We at the University of Michigan Model SCI Care System dedicate this newsletter issue to celebrate the life of Julie Harrison. She has touched the lives of many of us. Julie worked at our office as a part-time Research Assistant for just a few weeks before her death in November 2005. But for a few years now she has been contributing as a writer to our articles written by persons with SCI, and reviewing books about community-based resources and disability. Her reviews have been published by prior newsletter issues including this one. As a woman with SCI, Julie also worked for three years as a Research Assistant and research subject in our field initiated project funded by the National Institute on Disability and Rehabilitation Research, on issues of coping with stress among women with SCI. She served as a mentor to many other young women with disabilities but especially SCI. Like so many others who were drawn to Julie by her charm, courage, and warmth, we feel privileged to have known her as a colleague, worker, and friend. Many of us had the pleasure to also have known her parents, family and friends. Their memories of her confirm our own views of her as a talented, creative, delightful, determined, and loving person who inspired so many others as well.

The staff and faculty of the UM Model SCI Care System join me in extending our sympathy to all who knew her through personal experience, her art and her writing. A special fund has been established in her honor to fund research on women with SCI and depression.

Contributions can be made through our website or by calling our office. We thank her parents for this gift of love in her memory.

Denise G. Tate,
Co-Director, UM Model SCI Care System

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Celebrating the Life of Julie Harrison

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

Charles and Carla Beatty live in Ypsilanti Township. Both are educators. Charles has recently retired from guidance counseling in the Ypsilanti schools. After his spinal cord injury in 1991 from a motor vehicle accident, he struggled to return to his profession, successfully counseling troubled and at-risk students for many years to follow. The Beattys warmly opened up their home for an interview with Marcy Epstein.

Epstein: When did stem cell research come to your attention as a survivor of SCI?

Beatty: I have survived two spinal cord injuries, both resulting in paralysis from the neck down. (The first time) I had just won my second state championship in wrestling and was attending Michigan State University on a full scholarship. As a freshman in 1964, I was practicing with a teammate and dislocated my third and fourth cervical vertebrae paralyzing me from the neck down. After a successful cervical fusion, I was walking within three months. I was a student again with no signs of ever being paralyzed.

Twenty seven years later, November 2, 1991, I had an automobile accident which left me paralyzed again from the neck down. However, my injuries were more serious this time (C2 incomplete). I was a quadriplegic and vent dependent! There would be no medical intervention that could help me overcome my paralysis. My doctors left things to heal on their own. I began looking for alternatives. Five years later, Christopher Reeve had his injury. Suddenly, there is news about a new procedure that has the possibility of curing paralysis: Stem Cell Research.

Epstein: (to Mrs. Beatty) How do you feel about Charles’ paralysis and his interest in a cure?

Mrs. Beatty: I think he’s handled his paralysis very well. He enjoys his independence. If there is anything that he can do without assistance he does it and resents any help. He also has a problem with those ignorant of SCI.

Beatty: Checking in at a doctor’s appointment, the receptionist (who should know better) looked over at me and proceeded to ask my attendant “What is the patient’s name?” Then she asked my attendant, “How did he get this way?” By this time I was very upset and I told her that I may be physically challenged, but I’m not brain dead. I can answer all your questions, just talk to me.

Epstein: Why should the average SCI consumer stay abreast of advances in stem cell research?

Beatty: My feelings are that it keeps up a positive feeling, a hope that there is knowledge, information, and technology available to us that can help us, even help us overcome our paralysis, our sicknesses, our problems. Still there are scientists interested in making a difference in our lives. Just because we can’t do certain things, we still can’t shelter ourselves. We’re still alive! If I can read about stem cell research, and there’s all this research being done for you, the least you can do is read up on it, be knowledgeable enough to talk about it. The more you know about something, the more optimistic you will become.

Epstein: Why so?

Beatty: Because there’s always hope. I knew when I got injured that I would at some point be able to do half of what I could do before, whether it’s get a fly off my nose or go places without someone to help me cath.

Epstein: So do you see yourself as a “collector of hope” for people with SCI?

Beatty: I certainly do. Talk to other disabled people, and talk to others. Let them know you would like to do things for yourself, maybe walk again. I feel very confident that there will soon be a breakthrough in curing paralysis. We need to give ourselves the whole range of motion, physical motion and emotion. Stay sound in your body so your body is always ready for whatever comes. And you can email me at cbeattyjr@aol.com.

Marcy Epstein is a Research Fellow in the Department of Physical Medicine and Rehabilitation and an English professor. Dr. Epstein is currently working on a monograph.
My Evolving Decision: To Go or Not To Go?  
By Emily Blauw

After the devastation of a spinal cord injury (SCI), most people receive an explanation of their injuries from a doctor and a brief education about the spinal cord. They are often told that the probability they will walk again is very low. Having experienced this myself, I believe this is an outdated approach. Although an SCI cannot be reversed, there are growing possibilities that new research and technologies could restore function in some people with an SCI.

Things have changed rapidly in only a few years. In 2001, I was 16 years old when I was injured with a C-6 complete injury. When I was told there was little chance that I would be able to use my hands or walk again, my mom frantically searched the Internet and found only a single web site about SCI research. And I was not eligible for that experimental procedure.

While the search for information continued, I completed 5 months of rehabilitation and slowly learned to get back to life. This was not life as I knew it before. Nevertheless, I returned to high school, graduated with my class and began college. Still, my eyes and ears remained open to news of the latest research on the track for a cure for SCI. Research into SCI has grown internationally since 2001 since my mother’s first frantic search for information.

As I learned more about the research and opportunities to participate, I faced a difficult decision that people with SCI did not face only a few years ago—to go or not to go? As you will see, for me, this decision is not fixed—and you might say that even as I write this, it continues to evolve.

In the summer of 2004, my family and I became interested in a procedure performed by Dr. Carlos Lima in Lisbon, Portugal. The olfactory ensheathing glia (OEG) stem cell transplant takes nasal tissue cells and transplants them into the spinal cord. I qualified for the procedure, and my family and I researched the surgery, even meeting with Dr. Lima himself and his surgical team at the Detroit Rehabilitation Institute of Michigan (RIM).

Making the decision to pursue this – or any other new procedure – is not an easy task. When looking at a specific procedure, one must carefully weigh the pros and cons of treatment, and sometimes pros and cons are hard to know when things are so new. I knew people who had already had this procedure and others who were on the waiting list. Honestly, I had reservations since there were no published studies on the results. Finally, I feared that if something better becomes available, I would not be qualified to benefit from it.

In the middle of this decision-making process, I attended the UM Model SCI Care System’s Spring 2005 conference, “Connection to SCI Cure: The Science, Ethics, and Politics of SCI Research” which included guest speakers who covered current research offerings for SCI and future directions. Meeting other people with SCI, their family members and health professionals was an additional advantage of the conference. I discovered a specialized physical therapy program geared toward all SCI patients, the Recovery Project (Livonia, MI), where I learned and made great gains by taking part in this unique rehabilitation program over the summer of 2005. After much deliberation and consideration, I finally decided to sign up for the procedure in Lisbon, with a surgery date in May 2006. This left me with time to graduate from college and watch others have the procedure, and leaving me the option of dropping out.

By February 2006 my decision changed. First of all, there are no published reports describing the effects of the surgery. While I have met many people who have made great gains after the surgery, I am not convinced it is because of the surgery alone. To me, the rehabilitation before and after the procedure plays a substantial role in their recovery. Personally, I have not seen significant SCI level changes in those who have undergone surgery. I continue to be involved in the Recovery Project and have built some wonderful relationships with the therapists and staff; they have encouraged me and pushed me to make great gains and I am grateful for their support. They have helped so many people who have undergone surgery and those who have not. As always, I keep my ears, eyes and mind open to research and new technologies on the horizon. And as far as my decision, we’ll see what the future brings.

Emily Blauw will graduate from Hope College in Holland, MI with a Bachelor’s degree in Psychology in spring 2006. She then plans to pursue a Master’s degree in Speech Pathology and have a career in rehabilitation working with pediatric patients.

Editor’s Note: The cost of the procedure is estimated at about 40,000 Euros or $47,883 U.S. dollars (source: personal communication). Cost of a 3-month intensive
Book Review

In author Dennis Wholey's collection of 52 inspiring testimonials, *When the Worst That Can Happen Already Has: Conquering Life's Most Difficult Times* (1992, Hyperion Press), we gain personal insight into the wide realm of what is known as the human experience. Each essay delves deeply into the heart and soul of the human psyche during a major turning point in that individual's life which acts as a catalyst for spiritual growth.

Pain and suffering will undoubtedly touch every individual at some point(s) throughout their life span. When confronting circumstances of misfortune, a choice is left for us to make: we may decide to permanently wallow in despair or we may rise to the challenges and emerge like a butterfly, lighter and more beautiful as a result of the experience.

*When the Worst That Can Happen Already Has* is an inspiring examination of the latter – essays of human stamina, discovery, and revelation. Traumatic situations such as alcoholism, years of childhood abuse and surviving the Holocaust, test the limits of what the human species can endure. These individual accounts can aid us in the spirit of discovery towards our deepest and most powerful selves. In fact, this book is a testament to the old saying, "what doesn't kill you will make you stronger."

A common theme among the contributors begins to emerge: the author’s explorations through fear, pain and darkness is what has helped them develop the acceptance, gratitude, and beauty that they so fully experience today.

Be prepared because these stories will move you to tears, to love and to life! Enjoy.

About This Author

One of Julie Harrison’s many creative gifts was her ability and desire to write. She was a frequent contributor to our SCI newsletter, producing a number of reviews on disability-related popular books. These included *From There to Here*, a book about adjusting to SCI and John Hockenberry’s *Moving Violations*. She also contributed to national consumer publications, including *New Mobility* and *Special Living*. Julie wrote of her personal experience as a woman with a disability, of changed and new friendships, of seeking mentorship as she shaped her new life after injury.

In the first of our consumer article series, “Stories of Life after Spinal Cord Injury,” Julie told of her experience in Utah’s Modoc National Forest, where she and friends camped as a part of the Rainbow Gathering of Tribes, an annual event at which people gather, live in the wilderness and pray for peace. She marveled in the beauty of the outdoors and the company of friends while still acknowledging the frustration of cathing, maneuvering a wheelchair through sand and breaking a wheel; all annoyances that most other campers avoided.

Julie put her energies towards enhancing the lives of people with spinal cord injury by embracing freedom. One of the ways she did this was to work closely with the University of Michigan School of Engineering students to design an all-terrain wheelchair – giving her and others the freedom in the outdoors which she treasured. The day after she passed away, December 1, 2005, the wheelchair she had helped to build was completed.

In perhaps the most poignant reminder of Julie’s struggle was a story her mother told, of her response to a question on a job application at the People’s Food Co-op in Ann Arbor—“If you could do one thing to change the world, what would it be?” In characteristic style, Julie answered, “teach people to love themselves.” Yet, her mother reflected, this was the one thing with which Julie struggled the most throughout her life.

In her writing, like the one above, Julie’s personal and professional interests intersected to create meaningful and insightful pieces. Although Julie is gone, we hope that her beautiful writing style, insight and words will continue to touch readers.
Julie’s Delicate Power

As one of our staff reflected, “Julie Harrison constantly reminded me of the power and frailty of humanity.” She fully recognized that she suffered from depression since high school and reached out consistently and conscientiously for professional help. But, in spite of her insistent struggle to succeed with the most advanced medical treatments, she was unable to ever successfully recover from it. To us, as an office colleague and as a Research Assistant, Julie was a powerful breath of fresh air for both our personal spirits and our professional work. Her humor and laughter were contagious. Her fiery eyes would sparkle as she whirled into the office door at work; bright white grin; sexy hippie outfit; long dark, bohemian dreadlocks. Her charisma reflected her real enthusiasm and a sincere happiness about our connectedness. She was willing to spontaneously share her thoughts and feelings with refreshing authenticity, thus making those she touched not only comfortable, but also momentarily more enlivened. Although struggling herself with depression, she is mostly remembered for her broad smiles and positive, inspirational thoughts about others and the work we were doing for women who live with a spinal cord injury. When she transparently shared her feelings about her loves or her vexations, we each grew a little ourselves.

Julie was brought up, an only child, in a loving and nurturing family environment, participating in Girls Scouts, soccer and attending the University of Michigan. She studied abroad for several months and enjoyed visiting other countries and making new friends, trying new languages. She wanted to be a massage therapist and was a firm believer in the healing benefits of alternative medicine. She moved to Boulder, Colorado to attend massage school and loved the experience. She was physically active, an enthusiastic lover of the outdoors, self-determining, sometimes even described as tough and forceful. She not only liked running and gardening but also enjoyed meditating and reading. She played the fiddle and was an accomplished writer. Julie was immersed in a variety of interests, with an outspoken passion particularly about disability and environmental issues. Employing all that she was, Julie had a natural talent for honoring and empowering others.

Julie acquired her spinal cord injury (SCI) as a result of a fall during a suicide attempt in 2001. Since becoming paraplegic, she was unabashedly courageous about achieving her life goals by incorporating her limitations as a woman living with a SCI. She continued to volunteer in the community and served as a role model for other young women and men with physical disabilities. In her process of seeking a personal mentor for living well with a disability, Julie was invited to work as a Research Assistant in our department. As part of her interconnected quest for knowledge and desire to help others, she spent most of her time working on a research study about coping with stress among women with SCI. During her last year she worked with the U-M Model SCI Care System as a dedicated writer and book reviewer. She knew herself well and could also read others’ feelings and passions. She connected to the core with the Women with SCI Study’s participants who shared their life stories about living with a disability. On more than one occasion, tears flowed down her face as she read the narrative biographies of women with SCI who experienced abuse, neglect or degradation in the midst of catastrophic physical injury. She also radiated a glow at their joyful interludes or triumphs.

The project core work ended on October 31, 2005 as did Julie’s role as a Research Assistant. She had plans to travel and start a new project on SCI in the Department. She was also recently engaged to be married. But Julie’s private fight with depression ended on November 30, 2005 with a second fall; this time fatal. Her loss has been a reverberating and lingering shock for all of us—friends and co-workers. We still mull over the hidden depths of Julie’s unspoken and penetrating pain, a pain that one family mourned as “finally over.” We knew Julie’s delicate power. For us, she was a lovely young woman...fresh, hip, bright, straightforward, artsy, and fiery—with long, shiny black hair and a smile that lit up the room. As one friend says: “I was moved by the spectrum of human lives that Julie had touched, the variety of new and old friends who testified to her warm, creative, feisty ways.” Another co-worker makes this final observation about her: “I remember Julie as...frank and genuine. It was refreshing...”
Are You Depressed These Days?  
By Denise Tate, Ph.D., ABPP

The exact connection between a spinal cord injury and the experience of depression symptoms is not completely known. However, we do know that the incidence of depression among persons with SCI can vary from 25% for men to 47% for women, both much higher than the general population rates of 10 to 20%. Most people are at greater risk of depression if they themselves or a family member have had a prior history of depression, suicidal attempts, chronic pain, concurrent substance abuse, lack of social support or many life stressors. Depressive symptoms are not always openly recognized by the person and those around him/her. Depression can be masked by other symptoms but be chronically present at a low level for long periods of time without being detected.

The Consortium of Spinal Cord Injury Medicine has proposed guidelines for treating depression among persons with SCI. They propose the following acronym to evaluate one’s symptoms of depression. The acronym SIG E CAPS (sig-ee-caps) describes the symptoms of depression in SCI.

One type of depression, SAD or Seasonal Affective Disorder, is often a mild form of depression that occurs during the winter months, typically January and February. It seems to be related to the limited exposure to daylight and affects people differently. Some people get irritable and down, others less so. The symptoms are similar to those in SIG E CAPS, but they disappear when the sun light is back again.

What can you do about depression?

If you feel depressed or are told by others especially family members that you are depressed, **seek help**. Your doctor can prescribe medications or antidepressants when appropriate, he or she can also refer you to a psychiatrist, psychologist, social worker or counselor for therapy.

If you have a milder case you may be able to help yourself by just staying healthy, engaging in physical activity or mental activity such as reading a book, playing cards with friends, working in a joint winter project, listening to good music, eating healthy and getting sufficient rest and sleep. You can try buying a special wide-spectrum light for yourself, fixing a special meal, or visiting places that remind you of the great outdoors such as the Zoo, a butterfly exhibit or watching a great movie about the beautiful outdoors. In any case, find something healthy and fun to do, and keep busy, soon it will be Spring again!

Dr. Tate is a Clinical Psychologist at the Department of Physical Medicine and Rehabilitation at the University of Michigan Health Systems. Her clinical specialty is SCI care.

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The 2006 Spinal Cord Injury Lecture Series

Dr. Raymond P. Onders, Associate Professor of Surgery from Case Western Reserve University will be giving the second lecture of the year on March 15, 2006. Dr. Onders will present on The Current Status of Diaphragm Pacing for People with Spinal Cord Injury or Lou Gehrig’s Disease.

Dr. George Smith, Ph.D. Professor in the Department of Kinesiology, University of Kentucky will speak on April 12, 2006 regarding Axonal (nerve cell) Recovery in Spinal Cord Injury.

Dr. William Bauman, M.D., Director of the Rehabilitation Research and Development Center at the Bronx Veteran’s Affairs Medical Center in New York will speak on May 22, 2006, on Spinal Cord Injury and Secondary Conditions.

This year’s lectures are generously funded by the Michigan Chapter of Paralyzed Veterans of America. All lectures will take place in Rm. 2G321, University of Michigan Hospital, 2nd floor near the West Elevators from 5:00-6:00 PM.

Everyone is welcome so please join us! For more information, please contact our office at 734-763-0971.
Survey of SCI Consumers and Families Perspectives On Clinical Trials

By Claire Z. Kalpakjian, Ph.D.

The word “cure” in SCI has often been associated with that of “clinical trials.” Clinical trials are a way of investigating new and innovative treatments, drugs and techniques helping science find the “cure” for diseases, and improving and, sometimes, extending life. To better understand the perspective of consumers and their family members on clinical trials, the risks involved in experimental research, and the controversial issue of stem cells, we surveyed 60 of our conference attendees.

Both SCI consumers and family members believed they knew a fair amount about where to get information about clinical trials, the value of basic science in SCI research, the meaning of informed consent, where to find out about risks of a study, and ethical and political implications of stem cell research. In general, despite risks, both groups would be highly likely to participate in cure or restorative research trials in the U.S., but they were less willing to do so overseas. The highest rated reason for participating in such research was a chance to improve their condition. When it came to reasons not to participate, consumers and family members differed. A chance that the consumer may die was rated of more importance by family members than by the consumers themselves.

Finally, people were asked about their thoughts on embryonic and adult stem cell research. In general, people were very supportive of both types of research; only 3 people were totally against embryonic stem cells while no one was against adult stem cell research. Only 2 people said that embryonic stem cell research was against their religious beliefs; no one said this about adult stem cell research.

In general, this survey tells us that our attendees feel quite informed about the state of SCI research, are willing to take some risks to improve their condition and support embryonic and adult stem cell research. This survey is only a first step in understanding how people make decisions about experimental or therapeutic research. Future studies are needed to better understand these decision-making processes regarding the SCI cure and restorative research.

Spinal Cord Injury Research Registry

Clinical research on SCI has gained media attention and consumers – both newly injured and those living many years with injuries – are expressing interest in learning more about, and possibly participating in, studies going on around the U.S. and abroad. Because SCI does not happen to many people it is often difficult for researchers to find people with SCI to recruit them into their studies. Therefore, to help connect researchers with consumers interested in being involved in research, The University of Michigan Spinal Cord Injury Research Registry was launched in May 2005. Its primary purpose is to connect University of Michigan researchers with consumers who would like to be involved in research studies.

Joining the Registry is very simple – the individual signs the Registry Consent and completes the Enrollment Form which asks for demographics and other information such as level of injury, pressure sores and autonomic dysreflexia episodes. Then the process of connecting a researcher to a SCI consumer is simple. First, researchers at UM complete an application describing their proposed study, and after it has been approved, they give us a list of qualifications for people to meet. Then the Registry sends a letter to those who potentially qualify. From there, they may join the study or decline; anyone can say no at any time and still remain in the Registry – there is no obligation to participate! The SCI Registry is open to anyone with SCI (age 18 and up).

Since it began in May 2005, 103 people have enrolled in the Registry. The Registry is currently assisting UM researchers recruit in five projects. The Registry Director is Claire Z. Kalpakjian, Ph.D. and the Registry Coordinator is Jane Walters, M.A. If you have any questions or would like to receive an enrollment and consent form, please contact Jane at (734)763-9773 or email SCIRegistry@umich.edu. You can also visit our website at www.med.umich.edu/pmr/modelsci/registry.htm to download these forms.
On Saturday May 21, 2005, we held our annual consumer conference, entitled “Connection to Cure: the Science, Ethics and Politics of Spinal Cord Injury Research.” The day-long conference was conducted in partnership with the Ann Arbor Center for Independent Living and the Michigan Chapter of the Paralyzed Veterans of America. Over 200 people attended, most of whom were consumers with SCI and their family members, as well as clinicians and researchers.

The conference was comprised of 5 sessions. The speaker for the first session was Wise Young, M.D., Ph.D., Director of the W.M. Keck Center for Collaborative Neurosciences at Rutgers University. Dr. Young’s talk was entitled “Translating Research from the Laboratory to Clinical Trials.” It began with a history of SCI research, from 3000 B.C. to the present day. He described a wide variety of studies and avenues for progress, including studies of growth factors, blocking of neural growth inhibitors, cell transplantation, and use of embryonic and adult stem cells. Dr. Young stressed that doctors have historically been overly pessimistic about the prospects for recovery. As a result, people with SCI have tended to be “victims of pessimism,” feeling either hopeless or developing misleadingly positive interpretations of clinical results. He concluded by stressing the importance of funding for clinical trials including, but not limited to, those directed toward the cure of paralysis.

The next session, “Participating in Cure Research: Point-Counterpoint,” was a discussion between two consumers with SCI about their decision to either pursue or not to pursue experimental treatment for a cure. The participants, Mr. Jim Salem and Mr. Kassem Beydoun, have opposing opinions about participation in experimental treatments. The session was moderated by Dr. William Scelza, M.D., who is a PM&R physician at the University of Michigan and specializes in SCI care; Dr. Scelza also has a spinal cord injury. Mr. Salem, who was injured 4 years ago and has tetraplegia, chose not to pursue curative research. Mr. Beydoun, who has paraplegia and was injured 6 years ago, went to China in 2004 to have a procedure conducted by Dr. Hongyun Huang. It involved having olfactory ensheathing cells isolated from fetal olfactory bulbs injected around the injury site. While Mr. Beydoun said that he has had little improvement, he has no regrets about going to China for this experimental procedure. An audience member said that they also went to China and, while still paralyzed, they have had “greater improvement.” Dr. Scelza said there was also a third choice, which is the road he has chosen. He said he is happy with his life right now and is not interested in making a decision about the available treatments at this time, but might consider it at some point in the future.

After this there were a series of talks and discussion on the bioethics of stem cell research. The participants were Robyn Shapiro, J.D., Director of the Center for the Study of Bioethics at the Medical College of Wisconsin, K. Sue O’Shea, Ph.D., University of Michigan Professor of Cell and Developmental Biology, Jose Cibelli, DVM, Ph.D., Michigan State University Professor of Animal Biotechnology, David Prentice, Ph.D., Senior Fellow for the Life Sciences Family Research Council, Michigan State Representative Andrew Meisner, and SCI consumer Daniel Heumann, Founder of the Daniel Heumann Fund for Spinal Cord Injury Research. The moderator for this session was Bernie Siegel, J.D., Executive Director of the Genetics Policy Institute.

Dr. O’Shea described her research, which involves analyzing how nerve cells “determine” their ultimate functions. She explained how studies of paralyzed rats have shown improved locomotion after transplants of embryonic stem cells.
SCI Conference (continued)

Over 200 Consumers, Family Members and Professionals

Dr. Cibelli’s talk focused on experiments using nuclear transfer, a procedure that involves having genetic material from an embryo extracted and injected into another cell. The result is an undifferentiated cell, one that does not have a predetermined function the way that a skin or nerve cell does. He described experiments that have been done with mice in which mutant rats that lacked immune systems were induced to produce immune cells following the injection of nuclear transfer.

Dr. Prentice contrasted the use of adult stem and embryonic stem cells, highlighting the problems with using embryonic stem cells. These include the potential for rejection, gene instability, contamination with other cells, and serious ethical concerns. In contrast, he discussed the successful work that has been done using adult stem cells. They have been used in the treatment of 58 diseases, including Parkinson’s and heart disease. In addition, there are no ethical concerns with the use of adult stem cells.

David Gater, M.D., Ph.D., Assistant Professor and Co-Director of the University of Michigan Model Care SCI System and Daniel Ferris, Ph.D., Assistant Professor in the University of Michigan Neuromechanics Lab gave a joint talk entitled Exercising for Neuroplasticity: Practice Makes Perfect. In their work, people with SCI exercise on stepping machines using powered leg braces. It is thought that by stimulating the neural connections, neural tissues in the brain and spinal cord may be “reorganized” allowing for the new neural connections to develop. As a result, gait rehabilitation may occur.

The last session of the conference allowed members of the audience to ask questions of all of the day’s speakers. After the conference was over, attendees were surveyed about how much they learned and enjoyed the affair. The large majority felt that it had been a very positive experience.

All of the conference sessions were videotaped and are available in DVD and VHS formats—see the back page of this newsletter for more information.

Research Highlights: Alcohol & Substance Misuse Publications

In 2005, Martin Forchheimer, M.P.P., Senior Research Associate and David Gater, M.D., Ph.D., Co-Director published a paper with researchers from the U-M Department of Emergency Medicine concerning alcohol’s effect on impairment severity. The paper reports that people with SCI who were drinking when they were injured tend to have more severe neurological impairments.


In 2004, Denise Tate, Ph.D. Co-Director, and Mr. Forchheimer published another paper on the adverse effects of alcohol and substance misuse.


Dr. Tate and Mr. Forchheimer also co-authored a book chapter with researchers from Wright State University about the unique problems faced by people with both substance misuse and physical disabilities which will be published in early 2006.
I'm a periodontist, a dental specialist in what is known as “gum disease.” But for 7-plus years now I've also been a T-5, complete, SCIer. I well know the many time consuming “extras” of SCI life personal care.

Here I would like to share with you some basic dental health, disease and prevention information, including some particular to our SCI status.

Taking care of your natural teeth is very important. Healthy teeth are absolutely the best equipment you'll ever have for chewing foods. Dentures are no substitute.

So, what causes most tooth problems and loss? Cavities and gum disease, which are both caused by bacteria that naturally live in our mouths and can stick to/grow on the teeth (that soft film called “plaque”). In small amounts, these bacteria do not hurt us and even help by subduing the growth of harmful yeasts.

However, with frequent sugar contact, cavity causing germs produce acids that dissolve enamel, especially in tooth areas that don’t have a free flow of neutralizing saliva. If you wear an appliance on your teeth, like for controlling your chair/computer, the covered teeth are at more of a cavity risk from this sugar-acid attack. Avoid any sugar-containing between meal drinks or snacks.

Bacteria on the teeth next to the gums for more than a day irritate the gums, leading to the other big cause of tooth loss: gum disease. If not cleaned off, the bacteria inflame the gums, form “pockets” of growth under the gum edges, harden into “calculus” on the teeth (like barnacles on boats) and progressively dissolve the fibers that hold the teeth, gums and jawbone all together.

Without treatment, the body ultimately gets rid of the bacteria by dissolving all the teeth-jawbone attachments and letting the teeth fall out, taking the bacteria with them. Factors that weaken the immune system, like smoking or uncontrolled diabetes, speed up the destructive process. Antibiotics alone cannot solve the problem; they cannot remove the bacteria/calculus that is fused to the teeth (only dental instruments can do that).

Loss of teeth is not the only potential problem in this scenario. Inflamed tissue anywhere in the body (including from gum disease) is a factor increasing the risk for both diabetes and cardiac problems. (And any diabetes then also worsens any heart problems.) With SCI, our greatly reduced level of muscle activity already puts us at an increased risk for both Type 2 diabetes and heart problems. It can be a “double whammy.”

Additionally: germs from inflamed gum “pockets” get into the blood stream, travel through the body and can be a factor in artery wall plaques, heart disease, strokes and other problems.

So how can you have optimal dental health?

1. **Regular exams** (with x-rays). And get recommended treatment. Cavities, gum disease and many other dental problems are painless in their early stages. If untreated, early problems only get worse and are usually more complicated and expensive to treat.

2. **Professional cleanings.** Even if you clean your teeth very well, surface tartar deposits can develop that need to be removed with dental instruments before the gums are damaged.

3. **Thorough daily home care.** But it can be tricky cleaning every little tooth area. Your hygienist can help develop your technique. She/he can show you areas you missed, how to clean them better, and then watch as you demonstrate back the skills. Each day make time for this care of your teeth.

It is particularly important to clean the “in-between” sides of your teeth. Yes, that means flossing. No amount of brushing or rinsing can clean plaque from this difficult area. Irrigation devices and “antibacterial” mouth rinses may remove food debris but do not remove the sticky layer of bacteria. Fine, unwaxed, floss is good, especially if your teeth are close together. Brush the top surface of your tongue; it also collects bacteria.

Any oral appliances that you wear need to be thoroughly cleaned each day as well (per instructions from your dentist), as they also collect plaque growth, which can in turn harm the adjacent teeth/gums.

If you are a tetraplegic or have hand/finger control issues, “toothpick holders” and electric tooth-brushes (that do the “wiggling” for you) are good options. [See end for my recommendations.] Toothpick holders can be used one-handed and can be easier than flossing for a personal assistant to do. The tips of round wooden toothpicks are good at reaching between teeth, and the slight fibrousness of wood is terrific at cleaning off sticky plaque. Use the side of the toothpick tip to rub the “between” sides of the teeth.

(Continued on page 11)
Making the Big House Better

In March, 2005, Michigan Paralyzed Veterans of America (MPVA) met with University of Michigan Board of Regents to express concern about access to Michigan Stadium for people with disabilities. Since the University was planning to remodel the stadium, this seemed like a perfect time to ask that the stadium be brought into compliance with Americans with Disabilities Act (ADA) standards.

To the University’s credit, they set up a meeting with Athletic Department representatives, professionals working on the project and members of the disability community. University staff heard the concerns that disabled ticket holders said prevented them from fully enjoying the experience of a Michigan football game. These issues were presented:

- Wheelchair seating locations are not provided in all price ranges.
- Ramps to reach accessible seats are too steep for wheelchairs to easily navigate.
- The stadium entrance and M-Den Concession stand are not accessible.
- The ADA standard that 1% of the seats are available to wheelchair users is unmet.

MPVA is frequently asked to share knowledge on ADA compliance and accessibility, as concern for the rights and needs of disabled residents has increased. When partnerships are created, an advisory committee can become a resource rather than a threat. This is advocacy at its best, and it’s our hope that this work will have a long-lasting impact on the quality of life of residents with disabilities.

The ADA cannot act on its own; only through partnerships that can bring the legislation to life, does it ensure that people with disabilities have access to facilities without encountering architectural barriers. We think that project planners prefer to do it correctly the first time and communities want to accommodate the needs of all residents. Advocacy need not be antagonistic; change can be accomplished through partnerships and communication among all involved.

Final plans for the Michigan Stadium renovation will be reviewed soon. Construction will begin late in 2006, finish in 2008 and will include the installation of an elevator.

Go Blue!

If you have questions or comments, please call Mike Harris at (248) 476-9000 or e-mail him at mharris@michiganpva.org. For more about MPVA’s projects and mission, visit their website at www.michiganpva.org.

Mike Harris is an SCI consumer and Deputy Executive Director of the Michigan Paralyzed Veterans Association. He also serves on the UM Model SCI Care System Advisory Council.

Best Chewing Equipment You’ll Ever Have (continued)

If you use any of these tools or if an assistant helps with dental care, bring the tools and your helper along when you see the hygienist, so you both can learn “how to.”

Your natural teeth are not only your very best chewing equipment, important to your speech and part of the smile on your face, but also an important part of your mouth’s “sense of self.” Try to keep them!

Try the “perio-aid3” toothpick holder from Marquis Dental Mfg., tel. (800) 359-3206; get a couple to spare; and the “Oral-B 3D Excel” electric toothbrush, at stores.

Eric Appleberry retired from his practice of periodontics after his SCI accident in 1998; he teaches periodontal graduate students at UM Dental School, served on the UM Medical School Institutional Review Board from 1999-2003, serves on the UM Model SCI Care System Advisory Council, is Co-Editor of the SCI access Newsletter and does volunteer work at his church, the First Unitarian Universalist Congregation of Ann Arbor.
Dr. Tate Receives Award for Her Commitment and Dedication to Rehabilitation Research

Denise G. Tate, Ph.D., Co-Director of the U-M Model SCI Care System, was selected as the 2005 John Stanley Coulter Lecturer by the American Congress of Rehabilitation Medicine in Chicago last year. This distinguished lectureship was created to honor Dr. Coulter in recognition of professional achievements that have contributed significantly to the field of rehabilitation.

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 #H133N00009). 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.

Denise G. Tate, Ph.D., Co-Director, Co-Principal Investigator
David R. Gater, M.D., Ph.D., Medical Director, Co-Director, Co-Principal Investigator
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We hope you enjoy this publication. If you do not wish to receive it in the future, please call 734.763.0971 to be removed from the mailing list.

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