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IT IS WITH GREAT PLEASURE TO SHARE SOME OF THE HIGHLIGHTS AND SUCCESSES FROM FISCAL 2011-2012.

Having faced challenges typically encountered by any new organization, the Rick Hansen Institute has matured into one that works effectively and efficiently with a strong focus on collaboration, outcomes and accountability. In five short years, much progress has been made to improve treatment and care outcomes, and help reduce health care costs. While the name of our organization has changed over the years, collaboration remains the key to our success.

This past year in particular has been extremely productive and this issue of solutions discusses some of the highlights: our projects, engagement with our partner research network, new collaborations, Interdependence 2012: The Global SCI Conference and the many events and celebrations related to the 25th Anniversary of the Man In Motion World Tour.

Now that the federal government has renewed its commitment to RHI for five years, the goal going forward is to further refine our strategic research agenda, and continue on connecting the best researchers and caregivers in the global SCI research community. Everything we do must be directed at facilitating the translation of research results that will significantly improve the lives of people with SCI. While there may be no silver bullet for the cure, we must not be afraid to take the risks proposed by members of our network, some of the leading scientists in the field.

At this time, I would like to express my gratitude to the Board of Directors and our Translational Research Advisory Committee for their commitment and dedication, along with Rick Hansen and the staff and board of the Rick Hansen Foundation for their critical support and collaboration. I also gratefully acknowledge our primary funders – Health Canada, Western Economic Diversification – for their visionary support. Finally, I would like to thank the governments of Alberta, British Columbia, Manitoba and Saskatchewan for their significant commitments in helping RHI further its work.

We look forward to keeping you up-to-date as we continue to work toward a world without paralysis after SCI and improved quality of life for those living with SCI.

We firmly believe that our best work lies ahead of us.

Bill Barrable
CEO, Rick Hansen Institute
IN THE NEWS

- RHI was pleased to host two additional Project Showcases in Edmonton and Victoria earlier this year, the latest in a series of events that started last fall in Ottawa and Toronto where MPs, MLAs, MPPs, Senators and other government officials viewed first-hand some of the innovative projects led by our national network partners, and the progress being made to improve the quality of life of Canadians living with spinal cord injuries and related medical conditions.

- An Angus Reid poll conducted for RHI showed that 87% of Canadians grossly underestimated the cost of SCI on society and the health-care system, believing it was less than $100 million each year. In reality, SCI cost Canadians about $3 billion every year. The online survey conducted among 1,206 Canadian adults also found that more than half of Canadians (52%) severely underestimated the unemployment rate for people with spinal cord injuries. The poll also found that 89% of Canadians support the continued investment in related healthcare research and best practices.

- Rick Hansen was awarded an honorary doctorate by the Hebrew University of Jerusalem in June. Hansen delivered the convocation address to 2012 PhD graduates at the opening session of the 75th meeting of the Hebrew University of Jerusalem’s Board of Governors. Pictured right: (front row) Rick Hansen, (back row) Vanessa Noonan, Rick Hansen Institute; Connie Savage, Rick Hansen Foundation; Bernie Bressler, RHI Board Chair; Bill Barrable, RHI; Dina Wachtel, Canadian Friends of the Hebrew University of Jerusalem; and Dr. Phil Switzer, University of British Columbia.

- Have you taken the SCI Community Survey yet? Over 1,500 Canadians living with SCI have already completed the survey but we need more participants to make a difference! If you have friends, relatives, and or, are a Canadian at least 18 years of age and living with SCI, this is a unique opportunity for you to improve current SCI-related Canadian health and social services systems and policies. All participants receive a $25 gift certificate upon survey completion. Visit sci-survey.ca or call toll free 1-877-594-6333 for more information. Survey closes on August 31, 2012.

- Have you thought about stem cell research for SCI? Researchers at the University of British Columbia are interested in your views about the potential risks of participating in stem cell research for SCI. Their goal is to learn about the perspectives and priorities of different stakeholders to inform recruitment, enrolment and participation in trials, now and in the future.


Coming soon...

- RHI will be attending the 5th National Spinal Cord Injury Conference in Toronto, October 19-20, 2012.

- The Rehabilitation Environmental Scan Atlas: Capturing Capacity in Canadian SCI Rehabilitation (E-Scan) will be published Fall 2012. For the first time, policy makers, clinicians, patients and family members will have access to a single resource of Canadian spinal cord injury-related rehabilitation service delivery that includes patient demographics, resources, specialized services and expertise, best practices and outcomes. It will also serve as a method of knowledge translation and enable monitoring of adoption of best practices and standards over time. The Atlas will be available for download on the RHI website.
It was another busy year for staff and members of the Rick Hansen Institute partner network. New research is revolutionizing the treatment of spinal cord injury in the hospital and the community. The SCI community in Canada is invigorated, focused on priority areas of research, and engaged in national and international collaborations that are improving health outcomes for individuals with spinal cord injury, while reducing health care costs. In addition, new breakthroughs and discoveries, progressive drug therapies, and advanced surgical techniques are helping people to better manage quality of life issues associated with SCI, such as chronic pain, bladder and bowel complications, pressure ulcers, sexual dysfunction, and increased susceptibility to respiratory problems.

With the recently renewed support of the Government of Canada, the Rick Hansen Institute is playing a lead role in facilitating and coordinating this groundbreaking work, and enlisting the additional support of provincial governments.

At this time of unprecedented scientific progress and transformative global communications technology, a world without paralysis after spinal cord injury is possible.

Visit rickhanseninstitute.org to read the full Annual Report which includes a summary review of all RHI objectives and key activities and updates on all of our current projects from the period of April 1, 2011 to March 31, 2012.

The following are just a few of the highlights from our Annual Report:

- One of RHI’s key clinical research projects, CAMPER, is in full swing with two sites recruiting patients and two more expected to begin shortly. The goal of CAMPER – Cerebrospinal Fluid Pressure Monitoring and Biomarker Validation Study – is to limit secondary damage to the spinal cord by developing a procedure to help drain the cerebral spinal cord fluid (CSF), reducing swelling and pressure build-up at the injury site. In addition, the study aims to identify and validate the expression of specific proteins (biomarkers) after injury as a possible predictor for the severity of paralysis in people with SCI.
By the Numbers

In fiscal year 2011-2012, RHI supported 51 translational research, best practice implementation, community participation and networking projects.

Targeted translational research grant expenses, by expected outcome:\(^1\):

- **Reduced Paralysis**: 21%
- **Reduced Secondary Complications**: 15%
- **Enhanced Quality of Life**: 20%
- **Enhanced Physical Function**: 43%

Number of projects presented or published by the Rick Hansen Institute in the last five years:\(^2\):

- **Peer reviewed publications**
  - FISCAL YEAR 2010-2011: 11
  - FISCAL YEAR 2011-2012: 34
  - TOTAL SINCE 2007: 45
- **Non-peer reviewed publications**
  - FISCAL YEAR 2010-2011: 13
  - FISCAL YEAR 2011-2012: 61
  - TOTAL SINCE 2007: 74
- **Conference presentations**
  - FISCAL YEAR 2010-2011: 67
  - FISCAL YEAR 2011-2012: 75
  - TOTAL SINCE 2007: 142
- **Invited talks**
  - FISCAL YEAR 2010-2011: 63
  - FISCAL YEAR 2011-2012: 63
  - TOTAL SINCE 2007: 126
- **Workshops, courses**
  - FISCAL YEAR 2010-2011: 26
  - FISCAL YEAR 2011-2012: 14
  - TOTAL SINCE 2007: 40
- **National meetings**
  - FISCAL YEAR 2010-2011: 4
  - FISCAL YEAR 2011-2012: 3
  - TOTAL SINCE 2007: 7
- **Mass media / social media**
  - FISCAL YEAR 2010-2011: 4
  - FISCAL YEAR 2011-2012: 1
  - TOTAL SINCE 2007: 5

\(^1\) Translational research expenses by expected outcome, as a percent of all translational research spending targeting one expected outcome. Figures provided are based on actual grant expenses and project-based self-reporting. Percentages are estimates only and reflect actual expenditures from 2007-present.

\(^2\) Note that the figures provided in these tables for the year ending March 31, 2011 are different in some cases from the numbers shown in the 2010-2011 annual report. RHI’s performance measurement system was still in development at that time, leading to some adjustments in the figures provided. The revised numbers reflect the new performance measurement system.
It was great to see the optimism and feel the energy at Interdependence 2012. The SCI research and care community is more galvanized than ever and I look forward to working together as we forge new pathways to a world without paralysis. While we have come a long way in 25 years, just imagine how far we can go in the next 25.

– Rick Hansen

From May 15-17, the Rick Hansen Foundation and the Rick Hansen Institute co-hosted Interdependence 2012 (i2012). This inaugural conference brought together researchers, policy makers, spine surgeons, rehabilitation specialists and clinical professionals from around the world to share their work and present the newest treatments and technologies in the field of spinal cord injury research and development.

The next few pages highlight some of the activities that took place during this conference. To learn more, including a selection of conference presentations, visit rickhanseninstitute.org/publications-and-resources/interdependence-2012.

i2012 Fast Facts....
515 Delegates
230 Organizations represented
23 Countries in attendance
62 Abstract presenters
42 Guest speakers
45 Sponsors & Exhibitors
For the first time ever, RHI brought together nearly 100 members from our Clinical Research Network to Interdependence 2012. Members were not only recognized for their ongoing collaborative efforts which have been critical in allowing RHI to meet its strategic research objectives, but it was also an excellent opportunity for them to network with national and international colleagues while reviewing the latest scientific advances in spinal cord injury research.

“The preliminary survey results indicate that the Network meeting was a great success. It not only brought together some very smart people interested in solving problems relating to SCI, but created an opportunity to celebrate the success and help inform the direction for our future,” said Phalgun Joshi, Managing Director of RHI’s Translational Research Program. “Meetings like these cultivate ideas, and more importantly, foster relationships between people to bridge the gap between what is known and what we do with that knowledge.”

Eighteen presenters at the RHI Project Showcase Session highlighted a sampling of RHI-supported research projects. There were also a number of project specific focused concurrent sessions which allowed for in-depth project updates.

“Enabling future and regular meetings for our Clinical Research Network members is important not only for networking and problem-solving across the continuum of SCI care and research, but ensures that all project leads and coordinators have the opportunity to provide project-specific feedback plus creates a platform for inclusive and holistic knowledge translation within the Network,” says Erin Cherban, Director of Clinical Operations at RHI.

Watch interviews on RHI’s Youtube Channel (youtube.com/RickHansenInstitute) with Stacy Elliott, Michael Fehlings, Sukhvinder Kalsi-Ryan, Brian Kwon, Kathleen Martin-Ginis, and Arthur Prochazka, among other members of the RHI Clinical Research Network.
Sam Maddox: A delegate’s perspective

I was one of 500 delegates attending Interdependence 2012 Global SCI Conference, held in Vancouver. The international gathering of scientists, clinicians, professionals and those affected by paralysis made a strong case for progress in the field and for the potential development of new treatments for SCI. The conference was thought-provoking and quite hopeful. Here are some of my notes.

Rick Hansen’s Interdependence 2012 Global SCI Meeting
posted May 15, 2012

...Charles Tator, also a scientist/MD from Toronto provided the morning’s keynote address, an overview of the last 25 years of SCI research and a speculation about what needs to happen in the next 25. Much progress has happened toward restoring function in injured people, he said. “But the bad news is that our generation didn’t finish it. The good news, especially for young people here today, is that there still a lot of answers ahead, and lots of hope that we will get these answers into the pipeline.”

On the research side, Tator said that for what is a relatively young field of science, the fact that 10 prospective randomized clinical trials have taken place is important. OK, so none of the trials produced anything close to a treatment in universal use today, and two bankrupted the sponsor companies. Still, it’s a good sign and more trials are coming.

Some of the big ideas: government money is essential but vulnerable; is there a return on investment? Private sector, including Big Pharma, appears to be less interested in tough science such as SCI. Nonprofits need to secure patents.

Collaboration among scientists, and among those who fund them, is essential. The field needs to make a better economic case that SCI research is indeed an investment, and to make a case that any intervention reduces health care costs. What about charities working with industry to move research not just toward clinical relevance but toward commercialization – has happened in other conditions, e.g. cystic fibrosis.

i2012 Day Two: Marching Toward Translation
posted May 16, 2012

...A few highlights from a Tuesday session called “Advancing Neuroregenerative Innovations to Clinical Translation.” Panel included neurosurgeon/researcher Michael Fehlings, M.D. scientist (and Reeve Consortium lab member) James Fawcett, basic scientist Wolfram Tetzlaff, and scientist/entrepreneur Lisa McKerracher.

Underpinning the discussion, a difficult question: What has to happen before one or more promising strategies is ready to move from animal models to human trials? Good data for efficacy is a key thing, of course, and that may mean proof in a rodent is only a prelude to success in a larger animal model. There are other confounding factors, including dosage and timing, as well as understanding combinations of drugs or therapies. There is also the question of commercialization – the field will go nowhere if industry is not onboard.

Grading Drug Trial Candidates
posted May 22, 2012

...One of the bigger questions raised during the Interdependence 2012 Global Spinal Cord Injury Conference held last week in Vancouver: If clinical trials are so hard, so expensive, so tricky to get approved, and so prone to failure, what are the best chances to succeed the next time a trial is planned related to spinal cord injury?

Brian Kwon, a physician/scientist at the University of British Columbia, raised that question in a panel called “Key Challenges Related to Translating Experimental Research Discoveries into Clinical Therapies.” Kwon didn’t need to remind his colleagues that many years of SCI science have not produced therapies. But the record is much worse in the field of stroke: over 1000 experimental treatments led to 114 human trials – every single one failed. Kwon asks, are SCI scientists that much smarter or have better biology and better designed trials than the stroke people?

His point was twofold: The SCI field ignores the lessons from the stroke studies at its own peril. And, more importantly, how about establishing a way to grade pre-clinical evidence that a therapy (either neuroprotective or for recovery) really works before it goes to trial, thus directing resources at the best opportunities?

Sam Maddox is a critically acclaimed author, editor, publisher and journalist with broad experience in news and feature writing, publication and web-site management and journalism education. In recent years, his reporting specialty has focused on clinical medicine and neuroscience research related to spinal cord dysfunction.

Read Sam’s full posts from i2012 and more of his blog at spinalcordinjury-paralysis.org/research.
RHI SCI Global Investment Forum debuts at Biotech Showcase™ 2013

The Institute launches a new program in order to facilitate greater investment in SCI-related technologies and therapies.

RHI’s inaugural SCI Global Investment Forum will take place at the Biotech Showcase™ 2013, an annual conference, in January, produced by the Demy Colton Life Science Advisors and EBD Group. As with all future Forums, select companies will be pitching to an audience of life science and biotechnology investors in an effort to solicit the capital necessary to continue the commercialization process of their products.

Accessing the capital required to progress through the product development pathway for new therapeutics, medical devices and diagnostics is a huge barrier to overcome for firms developing new innovations for the treatment of paralysis following spinal cord injury (SCI) and associated secondary complications. Therefore, facilitating increased access to the capital for these firms will result in more new innovations available to those responsible for the care and treatment of the debilitating condition.

“We’re very excited to be partnering with the EBD Group and Demy Colton Life Sciences Advisors in order to hold our first forum at the Biotech Showcase™ in San Francisco,” says RHI CEO, Bill Barrable.

“The Showcase has an established reputation as an investor and partnering conference devoted to providing biotechnology and life sciences companies with an opportunity to present to, and meet with, investors and pharmaceutical executives in one place. It is the perfect platform for generating the kinds of partnerships needed in order for emerging companies to commercialize an innovative therapy or technology directly related to minimizing the both secondary complications and or paralysis after spinal cord injury.”

Call for applications opens on August 15, 2012 and submissions are due October 5, 2012.

Forum Eligibility & Application Criteria
Applicants to the RHI SCI Global Investment Forum at Biotech Showcase™ 2013 must meet the following criteria:

• The firm must be developing a therapeutic, diagnostic or medical device that has application to SCI and/or the secondary complications following SCI
• The firm must be at the Seed or Series A financing stage, with under $25M raised to as of the date of application submission, unless otherwise approved by the RHI SCI Global Investment Forum organizers
• The firm must be privately held
• All persons are of the legal age of majority in California or if not are represented or accompanied as appropriate by someone of the legal age of majority in California
• While a person can participate on one or more teams or submissions, they are not the lead for more than one team or submission

For more information about the RHI SCI Global Investment Forum, including the application process, or RHI’s commercialization program, contact:

John Barclay, MBA
Manager, Commercialization & Industry Relations
Rick Hansen Institute
e: jbarclay@rickhanseninstitute.org

For more information about Biotech Showcase™ 2013, or other partnering events produced by the EBD Group, please visit www.ebdgroup.com.
25th Anniversary: Rick Hansen’s legacy lives on

Jocelyn Tomkinson, Research Development Facilitator at RHI reminisces about her first encounter with Rick Hansen, as the 25th Anniversary Relay winds down.

On May 22, when Rick Hansen wheeled through the doors of the Blusson Spinal Cord Centre on his 25th Anniversary Relay, I was reminded of being seven years old. Back then, I had an autographed poster of Rick on my wall, when I watched Rick – someone like me, in a chair – wheel down the streets of my hometown returning from his Man In Motion World Tour like a conquering hero.

This May, Rick concluded his Relay in the building he helped to make happen. The Blusson Spinal Cord Centre is a place devoted to developing collaborative solutions for spinal cord injury, where I am both patient and team member. Together with patients, volunteers, researchers, clinical staff and graduate students, we celebrated all aspects of the progress that has been made for people with SCI since Rick’s tour that the Centre represents: social acceptance, increased function and rehabilitation, improvements in patient recovery and regeneration of injured tissue, and considerable progress in research and training.

When I was seven, Rick’s tour made it suddenly cool to be the kid in the wheelchair at school. Twenty-five years later, I get to support the research that might allow a generation of young people with SCI to recover.

Over 1,500 Canadians have completed the SCI Community Survey – the largest of its kind ever conducted in Canada – but we still need your input!

Take this opportunity to voice your opinions. As an individual living with SCI, participating in the SCI Community Survey will provide you with a unique opportunity to further describe your most critical needs and help guide how the Canadian health and social services system could better meet those needs. All survey participants will receive a $25 gift card upon survey completion.

Your participation makes a difference!

Participate in the SCIRE Program Evaluation Survey

The Centre for Effective Practice (www.effectivepractice.org) is working with the Rick Hansen Institute and Spinal Cord Injury Rehabilitation Evidence (SCIRE) to conduct an evaluation of SCIRE. We are currently recruiting clinicians and researchers involved in spinal cord injury to complete a 20-minute online survey.

Benefits of participating: By completing the survey, participants will be invited to enter a draw for ONE of 150 gift cards for the amount of $20 at Amazon online store.

To participate, visit: http://fluidsurveys.com/s/SCIRE/
MICHAEL WILLIER
EDMONTON, ALBERTA
CAUSE OF INJURY: FELL 10 METRES FROM A TREE
AGE AT ACCIDENT: 35 YEARS OLD

At RHI, we are inspired every day by the resilience of people living with spinal cord injury, such as Michael Willier, and by the commitment and dedication of those in our network working to improve their quality of life.

MY NAME IS MICHAEL WILLIER... I was born in Picture Butte, near Lethbridge, Alberta. I grew up with my grandparents and three cousins, and spent every summer hunting and fishing and going to powwows on weekends. I’ve lived in many places in western Canada and the US and have been in Edmonton, on and off for over 20 years.

On July 21, 2007, I was sitting on the branch of a tree – 30 to 40 feet up – in my backyard. The branch broke, and my feet got caught up so I came down head first. I broke my neck and both arms and had internal bruising, and damaged my heart. I was a skydiver, and worked in dangerous professions and here I fell out of a tree that I’d been climbing for years, and now was paralyzed from my chest down with a C5 complete injury. When I woke up I could only use my eyes.

My arms slowly came back...they told me I wouldn’t get my triceps back, but I did. I’m a stubborn person and began working out. The first year, I stayed in my manual chair, and also got some trunk and stomach muscles back. I didn’t want to use a power chair but had to as my broken wrist was too painful. I went back for surgery on it and they took some bone from my hip.

I was four months at the Royal Alex, and seven months at Glenrose Rehabilitation Hospital, plus one month at Sturgeon, in the middle.

I can’t imagine living in the country, on the reserve, with spinal cord injury. In Edmonton, I now live independently, but have a caregiver twice a day to help. I didn’t want anyone to help me, at first. I do my own cooking and grocery shopping.

My greatest challenge, day to day, is accessibility.

I would like to go out one day without worrying about if I can get into somewhere, if the bathroom is accessible. I worry about my power chair breaking down in cold weather. And I worry about infections and how clean bathrooms are. Many places that say they are accessible really aren’t. I was in one hotel that said they were accessible, but a rail in a bathtub is not enough...how are you supposed to get in? And the beds were too high.

I’d never volunteered before but after my injury, but I went to the CPA and asked them if I could volunteer. At first, it was a way to keep busy but I enjoy doing it – it gives me purpose and something to look forward to, and we get to help each other.

I’ve done some speaking for United Way to tell people about life with spinal cord injury.

I also volunteer with Wicihitowin: Circle of Shared Responsibility and Stewardship, as the co-chair of the Health Action Circle, to find out what the needs are, where funding is needed, to help urban aboriginals. I also volunteer in their mentorship program. It’s not easy to come from outside the city, with your family 400 miles away, and you don’t have anyone to talk to.

You can’t have the same life you’ve had before.

I was an iron worker before I got hurt and I loved my job...it was physically demanding. I don’t have one, now.

“One Day... I hope to leave my home and not worry about accessibility outside.”

Spinal cord injury devastates your family, your friends, not just you. It scares some friends away, because they don’t know how to talk to you. I’ve made new friends, and you come to understand who is really there for you.

SCI has brought something out in me that was always there...a mental strength. Nobody would ever understand what I’m going through. I wouldn’t want anyone to know what it’s like to be in a chair but I’m glad that there are people who understand and are willing to help.

Visit RHI’s website to read more stories about individuals with SCI and the researchers who are making a difference.
Partnerships are key for the development and implementation of programs at the Rick Hansen Institute and in advancing the care for Canadians living with spinal cord injuries.

The Rick Hansen Institute would like to thank our federal, provincial, corporate and foundation partners for their contributions to support essential advancements in research for a cure for paralysis after spinal cord injury, and make a positive difference by promoting the translation of promising research discoveries and best practices into real practical benefits. The Institute would especially like to thank Health Canada, Western Economic Diversification and the Rick Hansen Foundation for their generous contributions and visionary support.

Federal Partners

Provincial Partners

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