

I have Alzheimer's and I am 77 years old. At some point I decided that my forgetting words so often, along with my family history, meant it was time to "face the music." In the fall of 2004 I turned to Loyola Hospital for a diagnosis. After the usual battery of tests, I was given the mild 95 percent cognitive impairment award, some instructions on how to live the rest of my life, and sent on my way. My primary care doctor tried different memory drugs and finally we found one I could tolerate. And yes, they helped.

So now, I exercise on a regular schedule and try to exercise my brain by doing card games and puzzles.

My ability to recall things seems to be more age-related than disease-related, but then that might the denial that often accompanies this disease. I have never been sorry that I paid attention to my inner voice and got tested. Now I live a more careful life, exercise very regularly, try to eat wisely, and get a good amount of sleep. My social life is very active.

And of course, I got all my personal affairs in order with an elder lawyer. And I love *Neurology Now*.

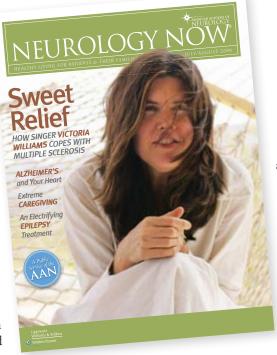
-Nadine Pankow

THE EDITOR RESPONDS: Thank you for your inspiring letter, Nadine. We have a story on advance directives in this issue on page 35.

The Cerebellum Blues

On the last page of the July/Aug 2009 issue, the article "The Cerebellum Blues" has a profound error, I believe. It says, "... blood is toxic to the brain. The very stuff so essential to life also kills brain cells."

The last I'd heard, the neurons in the brain die without the oxygen and nutri-



ents carried by the blood. Please clarify!
—Sterling Hartman

THE EDITOR RESPONDS: You're correct, Sterling. The writer was implying that while blood is essential, it can also be toxic under certain circumstances—for example, when a brain injury causes massive bleeding.

Tourette Syndrome

I have been an enthusiastic reader of your magazine for over a year. It would be helpful to see some articles on Tourette—many people, including myself, have loved ones afflicted by this. Also, please add Tourette Syndrome to your list of neurological disorders:

Tourette Syndrome Association tsa-usa.org 1-718-224-2999

—Alisa Yaffa

THE EDITOR RESPONDS: Thanks, Alisa. Look for a story on Tourette in an upcoming issue.

Seize the World

I am writing from Cairo to say thanks for publishing the article in the last issue about "Seize The World." Here is a recent e-mail from someone who saw the article

and then navigated to our site:

I found your article in *Neurology Now*! I am amazed at the ongoing journey you're taking to spread awareness about epilepsy. I have been struggling with epilepsy since I was 12 years old. Now, at the age of 22, I am more understanding of this disorder. Have a safe journey and let's keep in touch!

-Kelsey

The Seize The World Bicycle Tour is now in Cairo, and I will be flying to Mumbai, India, where the journey across mainland Asia begins in a few days. I'll be touring India, Southeast Asia, China, Japan, and then back to the USA. There is much work to do yet, and a great adventure still lies ahead.

—Stephen Allen

Thinking About Gingko

In "Thinking About Gingko?" (March/April 2009), Dan Hurley states that the "benefit of memantine may be as minimal as extending for just a few months the ability of a person with advanced Alzheimer's to us a bathroom independently."

While I am unfamiliar with this drug, I am a former caregiver of beloved elders. Let me emphasize that even a month of using the bathroom independently is not minimal! The inability to go to the bathroom independently is a major stressor for both the patient and caregiver.

I'm impressed by your publication and have recommended it to others, but I urge you to have greater awareness and sensitivity to the daily struggles faced by patients and those who love them.

—Valodi Foster Sacramento, CA

THE EDITOR RESPONDS: We appreciate that you pointed this out. We do understand that many of our readers have daily

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struggles related to the effects of neurological disease and will try harder to make this clear in all of our stories.

Unsung Heroes

This letter is in response to your question in "From the Editor" (May/June 2009) asking us about the unsung heroes in our lives. I was diagnosed with multiple sclerosis (MS) in October of 2006.

I would like to talk about a doctor that has become my hero. He showed me that a scientist can have a wonderful and caring heart.

His name is Dr. Benjamin Greenberg, and he works at the Southwestern Medical Center in Dallas, TX. What started as a second opinion became the best choice that I ever made in my MS life!

He was always willing and open to answering my questions, regardless of the time of day. Dr. Greenberg was able to learn the type of support I needed from a doctor. He tailored his treatment to me as a person. I never felt like I was just another patient, because he took the time to learn who I am.

In fact, I created a video that I call "Unsung Heroes" where I celebrate the wonderful work of the many scientists that I admire and that are dedicating their lives to finding a cure for MS and for the many other rare neurological disorders. You can see my video on my Web site **flowers4MS.com** where I help raise funds for MS research.

—Angela Cleary

Peripheral Neuropathy

I am part of a grassroots support group for people with peripheral neuropathy that meets every month and will expand over time. We are also putting together a 24/7 telephone peer support line. Our group is the Southern California/Palm Springs Neuropathy Support Group, and we meet every second Friday from 1:30-3:00 p.m.

at the Mizell Senior Center, 480 South Sunrise Way, Palm Springs, CA. The phone number is 760-323-5989.

—David Hines

THE EDITOR RESPONDS: Although we don't have the room to list regional groups and chapters in Resource Central, we hope that readers in your area will see this letter.

Frontotemporal Dementia

My husband has frontotemporal dementia (FTD). The disease took a number of years to diagnose. He was misdiagnosed as bipolar for many years and consequently treated with inappropriate antipsychotic drugs while the dementia progressed. He was in and out of the hospital 10 times and did two three-month stints in two different nursing homes. Luckily we were able to get a diagnosis by working with a wonderful neurologist and psychoneurologist.

FTD is on the National Institutes of Health's list of rare diseases and is fast tracked by Social Security for Disability. It is not like Alzheimer's—it strikes people at a much earlier age and has a shorter life span. It affects the frontal lobes, which control executive reasoning and cognitive function. Most patients afflicted with FTD lose their speech and ability to walk but not their memories. There are no drugs specifically designed for this orphan disease.

I want to share two Web sites to help others dealing with this disease. The first is for general information and caregiver advice: **ftdsupport.com**. The second is a support forum for family caregivers: **ftdsupportforum.com**.

—Mary Nurrenbrock Dayton, OH

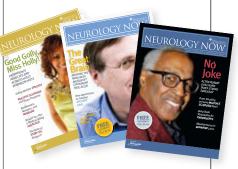
THE EDITOR RESPONDS: Thank you, Mary. Look for a story on dementia, including FTD, in the Nov/Dec issue.

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, 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.



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