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# ◆ THE DERBY CITY NSCIA NEWSLETTER ◆

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APRIL 2007

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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-*

*April'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. At this time we do not have a speaker, but we hope to have one scheduled at meeting time. If we do not have a speaker, we will show a video.*

*Refreshments will be provided.*

*May'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*

*From Reader's Digest, March 2007*

### **NANO-KNITTERS FOR NERVES**

By Laura McClure

Researchers at MIT have found a way to restore vision in damaged rodents. The innovative procedure uses nanotechnology to spur growth in damaged nerve cells. Scientists say the technique could someday be used to restore speech, hearing, vision and movement in people affected by stroke, brain trauma and spinal cord injuries.

How does it work? A clear liquid of amino acids is injected into the injured part of the brain. The amino acids assemble into a mesh-like structure that's similar to the body's connective tissue. This "scaffolding" allows nerve cells to grow and reconnect, restoring lost communication between the brain and the body.

MIT neuroscientist Rutledge Ellis-Behnke tested the solution in hamsters with severed optic tracts. Within 24 hours, the injured nerve cells began to regrow in both young and adult rodents. "The brain started to heal," Ellis-Behnke says. "We have never seen that before." Six months later, 75% of the animals had regained functional vision.

*From the Internet -ed*

### **NEW SCI TREATMENT AVAILABLE IN BOSTON**

It's been one year since Dana Reeve passed away. Dana and her husband, the late actor Christopher Reeve, became crusaders for spinal cord injury research after he became paralyzed.

NewsCenter 5's Heather Unruh reported Wednesday that a promising treatment once used by Christopher Reeve is now available to people in Boston. It's offering new hope to patients who may have once felt hopeless.

Richard Maloney was paralyzed in a swimming accident 20 years ago. He walked with crutches for the first time Wednesday. "All of a sudden, I was up, and doing it. It is really great. It's exciting," he said.

Bob Koniecko is hoping to walk on his own again, too. "They told me in no uncertain terms that I would never walk again," he said.

It is becoming possible for some spinal cord injury patients to walk again thanks to Locomotor Training Therapy, which is available at Boston Medical Center. It's partly funded by the Christopher Reeve Foundation. It is the same therapy Reeve was so excited about during his treatments that he pushed to make it available to as many people as possible.

"Many of the patients who have been treated at the centers have gone on to become good walkers with assistance, and some have actually gone on to walk without any assistance," Boston Medical Center's D. Williams 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**  
**NEWSLETTER**

Editor- Barbara Davis  
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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**

**NEW SCI TREATMENT, CONT'D**

Research shows that the intense therapy has profound benefits. Patients spend about an hour on the treadmill with the help of trainers. It's been proven to strengthen their muscles and to improve good health. The most unbelievable part of his therapy is how it helps paralyzed people to walk again.

“Walking is a stepping reflex that is controlled by the cord and it is through facilitation and input from standing and stepping that we are retraining the cord,” Williams said.

Maloney's result came after one month of therapy.” I just want to be able to stand on my own, too,” he said. “Whatever else is a bonus.”

Konieczko said that he is feeling stronger and getting back movement in his legs. He's dreaming of learning to walk again.

“I intend to take it all the way through and make this something that people can look at and say, ‘By golly, if that fellow can do it, I can do it, too!’”

*From Paraplegia News, November 2005*

**JOYSTICK CHOICES**

Position-sensing joysticks and switch arrays have been the traditional means of interface for power-chair chin-control users. However, in a study by researchers at the Human Engineering Research Laboratories (HERL), VA Pittsburgh Healthcare System, a force-sensing chin operated joystick has been developed as an alternative to these devices.

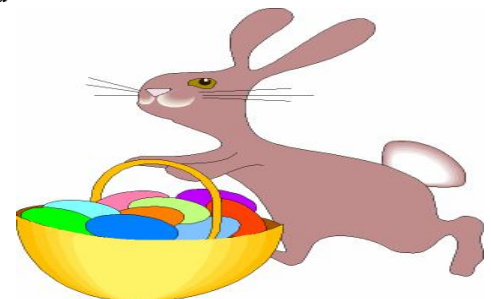
The important difference between a position-sensing joystick and the force-sensing type is that the latter requires no range of motion, which may allow for easier, more comfortable chin control.

The force-sensing joystick's mechanical design includes a base, force-sensing beam, covering case, and mounting bracket. The electrical design features two strain-gage bridges, two instrumentation amplifiers, Tattletale control board, and a digital-to-analog converter. Software has been designed so it determines the output characteristics.

The force-sensing joystick may provide an alternative to the position-sensing one. The hardware/software design provides a highly customized interface that could provide better control for users. The device also has the potential for conversion for use as computer control.

Contact: HERL, (412) 365-4854/365-4858 (FAX)/  
heinercm@pitt.edu

**HOPPY  
EASTER!!!**



# Refrigerator Calendar

## \*2007

### APRIL

**2nd - Elderly & Disabled Advisory Council Meeting. EVENING MEETING THIS MONTH**  
**Mon 6:00 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.**

**20th-22nd USQRA 20th Annual Wheelchair Rugby National Championship Tournament,**  
**Fri-Sun 9:00 a.m.-6:00 p.m.; Kentucky Fair and Expo Center, Broadbent Arena;**  
**VOLUNTEERS ARE NEEDED Please Call Jill or Karey at 582-7618 or 582-7411**  
**for more information.**

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

### MAY

**7th - Elderly & Disabled Advisory Council Meeting This date may change due to Holiday.**  
**Mon 1:00-2:30 p.m.; 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; 1 p.m. – 3 p.m.**  
**Sat**

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

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*From Paraplegia News, December 2005*

### **FLYING HIGH**

*Serena's Song* gives you a very special experience because it is reportedly the only accessible hot-air balloon in the United States.\* At any rate, it's the only one with a gondola (basket) a wheelchair can roll right into to get ready to go for a balloon ride.

My husband Bill and I were fortunate enough to run into the owner here in Denver at a recent balloon festival. You can find *Serena's Song* giving free tethered balloon rides at some hot-air balloon festival most weekends. There aren't many ways that are better than this to put you in the mood for your next trip. If you have never traveled before, perhaps a balloon ride will give you the frame of mind to try traveling. If you believe in yourself, anything is possible.

According to [www.serenasong.com](http://www.serenasong.com), this balloon is the only wheelchair-accessible one approved by the FAA. Since 1985, *Serena's Song* has carried more than 12,000 passengers with disabilities over countless miles all over the U.S.

The balloon was named for Serena Waldman, now in her twenties, who sustained complications during birth. When she was 2, her father Gary received an invitation for Serena to ride in a hot-air balloon. Until then, Serena was emotionless and unable to speak. But as the balloon soared upward, she screamed with delight. Because of her enthusiastic reaction, Gary decided to commit his life to recreating that experience for other people with disabilities. He bought a balloon and named it *Serena's Song*. Since that time, Gary and his partner, Phil Gray (the balloon's creator and its pilot), have traveled across the U.S. as they take *Serena's Song* to numerous communities and balloon festivals.

A newspaper article, "Looking for a Savior," detailed Waldman's story and solicited a national sponsor to assist with costs not covered by local donations. Without financial aid, the balloon's demise was imminent. ATC came to the rescue with a new van and a refurbished trailer. The company also pledged its 6,700 employees nationwide as volunteers to help disseminate information about *Serena's Song* to help get people to and from the balloon when it comes to communities served by ATC, and to spearhead local sponsorship drives in those locations.

Look for *Serena's Song* at a balloon festival in your part of the country. You can't miss it!

For information about the balloon and its tour schedule, go to [www.serenasong.com](http://www.serenasong.com). Information to contact Gary is available on the site as well.

\*An accessible balloon ride from Indiana was available at the Adam Matthews Balloon Festival in Louisville last fall. For more information contact [www.balloonglow.com](http://www.balloonglow.com) or (502) 499-2253.

### **SPINAL CORD CYSTS AND TETHERING**

Initial results of a research study in Colorado show surgery may slow down or even stop neurological loss due to some complications following spinal cord injury (SCI).

Studies of people living with SCI show that changes to the spinal cord can continue long after the injury happens. These changes usually involve scarring of the cord, referred to as "tethering." Depending on the tethering's severity, this can lead to changes in the flow of cerebrospinal fluid. In some cases a fluid-filled space or cyst can develop above or below the level of the original injury. These changes to the spinal cord can result in progressive loss or change in muscle or sensory function.

Symptoms from tethered and cystic spinal cords may occur anywhere from a few months to many years after the original injury. Some reports are of people up to 30 years post injury who have developed progressive myelopathies from tethering of the spinal cord or spinal cord cysts. The good news is, while tethering at the site of injury is common after SCI, only an estimated 5-10% of people will develop problems from it and subsequent cyst formation. The not-so-good news is that those who develop these problems may experience a continuing loss of function. This can include motor *and* sensation, which progressively worsens over time. These individuals may notice changes in their level of function and independence. Some people report increased spasticity or pain. In most severe cases, breathing may be affected and even the brain stem may be involved. The usual treatment for spinal cord cysts and tethering is surgery to release the scar tissue around the cord to help restore the normal motion and elasticity. In the case of a cyst, the surgeon may place a shunt—a thin tube that drains fluid from inside the cyst.

Investigators at the Rocky Mountain Regional Spinal Cord Injury System (RMRSIS) at Craig Hospital in Englewood, Colo., are looking at long-term outcomes of people who have surgery for tethered and cystic spinal cords. Although some studies report good results, these outcomes are typically soon after surgery. Short-term follow-up is not enough. Although progressive myelopathies respond well to surgery, sometimes the spinal tethering and cysts can reoccur.

**(Continued On Page Five)**

**CYSTS & TETHERING, CONT'D**

Between March 1993 and August, 2002, three hundred sixty-two people had surgeries at Craig Hospital for cystic and noncystic myelopathies. Most of the group, 311 individuals, had single surgeries; 44 underwent two surgeries; and 7 had three.

Comprehensive motor and sensory testing was done using the American Spinal Injury Association's (ASIA's) International Standards for Neurological and Functional Classification of Spinal Cord Injury. The same testing was performed 7-18 months post surgery and again 19-30 months and 31-42 months later. Although investigators have not finished the analysis, the results are encouraging. Follow-up testing indicates neurological function in these individuals is stable and they are not continuing to lose motor or sensory function.

"Although symptoms from post-traumatic spinal cord cysts are not common, we advise our clients to closely monitor their neurological status, sensory level, and muscle strength," says Susan Charlifue, Ph.D., one of the study investigators at Craig. "For instance, if you notice you're burning yourself with hot water, when before you were able to determine a safe temperature, it may be a warning sign."

Signs and symptoms of a spinal cord cyst or tethering include the following:

- Change or loss of sensation and/or muscle function
- Increased sweating or unusual sweating pattern (e.g.; sweating only when lying in a specific position, sweating only on one side of the face or neck, or profuse sweating)
- Change in spasticity
- New pain or change in typical pain patterns
- Autonomic dysreflexia (hyper-reflexia)
- One pupil appears larger than the other

Several of these symptoms, like increased sweating, may occur in other problems associated with SCI. However, significant loss of sensation or muscle function strongly suggests a change in the spinal cord. The changes may develop gradually. You may notice it is more difficult to do some everyday activities, such as holding a cup or dressing yourself. You may notice a change in your balance or find areas of your body where you had sensation and now you do not.

If you notice significant changes, contact your physician. Give him/her specific information about these changes. Your doctor may ask you to come in for a check-up, which will include an evaluation of your muscle and sensory levels.

For more information about this research study, contact Dr. Charlifue at [Susie@craighospital.org](mailto:Susie@craighospital.org).

**FOR SALE \*\*\***

**WC Lift;** \$7,000 new; only used 2 months; asking \$3,800. **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..*

**ATTN: ADULT WOMEN WITH SCI**

**Stories needed: experiences from employed or unemployed women w/SCI—returning to work, attempting to return to work, or would like to return to work. Purpose: To gain understanding of the return to work experiences of women with SCI as well as issues or barriers associated with the ability or inability to return to work. Factors influencing the quality of life will also be viewed. About the researcher: Elizabeth Lasher is a doctoral student in the Dept. of Education, Counseling, Psychology, and Rehabilitation at Pennsylvania State University. She has 10 years experience as a rehabilitation counselor in a hospital SCI unit prior to returning to school.**

**Survey: Can be accessed in 2 ways: go to [www.psychdata.com](http://www.psychdata.com) and enter survey #119800 or by directly using the link: [www.psychdata.com/s.asp?SID=119800](http://www.psychdata.com/s.asp?SID=119800). If you have additional questions contact Elizabeth Lasher at [eil155@psu.edu](mailto:eil155@psu.edu)**

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