Amnesia

I had a right temporal lobectomy done 15 years ago that practically cured me of epilepsy. My life was reborn after the surgery.

Four years ago I experienced an episode of confusion for a few days. I had trouble completing sentences and couldn't remember what I had done five minutes or five months ago. By the time I had my third episode, I was pursuing my third neurologist. The origin was considered idiopathic, and the result was a total memory loss of 10 years of my life. I had no memory of the major events like 9/11 or any social events. My doctors classified it as a transient global amnesia.

Please do a story on amnesia. This is a scary position to be in for anyone.

-Neil Benson

THE EDITOR RESPONDS: Thank you for your suggestion, Neil. Please see "Am I Nothing but What I Remember?" on page 24 for the story of a young woman who experienced "retrograde amnesia." Also see Resource Central, page 37, for a description of different types of amnesia.

Give Me 5 for Stroke

My compliments to *Neurology Now* for the well-done article (May/June 2008) on the new Give Me 5 for Stroke campaign sponsored by the American Academy of Neurology, American Stroke Association, and the American College of Emergency Physicians. All three organizations are very pleased with the tremendous response to this effort to build awareness of the signs of a stroke and the need to call 9-1-1 immediately if you or someone close to you experiences one of these symptoms.

Unfortunately, the Web site for the campaign was accidentally omitted from the article. We urge the public and stroke



professionals to go to **www.giveme5for-stroke.org** for additional information on this campaign.

—Rod Larson Deputy Executive Director American Academy of Neurology St. Paul, MN

Infant Stroke

Our seven-year-old daughter suffered a stroke in utero. We have used and continue to seek every imaginable stimulus to help her. She has right-sided weakness, lost her "speech center," and has right hemanopsia (blindness in half her visual field). Yet, she is amazing. As a baby, she never crawled. She would scoot on her bottom in an upright position to move from one place to another. She cried and cried through physical therapy. We convinced her rehab doc to prescribe "music therapy" in conjunction with her physical therapy. The music therapist would come and play guitar and bring huge drums for her to stand at and play during therapy. The improvement was amazing. We taught her "baby signs" as an infant when words were too difficult for her; they came later and are in abundance today.

The most remarkable part of her story (so far!) is that of her first steps. Jamie is the fifth of our six children. Our four older children all learned violin using the Suzuki method (by listening and much repetition). She has been surrounded by their music since before birth. Each summer, we take

the family to a meeting of Suzuki players. Jamie's second year of participating was the summer she was two and not yet walking unassisted. The children sat in a circle each day. The teacher asked each child to stand and to make his/her way around the circle to music in any fashion they chose (walk, trot, skip, bounce, etc). When it was Jamie's turn, we held our breath. The teacher called

her name. Jamie said, "Me march!" She stood up (alone, first time ever) and proceeded to march around that circle to the music her teacher played. We were filled with such joy! We stood there crying as she marched around that circle, head held high. When she got back to her spot, she just fell to a sitting position (plopped down, really) and sat there like she'd been marching her whole life. It was a moment I will never, ever forget. Today, she's trying to learn violin as well. It's difficult for her as she has little use of her right hand and wrist. But every time the bow scratches across the strings I imagine new neural pathways forming in her beautiful brain.

My hope is that someday your colleagues will put more time into studying these childhood/infant stroke victims. They are so full of potential and promise.

-Joanne Reardon

THE EDITOR RESPONDS: What a wonderful, inspiring story, Joanne. Please see "Speak Up" in this issue (page 40) for another story of a child who is thriving in spite of a stroke in utero.

Kids Talk

Of special interest to me was the article in March/April 2008 on sharing illness information with kids and family ("Kids Talk").

I have had Parkinson's disease for 10 years now and can tell you that the diagnosis and first several months (to a year) with the disease were devastating for

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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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neurologynow.com features an electronic version of the print magazine, dating to our premiere issue. The site also offers publication information, resource links, and web-exclusive content.

me. I only shared information with immediate family members and others on a "need-to-know" basis. I found that you, the patient, have to accept it all before being honest and open with others.

True story: one gal whom I'd been friends with for almost 30 years told me, upon hearing the news of my diagnosis, "I'm sorry you're so sick, but I have no time in my busy schedule for helping you or dealing with your health shortcomings." So much for compassion!

One resource that helped me immensely is *The Etiquette of Illness* by Susan Halpern, which deals with several sides of this delicate issue: being sick and telling others, and accepting help and talking about it, including with children.

I had deep brain stimulation two years ago (thank God for intelligent and skilled physicians and new technology) and am doing well. I also attend Parkinson's support group meetings and have found an exercise group particularly for those so afflicted. Take it a day at time is my best advice!

—Phyllis Ross St. Peters, MO

Stem Cells

I read with great dismay the article in the May/June edition of your magazine entitled "To China for Stem Cells." As the Chinese doctors admit, stem cell treatment has not been shown to cure or put ALS into remission. I believe it's just a way to swindle Americans of \$33,800.

I appreciate your bringing this information to the subscribers of your magazine, but I'm not really sure the warning will reach enough seriously ill people.

—Jan Sinclair Lawton. OK

I have multiple sclerosis and every day I look for help. I was interested in the article about stem cells in China. Many countries offer similar treatments, such as Canada and Mexico. Have stem cell therapies in these other countries proven effective?

I would like to see a whole story on gene therapy. It is used for a number of diseases, and many people—like me—are anxious to learn why more of these treatments are not available here in the U.S.

—Gail Thompson Hampton, IA

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*:

IN "PROCEED WITH CAUTION", (page 17) and "Freedom through Technology" (page 28), we discuss the importance of maintaining one's independence while living with neurological conditions. How do you balance your needs for independence and assistance?

DO YOU LIKE NEUROBICS, the regular collection of brain teasers in Waiting Room (page 10)? Let us know if you enjoy them or would like to see different kinds of puzzles.

WE SOMETIMES INCLUDE A DEPARTMENT CALLED PENNY WISE, about money management. Is this information helpful? What financial topics should we cover?