



THE CORD

FROM DOCTOR TO PATIENT by Dr. Stanley Yoo

I was raised in a suburb of New York City and went to college in NY as well. Since then I spent 6 years in Boston where I went to medical school and completed my internship. In the summer of 2007 I moved to the Philadelphia area for my residency training with the Temple University program in Physical Medicine and Rehabilitation.



I felt that PM&R was an appropriate career choice because my athleticism was always something I took pride in. I am admittedly a gym rat, and also have a background in Tae Kwon Do, which I started when I was 13. During my last year of medical school I started gymnastics. What I enjoyed most was the challenge: the ability to say that I was able to do something that most people could not do, or would not even consider trying. To me, my physical potential and skill in any sport was only limited by how much time I put into it. I wanted to pursue sports/musculoskeletal medicine because that part of my life was something that had given me a sense of accomplishment, and to put that into my professional practice seemed like the optimal way to blend my career with my extracurricular passions. The irony doesn't escape me that I ended up being a rehab patient for a spinal cord injury myself.

I was injured on November 8, 2008, when I landed on my neck while warming up on a trampoline before an adult gymnastics

class. Though I didn't fracture any of my vertebrae, I did suffer a dislocation at the C6/C7 level in my neck. Consequently, my spine became unstable and I suffered a spinal cord injury. Nearly immediately after the injury I was unable to move my legs and, though I could move my arms, my hands were profoundly weak. I did, however, have some sensation below my level of injury. I was taken to Jefferson Hospital and underwent surgery within a couple of hours of getting hurt.

Life immediately afterward was scary. Being in the field of PM&R and already having some knowledge about spinal cord injury can be a double edged sword. On the one hand, I knew that sensation below my level of injury was a very hopeful sign for functional recovery in the future, but on the other, I also knew right away that the bulk of neurologic recovery happens anywhere between the first 6 months to a year, and that the earlier the return of movement, the more potential for future recovery. So, from the beginning it felt as if I was racing against the clock to get function back, and every day that I couldn't move my legs or hands was nerve-racking.

I spent my 30th birthday at Jefferson Hospital. Becoming a year older is always kind of a time of reflection, and that goes especially, I think, for turning 30. Of all the places I thought I would be in my life, being nearly completely incapacitated in a hospital was definitely not one of them. Just about everything that comes along with a spinal cord injury is utterly emasculating, and going from being completely independent (functionally, financially, etc) to the complete opposite, literally in a matter of seconds, is absolutely surreal. Even though you know it's possible, you can't believe something

like that could happen to you. I felt as though my life was going in completely the wrong direction.

My time at Magee was everything that I could ask or expect from an inpatient experience. I arrived at Magee nearly one week after my injury, and therapy began the day after I was admitted. Being on a dedicated spinal cord service meant that everyone you interacted with, from the doctors to the nurses and therapists were all familiar with the intricacies and complications of SCI, which was a great advantage. There was also a sense of community which came with interacting with other SCI patients, that made you feel less isolated and less like you were going through this alone, since others were facing the same sort of issues that you were.

One of the times that stands out in my mind was the day I was first able to move my left leg. Before that the therapists and doctors always encouraged me, as they do everyone, to keep trying to move my legs, even if there was no response. That way, at least there was a chance that some of those signals were getting down to your limbs. In the couple of days before I actually moved my leg, I thought I felt it moving, but couldn't be sure. It was almost as if I had to imagine that it was moving in order to feel it. On a Friday, two weeks to the day after I was admitted to Magee and nearly 3 weeks after my injury, my physical therapist decided to do formal muscle testing of my legs. With gravity eliminated and my foot on a skate, I was able to extend my left hip and knee and dorsi-flex my foot. My physical therapist called over my family, nurses, my resident and attending, really just about anyone

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RESEARCH & EDUCATION

NEW! DIAPHRAGM PACING SYSTEM



The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) at Thomas Jefferson University Hospital and Magee Rehabilitation Hospital is excited to announce a new program available for those with ventilator dependent spinal cord injury, the NeuRx Diaphragm Pacing System™ RA/4.

The NeuRx RA/4 System is designed to help patients breathe by stimulation of their diaphragm muscles. Intramuscular diaphragm electrodes are implanted using standard laparoscopic surgical techniques. The implanted electrodes are connected to an external stimulator that delivers

repetitive electrical stimulation to the patient's diaphragm causing it to contract. As a result the patient will inhale in a manner similar to natural breathing. A physician will program the Stimulator so that it produces the right stimulation patterns. The user simply connects the device to the implanted electrodes and turns it on for use; no other controls are available or necessary for operation.

If you feel you may benefit from this procedure and may be interested or you would like further information on this new device, please call the **RSCICDV** office at **(215) 955-6579**.

Visit www.spinalcordcenter.org to learn more about the Regional Spinal Cord Center of the Delaware Valley.

STUDY OF ASSISTIVE TECHNOLOGY FOR MOBILITY IN SCI

The combined efforts of SCI Center staff from both Thomas Jefferson University and Magee Rehabilitation Hospital continue to support a new multicenter study entitled "Investigation of Assistive Technology for Mobility used by Individuals with a Spinal Cord Injury". Working together with SCI Centers in Pittsburgh, Georgia, Chicago, Washington DC, Ohio and Northern New Jersey, we are investigating the impact of policy changes on customizability and features of wheelchairs, and the number of working wheelchairs an individual owns. To collect this information, we are looking at the specifics of an individual's wheelchair usage, relative to the type of wheelchair they were provided, the amount of wheelchair breakdown, the skill of using the wheelchair and quality of life measures for the individual using a



wheelchair for primary mobility. Since it has been shown that reintegration into society following a disability depends on access to appropriate and adequate assistive technology such as wheelchairs, we hope to investigate the effects of the types of presently supplied wheelchairs and how they may be contributing to a person's functional limitations, even more so than the person's disability itself. The information (or data) collected over the four years may then be helpful in effecting policy change, relative to prescriptions and funding for wheelchair mobility equipment.

If you are interested in participating or would like more information, please call **Mary Patrick**, RN, RSCICDV Project Coordinator, at **(215) 955-6579**.

UPPER EXTREMITY STUDY

The Regional Spinal Cord Injury Center at Thomas Jefferson University Hospital and Magee Rehabilitation has developed a research tool to measure improvements in arm and hand function in persons with cervical spinal cord injury (neck region). We are seeking volunteers to help us make sure that the scale is valid (measures what it is supposed to measure). **Research participants must have sustained a cervical spinal cord injury.** Subjects will be required to come to Thomas Jefferson University Hospital or Magee Rehabilitation Hospital on either 1 or 2 occasions for about 1½ hours each visit. Those who participate will be reimbursed for time and travel and provided with free parking.

The research tool is called the Capabilities of the Arm and Hand in Tetraplegia (CAHT). The validation and reliability of this scale is very important because it will be used in future clinical trials to measure improvements in upper extremity function. To date, there is no reliable measurement for clinicians to use. This is a very important study and **we need your help.**

If you are interested in participating, please contact **Mary Patrick** in the Spinal Cord Injury Research Office at Thomas Jefferson University Hospital at **(215) 955-6579** and we will be willing to answer any of your questions.

MAGEE STAFF PRESENTING AT PENN STATE'S "WOUNDED WARRIORS" PROGRAM

Jessica Rickard, CTRS, SCI Team Leader and AJ Nanayakkara, Wheelchair Sports Coordinator are co-presenters at Penn State University for a program called Inclusive Recreation for Wounded Warriors. This program is a running class that will span over the next 3 years. The class is scheduled for 4 weeks a year. Jessica and AJ present for 3.5 hours about Spinal Cord Injury and the importance of Recreation Programming. The audience is personnel that facilitate recreation programs at military installations around the country.

If there are any questions about this program, please contact **Jessica Rickard** at jrickard@mageerehab.org.

PAIN STUDY FOR SCI AT JEFFERSON/MAGEE

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

We invite you to consider participation in the study if:

- You are at least 18 years old.
- You have pain associated with your traumatic spinal cord injury.
- You are dissatisfied with your current pain treatment.

- You are willing to come to our clinic for 8 visits over a 5 month period.

Participants who qualify will receive at no cost:

- Study related physician visits.
- Study procedures and lab testing.
- Study medicines.
- Additionally, you may receive compensation for your time.

If you are interested in learning more about this research study, please contact **Mary Patrick, RN**, RSCICDV Project Coordinator at **(215) 955-6579**.



ONGOING RESEARCH OF THE RSCICDV

Current

1. Investigation of assistive technology for mobility used by individuals with spinal cord injury. *Sponsor: NIDRR supported through SCI Model System of Care*
2. 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*
3. 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*
4. Development and validation of the Capabilities of Arm and Hand in Tetraplegia (CAHT) measurement for upper extremity function. *Sponsor: NIDRR supported through SCI Model System of Care*
5. A 15-Week, Randomized, Double-Blind, Placebo-Controlled, Parallel-Group, Multi-Center Trial of Pregabalin for the Treatment of Chronic Central Neuropathic Pain After Spinal Cord Injury. *Sponsor: Pfizer Pharmaceuticals*
6. A United States multi-center study to assess the validity and reliability of the Spinal Cord Independence Measure (SCIM III). *Sponsor: Craig H. Neilsen Foundation*

Completed Clinical Trials

1. Restoration of walking after spinal cord injury – Reliability of the maximal WISCI level. *Sponsor: National Institute on Disability and Rehabilitation Research (NIDRR)*
2. A phase II, double blind, placebo-controlled, multicentered 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*
3. Peripheral denervation following spinal cord injury (Using MRI to study nerve function following spinal cord injury). *Sponsor: American Paraplegia Society*
4. 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.*
5. 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)*
6. Study the effects of Body Weight Supported Treadmill Training in acute incomplete spinal cord injury. *Sponsor: National Institute of Health (NIH)*
7. 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.*
8. 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.*
9. 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.*
10. A four-week, prospective, randomized, double-blind, placebo-controlled trial to assess safety, tolerability, Pharmacokinetics and preliminary efficacy of AV 650 in patients with spasticity due to spinal cord injury. *Sponsor: Avigen*

UROLOGY CLINICAL TRIALS

A Multicenter, Double-Blind, Randomized, Placebo-Controlled, Parallel-Group Study of the Safety and Efficacy of Repeat Treatment with Two Dose Levels of BOTOX® (Botulinum Toxin Type A) Purified Neurotoxin Complex Followed by a Treatment with BOTOX® in Patients with Urinary Incontinence Due to Neurogenic Detrusor Overactivity

PI: Patrick Shenot, MD

Sponsor: Allergan

This study is an international multi-center study to determine the efficacy and safety of a new experimental medication for the control of urinary incontinence, a symptom of an overactive bladder, in patients with either thoracic or lumbar spinal cord injury or multiple sclerosis.

A Placebo-Controlled, Randomized, Safety and Efficacy Study of BOTOX® (Botulinum Toxin Type A) Purified Neurotoxin Complex in Patients with Neurogenic Detrusor Overactivity and Neurological Respiratory Impairment

PI: Patrick Shenot, MD

Sponsor: Allergan

This study is an international multi-center study to determine the efficacy and safety of a new experimental medication for the control of urinary incontinence, a symptom of an overactive bladder, in patients with cervical spinal cord injury or multiple sclerosis.

If you are interested in taking part in any of these studies or for more information, please contact **Christine Hubert** at **(215) 955-9954** or **christine.hubert@jefferson.edu**.

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**.



CURE-NOT CARE®

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she could, to show them. It was a great moment because, aside from being able to move my leg for the first time since I got hurt, it was a time when it was so apparent that everyone was rooting and pulling for you in earnest. Out of all the people who were there, I was actually the least excited one, mostly because throughout my time at Magee, I was trying to keep an air of cautious optimism. Still, right after I finished therapies that day I texted friends and co-residents to tell them the news and have them pass it on to others. At that point the decision was made to begin locomotor training with me. It was a good day. About another week or two after that, once I had already started locomotor training, I began to move my right leg as well.

I think the difficult times were when I had any real downtime, such as on weekends or holidays. The thing about therapy days was that it felt like you were actively working towards your recovery. Those were the times when I felt the most "normal" or at least like I was heading in that direction. And at the end of the day, sleep came easily enough for me since I was completely exhausted. On quiet days, the days when there was time for reflection, it also meant there was a whole lot of time

to get caught up in worries, fears, sorrows, and feel like you really have no power over them. It was a lot easier then to get overwhelmed by a sense of profound loss. Luckily, those times were less frequent than they could have been, since I regularly had visitors to talk with and take my mind off of things. Really, my saving grace was the outpouring of support that my friends, family and coworkers all showed. Having their company to talk, take my mind off things, and even allow for a little bit of humor was absolutely invaluable. I can't say enough for how far a smile or a laugh goes in making you feel more whole; more human.

The Day Hospital Program was a great transition between inpatient and traditional outpatient therapy. Having a full 9am -3pm day five days a week made me feel as though I didn't lose out on anything by leaving the intensive inpatient rehab setting, with the added benefit of being able to go home and sleep in my own bed at the end of the day. Additionally, I think there's an often overlooked advantage in the continuity of care that exists when staying within one healthcare system. Though at a different physical location, the therapists were well aware

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SPINAL CORD INJURY SUPPORT GROUPS

SCI FAMILY PEERS

Family Peer Mentors are family members and/or loved ones of individuals who have sustained a SCI and have successfully transitioned to living life with a disability. They are volunteers who are specially trained to guide and provide SCI related information and experiences to families and loved ones of newly injured

individuals.

Mentoring can be done in the form of participating in the family group which is held twice monthly at Magee or contacting a new family by telephone or face to face if possible. Given the geographic area Magee serves, we attempt to be creative and flexible with mentoring requests.

The SCI Family PEER Group meets two Wednesdays a month at 6 p.m. in the 5th floor lounge on the Spinal Cord Injury Unit at Magee Rehabilitation Hospital.

For more information or to become a Family Peer Mentor, please contact **Ruth Black, LCSW** at **(215) 587-3030** or **rblack@mageerehab.org**.



FAMILY PEERS ARE NEEDED!

As a family peer counselor your commitment will entail attending two evening training sessions. After training you assist families by meeting with them in person or over the phone and by becoming involved in the Family PEER Group.

As our family peer counselors can tell you, this will be the most rewarding volunteer experience you have ever had. You have the expertise and experience that families so desperately need.

To find out more, please contact **Ruth Black, LCSW** at **(215) 587-3030** or **rblack@mageerehab.org**.

SCI PEERS, sharing experiences

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

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

vocational experience.

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



SCI RESOURCE GROUP

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

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

We would like to add a new segment to the newsletter.

Do you have any tips or gadgets that make doing things with your disability more manageable?

Please share them at **sdibeler@mageerehab.org**.

WHEELCHAIR SPORTS

MAGEE WHEELCHAIR SPORTS TEAMS

Basketball: Magee Sixers Spokesmen

Magee has two wheelchair basketball teams!

Both teams practice Wednesday evenings from 6:30 pm – 9 pm (September—May)

D2 practice location: Carousel House (the corner of Belmont Ave. and North Concourse Dr., Philadelphia, PA 19131)

D3 practice location: Finley Playground (1000 E. Hortter St., Philadelphia, PA 19150)

Rugby: Magee Eagles

Practices are held Tuesday evenings from 6:30 pm – 9 pm (September—May)

Location: Carousel House (the corner of Belmont Ave. and North Concourse Dr., Philadelphia, PA 19131)

Soccer: Magee Kixx

Practices are held every other Sunday from 12:30 pm – 3:30 pm (September—June)

Location: Friends Select School (16th and Race Streets, Philadelphia, PA 19102)

Tennis: Magee Freedom

Practices are held Sundays from 12 pm – 2 pm (spring through fall).

Location: Cherry Hill Racquet Club (1820 Old Cuthbert Rd., Cherry Hill, NJ 08034)

Magee Wheelchair Sports are always looking for volunteers who would like to learn more about wheelchair sports and help our teams at practices and tournament. If you have any questions or would like more information on any of our teams, please contact **AJ Nanayakkara** at **(215) 587-3412** or **ananayakkara@mageerehab.org**.

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 the following universities: Temple, Widener, West Chester, Stockton College (NJ), University of the Sciences, University of Pennsylvania, and Philadelphia University. Our athletes have also lectured to students at the Franklin Learning Center, Temple, and Jefferson University.

Physical activity is an integral part of physical and psychological well being. Everyone, regardless of ability or disability, should have access to recreation, so we plan to actively recruit 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 leisure activity that we do not yet offer, please contact us!

Magee Rehabilitation is looking to expand its adapted sports program by adding more recreational activities for the disabled community. 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 add a specific activity to our program, please contact **AJ Nanayakkara** at **(215) 587-3412** or **ananayakkara@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**.

Alcoholics Anonymous

This group meets every Sunday at 6:30 p.m. in Magee's Cafeteria.

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

LEGAL CLINIC FOR THE DISABLED

The Legal Clinic for the Disabled provides free legal services to low-income people with disabilities in the five-county Philadelphia area, including current and former patients of Magee Rehabilitation

Hospital. Located in Magee's main hospital, the Legal Clinic provides free advice and representation on civil cases involving wrongful eviction, divorce, domestic violence and abuse, custody and support, identity theft,

unfair debt collection practices, healthcare coverage, powers of attorney, guardianship, wills and other issues.

For more information, contact the Legal Clinic at **(215) 587-3350**.

PATIENT RESOURCE CENTER

The Patient Resource Center is located on the 6th floor. 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 three computers spaced just right for patient, visitor and

staff access and to supplement these resources, we also have an assortment of VHS tapes and 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.

THE THEATRE ARTS PROGRAM AT MAGEE

The Theatre Arts program, also known as "The Magee Players" was started in 2000 by Theatre director Barbara Gregson and The Creative Arts Therapy Department at Magee Rehabilitation Hospital. They have had countless

shows in the Philadelphia community and at Magee to date.

Classes are directed by Barbara Gregson and will cover acting, improvisation, mime and masks as well as writing original pieces for performances.

Classes are open for adults with disabilities in the tri-state area.

If you or someone you know would be interested in learning more, please call **Keith Currens** at **(215) 587-3071**.



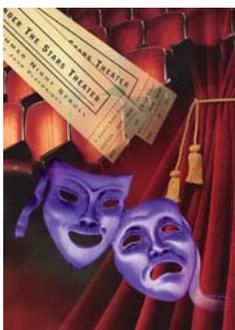
Hours of Operation

Monday & Wednesday
9:30 am - 8:00 pm

Tuesday & Thursday
11:00 am - 5:00 pm

Friday
9:30 am - 5:00 pm

Sunday
12:00 pm - 5:00 pm



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of treatment strategies and approaches at the main hospital and were able to incorporate that knowledge into their own treatments. In fact, it wasn't uncommon that a therapist would come over from the main hospital to fill in or help out for the day when the need arose. Each day would consist of an hour of PT and an hour of OT, with group therapy and recreational therapy also scheduled during the day. There were also psychological and nursing services available on a regular basis. Once a week there were also group outings to facilitate community reintegration and prepare for issues a patient might encounter when out in the "real" world.

I was excited to begin locomotor training while at the main hospital, because it represented the potential to ambulate again. Locomotor training has so far been studied most extensively in spinal cord injured patients, and has pretty convincingly showed benefit in certain patients in the SCI population. The advantage is that with the help of the harness suspension and the therapists, the patient can hopefully walk in a pattern and at a pace that more closely represents normal physiologic walking, and eventually can sustain this level of activity long enough to have benefit on restoring neurologic patterns needed for gait. I was fortunate enough to start this therapy early on in inpatient rehab and continue through the Day Hospital Program and outpatient therapy. The physical therapists were extremely well seasoned in locomotor training and in many cases that was what the therapist did almost exclusively. That allowed for the therapy to be appropriately challenging in just about every session. The downside to the whole experience was that the harness you're suspended in can get extremely uncomfortable and take some readjusting, but that's a small price to pay, I think, for progress.



I have my better and worse days, hours, even minutes. I would be lying if I said that there aren't times when I struggle. I have been extraordinarily fortunate in the amount of recovery that I have had so far as well as the amount of support I have received from those around me. I'm also lucky that I haven't encountered any serious medical complications since my injury. As of now, I have moved on from locomotor training and am walking independently without the use of any assistive device. I have also transitioned back to living pretty much independently and am driving again. Everyone is thrilled by my progress, and is even sometimes in a bit of disbelief. There are times when I look back myself and am in awe that I am as functional as I am now, when 6 months ago I couldn't move my legs and was being spoon fed by my family because I couldn't grab a fork.

Yet in spite of all that I have regained, there are still times - more than I like to admit - when I still feel that sense of profound loss. It's a tough thing to reconcile sometimes, that you can be so grateful for having improved and yet be resentful at the same time that you are in this position in the first place. My athleticism and physicality before I got injured probably meant more to me than anything else in my life, and as time passes, the realization has started to set in that I will likely never be as strong, fast, or coordinated as I was before. And

while everyone else celebrates the return of my function, I often feel as though I am just beginning to grieve its loss. It seems to me that this grief is one that continues for anyone who has been affected by a debilitating injury long after the dust has settled for those around them. It's a very solitary kind of grief in that no one other than the person experiencing it will ever know just how much that person has lost. Unfortunately, it is the cross that every SCI patient has to bear, and for the most part will have to learn how to bear alone. Of all the scars that can be left, I think the emotional one can quite possibly be the deepest and hardest to come back from.

I would like to offer words of wisdom I am trying to heed myself. Be patient. Recovery from an SCI is a marathon, not a sprint. Just because something doesn't come back today or tomorrow does not mean it's not going to come back at all. Each day, in a way, is a small victory, and small victories are still victories and they add up. Another piece of advice I am trying to follow myself is to believe and to hope, because both are very powerful things. With the first human trials in the US for stem cell treatment in the SCI population beginning soon, we are quite possibly entering an era where there will be disease modifying treatments for SCI. So long as there is hope for that, there is reason to try and to persevere.

I'll end with a quote, which hopefully can serve as a mantra to anyone undergoing a hardship in his or her life:

"... I will persist until I succeed.

The prizes of life are at the end of each journey, not near the beginning; and it is not given to me to know how many steps are necessary in order to reach my goal. Failure I may still encounter at the thousandth step, yet success hides behind the next bend in the road. Never will I know how close it lies unless I turn the corner.

Always will I take another step. If that is of no avail I will take another, and yet another. In truth, one step at a time is not too difficult.

I will persist until I succeed.

Henceforth, I will consider each day's effort as but one blow of my blade against a mighty oak. The first blow may cause not a tremor in the wood, nor the second, nor the third. Each blow, of itself, may be trifling, and seem of no consequence. Yet from childish swipes the oak will eventually tumble. So it will be with my efforts of today.

I will be liken to the rain drop which washes away the mountain; the ant who devours a tiger; the star which brightens the earth; the slave who builds a pyramid. I will build my castle one brick at a time for I know that small attempts, repeated, will complete any undertaking.

... So long as there is breath in me, that long will I persist. For now I know one of the greatest principles of success; if I persist long enough I will win.

I will persist.

I will win."

-Og Mandino, The Greatest Salesman in The World

MY SUMMER 2008 TRIP....BACK TO THE HOSPITAL! by Mark Chilutti

Usually I write this column about an exciting destination that I have been to, or try to provide tips on travel for those with disabilities. For this issue, I am going to tell you about my trip last summer. Only thing is, it was not an exciting destination. I write though to give tips, just like I usually do, for anyone who has to make a trip back to the hospital long after their initial injury.

My T5 spinal cord injury occurred on December 5, 1996, and other than keeping up with annual exams and tests, I had not really needed to spend time overnight in a hospital. That all changed after a routine test presented some complications. I was to be kept overnight, which then turned in to 19 days in acute care and 11 days back at Magee for conditioning and strengthening.

Since that summer visit, I ended up back in the ER twice, a 4 day stay in acute care, a same day surgery, a flap surgery, and another 36 days at Magee for extensive rehabilitation. Through all of these stays I was reminded of things that we need to look out for and be aware of, and I want to share those with you.

Some times other health issues become so important that they make a spinal cord injury seem so routine. But, the basics that we are taught right after our initial injury are still so critical, and maybe even more so when our systems become compromised.

CHECK YOUR SKIN!

Nobody knows your body better than you do. Laying in a hospital bed can cause many things, and skin issues is at the top of the list. All of the basics that we were taught need to apply. Checking your skin a few times daily is a must. Changing positions or turning throughout the day can help. In a few cases, I even had a special bed while in the hospital to help relieve pressure. The main point here is that unless you are in an SCI unit, the people providing your care might not be familiar with all of your needs. You know best what you need and can help everyone, including yourself, by advocating and educating those who are there to help you. Trust me; they can do it much better when they know your needs!

SHARE EVERY BIT OF YOUR MEDICAL HISTORY!

Most of us who have survived traumatic illness and injury have quite a medical history. Be sure to share it all when you have the need to be re-admitted to a hospital. It is so important that your treatment team knows as much as they can about you so that they can provide you with the best treatment and care. It will also help them understand your body and its needs much better.

FOOD AND NUTRITION ARE A CRITICAL PART OF THE TEAM!

During my first 19 day hospitalization I was very sick, in pain and not doing much; including eating. This caused me to lose about 30 pounds. While many people might have been happy to lose this weight, I did not have any to spare.

When I arrived at Magee, both times, I got to know the food and nutrition staff quite well. They played a huge part in providing me with nutrients and supplements to help with wound healing, help with gaining weight back the right way, and being sure that I got enough food every day to start gaining weight. I gained a ton of respect for the job that they do to help us in this important area.

SPEAK UP!

Probably some of my most interesting experiences in the acute care hospital and for subsequent procedures there involved transfers. Since all of this time was not spent in a spinal cord injury unit, it got real interesting every time I had to be transferred to a stretcher, table, or wheelchair. This was a time that I had to speak up and educate them on how to do it safely, and show them how 2 people can do it very easily.

We sometimes think that everyone in a hospital setting should know how to deal with us because they are doctors, nurses and technicians who work in a hospital every day. We need to remember though that our population is small, and most medical professionals do not know everything there is to know about spinal cord injuries, because that is not their specialty. That does not mean they skipped a class in school, or are not great clinicians. **It simply means we have to help them learn about us.** The more we can do that, the better it is for everyone involved.

HAPPIER DAYS AHEAD!

After a challenging six months, I left Magee on December 30th healed and healthy. I returned to work the next week, and, more importantly, jumped back on a plane about a month later. I have been in the air 4 times already this year, and have a lot more travel planned for the rest of the year. So, the good news is that my next article will get back to sharing stories of travel adventures. And, if all goes well, we are planning to celebrate Christmas in Rome. That will certainly make for a much better story to tell!

As always, I hope that you find what I write beneficial, as I am sure that many of you are just like me and had not been back in the hospital in a long time. It is so important to go back to the basics for care again, and, more importantly, just another reminder of how precious each and every day is! So, the warm weather is almost here...do something fun outside and enjoy it!