail from a group supporting that cause to everyone you know. For example, before the Senate vote on the stem cell research bill in July 2006, I forwarded to my family and friends an e-mail from the United Spinal Association ([unitedspinal.org](http://unitedspinal.org)) urging people to contact their senators to vote yes on the bill. And I e-mailed my own senators.

Some people prefer to write their own cause letters. The trick is to make it easy for other people to take action. This may include providing talking points, phone numbers, and e-mail addresses. In June 2005, after the House of Representatives passed the stem cell research bill, I e-mailed friends to put pressure on those representatives who voted against it to change their minds.

### ORGANIZATION ADVOCACY

Many groups raise money for neurologic disease research or services and raise awareness of these diseases; some provide advocacy training. Most raise money by dinners, walks, and golf outings. In general, these organizations welcome participation and will put you on their mailing and e-mail lists.

Travis Gleason was a 35-year-old chef in Washington State when he was diagnosed with multiple sclerosis (MS). Within months, he had to give up working full time because of weakness on his left side and difficulty concentrating. But he didn’t turn inward into his own pain; instead, he got involved with the National MS Society’s ([nmss.org](http://nmss.org)) Government Relations Subcommittee on Activism in Washington State.

“I have close relationships with key staffers for my local, state, and federal officials and try to be a resource to them as much as an advocate for myself and others living with MS and other debilitating conditions,” Gleason says. He also has a popular blog ([everydayhealth.com/blog/trevis-life-with-multiple-sclerosis-ms](http://everydayhealth.com/blog/trevis-life-with-multiple-sclerosis-ms)) and a Facebook page with nearly 1,500 members.

Gleason’s advice to potential advocates: “Start small and local. Find a topic you care about and research it. Develop an opinion and start talking about it. Our political system only works well if those who represent us know what’s important to us.”

Involvement in organization advocacy can be as simple as wearing a pin that represents the organization to participating in an event or being on the organizing committee. Fundraising

## The Principles of Cause Advocacy

- ▶ Be specific about what you want your audience to do.
- ▶ Provide information on the topic, including talking points.
- ▶ Provide contact information for the people you want them to contact, or an easy way of getting the information.



is a good way to involve family, friends, colleagues, and employers, who may want to do something but don't know what.

I have always been reluctant to ask friends for contributions. My cousin has been doing the ALS Association bike ride in Boston with her husband and several co-workers (who don't even know me) for several years. She asked me to contact my friends for help. I figured if she could ask people who don't know me to ride and contribute, I could certainly ask my friends. The response was phenomenal: The team raised a total of \$4,206, showing that a small group of people can make a big difference.

Working on the organizing committee of a major organization for a fundraising or an awareness event has the benefit that the organization provides most of the structure. When I worked on the organizing committee of a local MDA fund raiser, they provided the solicitation letter, which I personalized.

One final fundraising tip: It's much easier to get businesses to donate goods and services than money. Remind them it's not only a donation—it's also free advertising.

### **ADVOCATING FOR YOURSELF**

If you have a neurologic disorder, you may need to advocate for yourself for a variety of reasons.

For example, you may find yourself in need of services or medication that your insurance company denies. One way to appeal a denied claim is to have your doctor write a letter of medical necessity that explains why you need the service. Notes from other health professionals can also help.

Ask your insurance company to send you a letter of explanation for the decision, not a cryptic code. Read your policy and consult the social worker at your clinic—or if the stakes are high, hire a lawyer. The local chapter of your patient advocacy organization or the local bar association can recommend one. Put everything in writing and send it return receipt requested so you have a paper trail.

If you speak to anyone from your insurance company, get their names, take notes, and date the conversation. Keep in mind that you're not allowed to record a

conversation without permission from the other party.

The same principles apply to Medicare and Medicaid, but you're dealing with a bigger bureaucracy. Often, Medicare or Medicaid claims are denied because a doctor wrote down the wrong diagnostic or procedure code or didn't submit the necessary paperwork. If you suspect this is the case, contact your doctor and ask him or her to resubmit a corrected claim.

If you apply for social security disability payments or your company has disability benefits, fill out the forms carefully and provide the required documentation from your physician. With some diseases that have periods of remission, like MS, you might have a harder time proving you are unable to work than with a degenerative disease like ALS.

You might need to advocate for yourself for other reasons. Sometimes well-meaning caregivers or family members want to

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—CHRISTOPHER PENDERGAST, FOUNDER OF RIDE FOR LIFE

make decisions for you. It may be a big decision, like whether you're well enough to travel, or small, like what clothes you should wear. Although many neurologic diseases can impair a person's judgment and insight, a patient should still have some say over decisions affecting his or her care. Remember, you are your own best advocate.

### ORGANIZING AN EVENT

Christopher Pendergast was a 44-year-old elementary school teacher on Long Island, NY, when he was diagnosed with ALS in 1993. He quickly got involved with his local Muscular Dystrophy Association and ALS Association (ALSA; [alsa.org](http://alsa.org)) chapters. Pendergast considers himself lucky to have a slow progression. In 1995, he appeared on the MDA Telethon, which he describes as his “advocacy debut.”

“My emphasis shifted from concentrating on my illness to engaging the outside world,” Pendergast explains. He saw the ALSA plan to go to Washington and raise awareness of ALS among the legislators as an opportunity “to rally the troops and raise an uproar.”

In 1998, Ride for Life ([rideforlife.com](http://rideforlife.com)) was born. Pendergast's ingenious idea was to have people with ALS ride their

power wheelchairs from Yankee stadium (Lou Gehrig's home stadium) to Washington, D.C. The entire 350-mile journey took 14 days. On the first ride, Pendergast traveled alone during the middle of the journey, where he encountered “blistering heat and drenching rain.” Other ALS patients and supporters converged on the Capitol the last day. “It was a thrilling moment,” Pendergast recalls. The group met with President Bill Clinton and other lawmakers. Along the way, Ride for Life garnered national and local publicity and awakened awareness of ALS through their fearless trek.

The first ride raised \$30,000 by accident: What started out as an awareness event had turned into a fundraiser. The ride went to Washington, D.C., two more times. More recently, Ride for Life has travelled from the east end of Long Island to Manhattan.

Over the past 14 years, the group has raised more than \$3.5 million, and Pendergast has logged more than 2,000 miles and three months on the road. The organization supports cutting-edge research, provides grants to patients for respite care (short-term relief for caregivers) and legal assistance, and now offers a college scholarship for a New York high school senior who has a relative with ALS. One man with an outrageous idea and passionate supporters has made a huge difference. So can you. NN

## The American Academy of Neurology's Commitment to Advocacy

**L**ily Jung Henson, M.D., fellow of the American Academy of Neurology (AAN) is the medical director of the Swedish Neuroscience Institute Eastside and chief of staff at Swedish/Issaquah in Seattle, WA. She specializes in treating patients with MS. Dr. Jung Henson is an active advocate for her patients. “If not us [neurologists], who?” she says. She routinely helps her patients get the medications and tests they need and works with insurance companies to make sure they cover the cost of care. She also consults with her patients' employers to secure workplace accommodations.

Dr. Jung Henson is also a strong advocate for research funding and for programs that help patients manage their conditions. “I try to work within the legislative system to help my patients get the things they need,” she says.

The American Academy of Neurology Foundation ([aan.com/foundation](http://aan.com/foundation)) is committed to curing brain disease by supporting education and research in neurology and is dedicated to improving patient care, quality of life, and public understanding of neurologic disorders.

The AAN has a role in training neurologists to be better,

smarter advocates for their patients, according to Dr. Jung Henson—by working collaboratively with patient organizations at the local and federal levels on issues such as drug regulation, research funding, and access to care. Patients and their families can support the AAN Center for Health Policy by contacting Congress—the largest funding source for neurology research—for the following:

- ▶ To request \$35 billion for the National Institutes of Health (NIH), including \$1.857 billion for the National Institute of Neurological Disorders and Stroke (NINDS) for the Fiscal Year 2012.
- ▶ To request a permanent repeal of the Medicare Sustainable Growth Rate (SGR) formula, which will cut payments to physicians by 29.5 percent on January 1, 2012, if Congress does not act. Physicians who perform few procedures are at a great disadvantage, and many are having difficulty maintaining a practice.
- ▶ To support legislation in the Senate, S. 597, which would add neurology to a list of specialties eligible to receive a primary care bonus created by the new health reform law.