

◆ THE DERBY CITY NSCIA NEWSLETTER ◆

AUGUST 2009

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

Message From the President

Dear Members & Friends-

The August meeting will be held at Frazier Rehab Institute; 220 Abraham Flexner Way; Louisville; 11th floor, room number 1119.

In lieu of September's meeting we will have our annual picnic on September 20th at Camp Crooked Creek. Specific details are forthcoming in the next issue of this newsletter.

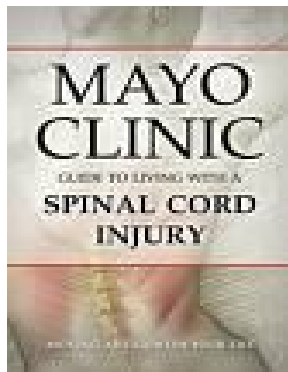
- David Allgood

Book Review from Internet—editor

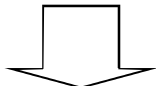
MAYO CLINIC GUIDE TO LIVING WITH A SPINAL CORD INJURY: MOVING AHEAD WITH YOUR LIFE

The multidisciplinary team of the Mayo Clinic Spinal Cord Injury Program offers accessible and well-illustrated advice to those who have sustained a spinal cord injury. Descriptions of the roles of members of the rehabilitation team and the effects of spinal cord injury comprise the opening chapter. Ensuing selections explore sexuality, fertility, overcoming limitations, and staying healthy. Skin care, home and car modifications, working with personal care attendants, and travel options are also covered. A return to work, resumption of favorite activities, and maintaining physical health and mental well-being is encouraged. A handy list of resource organizations and a glossary complete the content.

Verdict: A helpful, well-organized, reliable guide.



This book is now available at this site for \$13.46


<http://www.amazon.com/Clinic-Guide-Living-Spinal-Injury/>

All articles from the Internet. The one starting on the bottom of page three is condensed due to spacing issues –ed.

FIRST FULLY FUNCTIONAL QUADRIPLEGIC TO DRAG RACE BOAT

At the recent SDBA Nationals, Patrick Summerfield achieved another world's first by becoming the first fully functional spinal cord injury (SCI) quadriplegic in history to successfully race a drag boat. The drag run will be used to set a world water speed record. Mr. Rummerfield will also attempt a world record with electric aircraft.

In the sultry Texas heat, Mr. Rummerfield raced the Stock Eliminator class drag boat in front of a cheering crowd gathered at Marine Creek Lake in Ft. Worth, Texas.

Mr. Rummerfield was able to establish his newest world's first thanks to the support of Mike Albright, of Albright and Associates, in Odessa, TX, who made his "747 Wat'er the ODDS" drag boat available to Patrick.

"It's always an honor to go down in history as being part of the first time record," said Mr. Albright. "Since this was Patrick's first run we detuned the motor just a little to be on the cautious side. But after watching him at the starting line and through the run, we thought he was great—he raced like a pro! Pat is an inspiration to everyone!"

"I made it a point to ensure that my life's experiences are proof to those who are experiencing difficulties, that a 'can-do' attitude, determination, and an iron will plays a major role in going from the depth of despair to the feeling that the sky's the limit," said Mr. Rummerfield. "Every world's first is dedicated to those who never give up, to their friends and families, and to all those who support their efforts."

Mr. Rummerfield, who is rumored to be in talks with a car racing team for races in the NASCAR, ARCA, and ADRL circuits, navigated the drag boat at a speed around

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Refrigerator Calendar

***2009**

AUGUST

- 3rd - Elderly & Disabled Advisory Council Meeting.**
Mon 1:00 p.m.; TARC; 1000 W. Broadway; Board Room.
- 17th - Derby City Chapter SCIA meeting; 6:30; Frazier Rehab Institute**
Mon 220 Abraham Flexner Way; Louisville; Room 1119.
- 15th - Metro disAbility Coalition Meeting; 3:15 p.m.**
Sat Urban County Government Center; Barrett Avenue; Louisville

SEPTEMBER

- 7th - Elderly & Disabled Advisory Council Meeting**
Mon 1:00; TARC; 1000 W. Broadway; Board Room.
- 20th - Derby City Chapter SCIA picnic; Camp Crooked Creek**
Sun Details in next month's newsletter.
- 19th - 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

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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Visit Our Website at

www.DerbyCitySpinalCord.org

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to you through the generous support of Frazier
Rehab Institute**

QUAD TO RACE DRAG BOAT, CONT'D

65 mph. "Still quick for the water, but I'm sure he's going to go a lot faster!" commented Mike Albright.

Mr. Rummerfield commented that he will use this experience to prepare himself for the upcoming attempt at breaking another world record. Ed Dempsey, founder of Dempsey's World Record Associates (DWRA), is supporting Patrick's efforts by supplying the electric motors and running gear, and by modifying the boat that will be used by the DWRA race team to set the new world water record. Mr. Dempsey has also expressed an interest in developing an electric powered airplane to allow Patrick to take his electric racing records to the air.

"Can you imagine? A world record for speed in an electric vehicle set for land, water and air. This is what dreams are made of. This is what the American spirit is all about; you can't break it.!" commented Mr. Rummerfield, whose primary focus, when setting these records, is to bring awareness to the importance of activity based restorative therapy and paralysis research.

Patrick Rummerfield is the first fully functional SCI quadriplegic in medical history. Following a 1974 car accident that left him paralyzed from the neck down, Patrick entered an uncharted and grueling regimen of physical therapy and physical and psychological support. With sheer determination and iron will, Patrick regained function to his limbs, and went on to race marathons all over the world, including the Ironman Triathlon, the Gobi Desert march, and the Antarctica Marathon, to establish the FIA World Land Speed record on an electric car, along with 33 world firsts. Today Patrick works with the International Center for Spinal Cord Injury at Kennedy Krieger Institute and has co-founded Adventures on Wheels, a nonprofit organization developed to bring the world of adventure to those affected by spinal cord injury. Patrick is an accomplished motivational speaker and is in the process of writing his life story. For additional information visit Patrick Rummerfield's website at <http://rummerfield.homestead.com/>.

**PARALYZED WITH 7-14 DAYS TO DECIDE ON TEST
By Vanessa Flores, V.M.D., MA.**

In January 2009, Geron, a technology company located in Menlo Park, CA, got FDA clearance to inject spinal cells derived from human embryonic stem cells into paralyzed patients.

This is the first time a stem cell based therapy will be assessed objectively — that is, as part of a clinical trial — in human beings. As early as this summer, eight to ten patients with spinal cord injury will be selected to participate. This trial raises ethical concerns and USD phi

(Continued On Page Five)

The following articles are from the Internet—editor
“VIRTUAL LEGS” HELP TRAIN FIRST RESPONDERS AND SPINAL INJURY PATIENTS

A University of Utah invention stimulates walking and running in any environment while you see, smell, and hear everything around you. It's the work of university mechanical and computer engineers.

Inside a makeshift plywood room computers are interfaced with a robotic arm and harness, a unique wind tunnel, a six-by-ten foot treadmill and a three-sided screen take you any place you need to go.

“Here you don't even think about where you are stepping. You're totally focused on the environment and the experience you are having,” explains Dr. John Hollerback.

Emergency responders could soon use the simulator training to get a feel for like walking, running and side-stepping while monitoring the movement of toxic particles. Aromas will eventually simulate all kinds of smells.

The uniquely designed wind tunnel creates complex wind patterns that carry aromas moving in any direction or intensity, depending on where the user moves.

“We can actually change the wind angle in almost a hundred and eighty degree direction. This is the first time someone has built something like this,” Hollerbrook says.

The robotic arm pushes and pulls to simulate uneven terrain.

Victims of spinal injury going through rehab could also use this machine to experience what it's like out in the real environment, feeling sensations and knowing how the legs are performing.

Coordination training for rescuers, psychological studies, even learning how to walk on Mars; you name it, this device will take you there.

So far, the National Science Foundation has invested \$1.1 million in the project over the past 5 years. Neuroworx, a nonprofit clinic that specializes in rehabilitation for spinal cord injured patients, has already expressed a keen interest in the Utah invention.

Negotiations are also underway with another corporation which prefers to remain anonymous.

**OH
BOY!!**



philosopher Mary Devereaux led discussions about them at the Fleet Center and at the UCSD Medical School.

Prof. Devereaux brought several questions to the table. First, what makes getting an injection of spinal cells derived from human embryo different from, for example, an injection of bone marrow cells from a donor?

Second, given the physical and emotional trauma of patients recently paralyzed, can they fully grasp the risk they accept, when they agree to have Geron's spinal cells injected into their bodies? Third, does the Geron trial requirement for injection of the stem cell product within seven to fourteen days of injury raise further concerns?

The goal of embryonic stem cell research is to start out with a bank of cells that has the potential to grow or “differentiate” into almost any cell in the body and to orchestrate those cells to become one cell type, in this case, a cell found in the spinal cord, an oligodendrocyte. The job of oligodendrocytes is to provide support to neurons; they do so in two ways: produce molecular messengers that promote neuron health and myelin, an insulating material, that wraps the long fibers (axons) of neurons. Myelin allows neurons to conduct electrical messages speedily. In spinal cord injury, the loss of myelin contributes to loss of nerve function. The end result for many patients is paralysis.

Geron researchers have patented a way to differentiate human embryonic stem cells into oligodendrocyte progenitor cells. “Progenitor cells” are most of the way down the road to differentiation, they will complete the process once inside the body. Geron also holds a patent for manufacture of these cells into vials ready for distribution to hospitals and injection into patients. This population of living oligodendrocyte to progenitor cells makes up their “GNROPC1” product.

Geron is conducting a small trial in which GNROPC1 will be injected into the injury site of patients that have sustained spinal cord injury. The groundwork for this human trial is research conducted in rats in Prof. Keirstead's laboratory at the Reeve-Irvine Research Center. This research, partly funded by Geron, was published in 2005 in *The Journal of Neuroscience*. The Keirstead group severed the spinal cords of rats and then either seven days or ten months post-injury injected the injury site with GNROPC1. The rats injected at seven days showed improved locomotion; the rats injected at ten months did not. Eight weeks after injection, the rats were sacrificed and tissue slices of the spinal cord confirmed that the GNROPC1 cells had indeed completed differentiation into oligodendrocytes and, along with remyelinated axons, had filled the spinal defect. The spinal cords of the rats at ten months post-injury did not show remyelination.

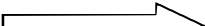
(Continued On Page Five)

7-14 DAYS TO DECIDE, CONT'D (& Under For Sale)

Up to seven U.S. medical centers, all referral centers for neurotrauma, have been selected to participate in the Geron trial. None of the locations have been announced and no patients have been injected to date. The patients who qualify for inclusion in this Phase I trial have functionally complete spinal cord breaks—in other words, waist-down paralysis. They will have GNROPC1 into the injury site within seven-fourteen days after injury. The aim of a Phase I trial is to establish safety of the GNROPC1 injection, not efficacy. These patients are not expected to recover the ability to move their legs because of this injection.

Blood and bone marrow cells are routinely harvested from donors for use in patients. Geron is able to manufacture cells that patients need. The donated cells differentiated inside a person as part of our biological development; the manufactured cells differentiated in a test tube using sophisticated technology. Does the origin of the cells make a difference?

Yes. First, products derived from embryonic stem cell banks may be contaminated with undifferentiated cells. This is because not every cell in a bank of stem cells that is induced to differentiate does. Second, of the cells that do differentiate, in vitro or “lab bench” observation reveals that some de-differentiate over time. This raises concern of future tumor growth at the product injection site since undifferentiated and de-differentiated cells retain/regain the ability to differentiate into any number of cell types. And this is a substantive difference and substantial risk unique to embryonic stem cell derived therapies.

In the case of GNROPC1, Keirstead’s study specifically looked for tumor formation and found none in the injected rats. The lack of tumors was attributed to Geron’s patented technology for producing “high purity” oligodendrocyte to progenitor cells. High purity, however, does not mean 100% oligodendrocyte progenitor cells make up the final product. Geron’s literature describes the product as a “cryopreserved cell population containing a mixture of oligodendrocyte cells progenitor cells and other characterized cell types.” There are other “characterized or contaminate cells in the product. The majority of cells in the product are oligodendrocyte to progenitor cells but will they remain so? Might some not revert? The technology for delivering a pure and definitively differentiated product simply does not yet exist. Eight weeks after injection the spinal cords of the sacrificed rats were tumor free. Is it reasonable to expect the same over the relatively lengthy lifespan of a human being? 

FOR SALE ***

2004 Buick Rendezvous CX, Gold Sport Utility 4D, AWD; 52,953 mi; seats 5—rear compartment contains Sonic scooter Bruno lift; new battery; numerous special features. \$8,800. Call Bryan Fantoni at 502-644-4446 or email at Bryan.Fantoni@mozlaw.com.

Easy Stand Glider 600; like new—barely used; allows transfer, stand and glider movement of legs. Paid \$6,000. Will sell for \$3,000. Call Shirley at 502/228-1271.

93” E150; EZ Lock WC System Elec. w/Quantum 600 wc/swivel captain’s chairs/3-way power driver’s seat/remote start burglar alarm/front-rear air/power wc lift/new upholstery. \$11,000, negotiable. **(502) 543-5948/(502) 773-2337.**

WC Lift; \$1,000; **Invacare Storm TDX 3 Power WC;** full reclining; less than 1 year old; \$1000; **Call David 588-8574.** **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.**

***Cookbooks for Sale:** Recipes compiled by Chapter members; \$10:00. Call David @ 585-8574.

***Video tapes for sale.** Various topics related to spinal cord injuries. Call David Allgood or Buddy Lawson.

♦ **SCI -Shirts for sale.** S, M, L, XL. David—589-6620.

****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.*

7-10 DAYS, CONT'D

Patients abruptly paralyzed are extremely vulnerable to discounting risks and to subscribing to false hopes in the immediate aftermath of injury. These patients might agree to almost anything offered by their doctor without full consideration of long-term consequences. Can these patients give meaningful consent to participate in a medical trial?

Patricia Duncan, Data Coordinator for the Shepherd Center in Georgia, a hospital specializing in spinal cord trauma, works on the frontline of patient recruitment for medical trials and reports success. When informed consent is secured over a period of days with the patient and the patient’s family told plainly that a medical trial is only one of many steps involved in finding a cure and that at this point there is no cure, then, in some robust patients, consent can be attained. Is this degree of understanding the risks possible within 7-14 days of injury? The time frame is created due to the possible formation of scarring and inflammation that forms within hours of injury, thus making rapid injection necessary.

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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