Getting a Better Grip

Dr. Arthur Prochazka’s ReJoyce arm and hand rehabilitation workstation may soon be common in rehab centres—and in people’s homes.

also inside:
ABCs of autonomic dysreflexia
Hitting the slopes in Quebec
Wheels In Motion 2010
On page six of this issue of Solutions magazine, you’ll read about Dr. Andrei Krassioukov’s work to create a critically important educational program that will help emergency responders and medical personnel recognize the presence of autonomic dysreflexia in people with SCI. Autonomic dysreflexia, or AD, is entirely treatable—but potentially deadly if not recognized in time.

What happens when Dr. Krassioukov finishes this important work? Ideally, there would be a readily accessible pipeline through which it could be offered to and accepted by all appropriate health care administrators, medical professionals and emergency responders across Canada.

Unfortunately, this scenario is far from our current reality. There is a disconnect between the research and clinical practices communities—one that is generally acknowledged by both parties. And therefore, work like Dr. Krassioukov’s often takes far too long to reach the front lines of clinical practice, if it makes it at all.

The problems are many. They include financial disincentives, unwillingness to accept change, and the sheer volume of new knowledge requiring translation into practice.

Regardless of the issues, how can we ensure that Dr. Krassioukov’s work is distributed and embraced by the right people? Should it be solely his responsibility to seek acceptance of his own work by our medical and emergency response professions? Wouldn’t it be better if Dr. Krassioukov could hand off his work to someone who specializes in implementing best practices, or collaborate with a team of experts in the field?

We believe so, and so too does our primary funder, Health Canada. In fact, our funding agreement with Health Canada stipulates that one of our three primary work areas is best practice implementation—guiding both existing SCI best practices and emerging SCI best practices from our own translational research through the process of being accepted as clinical practice in the appropriate health care disciplines.

As we now begin our second full year of existence, our other primary programs—our Translational Research Program and our Community Partnerships Program—are fully operational and moving forward. So the time has arrived for us to move forward with our Best Practices Implementation Program.

As I write this, the Rick Hansen Institute is seeking a Director of Best Practices Implementation. By the time you read this, my hope is that we’ll have secured the services of an inspirational professional to lead this critical part of our work. Watch for details in future issues.

Bill Barrable, CEO
SCI Solutions Network
### Roll Out Your Old Rims to Win!

Is your manual chair in disrepair? Were you sitting in your current wheelchair when you watched the Toronto Maple Leafs last win a Stanley Cup? Would MacGyver marvel at your duct tape skills?

If you answered yes to any of these questions, the Rick Hansen Institute is offering you the chance to win one of two brand new Invacare A4 manual wheelchairs, courtesy of Invacare Canada.

Please note that the chairs have already been assembled, and size choices are restricted to either 16 x 16 or 18 x 18 inches.

A basic cushion is included.

To enter, send us a high resolution, high quality picture of you sitting in your clunker, along with a short paragraph telling us why it’s time to trash it. Winners will be selected by April 30th, 2010, on the basis of creativity and need as determined by a panel of people living with SCI. If you win, your photo and story will appear on the Rick Hansen Institute website and in a future issue of *Solutions* magazine.

Email your photo and story to info@rickhanseninstitute.org.

The A4 has the reputation of being one of the toughest, most easily adjustable, lightweight, aluminum frame rigid wheelchairs on the market today. These chairs can be adjusted for maximum stability or fine-tuned for peak performance—quickly and easily. The new super lightweight frame is more compact and easier to transport, while the curved rear frame offers a sporty look. The camber tube clamp assembly allows you to fine-tune the center-of-gravity in an infinite number of settings.

For more info on the Invacare A4, visit www.invacare.ca.

### SCI Solutions Network is now the Rick Hansen Institute

On January 1st, 2010, we officially changed our name from the SCI Solutions Network to the Rick Hansen Institute (RHI).

The decision was made during an October 22, 2009 meeting of our Board of Directors, who voted unanimously in favour of the name change as a way to acknowledge the tremendous impact Rick Hansen has had in the field of spinal cord injury in the 25 years since he completed his epic Man In Motion World Tour.

“We felt that, given the contributions Rick has made here in Canada and abroad, and the fact that his vision and tenacity gave birth to this organization, it was only fitting to acknowledge him with our new name,” says Daryl Rock, Chair of the Rick Hansen Institute Board of Directors. “It’s particularly gratifying and appropriate to make this change as Rick kicks off the celebration of his 25th anniversary of the World Tour. We are certainly proud to have our organization bear his name, and it’s with great enthusiasm that we look forward to the work we will do under his banner during the next 25 years.”

Hansen has graciously given his blessing for us to use his name. He and the Rick Hansen Foundation (not to be confused with the Rick Hansen Institute) will continue to provide guidance and support as we continue our work in years to come.

You’ll notice that, while the name has changed, the graphic part of our logo has not. Nor has our mandate. It’s business as usual for the Rick Hansen Institute. Our objectives and strategies will not be altered. All of our work in progress and all of the partnerships we have created across Canada remain our top priorities.

The Board of Directors, staff and volunteers of the Rick Hansen Institute look forward to moving forward with our partners across Canada to achieve our collective mission of minimizing disability and maximizing the quality of life of people with SCI.

### Rules and Regulations

- Contestants must have a spinal cord injury
- Contestants must live in Canada
- Winners will have to answer a skill-testing question
- Prizes are for personal use and not for re-sale

One 16 x 16 chair and one 18 x 18 chair are available—please specify your preference.

Please email your high resolution photo and your explanation of why it’s time to replace your existing chair to info@rickhanseninstitute.org—be sure to type “Invacare Contest” in the subject line.

By entering the contest, participants consent to having their photo and explanatory text appear on the Rick Hansen Institute’s website and in future issues of *Solutions* magazine.

Thanks and good luck!
New technologies for people with SCI

Buggy Bag
The Buggy Bag Lap Blanket is designed to protect wheelchair users from the elements. It’s easy to put on and take off, thanks to a full length AquaGuard zipper opening and an inner layer of smooth nylon. A waterproof coated nylon outer layer with fleece lining keeps the wearer warm and dry. The large zippered pocket provides a convenient place to store your wallet, keys and cell phones, and reflective stripes make travelling safer on dark and dreary days. Every Buggy Bag Lap Blanket is custom-made to suit each customer’s individual needs by owner Leslie Cairns, a former film industry costume pattern maker who lives in Burnaby, BC. After her daughter was born, Cairns could not find a stroller blanket that met her needs, so she created one herself. From there, Buggy Bag was born, and it wasn’t long before Cairns was approached to design a similar product for wheelchair users. She’s in the midst of developing a line of wheelchair ponchos and scooter aprons, and expects to launch these products later in the year. For more information, visit www.buggybag.com.

Riding the Spyder
Google “Can Am Spyder” and “wheelchair” and you’ll quickly discover that Canada’s Bombardier Recreation Products (BRP) has hit a home run with wheelchair users with its innovative Can Am Spyder roadster. The Spyder’s three wheel design provides a great deal of stability at rest or in motion, and it turns without any counter steering or leaning. It has a 986 cc Rotax engine that produces 106 horsepower, and comes standard with a Vehicle Stability System (VSS™) that includes ABS, traction control, and stability control. For many people with SCI, the Spyder can be operated with three modifications—adding a way of controlling the brake by hand (a footbrake is standard), adding floorboards to support the feet, and creating a carrier to attach a folding wheelchair to use at a destination. The option of a semi-automatic five speed transmission with reverse resolves the problem of foot-shifting through the gears. To operate the Spyder, you need a motorcycle license. Visit www.spyder.brp.com to view videos and learn more.

Tongue Control
Researchers at the Georgia Institute of Technology have developed a system that allows people with high level tetraplegia to operate a powered wheelchair or control a mouse cursor using simple tongue movements. A small magnet the size of a grain of rice is attached to the user’s tongue with tissue adhesive. Movement of this magnet is then detected by an array of magnetic field sensors mounted on headphones. The sensor output signals are wirelessly transmitted to a portable computer, which is carried on the wheelchair. The computer then controls the movements of the cursor on a computer screen or the movements of a powered wheelchair. The Tongue Drive system can potentially capture a large number of tongue movements, each of which can represent a different user command. This would provide significant advantages over the common sip-n-puff switches. For now, the technology remains in experimental testing.

The Rick Hansen Institute in no way endorses, recommends, or approves the products described above. Consumers are urged to perform their own research prior to purchasing these or any other products.
Research Director Appointment
The Rick Hansen Institute is pleased to announce the appointment of Dr. Chris McBride to the position of Director, Translational Research Program.

Chris has worked with RHI for the past year and a half as Managing Director. Previous to that, he was Managing Director of ICORD (International Collaboration On Repair Discoveries).

Chris is also currently Co-Leader of the Disabilities Health Research Network. He obtained his PhD in neuroscience from UBC, where he studied the efficacy of preclinical neuroprotective approaches for SCI. Chris has served as an executive on the Board of the Rick Hansen Solutions In Motion Alliance, and has volunteered his time as Co-Chair of the Rick Hansen Wheels In Motion Vancouver Event and other community-related events, such as the World Wheelchair Rugby Championships which takes place later this year.

“Chris brings a unique combination of scientific knowledge and community experience to the position,” says Bill Barrable, RHI CEO. “One of our most important goals is better collaboration between SCI researchers and the SCI community, and Chris is well qualified to lead in this regard.”

Kwon Named Top 40 Under 40
Dr. Brian Kwon, spine surgeon at Vancouver General Hospital and an SCI researcher who is funded in part by RHI, has won the prestigious Vancouver Top 40 Under 40 Award.

The award was founded by Business in Vancouver to honour corporate leaders, entrepreneurs and non-profit leaders in British Columbia who have reached a significant level of success before.

Kwon, who is 38, became interested in SCI during his residency at the UBC, after he earned a medical degree from Queen’s University in Kingston. In 2004, he was one of six people to receive a New Investigator Award from Canadian Institutes of Health Research, and he has lectured about SCI across North America.

Kwon’s research interest is in the pressure of spinal canal fluid during acute SCI. RHI has provided funding for Kwon and co-investigators to conduct a multi-centre clinical trial to validate his method of determining this pressure and the role it plays in the days and weeks following a SCI.

Here’s what he described as the most important goal he has left to achieve: “Be able to tell a spinal cord injury patient and his or her family that there is in fact something we can do to treat their paralysis and improve their chance of walking out of Vancouver General Hospital.”

“Death Messenger” Prevents SCI Healing
The signaling molecule CD95L, known as “death messenger,” prevents the injured spinal cord from healing by calling for migration of immune cells to the injury site, according to a new study published by scientists at the German Cancer Research Center.

Previously, it had been thought that CD95L exerts its harmful effect in the injured spinal cord by causing programmed cell death (apoptosis).

The study, published in the journal Immunity, explains how the researchers blocked the death messenger using specific agents, causing the migration of immune cells to end, and allowing the injured spinal cords of mice to heal and the animals to regain better ability to move.

Substances which block the death messenger might offer a new approach in the treatment of acute SCI in humans. Such an agent might soon be available—a biotech company is already developing an inhibitor which specifically switches off the human CD95L molecule.

Once a Rink Rat, Always a Rink Rat
Halifax’s Kevin Murphy is one busy guy. Not only is he a National Solutions Coordinator for RHI’s Community Partnerships Program and a Rick Hansen Ambassador, he’s also the driving force behind the Kevin Murphy Hockey Fund Program.

Since 1986, this program has awarded a bursary to an outstanding youth who displays an incredible amount of commitment at the arena, in the classroom, and in their community. In 2009, Kevin expanded the program’s mandate to help Nova Scotia arenas purchase safety equipment and training to better deal with catastrophic hockey-related injuries including SCIs, lacerations and heart attacks. These efforts have resulted in the donation of first aid equipment, auto defibrillators, back boards, neck braces, and staff safety training.

Kevin became a quadriplegic at the age of 14 when he was injured during a bantam hockey game. That didn’t prevent him from getting a university degree in commerce, operating several businesses, or being a husband and proud father of a son and a daughter.

All along the way, his love for the game remained strong. “Hockey has played a huge role in my life,” says Kevin. “This program gives me the opportunity to give back to the game, and my community that means so much to me.” Learn more about the program by visiting www.kevinmurphyhockey.ca.
Back in 2004, Dr. Kim Anderson-Erisman no doubt turned some heads when she published results of a study that suggested that people with SCI had considerably different priorities than many of her colleagues in the SCI research field.

Anderson-Erisman, who is herself tetraplegic, was a researcher at the University of California’s Reeve-Irvine Research Center at the time. She analyzed the priorities of 681 people living with SCI in the study, titled *Targeting Recovery: Priorities of the Spinal Cord-Injured Population*. Participants were asked to rank the importance of functional recovery in seven areas: arm/hand function, upper body/trunk strength and balance, bladder/bowel function and elimination of dysreflexia, sexual function, elimination of chronic pain, normal sensation, and walking movement.

Just over half of the participants were tetraplegic. Of these, the vast majority—almost 49%—placed recovery of arm and hand function at the top on their wish list. The next closest priority was regaining upper body and trunk strength at 11.5%. Regaining walking movement was the highest priority for only 7.8%. (For the curious, regaining sexual function and bowel/bladder function were the highest ranked priorities for participants with paraplegia).

Anderson-Erisman, who is now Director of Education for The Miami Project to Cure Paralysis and a member of RHI’s Research Advisory Committee, may have surprised many with the results of her study. But Dr. Arthur Prochazka, professor at the University of Alberta’s Centre for Neuroscience and Department of Physiology, wasn’t among them. In fact, Prochazka has been working for more than 15 years to develop new methods for people with paralysis to regain hand function.

“For many people with tetraplegia or paralysis from other conditions such as brain injury, improvements in arm and hand function can make huge differences in quality of life,” says Prochazka. “Even small gains can mean the difference between independence and dependence, in terms of the ability to eat without assistance, operate a computer, or read a book.”

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ReJoyce revisited

After intensive testing and validation, Dr. Arthur Prochazka’s innovative ReJoyce arm and hand rehabilitation workstation is poised to become a fixture in rehabilitation centres around the world—and even in some people’s homes.
As we told you about in the Spring 2009 issue of Solutions, one of the ways that Dr. Prochazka has met the challenge of improving arm and hand function is through the development of the revolutionary ReJoyce hand and arm rehabilitation system. ReJoyce consists of a table-top mount, a spring-loaded arm, and hand dexterity trainer called a manipulandum assembly. The arm suspends the manipulandum assembly at a comfortable height for the hands, and gives a user the freedom to move the assembly through his or her entire range of motion. The manipulandum assembly features two horizontal handles, a pressure gripper, a doorknob, a key, a peg, a jar top, and two coin simulators, allowing for simulation of almost any task of daily living—from pulling on a pair of socks to pouring a glass of juice.

This hardware is integrated with a computer running game-based exercise and evaluation software. A patient can use the workstation alone or under supervision by a therapist, either in person or via a standard internet connection to allow long distance tele-rehabilitation.

The result is a system that can be used by itself, or in combination with a “HandStim” device to stimulate key paralyzed arm and hand muscles, in a daily exercise regime carried out over several months, to improve the ability to carry out common daily tasks involving grasping and manipulating objects. The improvements are clear and last after the regimen is finished.

For the past two years, ReJoyce has been in the clinical trial stage, with evaluations being conducted in Canada, the United States, Australia and New Zealand (RH1 has provided more than $360,000 to support this testing). Although clinical testing is not 100% complete, it has been clearly validated as an ideal method for treating and evaluating patients who have a wide range of neurological and physical challenges preventing normal arm and hand function.

Today, ReJoyce is in the final stages of regulatory testing in Canada and the U.S. Prochazka hopes that it will be commercially available across North America by April or May.

Once available for sale, ReJoyce will initially be offered to rehab centres and clinics throughout Canada by Rehabtronics, a privately-held medical services company based in Edmonton which is operated by Andy Prochazka, an engineer who also happens to be Arthur’s son.

The price tag will be surprisingly modest. “It’s very important that ReJoyce is affordable,” says Arthur Prochazka, explaining that ReJoyce will retail less than $10,000, compared to robotic arm and hand rehab devices that can cost upwards of $60,000. “There is little difference in the outcomes, if any, between ReJoyce, which is based on exercises involving the patient’s own efforts, and the more expensive systems, in which a complex robot assists movement.”

“We’ve already had a great response from rehab centres that have had a chance to use ReJoyce,” adds Andy Prochazka. “Patients have loved the system when they’ve had a chance to use it.”

The combination of effectiveness and affordability makes it likely that ReJoyce will become a fixture in rehab centres across Canada and perhaps around the world. But the modest price also means that it will probably be made available to individuals. “Having ReJoyce in clinics will certainly boost its credibility, but what we’re really excited about is the opportunity for people to use it in their homes,” says Andy Prochazka.

What will allow this unique and exciting aspect of ReJoyce commercialization is the fact that therapists can monitor and guide patients from a remote location, using a standard internet connection. This promises to reduce the need for people to arrange travel for the sole purpose of receiving therapy, and provide people outside of major centres more equitable access to therapy.

“Telehealth is increasingly being recognized as an effective and cost-efficient treatment option for people once they leave rehab,” says Arthur Prochazka. “It’s happening in Canada, and you can also see it becoming more of a focus in the USA where there is currently a bill before Congress to allow telehealth services to operate across state lines.”

So in addition to clear benefits to individuals who use the system, embracing ReJoyce likely means a significant cost savings for the Canadian healthcare system. First, there are the direct savings resulting from people becoming more independent in their homes—for example, increased hand function may allow some people to perform procedures such as catheterization without the assistance of a personal care attendant. Second, there are likely to be other human resource savings during rehab, as this type of therapy has been traditionally provided via a time-consuming, one-on-one approach. And third, given that ReJoyce can be offered in the home, there should be a corresponding reduction in institutional costs and overhead.

Rick Hansen Ambassador Jennifer Gabrysh is one of many people with SCI who have participated in the ReJoyce clinical trials and is looking forward to the commercial availability of the system. “I’m thrilled about the possibility of having the ReJoyce system produced and marketed for in-home rehabilitation,” she says. “I saw positive, practical results after my experience, and for me, access to this technology cannot happen fast enough.”

Gabrysh, who lives in Regina and is tetraplegic, is hopeful that others will benefit from ReJoyce the way she has. “Based on my experience in the SCI community, one of the main reasons why persons with a spinal cord injury quit taking part in a specific aspect of their rehabilitation is because it requires arranging transportation and an assistant to accompany them, both of which are sometimes tough to come by,” she says. “If the ReJoyce system were installed at home or at a rehabilitation facility where many people could access it on a daily basis, this would result in huge gains in people’s experiences and recovery.”

For more information, visit www.hometelemed.com.

You’re Invited to Niagara Falls...

Toronto Rehabilitation Institute’s 4th National Spinal Cord Injury Conference will be held at the Fallsview Casino in Niagara Falls on October 28 - 30, 2010. The Rick Hansen Institute is once again working with Toronto Rehabilitation Institute to provide funding for consumers with SCI from across Canada to attend this conference and learn more about exciting SCI research underway. If you’re interested, visit www.rickhanseninstitute.org for more information.
Visit the Owls Head Ski Area near Mansonville, Quebec on an average winter Saturday and you’ll see an amazing sight: dozens of people with SCI and other disabilities using state-of-the-art adaptive ski equipment, hitting the slopes with able-bodied skiers.

This hotbed of disabled skiing is largely the result of Quebec’s Adaptive Sports Foundation (ASF), formerly known as the Eastern Townships Disabled Skiers Foundation. ASF’s mission is to build a better quality of life for people with disabilities through sport.

“Winters are long for everybody, but for people who use wheelchairs, they can be even longer,” says Peter Treacy, ASF President. “It means so much when they have the opportunity to go skiing with family and friends, and ski as well as or better than everyone else on the hill.”

Founded in 1995 by Treacy, ASF operates and maintains educational programs that encourage kids and adults with physical disabilities to discover new active living opportunities through alpine skiing and water sports. Along with a team of dedicated volunteers, Treacy provides an opportunity that is changing lives.

A great example is Francis Courchesne, who has carved the ski hills near his home in Montreal for most of his life. On March 25, 2007, Courchesne lost a ski and crashed into a stand of trees. The only thing he remembers is waking up in a Montreal hospital seven hours later, unable to move his legs.

“It was devastating,” says Courchesne, who spent the next three months in rehab, learning to adjust to a new life with a SCI. In his most difficult moments, the thought of skiing again helped Courchesne persevere. “It was a big motivation,” he says, “to get back on that hill.”

As soon as he was out of rehab, Courchesne got online and began researching options that would allow him to ski again. His determination paid off—less than nine months after his accident, Courchesne was back on the slopes, doing what he loves most.

He made his first attempt as a sit-skier with the help of an instructor who he discovered online. After a couple times on the hill, the in-
In 2007, RHI and Wheels In Motion provided a $4,500 grant to support ASF, which also runs a summer program on Lake Massawippi in Ayer’s Cliff, Quebec, in partnership with MAB/Mackay Rehabilitation Centre. Participants can try their hand at sports such as water skiing, canoeing, kayaking and sailing. For more information on the ASF’s summer and winter programs, please visit www.fshe.org.
During rehab, people with SCI are read the riot act about autonomic dysreflexia, or AD. They learn that AD is a potentially life-threatening response to pain (or other stimulus such as bladder pressure) below the level of injury, and that anyone with an injury higher than T6 is at risk. Even though the pain may not be felt, the nervous system reacts by constricting the blood vessels and increasing the blood pressure. Other branches of the body recognize the increase in blood pressure and try to offset the change by slowing the heart rate while distributing signals to notify the blood vessels to relax. Due to the SCI, these signals can’t pass through to the brain. This causes the body to continue slowing the heart rate and sending signals to the blood vessels while the blood pressure keeps rising.

If left unchecked, the results can be as extreme as death due to seizures, heart attack and stroke. And even repetition of minor cases of AD can contribute to an increased risk of developing heart disease and stroke in people with SCI.

All of this is drilled into the heads of people with SCI by conscientious rehab professionals, in the hopes of ensuring that each person becomes an expert at

Autonomic dysreflexia can be deadly for people with SCI, but it’s also easily treated—providing emergency personnel and hospital staff recognize it. Unfortunately, that’s not always the case. Dr. Andrei Krassioukov is working to change that.
Unfortunately, many emergency and non-specialist medical personnel don’t ever receive the same specific training on AD. Recognizing and managing AD are challenging medical issues, and emergency personnel who aren’t in contact with people with SCI on a daily basis may fail to recognize the signs of AD. As a result, people with SCI could be in danger while in the care of the very people who are charged with saving lives.

“We have to recognize that SCI is an extremely small ‘disease’ in comparison with stroke, myocardial infarction or trauma,” says Vancouver’s Dr. Andrei Krassioukov, a world-renowned expert in AD. “Emergency room docs and paramedics are prepared for the major issues, or most common patients who will be admitted to the hospital.”

Krassioukov wants to remedy the situation—and believes it can easily be achieved through provision of a focused AD course for emergency room personnel and paramedics. The Rick Hansen Institute wants to help Krassioukov with this goal, and last year provided him and several co-investigators—Dr. Darren Warburton, Janice Eng, Karen Ethans and Cathy Craven—with a $96,558 Rapid Response Award to develop and validate an “ABC Course on AD” that would be similar to well-known life-saving CPR courses.

In addition to providing critical information on the more serious AD, it would also seek to provide education on orthostatic hypotension, which also results in spikes of blood pressure in people with SCI.

The project is well underway, with three provinces involved: British Columbia (GF Strong Rehabilitation Centre, Vancouver General Hospital, ICORD/UBC, and BC Paramedic Academy), Manitoba (Health Sciences Centre, Winnipeg), and Ontario (Toronto Rehabilitation Institute/Lyndhurst Centre and Sunnybrook Health Sciences Centre, Toronto).

“First, we used validated self-administered questionnaires on knowledge regarding unstable cardiovascular control and management of AD among the emergency room physicians and nurses, as well as paramedics,” explains Krassioukov. “Based on information obtained with the questionnaires and interviews, a special educational course for emergency room doctors and paramedics was then developed. The course has had a first testing in one centre, and we have made further changes and will start further testing and evaluation in April in all three centres.”

Krassioukov expects that the introduction of the ABC Course on AD will improve knowledge of emergency room personnel and paramedics and decrease the emergency room and hospital admissions related to SCI. “We also are proposing that this educational tool will be eventually widely accepted outside of the hospital environment,” he says.

“This is important work,” adds Dr. Chris McBride, Director of RHI’s Translational Research Program. “Once validated, we’ll work with Dr. Krassioukov to explore ways of making the ABC Course on AD widely available via the Internet, and other electronic or print resources. It’s an ambitious goal, but we would like to see this life-saving educational tool as widely accepted and utilized as the well-known CPR courses.”

Dr. Andrei Krassioukov

Dr. Krassioukov (Dr. K to many of his students) is recognized as a world leader in research of autonomic dysreflexia and dysfunction following SCI. He has chaired the International Committee for the International Autonomic Standards in SCI Patients (ASIA/ISCoS) for the past four years. The standards were developed and published in 2009, and have been translated into Chinese, Danish, and Portuguese.

In 2009, Krassioukov was the recipient of the inaugural Alan T. Brown Award from the American Spinal Injury Association (ASIA) for his leadership in this area of clinical work and research.

Krassioukov graduated medical school in 1979 in Volgograd, Russia. “My first SCI work started during my PhD training in Russia at the Ivan Pavlov Institute of Physiology, in St. Petersburg,” he explains. “During my PhD, I studied the mechanisms of blood pressure control by spinal cord neurons. My PhD supervisor was a brilliant Russian scientist, Dr. V. P. Lebedev. He pioneered numerous studies on spinal cord neuronal investigations. Following my PhD, I practiced neurology in Estonia for more than 10 years before I came to Canada. During my clinical practice as a neurologist, I followed numerous young patients with SCI and become aware of their horrific issues with autonomic dysfunctions. Since that time, my clinical and basic research has focused on autonomic dysfunctions, blood pressure regulation and role of the SCI.”

In 1991, Krassioukov came to Canada through the Canada-USSR medical research exchange program and started working at the University of Western Ontario’s Robarts Research Institute. In 2003, he moved to Vancouver to start his residency at UBC, in order to be able to certified to practice in Canada. Today, he holds a joint faculty position with ICORD (International Collaboration On Repair Discoveries) and the Division of Physical Medicine and Rehabilitation. He also has a clinical practice at Vancouver’s GF Strong Rehabilitation Centre.
Dedicated volunteers and support from Sam Sullivan’s Disability Foundation have helped to cultivate an innovative gardening program for people with disabilities in Vancouver.

Since 2003, the revitalized Disabled Independent Gardeners Association (DIGA) has helped make gardening an equal opportunity activity in Vancouver.

DIGA was originally established in 1987 by a group of passionate gardeners living with disabilities, but ceased operations in the mid-1990s. Then, in 2003, former Vancouver mayor Sam Sullivan began exploring his green thumb and the possibility of reviving DIGA. He offered the support of his Disability Foundation, recruited a dedicated board of directors (each one a gardener with a disability), and elicited guidance and support from David Tarrant, well-known author and television gardening personality. As a result, DIGA again flourished, providing a unique rehab and active living opportunity for people living with SCI and other disabilities in Vancouver.

“Gardening is not only a recreational activity, but also provides many therapeutic benefits while helping build confidence and independence,” says Betty Cheung, DIGA Program Coordinator. “Our primary goals are to encourage people with disabilities to seek the enjoyment and health benefits of gardening,
integrate disabled gardeners with their able-bodied counterparts, overcome physical barriers, and provide gardeners with the tools and support they require.”

DIGA hosts eight educational lectures and interactive hands-on workshops every year that are tailored to the needs of gardeners with disabilities. Last year, this included an introduction to gardening for people with disabilities at the Vancouver Wheels In Motion event (Wheels In Motion and Rick Hansen Institute have also provided financial support to DIGA).

People who participate in these lectures and workshops gain the knowledge they need to grow their own accessible gardens. They also have the option of contributing and benefitting from DIGA’s two accessible community gardens, which have been located at the Seymour and Pearson Park Community Gardens since 2008. These gardens are complete with wheelchair accessible paths, raised beds and table-tops. Unfortunately, the Seymour Garden is not available this year, but DIGA is pleased to be working with the new Pandora Park Community Garden in the city’s East End to set-up additional raised-beds for existing participants plus extra space for new members.

DIGA also works closely with the Tetra Society of North America to develop innovative equipment that allows people with disabilities to garden. Tetra technical volunteers work with DIGA gardeners one-on-one to create customized assistive devices such as adapted hand tools, garden stools, and devices to help people transfer between a wheelchair and the ground.

Central to DIGA’s success are dedicated volunteers, who assist members and participants at community gardens or one-on-one at home gardening. One of those volunteers is Eva Machalek. She has generously donated her time and knowledge to DIGA since 2008, assisting at lectures and workshops, planting seeds and harvesting in the community garden.

“We’re the people who can bend, stretch and reach a little more, so we can help with those physical tasks in the garden and workshops that the gardeners can’t manage on their own,” says Machalek. “Because we can get around more easily, volunteers can also drop by the garden to do some weeding and watering. It’s surprising how just a little bit of assistance can turn an activity from impossible to possible and lots of fun.”

Terry LeBlanc has reaped the benefits of being a DIGA member since 2006. An avid gardener before a diving accident resulted in quadriplegia, LeBlanc has been able to maintain a garden at his home thanks to the support of DIGA volunteers. Because limited mobility makes it impossible for him to tend to his garden himself, LeBlanc works with a volunteer on all aspects of his garden. “I talk,” he says. “I talk to the plants and I talk to the volunteers.” By working together with DIGA volunteers, Terry is able to enjoy the fruits—and vegetables—of their combined labour.

While the harvest is important, Terry also sees integration as one of the main benefits of accessible gardening. “It’s an opportunity for people with disabilities to work together with able-bodied people, which provides a benefit to the wider community,” he says. “I think the volunteers get as much out of it as the gardeners.”

For more details about DIGA, visit www.disabilityfoundation.org/diga.
Late last year, RHI’s Board of Directors decided to focus our translational research efforts more on secondary health complications of SCI. The Board asked staff to carry out due diligence necessary to recommend specific secondary health complications to address with a managed science approach from within the Translational Research Program.

The first thing we did was ask Canadians with SCI for their input. We put together a non-scientific, web-based poll that encouraged people with SCI in particular to identify their priorities from a list of the most common SCI secondary health complications. This method of seeking consumer input is consistent with the provisions of our funding agreement with Western Economic Diversification.

In December, RHI staff placed the poll online and advertised it prominently on the front page of our website. It consisted of three questions: Which secondary complication is most important to focus research on? Which secondary complication is second-most important? Which secondary complication is third-most important?

The choices for all three questions were secondary complications deemed to be of notable importance from a review of the scientific literature. They were listed in alphabetical order: autonomic dysreflexia, bladder function/urinary tract infections, bowel complications, cardiovascular disease/respiratory issues, neuropathic/spinal cord pain, osteoporosis/bone fractures, pressure ulcers, psychological distress, sexual health and functioning, and spasticity.

From December 12th to January 15th, 291 people responded to the poll. Of these, 81% identified themselves as having a SCI.

Bladder function/urinary tract infection was the clear priority for people with SCI. It was reported as the top priority for all three questions. The second most identified top priority was neuropathic pain. Pressure ulcers and bowel complications rounded out the four most commonly identified top priorities.

While lacking scientific rigor, the poll is interesting because it confirms the findings of several scientific surveys conducted in the past decade, here in Canada and around the world.

The takeaway here is that bladder issues and UTIs are critically important to you. So the next steps are to answer some important questions. What are your specific concerns in this area? For example, are UTIs most important, or is it regaining bladder function? What research is being done in Canada and around the world in this area? What best practices exist that are not widely employed in Canada? What is the capacity of the Canadian research community to work in this area?

Stay tuned for progress, and for more opportunities to voice your specific priorities in this area. And thanks to all who took the time to respond.

Researchers led by Dr. Karl Sievert at the University of Tuebingen in Germany believe that a technique called sacral neuromodulation is the key to restoring bladder function in people with SCI. The researchers published findings from their recent research project, titled “Early sacral neuromodulation prevents urinary incontinence after complete spinal cord injury,” in the January 2010 issue of the *Annals of Neurology*.

Sacral neuromodulation involves stimulation of the sacral nerves that control pelvic organs with an implanted electrode and a battery-powered pulse generator. The study’s aim was to “investigate potential influences on human nerves and pelvic organs through early implantation of bilateral sacral nerve modulators (SNMs) in complete SCI patients.” Sixteen patients were involved in the trial. Ten patients with complete SCI were provided with bilateral SNMs. Six patients declined and served as controls. The mean follow-up was 26.2 months.

The study confirmed that the procedure resulted in urinary continence and significant reductions in urinary tract infections (UTIs), and other benefits. “Early SNM implantation in SCI patients may revolutionize neurogenic lower urinary tract (LUT) dysfunction management; it prevented detrusor overactivity and urinary incontinence, ensured normal bladder capacity, reduced UTI rates, and improved bowel and erectile functionality without nerve damage,” wrote the study’s authors.
Since 2003, Rick Hansen Wheels In Motion has worked side by side with our SCI community partners to build a successful fundraising event that provides a meaningful experience for people with SCI and able-bodied people alike while raising crucial funds to improve the quality of life of people living with SCI. Partners such as the Canadian Paraplegic Association (CPA) and wheelchair sports organizations across Canada have been instrumental in helping Wheels In Motion raise in excess of $10 million to support more than 900 quality of life projects.

For the 2010 campaign, Wheels In Motion will be working more closely than ever with the CPA, having entered into agreements in several provinces to have the CPA take on a leadership role in producing the event.

“We are thrilled about the partnership between WIM and CPA for 2010 as it will give us greater strength to work towards our shared goal of improving the lives of people with spinal cord injury,” says Shelley Milstein, Events Manager for Wheels In Motion.

In the provinces of Alberta, Nova Scotia, New Brunswick, Newfoundland/Labrador, Quebec and PEI, CPA staff will work directly with Wheels In Motion volunteers to deliver the Wheels In Motion event. This partnership will help WIM achieve its goals of engaging Canada’s SCI community more fully in participation and fundraising and in promoting awareness of the impact WIM has in communities.

CPA National Interim Executive Director Bobby White has been instrumental in building the relationship with Wheels In Motion, and hopes that the model that has been established in Atlantic Canada can serve as an example going forward. “This project brings all of the Atlantic CPA’s together in a collective way to work together towards solutions for individuals with a SCI or other mobility disabilities,” says White. “This will also increase the capacity of our volunteers on a regional basis and help us touch the lives of people in rural areas.”

“As we move forward, we hope that this model will help similar partnerships develop so that we can continue to grow a strong network that is dedicated to improving the lives of people with SCI,” adds Milstein.

Wheels In Motion brings communities together and touches the lives of thousands of Canadians with SCI every year. Funds raised support a wide range of life-enhancing programs that allow people with SCI to fully participate in their community and live life to its full potential. To find out how to get involved and make a difference, visit www.wheelsinmotion.org.
We can not change lives.

Participate in your local Rick Hansen Wheels In Motion event and support Canadians living with spinal cord injury.

JUNE 13

Rick Hansen Wheels In Motion

presented by Scotiabank

Register or donate at wheelsinmotion.org