
◆ THE DERBY CITY NSCIA NEWSLETTER ◆

JUNE 2007

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

Message From the President

Dear Members & Friends-

June's meeting will be our dinner at Kingfish Restaurant, 3021 Upper River Road, Louisville, at 6:30 p.m. Meals for dues-paying members will be paid for by the Chapter. Alcoholic beverages will be out-of-pocket. So please come out to Kingfish on Monday, June 18, and join us for fun, fellowship, and good food.

July's meeting will be held at Frazier Rehab Institute, 220 Abraham Flexner Way, Louisville, in the 10th floor dining room at 6:30 p.m.

-David Allgood

All articles this edition are taken from the Internet-ed **POST-INJURY MRI PREDICTS SPINAL CORD RECOVERY**

MRI imaging is giving neurosurgeons good insight into whether patients with serious spinal cord injuries can recover, a new study shows.

Within 48 hours of the injury, these images should be able to provide a reasonable prediction of a patient's fate, Canadian researchers reported in the June issue of the journal *Radiology*.

Currently, MRIs are commonly but inconsistently performed on spinal cord injury patients, noted study co-author Dr. Michael G. Fehlings, professor of neurosurgery at the University of Toronto. In light of the study results, they should become the "standard of care, unless pressing medical circumstances preclude the test from being done," he said.

The U.S. National Spinal Cord Injury Association estimates that between 250,000 to 400,000 Americans now have spinal cord injuries or other spinal cord problems. Motor vehicle accidents are responsible for about 44 percent of spinal cord

injuries in the United States.

In the new study, Fehlings and colleagues examined 100 patients—79 men and 21 women—with severe spinal cord injuries, mostly as a result of motor vehicle accidents. The patients underwent MRI scans that "allow doctors to see the site of spinal cord injury and to appreciate whether the spine is fractured and whether there is pressure on the spinal cord," Fehlings said.

His team found that three factors—severity of spinal cord compression, bleeding and spinal cord swelling—were directly connected to poor outcomes. Essentially, the factors indicate a "more severe injury with less opportunity for recovery," Fehlings said.

But the prognosis was good for patients without those symptoms, even if they were severely injured.

In addition to predicting the likelihood of recovery, MRI images can help doctors determine whether patients should undergo spinal cord decompression surgery, Fehlings said.

There is, of course, a potential downside to a bleak prediction: It could leave patients with little hope for the future. But Fehlings said that's not necessarily so.

"Communication with patients is an art. It is important for physicians to communicate a sense of hope even in the setting of a severe spinal cord injury," he said.

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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
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Visit Our Website at
www.DerbyCitySpinalCord.org

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brought to you through the generous support of
Frazier Rehab Institute

POST-INJURY MRI, CONT'D

From another perspective, one doctor said it is important for patients “to understand the bleakness of the future” if there are signs of those factors discussed in the study.

“Better to know than to be given false hope,” reasoned Dr. Robert Quencer, a radiologist at the University of Miami/Jackson Memorial Medical Center.

**SUPPORT OUR CHAPTER
WITH A T-SHIRT!!**

**THE DERBY CITY CHAPTER OF THE
SPINAL CORD INJURY
ASSOCIATION NOW HAS
T-SHIRTS FOR SALE.**

**THESE SHIRTS ARE WHITE WITH
LONG SLEEVES, AND CONTAIN THE
DERBY CITY SPINAL CORD INJURY
ASSOCIATION NAME AND LOGO ON
THE UPPER RIGHT-HAND CORNER
OF THE SHIRT.**

**THE SIZES AVAILABLE ARE
S, M, L, XL, XXL.**

THE SHIRTS ARE \$10 EACH.

**CONTACT MICHAEL FEGER OR
DAVID ALLGOOD FOR MORE IN-
FORMATION.**



Refrigerator Calendar

*2007

JUNE

4th - Elderly & Disabled Advisory Council Meeting.
Mon 1:00 p.m.; TARC; 1000 W. Broadway; Board Room.

9th - Adapted Sports & Fitness Fair, Kosair Charities Offices, 982 Eastern Parkway
Sat. 12:00p.m.-3:00p.m., Contact Jill Farmer at 502-582-7618 for more information

16th - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.
Sat

18th - Derby City Chapter dinner; 6:30 p.m.; Kingfish Restaurant, 3021 River Road, Louisville
Mon

22nd National Senior Games Begin at various locations around the city. Volunteers are still needed
Fri so please go to www.2007seniorgames.com to register

JULY

2nd - Elderly & Disabled Advisory Council Meeting
Mon 1:00-2:30 p.m.; TARC; 1000 W. Broadway; Board Room.

16th - Derby City Chapter meeting; 6:30 p.m.; Frazier Rehab Institute.
Mon 220 Abraham Flexner Way, Louisville, 10th Floor dining room.

19th Divas in the Bluegrass-All Female Wheelchair Tennis Clinic, Bass Rudd Tennis Center,
Wed 9:00a.m.— 4:00p.m. Contact Jill Farmer at 502-582-7618 to register.

20th Divas in the Bluegrass-All Female Wheelchair Tennis Clinic, Bass Rudd Tennis Center,
Thu 9:00a.m.— 4:00p.m. Contact Jill Farmer at 502-582-7618 to register.

21st - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.
Sat

21st - Southern Parkway 1-Mile Race benefiting the Kentucky Wheelchair Athletics Association
Sat and the Metro Parks Adapted Leisure Programs; 5:00p.m.-11:00p.m. at the corner of
Southern Parkway and New cut Roads. The Race includes individual age divisions, a doggie
dash and a wheelchair & handcycle division. Contact Jill Farmer at 502-582-7618 for info.

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

DISABLED LAUD EFFORTS TO MAKE INTIMACY EASIER

Alan Tholkes expected good-natured ribbing when he shared his new product idea with colleagues at HealthPostures, the ergonomic furniture company in Glencoe, Minn., that he co-founded in 1999. The idea was a gliding chair with adjustable legs and back support, but it would not be something you'd take to a softball game.

The IntimateRider (www.intimaterider.com), now being launched nationally and retailing for just under \$500, is a sex aid for the physically disabled. That includes Tholkes, who became a quadriplegic at the age of 17 as the result of a car crash. The chair, he said, is especially helpful for people with spinal cord injuries, arthritis, chronic back pain and other debilitating ailments, offering support and ease of motion that allows many couples to enjoy sex again.

While inventor Tholkes, Minnesota's 1991 Entrepreneur of the Year, jokes that the "R&D (research and development) was a lot of fun," the chair, and the reason behind its development, is serious business. While tantalizing sexual messages rain down on the able-bodied, those with disabilities hear something quite different from advertisers, culture, and too often, their doctors: Silence.

"When I went through post accident rehab in the 1970's at age 18, it was one of those things that got shuffled under the rug," Tholkes said. "They taught me how to feed, dress, and take care of myself, but nobody brought up the subject of how I was going to have sex, which was at the top of my list."

As many as 11,000 Americans suffer spinal cord injuries every year, he points out, and more than 80 percent of them are males between the ages of 16 and 30. "You're young, aggressive, invincible," said Tholkes, 49, who maintains good arm function that allows him to move himself in and out of his manual wheelchair. "At that age, sex is still a predominant topic on your mind."

While many men and women with spinal

cord injuries regain all or some form of their sexual capabilities, depending on the degree of injury and its location, "society looks at someone in the wheelchair," Tholkes said, "and assumes you're not in that group anymore."

It's not only people in wheelchairs who face this reality. The website of the Arthritis Foundation (www.arthritis.org) offers "A Guide to Intimacy With Arthritis", that demonstrates a hunger for answers among a population whose sexual desires clearly haven't waned, despite often agonizing physical or emotional challenges. Among their questions:

- "Because of my gnarled, knobby joints, I'm embarrassed by my body. I worry no one will want me sexually because of how I look. I don't want to be alone!"
- How could I possibly believe that my guy won't sexually stray when an able-bodied woman would always have more to offer him physically?"
- "It has been so long since my wife and I have made love comfortably that I hardly know how to get started. Any suggestions?"
- "How will joint replacement affect my ability to have sex?"

(Continued

On Page Five)



TO ALL THE DADS IN
OUR READERSHIP.....

**HAPPY
FATHER'S
DAY!!!!**



SEXUALITY, CONT'D

Christ Kost, 37 of Shakopee, has heard these concerns and more, as a personal trainer for Accua Advanced Fitness Training in Savage and as a man who has lived with osteoarthritis for 16 years. Married to Erin Kost and the father of a 17-month-old son, he keeps physically fit, but can't deny that some days are marked by aches and pain that are unusual for a young man. A longtime volunteer for the Arthritis Foundation's north central chapter, which includes Minnesota, he also speaks to young people anxious about intimacy issues and particularly worried about whether able-bodied people will find them desirable.

Eight years ago, he delivered a candid talk to participants at the American Juvenile Arthritis Foundation's convention in Washington, D.C.

A lot of people are just worried about being able to live normal lifestyles,' he said. "They see media-made intimacy. Honestly, that's not the way it is. I told them, 'You're not going to be in a porn movie with cameras all around you. It's you and your significant other.'"

TIPS FOR DISABLED TRAVELERS

- Bicycle shops have all kinds of nifty, compact repair kits that you can bring with you to repair a flat on your chair tires.
- Don't rely on those 'wheelchair friendly' access symbols. Contact hotels, parks, etc, and ask specific questions about room size, door widths, and so forth.
- A pair of long nosed pliers are handy for inserting charge/debit cards into slots if you have limited use of your hands. They are also useful for pulling suitcase zippers and opening packages.
- For information on renting a scooter wherever you travel, contact www.scootaround.com, a national scooter rental agency, to find out if they have a branch in or near your destination.
- Parking and other traffic laws vary from state to state. Google the DMV department of the state you are traveling to for contact information to inquire about laws in that state.
- To get advice from other travelers to all kinds of destinations, Google "disability travel blogs." You will get a wealth of information. That's where these tips came from. –ed

FOR SALE ***



WC Lift; \$7,000 new; only used 2 months; asking \$3,000. **Invacare Storm TDX 3 Power WC;** full reclining; less than 1 year old; \$12,000 new; asking \$2,000. Quickie II manual chair; good cond.; \$800. **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!!



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, Kentucky 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**
David Allgood
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Louisville, KY. 40214