Here is such power in partnerships! From the team supporting Rick Hansen on the Man In Motion World Tour 25 years ago, to our expanding research network across Canada and internationally today, partnerships are the key to extraordinary progress.

This collective effort of like-minded individuals has led to significant advancements, including a dramatic improvement in survival rates after initial injury and a reduction – by almost half – of overall acute hospital stays, through early intervention.

But we have a long way to go to address the impact and staggering costs of treatment and care for the more than 86,000 Canadians living with spinal cord injury, and the thousands of new cases every year. It is estimated that traumatic spinal cord injuries cost the Canadian economy well over $3 billion every year.

The cost is also physical, emotional and social. While individuals struggle to deal with the impact of their injury, the well being of their families and communities are also profoundly affected – exacerbated by a 60% unemployment rate among individuals with SCI.

Yet, there is great hope. We’ve been inspired by many great personal stories of Canadians who have come out to support the relay to celebrate the 25th Anniversary of Rick Hansen’s Man In Motion World Tour.

And thanks to partnerships with our federal and provincial governments, Canada has become a world leader in spinal cord injury research and care. These investments – leveraged many fold with private and corporate donors – are already showing positive returns and will lead to even more advancements in care and associated reductions in healthcare costs.

We estimate that a 10% reduction in hospital readmissions for secondary complications that will result in direct cost savings of $66 million over a five-year period. And the savings are even more dramatic if best practices are applied to the wider patient population.

Canadians will soon benefit even more from our new global partnerships which, we believe, can accelerate the pace of research outcomes through strong multi-jurisdictional collaborations.

In this issue, we highlight some of the work of our partner network, including a milestone reached with the SCI Community Survey, and the innovative Global Research Platform. We appreciate your contributions to the steady and inspiring progress so far and I’m looking forward to what we can accomplish together, this year, and in the years to come.

Our best work is ahead of us.

Bill Barrable
CEO, Rick Hansen Institute

Then & Now
($26 million)
Funds raised during the original Tour.

$245 million
Leveraged investments towards spinal cord injury research, rehabilitation and quality of life initiatives.

30% Chance of some varying degree of recovery for an individual in Canada with a spinal cord injury.

70% Chance of some varying degree of recovery for an individual in Canada with a spinal cord injury.

Future need
60% Estimated increase in the number of people who will have mobility problems by 2030, due to aging and other factors.

IN THE NEWS

• The Rick Hansen Institute has become the first centre outside of the US to be invited to join the prestigious Consortium for Spinal Cord Medicine, which facilitates the development and distribution of clinical best practice guidelines across the international spinal cord medicine practice community. Membership in the Consortium will provide the Institute with a platform to share Canadian knowledge and expertise with other leaders in the field of spinal cord injury. For more information, visit scicpg.org/

• The Institute partnered with the Journal of Neurotrauma to publish a special issue: A State of the Art Review on Acute Spinal Cord Injury, available online free of charge. Guest edited by Dr. Michael Fehlings, this issue encompasses 17 articles addressing the most clinically-relevant issues within the acute care of spinal cord injury. Read the issue at liebertonline.com/jocn/rev29/8

• Congratulations to ICORD Associate Director – Rehabilitation Research, Dr. Andrei Krasieoukov and his team, who were awarded a Canadian Institutes of Health Research team grant of $1.9 million, to improve cardiovascular health for individuals with chronic SCI through optimized exercise and targeted education.

• Ottawa neurosurgeon and Rick Hansen Institute researcher, Dr. Eve Tsai, was voted most influential woman in the ‘Health’ category by Women of Influence Magazine.

Facebook | twitter | Online

Visit the Institute’s online Media Room anytime for all of our latest news.
REGARDLESS OF CAUSE OR AGE AT INJURY, SPINAL CORD INJURY HAS A DEVASTATING IMPACT ON AN injured person’s health and well-being, and far reaching consequences for their families and communities. Today, there are approximately 86,000 Canadians – and hundreds of thousands more around the world – living with this chronic, lifelong disability. Canada is a leader in spinal cord injury research and treatment, and with initiatives led by the Institute, well-placed to overcome the biggest barrier to progress in the field – insufficient access to people with an injury who can assist with further research.

Because of the high cost of specialized care and treatment over the lifetime of someone living with spinal cord injury, it is essential to find ways to reduce the burden on the healthcare system. The need is urgent, as the rate of injuries – from falls and illnesses – will increase, as the world’s population ages.

Canada isn’t enough

“It is estimated that Canada, at most, could provide only 30% of the participants required to support the number of clinical and research trials needed to bring a cure,” says Institute CEO, Bill Barrable. “With our mandate to accelerate the pace of new treatments and cures, we must collaborate with researchers, worldwide. “We can make our precious resources go further and reach our goals much faster by making this a coordinated, global effort.”

The innovative Rick Hansen Institute Global Research Platform (GRP) was developed to respond to this reality. A borderless, flexible and secure web-based data collection system, GRP allows for faster collection and reporting for research and prospective enrolments. Data can be accessed through an internet connection which means research facilities can easily set up multi-centre trials across vast geographic regions, and without huge investments in infrastructure. Already used to run the RHISC Registry Study in 32 sites across Canada, it is expected to become the platform of choice for other multi-site clinical trials, within our expanding international network of partners. In Brisbane, Australia, these efforts are already underway.

“We can’t answer all the questions in Canada alone. We need to reach out beyond our borders and that’s why we are partnering with premier SCI-related research organizations and healthcare facilities such as the China Rehabilitation Research Center, The Miami Project to Cure Paralysis and the Paralyzed Veterans of America,” said Dr. Marcel Dvorak, the Institute’s Scientific Director. “Everyone agrees that the more we work together, the sooner we’ll all reach our goals. It’s our hope that, by initiating these relationships, we are breaking down existing silos in the field and creating the foundation of a truly collaborative international network.”

“WE CAN MAKE OUR PRECIOUS RESOURCES GO FURTHER AND REACH OUR GOALS MUCH FASTER BY MAKING THIS A COordinated GLOBAL EFFort.”

Ultimately, Canadians living with spinal cord injury, and those living with other chronic diseases and mobility issues that result in painful secondary complications, will be the beneficiaries of these collaborative efforts. Mobilizing an international network of researchers, clinicians and individuals with spinal cord injury is the best hope, not only for a cure but to alleviate the extent of human suffering, improve quality of life, and reduce the staggering $3.6 billion annual care and treatment cost to the Canadian healthcare system.

New opportunities, new technologies

Ongoing challenges in coordination of research, and lack of standardization of collection and reporting of research data, have made it nearly impossible for researchers to build on the efforts of those before them. Much time and many resources can be wasted recreating the wheel, which delays important progress.

“We have an opportunity to strengthen these data with an internationally-coordinated data set allowing for long term follow-up. This makes for a much more powerful clinical and research tool.”

The conference explicitly enables cross-disciplinary interaction and knowledge-sharing among the different specialties in order to foster research collaboration and development innovative solutions to the problems faced by those with SCI today. It will be a catalyst for international collaboration and have a major impact on the journey for a cure,” says Michael G. Fehlings, Chair of the 2012 Research Program Advisory Committee.

The conference takes place when the city will be gearing up to welcome home the Rick Hansen 25th Anniversary Relay team, just a few days after the conference ends,” says Nancy Thompson, 2012 Conference Director. “The city is at its most beautiful in May, dressed up with cherry blossoms and spring flowers so we hope that conference participants will stay a bit longer, to enjoy the city and take part in the festivities planned.”

To register and see complete information on conference programs, including keynote speakers, please visit richhansen.com/interdependence2012.

We look forward to seeing you there.
NEW PARTNERSHIP TO HELP CANADA’S MILITARY & VETERANS

In October, the Rick Hansen Institute and the Canadian Institute for Military & Veteran Health Research (CIMVHR) signed an agreement to work together to improve the healthcare outcomes for Canadian military and its veterans living with spinal cord injury. Rick Hansen, Co-Chair of the Rick Hansen Foundation, and Bill Barrable, Rick Hansen Institute’s CEO and Alice Aiken, Director of CIMVHR, attended the signing in Kingston, Ontario.

In this new partnership, the Institute will act as the primary resource for spinal cord injury translational research and best practices implementation for the CIMVHR to translate into the unique context of the Canadian military. The collaboration will focus specifically on reducing the incidence and severity of permanent paralysis resulting from SCI, increasing restoration of physical function, and reducing the incidence and severity of secondary complications.

“More people have served in Afghanistan than served in Korea, and their injuries are more serious,” said Alice Aiken, an associate professor at Queen’s University, former member of the Royal Canadian Navy, and now Director of the CIMVHR. “It’s important to ensure relevant research is being done that will directly impact the lives of these Canadian heroes and those who have gone before them.”

“This is a significant milestone and an important step towards understanding veteran health issues related to SCI, and this partnership will help us move towards building a broader community dedicated to veteran and military health,” said Barrable.

For more information about the Canadian Institute for Military and Veteran Health Research, please visit cimvhr.ca.

RESEARCH PROJECTS SHOWCASED

We were pleased to host the first two of a series of Rick Hansen Institute Showcase events – in Ottawa on November 21, and in Toronto on November 30 – where Members of Parliament, Senators, Members of Provincial Parliament, and government officials viewed, first hand, some of the innovative projects underway by our national network partners.

The Ottawa event was co-hosted by the Honourable Alice Wong, MPP for Richmond, BC, and Manon Perreault, MPP for Montcalm, QC, and Toronto’s event by Elizabeth Witmer, MPP for Kitchener-Waterloo, ON. Those in attendance in Ottawa heard Minister Steven Fletcher give an inspiring speech reminding us all exactly why we’re working to improve the quality of life for tens of thousands of Canadians living with spinal cord injuries, and related medical conditions. In Toronto, France Gélinas MPP for Nickel Belt and Phil McNeely, MPP for Ottawa-Vanier, both gave warm welcoming speeches.

To view materials and photos from these showcases, visit our website.

2,350+ NOW IN REGISTRY

In late 2011, the 2000th Canadian signed up to participate in the Rick Hansen Spinal Cord Injury Registry. Active in 31 major Canadian acute care and rehabilitation hospitals across the country, the Registry tracks the experiences and outcomes of people with traumatic spinal cord injuries during their journey through acute care, rehabilitation and community reintegration. Stored in a central location, with individual privacy and information security rigorously ensured, the data can be used by researchers and clinicians to better understand SCI and the effectiveness of specific treatments, practices or programs for improving functional outcomes and quality of life after SCI; and used as a platform to support important new multi-centre clinical trials.

The Registry will expand internationally in order to increase the quantity and quality of data collected.

Did you know...

- The Registry runs on the Rick Hansen Institute Global Research Platform – a web-based, flexible and secure data management system.
- It currently operates in 15 cities and 9 Canadian provinces.
- Four new facilities came on board in 2011, including sites in Newfoundland and New Brunswick – making a total of 31 actively participating facilities across Canada.

Learn more

If you are a clinician or researcher who would like to learn more about the Registry, please visit rickhansenregistry.org.

MY NAME IS RILEY INGE...

I was born in a small southern town in Eutaw, Alabama on September 26, 1949. I had a large family with seven siblings who all still reside in the States. I am a professional singer, songwriter, vocal coach, actor, public speaker and the father of four beautiful children. I’ve been fortunate enough to earn a living as an entertainer over the past 37 years.

On August 27, 2010 my life changed. I was at an amusement park with my fiancé who suggested we take a ride on the roller coaster. Before the ride was over, I was paralyzed from the neck down.

My injury completely changed my life. Nothing is the same as it was before the accident and, at this point, we don’t know if it ever will be. I’ve had to learn how to walk again, how to hold a fork and spoon, how to eat properly, and how to take care of myself overall. All of my mobility skills went away from me. I’ve had to work hard in order to regain some normality in my everyday life. My awakening has been amazing as to the kinds of people I’ve met at GF Strong (Rehabilitation Centre) who have had various unfortunate incidents happen, and how they’ve coped. Thank God for GF Strong and the Rick Hansen Institute or I don’t know where I’d be today.

Institute or I don’t know where I’d be today.

I wanted to participate (in the Registry) because I see this as an opportunity to maybe make a difference in others lives. Through my experience I hope to enlighten and inspire others to not give up and let the hope be drained from them. There are many things we all can do to make a difference. I am but one voice with a multitude of melodies that flows through the experiences and outcomes of people with traumatic spinal cord injuries during their journey through acute care, rehabilitation and community reintegration. Stored in a central location, with individual privacy and information security rigorously ensured, the data can be used by researchers and clinicians to better understand SCI and the effectiveness of specific treatments, practices or programs for improving functional outcomes and quality of life after SCI; and used as a platform to support important new multi-centre clinical trials.

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Learn more

If you are a clinician or researcher who would like to learn more about the Registry, please visit rickhansenregistry.org.

Your donation makes a real difference. Donations to the Institute support spinal cord injury research across Canada. rickhanseninstitute.org/donate-now
Making a Difference

THANK YOU. Many individuals across the country are making a difference in their communities – and some have generously made Rick Hansen Institute the recipient of their extraordinary efforts. We can’t thank you enough!

ROAD TRIP RAISES MONEY AND AWARENESS

Paralyzed from the waist down from a herniated L4-5 disc, in June 2005, Bert Struik recovered most of his mobility and bodily functions – thanks to much help from experts in spinal column surgery and physiotherapy. Hugely grateful to Canada’s healthcare system and the work being done to improve services, Bert – accompanied by his wife Anne – tricycled 6,000 km from Vancouver to Halifax this summer. The trip was a longtime dream fulfilled, and helped to raise awareness and donations to the Rick Hansen Institute. Read his amazing day to day journal at tricyclecanada.blogspot.com.

RUNNING FOR NIC

When he found out that his friend and co-worker Nicolas had suffered a spinal cord injury, Brent Card wanted to help. To support and encourage his recovery, he decided to raise money by seeking pledges for running a 24-hour trail race in Mansfield, Ontario. Thanks to his efforts, Nicolas made a very generous donation of over $4,000 this fall!

Do you know someone who is making a difference for people with spinal cord injury...

Or have a story about how advances in treatment and care have helped someone?

We’d love to hear your stories.

Please send them to stories@rickhanseninstitute.org

A Message from Dr. Luc Noreau, Principal Investigator

S URVEY ON NEEDS OF CANADIANS REACHES 1,000

Thank you to the more than 1,000 Canadians with spinal cord injury (SCI) who have completed the SCI Community Survey. The team is indebted to all those who took the time to take this survey.

With the incredible support of a huge number of stakeholders and organizations like the Rick Hansen Institute and the Canadian Paraplegic Association, we initiated the largest national survey of its kind addressing various aspects of life for people with SCI. This study will help guide how the Canadian health and social services systems meet critical needs of those returning to community living after injury.

Normally, any researcher would be amazingly delighted with this number but we still have a long way to go to reach our target of 3,000 completed surveys. Currently, several regions are not well represented in our sample, and we encourage anybody living with SCI to take the survey.

Right from the start when we planned and designed the survey, we were committed to providing SCI advocacy organizations – from all regions of Canada – with information that would help them understand specific issues related to community living after SCI.

Even though discrepancies might not seem so large coast-to-coast for certain aspects of life of people with SCI, others (i.e. access/barriers to services, accessibility, employment, rural vs. urban issues, etc.) require a representative sample to conduct regional analyses to be useful in designing actionable solutions.

Please visit www.sci-survey.ca or call us toll free at 1-877-594-6333. And please encourage your peers to take the survey! If you already took the survey, we thank you for your support.

Meanwhile, I’m pleased to inform you that we have initiated the process of data analysis. This preliminary process will give us some hints as to the type of information that we will be able to to extract from the data in 2012.

Luc Noreau, Ph.D.
Professor, Rehabilitation Department
Université Laval, Québec, Canada

Take the survey today and receive a $25 gift card!

To participate in the SCI Community Survey, please visit sci-survey.ca or call 1-877-594-6333.

A Message from Dr. Luc Noreau, Principal Investigator
25TH ANNIVERSARY UPDATE

Twenty-five years ago, with unparalleled drive and determination, Rick Hansen wheeled through 34 countries in 26 months to complete the Man In Motion World Tour. His incredible journey inspired an entire country to believe that anything is possible and moved thousands to make a difference in their own communities.

On August 24, 2011, the 25th Anniversary Relay set out from Cape Spear, NL to re-enact the Canadian leg of Rick’s original tour. This time, one Man in Motion has become Many in Motion, with 7,000 Difference Makers carrying the Rick Hansen Medal through over 600 communities.

The Relay is making stops at Rick Hansen Spinal Cord Injury Registry and other Institute-affiliated locations across Canada to celebrate the progress of the Rick Hansen Institute network of researchers and clinicians.

Visit rickhansenrelay.com to view the progress of the relay as it makes its way across the country.

GLOBAL ACCESSIBILITY MAP: RATE BUILDINGS AND PUBLIC SPACES WORLDWIDE

Newly-revamped BC Place Stadium was the launch site for the Rick Hansen Global Accessibility Map, a unique web-based consumer rating tool that aims to address society’s growing accessibility and mobility needs.

Users can submit or obtain reviews from a mobility, hearing and sight perspective on the accessibility of buildings in their communities. Based on a five-star framework, this tool will allow all people – including people with disabilities, seniors and parents with strollers – to make informed everyday decisions about where to eat, shop, work and play. It will also create more awareness about the economic power of people with disabilities.

“Often, someone using a wheelchair goes with friends to a local pub to find there are steps,” explains Daryl Rock, Chair of the Global Accessibility Map steering committee. “Rather than making a fuss, they ask their friends to carry them in, so the inaccessibility has no economic impact. Now, it is easy to check on accessibility and make informed decisions when choosing a location. When accessible enterprises have more clients coming through their doors, it creates an (economic) incentive.”

Easy to Use

The Global Accessibility Map can be accessed by desktop, laptop, iPad, iPhone, BlackBerry Torch and devices using Android 2.2 or above on the Opera Mobile browser. Long term plans include the development of a professional ratings tool and ongoing enhanced functionality that meets the needs of all consumers.

Rick Hansen calls this journey his “ultra-marathon of social change”.

“The Global Accessibility Map is important from an accessibility perspective, a human rights perspective, and from social and economic perspectives,” says Hansen. “The world has moved from the need for accessibility, to the need for evidence to influence change. This map will provide that evidence.”

Visit globalaccessibilitymap.com to view the progress of the relay as it makes its way across the country.
It will not be a single discovery that solves the medical puzzle of spinal cord injury. It will be a series of breakthroughs energized by researchers and clinicians. Teamwork is the path to a cure for SCI.

Rick Hansen, Honorary Chair of Interdependence 2012