



THE CORD

SPINAL CORD INJURY FAMILY PEERS

SCI Family Peer Support is a group in which specially trained families who have experience with a spinal cord injury help others who share their struggles. Barry Oppenheim is just one of these valuable people who volunteer their time to help the families of those with new spinal cord injuries.

In 2000, Barry's wife suffered a spinal cord injury. As she worked toward her adjustment to this life altering event, Barry found he needed some help too. Barry turned to the family peers at Magee. The benefits Barry got from someone else's experience made him want to give something back. He decided to become a family peer.

Barry is motivated to be a peer by the satisfaction he gets helping people by offering them reassurance, support, and practical tips. He hopes he is able to help them avoid some of the mistakes he has made. Fulfillment is "seeing people's facial expressions that are grateful to learn that there is light at the end of the tunnel." They have hope; it may be hard

now but things will get better.

Barry gets a great deal of satisfaction being a family peer. "You are ultimately left with the feeling you are part of a very large family."



The family peer program at Magee Rehabilitation needs more individuals like Barry Oppenheim. If someone in your family has a spinal cord injury and you would like to help other families with new spinal cord injuries, please call **Pat Thieringer** at **215-587-3412** to find out more about becoming a family peer counselor.

The SCI Family Peer Support group meets on the second Thursday of every month at 6 p.m. in Room 537 on the Spinal Cord Injury Unit at Magee Rehabilitation Hospital.

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Thomas Jefferson University



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Magee Rehabilitation

Jefferson Health System®

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SPINAL CORD INJURY SUPPORT GROUPS

SCI-PEERS, BEEN THERE, DONE THAT

The SCI-Peer Consultant Program offers individuals with newly acquired spinal cord injuries the opportunity to benefit from the knowledge and experience of those who have "been there, 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 who are adjusting to their spinal cord injury, mentors can answer questions and address concerns with the knowledge based on their personal experience.

Peers can be matched according to injury level, social situations, age, gender, marital status, recreational interests, and vocational experience.

To request a peer consultation or become a peer mentor contact **Marie** or **Sonya** at **pcoordinator@mageerehab.org** or **215-587-3174**.



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 discussions often address

topics such as relationships, career issues, intimacy, and sexuality.

If you are interested in finding out more about this group or other psychological services, call **Dr. Nancy Rosenberg** at **215-587-3210**.



UNITED SPINAL ASSOCIATION

For over 57 years, United Spinal Association was known as Eastern Paralyzed Veterans Association, serving veterans with spinal cord injury or disease. The United Spinal Association mission has broadened and will now include all Americans with Spinal Cord Impairment. Membership is free and open to all individuals with traumatic spinal cord injury, congenital spinal disorders and spinal cord diseases such as multiple sclerosis and poliomyelitis. United Spinal continues to serve veteran members, while striving to assist a larger community of disabled children and adults.

Benefits include: Advocacy on civil rights issues for individuals with disabilities, home modification grants up to \$5000, advocacy on local, state, and federal legislative issues, guidance from professional staff on the eligibility criteria and application process for federal and state government benefits, and access to a range of exciting adaptive sports and recreational activities.

You can find out more about United Spinal Association online at www.unitedspinal.org or by calling 1-800-404-2898.

SCI RESOURCE & SUPPORT GROUP

You 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 p.m.** in the **2nd Floor Conference Room** (220/222) at Magee.

We are always looking for new topics. Please contact **Marie** or **Sonya** at **215-587-3174** or **pcoordinator@mageerehab.org**.

TENTATIVE TOPIC SCHEDULE

December 2004	Holiday Party
January 2005	Open Forum
February 2005	Funding for SCI
March 2005	Driving
April 2005	Research
May 2005	Travel



Visit the Magee Peer Website at www.mageepeer.org to learn about upcoming events, disability information and resources, peer support, and the sale or donation of durable medical equipment.

RESEARCH & EDUCATION

RESEARCH PARTICIPANTS NEEDED

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 assistive devices or assistance. Individuals will be required to come to Magee



Rehabilitation Hospital on two different occasions for about two hours each visit. Those who participate will be reimbursed \$100 per visit for travel expenses and provided with free parking.

If you are interested in participating or would like more information, please call **Mary Patrick, R.N.**, RSCICDV Project Coordinator, at **215-955-6579**.

Spinal Cord Society

The Spinal Cord Society meets at Magee Rehabilitation on the 6th floor at 1 p.m. on the first Saturday of every month. The Spinal Cord Society puts 100% of its funding into research for the cure of spinal cord dysfunction. If you want to support this research, consider attending one of these meetings. For more information, please contact Chris Cellucci at cellucci@ursinus.edu or 610-296-7429, or Dennis Ledger at dledger@csc.com or 856-468-4401.

NEW RESEARCH STUDY - PARTICIPANTS NEEDED

The Regional Spinal Cord Injury Center of Delaware Valley (RSCICDV) at Thomas Jefferson University, a cooperative program between Thomas Jefferson University Hospital and Magee Rehabilitation Hospital, is interested in evaluating new investigative drugs which may benefit persons with spinal cord injury. The RSCICDV is participating in an international clinical study to evaluate an investigational medication being developed that may improve motor function in individuals with motor incomplete chronic spinal cord injury. We are looking for participants who:

- **Are between 18 – 65 years of age**
- **Have a chronic, motor incomplete traumatic SCI** (at least 18 months post-injury)
- **Have an SCI level between C4 and T10**
- **Have no history of seizures within 2 years prior to study start**
- **Have no evidence of recent fractures (less than six months)**

The study will be double blind and placebo-controlled, which means that some individuals enrolled in these studies will receive a placebo, or sugar pill, for the

duration of the study, and will not receive the drug at any time during the study. Neither the investigators nor the study participants will know who is receiving drug or placebo until after the end of the study.

If you are interested in voluntarily participating in this study, some simple questions over the phone will help to determine if you are eligible. Overall participation in the study will include an initial screening visit and a study treatment period of approximately 26 weeks during which you will visit the SCI Center at Thomas Jefferson University Hospital for 10 outpatient visits. Each of these visits will require about 3 to 4 hours of your time. Reimbursement will be provided to you to cover necessary miscellaneous cost (such as travel) and free valet parking will be provided. Your participation in this research study is voluntary and you can end your participation, if you wish, at any time. Your care at Jefferson and Magee will not be affected if you choose not to participate in this study.

To see if you qualify, please call **Mary Patrick, R.N.**, or **Regina Cameron, R.N.**, at **215-955-6579**. Thank you in advance for your support.

RESEARCH FOCUS GROUP

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

held at Magee. You will be reimbursed for your time and receive free parking.

If you are a person with SCI and would like to participate or would like more information about the project, please call **Mary Patrick, R.N.**, RSCICDV Project Coordinator, at **215-955-6579**.

Important Web Pages

Find information on research, education, and community programs on these webpages:

www.spinalcordcenter.org

www.mageerehab.org

www.mageepeers.org.

RECENTLY COMPLETED Fampridine-SR (4-AP) TRIAL

The Regional Spinal Cord Center of Delaware Valley (RSCICDV) recently completed two Phase 3 multicenter clinical trials of Fampridine-SR (4-AP) sponsored by Acorda Therapeutics. The results of these studies did not reach statistical significance in their primary endpoints, meaning they did not show a reduction of spasticity (as measured by the Ashworth score) and/or an improvement of participant's Subject Global Impression (SGI) rating. However, in one of the studies, the data showed a strong positive trend toward improvement on the Ashworth score or a

decrease of spasticity. This positive trend is consistent with the results from previous Phase 2 studies.

The adverse events, including serious adverse events, seen in these studies were insomnia, paresthesias (numbness/tingling), dizziness and nausea, the majority of which were rated as mild to moderate. However, since Fampridine-SR is an investigational drug, safety and efficacy have not been fully determined. The RSCICDV would like to thank all of those who have participated.



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, Psychology, Podiatry, and Psychiatry are also available.

To schedule a follow-up appointment, please call 215-587-3406.

RSCICDV RESEARCH



Anthony S. Burns, MD, is the Assistant Director of the Regional Spinal Cord Injury (SCI) Center of the Delaware Valley, a partnership between Thomas Jefferson University Hospital and Magee Rehabilitation Hospital. He is the recipient of a research grant from the National Institutes of Health (NIH) to study changes that take place in nerve cells in the spinal cord following a SCI and the connections they make with muscles. For this project he is collaborating with basic scientists in the Department of Neurobiology and Anatomy at the Drexel University College of Medicine.

Small studies from humans have suggested that connections between nerves and muscles

are weakened over time following a SCI. Preliminary results from Dr. Burns' work suggest that a similar process occurs in animals following a SCI. The primary areas affected are the very ends of the nerves where they transmit their signals to muscles. The nerve connections to muscle become unstable. Results from this research were reported in October 2004 at both the Academy of Physical Medicine & Rehabilitation Annual Meeting in Phoenix, AZ, and the Society of Neuroscience Annual Meeting in San Diego, CA.

Future goals of the research include continuing to understand the process better and how it affects recovery following SCI. Long-term, Dr. Burns would like to develop strategies to prevent and reverse the process.

RESEARCH OF THE RSCICDV

Current

A phase II, double-blind, placebo-controlled, multicenter study to assess the efficacy and safety of HP184 at 100, 200, and 400 mg doses administered orally once daily for twenty-four weeks in adult subjects with chronic spinal cord injury. *Sponsor: Aventis Pharmaceuticals.*

A phase I/IIa dose-ranging study to evaluate the safety, tolerability, and pharmacokinetics of BA-210 and the neurological status of patients following administration of a single extradural application of Cethrin® during surgery for acute and cervical spinal cord injury.

Sponsor: BioAxone Therapeutics, Inc.

Restoration of walking after spinal cord injury - elements of a disability measure. *Sponsor: National Institute on Disability and Rehabilitation Research (NIDRR).*



Restoration of walking after spinal cord injury - a consumer preference for walking. *Sponsor: National Institute on Disability and Rehabilitation Research (NIDRR).*

Body weight support/locomotor training in chronic SCI. *Sponsor: Center for Disease Control (CDC) and the Christopher Reeve Foundation (CRF).*

Recently Completed Clinical Trials

Open-label extension of double-blind, placebo-controlled, parallel group study to evaluate safety, tolerability and activity of oral Famipridine-SR in subjects with chronic incomplete spinal cord injury.

Sponsor: Acorda Therapeutics.

Restoration of walking after spinal cord injury - validation of the Walking Index for Spinal Cord Injury (WISCI) scale for hierarchical ranking.

Sponsor: National Institute on Disability and Rehabilitation Research (NIDRR).

Study the effects of Body Weight Supported Treadmill Training in acute incomplete spinal cord injury. *Sponsor: National Institute of Health.*

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.*

Double-blind, placebo-controlled, 12-week, parallel group study to evaluate safety and efficacy of oral Fampridine-SR in subjects with moderate to severe spasticity resulting from chronic, incomplete spinal cord injury.

Sponsor: Acorda Therapeutics.

Eye-voice enablement technology: EVENTech, hands-free computer access for the disabled.

Sponsor: National Institute of Health.

WHEELCHAIR SPORTS

MAGEE PHILLIES SOFTBALL TEAM

Would you like to participate in America's favorite pastime? Consider joining the Magee Phillies Wheelchair Softball team as we prepare for our next season in spring 2005. The team consists of men and women of all ages with various disabilities and different skill levels. The team practices weekly from April through September on J. Hampton Moore School's blacktop field.

This past year the team traveled to Baltimore, New York and New Jersey for competitions. In

addition, The team hosted the Second Annual Phillies Wheelchair Softball Tournament in August, competing against the Boston Red Sox, the New York Mets, and the Long Island Ducks. They also competed in the Wheelchair Softball World Series at Shea Stadium this past September and placed fourth.



To learn more about the Magee Phillies, please call **Pat Thieringer** at **215-587-3412**.

WHEELCHAIR TENNIS

Wheelchair tennis is not much different from able-bodied tennis, as the only change to the rules is that wheelchair players can let the ball bounce twice. Everything else is the same!

Our Magee wheelchair tennis team consists of nationally ranked players who competed this year at tournaments in Baton Rouge, New York, Baltimore, Lehigh, Cherry Hill, Lancaster, and Delaware. Team members Mark Chilutti, Brad Evans, John Kistner, and Felix Suero had successful years in the USTA B division. Felix Suero captured the title in Lancaster, and teamed with Brad Evans to win two doubles titles. Walt Ramsey and newcomer Matt Bellen had great years in the C division. Walt made it to 3 finals, while Matt made it to one. In doubles, the team of Bellen and Ramsey won one title. All six players made

big improvements in their games this past season.

The team continued its partnership with the Philadelphia Freedoms and played at halftime of a pro match for the fourth straight year. This year the team also made their first appearance at the Advanta Womens Pro Tennis Championships at Villanova.

The Magee team practices most Sundays from 10 a.m. - noon at Cherry Hill Health and Racquet Club. There is always room for more players on the team, and we invite anyone interested to stop by and check it out! For more information, call **Pat Thieringer** at **215-587-3412**.



MARTIAL ARTS

Each Monday evening, Magee Rehabilitation Hospital offers a martial arts program suited to both wheelchair users and others with physical disabilities. For the past eight years, Michael Saulino, MD, PhD, a Magee Physiatrist and second degree black belt holder, has offered this martial arts training at no cost to participants. Dr. Saulino teaches an adapted Tae Kwon Do style of karate. In this program, students continue to advance in belt levels on the way to the coveted black belt.



Martial arts can help enhance physical abilities, build confidence, manage stress levels, and decrease vulnerability to physical attack. Students report that as they continue to practice, they notice a significant increase in strength, flexibility, endurance and respiratory control, and a decrease in their pre-existing pain.

The advantages of this program can be enjoyed by everyone. You are encouraged to find out more by observing this innovative program personally. For more information, call **Pat Thieringer** at **215-587-3412**.

Important Web Pages For Advocacy Issues

ADAPT www.adapt.org

United Spinal Association www.unitedspinal.org

Liberty Resources www.libertyresources.org

State Resources www.accessiblepa.state.pa.us

US Department of Justice Technical Assistance www.ada.gov

MAGEE SIXERS SPOKESMEN BASKETBALL TEAM

The Magee Sixers Spokesmen encourage new players to join their ranks this season. New players will learn basic skills and strategies of the sport and play a modified schedule of games against local teams. Equipment and uniforms will be provided in addition to travel expenses for the sport. If you love the game, you have to try this physically demanding team sport!

This is the eighth season the Philadelphia 76ers, one of 19 NBA teams sponsoring wheelchair basketball teams, have partnered with Magee to help support the Magee Sixers Spokesmen. As members of the Sixers organization, the team plays a halftime exhibition at the Wachovia Center, publish a team media guide, receive tickets to Sixer Games and participate in Sixers' Charity

events. This year the team has an exciting schedule of games at tournaments in New York, New Jersey, Virginia and Maryland. We are also invited to play in the United Spinal Goodwill Games in Puerto Rico this April.



For a copy of the Magee Sixers Spokesmen schedule call **Pat Thieringer** at **215-587-3412**. Mark your calendar for two local tournaments: The Carousel Tournament, February 11-13, 2004 and the Dan Sullivan Classic, January 22, 2005 at Temple University. All games are free and open to the public.

MAGEE EAGLES RUGBY TEAM

As the winter wheelchair sports season heats up, the Magee Eagles Wheelchair Rugby Team continue to build on last year's unprecedented success. This year's team features a strong core group of veterans, some with over a decade of rugby experience, as well as a few new enthusiastic rookies who have already begun contributing to the success of the squad. This marks the first full year that the team is being co-sponsored by the Philadelphia Eagles football team.

This year, the Eagles are scheduled to compete in regular season tournaments in Chicago, Pittsburgh, West Palm Beach, and Boston. In addition, the team hosted the 14th annual Best of the East tournament at the RiverWinds Community Center in Thorofare, NJ, on November. After the regular season ends in



February, the team plans to host and compete in the Atlantic Sectional Playoffs in March. A strong showing at the sectional playoffs would guarantee the Eagles a second straight berth in the National Championship Tournament, scheduled to be held in Louisville, KY, in April 2005. Although the team is not looking past this season's regular season matches against other teams from the East and the Midwest, their focus this year is to make a strong drive to get to Nationals and improve on last year's sixth place showing.

As always, the Magee Eagles encourage all prospective players and volunteers to come out and join the wheelchair rugby experience. Practices are held every Thursday from 6-9 p.m. at Carousel House on Belmont Ave., Philadelphia. Please call **Pat Thieringer** at **215-587-3412**, or **AJ Nanayakkara** at **215-205-3076** for more information.

COMMUNITY PROGRAMS

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.

If you have a spinal cord or brain injury and are interested in helping change behaviors and save lives, the Think First Program is looking for you. 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, call **Joe Davis**, Think First Coordinator, at **215-587-3400**.



hireAbility



hireAbility is a non-profit organization located at Magee Rehabilitation Hospital dedicated to assisting people with disabilities who are seeking employment opportunities

throughout the Philadelphia and South Jersey region. Since hireAbility works with a number of area businesses, it receives information on open positions on a daily basis and can refer

you to those for which you qualify. hireAbility also partners with various community agencies that provide computer and assistive technology training as well as other skills training. They can also make referrals to organizations that provide housing programs, transportation information, and many other services designed to help a person get back into the workforce.

For further information, please call **hireAbility** at **215-587-3080**.

COMPUTER TRAINING

Magee Rehabilitation Hospital 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 Word, Typing Tutor, and the Internet.

Students can pick from a variety of class times and topics.

For more information and a class schedule, call **Arezou Bigdeli** at **215-587-3063**.



LEGAL CLINIC FOR THE DISABLED

The Legal Clinic for the Disabled is a non-profit organization located at Magee Rehabilitation Hospital. Its mission is to provide free civil law legal services at no charge for low-income persons with physical disabilities. Cases include wrongful evictions, consumer fraud, employment discrimination, and compliance failures related to the Americans with Disabilities Act of 1990. Other services include estate planning and benefit counseling.

The Legal Clinic for the Disabled would like to work with you regarding any of the above issues. For more information about direct representation or outreach programs, please call the **Legal Clinic for the Disabled** at **215-587-3350**.



Narcotics Anonymous

The Narcotics Anonymous group meets in room 222-224 on Mondays from 5- 6 p.m.

All are welcome to this safe environment for addressing the issues of addiction.

Alcoholics Anonymous

This group continues to meet every Thursday at 8 p.m. in Magee's Cafeteria.

THE ARTS

MAGEE PLAYERS

An invitation to all individuals with physical disabilities who wish to develop their creativity, memory, sense of humor, communication skills, and want to meet new and interesting people from all over the Philadelphia region. Join the Theatre Arts class at Magee!

Some of the theatre techniques participants study include: mime and acting improvisation, comedy playwriting, and mask work. We also work on relaxation and visualization exercises to better prepare the actors for performances and to help reduce stress in students' everyday lives. We will perform in the community this summer.

Further opportunities abound in the theatre arts for future work and scholarships studying with the National Theatre for the Handicapped. In the summer, students from the Magee Theater Program attend the National Theatre for the Handicapped school in Maine.

For more information, please call **Arezou Bigdeli** at **215-587-3063**.

