

◆ THE DERBY CITY NSCIA NEWSLETTER ◆

APRIL 2008

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

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.

May'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

YOU ARE INVITED TO JOIN MS. WHEELCHAIR KENTUCKY FOR A...

DINNER RECEPTION, SILENT AUCTION AND RAFFLE THAT WILL SHOWCASE THE UNIQUE PRODUCTS, SERVICES AND ENTERTAINMENT OF THE COMMONWEALTH

FRIDAY, APRIL 11, 2008

7 P.M.—10 P.M.

**THE GALLERIA ROOM,
COLLINS AUTO GROUP
4220 BARDSTOWN ROAD
LOUISVILLE, KY 40218**

Donations accepted at the door.

Event is open to the public;

RSVP is encouraged.

Please call Jaime at 502-759-5665 or email mswheelky08@yahoo.com for more information or to RSVP.

DISABILITY 101: AN ESSENTIAL GUIDE TO THE ADA, DISABILITIES, & ACCOMMODATIONS

The first in a series of education seminars for Human Resource professionals & management

DATE: MAY 12, 2008 8:45 A.M.—2:30 P.M.

LOCATION: 12501 Lakefront Place, Louisville

Attendees will:

- Develop a basic understanding of the ADA
- Learn resources & practical solutions for accommodations
- Learn the legal requirements of ASL interpreters for deaf applicants & develop an understanding of deaf culture
- Hear from a fortune 500 company recruiter who works to promote the successful employment of persons with disabilities
- Increase knowledge of Autism Spectrum Disorders (ASD), and the inexpensive accommodations that work for them
- Share available resources and tools
- Learn training methods, facilitation techniques, instructional methods, and program delivery mechanisms for diverse groups.

COST: \$149 For Profit \$99 Non Profit
Includes light breakfast, lunch and 4 HR credits

FOR MORE INFORMATION OR TO RECEIVE A REGISTRATION FORM, CONTACT BARB DAVIS AT (502) 589-6620 or bdavis@calky.org

Table of Contents

President's Message/Upcoming Events.....	1
Voice Joystick.....	2
Calendar.....	3
Broken Back Can Leave You Homeless.....	4
Wise & Forever Young/For Sale.....	5

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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NSCIA

**DERBY CITY CHAPTER
NEWSLETTER**

Editor- Barbara Davis

Contributor- David Allgood

Visit Our Website at
www.DerbyCitySpinalCord.org

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

The following articles are from the Internet –ed.

VOCAL JOYSTICK

The spinal cord is the main conduit of communication between the brain and the nerves in the body. A spinal cord injury is a disruption in communication to and from the area below the point of injury. Generally, the higher up the spinal injury, the greater the degree of functional loss. An injury in the lower spine may only affect the limbs and bladder/bowel function. An injury in the neck area can affect the lower and upper limbs as well as the ability to breathe (due to loss of diaphragm function).

According to the National Spinal Cord Injury Information Network, between 227,080 and 300,938 Americans are living with a spinal cord injury. About 12,000 new cases occur each year. Males are affected about 4 times more often than females. The most common causes of spinal cord injury are motor vehicle crashes (42 percent), falls (27.1 percent), acts of violence (15.3 percent) and sports injury (7.4 percent).

Computers open a doorway to the entire world and provide information and entertainment at the click of a mouse. For people with disabilities, like a spinal cord injury, a computer and internet access can be a lifeline, enabling a user to communicate with others, get vital health information and shop online.

The standard equipment for computer use are a keyboard and a mouse. But people who have limited or no hand mobility are unable to use these tools. Instead, they may rely on one or more adaptive device, or software, like a trackball, a touch pad or touch screen, joystick, head-tracking device or pointer.

Voice recognition software is sometimes used to create documents, input data, surf the internet and control computer functions. However, it takes a considerable amount of training to “teach” the computer to recognize a user’s voice. In addition, the software is very inefficient for continuous tasks and is better suited for short commands.

Researchers at the University of Washington have developed a new type of computer access tool, called the Vocal Joystick. The device uses vocal sounds rather than words to control mouse commands. Different vowel sounds make the cursor move in the appropriate direction. Speed of the cursor is controlled by volume. The louder the sound, the faster the cursor moves on a page. Two other sounds, “k” and “ch” substitute for the mouse clicks.

Jeff Blines, Ph.D., Electrical Engineer and Researcher, says little training is needed for the Vocal Joystick. Volunteers that have tested the software learned to navigate the command in just a few minutes. So far, it has been used to play a video game, draw a picture and browse web pages.

(Continue On Page Four)

Refrigerator Calendar

***2008**

APRIL

7th - Elderly & Disabled Advisory Council Meeting.
Mon 6:00 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; 3:15 p.m.
Sat Urban County Government Center; Barrett Avenue; Louisville

MAY

5th - Elderly & Disabled Advisory Council Meeting
Mon 1:00; TARC; 1000 W. Broadway; Board Room.

19th - Derby City Chapter meeting; 6:30 p.m.; Frazier Rehab Institute
Mon 220 Abraham Flexner Way; Louisville; 10th Floor dining room.

17th - 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

Vocal Joystick, Cont'd

Researchers have even adapted the technology to control a robot arm. Eventually, investigators are hopeful the software can be applied to wireless home automation devices.

Blimes expect the vocal joystick to be available for downloading by June 2008. He says the technology could be used by just about anyone, as long as they can make vocal sounds. The only extra hardware required is a microphone and sound card. For more information go to <http://ssli.ee.washington.edu/vj/>.

BROKEN BACK CAN LEAVE YOU HOMELESS

A television presenter who broke her back says many people with similar injuries are being forced to live in care homes.

Victoria Hollingsworth shattered her spine in a car accident while filming Channel 4's property programme *A Place in the Sun* in Spain.

She has now made a report for Radio 4's *You and Yours* programme about patients who cannot return home because their properties are not suitable for wheelchairs.

The accident three years ago left Victoria with five broken ribs, a punctured lung and a spine shattered in three places. Victoria, who lives in London, said: "The doctors informed my distraught parents that there was a good chance I would be paralyzed. However, after nine hours of surgery my broken vertebrae were replaced by metal rods and screws and miraculously I re-learned to walk and returned to presenting three months later.

But Victoria says many patients cannot go back to their homes due to the lack of wheelchair access and have to be housed elsewhere.

She said, "I know of a girl around my age who was paralyzed following an accident and had to live in an old people's home for 18 months. Can you imagine your state of mind—coming to terms with life in a wheelchair and having to do that surrounded by people four times your age?"

"There is also the story of a man who was a new father immediately prior to his accident. His counsel housed him in a hotel and he rarely got to see his wife and baby. She worked full time and he couldn't afford to eat in the hotel so he had to rely on eating take-away food as he had no access to the kitchen."

Every year in Great Britain around 1,000 people sustain a spinal cord injury, according to the

Spinal Injuries Association (SIA).

(editor's note: this is probably not the same stat for the U.S.)

Aspire, a charity which helps people with spinal injuries, says around two thirds of people could face housing problems after spending between six and 18 months in a spinal centre.

Research carried out by the charity at one spinal centre revealed that over an 18 month period only 39% of people who were discharged were able to go back to a home which had been adapted.

One in three went home to houses which still had not been adapted, which meant sleeping in the living room because of lack of upstairs access, and 20% had to go to care homes or other hospital departments.

The number of people with spinal injuries is increasing, partly because advances in medicine mean there is a better survival rate.

The Department for Communities and Local Government said it is providing more support for measures designed to help people live independently in their own homes. It also said government funding for home adaptations such as wheelchair ramps has doubled since 1997.

Victoria's report can be heard on BBC Radio 4's *You and Yours* programme on 27 March between 1200 and 1300.

Editorial comment: Searching Google did not render any comparable reports of individuals with spinal cord injury becoming homeless in the United States as a result of inaccessible housing. However, there were a number of articles touting nursing homes and homeless shelters as being a viable source of "housing" for those with SCI. I also found several brief mentions of rehabilitation centers that keep a list of homeless shelters for patients with inaccessible homes.



TO BE WISE AND FOREVER YOUNG

By Tim Gilmer

When I was 21, I read *Rasselas, Prince of Abbyssinia*, written by Samuel Johnson in 1759. Its theme was “the vanity of human wishes.” I was new to paralysis, despondent, and accepted that my deepest wish—to turn back the clock to the day before my accident—was futile. I would be paralyzed forever.

In 1966 that’s what medical books taught, end of argument. That was also the year an article in the *Los Angeles Times* announced that scientists had enabled a paraplegic to stand by placing electrodes on his legs and applying pulses of electricity.

What has happened over these past 40 years, while frustratingly slow, gives reason for hope. In the ‘70s, functional electrical stimulation was studied; in the ‘80s it was refined; in 1990 Wise Young and colleagues overturned scientific dogma by discovering that methylprednisolone, administered soon after SCI, can improve recovery. A brief, post-injury window in which regeneration is possible began to be studied for clues to further regenerative therapies.

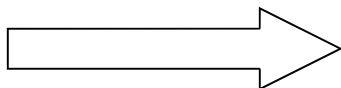
In each decade we heard the same promise: a cure is coming within 5-10 years, maybe longer. After hearing it repeatedly yet seeing no practical therapies, I stuck with my original conclusion: I would be paralyzed forever.

Today, thanks to Wise Young and other researchers, I’m beginning to believe. A “cure” will happen as the result of research involving combination therapies—stem cells, axon-growth stimulators, and growth inhibition blockers—followed by intensive therapy, based partly on what we’ve learned from FES dating back to 1966. And yes, it will happen in 5-10 years, maybe longer.

But it won’t happen without collaboration, commitment, and persistence, three earmarks of Wise Young’s career. “He’s creating a great body of work for scientists all over the world to draw from,” says John Smith, whose son Noah became a C-7 quad in 2002. Smith also moderates another of Young’s creative works, CareCure forum. “I’m biased,” he says, “but the man is a true genius, and so tireless. He has so much time for everybody.”

In 1975 Lewis Thomas’ collections of essays, *The Lives of a Cell*, compared a cell to a human body, a society, or even a universe, in which all parts work together to promote the integrity, and the future, of the organism. In SCI research, Wise Young has put this principle to work. In a 2005 interview in the Rutgers publication *Focus*, Young said, regarding his choosing the name, “W.M. Keck Center for Collaborative Neuroscience” for the facility he directs: “There were puzzled looks. Yes, scientists collaborate, but they also compete with each other. Interestingly, the scientific and education world has embraced the term.”

Continued Under For Sale



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!!

**S, M, L XL
\$10**



WISE AND FOREVER YOUNG, CONT'D

Young’s commitment to collaboration can be seen on a global scale in his creating the China SCI network. But that model needs to return to the United States. We can help by urging passage of the Christopher and Dana Reeve Paralysis Act, which would create six regional hubs for research that would emphasize, says Young, “reversal of paralysis.”

I have written that walking again is not high on my list of personal wishes. But to me, reversal of paralysis sounds like turning back the clock. And that’s exciting.



HAPPY THUNDER!!!

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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