Welcome to this special issue of Solutions magazine, commemorating the 25th Anniversary of Rick Hansen’s Man In Motion World Tour.

25 years ago, Rick Hansen had a dream—to make the world more accessible and inclusive and to find a cure for spinal cord injury. Inspired by a deep-seated belief that anything is possible, Rick’s “big dream” took shape in the form of the Man In Motion World Tour. For 26 months, he and his team wheeled more than 40,000 km through 34 countries, raising awareness of the potential of people with disabilities.

Following the Tour, Rick established the Rick Hansen Foundation (RHF) to continue his quest for an accessible and inclusive society and a cure for spinal cord injury (SCI). Under Rick’s leadership the Foundation functions as a social innovator, finding collaborative solutions to challenges in the community and the resources necessary to implement those solutions. It was also Rick’s vision that created the Institute that bears his name, and it is his vision that continues to motivate all those working together to reduce the impact of SCI and improve the quality of health of those living with a SCI.

The Rick Hansen Institute (RHI) works to reduce the incidence and severity of paralysis after spinal cord injury and maximize quality of life for people living with SCI (see pages 4 and 5 for more on RHI). Our primary objectives are to:

- Lead collaboration across the global spinal cord injury community including individuals with SCI, researchers, clinicians and other stakeholders.
- Provide resources and share advancements in infrastructure and knowledge developed in Canada with like-minded institutions around the world.
- Support the identification, development and validation of the most promising discoveries in SCI treatment and care worldwide into new treatments and adoption of best practices.
- Manage and grow the Rick Hansen SCI Registry to collect and analyze valuable data on SCI and to support the development of mult centre clinical trials.

RHI exists today because of Rick’s leadership and tenacity and his unparalleled ability to achieve “the impossible.” Plans and activities for the 25th Anniversary Celebrations are featured on pages 8 and 9 of this special issue.

We look forward with anticipation to the next two years as we continue to work toward a world without paralysis after SCI, improved quality of life for those living with SCI and a better, more inclusive society for all.

Bill Barrable, CEO  
Rick Hansen Institute

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The Rick Hansen Institute (RHI) is a collaboration of people with spinal cord injuries, researchers and service providers committed to addressing priority needs and generating solutions for people with spinal cord injuries (SCI).

Letters and suggestions regarding this publication are welcome. Please contact Dan Maekuch, Director of Marketing & Communications at dmaekuch@rickhanseninstitute.org.

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RHI does not endorse or recommend any devices, equipment, or procedures described in Solutions unless specifically indicated.

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A world without paralysis after spinal cord injury.

TOWARDS A GLOBAL IMPACT

IN THE NEWS

Read the latest on Rick Hansen Institute’s (RHI) research projects

- RHI’s Best Practices Implementation (BPI) Program and researchers at Queen’s University and the Knowledge Transfer Team at the Canadian Medical Association (CMA) is supporting the dissemination of Actionable Nuggets to more than 50,000 primary care physicians across Canada through the CMA. These nuggets are a series of 20 postcards summarizing common health problems in SCI, latest clinical evidence and concise best practices. They will be sent weekly to CMA members, along with email prompts and website links featuring additional research information. Each nugget represents the synthesis of current journal articles and clinical guidelines. Field testing shows that the nuggets are highly rated by family physicians in Canada and Australia. Actionnuggets.ca.

- RHI is aiming to improve the quality of care in health care organizations in Canada by funding the development of the first ever standards for a relevant, responsive and rigorous accreditation program for spinal cord injury (SCI) services with Accreditation Canada. The program begins this year and the standards are expected to be released in 2012. The project will increase knowledge and application of evidence and best practices, leading to improved health care system planning and performance. Accreditation.ca.

- RHI is partnering with the Ontario Neurotrauma Foundation (ONF) in order to coordinate the Best Practices Implementation activities in the areas of bladder management, pain and pressure ulcers. The goal of the Knowledge Mobilization Network (KMN) is to seek and assemble evidence to inform best practice needs throughout the system, translate this evidence for implementation into care-giving practices and policy-making and develop performance indicators for monitoring this implementation. The network will be developed in a way that generates new, actionable insights about knowledge mobilization in the health sector. Onf.org.

- RHI affiliated groups now have access to InSTeP (International Standards Training e-Learning Program) offered by the American Spinal Cord Injury Association (ASIA). InSTeP is an online course designed to enable clinicians to perform accurate and consistent neurological examinations of individuals with spinal cord injury. It provides a good overview of the anatomy and physiology of a spinal cord injury and is a great resource for those who may not need to be certified but want to learn about SCI. Asialearningcenter.com.

Learn more about RHI’s various research projects or sign up for our research newsletter by visiting our website, Rickhanseninstitute.org.
FILLING A GAP

In early 2010, as part of our commitment to our federal government funders, we undertook an independent external mid-term evaluation. The results were encouraging. The evaluators recognized the challenges of supporting action research intended to impact directly health service delivery across Canada and commented RHI for carving a unique, value-added niche in the SCI world. While there were many institutions working in SCI across Canada, there was no national mechanism to coordinate their efforts or to share information across silos. RHI clearly filled this important gap. It will be critical, they said, to ensure that we continue to work collaboratively with the various stakeholders to build the individual successes across the country.

THE END IS JUST THE BEGINNING

Looking back, I am both pleased and impressed with the outcomes we have achieved. By working closely with our partners and funders at the national and provincial levels we have put in place policies, structures and practices that will make a difference. We are leaner and more focused. We have a clearly articulated vision and mission (see our website for details). And we are now looking forward to a future where RHI will continue to play a strategic role in very concrete ways. The Registry will allow researchers and administrators to make informed decisions based on common data sets around the globe. This will improve the quality of health service delivery for people with SCI. We have more than 31 signed agreements with hospitals across Canada and with centres in Australia and Israel and are working to develop many more sites. We are working closely with Rick Hansen and the Rick Hansen Foundation as they roll out the Rick Hansen 25th Anniversary Tour. We are collaborating with researchers and research funders in the USA, Europe, Australia, the Middle East and Asia to ensure we build on each other’s best efforts. We have launched a program with Accreditation Canada to roll out new clinical practice guidelines in hospitals across Canada. We are working with the Canadian Paraplegic Association, the Neil Squire Society and other national, provincial and local consumer groups to help identify solutions and to raise funds for their work in the area of SCI. We are working with the Christopher and Dana Reeve Foundation in the USA, Ontario Neurotrauma Foundation and Moelle épineure et motricité Québec to fund innovative research in their respective jurisdictions. And finally we are working with our federal and provincial funders to ensure the work we do will meet their needs, and the needs of individuals with SCI and their families.

WHERE TO FROM HERE?

2012 marks the end of the initial round of federal funding for RHI. It is critical that we demonstrate our “value add.” Yes we have funded a lot of high quality research, yes we have built bridges between stakeholders across the country and around the world and yes we have set the stage for an international SCI Registry. But this is just the beginning.

As we move forward it will be important to expand the Registry to develop a critical mass of quality data. We must continue to fund international calibre health research. We must work with our partners in Canada and elsewhere to launch key clinical trials to test some of the important discoveries made to date.

But success can only be truly measured by the hard facts: have we reduced the severity of SCI trauma? Has our work contributed to more people walking away from a SCI than would have happened without our work? Have we reduced the impact of secondary complications?

Over the next five years we expect to answer “yes” to all of these questions. And it is simply not enough to fund quality research. We must continue to be strategic in the research work we fund. We must become even more focused on translating new evidence into practice.

Only this way will we be truly successful in meeting our mission — a world with fewer people living with SCI and a world where those living with SCI have the same quality of health as those living without one.

Daryl Rock is Chair of the Board of Directors for the Rick Hansen Institute.
RICK HANSEN REGISTRY GOES GLOBAL BECAUSE SCI KNOWS NO BORDERS

Wide-scale observational studies, facilitated through an empowered registry, are arguably the best and most efficient way to assess the effectiveness of a treatment or intervention in the real world environment. Although the Rick Hansen Spinal Cord Injury Registry (RHSCIR) is already capturing information on approximately 85% of all new injuries in this country, this data set is still too small to support the implementation of clinical trials and accurately identify and adopt best practices. To accelerate progress in these areas, far greater access to international data is required.

The value and potential of RHSCIR as a living database of information is not going unnoticed by leading SCI researchers around the world. Last December, the Rick Hansen Institute (RHI) signed a memorandum of understanding with the Institute of Medical Research Israel-Canada (IMRIC) which included the development of a new registry site to be operated out of the Sheba Medical Centre in Tel Aviv. The signing follows on the heels of a similar announcement with the Government of Queensland, Australia and there is growing momentum for a registry site in Beijing, China.

“The agreement that we have signed between the Rick Hansen Institute and the Institute for Medical Research Israel-Canada marks a significant milestone in the Canadian Friends of Hebrew University’s strategy of collaboration. This collaboration will not only enable major advancements in medical research but will also lead to a significant impact on the lives of many people worldwide,” said Rami Kleinmann, Executive Director of the Canadian Friends of Hebrew University.

“With the work being done in Israel in the field of SCI research, we are very excited to begin sharing and learning innovative treatment techniques and best practices with our international colleagues,” said Dr. Marcel Dvorak, Scientific Director, RHI and the Combined Neurosurgical and Orthopaedic Spine Program at Vancouver General Hospital. “SCI knows no borders so international expansion of the Rick Hansen Spinal Cord Injury Registry is both logical and necessary—we will generate the answers to important questions about SCI that much sooner.”

Q&A WITH THE RICK HANSEN INSTITUTE’S NEWEST BOARD MEMBER

The Rick Hansen Institute (RHI) is pleased to announce the appointment of Dr. Bernie Bressler as its newest member of the Board of Directors. Dr. Bressler, Professor, Department of Cellular and Physiological Sciences, Associate Member, Department of Orthopaedics, Vancouver Coastal Health Research Institute/University of British Columbia, has demonstrated a lifelong commitment to life sciences research and has a passionate belief in the value of commercializing intellectual property from universities and research hospitals. During his tenure as Vice President of Research at the University of British Columbia (1996-1999), he was actively involved in the growth of the University Industry Liaison Office, which has become a world leader in development and management of technology transfer and biotechnology spin-offs. In 2008, he was inducted as a Fellow of the Canadian Academy of Health Sciences. Read on as Solutions speaks with Dr. Bressler about the importance of international collaboration and RHI’s partnership in Israel.

SOLUTIONS: WHAT ARE THE BENEFITS OF INTERNATIONAL COLLABORATION?

BERNIE BRESSLER: In the global environment, in which we live and work, international collaboration connects talented individuals between countries working creatively to solve important problems. International collaborations provide opportunities for sharing resources, including financial, infrastructure and policy frameworks.

SOLUTIONS: FROM A MEDICAL/RHI STANDPOINT, WHY IS ISRAEL IMPORTANT?

BRESSLER: Israel is known for its impressive entrepreneurial culture. As a small country it has a reputation for research and development in medicine that has contributed many global “firsts” for diagnosis and treatment. Linkages with the Rick Hansen Institute brings together a “first” from RHH with the development of the Rick Hansen Spinal Cord Injury Registry (RHSCIR) with a country that has far too many people with SCI for its size. Together, both countries, as well as the global SCI community, will benefit from advances in treatment of people with spinal cord injury and disease.

SOLUTIONS: WHY WOULD A SPINAL CORD REGISTRY BE IMPORTANT OR BENEFICIAL FOR ISRAEL?

BRESSLER: Currently, a specifically designed registry for tracking, analyzing and developing new treatment options for people with spinal cord injury does not exist in Israel. With the large number of people with SCI in Israel, the registry will provide valuable information for care and treatment in Israel. Linkage with the RHSCIR will also provide an extremely valuable research tool for physician scientists in Israel by providing access to data from Canada for research as well as from other countries as RHSCIR is further developed internationally.

SOLUTIONS: AND HOW DO CANADIANS BENEFIT?

BRESSLER: Canadians benefit directly from information learned in other jurisdictions. In addition, it opens up linkages between Canadian and Israeli institutions and researchers in Israel and Canada in many fields, which will lead to further collaborative activities.

SOLUTIONS: COULD YOU BRIEFLY DESCRIBE YOUR ROLE IN THIS RECENT TRIP?

BRESSLER: The development of the Blusson Spinal Cord Research Centre during my tenure as Vice President Research at Vancouver Coastal Health brought researchers from the Vancouver Coastal Health Research Institute together with Rick Hansen and his team to apply for and receive an internationally peer reviewed award from the Canada Foundation for Innovation. This award along with a major gift by the Blusson family led to the development of a first-in-Canada facility purposefully built for research and treatment of people with spinal cord injury and disease.

I first heard about the plan by the Vancouver Chapter of the Canadian Friends of Hebrew University to honour Dr. Phil Switzer and raise funds for SCI in joint venture with Hebrew University, UBC and the Rick Hansen Foundation at a social function. With Phil Switzer being a close childhood friend from our days in Montreal, I offered to assess the strategic opportunities to invest the money that was raised to benefit people with SCI in both countries. As I have spent 13 years on the Board of the Canada Israel Industrial Research Foundation I have had the opportunity to make many contacts and to get to know first-hand many members of the entrepreneurial community in Israel both in the private sector and the academia. Then, what was left for me to do was to connect “good people” together and “good things” will happen and they have!

WHERE DID THE IDEA OF THE REGISTRY COME FROM?

Clinical registries have been used in many areas of medicine but the idea for a spinal cord injury research registry was first brought forward by a group of researchers that Rick Hansen invited to Vancouver about eight years ago. At the time, I was asked to lead the development of a Canadian Spinal Cord Injury Registry since we had been working on a spine registry at the Vancouver General Hospital Spine Program of which I was the head. As the registry evolved into the Rick Hansen Spinal Cord Injury Registry, it became apparent to Rick and I that the idea of moving beyond Canada’s borders would not only allow us to answer research questions more quickly but would also foster collaborations around the world. And a plan was hatched!

— Dr. Marcel Dvorak, Scientific Director, Rick Hansen Institute

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IT’S TIME TO CELEBRATE — 25TH ANNIVERSARY OF THE MAN IN MOTION WORLD TOUR

This year marks the beginning of the 25th Anniversary of the Man In Motion World Tour, providing an unprecedented opportunity to celebrate the accomplishments of the past two and a half decades, reacquaint people all over the world with Rick Hansen’s story, and chart a vision for the future.

Rick’s journey of leadership and social innovation continues to result in progress towards a cure, increased accessibility and improved quality of life for people living with spinal cord injury and related disabilities.

The 25th Anniversary is a global invitation to join Rick’s team: to come together to celebrate, innovate and participate through a variety of exciting initiatives, inspiring a new generation of difference makers. Moving from one man in motion to many in motion.

Together, we can build a better country, and leave this world a little better than when we arrived.

We have the power to change anything. Our best work is still in front of us.

Visit rickhansen.com to:
• Relive the journey
• Join the celebration
• Make a donation

International Outreach
Following the timeline and route of the original Tour, Rick and his team will be visiting Australia, China and the United States. With the objective of furthering international partnerships, announcing collaborative international agreements in regards to the Rick Hansen Institute's Spinal Cord Injury Registry and recognizing and inspiring the world’s next generation of difference makers — the international program is intended to continue Rick’s dream of inspiring change in others.

Interdependence 2012
The Interdependence 2012 conference and exposition (2012) is designed to provide a meaningful and practical forum for experts from around the world to share best practices, lessons learned, and to set the stage for international collaboration for the next 25 years. With a focus on creating accessible communities and furthering SCI research for a cure, the four-day conference and exposition will be held in Vancouver — May 15-18, 2012 — and will host an estimated audience of 3,000.

Global Accessibility Initiative
With a goal of creating a more accessible and inclusive world, the Global Accessibility Initiative is a five-point rating system and assessment tool that is being piloted in target markets and is designed to provide practical and consistent online information about the level of accessibility in the built environment. Through the Global Accessibility Initiative, people will be empowered to make informed decisions about accessibility features when visiting a variety of venues such as restaurants, parks, sporting venues — to name a few. With an intended global launch date of May 2012, this tool will also provide an impetus for policy makers, building owners, architects and others to create fully accessible communities.

Homecoming Celebrations
The 25th Anniversary campaign will culminate, as it did 25 years ago, with significant hometown events in Vancouver in May 2012. The festivities, including a youth rally, will honour the accomplishments in advancing Rick’s dream, celebrate the powerful impact that one person can have on millions and inspire individuals to make change happen.

“If you believe in a dream and have the courage to try, great things can be accomplished.”
— Rick Hansen

Rick Hansen 25th Anniversary National Relay
Designed to share Rick’s message of hope and inspiration, a coast-to-coast relay will re-trace the Canadian segment of the original Man In Motion journey—25 years to the day when he first wheeled across the country. Travelling through 600 communities, covering 12,000 kilometres and engaging over 7,000 participants, the relay will celebrate and showcase Canadians who are the pride of their communities, recognizing everyday heroes, including youth, who are making a difference in the lives of others and who motivate us all to better our country and world.
WHAT’S UP, CATHERINE TRUCHON?

Dr. Catherine Truchon, Rick Hansen Institute board member speaks about her involvement in SCI Research.

WHAT ARE YOUR ROLES IN THE SCI RESEARCH AND CARE COMMUNITIES?
I am the program leader for the SCI rehabilitation program at Institut de Réadaptation en Déficience Physique de Québec (IRDPQ), a site for the Rick Hansen Spinal Cord Injury Registry (RHSCR), a member of both the Board and Translational Research Advisory Committee of the Rick Hansen Institute, and a member of the Quebec Solutions committee, as well as other provincial trauma committees.

Our facility is part of the Centre d’expertise pour les blessés medullaires de l’est du Quebec (CEBMED), along with the Centre Hospitalier Affilé (CHA) - Hôpital de L’Enfant Jésus. We also have a large, long-term follow-up program: we follow over 1,200 patients with traumatic or non-traumatic SCI.

WHAT IS YOUR BACKGROUND, AND WHAT Brought YOU TO THE SCI FIELD?
I am a neuropsychologist by profession. I did my undergrad and masters at the University of Toronto, and a Ph.D. in clinical neuropsychology at Université Laval. The first patient I ever saw as a clinical psychologist was a young man who had suffered a C4 SCI (from a diving accident); he had just learned that he was going to be quadriplegic for the rest of his life, and this had a strong impact on me. Working with traumatic brain injury (TBI) patients, we saw people with both TBI and SCI, so SCI was a field that interested me.

WHAT INTERESTED YOU THE MOST ABOUT SCI?
The field of SCI, with its many opportunities – scientific and technological developments, working with young patients – it’s all very motivating. The people working in this field are extremely engaged and motivated.

CAN YOU DESCRIBE YOUR WORK ON THE RICK HANSEN SPINAL CORD INJURY REGISTRY (RHSCR), AND WHAT BENEFITS THIS WILL CREATE?
I oversaw the Registry implementation in Quebec and did most of the linking with Vancouver. I am assisted by two Principal Investigators as well as two coordinators who oversee the everyday aspects of the Registry.

The Registry has reinforced continuity between the acute care setting and rehab setting; we are informed of patients coming to rehab faster than we were before. It has also fostered links and relationships with the hospital, which is a great thing for partnerships, as it being linked with all the other Registry sites across Canada. That is the main phenomenon we see right now: this family that is growing and getting tighter. We have key people we can address questions to, and this leads to more projects and partnerships.

ON A PERSONAL NOTE, WHAT ARE YOUR HOBBIES?
Work! Is that a hobby? Mostly, taking care of my three daughters… I also like jogging, cross-country skiing, tennis, travelling and playing piano.

WHAT IS YOUR LIFE PHILOSOPHY?
See the positive in everything and everyone... there’s always a solution, an opportunity and sometimes a reward somewhere down the line!

Dr. Truchon’s partners on the Quebec City RHSCR team are:
Principal Investigator acute care: Dr. Jérôme Paquet - Neurosurgeon at CHA - Hôpital Enfant-Jésus
Principal Investigator rehab: Dr. Luc Noreau - Researcher and Scientific Director - CIRRIS, [Centre Interdisciplinaire de Recherche en Réadaptation et Intégration Sociale] Rehab registry coordinator: Mme Joëlle Vachon - Physiotherapist
Acute registry coordinator: M. Frédéric Morin - Clinical Nurse ICU

THE STORY BEHIND ICORD

Vancouver is emerging as a leading global centre of SCI research thanks, in part, to some unique programs based at the Blusson Spinal Cord Centre. The Blusson Centre was funded by federal and provincial grants to ICORD and a major donor to the Rick Hansen Foundation, and is designed to integrate spinal cord research and care. Home to the Rick Hansen Institute, Vancouver General Hospital’s Brenda and David McLean Integrated Spine Clinic, and ICORD, the building brings the field’s best minds together. Rick Hansen says this collaborative approach has “advanced SCI research exponentially.”

In this article, learn more about ICORD and some of the spinal cord injury research that is happening now.

ICORD 101
ICORD stands for International Collaboration On Repair Discoveries.

ICORD is an interdisciplinary research centre of Vancouver Coastal Health and UBC Faculty of Medicine focused on spinal cord injury (SCI). Both its Discovery and Clinical research is focused on a cure (looking for ways to accelerate the search for a cure for SCI) and QOL (to enhance the quality of life for people living with SCI). ICORD is located in the Blusson Spinal Cord Centre at the Vancouver General Hospital site. There are also many ICORD researchers whose main activities are at other sites such as GF Strong Rehab Centre, UBC’s Point Grey Campus and Simon Fraser University.

WHAT IS DISCOVERY RESEARCH?
Think microscopes, test tubes and centrifuges.

ICORD Discovery scientists are trained in subjects like zoology, anatomy, bioengineering and pharmacology. Discovery scientists are researching SCI at the molecular level, working on projects such as studying the effect of diet on recovery from SCI, and looking at the feasibility of using stem cells derived from a person’s own skin to repair injured parts of the spinal cord.

WHAT IS CLINICAL RESEARCH?
In this case, think innovative surgical techniques and new rehabilitation strategies.

ICORD Clinical scientists are trained in subjects like physical medicine, human kinetics, physical therapy, occupational therapy and engineering. Clinical research is performed using human research participants and can include anything from looking at the benefits of a new drug to evaluating wheelchair propulsion.

DO YOU WANT TO PARTICIPATE IN A RESEARCH STUDY?
There are many projects underway at ICORD research labs in the Blusson Spinal Cord Centre, and they are listed on the ICORD web site (address below). If you see a study that interests you and if you meet the criteria, contact the study coordinators to sign up.

HOW IS ICORD FUNDED?
• Individual ICORD research projects are funded by competitive research grants from federal, provincial, international and industry agencies.
• Operational support for research (including things like administrative and technical support staff, research meetings, collaboration between institutions, community outreach, and equipment for new faculty members) is funded by the UBC Faculty of Medicine, Rick Hansen Institute and Rick Hansen Foundation.
• Infrastructure costs (utilities, cleaning, maintenance) for clinical and research space in the Blusson Spinal Cord Centre are paid by Vancouver Coastal Health.

Individuals and groups with an interest in ICORD include patients, financial donors, foundations, members of the spinal cord injury community, provincial and federal government ministries, as well as staff, clinicians, executives of Vancouver Coastal Health and UBC, all supporting its research programs.

To learn more, please check out the ICORD website for information about its researchers, research studies, news and announcements. icord.org.

"CROSS POLLINATION IS THE KEY FOR ANY KIND OF REAL INNOVATION, THAT, AND AN INTENSE INTEREST IN AND LOVE OF WHAT YOU ARE DOING.”

— STEWART BLUSSON

Anniversary Issue | Man In Motion World Tour
NEW RESEARCH MEASURES EXTENT AND ASSOCIATED COSTS OF SCI IN CANADA

Two new reports commissioned by the Rick Hansen Institute (RHI) investigate the incidence, prevalence, and cost of spinal cord injury (SCI) in Canada. The resulting findings provide baseline measurements of the extent of SCI in Canada, and its associated costs, that were previously unknown.

The first report, The Incidence and Prevalence of Spinal Cord Injury in Canada: Overview and Estimates Based on Current Evidence, jointly released by RHI and the Urban Futures Institute, found that close to 86,000 Canadians are currently living with SCI, and that an estimated 4,300 new cases occur each year. By 2030, the number of Canadians living with SCI is expected to climb to 121,000 due to the aging population and more accidents occurring due to falls.

About 51% of SCI cases result from traumatic causes, such as motor vehicle accidents, with the remaining 49% resulting from non-traumatic causes, such as infection or disease.

Prior to the release of this report, little information was available on the extent of spinal cord injury in Canada. Right now there is no routine reporting of people living with a SCI — within or outside a hospital — something that a number of recent studies have called for.

“The report is a milestone in the understanding of the scope, scale, and impact of SCI in Canada. And the more we understand about spinal cord injury, the more we can determine what the most effective research and prevention strategies are, and improve upon the existing health and medical care that those affected by spinal cord injury receive,” said Daryl Rock, Chair of the Board of Directors at RHI.

This baseline measurement will allow researchers to estimate the number of people who could benefit from new therapeutic strategies, and compare and evaluate the impact or success that interventions and innovations could have on people living with SCI.

The second report, The Economic Burden of Spinal Cord Injury: A Literature Review and Analysis, prepared for RHI by Hans Krueger & Associates Inc., investigated the cost of traumatic SCI per individual in Canada. The study calculated a total lifetime cost per individual of $1.6 million for paraplegia and $3.0 million for quadriplegia.

The estimated 44,000 Canadians living with the impacts of traumatic SCI translates to a total national annual cost of $3.6 billion. This figure represents a conservative estimate of the total economic burden of SCI in Canada as it focuses exclusively on traumatic SCI; the substantial costs attached to the tens of thousands of Canadians dealing with the effects of SCI due to non-traumatic causes were not included in the $3.6 billion figure.

The two reports represent first-of-its kind research in Canada. “Up until now, we didn’t have a strong baseline from which to base research on spinal cord injury,” said Bill Barrable, CEO of RHI. “Further research will allow us to refine these estimates and increase our knowledge on the population living with spinal cord injury. It will ensure that our efforts are reaching the right people, and help us discover, develop and implement relevant solutions to improve their quality of life. We also hope to broaden public knowledge of SCI, and to increase public support for the work done by RHI and others in the field of SCI research and care.”

To learn more, visit the Rick Hansen Institute website. Rickhanseninstitute.org/media-room.

MEET ROBB DUNFIELD, RICK HANSEN AMBASSADOR

Robb Dunfield was left a ventilator-dependent quadriplegic at the age of 19, the victim of a fall from a third-floor balcony. His home became an eight-by-eight foot stall in a hospital room. He shared the space with 29 other men; white curtains providing them with their only sense of separation and privacy. The obstacles Robb faced seemed insurmountable: severely limited mobility; dependency on a ventilator; and the certain insurmountable: severely limited mobility; dependency on a ventilator; and the certain insurmountable: severely limited mobility; dependency on a ventilator; and the certain impossibility of living independently.

“For me, the most difficult barrier was privacy. The obstacles Robb faced seemed insurmountable: severely limited mobility; dependency on a ventilator; and the certain impossibility of living independently. I moved into my own apartment — a tiny one-bedroom — that I paid for, couldn’t use my hands, and couldn’t so much as go the bathroom. I couldn’t wash my own clothes. I had to rely on others, and that was something I had never done before.”

Robb Dunfield is a living example of what is possible, and what others can achieve. He’s an inspiring speaker and advocate, and has inspired people all over the world with his wit, humor, and determination. He has traveled the world raising awareness about the importance of spinal cord injury research and prevention.

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The two reports represent first-of-its kind research in Canada. “Up until now, we didn’t have a strong baseline from which to base research on spinal cord injury,” said Bill Barrable, CEO of RHI. “Further research will allow us to refine these estimates and increase our knowledge on the population living with spinal cord injury. It will ensure that our efforts are reaching the right people, and help us discover, develop and implement relevant solutions to improve their quality of life. We also hope to broaden public knowledge of SCI, and to increase public support for the work done by RHI and others in the field of SCI research and care.”

To learn more, visit the Rick Hansen Institute website. Rickhanseninstitute.org/media-room.

THE FACTS ON TRAUMATIC SCI IN CANADA
More than 44,000 Canadians live with the impacts of traumatic SCI.

Approximately 1,700 new cases of traumatic SCI occur each year.

Compared to the general population, people with traumatic SCI:

• are re-hospitalized 2.6 times more often
• have a far shorter life expectancy, from 15 to 30 fewer years
• require 30 times more hours of home care services

The total unemployment rate for those with SCI is up to 65%.

The total annual economic burden for traumatic SCI in Canada is estimated to be $3.6 billion.

In addition, annual disability payments related to traumatic SCI are estimated to be $139 million.

MAKING IT HAPPEN IN NEW BRUNSWICK —
MEET HALEY FLARO

Difference-makers are all around us. They, like Haley Flaro, Executive Director of the Canadian Paraplegic Association in New Brunswick (CPA NB), exemplify a can-do attitude that has resulted in a number of unique and highly effective programs and a community of collaborators, including the Rick Hansen Institute (RHI).

“I’ve always been very passionate about creating change in the world. My background is in community development so I take people’s stories and conceptualize them into projects and programs that make a difference for people living with disabilities,” says Flaro. Nearing her fourth anniversary as Executive Director, Flaro gives full credit to a deeply dedicated staff and equally committed Board.

“What You’d Never Know About Me...
I’m always looking for ways to express my creativity, such as making jewelry. I love policy development and was recently appointed to the Social Assistance Reform Advisory Committee as part of New Brunswick’s poverty reduction plan.

If I Didn’t Have to Work...
I’d probably be volunteering with an international development organization. My parents were always volunteering for various causes in the community, so I grew up in a household where empowering people was really important.

What I’m Reading Now...
I always have a few things on the go — something light and breezy, by someone like Nora Roberts — and a policy document on transportation strategies in rural communities. I’m a policy geek!

“I’VE ALWAYS BEEN VERY PASSIONATE ABOUT CREATING CHANGE IN THE WORLD. MY BACKGROUND IS IN COMMUNITY DEVELOPMENT SO I TAKE PEOPLE’S STORIES AND CONCEPTUALIZE THEM INTO PROJECTS AND PROGRAMS THAT MAKE A DIFFERENCE FOR PEOPLE LIVING WITH DISABILITIES.”

— HALEY FLARO

After noticing an increase in referrals for services from seniors, the organization quickly mobilized and applied a rehabilitation services model that has successfully diverted seniors with mobility disabilities from nursing home placements. She also led the Ability Matters project, a bilingual collection of short films that profiles the successes of persons with mobility disabilities in education and employment goals. The stories are now available on DVD and on www.cpanb.ca/videos.html, and are being used as a training tool in educational institutions. Looking forward to the next two years, Flaro and her team are extremely excited about being the first to fully implement a pilot project, Discovering the Power in Me®, which focuses on empowering individuals with disabilities. Originally developed by the Pacific Institute and the BC and Alberta branches of the Canadian Paraplegic Association, the program will be facilitated in both official languages and delivered and evaluated throughout New Brunswick with over 75 participants starting January 2011.

Hiring at a major rebranding that will be revealed in February 2011, Flaro recognizes that turning an idea into a solution is equally as important, if not more important, than identifying problems. “Finding solutions is energizing, and brings a sense of peace to the work we are doing,” says Flaro, who also holds the role of Director of Rehabilitation Services at CPA NB and is likely moving forward in a research capacity in the coming months. “We could not have made the progress we’ve had without a truly engaged board and staff. They all have a “make it happen” attitude that is energizing and keeps us focused on turning our ideas into reality.”

THE ART OF THE POSSIBLE —
THE MICHELLE BRITTON STORY

Michelle Britton suffered a spontaneous arterial dissection which caused a stroke at the age of 24. Here’s her story and how far she’s come since the event in a University of Victoria parking lot 11 years ago:

“After six months in an acute care hospital and two years in extended care, I moved to a townhouse with 24-hour caregivers. I was quadriplegic and eventually taught myself how to swallow. I ate and still eat pureed food and thickened drinks. Since the hospital, I have received support with an electronic TV remote I could control from bed. I can’t talk so was initially set up by Til, technology for independent living, with a laptop computer and a Morse code program to talk for me.

“Last September I went to Vancouver for hyperbaric oxygen therapy. After 40 sessions of one hour each I am now able to swallow better and taking speech therapy with which I hope to speak by the end of 2011.

“I have some movement in my right arm and use that to paint landscapes. I always loved art as a youth, while growing up in Kamloops, BC. That’s where I first met Rick Hansen, on his Man in Motion Tour 25 years ago.

“Since then, a grant from the Rick Hansen Institute helped me take private art lessons. I’m hoping to make my paintings my new business and this grant money allowed me to create a website to display my paintings and make a 2011 calendar. I sell everything in hopes to buy my own place. So this help has given me some freedom.”

Michelle’s work can be viewed at michellebritton.ca.

EXPERIENCES MATTER —
ISH BAINS, SCI RESEARCHER

Ish Bains started at the Spine Centre of Surgical and Clinical Research in the Department of Clinical Neurosciences at the University of Calgary in 2008. Warm and enthusiastic, she easily admits that her life is her work and her family, and it was not surprising to learn that many of her patients have become close friends.

“At the Spine Centre, we work with people with traumatic SCI and their families. I approach them about participating in the Registry and our clinical trials. Usually the answer is yes. In many cases being a part of the Registry reminds them that someone out there cares about their first-hand experiences and wants to use that knowledge to find better treatments and eventually perhaps even a cure,” says Bains. “They see what Rick Hansen has accomplished and it gives them a tangible sense of hope. Some of the clinical studies last for over five years. These individuals still participate and it’s because of him.”

HAVE A STORY TO TELL?
We’d love to hear from you! Send us your story ideas, comments or suggestions for future issues of Solutions magazine.

Email dmaceluch@rickhanseninstitute.org.

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Coinciding with the 25th anniversary of the Rick Hansen Man In Motion World Tour, the Interdependence 2012 conference and exposition will advance the original goals of the Tour – creating accessible communities and furthering spinal cord injury (SCI) research for a cure. i2012 will provide a meaningful and practical forum for experts from around the world to share best practices, lessons learned, and to set the stage for international collaboration for the next 25 years.

Join an international dialogue exploring the following themes:

**Creating Accessible Communities**
- Accessible and inclusive tourism
- International standards and rating systems
- Accessible transportation
- Legacies of major international multi-sport events
- Accessible public spaces
- UN Convention on the Rights of Persons With Disabilities

**Advancing SCI Research**
- Acute SCI interventions
- Chronic SCI interventions
- Regenerative neuroscience
- Registry, data management and clinical trials
- Rehabilitation

Learn more at www.rickhansen.com/interdependence2012