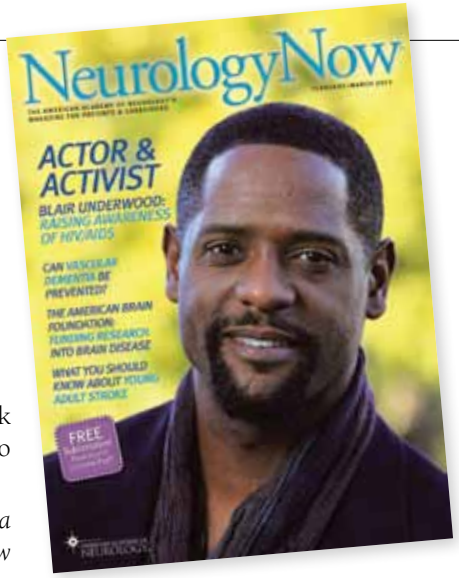

Blair Underwood

Just got Blair Underwood cover. Thank you! This will help so many get info about HIV/AIDS.

—nervylisa
from Twitter.com/NeurologyNow

What a Cure Would Mean: Multiple System Atrophy

In "From the Editor" (February/March 2013), Dr. Robin Brey asked readers to share what a cure would mean to them (**http://bit.ly/Z94Qca**). I am 69 years old and have multiple system atrophy (MSA). Since I was diagnosed in 2002, I have lived 11 years, which is considered very lucky because the average is five years.

My legs ache at night fiercely. I can no longer walk more than three or four steps without a walker. I need help bathing and grooming myself. Sometimes it's hard to fill my days; I used to be a quilter, but since my manual dexterity is failing, I can't quilt anymore. Even writing to you is difficult.

This is not to say I want your sympathy. After all, I already have made it six years longer than expected. I think there are reasons I have lived this long. For the first seven years, I went to the gym three days a week. I take the medications that have been prescribed. My family and friends have been enormously helpful, always willing to help me.

My hope is that my letter will help raise awareness of MSA and spare others from the difficulties I have experienced.

—Patricia C. Tocatlian
Ogdensburg, NY

THE EDITOR RESPONDS: Thank you for your letter, Patricia. Please see **http://bit.ly/YbBybF** for our coverage of MSA.

What a Cure Would Mean: Stroke

I had brain surgery almost five years ago to repair a bulging blood vessel. During the first year of recovery, I experienced terrible burning pain on the entire right side of my body, along with the headache and ear ringing that brought me to the doctor in the first place. Eventually, a neurologist looked at the MRI taken right after my surgery.

"Sit down," she said. "Has anyone told you that you had a stroke after your surgery?" She also told me that I had central pain syndrome as a result.

I pounded on the steering wheel of my pickup, weeping on the way home. I was angrier than I had ever been.

It took two years to find the best medical solution. I went from working 60-80 hours per week to barely 20. I hated life.

I started talking to a psychologist with expertise in chronic pain because I was suicidal. A cure for me would be quieting the electric impulses that cause me to feel the burning sensations. The medications together on a good day make it tolerable, as long as I sit still in my recliner.

—Rev. S. Scott Fontenot

THE EDITOR RESPONDS: Thank you for sharing your experience with us, Scott. Please see **http://bit.ly/Y2KstP** for *Neurology Now* coverage of central pain syndrome, and see page 26 of this issue for more on coping with chronic pain.

What a Cure Would Mean: Cavernous Angiomas

My son has cavernous angiomas. He had a brainstem bleed nearly three years ago when he was nine. He is doing very well, but his behavior and personality changes continue to be difficult for our family to deal with. They are more of a burden to my son, now 12, than the loss of sensation on the left side of his face and the slow recovery of his hearing and coordination on that side.

A cure would mean a lot of things to our family. We know the cavernous angiomas are hereditary, so my son's three siblings each have a 50 percent chance of having them as well. We know they are a ticking bomb inside my husband's brain as well.

Knowing all that, today, my best answer to what a cure would mean is this:

that my seven year old—that no one's seven year old—would have to ask "I know [my brother] has a brain injury, but why does he have to have it all the time?"

—*Michelle Wilkinson*
State Center, IA

I am a 34-year-old mother of four. Last year, after about two years of ongoing mystery health issues, I was diagnosed with a cavernous angioma deep into the brain stem. It has bled twice, I was told, making me a time bomb for another bleed anytime, with only 1 percent chance that this "bomb" would become inactive. The location, I was told by two local neurosurgeons, was inoperable. I then found several surgeons who told me the surgery is possible, but risky. My cure right now would be a successful surgery. A cure, the perfect one, of course would be to destroy such tumors in a noninvasive way, or best yet, prevent them from ever becoming active.

—*Lisa*
Cincinnati, OH

Central Pain Syndrome

Just a note of thanks for your article on central pain syndrome (**http://bit.ly/Y2KstP**). My wife has central pain syndrome, and we were both heartened to see the condition addressed in your magazine. Central pain syndrome is little understood, and many healthcare professionals would rather disregard its existence than admit they have nothing to offer in the way of help for patients. I know any medical treatments must be preceded by research, which requires funding, all of which may be set in motion by awareness, sometimes stemming from publications such as yours.

—*R. Gilstrap*

Young Adult Stroke

Thank you for your article "Age Is Just a Number" from the February/March 2013 issue (**http://bit.ly/ZaVNeV**). Who would have ever thought that a 45-year-old nonsmoker would have a stroke? That is exactly what happened to my husband in March 2009. After waking up and heading to the bathroom he threw up. It was flu season, so I told him to go back to bed. Twenty minutes later, I realized something was wrong when he couldn't turn on the shower because he was confused. We got dressed and went to the emergency department. I know

now that I should have called 911.

After extensive speech and physical rehab, he was able to come home. However, he started to slip into depression, so I made an appointment with a neuropsychologist. After a full day of different tests, written and oral, he was diagnosed with dementia.

Thank you very much for the information in your magazine.

—Cindy Grinstead-Glick
Galloway, OH

American Brain Foundation

The February/March 2013 issue contained a request for donations to the American Brain Foundation. A number of brain diseases were mentioned in the ad, but it seems they left off one disease that over 10,000,000 people [including children] suffer from: essential tremor. Is this not considered a brain disease? I have essential tremor, and my son and two of my grandchildren do as well.

—Anita Otis,
Independence, MO

THE EDITOR RESPONDS: Thank you, Anita, for reminding us of the many neurologic diseases that need research. The American Brain Foundation raises money for research into all brain diseases, including essential tremor, not just those that were listed in print.

Attitude Is Everything

Thanks you for "Attitude is Everything" and "Not Just Tremor" in the December 2012/January 2013 issue. Both articles address the need to manage depression in addition to neurologic disease. After meningioma surgery, my battle with depression was just as challenging as the meningioma symptoms and the recovery from surgery. Never having dealt with depression before, my feelings were hard to define at first. But when I realized I was experiencing depression, I found it manageable with therapy and antidepressant medication. Reaching out to a neuropsychologist and neuropsychiatrist was very helpful.

—V. Brown-Braxton
Glen Burnie, MD

Jennifer Grey

I really liked the cover story on Jennifer Grey in the December 2012/January 2013 issue (**http://bit.ly/VZxKKy**). It was very insightful, with tips on managing chronic pain that can be applied to other conditions. Most importantly, it was very inspirational. I give her and the magazine a lot of credit for sharing this story.

—Chun, via email

Myasthenia Gravis

I receive your magazine as a family member; one of my daughters was diagnosed with myasthenia gravis in 2009. I have become active with the Myasthenia Gravis Foundation of Illinois (MGF of Illinois) and am currently serving as Chair of the Board of Trustees.

The MGF of Illinois is a non-profit that was founded in 1972. We provide patient support and educational services, and we fund medical research. Based in Elmhurst, IL, we serve the entire state of Illinois and we have support groups in Indiana and Iowa.

Could our organization be listed in your Assistance Directory?

—Edward Rickert
McHenry, IL

THE EDITOR RESPONDS: Thank you for your letter, Edward. We would be happy to list your organization in the online version of Resource Central at **http://bit.ly/KxGL9U**.

I recently went to your website and read Gayle Franck's essay "The Well-Planned Life: Learning to Manage the Fatigue of Multiple Sclerosis" from February/March 2012 (**http://bit.ly/ArpPoZ**). Her advice is just as applicable to myasthenia gravis (which I have) as it is to multiple sclerosis. And, I would imagine, many neurologic conditions.

It has taken me years to accept that resting is a necessary activity, not a luxury, and, that if I wait until I get finished to rest, I'll never get finished.

—Mary Jo Dailey
Richmond, VA

THE EDITOR RESPONDS: Thank you for your letter, Mary Jo. For the full collection of *Neurology Now* articles on myasthenia gravis, go to **http://bit.ly/X7I2YR**.

CORRECTION

In "Not Just Tremor" (December 2012/January 2013), we incorrectly stated that the symptoms of early-onset PD appear "between the age of 50." The symptoms of early-onset PD appear *before* the age of 50.