Knowledge Translation: A Two-way Street

By: Kathie J. Albright, PhD

The National Institute on Disability and Rehabilitation Research (NIDRR) funds Model Systems to serve the needs of people with spinal cord injuries (SCI), traumatic brain injuries (TBI) and burn injuries (Burn). One of NIDRR’s major goals is to see that research is relevant to the needs of consumers and that research findings are made available and are useful to them. NIDRR has identified knowledge translation (KT) as an important part of seeing that this goal is met.

Knowledge translation is a process of ensuring that new knowledge and products gained through research and development will ultimately be used to improve the lives of individuals with disabilities and further their participation in society. Knowledge translation is built upon and sustained by ongoing interactions, partnerships, and collaborations among various stakeholders, including researchers, practitioners, policy-makers, persons with disabilities, and others, in the production and use of such knowledge and products (NIDRR, Federal Register, January 15, 2009, Vol. 74, No.10, p. 2564-5).

KT is not a one-way communication of research outcomes but requires the participation of stakeholders and consumers at all levels of research and development: planning, implementation and follow-up evaluation. In this way, research priorities and results are more likely to be accepted by and useful to stakeholders and consumers. Effective KT requires collaborative exchange; it is a two-way street.

To make sure that there is widespread distribution of practical information, NIDRR funds the Model System Knowledge Translation Center (MSKTC). MSKTC reviews and summarizes research that has been conducted, identifies important health information needs and develops consumer friendly resources. This work supports the various Model System programs across the country, meeting the needs of their consumers.

The MSKTC maintains a comprehensive website that includes:

- contact information for the Model Systems
- consumer-oriented information
- systematic reviews on research topics
- a database of research articles
- information on Model Systems research projects
- various other consumer resources

For people with spinal cord injuries (SCI), there are now factsheets available (through the website) that address the important topics of skin care and pain. These factsheets were produced through a collaborative process involving critical review and approval between the MSKTC and the SCI Model Systems. The health information in these factsheets is based on research evidence and/or the professional consensus of experts.

The University of Michigan SCI Model System encourages people with SCI and their families and friends to visit the MSKTC website, which is continually updated with new developments. It also includes resource links to most of the other organizations that work on behalf of people with SCI. There is a feedback system so that people visiting the site can ask questions, make comments about its contents, or voice concerns about unfilled gaps in health information. Please visit the MSKTC website at: http://msktc.washington.edu/sci/
Health Mechanics
Tools for Effective Self-Management of SCI/D

By Michelle Meade, PhD

When living with Spinal Cord Injury and Disease (SCI/D), your health impacts what you can do and how much energy you have to do it. While there is currently no cure for SCI, there are ways to manage the condition for optimal functioning.

Self-Management

Based on research evidence, self-management is an approach to chronic conditions that has been found useful in improving health and lowering the cost of care. A key to this is the ability to make necessary decisions and lifestyle choices.

Secondary disease conditions can be prevented or minimized by regular health-promoting behavior (like pressure reliefs to prevent skin problems). Taking action consistently, though, can be difficult. Self-management focuses on helping people develop the skills needed for best management of SCI.

Health Mechanics: Tools for Self-management*

Health Mechanics is a self-management program that was developed on the assumption that the person with the impairment or disability is the primary person managing their medical condition—while still trying to have a full life. Both individuals with SCI and health care professionals were consulted in developing the program. It is intended to be comprehensive yet flexible enough so that individuals, who have different backgrounds and experiences, can learn behaviors for improving their own SCI management.

The program manual is written in a conversational style so as to engage the individual with SCI/D who is using the program to gain useful skills. However, other people (be they family members, health care providers, peer mentors or others) can also use this guide. They can either directly quote or restate the concepts in the guide in order to help individuals with SCI/D benefit from the program.

The basic skills taught in this program are: attitude, self-monitoring, problem solving, communication, organization, and stress management. These skills are needed for individuals with SCI/D to best apply to their own lives information from their health care providers, from other books (such as the Yes You Can! Guide from the PVA) and from other people living with a disability. Once learned, these skills can be applied to the many challenges that an individual with SCI faces. In brief, the skill tools:

- **Attitude** refers to your approach to your life, your situation and the future. The right attitude, in living with SCI or any condition, is proactive, meaning that it is up to you to make things happen. It has five basic parts: expectations, assumptions, outlooks, responsibility and actions.

- **Self-monitoring** means observing and recording what is going on in your life or your body. Keep a log of such things as bowels, bladder/urinary, skin, exercise, diet, moods and any other concerns. By monitoring and tracking changes you can refer back and better work with health care professionals in managing your condition.

- **Problem solving** allows you to deal with the world by deciding what the problem is, creating different solutions (called brainstorming) and weighing the pros and cons for each. This allows you to stay flexible and try different approaches to various situations. A step-wise approach to problem solving is discussed in the program manual.

- **Communication** is a critical skill in conferring with those whom you want to or need to be in touch. Steps include deciding on the goal for the conversation, determining the best way to reach it and accepting responsibility for your own feelings.

- **Organization** is a system of arranging things to make them easier to manage to meet specific goals. In order to organize appropriately you need to know what your priorities are. There are two priority lists, a master list and a daily list (drawn from the master list). Both must receive attention.

- **Stress Management** can be pretty important. Initial adjustment to SCI can be very stressful and even later on problems of one nature or another often arise. Relaxation techniques and physical activities help dissipate stress.

Facilitating Health Mechanics*

As a companion to the Health Mechanics program, the Facilitating Health Mechanics guide was created to assist care providers (e.g., family members, physical and occupational therapists, nurses, physicians) in supporting the development and use of self-management skills—and to help this group think about their own assumptions, expectations and communication style. This program was based on the belief that people will receive the best health care when providers and patients have matching (or at least complementary) expectations.

You can request copies of both program manuals from the author, Dr. Michelle Meade (mameade@umich.edu), or download them from the U-M website: (http://www.med.umich.edu/pmr/research/projects.htm)

*Dr. Meade’s self-management programs, designed specifically for individuals with SCI/D, were developed with funding from the PVA Education Foundation (grant #576).
Tom Hoatlin: “I’m very fortunate to be here.”

After Terrible Trauma, A Life of Service to Others

By Eric A. Appleberry, DDS, MS

It was December 17, 1991, and Tom Hoatlin, at the time age 28, married and with a six-month-old baby daughter, was ten years into his planned career in restaurant and hotel management. At the time he was managing a Livonia, Michigan, location of a national hotel chain and was filling in for a front desk night clerk who had called in sick. Two men came in, pulled a gun, robbed the front desk of cash, forced him to open the office safe and then shot him (aiming for his head) in the back base of his neck, at the T-2/3 level, and left him for dead on the floor.

And Tom almost was. Alone and bleeding heavily, he lost an estimated 12 units before EMT people arrived after a hotel guest noticed that someone was on the floor in the back office.

Tom was transported to St. Mary Mercy Hospital in Livonia, then by helicopter to University of Michigan Hospital, in Ann Arbor, where he had surgery that night to remove the bullet and stop the bleeding. Amazingly, in just one week he was doing so well that he started inpatient rehabilitation.

But his progress came to a halt on January 22, 1992. While in the Physical Therapy gym at U-M Hospital, a blood clot from his leg veins broke loose and caused heart stoppage. He had suffered a Pulmonary Embolism. A “Code Blue” alert was called and while this team was reviving him, Tom’s sister, Beth, a neonatal nurse at U-M Hospital arrived for a visit. She took it upon herself to page Dr. Robert Bartlett, at the time Chief of General Surgery at U-M Hospital and the surgeon who had operated on Tom when he arrived in December.

Fortunately, Dr. Bartlett was able to hurry down and join with the now revived Tom while he was being transported to have an “angiogram” evaluation. While in the elevator, another blood clot again stopped Tom’s heart. Even though chances of surviving were grim, Tom was immediately rerouted to see if anything could be done to save him on an emergency basis.

Dr. Bartlett opened Tom’s chest as quickly as possible and massaged his heart to get some circulation. A massive blood clot in the lungs was found; it would be awhile before Tom’s lungs could do much oxygenation of his blood. The only chance for survival would be to put him on an ECMO, a heart lung bypass machine, which oxygenates the blood outside of the body. (This machine, pioneered by Dr. Bartlett, was originally developed for use with very prematurely born infants, whose lungs are not yet fully developed.)

It was several weeks before Tom could go off ECMO. Even then, his lungs needed six weeks of ventilator assistance before they could fully go it alone and enable Tom to get back into and finish the inpatient rehabilitation program (which is work; lungs that can breathe are needed).

During the many weeks of setbacks one of Tom’s key motivators for “hanging in there,” wanting to live, was his love for his infant daughter. During that six months after her birth, prior to his injury, Tom deeply bonded with her. He wanted to be there as a normal dad as she grew up.

Tom finally got to go home on Fathers Day, in June, 1992, which was also his daughter’s one year birthday. A BIG party was held, with family and friends present. His physical rehabilitation, however, would continue, as an outpatient, three times a week for another five years.

The Real Rehabilitation: Embarking on an Engaged Life

For Tom Hoatlin this started (but not at first) while he was still an inpatient at U-M Hospital. Clark Shuler, who at the time was with the Ann Arbor Center for Independent Living (Ann Arbor CIL) and eight years past his SCI, visited Tom in his hospital room. He talked about life with an SCI.

“But I shut it out,” Tom said. “In my mind I was going to have surgery to fix it and only be in a wheelchair for a few months. I was going to walk and fully feel my body again.”

“But Clark kept coming to visit and I attended the Independent Living Classes held in the hospital’s SCI unit. Clark talked about his work, driving, his family, and friends of his who also had an SCI. I finally realized I could get something from this man,” Tom said. “He had a good life—while using a wheelchair.”

“And then when I got home I found I could still really enjoy being with my daughter; the wheelchair made no difference to her,” Tom said. “Fortunately, because of my wife’s job, I also didn’t have to be ‘at work’ right away—and so could attend an introductory class at the Ann Arbor CIL about taking the ‘Peer Counseling’ training (the SCI social worker at U-M Hospital had recommended Tom do so). “After one class I was hooked.”

Tom started volunteering two days a week at the Ann Arbor CIL, and in two months, Jim Magyar, President of the organization, aware that Tom had management experience from his past career, asked Tom to be their Fundraising Coordinator. For the last ten years Tom has been the Ann Arbor CIL’s Director of Development and involved in many of its functions.

Tom coordinates the Ann Arbor CIL’s Independent Living hospital program that includes a comprehensive, seventeen module “Life after Spinal Cord Injury” course, covering everything from personal care routines to sexuality to travel. This course, co-taught with Cindy Douglas, Physical Therapist, and Patty Zuba, Occupational Therapist, is now a standard part of the U-M Spinal Cord Injury Model System rehabilitation care of...
Tips from the Trenches
Suggestions for Living Successfully with an SCI

By Mary Burton

Ed. Note: These tips for living successfully with SCI were collected from individuals with SCI by Mary Burton as part of Dr. Michelle Meade’s Health Mechanics program, developed with funding from the PVA Education Foundation, grant #576.

The tips are grouped into categories that seemed to make sense. Each tip is only listed once but some of the tips obviously belong in more than one category. This collection is not meant to be the final say in good advice, and may in your case, because of circumstances, actually be the wrong thing for you to do. So check with your personal physician, PT or OT professional if there is any question about it. Add to Dr. Meade’s collection by emailing: mjburton@med.umich.edu.

General:

1) In public, present yourself as someone confident and comfortable with having a disability. Never apologize about asking for access. You have the same civil rights as anyone else.

2) Keep a journal, even if it is brief. You can use this to keep track of good and bad days, accidents, what you eat or anything else. You can use a calendar, day planner or whatever works.

3) Get in the habit of putting something on top of your lap when you are setting objects on it, as you might when you are cooking. Something that has a non-slip surface that DOES NOT conduct heat will be the safest. For instance, you can use a wooden cutting board for this purpose. It is all too easy to place hot items in your lap and not even know it.

4) Keep a list of all telephone calls made and received from doctors, medical suppliers, insurance companies, etc. Be sure to note a contact name, what the call was about and a number in case you get disconnected. You cannot remember everything. Eventually you will get a bill you aren’t responsible for and having these names, dates and numbers will be invaluable for getting it resolved. A notepad by your phone works great.

5) Keep a file of all your medical records, receipts and explanation of benefits (EOBs).

6) Go back to your hobbies or sports any way you can. Try them a different way if your disability gets in the way of how you did them before. The sooner that you can do so, the better.

7) Contact the local PVA (Paralyzed Veterans of America) even if you are not a veteran. You can join for a one-time $50 fee and be a lifetime member. You will be put on their mailing list and receive PVA meeting dates. Their magazine, PN, has a wealth of information for people who use wheelchairs.

8) Subscribe to New Mobility magazine. Their Customer Service number is: 888-850-0344, ext.209. $27.95/year.

9) Contact your nearest CIL (Center for Independent Living) or Disability Network office. These are non-profit organizations at which half or more of the staff and volunteers have a disability. They have free counseling and a lot more to offer someone who has a disability—especially if the person is new to it.

10) Try to find a SCI support group. The early years can be a terrible struggle. Meeting with people like yourself, just sharing the same style, is really empowering. It can give you more knowledge, empathy and possibly a new friend. If you can’t find a dedicated SCI support group, a CIL is helpful. They are also a worthwhile place to volunteer.

11) Do as much for yourself as you have time and energy to do.

12) Some things aren’t fixable, but your overall condition depends strongly on your attitude and tenacity to strive forward. Try to lead the best life you can for yourself and your family.

13) Learn all you can, from the internet, books, etc., about your condition. Then, when you see your doctors you can communicate at higher levels, ask more intelligent questions, better understand recommendations and get more value from your visits.

Viability, Health, Safety:

14) When using a manual chair, regularly practice backing up hills—it can help balance your shoulder muscles. This can prevent shoulder injuries in the long run.

15) Make it a habit to stay stretched and do “range of motion” movements with your limbs.

16) Remember that the average person with a complete injury loses about 25% of their bone density in their legs and hips within one to two years. Because of this, avoid range-of-motions that involve twisting. Also avoid crossing your legs when you are pulling shoes and socks on and off. Your thigh bone (femur) can break all too easily when it is twisted.

17) Work on quitting smoking. Having an SCI is already hard on your lungs, your skin and other parts of your body. Plus, quitting will save you a ton of money.

18) Try to make exercise/activity part of your routine. Make sure the activity is something that you really like to do. Otherwise it’s hard to keep at it if you don’t like to do it anyway.

19) Go to your healthcare provider visits educated and prepared. Write down your questions so you don’t forget them.

20) Drink lots of water. You may no longer feel thirsty, so keep track of the amount of fluid you actually drink.

21) Dress in layers. You can feel cold even in mild weather.

22) Be sure your feet and legs are free and clear of obstructions before doing transfers. This is how legs get broken. One way this can happen is when getting in or out of a car. Also, be especially careful when transferring around your bed in the dark.

23) Carry a small flashlight on your chair. This can be helpful in public restrooms and anywhere, if the lights go out.

24) Get a cell phone. Keep it with you at all times, especially if you drive or transfer independently. If you can’t get back in your chair from the floor, you can call someone to help you.

25) Adjust or adapt your furniture (such as your couch or bed) to be as close as possible to the level of your wheelchair.

26) Get in the habit of checking the water temperature of your bath or shower before getting in, and always have water going

Continued on page 5
From One with SCI to Another; Tips from Trenches, cont’d

to a skin area where you can feel the temperature if increasing the heat. This can help prevent burns.

**Skin, Pressure Sores:**
27) Check your skin every day in the mirror. Look for areas of redness or other signs that you are getting a pressure sore.
28) A 2 1/2 inch overlay of high density foam on top of a mattress can protect you from skin ulcers (pressure sores) that could occur from not turning yourself every two hours or from having an overly firm mattress. [But, don’t use “memory foam,” because when trying to “lift” yourself for lateral movement, it will be harder to get clearance for your rear end.]
29) Keep enough air in your wheelchair cushion. Get in the habit of feeling the cushion’s “firmness/inside pressure” every time before you get on it. This can prevent the start of a pressure sore or infection. Keep a cushion air pump in your chair bag so you can add air as soon as it is needed.

**Cathing, Urology:**
30) The sugar d-mannose (effective ingredient in cranberry juice) is not metabolized by humans and is excreted via the kidneys. In the urinary tract system it does have an anti e-coli bacteria effect—and thus may help in the prevention of UTIs. The least expensive way to get it is through online supplement businesses, buying in 3 oz/85 gm units (largest available). But beware, d-mannose does not counteract an unclean cathing technique nor an “untimely” schedule that allows over filling of the bladder. There are pathogenic bacteria, not affected by d-mannose, which can take advantage of such opportunities.
31) For self-cathing when away from home: It is good to have a place for keeping clean supplies organized. One man had a stainless steel table made, small enough to fit in his chair back pack, but big enough to fit over the rear of a toilet seat. Hinged protrusions could be opened to keep the table stable in place.
32) If your insurance covers it or you can somehow afford it, use a new sterile catheter every time.

**Bowel Programs:**
33) If you use Magic Bullet suppositories, wait until there is only clear fluid on your gloved finger (upon withdrawal from your rectum) before you consider yourself “finished.” Your bowel program may take longer but it is the almost sure practical way to not have an accident later on. But, because there isn’t a way to be 100% sure, wear a depends-type brief for overnight or half a day afterwards.
34) Before you get on an airplane, perform a good bowel program. The air pressure in the plane is like being at 6,000-8,000 feet in elevation. Lower pressure expands any gas in your system, so if you haven’t done a bowel program before the flight, the lower cabin pressure could do it for you while on the plane.

**Accessibility when Traveling:**
35) Even if a hotel says they are accessible, ask about specifics: roll-in shower, door widths, etc. Not everybody has the same understanding of “accessible.” Be persistent and polite in asking for accommodations. You are your own best advocate.

**Personal Care Assistants:**
36) It is important to be familiar with someone who might work as an aid/care attendant for you and/or have trustworthy references. It increases the chance of it being a long-term arrangement. But, it is very important that your personal aid/care attendant has a clear understanding of your expectations. Duties, responsibilities, pay, the time they arrive/leave, what happens when they are late and the condition of the home when they leave should all be discussed ahead of time. Best is to have it all in writing!
38) When your caregiver leaves your house, make sure all is in order, i.e., your things are where you can reach them.

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**Tom Hoatlin, a Life of Service**

Continued from page 3

inpatients with SCI. Tom also meets with patients on a one-to-one basis, the way Clark Shuler did with him.

Tom also conducts Disability Awareness and Sensitivity trainings with employers, community organizations and in schools to increase disability awareness—and also to let people know that, instead of staring at people with disabilities, it’s OK to talk with and ask questions of them. Many people don’t realize that people with disabilities are normal and can still lead meaningful lives—like everyone else. Disability is a normal part of life; with age we all are going to take on disabilities.

The groups that Tom most enjoys talking with are elementary school children, college students and physicians. Children in the fourth grade are usually best, Tom says, for they are old enough to be open about their curiosity. And physicians who do not often see people with an SCI are commonly not aware of what life with an SCI is like—and how they can best interact.

“I have been lucky,” Tom said, “to have my Ann Arbor CIL job for the last fifteen years. I love coming here and being able to work for quality of life for people with disabilities. And the totality of need is overwhelming. All the time we get calls from individuals, or from the family of an individual, who have ‘what to do?’ or ‘where to go next?’ questions. Sometimes the questions are easily answered and sometimes the calls concern big problems. We do what we can here to provide information and helpful resources. I visit individuals and families in their homes to help figure out situations; I write letters and make telephone calls looking for solutions. We’re trying to transform lives, one person at a time.”

“I would rather be known for the work I do here, than for the fancy resort I might have been managing if I was still in the hotel business,” Tom said. “And the six to seven day, 70 hour weeks that hospitality work requires wouldn’t have allowed me to develop a close relationship with my daughter, which has been a treasure and a lifeline to me. She’s finished high school, is a freshman at Washtenaw Community College this year and next year will be going away to college. That will be another ‘transition in life’ for me,” Tom said.
Locomotor retraining of the neurons is done by suspending an SCI patient in a harness over a moving treadmill, with specially trained therapists moving his/her feet/legs to simulate walking, including the normal rotation of the hips and bottom of the feet receiving a “load” pressure from the surface of the treadmill. The sensory nerve feedback (of walking activity) to the lower back spinal cord nerves then reinforces/develops the generation of coordinated nerve signals for walking activity going back out to the muscles.

But some initiation of activity by the brain is needed. A person with a “complete” SCI, is not likely to develop walking ability, but with the training may still benefit with an improvement of balancing capability of the upper body while sitting.

Separate from the locomotor training, there is also benefit just in having a person with an SCI in a standing position for an hour a day. Dr. Harkema did a randomized clinical trial to compare locomotor training with “conventional” SCI rehabilitation. The conventional therapy controls in this study included having therapists holding patients in an upright standing position for an hour a day. These control patients seemed to do as well as those with the locomotor training, in terms of reduced muscle spasticity and improved circulation, blood pressure and balancing.

Dr Harkema emphasized, though, that for “incomplete” SCI patients, it is locomotor training that improves walking speed and endurance (beyond what just standing would accomplish).

[Editors Note: While hiring therapists to stand you up each day is not economically practical, reasonably priced mechanical standing frames are available, and there is one, the EasyStand Evolve Glider, that also allows you to do aerobic exercise!]

Key diagnostic symptoms for depression are a persisting loss of interest and/or a depressed mood. Unfortunately, many depressed people don’t get the benefit of a diagnosis. For instance, after an SCI, a health care professional’s attitude may be “well, that’s just the grieving process that he/she has to go through” and so does not treat or even consider making a referral for evaluation. This happens too often, Charles Bombardier, PhD, said in his January 29, 2010 lecture, Nervous Breakdown: Depression in People with Neurological Disabilities, at the U-M Physical Medicine and Rehabilitation’s Burlington Building facility in Ann Arbor. The lecture was supported by the Advanced Rehabilitation Research Training Program, which is funded by the National Institute on Disability and Rehabilitation Research and the SCI Model System’s Lecture Series fund. Dr. Bombardier is Project Director at the Northwest Regional SCI Model System, Seattle, WA.

Dr. Bombardier, a clinical psychologist, has for many years specialized in the rehabilitation of persons with traumatic brain injury, spinal cord injury and stroke. Since depression is a significant roadblock to any true or lasting recovery, he has also undertaken extensive research into the risk factors for and the diagnosis and treatment of depression.

Amongst the situations that put people at an increased risk for depression are “difficult life” factors such as spouse or partner problems, drug or alcohol addiction, poverty, lower level of education and a traumatic injury (including potential for post traumatic stress disorder). Women generally are at higher risk.

Additionally, injuries that are disabling, such as an SCI, may cause unemployment, with feelings of worthlessness, loss of social connections, boredom and a sedentary lifestyle—all factors that increase the risk for depression. However, Dr. Bombardier noted that these are all factors that can be modified.

If diagnosed, what are treatment choices? Those showing effectiveness include “cognitive” therapy, which focuses on how a person thinks (in order to help them replace negative thoughts with more positive/motivating thoughts) and advising people to “be more active” (at anything); especially good are sustained physical exercise activities. Regarding medications, the literature shows that anti-depressants have best effectiveness when treating moderately severe to severe symptoms.

Also significant, Dr. Bombardier said, is that using the telephone as a method for maintaining evaluation contacts with patients (and keeping them in treatment) is often more effective than having them come in to a facility.
Academia-Community Research Collaborations

By Eric A. Appleberry, DDS, MS & Kathie J. Albright, PhD

If community involvement is actively sought when developing a study, this leads to more relevant and better accepted findings.\(^1\) Thus newer ways of inviting community participation in research studies have gained in prominence. Two local projects involved such community-partnered collaboration for the benefit of people with spinal cord injury (SCI).

Improving research on stress with community help

Cortisol is the body’s natural stress-fighting hormone. Claire Kalpakjian, PhD, sought to evaluate, in people with and without SCI, hormonal cortisol levels and moods in relation to daily stress situations.\(^2\) “Normally,” when a person is under stress, cortisol levels very quickly go higher than typical for that particular time of day. Getting simultaneous stress, mood and cortisol information would require new collection methods.

To carry out her study, Dr. Kalpakjian needed to get saliva samples (that would reveal cortisol levels) at random times. When a beeper signaled, participants were to chew a cotton roll (saving it for later cortisol analysis) and record their mood and situational stress at the time. However, due to the hand/finger grasping problems of people with tetraplegia, the small vials usually used to hold/store the cotton rolls would be hard to manage, as would be the regular booklets for logging data.

The tote, the larger vials, the data booklet, the beeper

Two people with higher-level SCIs were called upon to help. Tom Hoatlin, T-2 injured, and Barbara Shoen, C-6 injured, tested out materials, selecting larger diameter vials with easily removed/replaced caps for holding the cotton rolls. They also recommended an easily grasped pen, an easy-flip-open booklet for marking mood and stress information, and an easily opened tote for holding it all (including the signaling beeper).

Fifty-one people participated in this study, 25 of whom had SCI. The non-SCI group was age and gender-matched to those with SCI to ensure a better comparison between the groups. As reported in the research literature,\(^2\) the findings showed differences between the groups. In the SCI group, cortisol levels were lower than normal for the time of day when social stress was present, which was not the case for the control group. In addition, mood levels in the SCI group were not “agitated” under stress, again in contrast with those of the controls.

Why those with SCI would have lower levels of cortisol and mood “reactivity” in stress situations is not clear. Does the SCI somehow “blunt” (reduce) signaling for cortisol production? Are people who have been through severe trauma (often associated with an SCI) subsequently less bothered by situations others find stressful? These are questions for further study.

Community-engagement research to improve accessibility

Because of its abundant cultural resources, the Ann Arbor/Washtenaw County area is an attractive place. However, in 2007 the Ann Arbor Center for Independent Living (Ann Arbor CIL) conducted a needs assessment on accessibility and found major inadequacies. The Ann Arbor Commission on Disability Issues has long identified problems, yet those problems remain. Thus, accessibility is a BIG issue.

Action for change may be forthcoming through a project designed to address disability-related accessibility in arts and culture in Ann Arbor. Els Nieuwenhuijsen, PhD, of U-M Physical Medicine and Rehabilitation, and an interdisciplinary steering committee drawn from academic and community organizations (including the Ann Arbor CIL, Ann Arbor City Council, Arts Alliance, and Wayne State University) have started a “three stage participatory action strategy” that has been successful in the field of public health.

As described by Dr. Nieuwenhuijsen,\(^3\) the vital first stage, stakeholder needs assessment, is coming to a conclusion. This stage involves gathering representatives of the community into focus groups to assess the current situation and develop action plans. The four focus groups gathered were: managers of arts and culture organizations, disability networks, caregivers and service providers, and a “miscellaneous other” group.

A report of the focus group results is now available.\(^3\) Major themes noted were: 1) lack of awareness of accessibility and disability related issues among managers of arts and cultural organizations and among people with disabilities; 2) need for a central connector or clearing house for information, and 3) need for governmental policies and enforcement (building codes, transportation, parking) and appointment of people with disabilities to boards and commissions.

Stage two, action research, involves plan implementation in the community and evaluation of what works best. The third and last stage, scaling up, involves duplicating and expanding on what has worked. Toward the end of this project, widespread publicity should draw people from surrounding communities to these more easily accessed places for cultural events, making Ann Arbor and Washtenaw County good places to be.

The University of Michigan Spinal Cord Injury Model System publishes SCI access. 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 U-M SCI Model System receives funding from the National Institute on Disability and Rehabilitation Research (Award #H133N060032). It is one of 14 SCI Model 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, PhD, Co-Director, Co-Principal Investigator
Anthony Chiodo, MD, Medical Director, Co-Director, Co-Principal Investigator
University of Michigan SCI Model System, 300 N. Ingalls, Room NI2A09
Ann Arbor, MI 48109-5491
Phone: 734.763.0971; Fax: 734.936.5492
Email: model_sci@umich.edu
Website: http://www.med.umich.edu/pmr/modelsci/

Regents of the University of Michigan: Julia Donovan Darlow, Laurence B. Deitch, Denise Iltich, Olivia P. Maynard, Andrea Fischer Newman, Andrew C. Richner, S. Martin Taylor, Katherine E. White; Mary Sue Coleman, ex officio.

Contributors: Eric A. Appleberry, Kathie Albright, Michelle Meade and Mary Burton.


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2010 World Stem Cell Summit at Detroit’s Ren Cen

Information is from the Genetics Policy Institute’s webpage: www.worldstemcellsummit.com/2010_conference_overview.html

The 2010 World Stem Cell Summit will be held October 4-6th at the Detroit Marriott Renaissance Center. Co-hosted by the University of Michigan, Michigan State University, Wayne State University and the Michigan Economic Development Corporation, the event is organized by the non-profit Genetics Policy Institute. The Summit’s program agenda is designed to unite the international stem cell community and highlight the field’s most brilliant minds and crucial pioneers to provide a state-of-the-art view of the expanding stem cell universe.

Program Overview
The diverse 3-day agenda will include morning keynote presentations, panel discussions, roundtable lunch conversations with experts, and a great number of smaller presentations in focused tracks and intimate workshops. There will be five major program categories: Science, Business/Law, Medicine, International Discussions and Ethics/Advocacy, with panel discussions and a variety of other presentations in each of these areas. (See website provided above for details.)

Conference Attendees & Exhibitors
The Summit is anticipated to attract more than 1,400 of the most influential stem cell stakeholders from more than 30 countries representing the fields of science, business, policy, law, ethics and advocacy. Additionally, more than 125 internationally renowned speakers will be present. And, 60 exhibiting stem cell companies, organizations, states and nations will showcase cutting edge products, research breakthroughs, investment strategies and government initiatives. The unique international environment is expected to foster collaboration, economic development, technology transfer, commercialization, private investment and philanthropy. Consumers are welcome, too.

Last fall, 2009, after the Detroit location for the 2010 Stem Cell Summit was announced, Mary Sue Coleman, President of the University of Michigan, issued this statement: “Stem cell research and discovery are of tremendous importance not only to scientists, patients and families, but also to transforming our state’s economy. The University of Michigan is excited to welcome the 2010 World Stem Cell Summit to Michigan.”

Great Lakes Independence Ride

The Ann Arbor CIL is excited to announce the 4th Annual Great Lakes Independence Ride (IRide) will take place August 5 - 8, 2010.

This all inclusive cycling event goes from Three Oaks (near Lake Michigan) to Ann Arbor with stops along the way.

The Ann Arbor CIL has a limited number of hand-cycles and other adaptive bikes that can be reserved.

To learn and participate in adaptive cycling, the Ann Arbor CIL holds weekly inclusive cycling rides every Tuesday from 6 - 8 pm, starting on April 20, through September 28. The ride begins at the Ann Arbor CIL, 3941 Research Park Dr, Ann Arbor

For more information on cycling or IRide, please contact Mary Stack at 734-971-0277 ext 22 or mstack@aacil.org