# NeurologyNow

# 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.



#### **SUBSCRIPTIONS**

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

PHONE: Call 1-800-422-2681

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ONLINE: Visit our Web site (neurologynow. com) and click on the subscription link.

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#### **IMPORTANT SAFETY INFORMATION (Continued)**

Do not take BOTOX® if you: are allergic to any of the ingredients in BOTOX® (see Medication Guide for ingredients); had an allergic reaction to any other botulinum toxin product such as Myobloc® (rimabotulinumtoxinB), Dysport® (abobotulinumtoxinA), or Xeomin® (incobotulinumtoxinA); have a skin infection at the planned injection site.

The dose of BOTOX® is not the same as, or comparable to, another botulinum toxin product.

Serious and/or immediate allergic reactions have been reported. These reactions include itching, rash, red itchy welts, wheezing, asthma symptoms, or dizziness or feeling faint. Tell your doctor or get medical help right away if you experience any such symptoms; further injection of BOTOX® should be discontinued.

Tell your doctor about all your muscle or nerve conditions such as amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease), myasthenia gravis, or Lambert-Eaton syndrome, as you may be at increased risk of serious side effects including severe dysphagia (difficulty swallowing) and respiratory compromise (difficulty breathing) from typical doses of BOTOX®.

Human albumin and spread of viral diseases. BOTOX® contains albumin, a protein component of human blood. The potential risk of spreading viral diseases (eg, Creutzfeldt-Jakob disease [CJD]) via human serum albumin is extremely rare. No cases of viral diseases or CJD have ever been reported in association with human serum albumin.

Tell your doctor about all your medical conditions, including if you: have or have had bleeding problems; have plans to have surgery; had surgery on your face; weakness of forehead muscles, such as trouble raising your eyebrows; drooping eyelids; any other abnormal facial change; are pregnant or plan to become pregnant (it is not known if BOTOX® can harm your unborn baby); are breastfeeding or plan to breastfeed (it is not known if BOTOX® passes into

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins, and herbal products. Using BOTOX® with certain other medicines may cause serious side effects. Do not start any new medicines until you have told your doctor that you have received BOTOX® in the past.

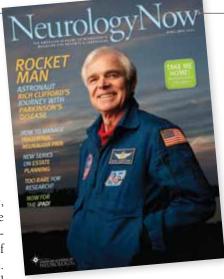
Especially tell your doctor if you: have received any other botulinum toxin product in the last 4 months; have received injections of botulinum toxin such as Myobloc®, Dysport®, or Xeomin® in the past (be sure your doctor knows exactly which product you received); have recently received an antibiotic by injection; take muscle relaxants; take an allergy or cold medicine; take a sleep medicine; take anti-platelets (asprin-like products) or anti-coagulants (blood thinners).

Other side effects of BOTOX® include: dry mouth, discomfort or pain at the injection site, tiredness, headache, neck pain, and eye problems: double vision, blurred vision, decreased eyesight, drooping eyelids, swelling of your eyelids, and dry eyes.

For more information refer to the Medication Guide or talk with your doctor.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please refer to full Medication Guide including Boxed Warning on the following page.



#### Parkinson's Disease (PD)

I was a caregiver for someone with PD, and I am now an advocate trying to raise awareness of PD. I was glad to see astronaut Rich Clifford on the front cover of the April/May edition of your magazine. However, you didn't mention that April is Parkinson's Disease Awareness Month. Please don't forget to mention this in the future! Many people with PD read Neurology Now and should be reminded.

—Linda Giorgilli Rice

THE EDITOR RESPONDS: Thank you, Linda, for reminding us that April is Parkinson's Disease Awareness Month. During that month, many patient advocacy organizations hold special events to raise awareness of PD and money for research. See Resource Central on page 44 of this issue for a list of patient advocacy organizations or see our full, online version of Resource Central on at http://bit.ly/KxGL9U.

I share Rich Clifford's philosophy: "Don't let PD drive what you do. Remember that you're in charge of your future."

I was diagnosed with PD in May of 2008 and have recently rediscovered the benefits of working out with weights. I am now using them to improve my balance, flexibility, and stamina.

—Tom Bryant

THE EDITOR RESPONDS: Thank you for sharing your experience, Tom. We want to remind everyone to talk with their neurologist before starting any exercise program.

I thoroughly enjoyed your article about astronaut Rich Clifford's journey with PD. As a pilot for many years, I understand Clifford's drive and perseverance in continuing to fly.

I was diagnosed with PD in May of 2011 at the age of 66. For about a year or so before that, I was getting hints that my body was changing: an intermittent resting right hand tremor; increasing stiffness; a gait that was not normal for me; and loss of smell. However, I attributed those changes to age.

Then, in early May 2011, my wife, Ann, and I were relaxing at a beach in Clearwater, FL. When it came time to leave, I was unable to put on my sneakers. My wife had to help me put on and tie them. It was time to go back to Mass General Hospital.

Upon arriving home a few days later, I visited my primary care physician and my neurologist, who diagnosed me with PD. From there on out, my life began to improve from what was physically a low point.

I researched the type of medications that the Federal Aviation Administration (FAA) would allow a pilot to take and discussed these with my neurologist. Remarkably, my lights turned back on, so to speak, within a few days of starting levodopa-carbidopa. Most of the symptoms disappeared, although my sense of smell has not returned to what it used

Within 10 days of starting the medication, I kept a scheduled appointment for a five-day recurrent course that included 12 arduous hours in a flight simulator. My instructor and FAA check pilot relayed to me how impressed he was with my performance.

After many sessions of physical therapy and extensive neurologic and psychological assessments-including a final report from my neurologist-I received clearance from the FAA medical team to continue flying corporate jet aircraft, which is such an integral part of my life.

> —Stephen C. Chapdelaine North Attleboro, MA

THE EDITOR RESPONDS: We appreciate you sharing that inspiring story with us, Stephen, and wish you continued success doing what you love. By the way, the American Academy of Neurology (AAN) has published an excellent book for people with taste and smell problems that includes tips and recipes: Navigating Smell and Taste Disorders, by neurologist and AAN member Ronald DeVere, M.D. Dr. DeVere has experienced problems with smell and taste himself. Go to patients.aan.com/go/neurologynowbooks for more information.

# The Buzz on NeurologyNow.com

The previous Quick Poll question on neurologynow.com—"Have you ever participated in a clinical trial?"—generated 1,671 responses:

- ▶ **571** of you replied, "Yes"
- 632 replied, "No, but I plan on it"
- ▶ 468 replied, "No, and I don't plan on it"

If you're one of the people who responded, "No, and I don't plan on it," email us at neurologynow@lwwny.com and let us know why!

And, don't forget to go to neurologynow.com to answer our next Quick Poll question: "Have you changed your financial or legal plans because of a neurologic condition?"

# HDSA Team Hope Walk, June 23

The Minnesota chapter of the Huntington's Disease Society of America is holding its Team Hope Walk and 5K Fun Run around Lake Harriet on Saturday, June 23, 2012, to raise money for Huntington's disease. Registration opens at 9 a.m; the walk/ run begins at 10 a.m. Register Online at hdsa.org/mn.



## **Trigeminal Neuralgia**

Thank you for the article on trigeminal neuralgia (TN). One part of managing TN that has been very frustrating for me is that the only way to make an appointment with many doctors is by telephone. However, the pain of TN can make it difficult to talk on the phone. To physicians treating TN: Please create a way for patients to schedule appointments, ask questions, and request refills by e-mail!

Thank you for having this magazine and for sending it out free to people with neurologic disorders. It's a reminder that somebody out there cares about this stuff and is working at better ways to treat it.

> —Charles Wolff Phoenix, AZ

**Neurology Now**® for the iPad®

Starting with the April/ May 2012 issue, you can enjoy reading Neurology Now on your iPad! The iPad edition features a print-like reading experience enhanced with

article-sharing features, multimedia links, and more. One reader commented, "This is awesome! I use my iPad for just about everything so I'm glad that I can put this app on my main screen. It'll be great to have archived issues also. So, thumbs up from me!"

The app is free and you can download it today. On your iPad home screen, open the App Store icon and search for "Neurology Now." Tap "Free" to install the app on your iPad, and then download the April/May and June/ July issues. Prompts in the app library will let you know when each new issue is available.

THE EDITOR RESPONDS: Thank you for your suggestion, Charles, and for reminding readers that Neurology Now, published by the American Academy of Neurology, is free to people with neurologic disorders as well as their families and caregivers. Neurology Now is also available for the iPaddownload at http://bit.ly/HkCPpK and receive complimentary access!

## Speak Up for Stroke

After reading the article about the Speak up for Stroke Campaign in April/May 2012, I wanted to share with you my experience of having a stroke. I am a registered nurse who has been practicing since 1982. Although I am well aware of the warning signs of stroke, I chose to ignore them in my own case. When I noticed that I was having trouble talking and my speech was garbled, I told myself I was having a panic

attack and that I couldn't be having a stroke because I have never had the typical risk factors—for example, I have always had low cholesterol and low blood pressure. Instead of going to the hospital, I took a nap, thinking it would settle my anxiety. When I woke up my speech was worse, so I went to the emergency room where I

was told I had a stroke.

My message is the same as in your article: Call 9-1-1 if you experience any of the signs of stroke. Every minute counts.

> —Mary T. Bruno, R.N. Hernando, FL

THE EDITOR RESPONDS: Thank you, Mary. As a reminder to our readers, call 9-1-1 if you experience any of these signs:

- Sudden numbness or weakness of the face, arm or leg, especially on one side of the body
- Sudden confusion, trouble speaking or understanding

- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- ► Sudden, severe headache with no known cause

#### Rare Diseases

I was so intrigued and encouraged by Dr. Robin Brey's request for readers to share their experience with a rare disease ("Not So Rare," April/May 2012). I am a rehabilitation specialist who works with many patients who have developed arachnoiditis, a pain disorder caused by the inflammation of one of the membranes that surround and protect the nerves of the spinal cord. I am also the parent of a young adult with arachnoiditis. Unfortunately, the condition often remains unrecognized-and patients underserved. Please consider doing an article on it.

—Terri A. Lewis

THE EDITOR RESPONDS: Thank you for the suggestion, Terri. We received many, many responses to Dr. Brey's article, including a large number requesting more information on arachnoiditis. We regret that we cannot publish all the responses in print, but please check the "Speak Up" section of neurologynow.com at http://bit.ly/JwoZmm for more letters to the editor. Also, look for coverage of arachnoiditis in upcoming issues. For information on arachnoiditis from the National Institute of Neurologic Disorders and Stroke, go to ninds.nih.gov.

**CORRECTIONS:** The article on trigeminal neuralgia in the April/May 2012 issue ("Facing Pain") erroneously states that Mary Harmon was treated with Gamma Knife; she was treated with the CyberKnife System. In addition, the article mistakenly states that oxcarbazepine does not cause low sodium levels.