# THE WAITING ROOM

THIS WAY IN

# To China for Stem Cells

If you have amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), and you've been in a wheelchair for a year or more, this ad from a company in China for a stem cell therapy (SCT) bolstered by a bone marrow transplant (BMT) is aimed at you:

"7 SCTs and 1 BMT at a total cost of $33,800.00 USD."

The ad, however, fails to note that no rigorous study has ever been conducted on the therapies to determine if they have any benefit on the course of the disease in ALS, in spinal cord injuries, or in any of a large number of neurological illnesses and conditions for which the company offers the treatments, which feature cord-blood derived stem cells.

Lucie Bruijn, Ph.D., scientific director and vice president of the ALS Association, says there's certainly been no evidence that bone marrow transplants have any value in treating ALS patients. She calls commercialization of these various unproven cell transplant therapies "unethical."

Sean Hu, Ph.D., chief executive officer of Beike, himself notes the limitations of the therapy in ALS patients.

"Before the treatment they could reach their hand only to the chest. After treatment they can comb their hair and wash their face," Dr. Hu says. "But the improvements don't last long. That's the problem." Still, he says, many patients return to repeat the therapy.

Some independent research suggests the immediate improvements sometimes seen after such treatments may be due to a powerful placebo effect, triggered in part by intensive community fundraising efforts and support. Dr. Hu disagrees, saying he believes that growth factors released during Beike's therapy are responsible.

Several American researchers have tried to find whether the cell treatments offered by commercial clinics in China have any effect. So far, there's been no clear evidence of benefit. Dr. Hu says that they hope to have trial data soon. "As we wait for our international trials to start, we believe we should conduct controlled studies here in China. This is what led us to do the optic nerve hypoplasia study, which we have worked on with physicians from the U.S. to make sure that it was designed in a way that will gain acceptance from the international scientific community."

Yet, after hearing about the billions of dollars allocated for stem cell research in California and elsewhere and reading the hopeful promotions by the stem cell clinics and companies, many patients refuse to wait for evidence of benefit.

"I need those stem cells," patients sometimes tell Bruce H. Dobkin, M.D., of the Reed Neurologic Research Center at the University of California-Los Angeles, and editor in chief of the journal *Neurorehabilitation and Neural Repair*. Usually, he can discourage the patient from going to the stem cell clinics after talking about what is known about the therapy and the risks, Dr. Dobkin says. "No one has reported a clinically important and lasting gain of function in patients." —*Larry Schuster*

**NEUROBICS** Can you figure out the common expression represented by each picture?


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SEE ANSWERS ON P. 12

PHOTO ILLUSTRATION MATT SELVA; PHOTO: DANIEL LOISELLE/ISTOCKPHOTO

OUR KIND OF GUY

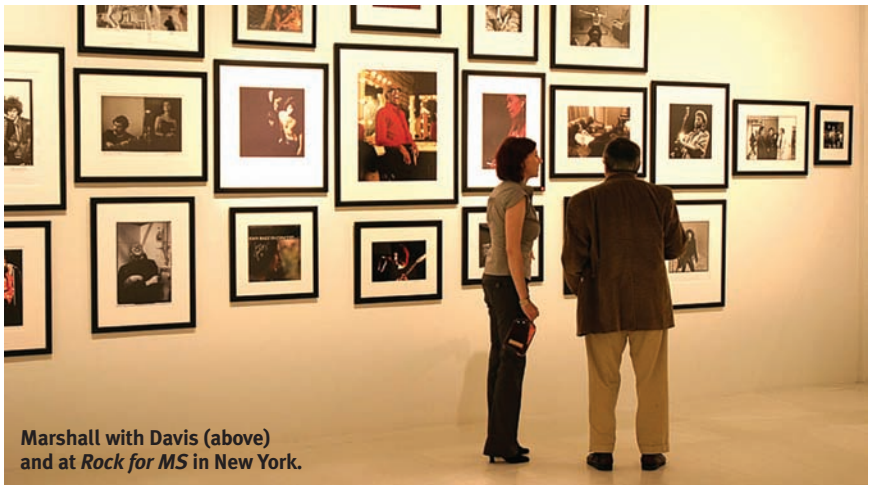
# Jim Marshall

More than 10 years ago, photographer Jim Marshall hired Amelia Davis as his assistant knowing she had multiple sclerosis (MS). At the time, he was already well established as one of the foremost photographers in America, specializing in portraits of musicians and entertainers. His photos of Johnny Cash, Jimi Hendrix, The Beatles, Janis Joplin, Miles Davis, Woodstock (where he was the only photographer allowed backstage), and the youth culture of the 1960s have become iconic images of that era. He demanded total access to his subjects, living with them 24-7 and capturing their personalities with unprecedented intimacy.

Since hiring Davis, Marshall has also become a passionate advocate for people living with MS. "Every other day she gives herself a shot. I can't *imagine* having to do that."

With his help, a group of incredibly talented photographers come together every year and donate their photographs to help raise money and awareness for people living with the disease. *Rock for MS*, which was conceived by Davis and inspired by Marshall, takes place in three cities each year: New York, Los Angeles, and Marshall's home town of San Francisco. "I support her totally," says Marshall, "and I don't support a lot of charities because I don't believe in a lot of them."

The LA event will take place on July 23, 2008, at the Key Club in West Hollywood. All proceeds go directly to supporting MSFriends, a small non-profit that provides a 24/7 telephone helpline for people living with the disease. Go to **msfriends.org** for more information; on the site, you can also watch a video of Marshall talking about his involvement with *Rock for MS* that showcases some of the photographs that have defined American culture. —*Mike Smolinsky*



**Marshall with Davis (above) and at *Rock for MS* in New York.**

QUICK TIPS

## Parkinson's Patch is Recalled

For those of you on the Parkinson's patch Neupro: Your neurologist will need to adjust your dosage because the drug is being recalled.

The skin patch was approved by the Food and Drug Administration in May 2007 to treat symptoms of early Parkinson's disease. Neupro works by delivering the drug rotigotine continuously through the skin using a silicone-based patch that is replaced every 24 hours. Rotigotine activates dopamine receptors in the body to compensate for the loss of dopamine-producing brain cells in Parkinson's.

The recall was prompted by a manufacturing problem that caused some of the skin patches to contain lower doses of the medication and thus be less effective. The company that makes the drug, UCB, said the recall will mean that Neupro will soon be out of stock. Therefore, if you currently take the drug, your neurologist must lower your dosage and eventually switch you to a similar—but oral—medication. Some of these drugs may be available in liquid form.

Anna DePold Hohler, M.D., assistant professor of neurology at Boston University, said that gradually lowering your dosage of rotigotine should ensure that you don't experience a significant worsening in symptoms.

Eric Miller, a spokesperson for UCB, warned that you should contact your health-care provider to initiate the change in dosage rather than stop taking the drug on your own. Patients with additional questions can contact the manufacturer at 1-800-477-7877 (option 9). —*Stephanie Cajigal*

(MARSHALL) PHOTOS COURTESY AMELIA DAVIS (2); *SHAKEN*: LILA FILMS

**NEUROBIC ANSWERS FROM P. 11:** WALK ON EGGSHELLS; THIRD WORLD; SQUARE MEAL; THROW A HAT INTO THE RING; CAN OF WORMS.

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SCREENING ROOM

# *Shaken: Journey into the Mind of a Parkinson's Patient*

(Written, produced, and directed by Deborah J. Fryer, PhD.; Lila Films, Inc. 2007)

Imagine being diagnosed with early-onset Parkinson's disease—the progressive motor system disorder characterized by tremor, rigidity, slowness of movement, and impaired balance—at the tender age of 33. That was the reality faced by electrical engineer Paul Schroder, who spent the next 10 years of his life taking 21 pills a day to cope with his increasingly debilitating symptoms. Dreams of having a wife, family, and career faded away, and Schroder eventually moved back home to seek help from his parents because on some days, he was completely unable to move his body.

That's when Schroder decided to undergo bilateral deep brain stimulation (DBS) surgery, although he was warned that the risky DBS hasn't been proven as a cure. *Shaken* chronicles Schroder as he makes the decision to pursue DBS, enters the operating room, and undergoes the surgery, in which electrodes are implanted in his brain and a neurostimulation device is implanted underneath his collarbone. We see MRI images of Schroder's brain and watch the neurosurgery team perform its magic.

And it is a kind of "magic." "We're going to tell you right now, we are not really sure how this works," a neurologist tells Schroder right before the surgery. Nevertheless, Schroder finds himself regaining many of the functions that Parkinson's disease had stolen from him—including his ability to smile.

While only 30 minutes long, *Shaken* is a poignant documentary that sheds light on the challenges of Parkinson's. The ending is bittersweet: An infection develops in Schroder's scalp, necessitating that the electrodes be removed, and Schroder once again is debilitated by tremors and stiffness. Yet as a testament to his determination, Schroder plans to have the DBS electrodes re-implanted a few years later.

Stay tuned for an expanded, feature-length version of this award-winning documentary that will follow Schroder's second brain surgery. Copies of the DVD can be ordered at **lilafilms.com** or (303) 442-1966. —*Elizabeth Stump*