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# ◆ THE DERBY CITY NSCIA NEWSLETTER ◆

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MAY 2010

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

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## Message From the President

*Dear Members & Friends-*

*There will NOT be a meeting in April or May. Our next meeting will be the Kingfish dinner in June. See the June issue of this newsletter for details.*

*- David Allgood*

*From the Internet—ed.*

### **DRUG COULD STOP SPINAL INJURIES RESEARCHERS SAY**

Shutting off a single gene can help stop the cascade of damage that can paralyze people with spinal cord injuries, U.S. researchers reported on Wednesday.

They propose using a common, generic diabetes drug in combination with a gene-silencing technique to stop spine injuries from getting any worse, and believe the approach may also work in people with stroke and traumatic brain injuries.

Their experiment, published in the journal *Science Translational Medicine*, shows it is possible to stop the bleeding that can cause the damage from an injured spinal cord to spread and worsen.

"What we're doing is preventing bleeding from occurring," said Marc Simard of the University of Maryland, which has licensed the technology to a company Simard works with called Remedy Pharmaceuticals.

When the spinal cord or brain is injured, the capillaries can burst, bringing in an overwhelming wave of chemicals called inflammatory factors that are meant to heal but that often worsen the damage. This is why stroke patients do not always show immediate symptoms but can worsen in the hours afterwards.

Simard's team demonstrated that a gene called ABCC8 starts this process. It controls a molecule called the sulfonylurea receptor 1 or SUR1.

"It gets activated after an injury like ischemia (when blood vessels are blocked) or trauma," Simard said. Simard's team blocked this gene in mice and rats using gene-blocking therapy called antisense and showed that after a spinal cord injury, the damage and effects were much less without ABCC8.

They also tested the spinal cords of seven patients who died within five days of a spinal cord injury and showed the same gene was active. The next step is to try this approach in people, said Simard.

"I think we are pretty darn close to a clinical trial," he said in a telephone interview.

The antisense drugs are easy to make, he said. And the common diabetes drug glyburide blocks the destructive SUR1 protein made by the gene.

Remedy Pharmaceuticals is working to make an infused version of both drugs that could work together to block the gene and block the protein that the gene makes. Glyburide is already in Phase I safety trials for treating traumatic brain injury and stroke, Simard said.

"My hope is eventually you could get it into the ambulance," Simard added. He hopes there will be no side-effects from giving the drug, even to lightly injured people, so that ambulance workers could give an immediate infusion to anyone with apparent brain or spinal cord damage to stop the deadly cascade of damage.

The potential market is large. "Worldwide, the incidence of spinal cord injury ranges from 10 to 83 per million people per year," Simard's team wrote.

Many teams are looking for ways to prevent the early damage that makes brain and spinal cord injuries so devastating. A team has engineered an enzyme that can gobble up scar tissue formed after spinal cord injuries, and is working with Acorda Therapeutics to develop it.

**(Continued On Page Three)**

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# **Refrigerator Calendar**

## **2010**

### **MAY**

- 3rd  
Mon**      **Elderly & Disabled Advisory Council Meeting.  
1:00 p.m.; TARC; 1000 W. Broadway; Board Room.**
- 17th  
Mon**      **Derby City Chapter, Spinal Cord Injury Asso.  
NO Meeting in May.**
- 24th  
Mon**      **Metro disAbility Coalition Meeting; 3:15 p.m.  
Spalding University; 845 S. Third Street; Louisville**

### **JUNE**

- 7th  
Mon**      **Elderly & Disabled Advisory Council Meeting  
1:00; TARC; 1000 W. Broadway; Board Room.**
- 21st  
Mon**      **Derby City Chapter, Spinal Cord Injury Assoc.  
Dinner at Kingfish Zorn Ave in Louisville. Details in next issue.**
- 24th  
Mon**      **Metro disAbility Coalition Meeting; 3:15 p.m.  
Spalding University; 845 S. Third Street; Louisville.**

**For More Information Call**  
**David Allgood at 502-588-8574**

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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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NEWSLETTER STAFF**

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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**

**DRUG COULD STOP SPINAL CORD  
INJURIES, CONT'D**

Another team found last year that injecting tiny polymer spheres into rats right after spine injuries helped the animals recover movement and prevented secondary nerve damage.

Yet another group found last year that a common and safe blue food dye might block inflammation.

**HEALTH WATCH: PARALYSIS**

People who suffer a spinal cord injury often end up at least partially paralyzed. It used to be that they had little hope of walking again, but there have been huge strides made in getting paraplegics moving again.

Getting paralyzed patients truly up and walking on their own is still a ways off, but getting moving with the help of a variety of assistive devices is starting to happen right now.

Two years ago, Lainy Loyola was a 16-year-old cheerleader at Churchill High School. A high-speed, one car rollover accident a year ago changed her life. She was the passenger. "I don't remember my accident at all, but he lost control of the car and the car flipped four times and we were ejected out of the car," she said.

Lainy suffered a severe spinal cord injury and is paralyzed from the waist down. She uses a standing chair to help with bone density, muscle tone and blood pressure.

"There are so many health benefits by standing that we take for granted. And then just even walking, to be able to walk and get the blood circulating," said Susan Loyola, Lainy's mother.

Now Lainy is heading to Philadelphia to take part in a groundbreaking study. At Moss Rehab, she'll be helping to test ReWalk, the first commercially-viable upright device that allows paraplegics to stand and even walk on their own.

It's part computer, part robot.

At 18, Lainy is the youngest person and one of the first women to help test ReWalk. She sees it as the first of many steps to wholeness.

"I'm young and there's a lot of medical breakthroughs going on right now, a lot of studies. I really think I'll walk again," she said.

Lainy is heading to Moss Rehab next month where she'll stay for a couple of months. She knows it will be hard physical work, but she and her family feel like she might in on the beginning of something big. Even if it doesn't get her to walk again, the health and psychological benefits of being upright are significant.

*From NewMobility.com –editor*

**AUTOMATE YOUR LIFE**  
**By Justin Moninger**

Simplicity is not a word generally used to describe life in a wheelchair — or my career in technology — yet I find myself continually striving to simplify my life. My latest attempt is signing up for mail-order medications.

I tried Walgreens mail order a few months back and was completely frustrated. Despite the mail order business and pharmacy being part of the same company, the departments seemed to have little access to each others' records, couldn't figure out billing and just didn't send my medications a few times. So I gave up and resumed my monthly trek to the pharmacy.

Later, returning to my quest for simplicity, I fired up the laptop one Saturday morning and typed "online drug store" into Google, hoping to find a company that wasn't distracted by its brick-and-mortar business. Rather than do a bit of research or taking time to read customer reviews, I clicked on the first link that came up — [Drugstore.com](http://Drugstore.com). It has a cool tagline — "the uncommon drugstore" — and an overly cluttered site that made me feel just like being in an actual drugstore. The pharmacy button took me to a page displaying a person in a white coat, so of course I went ahead and signed up. Yup, I have a few advanced degrees in technology, several certifications, and I decide that a website is legitimate after about three clicks. I really need to include some sort of "don't use my methods at home" disclaimer with this column.

The signup process was not exactly self explanatory, but I muddled through. First, I added all my medications and saved them to my profile, after indicating I had insurance. Then I went to a different place on the site and entered in my insurance info, which they validated after three or four days. I proceeded to get a copy of my prescriptions from my doctor and mail them in as instructed. At this point I was having difficulty convincing myself this was going to be simpler than the local pharmacy, but I was already invested. After another week I received an e-mail saying my prescriptions had been accepted. I had asked my doctor for 90-day prescriptions at my last annual visit, thinking that made perfect sense since the bottle is always about 10 times bigger than it needs to be and I'm supposed to be on these pills for the rest of my life. However, apparently my insurance company only allows 30-day prescriptions. Boy, do I wish I could lower my ramp into the side of that insurance exec's Beemer.

When I logged in to pay my co-pay via credit card, I noticed that instead of the regular \$10 co-pay for each of my three medications, one costs \$21, the second costs \$8, and the other \$3. All are generics, so I have no idea what is going on there, but I'm not about to let the extra \$2 a month derail my quest for simplicity. Now the uncommon drugstore sends me very common e-mail invoices, shipping notices, and my meds in the mail dutifully each month. Now if I could just find a website that would pump gas for me every week.

With my newly acquired freedom from drugstore runs, I had time to play with a couple of useful new iPhone apps. The first is Dragon Dictation, which allows basic voice dictation to a text pad within your iPhone. The gratis price tag makes this a must-download, even for those with full hand function. After launching the app and dictating some text, you have the options to send the text to an e-mail, the clipboard or a text message. I particularly like it for composing a quick e-mail on the go and text messaging smack talk to my friends on game day.

Another free app recently launched by Logitech is the Touch Mouse. This basically turns your iPhone or iPod touch into a wireless touchpad for your Mac or PC. I wouldn't recommend it if you already have a mouse or trackball setup that works well, but if you have some hand function without shoulder movement, this app could be fantastic. It also works well as a wireless mouse on your home theater PC.

My new favorite website is [www.dropbox.com](http://www.dropbox.com). This is basically a personal file sharing site that allows you to sync up to 2GB worth of files between computers and mobile devices for free. This completely erases the need to fumble with a USB thumb drive - yes, more simplifying. Dropbox has lightweight apps for Windows, Mac, Linux and iPhone, along with Web access if you're using a friend's computer. It also eliminates the need to ever e-mail yourself a file — and everything is automatically backed up.



## A MOTHERS DAY TRIBUTE By Barbara Davis

In honor of the upcoming Mothers Day, I wanted to include a tribute to mothers with spinal cord injuries. Instead, I spent 2 hours searching the internet only to find voluminous scientific articles on pregnancy and SCI, and pages of articles devoted to quadriplegic parents –mothers and fathers—who are fighting for custody of their children just because they have a disability; not because they have done anything neglectful or abusive.

For many years I have worked with people with disabilities. Some of these were parents. Many of them displayed amazing adaptability and incredible love. There were also some who didn't know how to be a parent. As a result, there were issues that had nothing to do with the disability.

The able-bodied parent population also comes in those who know how to parent effectively and those who don't.

I would love to see the day come when I can search for tributes to disabled mothers and find some immediately. After all, the internet is loaded with Mothers Day tributes to able-bodied mothers.

It would also be wonderful if people would stop automatically assuming that a person with a disability cannot be a good parent because of the disability.

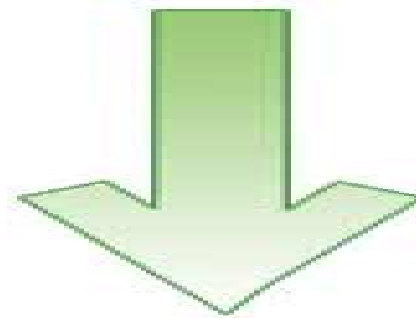
Being a good parent isn't about whether you have hands to change a diaper with. There are all kinds of adaptations for that and any other parenting task. Being a good parent takes love, maturity, responsibility and flexibility, among other qualities. Disabled people are totally capable of learning how to adapt the parenting tasks. They are equally capable of loving their children and keeping them safe, healthy and happy.

Children of disabled parents can and do grow up to be healthy, happy and well-adjusted. What better tribute is there that that?



*HAPPY MOTHER'S DAY!!*

## 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](mailto: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.

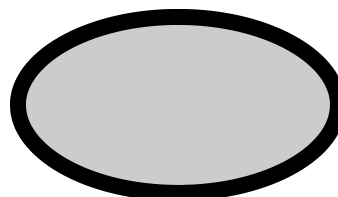
**93" E150; EZ Lock WC System Elec. w/Quantum 600 wc/swivel captain's chairs/3-way power driver's seat/remote start burglar alarm/front-rear air/power wc lift/new upholstery.** \$11,000, negotiable. **(502) 543-5948/(502) 773-2337.**

*\*\*\*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.*

**\*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.



*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: \_\_\_\_\_  
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 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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