



THE CORD

PROFILE: TOM ZINGANI

In 1999, Tom Zingani was visiting family and friends at a bar where they worked when three men robbed the place and shot him. The bullet nicked his spine leaving him completely paralyzed from the chest down. Tom experienced unbearable pain. With the insertion of a balcofen/morphine pump, Tom was able to go about life once more.

“Dr. Michael Saulino has really been a great inspiration to me,” says Tom. “His never give up theory, along with having the most wonderful wife in the world has given me a great sense of strength and structure.”

Before his injury, Tom was the manager of a bar and restaurant. Now he spends most of his time designing jewelry and writing poetry. He has written two poems so far that have been published. The first one, “A Father’s Love for His Daughter,” has won a bronze metal by the International Library of Poetry. It is published in The Colors of Life. It also won the editor’s choice award in February

2004. Tom’s second poem, “My Love for You,” was published in The Best Poems and the Best Poets of 2004.

Tom wrote the first poem for his daughter and mother. The second was written for his wife. His family has been his strength and motivation. “The meaning of the second poem is to cherish the people we love the most, each and every day,” says Tom. “When I was shot and fell to the floor all I thought about was that I never got to say goodbye to my wife and children. It’s a scary thing being shot and not knowing if you’re going to live or die. The pain is so intense your whole life spreads in front of you in a matter of seconds.”



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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.

MENTORS - If you have rehabilitated from a 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 a SCI, mentors can answer questions and address concerns based on their personal experiences.

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

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.

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.



Counselors offer reassurance, support and helpful practical tips.

This 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.

For more information, call **Pat Thieringer** at **(215) 587-3412**.

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



SCI RESOURCE & SUPPORT GROUP

This group provides education, recreation and support opportunities to individuals with spinal cord injuries. Meetings are held at Magee on the second Thursday of every month at 6 p.m. in the Second Floor Conference Room.

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.

TENTATIVE TOPIC SCHEDULE



May 2005	Research for the Cure
June 2005	Travel
July 2005	Picnic
August 2005	Baseball Game
September 2005	Canine Companions
October 2005	Ask The Nutritionist

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.

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; and**
- 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 this study will receive a placebo, or sugar pill, for the duration of the study,

RESEARCH FOCUS GROUP

The Regional Spinal Cord Injury Center of Delaware Valley (RSCICDV) at Thomas Jefferson University Hospital and Magee Rehabilitation is conducting focus groups to evaluate consumers' priorities in dealing with recovery following a traumatic spinal cord injury. If you are a person with SCI and would like to participate or would like more

and will not receive 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 costs (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.**, at **(215) 955-6579**. Thank you in advance for your support.

information about the project, please contact **Mary Patrick, R.N.**, RSCICDV Project Coordinator, at **(215) 955-6579**.

The focus group will be held at Magee Rehabilitation Hospital. You will be reimbursed for your time and free parking will be provided.

Important Web Pages

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

www.spinalcordcenter.org, www.mageerehab.org, www.mageepeers.org.

LOCOMOTOR TRAINING OUTPATIENT CLINIC

The Locomotor Training Clinic at Magee Rehabilitation Hospital is offering a comprehensive therapy program for ambulation training. "Locomotor Training" is a rehabilitative approach for persons with neurologic dysfunction that has been researched and proposed to effect a patient'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 being conducted to look at the effects of this intervention on overall health, including cardiovascular functioning, bone density and spasticity.

The systematic approach of Locomotor Training consists of three primary components:

- Step training using body weight support on a treadmill (BWST) and manual assistance;
- Overground Walking Training; and
- Community Ambulation Training.

RSCICDV RESEARCH

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

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, self-care activities, etc.).

At this time, referrals for outpatient therapy using Locomotor Training are being accepted for individuals with a history of spinal cord injury. Anyone referred to this clinic must be evaluated for appropriateness and medical stability prior to initiating this intervention. All standard outpatient therapy procedures will be followed. Those interested should contact the SCI Follow Up System of Care for an evaluation appointment.



normally used to repair small dural tears. This is a first in man study, which involves a single application of BA-210 during surgery within 7 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.

RESEARCH OF THE RSCICDV

Current

1. 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.*
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.*
3. Peripheral denervation following spinal cord injury (Using MRI to study nerve function following spinal cord injury). *Sponsor: American Paraplegia Society.*
4. Restoration of walking after spinal cord injury - elements of a disability measure. *Sponsor: National Institute on Disability and Rehabilitation Research (NIDRR).*
5. Restoration of walking after spinal cord injury - a consumer preference for walking. *Sponsor: National Institute on Disability and Rehabilitation Research (NIDRR).*
6. Development of Neural Recovery Rehabilitation and Research Centers (NRRRC) for functional, health and quality of life improvements after neurological injury. *Sponsor: CDC and The Christopher Reeve Foundation.*

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.*
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 Famipridine-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.*

RSCICDV RESEARCH NEWS



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 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.

WHEELCHAIR SPORTS

POWER SOCCER

*Time's running out...
I can't believe they tied the game on that lucky shot!
It's ok, we can still win this one.
Now it's my time...I'm due. I've come so close.
The hours of practice and training payoff now.
Here's the inbounds pass...
I break for the goal and find the opening I've been looking for!
The ball is loose, now's my chance!*

Does this mean anything to you? A memory of past glory, or a dream of something you always wanted but could never experience? For persons with higher-level spinal cord injuries and similar disabilities, team sports were just that - memories or dreams.

Well the times are changing...finally! Magee is starting a Power Soccer program. It's a game that ANYONE in a power wheelchair can play. Two teams of 4 powerchair 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 specifically for power wheelchair users, including persons with spinal cord injuries, multiple sclerosis, head trauma, muscular dystrophy, cerebral palsy, stroke and other disabilities.

MARTIAL ARTS

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



style of karate where students continue to advance in belt levels on the way to the coveted black belt.

by **SCOTT SIMPKINS**

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 and the competitive spirit of an athlete is in no way diminished by the use of a wheelchair.

There are three requirements for Power Soccer participants: a power wheelchair, a reasonable amount of control driving the chair, and a competitive spirit. Some people are probably conjuring up images of a power wheelchair demolition derby. While there is limited contact, referees are on the court looking for penalties such as charging, ramming, and loss of control. There are also multiple divisions for competition based on skill level.

Please plan on attending an organizational meeting in April and signing up for our exciting inaugural season! To learn more, please contact **Pat Thieringer** at pthieringer@mageerehab.org or **(215) 587-3412**.

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.

You are encouraged to find out more by observing this innovative program. For more information, call **Pat Thieringer** at **(215) 587-3412**.

MAGEE FREEDOMS WHEELCHAIR TENNIS

by **MARK CHILUTTI**

The Magee Freedoms are ready to start the 2005 season with a trip to Tucson, Arizona for the USTA Southwest Desert Wheelchair Classic. Team members Mark Chilutti, Brad Evans, Walt Ramsey, and Felix Suero have been practicing indoors during the winter months and will face some good competition.

The team will also play in tournaments in Lancaster, New York, Baltimore, Lehigh, Cherry Hill, Dallas, and Delaware, where member John Kistner, and newcomer Matt Bellen, will also play.

Practices are held each week at Cherry Hill

Health and Racquet Club, and the team is getting coaching support from high school player Jared Ringel, who comes out each week and runs the team through drills to improve their skills.



If you are interested in seeing wheelchair tennis live in action, or joining the team, stop by Sunday mornings and check it out! For more information, contact **Mark Chilutti** at **(215) 587-3226**.

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 PHILLIES WHEELCHAIR SOFTBALL TEAM

by **JIM FALLS**

Wheelchair Softball has changed my life. After losing a leg in an Amtrak accident in 1979, I was introduced to adapted athletics through Magee Rehabilitation Hospital. Wheelchair softball allows a person with a disability to participate in a sport normally limited to able-bodied athletes. With a little ingenuity and imagination, equipment is modified and rules are revised to accommodate the disabled athlete. Even the most severely disabled individual can participate in this activity that is both therapeutic and enjoyable.

Being on the Magee Phillies Wheelchair Softball Team has been a major accomplishment for me. We are on the road to becoming one of the top ranked teams in the nation. I've come to realize just how competitive and intense the sport of softball can actually be. Imagine yourself being offered a chance to participate in an organized sporting event after suffering a devastating

injury that has left you disabled for life. The programs offered through Magee Rehabilitation gives us back a part of our life that we truly believed was gone forever.



Once I am on the softball diamond, my disability seems to vanish and the game becomes everything. You can get a remarkable workout playing softball while enjoying the social aspects that come along with it. The feeling is magnificent and the benefits are unbelievable. The camaraderie of the team is evident wherever we play and the friendships that develop often last a lifetime.

We are currently seeking new members to join the Magee Phillies Wheelchair Softball team. We would love you to be a part of our winning team!! To learn more about the Magee Phillies, please call **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**.



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**.

COMPUTER TRAINING

To help individuals with disabilities keep up-to-date on today's changing technology, Magee Rehabilitation Hospital provides free computer training classes. Participants learn how computers work, and how to use the Internet and software packages such as Word and Typing Tutor.

Students can choose from a variety of class times and topics. For more information or to register, please call **Arezou Bigdeli** at **(215) 587-3063**.



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**.

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 benefit 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**.



Patient Family Resource Center and Medical Library Now Open Full Time

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.

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

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



THE ARTS

MAGEE PLAYERS

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

Classes are held 1 - 3 p.m. on Fridays through June 3rd. Registration for the class is \$15. For more information or to register, please call **(215) 587-3063**.



Web Pages

Philadelphia Museum of Art - www.philamuseum.org

Academy of Music - www.academyofmusic.org

Walnut Street Theatre - www.wstonline.org

The Academy of Natural Sciences - www.acnatsci.org

The Franklin Institute Science Museum - www.fi.edu



Magee Calendar 2006

Call for Artwork!



Magee Rehabilitation is developing an art calendar for 2006, which will highlight artwork created by our present and former patients. Each month will feature artwork from individuals with a wide variety of disabilities. Artists with disabilities are encouraged to submit works utilizing any media including but not limited to paintings, drawings, photography, sculpture and collage.

Free Art Workshops will be offered on selected Saturdays this summer.

The workshops will provide an exciting opportunity to create art for the calendar. A variety of materials will be supplied for you to use at the workshops. No prior art experience is necessary.

Please call **(215) 587-3063** if you would like more information on the art calendar or workshops.

SEPTA COMES TO MAGEE

All patients and former patients are invited to attend the "Bus Stops Here" program. This program includes a free demonstration on how to load and secure wheelchairs on an actual SEPTA bus, a review of SEPTA programs available for riders with disabilities, and a discussion session with questions about riding public transportation.

The program will be held **May 23, 2005** from **10 am - 2 pm**. The demonstration will take place at Magee Rehabilitation Hospital.



To sign up contact **Vera** at **(215) 587-3411** or at yftomyn@mageerehab.org.