



Myasthenia Gravis

I am contacting you to suggest a story regarding Myasthenia Gravis Awareness Month in June. Myasthenia gravis (MG) is an under-diagnosed and relatively unknown autoimmune neuromuscular disease. It affects people of every age, race, and gender and can cause slurred speech, double vision, drooping eyelids, weakness in the arms and legs, and difficulty breathing, chewing, and swallowing.

The lack of media coverage and public knowledge of this disease permits the suffering of thousands of people each year. A person may endure the symptoms of MG for much of his or her life without answers.

Additionally, our foundation receives heartbreaking calls each year from patients who are left untreated in emergency rooms, patients who are mistaken for being intoxicated, and patients who are ridiculed for taking handicapped spaces because their symptoms are often “invisible” to the average person. Please consider spotlighting this disease in June of this year in coordination with Myasthenia Gravis Awareness Month.

—Janet M. Golden
Myasthenia Gravis
Foundation of America, Inc.
1-800-541-5454
myasthenia.org

THE EDITOR RESPONDS: Thank you for your suggestion. Please see “Trials and Tribulations” (page 32) and look for a story on MG in May/June 2009.

Multiple Sclerosis

My name is Angela and I was diagnosed with multiple sclerosis (MS) two years ago. I had my first attack three

days after being told that I might have this serious chronic disease.

In the course of these past two years, I have had to change medications three times and have experienced three serious relapses. I have been able to learn a lot about MS by reading *Neurology Now* and find the articles about MS very interesting.

Instead of getting down on myself and letting fear of the unknown take over, I created a project that I called Flowers4MS. It allows me to raise awareness and funds for MS research. The project keeps me going and makes me feel grateful for each and every day. I share my story on the Web site at flowers4MS.com. Thank you for your informative coverage of such a debilitating disease.

—Angela Cleary
Help support research
to find a cure for MS!
Flowers4MS.com

Even Cowboys Get Migraines

There is a glaring error in the Sept/Oct 2008 story, “Even Cowboys Get Migraines.” The story says that World War II ended with an armistice: “This is a ‘common pattern,’ Dr. Cutrer observes, referring to the reports of ‘many soldiers at the end of WWII having a migraine the day after the armistice was signed!’” However,

it was actually World War I that ended with the armistice. I’m not sure if this is a typo or a historical inaccuracy.

Thank you for your very informative magazine; we’ve enjoyed it for years.

—Ed Snow

THE EDITOR RESPONDS: That’s an excellent question. Although “Armistice Day” officially refers to the end of WWI, as you point out, we used the term “armistice” informally here, to refer to the end of fighting in WWII.

Editor’s Letter

I agree with your concern on p. 7 of the Sept./Oct. issue of *Neurology Now*, but I also think you are preaching to the congregation.

It’s the professionals staffing emergency departments (ED) who need to be educated. Some ED doctors make light of TIAs—you are made to feel it was a waste of time coming. Three times I took my sister to the ED over the course of a year. Once she was told to come back if it happened again. Once she was told don’t come to the ER because nothing could be done.

Then when she had the stroke and was brought to the ED by ambulance (and we all are told you get quick attention if you come by ambulance), she was put in a wheelchair and dumped in the waiting room. I was the one who got hold of the nurse to tell her my sister’s speech was getting worse.

—Marilyn Erickson

Sharing Stories

I started receiving *Neurology Now* about three years ago, shortly after my father was diagnosed with amyotrophic lateral sclerosis (ALS, or Lou Gehrig’s disease). I read my first copy in the neurology department of the Mayo Clinic in Roches-

@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, 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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WEBSITE

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ter, MN, where I waited for my father and mother to return from the exam room only to hear the bad news.

Neurology Now is not only educational and informative, but it also provides a feeling of not being alone in the fight against an awful disease. I thought it might be nice if *Neurology Now* created a section for “sharing.” Not like the “Letters” section, as this relates to past articles or issues, but more of a place where patient, caregivers, and family members can write in and express their thoughts and feelings.

—Dawn Batten Navis

THE EDITOR RESPONDS: That’s a great suggestion, Dawn. We’re working on something similar for our Web site, neurologynow.com, so please stay tuned.

Hydrocephalus

Thank you so much for your recent feature on normal pressure hydrocephalus (NPH). I have been receiving your publication for two years and this is the first time I’ve seen information on NPH.

My husband was finally diagnosed with NPH two years ago, after I pleaded with his doctor to do a spinal tap for hydrocephalus. He made remarkable progress once the shunt started draining off the fluid. My heart goes out to all those people who don’t have an advocate and are misdiagnosed.

—Brenda Wolf
Boynton Beach, FL

Delirium, not Dementia

Earlier this year, while in the waiting room of a Michigan neurologist, I became aware of *Neurology Now*. My 78-year-old husband had had a recent bout with pneumonia and atrial fib with some residual short-term memory loss and confusion. The local neurologist in our small town in Illinois immediately diagnosed him with dementia. Our two daughters and I refused to accept this diagnosis; we ended up seeing two neurologists in Michigan and one wonderful internist. Thank goodness we did.

To our great relief, the internist and both neurologists diagnosed my husband not with dementia but with delirium. The Michigan doctors said the delirium could last for months, and it did—just about three months to be exact.

I feel there should be more public information regarding the causes and symptoms of delirium. There are, I’m sure, thousands of elderly who have had recent bouts of pneumonia or urinary tract infections who then suffer delirium, which is a temporary condition, but are diagnosed as having dementia.

Now, three months after its first manifestation, the delirium only appears momentarily and very infrequently. My husband is now doing all of our yard work, and keeps up with the activities he enjoyed prior to his illness.

—Ann Wiesemann

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The Circulation Department