Sustaining a spinal cord injury (SCI) can be both physically and psychologically traumatizing. Understandably, there is distress about regaining the functions you may have lost below the level of injury; most people want to recover lost abilities as soon as possible.

As SCI patients are often told, there are no validated drug or cell transplant treatments that will repair sustained damage or restore voluntary movement. While this is true, great advances have been made, and continue to be made, in the science of spinal cord repair and treatment. These investigations hopefully will one day improve living and quality of life for people with SCI.

In an effort to provide the most up-to-date information regarding clinical trials and research regarding SCI, Dr. Tate interviewed Dr. John Steeves. Dr. Steeves is an expert on SCI clinical trials. He is currently a Professor in the Department of Neuroscience at the University of British Columbia and a Principal Investigator at ICORD (International Collaboration on Repair Discoveries). ICORD is an inter-disciplinary research center focused on spinal cord injury. He was the Founding Director of ICORD and is the Chair of SCOPE (Spinal Cord Outcomes Partnership Endeavor). He obtained his B.Sc. and Ph.D. at the University of Manitoba, and completed his Post-Doctoral Fellowship at the University of Alberta.

Dr. Steeves, why are clinical trials important for persons with SCI?

Steeves: Because it can be surprisingly difficult to determine if a therapy or treatment is safe and really works, it is necessary to complete clinical trials to determine the validity of the treatment and to rule-out alternative explanations for the results, such as spontaneous recovery or the Placebo Effect (which happens in clinical trials when people who did not receive the treatment but thought that they had improved as a result of their expectations).

What are the building blocks of a good clinical trial?

Steeves: Clinical trials are used to determine whether a treatment is beneficial or not. This can only be known for certain when trials are run correctly. There are several necessary components to make a trial or human study valid. The first is gathering data from appropriate controls (participants not receiving the treatment). These data must be collected in the same manner and at the same time as the data from experimental participants (participants who are receiving the treatment). Without control data, we do not know whether any improvement, or damage, is actually due to the experimental treatment or to some other factor. The second essential component is the “blinded” assessment of outcomes. By blinded, we mean that the investigators must not know who is an experimental participant and who is a control. We are all biased (including scientists and clinicians), and this bias can potentially influence our assessment of a treatment and impact our conclusions. This is especially true if an investigator receives money for providing an experimental treatment. In this situation, there is strong financial motive for the investigator to report a positive result. Thus, if a study has no control subjects and no blinded assessment of outcomes, but does have a payment to the in-
Every day scientists around the world continue to study new ways to better understand and treat spinal cord injuries (SCI). The SCI Model Systems, funded by the National Institute on Rehabilitation and Research (NIDRR), are specialized centers designed to provide SCI care and innovative research to improve the quality of life of people with SCI. Currently NIDRR funds 14 centers across the country, of which the University of Michigan is one. Other SCI research is funded by the Department of Veterans Affairs, the National Institutes of Health and private foundations and individuals.

Current research at these centers focus on a number of issues. Studies interested in finding a solution for spinal cord repair include those which investigate mechanisms of neuroprotection to protect cells from further damage; regeneration to stimulate nerve growth; cell replacement which replaces damaged nerve cells; and plasticity, involving retraining our central nervous system circuits to restore body functions, such as walking.

A number of clinical trials are currently focusing on these issues. Information about current clinical trials can be obtained at clinicaltrials.org, the National Institute of Neurological Disorders (NINDS) at http://www.ninds.nih.gov/disorders/sci/ and other sites such as ICORD and SCIRE.

Neuroprotection clinical trials focus on preventing cell death, limiting or reducing inflammation and stopping over-excitability of cells. The goal is to decrease inflammation within or near the cord, which can restrict blood flow, affect nerve signal transmission and increase cell death. To do this, steroid drugs are used to reduce cell damage and suppress immune cell activity. Nerve cells often die after injury, leaving large numbers of glial cells in the area of damage which can inhibit the growth of nerve cells. Some anti-inflammatory drugs have been shown to encourage nerve regeneration by stimulating growth and inhibiting cell death that occurs after the injury. The potential of several cell types, including stem cells, to treat spinal cord injury damage has been the focus of several studies. Unfortunately, a lot is still unknown about stem cells and their role in SCI recovery. Active rehabilitation and exercise may play an important role in promoting connection between nerve cells and tissue, responsible for function. Specific training may promote brain re-organization and connectivity and thereby improve function, coordination of fine muscle movements, and overall strength and health.

Exciting and promising results in improving function in individuals with chronic SCI have been shown in studies using functional electric stimulation (FES). FES devices use a computer system and electrodes to deliver small bursts of a low-level electrical current to paralyzed muscles, to generate muscle contractions. Researchers are working to improve the electrode and computer interfaces so they can produce both more natural and complex movements. FES is being used to restore breathing without a ventilator, cough unassisted, enhance bladder and bowel control, increase hand movement and grasping, and improve blood flow to the skin.

Recently we heard encouraging news of a study conducted by Dr. Cladia Angeli at the Human Locomotion Research Center at Frazier Rehabilitation Institute, part of the University of Louisville’s Kentucky’s Spinal Cord Injury Center. The study used epidural stimulation with electrodes to reset the level of excitability of spinal cord neurons. While this is not a cure, it may be a treatment, that when used together with other treatments, will promote recovery of spinal cord function, allowing persons with SCI to regain movement.

Most recovery following SCI takes place within six months after injury. Major recovery after one year is not common, but researchers continue to look into ways to improve function in persons with chronic paralysis using robotic assisted therapies. These range from movement enabling devices to specific brain computer interface devices. Most individuals with tetraplegia have intact brain function but are unable to move due to injury or disease affecting the spinal cord. Brain-computer interface (BCI) technology is based on the finding that with intact brain function, neural signals for movement are generated in the brain and can be used to control computer-assisted devices. By implanting electrodes in the brain, individuals can be trained to practice thoughts which can then be used to control a variety of devices or computer displays. Researchers are working to develop BCI technology to offer persons with tetraplegia a natural and rich control mechanism for prosthetic arms or FES device to re-animate paralyzed arms. For more information go to: http://www.ninds.nih.gov/disorders/sci/detail_sci.htm.

These approaches to recovery and en-
From the Director

Continued from previous page

Abilities function through technology can be applied to many areas of SCI care including neurogenic bladder and bowel care. In our studies, we are focusing on how loss of these functions and difficulties in managing bladder and bowel may affect quality of life. This issue of SCI Access also discusses other important areas of care for SCI such as epidural stimulation, Botox injections and urinary incontinence, as well as a real life story about fertility and SCI. Enjoy! And let us know your comments.

Denise G Tate Ph.D., is Professor and Associate Chair for Research, Co-Director University of Michigan Spinal Cord Injury Model System

Steeves: At this time, there are several sources and the easiest way to access unbiased information is to start with the document you can download from ICORD and several other websites. It is written in simple terms by experienced investigators from across the globe and is freely available to all. It is called, “Experimental treatments for spinal cord injury: What you should know (Version 2).” In this document are also links to several other trusted sources of information about SCI.

Can you provide a brief overview of the types of trials currently being conducted?

Steeves: There are over a dozen trials underway. A list of valid clinical trials can be obtained from the SCOPE website, at the bottom left hand corner of the home page (http://www.scope-sci.org). It is updated frequently. In brief, there are trials examining the benefit of drugs to limit the amount of secondary damage that can occur after the initial injury. There are trials examining the benefit of cell transplants after either acute or chronic SCI. Finally, there are trials investigating the benefits of specific rehabilitation training strategies for both acute and chronic situations. Many of these studies are in the early stages of investigation.

Are there any trials aimed toward recovery in children with SCI?

Steeves: Clinical trials involving children are difficult. The main reason is that children are very different from adults in terms of their biology. Children are still growing and their brains and spinal cord are continuing to develop. Thus, there are biological mechanisms that are still active in children that have been shut down in adults. This means that the dose for any drug or cell transplant is likely to be unpredictably different in children and adults. Until we have data showing that a specific treatment has a benefit for adults, it is impossible to determine how we should adjust the treatment strategy for children or teenagers. However, on the positive side, we know that children have a greater ability to recover from injury than adults. They have greater brain and spinal cord plasticity. Therefore, active rehabilitation efforts can achieve even better recovery for activities of daily living, increased independence and improved participation within society.

ReWalk Update

The University of Michigan’s MedRehab Briarwood site has had an exciting first year introducing the use of Argo’s ReWalk™ system! The ReWalk™ exoskeleton is an ambulation alternative for wheelchair users, enabling people with lower limb disabilities, such as paraplegia, to stand and walk. Several patients have undergone the training program with successful results. Although eight weeks is the minimum requirement for the training program, most patients require about 12 weeks of physical therapy, three times per week, to develop their ReWalk™ skills. The personal device is awaiting FDA approval, which is expected soon. The price for an at-home personal device will be determined at that time. More information is available at www.REWALK.com.

If you are interested in being evaluated as a candidate for ReWalk™, please contact MedRehab Briarwood at (734) 998-7888.
Botox injections for neurogenic bladder

By: Dr. Anne Cameron

After spinal cord injury, over 90% of people have changes in their bladder function called neurogenic bladder. Most of these changes are in urinary retention (your ability to voluntarily empty your bladder). The healthiest way to empty the bladder for most people with SCI is with intermittent catheterization like self-cath. Intermittent catheterization solves the problem of the bladder not emptying, but does not help with another bothersome symptom of neurogenic bladder – bladder spasms that can cause accidents.

Since the bladder lacks input from the brain, it can become spastic, much like other parts of the body. We call this neurogenic detrusor overactivity, where the bladder muscles (detrusor) contract (become overactive) when they receive stimulation from a full bladder or other irritation (like a urinary infection). Because bladder spasms at high pressures can cause autonomic dysreflexia, urine backing up into the kidneys, or urinary leakage. Also, when high pressures occur frequently, the bladder becomes thicker and less flexible, so that it holds less urine and spasms occur even more often.

The first treatment for anyone who has neurogenic bladder, even without any signs of bladder spasms, is to begin taking medications called anticholinergics, as soon as they start neurogenic bladder – bladder spasms. People who still have bladder spasms when anticholinergics work do not tolerate them. Such medication work to block nerve receptors in the bladder for most people with SCI is with intermittent catheterization like self-cath. On average, patients with SCI and have found it to be very effective. On average, the bladder capacity (size) increases by 200 ml (6 ounces), so the bladder holds more and you need to catheterize less often. Likewise, dangerous bladder pressures are reduced by half. In studies on patients with incontinence, the amount of leakage was reduced by 70-90% (Linsenmeyer, 2013).

Bladder augmentation is a major surgical procedure where a section of bowel is added to the top of the bladder, making it much bigger and removing the spasms. It works very well, but is a serious procedure requiring a 7-10 day hospital stay. It can also result in a lot of mucous in the urine from the bowel section.

OnabotulinumtoxinA (Botox™) was approved by the FDA to treat neurogenic bladder in 2011, but was used for years prior in Europe as well as off-label use (a drug prescribed for a particular condition even though the drug has not yet received approval from the Food and Drug Administration for that condition) in the US for years prior. Botox™ works by preventing nerve endings from releasing a chemical responsible for bladder contractions and spasms. This is the same molecule that anticholinergic medicines block the receptor for, but Botox™ does this in a permanent way. Nerves must regrow their endings to cause bladder spasms again which is why Botox™ lasts so long.

Many clinical trials have been done to evaluate how Botox™ works in the bladder after SCI and have found it to be very effective. On average, the bladder capacity (size) increases by 200 ml (6 ounces), so the bladder holds more and you need to catheterize less often. Likewise, dangerous bladder pressures are reduced by half. In studies on patients with incontinence, the amount of leakage was reduced by 70-90% (Linsenmeyer, 2013).

We give Botox™ as an injection. A solution including 200 units is the most common and recommended injection, but up to 300 units can be injected at a time. Botox™ can cause a person to develop antibodies against the drug, increasing resistance to its effects. Therefore, multiple injections anywhere in the body need to be spaced out by at least three months. So if a person gets both their legs and bladder injected, the appointments scheduling need to be coordinated.

The injection can be done with sedation in the operating room, but it is simpler and faster to do it at a clinic visit. Upon arrival your urine will be tested for infection (UTI); if you have a UTI, we cannot do the injection without risking a severe infection. People who get frequent UTIs often submit a urine specimen and get treated the week before to prevent this from happening.

Using a catheter, a nurse then flushes the bladder with lidocaine; this is left in place for 20 minutes to numb the bladder. A cystoscope is passed into the bladder via the urethra (a flexible scope for men and a regular scope for women) so the physician can check for any abnormalities. The scope is equipped with a tiny needle and 20 injections are done all around the bladder. This takes approximately 5 minutes. The bladder is then drained and you can go home. It takes 7-10 days for the Botox™ to become effective, so be patient.

After the injection, the bladder or urethra can sometimes be sore or have a burning sensation which can be relieved with Tylenol or Motrin. It is normal to see a small amount of blood in the urine for a few days as well. It is possible to get a UTI from the procedure, but all patients are given a single antibiotic before the procedure to prevent this. There are other rare complications to the procedure that you should discuss with you doctor.

In general, the injection lasts nine months, but can range from three months to a year. Many patients call our office only when their symptoms return to arrange another injection appointment. Additionally Botox™ injections can be covered by Medicare.

For more information you can talk to your doctor or arrange a visit to our clinic to discuss if Botox is right for you. Please call University of Michigan Urology at 734-936-7030. Reference: Use of botulinum toxin in individuals with neurogenic detrusor overactivity: State of the art review. Todd A. Linsenmeyer J Spinal Cord Med. 2013 Sep;36(5):402-19
Andy McCormack

Age: 34
Date of Injury: April 17, 2002
Level of Injury: T4 Para (complete)

SCI Access: Tell us about your injury and rehab experience.

Andy: I made a lot of poor choices in the early morning hours of April 17, 2002. I got on my motorcycle after drinking with some friends at a local bar near Western Michigan University. After tempting fate and giving multiple rides, on the final ride, I didn’t return. I crashed the motorcycle going too fast around a curve. The accident left me with a displaced spine (T4/T5), 6 broken ribs, a punctured lung, broken right clavicle, broken left scapula and a lacerated liver. But with all that, there was not a scratch on my body other than a small puncture were my broken clavicle broke the skin (all interior injuries). My passenger only suffered a cut on his chin requiring 11 stitches, which is a blessing since his helmet came off in the accident.

After my accident I spent 13 days in the Intensive Care Unit (ICU) at Bronson Hospital in Kalamazoo, MI before being transferred to U of M. I spent 30 days rehabbing and learning how to do all the things that many take for granted. Getting my socks on for the first time was such an accomplishment. My goal was to be out of the hospital by June 1st, twelve days ahead of my projected discharge date. And I did it!

SCI Access: What are some accomplishments that you have achieved? What are your interests?

Andy: Prior to my accident, I was a Health, Physical Education (PE) and Recreation major, planning to become a PE teacher upon graduation. Being physically active and capable was something that I had always excelled at. As a result, I struggled while learning how to be completely independent again. I am very lucky to have had a great support system that didn’t allow me to get down and consistently told me that I could still do all the things I wanted to prior to the injury – just in a different way.

I enrolled at Olivet College that following fall to complete my degree in Health, PE, and Rec. with a minor in Biology. I then completed my student teaching experience at a local elementary and middle school teaching PE for grades Pre-K-5th. I was awarded the Student Teacher of the Year from Olivet’s Education Department. I graduated from Olivet in December of 2003.

After graduation I substitute taught and coached basketball in my home town of Marshall, MI. I coached 7th grade to Assistant Varsity levels at different times for both boys and girls. I landed my first teaching job at Battle Creek Central High School in 2007 as a Biology teacher. I was moved to the Guidance Counseling office once I completed my Masters in Counseling from Spring Arbor University in 2011. I became the Freshman Guidance Counselor for the Battle Creek Success Academy within Battle Creek Central High School. It was a great learning experience and I really enjoyed working there. I recently took a new position back in Marshall as the High School Guidance Counselor. The transition back to Marshall has been very exciting and I look forward to doing my part to help all of the students I come in contact with be successful and overcome any obstacles they might face.

SCI Access: What is something positive that came out of this experience?

Andy: A true blessing that came to me as a result of my accident was meeting my wife. I met her in Lifespan Medical Supply the day before Thanksgiving in 2004. She was home from nursing school and was working in the back doing some filing. While I was picking up my monthly supplies of catheters and such, the store clerk introduced us. We talked for just a minute but that minute was enough. I thought about her the whole way home and thought I should call and ask her out, but I didn’t make the call. Fortunately, she called me later that night! We made plans to go out the next weekend and have been together ever since. We got married May 5th, 2007. We have 2 young boys Max (3) and Drew (19 months). We received education about the possibilities and methods available for family planning from U of M’s fertility clinic – Shout out to Dr. Ohl and staff!

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New Research on Effectiveness of Epidural Stimulation

CHRISTOPHER REEVES PRESS RELEASE, APRIL 8, 2014

Four young men who have been paralyzed for years achieved groundbreaking progress – moving their legs – as a result of epidural electrical stimulation of the spinal cord, an international team of life scientists at the University of Louisville, UCLA and the Pavlov Institute of Physiology reported in the medical journal “Brain.” The study was funded in part by the Christopher & Dana Reeve Foundation and the National Institutes of Health.

Scientists at the University of Louisville, UCLA and the Pavlov Institute of Physiology reported in the medical journal “Brain.” The study evaluated the effects of epidural stimulation in the first participant, Rob Summers, who recovered a number of motor functions as a result of the intervention.

Now three years later, the key findings documented in Brain detail the impact of epidural stimulation in four participants, including new tests conducted on Summers. What is truly revolutionary is that the second, third and fourth participants were able to execute voluntary movements immediately following the implantation and activation of the stimulator. The results and recovery time were unexpected, leading researchers to speculate that some pathways may be intact post-injury and therefore able to facilitate voluntary movements.

“Two of the four subjects were diagnosed as motor and sensory complete injured with no chance of recovery at all,” Claudia Angel, Ph.D., senior researcher, Human Locomotor Research Center at Frazier Rehab Institute, and assistant professor, University of Louisville’s Kentucky Spinal Cord Injury Research Center (KSCIRC) and lead author. “Because of epidural stimulation, they can now voluntarily move their hips, ankles and toes. This is groundbreaking for the entire field and offers a new outlook that the spinal cord, even after a severe injury, has great potential for functional recovery.”

These results were achieved through continual direct epidural electrical stimulation of the participants’ lower spinal cords, mimicking signals the brain normally transmits to initiate movement. Once the signal was triggered, the spinal cord reengaged its neural network to control and direct muscle movements. When coupling the intervention with rehabilitative therapy, the impact of epidural stimulation intensified. Over the course of the study, the researchers noted that the participants were able to activate movements with less stimulation, demonstrating the ability of the spinal network to learn and improve nerve functions.

Beyond regaining voluntary movement, the research participants have displayed a myriad of improvements in their overall health, including the increase of muscle mass and regulation of their blood pressure, as well as reduced fatigue and transformational changes to their sense of well-being. Additionally, all four men were able to bear weight independently, as reported by the team, which also includes Yury Gerasimenko, Ph.D., professor and director of the laboratory of movement physiology at St. Petersburg’s Pavlov Institute and a researcher in UCLA’s Department of Integrative Biology and Physiology.

“This research brings up an amazing number of possibilities for how we can develop interventions that will help people recover movement they have lost,” said V. Reggie Edgerton, Ph.D., UCLA distinguished professor of integrative biology, physiology, neurobiology and neurosurgery. “The circuitry in the spinal cord is remarkably resilient. Once you get them up and active, many physiological systems that are intricately connected and were dormant come back into play.”

Providing Hope for People Living with Paralysis

With nearly six million Americans living with paralysis, including 1.275 million spinal cord injuries, this study confirms a significant breakthrough in terms of developing clinical therapies to advance the treatment of paralysis. The participants ranged in neurological level from C7-T5 and were at least two years post-injury at the time of the intervention. The initial research hypothesis stated that the two participants with the American Spinal Injury Association Impairment Scale (AIS) classification of AIS A would not elicit any voluntary movement, despite the therapy intervention, and the two participants who were AIS B would develop voluntary movement following a combination of training and epidural stimulation. However, in the presence of epidural stimulation, all four recovered voluntary control of their lower extremities, surprising researchers who believed at least some of the sensory pathway must be intact for epidural stimulation to be successful.

As the first epidural stimulation participant, Rob Summers moved the needle for the entire field with his unprecedented recovery. With a C6 injury, he was paralyzed below the chest after being struck by a vehicle in 2006. Summers currently resides in Portland, Oregon. The other three research participants include:

- Kent Stephenson was the second person to undergo epidural stimulation after sustaining an injury at T5-T6 during a motocross accident in 2009. He resides in Mount Pleasant, Texas.

- Andrew Meas was in a motorcycle accident in 2007, resulting in an injury at C6-C7. Meas was the third person implanted and lives in Louisville, Kentucky.
• Dustin Shillcox injured his spine at T5 in an auto accident in 2010. He was the fourth participant and resides in Green River, Wyoming.

“With this study the investigators show that their findings about a motor complete patient regaining movement, as published three years ago in The Lancet, were not an anomaly,” said Susan Howley, executive vice president for research at the Christopher & Dana Reeve Foundation. “At the present time, other than standard medical care, there are no effective evidence-based treatments for chronic spinal cord injury. However, the implications of this study for the entire field are quite profound and we can now envision a day where epidural stimulation might be part of a cocktail of therapies used to treat paralysis.”

Investing in Epidural Stimulation

The research was funded by the Christopher & Dana Reeve Foundation, the National Institutes of Health (R01EB007615, P30 GM103507), the Leona M. and Harry B. Helmsley Charitable Trust, the Kessler Foundation, the University of Louisville Foundation, Jewish Hospital and St. Mary’s Foundation, Frazier Rehab Institute and University of Louisville Hospital.

“When we first learned that a patient had regained voluntary control as a result of the therapy, we were cautiously optimistic,” said Roderic Pettigrew, M.D., Ph.D., director of the National Institute of Biomedical Imaging and Bioengineering, which provided support for the study. “Now that spinal stimulation has been successful in four out of four patients, there is evidence to suggest a large cohort of individuals, previously with little realistic hope of any meaningful recovery from spinal cord injury, may benefit from this intervention.”

Epidural stimulation, in the context of paralysis of the lower extremities, is the application of continuous electrical current, at varying frequencies and intensities to specific locations on the lumbar-sacral spinal cord, corresponding to the dense neural bundles that largely control movement of the hips, knees, ankles and toes.

Dr. Angeli and her colleagues are optimistic that the therapy intervention will continue to result in improved motor functions. In fact, based on observations from the research, there is strong evidence that with continued advancements of the epidural stimulator, individuals with a complete spinal cord injury will be able to bear weight independently, maintain balance and work towards stepping.

For more information about epidural stimulation and other spinal cord injury research, please visit http://chartingourcourse.org/research/victory.html and www.christopherreeve.org/epi

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For research information, patient bios and multimedia, please visit https://app.box.com/s/22yptu3trdhdd57fj69i

Bibliographic details:


Alumni News, Continued from page 5

SCI Access: Do you have any advice for others, about some of the obstacles you’ve faced, that might help them or give them some insight?

Andy: The advice that I have for others who are in a similar circumstance is that things can and will get better if you make the choice to respond to the situation positively. I am a big fan of the quote from Charles R. Swindoll - “The longer I live, the more I realize the impact of attitude on life. Attitude, to me, is more important than facts. It is more important than the past, the education, the money, than circumstances, than failure, than successes, than what other people think or say or do. It is more important than appearance, giftedness or skill. It will make or break a company...

Things can and will get better if you make the choice to respond to the situation positively.

a church... a home. The remarkable thing is we have a choice everyday regarding the attitude we will embrace for that day. We cannot change our past and we cannot change the fact that people will act in a certain way. We cannot change the inevitable. The only thing we can do is play on the one string we have, and that is our attitude. I am convinced that life is 10% what happens to me and 90% of how I react to it. And so it is with you... we are in charge of our Attitudes.”

Overcoming challenges and adversity – It will all get better in time. There are some things that are easier to deal with when it comes to SCI and others that are major lifestyle changes. I don’t think you can just overcome everything all at once, some things take time to process and really wrap your head around. I know that was true for me. Learning how your body functions differently and getting used to new ways of sensing when you need to do things like pressure relief (because you can’t feel your butt anymore) or when you have to go to the bathroom off schedule so you don’t have an accident. That’s never cool. Unfortunately, you have to learn some of those things the hard way to find out what your body was trying to tell you. Keep a positive frame of mind.

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The SCI Access Newsletter would like to include news and advice from you, our alumni, in future newsletters! Please contact us at SCI-Model-System@umich.edu to share your story.
Meet the Team!

Ever feel like you need a face to put with the name that is calling you? Take a moment to “meet” and get to know our research staff!

**Rachel Hartwig, Project Coordinator**

Rachel has been a part of the SCIMS team for the past 2 years, doing it all; from managing the national database, to recruiting new participants, to interviews and more! She just can’t get enough research and is involved with almost all of the studies going on currently in one way or another. Even though Rachel works for U of M, she is a Spartan through and through, having gotten her bachelor’s in psychology from MSU a few years ago. Her favorite part of the job is getting to know everyone and hearing their stories. She is inspired every day by their tales of strength, renewal, and hope.

When Rachel is not making graphs or talking with participants, you can find her elbow-deep in the garden or wrapped up in a new novel. Her joy in life is laughing and loving with family and friends. Rachel’s downfalls are Pinterest and anything coffee related. The next challenge on the horizon (besides graduate school for counseling) is a 2-day relay run in Kentucky. Let’s hope she makes it to the finish line!

**Gina M. Jay, Ph.D., Research Technician**

Gina, our newest team member, took a long and winding road to the University of Michigan Spinal Cord Injury Model System. She completed her undergradate degree at UM-Dearborn in psychology and sociology, her graduate work at Penn State University in human development and family studies, and her postdoctoral work in public health and gerontology here at UM, before taking a position in survey methodology at the Institute for Social Research. She took an 18-year hiatus from formal research work to focus on raising her family and doing community work. Gina is currently busy with the SCIMS database work and conducting interviews for the site-specific intervention study, Applying Health Mechanics to Enhance Bowel and Bladder Health for Persons with SCI.

In her free time she enjoys volunteering at Arbor Hospice, writing children’s/young adult fiction, and creating beautiful, or at least interesting things, using her sewing machine, screen printing supplies and gardening tools.

**Lisa Konkol MPH, Research Technician**

A native of Wisconsin, Lisa completed her undergraduate degree at the University of Milwaukee majoring in psychology and biomedical ethics. After that, she pursued her Master’s degree in Health Behavior at the School of Public Health in Birmingham, Alabama (she loves those Dixie winters). After completing her public health internship at the Stanford Arthritis Center in California she went on to pursue doctoral work in Health Behavior and Health Education at the University of Michigan School of Public Health. She continued to work at the University in different capacities as a Research Assistant focusing on folks living with chronic illness. Having found a research “home” with the Spinal Cord Injury Model System, she has been with the research team since 2010. In her spare time, she enjoys listening to music, reading, and movie-going. She also plays a mean game of putt-putt golf. Learning how to play regular golf is one thing on her bucket list that she hopes to tackle soon.

**Connie Pines RN, CCM**

Being an avid sports enthusiast, as a young girl, Connie dreamed of being the first female quarterback in the NFL. Sadly, that never happened. A playful spirit, compassionate, strong and self-reliant would best describe her along with a passion for good health.

Her role here at UM Spinal Cord Injury Model System is that of Clinical Recruitment Coordinator which entails meeting with our patients and their families shortly after their admission to UM Rehab Unit. Both adults on 6A and children at UM Mott Children’s Hospital with traumatic spinal cord injuries are offered the opportunity to participate in our SCIMS long-term Study. She also meets and screens our SCI patients population in the Outpatient Clinics and presents to them various studies they may qualify for and participate in. She serves on the Spinal Cord Injury Advisory Committee which meets annually.

During her 40 year nursing career, numerous ‘never to be forgotten’ moments have touched her in a most profound way which she will carry with her throughout her life.
After 37 years in the field of Cardiology/Cardiothoracic Surgery at The University of Michigan and the Ann Arbor VA Medical Center, life’s circumstances brought her to UM Spinal Cord Injury Model System for employment in 2011. It has become her legacy of work left to be fulfilled by her late husband, Greg. A tetraplegic himself, he participated in UM’s Rehab program following his auto accident in 2003.

Cycling, fitness, travel out West, summer vacations up north and frequenting the North Carolina area, are activities that consume her time away from work. Also, she enjoys walking/hiking just about anywhere. Live performances are great including string quartets, small clubs and local theater in the Ann Arbor and Chicago areas. While vacationing, she likes to explore museums, old churches, galleries and woodlands.

Playing the piano, learning the game of golf and traveling are on a list she wishes to pursue in the near future. Currently, she resides in Ann Arbor and loves her role as ‘Grandma Connie’ to her grandchildren, Erin-8 and Jack-4.

**Maggie Travin, M.A., Dissemination Coordinator and Research Technician**

Maggie began with UM SCIMS one year ago after working in community mental health for two years. She completed her undergraduate degree at the University of Michigan where she studied Psychology and Political Science. After working in business management for two years, Maggie pursued a Master’s degree in Clinical Psychology with a concentration in Trauma Assessment and Treatment focusing on the effect of chronic health issues on trauma treatment. She works full-time with SCIMS and also works as a clinical mental health counselor in private practice. Maggie has dedicated much of her time to working with people with disabilities and helping to improve the lives of others.

Maggie is extremely interested in health and wellness. She is an avid runner and athlete. She spends her personal time traveling, cooking, playing with her dog, and volunteering. Currently, she is also a Field Advocate for the American Foundation for Suicide Prevention where she is active in promoting suicide prevention legislation in Washington D.C.

**Brad Trumpower, M.S., Research Technician**

Brad graduated from Texas A&M – Corpus Christi with a Master of Science in Counseling with a focus in clinical mental health. He is an 8-year veteran of the Army National Guard including a 1-year combat deployment for Operation Iraqi Freedom. Brad’s focus is on interventions, regulatory management and data management. Prior to working for the U-M, Brad worked in community mental health with adolescents. Brad is known around the office as the resident chart/graph master and comedian. Brad’s next great life goal is raising two kittens.

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**SCIMS Current Research Studies**

**Are you interested in participating in research? Here is what is currently going on at SCIMS**

**Site-specific Study 1: Bladder and Bowel Complications and their Impact on Quality of Life after SCI:** This study examines the nature of bowel and bladder management and the relationship of these and other factors to complications and quality of life (QOL).

**Site-specific Study 2: Bowel and Bladder Complications after SCI in Daily Life:** A group of the participants in the first study are participating in an in-depth study that is looking at the impact of bladder and bowel issues on daily life. Participants track this impact for one week.

**Site-specific Study 3: Applying Health Mechanics to Enhance Bowel and Bladder Health for Persons with Spinal Cord Injury:** This clinical trial evaluates the efficacy of the Health Mechanics self-management program to improve bowel and bladder health among people living in the community with SCI.

**Multi-Center Study 1: Evaluating the sensitivity and responsiveness of the SCI-QOL CATs:** The SCI-QOL was developed to measure quality of life in terms of physical activity, medical issues, emotional functioning and social participation. This U-M led study evaluates how well the SCI-CAT shows if clinically meaningful changes have occurred.

**Multi-Center Study 2: Enhancing and Evaluating the SCI-FI:** The SCI-FI evaluates functional well-being in terms of Ambulation, Basic Mobility, Fine Motor Function, Self-Care and Wheelchair Mobility. The measure was refined and the study’s final phase will test how respondent’s scores change over time.

**National SCIMS Data Set: Preparing for Future Changes:** This study will evaluate how changes in Medicare will affect people with SCI.

To participate please contact 734-763-0971 or SCI-Model-System@umich.edu
Having children can be difficult for anyone, but because I am paraplegic, my wife and I had a unique set of challenges. There was a lot of uncertainty about how we were going to accomplish parenthood. Two years after my wife and I got married and ten years post-injury, we decided it was time to figure it out. After speaking with several of my friends who are also paraplegics it seemed like there was a consensus to speak with a urologist that specialized in this kind of thing. We did a lot of research and through some of our friends found Dr. Ohl at the University of Michigan Health System. Thank goodness for Dr. Ohl! He made most of my challenges seem insignificant and he made me feel as though I was no

different than anyone else. After our visit, Dr. Ohl reassured me that my sperm count was good and that I could still have children. From there it all came down to timing.

In addition to timing it right, we also decided to use a fertility clinic. This gave us a better understanding of my wife’s reproductive cycle. Narrowing the window of conception increased our odds tremendously. We also opted for Intrauterine Insemination (IUI), which allowed for my sperm to pass her cervix for a better chance of survival. IUI is a procedure that involves placing sperm inside a woman’s uterus to facilitate fertilization. Although this is what worked for us, it is important to have a physician make the best recommendation for you, given the sensitivity of each disability.

Additionally, we used a device called the “Ferti Care.” The Ferti Care is a medical device used to assist men with SCI ejaculate, otherwise it can be difficult. Using this device, on the first attempt I was able to ejaculate, it had been ten years since I had done that. It is easy to stress out about the inability to ejaculate but there are options! I now use it 1-2 times a month and have received other benefits from it too, including being able to retain more urine. It has made a huge difference in my life. We even nicknamed the device “Ferdinand,” because finding humor in all types of situations helps get you get through when things aren’t going your way.

On August 7, 2011, my beautiful wife Breanne and I had a gorgeous, healthy baby girl. We are very blessed to live in the time that we do. If it weren’t for advancements in medicine my wife and I would have never been able to experience the gift of parenthood.

Being a parent with paralysis has its challenges, but often-times it’s simply about being innovative and adapting to the situation to make it work. For me, changing her diaper, bathing her, and taking her places by myself can be difficult. But for each of those challenges I have come up with solutions. For example, we created a changing station that I can roll up to, with a rubber-lined changing pad that doesn’t slide around. We also keep the diapers, wipes and diaper cream within easy reach.

In the beginning, my daughter was light enough for me to lift her. But as she grew it became more difficult. Fortunately, by that time she had already started to walk. Our solution was to have her climb up to the changing table using a series of small, safe steps. I make it like a challenge for her and reward her with cheering and praise once she’s on the pad. You have to create things that work for you in your own situation. This is what is working for me at the moment but obviously our ultimate goal is potty training. That will be an awesome day! Another example is bathing my daughter in my shower. I wear my swim trunks and we pretend it’s a fun game. We turn music on and she gets to hold the shower handle and spray water all over the place. I soap her up from my shower chair and rinse her off. It may take a lot of time, but it works for us.

My wife Breanne and I have custom made a plan to make sure that we are sharing raising our daughter together. You don’t
want childcare to be one-sided. If you look at raising your kid like a balance scale, you never want one side of the relationship doing more than the other or the scale will tip. I have learned that if you pitch in with simple tasks, like brushing your child’s teeth or playing outside for an hour a day, it can make all the difference, as it gives your spouse a much needed break.

With only less than three years of experience raising my daughter, I still have a lot to learn. I have learned a great deal about being a good parent while being in a wheelchair from my friends who also use wheelchairs. Fatherhood is a gift and I am constantly reminded how lucky I am when I look at my daughter.

Sometimes I want to be like every other able-bodied dad out there, but I don’t allow that to get me down. Reality is that sometimes I have to put my pride in my back pocket and sit on it. It’s not the end of the world if I have to wear a baby harness to carry my daughter in a store, or use a child harness with a lead so that my daughter doesn’t run away from me in public. At the end of the day, it’s a gift not a sacrifice. The younger years are tough, but as they grow some things become easier (although I have been warned about those teen years…).

We are lucky to live in a day and age with options. We all have to keep faith that God has a plan and everything will work out some way or another.

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Dr. Bruns is focused on developing neuroprostheses for individuals with neurological disorders. These are medical devices that are designed to replace lost nerve function. His research group is working on a neuroprosthesis to restore bladder control for people with a spinal cord injury. This device will use electrical stimulation, like a pacemaker, to activate sensory nerves that drive reflex control over the bladder system. Just like tickling your nose in a certain way can lead to a reflex sneeze, there are certain nerves that can be stimulated (tickled) to cause reflex bladder responses. This device will also record sensory signals from the bladder that will allow the fullness of the bladder to be determined. The unique feature of this approach is that the device will be able to detect when the bladder is full and leakage may occur, and will trigger the appropriate stimulation to maintain continence. Then, when an individual with this device is ready to empty their bladder, the device will be switched to stimulate the bladder to empty. While Dr. Bruns and his colleagues are currently performing pre-clinical experiments towards making this device a reality, they are looking forward to doing research studies with people that have spinal cord injuries in the coming years.

Tim Bruns joined the Biomedical Engineering department at the University of Michigan in September of 2013. He came to Ann Arbor after receiving a Ph.D. in Biomedical Engineering at Case Western Reserve University and a postdoctoral fellowship in the Physical Medicine and Rehabilitation department at the University of Pittsburgh. Dr. Bruns is establishing his research group, the Peripheral Neural Engineering and Urodynamics Lab, while also seeking collaborations across the Medical School and College of Engineering. His primary goals are to develop interfaces with the nervous system to restore function and to study how the nervous system works.
SAVE THE DATE: June 24, 2014
Peer Mentoring Lecture

A mentor can make all the difference in someone’s life, especially after a catastrophic spinal cord injury. When someone who has literally “been there and done that” is matched with a new patient, or with someone who is struggling, a friendship evolves from the support that is provided and the hope that is discovered in informal conversations.

Tom Hoatlin will present a lecture on The Power of Peer Mentoring. He will introduce the PESP, a national peer-to-peer network, by demonstrating the impact this program has had in this region and across the country. Participants will learn about what makes an effective Peer Mentor, Ethics, Communication, and about the Peer Resource Center that provides vital resources for people living with paralysis both locally and nationally.

We hope you can join us on Tuesday, June 24th from 1:30 PM-2:30 PM directly following the spinal cord support group at MedRehab, 355 Briarwood Circle, Building #4, Ann Arbor, MI 48108

For more information please contact:
Maggie Travin at 734-936-9334
or mtravin@med.umich.edu

SAVE THE DATE: October 4, 2014
SCI Foundation Charity Brunch

With firsthand knowledge of the challenges faced by individuals with a SCI, and an understanding that his career opportunities were a direct result of his education, Blake Heidenreich founded the Spinal Cord Injury Foundation (SCIF) to support others with a SCI pursue a career. SCIF, founded in 2012, aims to support individuals with a SCI in becoming independent and employable through further education, by providing educational scholarships and mentoring to recipients. The board of director and leadership team includes Anthony Chiodo, MD, MBA from the University of Michigan PM&R, Tom Hoatlin, who shares his 20+ years of business development experience related to the spinal cord injured community, and Brock Mealer, an inspirational individual personally touched by a SCI.

SAVE THE DATE: The SCIF’s second annual event, an afternoon brunch with silent auction, is scheduled for Saturday, October 4th at the McKinley Center in Ann Arbor. Check out the website at spinalcordscholarship.org and mark your calendar for October 4! Registration begins on the website in June. Come enjoy great food, hear of the SCIF’s future goals, and congratulate our first two $1000 scholarship recipients.