William Scelza, M.D., Returns to UM as SCI Physician

by Kathy Klykylo

The UM Model SCI Care System is very pleased to welcome back William Scelza, M.D., who completed his residency in the Department of Physical Medicine and Rehabilitation at the University of Michigan Health System in 2002 and returned in July as a staff physician focusing on the care of patients with spinal cord injury. He spent the last year completing a fellowship in SCI medicine at the Kessler Institute for Rehabilitation in New Jersey. Dr. Scelza also has a great deal of personal experience with spinal cord injury, sustaining a spinal cord injury himself when he was 17.

Scelza states, “I am very happy to be back at UM, using my skills and my own personal experiences to treat people during the acute phase after their injury and over their lifetime.” His calm demeanor and optimistic attitude are distinct assets in his work with individuals with spinal cord injury. Scelza approaches individuals with SCI the same way he does other patients with serious or life-threatening conditions. While not forcing the issue, he wants them to see first-hand that a spinal cord injury does not have to stand in the way of a career and a full life.

Dr. Scelza praises the Model System’s team approach during rehabilitation after a SCI. The entire team, including the nursing staff, therapists, and other social support staff, all contribute to the goal of helping a person with SCI achieve as much independence as possible.

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Matt Medendorp’s life took a sudden turn at the start of his senior year in high school. On August 31, 2002, he fell while running into a lake, injuring his spinal cord at the C4-C5 level, leaving this swimmer and water polo competitor unable to move his arms or legs or breathe on his own. Matt eventually came to the University of Michigan Hospital with the primary goal of breathing without the assistance of a ventilator, reaching this goal two weeks before he went home in November 2002.

After his hospital discharge, Matt received tutoring at home and resumed full-time high school classes in January, while attending outpatient therapy at Mary Free Bed Hospital in Grand Rapids. He took his girlfriend, Karen, to the Senior Prom, and he graduated with his Grandville, Michigan, high school class in May. This Fall, he enrolled in two on-line college courses, calculus and telecommunications history.

Matt is a friendly, soft-spoken young man, often given to kidding. He seems reluctant to be in the spotlight and underplays the achievement of staying on track with his life plans while successfully dealing with the major challenges and frustrations of life with a new spinal cord injury. While he is determined to overcome his injury, Matt’s life is clearly more than his injury. I asked Matt to describe the most memorable part of his inpatient rehabilitation, and he stated, “Going to the water polo eastern regionals and going to UM football and hockey games, arranged by Rob Wolfe, a UM Recreation Therapist.” A year later, Matt’s physical rehabilitation continues, but he also takes college classes, hangs out with his friends, goes to the movies, listens to music and is a connoisseur of good food.

Matt has a wide circle of individuals who provide the personal care and emotional support that have helped him become involved in his world again. At the center of this circle are his father, Jack, his mother, Marcy, who was also interviewed for this article, and his 16 year-old sister, Laura. Marcy Medendorp, a warm and lively woman, is the author of “Matt Update,” an email listserv that is circulated to an ever-widening group of friends and supporters, chronicling Matt’s latest activities and achievements. Matt’s story is also very much the story of his father, mother and sister, all of whom have demonstrated remarkable energy, ingenuity and love over this past year as they have supported Matt in his rehabilitation.

Matt continues to attend therapies, including Scenar therapy, an alternative treatment involving biofeedback and electrical stimulation, with the goal of eventually regaining some function in his limbs. He operates his wheelchair and has become skilled in the use of assistive technology, including computer voice recognition. His house was recently wired for voice activation to open doors, answer the phone, turn on lights/fans, and operate TV/DVD/stereo.

Both Marcy and Matt are bemused but pleased about the many strangers who have come to know Matt through Marcy’s email newsletters, through fundraisers to help defray some of his medical expenses, and through seeing him in the community. Matt’s determination and accomplishments have clearly had a far-reaching impact on many others.

Matt’s future holds a number of possibilities, among them, teaching history or working in disability rights. In the meantime, he takes classes, sees his girlfriend and socializes with friends and family. With no function below his shoulders and needing to depend on others for personal care, life is often frustrating and a challenge. However, in many ways, Matt’s life is again very normal, and with quiet determination, he continues on. A recent letter from a friend included the following, which may capture Matt’s view of his world: “Disappointed? Yes. Discouraged? Sometimes. Defeated? Never.”
Conference for Women Brings the Gift of Hope  by Shelia Starks

Networking, fellowship and education were paramount at “Sharing Our Gifts, a Conference for Women with Spinal Cord Injury,” held at the Rehab Institute Satellite in Novi, Michigan, on September 20, 2003. The conference was sponsored by the UM Model SCI Care System, The Rehabilitation Institute of Michigan and the Ann Arbor Center for Independent Living. A primary goal of this conference was to promote the well-being of women with SCI and to provide them an opportunity to benefit from learning from and networking with each other. “It was a great experience to see old friends, meet new ones and to finally see in person those we had only spoken with by phone, says Shelia Starks, an African-American woman with a SCI.

The tone for this successful conference, which included a diverse audience of Caucasian and Minority women with SCI, was set by Marva Ways, a member of the UM Model SCI Care System Advisory Council. In her inspiring keynote speech, entitled “The Gift of Hope,” Ms. Ways encouraged women with SCI to confront their daily struggles with a strong note of optimism. Her recipe included increasing involvement in physical, social and personal activities so that we stay “Too busy to be bored,” “Too positive to be doubtful of ourselves,” “Too determined to be defeated” and “Too optimistic to be fearful.”

The rest of the day’s program consisted of several presentations addressing issues key to the well-being of women with SCI. Dr. David Gater spoke about medical issues relevant to women with SCI, followed by a lively discussion and question & answer session. Barbara Schoen, M.A., a woman with tetraplegia and also a UM Model SCI Care System Advisory Council member, spoke about networking and mentoring. Dr. Tara Jeji and Ms. Shelia Starks spoke about the joys and tribulations of being a parent with an SCI, and Liina Paasuke, M.A., talked about work and volunteer roles. The day was filled with very interesting topics, and we have received rave reviews from attendees. If you missed this year’s annual consumer conference, don’t be discouraged — we are already planning next year’s conference!

In this candid memoir, Emmy Award-winning print and broadcast journalist John Hockenberry provides an up-close and personal account of his many adventures as a foreign correspondent and investigative journalist. Injured in 1976 in a car accident that left him paraplegic at the age of nineteen, Hockenberry describes life on wheels before the Americans with Disabilities Act (ADA) was passed. As he navigates through obstacle-ridden cities and prejudicial attitudes, the result is a study of human nature on all levels.

Using his great, often blunt, wit and gift for storytelling, Hockenberry provides a poignant, humorous, and insightful account of the human spirit. His topics range from sex and relationships to politics and philosophy to catheterizing and drugs. Whether we find him skiing down a black diamond slope or interviewing Kurdish refugees, this book promises to keep us turning the pages late into the night.

Hockenberry challenges stereotypes, reaches for dreams, and emerges a winner. There is never a dull moment as we are propelled through this inspiring journey that will leave us laughing, crying, cheering and taking in all that life has to offer!

~ Julie Harrison

Toll-Free Hotline for Air Travelers with Disabilities

The U.S. Department of Transportation (DOT) has established a toll-free hotline to assist travelers with disabilities. The hotline provides general information to consumers about the rights of air travelers with disabilities, responds to requests for printed consumer information, and assists air travelers with time-sensitive disability-related issues that need to be addressed in “real time.” The line is staffed from 7:00 a.m. to 11:00 p.m. Eastern time, seven days a week. Air travelers who experience disability-related air travel service problems may call the hotline at 1-800-778-4838 (voice) or 1-800-455-9880 (TTY) to obtain assistance.
Model System Lecture Series

We’ve had a wonderful series of SCI lectures since the last SCI access was published, and I’d love to share a few highlights! In March, Dr. Edward McGuire from the University of Michigan presented on the Management of Neuropathic Urinary Tract Infections and did a great job bringing some complex material into very simple terms: beware the small, contracted bladder, and realize that most people with SCI will develop bladder bacteria that do not require treatment with antibiotics. In May, Dr. Edward Nieshoff from the Rehabilitation Institute of Michigan presented his original research on Cardiovascular Autonomic Dysfunction Due to SCI, primarily looking at management of low blood pressure with a relatively new medication called midodrine that raises blood pressure and can reduce fatigue. Dr. Nieshoff is also using midodrine to combat low blood pressure that comes with strenuous exercise, with promising results! Eva Feldman, M.D., Ph.D., of the University of Michigan presented on Gene Therapy in the Treatment of Spinal Cord Injury in June. She spoke about her current laboratory research on repairing nerve cells and the limitations of this research that will need to be overcome in order for it to be used for a cure of SCI in the future. In September, Dr. Peter Ubel of the University of Michigan gave a thought-provoking presentation on Too Much of a Good Thing? The Hazards of Giving Patients Information to Help Them Make Health Care Decisions. His research shows that sometimes patients can make poor decisions about their care when given too much information, despite their best intentions. Finally, in November, Jim Magyar and Tom Hoatlin, from our partner, the Ann Arbor Center for Independent Living, presented on a topic that is at the core of our work, Nothing About Us Without Us. Principles and Practices of Independent Living. All in all, it has been an interesting and intriguing lecture series, and we encourage you to participate in our future presentations that will appear on the Model System web site.

Database Update

All 16 Model Spinal Cord Injury Care Systems maintain a database where information collected during telephone follow-up interviews is confidentially stored and used for a wide range of research projects. The University of Michigan Model SCI Care System database is managed by Jane Walters, who oversees information from over 900 patients with SCI admitted to the University of Michigan since 1985.

In the previous edition of SCI access, we explained that the information we collect during our phone interviews from Model Systems participants is used in a number of different research projects at the University of Michigan. Did you know that you are helping out with a much larger resource? The information you provide also becomes a confidential part of the National SCI Database at the National SCI Statistical Center at the University of Alabama in Birmingham, which collects data from all 16 Model SCI Care Systems across the country.

The National SCI Database is the largest of its kind, and it currently includes information on over 22,000 individuals. Researchers from the United States and around the world request information from this resource for projects that improve the care and the quality of life of individuals with SCI. This database is also a primary resource for support of the development of legislation, benefits and social policies that support individuals with SCI.

The Model SCI Care Systems collect information from individuals over their lifespan, and we have been in touch with some of you for almost twenty years. As more and more individuals with SCI live into their 70s and 80s, this long-term information is especially helpful in dealing with the changes that come with spinal cord injury and aging.

We want you to know that your individual answers to our questionnaires are important to us, and we hope that you will continue to take part in this research. Without each of you, this database would not exist as the valuable resource that it has been for so many years. Thank you, again, for taking your time to contribute to this very important work.

To learn more about the National SCI Statistical Center and Database, go to: main.uab.edu/show.asp?durki=10766
Also, see Spinal Cord Injury Facts and Figures at a glance, a product of the National SCI Statistical Center: www.spinalcord.uab.edu/show.asp?durki=21446
Trail’s Edge: Just Like Any Other Camp, but Different

by April Saval

Most of us have fond childhood memories of camp, including playing pranks on other campers, staying up late around the campfire, meeting new friends and getting away from our family. For a ventilator-dependent child with a spinal cord injury, summer camp is usually not a possibility. Trail’s Edge, a unique camp for ventilator-dependent children, sponsored by the University of Michigan C.S. Mott Children’s Hospital, fills this need. Staffed by more than 50 medical professionals and other volunteers, the camp offers a full week of adventure to campers ranging from 5 to 18 years of age. The first camp of its kind, Trail’s Edge provides typical camp activities and gives parents a much-needed respite from the difficult tasks necessary in caring for a medically fragile child.

This was my first year at Trail’s Edge, and I was partnered with a nine year-old boy, Brandon. I wondered if his camp experiences would be like my own or something totally different, and I quickly learned it would be both.

Many of the children used wheelchairs. All were dependent on ventilators and had serious medical conditions. However, that did not stop these kids. They played sports, had races, put on a talent show, went fishing and boating, played pranks on each other and did a lot of late-night snacking. This year, Trail’s Edge even had a huge, totally accessible treehouse. I am especially proud to say that Brandon kept busy with hockey and was an excellent goalie.

Campers did everything I had remembered doing at camp, in a setting that supported their medical needs. I ended the week feeling tired but also very happy about being a part of Brandon’s and the other children’s camp experience. As everybody left and said their goodbyes, Brandon yelled out, “I can’t wait till next year.” My thoughts were exactly the same.

WILLIAM SCELZA

FROM PAGE 1

He emphasizes that rehabilitation does not end after discharge from the hospital but continues throughout life, with the Model System team being a part of this life-long process.

During his UM residency, Dr. Scelza led a study with co-investigators Denise Tate, Ph.D., and Eric Zemper, Ph.D., to identify barriers to physical fitness for patients with SCI. He states, “With improved care and technology, individuals with SCI are living longer, but they are also developing physical problems that come with aging. We believe that exercise and fitness will help people with SCI remain healthy.

People with SCI may fear exercise will make their injuries worse, or they may not know how to exercise properly.” Scelza does note that the wrong kind of exercise may potentially be harmful. However, not exercising at all may contribute to other conditions such as diabetes and heart disease. Research has shown that heart disease accounts for 22% of all deaths in people with SCI, a number he hopes to help reduce. This research also found that about 3 out of 4 participants would like to exercise, but fewer than half of the subjects were actually participating in an exercise program. The barriers to exercise that the subjects identified included lack of motivation, lack of energy, cost of exercise programs, and feelings that fitness centers would not be able to meet their needs as a person with SCI. Dr. Scelza expects to continue his involvement in research at the UM, including the long-term effects of exercise on individuals with SCI.

Dr. Scelza was an athlete before his injury and remembers being inspired watching a wheelchair basketball team while he was in rehabilitation. He later competed nationally with the Cleveland Wheelchair Cavs basketball team and continues to be involved in numerous sports, including basketball and handcycling. Dr. Scelza and his wife Beatriz also stay physically fit by chasing their one year-old son Dominik around the house. He notes, “Dominik has been a great addition to our family and keeps us busier than we could have imagined.”
Focus on Research  

by Kathy Klykylo

The Model System continues to be very productive with SCI research on areas ranging from alcohol abuse to depression to environmental barriers to wellness. Below are some highlights of Model System research appearing in the coming months. We welcome your questions about any of these upcoming publications and presentations, so please do not hesitate to give us a call!

Scheduled for the American Journal of Physical Medicine and Rehabilitation, December 2003:

- Assessment of a Holistic Wellness Program for Persons with Spinal Cord Injury. 
  by Eric D. Zemper, Ph.D., Denise G. Tate, Ph.D., Sunny Roller, M.A., Martin Forchheimer, M.P.P., Anthony Chiodo, M.D., Virginia S. Nelson, M.D., M.P.H., and William Scelza, M.D.

Submitted for publication in The Archives of Physical Medicine and Rehabilitation, 2004 Special Issue Dedicated to Spinal Cord Injury:

- The Frequency, Phenomenology and Correlates of Probable Major Depression One Year After Spinal Cord Injury.  
  by Charles H. Bombardier, Ph.D., J. Scott Richards, Ph.D., James S. Krause, Ph.D., David Tuisky, Ph.D., and Denise G. Tate, Ph.D.

- Patterns of Alcohol and Substance Use and Alcohol Abuse in Persons with Spinal Cord Injury: Risk Factors and Correlates.  
  by Denise G. Tate, Ph.D., Martin Forchheimer, M.P.P., James S. Krause, Ph.D., and Charles Bombardier, Ph.D.

Submitted for publication in Neurorehabilitation:

- Environmental Factors and Their Role in Participation and Life Satisfaction After Spinal Cord Injury.  
  by Gale Whiteneck, Ph.D., Michelle Mead, Ph.D., Tamara Bushnik, Ph.D., and Denise G. Tate, Ph.D.

Presentation Abstracts Submitted to the American Spinal Injury Association Conference (ASIA), May 2004:

- Patterns of Alcohol and Substance Use and Alcohol Abuse in Persons with Spinal Cord Injury: Risk Factors and Correlates.  
  by Denise G. Tate, Ph.D., Martin Forchheimer, M.P.P., James S. Krause, Ph.D., and Charles Bombardier, Ph.D.

- Forgiveness and Health in Spinal Cord Injury.  
  by Denise G. Tate, Ph.D., Claire Z. Kalpakjian, Ph.D., Jon Webb, Ph.D., Loren Toussaint, Ph.D., and Jane Walters, M.A.

- Long-Term Mechanical Ventilation and Health after Spinal Cord Injury.  
  by David Gater, M.D., Ph.D., Seth Warschausky, Ph.D., and Jane Walters, M.A.

- The Role of Environmental Barriers in Explaining Depression Among Persons with SCI Following Community Re-Entry  
  by Denise Tate, Ph.D., Marty Forchheimer, M.P.P. and Jane Walters, M.A.

Ask the Doctor  

by William Scelza, M.D.

Question:

I’ve been a quad for a little over 35 years, and over that time I’ve probably tried just about every possible combination of bowel program schedules, suppositories, and laxatives. Typically I use one bisacodyl suppository and several glycerine suppositories and sometimes a glycerine or saline enema. However, it occurs to me that I know virtually nothing about how these various things work on the body, and I’m wondering what your thoughts are on both bowel program schedules and the effects of glycerine, bisacodyl, and other substances on the body.

Answer:

The goal of any bowel program is to have predictable bowel movements when you want to have them. Eating regular meals that are high in fiber (or adding fiber supplements like Metamucil or Fibercon) and adequate fluid intake are essential for a healthy bowel program. Suppositories (Magic Bullet, Dulcolax) act as irritants to the bowel to stimulate peristalsis. Magic Bullet suppositories have actually been shown to work faster and be more effective because they have a water-soluble base that allows the medication to act much more quickly and effectively. Digital stimulation is also a very important aspect and can improve the effects of your bowel program. The regular use of enemas is not an ideal way to do your bowel program, as one may require increasing volumes for effectiveness. If you are having trouble with your bowel program, do not hesitate to contact your spinal cord physician.

Question:

There’s conflicting information out there on hormone replacement therapy/ bone loss/heart disease for women as they reach menopause. Do you have any advice on this topic for those of us whose menopause is made even more complicated because we have an SCI? What about exercise to help with bone loss? What about Fosamax?

Answer:

After spinal cord injury there is bone loss that occurs below the level of injury, particularly in the legs. This is due primarily to the fact that our muscles are not stimulating the bones to keep the natural balance of calcium. For this reason it is important to always be careful with your bones as they can fracture more easily. To date, there has been no evidence that taking medications such as Fosamax prevents such bone loss after injury. Women with SCI who are approaching menopause also may be more likely to have decreased bone density not only in their legs but throughout their body. Thus calcium, vitamin D supplements and other medications may be indicated to treat this and other symptoms related to menopause. Your spinal cord injury physician will be happy to discuss these conditions further. Exercise is always a good thing and will help to preserve bone mass above the level of the injury but has not been shown to have benefit in bones below the level of injury.

This column was established to help answer our readers’ important health-related questions. If you have non-urgent questions for a physician or psychologist who specializes in SCI, please contact our office.
What’s Up on the Web  

by Brad Gronvall

This issue’s web update features sites on sports for beginners to competitors. Physical activity benefits your mind and body. Whether you are spectator or a participant, check these out!

**Michigan Adaptive Sports**
Learn or compete in downhill snow skiing, water skiing, kayaking and handcycling. Ski clinics at Pine Knob, ski trips to Crystal Mountain. Check out the website for additional information, including volunteer opportunities. [www.michiganadaptablesports.org](http://www.michiganadaptablesports.org)

**Disabled Sports U.S.A**
DSUSA’s Mission: To improve the quality of life for people with disabilities by providing affordable inclusive sports and recreational experiences that build self-esteem and confidence, enhancing active participation in community life. [www.dsusa.org](http://www.dsusa.org)

**American Association of Adaptive Sports Programs**
A site for America’s after-school sports leagues for youth with disabilities. [www.aaasp.org](http://www.aaasp.org)

**Buckmasters American Deer Foundation’s (BADF) Disabled Services**
An estimated 1.7 million people with severe physical handicaps enjoy hunting and shooting sports in the U.S. The most comprehensive site for disabled hunters on the web. [www.badf.org/DisabledHunters.html](http://www.badf.org/DisabledHunters.html)

**Handicapped Hunting Resource Guide**
Rules, regulations and permit information for each state. [www.ismi.net/handicapinfo](http://www.ismi.net/handicapinfo)

It’s Happening at the CIL  

by Tom Hoatlin

First installment of a new regular column in SCI access

Fall and winter are very active times at the Ann Arbor Center for Independent Living. New services and programs mean more choice and opportunity to participate. As always, Model Spinal Cord Injury Care System participants and their families are welcome at any of the Center’s events. For information, call (734) 971-0277 or visit www.aacil.org.

"My Chance to Dance" Education and Dance Instruction Series

These free, fun events put on by My Chance to Dance provide education and dance instruction for youth with disabilities – no experience necessary! Meet Glen Ashlock of The Thunderbirds, nationally-ranked wheelchair basketball team, as he talks about recreation options. Then learn dances with maracas, flags, and pompons. The following event features members of the Corner Health Center’s acting troupe plus dance instruction on party dances. Learn the YMCA, the Chicken Dance, and the Hokey Pokey. After that it’s the CIL’s adult mentors discussing how to make and keep friends. Dance instruction will focus on everything from the preceding weeks. The series will repeat in January. Call (734) 971-0277, ext. 30, to register and for specific event dates and locations.

Upcoming Classes

- **Beginning speech reading:** 6 or 12-week course for hard of hearing and late-deafened people. Contact Nan Asher at Heartech@ix.netcom.com for details.

- **Healthy Cooking and Eating for Seniors:** sponsored by Hope Clinic and Washtenaw County MSU Extension. Call Cam Landry at (734) 222-3812 for details.

Save the Date! Walk & Roll 2004  

Saturday, April 17, 2004, 10:00 a.m. – 2:00 p.m.

Support the CIL’s youth services by putting a team together for this fun event at Bowen Field House on EMU’s main campus. Call Brad Gronvall at (734) 971-0277, ext. 16, for details.
The University of Michigan Spinal Cord Injury Care System publishes SCI access twice annually. 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 UM Model SCI System receives funding from the National Institute on Disability and Rehabilitation Research (Award #1H133N00009). It is one of 16 Model SCI 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.

David R. Gater, M.D., Ph.D., Medical Director, Co-Director, Co-Principal Investigator
Denise G. Tate, Ph.D., Co-Director, Co-Principal Investigator

SCI access is available free of charge by contacting the project at the following address:

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Ann Arbor, Michigan 48109-0491
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E-mail: model.sci@umich.edu.
Web: www.med.umich.edu/pmr/model_sci/
Please notify our office if you have address additions or corrections.

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