
◆ THE DERBY CITY NSCIA NEWSLETTER ◆

MAY 2007

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 Institute, 220 Abraham Flexnor Way, Louisville, in the 10th floor dining room at 6:30 p.m. Our speaker will Dr. Scott Whittemore, of the University of Louisville. Dr. Whittemore will discuss the advances in stem cell research and treatment of SCI. So please join us for what is sure to be an interesting and informative meeting.

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

-David Allgood

From New Mobility.com

CRUISING FOR COMPLIANCE

The U.S. Department of Transportation recently issued a formal proposal to ban all cruise ships that dock in U. S. ports, including foreign-owned vessels, from discriminating against passengers with disabilities. Proposed regulations should be finalized later this year.

Other U.S. public transportation industries, such as airlines, railway and buses, have complied with ADA policies and procedures.

“We don’t have any rules for cruise ships right now,” says Candy Harrington, author of Barrier-Free Travel. “We have this big ruling from the Supreme Court that says they are covered, but we don’t have any specific rules.”

The U.S. Access Board has proposed architectural guidelines, and DOT is in the process of approving policy and procedures; changes will include same pricing for accessible cabin, elimination of medical certification to board, and allowing durable medical

From the Internet—ed.

STEM CELL RESEARCH CENTER OPENS ‘DOORS OF POSSIBILITY’

By David A. Michaels

It looked empty, but the first piece of New Jersey’s new stem cell research center filled Saturday with the hopes and expectations of people who think it may change lives.

The center, in the New Brunswick area, is the nation’s first to be publicly funded, officials said. Acting Gov. Richard J. Codey told Saturday’s dedication ceremony that New Jersey’s researchers would spearhead efforts to improve health worldwide.

“We are opening...what some would call the doors of possibility, and unlocking the potential to erase suffering, treat and cure diseases, and save lives,” Cody said before cutting the ribbon on the laboratory.

The audience was filled with families whose loved ones suffer from incurable diseases or paralysis. As Codey spoke, Alex Pitts, 6, leaned back in his red motorized wheelchair and grabbed his mother’s hand, pressing it to his face.

An outgoing boy who smiles easily, Alex suffered a spinal cord injury at birth and has been paralyzed since. His mother hopes that research on embryonic stem cells, which scientists think can be used to repair damaged tissue and thus cure diseases and spinal cord injuries, could open up a new, independent life for him.

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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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NSCIA
DERBY CITY CHAPTER
NEWSLETTER

Editor- Barbara Davis
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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**

STEM CELL RESEARCH CENTER, CONT'D

Strength in his arm's triceps muscles would permit Alex to move himself from wheelchair to bed, allowing him to live without help from an attendant. "At this point, I would love a home run, but quality of life would do," said Melissa Pitts, his mother.

Pitts and others credited Dr. Wise Young, a Rutgers University Neuroscientist who championed the establishment of the Stem Cell Institute of New Jersey, with renewing their hope. Young has grown close to many of the families that attended the ribbon-cutting. Walking through a hallway on Saturday, he was always a few steps from the next hug. One boy, whose sister is partially paralyzed because of cancer, asked for his autograph.

"When I first talked to Wise, he and Christopher Reeve were the ones who gave us hope," Pitts said. A section of Saturday's program honored Reeve, the actor and New Jersey native who played Superman and who became a champion for stem cell research after being paralyzed in 1995. Reeve died in 2004, but everywhere one looked on Saturday, Superman was there.

Richard Gaskin wore the superhero's famous "S" on a gold dog tag as he performed a rap song titled, "You'll always be Superman." Gaskin, 40, said he hoped the center's researchers would find a cure for the paralysis he has suffered since being shot in the neck in 1987.

"When a lot of new injuries come into the hospital, weeks or months later, they can walk out," Gaskin said. "They don't have to spend 20 years like myself in a wheelchair."

The center is scheduled to open in a few years, Young said. He added that he thought clinical trials would show stem cells' potential to cure diseases such as diabetes "in the next few months, the next few years at most."

If that is the case, there are not enough embryonic stem cells to help all the patients that need them, Young said.

"This is a humanitarian crisis," he said.

Many social conservatives oppose embryonic stem cell research because it requires the destruction of human embryos. Some critics compare the process to abortion.

John Tomicki, executive director of the League of American Families, said the Legislature is risking public investment in a field whose benefits have not been proved. Tomicki added that the Legislature should have asked for public approval for its initial investment of \$270 million.

"They seem to be bent on moving into the embryonic field, which of course destroys human life," Tomicki said. "Not one cure or treatment has evolved from embryonic research."

The state, which thinks stem cell research could boost the state's economy, is focusing next on funding research. The \$270 million it approved last year is being spent on the

(Continued On Page Four)

Refrigerator Calendar

***2007**

MAY

7th - Elderly & Disabled Advisory Council Meeting.
Mon 1:00 p.m.; TARC; 1000 W. Broadway; Board Room.

21st - Derby City Chapter meeting; 6:30 p.m.; Frazier Rehab Institute.
Mon 220 Abraham Flexnor Way, Louisville, 10th Floor dining room.

19th - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.
Sat

JUNE

4th - Elderly & Disabled Advisory Council Meeting
Mon 1:00-2:30 p.m.; TARC; 1000 W. Broadway; Board Room.

18th - Derby City Chapter meeting; 6:30 p.m.; Frazier Rehab Institute.
Mon 220 Abraham Flexnor Way, Louisville, 10th Floor dining room.

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

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

STEM CELL RESEARCH CENTER, CONT'D

buildings at Rutgers, the New Jersey Institute of Technology in Newark and a center in Camden.

The Legislature is close to approving a ballot initiative—the Senate has already passed a bill—that would ask voters in November to allot \$300 million to \$500 million for research, Codey said.

“The last thing we want is three empty buildings,” Young said.

RESEARCHERS EYE NANOTECHNOLOGY TREATMENT FOR SCI

Nanotechnology is showing promise in treating spinal cord injuries and could conceivably reverse paralysis, according to a report on the future of the emerging technology in medicine.

The report, released at a Washington forum this week, said nanotechnology—or the use of materials on the scale of atoms and molecules—may also help cure other ailments believed to be intractable by repairing damaged organs or tissue.

This suggests damage from heart attacks or strokes, bone or tooth loss or ailments such as diabetes and Parkinson’s disease could be treated with nanotechnology, researchers said.

A presentation by Northwestern University researcher Samuel Stupp showed mice that had been paralyzed by damaged spinal cords regained the ability to use their limbs after receiving an injection of a solution designed to regenerate damaged nerve cells through nanotechnology.

The solution includes molecules designed to reassemble into the type of tissue that normally cannot be healed or regenerated naturally such as bone

or nerve, Stupp said.

“By injecting molecules designed to self-assemble into nanostructures in the spinal tissue, we have been able to rescue and regrow rapidly damaged neurons,” he said, after showing a video of the mice before and after treatment in a forum at the Woodrow Wilson International Center for Scholars.

“We are very excited because this gives us an entry into the area of neuro-degenerative disease.”

Stupp said the treatments used in research so far have not used stem cells—which are the base cells for human embryos that can form into different cells—but that stem cells may increase the potential for nanotechnology treatment.

The researcher said his team’s basic research for spinal cord treatment has been published in

paralysis are now being reviewed for publication.

He said researchers hope to begin clinical trials on humans for spinal cord treatment “within a couple of years.”

Another experiment showed mice recovering from the symptoms of Parkinson’s disease after being exposed to the nanostructures developed in Strupp’s laboratory.

LOOKING FOR MR. WHEELCHAIR

Dreams Inc. is taking applications for the first Mr. Wheelchair America competition. The winner will be chosen based on achievements since onset of disability.

“Winners will be allowed their own platform while representing Mr. Wheelchair,” says former Ms. Wheelchair Iowa and Dreams Inc. founder Judy Holt. “We also feel this can be a mentorship for (disabled) service people coming back from war.”

The competition is open to 21-60-year-old men who use wheelchairs for 100 per cent of their daily mobility. Applications, available at www.dreamsforever.info, are due



TO ALL THE MOMS IN OUR READERSHIP.....

HAPPY MOTHER'S DAY!!!!



MAKING EMERGENCY TRIPS WITH SCI**By Barbara Davis**

Most of us with disabilities know that taking a trip anywhere, no matter how short the distance or stay, requires much planning. This is particularly true if a condition entails the need for durable medical equipment, medications, or is one that could flare up at a moment's notice, such as asthma or MS. We research our destination to find out about accessible hotels and transportation. We check the TSA (Transportation Safety Administration) website to find out the most recent list of taboo items, and we check with those who have been there before about accessibility, medical facilities and what-not. We put instructions on our wheelchair. Then after all that work and worry, we get to the airport, train/bus station, or cruise dock and pray everything will go smoothly. Most of the time it does. Sometimes it doesn't.

But what do we do if we have a family emergency that requires traveling ASAP to a destination in another state or country, and we have no time for trip planning or research?

The trick is to plan in advance for the possibility of such an emergency, no matter how remote the chances of such an event happening seem to be.

I learned this lesson the hard way. Having grown up in a large family in Central Florida, I left the family and Florida behind when I relocated to Louisville many years ago. Several years after this my sister collapsed in an emergency room and doctors did not think she was going to make it through the night. I immediately began calling airlines. This was a nightmare. My sister got sick in March, which means it was spring break. In Florida. Good luck.

And of course I had no phone numbers in my address book, the computer was not cooperative, and the phone lines were constantly busy. When I finally reached an airline, I was told that all I could do was come to the airport and wait for a cancellation and get on that flight. I was told it was best to come right away, as there was a flight leaving for Tampa in 45 minutes (this was pre-9/11) and one leaving for Orlando in three. I had no time to pack. Fortunately a relative living nearby took me to the airport. I arrived in Florida without hearing aid batteries, asthma medication, or my cane. Of course I had a flare-up of both the asthma and the MS in-flight.

Since Florida is my home state, I knew where the pharmacy and anything else I needed was. But I learned a valuable lesson from that experience. I now have a small tote bag loaded with an extra pack of hearing aid batteries, which I check periodically to be sure they work, a folding cane, an extra inhaler, plus a change of clothes and a small umbrella. My son has his own emergency bag backed. My address book contains phone numbers for airlines and

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..*

EMERGENCY TRIPS, CONT'D

travel agents, and I keep a constant check of TSA's websites so there are no nasty surprises at the airport. I no longer use a wheelchair, thanks to hip replacement surgery, but if I did, instructions on how to transport it would ALWAYS be on the back of it in case of emergency. I would also have accessibility information on every location where I had a close relative or friend in my tote bag or purse at all times. As it is, I have the phone number for the pharmacy nearest a relative's home in Memphis, Chicago, Montgomery and Atlanta. This way, if I have to take an emergency flight and need hearing aid batteries or an inhaler (or anything else) I know how to find out where to get them.

I also frequently check with Greyhound and various airports in Florida. I now know how to get home in an emergency during spring break—even if it means flying to Jacksonville or Miami and taking a Greyhound bus home from there.

No one wants our loved ones to experience any type of crises, especially a medical emergency. But for those of us with disabilities, it is a good idea to plan for one just in case.



