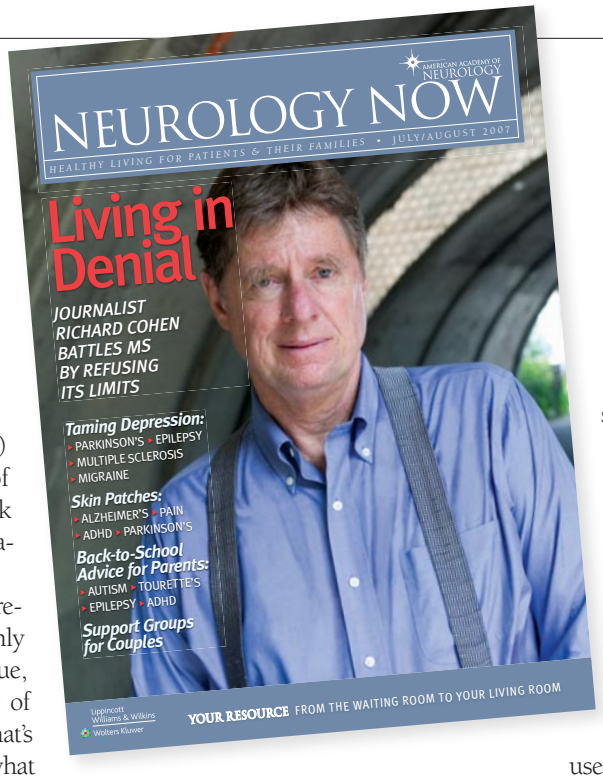

Myasthenia Gravis

I am a myasthenia gravis (MG) patient and am on the Board of Directors of the Metro New York Chapter of the Myasthenia Gravis Foundation of America.

In all the months I have been receiving *Neurology Now* I have only seen one tiny piece on MG. True, there are probably only 70,000 of us with MG in the U.S., but that's the problem: no one knows what it is. There are a lot of doctors out there who are not familiar with the state of MG today and only know what they learned in medical school—information that could be very old. As a result, patients go misdiagnosed. Treatments have been updated, there is research going on, and there are neurologists who do see many MG patients and are up to speed on current protocol.

So how about an article on MG? Help us out—it's tough to raise awareness and fund-raise when no one can even pronounce the disease you have.

Susan Klinger
Secretary, Board of Directors
Metro NY Chapter, MGFA

THE EDITOR RESPONDS: Thanks, Susan. We took your suggestion and did "By the Numbers" on MG (page14).

Trigeminal Neuralgia

I received my first copy of your wonderful publication yesterday, and enjoyed reading it cover-to-cover. But as I am always looking for information on the neurological disorder known as the "worst pain known to mankind." Is there a plan to publish information on this subject?

Bob Moses
Hamilton, NJ

THE EDITOR RESPONDS: Please see "Ask the Experts" in last month's issue and look for other stories on TN in upcoming issues.

Body Myositis Study

I am a research study coordinator in the division of rheumatology at the University of Pittsburgh, where we are conducting a multi-center clinical trial for myositis patients. Does *Neurology Now* have space to announce the study and help us in our effort to boost enrollment?

Jennifer Jablon

THE EDITOR RESPONDS: Thank you for your letter, Jennifer. We hope this announcement helps your recruiting efforts.

MYOSITIS TRIAL

To enroll in the Rituximab in Myositis (RIM) study, please contact the coordinating center at 412-647-3241 or visit the RIM study Web site at **RimStudy.org**.

Sleep Apnea Options

In 1984, after much prodding from my wife—who could no longer tolerate my snoring and her constant worrying over whether I was going to start breathing again—I was diagnosed with sleep apnea. After two sleep studies I was put on continuous positive airway pressure (CPAP) but found it hard to exhale against the high pressure prescribed. After another study I was put on bi-level positive airway pressure (BiPAP) instead and it has worked very well. I use it every night with good results. The full face mask over a full beard is a bit of a challenge, but I've made it work.

I was disappointed in that the author of "The Risks of Slumber" (May/June 2007) seemed to imply that the mandibular device was the only mechanical alternative for those who cannot use CPAP.

Jim Burnett Sr.
Portland, OR

Living in Denial? Far From It!

What a grand celebration of life Mr. Richard Cohen is! Thank you for sharing his inspirational story in your July/August 2007 article "Living in Denial." Mr. Cohen is a shining example of a person who deeply understands his capacity and how to push it wherever possible.

However, refusing to live within the apparent limits of one's condition is not, in any sense of the term, living in denial. I understand the headline was written to grab attention—it did mine. And I don't believe you implied there was anything self-destructive in Mr Cohen's attitude; the article itself does an excellent job portraying his perseverance and vivacity.

But someone could easily read the headline and never make it to the article, let alone understand the subtle distinction between refusing to accept limits (healthy) versus denying that loss

has occurred (unhealthy). As a Catholic deacon serving the brain-injured community, I work with many people who refuse—in an unhealthy way—to accept the limits of their disability, to the detriment of themselves and their families.

As Dr. Brey's editorial points out, there is a tremendous need for people with loss of function to grieve those losses. In my experience, the five stages of grief which Dr. Brey introduces often leave people stuck at the acceptance stage. Dr. Kubler-Ross developed these stages for people who are dying. But for people whose losses are not terminal, or even immediately terminal, they often reach the acceptance stage and enter depression because they are at a loss how to proceed.

I invite you to consider the additional two stages of grief that I have added.

6. Integration: How is life different? The same? Who am I now? OK, fine, I accept my loss, but what does it mean for me and my daily life?

7. Co-Creation: I'm ready to contribute now. What are my passions and how can I harness them as I strive to contribute to my family, my friends, my community, my world?

Blessings,
Patrick Jones
BrainInjuryChaplain.com

CORRECTIONS:

In the May/June 2007 issue, the photo that appeared in the "CPAP Recall" box in the article "The Risks of Slumber" is of a product (OptiLife™ mask) manufactured by Respironics®, Inc., a leading provider of innovative products and programs that serve the global sleep and respiratory markets. No Respironics product is associated with this recall. We apologize for any confusion that this may have caused to readers or customers of Respironics.

In the July/August 2007 issue, the URL for the school Barbara Arrowsmith Young started was listed incorrectly. The correct URL is **www.arrowsmithschool.org.**

LET US HEAR FROM YOU

We always want to know if a story has touched you or helped you—or rubbed you the wrong way. Plus, here are three questions for you, based on stories in this issue of *Neurology Now*.

MEDICAL NEWS:

In "Miracle Drug! Or not" (page 40), we help you read and understand medical news. Where do you get most of your medical information?

ON THE JOB:

In "Know Your Rights" (page 34), we provide tips on how to protect yourself from workplace discrimination. Has your neurological condition affected your employment?

SMART CONSUMER:

Would you like to see more information in *Neurology Now* on consumer products? If so, what kind?

Email your thoughts to neurologynow@lwwny.com. You can also fax your letter to 646-674-6500 or mail it to Wolters Kluwer, Neurology Now, 333 Seventh Ave., 19th Floor, New York, NY 10001. Letters may be edited for purposes of space and clarity.

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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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