

Kids Talk

Thanks for the great article, "Kids Talk" in Mar/Apr 2008. My mom had multiple sclerosis (MS) from the time I was one. Mom passed away in 1995 after 38 years of MS. I created a way to honor her in 1997 by establishing a scholarship program in her name. The program has grown tremendously and now includes all Michigan high schools.

This fall I will offer a scholarship to the senior from all 50 states who raises the most funds for MS research. Your readers can find out more at **msscholarship.org**.

-Rick Szczepanski

Patched Up

Researchers had touted the long-awaited rotigotine (Neupro) skin patch for its consistent delivery of a once-daily dose directly into the blood stream. The patch was supposed to be particularly beneficial for early-stage Parkinson's disease. Impatiently awaiting FDA approval, I was about ready to go overseas to get it when my neurologist announced free samples had arrived. I was optimistic that my chronic symptoms would stabilize or abate.

The insert's disclaimers were the usual: may cause hallucinations, sleepiness, edema, etc. Nothing new. To mitigate sensitivity to the adhesive, one-inch square, patients are advised to rotate the location of the patch daily and avoid creases in the skin's surface.

But as I titrated to the next stages, the size of the patch increased to two- and then three-inch squares, which became impossible to camouflage. Because this "appliqué" broadcasts your Parkinson's disease diagnosis, it would be great if the manufacturer could spruce it up by offering a choice of skin tones, colors, or motifs.

—Cheryl Kingston

THE EDITOR RESPONDS: Thank you, Cheryl. This patch is actually being recalled—See page 12.

Cervical Dystonia

There need to be a few clarifications regarding "Rem Murray: Home on Ice," in the Jan/Feb 2008 issue of Neurology Now. It is well known that the "Reaching Your Goals" campaign is funded by Allergan. There is another botulinum toxin-Type B (Myobloc)-that is FDAapproved for cervical dystonia (myobloc. com). They provide financial assistance to those who are immune to botulinum toxin Type A. In addition, many experts feel that deep brain stimulation surgery is becoming the primary treatment for movement disorders. Finally, there are several other dystonia-focused organizations that should be listed as resources:

- Care4Dystonia, Inc: care4dystonia.org
- Dystonia Association of Kentucky: dystoniaassociation.org
- Bachmann-Strauss Dystonia and Parkinson's Foundation: dystonia-parkinsons.org
- National Spasmodic Torticollis Assocation: torticollis.org
- ► For clinical trials: clinicalconnection.com

—Beka Serdans, RN, MS, NP Founder, Care4Dystonia, Inc THE EDITOR RESPONDS: Thank you for your letter, Beka. We chose to interview Rem because his story is inspiring and because he speaks out publicly about cervical dystonia. We did not mean to give unfair preference to any particular treatment or source of assistance and appreciate these additional resources.

Music Therapy

Thank you for the article on Dr. Oliver Sacks in your Jan/Feb 2008 issue. Here in Spokane, WA, we enjoy and benefit from singing sessions with our chapter of the Tremble Clefs. Started in Scottsdale, AZ, Tremble Clefs groups across the country help to retain and improve the voices of people with Parkinson's disease. While studies show that singing is physically therapeutic, as Dr. Sacks mentioned, we find that the friendship and support within the group is even more powerful, lifting our spirits and filling our hearts with hope.

We recently began using rhythm instruments, which add a dimension of lighthearted fun to our gatherings. We don't strive for a lot of polish, but we do have a great time leading sing-a-longs at local care centers.

—Ruth Palnick, song leader and person with Parkinson's (8 years); and Sara Nielsen, speech therapist

The Jan/Feb 2008 issue contains a wonderful message from Dr. Robin Brey that refers to the article "Unchained by Melody," based on an interview with Dr. Oliver Sacks. As a board-certified, neurologic music therapist, I am thrilled with the exposure and accuracy of your coverage on music therapy. ["Unchained by Melody," Jan/Feb 2008] However, Resource Central did not give any contact informa-

NEUROLOGY NOW

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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tion regarding music therapy. Please refer your readers to:

The American Music Therapy Association, Inc. (301) 589-3300 musictherapy.org

—Becky Engen, Ph.D., N.M.T., MT-BC Associate Professor of Music Therapy Queens University of Charlotte Charlotte. NC

I am 56 and have been deeply affected by recreational music throughout my life. Over the past year, I developed a new percussion instrument and activity program specifically for the elderly. Called "tap dancing rhythm for your hands," it was birthed out of a very painful time of my life. I share it with people in nursing homes and with the disabled. You can find out more about it at dancinghandstaps.com.

—Laurie Lunsford

Spastic Paraplegia

I have a rare upper motor neuron disorder called hereditary spastic paraplegia (HSP). For the past six years I have been involved with the Spastic Paraplegia Foundation (SPF), the only organization

dedicated to two groups of neurodegenerative disorders: spastic paraplegia (hereditary and apparently sporadic); and primary lateral sclerosis (PLS). These spinal cord disorders cause progressive weakness and spasticity in the muscles of the lower body. People generally go from difficulty walking to needing a cane to eventually a wheelchair. In PLS, the disease also affects muscles in the upper body, causing problems with the arms, voice, and swallowing.

The impetus for forming the SPF was the accelerating pace of research. Dramatic breakthroughs have been made in the past decade, catapulting these conditions from being poorly understood to being on the threshold of significant treatment and cures. As both of these disorders are very rare, I would appreciate it if you would add our organization to your Resource Central section.

—Annette M. Lockwood President, SPF **sp-foundation.org**

THE EDITOR RESPONDS: Thank you, Annette. We are happy to add SPF to our list of patient organizations in Resource Central.

LET US HEAR FROM YOU

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

- **DON PAGE 26**, we discuss the potential benefits of massage for pain relief. What do you find are the best ways to relieve the pain associated with your condition?
- ▶ ON PAGE 10, we report on people traveling to China for stem-cell therapies unavailable in the U.S. Would you ever consider going abroad for medical treatment? Would you discuss this with your neurologist first?
- ▶ ON PAGE 17, we discuss the ways that epilepsy affects women over the course of their lives. Are you a woman with epilepsy? How has epilepsy affected you?