

---

---

# ◆ THE DERBY CITY NSCIA NEWSLETTER ◆

---

MAY 2006

---

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

---

## Message From the President

Dear Members & Friends-

*Our speaker this month is Dr. Susan Harkema,, Ph.D. Dr. Harkema is the newest faculty member to join the Department of Neurological Surgery and the Kentucky Spinal Cord Injury Research Center at the University of Louisville and she will be directing clinical research at Frazier Rehab Institute. This partnership has formed the Neuroscience Collaborative Center at Frazier Rehab Institute that will facilitate the translation of basic science into clinical applications.*

*Patients at Frazier Rehab Institute now have access to the latest in advanced rehab medicine at Frazier Rehab Institute with new strategies to retrain the nervous system after injury.*

*The work by Dr. Harkema and colleagues have resulted in the development of an intervention called Locomotor Training for people with spinal cord injuries and other neurological disorders. Locomotor Training re-teaches the body to walk by providing appropriate sensory cues that can be recognized by the neural circuitry of the spinal cord. It has 3 components, which Dr. Harkema will discuss in her speech. A side benefit to this training is that patients experience better overall health and report better quality of life.*

*June's meeting will be held at 6:30 at Frazier Rehab, 10th floor dining room. - David Allgood*

**REMINDER:  
MAY'S MEETING IS MAY 22. .**

### Table of Contents

President's Message/Celebrity Fundraiser.....	1
Refrigerator Calendar.....	3
SCI Treatments Studied/Monkey Help.....	4
For Sale.....	5

*From the Internet—ed.*

## **'SPORT OF KINGS' HELPS FIGHT PARALYSIS**

**By David Crary**

At first glance, it looked like many of the polo games that are played among the rich and famous in Florida during the winter months, but the purpose of this particular match pointed up an irony that few could miss.

On a grass field at the International Polo Club Palm Beach recently, horses thundered back and forth while players leaned over the horses massive bodies at precipitous angles to swing their mallets at the ball.

The steeds, exhausted by their runs, were changed after every seven-minute period. Not so the players, who continued, sweating and panting, until the match was over. There were no accidents, and no injuries or falls that could paralyze, and that was fortunate, since the players wore only helmets as protective gear.

However, some of those watching off the field were not so lucky. Several were in wheelchairs, victims of several accidents that had left them with spinal cord injuries.

This celebrity match was, after all, an event sponsored by the Buoniconti Fund to Cure Paralysis, which raises funds for the Miami Project to Cure Paralysis. When the evening was over, \$600,000 had been collected for the research.

The irony of riding horses to raise money on behalf of people who have often been injured in equestrienne or other sporting events was not lost on the big-name participants.

"There's not a polo player who doesn't have a friend who limps or is in a wheelchair or is dead," said Oscar-winning actor Tommy Lee Jones, fresh off the polo field after his match. "Spinal cord injury doesn't discriminate. It is in our best interest as a community to engage in community service," He said.

John Walsh, of America's Most Wanted, still in pain from an equestrienne accident five weeks ago, in which he broke two vertebrae and two ribs, said of that incident, "I was an inch away from a wheelchair. I was in a tournament, got launched, and was knocked out for 10 minutes. This is my first time on a horse."

**(Continued On Page Two)**

**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.

\*\*\*

**OFFICERS**

**PRESIDENT**

David Allgood - (502) 589-6620

**VICE PRESIDENT**

Adam Ford - (502) 425-2206

**TREASURER**

Tom Stokes- (502) 957-5865

**LIAISON TO FRAZIER INSTITUTE**

Jill Farmer, CTRS—(502) 582-7618

**FUNDRAISING CHAIR**

Betty Perry—(502) 647-0368

**CORRESPONDING SECRETARY/WEB MASTER**

Michael Feger- (502) 647-0368

**PAST PRESIDENT**

Adam Ford- (502) 425-2206

**BOARD MEMBERS AT LARGE-**

Mike Perry  
Kelly Young

**NSCIA**  
**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.**

**POLO FUNDRAISER, CONT'D**

Dawn Jones, the wife of Tommy Lee Jones, said the field was so slippery that she had to slow her turns down considerably.

Perhaps no one brought attention to the cause of spinal cord injury than the late Christopher Reeve, who was paralyzed in an equestrienne accident in 1995 and died in 2004, but the Miami Project has attracted its share of headliners.

Gloria Estefan, who was temporarily paralyzed 16 years ago after a tour bus accident, recently donated a million dollars to the cause on behalf of herself and her husband, Emilio.

Tim Gannon, founder of Outback Steakhouse and one of the organizers of the event, said that every person he called responded.

The realities of life in a wheelchair and of scientific efforts to restore mobility seemed far removed from the rarefied atmosphere of the fundraiser, with its fire jugglers and stilted harlequins moving through the throng of rich and glamorous benefactors. But, in fact, the two worlds are symbiotic, in a way, for it is the money that will enable the search for a cure.

The world has seen several potential cures already that didn't pan out. Right now, scientists and patients are pinning their hopes on stem cell regeneration, specifically on Schwann cells. Schwann cells are a particular type of cell that grows to form the myelin sheath that protects nerves.

"Cellular implants are the future, said Barth Green, president and founder of the Miami Project. "We expect to start clinical trials in three to five years. It's been proved in rats and now in primates."

In 2004 Miami Project investigators announced improvements in motor in animals (rats and primates) with spinal cord injuries who had been treated with Schwann cell grafts. The center is hoping to start clinical trials within three years.

That's good news to Mark Buonticonti, who sustained a spinal cord injury during a college football game in 1985, and who was one of the event's hosts. His father, NFL Hall of Fame linebacker, Nick Buonticonti, founded the Miami Project with Green after his son's injury.

When asked if he was optimistic about the prospect of stem cell research, he responded, "Of course it'll work in humans, and I'll still be young."

**HAPPY MOTHER'S DAY!!**



# **Refrigerator Calendar**

## **\*2006**

### **MAY**

**1st - Elderly & Disabled Advisory Council Meeting**

**Mon 1:00-2:30 p.m.; TARC; 1000 W. Broadway; Board Room.**

**22nd - Derby City Chapter Meeting, 10th floor dining room; 6:30 p.m.**

**Mon Frazier Rehabilitation; 220 Abraham Flexnor Way. Speaker: Dr. Susan Harkema. She will be discussing the Locomotor Training for people with SCI.**

**20th - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.; PVA Office on Goss Avenue.**

**Sat Speaker to be announced; if questions, contact Terri Leasor at 589-6620 or at mdclouky.org**

### **JUNE**

**5th - Elderly & Disabled Advisory Council Meeting**

**Mon 1:00-2:30 p.m.; TARC; 1000 W. Broadway; Board Room.**

**19th - Derby City Chapter Meeting, 10th floor dining room; 6:30 p.m.**

**Mon Frazier Rehabilitation; 220 Abraham Flexnor Way. Our annual Kingfish dinner will take place in July.**

**17th - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.; PVA Office on Goss Avenue.**

**Sat Speaker to be announced; if questions contact Terri Leasor at 589-6620 or mdclouky.org**

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

---

*From the Internet—ed*

### **SPINAL CORD INJURY TREATMENTS STUDIED**

University of Iowa scientists have found that intervention and electrical stimulation can reduce osteoporosis and atrophy caused by spinal cord injuries.

Researcher Richard Shields, a professor of physical therapy and rehabilitation, and colleagues say electrical stimulation causes muscle contraction and exerts mechanical loading on targeted bone, thereby significantly reducing severe osteoporosis and significantly reducing atrophy caused by spinal cord injury.

Virtually every spinal cord injury patient develops osteoporosis and muscle atrophy after injury. The bone thinning that occurs very rapidly—an average loss of 30 percent in bone mineral density in just three years—makes the paralyzed limbs particularly vulnerable to fracture.

“Will an 18-year-old injured today be a good candidate for a cure or repair if their bone is so brittle it can’t bear weight or their muscles are virtually useless?” Shields asks.

“The long-range issues relate to helping people now remain good candidates for a future cure,” says Shields. “The short-term effects are improving the patient’s health quality and preventing secondary complications.”

This research appeared in the March issue of *Spine*.

Found on the internet –ed.

### **PARALYZED FLORIDA WOMAN GETS HELPING HAND FROM A SIX-POUND MONKEY**

By Sallie James

When Linda Brown wants to hear music, watch TV or adjust her bedroom lights, she calls on Tracey. Tracey can slip a CD into the player, flip a light switch or hand Brown the television remote with deft fingers.

“It doesn’t sound like a lot, but that’s my world, and it makes it more bearable,” said Brown, 51, a quadriplegic. “She’s friendship, she’s a companion, and she senses a lot.”

Tracey is also a highly trained capuchin monkey whose job is assisting Brown with simple tasks. Owned by Helping Hands: Monkey Helpers for the Disabled, Tracey is the Boston agency’s only active service monkey in Florida and one of 108 placed nationwide since 1979. The agency is funded by private donations, corporate support, and grants.

The little monkey began changing Brown’s life two

Tamarac, who suffers from syringomyelia, a degenerative spinal cord condition that causes paralysis and pain. “I was really not adjusting to life in a wheelchair. I would have thrown myself off a balcony if I could have found a balcony.”

Enter Tracey, a 6-pound *Cebus apella* whose mischievous nature gave Brown a reason to want to live. The monkey also gave Brown’s husband and caretaker, Craig, a much-needed break.

“What’s unique about Tracey is that she can help me with simple objects. It’s that little bit of freedom. I don’t have to yell, “Craig, come help me!” said Brown, who has only minimal arm movement.

About five years ago, Brown’s doctor suggested she look into monkey helpers, so her husband went online and found the Helping Hands website. Three years later, the Helping Hands agency matched Brown with Tracey, and soon Brown found herself doing something she hadn’t done in years: laughing.

Brown directs Tracey by pointing a laser light at an object and using simple commands. If Brown aims the laser light at the TV remote and says, “Fetch clicker,” Tracey will pick it up off the floor and hand it to Brown.

With the command, “Do bucket,” Tracey crawls across Brown’s prone body and tosses a crumpled tissue into a wastebasket. “Do sun” tells Tracey to flip on a light switch. “Open” means to go to the refrigerator and “push” is for switching on a CD player.

“She can pick up the portable phone and hand it to me, or she will give me the headset. Or she can turn on the speakerphone,” said Brown.

Monkeys like Tracey initially spend six or seven years in foster homes, where they learn how to interact with people, to fetch, be diapered and take baths, said Megan Keppler, director of placements for Helping Hands. Then they attend the “Monkey College” in Boston, where they are trained to imitate their trainers, Keppler said. School can last 18-24 months.

Couple that with breeding and placement, and each monkey costs the nonprofit agency about \$33,000, she said. Brown pays for Tracey’s food, medicine, and diapers, about \$3,500 a year, and will keep Tracey as long as she needs her. If Brown’s needs change, Tracey will be placed with another patient, Keppler said.

When a monkey is matched to a recipient, a trainer spends about 8 days in a recipient’s home, teaching that person how to work with and care for the monkey. Afterward, the patient and trainer remain in telephone contact.

“What we look for in our recipients are people who say there is more out there than this and I want to do everything I can,” Keppler said. “Linda is amazing, such a good person with a great attitude. What keeps her going is the monkey.”

**(Continued On Page Five)**

**Monkey, Continued From Page Four**

On this day, Tracey banged on her cage door, frantic to be free. The monkey was upset because Brown had been away for hours. Brown unlocked the cage door, and Tracey scampered out.

"Fetch lease," she told Tracey, who lifted up a black nylon leash and handed it to Brown. Tracey immediately took her place on the pillow beside Brown's head. The monkey began combing Brown's curly gray hair with her long fingers, picking bits of hair spray off the strands and licking it off her hands.

If Brown is slow to offer a peanut butter reward, the monkey impudently claps her hands in irritation. If Brown still doesn't respond, Tracey claps louder, then begins screeching. Brown likens her sometimes-pouty behavior to that of a two-year-old.

Occasionally, Tracy's nails need to be filed, so Brown showed Tracey how to do it herself. Now the capuchin jerks to a halt and begins filing her own toenails whenever she comes across an emery board.

Tracey loves the "Today" show, "Star Trek", and Martha Stewart. But don't turn on Oprah, because she doesn't like it, Brown said. Really.

"We see monkeys who love weathermen because they look like they are talking at you and waving their hands," Keppler said.

On some days, Brown has trouble breathing and needs oxygen. Tracey senses her distress and helps Brown regain her composure.

Brown's disability stems from a 1991 car crash in which she suffered a hairline fracture to the neck. The injury later developed into syringomyelia, in which a cyst forms inside the spinal cord, causing pain, nerve damage, loss of body functions, and paralysis.

For a time, she took powerful medications such as oxycontin, but she quit taking the drugs because she felt incoherent. Today, Tracey is her best medicine.

"Tracey came into my life, and life was great," Brown said. "She is truly the reason I keep going." She just may be a monkey, but she's more than a monkey to me. She's a companion."

Tracey, equally at peace with the match, curled her tail around her body, cuddled up to Brown's heart, and nodded off to sleep.

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

**97 Mercury Sable LS**; station wagon. Leather interior; 6-cylinder; 6-passenger seating; rear-facing third seat; Braun wc top; Monarch hand controls. 93,000 miles. Price negotiable. **Call Ruth @ 239-9754 after 5 p.m.**

**2001 Dodge Intrepid**. 30,000 mi; leather interior; automatic transmission; Braun overhead wheelchair carrier & hand controls. **Call Ruth at 239-9754 after 5 p.m.**

**\*2003 Ford F-250 lift-equipped green/gray van**; leather seats, TV, DVD player. Playstation hookup, am-fm radio. Rick Miller, 937-2245.

**\*Shower Chair**; 2 yrs old, negotiable; **2 RoHo cushions; low profile**; \$150 each; **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 candidates.*

**IF YOU WOULD LIKE TO PLACE A  
FREE AD IN FOR SALES,  
CALL 589-6620.  
ASK FOR BARB OR DAVID.  
YOU CAN ALSO EMAIL THE INFO TO  
bdavis@calky.org**

**BUSINESSES WANTING TO RUN A  
YEAR'S PAID AD SHOULD CALL  
DAVID AT 589-6620.**

**HAPPY DERBY PARTY!!**



*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 Center, 4th floor Dining Room  
220 Abraham Flexner Way*

**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  
6703 Triangle Drive  
Louisville, KY. 40214