

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

Madison SCI Group Celebrates It's 3rd Year

By Dawn Ziegler



The Madison SCI Group is going to celebrate its third year anniversary this November. Thanks to the dedication of our coordinator, Monica KamalRossa, the group has grown into much more than the typical "support group".

How it all began: The idea of forming a SCI group of peers started as a vision. After several years living with a SCI, Monica felt something was wrong with just dealing with things on one's own, "I knew I wasn't the only person going through these struggles...how much better it could feel to have others to talk with, share perspectives, learn about helpful information..." She thought, "How beneficial it would also be for our family members and caregivers to have access to others who also share their same life adjustments." It was with those ideas that Monica began pursuing a plan to start a SCI group.

On November 29, 2006 with only three members, the Madison SCI Group held its first meeting. Through participation in the UW

Hospital's SCI Peer Mentoring Program & involvement in our community, the group has grown to over 43 members.

Along with bringing a wealth of information to our meetings through speakers, our group has been increasing its presence in the surrounding community. Several of our members are active in other programs that promote adaptive recreation & sports and accessibility in and around the county. We have an ongoing collaboration with the UW Mechanical Engineering School in which students work with us in creating assistive technology projects. Our group is also in the process of merging with NSCIA - SWC to combine resources to enhance both our programs.

This past summer, Monica created an open forum to promote the discussion of spinal cord injury, disease & paralysis issues. This fun social network has the potential to become a worldwide exchange of ideas, information, experiences, opinions & events, but it will only be effective if people participate. It's fun and easy, so we hope you join!

**Get Involved, Be Part of the Dialogue!
Join the SCI Forum
Go To: www.SCI-Madison.com**

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Reflections from our members: Speaking for myself, I have made some truly great friendships. I'm continually amazed at the diverse backgrounds and interests the members in this group have, and the wide range of information that is shared among us. But don't take my word. Read the comments others have shared about their experiences being in this group...

"I have learn so much from my peers and their families!!! Everyone in our group is so witty and funny. Every meeting provides me with a

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ASSISTIVE TECHNOLOGY

Assistive Technology Expo Showcases Possibilities for Persons with Disabilities

Edited Article Written By Kerry G. Hill

Monica KamalRossa emphasizes the importance of assistive technologies for persons with disabilities by asking a question: "How many of you can live without your shoes every day, every season – yes, even in winter?"

KamalRossa, coordinator of Madison's Spinal Cord Injury Group, explains, "Our canes, wheelchairs, and computer systems are how we navigate to get around to school, work, and our places of worship." Assistive technology doesn't only effect transportation. Imagine trying to live completely without a telephone, she says. "Without voice-command software and other technology, some persons with disabilities can't communicate at all."

"Assistive technology is a foundation to the quality of life that almost all persons with disabilities require," says KamalRossa, who injured her spinal cord in a 2001 skiing accident and uses wheelchairs to get around. Such technologies enable more people to participate in their communities, which benefits the entire community, she adds.

KamalRossa is the lead organizer for the 25th annual Assistive Technology Expo. The event showcases some of the latest advances in technology that can offer people with disabilities new opportunities to participate in school, employment and community life.



The Expo debuted on October 18, 1985. The event was a joint effort to seek a project that could benefit rehabilitation professionals, people with disabilities, and the community in general, says Norm Berven, professor of rehabilitation psychology who coordinated the Expo for 20 years. He says, "Technology has changed dramatically since 1985, and advances in technology have opened many possibilities for people with disabilities, and it is these advances that are highlighted at the Expo."

He credits the active participation of UW-Madison's College of Engineering for taking the expo to a new level, especially Jay Martin, a professor in Mechanical Engineering and Biomedical Engineering. "Professor Martin has involved a number of faculty



AT Expo 2009 Free Event

Featuring: Motor Vehicles, Speech Recognition, Innovative Design, Telecommunications, Rehab Robotics, Wheelchair Designs, Computer Technologies, & Adaptations in Sports & Fitness

When: Wed., Nov. 4, 2009

Time: 10 am - 3 pm

Where: UW Madison Engineering Centers Building, 1550 Engineering Drive, Madison, 53706

Keynote Speaker: 11:30 am Prof Roger Smith Ph.D., O.T. from UW Milwaukee on Assistive Technology Abandonment

Panel Discussion: 1 - 2 pm Adaptive Technology in Recreational Sports & Fitness Speakers - Andy Janicki, Monica KamalRossa, Betty Merten, & Dawn Ziegler

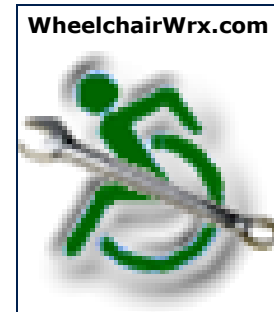
More Details on AT Expo: <http://atexpo.blogspot.com/>

Contacts for Questions: Sarah Lincoln at Sarah.Lincoln@dhs.wisconsin.gov or Monica KamalRossa at Monica@SCI-Madison.org

(See Assistive Technology Expo...continued on page 8)

Wheelchair Maintenance & Repair... Website Project Designed to Keep You Rolling

By Monica KamalRossa



Even a minor mechanical breakdown with your chair can mean a major setback in your ability to experience life to its fullest. When it comes to wheelchair repairs, users are often at the mercy of the repair service providers. However, this doesn't have to be the case! By spending just a few minutes on wheelchair maintenance, you can cut down the need for repairs and you'll be sure to get where you need to be. The real question is...how can you maintain your chair?

You don't have to be an experienced technician to keep your wheelchair in top condition. At our October SCI Group meeting, Prof Jay Martin conducted a mini course on "How to Change a Tire". Topics reviewed included: common tools needed for repairs, adjustments on foot plates & side guards, wheel & caster repairs, lubricants, and other common issues with wheelchairs (check out SCI Forum for review of Oct. meeting). The concept of the course was to demonstrate that wheelchair repairs are not out of our reach and to educate us on simple maintenance tips that we can do to keep us rolling.

The mini course is developed through a project with the UW-Madison Mechanical Engineering School and the Dept. of Human Services. Although still under construction, the scope of this project includes a website containing links to inspection videos, do-it-yourself tips for common repairs, a wheelchair maintenance & repair log book, a professional services guide for lists of reputable service providers, and tips on working with service technicians.

Feedback on the website is needed. Go to www.wheelchairwrX.com to check out the website yourself. Sections of the site are still under development, so some links may not respond. If you have any comments, questions, ideas or would like to be a reviewer of the website project, please contact Monica KamalRossa at: Monica@SCI-Madison.org.

UW Mechanical Engineering Students Share Projects with SCI Group

At the September SCI Group meeting, UW Prof. Jay Martin and his senior ME students met with our members to share their fall projects and get feedback from the group. The list of projects include: Advanced Powered Wheelchair Systems, Button and Switch Actuator, Blue Moon Surfaces (extendable table top), Wheelchair Lift Systems (portable ramp), Manual Wheelchair Storage Systems, Air Sling, Anywhere Reader, and Videos on Wheelchair Maintenance.

If you have an idea for a project or to get more information on a current project, contact Monica KamalRossa at Monica@SCI-Madison.org.



ME student presenting the Advanced Powered Wheelchair System project

Madison West Kiwanis Ski Scholarship

The Madison West Kiwanis Club Foundation received a generous gift from the Ethel Allen Trust that provides scholarship funds for up to four people from the greater Madison area to learn to ski under the careful direction of the Adaptive Sports Association (ASA) ski instructors in Durango, CO. The ASA is one of the country's best ski schools for people with disabilities.

Those awarded a scholarship will travel to the Durango Mountain Resort in the San Juan Mountains of Southwest Colorado. A mountain atmosphere, friendly people, and an exciting life changing experience will be part of a five-day, all expense paid trip. The scholarship provides an opportunity for adults with a physical disability to rediscover their potential, meet and overcome challenges, learn and enjoy a new sport, travel and make new friends.

Although all applicants will be considered, ideal candidates are local adults over 18 with an acquired physical disability. They should want to or already participate in athletic activities, are able to travel by air to Durango, CO, are new to adaptive skiing or



Casey Kaim 2009



Jim Hamre 2009

snowboarding, and who can help "spread the word" about the program within their communities.

The only cost to scholarship recipients will be any out-of-pocket expenses in Durango. If you require an attendant, he/she may accompany you on this trip, but you will be responsible for all of your attendant's expenses.



Brad Dakan 2008



Dawn Ziegler 2008

Scholarships will be awarded annually until donated funds are depleted. Applicants not chosen are encouraged to reapply the following year. Applications can be downloaded and printed from the Kiwanis website at www.madisonwestkiwanis.com. Here are the important dates for the scholarship application process:

November 2, 2009: Deadline for applications to be submitted to Kiwanis.

Nov. 9-13 & Nov. 16-20, 2009: Period interviews will be scheduled. Applicants will be contacted by phone or email about interview date & time.

December 15, 2009: Date the Kiwanis ASA Scholarship recipients will be notified.

March 1, 2010 - March 6, 2010: Dates scholarship recipients will travel to Durango, CO, for 4 days of skiing. Flight arrangements will be made on your behalf.

Mail or Fax Applications to: Madison West Kiwanis ASA Scholarship, c/o Ken Saville, 4106 Melody Lane, Madison, WI 53704; or FAX to: 608-277-8333.

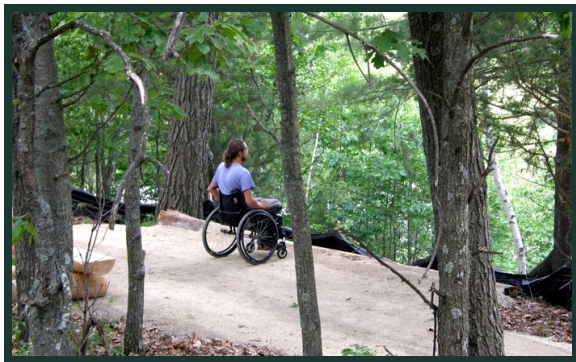
To View a Video, Go To: <http://www.youtube.com/watch?v=rpoXuxvB6h4>

For more info, contact Ken Saville at 608-277-8288 ext. 108, or email him at ksaville@wi.easterseals.com. Visit the ASA Durango website www.asadurango.org for additional information about this program.

The Bohn Lake Accessible Hiking Trail

By Jennifer Addis

Since 2006, the Ice Age Trail Waushara Chapter Board Members had been advocating for an accessible hiking trail on the Bohn Lake State Ice Age Trail area in the town of Deerfield. In March of 2008, their vision was approved. The Wisconsin Natural Resources Board included an accessible rustic trail in the Wisconsin's DNR's management plan for Bohn Lake marking a huge accomplishment for this community.



The site is now called the *Bohn Lake State Ice Age Trail Area* as a result of the purchase of properties that were acquired and now managed by the Wisconsin DNR. The property consists of 237 acres of natural prairie, grassland, forest and Bohn Lake. The newly finished *Accessible Hiking Trail* is approximately a ¼ mile long, 5 foot wide trail leading up to a scenic vista with a rustic bench overlooking Bohn Lake. There will also be an interpretive pedestal with historical information on site. A 10-car parking lot has been constructed and an informational kiosk will be installed as well. The view will not only include Bohn Lake, but also portions of Wisconsin's Ice Age Trail.

The unique aspect of the newly created trail is that it provides access for people with mobility related disabilities to witness the

beauty of Bohn Lake and the Ice Age Trail. The crushed limestone trail is capable of allowing easy passage to people using wheelchairs or scooters. There is no wondering whether your wheelchair would get you there without getting stuck due to rough terrain or trying to tackle branches and trees lying in the way. It is everything I imagined. For me, accessibility equals independence. It gives anyone who visits Bohn Lake, both disabled and able-bodied, an opportunity to enjoy Wisconsin's glacial history.

The *Bohn Lake Accessible Trail* was open to the public on October 10, 2009 for the Annual Fall Color Hike. Proceeds from the hike went to the development and protection of the trail in Waushara County.

Autumn is a perfect time to check out the beautiful fall colors at the Bohn Lake State Ice Age Trail Area! Go and enjoy the panoramic view of the lake from the 1/4 mile wheelchair accessible spur trail. It is suitable for all ages and abilities. The Bohn Lake parking lot is located Southeast of Hancock, WI, on 9th Drive (1/2 mile North of County Highway C).

For more info or to donate, go to: <http://inspirationspeaks.webs.com/wiiceagetrail.htm> .



REFLECTION ON SUMMER 2009

By Dawn Ziegler

The members in our SCI group love to keep busy pursuing lots of interesting activities as a group and individually! This past summer was no exception. Read on to get a glimpse of how the summer was spent by some of us.

JUNE

CAMPING - Adam Groener (with girlfriend Amy) went camping and kayaking at Devil's Lake. Adam shares



their experience, "It was my first time camping since my injury. It was a fun and challenging experience. We found a relatively level regular tent spot and spent the night in the tent on an elevated air bed. I think starting the fire was my biggest challenge being in the chair, but I will definitely do it again!"

ADAPTIVE SPORTSMEN FISHERY - The 6th annual Fishery outing was held on June 20th. John Martinson describes the event, "It was



one of our best outings yet with sunny weather and some really great fishing! Fifteen members went out in two groups: one from 1pm-4pm and a later group from 5pm-9:15pm.

Thanks to Captain David Pike for keeping us out on the water because the bluegills really started biting right at dusk. Besides the cool t-shirts from Ameriprint in Sun Prairie, each participant received a nice fishing rod/reel combo with the help of Ace Hardware in Sauk City and American Packaging in Columbus. The Fishery wouldn't have been a success without the help of our guides Scott Hogland, my brother Steve, my son Kenny and Bruce Gehrke, or the use of the MSCR pontoon boats. Take care, and I hope to see all of you next year. Good luck fishing!"

ORGANIC GARDENING - Kurt Christensen & the Dane County Transitional School worked together on a community project to build raised garden beds on his land this past spring. In his efforts to improve his overall health, Kurt became interested in organic gardening. By late June, he was able to begin enjoying a variety of organic vegetables grown himself!



JULY

HORSEBACK RIDING - Monica KamalRossa pursued something very different this past summer. "Hippo Therapy at 3 Gaits is something new I had to try. I have loved horses since I was a kid, but I haven't ridden since my accident 9 years ago.

It's a wonderful challenge! The balance work I must do for the 20 minutes I'm on the horse is so much work! I'm so exhausted afterwards, but it feels good to move around on the horse. I hardly notice the fatigue until I'm finished and trying to transfer into my van. Although Nora is the horse in the picture, Snowcap is the horse I've been riding. We must work together because he just had surgery and physical therapy on his leg, so together we're working at building up our muscles. Thank you 3 Gaits for your program!"



HAND CYCLING - Several members of our SCI group teamed up with Joel Berman, director of Adaptive Adventures, to go hand cycling on the beautiful Capital City Bike Trail. Joel was very



generous bringing up 5 hand cycles so a few of our newest members could experience biking for the first

time since their injuries. With the help from UW students Erica Peterich, Kara Mathys, and David Nguyen, and from our Achilles Club Allegra and Linda Roberts, this ride was a great success. Hopefully next year we'll be able to plan more rides throughout the summer!

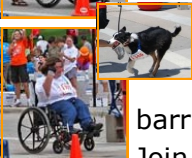
MADISON HOPE & POSSIBILITY 5K RACE

- Hosted by the Madison Chapter

Achilles Track Club, our SCI group had 4 hand cyclists and 2 wheelchair racers competing with



Trisha Meili, the Central Park Jogger, and some of our Achilles teammates. Over 60 participants

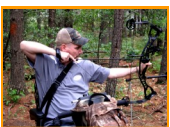


including "Rocky" (the 3-legged dog) ran, walked & wheeled in support of breaking down

barriers to mainstream athletics.

Join us next year to demonstrate the hope & possibility that exists in all of us!

3D ARCHERY SHOOTING - Tim Austin, a hunting & fishing enthusiast, explored the wild side at a 3D shooting course in Sparta, Wisconsin. "Had a blast shooting 3D this year with several events here in Wisconsin and one in Wabash, Indiana. Fishing



wasn't the best this year but always enjoy getting out on the water. All set for hunting, can't wait for the season to begin!"

AUGUST

WATERSKIING - Devin Elmer, Melissa Madole and Brad Dakan went to Twin Lakes, Wisconsin, to try their skills out on the water. Hosted by GLASA (Great Lakes



Adaptive Sports Association) & Adaptive Adventures, several people with various disabilities got to experience waterskiing and wakeboarding. This is an amazing program with very energetic instructors and volunteers that you must checkout next summer!

KAYAKING - Seven members of the SCI group & their families went

on a kayak picnic outing with the Rutabaga Outdoor Program. It was a



hot and humid day making it perfect to be out on the water. Three creative Rutabaga instructors helped get us

fitted into kayaks and paddled with us. Even though our picnic was cut short due to storms rolling in, it was a fun and adventurous day!

INTERNSHIPS - Mike Mohr was a summer associate at a law firm this past season. He's been in Law School at UW-Madison from which



he will graduate this December. Mike has been offered a job as an associate at the law firm where he spent his

summer and will begin working there in February 2010. Best of luck, Mike!

SCI GROUP PICNIC - At the end of August, we had our 2nd annual group picnic at McKee Farms Park in Fitchburg. It was a pleasure



to end the summer with great people, tasty food and beautiful sunny weather! It was especially nice to have four of our newest



members join us. Hope to see you next year!

This SCI group has such energy and character! It's no wonder why joining this group tends to bring the best out of a person. See page 9 for our group contact & meeting info. For links to programs mentioned in this article, see page 10.

(Celebrating 3 Years...continued from page 1)

learning and laughing opportunity. What more can I ask for?" --Liza Perez

"I have really enjoyed getting to know everyone in the group. My kids had fun with biking on the trail this summer, and I'm hoping we can do more activities like this in the future. These are the things my boys and I have done before my accident and now can do again." --Devin Elmer

"Thank God there's a group like this because not everyone can relate to what you go through day by day. Only people who have a SCI or the sort really understand that day to day things are not always easy, but if you got the will to keep going, then you will. Thanks." --Theresa Herbert

"I have only been a member of the group for a short time now, but have found it beneficial. The topics, speakers, and advice from other members have all been helpful and I have enjoyed the camaraderie as well." --Mark Laufenberg

"Wow, it's been three years!! It's great watching this group grow and meeting everyone - cheers

to the future!" --Tim Austin

"It's been a hoot! Hell of a nice bunch of people proving once again that, "With every adversity, is the seed of a greater benefit", (Buddha)." --Kurt Christensen

"I love all the new friends I make in wheelchairs and out of wheelchairs!" --Monica KamalRossa

"It's been great meeting positive people. Being part of the SCI group introduced me to the Achilles Track Club. I know I wouldn't be doing all the activities I do now if it wasn't for the support I feel from both groups. Thanks to Monica for all that she's done to make this group a success! I know she's had some help along the way, but it has been her motivation that got it all started. Let's hope for many more great years together!" --Brad Dakan

The friendships and life experiences that are shared between us can make all the difference in one's outlook on life. If interested in finding a group focused on LIVING with a spinal cord injury or other disability, then this is the group for you!



(Assistive Technology Expo...continued from page 2)

and programs in Engineering and has also organized poster presentations by his students, demonstrating innovations that they have been involved in developing," Berven says. "He has also brought some important keynote speakers and panels to give presentations at the Expo." This year, UW Milwaukee Professor, Roger Smith Ph.D., will be the keynote speaker discussing Assistive Technology Abandonment. A new panel topic on Health and Wellness will be examined through the presentations of four people with disabilities sharing their experiences with adaptations in hand cycling, sit skiing, downhill skiing, rowing, kayaking, and camping.

KamalRossa became acquainted with Martin and other members of the expo's planning committee through her active involvement, as participant and volunteer, in adaptive fitness and recreation and assistive technology projects. That eventually led to her role with the expo. "I have attended a few AT Expos over the years because it is such an important event," she says. "I am always curious about what is new and I want to try out the 'solutions' and ask questions."

The Expo is free and open to the general public. For specific details, see page two or visit the website at <http://www.atexpo.blogspot.com/>, and to read this article in full, go to: <http://www.education.wisc.edu/news/details/2006.aspx?articleid=233&zoneid=1&>

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

To join the SCI group:

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

SCI Forum:

www.SCI-Madison.org
Click on *Our Forum*

SCI email Yahoo group:

www.SCI-Madison.org
Click on *SCI-Madison Yahoo group*

Website & Forum Updates:

Monica@SCI-Madison.com

Newsletter:

Contact Dawn Ziegler at 608-833-9453 or email to Dawn@SCI-Madison.org or info@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.

Join the SCI-Madison Forum

This is an open forum for discussion on spinal cord injury, disease, & paralysis topics including wheelchair sports, recreation, accessibility, new research & therapy, and other related topics. The forum is a place to share fun information or opinions for other members to read and comment on. It's also a great social network to create a group or announce an upcoming event and track RSVP replies.

Anyone can access the SCI forum link and view the list of members, discussion topics and responses, events, and groups created. However, if you would like to create and/or participate in a discussion, then you must become a member of the forum.

Joining the forum is easy. **Go to www.SCI-Madison.org and click on the *Our Forum* link.** Fill out your info and submit for membership approval. Once approved, you can change & design the appearance of your page, post photos, invite others to join, create and reply to discussion topics, announce events, and be part of a great social network! Check it out!



Madison SCI Group Picnic
August 30, 2009

Seeking More Accessible Activities & Events?

Go To:

Achilles Track Club:

Kim at 608-444-9424 or
achillesland.blogspot.com

Adaptive Adventures:

Joel at 866-679-2770 or
www.AdaptiveAdventures.org

Adaptive Sports Association:

www.asadurango.org

Adaptive Sportsmen:

www.adaptivesportsmen.org

MSCR:

www.msgr.org

NSCIA-SW Chapter:

www.spinalcordwi.org/
events.html

Rutabaga Outdoor Programs:

Nancy at 608-223-9300 x225
or nancys@rutabaga.com

Three Gaits Horseback Riding:

www.3gaits.org

Wilderness Inquiry:

www.wildernessinquiry.org/

CALENDAR OF EVENTS

October

24 NSCIA Annual Dinner (<http://spinalcordwi.org/events.html>)

November

4 Community Conference (8:30am-noon), Anderson United Way Center, 2059 Atwood Ave, Madison

4 Assistive Technology Expo (10am-3pm), UW-Madison Engineering Centers Building, 1550 Engineering Dr, Madison

7 Adaptive Sportsmen Pheasant Hunt for the Physically Disabled, Smith's Pheasant Hunt, Oxford (www.adaptivesportsmen.org)

9 **SCI Group Meeting at 5:30pm / SCI Group Anniversary Dinner following meeting at 6:45pm**

December

14 **SCI Group Meeting at 5:30-7pm**

January

11 **SCI Group Meeting at 5:30-7pm**

SCI GROUP ANNIVERSARY DINNER

November 9, 2009

6:45 pm

Benvenutos Restaurant
2949 Triverton Pike Drive
Fitchburg, 53711
(608) 278-7800

RSVP to info@SCI-Madison.org
(Each person responsible for own
dinner. Cake will be provided.)

Thanks to Our Most Recent Speakers

*Tim Klemm, Managing Director of Empathy Rehab Facility (www.empathyrehab.com) and his presentation on Functional Locomotion Therapy.

*Jay Martin, Professor at UW Madison (martin@engr.wisc.edu), and his Mechanical Engineering students for their time and energy in discussing and developing their group projects.

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