MAKING A DIFFERENCE IN THE LIVES OF HIS STUDENTS

“Mr. Bronstein’s passion for life and teaching makes him such an inspiration to his students, especially me . . . I came to his class indifferent to chemistry . . . [with] less then spectacular grades . . . [He] saw potential in me and took it on himself to bring it out . . . he helped mold me into an A student . . . [and] I am currently at Villanova University working on a major in chemical engineering.”

These comments are from one of Alan’s former students in describing the impact he has made on her life. This is making a difference.

In 1985, Alan was injured trying to get his car out of the snow. He was trapped between a parking meter and the car door, and his injury left him a T-3 complete. Like many with SCI, Alan realized he could not continue in his business and had to figure out his new life. He sold his business and returned to home to Philadelphia. He took time in difficult introspection. He learned from false starts and rekindled friendships to find his new direction. Alan battled insecurities yet returned to his earlier passion, teaching - now from a wheelchair - and the financial pressure of a significant salary cut. With the support of his wife, Alan pressed on.

Alan Bronstein has succeeded big time! On May 5, 2009 he was honored with The Freida J. Riley Award. Named for the teacher made famous in the movie October Sky, this honor is awarded annually to an American educator who overcomes adversity or makes an enormous sacrifice to positively impact students. Alan has also been nominated to Who’s Who Among American Educators by his students six times!

“I have not considered that I have ‘overcome adversity.’ I have just been ‘doing what has to be done’ and doing what makes life worth living.”

“People comment on my attitude and wonder how I manage to stay upbeat. I am finally reading in the literature what I have believed for a long time: Attitude makes all the difference. We decide for ourselves if we are going to be happy. Happiness comes from inside, not really from external stimuli. Sure, things can make us happy, but for the most part the happiness is a result of how we choose to view those things. I choose to be positive.”

Alan sums up his post injury life experience by citing the power of attitude. To paraphrase him: “If we are angry or miserable, we drive people away. If we deal with our situation and make the best of what we have, we find the chance for rewarding lives. Life can be strange. Here I am teaching chemistry at my old high school rather then seeking financial wealth. I have found there are other kinds of riches and they help make life worth living.” And they have made a difference in the lives of his students.

This project is supported, in part, by:
The National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education, Washington, D.C., grant #H133N-000023 and the Friends of Jerry Segal.
RESEARCH & EDUCATION

RESEARCH PARTICIPANTS NEEDED!

The Spinal Cord Injury Center at Jefferson and Magee is looking for individuals with SCI to participate in a research study to examine the reliability of a spasticity and joint position test. The participant will be asked to:

- Have 2 separate physical therapists perform a spasticity and joint position test on your legs.
- Come back into Magee a week later to have the same 2 physical therapists test spasticity.

If you:

- have a traumatic spinal cord injury
- Level of Injury T12 or higher
- Willing to come to Magee Rehab Hospital for 2 outpatient visit
- 3 or more months post injury

If interested, please contact Mary Schmidt at (215) 587-3151.

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.

Those who participate will be reimbursed for time, travel and parking.

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.
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.

The Spinal Cord Injury Patient-Family Teaching Manual can be found here in both English and Spanish.

CHRONIC NERVE PAIN POST SPINAL CORD INJURY

The Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) at Thomas Jefferson University/Magee Rehabilitation is participating in a new clinical research study. The study is designed for men and women with chronic nerve pain after spinal cord injury (SCI). This clinical research study will evaluate the safety and effect of a study medication in relieving chronic pain associated with spinal cord injury.

This study might be appropriate if you:

- Are at least 18 years old
- Have chronic nerve pain after spinal cord injury
- Have had a spinal cord injury more than one year ago

If you qualify for this study, you will be required to attend eight (8) scheduled doctor visits over a 5-month period.

Qualified study participants may receive study-related:

- Medication or placebo (inactive substance)
- Physical and neurological exams
- Electrocardiograms
- Laboratory tests

To find out if you qualify for this research opportunity, please call the Spinal Cord Injury Center at Thomas Jefferson University at (215) 955-6579 and ask for Mary Patrick or Marilyn Owens or visit the website at www.spineinjurypain.com.
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.

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.

JOHN DITUNNO, JR., M.D. RECEIVES TOP AWARD AT THE INTERNATIONAL SPINAL CORD SOCIETY

John F. Ditunno, Jr, M.D., Former Director of the Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV) at Jefferson/Magee and Former Chair of the Department of Rehabilitation Medicine at Thomas Jefferson University received the Sir Ludwig Guttmann Lectureship at the 48th Meeting of the International Spinal Cord Society (ISCoS) in Florence, Italy on October 21, 2009. The Sir Ludwig Guttmann Lectureship was established by the International Medical Society of Paraplegia, now the International Spinal Cord Society, to recognize the pioneering work and lifelong contribution of Sir Ludwig Guttmann, the originator of modern multidisciplinary spinal cord care. Dr. Ditunno presented on the Outcome Measures: Evolution in Clinical Trials of Neurological/Functional Recovery in Spinal Cord.

A HEALTHY URINARY SYSTEM

An article titled “Living with Spinal Cord Injury” at the website [www.spinalinjury.net](http://www.spinalinjury.net) talks about a healthy urinary tract system.

To avoid problems with your urinary system you should empty your bladder completely. When using clean technique catheterization always use clean equipment and wash your hands before and after cathing. When changing your indwelling foley catheter maintain sterile technique to avoid introducing bacteria into the urinary tract system.

Drinking the recommended amount of liquid for your bladder program will help to keep stones from forming. The article suggests for individuals with an indwelling foley should drink 15 – 80zs of fluids each day, this is the equivalent of 3 quarts. For intermittent catheterization it recommends a fluid intake is 8 to 10 – 8 oz glasses per day between breakfast and dinner which is 2 quarts, with water being your number 1 beverage. Limit carbonated beverages to 1 per day.

You can find references on how your urinary system works after a spinal cord injury to keeping your pressures low in the article.
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


7. Spasticity and Joint Position Testing in Individuals with SCI. Sponsor: Regional Spinal Cord Injury Center of the Delaware Valley

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 access 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


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)


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.


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
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.

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.

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.

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
Practices are held Wednesday evenings from 6:30 pm – 9 pm (September—May)
D3 practice location: Carousel House (the corner of Belmont Ave. and North Concourse Dr., Philadelphia, PA 19131)

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.
employer with ten employees needs time off for treatment, neither the ADA nor the FMLA applies, but the PHRA does. However, under the ADA and PHRA, the employer need not make an accommodation to a disabled employee if it results in an “undue hardship” to the employer. The smaller the employer, and the longer the requested leave, the easier it would be to claim a medical leave presents such a hardship, and need not be granted.

Under the FMLA, if an employee is caring for an immediate family member (parents, spouse or children) who has a serious health condition, that employee (assuming the employer is large enough, and the employee worked enough hours) can ask for time off. Allowing time off to care for someone else is not required under the ADA or PHRA."

LEGAL CLINIC FOR THE DISABLED

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.legalclinicforthedisabled.org.
ON STAFF AT THE LEGAL CLINIC

"Ben Beck-Coon, a 2009 Temple Law graduate, recently joined LCD as a staff attorney and Independence Foundation fellow. Ben’s work will focus on individuals with disabilities who are experiencing domestic violence. The primary goal of the project is to help clients live more safely and independently. Ben is part of a medical-legal partnership between LCD and a local nurse-managed community health center, where he regularly see clients on-site as part of the healthcare and social service team. This multidisciplinary approach to patient health and well-being has been shown to achieve greater results for clients than could be achieved by professionals working alone.”

"LCD is fortunate to have David Sparrow, graduate student in social work from Temple University, as our social work intern three days a week. David’s hometown is Pittsburgh and prior to enrolling at Temple he worked with high-risk youth. LCD’s staff attorneys have relied on David to assist clients with an array of issues such as securing subsidized housing, completing the SEPTA paratransit application process and providing a hearing impaired client with in-home voice relay assistance. David has the patience of Job and continues to be a benefit for the clients we serve."

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 Joe Davis, Think First Coordinator, at (215) 587-3400.

ThinkFirst PARTNERS WITH ANTI-GUN VIOLENCE GROUP FOR 5K

Magee's ThinkFirst Program has joined with Physicians for Social Responsibility to co-host the 4th annual Legs Against Arms 5K Run/Walk/Roll/Stroll, held at St. Joseph’s University on Sunday, April 11.

Both organizations are trying to decrease the episodes of violence in the community as well as increase the awareness of violence.

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 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.
MAKING A DIFFERENCE HAPPENS IN MANY WAYS  by Mark Chilutti

Since the theme of this edition is “Making a difference,” I thought I’d shift from the direction that my articles usually take, which is about travel tips, to talking about how we can make a difference.

December 5th marked 13 years since my spinal cord injury, and I think that as each year goes by, I can’t help but reflect back. I don’t do it to think about opportunities lost, but more to look at just how much I have been able to accomplish in my life since then. When I do this, I always arrive at the same conclusion every year, and that is that I have found a way to live a very productive and meaningful life…I just do it sitting down!

The great thing about the world we live in is that each one of us can make a difference if we choose to. But, like most things in life, it is truly up to you to decide the path that you want to be on. Do you want to make things happen, watch things happen, or wonder what happened?

I see people at Magee making a difference every day. Our staff members go out of their way, in so many different ways, to make a difference for our patients and their families. Our volunteers make a difference too. Some of them are former patients who want to “give back.” Others are people who just want to help. No matter which category they fall in, they all are doing the same thing; making a difference.

Many of you might be reading this and wondering how can YOU make a difference? While there is no textbook answer to this question, you shouldn’t have to think too hard about things that you can do to accomplish this. Here are just a few:

- Share a smile and a pleasant greeting with those you encounter. Sometimes this small gesture can really brighten someone’s day.
- Get out and get involved with something that you care about. Find a group to volunteer with, and find a meaningful role that leaves you feeling good, while doing something to help others.
- Mentor a newly or more recently injured patient. Our peer mentor program has been instrumental in helping people adjust to life after injury and your help there could be valuable!

Making a difference gives me such an awesome feeling and I can’t think of anything that makes me feel better than someone telling me thanks for making a difference in their day, or their life. That is all that I need to keep going!

Try it!

WEBSITES OF INTEREST

Christopher and Dana Reeve Foundation  www.christopherreeve.org
Disability Community  www.disaboom.com
Disaster Preparedness for People with Disabilities  www.disability911.com
New Mobility  www.newmobility.com
SCI Care  http://sci.rutgers.edu