Much is happening in Spinal Cord Injury (SCI) research these days. One only has to google clinicaltrials.gov to see how many new trials start every day in hopes to bring recovery into the spotlight. Just recently, Detroit hosted the 2010 World Stem Cell Summit to provide a forum for researchers across the globe to discuss stem cells and their potential in addressing health issues. Given their unique regenerative abilities, stem cells may offer promising new treatments for diseases such as diabetes, ALS, and heart disease as well as brain and spinal cord injuries. However, much work remains to be done in the laboratory and the clinic to understand how to use stem cells and cell-based therapies to most effectively treat diseases. Speakers at the World Stem Cell Summit included Drs. Eva Feldman and Sean Morrison from the University of Michigan and our own advisory board member, Danny Heumann from Heumannly Capable. Also presenting was Thomas Okarma, Ph.D., M.D., President and Director of Geron Corporation.

The Geron trial is currently the first U.S. clinical trial approved by the Food and Drug Administration (FDA) to use human embryonic stem cells. The trial is studying the effects of GRNOPC1 on individuals with acute SCI. GRNOPC1 contains human embryonic stem cell-derived oligodendrocyte progenitor cells, which have demonstrated remyelinating and nerve growth stimulating properties in animal models. In the current trial, GRNOPC1 will be injected into the site of the spinal cord injury to determine its safety and potential to produce recovery in movement or functional locomotor behavior. Most of our current knowledge on GRNOPC1 is based on a rat model, where the animals typically regain some ability to ambulate but continue to have other problems such as incontinence, for example. This trial will start by assessing the safety and tolerability of GRNOPC1 in patients with complete SCI (ASIA A classification) at the thoracic level (SCI level T3 to T10). Participants must be newly injured, and have the GRNOPC1 injected at the site of the spinal cord injury within 14 days of injury. It is expected that seven medical centers in the U.S. will participate in this trial; however, only one (Northwestern Medical Center in Chicago) was enrolling patients at the time this newsletter went to press. The most up-to-date information about enrollment will be available at www.clinicaltrials.gov or the Geron website (www.geron.com/patients/clinicaltrials/hESC.aspx).

While the Geron trial represents an important step in the study of physical recovery following SCI, much still remains to be done. Questions include: What if it does not work? What if the gains are minimal and not functional? Will stem cells benefit individuals with SCI who are no longer in the acute phase? Where do we go from here? Finding the answers to these questions will be a complex process involving many different areas of research and clinical programs.
TOWARDS RECOVERY
UM Focus

Director’s Corner

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Some non-surgical trials are now focusing on combined approaches to the problem such as drugs and or activity-based therapies or intense physical therapy during the intervention.

As we aim for recovery, keeping healthy (physically, mentally and emotionally) seems to make a lot of sense to me. With current advances in biomedical technology, pharmaceuticals, genetic treatments, robotics and bioengineering, it is only a matter of time until the right approach is found. The University of Michigan SCI Model System program started in 1986 with the goal of bringing the best care and cutting edge knowledge to those who can benefit the most - our patients. Our center is connected with 13 others around the country and participates in clinical trials and studies related to depression, quality of life, participation, and measurement of neurological functioning and trunk stability. We believe in the power of remaining active in one’s community. Two of our projects focus on determining the best ways of assessing participation and its impact in quality of life.

For more information on clinical trials related to SCI please consider visiting the following websites: www.clinicaltrial.gov or the National Institutes of Health (NIH) website at http://stemcells.nih.gov/info/basics/basics/. For more information about the UM SCI Model Systems or if you have questions about SCI rehabilitation and treatment, contact us at spinalcordinjury@umich.edu or 734-763-0971.

Conversation with Danny Heumann:

A Word from One of Our Advisory Board Members

By Denise G. Tate, Ph.D.

Daniel Heumann is a dynamic motivational speaker, advocate, fundraiser, lawyer and businessman; he is also an individual with a SCI. Mr. Heumann serves as the Vice President of the Daniel Heumann Fund for Spinal Cord Research, a tax-exempt fund dedicated to helping medical science find a cure for paralysis caused by spinal cord injury and is a member of the Board of Directors of the Christopher & Dana Reeve Foundation. His motto is “Ten percent of life is what happens to you. Ninety percent is how you handle it.” We are truly fortunate to have him participate as part of the SCIMS Advisory Board.

Access: Recently you attended the World Stem Cell meeting in Detroit. What are some of the things you learned from this experience that you would like to share with our readers?

Heumann: There is a lot of hope out there. Science is doing everything in its power to come up with cure and treatments or solutions to health problems related to injuries and diseases such as SCI, but at the same time we need to realize that although science advances fast it cannot go fast enough so we have to do everything in our power to live healthy and fulfilling lives. One of my philosophies is that I live for today and hope for tomorrow.

Access: What should persons with SCI do in order to be part of these trials?

Heumann: First, get involved in NACTN (the North American Clinical Trial Network) by checking its website for information on SCI recovery and to find out about what is going on with respect to new opportunities and trials. Second, people need to realize right now that there are many charlatans out there that have no problem praying on the good will and desperation of people with SCI who are looking for help. Once you find new information check it out first. Talk to people in your community you trust and your doctor whenever you are in doubt or need more information.

Access: Any words of caution in terms of negative consequences, from your own experience and knowledge?

Heumann: I have never been involved in a “cure” clinical trial so I have had no negative consequences to this effect but from my experience and knowledge, I believe some people go to these foreign countries and get no benefits back. People need to keep in mind that with these “pseudo” clinical trials going on overseas, there are no data so far that is being presented that shows improvement in people function”.

Go to Danny’s website to learn more about Daniel Heumann and his organization: http://www.heumannlycapable.com

More information on the North American Clinical Trials Network can be found through the Christopher Reeve Foundation at www.christopherreeve.org.
The first human clinical trial of stem cell therapy for SCI in the United States was approved by the FDA in October 2010... The primary purpose of this trial is to investigate the safety of the procedure; the secondary purpose is to measure neurologic improvement.

What are the next steps in stem cell research?

As safety trials in the United States are completed, further studies will likely be designed to investigate neurologic improvement after stem cell treatment. There is much research to be done regarding the safest and most effective type of stem cells, timing of stem cell treatment after initial injury, and method of stem cell transplantation. The pace of progress from animal experiments to human experiments has been rapid, and while there are many unanswered questions the promise of stem cell therapy in treatment of SCI remains high.
Gait Training & Locomotor Therapy

By: UMHS Lokomat SuperUser Team*

Return to walking is the ultimate goal and dream of many individuals who have experienced a spinal cord injury (SCI). Depending on the degree and level of injury, this goal may be at least partially attainable. With the many advanced technologies, our growing knowledge of neuroplasticity, and the right combination of rehabilitation therapies, walking seems to be a much more realistic possibility than ever before. In particular, gait training along with locomotor training and overground practice are proving to be a beneficial combination that can improve some people’s ability to ambulate again.

Neuroplasticity refers to the ability of the neurons (nerve cells) in the brain and spinal cord to change in response to new demands and situations. The neurons do this in several ways. The axons of undamaged neurons may grow new nerve endings to reestablish damaged links and existing connections. Axons in undamaged nerve cells may also grow new nerve endings to form new connections with different (undamaged) nerve cells. Finally, “synaptic pruning” may occur, reducing connections and links that are no longer functional. Age, genetics, and environment all influence neuroplasticity, as does a person’s actions. For individuals with SCI, research suggests that neuroplasticity of the spinal cord may be activity dependent; that is, that new connections for the neurobiological control of walking may be able to occur with a lot of repetition of correct movements and patterns.

Gait training is the term used to describe the various treatment activities that help a person relearn to walk safely and efficiently. It is usually done by physical therapists (PTs) and PT assistants, who first evaluate a person’s gait for problems or abnormalities. Once the deficits are identified, a treatment plan can be developed to address specific components. Treatments may involve improving range of motion, strengthening, increasing core stability, coordination and balance training. Gait training often incorporates the use of assistive devices such as parallel bars, walkers, canes, and braces in order to promote safe ambulation and good positioning. Working on the essential components of gait is necessary as part of the treatment regimen to return to walking.

Locomotor training refers to the specific process of repeatedly practicing stepping patterns, usually with the help of multiple therapists or devices that allow the legs to be moved while the body is supported. One of the newer technologies available at UMHS for this type of training is the Lokomat.

The Lokomat is a robotic gait training system that involves the use of a harness for unweighting and supporting the body while a powered exoskeleton positions and moves the legs and feet. It can be adjusted to the functional level of each person, varying the amount of weight it supports or the degree of assistance it provides based on the individual’s abilities. The Lokomat appears to be most effective when used 3 to 5 times per week and when sessions are followed by overground practice focusing on the same muscles and gait patterns.

For individuals with SCI to use the Lokomat for gait training, they must meet several criteria:

- Must have an incomplete injury, which means there is still some functioning below the level of injury. In addition, there must also be some (however small) ability to produce motion in the legs.
- Must be medically stable.
- Must be able to tolerate standing.
The last ten years have seen tremendous attention and energy directed towards the possibility of treatments to improve recovery after spinal cord injury (SCI). The political climate has been conducive to research and much understanding has been reached. Anticipation should be present - there is currently a clinical trial on the safety of stem cell transplantation after acute complete SCI in humans. These early experiments will yield much information that will direct future research toward treatment.

However, as the trials in China, Portugal and elsewhere have shown, there is still much to be learned before the elusive cure to spinal cord injury is achieved. As many of you know, physicians in China and Portugal have been implanting stem cells into folks with SCI by injecting them into the area of injury during surgical decompression. These oversea surgeries have more recently been paired with intensive rehabilitation here in the United States, so that if patients see any return, they have the opportunity to make use of it. This pairing has also allowed for more standardized assessment of functioning both prior to and after surgery.

Hundreds of individuals with SCI have received those surgeries and been implanted with stem cells and, as of yet, there is no evidence of meaningful benefit in terms of improved sensation, movement or functioning in this population. The problems are multiple. Scarring in the area of the injured spinal cord occurs much earlier after spinal cord injury than expected, and a method must be developed to prevent scarring that might interfere with the recovery process. Oftentimes, in people with complete injuries, the gap or disconnection between neurons in the spinal cord is too wide to be re-established or connected. But in people with incomplete spinal cord injuries, the question becomes that of how to deliver cells for treatment without causing additional damage to the spinal cord. Any recovery treatment, whether stem cells or something else, would have to be result in enough correction in the anatomical injury to improve sensation and strength without causing spasticity or pain.

So what can you do now?
Simply speaking, any future treatment will need patients who are ready for it. Readiness will require two things - good health and fitness. Good health comes from preventing secondary conditions, those complications that are common and directly related to spinal cord injury. Best practice includes learning how to best take care of yourself. Work with your SCI physician and rehabilitation team to be as knowledgeable and independent as possible to prevent secondary conditions. Health also comes from preventing health conditions that are common that occur with natural aging. Primary care guidelines for the assessment for common health problems, modified for your risk based on lifestyle and genetics, are followed to minimize the likelihood of developing a health problem that will affect your health and life.

The second important consideration is fitness. Fitness is strength and endurance that allows you to do activity and to do prevent further injury. Fitness will also allow you resilience to sustain any treatment that might become available.

The pace of research and discovery is not something over which you have control. Your health and fitness are things over which you can have a tremendous impact.
MedRehab Offers State-of-the-Art Rehabilitation

MedRehab is an outpatient facility that is part of the University of Michigan Health System (UMHS). This particular site specializes in treating individuals with spinal cord injury (SCI), in addition to working with those with many other diagnoses. The facility is conveniently located near the I-94 State Street exit in the Briarwood Mall area. Hours of service are from 7am to 6pm Monday through Friday and there is free parking and immediate access to the facility.

A full range of therapeutic services are offered at MedRehab, including physical therapy (PT), occupational therapy (OT), speech therapy, rehabilitation psychology and neuropsychology, case management and family counseling. MedRehab is also excited to offer interactive computer therapy as an adjunct to traditional treatment.

The staff are highly trained, experienced and committed to providing the best of care for all individuals. As a patient you will receive a comprehensive evaluation, a plan of care developed specifically for you, one-on-one individualized treatment and state-of-the-art equipment and facilities.

State of the Art Equipment
MedRehab offers state-of-the-art equipment that is wheelchair accessible. We have one of the few Lokomats (a robotic-assisted treadmill walking system) in Michigan. There are also many other pieces of equipment that provide active-assisted movement for individuals who are able to activate their muscles but need assistance to complete a motion, including:

- the Motomed, a motor assisted arm and leg cycle;
- RTI Electrical Stimulation Cycle, which helps to improve circulation, build muscle, improve joint range of motion, and reduce muscle spasticity;
- Biodex Unweighting System for supported walking;
- multiple types of Hydraulic Standing Frames
- Nustep recumbent exercise bikes;
- a four-tower Magnum Strengthening System;
- a Versatrainer Resistance System;
- the BTE upper extremity simulator.

Supportive Services
As a part of the diverse UMHS, MedRehab has access to a wide variety of supportive services and specialists. MedRehab PTs and OTs are able to easily work in collaboration with the UM Wheelchair Seating Services. The therapists at MedRehab also work closely with the UM Orthotics and Prosthetics Division to ensure that each individual’s unique set of needs are being met. To assist with the facilitation of school or vocational goals, therapists can refer individuals to Michigan Rehabilitation Services (MRS). Therapists collaborate with the staff at MRS to provide information regarding a client’s goals, medical status and present needs. Individuals are generally provided with contact information to the Ann Arbor Center for Independent Living, which provides a multitude of personal and community resources and programs. If public transportation is needed, therapists assist individuals with transportation services/options through the Ann Arbor Transit Authority (AATA) to increase their independence in the community.

Programs
MedRehab also offers several programs, clinics and groups designed to meet specific client needs:

The Post Rehab Gym Clinic
is available for individuals who have completed their therapy at any of the UM PM&R sites and want to continue with an exercise program. The Post-Rehab Gym Clinic allows members to continue their
home exercise program in the clinic setting and to allow access to equipment that they may not have at home. This clinic allows former clients to utilize much of MedRehab’s wheelchair accessible equipment, while being indirectly supervised by staff for assistance with set-up and exercise progression.

The Momentum Advanced Gym Clinic
is an advanced gym clinic tailored to the rehab patient population. In addition to the equipment that is available at the Post-Rehab Gym Clinic, members of Momentum have access to additional gym equipment such as the RTI Electrical Stimulation Cycle. Members are also provided with more hands-on assistance. For information regarding times and cost of the Post Rehab Gym Clinic and the Momentum Advanced Gym clinic, please contact our facility.

The Drive-Ability Program
offers a comprehensive evaluation for individuals with physical, visual/perceptual and/or cognitive deficits. Services are coordinated with certified driving rehab specialists, driving instructors, equipment vendors and the Department of Motor Vehicles as needed.

Home Assessments
provide individuals with recommendations for home accessibility, barrier free modifications and equipment needs. This type of evaluation is performed when the client, therapist or physician identifies obstacles for accessibility and safety in the clients home.

Community Re-Entry Groups
provide an opportunity for individuals to experience a successful transition to community based activities in a supportive environment. Activities are addressed and modified, based on each client’s individual needs and interests.

Educational/Support Groups
provide individuals with information from staff or peers that will guide and teach them to apply newly learned skills. Groups are informative and interactive, therefore allowing participants to work together, to resume their independence in daily life activities.

For a tour of our facility or for more information about our services, please contact us at (734) 998-7888.

The SCI Research Registry is a bridge between individuals with SCI wanting to be involved in research and investigators trying to improve treatment and quality of life for this population. Any individual with a spinal cord injury or disease is welcome to join. Access to the Registry is controlled to ensure your safety and confidentiality. For more information, or if you would like to join, please contact Dr. Claire Kalpakjian by email: SCIRegistry@med.umich.edu.
New Center ROARs to Life at UM

By: Pamela Kisala

The UM Department of Physical Medicine and Rehabilitation (PM&R) is excited to be the home for the new Center for Rehabilitation Outcomes & Assessment Research (ROAR). ROAR was founded to enhance the assessment of health, functioning, and quality of life (QOL) for individuals receiving medical rehabilitation, including assessments for individuals with spinal cord injury (SCI). The Center is led by Dr. David Tulsky and will consist of an interdisciplinary group of 4 PhD level Professors and two Masters level Research Associates, who have extensive expertise in measurement, psychological test development, and outcomes assessment. Current personnel include Noelle Carlozzi, Ph.D. (Assistant Professor), Pamela Kisala, M.A. (Research Associate), and Donna Omichinski, B.A., CCRP (study coordinator).

Dr. Tulsky was recruited from Kessler Foundation Research Center in New Jersey (NJ) to serve as ROAR director and Director of Research within the Department of PM&R. At Kessler, he had served as Vice-President of Outcomes & Assessment Research, Director of SCI Research, Principal Investigator (PI) of the Northern New Jersey SCI System (NNJSCIS) and a Co-Investigator on the Northern New Jersey Traumatic Brain Injury (TBI) System. Prior to entering the world of rehabilitation, he was the director of the cognitive assessment research team at the Psychological Corporation, a division of Harcourt Assessments. There he served as the lead Project Director for the most widely used cognitive scale in the world, the Wechsler Adult Intelligence Scale, Third Edition (WAIS-III).

Dr. Carlozzi has a Ph.D. in Clinical Psychology and currently serves as PI on a grant to develop a health-related quality of life measure for use in Huntington’s disease as well as a co-investigator on a number of different measurement development and validation grants. Through her roles on these projects, Dr. Carlozzi has expertise conducting focus groups with individuals with disabilities (specifically SCI, TBI and Huntington’s disease), and has been responsible for coordinating the qualitative analysis and item development process for these projects. She also has extensive experience training and supervising data collection for large scale, multi-site projects (including training and supervision for extensive neuropsychological assessments), and works closely with the other testing sites to ensure timely data collection.

Ms. Kisala holds an M.A. Degree in Quantitative Methods in the Social Sciences and has extensive experience in the qualitative components of outcomes research including grounded theory qualitative analyses, using NVivo software, and developing item banks and writing new items. She also serves as a key liaison with the co-investigators and project managers for several multisite studies. Ms. Kisala has experience as project manager coordinating research activities at several sites and she currently manages many of ROAR’s funded studies.

Ms. Omichinski holds a B.A. degree in General Studies from UM-Dearborn, and has been certified by the Society of Clinical Research Associates as a Certified Clinical Rehabilitation Professional. Prior to her work with ROAR, Ms. Omichinski worked as a study coordinator in the Adaptive Cognitive Assessment Lab which is also part of the UM Dept. of PM&R.

ROAR Research

ROAR has already received funding from numerous agencies to develop and validate new outcomes measurement instruments targeted for rehabilitation populations.

Among the other Patient Reported Outcome projects that Dr. Tulsky and ROAR researchers are involved in are:

- a grant to test and validate the PROMIS for children with disabilities (NIH);
- a large 5-year, collaborative research grant from two NIH institutes (NICHD and NINDS) to develop a version of the PROMIS for use in SCI research and practice;
- a collaborative SCI Model System grant from the National Institute of Disability and Rehabilitation Research (NIDRR) to develop a measure of functional ability and activity limitations for individuals with SCI;
- two NIDRR funded projects to develop a similar PROMIS assessment for individuals with TBI as part of the TBI Model Systems and Field Initiated Research grants programs (the “TBI-QOL” project);
- the NIDRR Rehabilitation Research and Training Center (RRTC) on Outcomes Assessment to adapt and validate the NIH Toolbox for use in clinical rehabilitation populations (e.g., SCI, TBI, and Stroke); and
- a Veterans Administration (VA) project which extends the TBI-QOL measurement system for the veteran population, developing a PRO measure specifically for deployment-related TBI.

For more information about ROAR or ROAR projects, please contact the center at 734-763-3979 or PMR-ROAR-Research@med.umich.edu.
Participating in experimental treatments

by: Michelle A. Meade, Ph.D.

Individuals with spinal cord injury (SCI) live with the hope that a cure will soon be available - something to repair their spinal cord and let them go to the bathroom like they used to, regain use of their hands, or walk again. This newsletter contains information about the potential that stem cells may offer sometime down the road. It also discusses some of the current possibilities for improvement that exist in locomotor training. But how do you know what treatments are worth trying or what research studies to pursue?

Someone usually has a suggestion – maybe your brother saw something on the internet about a new treatment or you talked to someone with a spinal cord injury who either had a certain treatment or knows someone who did. But not all information is equally reliable or trustworthy - but how do you know?

Here are a few suggestions that may help:

1) Collect information from a wide variety of resources, but don’t treat them all as equal. Rather, use them as a starting point to begin asking questions.

2) Ask questions of the right people. Your physiatrist should have the latest information. Other good sources are non-profit and government organizations - such as the Christopher Reeve Foundation, the Cure Community through the Keck Center for Collaborative Sciences, and the National Institutes of Health.

3) Remember that all research studies and medical treatments have limitations. Beware of any studies or programs that promise results without discussion of who it may work on or why. One of the big problems that can come up with taking advice from people who are not health care professionals is that – even if they are experts on what happened to them – they do not know how it applies to you. Many individuals with SCI have complex medical histories. You have a certain injury level and severity that is impacted by your genetics, age and health history. All of these need to be considered when determining if a treatment is something you should consider.

4) Make informed choices about possible risks and benefits associated with participating in experimental treatments. For many initial research studies, the benefits offered are typically the opportunity to help others rather than personal gain. This is valuable for moving the field forward, but it is important that you know if this will improve your health, if it may lead to future problems, or if it may limit the treatments you may try later.

5) Consider the research. Find out if studies have been conducted that have shown that the benefits people report when they talk about a treatment have been proven scientifically. Much of the research that we are doing here at the University of Michigan is either to develop tools that will allow for the accurate measurement of changes in health and functioning or to determine if specific interventions or treatments actually do help to improve health, mood or quality of life for individuals with SCI.

6) Consider cost. By cost, I refer to the time, money, effort or emotional investment that you and/or your family will need to make to participate in a program, therapy or research experiment. Some experimental treatments – particularly those going overseas – require a lot of money to participate. Some of our patients have mortgaged their houses to be involved. You need to make the choice that is best for you, but don’t make those choices lightly.

7) Finally, don’t forget what you currently have. Yes, work for progress, restoration, or recovery, but life is about what you do with the now - the relationships you form and the things you do. Don’t forget to live your life as you wait for the future to come.

Here are some websites that you might look at to provide additional information about new research and experimental treatments.

**Useful Websites:**
- www.christopherreeve.org
- www.sci.rutgers.edu
- www.ninds.nih.gov/disorders/sci/sci.htm
- www.spinal-research.org

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**ROAR, Continued from previous page**

The Center is particularly involved in the development of the Patient Reported Outcomes Measurement Information System (PROMIS) that is part of the National Institute of Health’s (NIH’s) Roadmap Initiative. Patient reported outcomes (PROs) are important predictors of long-term life satisfaction and include assessment of outcomes such as quality of life (QOL), which includes physical health, level of social support, participation in the community, and emotional well-being. Currently, there are no measures of QOL that have been developed or tested specifically for individuals with SCI. As mentioned above, Dr. David Tulsky has been awarded a large collaborative grant to develop a new, SCI-specific QOL measurement system. This project, the “SCI-QOL,” is currently in its third year. To date, the SCI-QOL includes items in Physical-Medical Health, Emotional Health, and Social Participation. All of the items have been tested in a large (>600) sample of individuals with SCI, and data analysis is currently underway. The final product will be a set of Computerized Adaptive Tests (CATs), which are “smart” tests that select the items most appropriate for a given person. This type of test is much shorter, more precise, and much more sensitive to change over time than a traditional, paper-and-pencil test. These SCI-specific CAT measures will be made available to all SCI researchers.
Paul Schulte: A Success by Any Standard

By Eric A. Appleberry, DDS, MS

As part of the James T. Neubacher Disability Awareness Week events at U-M, an annual wheelchair basketball “Tip-Off” event is staged to showcase the abilities of those in wheelchairs. The Ann Arbor Thunderbirds, a local wheelchair basketball team, have always been involved. This year the game was designated the Army-Navy Game, in honor of the many disabled veterans our wars have produced. The players were veterans and non-veterans with disabilities as well as some non-disabled veterans who were using a wheelchair for the game. This year the game was held on October 29th at Saline High School. Paul Schulte, a world-class wheelchair basketball player with deep roots in this area and with the Thunderbirds, was able to come and play in this game. He was gracious enough to share some of the story of his life and his spinal cord injury.

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It was March 6, 1989, the day after Paul Schulte’s tenth birthday. He was in the back seat of a car his mother was driving when a 30 mph head-on collision “whip lashed” Paul’s body at the lower back level (the car had lap-type seat belts in the back, with no restraining shoulder belt).

Paul suffered a “complete” L-2 spinal cord injury (SCI) while his mother’s head and face went into the steering wheel (remember, air bags were not regular features on cars then). Paul’s younger brother, Peter, was in the other front seat and did not receive any serious injuries, as he had on a “3-point” restraint that included a shoulder belt. From the Chelsea, Michigan location of the accident, they were transported via ambulance to the University of Michigan hospital in Ann Arbor. Paul’s mother required nine hours of surgery to reconstruct her shattered face. Paul did not require surgery (vertebrae were not displaced) but instead was placed in a “body cast” for nine weeks to stabilize his lower back, and after a total three months (including initial rehabilitation at Mott Children’s Hospital), he was released to go home with outpatient rehab at U-M’s Chelsea facility.

While Paul was out of school for the rest of that academic year, a teacher and a family friend came to help him in his studies. The next fall he returned to school and soon became close friends with a fellow wheelchair user in his class, Bobby Hayden. Bobby was in a power chair due to rapidly progressive muscular dystrophy. Through the years, the two maintained a close friendship.

Prior to the accident Paul and another friend, Jimmy Donnellon, loved playing sports, especially football and baseball. As Paul gradually recovered, he and Jimmy adapted their play technique so that Paul could participate. In 6th grade, they added basketball; Paul was happy to find he had enough strength to play. A chance meeting with the mother of an Ann Arbor Thunderbird’s player led Paul to become aware of wheelchair basketball as a team sport. But, at the time he did not feel it would be something in which he could be competitive—and so he did not pursue it. Two years later, though, in another chance meeting, Thunderbirds player Kevin Wolfe noticed that Paul looked like “an active guy” who might do well at wheelchair basketball. He extended an invitation to attend the Thunderbirds’ practices, held at the Ann Arbor Recreation Center. This time, with Bobby’s encouragement, Paul went. “Bobby never showed any sign of envy at what I might be able to do. In
fact, as I got into more basketball activities, Bobby was excited to hear what I was doing; he was my biggest cheerleader and a very special person in my life.”

After a couple of sessions at the Rec Center, the Thunderbirds put Paul in a “sports” wheelchair; he was amazed at how fast he could go. He was hooked. Jerry Sarasin, one of the Thunderbirds, and two other team members, Kris Lenzo and Maurice (Mo) Phillips, saw Paul’s enthusiasm and natural talent and took it upon themselves to help Paul develop his skills. They also counseled him about the college level wheelchair basketball teams, and that if he got good at it and achieved good grades at school, he might be able to get a college scholarship. Paul says his previous lackluster attitude towards grades turned into serious efforts to do well through the rest of high school.

Another factor that cemented Paul’s involvement in wheelchair basketball was a summer basketball “camp” he attended at the University of Illinois when he was 14 years old. The program was run by Brad Hedrick, a Hall of Fame coach for wheelchair basketball. For a whole week about 75 young teens who used wheelchairs stayed on the college campus, ate and slept in the dorms, and played/coached in wheelchair basketball. It was the first time Paul had independently taken total care of himself. At the camp, Paul’s immediate counselor for the week was Rob Knight, a 6’6” athlete with a single-leg amputation who played center on the University of Illinois wheelchair basketball team. As Paul saw it, “He was in college, had a car, had a girlfriend and was averaging 18 points a game. He was doing everything I dreamed of doing.”

During high school, Paul became good enough to play with and be a regular part of the Thunderbirds team. Seeing his potential even then, Invacare/Top End began sponsoring his wheelchair basketball career, providing wheelchairs for sports and everyday use. When it was time for him to go to college, Paul was recruited and offered a full scholarship by Jim Hayes, head coach of the University of Texas Arlington wheelchair basketball program. Paul arrived during the heat of August, began working out with the team right away, and played his first college game in late October. He majored in mechanical engineering, with which he had some familiarity as it was his father’s profession. Paul completed his degree in 2005 and started working as a primary design engineer for Invacare/Top End, the manufacturer of handcycles and sport wheelchairs that had been supporting him all these years.

At the age of 31, Paul is considered one of the best wheelchair basketball players in the United States. He has Gold Medals in the USA Men’s Team in 1998 and the 2002 Gold Cup (World Championships), a Silver Medal in the 2006 Gold Cup, and a Bronze Medal in the 2000 Paralympics. He was selected tournament MVP of the 2002 Gold Cup. His next big goal is to pursue a Gold Medal in the 2012 Paralympics in London, England. Off the court, Paul also has a family life. He married his high school sweetheart, Meghan, and they have an eight month old son, Brady.

“Prior to the accident, all my visions of things I might do some day included use of my legs. With those dreams gone, I was pretty depressed about my future. But with these examples and encouragements, I could see possibilities for myself; that life in a wheelchair didn’t have to be a downhill thing.”

A few years ago Paul and Meghan started the Paul Schulte Foundation to provide scholarships to allow teenagers to attend wheelchair basketball camps, of which there are now several around the country. Tax deductible donations may be sent to them at: Paul Schulte Foundation, 4226 32nd Lane East, Bradenton, FL 34208 or www.paulschulte.com/foundation/
Wheelchair basketball is a fast-paced, exciting game for both players and spectators. “Chair ball” is very similar to stand-up basketball; it is played on the same sized courts using baskets at the same height and with most of the same rules. It can be played recreationally or competitively by women and men of all ages and abilities. There are leagues that play at the local, college, national, and international level. It is a much more fast-paced and physical game than most people expect and is every bit as exciting to play and watch as the standard game.

There are only a few changes to the typical rules. Travelling in wheelchair basketball is called when the athlete touches his or her wheels more than twice after receiving or dribbling the ball. There is no double dribble and players are allowed a little longer in the lane and to get the ball over half court on offense. The chair is considered part of the body and physical contact fouls are called the same way as in stand up ball. Players can’t use their chair to hold an opponent or push them out of position.

Differences in the way athletes move in the wheelchair make team play especially important. It is harder to move laterally and to start and turn quickly while dribbling so there is less focus on one-on-one attacks with the ball. Picks and screen are very effective and positioning the wheelchair to hold players out and gain an advantage in numbers is a strategy that is often used. Since no one can jump, position is the most important factor in playing defense and rebounding, making good chair handling skills an important part of the game.

New participants can start off playing effectively in their everyday wheelchair, but as the competition evolves it is necessary to upgrade to a basketball-specific sports wheelchair. Basketball chairs can be pushed faster, turn sharper, are more stable and hold up better to the rigors of the game. There are adjustable sports chairs that let players determine the configuration that works best for their style of play and disability characteristics. Once a player knows the set-up they like, a custom made chair will cut down on weight and be more reliable.

Wheelchair basketball is played primarily by people with lower extremity impairments – including those with paralysis and amputations; however, the game is also open to players who are able to walk but are limited in their ability to participate fully in stand up basketball. Competitive leagues use a point system to classify the functional abilities of players where those with more restricting disability characteristics receive a low number and those with more agility receive a higher number. Limiting the number of points allowed on the court at one time keeps a balance between players with varied levels of disability.

Michigan has established teams in the areas around Detroit, Grand Rapids, and Saginaw. To learn more about the game or to find a team near you contact your local Center for Independent Living (www.dnmichigan.org/contacts/), adapted sports provider (www.adnpage.org/coalition.html), or the National Wheelchair Basketball Association (http://nwba.org).
The Michigan Spinal Cord Injury Association, or MSCIA, is a relatively new addition to the disability scene in Michigan. It was started in late 2009 with the backing and support of Americare Medical Incorporated, whose leadership was troubled by the lack of a central resource for individuals with spinal cord injury and disease (SCI/D) in Michigan. “On a national level, there is quite a lot of information readily available on SCI/D. However, on a local level, we did not have a resource center allocated to provide information that impacts Michigan and our residents,” says Stacey Murphy, Vice President of Corporate Development for AmeriCare Medical and MSCIA Board Member.

While Michigan has any number of medical centers and universities that provide treatment to those with SCI/D, a state-wide organization was not available to make sure that all parts of Michigan – from Grand Rapids to Detroit and from Marquette to Ann Arbor – had information about updates and advances in the field as well as the resources available in their area.

“Michigan is a world-renowned destination for SCI&D rehabilitation,” says registered nurse Kathryn Warner, MSCIA board member and medical case manager of the Tenon Group. As such, it only made sense to AmeriCare Medical and MSCIA President Greg Jamian to invest continued efforts into creating a center designed specifically to provide information and resources to those with SCI&D and their friends and families. “As a health care executive with over thirty years of experience, our passion to empower our clients with the vital information that will help them make life-changing decisions has grown each year,” says Jamian. “We are excited to offer this invaluable tool in hopes of providing a beneficial impact to individuals and to the community as a whole.”

The mission of the MSCIA is to enhance and empower the lives of individuals with spinal cord injury and disease (SCI/D) through advocacy, education and research. A main focus of the organization is to connect resources to each and every person with spinal cord injury and disease. Access is primarily through their website: www.mispinalcord.org. This colorful and well-designed site is frequently updated to provide information on a number of topics, including health care reform, research news, and upcoming events. MSCIA also has a Facebook site and Twitter page which feature daily posts relevant to individuals with SCI. Members and others are free to use this site to post questions and comments. MSCIA does not yet have regular meetings, however it does provide a list of support groups that occur throughout Michigan.

MSCIA is an independent chapter of the National Spinal Cord Injury Association and a non-profit 501(c)(3) organization. As such, they are dependent upon fundraising efforts, sponsorships and donations to support their mission. However, membership in MSCIA is free to those with SCI and there is a suggested annual donation of $25 for family members and friends. For more information about MSCIA or to join, check out the website; email them at info@mispinalcord.org; or call (800) 782-3394 (or 248-288-2270 if in the greater-Detroit area).
I am hoping that everyone enjoyed very healthy and happy holidays. My wish for your new year is that it is filled with Love, Peace, Joy, Good Health and Happiness.

With our holidays behind us, now we can begin to enjoy our Michigan Winter Wonderland! There are those who say that people with disabilities can’t enjoy winter because it’s too cold and has too much snow. That tracking dirt and snow is too messy for our wheelchairs to be going in and out of our homes or the homes of family and friends. Nonsense! You don’t want to spend the entire winter months staying inside depriving yourself of all the beauty and enjoyment that our Michigan winters affords us. I hope to offer some suggestions that will help you solve these problems and have some fun during the process.

Monitor the weather. It will not be snowing or freezing every day all winter! Being well informed will help you to better plan and be prepared.

When going out, always dress in layers – thermal underwear, pants, shirt, turtleneck and sweater. You choose the combination that’s best for you. You can also choose lightweight silk thermals that are very warm they also come in socks and glove liners. – they have many different colors, not just black or cream, and for ladies they also come in pink and light blue. We can’t forget our gloves, hat, scarf and boots.

Always try and keep your vehicle’s gas tank half filled. If at all possible, invest in a remote car starter; that will allow you to preheat your vehicle before entering and on very cold days you can start car or van and let it run to keep battery charged. Make sure your vehicle is cleaned of all snow and ice before driving off.

Try and plan to complete a number of errands when going out for example grocery shopping, post office, drug store etc.

At least twice a month, plan a fun day when you and friends can visit, go to dinner, shopping, see a movie, musical concert or play.

Check with your local disabled sports organizations, local Disability Network or Center for Independent Living Organizations for winter sport activities. Even if you don’t want to physically participate you can go to encourage and cheer others on. They have such activities as ice hockey, snow ski, and bob sledding just to name a few.

Winter can still be interesting and enjoyable for those times when you would rather stay inside as well. It can be very peaceful and relaxing watching snowflakes fall. Some may be inspired to capture the beauty of this experience through painting or words of expressions.

Have friends over for game night; don’t forget the refreshments. This is a great opportunity to connect with friends and have some fun. (An easy way to clean off excess snow and ice from visitors wheelchairs is to place a throw rug with rubber backing at entrance of door. As guest come in have someone remove excess snow with a brush and towels drying wheels during the process.)

Now you have time to read that favorite book, or it’s the perfect time to organize and catalog all those favorite old photographs.

Call someone you know who isn’t feeling well to cheer them up send them flowers or a gift basket just because. Start making plans of all the fun ways you will enjoy the warm weather that is just around the corner because winter will soon be over.

Mainly, though, have a safe and happy season!
The SCI team here at the University of Michigan wants to encourage you to get out and participate in activities and events in the community. These events are not limited to those supported by the Model System, but rather are located throughout Michigan. We encourage all interested parties to double-check information before making plans to attend, as places and times of meetings sometimes change. In addition, if you are aware of events that should be included, please e-mail us at modelsystems@umich.edu and we will include them in future issues.

**Highlights**

**Dr. Kevin Chung to present**

**Controversy in Upper Extremity Surgery for Patients with Tetraplegia**

February 4, 2011, Noon-1pm at 2C224 University Hospital, Ann Arbor, MI

Dr. Chung is a hand and upper extremity surgeon who performs a wide variety of reconstructive procedures in the fields of rheumatoid arthritis, congenital hand problems, spinal cord injuries, nerve injuries, and complex fractures. His research interests involve the structuring of evidence-based practice and research in hand surgery. His projects have focused on epidemiology studies and clinical trials to derive the best evidence to guide treatment for upper extremity conditions. Contact Kay Morefield at 734-763-0971.

**Michigan Adaptive Sports**

Michigan Adaptive Sports (MAS) is a chapter of Disabled Sports USA, a non-profit, tax-exempt educational organization established for the purpose of providing sports, recreation and physical fitness opportunities for persons with disabilities. They host many annual clinics and events, including teaching kayaking, waterskiing and wheelchair racing. Winter generally means skiing, though. So those interested in learning to ski or to race should see their website http://michiganadaptivesports.org or e-mail them at michiganadaptivesports@gmail.com for more information. Dates are scheduled for January through March.

**Michigan Sled Dogs Adaptive Hockey**

Sled hockey is a sit down version of ice hockey designed for individuals who have a disability that prohibits them from playing stand-up hockey. The Michigan Sled Dogs began in 2004 and have grown into a competitive traveling sled hockey team. Their home rink is the Great Lakes Sports City Ice Arena located in Fraser. The team consists of fifteen athletes, both male and female, with a variety of disabilities including: amputees, Spina Bifida, Muscular Dystrophy, Cerebral Palsy, and spinal cord injuries. The teammates range in age from eight to their mid-forties.

**Upcoming Games: League Games at Fraser- Jan. 8-9; in Fort Wayne- Feb. 12-13, and in Grand Rapids- March 5-6; Nationals in Blaine, MN- April 1, 2, 3**

See www.missleddogs.com or e-mail MI_Sled_Dogs@yahoo.com for more information.

**Michigan Sports Unlimited, Inc.**

Michigan Sports Unlimited was developed to provide opportunities for individuals with disabilities to stay active and engage in recreational activities. It supports both indoor and outdoor events, including power soccer, rugby, and handicycling. For more information see their website at www.misportsunlimited.com or call (989) 771-5530 for more information. Also begin planning for June events including:

June 4, 2011: Paralympic Academy
June 3rd – 5th, 2011: 4th Annual Thunder in the Valley Games

**April 29, 2011: 2011 Rehabilitation Symposium Presented by the Rehabilitation Institute of Michigan**

8am – 3:15pm at Motor City Hotel & Casino, Detroit, Michigan

Keynote Speaker: Dr. John McDonald, International Center for Spinal Cord Injury, Kennedy Krieger Institute

See www.rimrehab.org or contact Cheryl Angelelli, Director of Marketing & Public Relations, RIM, at 313-966-8490 for more information.

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**Ongoing Events**

**Centers for Independent Living (CILs)** throughout Michigan offer ongoing events aimed at health, socialization and personal enrichment. Below is a list of the Centers and the contact info for each. Please call or check their websites about upcoming events in your area:

- **Ann Arbor CIL:** 3941 Research Park Drive, Ann Arbor, MI 48108; call (734) 971-0277 or see www.annarborcil.org
- **Blue Water CIL:** (Administrative Office): 1042 Griswold, Suite 2, Port Huron, MI 48060; call (810) 987-9548 or see www.bwcil.org; the Blue Water CIL also has offices in Lapeer, Sandusky, Tuscola, and Bad Axe
- **Capital Area CCL:** 2812 N. Martin Luther King Jr. Blvd., Lansing, MI 48906; call (517) 999-2760 or see www.cacil.org
- **Disability Advocates of Kent County:** 3600 Camelot Dr. SE, Grand Rapids, MI 49546; Call (616) 949-1100 or see www.disabilityadvocates.us
- **Disability Connection – Muskegon:** 1871 Peck St., Muskegon, MI 49441; Call (231) 722-0088 or see www.dcmlmi.org; Newaygo Office: 4242 W. 48th St., PO Box B, Fremont, MI, 49412, (231) 924-7618.
- **Disability Connections:** 409 Linden Avenue, Jackson, MI 49203; Call (517) 782-6054 or see www.disabilityconnect.org
- **Disability Network/Lakeshore:** 426 Century Lane, Holland, MI 49423; Call (616) 396-5326 or see www.dnlakeshore.org
- **Disability Network/Mid-Michigan:** 1705 S. Saginaw Rd., Midland, MI 48640; Call (989) 835-4041 or (800) 782-4960 or see www.dnmnn.org
- **Disability Network/Northern Michigan:** Traverse City, MI 49684; Call (231) 922-0903 or see www.disabilitynetwork-nmi.org
- **Disability Network/Southwest Michigan:** 517 E. Crossover Parkway, Kalamazoo, MI 49001; call (269) 345-1516 or see www.dnswm.org
- **Disability Network of Wayne County (Detroit CIL):** 5555 Conner, Suite 2075, Detroit Michigan 48213; Call: 313-923-1655 or see http://www.dnwayne.org
- **Superior Alliance for Independent Living:** 1200 Wright St., Suite 3, Marquette, MI 49855; call (800) 379-7245 or (906) 228-5744 or see www.upsail.com

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**Questions? Suggestions? Feedback?**

Let us know what you think!

Contact us at 734-763-0971 or spinalcordinjury@umich.edu.
The University of Michigan Spinal Cord Injury Model System publishes SCI access. This newsletter is designed to provide information on research, treatment, and social issues related to rehabilitative care, spinal cord injury and disability. Established in 1985, the U-M SCI Model System receives funding from the National Institute on Disability and Rehabilitation Research (Award #H133N060032). It is one of 14 SCI Model Systems in the United States. The purpose of this research and demonstration project is to improve outcomes of medical and rehabilitative care provided to individuals with spinal cord injury.

Denise G. Tate, PhD, Co-Director, Co-Principal Investigator
Anthony Chiodo, MD, Medical Director, Co-Director, Co-Principal Investigator
University of Michigan SCI Model System, 300 N. Ingalls, Room NI2A09
Ann Arbor, MI 48109-5491
Phone: 734.763.0971; Fax: 734.936.5492
E-mail: spinalcordinjury@umich.edu
Website: http://www.med.umich.edu/pmr/modelsci/

Regents of the University of Michigan: Julia Donovan Darlow, Laurence B. Detch, Denise Uttech, Olivia P. Maynard, Andrea Fischer Newman, Andrew C. Richner, S. Martin Taylor, Katherine E. White; Mary Sue Coleman, ex officio.

Editors: Michelle Meade, Eric Appleberry, Linda Berlin, Marty Forchheimer, and Cynthia Kay Morefield

We hope you enjoy this publication. Previous SCI access issues can be accessed at our (above) website. You may request addition to or removal from the mailing list or report a change of address by calling 734.763.0971

Informing the Research Agenda: State of the Science Conference to be held in DC

In June 2011, researchers, policy makers and advocates from around the globe will gather in Washington DC to discuss Spinal Cord Injury Rehabilitation. The event is a “State of the Science” conference. The research presented and discussion generated at this conference will be used to create an international agenda for SCI rehabilitation research through 2020. For this to happen though, it will be critical that you — individuals with SCI and your family members — are there to provide your expertise and reactions.

The State of the Science conference will offer the opportunity to learn about the latest efforts going on with four areas — neurologic and functional recovery; aging and secondary complications; technology for mobility and function; and psychosocial, vocational and quality of life outcomes. Presenters and panelists will include well-known researchers and disability advocates, including Dr. James Fawcett, whose research focuses on regeneration of the spinal cord; Gary Karp, author, disability educator, and individual with SCI; and Lex Frieden, one of the founders of the “independent living” movement.

The conference planners have built in plenty of opportunities for question-and-answer sessions as well as small group discussions. Based on the information presented and discussion generated, recommendations for SCI research will be developed in each area and voted on by the attendees.

The event will be held at the Grand Hyatt Washington Hotel from June 5th through the 7th and early registration is $200. The meeting is sponsored by multiple public and private entities including the SCI Model Systems, the Rehabilitation Engineering Research Center on Spinal Cord Injury, the National Institute on Disability and Rehabilitation Research (NIDRR), the National Institutes of Health (NIH), and the Department of Veterans Affairs (VA). More information about the conference can be found at www.ASIA-ISCOS2011.org/state_of_science.php