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# ◆ THE DERBY CITY NSCIA NEWSLETTER ◆

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MARCH 2008

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*The Derby City Chapter of the National Spinal Cord Injury Association Network- Serving Kentuckiana.*

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Message From the President

Dear Members & Friends-

*This month's meeting will be held at Frazier Rehab Institute at the address below. We will hopefully have a speaker, but if not, videos will be shown, and refreshments provided.*

*April's meeting is at Frazier Rehab Institute, 220 Abraham Flexner Way, Louisville, 10th floor dining room, at 6:30 p.m. Refreshments provided.*

*-David Allgood*

**FRIENDS FOR MICHAEL  
PRESENTS.....  
"THE LEGACY CONTINUES"  
DINNER/SILENT AUCTION  
MARCH 25, 2008  
6 P.M.—10 PM  
HURSTBOURNE COUNTRY CLUB  
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*From New Mobility.com—Cover story, March 08 issue.*

**STEM CELL GAMBLE**

By Tim Gilmer, March 2008

*The rise of stem cells as a possible source of restorative therapies is both hopeful and uncertain. In the age of instant information, faith in science runs far ahead of available therapies, making experimental procedures more alluring. But what about risk? Which procedures are safe? In the summer of 2005, James Parsons, a T6 para, and his father, Roger, set out to gather all the information they could about the current state of restorative procedures for paralysis. In the process, they discovered an entire community of people who was just as eager as they were to find the cure.*

Newly-employed and a recent college graduate, James Parsons, 22, was driving on the freeway in November 2001 when the SUV in front of him ran over a construction sign and sent it airborne. Parsons swerved to miss it, but his car rolled and skidded into a fir tree at the side of the freeway. Parsons, from Carmas, Wash., was life-flighted to Emanuel Hospital in Portland, Ore., where three days later he regained full consciousness and learned that he was paralyzed. Thus began his involuntary immersion into the world of spinal cord injury.

A little more than three years later, James and his father, Roger, a United Airlines overseas captain, began researching SCI restoration possibilities seriously. "We went on CareCure forum, all the sites that we could, and started compiling information," says James.

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**Derby City Area Chapter**  
*of the*  
**National Spinal Cord Injury**  
**Association**

**ABOUT THE ORGANIZATION**

The Derby City Area Chapter of the N.S.C.I.A. is a membership organization for individuals with spinal cord injuries, their families, and health professionals. Founded in 1984 as a Charter Member of the N.S.C.I.A., it was incorporated under IRS Section 501 (c) 3 as a not for profit organization. The Board of Directors consists of the Officers, Past President and the Board Members At Large.

\*\*\*

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**DERBY CITY CHAPTER  
NEWSLETTER**

Editor- Barbara Davis

Contributor- David Allgood

**Visit Our Website at**

**[www.DerbyCitySpinalCord.org](http://www.DerbyCitySpinalCord.org)**

**The Derby City Area Chapter Newsletter is  
brought to you through the generous support of  
Frazier Rehab Institute**

**Stem Cell Gamble, Cont'd**

Renowned Rutgers University SCI researcher Dr. Wise Young had initiated the CareCure Community website in July 2001 ([www.sci.rutgers.edu](http://www.sci.rutgers.edu)). In an early poll, 75 percent of 84 members thought a cure for paralysis would be discovered in less than 10 years. One member complained that experts had been predicting a cure within 5 to 10 years since he was injured in 1990. A paralyzed Vietnam vet wrote from his (1960s) perspective: "The answer then was no way in hell can we fix your spine." Others debated the meaning of "cure" or emphasized the importance of hope.

The Parsons learned about a surgical procedure in China performed by Dr. Hongyun Huang, a former postdoctorate fellow under Young at Rutgers. During one of his overseas flights, Roger arranged to visit Huang in Beijing, where he met a few Americans who were there for surgery. Roger concluded in an email to James: "Everything I saw and heard there made me extremely optimistic about the procedure."

One of the Americans Roger met at Xi Shan Hospital in Beijing was Aaron Dempsey, 35, a C5 quad who had been injured 15 years earlier. Aaron and his wife, Kendra, from Porter, Texas, had found numerous people treated by Huang on the CareCure website, among them, Bob Smith, another C-5,6 quad. "He was one of the main reasons that convinced us to go over there," says Kendra. "He is able to sweat now and has gotten quite a bit back."

Those treated by Huang, on average, regain about 2 levels of motor and 4 levels of sensory return (each vertebra represents 1 level). This amount of restoration can be more critical for a quad than for a para, since even modest gains might improve breathing capacity, arm or hand dexterity. "I'm not a real optimistic person," says Aaron. "But once I finally talked to Bob Smith, I started to get excited."

Huang has done as many as 1,000 OEG (see "What Does it Mean?" below *For Sales*) procedures, including some on people with ALS, but evidence is mostly anecdotal and there is no structured follow-up. Published data is found mostly in Chinese journals. Both complete and incomplete SCIs are accepted for the procedure, time span of injury varies widely, and supplemental treatments both before and following surgery are not consistent. However, Wise Young says Huang's SCI procedure is considered relatively safe, although limited. Those with ALS, who received OEG injections in their brains, also report moderate benefits, but these are temporary, and the procedure is riskier. When degeneration returns, the incurable disease runs its course.

The Dempseys corresponded with both Huang and Dr. Carlos Lima of Portugal, whose techniques are related. Lima takes olfactory ensheathing glial cells from the person being treated and implants them in the spinal cord, while Huang

**(Continued On Page Four)**

# **Refrigerator Calendar**

## **\*2008**

### **MARCH**

**3rd - Elderly & Disabled Advisory Council Meeting.**  
**Mon 1:00 p.m.; TARC; 1000 W. Broadway; Board Room.**

**17th - Derby City Chapter meeting; 6:30 p.m; Frazier Rehab Institute.**  
**Mon 220 Abraham Flexner Way; Louisville; 10th floor dining room.**

**22nd - Metro disAbility Coalition Meeting; 3:15 p.m.**  
**Sat Urban County Government Center; Barrett Avenue; Louisville**

### **APRIL**

**7th - Elderly & Disabled Advisory Council Meeting**  
**Mon 6:00; TARC; 1000 W. Broadway; Board Room.**

**21st - Derby City Chapter meeting; 6:30 p.m.; Frazier Rehab Institute**  
**Mon 220 Abraham Flexner Way; Louisville; 10th Floor dining room.**

**19th - Metro disAbility Coalition Meeting; 3:15 p.m.**  
**Sat Urban County Government Center; Barrett Avenue; Louisville**

**For More Information Call**  
**David Allgood at 502-589-6620**

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### Stem Cell Gamble, Cont'd

uses OEG cells from aborted fetuses. Lima advised Aaron that he was not a good candidate because his injury was incomplete. Lima's procedure is more invasive than Huang's, and those with incomplete injuries have more to lose. Surgery always carries a risk.

Huang's surgery costs \$20,000 and airfare runs around \$2,000. The Dempseys needed additional funds for intensive follow-up physical therapy at the Rehabilitation Institute of Michigan's Center for SCI Recovery, where Americans are advised to go. It is crucial to maximize whatever benefits the surgery might make possible.

While at Xi Shan Hospital in November 2005, Roger Parsons also met David Landewee, who was treated by Huang and frequently returned to meet with him. Landewee's progress impressed both Roger and James. "David Landewee looked like the one who had gotten the most back, so he was definitely the example of what could happen potentially," says James.

Landewee, 45, from Liberty, Mo., a T4 complete para from a 1995 car accident, says his surgery involved incisions above and below the point of injury and injections of 500,000 OEG cells into the spinal canal at each site. "I started noticing improvements in my abductors and hip flexors right away," he says. For the next four weeks, he received treatments of acupuncture, massage and physical therapy six times per week.

When he returned home, he went to a rehab institute in Kansas City, Mo., where he stood and walked with braces in a walker for the first time. "I continued to improve for about 18 months. Then it leveled off. That's what I got back—I could feel my stomach, my abdominals, my lower back." At first, using a walker, he could cover 20 feet, but it was exhausting. "As it got easier, I could go about 100 yards with a walker, but it took me about 20 minutes, and I'd have to stop about every 30-40 feet." He still stands and walks with braces in a walker, but only for exercise.

Landewee says he also got feeling back in his internal organs. "Before the surgery, I would have bladder accidents, but I haven't had one since the surgery," which he attributes to better awareness of his need to cath.

Functionally, Landewee went to being a relatively high-level para to being a relatively low-level para, but he still depends on a manual wheelchair. He says that he is glad he went to China, but

he has become a little disappointed over time, which he thinks is normal. "As long as you keep improving, you're just tickled to death. Once it plateaus, then you want more."

While James Parsons was impressed with Landewee's progress, he was beginning to realize that making his own decision would not be easy. "The hard thing is you do as much research as you can online, but unless you actually go and meet each person that's been through it and actually see videos of the before and after, and follow up with them for a couple of months, it's hard to know," he says. "Even another T6 para has different sensation levels and feelings, and a huge gain to me might not be a huge gain to someone else, so it's really hard to gather objective information."

Faced with a wait list of more than one year, James decided to secure a spot just to keep his options open, so he arranged to have a current MRI and a motor, touch, and pinprick test score sent to Xi Shan Hospital.

While Roger Parsons was favorably impressed with what he saw at Xi Shan Hospital, Aaron Dempsey's initial experience there sounds like a nightmare of cultural shock: "I thought we had the wrong place when we arrived," he says. "I'd never been out of the U.S., I had expectations of certain levels of comfort, and they had absolutely none of that. It looked like a rundown hospital. I was a little disappointed. After the first few days, I almost turned around and came back home." But the Dempseys stayed, and Aaron was operated on a week later.

"Just before the surgery, I was scared to death, he says. "I couldn't understand what they were saying. I was trying to ask the doctors what the procedure would be like, and they would just look at me with a blank stare and that's when I started freaking out." The next thing he knew he was waking up in his room. "My neck hurt so bad—it was worse than after my accident. Then after a few days, the soreness went away and the only thing that hurt was my shoulders. Apparently they leaned me over something to work on my neck. I was wrapped around this thing for about 6 hours, and it really tore my shoulders up."

After a week, Dempsey began to notice changes. "I could feel more when someone would touch me, and I was sweating a lot more. I thought it was a great sign. And I was able to move my leg a lot better (he could move his right leg slightly before the procedure).

Like many others with SCI treated by Huang, Dempsey noticed sensory improvements most of all. "Before, I could feel my right side but nothing on the front of me. I could now feel my stomach on the right side of my body, and I couldn't feel there before. The left side was still more or less numb, but I could feel it just a little bit better."

Areas of new sensation, he said, improved daily and then plateaued about three weeks post-surgery. "From what Huang said, I was expecting that it would take a lot longer

**(Continued On Page Five)**

### Stem Cell Gamble, Cont'd

But it reached a point where it didn't do any more while I was still there." He says there has been no change in his bowel and bladder, but he has slight improvement in internal sensation.

The Dempseys went directly to RIM in Detroit for intensive therapy when they returned to the states. "I stood up on the walker for the first time and used a gait trainer, suspended on a treadmill. It felt really good. I got a lot stronger while I was there, but unfortunately we ran out of money and had to come home. My stomach got stronger and also my legs. I think the therapy is probably the most important thing."

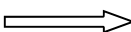
When asked if he would do it again, he answered, "I probably would. I didn't lose anything from going over there. All I could do would be to gain from it."

James Parsons secured a surgery date—Sept. 18, 2006—at Xi Shan Hospital—but prior to that date he and his father wanted to talk to two experts, Wise Young and Steven Hinderer, director of the SCI recovery program at RIM. Young, because he was on sabbatical at Hong Kong University, proved difficult to contact. In the meantime, James and his father regularly trolled the CareCure website in search of other "cure" stories.

Websites outside the CareCure community advertise more controversial procedures than Huang's. One—www.stemcellschina—includes personal testimonials but no objective verification. One of the more dramatic stories involves David Aldrich, 50, who traveled to Schenzhing, China to undergo umbilical cord blood cell injections overseen by Dr. Sean Hu, founder of Blake Biotechnology, a multinational company offering treatments at several hospitals.

Aldrich, from Delray Beach, Fla., had sustained a C-3-4 incomplete SCI when he fell from a boat in shallow water on May 27, 2002 and, in his own words, "drowned." Brain damage from hypoxia resulted in near total blindness and deafness. "I spent a total of 359 days in the hospitals," he says, still speaking with difficulty. He was finally discharged from Craig Hospital, having arrived weighing a meager 120 pounds, half his pre-injury body weight. He still had severe vision and hearing problems in addition to incomplete quadriplegia.

After leaving Craig, Aldrich's motor ability improved slowly over the next three years. Effects from his brain injury also diminished, but by the time he went to Schenzhing, his vision was still blurry, he could not read and hearing was difficult. He had limited movement in his arms, no movement in his hands, he could move his left leg slightly, and had a "twitch" in his right leg but no real muscle control.

This story will be continued in next issue. See below *For Sales* for the promised definition of terms. 

## FOR SALE \*\*\*

**WC Lift; \$1,700; Invacare Storm TDX 3 Power WC; full reclining; less than 1 year old; \$1500; Call David 589-6620.**

**NC topper; used; 3 E&J Manual chairs; used; 1 Quicksilver Action manual chair; Monarch hand controls. 93,000 miles. Price negotiable. Call Ruth @ 239-9754 after 5 p.m.**

**\*Shower Chair; 2 yrs old, negotiable; Invacare 900 Action Power Chair; 4 yrs. Old; \$600. Call 448-5296.**

**\*Cookbooks for Sale:** Recipes compiled by Chapter members; \$10:00. Call David @ 589-6620.

**\*Video tapes for sale.** Various topics related to spinal cord injuries. Call David Allgood or Buddy Lawson.

*\*\*\*If assistance is needed to pay for any of the above items, contact Kentucky Assistive Technology Loan Corporation at 1-800-327-5287 for information on loans at 5% interest to qualified individuals.*

## DON'T FORGET ABOUT OUR SHIRTS!!

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\$10**



### What Does It Mean?

#### **Olfactory ensheathing glial cells (OEG or OEC):**

Origin: The olfactory bulb in the brain of the person to be treated or an aborted fetus. OEG have been shown to stimulate nerve axon regeneration and myelination in animals, and are differentiated fetal cells, not stem cells.

#### **Umbilical cord blood cells (UCB cells):**

Origin: placentas and detached umbilical cords of newborns. UCB cells are fetal stem cells that are currently used to treat blood diseases. They may or may not be useful as a treatment for spinal cord injury.

#### **Human embryonic stem cells (HESC):**

Taken from the blastocyst stage of embryonic development, HESC have the ability to differentiate into different cell types, such as neuronal cells.

*You are cordially invited to join us!*

*The Derby City Chapter of the National Spinal Cord Injury Association consists of people with spinal cord injuries and similar physical conditions, their family members, friends, and professionals or other interested parties.*

*We meet:*

*WHEN- Third Monday of every month from 6:30 to 9:00 PM*

*WHERE- Frazier Rehab Institute, 10th floor Dining Room  
220 Abraham Flexner Way, Louisville, KY 40202*

**If you wish to be a member, donor, and/or be on the mailing list of the Derby City Chapter of the National Spinal Cord Injury Association please complete and mail the following form to the address below**

**National Spinal Cord Injury Association**

**Derby City Chapter**

**Membership & Organization Sponsorship Form**

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 Level of Disability \_\_\_\_\_ Other Disability \_\_\_\_\_  
 Able-Bodied(yes/no): \_\_\_\_\_  
 New Member: \_\_\_\_\_ Renewal \_\_\_\_\_ Newsletter Subscription  
 (only \$12): \_\_\_\_\_

Special Interests /Hobbies/Sports: \_\_\_\_\_

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Membership is open to all individuals and sponsorship to all organizations interested in spinal cord injury.

Mark Type of TAX DEDUCTIBLE Individual Membership or Organization Donor Category Desired\*\*\*

- |                                    |  |
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| _____ Regular-\$12                 | _____ Bronze Organization-\$100-249        |
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