

The Cord

SCI VIDEO BLOG & FOUNDER ATHER SHARIF

SCI Video Blog launched on May 15th, 2014, just over a year ago. With its simple concept, SCI Video Blog covers areas that have been difficult to traverse for people with spinal cord injuries through video tutorials and blog articles. With several videos encouraging independence, SCI Video Blog offers a unique mode to assist people with their independent living. An individual can look up what they are interested in, when they are interested, in the comfort of their home, and at their pace - not in a way that is reliant on professionals. The videos and articles can be filtered based on the injury level, injury completeness, ASIA level, gender and complications, besides the general keyword search.

In the time since the launch, SCI Video Blog's impact has grown quickly. SCI Video Blog has had over 40,000 views of the informational videos. The people who have come to the site represent 82 different countries, and all 52 states. Recognizing the importance for inclusion, the entire site is available in 80 languages. Nearly all videos have subtitles to ensure that the material maintained its quality for people with hearing impairments. Some videos have subtitles in French and German, in addition to English. SCI Video Blog also has options for large font to target people with vision impairment. Blog articles target all wheelchair users with or without spinal cord injuries. The website also has a mobile friendly version.

SCI Video Blog is going through a huge renovation and hoping to launch by the end of July. The site will search the entire Internet and show the most relevant results. It will also feature a community chatroom. Check out the site for all the other features it will be adding.

INSIDE THE CORD:

Research & Education	6
Spinal Cord Injury Support Groups	10
Recreation Resources	11
Community Programs	12
Community Members Wanted	13
Gaining Ground	14

Already, SCI Video Blog has been recognized as a national resource by National Spinal Cord Injury Association and ABC Medical, and was nominated for the Access Achievement Award 2014 organized by the Mayor's Commission of Disabilities. SCI Video Blog has also organized a national video and photo contest to create awareness of SCI.

SCI Video Blog is currently managed and run by former Magee patient Ather Sharif and Justine Noel. Nelyo Tatala, Melissa Nunn, Michael Nacci and Siri Urquhart are volunteers, who have made substantial contributions to the project.



Ather is a software engineer and a graduate student at Saint Joseph's University. He was injured in a car accident on March 15, 2013. At the time of his injury, Ather admits "I didn't even know what SCI was." When it was time to choose a rehabilitation hospital, Ather picked Magee. He entered inpatient therapy in April 2013 and was discharged that July, transitioning to Day Rehab, Outpatient, and eventually the Wellness program.

"When you have an injury, there's an attitude that can creep in and make you feel like the unluckiest person in the world," Ather says. "But as you progress in therapy, you see how lucky you are to have the life you have."

Ather worked extremely hard to regain his independence, and today, he's using his skills as a software engineer to change the way people with disabilities experience the web.

In January, Ather launched EvoXLabs, a non-profit run completely on volunteer power that aims to provide people with vision impairment an improved web experience. EvoXLabs also creates modern, accessible websites and apps for local nonprofits, free of charge. Ather didn't have to go far to find their first client: Legal Clinic for the Disabled, housed on the 2nd floor at Magee.

At this year's Philly Tech Week, with attendees numbering 25,000+, EvoXLabs hosted evoHaX - a programming contest inviting college students to develop web accessibility solutions in a 24-hour "hackathon."

Since his injury, Ather's has also found time to be a guest speaker at the Hack4Access Hackathon; joined Unlock Philly, an organization to improve facility and transit accessibility; and even was invited to attend the 24th International World Wide Web Conference in Florence, Italy. At the conference, Ather was honored with The Delegates Award, which is determined by audience votes and recognizes cutting edge research in the area of web accessibility.

"When you stop complaining and whining, it helps you come back to life," Ather says. Ather's spirit inspired both his peers and the team at Magee. At a ceremony in February, he received a 2015 Patient Award. In her speech honoring Ather, Case Manager Sarah Myer said, "He epitomizes the notion that one does not need to be limited by disability."



Regional Spinal Cord Injury Center of the Delaware Valley NIDRR-designated



MAGEE REHABILITATION HOSPITAL

The Cord 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 #H133N110021 and the Friends of Jerry Segal.

SPINAL CORD INJURY RESEARCH & EDUCATION

Upper Extremity Reconstruction Program



The Upper Extremity (UE) Reconstruction Program of the Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) continues to be available for persons with ANY neurologic diagnosis that presents with a problem in their upper limb. Magee Occupational Therapy staff collaborate with the Rothman Institute and Thomas Jefferson University Hospital, to provide a clinical program that focuses on problems with upper extremity neurologic

dysfunction.

We are pleased to announce that we will now have the services of TWO Rothman Institute surgeons specializing in rehabilitation of the Upper Extremity. We will continue to see Dr Charles Leinberry, specializing in Hand and Elbow (and all areas between). We are pleased to now also have Dr. Surena Namdari, specializing in Shoulder and Elbow. Both surgeons and the Magee Occupational Therapy staff will be available for monthly clinics held at Magee Rehab's Main Hospital in the first floor Follow Up Clinic, on the 3rd Wednesday of each month. Magee's Case

Managers also play a critical role in helping individuals sort out the resources necessary to benefit from this program. The UE Reconstruction Program focuses on issues related to skeletal reconstruction, tendon releases, or tendon transfers covering the shoulder down through the hand. The goal is to enhance function of the arm and hand.

They can see either inpatients, or outpatients, for either evaluation or surgical consideration. Persons with any diagnosis can be referred. These clinic evaluations can result in any of the following recommendations:

- Recommendation for

therapy intervention only

- Recommendation for therapy first, possible surgery to follow
- Recommendation directly to surgery, with subsequent therapy follow up

If you would like more information on accessing this Clinical Evaluation program, please contact the Upper Extremity Clinic at **(215) 587-3116**.



Capabilities of Upper Extremity – Ongoing Research

The Spinal Cord Injury Center has received a two-year grant from the Craig H. Neilsen Foundation to continue development of an objective evaluation of arm and hand function in people with cervical spinal cord injury. Currently there is not an accepted standard test for upper extremity function to evaluate the effectiveness of interventions. We have already

developed a standardized assessment, called the Capabilities of Upper Extremity Test (CUE-T), which has demonstrated good test-retest reliability in people with chronic spinal cord injury. Now we will test people who have recently been injured or who are about to have surgery to improve arm or hand function, in order to determine how well the CUE-T detects changes in their ability

to use their arms and hands. We have recruited researchers from Case Western - Metro Health in Cleveland, OH; Shepherd Center in Atlanta, GA; and Frazier Rehabilitation Center in Louisville, KY to work with us on the project. Thank you to all the participants who volunteered for preliminary testing of the CUE-T. We couldn't have gotten to this point without you. For any

questions concerning this research or if you think you may be a candidate for this phase of the study, please contact the **RSCICDV at (215) 955-6579**.



Research Participants Wanted

As part of the Regional Spinal Cord Injury Center of Delaware Valley's current research, a small team of researchers and research assistants are conducting interviews with people who are at least 60 years old and have been living with spinal cord injury for five years or more. We are also interested in interviewing your family caregiver or paid caregiver, too. Also, we would also like to interview individuals who've been

injured for less than five years, too. The interview will occur at your home and will take less than 90 minutes. In this research project we are interested in improving our understanding, in your words, of the experience of aging with a spinal cord injury, the changes in your abilities to participate in activities, the care you need and receive, and your satisfaction with your routines. Your experiences

and those of your caregivers will greatly help us learn about any changing health needs and develop programs to meet those needs. The interview is audiotaped and you will have the opportunity to review your transcribed interview to make sure it captures what you've told the researcher. As a thank you, you will receive a gift card in the amount of \$25.00.

If you are interested in participating in this research, please call **Dr. Stephen Kern** at **(215) 503-8010**, or email **Stephen.kern@jefferson.edu**

Participation in a Research Study

Are you:

- A person with a recent spinal cord injury?
- Not yet discharged from acute care hospitalization?
- 18 years of age or older?
- Concurrently enrolled into the National Database Study of the Regional Spinal Cord Injury Center

of the Delaware Valley (RSCICDV)?

- Able to answer questions about your ability to complete different functional activities?
- Able to give 45 minutes to 1 hour of your time to participate in this paid research study?

If you've answered 'yes' to the questions above, you may be eligible for participation. The goal of this research project is to assess the long-term

responsiveness and ability of a newly developed computer-based survey to detect clinically meaningful changes in the functional abilities of persons with spinal cord injury. This new instrument will allow researchers to learn more rehabilitation and other treatments for spinal cord injury.

For more information, please contact **Brittany Hayes** at the RSCICDV at Thomas Jefferson University at **(215) 955-6579**.

Ongoing Research of the RSCICDV Staff

Current

1. A Single-Blind, Randomized, Parallel Arm, Phase II Proof-of-Concept Study of the Safety and Efficacy of HuCNS-SC Transplantation in Cervical Spinal Cord Injury. *Sponsor: StemCells, Inc.*
2. Multicenter, Randomized, Double-blind, Placebo-controlled parallel group study to evaluate the Efficacy, Safety and Pharmacokinetics of SUN13837 Injection in Adult Subjects with Acute Spinal Cord Injury. *Sponsor: Asubio*
3. Responsiveness of a Neuromuscular Recovery Scale for Spinal Cord Injury: Inpatient and Outpatient Rehabilitation. *Sponsor: Department of Defense and Craig Neilsen Foundation*
4. Health Outcomes after Locomotor Training in Spinal Cord Injury. *Sponsor: Department of Defense and Craig Neilsen Foundation*
5. Responsiveness of the Capabilities of the Upper Extremity Test. *Sponsor: Craig H. Neilsen Foundation*
6. Predicting neurological recovery after traumatic spinal cord injury (SCI). *Sponsor: NIDRR supported through SCI Model System of Care*
7. Enhancement and evaluation of the SCI-FI Instrument (v.2). *Sponsor: NIDRR supported through SCI Model System of Care*
8. Modification of the ABLE (Activity-based Balance Level Evaluation) Scale: A factor analysis study. *Sponsor: Team Reeve and NeuroRecovery Network*
9. EQUATE: Equity and Quality in assistive Technology study. *Sponsor: NIDRR supported through SCI Model System of Care*
10. Zoledronic Acid to prevent bone loss after acute spinal cord injury. *Sponsor: NIDRR supported through SCI Model System of Care*
11. Understanding the health care needs of individuals aging with spinal cord injury. *Sponsor: NIDRR supported through SCI Model System of Care*
12. The Value of MRI and DTI as biomarkers for classifying acute spinal cord injury. *Sponsor: Department of Defense*

Completed

1. Acute multi-center study on efficacy and safety of SUN13837 injections in adults with acute spinal cord injuries. *Sponsor: Asubio Pharmaceuticals, Inc.*
2. A new measure of neurological and behavioral recovery after spinal cord injury. *Sponsor: Craig H. Neilsen Foundation and Department of Defense*
3. Reliability of the Capabilities of the Upper Extremity Test. *Sponsor: NIDRR supported through SCI Model System of Care*
4. Effects of two Different Functional Electrical Stimulation (FES) Cycling Paradigms. *Sponsor: Craig H. Neilsen Foundation*
5. A Phase 1 Safety Study of GRNOPC1 in Patients with Neurologically complete, subacute, spinal cord injury. *Sponsor: Geron Corporation*
6. Investigation of assistive technology for mobility used by individuals with spinal cord injury. *Sponsor: NIDRR supported through SCI Model System of Care*
7. UAB Index of Motor Recovery – Validation of an outcome measure for motor recovery in incomplete spinal cord injury. *Sponsor: NIDRR supported through SCI Model System of Care*
8. Development and validation of the thoracic-lumbar control scale to measure strength and coordination of trunk muscles. *Sponsor: NIDRR supported through SCI Model System of Care*

New Research - Factors associated with shoulder pain in manual wheelchair users with SCI

The Department of Physical Therapy and Rehabilitation Science at Drexel University is conducting a study to detect impairments prior to the onset of shoulder pain in an effort to reduce the subsequent decline in activity and participation levels. This approach will alter the current approach to management of shoulder pain in the Spinal Cord Injury (SCI) population by employing a proactive

model of patient management. The specific goals of this investigation are to identify neuromusculoskeletal factors associated with shoulder pain in manual wheelchair users and identify specific neuromusculoskeletal impairments that predict development of shoulder pain.

The study involves a one-time testing session of

approximately 2.5 hours in which shoulder girdle motion will be evaluated with 3-dimensional motion analysis. Health of the rotator cuff will be assessed with non-invasive ultrasound and clinical measures of muscle length. Shoulder muscle strength will be assessed.

Participants may be compensated up to \$75 for their time and effort and

\$15 for transportation expenses.

If you are interested in participating in this research or to learn more about this study, please call **Dr. Margaret Finley, PT, PhD at (267) 359-5583** or email at **maf378@drexel.edu**.



Magee receives \$300K grant for SCI Medical Home

Awarded by the Craig H. Neilsen Foundation, this grant supports the creation of a Specialized Medical Home, providing proactive support for, and improving the quality of life of, persons with spinal cord injury.

The Craig H. Neilsen Foundation has awarded Magee a grant of \$300,000 to support the creation of The Spinal Cord Injury (SCI) Medical Home at Magee Rehabilitation Hospital.

The SCI Medical Home at Magee will provide proactive clinical and support services to maximize the health outcomes for persons with SCI, after discharge from inpatient rehabilitation. The primary goal is to reduce emergency room visits, readmissions, and medical complications, all while improving the quality of life of patients with SCI.

“Magee is truly honored to have received this generous grant from the Neilsen Foundation,” says Marci Ruediger, SCI Medical Home Project Director and Director of Performance Excellence at Magee. “This funding allows Magee to

take its existing lifetime follow-up clinical care system to the next level, helping to ensure good health and the fullest possible life for our patients with spinal cord injury.”

A medical home, also referred to as a patient-centered medical home, is a team-based health care approach, led by a physician, that provides comprehensive and continuous medical care to patients, with the goal of maximizing health outcomes. Dr. Mendel Kupfer is the Medical Director for the SCI Medical Home. He is board certified in Physical Medicine and Rehabilitation and Sports Medicine. Dr. Kupfer has been treating patients with SCI at Magee since 2006 and has published and lectured on many aspects of SCI care.

A partner with Thomas Jefferson University

Hospital to form one of only 14 model systems for SCI nationwide, Magee will provide specialized medical home services to outpatients with SCI over the three-year grant period. Priority for enrollment will be given to patients at highest risk for complications, due to medical complexity and/or socio-economic factors.

The SCI Medical Home will utilize internal medicine and primary care physicians to provide primary care alongside Magee physiatrists, who have specialized knowledge of the care of SCI patients. In addition to addressing medical needs, the SCI Medical Home will also problem-solve environmental barriers to care, such as transportation, accessibility, employment, financial issues, and other concerns.

New Publications/Presentations by RSCICDV Staff

- 1) Biering-Sorensen F, Alai S, Anderson K, Charlifue S, Chen Y, Devivo M et al. Common data elements for spinal cord injury clinical research: a National Institute for Neurological Disorders and Stroke project. *Spinal Cord* 2015; 53(4):265-277.
- 2) Bridwell KH, Anderson PA, Boden SD, Kim HJ, Vaccaro AR, Wang JC. What's New in Spine Surgery. *J Bone Joint Surg Am* 2014; 96(12):1048-1054.
- 3) Dvorak MF, Itshayek E, Fehlings MG, Vaccaro AR, Wing PC, Biering-Sorensen F et al. International spinal cord injury: spinal interventions and surgical procedures basic data set. *Spinal Cord* 2015; 53(2):155-165.
- 4) Fehlings MG, Nater A, Chapman J, Harrop J, Mroz T. Systematic reviews of value-based surgical spine care: What do we know? Where are the limitations? *Spine* 2014; 39(22):S3-S6.
- 5) Ghobrial GM, Amenta PS, Maltenfort M, Williams KA, Jr., Harrop JS, Sharan A et al. Longitudinal incidence and concurrence rates for traumatic brain injury and spine injury - a twenty year analysis. *Clin Neurol Neurosurg* 2014; 123:174-180.
- 6) Ghobrial GM, Maulucci CM, Maltenfort M, Dalyai RT, Vaccaro AR, Fehlings MG et al. Operative and nonoperative adverse events in the management of traumatic fractures of the thoracolumbar spine: a systematic review. *Neurosurg Focus* 2014; 37(1):E8.
- 7) Glennie RA, Ailon T, Yang K, Batke J, Fisher CG, Dvorak MF et al. Incidence, impact, and risk factors of adverse events in thoracic and lumbar spine fractures: an ambispective cohort analysis of 390 patients. *Spine J* 2015; 15(4):629-637.
- 8) Harrop JS, Ghobrial GM, Chitale R, Krespan K, Odorizzi L, Fried T et al. Evaluating initial spine trauma response: Injury time to trauma center in PA, USA. *J Clin Neurosci* 2014; 21(10):1725-1729.
- 9) Harrop JS. Spinal cord injury: debating the efficacy of methylprednisolone. *Neurosurgery* 2014; 61(1 Suppl):30-31
- 10) Kepler CK, Vaccaro AR, Dibra F, Anderson DG, Rihn JA, Hilibrand AS et al. Neurologic injury because of trauma after type II odontoid nonunion. *Spine J* 2014; 14(6):903-908.
- 11) O'Boynick CP, Kurd MF, Darden BV, Vaccaro AR, Fehlings MG. Timing of surgery in thoracolumbar trauma: is early intervention safe? *Neurosurg Focus* 2014; 37(1):E7.
- 12) Oleson CV, Marino RJ. Responsiveness and concurrent validity of the revised Capabilities of Upper Extremity-Questionnaire (CUE-Q) in patients with acute tetraplegia. *Spinal Cord* 2014; 52(8):625-628.
- 13) Sidhu GS, Henkelman E, Vaccaro AR, Albert TJ, Hilibrand A, Anderson DG et al. Minimally invasive versus open posterior lumbar interbody fusion: a systematic review. *Clin Orthop Relat Res* 2014; 472(6):1792-1799.
- 14) Sinnott KA, Dunn JA, Rothwell AG, Hall AS, Post MW. The development of the NZ-based international upper limb surgery registry. *Spinal Cord* 2014; 52(8):611-615.
- 15) Vaccaro AR, Fisher CG, Whang PG, Patel AA, Thomas KC, Mulpuri K et al. Evidence-based recommendations for spine surgery. *Spine* 2014; 39(19):E1183-E1189.
- 16) Yeung V, Formal C. Lower extremity hemorrhage in patients with spinal cord injury receiving enoxaparin therapy. *J Spinal Cord Med* 2015; 38(2):236-238.
- 17) Janice Schuld CRNP, Marci Ruediger, PT, Deborah Long, RN. Patient Engagement Project (PEP) Celebrates Independence-Poster. National Academies of Practice Annual Forum- Engaging the Patient and Family in Patient-Centered Care: An Interprofessional Approach, Alexandria, VA April 17-18, 2015.
- 18) Janice Schuld CRNP, Marci Ruediger, PT, Deborah Long, RN. Patient Engagement Project (PEP) Celebrates Independence-Poster. The 6th Annual National Nursing Research Symposium- An Interprofessional Exploration of Transitions in Health Care, Stanford, CA May 4, 2015.
- 19) Todd Lewis PhD and Brian Kucer MD. Management of Agitation in the Neurologically Impaired Patient: Behavioral and Environmental Strategies to Reducing Restraints and Increasing Safety. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 20) Richard Pacitti, PharmD and Donna Peterson, PharmD. Safe Transitions of Care into and out of Acute Rehabilitation: Focus on Medications. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 21) Richard Pacitti, PharmD and Donna Peterson, PharmDA plus Deb Long, RN, Angie Ruggieri, RN, Betsy Schmidt, RN, Tama Berman, RN, Elizabeth Masi, RN. Quality Improvement Process to Minimize Central IV line Occlusions. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 22) Helen Davey, PT and Rebecca Wagner, OTR/L. CRE Implications for Inpatient Rehabilitation Management in the SCI Population. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 23) Reem Issa, RN, Nia Lawson, RN, Deb Long, RN, Janice Schuld, CRNP, Gina Cooke OTR/L, Amy Fleming OTR/L, Sarah Myer, SW. Team Approach to Patient-Centered Neurogenic Bladder Management. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 24) Dr. Henry Chou (PM&R Resident) and Janice Schuld CRNP and Guy Fried MD. Case Series of Increased Weight Loss in Patients with SCI Resulting from Gunshot Wound. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 25) Kristen Gill, OTR/L and Andrew Stamatelos, PT. Utilizing high intensity interval training as therapeutic intervention for patients on prolonged bed rest following skin flap surgery - a case report. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 26) Erin Kelly, PT and Erin Trudell, PT. Using Technology to increase staff and client safety during early mobilization. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 27) Janice Schuld CRNP, Marci Ruediger, PT, Deborah Long, RN. Patient Engagement Project (PEP) Celebrates Independence-Poster. 3rd Annual National Summit on Safety & Quality for Rehabilitation Hospitals Rehab Summit, Arlington, VA, April 20, 2015.
- 28) Ms. Priya Patel, Medical Student and Janice Schuld, CRNP, and Guy Fried MD. Maximizing Quality of Life of Spinal Cord Injury (SCI) patients with Carbapenem-Resistant Enterobacteriaceae (CRE) Infection. ASIA/ISCOS Meeting, Montreal, Canada, May 14-16, 2015.
- 29) Dr. Henry Chou (PM&R Resident) and Janice Schuld CRNP and Guy Fried MD. Case Series of Increased Weight Loss in Patients with SCI Resulting from Gunshot Wound. ASIA/ISCOS Meeting, Montreal, Canada, May 14-16, 2015
- 30) Bill Waring MD, Steven Kirshblum MD, Mary Schmidt Read DPT, Linda Jones PT, Ron Reeves MD. Annual ASIA International Standards and Education Committee Updates. ASIA/ISCOS Meeting, Montreal, Canada, May 14-16, 2015.

SPINAL CORD INJURY SUPPORT

SCI Peer Mentor Program

Through the SCI Peer Mentor Program at Magee people who are living with a life-changing disability have the opportunity to talk with someone with a similar disability who has not only adjusted but is living a good life again. Peer mentors provide a picture of what is possible and share tips and resources that have helped them along the way.

The Peer Mentor Program at Magee consists of specially trained volunteers who have survived a spinal cord injury, and have learned to cope with their disability. Peers are matched based on level of injury, social situations, age,

gender, marital status, recreational interests, and vocational experience. There are also specialty areas for peers with experience in ostomies and wounds.

In addition to one-on-one mentors, the Peer Mentor Program offers support in group settings:

The SCI Family Peer Support Group – specially-trained families who have experienced the disability of a loved one. They share their experiences, insights, and coping strategies with those who are new to Magee and the spinal

cord injury experience. The family group is held twice monthly on Wednesday at 6 pm at Magee.

The SCI Resource and Support Group provides opportunities for individuals with a spinal cord injury, as well as their family and friends, to interact and relate on a level where everyone “gets it.” Through discussions, resources are shared, support is given, and a great camaraderie is born. This group meets on the second Thursday of each month at 6 pm at Magee.

For more information on the SCI Peer Mentor Program

and Support Groups, please contact **Marie Protesto, RN, BSN** at **(215) 587-3174** or **Ruth Black, LCSW** at **(215)587-3030** or email **peers@mageerehab.org**.

SCI PEER MENTOR PROGRAM

In Partnership with



Join the E-Community



The E-Community is an e-mail list of individuals with spinal cord injuries, amputations, strokes, and brain injuries kept by the Peer Coordinators for the

dissemination of information from new innovations to classifieds. It is a place to ask questions and share your knowledge. Ever wonder where the Ask a Peer info

comes from on the Magee Blog? This is it.

For more information or to be added to the list contact **peers@mageerehab.org** with your name and disability.

Addictions Mentors

The Addictions Mentor Program at Magee Rehabilitation Hospital is designed to offer those who struggle with addiction issues the opportunity to talk with a specially trained person who has experience as an addictions advocate.

Addictions mentors can:

- Offer support
- Share information and resources
- Accompany patient to AA/NA meetings held at Magee Rehabilitation Hospital

In addition, the Addictions Mentor can:

- Help patients connect to local AA/NA groups and sponsors in their communities and, if appropriate, continue to sponsor patients beyond Magee.
- Accompany patients to disability friendly AA/NA meetings after discharge.

If you would like more information about the Addictions Mentor Program or would like to be an Addictions Mentor, please contact **Ruth Black, LCSW** in the Peer Office at **rblack@mageerehab.org** or **(215) 587-3030**.



SCI Peer & Family Peer Mentors Wanted!

Have you or a loved one had a spinal cord injury? Would you like to make a difference in someone's life? Become an SCI Peer Mentor or Family Peer Mentor!

The Peer Mentor Program is looking for experienced survivors willing to:

- Talk with current inpatients,
- Listen and help them grieve, and
- Offer practical tips and be a support system.

This program requires:

- 2 training sessions,
- Visits and follow-up phone calls, and
- Yearly PPD and seasonal flu shots.

For more information, please contact **Marie Protesto, RN, BSN**, SCI Peer Coordinator at **(215) 587-3174** or **Ruth Black, LCSW**, Family Peer Coordinator at **(215) 587-3030** or email **peers@mageerehab.org**.

MAGEE RECREATION RESOURCES

Physical activity is an integral part of physical and psychological well being. Everyone, regardless of ability or disability, should have access to recreation, we are actively recruiting new athletes to join our teams. If you already play a wheelchair sport and would like more information

about our program, or if you are interested in a recreation activity that we do not yet offer, please contact us!

Magee Wheelchair Sports teams are always looking for volunteers who would like to learn more about

wheelchair sports and help during fundraisers, at practices and tournaments. If you have any questions or would like more information on any of our teams, please email sports@mageerehab.org or call **(215) 587-3412**.

Magee Co-ed Wheelchair Sports Teams

BASKETBALL: MAGEE SIXERS SPOKESMEN

Practices are held every Wednesday evening from 6:30 pm—9 pm (Sept.—May).

Location: Carousel House (corner of Belmont Ave. & Ave. of the Republic, Philadelphia, PA 19131)

RUGBY: MAGEE EAGLES

Practices are held Tuesday evenings from 6:30 pm—9 pm (Sept.—May).

Location: Carousel House

TENNIS: MAGEE WHEELCHAIR TENNIS TEAM

Practices are held each Sunday from 12 pm—2 pm (10 am—12 pm in the summer).

Location: Cherry Hill Health & Racquet Club (1820 Old Cuthbert Road, Cherry Hill, NJ 08034)

RACING: For more info **contact sports@mageerehab.org or 215-587-3412.**

Our wheelchair athletes recognize how fortunate we are to have a rehab hospital such as Magee fund our sports program, and we give back to the community by performing outreach events in the Philadelphia area. This season, our teams performed demonstrations at many universities and organizations including: University of Pennsylvania, West Chester University, YMCA West Chester, Wells Fargo Center, Radnor High School, University of the Sciences Philadelphia, and Richard Stockton College of New Jersey.

We encourage everyone to become involved in physical activity, whether it is in a competitive sport or at an intramural level. Please join us as we add more recreational opportunities in the coming months and years. If you would like Magee to consider adding a specific activity to our program, please call **(215) 587-3412**.



Upcoming Adaptive Sports Events & Organizations of Interest

- **PA Center for Adaptive Sports:** Promotes adapted recreation, and sport opportunities for persons with physical and neurological disabilities. Rowing , Cycling and Skiing. www.centeronline.com
- **IM ABLE Foundation:** Created to build on the active lifestyles that founder, Chris Kaag, promotes for individuals with disabilities. www.getupandmove.org
- **Magee Wheelchair Tennis Tournament:** From August 14, 2015 to August 16, 2015 at the Cherry Hill Health and Racquet Club, 1820 Old Cuthbert Rd., Cherry Hill, NJ 08034

COMMUNITY PROGRAMS

Legal Clinic for the Disabled

The Legal Clinic for the Disabled provides free legal services to low-income people with physical disabilities in Philadelphia, Bucks, Chester, Delaware and Montgomery Counties, Pennsylvania.

Since 1990, the Legal Clinic for the Disabled, a 501(c)(3) non-profit corporation with

offices at Magee Rehabilitation Hospital, has helped thousands of people. We help victims of domestic violence get legal protection from their abusers. We represent victims of identity theft and consumer fraud. We help parents and care givers access healthcare for their children. We write wills, powers of attorney, and living wills. Most of our

clients experience physical limitations in their daily activities, and many have suffered catastrophic injuries or illnesses like stroke, spinal cord or brain injury, multiple sclerosis, cancer, advanced diabetes, glaucoma, AIDS, amputation, or epilepsy. Our services help them overcome legal problems and continue living

comfortably and independently in the community.

For more information about our clinic, please visit our Web site at: www.lcdphila.org.



Healthy PA – Gov. Corbett’s Answer to Medicaid Expansion by Tom Bednar

On August 28, 2014, the federal Centers for Medicare & Medicaid Services (CMS) came to an agreement with the Corbett Administration on the Governor’s proposed plan for expansion of Medicaid in Pennsylvania. The plan is called Healthy PA and would effectively expand the coverage of Medicaid, the state-and-federal cooperatively managed health insurance plan for low-income individuals, to Pennsylvania residents that make up to 138% of the Federal Poverty Line (FPL - approximately \$32,913 per year for a family of 4). This means that between 500,000 to 600,000 Pennsylvanians may now be newly eligible for Medicaid services.

Under the Affordable Care Act (ACA), states were initially mandated to expand their Medicaid programs to include a wider range of individuals, which was intended to close the gap between those eligible for

Medicaid and those who would be eligible for coverage through the new healthcare exchanges. In 2012 this changed when the Supreme Court upheld the constitutionality of the ACA but stated that states could not be forced to expand Medicaid. Since the ruling the federal government has kept its offer to foot the bill for Medicaid expansion for every state and to date 28 states have taken them up on it.

However, unlike every one of its neighboring states, Pennsylvania has not chosen to take the federal government up on its standing offer to simply cover the cost of Medicaid expansion. Instead Pennsylvania has decided to take the money and make changes to its Medicaid program. The new Medicaid landscape creates three broad Medicaid plans: Healthy, Healthy Plus, and PCO (Private Coverage Option). The Healthy and

Healthy Plus plans differ in terms of the level of benefits that they provide and eligibility is based upon a determination of “medical frailty.” Those who are considered medically frail will receive the more comprehensive Healthy Plus plan. In December 2014, current Medicaid recipients received letters informing them which of the two plans they would be placed into along with information on how to appeal that determination. The third plan, the PCO, is intended for newly eligible individuals and will offer a choice between a minimum of two competing benefits plans administered through private health insurance agencies. Regardless of which plan recipients find themselves in, all three offer a lower degree of benefits coverage than prior to expansion, with a particular cut in benefits for those with mental health issues.

Implementation of Healthy

PA began with enrollment in December 2014, and services started in January 2015. This process has already experienced significant delays, with an estimated 100,000 newly eligible individuals awaiting benefits. Furthermore, lawsuits have been filed against the state for the level of coverage that the plans provide and the opaque nature of the medical frailty determination process that the state has created. With the recent election of Governor Tom Wolf, the future of Healthy PA remains in flux. Though many contracts with private insurance companies have been signed for the PCO and would be difficult to do away with, Governor Wolf campaigned heavily against Healthy PA. Regardless of its future nature, it is likely that Medicaid expansion, in one form or another, will continue to be a reality for low-income uninsured Pennsylvanians.

Spinal Cord Society

The Spinal Cord Society 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.

The Spinal Cord Society puts 100% of its funding into research for the cure of spinal cord dysfunction. The Spinal Cord Society meets at Magee Rehabilitation Hospital on the 6th floor at 1 pm 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.



Patient Resource Center

The Patient Resource Center is located on the 6th floor of the Main Hospital. Feel free to stop by. We have tons of interesting fiction, a number of best seller books including notable books that made Oprah Winfrey's Book Club list. There are about 600 leisure/romance/mystery novels to choose from as well as a broad selection of relevant professional periodicals. You may have noticed that we have

computers spaced just right for patient, visitor, and staff access and to supplement these resources, we also have an assortment of DVDs.

Please allow us the opportunity to provide you with extraordinary customer service and an enviable user friendly environment.

You may contact **Venus Bradley** at **(215) 587-3146** with any questions, concerns or suggestions.

Resource Center Hours of Operation

Monday & Thursday
9:30 am - 7:00 pm

Tuesday & Friday
9:30 am - 5:00 pm

Wednesday
9:30 am - 1:30 pm

Saturday & Sunday
12:00 pm - 5:00 pm

Hours are subject to change.

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 a video, 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 **Keith Newerla**, Community Programs Coordinator, at **(215) 587-3412**.



Wanted: Community Members to Participate in Magee's Infection Prevention Committee

If you have interest or expertise and are able to assist our Infection Prevention Committee in the prevention of infection at Magee, we would love to hear from you. Input from former patients and other community stakeholders is needed. Your perspective as

a health care consumer is invaluable to us, as we work to determine the best courses of action in the prevention and treatment of infections at Magee.

The committee meets six times per year at the Hospital, usually on the first

Thursday of the month, from 1- 2 pm. (February, April, June, August, October, and December)

If you are interested or would like more information, please contact **Carol Vinci** at **(215) 587-3333** or **cvinci@mageerehab.org**.

Wanted: Community Members to Participate in Magee's Safety and Quality Committee

We are looking for community members with interest and/or experience in performance improvement or safety to participate on our Safety and Quality Committee. This inter-disciplinary committee

meets monthly, usually on the 3rd Thursday of the month, from 12- 1:30 pm. The perspective of community members is extremely valuable as we review safety data and make

decisions about process changes and priorities.

If you are interested or would like more information, please contact **Karen Ayres** at **(215) 587-3451** or **kayres@mageerehab.org**.

Gaining Ground

Recovery following a neurological injury does not follow a set timeframe and is not the same for each person. Recovery is a long, slow process and is about more than just walking. Recovery is about regaining function, how you live your life, and improving your overall quality of life. Research has shown that without external stimulation, the nervous system will not improve, and you will lose bone density, muscle mass, and activation of your nervous system.

Gaining Ground is a specialized exercise program specifically tailored to the individual with sole focus on increasing function, taking into account the goals and abilities of the client. The program includes an initial evaluation by a physical therapist and a fitness assessment by an activity based therapy aide/personal trainer, customized exercise prescription program and one-on-one training.

Each day includes a one-on-one training session with an activity based therapy aide, a session with a physical therapist, a session optimizing lower extremity weight bearing using the Lokomat system or Ekso robotic exoskeleton, a session using the RT300 FES cycle or RT200 FES elliptical trainer, and a self-paced group exercise class. This session is designed to help increase strength, improve cardiovascular endurance, and enhance overall well-being. Exercises emphasize the muscle groups of the upper extremity and core necessary to complete daily functional activities. The group environment fosters interaction with others working towards a common goal.

Equipment utilized during the program may include the RT200 or RT300 by Restorative Therapies, the Lokomat by Hocoma, and the Ekso by Ekso Bionics as

indicated above as well as the Rifton Tram, the Power Plate, Biodex, Equalizer Rickshaw Exercise machine, Equalizer 1000 Series Exercise Machine, PowerTower Total Gym, rowing ergometer, NuStep T5xr, upper body ergometer, MultiTrainer Resistance Band System, EasyStand Evolv Glider and electrical stimulation in conjunction with functional movement patterns.

An education session is offered 1-2 times per week covering topics such as nutrition, sexuality, travel, wheelchair sports, recreation therapy, and art therapy.

Results that you may notice during the Gaining Ground program include:

- Improved health and well being
- Increase in central nervous system activity
- Increased sensation

- including changes in bowel and bladder sensations
- Increased muscle mass
- Increased function below level of injury
- Improved posture and trunk control
- Decreased pain
- Decreased medication use

The program you follow each day in the clinic will be adjusted and changed based on how your body is recovering. For continued progress after the program, you will need to reproduce the workout regimens on your own. We will provide the training materials necessary to continue with the program, but you must be consistent with your training.

For additional information including rates and program dates, please contact our Gaining Ground Coordinator at **EWatson@MageeRehab.org**. Please note that this program is not covered by insurance.

MAGEE PEER MENTOR PROGRAMS

SCI PEER	One-to-one with someone with a similar disability who has not only adjusted but is living a good life again. Matches can be based on level of injury, age, gender, marital status, recreational interests, and job experience. There are also specialty areas for peers with experience with ostomies and wounds.	Please call Marie Protesto at (215) 587-3174 or mprotesto@mageerehab.org
SCI FAMILY PEER	One-to-one meeting with the loved one of someone with a spinal cord injury. Can meet in person, by phone or email to share experiences, insights and coping strategies.	Please call Ruth Black at (215) 587-3030 or email rblack@mageerehab.org .
AMP-PEERS	Individuals who have had amputations volunteer their time to encourage and offer advice. Matches can be made according to level, age, gender, social roles, and recreational interests.	Please call Sonya Dibeler at (215) 587-3205 or e-mail sdibeler@mageerehab.org .
STROKE PEERS & FAMILY PEERS	Individuals are available to meet one-to-one to answer questions regarding life after a stroke. They have various levels of disability as well as life experiences. Family and loved ones are also available to meet one-to-one.	Please call Jennifer Salomon at (215) 587-3411 or email jsalomon@mageerehab.org
TBI PEERS & FAMILY PEERS	Individuals are available to meet one-to-one to answer questions regarding life after a traumatic brain injury. They have various levels of disability as well as life experiences. Family and loved ones are also available to meet one-to-one.	Please call Jennifer Salomon at (215) 587-3411 or email jsalomon@mageerehab.org
ADDICTIONS PEERS	Offers those who struggle with addiction issues the opportunity to talk with a specially trained person who has experience as an addictions advocate.	Please call Ruth Black at (215) 587-3030 or email rblack@mageerehab.org .