THE CORD
Keeping you in touch with SCI community programs and research

Magee Rehabilitation and the Regional Spinal Cord Injury Center of Delaware Valley

GO ONLINE WITH SCI PEERS!
The SCI-Peer Web Page is up and running! SCI-Peer Coordinator Mike Nacci worked hard to design this web page. It will be managed by the Peer Coordinators.

This web page has much of the practical information and support that you have come to expect from our SCI-Peers. This page includes:

- a message board - your questions are answered by your peers
- frequently asked questions - especially those common “coming home” questions
- a classified page - a place online to buy, sell or donate your used medical and adaptive equipment.
- recreational opportunities - our entire recreation resource guide online.
- A calendar - see what’s happening at Magee and beyond!
- community resources, and more.

We welcome your suggestions regarding the content of this web page. You will be able to reach it online at www.mageepeers.org

E-MAIL ADDRESSES NEEDED!
We would like to start using e-mail to send out SCI RESOURCE & SUPPORT GROUP monthly flyers. If you have an e-mail address please send it to pcoordinator@magerarehab.org. Please type SCI group flyer in subject area. This group e-mail list will also be used to send you the monthly flyers in addition to other SCI program information such as special events, focus group information, recreational opportunities, etc, in a timely manner. We encourage everyone to sign up now for these updates.

For those who wish to continue to receive the support group flyers by mail, please call the Peer Coordinators at (215) 587-3174 to verify your current address.

FALL/WINTER 2002/2003

Special thanks to The Friends of Jerry Segal for funding the publication and many of the SCI-Peer Support Services.

Magee Rehabilitation offers numerous opportunities for support, networking, and information-sharing after your discharge from rehabilitation.

These services (most of them at no cost) are available to anyone with spinal cord dysfunction.

TOPICS OF INTEREST:
- RESEARCH
- RUGBY FROM A PLAYER’S VIEW
- DANCE
- SKIING
- RESOURCE AND SUPPORT GROUP MONTHLY TOPICS

Editor: Pat Thieringer
Assistant Editor: Sonya Dibeler
RESEARCH AND EDUCATION

RESEARCH PARTICIPANTS NEEDED!

1. The SCI Center has developed a research tool to measure improvement in walking in persons with spinal cord injury. We are seeking volunteers to help us validate the scale and make sure it is reliable. Research participants must be motor incomplete and able to walk short distances with or without devices or assistance. Subjects will be required to come to Thomas Jefferson University Hospital on 2 different occasions for about 2 hours each visit. Those who participate will be reimbursed $50 and provided with free parking.

If you are interested in participating or would like more information, please contact Mary Patrick, RN, SCI Project Coordinator at (215) 955-6579.

2. A research study is being conducted examining whether or not a spinal cord injured adult’s acceptance to their disability is related to how they may have perceived they were parented in childhood and/or adolescence. Those interested in participating must fit the following criteria:

   1. Is currently between the ages of 18 and 30
   2. Have a spinal cord injury that occurred between the ages of 15 and 25
   3. Have had their spinal cord injury for at least 2 years

Participating in this study consists of filling out 3 questionnaires, one regarding your perceptions towards your spinal cord injury and two pertaining to your perceptions of how your parents raised you. The total time it will take to complete the questionnaires is between 15-20 min. All names are kept confidential and will not be linked to your survey in any way. Individuals participating in the study will be eligible to be entered in a drawing to win $50. It is hoped that participation in this study can contribute to the increasing knowledge and research on the acceptance of spinal cord injured individuals to their disability.

If you are interested in participating, please contact the researcher via e-mail at Mestraphd@aol.com or phone (215) 878-4135 to have a survey packet mailed to you.

3. A research study is being conducted to understand the meaning of the experience of living with a spinal cord injury for the family unit in the years following the initial injury. Spinal cord injured persons and their identified family members will need to participate in one to two interviews. The interviews will last approximately 1 hour. The interviews will focus on you and your family members’ experience of living with spinal cord injury from your own personal perspective.

If you are interested in participating or have any questions, please call Susan DeSanto-Madeya at (610)954-3442 or e-mail at desants@moravian.edu.
CURRENT ONGOING RESEARCH OF THE RSCICDV


7. Technological adaptation of art therapy media with quadriplegic patients to address emotional adjustment to the illness and increase range of self-expression: A phenomenological study. Sponsor: Doctoral candidate, Drexel University.

RECENTLY COMPLETED CLINICAL TRIALS

1. A multi-site, open label study to evaluate 250 mg oral Neotrofin™ BID in patients with subacute complete spinal cord injury over 12 weeks. Sponsor: Neotherapeutics, Inc.

2. Eye-voice enablement technology: EVENtech, hands-free computer access for the disabled. Sponsor: National Institute of Health (NIH).

RESEARCH FOCUS GROUP

The Regional Spinal Cord Injury Center of Delaware Valley (RSCICDV) at Thomas Jefferson University Hospital and Magee Rehabilitation is conducting focus groups to evaluate consumer’s priorities in dealing with recovery following a traumatic spinal cord injury.

If you are a person with SCI and would like to participate or would like more information about the project, please contact Mary Patrick, RN, RSCICDV Project Coordinator at (215) 955-6579.

The meetings will be held at Magee Rehabilitation Hospital and free parking will be available.
The Regional Spinal Cord Injury Center of Delaware Valley at Thomas Jefferson University Hospital and Magee Rehabilitation Hospital recently updated the Spinal Cord Injury Education Manual for individuals with spinal cord injury and their family members. The manual includes 20 chapters consisting of various topics ranging from bowel/bladder management and respiratory care to activities of daily living and recreational resources. The manual is now available online at www.spinalcordcenter.org.

The Center would like to extend special thanks to Cynthia Fine, RN, MSN for continuing to lead this tremendous effort, special thanks to the Geoffrey Lance Foundation for supporting this effort, and Dane Hawley and Frank Lindgren for all their hard work in posting the manual on our new web site.

**FOLLOW-UP REMINDER!**

Don't forget to schedule annual follow-up appointments with the outpatient department at Magee! Magee has outpatient programs in Rehabilitation Medicine, Pain Management, Stroke, Urology & Continence, Skin Program, Intrathecal Baclofen Therapy, Botox Injections, Electrodiagnosis, and Equipment Clinic.

Consultative Services in Urology, Psychiatry, Podiatry, Psychology, and Gynecology are also available.

Call (215) 587-3394/3144.

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**THE ARTS**

**UNIVERSAL DANCESPORT CENTER**

Fortuna’s Universal Dancesport Center would like to extend a special invitation to join us for a preview of Wheelchair Ballroom Dancesport. We are privileged to be the first able-bodied dance center on the east coast to incorporate wheelchair dancing into our dance program. We will host an Open House at our school on Rt. 130 S, Collingswood, NJ on December 1, 2002. We will present demonstrations of Wheelchair Ballroom Dancesport and a sample class of Wheelchair ballroom dancing.

Our objective is to create an environment where disabled individuals can learn dance, and ultimately use these skills both socially and competitively regardless of function. The classes will be divided into levels depending on physical ability and interest.

We hope you will take the time to view Wheelchair Ballroom Dancesport in the flesh. Be assured that this is real dancing. We have kept the character, rhythm, and feeling of dances like the waltz, rumba, hustle, cha-cha, and salsa intact. It is new and innovative, and promises to integrate the disabled an able-bodied world in a social recreation enjoyed by people and cultures all over the world.

RSVP is required. To register or get more information, call our studio at (856)869-0010. Manual and power wheelchairs are welcome.
COMMUNITY DANCE PROJECT

Wheelchair dance companies have been forming all across the country for several decades. Many of them include disabled and non-disabled people dancing together. Kardon Institute for Art Therapies in conjunction with Magee Rehabilitation and Moss Rehabilitation hospitals is starting a Community Dance Project. The mission is to provide the dance experience for disabled and non-disabled people ages 18 and older to dance together and learn more about the art form.

Two groups will be formed. One is a Dance/Movement Group for people who would like to experience the process of learning and creating dance. The other Dance/Movement Group will be for individuals wanting to learn more about dance making and performance.

No experience is necessary for this project. The only requirement is having the desire to dance and the willingness to experiment through movement by moving with others in creative and expressive ways. The director/choreographer will lead warm-up exercises that will promote strength, flexibility, and coordination. She will also provide supportive structures to facilitate the group in experimenting and discovering new ways to move and dance.

We will meet at Kardon Institute for Art Therapies on September 17th at 2:00 p.m. for the first time. For directions or for more information, please contact Martha Hess, director/choreographer of Community Dance Project at (215)587-3078 or e-mail her at Mhess@mageerehab.org.

‘MAGEE PLAYERS’

Calling all people with physical disabilities who wish to develop their creativity, memory, sense of humor, communication skills, and wish to meet new and interesting people from all over the Philadelphia area... Join our Theatre Arts Class at Magee!

Starting September 27 through December 13. Class times are from 1:00 to 3:00 p.m., mainly on Fridays. We are starting our third year and have a core of returning students but are opening up the class to new students.

Some of the theatre techniques we will study are:

- Mime and acting improvisation
- Comedy
- Playwriting
- Voice
- Mask work

We will also work on relaxation and visualization exercises this term to better prepare the actor for performances and to help reduce stress in students’ every day life.

We will perform at Magee on December 13th as well as perform at Moss Rehabilitation this winter.

Call today to register and leave a message for Barbara Gregson at (215)587-3078.

We are asking for a $15.00 registration fee this year to help to defray costs.
Just this past February, as I sat in the Magee waiting room before seeing my doctor for my annual check-up, I happened to glance at a Magee SCI newsletter. I came across an article about the Magee Rebels quad rugby team. “That’s it!” I thought, “Here is my chance to meet some people!”

I had heard of quad rugby before, but I never was interested in playing it until after reading that article. When I came out for my first practice, I instantly fell in love with the game. It’s a crazy game! I describe quad rugby to my friends who have never seen it as a combination of water polo and bumper cars. Oh, by the way, we play it in armored wheelchairs on an indoor basketball court using a volleyball. It’s amazing! Where else can a bunch of quads get into metal cages on wheels and slam into each other?!

What drew me to quad rugby, more so than the physical nature of the game, were all the benefits that had nothing to do with the game itself. First, and probably foremost for me, it feels great to be a part of a team again. After playing tram sports every year of high school and college, and believing for so long that I would never again feel the thrills that come with competitive physical activity, quad rugby gave me the chance to feel like an athlete again. The exhaustion after a tough workout, the bickering between teammates when someone does something wrong, the sweet taste of a hard fought win, the painful sting of an equally hard fought loss, and the satisfying ache of your muscles the next day that sometimes lasts until the next practice are aspects that all athletes endure, whether they are disabled or not.

Also, playing quad rugby has given me the opportunity to do something that I love: to travel. Although I came on board with only a month left in the rugby season, I traveled to tournaments in Georgia and Montreal, Canada before our summer break.

Besides learning a lot about my teammates, I’m learning much from them. Since my injury, I had thought that quads could do very little for themselves, and that, as a rule, the ones who were independent were lucky exceptions. I had believed myself to be one of those exceptions that were fairly independent. These illusions were shattered when I came to my first practice. For instance, I was the only person there with a transfer board. Most guys could transfer into their rugby chairs, car/van seats and even into their beds without a transfer board and usually without assistance. They showed me how to simplify tasks that I previously had trouble performing, and they showed me intriguing ways to solve some problems that I still couldn’t work out. I am not sure if I will ever be as independent or as skilled at performing my daily tasks as some of my friends, but it is certainly something to aim for.

My joining the Magee Rebels quad rugby team has provided me much in improving the quality of my life. I enjoy the camaraderie of being part of a team. I’m learning a lot from my teammates, I get to travel, and I’m expanding my horizons to places that I never before thought that I would go. I even started learning how to SCUBA dive. Oh, yes, I almost forgot, I also was able to meet a whole bunch of cool people in wheelchairs!
**MAGEE ROLLING REBELS RUGBY SCHEDULE**

November 9-10  
EPVA Jets Tournament, New York, NY

December 2002  
Chicago Tournament

January 2003  
Connecticut Tournament

January 2003  
Carolina Tournament

February 21-23  
Atlantic North Regionals at Widener College

March 2003  
Atlantic Sectional, if qualified

April 2003  
USQRA National Championships, if qualified

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**MAGEE PHILLIES WHEELCHAIR SOFTBALL**

The Philadelphia Phillies teamed up with Magee to sponsor a wheelchair softball team. The Phillies organization provided official Phillies jerseys and baseball caps. This first season was a learning experience for the team. The team managed to do well, making it to the championship game at the Baltimore Tournament. Two players were recognized at the Bulova Park Tournament: Laura Schwanger for 2nd Base and Bobbi Jo Torres for Sportsmanship. The team is looking forward to next season.

Team members include: Coach Dan Drach, Jim Falls, Steve White, Joe Bradley, Gene Tatum, Bobbi Jo Torres, Laura Schwanger, Gary Kreeb, Bihn Scott, Mike Looney, Mike Osbourne, John DeAngelo, Sonya Dibeler, and Michael Johnson.

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**MAGEE SIXERS WHEELCHAIR BASKETBALL**

Basketball fans are invited to cheer for the Magee Sixers Spokesmen at the following home games:

- **Nov. 22-24**  
  Carousel House Tournament in Philadelphia  
  TBA

- **Dec. 14**  
  Dan Sullivan Classic at Carousel  
  9:00–7:00 PM

- **January 4**  
  Magee Sixers Spokesmen vs. Scranton at Carousel  
  2:00 & 4:00 PM

- **January 23**  
  Sixers’ Halftime Game – First Union Center  
  7:00 PM

- **Jan. 31- Feb. 2**  
  Bayada Tournament at Carousel House  
  TBA

Practices and home games are played at Carousel House, Belmont & North Concourse Drive, Philadelphia. Practices are held from 6:00–9:30 every Wednesday from September through March. New players are encouraged to join throughout the year. For more information, please contact Pat Thieringer, (215) 587-3412.
**WHEELCHAIR TENNIS**

Magee's Wheelchair Tennis Team has continued to perform well at major tournaments and is actively promoting wheelchair tennis in the USTA Middlestates Region. Team members have had strong showings at tournaments in Landisville, PA, Lehigh University, Baltimore, and the popular Philadelphia Tournament which is co-sponsored by Magee along with the Carousel House and Moss Rehab. In September, the team competed in the Middlestates Clay Court Sectional in Wilmington, DE and the Clay Court Championships in Hilton Head, SC.

Team members have improved greatly under the coaching of Delynn Orton, who has volunteered her time as instructor and coach for the past three years. The team also benefits greatly from the generous support of Cherry Hill Racquet Club which provides court time for the team's weekly practice sessions.

In addition to their strong tournament play, team members have enjoyed many opportunities to promote wheelchair tennis and to demonstrate how they have overcome disabilities—both as athletes and in their everyday lives. The team has participated in demonstrations and discussions about disabilities at local schools, as well as in a variety of community tennis events in Pennsylvania and New Jersey. On July 10, team members put on an exciting exhibition of wheelchair tennis at the Philadelphia Freedoms World Team Tennis match with the Springfield Lasers. Meeting Billy Jean King was a special highlight for the team. The team has also had many opportunities to introduce Up/Down team play that integrates wheelchair tennis with the able-bodied community.

In Up/Down team play, each team consists of an able-bodied player and a wheelchair player.

Members of Magee's wheelchair tennis team are: Ric Costow, Mark Chilutti, John Kistner, Larry Soular, Felix Suero, and coach Delynn Orton.

**MARTIAL ARTS TRAINING**

Free instruction in the martial arts is offered by Dr. Michael Salino, a Magee Physiatrist and black belt holder. Classes are held every Monday evening from 7:00–8:30 p.m. at Magee Rehabilitation. Dr. Salino has helped many wheelchair athletes achieve various belt levels this year. For more information, contact Pat Thieringer, (215)587-3412.

**SKIING FOR PEOPLE WITH DISABILITIES**

The Pennsylvania Center for Adapted Sports operates a ski program for people with disabilities at Camelback Mountain in the Poconos. Their state of the art adaptive equipment and their certified adaptive instructors make it possible for people with spinal cord injuries, amputations, and many other disabilities to enjoy the exciting sport of skiing. Whether you were a seasoned skier before your injury or you never skied before, you will have a great outdoor experience. Plan ahead for the winter and book your lessons early. For further information, call Isabel Bohn at (215)765-5118.

Adult sled hockey team is forming. Call as soon as possible! If you are interested, call Isabel Bohn at (215)765-5118 for more information.
SUPPORT GROUPS AND MORE

SCI PEERS, BEEN THERE, DONE THAT

The SCI Peer Consultant Program offers newly spinal cord injured the opportunity to benefit from the knowledge and experience of those who have “been there and done that.”

MENTORS– For those who have weathered a spinal cord injury, please consider volunteering as a peer consultant to help others through the difficult adjustment process.

PROTEGES– For those of you who are adjusting to your spinal cord injury or have questions that the more experienced person with an injury can answer. Please call and request a peer consultation. Peers can be matched according to injury level, social situations, gender, marital status, recreational interests, and vocational experience.

Please call the Peer Coordinators at (215) 587-3174 or e-mail at peers@mageerehab.org.

YOUR FAMILY MEMBERS ARE NEEDED!

Their experience is needed by families of the newly injured!

Remember the first few months after your loved one became injured? The questions, the worries, the grief… If only you could talk with someone who had been through this experience to help you through the troubling times! We now have a family peer support group in which families who have experience with a disability can help families of the newly injured.

As a family peer counselor your commitment will entail attending one evening training session. After training you assist families by meeting with them in person or over the phone and by becoming involved in our family support group. As our family peer counselors can tell you, this will be the most rewarding volunteer experience you have ever had. You have the expertise and experience that families so desperately need.

To find out more, please contact Pat Thieringer at (215) 587-3412.

FAMILY Peer SUPPORT GROUP

Family Peer Support is a group in which specially trained families who have experience with a disability help others who share their struggles. Family members and significant others of individuals who have had a stroke, brain injury, spinal cord injury, and other disabilities are encouraged to attend. Inpatient and outpatient families are welcome. Family Peer Counselors offer support and practical tips. This group meets on the second Thursday of every month at 6:00 p.m. in the patient lounges.

For more information call Pat Thieringer at (215) 587-3412.
**SCI RESOURCE & SUPPORT GROUP**

Your are invited to join this group which provides opportunities for education, recreation, and support for individuals with spinal cord injuries. This group meets the second Thursday of every month at 6:00 p.m. in the Second Floor Conference Room (220/222).

**TOPIC SCHEDULE**

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<td>Cure Research</td>
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<td>December 2002</td>
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<td>January 2003</td>
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<td>March 2003</td>
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We are always looking for new topics. Please call the **Peer Coordinators** at (215)587-3174 or e-mail at **peers@mageerehab.org**.

**WOMEN’S DISABILITY SUPPORT GROUP**

This is a supportive psychotherapy group that meets at Magee every Monday afternoon. A clinical psychologist with expertise in disability rehabilitation leads this group focusing on women’s issues. Women are encouraged to explore their thoughts and feelings about life with a disability. The discussion often addresses topics such as relationships, career issues, intimacy and sexuality.

If you are interested in finding out more about this group or other psychological services, contact **Dr. Nancy Rosenberg**, Psychology Department, at (215)587-3071.

**LEGAL CLINIC FOR THE DISABLED**

The Legal Clinic for the Disabled, a nonprofit organization that provides free legal representation to low-income persons with physical disabilities, announces the beginning of a program to provide direct representation to individuals who are abused or neglected by their attendant care providers or other caregivers. The clinic will also be conducting outreach programs on this issue starting this winter.

Unfortunately, people with disabilities are much more likely to experience abuse and neglect than other individuals. Often, their abusers are the people that are responsible for assisting them with activities of daily living, including attendants and family caregivers. “Abuse” is more than just physical assault and also includes emotional abuse, verbal abuse, sexual abuse, neglect, and abandonment. Many people do not report abuse and neglect because they feel that nothing can be done or because they are afraid to handle the problem on their own.

We would like to work with you if you are being abused or neglected by an attendant care worker or other caregiver, or you feel uncomfortable with the way a caregiver is behaving. For more information about direct representation or outreach programs, please contact **Kate Reznik** at the Legal Clinic for the Disabled at (215)587-3214.


**Think First!**

Think First is a nationally coordinated assembly education program for elementary school children, teens, and young adults. The goal of this program is to prevent disabling head and spinal cord injuries among this population. To reach this goal, we schedule dynamic presentations at schools. These presentations consist of injury prevention lessons and testimonials from young trauma survivors.

Think First is looking for individuals with spinal cord or brain injuries who are interested in helping change some behaviors and save some lives. We need your help to talk to middle and high school students about your life.

Because Magee values your experience, you will be paid for your time. If interested, contact Joe Davis, Think First Coordinator, at (215)587-3400.

**Computer Training**

Magee Rehabilitation offers free computer training sessions for persons with disabilities. These classes introduce participants to the workings of the computer and teach basics of popular software packages including the internet and web page design.

Adaptive equipment is provided as needed.

For more info and a class schedule contact the Magee Patient Learning Resource Center at (215)587-3423.

**Volunteer Positions**

- Volunteers are needed to serve as patient visitors and recreation aides
- Gift Shop Cashier - In Magee’s Alcove Gift Shop
- Computer skills needed - volunteers are needed for numerous projects requiring computer skills such as word processing, Microsoft Publisher, and database programs
- Green Thumbs needed - Horticulture Therapy volunteers are needed to assist with patient groups and greenhouse/garden care
- Patient Assistant Volunteers - assist patients by helping them in the cafeteria and transporting them throughout the hospital; weekend help is especially needed

Consider participating for a few hours a week or a few hours a month. You can make a difference!

For more information, please contact Susie Toland, Volunteer Coordinator, at (215)587-3140.
FACING ADVERSITY

A young woman was complaining to her father about how difficult her life had become. He said nothing but took her to the kitchen and set three pans of water to boiling. To the first pan, he added carrots. To the second, eggs. And to the third, ground coffee. After all three had cooked, he put their contents into separate bowls and asked his daughter to cut into the eggs and carrots and smell the coffee.

“What does this all mean?” she asked impatiently.

“Each food,” he said, “teaches us something about facing adversity, as represented by the boiling water.” The carrot went in hard but came out soft and weak. The eggs went in fragile but came out hardened. The coffee, however, changed the water to something better.

“What will you be like as you face life?” he asked.

Will you give up, become hard, or transform adversity into triumph? As the ‘chef of your own life, what will you bring to the table?

-Unknown