



## Multiple Sclerosis

“Hitting the Mattress with MS” (January/February 2009) should be mandatory reading for anyone who has multiple sclerosis (MS) or lives with someone who does. As an MS patient, the explanation of the problems around sleeping was right on. I suffer terribly at night with spasms, pain, and tingling and have lost the ability to turn over lying down. Plus, I wake up approximately every two hours having to go to the bathroom.

—*Rachael Kunkel  
Hudson, FL*

## The Cost of Care

Your recent editorial on the cost of care really hit home for me as the mother of a 22-year-old with a seizure disorder. My daughter has been taking two generic anti-epileptic drugs for her condition, as was approved by HMO. After being seizure-free for years, she had a seizure recently while riding her bicycle, and tests in the ER showed her medication blood levels were low. We learned from her neurologist that generics generally work poorly for seizure disorder, but many health insurers deny brand name drugs anyway due to the cost, even if the doctor specifies ‘no substitutes.’ This leaves the patient with the choice of the often-ineffective generic or paying out-of-pocket for the brand-name drug. Usually there is no appeal policy, so the patient is stuck.

—*Holly T. Tyler  
Santa Cruz, CA*

## Assisted Suicide

Thank you for addressing such an important and contentious topic (“Assisted Suicide Legal in Washington,” Jan/Feb 2009) and for clarifying the difference between assisted suicide and euthanasia.

The author states that many people suffering from neurological diseases would not be able to take advantage of assisted suicide—even if legal—because they would be physically incapable of self-administering the drugs by the time they are six months from probable death. I think a way to ensure an individual’s right in this area would be to prepare an advance directive at the time of diagnosis. Why would someone with a terminal disease have to wait until six months of death, especially when the illness will rob them of the ability to physically self-administer the drugs?

A mandatory (or even voluntary) advance directive would also allow someone to make their wishes known while they are cognitively competent to do so. Then, if someone asks for a prescription to end their life at a point when there is a question about their mental competency (due to disease progression), the request can be compared to a recent advance directive.

It is not comforting to some of us that we may have to choose a messy or painful way to end our lives if faced with a debilitating, terminal illness because we can’t trust that reason and not emotion will rule the day.

—*Stephanie H. Corkran, M.A.  
San Diego, CA*

## Seizure Dogs

On the Letters page of the Jan/Feb 2009 issue, John Trefil, M.D., asked where he could obtain a seizure-alert dog for his daughter. Dr. Trefil should contact Canine Companions for Independence. This is an excellent non-profit that should suit her needs very well:

**Canine Companions for  
Independence**

**Nat. Headquarters & NW  
Regional Center**

**2965 Dutton Ave., P.O. Box 446  
Santa Rosa, CA, 95402-0466  
Phone: 707-577-1700.**

—*Carol Stockbridge  
Walnut Creek, CA*

## Neurology Touches Us All

My interest in neurological disorders is personal. I survived a “neurological incident/brain injury” (subarachnoid cerebral aneurysm) and over the years have learned of neurological disorders diagnosed amongst family members and friends. These include a son diagnosed with Parkinson’s disease at age 45, a paternal nephew recently diagnosed at age 43 with multiple sclerosis, a 38-year-old maternal nephew suffering lingering symptoms from a traumatic brain injury, and a close friend who has suffered recurring strokes (the more recent severely affected her ability to communicate verbally...and she was known as a great conversationalist!). Please continue with the publication. Know that I have referred it to many friends and family members.

—*Lorrie G. Goodrich*

## CRPS

Thank you for your article (“More than a Feeling,” Mar/Apr 2009) about complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy

# @Your Service

## YOUR VOICES

**LETTERS TO THE EDITOR:** Correspondence for publication on this LETTERS page must include name, address, and daytime phone number, and may be edited for purposes of space and clarity. It should be e-mailed to [neurologynow@lwwny.com](mailto:neurologynow@lwwny.com), faxed to 646-674-6500, or mailed to 333 Seventh Ave., 19th Floor, New York, NY 10001.

**PERSONAL ESSAYS:** The SPEAK UP essay is a forum for people who live with neurological conditions and those who care for them. Submissions should be kept to 600 words and sent to the addresses above.

**ASK THE EXPERTS:** If you have a question for a doctor to answer in our ASK THE EXPERTS department, send it to the addresses above.



## SUBSCRIPTIONS

You may order a subscription—available for free to individuals with a neurological disorder and their families and caregivers—through the following methods.

**POSTCARD:** Fill out one of the cards bound into this issue and return it by mail or fax.

**ONLINE:** Visit our website ([neurologynow.com](http://neurologynow.com)) and click on the subscription link.

**SUBSCRIPTION CHANGES:** For change of address, e-mail [now@computerfulfillment.com](mailto:now@computerfulfillment.com).

**BACK ISSUES:** E-mail requests to [now@computerfulfillment.com](mailto:now@computerfulfillment.com).

## WEBSITE

[neurologynow.com](http://neurologynow.com) features an electronic version of the print magazine, dating to our premiere issue. The site also offers publication information, resource links, and web-exclusive content.

(RSD). I suddenly had the symptoms of RSD one morning in May 2004. I had no idea what was happening to me, but I experienced all the symptoms described in your article and more. I was mostly bedridden for about 3 months.

Then began a litany of visits to specialists, including neurologists, neurosurgeons, and anesthesiologists, each of whom wanted to help me, but who had minimal (if any) understanding of RSD. It was January 2005 before I was given the diagnosis of RSD, and in 2007 a second doctor confirmed my diagnosis as CRPS, Type I. It was affirming for me to read your accurate and hopeful article. Having this condition has pushed me more to focus on the working parts of my body and my life—I am now always looking for that part of the glass that is half full.

—Graceann T. Mayo  
Santa Fe, NM

I was disappointed at author Debra Gordon's choice of adjectives in describing a patient's CRPS following hip replacement surgery. The patient was said to have developed CRPS as a result

of a "botched" hip replacement.

Sciatic nerve injury is a well-known potential (though rare) complication of that procedure, and orthopedic surgeons carefully review all the potential complications pre-operatively with their patients.

—Frank Quagliari, M.D.  
Reno, Nevada

**THE EDITOR RESPONDS:** Thank you for pointing that out, Dr. Quagliari. We apologize for what must have come across as flip and uninformed.

## Follow the Reader

In your Editor's Message from Mar/Apr 2009 ("Follow the Reader") you asked what stories we like and what we'd like to see more of. From that issue, I especially liked "Speak Up" and the new photo essay, "Pictures of You." The photos are engaging and the interview intimate, drawing the viewers to a personal conclusion of the reality of illness and the human spirit. Here's what I'd like to see: post-stroke noise sensitivity, which I experienced firsthand.

—Cari Biamonte

## DEAR READER!

Why not give someone you care about the gift of *Neurology Now*®?

There's a new feature on our Web site ([neurologynow.com](http://neurologynow.com)) that we would like to make you aware of. We've added a subscription form that can be printed out and copied so that you can easily share with friends, family members, or members of a support group you may belong to. This form is larger and easier to fill out than the card in the magazine. There's even a fax number on the form to simplify submission.

So, if you have an opportunity to let others know about *Neurology Now*®, we encourage you to do so! Of course, you can also tell family and friends that they can subscribe instantly online by visiting [neurologynow.com](http://neurologynow.com) and clicking on "Subscribe/Renew."

Thanks for helping us share *Neurology Now*®.

The Circulation Department