SCI: the Challenge of Staying Healthy

By Eric A. Appleberry, DDS, MS

A spinal cord injury (SCI) is a major hit, not only to the physical body of a person, but to the psyche as well. Yes, a person now usually lives, but afterwards, even with optimal healing (as of now), permanent, life altering damage remains. Yes, SCI care has evolved numerous compensating strategies to preserve the body tissues, organs and systems, but, it is a real task to consistently follow through on all of them.

How well an SCIer compensates for the SCI changes, however, has a huge effect on how his/her life will go. See the article on Rosanne Bloomer (page 3), as an example of someone who is doing well. In contrast, we all know how an “out of control” pressure sore can put you in bed for many weeks—or even lead to your demise.

Some of the adaptation needs are of an immediate, daily importance (e.g., cathing to void urine) while for others it may be important for the multi-year effect (e.g., regular exercise to preserve cardio-vascular-respiratory health and calorie burning muscle metabolism). They are all relevant.

This article provides a list of many “should/ought to” do things in SCI life (not a complete list, which will vary with injury level). Subsequently, we will go into the list in more depth to discuss the reasons for the recommendations, especially for those items where SCIers are not so compliant. A partial list (roughly, missing things):

Bladder management: fluids; keep flushed;
Medication for neurogenic or “overactive” bladder;
Cath regularly so don’t overfill bladder.
Bowel program: every 1-3 days.
Seating: air cell cushions; pressure lifts; bed surface.
Skin inspection for pressure sores: regularly.

[Regarding what I say: because of the great variability in people, you may have a situation whereby my recommendation would not specifically apply to you; consult your physician about your situation—EAA.]

Aerobic exercise: 3X/week; resistance (wts.): 2X/week.
NO tobacco use; moderate (at most) alcohol use.
Knowledgeable/healthy eating regimen.
Health professions; regular care & timely care of illnesses.
regarding medical visits, see Ask the Doctor, page 6)
Meaningful activities/work.
Adequate sleep and relaxation time with family, others.
Keep updated on SCI care & in touch with SCI community. (series to be continued)

Dr. Tony Chiodo, left, and Carl (Pete) Hypio, President of the Indian River Chapter, Fraternal Order of Eagles, at the presentation of a $10,000 donation to the U-M Model SCI Care System. See story on page 2.

Adjustment to SCI & Making the Most of One’s Resources
Presented by Gary Karp
October 22, 2007 at 3:15 p.m.
PM&R Gym, 1st Floor, U-M Hospital
Karp, a well recognized writer and speaker who had an SCI at age 18, incorporates juggling into his talks.
Sponsored by the Christopher & Dana Reeve Foundation
For more information call Mary Burton at 734-936-9334
What You Should Know About SCI Clinical Trials

By Denise Tate, PhD

Although there is currently no cure for SCI, great advances are being made in the science of spinal cord repair and treatments that will improve function after SCI. These treatments are starting to move from the laboratory to the clinics. The only way to scientifically determine the merits of a treatment is by clinical trials. This is important not only to inform you if a treatment is really working and worth the money, but also to ensure your safety when undergoing these experimental treatments. No one wants a person to be harmed by any treatments.

At the 2007 American Spinal Injury Association (ASIA) meeting in Tampa, Florida, my colleagues and I had the opportunity to attend an excellent presentation on issues about current SCI clinical trials. The presentation, made by John Steeves, from the University of British Columbia, highlighted concerns about both past and present trials.

Past trials investigated the use of particular substances to protect/prevent spinal cord nerves from deterioration after an SCI, other substances to improve the function of spinal cord nerves that had been spared after an SCI and rehabilitation strategies for improving the walking function of people with chronic incomplete SCI.

What have we learned from these past trials? One important result is data regarding the degree to which spontaneous recovery can occur after SCI. While some therapies are still being investigated as treatment options, most experimental treatment trials did not show clinical benefits, and therefore do not meet FDA regulatory criteria as viable treatments for SCI. Moreover, result irregularities from experimental animal studies suggest that these treatments might not even have been clinically appropriate for humans. Treatments that raise patient expectations far above the likely result can cause disappointment and perhaps, destroyed hope.

Although these previous clinical trials did not provide the “cure” that we were/are all looking for, they did give us a “no” answer on what were at one point thought to be promising avenues of pursuit. This is progress. We can now move on to investigate newer approaches.

It is good to remember that all clinical “cure” research projects on patients with SCI are plagued with two chronic problems that distort results.

One problem, called the “placebo effect” is that, being in a treatment study may strengthen one’s beliefs and hopes resulting in some form of improvement or perception of improvement. The other problem is that immediately after SCI most people will show some “spontaneous recovery” even without treatment. This is especially true for those with incomplete SCI, particularly during the first three months after injury. These two issues make it difficult to determine if a “treatment effect” is due to the treatment being tested or due to one of these other factors, especially if the treatment is given soon after the SCI.

The scientific rigor of well-designed clinical trials, of adequate length in follow-up time to get past any temporary effects, is the only way to negate these two major problems in assessing the results of SCI treatments, and the only reliable pathway to an eventual cure.

For more information on clinical trials, search www.clinicaltrials.gov, which has a list of all registered current trials for SCI. Other resources include the ASIA website, where you can read about the 2007 meeting (www.asiaspinalinjury.org/annualMeeting/2007info.php) and the International Campaign for Cures of Spinal Cord Injury Paralysis (ICCP) at www.campaignforcure.org.

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**Current Clinical Research Trial Programs for SCI:**

Transplantation of activated macrophages for neuroprotective/regenerative therapy for acute SCI (Phase 2, USA/Israel).

Bone marrow cell infusion, chronic SCI (Phase 2, Brazil).

Minocycline as neuroprotective therapy for acute SCI (Phase 1, Canada).

Rho inhibitor as neuroprotective/regenerative therapy for acute SCI (Phase 1, Canada/USA).

Transplantation of olfactory cells from nasal mucosa for chronic SCI (Phase 1, Australia).

NOGO antibody as a regenerative/plasticity therapy for acute SCI (Phase 1, Switzerland/Germany).

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**Eagles Donate $10,000 to U-M Model SCI Care System**

On June 15th, the Indian River Chapter of the Fraternal Order of the Eagles (FOE) donated $10,000 to the U-M Model SCI Care System. Co-Directors Dr. Tony Chiodo and Denise Tate PhD accepted the generous check. The funds allow the purchase of educational materials, such as the Spinal Network, a valuable resource book which is given to new SCI patients at the University of Michigan Health System. The U-M Model System cannot use its federally-provided funds for educational materials.

Founded in 1898, and with chapters in nearly every community across the United States and Canada, the FOE is a charitable organization that has raised over $10 million for many causes, including the needs of children and elderly people, heart, kidney and diabetes medical research. The Indian River chapter, which has generously given to the U-M Model SCI Care System since the mid-1990s, is headed by President Carl (Pete) Hypio.
Rosanne Bloomer

Still on the Job — in Spite of an SCI for the Last 15 Years

By Eric A. Appleberry, DDS, MS

Rosanne Bloomer is one busy lady. She is the Senior Financial Service Officer for the Washtenaw/Wayne County office of Greenstone Farm Credit Services, part of a national cooperative offering mortgage credit services for farm operations and land investment. She is also on the Washtenaw County Land Trust Board, the Washtenaw County Agricultural Advisory Board, and FSEP, an organization of five southeast Michigan counties that promotes utilization of local foods and local agricultural development. She knows just about every area farmer, and is herself a farmer.

In her “spare time,” Rosanne helps Tom, her husband of 29 years, work their 160-acre Bur Oaks Farm in nearby Webster Township, where they produce food-grade soybeans and gourmet red popcorn. She also raises and freezes her own garden vegetables, tends flowerbeds, mows the lawn and drives a tractor.

Rosanne, 56, sure doesn’t fit the old stereotype of a “disabled wheelchair person,” but she is a paraplegic with a complete, T-11 SCI. On a snowy day in January of 1992, she slipped and fell while climbing up an outside ladder to the 3rd floor of their large barn. She landed on her back on the frame of a tractor below. Tom couldn’t hear her calling for help, but after about 20 minutes with no sound of the tractor running, he came to see if there was a problem. Rosanne was airlifted to the University of Michigan Hospital and underwent surgery two days later.

In six weeks, Rosanne completed initial rehabilitation and was out of the hospital. A week later, she returned to work part-time. Two weeks later, she began working full time. Because she had been with Greenstone for sixteen years and knew the business so well, “They were very anxious to get me back,” she recalls.

Rosanne first began working at Greenstone in 1976, after getting a Bachelor’s degree in business and doing some graduate work in agricultural economics at Michigan State University. She grew up working with her family on a large farm, and loves farming and farm-related endeavors. With this background, she had become a valuable employee and a vital member of the area’s agricultural community. “The customers all wanted me back too,” she says. “I felt really appreciated by everyone, and this helped me a lot in adjusting to my new situation.”

When she first returned to work, “The place wasn’t wheelchair accessible, so in the morning the other employees carried me in, and in the afternoon they carried me back out.” However, with determination and ingenuity, the organization soon installed an elevator, giving her independent access.

“But it wasn’t all easy. There was a period I had to go through, with times when I would get angry and wonder: ‘Why did this happen to me?’ But... things like this happen on a farm. You just have to move on and do the best you can. I truly admire people who stand up and get going again after a tragedy in their lives. I want to be like that too. Actually, I am very lucky; my injury wasn’t as severe as some peoples-I still have use of my hands and arms.”

As a T11, she also has use of her “trunk” muscles for activities requiring upper body balance-such as driving the hand-controlled mower and tractor on the farm, and getting in and out of her vehicle. The driver’s seat of her SUV is considerably higher than her wheelchair seat, but Rosanne can “pop” herself up into the seat without a transfer board, then reach down to take apart her rigid-frame chair and pull the pieces inside-all in under three minutes. It is poetry in motion.

Although the low level of her injury helps, Rosanne maximizes her physical capabilities by working hard to stay fit. She had always tried to eat healthily and be physically active, and her accident didn’t change that. “I used to be a runner. After my injury, I started using a hand crank exercise bike with which, using my arms, I could also ‘bicycle move’ my strapped-in feet and legs. Now, I use an (RTI brand) ‘FES’ bike three times a week.” The bike’s computer-controlled Functional Electrode Stimulation works her leg muscles against precise levels of pedal resistance (which can be increased over time). “My breathing and heart rates go up; I get a good workout and my legs have gotten much stronger.”

But in the end, it’s not just physical skills and fitness that make Rosanne a success; it’s also her determination to carry on with her life and to contribute as she always has to the local farming community. Greenstone and the area’s farmers are fortunate to be served by someone as knowledgeable and dedicated as Rosanne Bloomer.
SCI: A Story, and a Tribute to Our Health Care

By Eric A. Appleberry, DDS, MS

“What’s your injury level? What happened? Did the EMT people get there quickly? Aren’t they great?

I’m a T-5, complete. My accident was a ladder fall when I was fatigued, at the end of the day and trying to get a job done at home. Somebody happened to see me fall so a 911 call got in right away. I also have the good fortune to live pretty close to St. Joseph Mercy Hospital. But it was nip and tuck even so; besides the broken back, I had many broken ribs which collapsed both my lungs; and, my right kidney artery was torn and bleeding me out.

I don’t have much memory of that night, but my wife says what I was really worried about was whether or not somebody had put away my John Deere tractor.”

If you have an SCI you’ve had conversations like this when meeting another SCIer for the first time. We compare notes, recognize having had some good luck and find humor in what we know were grim situations.

Yes, grim, and it doesn’t always stop with the initial accident situation. A couple of weeks after mine I had a blood clot break loose and go to my lungs (a pulmonary embolism), which caused a minor heart attack.

I almost didn’t make it, again, but gratefully, I did.

It took a couple months of healing before I was able to start my rehabilitation work, for which I transferred to the University of Michigan Hospital. The wonderful Model SCI Care System physicians, nurses and therapists have great rehab experience in both caring for and teaching the SCI patients how to take care of their own bodies.

Another benefit of the U-M Model SCI Care System is that it is co-directed by a psychologist. When one’s life is suddenly turned upside down by SCI, there is a significant risk for post-injury depression. I got a taste of this, when, after being/living in a hospital for 3+ months, I got a pass to go home Thanksgiving Day and Friday. All my family came for the occasion, and it was great seeing them. But also, “in my face,” were all the things at home I could not now do. I got “kind of blue,” as the saying goes, that weekend, and was glad to have the psychologist stop by to chat and reassure me that actually I was doing well.

So, I would now like to sing some high praises for our health care system, talk a bit about staying healthy to get some distance out of all the help that was given me and consider the residual effect on my worldview.

It really is a fortunate time and place in history that we live. It wasn’t that long ago a spinal cord injury was, if not right away, soon a death sentence. But now, the majority of people with SCI can get back to a productive and reasonably independent lives. I have a friend who’s 45 years past his C-6 SCI and still teaches full time. And occasionally in disability magazines I’ve read of healthy SCIers of even longer duration.

Over time, there has been a vast amount of scientific discovery, research, technology and skills development done by many scientists and physicians to make this possible. Practically speaking, though, the actual delivery of all this is not possible without a whole host of other people in our complex health system, e.g.: the many specialized types of nurses, and therapists, pharmacists, technicians that run the many machines, administrators, clerks, ward assistants, etc., etc., etc. They are all vitally important to good patient care, from the 911 call operator to the assistant who (with pleasant greetings) empties your urine drain bag.

Once released from the hospital, there is usually more rehab work still to be done on an outpatient basis. This is a time to get compliant in your home exercise program-so you can find out where you are having problems while still having a therapist handy to help fix them.

It’s also the time to start implementing the multitude of important SCI and generally health related things to do (see article about the challenge of staying healthy with SCI, page 1). What we should be doing, I think you will agree, is mostly no secret. It’s the consistent doing of it over time that seems to be problematic.

Another extremely important part of long term SCI health is keeping up with periodic PM&R evaluations. (Please also see the “Ask the Doctor” article, page 6.) These are times when patients can bring up concerns they may have and opportunities for the physiatrist (PM&R doc) to re-evaluate known situations—and also to try to find early (but painless) signs of things that may later become big problems. Early treatment is always best and easiest.

Due to our fine health care system I have the gift of additional life. Although I indeed do miss some of my pre-SCI activities, I find there is much I can still do. And I’ve been given opportunities to perform community volunteer work which has, in turn, greatly enriched my life.

And that John Deere utility tractor I was so worried about has been modified so I can still use it.
Successful Women and Their Wheelchairs Shine on 42nd St.

GLAMOUR ROCKS . . . and . . . ROLLS at Fashion Week Event in New York City

By Cynthia Hewa

The hottest models in NYC’s Fashion Week weren’t the ones walking down the runway. They were the models rolling in — in glitzy, gilded, sparkling wheelchairs — that brought down the house with applause. In the first annual Rolling with Style Gala, women in wheelchairs were celebrated for their “style and success,” says Marilyn Hamilton, one of the four chairwomen of Discovery Through Design, the non-profit organization which orchestrated the event.

Top-name designers—St. John, Nicole Miller, Baby Phat, Thom Browne—eagerly took on the challenge of creating a high-fashion wheelchair, and matching ensemble, that highlighted the beauty and glamour of each woman.

Wendy Crawford and Julia Stockton Dorsett came up with the idea of engaging designers for a charitable event, thus, Discovery Through Design was born. Ashley Lauren Fisher and Hamilton added power to the push to get great designers. All of the women at the helm of this women-focused organization use a wheelchair.

“We want to demonstrate that women in wheelchairs are fashionable and can achieve anything through determination and perseverance,” Hamilton says. She knows first-hand the fruits of determination after a hang-gliding accident left her a paraplegic. Hamilton co-founded Quickie Wheelchairs using hang-gliding materials.

Lesley Stahl of “60 Minutes” emceed the black-tie event, held in February 2007, at the elegant Cipriani Restaurant at 42nd Street. Guests included Ms. Zuleyka Rivera, Miss Universe 2006, Dr. Ruth and supermodels Kim Alexis and Carol Alt. Nearly $1 million was raised for spinal cord research.

Finding inspiration was easy. The four “roll” models, all chosen for their active and admirable lives in a nationwide competition, have amazing life stories.

Jenny Smith, wearing a silk dress with big red roses on black, by designer Zang Toi, blossomed in her new role as a runway model. Her chair was covered in the same fabric. Before her accident at age 16, Smith was an accomplished gymnast. A practice tumble on wet grass landed her in a wheelchair. Now, still very active in many sports and numerous projects, Smith works for The Mobility Project, which distributes wheelchairs in Mexico, Costa Rica and Afghanistan.

“A wheelchair may accompany me on my adventures, but it does not determine my future,” says Smith. “I continue to push the limits because I have the freedom of mobility that allows me to.”

Michelle Boardman, born with multiple heart defects and diagnosed with multiple sclerosis at age 16, has achieved outstanding academic success. She is now planning a career in pediatric genetic counseling. Designer Kimora Lee Simmons of Baby Phat dressed Boardman in a sexy pencil skirt, ruffled V-neck top and black stiletto heels, and covered her chair in an animal print and pink crystals. “The impression I leave with people is very important to me,” says Boardman. “I try to create an image that’s simple, sexy and classic.”

Designer Doris Wishmyer of St. John reached for the gold with her design for Rosemary Rossetti, PhD, and created a masterpiece. The chain that circles the hand rims of Rossetti’s chair and the buttons on her chic couture jacket were dipped in 24-karat gold. Says Rossetti, who was paralyzed when a 3-1/2 ton tree crushed her during a bicycle ride, “Looking your best is important in the business world.” She should know. Rossetti is an internationally known speaker, an award-winning businesswoman and a syndicated columnist.

Finally, roll model Melissa Holley awed the crowd in a black velvet gown by designer Marc Bouwer. Bold crystal brooches studded her gown as well as her wheel hubs. “Style and fashion are just one way I express my personality and self-confidence as a capable and beautiful woman,” states Holley. After one year of college, a traffic accident left Holley a paraplegic. Choosing hope, Holley volunteered for the first experimental macrophage spinal cord procedure in Israel and still advocates for spinal cord research.

Perhaps the most thunderous applause was for U.S. Army SFC Diane Cochran, who received the “Rolling with Style” award. Cochran is a military leader who was injured in Afghanistan and is the mother of a soldier fighting in Iraq. She represented the accomplishments of not only women with SCI, but all women who serve.

For more information, visit discoverythroughdesign.org and themobilityproject.org.
Ask the Doctor

Why are Regular Medical Visits So Important for People with SCI?

By Gianna Rodriguez, MD

To maximize health, fitness and well-being, it is vital for people with SCI to have regular follow-up visits with a physician trained in SCI care. The early identification of problems usually can prevent future complications. Visits should occur about every three to four months in the first year after injury, and once a year after that. The specifics of each person’s visit will vary, depending on their needs.

A follow-up visit usually includes a review of your medical history, a general physical exam and an SCI-specific exam, blood tests and other lab evaluations. X-rays of the abdomen and chest may be taken, too.

Your physician may discuss the amount of physical activity you are getting. It is very important for people with SCI to be active to maintain fitness, flexibility, strength and endurance. Activity also helps avoid a tendency to gain weight. Since fewer calories are burned after an injury, people must stay active and/or eat fewer calories to avoid this problem. Weight gain and increased cholesterol/fats in the blood can lead to serious health problems such as Type II diabetes, coronary artery disease (blockages in the arteries) and stroke. Nutrition counseling may be needed to avoid foods that are high in calories but poor in nutrients.

Heart and lung system concerns include autonomic dysreflexia (AD), high or low blood pressure, coronary artery disease, irregular heart rhythms, pneumonia, and declines in lung function.

Urinary system screening includes checking for possible infections, kidney disease, stones or masses, and uncontrolled bladder pressures. Bowel function should be reviewed to determine if you have regular, predictable stools, and not any problems such as bowel obstructions.

If you have muscle/bone and/or nerve pain, or excessive spasticity problems, which can also cause pain and joint deformities, medication adjustments may reduce the problem and maximize your functioning. To stay as active and functional as possible, also be sure to discuss any home equipment needs or social concerns you may have.

The skin should be examined closely for infections, which can easily lead to pressure sores and bone infections. Any seating and posture problems should be corrected early to prevent pressure sores and spine deformities.

People with SCI have the potential of developing secondary health problems related to their injury. These range in severity from being merely annoying to life-threatening. Regular visits and a good relationship with a health provider can make a huge difference in your well-being. Having a disability is not synonymous with being unhealthy, but controlling and preventing SCI-related illnesses must be a priority so that you can continue to have an active lifestyle for many years to come.

Relationships, Adjustments & SCI

By Abby Howard, PhD

Adjustment challenges occur in all areas of a person’s life after an SCI but one of the most difficult may be personal relationships. Despite mutual concerns about how to relate to each other, the person with SCI is the one who needs to take the lead in getting relationship communications started (or restarted).

People take cues from the willingness of the person with SCI to interact. So, be open with others; create opportunities to discuss what’s changed and what is still the same.

Relationships, whether with family, friends or a romantic partner, always require a lot of work, attention, and care. And this needs to start with you.

First, take a look inside and be honest with yourself. What are your hopes and expectations within a relationship? Talk with the other individual(s) involved in the relationship and clarify this with them.

Don’t assume you’re on the same page as others, or that someone knows what you want, or how you feel, and vice versa. Clearly explain your thoughts and feelings, openly and honestly, and ask them to respond in kind.

Most importantly, listen to what others are telling you. Relationships don’t work well unless each participant listens as well as talks. Listen with an open mind, rather than one that’s already made up. Don’t plan what you want to say while the other person is talking.

If something isn’t clear to you, then ask for clarification. This can help you avoid the pitfalls associated with assumptions and misunderstandings.

Finally, make relationships a priority. Commit to putting in the time and effort necessary to making them a success.

If you’re not willing to, why should anyone else be?

If this is difficult for you, you’re not alone. Communication and relationships are difficult for most people, whether they have had an SCI or not.

Also, it may be beneficial for you to consider additional assistance in the form of counseling, whether individually or with family, friends, or significant others. Counseling can help with the identification and expression of issues that you have, individually, or within a relationship.
How Do You Accomplish Successful Advocacy?

By Carolyn L. Grawi, MSW, LMSW, ACSW

“A small group of thoughtful people can change the world. Indeed, it's the only thing that ever has.”

—Margaret Mead

Ad·vo·ca·cy (ādˈva-ka-sē) n. Webster’s Dictionary defines advocacy as “the process of actively speaking out, writing in favor of, supporting, and/or acting on behalf of oneself, another person, or a cause.”

This article will cover some basic points about making your efforts to influence change in your community more successful. The example used in this article concerns change at the legislative level, which can be done in Lansing, in Washington, DC, or in your local district with your legislator. You can use these same skills to afford change at the city, township or county level with your mayor, city council, or commissioners.

The following ten considerations can make a world of difference when working to improve a system:

• **Know the Players.** Who are your representatives, what are their committee assignments, what are their professional and personal backgrounds?

• **Start Early.** Contact the appropriate parties with your concerns as soon as possible. The elected officials are working for you, the public, so do not hesitate to bring your concerns forward.

• **Be Informed.** Study the facts and the supporting and opposing arguments before meeting with public officials to advocate a position. This allows you to be proactive in asking, explaining and answering others’ questions.

• **Be Specific and Concise.** Keep the message simple and focused on what you are asking the legislator or staff person to do.

• **Be Truthful.** Make a good case, but don’t exaggerate. Never give inaccurate information. When in doubt, offer to get back to the legislator with follow-up information.

• **Listen Carefully to What the Legislator Says.** It’s important to know what he/she is thinking or requesting. Be patient; ask about their specific concerns and how you can help.

• **Retain a Good Working Relationship with the Legislator Regardless of the Outcome on a Particular Issue.** Be friendly and willing to contact legislators not only when you need their assistance but to stay informed and to inform them.

• **Be a Resource.** Remember that due to term limits and limited staff resources, legislators are relying more and more on constituents, organizations, lobbyists, and others to educate them. The least effective people are those who go to their legislator with a negative or attacking style.

• **Challenge the Issue, Not the Person.** Recognize that there are legitimate differences of opinion. When you offer criticisms, also offer alternatives and solutions.

• **Commmend Positive Efforts of Your Legislator.** They get requests daily for assistance and action, but few people remember to thank them for their work.

Good luck with obtaining the changes you are seeking. If you need further assistance with these skills, feel free to contact Carolyn Grawi at the Ann Arbor Center for Independent Living at 734-971-0277, ext. 47 or by email at: cgrawi@aacil.org.

You may also have a center for independent living in your community. Here is a web link for the partners in our Disability Network, Michigan’s Centers for Independent Living: http://www.dnmichigan.org/contacts/default.aspx

Recognition of Participants in U-M Model SCI Care System’s 22 Years of Research Projects

By Martin B. Forchheimer

The U-M Model SCI Care System has existed for 22 years. Of the 14 current Model Systems, only five are older than ours. The primary reason for our longevity has been the involvement in our research by you, the project’s participants. One of our most important research activities has been helping to develop a nationwide description of the nature of life with SCI as well as how this has changed over time.

We have conducted numerous other projects too. Together with the Ann Arbor Center for Independent Living, we helped develop a program to assist people with new injuries to more easily return to their communities. Then, we evaluated the effectiveness of this program. Other projects have been on topics ranging from employment and community involvement to medical complications, physical fitness and the specific needs of people who use ventilators.

The results of our work have been used in developing better services for those with SCI. Project results have also been useful in educating researchers, clinicians, people with SCI, and those close to them. This has been accomplished through papers that we write for scholarly journals and consumer publications, as well as through numerous presentations. We appreciate the time you have spent participating in our Model System’s activities and surveys. We want you to know that you are making a big difference in the understanding of life with SCI.
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, Mary Burton, Shonnie Becker and Martin B. Forchheimer.

We hope you enjoy this publication. To request removal from the mailing list or report a change of address, call 734.763.0971.

When Is Spasticity Good?
By Ashraf Gorgey, PT, PhD

We all know about the negative effects of spasticity on people with SCI; it can limit a person’s range of motion, interfere with transfers and even lead to joint deformities and bed sores. But did you know spasticity may have an upside, too?

The positive effects of spasticity had never been studied until Ashraf Gorgey, PhD, a post-doctoral fellow at U-M, and Dr. Anthony Chiodo, Associate Professor in the Department of Physical Medicine and Rehabilitation (PM&R), joined forces.

Working at the new PM&R Human Performance Laboratory in Ann Arbor, the investigators evaluated 15 people with a history of SCI and muscle spasticity for evidence of “metabolic syndrome”—and what effect anti-spasticity medication may have.

Following an SCI, a host of body changes soon start to occur, including the atrophy of muscles that are paralyzed/not being actively used. Loss of the metabolic activity of these muscles is likely a factor in the body’s metabolic shifts that starts within just a few weeks.

These changes in metabolism can include what is called “metabolic syndrome,” characterized by one or more of the following: increased abdominal fat, high blood pressure, high glucose (blood sugar), increased cholesterol and lipids (fats). These traits increase one’s risk for developing Type II diabetes and cardiovascular disease, which can lead to additional health problems and a reduced ability to carry out routine tasks and activities.

Preliminary findings suggest that spasticity, which is a very intense activity of the muscles, can be good news; it may have a positive effect in preventing muscle loss and can defend against an increase in fat mass and deterioration in metabolic profile after SCI. These findings will soon be presented at an American Academy of PM&R meeting in Boston.

Tell Us What You Think
We would like to know more about our readers and which SCI Access Newsletter features they find most valuable. This information will enable our staff to design a better newsletter. If you have internet access, please go to the survey posted at “Survey Monkey”. The web address is: www.surveymonkey.com/s.aspx?sm=ahzWYp3ezYI5cNxM_2bC_2bjCw_3d_3d.

We apologize for the long, complicated address. This brief survey should take about ten minutes.

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

Thank you in advance for giving us your opinion.