

## Madison's Spinal Cord Injury Group - We Plan, We Go, We Conquer!

### **Know an Organization: The Bryon Riesch Paralysis Foundation**

by Monica KamalRossa

Do you have family members, friends, and companies who want to support an organization that wants both to help individuals affected by neurological disorders and to support research for solutions? Then here is an organization for you to consider!

**Mission Statement:** The Bryon Riesch Paralysis Foundation's goal is to find a cure for paralysis through funding the latest in medical research and to provide assistance to those that suffer from neurological disorders.

his arms. In order to assist Bryon and his family through a difficult time, friends and family quickly pulled together to help with a fundraiser. Those same individuals have now helped to form the Bryon Riesch Paralysis Foundation (BRPF) to help others faced with a similar situation.

Established in January of 2001, the BRPF is a 501(c)3 that has utilized the tremendous support and community reaction that was demonstrated after Bryon's injury.

**Reasons for Hope:** By supporting some of the brightest scientific minds of today, advances are happening faster than ever from therapeutic vaccines to axonal regeneration, stem cell transplantation to exercise and treadmill studies. All of these move the scientific community closer to finding a cure for paralysis. However, without funding, even the most promising research will not lead to a cure for paralysis. Today, the need for donations are needed more than ever. To learn more about fundraisers or to make a donation to BRPF go to: [www.brpf.org](http://www.brpf.org)

### In This Issue

Raised Garden	2
LVM Dreams Big Playground	3
Conference on Adaptive Rec	4
Adaptive Kayaking	4
Upcoming Events	5
Race Info	6
Adaptive Tech	7
SCI Group Info	8
Calendar	9

**Getting Help:** Do you have a medical equipment need that insurance can't pay for but you really need? Here is a link on how to apply for a charitable grant: [www.brpf.org/Grants.htm](http://www.brpf.org/Grants.htm)

Are you a student with a neurological disorder or a parent with a neurological disorder who has a child working towards an advanced degree? Check out scholarship opportunities at: [www.brpf.org/scholarships.htm](http://www.brpf.org/scholarships.htm)



Jennifer Addis, Bryon Riesch, our own Mike Mohr, and Monica KamalRossa at the 10<sup>th</sup> anniversary of the foundation. It is wonderful to have an organization that supports our local Madison members. **Thank you!**

**The Story:** On April 25, 1998 the life of a Marquette University student, Bryon Riesch, changed forever. A devastating accident left Bryon paralyzed from the chest down, with limited use of

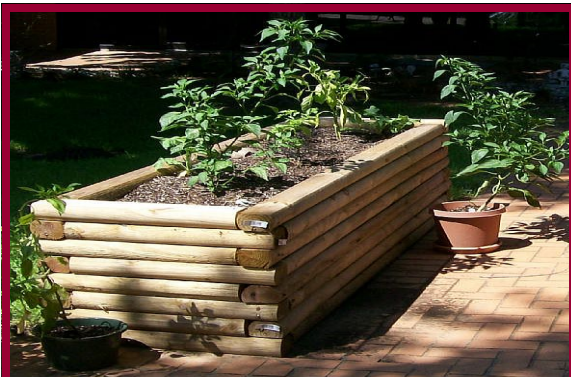
## Raised Garden Beds Lift Spirits for Those Of Different Abilities

By Kurt Christensen

Judy Reed, principal of Dane County Transition School (DCTS), decided to create her own version of "Pay It Forward". She visualized a project that could teach her students new skills while giving back to the community by benefiting others in need of services. Judy's kids, ages 14-19 years old, come from all parts of Dane County. They are students who are at risk of not graduating from high school. The Dane County Transition School is supported by charitable contributions throughout the community.

The project involved building raised garden beds which make gardening accessible to individuals who have difficulty reaching the ground. Students learned practical skills of carpentry and mathematics by building wooden garden boxes. They started with six 4' x 4' garden boxes which were divided up into four 1 ft. square areas to separate plants and to keep everything simple. The raised garden boxes are accessible to Madison Spinal Cord Injury group members who also use wheelchairs and experience physical challenges when gardening.

Realizing the health benefits of growing and eating organic fresh vegetables was another inspiration for this sustainable project.



A different style of a raised garden bed

Much of the produce grown will be given to the local food pantry and Second Harvest, thus continuing the "Pay it Forward" benefit to others in our community.

Kurt and Susan Christensen donated their time and land for this project. Kurt is a quadriplegic and knows firsthand the importance of getting out in nature, eating



The kids from DCTS and Kurt building the garden boxes.

organically, breathing fresh air and staying active especially for people in wheelchairs. Wes Pulver, Kurt's caregiver, was instrumental in working with these kids and showing them how to work with their hands.

Anyone interested in learning more about organic raised garden beds should pickup a copy of Square Foot Gardening by Mel Bartholomew. If you would like more information on this wonderful project, please call Kurt Christensen at (608)852-6853.

## Fore Friends Golf Outing

The fifth annual golf outing benefits the Friends of MSCR. They are dedicated to helping MSCR in providing recreation & enhancement opportunities accessible to all.

**When:** Friday, July 17, 2009 at 2pm

**Where:** Yahara Hills Golf Course

\*Registration at 1pm; 2pm shotgun start; 5:30pm cash bar, dinner, silent auction & awards. For details call (608) 204-0557 or email [Ichaffin@madison.k12.wi.us](mailto:Ichaffin@madison.k12.wi.us)

## ***LVM Dreams Big* - First Boundless Playground in Wisconsin**

A small group of parents set out to build a playground where all children and adults, regardless of physical ability, could play side by side. *LVM Dreams Big* made this a reality in an extraordinary community project at Elvehjem Elementary School.

Kelli and Joel Betsinger became aware of playground issues when their son, Noah, who uses a wheelchair, began at Elvehjem. The school was accessible; however, the playground had very little that kids with physical disabilities could play on or even reach. Since then, the *LVM Dreams Big* movement has grown into a full-blown boundless playground.

Since 2005, a committee worked to raise funds for improving accessibility, promoting physical fitness and increasing safety for all children. Through monthly family events, grants, and business and community leader support, the first boundless play structure in Wisconsin was completed in August 2008 opening the world of play to all children and families with disabilities.



Brad Dakan (far left) and his son, Tony, are able to play side by side on a playground for the first time since Brad's spinal cord injury.

Help raise funds for maintaining the playground. To make donations go to: [www.playgroundsupport.com](http://www.playgroundsupport.com) or send questions to Kelli Betsinger at [LVMDreamsBig@yahoo.com](mailto:LVMDreamsBig@yahoo.com). Donations may also be made by sending checks payable to: Foundation for Madison's Public Schools, attn: LVM Dreams Big (in memo line) and send to 455 Science Drive, Suite 130, Madison, WI 53711.

### **Volunteers Needed**

By M. KamalRossa

After doing a presentation for Kiwanis West, I am proud to say that Kiwanis West is interested in helping our Madison SCI Group by having volunteers available for helping with handcycling, our picnic, kayaking or some of our other outings. We need to give them enough notice to coordinate with them. If you have an outing you are organizing and need able body volunteers, send an email to [Monica@SCI-Madison.org](mailto:Monica@SCI-Madison.org) with dates and times and approx. number of volunteers needed. If you are interested in volunteering or know of an organization that may be interested in helping us out, please contact me. We need help with transfers and a variety of other things.

Thanks to all of the volunteers that have helped us in the past!

# ADAPTIVE RECREATION AND SPORTS

## Creating a Conference Promoting Adaptive Recreational Pursuits

By Jim Hamre

An idea is blooming to design a conference that will bridge the gap between adaptive recreation and persons with a disability. The development and facilitation of this conference will be conducted by a committee of disabled individuals who have experienced the benefits of adaptive recreation. The target audience for this conference are the

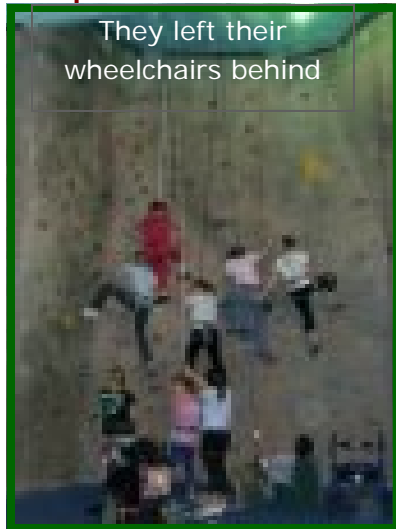
health and human resource professionals who work with clients who have a disability. The goal is to provide these professionals with the resources for connecting their clients to the world of adaptive recreation and sports.

Conference objectives include educating professionals on the benefits adaptive

recreation has on a person with a disability, how to locate opportunities and resources, and how to break through barriers that prevent their clients from participating in activities. It's important at this stage to gather ideas and experiences from our community of disabled individuals who incorporate recreational activities into their lives.

What are we asking for? We need individuals now to be part of a steering committee which will brainstorm ideas that will guide us in creating this conference. Who better knows how to address the needs and desires of folks that are disabled than those who live it everyday!

Any type of involvement is welcome. The projected date for this conference is in the spring of 2010. If interested, please email Jim Hamre at [jameschamre@verizon.net](mailto:jameschamre@verizon.net)



They left their wheelchairs behind

## DNR Adaptive Kayaking Opening the Outdoors to People with Disabilities

by Andy Janicki

For individuals with mobility impairments, the Wisconsin Department of Natural Resources now offers a unique way to experience the outdoors. Buckhorn, Devil's Lake, and Mirror Lake State Parks have specialized kayaks available exclusively for persons with disabilities.

The adaptive kayaks are equipped with adjustable outriggers which provide incredible stability on the water and a



raised back with side supports that offers a comfortable and secure seat while paddling. Also, there are paddles with hand adaptations to assist persons with limited hand

grip. All of these resources can be adjusted or removed depending on the paddler's level of function.

Whether you kayaked prior to a disability or haven't had an opportunity to try it due to an injury, we encourage you to go to one of these state parks and give it a try!

## GET OUT...MEET GREAT PEOPLE...HAVE FUN!

### Free Canoe & Pontoon Rides with MSCR

**When:** Fourth Sunday of the month -  
June 28, July 26, August 23, and Sept. 24

**Times:** 10am, 12pm, 2pm, 4pm  
(1½ hour boat rides or paddling)

**Where:** Tenney Park, (1500 Sherman Ave,  
Madison)

\*No registration required. Arrive 15 minutes before departure time to increase chance of securing spot on pontoon or in canoe. For more info see [www.MSCR.org](http://www.MSCR.org)

### SCI Group 2nd Annual Picnic

Come join us & meet the members of our group at our 2nd annual group picnic. Bring your family and enjoy good conversation, games & food! This is a potluck so bring a dish to pass & your own beverage.

**When:** August 30, 2009, 11am - 3pm

**Where:** McKee Farms Park, 2930 Chapel Valley Road, Fitchburg

Please RSVP to: [info@SCI-Madison.org](mailto:info@SCI-Madison.org)

### Madison Achilles Track Club

Achilles is an international group created to enable people with all types of disabilities to participate in mainstream athletics, promote personal achievement, enhance self esteem and lower barriers. Our Madison group meets weekly for walking/wheeling workouts. Checkout their blog by going to <http://achillesland.blogspot.com>

**When:** Thursdays from 5:45pm - 6:45pm

**Where:** Outside at Fleet Feet (8440 Old Sauk Road, Madison) \*rain days at Westgate Mall (corner of Odana Rd & Whitney Way)

For more details, call Kim at (608)444-9424.

### Hand Cycling

Adaptive Adventures & the SCI-Madison Group invite anyone interested in hand cycling to join us! Experience hand biking on some of our area's beautiful bike trails with lunch afterwards.

**When:** Friday, July 24 & Friday, Sept. 18

**Where:** Meet at a picnic area along a bike trail outside Madison (location & time TBA)

To register, contact Dawn at (608) 833-9453 or email at [dziegler222@aol.com](mailto:dziegler222@aol.com)

### Wisconsin State Fair

NSCIA needs volunteers to help at the wheelchair, stroller, & scooter rental tents. You get free parking and free admission to the Wisconsin State Fair!

**When:** August 6 - 16, 2009

**Where:** Wisconsin State Fair, Milwaukee

**Shifts:** 7:30am - 12pm, 11:45am - 4pm,  
3:45pm - 8pm

Contact Valerie Schwalbe at 414-384-4022 or [Volunteers@spinalcordwi.org](mailto:Volunteers@spinalcordwi.org)

### SCI Group Book Club

Members of the SCI Group started a book club and want to invite anyone interested to join them. All books selected are available on CD or tape. Suggestions welcome!

**When:** 3rd or 4th Wednesday of the month

**Time:** After 1pm

\*Meeting place varies

For questions or more information, email Sandy Y. at: [youngsandradee63@yahoo.com](mailto:youngsandradee63@yahoo.com) or Liza P. at: [Imp9107@yahoo.com](mailto:Imp9107@yahoo.com)

# RACE ON!!!

## The Wheels & Heels 5K Race

The National Spinal Cord Injury Association's S.E. Wisconsin Chapter (NSCIA/SWC) created the *Wheels & Heels 5K Race* to help raise awareness and research money. A good portion of the proceeds will be given to research on finding a cure for paralysis.

In their 22nd year, the *Wheels & Heels Race* takes place on the opening night of *Festa Italiana*. All participants receive free admission to *Festa Italiana*! Following the 5K race will be the popular "Chariot Race" where able bodied corporate or community teams of four use wheelchairs in a timed relay race.

**When:** Thursday, July 16, 2009 at 6:00 PM

**Where:** Milwaukee's Lakefront

**Fees:** \$17 for 5K/1 Mile Walk, \$50 family, \$250 for Chariot Race (fees increase after 7/9, registration closes July 13, 2009, 4pm)

For details, to register, to learn more about the NSCIA-SWC, or to make donations go online to [www.spinalcordwi.org](http://www.spinalcordwi.org)

## Hope & Possibility 5K Race

Our Achilles Club is hosting Madison's first Hope & Possibility Race! This race is named after the personal memoir, "I am the Central Park Jogger: A Story of Hope & Possibility" written by Trisha Meili. The race signifies the enduring hope and endless possibility that exists in all of us! Mary Bryant, VP of Achilles NYC, and Trisha Meili will be here. Special categories available for disabled athletes.

**When:** Sunday, July 26, 2009 (registration at 11am, 5K race & 1mile walk start at 1pm)

**Where:** Capital Square, Madison, WI

\*Start line at corner of State St. and E. Mifflin. 5K course is 5 laps around the Capital Square.

**Fees:** \$20/adult, \$10/child (\$23/adult, \$13/child after July 19, 2009)

For more information contact Dawn Ziegler at [dziegler222@aol.com](mailto:dziegler222@aol.com) or (608) 833-9453.

To register online, go to [www.active.com](http://www.active.com)

To volunteer at the race, email Monica KamalRossa at [Monica@SCI-Madison.org](mailto:Monica@SCI-Madison.org)

## THE MADISON MARATHON....A Day for Breaking Personal Records!

By Dawn Ziegler



The Madison Marathon was held on Sunday, May 24, 2009. The conditions couldn't have been better....sunny, temps in the upper 60s, slight winds, and the World's Largest Brat Fest waiting at the finish.

This year three of our Madison Achilles athletes competed in the marathon. All three competed in their first marathon last November in



New York City. Here in Madison, on a much hillier course, they each set new personal records!

Kathy Ducat, who has a visual impairment, finished in 5hr 47min (NY 6:01). In Madison's first hand cycle division, Brad Dakan finished in 2hr 35min (NY 3:27), and Monica KamalRossa finished in 2hr 48min (NY 3:07).



We look forward to seeing what each of these amazing athletes accomplishes next! Terrific effort by all!!!

## ADAPTIVE TECHNOLOGY

### Information Technology Research Participants Wanted

The Trace R & D Center is a research and development center at the UW-Madison. They are looking for individuals who have physical disabilities to participate in a study for evaluating usability of technology. You will be asked to visit the University of Wisconsin on up to four separate occasions. You will be compensated at a rate of \$15.00/hour and will receive a \$50 bonus for completing all sessions. You will also be paid for transportation costs incurred traveling to or from study location (bus fare, car mileage at 33 cents per mile or local taxi service if required). Travel time is included in the hourly rate.

If you are interested in making information technology devices more accessibly, please contact them at: 608-263-1156 or email at [tracestudy@trace.wisc.edu](mailto:tracestudy@trace.wisc.edu)

### Mechanical Engineering Students Team Up with SCI Group for Their Semester Projects

Every year, UW Prof. Jay Martin challenges his senior ME students to design and develop projects that would enhance a person's quality of life. This past fall and spring semesters, a group of ME students collaborated with our SCI group on several project ideas. Projects that were completed were displayed at the UW's Engineering Technology Fair.

We are looking forward to working with the ME students again this fall. If you have a problem or idea that you would like to present to the ME students for possible consideration, come to our September SCI group meeting or write to: [info@SCI-Madison.org](mailto:info@SCI-Madison.org)

### Chicago Abilities Expo

The Abilities Expo is the leading event for 54 million Americans with disabilities, their caregivers, healthcare professionals and corporate ADA/HR administrators. The Expo highlights the latest in life-altering technologies, products and services designed to meet the daily challenges of people with disabilities.

The 2009 Chicago show offers all of the expo favorites combined with some new professional conferences and educational seminars. Enjoy free, fun, and informative workshops that focus on everything from disability-friendly travel to low-cost home modifications to tips on how to get the best accessible vehicle. Demonstrations highlighting the hottest products will take place throughout the three day event.

**When:** June 25-27, 2009

**Where:** Schaumburg Convention Center (Schaumburg, IL)

**Admission:** Free for people with disabilities, their families and caregivers

For details, call (310) 450-8831 x130 or go to: [www.abilitiesexpo.com](http://www.abilitiesexpo.com)

The SCI newsletter is published quarterly (January, April, July, October). Copies of most articles, event details, product descriptions, and organization information can be viewed in full by going to [www.SCI-Madison.org](http://www.SCI-Madison.org).

To submit an article, promote an event or product, or place an advertisement, contact Dawn Ziegler at 608-833-9453 or email both [Dawn@SCI-Madison.org](mailto:Dawn@SCI-Madison.org) and [info@SCI-Madison.org](mailto:info@SCI-Madison.org)

# SCI-MADISON GROUP INFO



Just a sample of the members in our SCI group!

## **CONTACT INFO**

### **Madison SCI Coordinator:**

Monica KamalRossa,  
Monica@SCI-Madison.org

### **SCI web site:**

[www.SCI-Madison.org](http://www.SCI-Madison.org)

### **To join the SCI group:**

Simply join us online or attend one of our meetings or events.

### **SCI Forum:**

[www.SCI-Madison.org](http://www.SCI-Madison.org)  
Click on *Our Forum*

### **SCI email Yahoo group:**

[www.SCI-Madison.org](http://www.SCI-Madison.org)  
Click on *SCI-Madison Yahoo group*

### **Newsletter:**

Contact Dawn Ziegler at 608-833-0453 or email both Dawn@SCI-Madison.org or info@SCI-Madison.org

### **Website & Forum updates:**

Email Monica@SCI-Madison.org

## **SCI Group & Meeting Information**

Madison's Spinal Cord Injury Group started in November 2006. Our objectives are to: provide an open forum for discussion on spinal cord injury, disease, & paralysis issues; provide mentoring & awareness; offer adaptive & accessible events & activities for the individual & their family; and have FUN! We always welcome new members & sponsors to our group.

Our group members plan many accessible activities to participate in together including: kayaking, hand biking, bowling, golfing & fishing to name a few. We also enjoy meeting at the Memorial Union, Concerts on the Square, book club discussions, picnics, & movie nights. Our members' diverse backgrounds bring a lot of personality & friendship to our gatherings. Join us and add to the great character of this group!

Meetings are held on the second Monday of every month. Spouses, family members & caregivers are welcome! **Meetings are 5:30 - 7pm at the Fitchburg Community Center, Stoner Prairie Room (lower level - enter in back), 5510 Lacy Rd, Fitchburg, WI.** Topics are confirmed one month in advance. If you have a topic or speaker you would like to introduce, contact Monica KamalRossa at 608-288-0340 or email Monica@SCI-Madison.org.

## **Thanks to Our Most Recent Speakers**

\*Dr. Margie Wilsman of Springdale Yoga ([www.SpringdaleYoga.com](http://www.SpringdaleYoga.com), 608-437-4082 ), for presenting May's topic on "Yoga Breathing".

\*Janet Estervig, RN, Director of Personal Care Services (608-242-8335 x3206) and Theresa Fishler ([fishlert@clanet.org](mailto:fishlert@clanet.org) or 608-242-8335 x3118) at Community Living Alliance, 1414 MacArthur Road, Madison, Wisconsin 53708-8028.

\*Dr. Judy Davis (608-241-2004), for her discussion on "Body posture and nutrition" at the February meeting. She is with Accent On Health Chiropractic, 4237 Lien Rd #J, Madison, WI 53704.

\*Liam Martin (<http://stemmidwest.org/>), for presenting "What is the STEM project at UW-Madison?"

\*UW-Madison Prof. Jay Martin ([martin@engr.wisc.edu](mailto:martin@engr.wisc.edu)) and his Mechanical Engineering students for their time and energy in discussing and developing their group projects.

\*Mary Ridgely, for her presentation on "Going back to work and benefits".

\*Kris Eiring, Ph.D., Licensed Psychologist, for her presentation on depression.

\*Dr. Perez on his discussion on pain management.



**SCI GROUP PICNIC  
(potluck style)**

**Sunday, August 30, 2009  
11am - 3pm**

**McKee Farms Park  
2930 Chapel Valley Road  
Fitchburg**

**Please Join Us!!**

**RSVP by sending an email  
to [info@SCI-Madison.org](mailto:info@SCI-Madison.org)**

**Seeking More Accessible  
Activities & Events?**

**Go To:**

**Achilles Track Club:**  
Kim at 608-444-9424 or  
[achillesland.blogspot.com](http://achillesland.blogspot.com)

**Adaptive Sportsmen:**  
[www.adaptivesportsmen.org](http://www.adaptivesportsmen.org)

**MSCR:**  
[www.mscr.org](http://www.mscr.org)

**NSCIA-SW Chapter:**  
[www.spinalcordwi.org/  
events.html](http://www.spinalcordwi.org/events.html)

**Rutabaga Outdoor Programs:**  
Nancy at 608-223-9300 x225  
or [nancys@rutabaga.com](mailto:nancys@rutabaga.com)

**Wilderness Inquiry:**  
[www.wildernessinquiry.org/](http://www.wildernessinquiry.org/)

# CALENDAR OF EVENTS

## June

- 25-27 Chicago Abilities Expo (Schaumburg, IL)
- 28 Pontoon & Canoe rides with MSCR (Tenney Park, Madison)

## July

- 13 **SCI Group meeting** (Topic - Travel tips from SCI members)
- 16 Wheels & Heels 5K Race (Milwaukee Lakefront, Milwaukee)
- 17 Fore Friends Golf Outing (Yahara Hills Golf Course, Madison)
- 24 Hand biking with Adaptive Adventures & Madison SCI Group
- 26 Hope & Possibility 5K Race (Capital Square, Madison)
- 26 Pontoon & Canoe rides with MSCR (Tenney Park, Madison)

## August

- 6-16 Wisconsin State Fair (NSCIA - Milwaukee, WI)
- 10 **SCI Group meeting** (Topic - Pressure sores, burns, & other injuries)
- 23 Pontoon & Canoe rides with MSCR (Tenney Park, Madison)
- 30 **SCI Group Annual Picnic** (McKee Farm Park, Fitchburg)

## September

- 14 **SCI Group meeting** (Topic - UW Madison Mechanical Engineering student project discussion)
- 18 Hand biking with Adaptive Adventures & Madison SCI Group
- 24 Pontoon & Canoe rides with MSCR (Tenney Park, Madison)
- 26 NSCIA Annual Picnic (<http://spinalcordwi.org/events.html>)

## October

- 12 **SCI Group Meeting**
- 24 NSCIA Annual Dinner (<http://spinalcordwi.org/events.html>)

## November

- 9 **SCI Group Meeting** (3rd Anniversary Party)

## December

- 14 **SCI Group Meeting**

**A special thank you goes out to the Fitchburg Community Center for permitting our group to meet at their wonderful facility!**