
◆ THE DERBY CITY NSCIA NEWSLETTER ◆

JULY 2007

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

Message From the President

Dear Members & Friends-

July's meeting will be held at Frazier Rehab Institute, 220 Abraham Flexner Way, Louisville, KY 40202 in the 10th floor dining room at 6:30 p.m. To date we do not have a speaker scheduled. We hope to have one scheduled at meeting time, but we will show a video presentation in the event that one is not scheduled. Refreshments will be provided.

August's meeting will be held at Frazier Rehab Institute, 220 Abraham Flexner Way, Louisville, KY 40202 in the 10th floor dining room, at 6:30 p.m. Refreshments will be provided.

-David Allgood

From the Courier-Journal, 6/7/07 -ed

STEM CELL TECHNIQUE COULD BYPASS ETHICAL CONCERNS **By Nicholas Wade**

In a surprising advance that could sidestep ethical objections to stem-cell research, three teams of researchers have come much closer to converting a patient's cells into specialized tissues that might replace those lost to disease.

The advance is an easy-to-use technique for reprogramming a mouse's skin cell back to the embryonic state. Embryonic cells can be induced in the laboratory to develop into many of the body's major tissues. If the technique can be adapted to human cells, researchers could use a patient's skin cells to generate new heart, liver or kidney cells that might be transplantable and would not be rejected by the patient's immune system.

That could avoid the need to get stem cells from human embryos, which involves destroying embryos, an action many people oppose. The find-

the House is set to vote today on a bill that would loosen President Bush's 2001 restrictions on the use of human embryos in the stem cell research.

Acutely aware that their new work could undermine that key political goal, scientists caution that their success with mouse cells does not guarantee quick success with human cells. They called for legislation that would give federally funded researchers access to embryos slated for destruction at fertility clinics.

"A human is not a mouse, so a lot more work has to be done," said Marius Wernig, who was on the team led by Rudolph Jaenisch of the Whitehead Institute for Biomedical Research in Cambridge, Mass.

If approved, the bill, similar to one approved by the Senate, would go to the president. The White House has already said that the president would veto it.

Previously, the only way to convert adult cells to embryonic form has been by nuclear transfer, inserting an adult cell's nucleus into an egg whose own nucleus has been removed. The egg somehow reprograms the nucleus back to an embryonic state. That procedure is known as therapeutic cloning when applied to people, but no one has yet succeeded in doing it.

The new technique, developed by Shinya Yamanaka of Kyoto University in Japan, depends on inserting just four genes into a skin cell.

(Continued On Page Two)

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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
Contributor- David Allgood

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www.DerbyCitySpinalCord.org**

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Frazier Rehab Institute**

STEM CELL TECHNIQUE, CONT'D

The technique, if adaptable to human cells, is much easier to apply than nuclear transfer, would not involve the expensive and controversial use of human eggs, and should avoid all or almost all of the ethical criticism directed at the use of embryonic stem cells.

“From the point of view of moving biomedicine and regenerative medicine faster, this is about as big a deal as you can imagine,” said Irving Weissman, a leading stem cell biologist at Stanford University. He was not involved in the new research.

David Scadden, a stem cell biologist at the Harvard Medical School, said the finding that cells could be reprogrammed with simple biomedical techniques is “truly extraordinary and frankly something most assumed would take a decade to work out.”

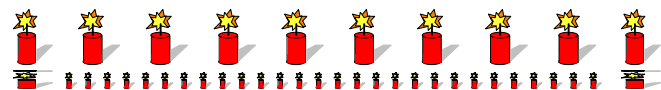
The technique seems likely to be welcomed by many who have opposed human embryonic stem cell research. It “raises no serious moral problem, because it creates embryonic-like stem cells without creating, harming, or destroying human lives at any stage,” said Richard Doerflinger, the U.S. Conference of Catholic Bishops’ spokesman on stem cell issues.

Ronald Green, an ethicist at Dartmouth College, said it would be “very hard for people to say that what is created here is a nascent form of human life that should be protected.”

A report on the new technique by Yamanaka last year riveted the attention of biologists elsewhere. Two teams set out to repeat and extend his findings. One team was led by Jaenisch and the other by Katherine Plath of UCLA and Konrad Hochedlinger of the Harvard Stem Cell Institute. Yamanaka, too, set about refining his work.

In articles published today in *Nature* and a new journal, *Cell Stem Cell* (The first word in the journal’s name refers to its publisher, Cell Press), the three teams show that injection of the four genes identified by Yamanaka can make mouse cells revert to cells indistinguishable from embryonic stem cells.

An immediate issue is whether the technique can be reinvented for human cells. One problem is that the mice have to be interbred, which cannot be done with people. Another is that the cells must be infected with a gene-carrying virus, which is not ideal for cells to be used in therapy. A third issue is that two of the genes in the recipe can cause cancer. Indeed 20 percent of Dr. Yamanaka’s mice died of the disease. Nonetheless, several biologists expressed confidence that all these difficulties will be overcome.



Refrigerator Calendar

*2007

JULY

- 2nd - Elderly & Disabled Advisory Council Meeting.**
Mon 1:00 p.m.; TARC; 1000 W. Broadway; Board Room.
- 14th - Metro disAbility Coalition Meeting; 3:15 p.m.**
Sat Urban County Government Center; Barrett Avenue; Louisville
- 16th - Derby City Chapter meeting; 6:30 p.m.; Frazier Rehab Institute.**
Mon 220 Abraham Flexner Way; Louisville; 10th Floor Dining Room.
- 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.

AUGUST

- 4th - 2nd Annual Larosa Loop Event held in honor of Dr. Ethel Larosa former Pediatric Physician**
Sat at Frazier Rehab Institute. Event includes a 1, 3 & 5 Mile Walk/Roll and a 10 & 25 Mile Bike/
Handcycle ride into beautiful Southern Indiana; \$25.00 donation per family which includes
registration, T-shirt and lunch. For more information please call Jill Farmer at 502-582-7618
or Judy Eberenz at 502-582-7687.
- Sat. 6th - Elderly & Disabled Advisory Council Meeting**
Mon 1:00; TARC; 1000 W. Broadway; Board Room.
- 10-12 - Friends For Michael Day at KY Speedway**
F-S Tickets first come, first served. Contact Cindy Norton at cnort4@insightbb.com
- 11th - Metro disAbility Coalition Meeting; 3:15 p.m.**
Sat Urban County Government Center; Barrett Avenue; Louisville
- 20th - Derby City Chapter meeting; 6:30 p.m.; Frazier Rehab Institute.**
Mon 220 Abraham Flexner Way; Louisville; 10th Floor dining room.

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

An excerpt from New Mobility, September 2006
VENT USERS AT THE PERFORMING ARTS
By Paul Kahn

Many years ago, shortly after I had starting using a ventilator, I was sitting in my wheelchair near the back of a theater. As the lights dimmed and the play was about to start, a woman a few rows in front of me turned around and hissed angrily, "Who's snoring back there?"

The embarrassment of that moment has stayed in my mind ever since. Fortunately, in the close to 19 years I have been using a vent—now a Respi-ronics PLV 100—there haven't been many others like it. But the fact is, ventilators make noise. The air intake whooshes, and the safety alarm that triggers if the pressure in the system is too high or low or the battery fails, is very sensitive. The noise, except for the shrill alarm, isn't very loud, so in most circumstances, it doesn't matter. But in a concert hall or theater, where you're supposed to be quiet for the sake of the performers and the audience, it can still make me self-conscious and afraid of annoying people.

Other vent users have had similar experiences. Betty Laitinen from West Roxbury, Mass., who has muscular dystrophy and uses a Puritan Bennett LP-10, remembers being at a play when too much congestion in her airways made her ventilator alarm go off. "The timing was really bad because it was at the climax of the show," she says. "It was embarrassing. Now I'm tentative about going to shows and afraid that the alarm will sound and shock people." And Tedde Scharf of Tempe, Ariz., who also has muscular dystrophy and uses a Pulmonetic LTV 950, writes in Ventilator-Assisted Living, the newsletter of the International Ventilator Users Network, about going to a solo classical performance: "A fellow patron of the arts during intermission turned around, pointed a long, bony finger at me and said loudly, "YOU should not be allowed in this theater!"

As more of us with severe disabilities are living longer and better, thanks to lighter, more reliable ventilators, and other equally noisy respiratory equipment, such as oxygen tanks and concentrators, these unpleasant encounters are happening more often. They bring up some important questions. Whose rights should win out—the right of the equipment user to go to a cultural event or the right of the audience to enjoy the event undisturbed? What are the best ways that theaters can deal with these conflicts? What does the ADA say about this issue? What are the ventilator

manufacturers doing to solve the problem?

The ADA seems to provide general guidance but not much specific help about resolving the question of rights. Basically the law is supposed to make sure that people with disabilities have an equal opportunity to participate in any program or service and are not discriminated against on the basis of their disability. So, performing arts organizations have to make "reasonable accommodations" to the needs of patrons with disabilities. As Kathy Gips, director of training at the New England ADA Center says, "The concept of reasonable accommodations" is really critical because it requires businesses and organizations to be flexible in terms of what somebody with a disability needs. The balance to that is, if a policy, practice, or procedure is fundamental to the way an organization performs its mission, then it does not have to make a modification. This gets down to what level of quiet is essential to a performance. It's going to be different for a rock concert than it would be for a string quartet or a theatrical performance." Gips also makes clear that the noise made by life-sustaining equipment is a different issue than other types of noise, such as a barking dog. "Service animals that are not behaving are not OK. An animal has to be under control of its owner."

So far it seems nobody has brought a suit under the ADA for being denied access to a performance because of noisy respiratory equipment. Until there are some precedents established, she believes that "this is a topic that reasonable people could have very different opinions on."

Among people with disabilities there are two camps of opinion—the hard liners and the compromisers. Laura Hershey of Denver, Colo., who uses a Puritan Bennett KnightStar 330, is a typical hard-liner. She says simply and flatly, "Everyone has the right to be in public spaces, regardless of disability. Respiratory equipment y other disability-related should never ever be a reason to exclude people from attending concerts or shows."

Barbara Rogers of NY, who only uses a ventilator at night, is an example of a compromiser. "We have to temper our rights with just being good public citizens and neighbors. We have to be conscious of our neighbors' comfort. Some people feel that they are willing to make concessions, such as sitting in a separate area of the theater. I am not opposed to that," she says.

A few theater managers, who I won't name because their opinions weren't given in a public context, want to take this separation issue even further. At least one I know has recommended that patrons with "noisy respirators" be told that the attendance of ANY noise-producing equipment, animal or human being—like babies—at a performance involving sound would be

(Continued On Page Five)

VENTILATORS, CONT'D

unacceptable, and as such cannot be permitted." Her idea of a reasonable accommodation is a separate, soundproof or remote room with video and assistive listening devices. To me, lumping people with disabilities in with crying babies is incredibly insulting. And segregating us as though we were contagious is not much better. It might be true, as Barbara Rogers says, that "people pay good money to go out and get away from reality," but why should we give in to their prejudice? Another argument against separation is that it robs us of one of the unique things about live performance—its communal aspect. Sitting with hundreds of other people and laughing at the same jokes in a comic play, or being moved in similar ways by beautiful music, unites us human beings in a way we don't experience anywhere else, except in church, temple or mosque.

Luckily, there are many others in performing arts management who really want us to be audience members. The way they handle any complaints about the noise of respiratory equipment and I think this is best—is to move the person complaining to a different seat. Rae Atira-Soncea, accessibility coordinator at the Overture Center for the Arts in Madison, Wis., follows this practice and teaches it to a staff of 500 volunteers. "We train them to be very sensitive to the issues that come up and to be aware of each person's right to attend the theater with dignity and independence," she says. Sometimes equipment users feel uncomfortable and ask to be moved. If it is their idea, Overture staff will move them, "but we never ask them to move." Some theaters also try to sensitize performers. Deborah Knox, house manager at City Theater in Pittsburgh, says, "When I see a patron with any type of breathing apparatus, I simply tell the stage manager to alert the actors that they may see a light on a machine or hear a rhythmic sound."

The definitive solution to the problem of noise—quieter respiratory machines—lies with the manufacturers. Angela King, senior clinical director with Viasys/Pulmonetic systems, makers of the LTV ventilator, says, "We are continually striving to make our device quieter—and have been successful with our efforts." She also pints out that FDA regulations determine the volume of the alarms.

I think that the smaller, newer ventilators are actually noisier. The way to progress, Barbara Rogers says, "is to create a task force that would include the manufacturers. They are working more toward portability and medical outcomes rather than thinking about the social aspect of noise." I'm pessimistic about the manufacturers listening to us, because we don't have the clout of clinicians who prescribe the equipment, or insurance companies who pay for it. In the meantime, we can educate the public and figure out best practices allowing us all to live with it.

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 toppler; 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.*

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If you are interested in being a part of a story about young activists with disabilities, contact: Laura Kaminker, Associate Editor of Kids on Wheels at:
Laurakaminker@gmail.com or (212) 781-2238

Coming next month: "Ventilator-free Options"

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

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Membership is open to all individuals and sponsorship to all organizations interested in spinal cord injury.

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David Allgood
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