The Surgeon General has reported that individuals with spinal cord injuries (SCI) can benefit from physical activity much like people without a disability. However, individuals with SCI are less likely to participate in regular physical activities. This is partially because many people with SCI feel as though they are unable to participate because of their physical limitations, lack of access, or they feel that there is no benefit in them participating in physical activity. This is not true. It has been found that most individuals with SCI can get significant health benefits from 20-30 minutes of physical activity every other day. This activity does not need to be strenuous to be beneficial. There is research that says that inactivity and deconditioning may increase your likelihood of urinary tract infections, pressure sores, respiratory infections, and constipation.

Wellness is defined as a process of living healthier and growing in appreciation for yourself. When you feel good physically, you are more likely to feel good about yourself. Health promotion includes all things people do to become healthier and achieve wellness. This includes physical, mental, social, and spiritual health. Health promotion also includes nutrition and weight control, physical activity and exercise, smoking cessation, stress management, and good sleep habits.

Before beginning or changing an exercise program it is important to talk to your doctor. As an individual with an SCI it is also important that you visit your primary care physician and/or the Magee Lifetime Follow Up Clinic at least once a year for a checkup. Always think about your safety first. Always be aware of danger signs such as a headache, chest pain, joint pain, cramping, or increased loss of function. These can be signs that you may have overexerted yourself. They can also be signs of other medical issues such as autonomic dysreflexia or overuse syndrome. If these occur, stop exercising and try to find out what may be causing your symptoms. Lastly, make sure to drink plenty of water when exercising. Water helps a person regulate body temperature and helps with the digestion of food. It can also help prevent urinary tract infections and kidney and bladder stones.

The following is a list of benefits of participating in physical activity after an SCI.

- Lowers risk for premature death and the development of high blood pressure, heart disease, some forms of cancer, respiratory illness, and diabetes
- Helps manage chronic pain, bowel functioning, weight gain/loss, and muscle spasms
- Helps decrease feelings of anxiety, loneliness, depression, and stress
- Helps improve posture, strength, circulation, blood sugar, energy level, bone density, and ability to fall asleep and sleep well

This project is supported, in part, by:
The National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education, Washington, D.C., grant #H133N-000023 and the Friends of Jerry Segal.
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. Subjects will be required to come to Magee Rehabilitation Hospital on two different occasions for about two hours per 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.

NEW PAIN STUDY FOR SCI AT JEFFERSON/MAGEE

The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) at Thomas Jefferson University/Magee Rehabilitation is currently taking part in the SPINAL research study. This study will test to see how well an investigational drug works for pain associated with your traumatic spinal cord injury.

We invite you to consider participation in the study if:

• You have pain associated with your traumatic spinal cord injury
• You are dissatisfied with your current pain treatment
• You are willing to come to our clinic for 8 visits over a 16 week period

Participants who qualify will receive at no cost:

• Study procedures and lab testing
• Study medicines
• Additionally, you may receive compensation for your time

If you are interested in learning more about this research study, please contact us at (215) 955-6579.

PARTICIPANTS NEEDED FOR STUDY ON MOTHERING WITH SPINAL CORD INJURY

Being a mother is an important role for many women, yet relatively little is known about mothering with an SCI, from the perspective of the mother. This study focuses on the experience of mothers with SCI and explores their participation in parental activities, satisfaction with this involvement and sense of well-being. In addition, the influence of social support and perceived health will be examined.

Mothers actively parenting a child or children ages 12 and younger can participate in this study. Women will be mailed a set of four questionnaires, some background questions and a self-addressed stamped envelope. This should take approximately 45 minutes to complete (or she may be interviewed by phone). The confidentiality of all participants will be maintained.

If interested in participating in this study or if you have questions, please contact Ruth Farber, PhD, OTR/L (Temple University, Department of Occupational Therapy) at msmoms@temple.edu or Michelle Sonabend, OTR/L at (215) 901-6175.
NEW RESEARCH PROJECT FOR THE REGIONAL SPINAL CORD INJURY CENTER OF DELAWARE VALLEY!!

Starting this spring, the combined efforts of SCI Center staff from both Thomas Jefferson University and Magee Rehabilitation Hospital will support a new multi-center study entitled “Investigation of Assistive Technology for Mobility used by Individuals with a Spinal Cord Injury”. Working together with SCI Centers in Pittsburgh, Georgia, Chicago, Washington DC, Ohio and Northern New Jersey, we will investigate the impact of policy changes on customizability and features of wheelchairs, and the number of working wheelchairs an individual owns. To collect this information, we will be looking at the specifics of an individual’s wheelchair usage relative to the type of wheelchair they were provided, the amount of wheelchair breakdown, the skill of using the wheelchair and quality of life measures of participation for the individual using a wheelchair for primary mobility. Since it has been shown that reintegration into society following a disability depends on access to appropriate and adequate assistive technology such as wheelchairs, we hope to investigate the effects of the types of presently supplied wheelchairs and how they may be contributing to a person’s functional limitations, even more so than the person’s disability itself. The information (or data) collected over the next four years may then be helpful in effecting policy change, relative to prescriptions for wheelchair mobility equipment.

ONGOING RESEARCH OF THE RSCICDV

Current


2. 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.


Completed Clinical Trials

1. A phase II, double blind, placebo-controlled, multicentered study to access 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.

2. Peripheral denervation following spinal cord injury (Using MRI to study nerve function following spinal cord injury). Sponsor: American Paraplegia Society


6. 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.

URINARY TRACT INFECTIONS

A urinary tract infection (UTI) occurs when bacteria get into the bladder and kidneys and causes an individual to have symptoms. It is important to know the difference between an infection and bacteriuria (having bacteria in the urine, but no symptoms).

**Symptoms** of a Urinary Tract Infection (things you may feel):
- Fever and chills
- Increased spasms of legs, abdomen, or bladder
- Feeling the need to void immediately (urgency)
- Leakage or voiding between catheterizations
- Need to catheterize more often (frequency)
- Burning of the urethra, penis, or pubic area
- Nausea
- Headache, mild low back pain, and fatigue

**Signs** of a Urinary Tract Infection (things you may notice):
- Sediment (gritty particles) or mucus in the urine or cloudy urine
- Bad smelling urine (foul odor)
- Blood in the urine (pink or red urine)

The appearance and smell of your urine may change because of changes in your diet or fluid intake. If you have changes in the urine, but no symptoms, you do not need to seek treatment for a UTI.

PRESSURE MAPPING TECHNOLOGY

Magee Rehabilitation Hospital is privileged to be able to use a computerized pressure mapping system that provides clinicians with another tool to help identify the seating system or cushion that will help clients avoid complications of skin breakdown or pressure sores. Pressure mapping is indicated if a client has past or current skin breakdown or is at an increased risk for breakdown due to his or her diagnosis.

At Magee we use pressure mapping technology to get a general picture of pressure distribution on a particular wheelchair seat cushion. The pressure reading numbers are not looked at as a precise measurement of capillary pressure, but rather give us a picture of overall pressure distribution. This allows us to compare cushions in order to maximize the distribution of pressure on the cushion which can reduce the possibility of decubitis ulcer development. It also allows us to visualize with the client, the effectiveness of their selected pressure relieving technique. It may also guide us regarding the need for wheelchair seating component changes (i.e. backrest angle changes, addition of lateral support). Finally the data can be used to help support the recommendation of one particular cushion or seating feature (tilt, recline) vs. another.
SPINAL CORD INJURY SUPPORT GROUPS

SCI PEERS, sharing experiences

The SCI-Peer Consultant Group provides individuals who have suffered an SCI the chance to learn from those who have rehabilitated following such an injury.

Magee can match peers based on injury level, social situations, age, gender, marital status, recreational interests and vocational experience.

To request a peer consultation, or to volunteer as a mentor, contact Marie Protesto or Sonya Dibeler at peers@mageerehab.org or (215) 587-3174.

SCI FAMILY PEERS

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. Family members and significant others of individuals who have had a spinal cord injury are encouraged to attend. Inpatient and outpatient families are welcome. Family Peer Counselors offer reassurance, support and helpful practical tips.

This group meets on the third Wednesday of every month at 6 p.m. in the 5th floor lounge on the Spinal Cord Injury Unit at Magee Rehabilitation Hospital.

For more information, call Pat Thieringer at (215) 587-3412 or pthieringer@mageerehab.org.

SCI RESOURCE GROUP

This group provides education, recreation and support opportunities to individuals with spinal cord injuries. Traditionally, meetings are held at Magee on the second Thursday of every month at 6 p.m. in the Second Floor Conference Room. However, social outings are scheduled based on availability and pricing.

We are always looking for new topics. If you have an idea for a topic or would like more information, please call Marie Protesto or Sonya Dibeler at (215) 587-3174, or e-mail peers@mageerehab.org.

WOMEN’S DISABILITY SUPPORT GROUP

To help women with spinal cord dysfunction explore their thoughts and feelings about life with a disability, Magee provides a support group each Monday afternoon. This group addresses topics such as relationships, career issues, intimacy and sexuality.

For more information about this group, call Marie Protesto or Sonya Dibeler at (215) 587-3174.

The Spinal Cord Society (SCS) is a large grass roots organization with thousands of members throughout North America and other countries. Its goal is to find a cure of chronic spinal cord injury paralysis. SCS puts 100% of its funding into research for the cure of spinal cord dysfunction.

The SCS meets at Magee Rehabilitation on the 6th floor at 1 p.m. on the first Saturday of every month. If you would like 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.
WHEELCHAIR SPORTS

MAGEE FREEDOMS TENNIS TEAM

The Magee wheelchair tennis team has a full schedule lined up for this year. Members of the team will travel to Florida, Pennsylvania, New York, Maryland, Delaware and St. Louis to compete in top level tournaments. Building on their success from last year, the team features the #1 ranked B division doubles team of Felix Suero and Brad Evans, as well as Mark Chilutti, Matt Bellen and Walt Ramsey.

The team practices most Sundays at Cherry Hill Racket Club from 12 to 2 and has been receiving coaching help each week from a local pro. The rules of wheelchair tennis aren't very different. The only change is that the players are allowed two bounces of the ball.

Magee Rehabilitation will be partnering with Carousel House and Moss Rehab to present the Philadelphia Wheelchair Tennis Tournament at Cherry Hill Racquet Club, in Cherry Hill, New Jersey from August 2 through August 4, 2007.

If you are interested in seeing wheelchair tennis, or want information on our local tournaments, please contact Pat Thieringer at (215) 587-3412 or pthieringer@mageerehab.org.

The Seventh Annual Night of Champions
Friday, May 11, 2007

The star-studded event includes dinner, live and silent auctions and raffle prizes, all for a great cause! This event raises funds for Magee Community Programs which support various Magee programs for individuals with disabilities, including wheelchair sports, computer training, peer member programs and injury support groups.

Billy Cunningham, Scott Palmer, John Harbaugh, Brian Propp, and Howard Eskin are among some of the celebrities attending. The 2007 Champion in the Community award will be presented to Dr Bob Carr and Howard Eskin in honor of their generous support of Magee’s patients and programs.

For more information on the Night of Champions, including sponsorship or auction donation opportunities, please call Magee’s Development office at (215) 587-3090.

LIFE — BE IN IT!

Staying active is the key to a happy and healthy life. Magee Rehabilitation and other Philadelphia agencies offer numerous specialized recreation opportunities at little or no cost. For more information on additional Magee sports and other specialized recreational opportunities, please consult the Magee Recreation Resource Guide.

For a copy of the resource guide, please email Pat Thieringer at pthieringer@mageerehab.org.

Informative Websites

National Spinal Cord Injury Association - www.spinalcord.org
Amputee Coalition of America - www.amputee-coalition.org
Brain Injury Association - www.biausa.org
American Stroke Association - www.strokeassociation.org
National Multiple Sclerosis Society - www.nationalmssociety.org
# MAGEE WHEELCHAIR SPORTS TEAMS

<table>
<thead>
<tr>
<th>SPORT</th>
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<th>PRACTICE TIMES &amp; LOCATIONS</th>
<th>SEASON</th>
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<tr>
<td><strong>Magee Eagles</strong></td>
<td>Quad Rugby is a unique, competitive sport for individuals with quadriplegia. The game is played on a basketball court by four-member teams using a volleyball. The objective is to carry the ball across the opponent's goal line.</td>
<td>Thursdays, 6 pm-9 pm, Carousel House Belmont &amp; North Concourse, Philadelphia Sundays, 12 pm-2 pm, Old Pine Community Center 401 Lombard Street, Philadelphia</td>
<td>The season runs from October through March. Each year the team competes in tournaments all along the East Coast and regularly qualifies for the national playoffs.</td>
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<tr>
<td><strong>Magee Sixers Spokesman</strong></td>
<td>The Magee Sixers Spokesmen are one of 18 teams nationally that are affiliated with their local NBA teams. The Sixers Spokesman are nine-time Mid-Atlantic Conference Champs! New players are encouraged to join our developmental team.</td>
<td>Developmental Team Wednesdays, 6:30-9 pm, Christy Rec Center 56th &amp; Christian Philadelphia Division II Team Wednesdays, 6:30-9 pm, Carousel House Belmont &amp; North Concourse, Philadelphia</td>
<td>The season runs from October through March. The team competes in games and tournaments along the East Coast! The Magee Sixers are ranked in the Top Ten Teams in the country.</td>
</tr>
<tr>
<td><strong>Magee Kixx Power Soccer</strong></td>
<td>A new sport for power wheelchair users, played on a basketball court with four players who attack, defend and maneuver an oversized soccer ball in an attempt to score points on a goal.</td>
<td>Sundays, 12 pm-3 pm Old Pine Community Center 401 Lombard Street, Philadelphia</td>
<td>The team is encouraging the growth of other teams in the area to allow for local competitions.</td>
</tr>
<tr>
<td><strong>Magee Freedoms Tennis</strong></td>
<td>Wheelchair tennis can readily be enjoyed with able-bodied friends. The sport follows the rules of the U.S. Tennis Association with one exception—the wheelchair tennis player is allowed two bounces instead of one.</td>
<td>Sundays, 12 pm-2 pm Cherry Hill Racquet Club, New Jersey</td>
<td>The season runs from March through October. Each year the team competes in tournaments throughout the country.</td>
</tr>
</tbody>
</table>

## Websites & Contacts for Health & Fitness

- www.spinalcord.uab.edu
- www.craighospital.org/SCI
- www.sharp.com/services
- www.richealthfit.org/programs/progdesc.htm
- www.nationalwellness.org

Pennsylvania Center for Adapted Sports—www.centeronline.com
Magee Adapted Wheelchair Sports Program—pthieringer@mageerehab.org
COMMUNITY PROGRAMS

THINK FIRST
To help prevent disabling head and spinal cord injuries among children, teens and young adults, Magee’s Think First Program holds dynamic presentations at schools. Our program is part of the nationally coordinated Think First program. Presentations consist of injury prevention lessons and testimonials from adults with disabilities.

If you have a spinal cord injury or brain injury and are interested in changing behaviors and saving lives, please consider joining Think First and speaking to students. Because Magee values your experience we will reimburse you for your time.

If you are interested, or know of a school that would like to host one of our assemblies, please call Joe Davis, Think First Coordinator, at (215) 587-3400.

Narcotics Anonymous
The Narcotics Anonymous group meets every Sunday at 7 p.m. in room 222-224. All are welcome to this safe environment for addressing the issues of addiction.

Alcoholics Anonymous
This group meets every Tuesday at 8 p.m. in Magee’s Cafeteria.

For more information about NA or AA, please call Joe Davis at (215) 587-3400.

HIREABILITY
hireAbility is a nonprofit organization dedicated to helping individuals with disabilities seek employment throughout Philadelphia and South Jersey. Headquartered at Magee Rehabilitation Hospital with offices in Blackwood, NJ, hireAbility works with a number of area businesses and receives daily updates on open positions in the region.

The organization also partners with various community agencies that provide computer and assistive technology training as well as other skills training. In addition, hireAbility can refer you to organizations that provide housing programs, transportation information and other services designed to help individuals return to work.

hireAbility is offering a Job Search Workshop. This is a fun, informative, interactive week-long session to learn how to get the job you want from the professionals with proven results. This is offered in conjunction with their Job Search “Club” and Support Group. Some of the goals of the Job Club are to provide strategies to obtain and maintain employment, practice interview skills, and networking.

For more information, please call (215) 587-3080.

LEGAL CLINIC FOR THE DISABLED
The Legal Clinic for the Disabled provides free civil law legal services to low-income individuals with physical disabilities. Located at Magee Rehabilitation Hospital, the nonprofit organization can help with cases involving wrongful evictions, consumer fraud, employment discrimination and failure to comply with the Americans with Disabilities Act of 1990. Other services include estate planning and benefits counseling.

The Legal Clinic would like to work with you regarding any of the above issues.

For more information about direct representation or outreach programs, please call (215) 587-3350.
MAGEE PLAYERS

The Magee Players will be beginning their 7th year at Magee this Spring, on April 20, 2007 with a new theatre/acting class from 11:00-12:00 p.m. for new students as well as begin rehearsals for the Magee Players. This group has been studying theatre and performing at Magee since 2000 and has had 14 shows at Magee. The Magee Players have also performed in the community at Inglis House and Nursing Homes in the area. Last spring the class was featured on WHYY’s “Circle of Care”, a documentary about the arts and its power to help people with disabilities and healing. Many of the more advanced Magee Players have received scholarships to study acting and singing for a ten-day course at the National Theatre for the Handicapped in Maine for the past four summers and have been asked to return.

The Magee Players is the only theatre group/class for adults with disabilities in the city of Philadelphia and has the unbelievable tuition fee of only $15.00 a term or free for many that have volunteered at Magee or cannot afford the full tuition. Our students come from all over the tri-state area and have a wide range of disabilities, (such as people who have suffered from strokes, paralysis, cerebral palsy, visual impairments, etc.)

Students learn mime, mask making, acting, improvisation, play writing, poetry, painting on fabric textile and set design. The courses have been taught and directed by theatre artist Barbara Gregson. The courses run for 10-14 days once a week for several hours during the Fall and Spring terms. We have also worked with a variety of professional artists, such as sculptors, poets, storytellers. fabric painters, and musicians. Each show has been written by the Magee players, directed by Barbara Gregson and is accompanied by original live music. Our musicians have been Josh Robinson and Skip Burton.

We now move on to our 7th season and are proud to announce that we have been asked to participate in the first Arts/Theatre Festival specifically created for artists with disabilities to showcase their work. The festival will be held in October-November in the City of Philadelphia. We will be playing in a professional theatre space as well.

Please call Mari Doran at (215) 587-3203 or Barbara Gregson at (267) 886-9554 to register for the new theatre class on Fridays 11:00-12:00 pm and for further information.

THE ARTS

PATIENT FAMILY RESOURCE CENTER & MEDICAL LIBRARY

Are there wheelchair accessible hotels in Philadelphia? Where can I buy a home access ramp? How does my injury affect my spouse and family members? What are the latest therapies related to my injury or medical condition? These questions are the order of the day for the Magee Patient Family Resource Center and Medical Library.

Staffed by a medical librarian, our facility has a unique collection of books, journals, tapes and other media to answer questions related to physical disability. Guests are also free to use our computers for Internet access and browse our leisure reading collection of daily newspapers, popular fiction, books on tape and large print books.

For more information, contact Laura Koepfner, MLS, Library Service Manager, at (215) 587-3423 or lkoepfler@mageerehab.org.

Hours of operation
Monday and Friday
8:30 am - 5:00 pm
Tuesday, Wednesday, Thursday
8:30 am - 8:00 pm
Sunday
1:00 pm - 5:00 pm
CONSUMER ARTICLES

TRAVEL TIPS, PART 2 - HOTEL ACCOMMODATIONS

Mark Chilutti

I never knew that “handicap accessible” or “wheelchair accessible” had so many different definitions until I tried to reserve a hotel room. I didn’t think that being able to take a shower would be a “bonus” when staying in a hotel, but, often that has turned out to be the case. There are still some measures that can be taken to ensure that you understand what type of accommodations hotels offer. So, here are some tips to follow when booking a room:

Call the hotel directly. While a toll free number might seem like the easy route to go, often the person you are speaking with is not in the actual hotel you want to reserve a room in. When you call the hotel directly, you can get better answers as to what type of rooms they have available.

Ask a lot of questions. Does the room have a tub or a roll-in shower? If it’s a tub, do they have a bench to transfer on to? If it’s a roll-in shower, do they have a shower chair there?

Be very direct in seeking the answers to your questions. Many times I have found that the people with the best answers were in the housekeeping department. You can also ask them to check the room out and give you a call back.

Remind them that just like every other paying customer, all that you want is to be able to sleep in a bed, use a bathroom, and take a shower. This should not seem like expecting too much, right???

If you need transportation from the airport, ask if they have a free shuttle. Once they tell you that they do, then ask the important question.....is it accessible? The answers will vary. If it is not accessible, ask them how they can help you. They should realize that they need to make arrangements for you, and usually are helpful. I have had some experiences where they have arranged for a cab and paid for it, and some have set it up with an accessible shuttle from somewhere else. Again, all you are expecting is the same things that they offer to all of their customers.

OK, so now that you were successful in reserving a room that should meet your needs, here are some things to look for upon arrival:

I usually head straight for the bathroom to make sure it is what I was expecting and that it will work. Sometimes they might put you in a different room than you had requested, and there is no point settling in until you know it will work.

Look for the shower chair, if you need one. If it is not there, just ask them to bring it up to the room.

If I am staying by myself, I also look to see that I can reach the hand-held shower unit. Often it is too high, and it is easier to ask someone to lower it now than when you are ready to shower!

Look to see that the phone and/or alarm clock are on the side of the bed that you will be sleeping on and within reach. If not, ask someone to move them over for you.

Remember that the hotel staff wants to make your stay enjoyable, so don’t feel like you are bugging them. They are happy to help with these little things that are very important to those of us with special needs!

The last area to be aware of is these new, super high beds that are popping up in hotels these days. When I look at them, I often think that an able-bodied person would need a step ladder to get into them, so how can I???

If your room has a high bed, ask them to lower it. They can take it off of the frame and bring it down to a more functional height without too much effort. Don’t struggle to get into bed and risk your safety! After all, remember that you are paying for this room!

I have found the staff at most hotels to be very helpful and accommodating. Often, they go out of their way to help, and when they do, be sure to thank them for their efforts. Everyone likes to be told they are appreciated, and they are in the service industry, so when they do good work, it is our responsibility to recognize them accordingly.

I also would suggest that when you find a particular hotel chain or local hotel that works for you... stick with them! I tend to travel to Dallas several times a year and, by staying in the same hotel, I can tell them which room I want to stay in, remind them to lower the bed before I get there, and arrange for an accessible taxi.

I hope that these tips will be helpful to you as you make hotel reservations. Oh, one thing I forgot to tell you...just in case things don’t work out with the shower, try washing your hair in the sink. I have often resorted to that rather than sacrificing my safety in the shower. If all else fails, I always bring a baseball hat along!

Happy travels!