Rick Hansen Institute
ANNUAL REPORT
A world without paralysis after spinal cord injury 2013-2014
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Who We Are

The Rick Hansen Institute is a Canadian-based not-for-profit organization committed to accelerating the translation of discoveries and best practices into improved treatments for people with spinal cord injuries (SCI).

Vision

A world without paralysis after spinal cord injury.

Mission

- Lead collaboration across the global SCI community by providing resources, infrastructure and knowledge.

- Identify, develop, validate and accelerate the translation of evidence and best practices.

- Reduce the incidence and severity of paralysis after SCI, improve healthcare outcomes, reduce long-term costs, and improve the quality of life for those living with SCI.
I am truly grateful for this opportunity to reflect back on another amazing year of progress by the passionate professionals who work for and with the Rick Hansen Institute. Recognizing the simple truth that more can be accomplished if we work together, our goal is to achieve a common vision and purpose in the global SCI community: a world without paralysis after spinal cord injury.

To ensure this happens, the Rick Hansen Foundation – as the founder and fundraiser for RHI – directed $20 million over 10 years to the Blusson Integrated Cures Partnership in 2013. This collaborative partnership among the participants in
the Blusson Spinal Cord Centre, located in Vancouver, BC, is designed to accelerate clinical research and identify new, innovative treatments toward cures for SCI. Through our collective work, we aim to decrease paralysis after SCI, improve quality of life and reduce costs to the healthcare system.

The Government of Canada, meanwhile, renewed its funding to RHI with a $35 million, five-year grant to magnify the impact of the Institute and further augment the power of the Blusson Integrated Cures Partnership. This combined funding – and more from the governments of Alberta, BC, Ontario and Manitoba, among other governments and individuals – has allowed the Institute and its partners to achieve the following milestones in the last year:

> **The Rick Hansen Spinal Cord Injury Registry (RHSCIR), the first and only national database of spinal cord injury patient information in Canada**, is approaching its 10th anniversary and now includes more than 4,000 participants. The data collected through RHSCIR and subsequent analysis helps researchers understand the epidemiology of SCI in Canada, the challenges and opportunities for improved care, and the potential for cost savings to healthcare systems.

> **RHSCIR is at the heart of RHI’s international expansion of its research partner network.** RHSCIR is being adopted internationally to facilitate the translation of research into clinical practice and promotion of evidence-based practices. By increasing our international presence, we have had the opportunity to cultivate new avenues of funding and partnerships.

> **The depth and breadth of global collaboration has accelerated through RHI’s participation at international SCI conferences, the RHI SCI Global Investment Forum and hosting a workshop at the International Spinal Cord Society (ISCoS) meeting.** New projects in the United States of America, United Kingdom, Australia, China and Israel are also fueling greater global knowledge, investment and collaboration within the SCI community.

We would not be able to accomplish these integral milestones without the tremendous support we have received from governments, corporations, foundations, philanthropists and the general public over the years to continue to fuel our extraordinary progress. We are truly grateful for that support.

At the Rick Hansen Foundation, it is our aim to break down the barriers faced by people with disabilities to create a more accessible and inclusive society for people with spinal cord injuries, and other disabilities. As a result, the Rick Hansen Institute was developed from a dream of true collaboration across the SCI community.

Through these initiatives, the Institute, Foundation and our partners are not only leading the way in raising awareness and resources to reach our goal, we are empowering others to dream of a world without paralysis. Only by working together can we make that dream a reality.

Thank you.

**Rick Hansen, C.C., O.B.C.**  
Chief Executive Officer  
The Rick Hansen Foundation
It’s been a great year for the Rick Hansen Institute. Major funding contributions in fiscal year 2013-2014 allowed us to devote the year to strategic development and planning. Going forward, our efforts will focus on accelerating the identification of cures for spinal cord injury (SCI), effectively translating research results into the medical and technological interventions required to improve health outcomes, and promoting the optimization of SCI care across Canada to reduce healthcare costs and improve quality of life for individuals with acute and chronic SCI.

To achieve these objectives we developed a framework that will help focus our work, determine activities going forward and ultimately, work towards our vision of a world without paralysis after spinal cord injury. Within this framework, four key outcomes emerged in which we can measure our progress:

- **SCI research accelerated towards the cure.**
- **Improved and standardized delivery of care across Canada and internationally.**
- **Increased development and commercialization of innovations.**
- **Increased opportunities for participation in research and health decision-making among consumers.**

These desired outcomes led to the development of four distinct, but inter-related programs: **Cure Program, Care Program, Commercialization Program** and **Consumer Program**.
Activities and progress from each of these programs are highlighted throughout this report.

Also critical to the success of these programs is continued collaboration with other SCI organizations. We have partnered with numerous organizations to collaborate on research projects and tools and provided funding opportunities through open calls and scholarships to support promising SCI researchers. We are also working closely with colleagues at the International Collaboration on Repair Discoveries (ICORD) through the Blusson Integrated Cures Partnership to advance SCI research and best practices. On the international front, we are pleased to report on several unique partnerships to expand clinical trials, improve best practices and share knowledge at a global level.

All of this work was made possible with the support of the SCI community, and especially, the RHI network — researchers, clinicians, coordinators and staff — whose dedication and hard work is helping to accelerate progress in SCI research and care.

We would also like to express our gratitude to RHI’s Board of Directors, program and research committees, and grant reviewers for their commitment and dedication. We are tremendously grateful to our funders — the Government of Canada (through Western Economic Diversification), provincial governments and supporters, and especially Rick and the Rick Hansen Foundation team, who continue to raise awareness and precious funds for SCI and physical disabilities 27 years after it was founded.

We hope you enjoy reading RHI’s 2013-2014 Annual Report and look forward to keeping you up-to-date as we continue to work toward a world without paralysis after spinal cord injury.

Sincerely,

Bernie Bressler
Chair, Board of Directors

Bill Barrable
Chief Executive Officer

Highlights from Fiscal Year 2013-2014

- Identified long term objectives and goals for RHI’s Cure, Care, Commercialization and Consumer Programs.
- Developed partnerships with community organizations to promote SCI research participation and educate individuals with SCI and their families about the SCI research process.
- Developed a free web-based clinical examination tool to determine the motor and sensory impairment and severity of a SCI.
- Solidified new partnerships to collaborate internationally on SCI research and best practices.
- Facilitated connections between early-stage and emerging companies to potential investors and partners.
- Implementation of a best practice in pressure ulcers, through the Knowledge Mobilization Network.
- Accreditation of the acute and rehabilitation facilities in Halifax using Accreditation Canada’s SCI Standards.
- Collaboration across Canada on the standardization of clinical assessment of many secondary complications.
Fiscal Year 2013-2014: By the Numbers

Involvement in Canada and Around the World

CANADIAN TOTALS
166 + 914 < 23,470

INTERNATIONAL TOTALS
16 + 106 < 40

Facilities involved in RHI projects
Project team members
People with SCI engaged
Program Outcomes

- **Requests for RHSCIR data**: 11
  Researchers and health-care providers at six sites across Canada made requests for RHSCIR data in fiscal year 2013-2014 for their own research or administrative purposes, confirming once again the value of a national repository of SCI data.

- **Facilities accredited to SCI standards**: 2
  The first two facilities in Canada (located in Halifax) are now accredited to the new SCI standards developed with the support of RHI.

- **RHI SCI Global Investment Forum held**: 1
  The SCI Global Investment Forum was held at BioPharm America in Boston, Massachusetts in September 2013, facilitating the connection between new SCI innovations and potential investors and partners.

- **People with SCI engaged**: 1,000+
  Through the Rick Hansen Registry and other RHI projects, in fiscal year 2013-2014 RHI succeeded in engaging over 1,000 people with SCI.

### Other Performance Metrics

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<th>Metric</th>
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<tr>
<td>Non-peer-reviewed publications</td>
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<td>Conference presentations</td>
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<td>National meetings</td>
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<td>New project sites/partner organizations</td>
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<td>New project team members</td>
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<tr>
<td>Meeting attendees</td>
<td>73</td>
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<td>New participants enrolled in RHSCIR</td>
<td>638</td>
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<td>New participants enrolled in other studies (estimate)</td>
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<td>Number of awards won for RHI-supported projects</td>
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* Total since 2003
RHI’s Framework for Results

RHI’s work falls within a set of six strategies which together contribute to four main outcomes. The diagram below shows these strategies and outcomes, which over the longer term contribute towards achieving its vision of a world without paralysis after spinal cord injury.

This annual report is outcome-focused and hence structured according to the four outcomes which are organized according to programs of the same name: cure, care, commercialization, and consumer.

A summary of results for the fiscal year structured according to strategy is also provided: this can be found in Appendix II of this report. Appendix II aligns with RHI’s Business Plans, Operational Plan, and financial reporting.

**Strategies:**

- Translational Research
- Best Practice Implementation
- Informatics
- Network Development
- Best and Brightest
- Consumer Engagement

**Outcomes:**

- **CURE PROGRAM**: SCI research accelerated towards the CURE
- **CARE PROGRAM**: Improved and optimized delivery of CARE across Canada and internationally
- **COMMERCIALIZATION PROGRAM**: Increased development and COMMERCIALIZATION of innovations
- **CONSUMER PROGRAM**: Increased opportunities for participation in research and health decision-making among CONSUMERS

**Vision:**

A world without paralysis after spinal cord injury
Thank You to Our Funders and Supporters

Our funders have played a leading role in supporting spinal cord injury research and community services by providing critical investments and services. This support has distinguished Canada as a leader in medical research treatment and care for people living with SCI.

The Rick Hansen Institute would like to thank the following for their generous support in fiscal year 2013-2014:

- Government of Canada through Western Economic Diversification Canada
- Rick Hansen Foundation
- Government of British Columbia
- Government of Alberta
- Government of Manitoba
- Government of Ontario

We would also like to express our gratitude to individuals, corporations and other organizations who have made contributions to the Rick Hansen Institute.

It is thanks to the tremendous collaboration of our partners and funders that we can say we are truly affecting change to improve the health and quality of life of those living with a spinal cord injury in Canada and abroad.

Thank you!
Cure Program

Focuses on the generation of knowledge and the establishment of treatments that will ultimately result in a cure for paralysis after SCI.

EXPECTED OUTCOME:

SCI research accelerated towards the cure.
Program Overview

The Cure Program at RHI is focused on leveraging its strengths and resources to participate in international collaborative efforts towards curing spinal cord injury. The Program’s Advisory Committee is chaired by surgeon-scientist Dr. Brian Kwon (Associate Professor, Orthopaedics, University of British Columbia) and was created to provide RHI with guidance for cure-related activities and recommendations for future activities. The committee is comprised of national and international SCI experts selected to provide strategic representation in clinical and preclinical research.

The objectives of the RHI Cure Program are to:

1. Further our understanding of the biology and physiology of SCI.
2. Develop promising therapies for neuro-restoration in acute and chronic SCI.

Key Accomplishments in Fiscal Year 2013-2014

Roadmap for Cures

In March 2013, RHI’s first five-year strategic plan came to an end and a new one began, aided by the Government of Canada and the Rick Hansen Foundation’s commitment to renew long-term funding. A major effort was undertaken to engage RHI’s network and reach consensus on the way forward for the organization. One of the clear messages arising from this stakeholder engagement was the need to prioritize the cure – or cures – for SCI. For this reason, “cure” was selected as one of RHI’s four major programs over the next five years. RHI’s Cure Program is focused on supporting cure discoveries through preclinical research through to evidence-based practice.

In fiscal year 2013-2014, RHI held the Cure Program Advisory Committee Meeting to develop the Global Cure Roadmap and outline the objectives and strategies for the Cure Program.

The Cure Roadmap outlines the following way forward: at the earliest stages of a promising discovery, RHI intends to support preclinical research (research undertaken before human testing, such as animal model research) and will support translation of promising preclinical findings into clinical (i.e., human) research, as well as back-translation from clinical to preclinical when questions arise.

What is a Cure?

RHI recognizes that a “cure” for paralysis after spinal cord injury may in fact lie in several, incremental cures. We define a cure as any intervention to return a person to greater functionality after a spinal cord injury, whether by protecting the injured spinal cord tissue from secondary degeneration, by promoting neuroplasticity and/or regeneration, and by rehabilitation strategies that could enhance these regenerative efforts. Cure applies to the newly as well as the chronically injured.
during human testing. To support newly emerging areas of research that utilize human samples, such as blood and cerebrospinal fluid, RHI, in partnership with the International Collaboration on Repair Discoveries (ICORD), will support the establishment of a SCI biobank to store these samples and make them available for research purposes.

Once safety and feasibility questions are proven in preclinical research, RHI will support a number of large, multi-centre clinical trials. Two existing cure-related clinical studies – CAMPER and Minocycline – will continue, with plans to commence at least two more, in cure-related areas including neuro-regeneration, neuro-plasticity and neuro-protection. RHI may play different roles in each study, from that of funder, sponsor (overall responsibility for carrying out the study), providing technical expertise, IT infrastructure (e.g. data collection and management) or clinical site support.

As a direct result of the Cure Roadmap, RHI was successful in developing partnerships with various international organizations pursuing the same goal, including the North American Clinical Trials Network and AOSpine. This past fiscal year, RHI also launched a funding opportunity for preclinical research, entitled Preclinical SCI Research Towards Cures. The application deadline was April 30, 2014 and the external review process is now underway. Applicants will be notified of the results this summer and successful applications will be announced on RHI’s website.

The next steps for the Cure Program are the implementation of the roadmap and the elaboration of a full strategy, which will identify funds, milestones and the establishment of a formal partnership strategy for RHI, to be completed in fiscal year 2014-2015.

The Cure Roadmap is available at www.rickhanseninstitute.org.
Reaching out Globally to Ensure an Integrated Program Approach

Essential to the success of RHI’s four programs (Cure, Care, Commercialization and Consumer) is the recognition and need for an integrated approach. For example, in order to assess the effect of potential cures for SCI it requires standardized care and an accessible and informed patient population. The development of cures and advances in care also involve overcoming commercialization challenges faced by innovators and require direct involvement of consumers – people with SCI. Leveraging its role in Canada, RHI is now reaching out globally to share knowledge, and best practices and obtain greater access to patient populations for clinical trials. Below are just a few examples from fiscal year 2013-2014 on how RHI is reaching out beyond Canada’s borders:

- **Peking University Third Hospital, China:** Participation in a global registry is recognized as one efficient way to obtain a large enough dataset to accelerate the number of clinical trials that can be conducted, and identifying and adopting best practices. In fiscal year 2013-2014, an agreement to create an international registry site was signed with the Peking University Third Hospital (PUTH) in Beijing, China. PUTH is one of China’s leading hospitals for SCI research and houses one of the country’s best spinal surgery and rehabilitative departments. RHI will also be working with PUTH and Accreditation Canada International to develop and implement best practice standards for acute and rehabilitative care for spinal cord injuries in China.

- **Princess Alexandra Hospital, Australia:** One of Australia’s leading academic and research centres, Princess Alexandra Hospital is the first international site of RHI’s Access to Care and Timing (ACT) project. A longstanding project of RHI, in partnership with the UBC’s Sauder School of Business, ACT aims to build a simulation model to describe the processes of care from the time of injury until discharge into the community for individuals sustaining a traumatic spinal cord injury.

- **Ongoing International Work:** In fiscal year 2013-2014, RHI laid the groundwork for future international partnerships: RHI’s two existing cure-related clinical studies, Minocycline and CAMPER, are being expanded internationally to help recruit more study participants and both are expected to be initiated by the end of fiscal year 2014-2015. This fiscal year, RHI provided funding to AOSpine North America to conduct the development of human MRI-based biomarkers for measuring the efficacy of the drug Riluzole as a neuroprotective agent in acute SCI in Phase III clinical studies at the University of Maryland and the Medical College of Wisconsin; and the Stoke Mandeville Spinal Foundation for a study on the locomotor outcome in animal models.
Care Program

Focuses on the creation of new knowledge and adoption of best practices to optimize care delivery for persons with SCI to maximize function.

EXPECTED OUTCOME:

Achieve evidence-informed equitable and optimal care for Canadians sustaining a spinal cord injury.
Program Overview

The Care Program at RHI aims to identify and fill gaps in knowledge regarding the clinical management of SCI and to promote best practices in SCI care delivery based on existing evidence for Canadians who are newly injured or those living with an existing SCI. The key indicator of success for the Care Program is to have 50% of SCI centres in Canada accredited by 2018, according to the SCI Standards that were developed by RHI in partnership with Accreditation Canada in 2012.

The Program’s Advisory Committee, chaired by Dr. Katharina Kovacs Burns (Associate Director, Health Sciences Council & Director, Interdisciplinary Health Research Academy, University of Alberta and Chair of RHI’s Translational Research Advisory Committee), was created to provide ongoing advice in care-related activities and recommendations on future activities. The current membership includes a comprehensive group of SCI researchers, clinicians, administrators, national partners and consumers.

Key Accomplishments in Fiscal Year 2013-2014

Roadmap for Care

In fiscal year 2013-2014, RHI held the Care Program Advisory Committee Meeting to guide the direction taken by RHI and stakeholders in future care activities.

The Care Roadmap identifies RHI’s role in supporting care-related research and best practice implementation.

The Care Roadmap is available at www.rickhanseninstitute.org.

Accrediting SCI Centres

Last year, RHI and Accreditation Canada announced the results of their collaboration: the first ever comprehensive, evidence-based standards for SCI services delivered in Canada, called the SCI Acute and Rehabilitation SCI Services Standards (SCI Standards). Since then, RHI has continued to work closely with Accreditation Canada as well as Rick Hansen SCI Registry sites to advocate for and support the adoption of the SCI Standards into practice.

The Need for Optimized Treatment of SCI in Canada

The provision of spinal cord injury care across the country is not standardized and as a result, there is tremendous variability in the care provided. There is a critical need to ensure best practices are implemented nationally to reduce this variability. This will improve care delivery and result in improved patient outcomes and ultimately in cost savings for the healthcare system. As advances are made in cures for SCI, it will also facilitate the investigation and implementation of these treatment advances if SCI care is similar across SCI Centres in Canada.
The SCI Standards are a strategic part of RHI’s Care Program. RHI will orient care-related projects to focus on the key indicator of 50% of SCI centres in Canada accredited by 2018.

In 2013, Halifax’s Capital District Health Authority became the first site to be granted national accreditation status as a centre for SCI care by Accreditation Canada. The site met 100% of the mandatory criteria and over 95% of other criteria for the acute and rehabilitation services standards.

The SCI Standards have been piloted in a number of RHSCIR sites, with more sites working towards adoption in 2014 and 2015. The accreditation project team at RHI has developed a multi-pronged strategy with the aim of spreading adoption of the SCI standards among RHSCIR sites. The strategy includes engagement of clinical and operational champions and early adopters, development of accreditation tools to help sites seamlessly integrate the SCI standards within their normal Accreditation Canada Qmentum preparation processes, and ultimately fostering a community of practice to identify common opportunities for improvement, share lessons learned, develop knowledge translation and practice implementation toolkits, and help sites embed the SCI standards into their daily practice.

**Rick Hansen SCI Registry (RHSCIR)**

RHSCIR, now approaching its 10th anniversary, reflects a collaboration of over 70 principal investigators, coordinators and clinical staff from 31 facilities across Canada. It is a national registry of individuals sustaining a new traumatic SCI in Canada that contains demographics, injury details, diagnoses, procedures and patient outcomes and captures data from the point of injury through the course of their lives. In fiscal year 2013-2014, RHSCIR surpassed 4,000 participants enrolled to date, establishing the registry as the most robust and comprehensive data source on individuals with traumatic SCI in Canada. RHSCIR data also supported numerous peer-reviewed articles, publications and conference presentations (see Appendix I for full details). These papers and presentations, and others soon to follow, capture the results of important research that can only be done with a national repository of SCI data. This research is also filling important gaps in knowledge of SCI care by adding to the evidence regarding the timing to surgery, describing the heterogeneity of SCI and the incidence of secondary complications such as neuropathic pain, among others.

In fiscal year 2013-2014, work was completed to enable RHSCIR to update and improve the data it collects, particularly in the areas of complications and clinical outcomes in rehabilitation. This updated version – RHSCIR 2.0, which will begin implementation in fiscal year 2014-2015 – is the result of collaboration among the RHSCIR network and subject matter experts, to ensure the data can be used to answer the most current research and clinical questions, in addition to aligning with Accreditation Canada’s SCI Standards, and supporting SCI programs. Work accomplished this

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1 Capital District Health Authority encompasses several hospital facilities, of which two are involved in SCI care and treatment. Facilities accredited under the SCI Standards at Capital District Health Authority include QEII Health Sciences Centre - Halifax Infirmary Site (acute facility) and QEII Health Sciences Centre - Nova Scotia Rehabilitation Centre (rehabilitation facility).
fiscal year included formation of an outcome measures implementation group, development of updated RHSCIR 2.0 data to be collected, initial development of “modules” or training packages for each outcome measure area, necessary regulatory changes, and the commencement of training at sites on how to capture data in these new areas.

**Spinal Cord Injury Knowledge Mobilization Network**

Efforts to encourage adoption of best practices in the care of people with SCI are ongoing at many health facilities across Canada. However, until recently no infrastructure existed to coordinate these efforts, to share lessons learned on best practice implementation across sites, or to help ensure these centres are using the most effective methods of implementation.

To address these challenges, the Ontario Neurotrauma Foundation, with support from RHI and the Alberta Paraplegic Foundation, developed the Spinal Cord Injury Knowledge Mobilization Network (SCI KMN). SCI KMN is a network of six participating facilities in Ontario, Quebec and Alberta, whose aim is to build expertise and capacity in implementation science in order to facilitate the adoption and utilization of the best evidence in SCI care. SCI KMN uses an evidence-informed approach that systematically outlines the steps required for successful implementation. A key long-term objective is to embed this enhanced capacity for implementation within sites to ensure the sustained ability to adopt practices and innovations as evidence and context directs.

SCI KMN’s current focus is on best practices related to pressure ulcers. Patients are educated in group or individual sessions by nurses, physiotherapists, occupational therapists and occasionally other individuals throughout their rehab stay. Patients receive structured and unstructured education on topics such as understanding the function of skin; the need for daily skin inspection of boney prominences; the causes and risk factors for pressure ulcers; the ability to identify individual risk factors; methods for prevention of pressure ulcers; and instructions on what to do if alterations in skin integrity are discovered.

In fiscal year 2013-2014, an independent assessment of SCI KMN was undertaken to examine the project’s progress to date. Below are highlights from the assessment:

- **SCI KMN is addressing a demonstrable need** to improve SCI rehabilitation practices through systemization and intensified adoption of professional and organizational practices that have demonstrated improvements to patient and health system outcomes.
- **There is a strong commitment to supporting best practice implementation** among all participating SCI health centres. The majority of respondents (81%) believe that implementation of best practices to improve outcomes among SCI patients is effective at improving patient care.
- **Network capacity has been built and is beneficial to practice** at all sites.
- **Potential to improve patient outcomes is estimated be high.** It is expected that improved outcomes, including improved quality of life,
reduced hospitalization and healthcare costs, may become visible in the next two to five years, but only if current resource levels, and especially a dedicated transformation specialist at each site, are maintained.

Next steps for the SCI KMN include expansion into other areas of the healthcare continuum and other rehabilitation sites across Canada.

**ISNCSCI Algorithm**

The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) is an examination used to determine the motor and sensory impairment and severity of a SCI. The American Spinal Injury Association (ASIA) International Standards Committee is responsible for reviewing and revising the ISNCSCI to reflect current evidence.

A group of international experts worked with RHI to develop the ISNCSCI Algorithm. The algorithm utilizes raw test scores from the exam to determine the motor and sensory impairment and severity of a spinal cord injury, thus improving the consistency and accuracy of exam scoring.

Use of the beta site was quite popular: over 5,500 return users from 108 countries around the world accessed the tool. In total, the ISNCSCI Algorithm website received over 12,000 hits in fiscal year 2013-2014. In addition, due to requests for the source code from international groups, RHI produced an open source format of the algorithm free of charge to support groups who want to integrate it into their own research databases and electronic medical records. After rigorous beta site testing, the first complete and fully validated version (version 1.0) of the ISNCSCI Algorithm was launched in May 2014 (www.ISNCSCIAlgorithm.com). The International Spinal Cord Society (ISCoS) also provides information about the algorithm on their website for their international members (www.iscos.org.uk/international-standards-and-spinal-cord-independence-measure-scim).

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**Feedback on the ISNCSCI Algorithm...**

“I appreciate the tool and use it often in my work. I find it easy to use and it provides me with an additional confidence in my ASIA coding.”

“This is an excellent website, practical and easy to use. By the way... I really, really like the graphics now. Outstanding!”

“Great tool. Excellent platform, great tool for teaching. Thank you so much [for creating] it and [making] it available.”

Thank you so much for the code! We have downloaded the code and the tech guy is working on it. We are very happy and delighted of the collaboration, and hope this will be fruitful for both you and us.
**Perinatal Care for Women with SCI**

Sexual health is a top priority among people with SCI. In 2012, the SCI Community Survey, supported by RHI, found sexual dysfunction to be highly prevalent and limiting and identified sexual activity in general as an area of deep dissatisfaction among survey respondents.

To address this challenge, RHI funded a one-day workshop in November 2013 involving consumers, clinicians and researchers with an interest in sexuality, SCI, fertility and reproductive health. Through a series of facilitated discussions, workshop participants validated three themes: 1) lack of knowledge for consumers and care providers; 2) gaps in access to services and information; and 3) need for collaboration between consumers and healthcare providers and amongst healthcare providers throughout the perinatal journey.

Workshop participants envisioned a “roadmap” that would guide and empower consumers, their families, and healthcare providers at all stages of the perinatal journey. Creating a roadmap would “connect the dots” in the journey, link resources that are already available, and establish a collaborative framework for addressing the remaining gaps. This roadmap would allow consumers to identify what stage of the perinatal journey they are on and determine what information they need to know or ask at each stage. Ultimately, addressing these gaps will help consumers to access the resources necessary to increase the likelihood of a positive outcome.

The workshop was well-received with the general consensus that it was rare to bring together a group of individuals who represented a diverse mix of organizations, backgrounds and personal and professional experiences. Despite these differences, all participants shared a common desire to improve the perinatal care for women with SCI. One participant referred to the “great energy [and] great knowledge” in the room and another reflected on “the positive and collaborative spirit of all participants.”

**Participant Feedback**

90% of respondents agreed that the workshop had increased their understanding of perinatal care for women with SCI

100% of respondents agreed that it increased their desire to collaborate on this important topic.
Commercialization Program
Focuses on facilitating the development of innovative therapeutics, medical devices, diagnostics and health-IT related technologies with direct application to SCI towards commercialization.

EXPECTED OUTCOME:
Increased development and commercialization of innovations.
Program Overview

RHI’s Commercialization Program, chaired by Ross Mason, Executive Director and Founder, Healthcare Institute for Neuro-Recovery and Innovation, aims to facilitate the development of innovative pre-commercial therapeutics, medical devices and diagnostics and health-IT related technologies that will improve the lives of those living with SCI with application to SCI towards commercialization.

The Commercialization Program at RHI is focused on leveraging the strengths and resources of RHI’s network in SCI research and care (“domain expertise”) to gain development and commercialization expertise (“process expertise”). The Committee’s mandate is to advise RHI on how to best leverage program strengths, while ensuring alignment with RHI’s Cure, Care and Consumer Programs. The Committee is comprised of professionals with a wide range of business development and commercialization expertise in the life sciences.

The goal of the RHI Commercialization Program is to help facilitate a greater number of innovations brought to market that will directly benefit people with SCI.

Objectives of the RHI Commercialization Program are:

- Accelerating the commercialization process for innovative therapeutics and medical devices for paralysis and secondary complications following SCI.
- Increasing the pipeline of potential innovative therapeutics and medical devices for SCI and secondary complications.
- The implementation of innovative therapeutics and medical devices into the delivery of healthcare for people with SCI.
- Increasing investor and industry engagement and participation in SCI research and development.

Areas of Focus

RHI will act as an accelerator for innovative technologies (therapeutics, medical devices, diagnostics and health-IT technologies) that will benefit people with SCI. It will do this through the following three areas:

- **RHI network**

  RHI will determine how to operationalize resources within its network in support of development and commercialization initiatives. RHI will expand and continue to strengthen its global network of collaborations in SCI research and care. Expansion will include connection into existing networks of investors, industry, payers and service providers internationally. In order to ensure alignment to RHI’s Consumer Program, this process will also include more engagement of local and international consumer groups.
Early stage evaluation of technologies
RHI will introduce mechanisms/criteria that will proactively evaluate technologies for their applicability and benefit to people with SCI from a commercialization perspective. The types of technologies that will be evaluated through these mechanisms/criteria will be limited to those that align to the Cure and Care Programs.

Policy and advocacy
RHI will develop mechanisms related to health economic evaluation, impact analysis, regulatory considerations and advocacy in order to provide the evidence for reimbursement of innovations by payers. These mechanisms will leverage resources of RHI’s Care Program.

Key Accomplishments in Fiscal Year 2013-2014

SCI Global Investment Forum
One of the biggest challenges for start-up companies particularly those in the life sciences and biotechnology field, is to secure bridge funding to test an idea through proof of concept to the point in which it is able to secure the investment necessary to continue its development. This is often described as the commercial “valley of death” (see more on page 25).

The first step for RHI’s Commercialization Strategy was to pilot the RHI SCI Global Investment Forum. The Forum is intended to facilitate connections between early-stage and emerging companies, developing therapeutics and medical devices with application to SCI and the secondary complications, to potential investors and partners. This is done by providing these companies the opportunity to pitch their company and SCI-related technology at an event that is attended by potential investors and partners from the broader life sciences and biotechnology community. RHI has hosted two Forums to date: the Biotech Showcase in San Francisco, California (held in the previous fiscal year) and BioPharm America in Boston, Massachusetts (September 2013).

The Forum at BioPharm America involved four early-stage and emerging companies giving short presentations that included information on their particular technology and its application to SCI, corporate background, management team, financial forecast and commercialization strategy in order to attract investment or corporate partnerships. The forum was successful in bringing investor attention to the area of spinal cord injuries.

Two additional RHI SCI Global Investment Forums are planned in future years.

Supporting Emerging Interventions and Innovative Technologies
In February, RHI launched a new open funding opportunity entitled Emerging Interventions and Innovative Technologies. Influenced by discussions with RHI’s Care Committee, this funding opportunity directly helps advance objectives set out in RHI’s Business Plan for 2013-2018 and will ultimately help RHI move closer towards achieving its vision of a world without paralysis after SCI. The application deadline was April 30 and the review process is now underway. Applicants will be notified of the results process this summer and successful applications will be announced on RHI’s website.

How Does RHI Define Commercialization?
RHI defines commercialization as the process of introducing a new product or production method into the market, including the sustainable implementation into the delivery of healthcare, in order to achieve a return for stakeholders.

Commercialization is the goal while development is the series of activities leading towards commercialization.

RHI defines Return on Investment (ROI) as improved outcomes divided by the cost of obtaining those improved outcomes.
Championing Change to Accelerate the Pace of Cures for Paralysis after SCI

Spinal cord injury is one of the greatest survivable catastrophes experienced by a human being. Required care is highly specialized and complex, resulting in substantial financial costs for payers. In Canada, the cost of care for people with traumatic SCI is now estimated at approximately $2.7 billion per year. Despite the amount of funding that supports basic research, few discoveries achieve their potential. The various transitions from bench-to-bedside research are so fraught with obstacles that they are often referred to as the “valleys of death”.

RHI has developed a solutions-focused model to overcome specific obstacles in the research continuum of SCI discoveries to achieve the ultimate goals of improved healthcare outcomes for people with SCI and decreased financial impact on the healthcare system. RHI refers to it as the Praxis Model. Praxis (from the Greek “doing”) aims to accelerate the rate in which research knowledge is translated into practice in order to benefit people with spinal cord injury.

The Praxis Model enables RHI to achieve a better return on investment (ROI) for its funders than other models (RHI defines ROI as improved outcomes for people with SCI divided by the cost of improved outcomes).

RHI’s Praxis Model includes three essential components:

- **Coordinated Program Strategy:** Cure, Care, Consumer and Commercialization
- **Knowledge Cycle:** Environmental Scan, Knowledge Generation & Synthesis, Knowledge Validation and Implementation
- **Infrastructure & Resources:** Funding, Clinical Research Operations, Research & Best Practices Implementation, Informatics, Consumer Engagement, Collaborative Networks and Strategic Partnerships

Each one of the components on their own is not unique to RHI. What is unique is the combination of the component areas and RHI’s role as a champion of change. This enables RHI to take a leadership role and to take responsibility for developing solutions to the problems encountered by those with SCI. In the case of RHI, the problems are paralysis and the secondary complications after the injury. By developing solutions to these problems RHI can play a role in improving the quality of life until for those who have suffered an SCI.

Learn more about RHI’s Praxis Model at www.rickhanseninstitute.org/about-us/who-we-are/praxis-model.
Consumer Program

Focuses on involving more individuals with SCI in research.

EXPECTED OUTCOME:

Increased opportunities for participation in research and health decision-making among individuals with SCI.
Program Overview

The Consumer Engagement Program aims to provide resources and tools to people with SCI and their families to help answer their most critical questions in the first months after injury. The program also involves developing activities and tools that promote research participation and educating consumers about SCI research progress and its value, such as a plain language research newsletters or consumer-focused sessions at research meetings.

The program’s goal is to support evidence-based health decisions during a time of high need and difficulty, and to engage people with SCI in the research process by improving awareness of SCI research knowledge and value. Additionally, the program aims to identify activities that could engage consumers, prioritize potential opportunities and collaborate to leverage resources to improve consumer engagement in research activities at the Blusson Spinal Cord Centre.

Areas of Focus

- Developing an evidence-based, “go-to” resource that answers critical questions for the newly injured and their supporters about the healthcare, services and resources available to best support recovery after SCI.

- Increasing opportunities for participation in SCI research and knowledge of its benefits among people with SCI and their supporters. Through collaboration with other SCI organizations on events and tools, the Consumer Program attempts to put research into the hands of consumers in useful formats.

- Supporting a BSCC Consumer Advisory Board, a group of up to 12 people with SCI, supporters & advocates who can best represent the SCI population. This group will guide efforts to engage people with SCI in research, shape evidence-based resources and identify consumer research priorities for RHI and the Blusson Integrated Cures Partnership. An Advisory Committee is in the process of being assembled in fiscal year 2014-2015.

Did You Know...

There are approximately 86,000 Canadians living with spinal cord injury with an estimated 4,300 new cases each year. This number is expected to increase as our population ages.
Key Accomplishments in Fiscal Year 2013-2014

Partnership with Unite2Fight Paralysis

A grassroots advocacy organization, U2FP brings together scientists, clinicians, investors, SCI consumers and their families who are committed to finding a cure for spinal cord injury. As part of RHI’s Consumer Engagement Strategy, RHI is a sponsor of U2FP’s annual conference, the Working2Walk Symposium, held October 2014, in Seattle. RHI will also provide financial support for Canadians with SCI and researchers to attend the conference.

Ontario SCI Solutions Alliance

RHI presented its Consumer Engagement Program at the Ontario SCI Solutions Alliance annual meeting. The goal of the presentation was to engage community service groups to gain feedback and identify opportunities to work together. Valuable discussion and key feedback was gained which led to the exploration of ongoing partnerships and efforts to engage SCI consumers.

Community Research Meeting

A vital component of the Consumer Engagement Program is educating and engaging consumers about current SCI research. As a result, RHI teamed up with ICORD to host a Community Research Meeting which preceded ICORD’s Annual Research Meeting in March. Leading SCI scientist, Dr. Jerry Silver from Case Western Reserve University presented the latest on SCI regeneration research, followed by a lively and interactive Q&A with participants. Over 61 researchers and consumers participated in person or via streaming webinar.

SCI Community Survey Dissemination Project

This pilot project will involve four regional collaborations (BC, Alberta, Ontario and Atlantic Canada) of community groups and clinicians conducting an independent best practice implementation project. It will include assessment of the implementation process, and identification of barriers and facilitators to improving service delivery. Project members include Dr. Luc Noreau (Scientific Director, Center for Interdisciplinary Research in Rehabilitation and Social integration), Bobby White (National Executive Director, Spinal Cord Injury Canada) Teren Clarke (Executive Director, Canadian Paraplegic Association Alberta) and Jocelyn Tomkinson (Consumer Engagement Lead, RHI).
A Centre for True Collaboration: The Blusson Spinal Cord Centre

November 2013 marked an important milestone for the staff at the Rick Hansen Institute. With colleagues at UBC’s International Collaboration on Repair Discoveries (ICORD), the Brenda & David McLean Integrated Spine Clinic of Vancouver Coastal Health, and community partners, volunteers, supporters and funders, Blusson celebrated its 5th Anniversary, since opening in 2008.

Blusson – a true gem made possible by the generosity of Stuart and Marilyn Blusson, Government of British Columbia, Canada Foundation for Innovation, University of British Columbia, Vancouver Coastal Health and Rick Hansen Foundation around Rick Hansen’s vision of a collaborative working environment – is the place over 300 professionals call home.

Blusson is where thousands of individuals meet each year to receive treatment and support and exchange ideas. It is also where researchers, staff and clinicians work to solve one of the most devastating and expensive healthcare challenges in the entire medical system: paralysis from spinal cord injury. Together, this partnership spans basic and clinical research, clinical care and knowledge translation informing best practices locally, nationally and internationally.
Additional Highlights from Fiscal Year 2013-2014
Rick Hansen Foundation: In April 2013, the Rick Hansen Foundation announced a grant of $20 million over 10 years to support researchers and clinicians at the Blusson Spinal Cord Centre to accelerate clinical research. The funding is aimed at progressively strengthening the partnership between RHI and the International Collaboration On Repair Discoveries (ICORD). ICORD is a joint University of British Columbia-Vancouver Coastal Health Research Institute research centre based at the Blusson Centre. The Partnership leverages the existing strengths of each organization to accomplish the following: become the world’s leading partnership in innovative and collaboration preclinical and clinical research to accelerate the discovery of SCI cures; develop and promote an International Clinical Trail and Research Network that will enable international collaboration in promising clinical trials and research efforts; and inform, empower and include people with SCI to be champions and active participants in Rick Hansen’s efforts to create a world without paralysis after spinal cord injury.

Government of Canada: In June 2014, the Government of Canada announced an investment to RHI of $35 million over five years to assist in the ongoing mission to achieve breakthroughs in SCI research and treatment, generating new knowledge, new technologies and knowledge-based jobs, while improving patient outcomes and quality of life, and ensuring long-term prosperity for all Canadians. In addition, this support will help with all elements of SCI treatment and care for newly, acutely and chronically injured individuals, including developing new therapies and decreasing the time required for research to be translated into real-life benefits. To view the details of RHI’s five year business plan which outlines the goals RHI aims to achieve by 2018, please visit www.rickhanseninstitute.org.

Government of Manitoba: In March 2014, Manitoba Minister of Health, the Honourable Erin Selby, announced that the Government of Manitoba will be investing $3 million over five years with the Rick Hansen Institute and Canadian Paraplegic Association Manitoba to help Manitobans with spinal cord injuries successfully transition back into their homes and jobs and further advance healthcare and research initiatives in the province.
**Blusson Spinal Cord Centre Tours:** Home to RHI, ICORD and Vancouver General Hospital’s Brenda and David McLean Integrated Spine Clinic, the Blusson Spinal Cord Centre is a state-of-the-art facility located in Vancouver, BC. It brings together over 300 professionals to provide a one stop shop for research innovation, collaboration and treatments for people with spinal cord injuries. Along with colleagues at ICORD and VCHRI, RHI was pleased to host BC Minister of Justice, the Honourable Suzanne Anton (January 2014) and Minister of State for Western Economic Diversification, Honourable Michelle Rempel (April 2014) to showcase Blusson and the innovative work taking place in the building.

**Best & Brightest:** The goal of RHI’s Best and Brightest strategy is to nurture new SCI researchers and provides mentorship opportunities with well-established SCI investigators. RHI partnered with the Michael Smith Foundation for Health Research, the University of Ottawa’s Faculty of Medicine and the Manitoba Health Research Council to provide funding opportunities to Canadian SCI researchers. These awards will offer significant benefits to the SCI research field in Canada by developing leadership and expertise in targeted areas of science that are critical to RHI’s goals and accelerating the progress on RHI’s vision and mission.
Looking Ahead: the Next 25 Years

In consultation with stakeholders, RHI has set ambitious milestones over the next 25 years in order to work towards our vision:

- **2013**: Renewed funding from the Government of Canada and the Rick Hansen Foundation.
- **2014**: Development of RHI’s international SCI cure strategy.
- **2018**: International collaboration on two promising neurorestorative novel therapies. This goal will be facilitated by 50% of newly-injured Canadians receiving standardized care.
- **2023**: International collaboration on five promising neurorestorative novel therapies. This goal will be facilitated by 75% of newly-injured Canadians receiving standardized care.
- **2038**: All Canadians have access to SCI-specific novel therapies. This goal will be facilitated by all Canadians receiving standardized care.

After only a few years, RHI has arrived at the intersection of unprecedented scientific progress in knowledge and transformative global communications technology. With its multi-faceted, integrated and collaborative strategies, RHI is galvanizing an army of people across this country and around the world to harness and share their collective knowledge and ability to deliver results at an astonishing rate.

We believe that rigorous implementation of this strategy to its fullest potential will have a far-reaching impact – not only for Canadians and our healthcare system, but for people around the world – and will further solidify Canada’s reputation as an inventive, global leader in SCI research and care.
## Financial Summary

*Please refer to our website for full audited financial statements.*

### Statement of Financial Position

For the year ended March 31, 2014.

<table>
<thead>
<tr>
<th></th>
<th>March 31, 2014 $</th>
<th>March 31, 2013 $</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Current assets</strong></td>
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<td></td>
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<tr>
<td>Cash and cash equivalents</td>
<td>979,269</td>
<td>415,917</td>
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<tr>
<td>Short-term investments</td>
<td>5,834,661</td>
<td>5,933,851</td>
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<td>Accounts receivable</td>
<td>56,616</td>
<td>39,451</td>
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<tr>
<td>Funding receivable</td>
<td>-</td>
<td>1,082,500</td>
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<tr>
<td>Prepaid expenses</td>
<td>23,886</td>
<td>23,097</td>
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<tr>
<td><strong>Total current assets</strong></td>
<td><strong>6,894,432</strong></td>
<td><strong>7,494,816</strong></td>
</tr>
<tr>
<td><strong>Capital assets</strong></td>
<td>131,357</td>
<td>196,204</td>
</tr>
<tr>
<td><strong>Liabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Current liabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable and accrued liabilities</td>
<td>736,377</td>
<td>779,280</td>
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<tr>
<td><strong>Deferred contributions</strong></td>
<td>6,020,705</td>
<td>6,693,648</td>
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<tr>
<td><strong>Deferred capital contributions</strong></td>
<td>131,357</td>
<td>196,204</td>
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<tr>
<td><strong>Unrestricted funds</strong></td>
<td>137,350</td>
<td>21,888</td>
</tr>
<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>7,025,789</strong></td>
<td><strong>7,691,020</strong></td>
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## Statements of Operations and Fund Balances
For the year ended March 31, 2014.

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenue</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grants and contributions</td>
<td>7,753,264</td>
<td>9,150,255</td>
</tr>
<tr>
<td>Donations and sponsorships</td>
<td>69,073</td>
<td>23,564</td>
</tr>
<tr>
<td>Investment income</td>
<td>91,711</td>
<td>106,574</td>
</tr>
<tr>
<td>Other income</td>
<td>92,059</td>
<td>5,263</td>
</tr>
<tr>
<td>Amortization of deferred capital contributions</td>
<td>109,888</td>
<td>171,701</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td>8,115,995</td>
<td>9,457,357</td>
</tr>
</tbody>
</table>

| **Expenses**            |        |        |
| Translational research  | 3,642,388 | 3,715,140 |
| Best practice implementation | 1,527,782 | 1,900,163 |
| Informatics             | 1,161,146 | 1,440,964 |
| Network development     | 249,046  | 1,048,425 |
| Best & brightest        | 158,425  | -      |
| Consumer engagement     | 821,859  | -      |
| Fundraising             | 87,509   | 167,219 |
| Management and administration | 352,378 | 1,175,683 |
| **Total Expenses**      | 8,000,533 | 9,447,594 |

**Excess of revenue over expenses for the year**

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>115,462</td>
<td>9,763</td>
</tr>
</tbody>
</table>

**Unrestricted fund balance - Beginning of year**

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>21,888</td>
<td>12,125</td>
</tr>
</tbody>
</table>

**Unrestricted fund balance - End of year**

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>137,350</td>
<td>21,888</td>
</tr>
</tbody>
</table>
Revenues by Source

- Government and other grants: $7,753,264 (95.5%)
- Donations & Sponsorships: $69,073 (0.9%)
- Investment and other income: $183,770 (2.3%)
- Amortization of deferred capital contributions: $109,888 (1.3%)

Total revenues: $8,115,995 (100%)

Expenditures by Type

- Translational research: $3,642,388 (45.5%)
- Best practice implementation: $1,527,782 (19.1%)
- Informatics: $1,161,146 (14.5%)
- Network development: $249,046 (3.1%)
- Best & brightest: $158,425 (2.0%)
- Consumer engagement: $821,859 (10.3%)
- Fundraising: $87,509 (1.1%)
- Management and administration: $352,378 (4.4%)

Total expenditures: $8,000,533 (100%)
Board of Directors and Committees

We greatly appreciate the contributions our board of directors and program committee members who help us work towards our vision of a world without paralysis after SCI. These individuals represent the breadth and diversity of the international SCI community, each committed to helping improve the quality of life for individuals with SCI. Thank you!

Board of Directors

Bernie Bressler, [Chair], Associate Member, Department of Orthopaedics, Vancouver Coastal Health Research Institute/University of British Columbia

Ryan Barrington-Foote, Managing Director, Accounting, Jim Pattison Group

Gary Birch, Executive Director, Neil Squire Society

Tung Chan, Vice Chair, Canadian Museum of Immigration at Pier 21

Graham Creasey, Professor, Med Center Line, Neurosurgery, Stanford School of Medicine

Katharina Kovacs Burns, Associate Director, Health Sciences Council & Director, Interdisciplinary Health Research Academy, University of Alberta

Kevin Lamarque, Past Chair, CPA Nova Scotia

Colleen Nelson, Professor and Chair, Prostate Cancer Research; Institute of Health and Biomedical Innovation, Queensland University of Technology

Colleen O’Connell, Research Chief, Stan Cassidy Centre for Rehabilitation

Sam Sullivan, MLA, Vancouver-False Creek

Catherine Truchon, Senior Advisor, Trauma Team, Institut National d’Excellence en Santé et Services Sociaux

Marie Trudeau, Former Board Member, SCI Solutions Alliance

Translational Research Advisory Committee (TRAC)

RHI Board Members

Katharina Kovacs Burns, [Chair] Associate Director, Health Sciences Council & Director, Interdisciplinary Health Research Academy, University of Alberta

Gary Birch, Executive Director, Neil Squire Society

Marie Trudeau, Former Board Member, SCI Solutions Alliance

Catherine Truchon, Senior Advisor, Trauma Team, Institut National d’Excellence en Santé et Services Sociaux

Knowledge Translation & BPI Experts

Mark Bayley, Medical Director, Brain and Spinal Cord Rehabilitation Program, Toronto Rehabilitation Institute - University Health Network

Anthony G. Phillips, Scientific Director, Institute of Neurosciences, Mental Health and Addiction, CIHR

Clinicians/Scientists

Stephen Burns, Program Director, United States Department of Veterans Affairs Puget Sound Health Care System Spinal Cord Injury Service

Anthony Burns, Staff Physiatrist, Brain & Spinal Cord Rehabilitation Program, University Health Network – Toronto Rehabilitation Institute

Wolfram Tetzlaff, Director, International Collaboration on Repair Discoveries

Ronald Reeves, Medical Director, Inpatient Relations, Mayo Clinic
Consumer Representatives

Courtney Keenan, President, Ability New Brunswick
Kevin Lamarque, Past Chair, CPA Nova Scotia
Shauna Petrie, Travel Writer and Speaker; Co-founder, Sea Wheels Inc.

Ex-Officio

Bill Barrable, CEO, Rick Hansen Institute
Susan Charlifue, Senior Principal Investigator, Craig Hospital
Erin Cherban, Director Clinical Research Operations, Rick Hansen Institute
Phalgun Joshi, Managing Director, Program Operations and Support, Rick Hansen Institute
Vanessa Noonan, Director, Research & Best Practice Implementation, Rick Hansen Institute
Jocelyn Tomkinson, Consumer Engagement Lead, Rick Hansen Institute

Cure Committee

Brian Kwon [Chair], Associate Professor, Orthopaedics, University of British Columbia
Steve Casha, Assistant Professor, Clinical Neurosciences, Surgery, University of Calgary
Michael Fehlings, Professor, Neurosurgery, University of Toronto
James Guest, Clinical Professor, Neurological Surgery and the Miami Project to Cure Paralysis Miller School of Medicine, University of Miami
Susan Harkema, Rehabilitation Research Director, Kentucky Spinal Cord Injury Research Centre
Vanessa Noonan, Director, Research & Best Practice Implementation, Rick Hansen Institute
Wolfram Tetzlaff, Director, International Collaboration on Repair Discoveries
Mark Tuszyński, Professor, Neurosciences, University of California San Diego
Scott Whittemore, Scientific Director, Kentucky Spinal Cord Injury Research Center
Care Committee

Katharina Kovacs Burns [Chair], Associate Director, Health Sciences Council & Director, Interdisciplinary Health Research Academy, University of Alberta
Mark Bayley, Associate Professor, Physiatry, University of Toronto
Lise Belanger, Clinical Nurse Specialist, Acute Spine Program, Vancouver General Hospital
Janice Eng, Professor, Physical Therapy, University of British Columbia
Sean Christie, Assistant Professor, Surgery, Dalhousie University
Teren Clarke, Executive Director, Canadian Paraplegic Association (Alberta)
Cathy Craven, Assistant Professor, Physiatry, University of Toronto
Brian Kwon, Associate Professor, Orthopaedics, University of British Columbia
Vanessa Noonan, Director, Research and BPI, Rick Hansen Institute
Luc Noreau, Professor, Rehabilitation, Université Laval
Stefan Parent, Assistant Professor, Surgery, Université de Montréal
John Shepherd, Affiliated Scientist, Toronto Rehabilitation Institute - University Health Network
Catherine Truchon, Senior Advisor, Trauma Team, Institut National d’Excellence en Santé et Services Sociaux
Dalton Wolfe, Scientist & SCI Research Group Co-Lead; Aging, Rehabilitation & Geriatric Care Research Centre; Lawson Health Research Institute; Parkwood Hospital, St. Joseph’s Healthcare London

Commercialization Committee

Ross Mason [Chair], Executive Director & Founder, Healthcare Institute for Neuro-Recovery & Innovation
John Barclay, Manager, Commercialization and Industry Relations, Rick Hansen Institute
Elona Baum, General Counsel & VP, Business Development, California Institute for Regenerative Medicine
Jason Coonan, General Manager, Contract and Asset Management, UoM Commercial
Rich Howlett, Director, Operational Alliances, Novartis Institutes for Biomedical Research
Michael May, CEO, Centre for Commercialization of Regenerative Medicine
Hunter Peckham, Executive Director, Institute for Functional Restoration, Case Western Reserve University
Chris Wagner, CEO, Contextual Genomics
APPENDIX I

Publications in Fiscal Year 2013-2014

Access to Care and Timing


Physical Activity Guidelines for Adults with SCI


Rehabilitation E-Scan


RHSCIR Study *(Please note this list is not exhaustive as not all local RHSCIR sites that have used RHSCIR data are mentioned.)*


SCI Chronic Pain Self-Management: A Clinical Demonstration Study


Spinal Cord Injury Rehabilitation Evidence (SCIRE)

Guy S, Mehta S, Leff L, Teasell R, Loh E, & SCIRE Research Team (2014). Anticonvulsant medication use for the


**RHI-Affiliated Projects**


**Abstracts** *(includes presentations between April 1, 2013 and March 31, 2014)*


Engel L, Bryan S, Noonan VK, Whitehurst DG. Determining the current state-of-play for variants of the Short Form health-related quality of Life instrument in spinal cord injury: a systematic review. Accepted for the International Society for Pharmacoeconomics and Outcomes 18th Annual Meeting (poster presentation). New Orleans, LA; May 18-22, 2013.


# Appendix 2: Update on the RHI 2013-2014 Operational Plan

## Translational Research

<table>
<thead>
<tr>
<th>Deliverable</th>
<th>Description</th>
<th>Planned Tasks FY2014</th>
<th>Progress to Date</th>
</tr>
</thead>
</table>
| **TR-01 Global Cure Strategy**  
Funder: WD | RHI is supporting the development of a strategy towards the cure, which will require an assessment of existing knowledge, identifying gaps, a definition of the path forward with defined milestones and targets and the resources required to execute the strategy. The Global Strategy will consist of methods to assess the readiness of emerging therapies for use in human clinical trials. An assessment of ongoing clinical trials and ways to address regulatory and funding hurdles will be included. The development of the strategy will include consultation with experts and international representatives from various stakeholder groups. Collaboration will encompass participation in international studies, sharing of research data, KT and ensuring that the trial patients all receive standardized care before and after initial treatment to reduce variability in study outcomes. | Identify leadership  
Identify timelines for development of strategy  
Confirm international partners for cure strategy execution | Completed.  
Completed.  
Ongoing. |
| **TR-03 Existing Clinical Studies: CAMPER**  
Funder: WD | RHI is currently supporting two neuro-protection studies, The Canadian Multi-Centre CSF Pressure Monitoring and Biomarker Study (CAMPER) and Minocycline. The CAMPER study | Initiation of 6th Canadian CAMPER study site | Completed. |
<table>
<thead>
<tr>
<th>Deliverable</th>
<th>Description</th>
<th>Planned Tasks FY2014</th>
<th>Progress to Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>TR-03 Existing Clinical Studies: Minocycline</td>
<td>The Minocycline study will determine whether Minocycline (a generic antibiotic) is efficacious in the neuro-protection of the spinal cord after injury. This multi-centre study is currently underway in Canada. RHI intends to expand the project internationally and expects to complete the project by 2018.</td>
<td>Initiation of first international CAMPER study site</td>
<td>Ongoing discussions with four sites in the US.</td>
</tr>
<tr>
<td>Funder: WD</td>
<td>Enrollment of 25 new subjects into CAMPER</td>
<td>Ongoing. 19 subjects enrolled in F2014, for a total of 40 subjects.</td>
<td></td>
</tr>
<tr>
<td>TR-06 Outcome Measures Development</td>
<td>Outcome measures are a means to establish the baseline impact of a disease on an individual and the changes experienced over time. Although there are currently more than 150 outcome measures that have been developed for use in individuals with SCI, there is a general agreement within the SCI community on the need to validate them for use in SCI clinical trials. RHI will plan to support studies examining the psychometric properties of five outcome measures. New outcome measures will be incorporated into the Rick</td>
<td>Identification and initiation of new outcome measure working groups for RHSCIR 2.0 dataset</td>
<td>Completed.</td>
</tr>
<tr>
<td>Funder: WD</td>
<td>Identification of new outcome measures for RHSCIR 2.0 dataset</td>
<td>Completed.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Begin site training of new outcome measure data collecting for RHSCIR 2.0</td>
<td>Completed.</td>
<td></td>
</tr>
<tr>
<td>Deliverable</td>
<td>Description</td>
<td>Planned Tasks FY2014</td>
<td>Progress to Date</td>
</tr>
<tr>
<td>----------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Injury Registry (RHSCIR).</td>
<td>The RHSCIR is the only Canadian prospective, observational, longitudinal study which follows people with traumatic SCI from the time of injury over their lifetime. The RHSCIR study's aim is to create a data repository to inform the Global Strategy to Cure Paralysis after SCI and support the effort to accredit SCI Centres.</td>
<td>Submission of 3 RHSCIR national publications</td>
<td>Completed.</td>
</tr>
<tr>
<td>TR-07 RHSCIR</td>
<td>Building on RHSCIR data and other sources, the Access to Care and Timing (ACT) has built a simulation model to describe the processes of care from the time of injury until discharge into the community for individuals sustaining a traumatic spinal cord injury and projects long term-outcomes (e.g. life expectancy, health utilization, costs and health utilities). Using the simulation model, the effect of implementing best practices related to the “setting” (where patients are treated) and the “timing” (when treatment is provided) are tested (simulated) and the impact on patient and system outcomes can be evaluated. This will inform the Global Strategy to Cure Paralysis and support the effort to accredit SCI Centres.</td>
<td>ACT dissemination workshop</td>
<td>Completed.</td>
</tr>
<tr>
<td>Funder: WD</td>
<td></td>
<td>One national ACT paper submitted</td>
<td>Completed.</td>
</tr>
<tr>
<td>TR-07 ACT</td>
<td></td>
<td>Consulting to two ACT sites for local application of the ACT Model Version 1.0</td>
<td>Completed.</td>
</tr>
<tr>
<td>Funder: WD</td>
<td></td>
<td>Make announcement</td>
<td>Completed. Announcement posted on <a href="http://www.rickhanseninstitute.org">www.rickhanseninstitute.org</a></td>
</tr>
<tr>
<td>Deliverable</td>
<td>Description</td>
<td>Planned Tasks FY2014</td>
<td>Progress to Date</td>
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<tr>
<td>Technologies and Interventions Funder: WD</td>
<td>RHI’s 5 year goals. This support will also apply to innovations that have been proven effective in other indications and have sufficient rationale for testing in SCI.</td>
<td>Have open call</td>
<td>Completed.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Begin application review</td>
<td>Completed.</td>
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<tr>
<td></td>
<td></td>
<td>Select projects for award</td>
<td>Ongoing.</td>
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</tbody>
</table>
## Best Practice Implementation

<table>
<thead>
<tr>
<th>Deliverable</th>
<th>Description</th>
<th>Planned Tasks FY2014</th>
<th>Progress to Date</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BP-01 Implementing Best Practices</strong>&lt;br&gt;<strong>Funder: WD</strong>&lt;br&gt;Since 2007, RHI has supported a number of BPI projects that have centred around the rehabilitation services currently available to people with SCI and synthesized research evidence for clinicians. These projects will continue to receive support during the 2013-2018 period as they inform current and future BPI efforts.</td>
<td>Map SCI content from RHI projects (e.g., RHSCIR, E-Scan) to SCI goals</td>
<td>Completed.</td>
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<tr>
<td></td>
<td>Draft materials for an advisory committee as part of the Canadian SCI Care Strategy</td>
<td>Completed.</td>
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<tr>
<td></td>
<td>Host Rehabilitation E-Scan workshop (to be held in concert with ACT workshop if possible) to identify priority best practices for implementation</td>
<td>Completed.</td>
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</tr>
<tr>
<td><strong>BP-02 Knowledge Mobilization Network</strong>&lt;br&gt;<strong>Funder: WD</strong>&lt;br&gt;RHI recognizes the importance of developing an infrastructure of leaders in knowledge translation for the effective dissemination and promotion of the uptake of knowledge and best practice guidelines. RHI has therefore initiated a pilot KMN comprised of six sites in Alberta, Ontario and Quebec. The network consists of leaders working collectively to implement guidelines in real-world practice.</td>
<td>Data collection tools completed</td>
<td>Completed.</td>
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<tr>
<td></td>
<td>Data collected through surveys, interviews, literature review</td>
<td>Completed.</td>
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<tr>
<td></td>
<td>Draft assessment report prepared</td>
<td>Completed.</td>
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<tr>
<td></td>
<td>Assessment report finalized</td>
<td>Completed.</td>
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<tr>
<td><strong>BP-03 Clinical Practice Guideline Development</strong>&lt;br&gt;During the 2013-2018 period, RHI will develop three clinical practice guidelines (CPG) for implementation, addressing areas such as pain,</td>
<td>Arrange meetings with international experts to discuss opportunities for collaboration</td>
<td>Completed.</td>
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<tr>
<td>Deliverable</td>
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<td>Progress to Date</td>
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<tr>
<td><strong>Funder: WD</strong></td>
<td>bladder management or autonomic dysreflexia.</td>
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<tr>
<td><strong>BP-05 SCI Patient Self-Management Program</strong></td>
<td>During the period 2013-2018, RHI intends to develop a strategy and implement a pilot SCI patient self-management program. This program will be developed and implemented in partnership with all stakeholders including clinicians, people with SCI and consumer organizations. The successful implementation of this program will result in not only lower rehospitalization rates, but an increase in the quality of life of people with SCI as they will be empowered to self-manage other issues such as physical activity, diet and sexual health.</td>
<td>Complete environmental scan of patient self-management resources</td>
<td>Completed.</td>
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<td></td>
<td></td>
<td>Conduct focus group with SCI consumers on self-management resources</td>
<td>Ongoing.</td>
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<tr>
<td></td>
<td></td>
<td>Identify partners and establish partnership agreement</td>
<td>Completed.</td>
</tr>
<tr>
<td><strong>BP-06 Commercialization</strong></td>
<td>Many hurdles exist to commercialization of new therapeutics, diagnostics or devices for SCI, including lengthy regulatory requirements and limited investment from funders. In the 2013-2018 period, RHI will continue to develop and implement mechanisms that will facilitate greater investment into companies to encourage an increased number of new therapeutics, medical devices and diagnostics that will benefit those with SCI.</td>
<td>Explore the possibility of commercializing the ACT Model</td>
<td>Completed.</td>
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<tr>
<td></td>
<td></td>
<td>Confirm forum location and timing</td>
<td>Completed.</td>
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<tr>
<td></td>
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<td>Release program guidelines</td>
<td>Completed.</td>
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<td></td>
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<td>Select presenting companies</td>
<td>Completed.</td>
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<td>Presentation feedback and strengthening process</td>
<td>Completed.</td>
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<tr>
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<tr>
<td>Intellectual Property Policy Document</td>
<td>Development: draft document received from Gowling Lafleur Henderson LLP</td>
<td>Completed.</td>
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<tr>
<td>Final document received from Gowlings</td>
<td></td>
<td>Completed.</td>
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</tr>
<tr>
<td>Submit document for approval by Board</td>
<td>by Board of Directors</td>
<td>Completed.</td>
<td></td>
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<tr>
<td>Developed RHI intellectual property</td>
<td>strategy document</td>
<td>Completed.</td>
<td></td>
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<tr>
<td>Development of a business and</td>
<td>development strategy for GRP, including cost recovery plan and feasibility study</td>
<td>Ongoing.</td>
<td></td>
</tr>
<tr>
<td>BP-07 SCI Education Credits</td>
<td>This project builds on the Action Nuggets project previously supported by RHI. The project aims to equip generalist physicians with the information they need to offer evidence-based best practice in the primary care of patients with SCI. Researchers at Queens University and the Knowledge Transfer Team at the Canadian Medical Association will work collaboratively with RHI to synthesize existing content and make it available through a CMA web-based platform. The system will allow physicians to review the content, be evaluated on their familiarity with it, and then receive education credits on CMA website.</td>
<td>Launch education credits on CMA website</td>
<td>Completed.</td>
</tr>
<tr>
<td>Funder: WD</td>
<td></td>
<td>Begin evaluation of CMA education credits</td>
<td>Completed.</td>
</tr>
<tr>
<td>Deliverable</td>
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<td></td>
<td>CME credits for successful completion. The utilization of the CMA credentialing process and knowledge transfer infrastructure will accelerate access to best practices for the management of the most common conditions associated with spinal cord injury.</td>
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<tr>
<td><strong>BP-X1 Other BPI Activities: Care Program</strong></td>
<td>RHI is undertaking work related to the oversight of its new Care Program.</td>
<td>Committee formation</td>
<td>Completed.</td>
</tr>
<tr>
<td>Funder: BC</td>
<td></td>
<td>Committee meeting</td>
<td>Completed.</td>
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<tr>
<td></td>
<td></td>
<td>Dissemination paper</td>
<td>Completed.</td>
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<tr>
<td></td>
<td></td>
<td>Care Roadmap available at <a href="http://www.rickhanseninstitutue.org">www.rickhanseninstitutue.org</a>.</td>
<td></td>
</tr>
<tr>
<td><strong>BP-X1 Other BPI Activities: Commercialization Program</strong></td>
<td>RHI is undertaking the development of a roadmap and strategic plan to guide commercialization activities.</td>
<td>Commercialization document development</td>
<td>Completed.</td>
</tr>
<tr>
<td>Funder: BC</td>
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</table>
## Network Development

<table>
<thead>
<tr>
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<th>Progress to Date</th>
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</thead>
<tbody>
<tr>
<td>ND-04 Central Patient Recruitment Model</td>
<td>One of the major challenges faced by SCI researchers worldwide is the inability to recruit sufficient patients for clinical research studies, due to the low number of people with SCI compared to other indications and limited ability of people with SCI to get to clinical research sites due to transportation, accommodation and Canadian distance issues. However, one of the main reasons for limited participation in clinical studies is the lack of awareness of the existing clinical research studies by people with SCI willing to participate in such studies. During the 2013-2018 period, RHI intends to develop a patient recruitment model focused on creating an inventory of all SCI related clinical research studies and informing potential participants about their eligibility. RHI will ensure that all features of this recruitment model will meet appropriate privacy and security standards. Funding from WD will support the development of the patient recruitment model itself. Funding provided by RHF, as part of the Blusson Integrated Cures Partnership, will support partnership-building activities with consumer groups, in order to enhance participation of patients in clinical trials.</td>
<td>Identify project team</td>
<td>Completed.</td>
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<td></td>
<td></td>
<td>Develop multi-year project plan (Phase 1 - identify requirements in year 1)</td>
<td>Completed.</td>
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<td>Project Manager to work with internal and external personnel to identify project requirements</td>
<td>Ongoing.</td>
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<td></td>
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<td>Present Phase 1 plan to TRP Directors</td>
<td>Completed.</td>
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<tr>
<td>Deliverable</td>
<td>Description</td>
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<td>Progress to Date</td>
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</tbody>
</table>
| **ND-05 Strategic Relationships**  
Funder: WD | The success of RHI in its efforts to achieve its mission is dependent on the productive relationships it enjoys with all its strategic partners. Strategic partnerships will be established with individuals, governments, non-governmental organizations, trade associations, research and healthcare institutions, or corporations, and are developed locally, nationally and internationally. | Identify strategic needs  
Identify partners  
Complete partnership agreements | Completed for fiscal year.  
Completed for fiscal year.  
Completed for fiscal year. |
| **ND-06 Co-Funding and Leverage Funding Opportunities**  
Funder: WD | In partnership with the Rick Hansen Foundation, RHI will seek funding from provincial governments and funding organizations, persons of high net worth, corporations, and other SCI organizations and governments around the world. The efforts required to obtain funding involve travel and meetings with key individuals, attending conferences and network events, hosting events showcasing RHI and network accomplishments and the use of consultants. | Meet with funders/provinces  
Submit proposals  
Complete funding agreements | Completed for fiscal year.  
Completed.  
Completed. |
| **ND-07 International SCI Research Collaboration**  
Funder: RHI | RHI and ICORD will develop collaborations with at least 15 countries to conduct preclinical and clinical studies. This may first be achieved through the expansion of the Rick Hansen Spinal Cord Injury Registry (RHSCIR) to enable the prospective collection and comparison of data. | Travel for RHI staff to cure related conferences | Completed. |
### Deliverable Description

<table>
<thead>
<tr>
<th>Deliverable</th>
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<tbody>
<tr>
<td>FY2014</td>
<td>Progress to Date</td>
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<tr>
<td>standardized SCI data to be used in future clinical trials.</td>
<td></td>
</tr>
</tbody>
</table>

#### Informatics

<table>
<thead>
<tr>
<th>Deliverable</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>IN-01 Global Research Platform</td>
<td>The RHI Global Research Platform (GRP) is an electronic data capture and warehousing system. The RHSCIR program and the collaborative networks of RHI depend on the GRP as the technological infrastructure for managing data and SCI-related studies. The RHI GRP currently enables the collection of standardized and high quality SCI data that includes demographic and clinical data. Although the data collected provide important information regarding the injury, it currently lacks critical non-clinical information to not only better understand the nature of the injury but also permit the evaluation of additional outcome measures for assessing recovery. During the 2013-2018 period, RHI intends to adapt the GRP to interface and capture data from external systems containing patient imaging, proteomics/genomics, and electrophysiology data. Collection of this data will enhance the value of RHSCIR to researchers as they will have access to more comprehensive datasets.</td>
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</tbody>
</table>

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<thead>
<tr>
<th>Planned Tasks FY2014</th>
<th>Progress to Date</th>
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</thead>
<tbody>
<tr>
<td>Identify research questions for use of expanded dataset</td>
<td>Completed for fiscal year.</td>
</tr>
<tr>
<td>Identify collaborators for proteomics, genomics, and imaging data</td>
<td>Completed.</td>
</tr>
<tr>
<td>Development of a feasibility study and cost-recovery plan for GRP</td>
<td>Ongoing.</td>
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<td>Deliverable</td>
<td>Description</td>
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<td>data related to the patients’ injuries. Funding from WD relating to this deliverable will be focused on building the necessary technology, while funding from RHF (relating to the Blusson Integrated Cures Partnership) will support research that allows this technology to move forward.</td>
</tr>
<tr>
<td></td>
<td>A number of other software solutions are under consideration by RHI that are complementary to the RHI GRP. For example, RHI is currently leading the development of a calculator for the International Standards for the Neurological Classification of SCI (ISNCSCI). The calculator will be compatible with a tablet or other mobile device that a clinician can use to capture and calculate neurological impairment using the standards with fewer errors than seen in manual calculation.</td>
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<tr>
<td>IN-03 Data Warehousing, Reporting, Statistical</td>
<td>The RHSCIR study activities and the support of clinical trials require the collection, warehousing, analysis and reporting of large</td>
</tr>
</tbody>
</table>

Funder: WD
<table>
<thead>
<tr>
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<th>Planned Tasks FY2014</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Support and Data Management</strong>&lt;br&gt;Funder: WD</td>
<td>sets of data that are collected as part of the studies. The RHI GRP provides a robust technical solution for these needs. The data warehouse capability of GRP, currently under development, will provide a facility for linkage between different data sources, the ability to analyze and report on data, and easily produce data extractions for research use. During the 2013-2018 period, RHI will continue a number of critical services that support network activities, including data management, data analysis, program/project consulting, and other support services.</td>
<td>Search for innovative database linking partners and technologies</td>
<td>Completed.</td>
</tr>
<tr>
<td><strong>IN-04 Innovative Database Linking Capabilities</strong></td>
<td>In support of its informatics strategy, RHI will investigate innovative technologies related to data linking while maintaining security and anonymity; and techniques for linking healthcare “big data” including proteomics and genomics data.</td>
<td>Investigate appropriate and relevant database linking technologies</td>
<td>Completed.</td>
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</table>
**Best and Brightest**

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<thead>
<tr>
<th>Deliverable</th>
<th>Description</th>
<th>Planned Tasks FY2014</th>
<th>Progress to Date</th>
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<tbody>
<tr>
<td><strong>BB-01 Best and Brightest</strong></td>
<td>There is an on-going need to increase the amount of SCI research capacity in Canada and to encourage promising young researchers to pursue research in SCI. Towards this goal, RHI intends to co-fund academic Post-doctoral Scholars in late stage preclinical stem cell research in the treatment of SCI, and in implementation and KT sciences.</td>
<td>Announce calls for proposals</td>
<td>Completed.</td>
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<tr>
<td></td>
<td></td>
<td>Identify partners for co-funding</td>
<td>Completed.</td>
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<td></td>
<td></td>
<td>Review and select candidates</td>
<td>Ongoing. To be completed F2015.</td>
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</table>
## Consumer Engagement

<table>
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<tr>
<th>Deliverable</th>
<th>Description</th>
<th>Planned Tasks FY2014</th>
<th>Progress to Date</th>
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<tbody>
<tr>
<td><strong>CE-01 Go-To Resource</strong></td>
<td>This resource will include information about SCI from injury to community, self-management best practices, available clinical trials for participation for acute and chronic SCI and sources for funds for accessibility requirements. This resource will be developed and distributed in collaboration with consumer groups and partners.</td>
<td>Complete background research on resource content and need</td>
<td>Completed for fiscal year</td>
</tr>
<tr>
<td><strong>Funder: RHF</strong></td>
<td></td>
<td>Create Working Group with stakeholders and consumers</td>
<td>Ongoing.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Complete consumer focus group with best practice</td>
<td>Ongoing.</td>
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<td></td>
<td></td>
<td>implementation</td>
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<td>List consumer-focused best practices and resources for</td>
<td>Ongoing.</td>
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<td>optimizing recovery and research opportunities</td>
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<td></td>
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<td>available to consumers</td>
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<td>Pilot iterations to identify most relevant content and</td>
<td>To be completed F2015.</td>
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<td></td>
<td></td>
<td>format of resource</td>
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<tr>
<td><strong>CE-02 SCI Research Participation</strong></td>
<td>Increase opportunities for participation in SCI research and knowledge of its benefits among people with SCI and their supporters. It will do so by providing:</td>
<td>Scope opportunities and complete background research</td>
<td>Completed.</td>
</tr>
<tr>
<td><strong>Funder: RHF</strong></td>
<td>• Information about opportunities available in acute and rehab facilities for people with SCI wishing to pursue further recovery of</td>
<td>for Research Participation &amp; Support</td>
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<td>Launch consumer research update newsletter “solutions”</td>
<td>To be completed F2015.</td>
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<td>Form Blusson Knowledge</td>
<td>To be completed F2015.</td>
</tr>
<tr>
<td>Deliverable</td>
<td>Description</td>
<td>Planned Tasks FY2014</td>
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<td>function.</td>
<td>Exchange group and identify priorities</td>
<td>To be completed F2015.</td>
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<td></td>
<td>Information about SCI research news and opportunities to participate.</td>
<td>Trial Research Participation Funding Call</td>
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<td>Support to encourage participation in clinical research through matchmaking, education, and funding.</td>
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<td>Coordination among BSCC partners to make research knowledge more meaningful for consumers.</td>
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<tr>
<td>CE-03 Consumer Advisory Board</td>
<td>This is a representative group of consumers and advocates that will reflect consumer priorities and provide insight into BSCC Partners and Partnership activities.</td>
<td>Complete review of Consumer Advisory Board terms of reference, models</td>
<td>To be completed F2015.</td>
</tr>
<tr>
<td>Funder: RHF</td>
<td></td>
<td>Finalize Consumer Advisory Board recruitment guidelines/strategy</td>
<td>Ongoing.</td>
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<tr>
<td></td>
<td></td>
<td>Call for recruitment/nomination for Consumer Advisory Board</td>
<td>Ongoing.</td>
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