

◆ THE DERBY CITY NSCIA NEWSLETTER ◆

AUGUST 2011

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

Message From the President

Dear Members & Friends-

Our August meeting will be held at Frazier Rehab Institute; 220 Abraham Flexner Way, Louisville, in the 10th floor dining room. Pizza and video will be provided.

WE WILL NOT HAVE A MEETING IN SEPTEMBER.

In lieu of our October meeting, we will have our annual picnic at Camp Crooked Creek on October 2. Details in next issues of newsletter.

- David Allgood

From NewMobility.com

PLANNING FOR SPONTANEITY

By Ian Ruder

At first glance the term “planning for spontaneity” makes as much sense as the latest guide to Medicare. In fact, “planned spontaneity” ranks right up there at the top of the list of most confusing oxymorons such as “deafening silence” and “jumbo shrimp.”

But if you bring up the concept with any wheelchair user, it’s likely that their eyes will light up with understanding. Almost every chair user has had a much-anticipated adventure or excursion cut short by something as simple as an unexpected staircase, an impassable road or a sudden health need. Without a chair, they’d be minor obstacles. With a chair they can kill the moment and bring a quick end to what could have been an adventure.

Gabby Richards has worked as a reporter and editor for the Washington Post and has traveled all over the world in her chair. In the 22 years since a car accident has left her a C5-6 quadriplegic, she has learned the keys to planning for spontaneity.

“It’s all about being able to plan but not boxing yourself in by that plan,” she says. “If you are able to plan for unexpected occurrences, then you are better able to respond to the unexpected. I plan as much as possible so that whenever the unexpected does happen and I want to be spontaneous, I am able to do that.”

Like many quads, Richard’s home schedule revolves around when her caregivers are coming. Because of her set schedule she has passed up invitations for late-night drinks and last-minute morning meetings. “It’s very difficult for quadriplegics in particular to be spontaneous,” she said. “In the morning I am locked into when my caregiver comes, so if somebody calls and wants to meet me earlier or something, I can’t do it because I know what time my caregiver comes and exactly what time I will be out of bed.”

Knowing her limitations, Richards says thinking outside the box is critical to taking advantage of opportunities for spontaneity. “It’s just a matter of being creative with things, of being realistic and planning like crazy, so when you get to where you’re going you will be able to do spontaneous things instead of feeling like you have to have everything planned out.”

Thinking creatively about ways to keep yourself healthy is one of the best ways to increase your ability

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Refrigerator Calendar

2011

AUGUST

**1st
Mon** **Elderly & Disabled Advisory Council Meeting**
1:00; TARC; 1000 W. Broadway; Board Room
(Note meeting is 2nd Monday due to 4th of July holiday)

**15th
Mon** **Derby City Chapter-National Spinal Cord Injury Association; 6:00 p.m.**
220 Abraham Flexner Way, Louisville, KY 40202; 10th floor dining room

**22nd
Mon** **Metro disAbility Coalition Meeting; 3:15 p.m.**
Spalding University; 845 S. Third Street; Louisville

SEPTEMBER

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

**19th
Mon** **Derby City Chapter-National Spinal Cord Injury Association; 6:00 p.m.**
220 Abraham Flexner Way, Louisville, KY 40202; 10th floor dining room
NO MEETING IN SEPTEMBER.

**26th
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

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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Contributor- David Allgood

Visit Our Website at
www.DerbyCitySpinalCord.org

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Rehab Institute**

PLANNED SPONTANEITY, CONT'D

to be spontaneous. Richards keeps drinking water with her whenever she is out and about. Keeping hydrated can be critical in staving off dysreflexia or UTIs, and you never know when a traffic jam might keep you in a locale longer than expected. Carrying extra cathing supplies is also a must, but some chair users take it a step farther, carrying extra antibiotics. One quad contacted for this story said he asked his doctor to prescribe extra antibiotics when he did have UTIs. Then he takes them on trips to nip nascent infections in the bud. Having antibiotics on hand can save 1-2 days of testing and feeling terrible, and can get you back in the swing within hours.

Google can be another time saver. As a freelance film and media consultant in Philadelphia, Matthew Clark is constantly traveling between some of the busiest metropolitan cities in the country. In addition to carrying bus maps, subway maps and always having multiple backup plans, Clark, who has lumbrosacral agenesis, previews areas he hasn't visited using Google street views to check for any obstacles. "It's probably not how they envisioned anyone using it," he says, "but it really helps with the chair."

Having a flat kit with him at all times has also proved useful. He added the kit to his repertoire after a summer of clubbing where he endured 3 flats in rapid succession.

Clark, 29, says he used to be frustrated about having to call ahead to ask about accessibility or special accommodations, but has found a more relaxed approach to be advantageous. "There are time for social protest, but sometimes you just want to go out and have a good time with friends," he says. "If I'm not able to roll with it, I could sit around writing letters and being pissed off for the rest of my life and not have to worry about going anywhere."

Kelsey Little, 23 and a paraplegic, advises traveling with a good friend who knows your needs and will fight for your rights. She says her friends often throw her on their backs and carry her places she wouldn't otherwise be able to go. If you're willing to live in the moment like that, she says the chair can sometimes help you get in places you might not otherwise have been able to. "All you got to do is be a strong person and talk a bunch of mumbo jumbo to people and mention the ADA and lawsuits and

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PLANNED SPONTANEITY, CONT'D

people will let you by," she says. "All you have to do is let them think you know more than they do."

This approach paid huge dividends on a recent trip to Las Vegas. Over a discussion on access, Little defended some of the bouncers and they quickly became her personal escorts through some of the craziness that is late-night Las Vegas. "They escorted us anyplace we wanted to go," she says. "They would let us in through a special gate and we didn't have to pay."

Chair users traveling abroad can face a whole set of obstacles impeding their ability to be spontaneous. Not knowing the language or the customs can seem like minor inconveniences when travelling in countries without curb cuts, sidewalks, or, in some cases, even a concept of accessibility.

As the vice president of marketing for wheelchair manufacturer TiLite, Josh Anderson has travelled everywhere from Dubai to China to South America and back in his chair. His advice on international travelling is simple: "It starts getting frustrating if you compare every place you go with where you live," he says. "My whole thing is, it's an adventure, every part of it is an adventure, so just figure it out. I don't find that there are a lot of things you really need to have, but it's good to kind of think about where I'm going and what I'm going to do and go for broke."

After staying in a room where he had to transfer to the floor and crawl to the bathroom on one trip abroad, one thing Anderson always does is call hotels he's booked in to find out about access. "Typically if I call there are some more accessible rooms than others, though they're not necessarily accessible by U.S. standards," he says.

Simple things you wouldn't do at home, like adding retractable push handles to your chair or carrying extra tubes and patch kits can make all the difference when it comes to sizing opportunities abroad. "For somebody who is in a chair, adaptation is a part of everyday life, so why not carry that over into your travel?" he asks.

For Richards, that adaptation takes the form of giving up her power chair for a manual chair with airless tires when she travels to Europe. While the manual chair takes away some independence, it al-

lows her to cope with nonexistent curb cuts, cobblestone roads and unexpected stairs. She says that modern technology can give chair users a wheel up on their pre-planning efforts. "The internet is one of the greatest resources for a person with a disability because you can Google anything and you'll either find somebody who has done whatever you're going to be doing before you, or you can connect with people who are going to," she says. Thanks to Google, Richards knows that when she gets to the ruins at Ephesus in Turkey this summer she'll need to find "two hunky Turkish men" to carry her up a set of stairs.

"What's cool about travelling is that I've never been anyplace where people weren't willing or overly willing to help you," Anderson says. He has had Chinese tourists carry him to the top of the Great Wall and had Hungarian business partners carry him all around a boat on a business cruise. "We actually had a great time," he says, "but if I look at it from the standpoint of 'I can't get around here anywhere by myself,' it probably would have put a sour taste in my mouth."

No amount of preparation or planning can change the fact that you are in a chair, but the right attitude and a few hours spent researching where or what you want to do can make a huge difference in how much you can enjoy your life.

**DISABILITY MENTORING DAY (DMD)
OCTOBER 19, 2011**

CENTER FOR ACCESSIBLE LIVING IS NOW TAKING CALLS FROM THOSE WISHING TO SHADOW A MENTOR FOR DISABILITY MENTORING DAY. THIS IS AN EXCELLENT CAREER-EXPLORATION OPPORTUNITY FOR THOSE WHO HAVE NEVER WORKED OR FOR THOSE WHO SEEK A CAREER CHANGE DUE TO DISABILITY. IF YOU ARE INTERESTED IN PARTICIPATING IN THIS 2-HOUR MORNING EVENT, CONTACT LARRY HOSEY AT 502-589-6620. FOR MORE INFORMATION ON DISABILITY MENTORING DAY VISIT www.calky.org.

From Foxnews.com

FEDERAL JUDGE TOSSES OUT SUIT OPPOSING OBAMA FUNDING OF STEM CELL RESEARCH

A law suit that had threatened to end the Obama administration's funding of embryonic stem cell research was dismissed Wednesday, allowing the U.S. to continue supporting a search for cures to deadly diseases over protests that the work relies on destroyed human embryos.

The lawsuit claims that research funded by the National Institutes of Health violated the 1996 Dickey-Wicker law that prohibits taxpayer funding for work that destroys an embryo. But the administration allows research on embryos that were culled long ago through private funding.

U.S. District Judge Royce Lamberth, chief of the federal court in Washington, last year said the lawsuit was likely to succeed and ordered a stop to the research while the case continued. But under swift protest from the Obama administration, the U.S. Circuit Court of Appeals here quickly overturned Lamberth's injunction and said the case was likely to fail.

Lamberth said in his opinion Wednesday that he is bound by the higher court's analysis and ruled in favor of the administration's motion to dismiss the case.

"This court, following the D.C. court's reasoning must find that the defendants reasonably interpreted the Dickey-Wicker Amendment to permit funding for human embryonic stem cell research because such research is not 'research in which a human embryo or embryos is destroyed,'" Lamberth wrote.

Researchers hope one day to use embryonic stem cell research in ways that cure spinal cord injury, Parkinson's disease and other ailments. Opponents of the research object because the stem cells were obtained from destroyed human embryos.

Proponents say the research cells come mostly from extra embryos discarded anyway by fertility clinics.

President George Bush also permitted stem cell research, but limited the availability of taxpayer funds to embryonic stem cell lines that were already in existence and "where the life and death decision has already been made." Obama's order removed that limitation, allowing projects that use stem cells

(Continued Under For Sale)

FOR SALE ***

2003 Dodge Grand Caravan; excellent condition—well maintained. 10 inch lowered floor, side entry ramp; removable power driver and passenger seat; multiple securement positions. \$11,900. Call David Allgood @ 550-272.

***If assistance is needed to pay for any items **ABOVE** in *For Sale* contact KY Assistive Technology Loan Corporation at 1-800-327-5287 for information on 5% interest loans 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 at 588-8574.

♦ **SCI -Shirts for sale.** S, M, L, XL. David—588-8574.

***IF YOU HAVE ITEMS FOR SALE,
PLEASE CONTACT DAVID
AT 588-8574 OR EMAIL BARB DAVIS AT
davis.barbara33@gmail.com***

JUDGE TOSSES SUIT, CONT'D

that have already been destroyed or are to be destroyed in the future.

To qualify, parents who donate the original embryo must be told of other options, such as donating to another infertile woman.

The Obama administrations rules expanded the number of stem cell lines created with private money that federally funded scientists could research, up from the 21 that Bush had allowed, to around 100 so far.

The lawsuit was filed in 2009 by two scientists who argued that Obama's expansion jeopardized their ability to wind government funding for research using adult stem cells—ones that have already matured to create different types of tissues—because it will mean extra competition.



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: () _____
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 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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