Scott Simpkins suffered a C4-5 spinal cord injury from a mountain bike accident on vacation in 2000. Besides working full-time, he is committed to helping individuals living with paralysis.

Scott started advocating for the cure of spinal cord injuries after the death of Christopher Reeve. “It was a wake up call for me. Before his death, it was easy. Someone did it for you. It was Christopher Reeve - Super Man.” Scott knew he had to advocate for himself. “Cure is no longer a question of when. We need to work together to get out of chairs.”

Scott joined an online community of individuals with spinal cord injuries on the internet at Carecure.org. This group is a grassroots movement for the support of the Christopher Reeve Paralysis Act. He continued his efforts by contacting his local senators and representatives. In 2005, Scott attended his first rally in Washington D.C. with up to 200 people with spinal cord injuries, Dana Reeve, celebrities like Susan Sarandon, and politicians. This was Scott’s first trip since his injury. “It was empowering.” Unfortunately, the bill has not made it out of committee.

Scott attended another rally in Washington in April 2006. Just before this rally, Dana Reeve lost her battle with lung cancer. Sadly, with the passing of both Christopher and Dana the Act is losing exposure. Scott continues to send emails to people regarding the bill to raise awareness. “The bill is not controversial. Unfortunately, Christopher Reeve’s name is linked with stem cell research. Stem cell research is not part of the CRPA.” The legislation focuses attention on research related to paralysis resulting from a variety of neurological events and encourages cross-discipline and cross-institution collaborations.

Scott is also advocating for the Stem Cell Research Enhancement Act. This act will provide government funding for stem cell research. This bill was recently passed by both the Senate and House of Representatives.

Unfortunately, the bill was vetoed by President Bush. It is the only time President Bush has used his power of veto. In addition to this stem cell bill, Scott is working to have the NJ assembly put a referendum on the ballot to determine if there is support for a stem cell center in New Jersey. There is $200,000,000 in a stem cell bond to establish a center for stem cell research and bring in scientists. So far the Assembly has resisted putting the referendum forward.

In advocating for himself, Scott feels a sense of self-achievement. He can make a difference. An added bonus is that he is meeting other people in similar situations from around the world.

Scott stresses that being an advocate doesn’t have to take a lot of work. “Anyone can do it. You don’t have to attend a rally. Just pick up the phone and call your politicians. Send an email or write a letter.” Family and friends can also be involved. Spinal cord injury affects the lives of everyone around you. “If you tell your story, it gives a lot more credence to what you are fighting for.”

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.
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. 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 each visit. Participants 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.

The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) a partnership between Thomas Jefferson University Hospital and Magee Rehabilitation Hospital, will receive a $2 million federal grant to allow the center to continue its work to research and treat spinal cord injuries.

In addition to awarding Jefferson University $464,000 per year for a five-year period, the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education again designated the RSCICDV as a Model Spinal Cord Injury System of Care for a five-year period, making it one of only 14 such facilities in the United States and the only one in the Delaware Valley.

For the last five-year grant cycle, there were 16 federally-designated centers in the U.S. Jefferson/Magee have been funded as a Model Spinal Cord Injury System of Care since 1978. To qualify, a center must demonstrate that it has a comprehensive system of care for persons with spinal cord injury and that it can participate in education and collaborative and on-site research.

“Our staff is very proud to be recognized again as a center of excellence in clinical care and research,” said Ralph J. Marino, M.D., clinical director of the Regional Spinal Cord Injury Center, Thomas Jefferson University Hospital, Philadelphia, and associate professor of Rehabilitation Medicine, Jefferson. “We are gratified by the NIDRR’s support of our work through this funding.”

“We are especially pleased to be able to continue the support of those we serve in the community”, said Mary Schmidt Read, PT, MS, SCI Program Director at Magee Rehabilitation. “Over the years, the RSCICDV has been a strong lifelong resource for persons with spinal cord disorders.”

The Regional SCI Center of the Delaware Valley is a collaborative program with experts in orthopaedics, neurosurgery, rehabilitation medicine, trauma surgery, neuroradiology and urology, providing a continuum of care at both Thomas Jefferson University Hospital and Magee Rehabilitation Hospital. Jefferson and Magee have been named by U.S. News & World Report in the magazine’s “America’s Best Hospitals” issue as among the top medical rehabilitation facilities in the nation.

The center, which has treated more than 3,000 persons with spinal cord injury, provides for the multidisciplinary coordination of emergency and acute medical/surgical care, rehabilitation beginning at the onset of acute care and continuing lifetime, vocational evaluation and training, and lifetime follow-up care for persons with spinal cord injury. With over 50 percent of persons with spinal cord injury admitted within three days of injury, the Regional Spinal Cord Injury Center has demonstrated a mortality rate of five percent and has significantly reduced the severe secondary complications of traumatic spinal cord injury.
WORLD CONGRESS & EXPO ON DISABILITIES

The World Congress & Exposition on Disabilities is here for the second year at the Pennsylvania Convention Center on November 17 – 19, 2006. It’s your chance to meet with over 200 exhibitors representing a wide range of industries and associations including pharmaceutical, assistive technology, automotive, mobility, durable medical equipment, personal care, computer and many others. You’ll learn about new products and services that are helping improve the lives of those with disabilities. You’ll be thrilled at the athletic prowess of Magee’s wheelchair athletes as they demonstrate wheelchair rugby, power soccer, and wheelchair basketball. Gather information, compare products and services, or take advantage of discounted pricing and show specials. And don’t forget to visit the Philly non-profit pavilion to learn about local agencies and services for people with disabilities. For more information, contact 201-226-1446 or www.wcdexpo.com. Register online for free admission!

ONGOING RESEARCH OF THE RSCICDV

Current

1. 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.

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


Completed Clinical Trials


4. 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.


7. 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.
NEURORECOVERY NETWORK EXPANSION

An exciting opportunity exists at Magee Rehabilitation Hospital, titled the NeuroRecovery Network (NRN). This network is supporting the translation of basic science and applied research into intensive activity-based rehabilitation treatments. Last year, as part of this network, we established an outpatient “LOCOMOTOR TRAINING CLINIC” at Magee, 1513 Race Street, Philadelphia, PA. This year we expanded this clinic to our Riverfront Outpatient facility on Delaware Ave.

The Locomotor Training (LT) Clinic at Magee Rehabilitation Hospital offers a comprehensive outpatient therapy program for ambulation training. “Locomotor Training” is a rehabilitative approach for persons with neurologic dysfunction that has been studied and proposed to affect a person’s recovery of walking and community ambulation. This intervention is based on current knowledge of how the brain and spinal cord control stepping and how the nervous system learns a motor skill. Present studies are also looking at the effect of this intervention on overall health, including cardiovascular functioning, bone density and spasticity.

Therapy sessions include time spent retraining on the BWST system, and transposing the skills practiced on the treadmill to the over-ground environment and into functional skills (ambulation, transfers, self-care activities, etc.). At this time, referrals for this outpatient therapy are being taken for individuals with a history of motor incomplete spinal cord injury. Anyone referred to this clinic must be evaluated for appropriateness and medical stability for this intervention. All standard outpatient therapy procedures will be followed.

For further preliminary information on what this therapy includes, or appropriateness, you may directly contact the Locomotor Training Clinic, (215) 218-3915 or locomotoreclinic@mageerehab.org.

SPINAL CORD SOCIETY

The Spinal Cord Society (SCS) is a large grass roots organization with thousands of members throughout North America and other countries. Its goal is 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.

This group also provides education on the status of national and international research for the cure. The majority of members are individuals with spinal cord injuries and their loved ones.

For more information, please contact:

Chris Cellucci at (610) 296-7429 or cellucci@ursinus.edu
SPINAL CORD INJURY SUPPORT GROUPS

SCI PEERS, sharing experiences

The SCI-Peer Consultant Group provides individuals who have suffered a 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 pcoordinator@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.

SCI RESOURCE & SUPPORT 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 pcoordinator@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.

Visit the Magee Peer Website at www.mageepeers.org. The Magee Peers Website is the first of its kind. The entire site is specifically for persons with spinal cord injuries. www.mageepeers.org contains disability information and resources, learn about upcoming events, peer support, and the sale or donation of durable medical equipment. Links to OVR, DVR, and hireAbility are provided.
WHEELCHAIR SPORTS

THE ZEN OF WHEELCHAIR RUGBY

BY ADAM G. WHEELER

The first time I sat in a rugby chair I felt like Lance Armstrong hopping into a Formula One Racer. The speed, agility, and feel were nothing like my everyday wheels. I felt powerful. I felt like I had been wasting my time since sustaining a spinal cord injury six years before; finishing my degree, focusing on work, ignoring the athletic instincts that had helped shape my entire life. I rolled onto the court that night and pushed with everything I had, never stopping for two glorious hours. I hit other people in wheelchairs. I rammed into them with all the force I could muster, disregarding technique or strategy. In my mind I was back on the football field, sprinting towards the end zone, kicking field goals, tackling halfbacks. I crashed repeatedly into the floor, struggling each time to pull my paralyzed body back up into the chair. Small beads of sweat welled up on my forehead as my fingers became blackened by rubber and blistered from friction. I was born again.

But who would’ve ever thought “Wheelchair Rugby?” The entire concept of quadriplegics crashing their wheelchairs...it’s illogical. I was an athlete. I had scholarship offers for football and dreams of playing professional basketball in Europe. Now I was paralyzed. I was a wheelchair user that needed to have a family, get a good job, and prove to the world that I was not crippled or handicapped. My athletic days were a passing moment of glory.

Then again, athletics have always had meaning much deeper than physical attributes. The gladiators actually fought for their lives while entertaining the roaring masses. The Greeks showcased their athletic prowess to the world, symbolically demonstrating dominance and power. Even today, athletics are much more than homeruns and slam dunks. Sports teach discipline, hard work, humility, achievement, and perhaps most importantly, the power to succeed. Wheelchair rugby has every component of true athleticism, combining speed, strength, strategy, and endurance. But much deeper than that, it has the ability to evoke ambition and the power to heal what science cannot.

In my 12 short years of an injured spinal cord, I’ve discovered a much deeper meaning in many parts of life. But, I would have never guessed that a personal love of sports would become the catalyst of my personal recovery, ambition, and mission. For all of us, it all starts with a simple transfer into a wheelchair very different from our own. A wheelchair with the dents, scrapes, and crashes of LIFE scarred all over it...standing strong and ready for action. A chair that is capable of transforming you into an unstoppable force, a storm, driven to accomplish more than you had ever set out to do. It is a bone-crushing tool capable of guiding a damaged spirit to the highest channels of enlightenment.

To learn more about the power of Wheelchair Rugby, consider joining the Magee Eagles Wheelchair Rugby team by contacting Pat Thieringer at (215)587-3412 or pthieringer@mageerehab.org. Stop by the Beast of the East Wheelchair Rugby Tournament, November 3-5 at Riverwinds Community Center in West Deptford to witness the National Champion Magee Eagles team deliver the hits.

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.
MAGEE SIXERS SPOKESMEN BREAK TOP TEN

The Magee Sixers Spokesmen joined the elite ranks of wheelchair basketball this past season by breaking into the Top Ten rankings of the National Wheelchair Basketball Association. During the ’05/’06 season the team experienced incredible growth in both size and skill level. With a strong core of seasoned veterans and a young crop of new talent, the upcoming season promises to be our best ever.

With a roster of 24 athletes Magee fielded both an elite Division II team and a developmental Division III team. While the incredible skills of our Division II team are highlighted in the media, the Division III team quietly introduces new athletes to the sport each season. The real thrill of victory for the rookie players is to rediscover the joy of athleticism through the fast-paced game of wheelchair basketball. Novice players are introduced to the sport through veteran players and coach Joe Bradley, a wheelchair basketball player with 30 years of experience.

Both teams have a tough tournament schedule this season which demands extensive tournament travel. But you can catch teams both at home at the Sullivan Classic on December 16-17 at the Riverwinds in West Deptford, New Jersey. To join the team or receive a copy of our full schedule, please contact Pat Thieringer at (215) 587-3412 or pthieringer@mageerehab.org.

MAGEE KIXX POWER SOCCER

Some great people have already turned out for this exciting new sport and we are always looking for more players for our Power Soccer Team. Power Soccer is a game ANYONE in a power wheelchair can play. Two teams of four power chair users attack, defend, and maneuver an oversized soccer ball in an attempt to score points on the opponent’s goal. The game is similar to the non-stop action seen in a typical indoor soccer game. Power Soccer is the first competitive team sport designed and developed specifically for power wheelchair users. Players include persons with quadriplegia, multiple sclerosis, cerebral palsy, muscular dystrophy, head trauma, stroke and other disabilities.

Sports do more than exercise your body - they engage your brain. A catastrophic injury may have disabled your body, but your mind is fine and inner fire still burns. Watching sports and rooting for your team is fun, but nothing compares to a little friendly competition. The will to win, the competitive spirit of an athlete is in no way diminished because of the use of a wheelchair.

Recently, teams from around the world met and set up international rules. These new rules will enable power soccer to be considered for the Paralympics.

Equally exciting is the sponsorship of the Philadelphia Kixx this year. As sponsors, the Kixx will be providing jerseys for the team.

Please join us! To sign up, please contact Pat Thieringer at (215) 587-3412.
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. Since 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.
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 Koepfler, MLS, Library Service Manager, at (215) 587-3423 or lkoepfler@mageerehab.org.

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 serviced 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 of outreach programs, please call (215) 587-3350.

MAGEE PLAYERS

Magee Rehabilitation Hospital is hosting a theatre arts program for individuals with disabilities in the Philadelphia region. This marks the seventh year Magee has provided this program.

Participants will study a number of performing art genres including improvisation, play writing, mime, acting and comedy. The class is also designed to help individuals enhance memory, analytical and communication skills, body awareness, creativity, self-confidence, public speaking, flexibility and social skills.

Registration for the class is $15.

For more information or to register, please call (215) 587-3063.

THE ARTS

Hours of operation
Monday, Wednesday, Friday
8:30 am - 5:00 pm
Tuesday and Thursday
8:30 am - 8:00 pm
TRAVEL

This is a new section offering tips and stories on traveling with a disability written by Mark Chilutti. Mark is the Director of Major Gifts at Magee Rehabilitation.

Travel Tips for Individuals with Disabilities

Travel for individuals with disabilities is easier than you might think and, with the proper amount of advance planning, can be as smooth as silk!

Since my injury almost 10 years ago, I have traveled extensively in the air and at sea. I’ve found that the best way to be assured of the service that I need is to actually know what I need, and how people can help me. In this article, I will focus on some tips for travel by air.

I book most of my flights online. Many of the major air carriers give you the opportunity to list special needs (like needing a wheelchair, etc) on their website. I always do this, but don’t stop there. I will always place a follow-up call to the airline to reinforce my needs, as well as to talk about my seating needs/assignments. A lot of times you cannot access the best seats at the front of the plane without actually talking with someone live.

I always arrive at the airport in plenty of time to be able to check in, pass through security, and get to the gate with time to spare. Once the representatives that will be working my flight arrive, I will approach them to remind them that I need an aisle wheelchair to get me from the jet way to my seat, and also that I need to “gate check” my chair. This gets a special tag on my chair so that once we arrive it will be delivered to the gate for me when I depart the plane. I also make sure that I am assigned to a seat that will work best for me, as the gate agents know the plane the best, plus have the ability to access any seat on the plane. Sometimes, they might even upgrade you to first class!

I will honestly tell you that despite the few bad stories that you may have heard, taking a flight somewhere is really an easy thing to do. I will also remind you that a smile and a positive, helpful attitude make the whole experience much better for everyone involved! Say thanks, and let them know you appreciated the help that they provided. That helps them appreciate the work that they do, and makes them that much more willing to help the next passenger with a disability that needs their assistance. Get out there and enjoy the friendly skies!