

SCI *access*

Fall 2008

Insights and Information for People with SCI

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Greetings! We are happy to offer you our latest newsletter, with a special focus on the importance of remaining physically active throughout our lives. This issue features articles on topics such as our new Lokomat; the benefits of being active and risks of being inactive; stretching to help spasticity; and ways to motivate ourselves to exercise. In addition, we have a personal story, updates on the Advisory Council and research, and an Independent Living section. Enjoy!

Lokomat at U-M Med Rehab is Up and Walking

By Eric A. Appleberry, DDS, MS

The Lokomat, a computer-controlled mechanism for weighted treadmill walking/training is now installed and “up and walking” at the U-M Med Rehab facility on Briarwood Circle in Ann Arbor. Weighted treadmill walking has been shown to be of significant help in the walking rehabilitation of people with certain incomplete SCIs.

The Lokomat automatically moves the upper legs, lower legs and feet in a very smooth motion that is the same as natural walking (but without hip rotation). This is a big advantage over the traditional method where therapists manually pick up and move each lower leg (a fairly stumbling/awkward placement of one foot in front of the other on a moving treadmill). The Lokomat’s harness support/weight pressure can be adjusted from minimal to the full body weight on the patient’s legs/feet, as can the speed of walking, according to Physical Therapist Craig Fox, who runs the local unit.

The Lokomat stands so tall that major renovations (raising the building’s ceiling and roof) were needed to make room for it.

A referral from a physician is needed. Be sure to check with your insurance, as coverage varies (and is unlikely for someone with a complete SCI). For questions or to make an appointment for the Lokomat, please call Michelle Semple or Craig Fox in the Physical Therapy Department at U-M Med Rehab (734) 998-7888.

My Experience on the Lokomat

By Brock Mealer

Brock Mealer, 23, was involved in a motor vehicle accident in December, 2007, and sustained an L1 ASIA B injury. He began working on the Lokomat while he was still an acute rehab inpatient at U-M Hospital, and continued therapy after discharge.

I first heard about the Lokomat when I arrived at U of M and was intrigued at the opportunity to stand and walk again. It took a month of therapy to tolerate standing and get my leg muscles working.



Brock Mealer on the Lokomat

The first time I used the Lokomat, I was simply thrilled to be walking again. I pictured myself out on the sidewalk. I’ve been on the Lokomat nearly a dozen times; it has given my legs a taste of what they are meant to be doing. My goal seemed more achievable once I saw myself in a picture, walking with the help of a machine.

Continued on page 3...

Ask the Doctor...

Exercise and Post-SCI Spasticity

By Frederick M. Maynard, MD, AAPM&R

Dr. Maynard served as the first Director of the SCI service at the University of Michigan during the '80s and '90s, and was the first principal investigator of the Model System grant. He is currently a physician with UP Rehab Medicine Associates PC in Marquette, Michigan.



Many people with SCI experience problematic spasticity symptoms, such as painful spasms or excessive tightness of leg muscles that prevent performance of some activities, in spite of medications. One of the best ways to control spasticity is through repeated stretching of the spastic muscle(s). Patients are often taught ROM (range of motion) exercises for their legs designed to maintain normal movement of joints in paralyzed lower limbs.

However, more important than stretching joints is actually stretching the muscles that cross the joints. Most joint contractures (limited joint movement) after SCI result from shortening of the muscles that cross the joint and then act as a restraint. For muscles that have frequent spasms or intermittent excessive tone, improvement can often be achieved by repetitive (10-20) prolonged (6-10 seconds) stretching of tight spastic muscles. Positioning symptomatic muscles during sitting or in bed so that the muscle is at a mid-position (not stretched or shortened),

may also decrease spontaneous spasms.

Beyond specific stretching exercise routines, aerobic exercise bouts (also known as cardio conditioning routines) can also be helpful in reducing spasticity. Hybrid exercise routines using Functional Electrical Stimulation (FES) of paralyzed leg muscles while functioning arm muscles push an ergometer (arm bike wheel) are best, if available and feasible. Exercise bicycles that involve arm push/pull and lower limb passive movement also can be helpful because the legs get repetitive stretching.

Participation in wheelchair sports that involve enough prolonged arm use to become aerobic are also likely to be helpful, probably by release of endorphins and generalized relaxation with feelings of improved well-being that are known to follow bouts of aerobic exercise. Most studies of wheelchair athletes suggest they experience improved health and well-being, including less problematic spasticity, than people with SCI who do not participate in sports.

Where to get a Mammogram—for women using wheelchairs

When women reach a certain age, it is recommended that they get regular mammograms to screen for breast cancer. If you use a wheelchair and have reservations about your ability to complete this procedure, here is some good news for you:



Mammograms for women who use wheelchairs and are unable to stand up to use the x-ray equipment are available at the University of Michigan's Cancer Center.

Staff at the Cancer Center will help to lift and trans-

fer a person from her wheelchair to the x-ray equipment. They will attempt to do the mammogram in a supported leaning position (this may work even for someone who is unable to stand at all). If that doesn't work, or if the person is unable to remain still, an ultrasound exam will be done instead.

Routine screening mammograms are scheduled a year ahead of time. If you would like to be seen sooner, call to see if there have been cancellations. The Cancer Center's appointment line is (734) 936-6274.

The Many Benefits of Exercise*

By Michelle Meade, PhD

Remaining physically active continues to be important throughout our lives, at all ages and levels of ability. Research tells us why:

Physical Health Benefits

Physical activity is good for people with SCI because it can help with the following:

- It can increase the length and quality of your life.
- It decreases health problems, including number of pressure ulcers, urinary tract and respiratory infections, and severity of spasticity.
- It decreases the number and cost of hospitalizations.
- It decreases time in bed.
- It helps prevent diseases such as hypertension, diabetes and obesity.

Psychological Benefits

Recreational and leisure activities can also provide many psychological benefits. The idea is to do something that you enjoy, interact with others and have fun! These activities can:

- Improve your social life—a great way to connect with friends and family or to meet new people!
- Improve your mental health; decreasing feelings of anxiety, depression, sadness, and listlessness.
- Assist with adjustment to disability.
- Provide a sense of accomplishment.
- Serve as a coping mechanism and provide a way of managing stress.
- Increase confidence in your ability to perform both sport-specific and general activities of daily living.

If you are interested in this topic, you might want to check out the *National Center for Physical Activity and Disability* (NCPAD) either online at www.ncpad.org or by calling them at 1-800-900-8086 (voice and TTY) from 9am to 6pm (EST).

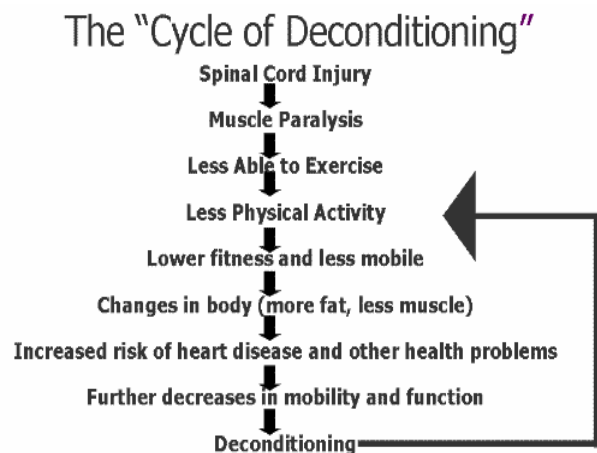
Finally, if you plan to start a new physical activity, check with your doctor to see what precautions you may need to take, so you can be safe, healthy, and happy!

*Slater D, Meade M. (2004). Participation in Sports and Recreation for Persons with Spinal Cord Injury: Review and Recommendations. *Neurorehabilitation* 19 (2), 121-129.

Risks of Inactivity after SCI *

Moving about is often difficult for people with SCI, and sometimes it's just easier to avoid physical activity, even though we know it is important for good health. Not exercising can put the body into a cycle of deconditioning where lack of activity causes changes in the body that make it even harder to start moving about and being active. And the harder it is to start, the less motivated we become.

As the diagram below shows, loss of fitness may begin with the sudden changes in your muscles caused by SCI, but it is made worse when you avoid physical activity. Long-term inactivity has harmful effects on the body: slowing bowel motility; weakening bones, joints, and muscles; causing the heart and lungs to work harder; and all these things make it even harder to get moving. So, make an effort to stay active—you'll be glad you did!



*Adapted from the article "Fitness after SCI: How to get started" by Catherine Warms, PhD ARNP CRRN, in *SCI Update*, Fall 2004, with permission from the Northwest Regional Spinal Cord Injury System, University of Washington, Department of Rehabilitation Medicine, Box 356490, Seattle, WA 98195. For more great information including videos, see http://sci.washington.edu/info/forums/reports/universal_fitness.asp

My Experience on the Lokomat (cont from p. 1)

For feedback, a monitor will show you a smiley face that increases as you work to put more force through your legs. When you take a break, it will change to a frown, but there's always a smile on my face.

After 4 months of rehab, I have progressed from not being able to sit up for 5 minutes, to being able to walk with leg braces and a walker. At times it seems results from the work cannot come fast enough, but I have learned that with persistence the results will come. It can be a mental battle, but the Lokomat helps my mind grasp what it will take to make it to the next step.

Check out YouTube.com: search for "Lokomat"

Motivation and Exercise

By Michelle Meade, PhD

Michelle A. Meade, Ph.D. is a rehabilitation psychologist at the University of Michigan. She serves as chief of the SCI service for the Division of Rehabilitation Psychology and Neuropsychology and as an investigator for the U-M SCI Model System. Dr. Meade's research interests focus on health disparities, health management and community integration / participation.

Physical activity and exercise are extremely important and are considered by many to be the best medicine available. Among the many benefits are the prevention of obesity, reduced risk for heart attacks, and improved mood. Physical activity, exercise and recreation can also be a great first step towards family and community reintegration. Often, sports and activities can be enjoyed with friends and family members in settings that level the playing field. They also provide a great opportunity to get out, socialize, problem-solve, gain a skill and just have fun.

Unfortunately, for many of us, activity, exercise and recreation lose out as we spend more time at work or school and less time at play. For individuals with SCI, the idea of devoting time and energy to recreation and physical activity is too often not even on the radar, due both to other priorities that fill up the day as well as the barriers involved in negotiating the environment.

It is time that we recognize the importance of recreation for all individuals. For one thing, the physical and mental health benefits from activity have been clearly documented in medical studies.

Below are some steps that you might want to consider when thinking about starting a new physical or recreational activity:

1. Think about what you like to do. Do you enjoy spending time with other people or do you prefer to have time alone when you can focus on a specific activity or skill? You may want to consider what your functional limitations are, but don't dwell on that too much. There are many options and adaptations out there that you may not be aware of. Keep an open mind.

2. Consider your goals. What is it you would like to accomplish? Lose weight? Improve health? Meet people? Relaxation? Your goals may suggest specific types of activities. If your goal is to lose weight, you may want to consider some combination of cardiovascular exercise, strength / resistance training and flexibility exercises.

3. Think about what resources you have. It is important to be realistic about what types of activities you might be able to sustain long-term. Especially think about your finances. Given increased gas prices, you really want to consider how far you need to go to do what

you planned. Think also about your physical resources, your energy level, and your social support. All of these are going to affect your ability to sustain an activity.

4. Consider your environment. Does it offer safe places to recreate? Is there a place that you can walk or wheel your chair? Is there a community center or gym in your area? If so, is it accessible? The more convenient an activity is, the more likely you are going to be able to engage in it.

6. Ask for assistance and ideas from others. If you interact with rehab on a regular basis, ask one of the professionals for advice. Your physician may be able to suggest types of activities that you can do. A physical therapist may be able to help create an exercise program or a therapeutic recreation specialist might be able to introduce you to the many options available to you. Many county parks and recreation departments also have inclusion specialists available to adapt courses and activities to meet your needs.

7. Get specific. Once you determine what you want to do, figure out how, when and where you will do it. Say you want to start power walking / rolling. Is there a track you can use? When is it available? What days can you fit it into your schedule? Will you exercise in the morning, afternoon, or evening? The more specific you can get in determining when you can exercise – especially figuring out when in the next week that you can engage in that sport or physical activity – the more likely it is to occur.

8. Find someone to participate with. For most of us, we are more likely to exercise if we have someone else to participate with. This person can not only hold us accountable, but they can also provide needed encouragement and practical support.

9. Don't try to do too much too fast – slowly increase your frequency and intensity of participating. If you are starting a new exercise program or sport, it is important that you don't try to do too much too soon. While you may be able to hit it hard at first, your body will yell at you later. Many individuals with SCI – especially wheelchair users, cannot afford to injure their arms or shoulders because it will affect self-care. However, exercise and physical activity done right can increase endurance, independence, and functional ability.

Ron Yatich

Carrying on with a Meaningful Life after a High Level SCI

By Eric A. Appleberry, DDS, MS

It was March 13, 2007. After being in the air for an exhilarating 4 1/2 hours, hang-gliding cross-country from one “up thermal” to another for some 60 miles, Ron Yatich found himself dehydrated, tired, losing altitude and not yet at the target landing field near Tampa, Florida. With no thermal around in this latter part of the day, he had no choice but to put down...somewhere. A small field in front of a building (with two police cars nearby) was his only option. Unfortunately he misjudged his altitude, came in too fast and crashed the landing. He knew right away he’d broken his neck. “I thought I was going to die.”

Luckily, the policemen saw him crash and responded quickly. A helicopter rescue flight took him to a Tampa hospital, where he had surgery and post-op recovery. Ten days later he was on a chartered Lear jet flight to Willow Run airport in Michigan and five weeks of rehab at U-M Hospital’s SCI Care program.

Hang-gliding is an enthralling sport, Ron says; it brings you the experience of flying. “It’s risky, however, and even with my 26 years at it, accidents like this can happen. But challenges have been my life. I had put in over 27 years teaching at a training school for delinquent adolescent boys—tough work, but I enjoyed helping them. When I retired from teaching in August, 2006, I sold my house in Traverse City, Michigan, got on my 30 foot sailboat and, at age 54, set out to see the world.”

Ron sailed the boat down Lake Michigan, through the Chicago Canal and a series of rivers to reach the mighty Mississippi. But instead of taking that all the way to the Gulf of Mexico, Ron went from the Mississippi up the Ohio and into the Tennessee River. Then, connecting from one river and canal to another, he wound his way through the states of Kentucky, Tennessee and Alabama, finally entering the Gulf at Mobile, Alabama.

From the Gulf, Ron sailed down to the Florida Keys, the Bahamas, and then to Ft. Lauderdale, Florida. There, he parked the boat and headed up to the Wallaby Ranch (near Orlando, Florida), where he had been taking hang-gliding vacations since 1987.

This half-year of sailing was “the trip of my lifetime!” Ron said, “and probably vital to my emotionally surviving the [yet to come] spinal cord injury. For most of my adult years I’ve had some tendency towards negative thinking and depression. But during this trip I really learned to live in the moment, concentrating upon and appreciating just that new river, canal, town, port, store,

or person that was right there before me at the time. I learned to ‘smell the roses’ in what was available.”

But with the accident his positive thinking took a big hit. Ron, now a C4-5 tetraplegic, was still in chronic pain during rehab (in spite of strong medications) and despite encouragement from the professionals who worked with him, was in denial about his whole situation.



Ron Yatich

Then with only three days warning, Ron was notified of his impending discharge, for which he had made no preparations. It shook him up. “I realized I had a choice to make of either being lost into a really deep depression, with my life adrift, or of again looking for the positives and being involved in the decisions that affect me,” Ron said. “A lesson from hang-gliding, is: ‘you are the pilot in charge of your life.’ It was an obvious choice.”

Ron now resides in the Tendercare Traverse City nursing home. He has developed good relationships with the staff people there; they are his friends. And he reports that his chronic pain problems have been greatly reduced in recent months. He has a computer that is set up with “Dragon NaturallySpeaking” software, which facilitates its use. Ron invites others to correspond with him via email; his address is: hg.pilot@att.net.

Ron also has a power chair and a converted minivan, and with the driving help of a dozen of his many friends, he makes frequent trips out and about in the area. Traverse City is not far from Gaylord, Michigan, where one of his two sons (and daughter-in-law) live. They come over on Sundays and all go to service at the Unitarian Universalist Congregation of Traverse City.

Shortly after moving to Traverse City in 1999, Ron, who grew up in a secular family but had gradually developed his own understanding of religion, found himself wanting to join a congregation. The UU church welcomed him.

The congregation’s activities in educating their children has provided a way for Ron to continue his work with young adolescents. Their OWL (Our Whole Lives) program, in a small group seminar format, discusses not only human sexuality but also interpersonal relationships, healthy choices and dealing with peer pressures during these important early years.

“I love working with the kids,” Ron says.



AACIL Corner (www.aacil.org)

by Tom Hoatlin, SCI Support Program Manager & Director of Development

734 971-0277 ext. 18, thoatlin@aacil.org.

(SCI Resource Group: Mike Bell, 734 971-0277 ext. 21)

SCI Resource Group at AACIL Evaluates Local Recreation Center

By Tom Hoatlin

The AACIL has a new activity-based resource group for people with spinal cord injuries that meets periodically, usually at the AACIL. This diverse group of individuals with varying levels of SCI has focused on topics and activities such as adaptive sports, new technologies, medical equipment, medical research, community events, and peer support by sharing life experiences and information with each other. This is a participant-driven program, and ideas from participants on activities that interest them are welcomed and encouraged.

In February 2008, the group visited Washtenaw County's Mary Lou Murray Recreation Center for a tour and a look at its accessible features. Each participant had the opportunity to try out the accessible, multi-station

weight machine, the NuStep exerciser, and the fully accessible locker room.

This Rec Center also has a four-lane wheelchair-accessible swimming pool with a ramp, a single-user locker room with changing bench and roll-in shower, a hand-pedaled exercise unit for people with little to no leg movement, and a two-lane walk/run/roll indoor track. The Center also has cardio training equipment, including stationary bikes, stepper units, rowers, treadmills, and cross trainers, and it features two full multi-sport courts. Annual memberships and daily passes are available and affordable. People with disabilities who live or work in Ann Arbor receive a generous discount.

Ann Arbor CIL gets New Building

by Tom Hoatlin

After leasing space in a shopping mall for over 30 years, the Ann Arbor Center for Independent Living made a move that realized its founder's dream: for the CIL to have "a home of our own!" In early August of 2007, the Ann Arbor CIL made a down payment on a single story, 16,000 square foot building on two acres of land located at 3941 Research Park Drive.

In December 2007, after some minor renovations to enhance accessibility, the organization moved into its new home and what is now known as the "Gathering Place." The building will serve as a meeting grounds where peer support and advocacy flourish, where people with disabilities rally for change, convene to do business, and relax with food, entertainment, and recreation.

With over 3,500 square feet of meeting and education space, the Ann Arbor CIL can now pursue opportunities to collaborate with more community partners.



Architect's Rendering of New Building Concept

Three non-profit organizations with complementary missions already have office space at the CIL.

Jim Magyar, President and CEO, said: "Even before our renovations that will allow more versatile gathering space, we hosted our Gala & Benefit Auction for over 130 people – and it was a huge success."

The Ann Arbor CIL also has plans to launch its *Gathering Place Capital Campaign* to pay off the mortgage and renovate the existing building to become a model of workplace accessibility.

Model System Advisory Council Makes Important Contributions

By Denise Tate, PhD

Advisory Council's New Chair

A warm welcome to our new Chair, Tom Hoatlin! He is a longtime Advisory Council member and valued contributor. Tom also serves as both Spinal Cord Injury Support Program Manager and Director of Development for the Ann Arbor Center for Independent Living.

Remembering David Kurnit

Dr. David Kurnit, MD, PhD, who was a member of our advisory council, passed away in January, 2008. He was a Professor of Pediatrics and Human Genetics at the University of Michigan Medical School.

He will be missed for his keen, and at times humorous observations during our advisory council meetings.

Dr. Kurnit will be remembered for his special concern regarding the lives of people with SCI, advocacy role for persons with disabilities in our Medical School, and his work as a researcher and mentor.

In Memory of Don Anderson

Don Anderson served as chair of the Advisory Council for the U-M Model SCI Care System for several years. We chose him because he, more than anyone else, could clearly voice the needs of persons with SCI. He was the man to make things happen—a visionary and a leader. Sadly, he passed away in December of 2007.



Don sustained a C-5 tetraplegic injury in a diving accident at age 14 and went on to graduate from Michigan State University with both his Bachelor's and Master's degrees. His life's passion was working for the full inclusion of people with disabilities in all aspects of society. His career was dedicated to ensuring access to higher education for people with disabilities, and he served as Director of Access Services for Eastern Michigan University. He was devoted to improving the lives of persons with disabilities. He will be sorely missed.

Research Update: 2 Clinical Trials Focus on Depression

By Kathie Albright, PhD

1: Preventing Depression After SCI: an Inpatient Study

From other research, we know that extraordinary stress can place people at risk of developing depression. We also know that the first year after SCI is often a very stressful time for patients: many new problems need to be solved and major adjustments need to be made in relation to life changes.

We would like to learn more about how to prevent an episode of major depression from developing during the first year after SCI, so we designed a study to test whether an anti-depressant medication may help prevent newly injured patients from developing an incapacitating (major) depression and pain. SCI inpatients who do not have severe symptoms will be invited to participate in this study and will be followed for a year.

At the end of this study, we hope to determine whether starting this anti-depressant soon after an SCI helps to prevent worsening depression and in managing pain.

2: Treating Depression after SCI: an Outpatient Study

This is a national multiple-site clinical trial to look at how well an antidepressant works in treating serious symptoms of depression and pain in people with SCI.

It has been estimated that one out of five people with SCI report problems with sleep, poor energy, low mood, loss of interest, and appetite changes. Antidepressant medications are designed to rebalance brain chemistry and improve these basic biological functions. Despite widespread use of antidepressants, they have never been studied in people with SCI.

Initially, we will invite people into the study whose SCI occurred at least one year ago and who have some symptoms of depression and pain. Later, it may be expanded to reach out to people with more recent injuries.

Participants will receive a 12-week course of either the study drug or a placebo. Those who receive the placebo and still have symptoms at the end of the trial will be offered free treatment with the study trial.



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The **University of Michigan Model Spinal Cord Injury Care System** publishes SCI access bi-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 #H133N060032). It is one of 14 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.

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Editors: Eric A. Appleberry, Linda Spencer

We hope you enjoy this publication. You may request removal from the mailing list or report a change of address by calling 734.763.0971

This newsletter may be accessed in two alternate formats: audiotape and large print. To request these versions, please call or write our office.

A Chance to Help Others with SCI...

With great respect, we at the UM Model SCI Care System would like to offer you the opportunity to share *your* experience of SCI and how you managed to cope with the massive changes that followed.

For people with new injuries, or those struggling with adjustment, seeing that there can be an active, productive, happy life after SCI is very important, and *your* story may be just the one they need to hear.

Here's your chance to inspire someone, to give hope in a time of need!

If you have a story to share, but need a scribe or would like help with the writing, we are happy to help you share your story!

Please call us or email our office:

(734)763-0971

model_sci@umich.edu

From Our Online Survey: Some of Your Thoughts So Far...

From a man aged 41-50 with SCI who would like to see more articles about people living with SCI:

Sometimes we focus on research and forget that people have to live for the moment. Issues that focus on improvements in "quality of life" are important.

From a woman aged 41-50 with SCI who would like to see more general information about SCI:

Include a Topic Corner that addresses issues and provides resources and insight from a person of competency (researcher or person with SCI). Topic ideas — dating, caregiver support and options, intro to different areas of importance.

Go Online and Tell Us What You Think

We would like to know more about our readers and which newsletter features they find most valuable. This will help us design a better newsletter, and it only takes about 10 minutes. Click "Take the Survey" at:

<http://www.med.umich.edu/pmr/modelsci>

If you do not use a computer, we can mail you a survey. Please call us at (734) 763-0971.