AJ Nanayakkara suffered a spinal cord injury in 1994 that left him with quadriplegia and a poor outlook on life. After learning about Magee’s quad rugby team, AJ realized life, though different, can go on.

As a member of the Magee Eagles quad rugby team, AJ always strives to be the best at whatever he does. According to AJ, he is not by nature an athletic person, so he feels that he must work harder than everyone else just to be an average athlete. His motivation to be the best makes him train even harder. “I love the game of quad rugby! My position in any line-up is usually considered the weakest link on the floor. In order to give my team the best chance to win, I must be as strong and as fast as I can be. I live to be able to shut down an opponent who is supposed to be much better than me!”

AJ Nanayakkara chose to test his athletic skills against the nation’s top wheelchair rugby athletes. He was invited to try out for Team USA’s developmental squad. AJ held his own and was named to the 16-member squad.

As a member of the 2005 Team USA Wheelchair Rugby squad, A.J. traveled to Rio de Janeiro, Brazil, to take on the best wheelchair rugby teams in the world. Nanayakkara’s USA Stripes team took home the gold medal.

“I was very proud and honored to represent my country at the World Wheelchair Games,” says AJ. “It was a cool feeling when they put the gold medal around my neck. To be considered one of the best in the world at what you do is a great feeling. My parents were there watching, and they were very proud.”

AJ’s family has been very instrumental in his success as a person. Throughout his years of depression and hopelessness, his family, especially his parents, were always loving and non-judgmental. He has only recently begun to appreciate the support and love that his family has given him through the years. “My family’s pride in me is one of the biggest motivators in my life,” says AJ.

AJ is looking to the future. He is training to make the U.S. Olympic team some day. He hopes through hard work and a consistent training regimen to earn a spot on the team that competes in Beijing in 2008 or London in 2012. As for the Magee Eagles, AJ’s goal is to help them be the best team that they can be. He hopes to eventually get into coaching quad rugby and help teach new players to appreciate the game.

“There are so many potential rugby players in the Philadelphia area who could benefit from coming out for the team, and I want to introduce the game to as many new initiates as possible.”

Nanayakkara also gets a great feeling helping other wheelchair users. As a member of Magee’s volunteer Spinal Cord Injury (SCI) Peer Mentoring Program, he helps lead inpatient groups and conducts one-on-one...
The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) at Thomas Jefferson University, a cooperative program between Thomas Jefferson University Hospital and Magee Rehabilitation Hospital, recently participated in a study to evaluate the effect of HP184, an investigational medication, on improving motor function for individuals with motor incomplete chronic spinal cord injury. Results of this study will be reported in the future, following data analysis and publication. Thanks to all those who participated. A follow-up study is planned for the Fall/Winter 2006.

**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 2 different occasions for about 2 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.

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**RESEARCH & EDUCATION**

**HP184 STUDY COMPLETED**

The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) at Thomas Jefferson University, a cooperative program between Thomas Jefferson University Hospital and Magee Rehabilitation Hospital, recently participated in a study to evaluate the effect of HP184, an investigational medication, on improving motor function for individuals with motor incomplete chronic spinal cord injury. Results of this study will be reported in the future, following data analysis and publication. Thanks to all those who participated. A follow-up study is planned for the Fall/Winter 2006.

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**GRANT AWARDED**

Anthony Burns, M.D., Assistant Director of the RSCICDV, was recently awarded a grant from the American Paraplegia Society, titled “Peripheral Denervation Following Spinal Cord Injury” which uses Magnetic Resonance Imaging (MRI) to study nerve function following spinal cord injury. After sustaining a spinal cord injury, the signals that travel from the brain to the body are interrupted. When the injury is severe enough, the individual is paralyzed and unable to feel his or her body below the injury. There is some evidence in the medical literature that nerve cells and nerves cut off from the brain become sick and some may even die. Despite being first described over 30 years ago, little is known about this process. It is important to understand this process better because treatments that restore signal conduction through the injured spinal cord, for example stem cell transplants, will require healthy nerves below the injured area. In this study, we want to use special MRI techniques to study how healthy the nerves are in the paralyzed muscles below a spinal cord injury. We hope to be able to identify which muscles are abnormal and how severely the nerves are affected. The information obtained will be important to know in order to maximize the beneficial effects of future treatments.

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AJ NANAYAKKARA continued from page 5

peer counseling. He listens to patients and empathizes with them as well as educates them on practical tips for performing activities related to daily living and staying healthy. “It makes me feel good to talk to patients at Magee because I can relate to them,” he says. “If I can help incoming patients adjust better, then that makes me proud. My main piece of advice to someone with a spinal cord injury is to get involved in something, anything. Make sure to find a social outlet where you have an opportunity to routinely interact with others. Eventually, life in a chair can be as normal as you choose to make it.”

AJ also creates artwork. Though he liked drawing when he was growing up, his passion for art was sparked after an art therapist got him to draw. Art offered him an outlet to do something fun and it allowed him to express his emotions without directly coming out and saying them. AJ has twice been included in Magee’s annual calendar that features art created by individuals with disabilities. In addition, he is studying psychology at Temple University and wants to become a clinical psychologist for individuals with disabilities.
CLINICAL TRIAL

The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) at Thomas Jefferson University is currently conducting a clinical trial to investigate the potential of a new therapy, BA-210 (Cethrin®), in acute spinal cord injury. BA-210 is a recombinant protein drug, which acts as a Rho antagonist to promote neuroregeneration and neuroprotection in the Central Nervous System (CNS). BioAxone Therapeutics, Inc is sponsoring this trial. BioAxone Inc. has shown in animal studies that BA-210 reduces the damage from spinal cord injury and stimulates axon regeneration when applied to the spinal cord. Further, BA-210 applied to the dura mater can penetrate into CNS tissue. In this clinical trial, BA-210 will be applied to the surface of the dura mater of the spinal cord together with Tisseel®, a fibrin sealant normally used to repair small dural tears.

This is a first in human study, which involves a single application of BA-210, during surgery within seven days following spinal cord injury. Male or female patients aged between 16 and 70 years with acute thoracic or cervical spinal cord injury (with no motor or sensory function in the sacral segment) can be enrolled. The primary goal of this study is to determine the safety and tolerability of BA-210 when administered in conjunction with fibrin sealant to the dura mater of the spinal cord. Also, this study is designed to determine the effects of BA-210 on neurological function in subjects with complete spinal cord injury. James Harrop, M.D. from the Department of Neurosurgery at Thomas Jefferson University will serve as the Principal Investigator.

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
1. 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.**

2. 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).**

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

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.**

5. 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.**

6. Eye-voice enablement technology: EVENtech, hands-free computer access for the disabled. **Sponsor: National Institute of Health.**

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.**
A grant was awarded from the Roberts Trust to start a “Community Transition and Education Rehabilitation Program Serving Individuals with Disabilities from Childhood through Adolescence through Adulthood.”

This program will allow Magee to expand its comprehensive services for adolescents who have incurred a life changing injury or illness. It is likely this program will include case management, education and perhaps community re-entry services for younger individuals. The program is now developing and more information will be provided in the future.

**SCI PATIENT MANUAL IN SPANISH**

We would like to announce that Magee has just received a grant for $50,000 to support the translation of the SCI Patient Education Manual of the Regional Spinal Cord Injury Center into a Spanish version!

The grant is from The Craig H. Neilsen Foundation, from California. This organization supports innovative and supportive programs for those with spinal cord injuries.

**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 are expanding 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.

The systematic approach of Locomotor Training consists of three primary components to retrain the nervous system to walk:

1. Step training using body weight support on a treadmill (BWST) and manual assistance.
2. Overground Walking Training, and/or Functional Skills Training.

Therapy sessions include time spent retraining on the BWST system, and transposing the skills practiced on the treadmill to the overground environment and into functional skills (ambulation, transfers, selfcare 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. Those interested should contact the SCI Follow Up System of Care for a physician/therapy evaluation appointment. For further preliminary information on what this therapy includes, or appropriateness, you may directly contact the NRN Administrative Director: Mary Schmidt Read, PT, MS, Spinal Cord Injury Program Director, mschmidt@mageerehab.org or (215) 587-3151.

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 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.

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.

MENTORS - If you have rehabilitated from an SCI, please consider volunteering as a peer consultant to help others as they adjust to life with an injury.

PROTEGES - For individuals adjusting to life with an SCI, mentors can answer questions and address concerns based on their personal experiences.

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, call Marie Protesto or Sonya Dibeler at (215) 587-3174, or e-mail pcoordinator@mageerehab.org.

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 poordinator@mageerehab.org.

**WOMEN’S DISABILITY SUPPORT GROUP**

To help women with a disability explore their thoughts and feelings about life with a disability, Magee provides a supportive, psychotherapy group each Monday afternoon. A clinical psychologist with expertise in disability rehabilitation leads the group, which addresses topics such as relationships, career issues, intimacy and sexuality.

For more information about this group or other psychological services, call Dr. Nancy Rosenberg at (215) 587-3210.

**TENTATIVE TOPIC SCHEDULE**

- **May 2006** Advocacy
- **June 2006** Research for the Cure
- **July 2006** Picnic
- **August 2006** Open Forum
- **September 2006** Phillies
- **October 2006** Winter Sports

**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.

Whatever you need to know is in there!
WHEELCHAIR SPORTS

MAGEE FREEDOMS TENNIS TEAM

The Magee wheelchair tennis team is ready to get the 2006 season started. The team of five has been practicing all winter long at Cherry Hill Racket Club. This season, members will travel to tournaments in Pensacola, Lancaster, Atlanta, New York, Baltimore, Lehigh University, Cherry Hill, and Wilmington.

All team members have national rankings, and compete in both singles and doubles. Last year, team members picked up several titles in both singles and doubles. Hopefully, they will improve on their performance this year! The team has had a tennis pro working with them since the fall, and she has added a wonderful workout program to the weekly practices. Best of luck to Matt Bellen, Mark Chilutti, Brad Evans, Walt Ramsey, and Felix Suero as they start the season!

SPORT WEBSITES OF INTEREST:

Power Soccer - www.powersoccer.net
Wheelchair Tennis - www.usta.com/usatenniswheelchair/
Sled Hockey - www.sledhockey.com
Paralympics - www.usolympicteam.com/paralympics/

MAGEE EAGLES WIN NATIONALS

The Magee Eagles wheelchair rugby team recently notched its first-ever national championship. The squad dominated its way through the competition at the United States Quad Rugby Association (USQRA) Division II National Tournament, held April 7-9 on the University of Texas at Austin campus. The Eagles finished with an impressive 5-0 record, capped by a thrilling 38-33 championship victory against the top-seeded OG’s from Southern California. The Magee Eagles, sponsored by Magee Rehabilitation Hospital and the Philadelphia Eagles, lost in the finals last year. Coached by Tom Hamill of Voorhees, NJ, the members of the National Champion Magee Eagles are: Eric Anderson of Philadelphia, PA, A.J. Nanayakkara of Roslyn PA, Adam Bencsik of Plymouth Meeting, PA, Keith Newerla of Absecon NJ, Everett Deibler of Lebanon, PA, Jim Thompson of Cherry Hill NJ, Rob Deller of Lebanon, PA, Brian Yarrusso of New Castle DE. Bencsik was named the USQRA Division II Most Valuable Player for his performance in the tournament.
POWER SOCCER

If you have pined for the chance to compete in sports and been denied opportunities due to your need for a power wheelchair - your wait is over.

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 nonstop action seen in a typical indoor soccer game. Power Soccer is the first competitive team sport designed and developed specifically for power wheelchair users.

Power Soccer players include persons with quadriplegia, multiple sclerosis, muscular dystrophy, cerebral palsy, 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. To prove you can do it just as good (or maybe a little better) than the other guy. The will to win, the competitive spirit of an athlete is in no way limited or diminished because of the use of a wheelchair.

In June we are looking forward to attending Nationals in Birmingham, AL. New players will be taught basic skills and strategies of the sport and play a modified schedule of games against local teams. Ball guards, uniforms and coaching will be provided in addition to most travel expenses for the competitions. Please join us!

To sign up, please contact Pat Thieringer at pthieringer@mageerehab.org or (215) 587-3412.

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.
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.

Think First received a grant from the Roberts Trust which will support Magee’s Think First program with specific funds to produce a new video for the program. This will be the first new video for the program in 15 years, and will be an exciting addition to an already wonderful program.

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

**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.

**THE ARTS**

**MAGEE PLAYERS**

Magee Rehabilitation Hospital is hosting a theatre arts program for individuals with disabilities in the Philadelphia region. This marks the sixth 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.
Fishing Festival

This year’s Fishing Festival will be held in conjunction with Fairmount Park’s Walk, Fairmount Park’s Run and Coast Day. It will be one full day of events in the park!

Please reserve Saturday, September 16th in your calendars for this fun-filled day.

For information please call Tiffany Ledesma Groll at (215) 499-3756.

HELP WANTED FOR NEWSLETTER!

Are you tired of seeing some of the same things in every newsletter? We have heard from some of our readers and are looking forward to making some changes to the newsletter beginning in the fall.

In order to incorporate these changes, we need you to assist with the newsletter!

We want to know how you are doing - what have you accomplished, where have you been, and what have you done. You can pass along some tips that have helped you cope with your disability. Maybe you have some ideas for a regular column, have an idea for an article, or are interested in writing an article.

We need your input to make this work!

Please contact Sonya at (215) 587-3174 or pcoordinator@mageerehab.org.

Here is a sample list of some of the new information they would like to see in the newsletter:

• People profiles - human interest
• Stories on Magee Alumni
• How do I?
• Press releases
• Update on Research
• Travel Section - Travel Stories - tips
• Advocacy/Legislation updates