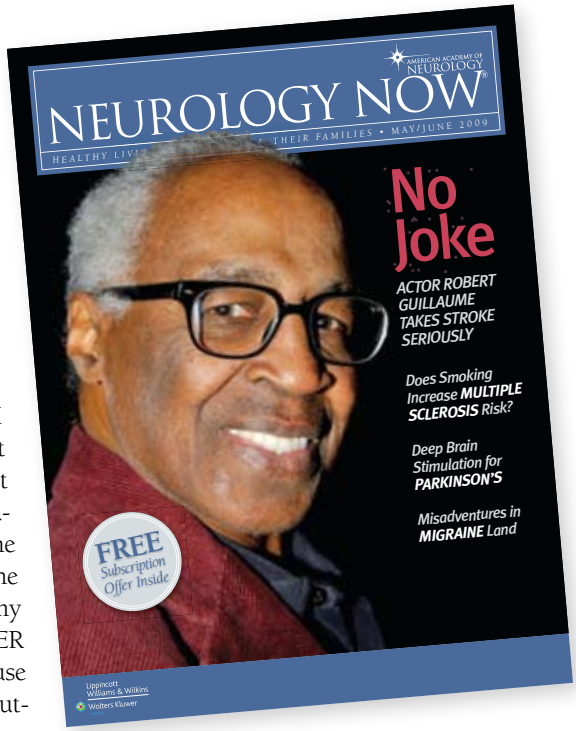

Encephalitis

Please let your readers (and doctors) know about encephalitis. I was lucky to be diagnosed right away by a wonderful neurologist who had seen a case of encephalitis kill his roommate when he was in college. He recognized the symptoms right away when my husband brought me to the ER back in December of 1995. Because of his early diagnosis and his putting me on IV acyclovir right away, I do not have many of the residual problems that others have.

I began running a support group that has evolved into a nonprofit organization, Encephalitis Global, Inc., consisting of survivors and their caregivers. We have no professionals on the Board nor any doctors involved, so I am hoping that you can let people know about our Web site: **encephalitisglobal.org/Home.asp**.

We will be having our "Faces to Faces" conference this year in Las Vegas in September (noted on the site) and we would love to have your readers attend.

—Ingrid R. Guerci
Tarrytown, NY

THE EDITOR RESPONDS: Thanks, Ingrid. We are happy to publish your Web site and wish you well in your conference activities.

Seizure-Response Dogs

On the Letters page of the May/June issue of *Neurology Now*, you list Canine Companions for Independence (CCI) as a provider for Seizure Alert/Response dogs.

CCI is a nationwide nonprofit organization that provides highly trained assistance dogs for people with disabilities. Although we do not train our dogs specifically for seizure alert, we do not deny or discourage anyone from applying to the CCI Program. I recommend the Web site of Assistance Dogs International (ADI). ADI is a membership organization that assistance-dog providers may belong to. ADI does not train or place dogs, but their members do. Go to **assistancedogsinternational.org**. Click on "Regions" and then "Membership Directory/List and Links" to view a worldwide listing of their members. Since each member has their own guidelines for acceptance into their program, interested parties should contact them directly.

—Suzi Hall
CCI National Headquarters
Santa Rosa, CA

THE EDITOR RESPONDS: Thanks for setting the record straight.

African Americans and Stroke

I am an African American woman who will be 60 years old on October 25, 2009. I was shocked by your story on African Americans' high risk of strokes ("Black, White, and Gray," May/June 2009). I am an insulin-dependent diabetic with hypertension and high cholesterol. Recently I went to my neurologist and he asked me to cross my arms and stand up out of my chair. I could barely stand up. He told me that I need to start walking regularly for exercise.

I really don't think that African Americans are getting the message—including myself, until I read your story. Many of us don't know the big picture, and when we do, it's too late.

—Linda Raskin
Desert Hot Springs, CA

Parkinson's Resources

I was diagnosed with Parkinson's disease (PD) three years ago, when I was 75 years old. Like most folks with PD, I lost a lot of physical mobility but fortunately retained most of my marbles. While dealing with my "diminishments" (a phrase I learned from your December 2008 issue), I kept thinking about the dormant power of the total Parkinson's community, which includes patients, families, and concerned friends. I envisioned some sort of nationwide PD project that focused on something other than the disease itself. Three months ago, I decided that my program would be a fundraising initiative supporting a deserving international non-profit organization.

I called on two of my sons to create a Web site called Movers and Shakers, (**movers-and-shakers.org**), which explains our philosophy. I was amazed at the very warm reception and the substantial number of donations.

I am now in the process of building a prospect list of over 300 Parkinson's support groups across the country. I am referring to my activity as "the PD support group with a twist."

—Pat Howe, South Kent, CT

THE EDITOR RESPONDS: Wow, Pat, please accept our congratulations and admiration for your work. How fortunate the PD community is to have a mover and shaker like you!

Unsung Heroes

This letter is in response to your question in "From the Editor," May/June 2009, about the unsung heroes in our lives. I suffered with consistent migraines for several years brought on by everything from stress to weather changes. I was virtually living on a butalbital/codeine/NSAIDs cocktail at least once a week (if not more) just to keep myself going and hold a job. This was my life for almost two full years until, after a change in my company's health plan, I was blessed enough to find an incredible doctor: Dr. John H. Jacobsen, neurology specialist in Chicago. He stuck with me and found me the best help possible.

One of the most important ingredients in getting better is a dedicated, concerned, and innovative doctor. If not for him, my migraines would have continued to control my life.

—*L. Moreno*

Communication

I'm a family nurse practitioner as well as the mother of a 23-year-old son with autism and the wife of a 57-year-old man with early-onset dementia. Communications in our family have never been normal.

Social workers are not trained to recognize the signs of early dementia. Looking back, I now realize that my husband's disease went undiagnosed for years. We went to family counseling because of tension between my husband and son. I knew that the problems were largely due to my husband's distorted interpretation of things, but I couldn't make any counselor recognize it for what it was.

My husband can speak and hear, but he misinterprets things. My son, on the other hand, understands everything and forgets nothing, yet he cannot always make himself understood or give information back. Our family dynamics are completely atypical, and I am the constant go-between (and often the bad guy).

Now I know why I have always leaned toward surgery: I can almost always promise a patient that the pain will get better eventually. Kudos to those practitioners who deal with chronic illness—and in particular neurologic conditions—on a daily basis.

—*Name Withheld*

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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.

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