
◆ THE DERBY CITY NSCIA NEWSLETTER ◆

MAY 2009

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

Message From the President

Dear Members & Friends-

May's meeting will be held at Frazier Rehab Institute; 220 Abraham Flexner Way; Louisville; in the Michael Brent room on the 11th floor— room number 1119. Please note that this is a permanent change. Also, there will not be a meeting in June.

- David Allgood

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From the Internet –ed.

SPINAL PATIENT SPINS A COMEBACK

By Claire Martin

Ten years ago, Leah Potts was a patient at Craig Hospital, after a skiing accident that broke her neck and damaged her spinal cord. The first doctors she saw warned her she might never walk again.

Today, Potts teaches Spinning, the popular and intense indoor group bicycling class. The Aspen resident can walk (with a cane). She skis again (with outriggers). And she blogs about her progress at leahpotts.com.

"I remember lying there in bed at the beginning," she said. "I remember lying there thinking, 'OK. This doesn't sound too good. I have two choices: Lie here and cry about it, or get up and do something about it.' I was 23 years old. I'd just graduated from college. I felt like my life was just beginning."

When she left Craig Hospital after three months, Potts relied on a walker or wheelchair to get around. Using the walker was exhausting. It took all her energy to move from the front door to her living-room sofa. She had to rest before getting up again to go to the next room.

Reclaiming her body became Pott's full-time job. She spent at least three hours a day in rehabilitation treatment, sticking to a grueling schedule that later cost her her short marriage to Dan Roland.

"I thought I had to do it on my own, and it turned out to be the best thing I could have done," she said recently. "I had an acupuncturist who told me, 'Your body is like a house. If the window breaks and you don't fix it, or the roof leaks and you don't fix it, who'd want to move in?' It wasn't pretty. It wasn't fun. I'd cry. It's still hard. But it's harder not to do anything, and it gets easier."

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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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Visit Our Website at

www.DerbyCitySpinalCord.org

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to you through the generous support of Frazier
Rehab Institute**

COMEBACK, CONT'D

For a while, she lived in Kansas City, Mo., working with a personal trainer who volunteered his time when he heard her story. She got strong enough to give up the wheelchair, using the walker to get from her home to the gym.

In time, Potts returned to Aspen. She enrolled in a Spinning class and, three years ago, began teaching the group cycling workouts. That's how Diane Moore met her.

"She was a powerhouse," said Moore, an Aspen photographer who quickly became friends with Potts. Moore still remembers the first workout—a hard climb that stayed intense for a full 60 minutes.

"I was really surprised when she got off the bike, picked up her cane and began working her way across the room," Moore said. Until that moment, she hadn't realized that Potts was anything but able-bodied.

When Craig Hospital doctors hear stories like that, they are unsurprised.

"Our policy here is 'Never say never,' because frankly, we don't know, and we always want to encourage people to have hope for the future—especially people with incomplete injuries," said Craig spokesman Kenny Hosack. "Think of an incomplete injury as being like an electrical cord the size of your pinkie, with 4 million tracks running through it. If it's completely severed, there's no neurological signal getting from the brain to the body. About 55 percent of our patients are incomplete injuries, and there's motor or sensory to varying degrees. Meaning, they can feel or move."

Last year, after some community fundraisers, Potts made two trips to India. There, she received human embryonic stem-cell transplants currently unavailable in the United States because of moral and legal controversies.

Potts credits her improvement, in part, to the transplants.

"It's a rather large job, difficult and time consuming; teaching these stem cells what they're supposed to do," she wrote in a January blog post, "and to overcome atrophied muscles after 10 years of immobility. However, with persistence, dedication and patience day in and day out, changes do come. With the stem-cell treatments the return comes faster. I'm seeing improved range of motion, new strength and stability in smaller muscles with less tightness throughout my body."

Potts hopes for at least one more stem-cell transplant, an expense she calculates to be about \$75,000. Another Aspen fundraiser will be held Saturday at the Aspen

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Refrigerator Calendar

***2009**

MAY

- 4th - Elderly & Disabled Advisory Council Meeting.**
Mon 1:00 p.m.; TARC; 1000 W. Broadway; Board Room.
- 18th - Derby City Chapter SCIA meeting; 6:30; Frazier Rehab Institute**
Mon 220 Abraham Flexner Way; Louisville; Room 1119 (Michael Brent Room).
- 16th - Metro disAbility Coalition Meeting; 3:15 p.m.**
Sat Urban County Government Center; Barrett Avenue; Louisville

JUNE

- 1st - Elderly & Disabled Advisory Council Meeting**
Mon 1:00; TARC; 1000 W. Broadway; Board Room.
- 15th - Derby City Chapter Annual Dinner; 6:00; Zorn Avenue Kingfish; Louisville**
Mon 3021 Upper River Road; Meal provided by Chapter for dues-paying members.
- 20th - 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


COMEBACK, CONT'D

Athletic Club: a 12-hour Spin-a-Thon, with various instructors, including Potts, leading hour-long workouts.

"The treatments are a roller-coaster," Potts said. "You're excited about what could be, in a good way—and a bad way. Therapy has turned into a 24/7 job for me. I do three hours of work every day—yoga, tai chi, Pilates, physical therapy, biofeedback, massage, acupuncture. Fundraising, talking about it, healing and just dealing with it is a full-time job."

It literally is her full-time job. She supports herself through her blog, where she solicits donations and writes in detail about her treatments, personal life, emotions as well as her physical activities.

Has her dedicated therapy sped her recovery? Though no scientific literature suggests that it does, Craig spokesman Hosack observed that patients who fully commit themselves to physical therapy often "experience more neurological recovery" than those who don't.

"Those who do work hard in neurological recovery tend to do better in life," Hosack said. "Ninety-five percent of our athletes go back to being athletes, regardless of what injury they've had. Their athletic background helps them in rehab. So does their work ethic and tolerance for pain." 

The following are from the Internet –ed.

PARALYZED VASTLY OUTNUMBER ESTIMATES

Approximately 1 in 50 Americans have some degree of paralysis, five times more than doctors thought are living with a spinal cord injury—nearly 1.3 million—says a startling study released last week.

It's a largely hidden population that neither the government nor medical organizations ever had attempted to fully count, and the findings promise to help health authorities understand the scope of need.

"Paralysis is not rare," said Dr. Edwin Trevathan, disabilities chief at the U.S. Centers for Disease Control and Prevention, which helped design the study. "These data demand that we recommit...to help this population."

"Those are startling, startling numbers," said Rep. Jim Langevin, D-R.I., who has a spinal cord injury himself and urged more investment not just in medical research but transportation, job opportunities and other day-to-day needs of the paralyzed.

The report found almost 5.6 million people have some degree of paralysis because of a variety of neurological problems. Stroke and spinal injury are the leading causes, but they also include multiple sclerosis, brain injury, birth defects, surgical complications and a list of other ailments.

That's about 30 percent higher than previous estimates.

But for spinal cord injury alone, previous estimates were woeful—suggesting just a quarter million people were living with a trauma, a count that mostly included people like Christopher Reeve, who wound up at specialty treatment centers.

How could so many people have been missed? People are living much longer with paralysis, said CDC's Trevathan. And now they're starting to face the added complications of aging on top of a disability.

"There's no road map for somebody like me," said Alan T. Brown of Hollywood, Fl., who broke his neck 21 years ago, just before his 21st birthday.

From a youth spent in wheelchair marathons, he's entering middle age suddenly needing more care, like an electric wheelchair instead of a manual. He's getting more infections, 17 urinary tract infections last year alone. That's on top of the extra hurdles to arrange routine care, such as a colonoscopy.

"This is finally going to open up people's lives to see what we live with," he said.

For the new study, funded by the Christopher & Dana Reeve Foundation, University of New Mexico researchers designed a survey of 33,000 U.S. households to measure the full gamut of paralysis—how many people either cannot move or have difficulty moving an extremity.

The study points to a sobering picture of the cycle of paralysis and poverty. Sixty percent of people with paralysis have an annual income of less than \$25,000. Worse, about a quarter report household incomes below \$10,000, compared with 7 percent of the U.S. population, the study found.

Patients often lose their jobs, and caregiving needs can cost a spouse a job, too, ending employer-provided insurance. Treatment, including the physical therapy that can improve independence and sometimes movement, is costly. There are income limits to qualify for Medicaid, and cash-strapped states are limiting coverage.

(Continued On Page Five)



PARALYZED OUTNUMBER ESTIMATES, CONT'D

The Reeve Foundation plans to use the findings to push for health policy changes, including ending a federal requirement that disabled workers wait 24 months before getting health care through Medicare. ☞

A MOVE TOWARD ACCESSIBLE HOTELS

The worst thing about most "handicap accessible" hotel rooms is, they aren't accessible!

For the 2003 World Congress on Disabilities and Exposition (WCD), I stayed at the Rosen Plaza near the Orange County (Fla.) Convention Center. The staff was gracious, the room was clean, the bar was amicable, and the restaurant had fine food.

But my room had an unnecessary table near the bureau, a coffee table squeezed next to a sofa, not much room for wheelchair users (as I am) to shut the room door, the sink was outside the bathroom where the towels were, no one who has difficulty leaving a manual chair could use the toilet, and I'm still discerning how anyone uses the roll-in shower without (God forbid) another hurricane.

The WCD is produced by WCD Expo, Inc., of Paramus, N.J., in conjunction with Exceptional Parent Magazine. When attending it this year, I got smart. I stayed at the Microtel near the convention center. Microtel Inns & Suites was one of the major corporations that staffed some of the WCD's exhibition booths. The company used a variety of giveaways to attract people to their exhibit in order to help encourage everyone to complete a detailed survey to identify hotel needs and priorities of travelers with disabilities.

A typical Microtel has 130 rooms and suites and offers data ports in each room, a swimming pool, 24-hour front desk, fax service, free coffee 24/7, smoking or non-smoking rooms, and irons/ironing boards.

Especially important if you're a traveler with a disability, Microtel Inn & Suites has accessible rooms in more than 265 U.S. locations, and beyond. Children 16 and under stay free when accompanied by an adult, and some Microtels allow pets in guest rooms.

Microtel was designed for business travelers who have disabilities as well as those who are able-bodied. Every hotel features interior corridors for safety, working space with room to roll the wheelchair under the desk, and remote cable TV with ESPN, CNN, and HBO.

(Continued Under For Sale) ➡

FOR SALE ***

2004 Buick Rendezvous CX, Gold Sport Utility 4D, AWD; 52,953 mi; seats 5—rear compartment contains Sonic scooter Bruno lift; new battery; numerous special features. \$8,800. Call Bryan Fantoni at 502-644-4446 or email at Bryan.Fantoni@mozlaw.com.

Easy Stand Glider 600; like new—barely used; allows transfer, stand and glider movement of legs. Paid \$6,000. Will sell for \$3,000. Call Shirley at 502/228-1271.

93" E150; EZ Lock WC System Elec. w/Quantum 600 wc/swivel captain's chairs/3-way power driver's seat/remote start burglar alarm/front-rear air/power wc lift/new upholstery. \$11,000, negotiable. (502) 543-5948/(502) 773-2337.

WC Lift; \$1,000; **Invacare Storm TDX 3 Power WC;** full reclining; less than 1 year old; \$1000; **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.**

***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.

♦ **SCI -Shirts for sale.** S, M, L, XL. David—589-6620.

****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.*

ACCESSIBLE HOTELS, CONT'D

If you're meeting associates, you can reserve a suite with microwave oven, mini-refrigerator, coffee maker, and separate seating area.

By the time you read this, Microtel, Hawthorne, and America's Best will provide free high-speed wireless Internet access to go with free local and long distant telephone calls (reservations at 888-771-7171 (VOICE)/824-2082 (TDD), or through your travel agent).

Michael A. Leven, 66, president/CEO of Atlanta-based U.S. Franchise Systems, Inc. (USFS), franchises Microtel, Hawthorne Suites, and America's Best Inns & Suites. He says, "I discovered Microtel as a product that met my qualifications. The need for such a was apparent, but the economy/budget segment was made up almost entirely of older, inconsistent, poor-quality products. The industry's largest potential customer base was being neglected."

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

Name: Mr./Mrs./Ms./Dr. _____ Date _____
 Address: _____ Apt.# _____
 City/State/Zip: _____
 Business (if any): _____
 Home Phone: () _____ Work Phone: () _____
 Date of Birth _____
 Para: _____ Quad _____ Hemiplegic: _____
 Level of Disability _____ Other Disability _____
 Able-Bodied(yes/no): _____
 New Member: _____ Renewal _____ Newsletter Subscription
 (only \$12): _____
 Special Interests /Hobbies/Sports: _____

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***

- | | |
|------------------------------------|--------------------------------------------|
| _____ Regular-\$12 | _____ Bronze Organization-\$100-249 |
| _____ Sponsor-\$25 | _____ Silver Organization-\$250-499 |
| _____ Patron \$50 | _____ Gold Organization- \$500-999 |
| _____ Benefactor-\$100 | _____ Platinum Organization-\$1000-2499 |
| _____ Permanent- \$1000/lifetime** | _____ Diamond Organization-\$2500 Or Over. |

Please make checks payable to: **NSCIA Derby City Chapter**

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