RHI ANNUAL REPORT 2010-2011

A world without paralysis
After spinal cord injury
RHI’s work seeks to achieve six objectives:

1. A significant reduction in the incidence and severity of permanent paralysis resulting from SCI by 2015.

2. A significant increase in restoration of physical function following SCI by 2015.

3. A significant reduction in the incidence and severity of secondary complications associated with SCI by 2015.

4. A significant increase in level of satisfaction with quality of life and community participation among people with SCI by 2015.

5. Ensuring that customized responses to priority unmet needs are available to 100% of individuals with SCI throughout their journey to full participation by 2015.

6. Establishing a world class Canadian SCI registry and data management platform by 2012.
EIGHT STRATEGIES

To achieve these objectives, RHI implements eight strategies:


2. Supporting multi-centre clinical trials in acute care, rehabilitation and community, fostering global collaboration where possible; supporting pre-clinical research imminently ready for translation.

3. Supporting the development of a Best and Brightest program to nurture new SCI researchers.

4. Collecting and analyzing data on SCI in Canada, including acute, rehabilitation and community components and supporting research and multi-centre trials, utilizing a web-based national technology platform and collaborating globally where appropriate.

5. Facilitating the adoption and implementation of validated best practices as identified by the Translational Research Program and through properly evaluated public policy and community-based programs aimed at improving treatment, care and support and communicating these best practices directly to Canadians with SCI.

6. Working with RHI partners to enhance service delivery through the full implementation of the Solutions Model (solutions team, navigators).

7. Working with RHI partners to enhance capacity and develop initiatives that respond to the priority needs of people with SCI, utilizing collaborative funding mechanisms such as Scotiabank Wheels In Motion (S-WIM), and provincial/territorial 20th Anniversary investments, etc.

8. Providing excellence in leadership, coordination and program support at the national and international level.
OUR VISION

A world without paralysis after spinal cord injury

OUR MISSION

To lead COLLABORATION, across the global SCI community, by providing resources, infrastructure and knowledge; and to IDENTIFY, DEVELOP, VALIDATE and ACCELERATE the translation of evidence and best practices to reduce the incidence and severity of paralysis after SCI, improve health care outcomes, reduce long-term costs, and IMPROVE the quality of life for those living with SCI.

SCISN is now RHI!

Over the past year, the Spinal Cord Injury Solutions Network (SCISN) has been operating under the name Rick Hansen Institute (RHI) but has remained legally incorporated under its former name. In January 2010, the SCISN Board of Directors approved a decision to change the organization’s name to the Rick Hansen Institute as a way to emphasize the relationship between Rick Hansen’s vision and the work that the Institute is undertaking to realize this vision. The organization began operating under the name RHI from that point on and filed for legal approval from Industry Canada. On Tuesday, April 5th 2011, Industry Canada officially recognized the Rick Hansen Institute as the new name for our organization.
# TABLE OF CONTENTS

Message from the CEO .................................................. 2
Message from the Board Chair ........................................ 4
Background ................................................................. 6
About RHI ................................................................. 7
What We Do .............................................................. 7
Our Impact ............................................................... 8
Results Achieved, 2010-2011 ......................................... 10
Translational Research .................................................. 10
Rick Hansen SCI Registry and Data Management Platform ........ 14
Best Practice Implementation ......................................... 17
Community Partnerships .............................................. 21
Strategic Partnerships .................................................. 24
Leadership and Governance ......................................... 25
Next Steps .............................................................. 32
Appendices ................................................................ 34
MESSAGE FROM THE CEO

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

Following the Tour, Rick established the Rick Hansen Foundation (RHF) and later, the Institute that today bears his name to motivate all those working together to reduce the impact of SCI and improve the quality of health of those living with a SCI.

We are now into our second full year operating under The Rick Hansen Institute (RHI) banner. Our focus has tightened on maximizing our impact in our areas of strategic focus (restoration of function, minimizing paralysis and secondary complications), continuing the advancement of our Registry and Global Research Platform, and accelerating progress with new partnerships and greater international collaboration.

Looking back, we can say we made much progress over the last year. Through our project work we have:

- Signed partnership agreements that will lay the foundation for exciting international collaboration with the Queensland University of Technology (QUT) and the Institute of Medical Research Israel – Canada (IMRIC) at Hebrew University.
- Formed a partnership with Accreditation Canada to ensure best practices are implemented in hospitals.
- Teamed up with the Government of Saskatchewan to announce a $4.3 million commitment to fund SCI research and other disability initiatives in the province.
- Helped launch, along with McMaster University and SCI Action Canada, the first physical activity guidelines developed specifically to support people with SCI in living healthier, more active lives.
- Cemented the Rick Hansen Global Research Platform (GRP) and SCI Registry in centres across Canada.
- Launched a new Best Practice Implementation program to help translate evidence into practice.
- Released ground-breaking reports on the incidence and prevalence of SCI in Canada and the associated costs to individuals and the country.
What follows is a summary review of all RHI activities from the period of April 1, 2010 to March 31, 2011.

At this time, I would like to express my gratitude to the Board of Directors – especially our chair Daryl Rock – for their commitment and dedication, along with Rick Hansen and the staff and board of the Rick Hansen Foundation for their critical support and collaboration.

I would also gratefully acknowledge our primary funders – Health Canada, Western Economic Diversification and the Rick Hansen Foundation – for their visionary support. Finally, I would like to thank the governments of Alberta, BC, Manitoba and Ontario for their significant commitments (administered by RHI) to support SCI research that is in direct alignment with our own goals.

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

Sincerely,

Bill Barrable, CEO
Rick Hansen Institute
MESSAGE FROM THE BOARD CHAIR

The Rick Hansen Institute (RHI) has come a long way since its inception five short years ago. Looking back, I am both pleased and impressed with the outcomes we have achieved. By working closely with our partners and our funders at the international, national and provincial levels we have put in place policies, structures and practices that are making a difference.

We are leaner and more focused. We have a clearly articulated vision and mission. As a catalyst organization, we bring together the best and brightest in SCI: consumers, researchers, clinicians and policy makers to identify and solve often complex SCI health problems. We influence all elements of SCI treatment and care, developing new therapies and decreasing the time for research to be translated into real-life benefits. Research must lead to action. For this reason, we have invested significant time and resources into Best Practice Implementation strategies.

In this message, I would like to focus on progress made in the last year, a year which saw us both cement our strategies in Canada, and increase our collaboration with clinicians, researchers and research funders in the USA, Europe, Australia, the Middle East and Asia to ensure we build on each other’s best efforts and work together to improve the quality of health for people with SCI.

We have launched a program with Accreditation Canada to roll out new clinical practice guidelines in hospitals across Canada. We are working with the several provincial chapters of the Canadian Paraplegic Association, the Neil Squire Society and other national, provincial and local consumer groups to help identify solutions and to raise funds for their work in the area of SCI. We are working with the Christopher and Dana Reeve Foundation in the USA, Ontario Neurotrauma Foundation and Moelle épinière et motricité Québec to fund innovative work in their respective jurisdictions. And finally, we are working with our federal and provincial funders to ensure the work we do will meet their needs, and the needs of individuals with SCI and their families.

We have also taken our SCI Registry international creating a Global Research Platform to allow researchers and administrators to make informed decisions based on common data sets around the globe. We have more than 27 signed agreements with hospitals across Canada and with additional centres in Australia, China, USA and Israel and are working to develop many more sites.
So where to from here?

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

As we move forward it will be important to expand the GRP and Registry to develop a critical mass of subjects for recruitment to the clinical studies and trials that we are planning, to expand the quality data used to identify successful interventions and best practices. We must also continue to fund international calibre health research. We must work with our partners in Canada and elsewhere to launch key clinical trials to test some of the important discoveries made to date. But success can only be truly measured by the hard facts: have we reduced the severity of SCI trauma? Has our work contributed to more people walking away from a SCI than would have happened without our work? Have we reduced the impact of secondary complications? Over the next five years we expect to answer “yes” to all of these questions. And we must become even more focused on translating new evidence into practice. Only this way will we be truly successful in meeting our mission — a world with fewer people living with SCI and a world where those living with SCI have the same quality of health as those living without one.

I echo Bill’s expression of gratitude to our funders and partners across Canada. Additionally, I want to thank all Canadians with SCI, along with their families and friends, who have become involved in our movement.

And, finally, as I step down as the inaugural chairman of the Rick Hansen Institute, I would like to extend my thanks to the board and staff of RHI and to all the partners and stakeholders with whom I have worked over the past few years. It has been an exciting challenge and a great opportunity to work with such a group of committed individuals across Canada and around the world to build an organization that will, I believe, achieve its goal of improved health outcomes for the newly injured and all those living with an SCI.

Finally, I want to say a special thanks to Rick Hansen. RHI exists today because of Rick’s leadership and tenacity, and his unparalleled ability to achieve “the impossible.” Over the past 25 years, Rick has become a personal friend and remained a true inspiration to me. I wish him well and look forward to working with him and his Foundation over the next year as, during his 25th anniversary tour, he mobilizes tens of thousands of Canadians across this country to make a difference in their community.

Daryl Rock,
Chair of the Board of Directors for the Rick Hansen Institute from 2009 to 2011
BACKGROUND

Figure 1 below shows the timeline of events from Rick Hansen’s vision to the evolution of today’s RHI.

Twenty-five years ago, Rick Hansen had a dream – to make the world more accessible and inclusive and to find a cure for paralysis after spinal cord injury. Inspired by a deep-seated belief that anything is possible, Rick’s “big dream” took shape in the form of the Man In Motion World Tour. For 26 months, he and his team wheeled more than 40,000 km through 34 countries, raising awareness of the potential of people with disabilities. Following the Tour, Rick established the Rick Hansen Foundation (RHF) to continue his quest for an accessible and inclusive society and a cure for spinal cord injury (SCI).

Under Rick’s leadership the Foundation functions as a social innovator, finding collaborative solutions to challenges in the community and the resources necessary to implement those solutions. Rick Hansen has also nurtured a dream of true collaboration across the SCI community. Seven years ago, his dream began to be realized when the SCI Network was established as a program with funding from the federal government (Western Economic Development) and the Rick Hansen Foundation. Three initiatives evolved — the SCI Solutions Alliance, the Rick Hansen SCI Registry, and the SCI Translational Research Network, the latter of which was funded by a $30 million investment from Health Canada. In April 2008, a decision was made to combine these three entities into a single organization, to more effectively address priority needs and generating solutions for people with SCI. The Rick Hansen Institute (RHI) became incorporated in March, 2009. We received charitable status from Canada Revenue Agency (CRA) in January 2010 and now operate as an independent organization.
What We Do

RHI exists to move research into action, ultimately to find a cure for SCI, and to reach a stage, as articulated by our Vision – **A World Without Paralysis After SCI**. It does this through its two, inter-related, core business areas: Translational Research and Best Practice Implementation. Both of these are supported by our national network.

Translational Research is sometimes referred to as moving “from bench to bedside”: At RHI, we take promising ideas from basic science or other research disciplines and push them to larger-scale, human studies, and ultimately into the real world of clinical practice.

Part of the role of RHI’s Translational Research Program is to identify best practices: those interventions, services, strategies or policies that are most suitable for enhancing the health of people with SCI, according to available evidence.

Once identified, RHI works to implement these best practices. The focus of our Best Practice Implementation Program is to influence practice level changes, resulting in altered behaviour of clinicians and, in some cases, patients towards better care of people with SCI.

Key to RHI’s success is its network. Our pan-Canadian network of researchers, clinicians, people with SCI and others accelerates and improves research, and helps turn knowledge created into action on the ground.
Our Impact

Since RHI’s beginnings in 2007, we have undertaken 68 translational research and best practice implementation projects. We have developed a pan-Canadian registry of SCI patients. And we have provided support to improving the lives and community participation of individuals across Canada. The following are a few results of our activities over these past four years:

### Products

- Peer-reviewed publications: 56
- Conference presentations: 52

### Stakeholders engagement and collaboration:

- Project team members: 459
- Project participants (41% of which are people with SCI): Over 1,700
- People with SCI in RHSCIR: 1,753
- People with SCI benefitting from WIM grants: Over 4,000
- Engaged through provincial and territorial partnerships: Thousands more

A review of a sample of completed Translational Research and BPI projects have shown the following outcomes:

**RHI projects have demonstrably influenced further research.**

Many of RHI’s projects have had a strong influence on the research done on SCI. Over 50% of our projects have influenced further research; by 2017, the percentage is anticipated to climb to 73%. For example, the RHI-supported GRASSP project (grant #2008-14 & 2008-16) developed an outcome measurement toolkit to measure hand dysfunction among SCI patients with greater sensitivity than was previously possible. This toolkit has since been used in other research studies examining hand dysfunction, including the RHI-supported FES project (grant #2009-36) and Upper Limb Rehabilitation (grant #2009-34).

**RHI projects have demonstrably affected clinical practice in Canada.**

In the long term, the objective for many of RHI’s projects is to improve the way care is provided for people with SCI in a clinical setting. To date, an estimated 31% of RHI projects have demonstrated influencing clinical practice in Canada and internationally. It is anticipated that by 2017, 66% of RHI projects will have done so. Other projects
are not aimed specifically at changing clinical practice. For example, RHI supported the development of Physical Activity Guidelines and Guides for people with SCI, directed at both clinicians and consumers. RHI and SCI Action Canada have been promoting these guidelines through a variety of methods, including traditional and social media approaches. The guidelines have been adopted by clinicians, caregivers and others and are being incorporated into physical activity programs involving people with SCI, as demonstrated in the quote below.

_The Physical Activity Guidelines for Adults with SCI are a great resource for someone looking to improve their general health and fitness…. In integrating someone into an ongoing program, these guidelines are also useful within the coaching community to build comfort around the baseline health and fitness needs of someone with SCI._

_David Greig_, National Coach, Talent Development, Para-Athletics/Athletics Canada

It can take several years for research to translate into action on the ground. To date, an estimated 31% of RHI projects have demonstrated influencing clinical practice in Canada and internationally. It is anticipated that by 2017, 66% of RHI projects will have done so. Other projects are not aimed specifically at changing clinical practice.

**RHI projects have demonstrably affected how Canadians with SCI care for themselves.**

Some of RHI’s projects have been aimed directly at people with SCI, to improve their capability to address their own needs through self-care, thus lowering the cost on the health care system. Although the majority of RHI projects are not aimed at influencing self-care, 24% of our projects have done so to date. It is expected that, by 2017, 45% of RHI’s projects will have had demonstrated impact on how people with SCI care for themselves. An example of this is the “Discovering the Power in Me” program (grant #2010-45), a self-management curriculum for people with SCI. RHI has supported an evaluation of this project, which is showing strong results.

_Taking the Discovering the Power in Me program gave my heart, mind and soul a two day workout! It challenged me to have a better balance in all aspects of my life, and since I have tried this, I have found my life to be more worthwhile!_  

_Barry Amos_, Miramichi, NB
RESULTS ACHIEVED
2010-2011

This section presents the results achieved by RHI in fiscal year 2010-2011, within its key priority areas of Translational Research, Rick Hansen SCI Registry and Data Management Platform, Best Practice Implementation, and Community Partnerships.

In October 2010, RHI carried out an online survey of its stakeholders, regarding perceptions around RHI’s brand. This survey underscores the perceived need and success of RHI. Among some of the results:

- There was almost universal agreement that each of RHI’s areas of work is very important.
- 80% of respondents who could offer their opinion believe RHI has been “very” or “somewhat” successful in their work.
- Regarding RHI’s primary objectives, the health care/research community is extremely supportive of what the RHI is trying to accomplish.

Translational Research

RHI’s Translational Research Program focuses on the application of ideas, insights, and discoveries generated through basic scientific inquiry to the treatment of spinal cord injury (SCI). Two priorities of Translational Research, for RHI, are the development and validation of clinical practice guidelines, and promotion of large-scale, multi-centre clinical research in key areas relevant to SCI.

In fiscal year 2010-2011, RHI had 24 active Translational Research projects, of which four were intramural (sponsored and led by RHI): Access to Care and Timing, CAMPER, Minocycline and the SCI Community Survey. The following are a sample of some of the projects RHI has undertaken in the past fiscal year. For a description of all Translational Research projects this fiscal year, see Appendix II.
The Canadian Multicentre CSF Pressure Monitoring and Biomarker Study (CAMPER)

CAMPER is a three-year, multi-centre acute spinal cord injury clinical research study that aims to characterize changes in intrathecal pressure, in order to provide more advanced practice guidelines on the management of blood pressure in acute SCI, and assess the ability of certain biomarkers (specific proteins produced as a result of the cord injury) to predict injury severity and neurologic outcome.

After a successful pilot in Vancouver, the multi-centre CAMPER study was designed in fiscal year 2010-2011, and will be rolled out to RHI Clinical Research sites across Canada in the upcoming fiscal year. A number of start-up activities to facilitate the multi-centre study have been completed to date, including finalization of the study protocol, budget, research contracts, operational logistics and identification of sites. Some sites have already received ethics approval.

The Vancouver General Hospital ICU team is always interested in furthering its knowledge on how to provide optimal care to all patient populations. Over the past four years, VGH has participated in the CAMPER study, in collaboration with the study’s Principal Investigator, Dr. Brian Kwon.

Collaborating with Dr. Kwon on this study has provided the Intensive Care Unit Team with the opportunity to learn more about the spinal cord injury patient population. It has led to an increase in knowledge, and to a change in clinical practice here. For example, our staff is now paying increased attention to the blood circulation of SCI patients. SCI patients often have unstable blood pressure when they first arrive at the hospital. We have found through clinical observation that managing blood pressure in the first five to seven days after injury may have a positive influence on patient outcomes. The evidence for this will not be conclusive while the study is ongoing, but we at VGH are proud of our contribution to building the evidence through our participation in this study.

Dr. Dean Chittock, Senior Medical Director, Vancouver General Hospital, Vancouver – Acute Services, and Regional Medical Director Critical Care Medicine, Vancouver Coastal Health.
Access to Care and Timing (ACT)

While providing expert care in a timely manner is a guarantee of better patient outcomes, knowing how to make this a reality remains a constant challenge in an increasingly complex health care system. Policy-makers, administrators and clinicians need tools that will enable them to make decisions that are cost-effective and produce the best health outcomes for Canadians.

This is the first project of its kind to examine the clinical care for people with traumatic SCI using computer simulation models. Specifically, these models will enable clinicians and administrators to build business cases for better access and improved timing of care spanning from the time of injury through to discharge in the community. The models will be able to produce outputs that include both the immediate and long-term costs and patient outcomes. To achieve this, RHI is collaborating with SCI researchers and clinicians across Canada, as well as analysts from the Centre for Operational Excellence at the Sauder School of Business at the University of British Columbia.

In fiscal year 2010-2011, the first phase of this nation-wide, three-phase study was launched at existing Rick Hansen SCI Registry sites. This phase began with a survey capturing information on the facility, resources, staffing and provision of care for SCI across Canada. Preliminary results from the model have been obtained to answer questions such as ‘what are the direct and indirect effects of reducing secondary complications during acute phase of care?’ and ‘is it better to add more beds to the acute phase or the rehab phase of care to improve patient flow?’.

Plans are underway to engage the Vancouver Coastal Health administration and determine what questions they would like to answer using the models developed for the Vancouver acute and rehabilitation site.
Other Research

Beyond its grants to external researchers and its internally-led projects, RHI staff also undertake research into areas of SCI that are not tied to a specific project. In fiscal year 2010-2011, RHI supported the release of three reports on SCI in Canada:

- Incidence and Prevalence of Spinal Cord Injury in Canada: Overview and Estimates Based on Current Evidence, December 2010
- Spinal Cord Injury: Progress in Care & Outcomes in the Last 25 Years, March 2011
- Economic Burden of SCI in Canada: A Literature Review and Analysis, December 2010

RHI continues to develop papers in the areas of bladder and bowel function, neuropathic pain, non-traumatic SCI epidemiology, and knowledge translation in the area of SCI.
Rick Hansen SCI Registry and Data Management Platform

RHSCIR Study

The Rick Hansen SCI Registry (RHSCIR) is a national observational longitudinal study that collects information on the continuum of care for persons sustaining a traumatic SCI at 27 major Canadian acute care and rehabilitation facilities across the country. RHSCIR has created a truly Canadian database of information about traumatic SCI that will benefit all Canadians with SCI and every professional involved in the SCI continuum of care far into the future. RHSCIR will be an invaluable resource for researchers, clinicians and administrators seeking to better understand SCI and the effectiveness of specific treatments, practices or programs for improving functional outcomes and quality of life following SCI.

RHI continues to expand the RHSCIR network. In fiscal year 2010-2011, RHI added one more hospital to the network (Lyndhurst, in Toronto), for a total of 27 facilities, located in 12 cities and seven provinces, encompassing almost all of Canada’s major SCI trauma units and rehabilitation hospitals. Data sharing agreements for another three facilities will be signed within the next three months.

RHI sustains existing RHSCIR sites through capacity building on measurement and good clinical practice, monitoring and other activities. In October 2010, RHI brought all RHSCIR Data Coordinators together in Vancouver for the second ever RHSCIR Coordinator’s Meeting. This meeting was very well received, and led to improved understanding and engagement among the attendees.

RHI has taken steps to assess the percentage capture of patients at sites, aiming to improve its enrollment rate to 100% of new traumatic SCI patients. We instituted a reconciliation process in Vancouver with hospital records, resulting in 100% coverage of SCI patients at that site. This process will be rolled out to other sites over the year, so that percent coverage will be identified and the reconciliation made to improve this coverage.

***RHSCIR STUDY RESULTS THIS FISCAL YEAR***

- Number of facilities added: 1 (total 27)
- Number of SCI patients enrolled: 634 (total 1,753)
- Coverage at site: 100% (Vancouver data only)
- Number of publications: 3
- Number of book chapters: 1
- Number of presentations: 1
Sites engaged in the RHSCIR Study have benefited from their participation in a number of ways, including in the use of the data generated for their own purposes. In the case of Vancouver General Hospital, RHSCIR data helped them get a clearer picture of the SCI patient population for staffing purposes:

*RHSCIR provides us with unique information that we can’t get anywhere else. Getting a clear picture of trends in acuity [types of disorders and their severity], dependency, and other patient characteristics helps us better understand and predict the types and levels of care required in our hospital for this group of patients. As a result, we are better able to support our budget and anticipate the need for new staffing or changes to our staffing model.*

*The complexity of SCI is in general not well understood, and RHSCIR fills this gap by providing us with the data we need to properly understand this complexity. As a result, we’ve seen a large change in the levels of understanding about SCI and its implications for clinical practice.*

*Lise Belanger*, Clinical Nurse Specialist, Acute Spine Program, Vancouver General Hospital (Site Coordinator for RHSCIR in VGH)

In the coming fiscal year, RHI will take two important, large steps in the development of RHSCIR. The first is the release of data to researchers across Canada, which will accelerate the pace of research on SCI in Canada, allowing researchers to test hypotheses more quickly and at a much lower cost than would otherwise be possible. Secondly, RHI plans to take RHSCIR international. RHI has been exploring the expansion of RHSCIR to sites in other countries, including Israel, Australia and China, in order to provide the patient numbers needed to obtain statistical power for powerful clinical research studies.
Training on the International Standards for the Neurological Classification of SCI (ISNCSCI)

For more than five years, RHI has been building capacity within SCI care and treatment facilities across Canada in the assessment of SCI impairment. Recognizing the need in Canadian SCI sites for accurate, standard measures of SCI impairment, RHI has been providing training on the International Standards for the Neurological Classification of Spinal Cord Injury. Adherence to international standards will allow for more accurate diagnoses leading to better care, and greater consistency in outcome measurement across sites enabling research-ready data.

Since September 2006, RHI training efforts have covered all RHSCIR facilities across Canada. Feedback from participants has been overwhelmingly positive: 98% of participants found the training helpful, and almost two-thirds (65%) expressed confidence in being able to apply the standards in their work after the training.

Global Research Platform (RHI GRP)

In carrying out the RHSCIR study described above, RHI recognized the need for an IT platform robust and flexible enough to collect, store and analyze the large datasets needed for this unique study. In fulfillment of this need we have created our own, in-house technology to suit this purpose.

The Rick Hansen Institute Global Research Platform (RHI GRP) is a state-of-the-art, web-based, secure data collection and research management platform that enables easy and efficient capturing of data that can be readily accessed. The RHI GRP is highly adaptable and can be used to run multi-centre clinical trials and as a spine data collection tool. The RHI GRP is critical to the success of both the Translational Research and Best Practice Implementation programs, serving as a state-of-the-art secure data collection platform to support translational research, and track the outcomes of newly implemented best practices. The web-based technology Platform greatly facilitates the recruitment of participants for clinical trials, by identifying suitable candidates for future studies. The research platform was developed to meet international best practice standards for spinal cord injury treatment and care, such as the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), and meets global privacy and security standards.

The RHI GRP platform was developed and launched in January 2011. It is being prepared for use with the RHSCIR Study as well as for other studies including CAMPER and Access to Care and Timing.
Best Practice Implementation

In fiscal year 2010-2011, RHI appointed a Director of Best Practices, launching our Best Practice Implementation (BPI) Program. This fiscal year RHI successfully undertook 19 projects, of which eight were intramural (sponsored and led by RHI), involving the identification, validation, and implementation of best practices in the management of secondary complications by engaging clinicians, researchers, and people with SCI in an integrated knowledge translation process.

The following are a sample of some of the projects RHI has undertaken in the past fiscal year. For a description of all BPI projects this fiscal year, see Appendix II.

Spinal Cord Injury Rehabilitation Evidence (SCIRE)

**www.scireproject.com**

SCIRE is a web-based synopsis and critical review of existing scientific literature on a broad range of topics in SCI rehabilitation, the result of the combined efforts of expert scientists, clinicians, consumers and stakeholders across Canada. It is expected that the pre-appraised, synthesized research from SCIRE will translate into improved health for Canadians with SCI by increasing the accessibility of up-to-date, quality information to health care professionals, scientists, policy-makers, and individuals with SCI.

SCIRE has become a very popular resource for researchers, clinicians and people with SCI who want accessible and comprehensive information on SCI rehabilitation. The sidebar shows some of the feedback received by the SCIRE team on their offerings.

RHI has provided ongoing core support to the SCIRE project, and has contributed to targeted efforts such as an outcome measurement toolkit, which will help standardize measurement of SCI impairment across Canada.
The Spinal Outreach Team has always had a focus on the years after spinal cord injury, striving to improve lives now and into the future. We have learnt from our research into the years following spinal cord injury how important reliable information can be in maintaining health and wellness. We use the SCIRE website as a reference point and it has been a great resource for us, thank you for this initiative.

Kiley Pershouse, Manager/Social Worker - Spinal Outreach Team at the Queensland Spinal Cord Injuries Service, Australia

Accreditation Canada

RHI is aiming to improve the quality of care in health care organizations in Canada by funding the development of the first ever standards for a relevant, responsive, and rigorous accreditation program for SCI services. The project with Accreditation Canada will increase knowledge and application of evidence and best practices, leading to improved health care system planning and performance.

As of March 31st 2011, RHI and Accreditation Canada have completed an initial literature review, established the project governance structure, and issued a news release on the partnership.

This project has the potential to improve spinal cord injury care and services around the world. It is essential that anyone who sustains a spinal cord injury receives evidence-based care to maximize functionality and to achieve the best outcome possible. Our accreditation program is well respected for being rigorous, adaptable, and focused on ongoing quality improvement. We expect this initiative to generate interest from existing national and international Accreditation Canada clients, as well as from any facility worldwide seeking to provide the best spinal cord injury services possible.

Wendy Nicklin, President and CEO of Accreditation Canada (Project Co-Lead)

The great thing about standards is that it helps to set a benchmark across Canada and then, hopefully, later on, you can build upon those standards to improve the care even more. I think anything you can try to improve care for patients is great and I truly support it.

Dr. Eve Tsai, Neurosurgeon - Ottawa Hospital, Associate Scientist Neuroscience Research at Ottawa Hospital Research Institute
Physical Activity Guidelines and Guides for Canadians Living with SCI

In 2010, RHI provided support to a Translational Research project to develop physical activity guidelines and guides for spinal cord injury patients. Two guidelines were released, one directed at clinicians and the other directed at people with SCI. They are the first ever evidence-based physical activity guidelines specifically tailored for people with SCI.

Once the guidelines were released on March 17, 2011, the project became a Best Practice Implementation initiative. SCI Action Canada and RHI are working collaboratively to implement these guidelines through various campaigns, including a nation-wide news release, RHI e-blast, SCI Action Canada communication, posting to the RHI website and social media communications.

The Guidelines recommend that healthy adults with SCI participate in both aerobic activity and strength training twice per week. Physical activity for people with SCI can reduce the likelihood of secondary health complications and chronic diseases that are often linked to physical inactivity.
**ABC’s of Autonomic Dysreflexia Course**

Autonomic dysreflexia (AD) results when an irritating stimulus is introduced to the body below the level of the spinal cord injury. Over-activity of the autonomic nervous system causes an abrupt onset of excessively high blood pressure. If not treated properly, this condition can be life-threatening. Since this condition is unique to SCI patients, many health care professionals are not familiar with the signs and symptoms of AD, leading to the risk of misdiagnosis.

In response to this problem, RHI supported a project to develop a curriculum for an ‘ABCs of AD’ course for emergency room personnel and paramedics. This project addresses a gap of knowledge that directly affected the lives of people with SCI. 133 doctors, nurses and paramedics attended a one-hour educational workshop in Vancouver, Toronto and Winnipeg. Based on the initial project, other hospitals providing acute SCI care are also showing interest in the program, including the Boston Medical Centre, Frazier Rehab Institute in Louisville, KY and the Shriners Hospital for Children in Chicago, IL.

*Because AD is a daily experience for me as someone with lesions above T6, going to an emergency room where the staff know how to recognize and manage it means I’m at lower risk for eventually suffering a stroke or heart attack.*

**Brad Zdanivsky**, Quadruplegic, Mountain Climber, Vancouver, BC  
verticalchallenge.org
Community Partnerships

RHI has been active in helping people with SCI improve their quality of life and community participation, across Canada. In fiscal year 2010-2011, it did so in two ways: through partnerships with community organizations, and through targeted “Wheels in Motion” grants to individuals or communities across Canada.

Provincial and Territorial Partnerships

RHI partners with a number of organizations in each of the provinces and territories of Canada in support of its Community Partnerships objectives. These provinces and territories pursued initiatives that aligned with one or more of the six RHI objectives, according to the needs of their specific populations. All of the provincial and territorial partners delivered services that directly or indirectly met the priority needs of people with spinal cord injuries and furthered their quality of life.

RHI provided crucial linkages for our provincial and territorial partners to the national SCI network, and supported Provincial/Territorial Solutions Teams in their mission to identify, create and deliver solutions that respond to the priority needs of people with spinal cord injuries. For example:

- In several provinces, RHI supported peer support programs, and collaborative development and implementation of provincial/territorial SCI Strategies and Enhancing Active Living opportunities for people with SCI.
- In the NWT and Yukon, RHI supported client services and funded solutions customized to overcome unique geographical challenges: winter weather conditions, relative isolation, and reduced access to health care specialists and services.

Initiatives in additional areas such as research were pursued where the capacity existed. A few examples are as follows:

- In Ontario, RHI partnered with the Ontario Neurotrauma Foundation (ONF) to develop capacities for research, through funding to trainees (Best and Brightest Young Investigators), leadership chairs and secondments.
- In BC, RHI partnered with ICORD to foster scientific collaboration and to implement an international exchange program for post-doctoral fellows.
These initiatives are of vital importance to RHI’s work for a number of reasons:

- They help recruit researchers and clinicians into the national SCI network;
- They facilitate collaborations by accelerating provincial participation in RHI’s national projects (for example, Manitoba’s involvement in the online pressure ulcer clinic);
- Capacity building and researcher development initiatives (scholarships, fellowships, research coordinator positions, travel funds, grants to new researchers) help ensure skills exist to carry on SCI research in the future.

While each province is able to set their own research priorities, they are encouraged to align their priorities with RHI’s national priorities, thereby maximizing opportunities for collaboration, leveraged funding, and research impact.

**Wheels in Motion Grants**

Using funds raised from the Rick Hansen “Wheels in Motion” campaigns, RHI provides support to individuals with SCI and to communities in the form of grants for targeted, small-scale projects to help improve their quality of life and better integrate into their communities. In fiscal year 2010-2011, RHI awarded 103 grants totalling over $1.25 million. Including amounts leveraged from other sources, the total amount of these projects is estimated to be nearly 13 times greater.

With the help of the Canadian Paraplegic Association Ontario, Randy Romain, an individual with SCI in Ottawa, ON, was provided a WIM grant for an insufflator. An insufflator is a device that helps a person cough who has lost the ability to do so. “It’s given me a lot more freedom, less health problems because it helps me to cough and now I am able to keep active, living in an apartment with my wife,” he reports. “I am able to live within the community and perform my various volunteer activities…. It has made my health condition much easier to bear and given me a better quality of life.” Randy’s wife also benefitted from this project: “With the insufflator Randy can stay alone at home and does not need suction all the time. With that I can work and have a healthier life.”
Let’s Play

Let’s Play offered grants for the creation of accessible public play spaces and built awareness of accessible play and related best practices. The project focused on children aged 0 to 6 and their caregivers with mobility-related impairments. In 2010-2011, RHI provided four Let’s Play grants: one for a public park and three for public schools, for a total value of $131,710.

Throughout this the project, Let’s Play has had a significant impact in communities across BC, both in terms of raising awareness of accessible play and related best practices and in terms of creating a legacy of accessible play spaces that are already increasing quality of life for young children and caregivers with mobility-related impairments.

Statistics from our report-back forms speak to the level of accessibility provided at these play spaces, as shown in the sidebar. More details on the results of Let’s Play initiative are available in RHF’s Let’s Play Project: Final Report, December 23, 2010.

**LET’S PLAY**
**LONG-TERM RESULTS**

Percent of respondents describing as “absolutely true” that the play space design encourages shared and inclusive play: 98%

Percent of respondents describing as “absolutely true” that a significant majority of play elements are accessible to children with mobility impairments: 93%

Percent of respondents reporting that the number of children with mobility related impairments accessing the play space has increased since construction/renovation: 84%
Fiscal year 2010-2011 was a highly successful one for RHI’s Strategic Partnerships Program. Beginning with the recruitment of a Director, Strategic Partnerships & Initiatives and Senior Manager, Corporate Partnerships, early in the period, leading to:

- Submission of four Provincial proposals for funding, totalling nearly $44 million;
- Visits by RHI to China, Jordan, Israel, the USA and Australia, to explore new opportunities for partnership and expand to new Registry sites, which led to three Memoranda of Understanding (see below);
- A visit from Dr. Li Jianjun, Director of the China Rehabilitation Research Centre; and
- Launch of the preliminary program for Interdependence 2012 (i2012), a global conference and exposition to be held in May 2012 in Vancouver, designed to accelerate progress toward a healthy and inclusive world through two complementary pillars: making communities accessible for all and furthering spinal cord injury research for a cure.

These activities have yielded very positive results for RHI, with new partnerships and collaborations opening new doors for the advancement of SCI research internationally.

**Government of Saskatchewan partners with RHI to fund SCI research in the province**

On March 15, 2011, Rick Hansen joined the Honourable June Draude, Minister of Social Services, and the Honourable Bill Huchinson, Minister of Tourism, Parks, Culture and Sport, at the Saskatchewan Legislature to announce a $4.3 million commitment to fund SCI research and other disability initiatives.

**New international agreements**

During the fiscal year, RHI signed partnership agreements that will lay the foundation for exciting international collaboration with the Queensland University of Technology (QUT) and the Institute of Medical Research Israel – Canada (IMRIC) at Hebrew University.
LEADERSHIP AND GOVERNANCE

Sponsorship of Events

RHI sponsors a number of conferences, meetings and other events related to SCI in Canada, in order to accelerate collaboration and new insights into the issues around SCI. A list of sponsored events can be found in Appendix II.

Responding to the Midpoint Review

2010-2011 was a year of re-focusing for RHI. The final report of the Midpoint Review of RHI’s activities under Health Canada funding was released in June 2010, which reaffirmed RHI’s achievements to date and provided valuable lessons for greater success in the future. The Midpoint Review report provided evidence that RHI:

- Had created an innovative design and approach to connecting research on SCI to tangible results, through a focus on knowledge translation;
- Was successful in the creation of collaborations across the SCI care continuum; and
- Showed early evidence of benefits to SCI subjects through translational projects funded to date.

However, this period of transition and early learning was not without its challenges. The Midpoint Review described a number of challenges experienced by the organization, and presented a set of 14 recommendations for improvement. The following table lists these recommendations, with an update on the actions taken by RHI to respond to each.

RECOMMENDATION 1
Continue with an integrated and more strategically focused approach.

ACTIONS TAKEN
Consistent with the direction of the RHI Board of Directors, RHI has developed and implemented a new vision and mission statement. Through the establishment of a Planning and Priorities Committee comprised of senior managers, along with regular reporting against its Annual Operational plan at project meetings, RHI is ensuring its activities continue to align with its long-term objectives.
RECOMMENDATION 2
Reset performance expectations taking into account RHI’s narrowed focus, the challenges inherent in successful knowledge translation, the progress to date, and the long length of time generally needed for it to occur.

ACTIONS TAKEN
RHI conducted a review of its Performance Measurement Framework and logic model. This review is useful in improving RHI’s performance measurement system (see recommendations 11 and 12 below), but performance expectations will not be reset at this time. After discussion with Health Canada, it was decided that the results of the review will inform strategic planning for the next strategic period: 2012 to 2017.

RECOMMENDATION 3
Actively lead (fewer but significant) projects using dedicated RHI staff.

ACTIONS TAKEN
RHI is now making a more significant investment in a more focused set of projects. Until 2010, RHI followed a granting agency model, investing exclusively on “extramural” projects (i.e., grants for projects not directly managed or overseen by RHI). In 2009-2010, it became clear that another area of activity was required: RHI needed to leverage its national network of people and infrastructure, as well as its expertise in SCI translational research and best practice implementation, to sponsor its own projects. Although these “intramural” projects may include a grant component, RHI staff lead them, holding overall responsibility for project design and implementation.

RHI now focuses its internal efforts on 14 intramural projects, while still maintaining existing extramural grant projects.

RECOMMENDATION 4
Seek opportunities for shared learning through greater collaboration with other organizations funding knowledge translation and best practices management.

ACTIONS TAKEN
Since his appointment this past year, the Senior Director, Strategic Partnerships and Initiatives has been working to deepen and develop collaborative relationships with key organizations both nationally and internationally. RHI has held numerous meetings with personnel from the Canadian Institutes of Health Research (CIHR) in order to identify and develop areas for partnership. Memoranda of understanding have been developed or are in development for the Ontario Neurotrauma Foundation, the Canadian Medical Association and Accreditation Canada, among others.
RECOMMENDATION 5
Organizational consistency and stability, particularly amongst RHI’s senior leadership positions, along with effective communication (to all key stakeholder groups) will be key going forward.

ACTIONS TAKEN
Organizational consistency and stability:
After achieving clarity of focus through its revised vision and mission, RHI finalized its new organizational structure in February 2011. This new structure was developed to ensure that our staff works together by optimizing use of internal resources. The structure is based on a matrix model, where project teams cut across functional areas.

RHI has solidified the leadership team, with the recruitment of the following in-house personnel:

- Director of Marketing and Communications, who will help RHI develop closer relationships with the organization’s broader stakeholder groups;
- Director of Best Practices Implementation, who will help ensure the best practices identified through RHI’s research are translated into clinical practice;
- Director of Clinical Research Operations, who will oversee the management of RHI’s large, multi-centre clinical studies, and further develop RHI’s clinical research network;
- Director of Quality and Compliance, who will develop and ensure the implementation of policies and standard operating procedures to align RHI activities with privacy and other regulatory requirements; and
- Senior Evaluator, who will help RHI improve its performance measurement system and prepare for the upcoming Summative Evaluation.

In addition, the past year saw the creation of the Translational Research and Advisory Committee (TRAC), an advisory body that provides strategic direction and oversight to the Translational Research Program at RHI. TRAC is tasked with, among other things, providing oversight of the processes of evaluation and relevancy of projects undertaken by RHI.

Effective communication:
RHI developed a Marketing and Communications Operations Plan 2010-2012 in Sept 2010. This plan highlights our strategies for reaching out to all RHI stakeholders, including the clinical research community, service providers, regulatory bodies and related organizations, individuals with SCI and their immediate families, strategic partners (government, community, corporate, international), as well as thought leaders and opinion influencers in government, academia, business, NGOs and media. Over the past six months we have been effectively rolling out this plan, and have noted successes in the attention and engagement generated.
RECOMMENDATION 6
Focus less on differentiating “how” (process) and spend more time specifying “who”, “what” (difference or change we expect to see in people and system ‘uptake’ and/or behaviour), and “why” (the expected impact on people with SCI).

ACTIONS TAKEN
RHI has undertaken a change in how it manages its projects, to focus more on results and on the ultimate intended beneficiaries: people with SCI. This focus is being incorporated into our projects starting from the project planning stage, and is reinforced through communications with our grant recipients.

RECOMMENDATION 7
Further develop, understand and possibly merge knowledge translation and best practices strategic elements.

ACTIONS TAKEN
In fiscal year 2010-2011, RHI established the Best Practice Implementation (BPI) program with the recruitment of a Director, Best Practices, development of a BPI Roadmap, and initiation of BPI projects.

To further its work in knowledge translation (KT), RHI has incorporated a KT requirement into its new Relevancy Criteria. We are working to develop a knowledge translation plan, covering both intramural and extramural projects.

RECOMMENDATION 8
Clarify key terms in the mechanisms of support like “grant” and in the technical areas of support like “clinical trials.”

ACTIONS TAKEN
RHI has developed a glossary of key terms relevant to its mechanisms of support and technical areas of support.

RECOMMENDATION 9
Look for translational projects close to implementation for possible ‘quick wins’ that would benefit Canadians with SCI (relevancy criteria/potential for impact and knowledge translation readiness)

ACTIONS TAKEN
RHI has developed a relevancy framework for identification of new projects, which includes as one criteria the concept of “quick wins“.
**RECOMMENDATION 10**

Keep in mind the importance of infrastructure in supporting innovation – such elements as standards, codes, protocols, data bases etc. These are areas in which experience suggests that most key stakeholders on their own will under invest in because the benefits accrue to everyone (i.e. there is a bit of a free rider syndrome). RHI – as a key advocate for people with SCI and the integrator of group interests – is in a unique position to ‘broker’ common standards and technology infrastructure.

**ACTIONS TAKEN**

RHI fully recognizes the value of its activities undertaken to develop the “infrastructure” needed to support innovation. We will continue to place priority on our RHSCIR Study and SCIRe projects, both of which by their nature promote common standards across fields related to research on and care and support of people with SCI. Secondly, infrastructure building will become a key component to the early development of our sponsored clinical research projects: in order to conduct clinical studies, all sites involved need to have the infrastructure in place to support them. Currently few sites have this needed infrastructure. A large focus of our sponsored projects, at least in the early stage, will be on infrastructure development: determining institutional differences and variations in clinical care across Canada to begin standardizing clinical research practices by implementing standard operating procedures; building on the standardization process of Accreditation Canada to implement clinical research best practices at each site; delivering clinical (for example, ASIA) and research (ICH-Good Clinical Practice) training to ensure the ability to perform each research protocol.

**RECOMMENDATION 11**

Continue recent work to augment specific performance expectations, planning, measurement and reporting to reflect recent work in evaluating knowledge translation and provide stronger evidence of results progress.

**ACTIONS TAKEN**

After the hire of its new Senior Evaluator, RHI undertook a review of its performance measurement system. Starting with the logic model and Performance Measurement Framework contained in its Results-based Management and Accountability Framework (RMAF), RHI is working to integrate performance measurement into all of its programmatic activities, to ensure appropriate and useful data are collected and used. This performance measurement system ensures alignment with project planning and implementation, grant management, financial processes, revenue generation processes, communications, and almost all other areas of RHI activities.
RECOMMENDATION 12
Drawing on its encouraging results tracking efforts to date, RHI should define appropriate project/program/strategy outcomes and measure going forward and then actively monitor them. This will help with good management as well as with summative evaluation readiness.

ACTIONS TAKEN
As above actions taken for recommendation 11.

RECOMMENDATION 13
Refine the summative evaluation strategy in light of the narrower focus and the revised priorities, and implement a case study approach on the major translational projects going forward;

ACTIONS TAKEN
The framework for the summative evaluation has been developed and submitted for review, both internally and externally. It is in the process of being finalized.

RECOMMENDATION 14
Dedicated in-house resources, along with active engagement and support by RHI staff and leadership will be critical moving forward.

ACTIONS TAKEN
As noted above (recommendation number 5), RHI has recruited new internal personnel to deliver on its mission. To foster engagement and support among RHI staff, both new and existing, the organization has increased its communications with its staff, through regular meetings and more informal methods. Its new, matrix-based structure encourages cross-fertilization and a team approach to all tasks.

RHI has also elaborated and formalized RHI’s processes and procedures to ensure quality, consistency and efficacy. A number of new policies, guidelines and standard operating procedures have been formally approved and implemented over the past year. These include a relevancy framework on the selection of new research and BPI projects, privacy and security protocols, and guidelines and an SOP on grant management. Training, monitoring and audit mechanisms have been set up to ensure the policies and SOPs are followed by all RHI staff and, as applicable, our sponsored sites.
RHI continues to strive to improve its program delivery and strategic alignment. We will continue to implement the action plan developed in response to the Midpoint Review. In the next fiscal year, the Summative Evaluation of RHI’s initiatives supported by Health Canada will be another important opportunity to obtain information on our strengths and areas for improvement.

**Privacy Impact Assessments**

In the fall of 2010, RHI commissioned Deloitte to carry out two Privacy Impact Assessments (PIA) on the deployment of the RHSCIR Study, in order to assess the Study’s current and future state implications for personal privacy. The PIAs identified privacy risks and presented recommendations by which these risks may be addressed by RHI. In the upcoming fiscal year, RHI will continue implementing these recommendations as applicable. In addition, RHI is continuing to strive for a gold standard of privacy protection: for example, it is taking further steps to improve its privacy policies, procedures and communication tools with RHSCIR study sites and REBs at these sites.

PIAs will be performed annually. The next PIA, the scope of which will cover the entire RHI organization, has been planned for December 2011.
In the coming fiscal year, RHI will implement the final year of its current strategic plan, and begin the process of developing a new strategy for the period 2012 to 2017.

By March 2012, we will achieve the following:

- With our translational research work, we will continue to engage researchers, clinicians and people with SCI, and will create new knowledge and identify best practices. We will focus more deeply on our intramural projects (ACT, CAMPER, Minocycline and the SCI Community Survey), while working with our external researchers to increase the focus on knowledge translation and outcome achievement in our extramural projects.

- With the RHI Spinal Cord Injury Registry (RHSCIR), we will achieve our goal of a truly pan-Canadian registry, with the addition of two new sites to the RHSCIR study, and will continue to take our Registry international. We will begin the process of encouraging use of RHSCIR data among researchers at RHSCIR sites. To support this Registry and other studies, we will further develop our IT platform for clinical research studies, the RHI Global Research Platform (RHI GRP).

- With our work in best practice implementation, we will develop standards of care for people with SCI, as the basis for an accreditation program for facilities serving SCI patients; establish a network to mobilize knowledge on best practices; influence the behaviour of physicians through nuggets; and improve the physical activity levels of people with SCI through the dissemination of guidelines.
• We will continue to develop and sustain partnerships with key institutions, including CIHR and other federal/provincial/territorial granting institutions, as well as other organizations that can help RHI achieve its mandate.

• Operationally, we aim to update and implement internal policies and procedures, improve our performance measurement system and our risk management policy and framework, and continue building awareness and understanding of RHI among our external stakeholders.

• Beginning in 2011, RHI will engage an evaluation consulting firm to conduct a summative evaluation of its achievements supported by Health Canada funding. RHI anticipates this exercise will be useful in helping prepare its next, five-year strategic plan.

• In fiscal year 2011-2012, several of RHI’s agreements with its funders will come up for renewal, including that with its primary funder, Health Canada. RHI has begun preparation for this renewal process, with the development of proposals and business plans for respective donors, based on its draft strategic plan.
APPENDICES

I. Map of Involvement, Fiscal Year 2010-2011

II. Results of RHI Projects during the Fiscal Year
APPENDIX I

Map of Involvement, Fiscal Year 2010-2011

The map below shows RHI’s engagement of key stakeholders all over Canada in fiscal year 2010-2011. For each province and territory, the map shows the number of RHSCIR facilities that were active in the fiscal year, the number of Translational Research and Best Practice Implementation projects that were active in fiscal year 2010-2011, the number of project team members in active projects, the number of Wheels in Motion grants distributed in the fiscal year, and the number of community grants awarded by our provincial and territorial partners.

1 In certain cases, one WIM grant was awarded to a provincial or territorial partner, who was then responsible for sub-awards to grant recipients.
Results of RHI projects during the fiscal year

The tables below show all RHI projects undertaken in fiscal year 2010-2011, along with the results achieved this fiscal year.

STRATEGY 1

Development and validation of best practice guidelines for emergency response, treatment & access to primary health care
Access to Care and Timing, Phase I

Grant number: 2011-145
Project status: Ongoing

DESCRIPTION
The Access to Care and Timing (ACT) project 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. Using the simulation model, the effect of implementing clinical practice guidelines related to the “setting” (where patients are treated) and the “timing” (when treatment is provided) will be tested (simulated). It is hypothesized that patient outcomes and cost-effectiveness will both be improved if care is provided in a timely manner and in a specialized centre.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
ACT1 is launched. In ACT1, the model will be used to examine the effect of implementing specific clinical practice guidelines related to the ‘setting’ and the ‘timing of interventions’, on system and patient level outcomes. We hypothesize that the implementation of these clinical practice guidelines will positively impact both of these outcomes.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
In fiscal year 2010-2011, the first phase of a nation-wide, three-phase study was launched. As of March 31st, 2011, Level I mapping has been completed in five of the 27 facilities, and Level II mapping has been completed for one site, Vancouver, as part of the pilot. Four additional sites have been identified for Level II mapping over the coming fiscal year.

The model has been used to produce preliminary results to questions related to reducing secondary complications and adding more beds to facilities, as demonstration of the model’s utility.

The literature review conducted as part of the ACT project has been used to support the standard development process conducted by RHI and Accreditation Canada.

A workshop was undertaken in June, 2011, at the ASIA/ISCoS conference.

Plans are underway to encourage adoption of the pilot model (for the Vancouver site), through workshops and a presentation to be provided to the Vancouver Coastal Health administration.
SCI Community Survey  
*Grant number: 2010-03*  
*Project status: Ongoing*

**DESCRIPTION**

The SCI Community Survey is the largest consumer survey of its type ever undertaken in Canada. This nationwide survey, administered to people with SCI living in the community, will examine whether or not the needs of people with SCI are being met by existing health and social service programs.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**

As of March 31st, 2011, the survey protocol has been finalized and all materials (e.g., website, marketing materials, etc.) have been developed in both official languages. The survey was launched on May 16th, 2011.

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Upper Limb Rehabilitation in Acute SCI: Piloting a Novel Computer and Robotic Assisted Rehab Device  
*Grant number: 2009-34*  
*Project status: Ongoing until June 2011*

**DESCRIPTION**

This pilot project examines the feasibility of utilizing the Armeo device for application in a large-scale in-patient upper limb rehabilitation study in SCI. This project also supports the protocol development for this application. Specifically, the focus is on the implementation of the Armeo device in sub-acute rehabilitation environments, and on the development of acceptable limits of a training application in individuals with tetraplegia.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**

In fiscal year 2010-2011, this project expanded from a single site to a two-site trial (Toronto and Vancouver). Out of a total of 15 patients enrolled, 12 completed the full training and follow-up.

Early indications are showing the Armeo device is an effective complement to traditional methods of therapy to restore function to arms.  
Publications: 2 (submitted for review)  
Abstracts: 1
FES Therapy: Restoring Voluntary Grasping Function in Chronic SCI
Grant number: 2009-36
Project status: Ongoing until December 2011

DESCRIPTION
This randomized controlled trial investigates whether a series of orchestrated functional electrical stimulation (FES) treatments can retrain/improve voluntary grasping function in individuals with chronic SCI, and whether this therapy will yield better results than conventional occupational therapy.

The study also evaluates if the improvements in hand function will improve participants’ activities of daily living skills and their satisfaction with life.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Completion in December 2011

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
A total of 21 patients have been enrolled in the study, of which 19 have completed the full study plus the follow-up.

Although the analysis is still ongoing, early indications, based on subjective feedback, are that the therapy is beneficial and contributes to quality of life of the patients.

Due to some delays in recruiting patients, it is likely that this study will extend until early 2012, a few months later than expected.

Based on the success of this research a beta version of the device for commercialization is being developed.
Effect of Locomotor Training on Children with Incomplete Spinal Cord Injuries
Grant number: 2009-38
Project status: Ongoing until November 2011

DESCRIPTION
This project examines how well children with incomplete SCI of greater than 12 months duration who remain non-functional ambulators improve through body weight assisted treadmill training (BWATT).

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Team is looking to increase enrollment by taking the study multicentre.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
In fiscal year 2010-2011 the study expanded from a single site to three sites (Toronto, Edmonton and Montreal). In coordination with the two extra sites, the protocol is being amended. However, due to difficulties enrolling patients the project is currently on hold and RHI is reviewing options for further action.

The Impact of a Brief Cognitive Behaviour Therapy Intervention Aimed at Improving Emotional Well-being and Quality of Life for Individuals with SCI
Grant number: 2009-39
Project status: Completed June 2010

DESCRIPTION
This study investigates the potential efficacy of a group cognitive behavioural therapy (CBT) intervention aimed at improving emotional well-being, specifically mood, adjustment and quality of life (QOL), after Spinal Cord Injury (SCI).

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Completion expected Q2 2010.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
A total of 68 individuals consented and 46 participated. Test results demonstrated that providing brief cognitive behavioural therapy (CBT) in a group format to patients diagnosed with either traumatic or non-traumatic SCI does significantly decrease overall levels of emotional distress. Also, the CBT protocol was found to be equally effective for individuals living with SCI in the community, even many years post-injury/illness onset.
From Research to Clinic: the Translational Step with Functional Magnetic Resonance Imaging of the Human Spinal Cord (spinal fMRI)

Grant number: 2009-32
Project status: Completed June 2010

DESCRIPTION
Current clinical methods for assessing human spinal cord function may not always deliver the detail needed by clinicians to determine the most effective form of treatment after trauma. This multi-site pilot study examines a new non-invasive assessment method based on functional magnetic resonance imaging (fMRI).

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Completion in August 2010.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
Forty individuals participated in this study, including 20 with SCI. The progress achieved over the course of this grant was the basis for two grant applications for longer-term funding, to CIHR and to the Craig H. Nielsen Foundation.

The outcomes of this project include the development and testing of a completely automated thermal stimulation device (Self-Timing Automated stimulus DeliverY System, or STADYS) that makes it practical to carry out spinal cord fMRI in hospital MRI units. This project demonstrated that data for one fMRI run can be achieved with the addition of only 7 minutes of scanning time with little additional time, space or personnel training. This project demonstrated the effectiveness and practicality of collecting data from a number of people, in both a research MRI unit and in a hospital MRI unit. This device will be the primary tool used for a number of future SCI fMRI studies and is the basis of a practical clinical assessment method.

Publications: 1
Presentations: 8
Can Pregabalin Prevent the Development of Neuropathic Pain Following Spinal Cord Injury?

Grant number: 2009-40
Project status: Ongoing until October 2011

DESCRIPTION

This study examines the effectiveness of Pregabalin as a treatment in preventing post-spinal cord injury neuropathic pain.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011

Good results would see this work parlayed into consideration for secondary health complication framework.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011

There have been delays in this project due to recruitment challenges. Four patients have been recruited to date.

SCI Chronic Pain Self-Management: A Clinical Demonstration Study

Grant number: 2009-37
Project status: Completed March 2011

DESCRIPTION

This project examines the effectiveness of an SCI-specific Pain Management Group (PMG) based at the Lyndhurst Centre for helping clients manage chronic pain (pain persisting longer than six months after SCI).

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011

Will extend through 2010-2011 to allow for inclusion of an additional cohort of participants, conference presentation, and manuscript writing.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011

Project completed March, 31 2011. Results of the project include a submitted manuscript and a revised pain resource binder used for study.
Economic Evaluation of Early Surgical Decompression for Traumatic Cervical SCI

Grant number: 2009-33
Project status: Ongoing

DESCRIPTION

Using Ontario-based health costing data and data from STASCIS, another RHI-supported study (see grant #2008-16, STASCIS), this project examines whether early surgical decompression of spinal cord (< 24 hours since spinal cord injury) is more cost effective than the late surgical intervention (>24 hours) in the management of patients with acute cervical SCI.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011

Results are expected in the fall of 2010, including preparation of additional peer-reviewed manuscripts.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011

This project is nearing completion. Expected results within the coming fiscal year include publication and a peer-reviewed manuscript on the results of the research.
Global Blueprint for Stem Cell Innovation: Translation & Commercialization
Grant number: 2010-90S
Project status: Completed September 2010

DESCRIPTION
On May 21st and 22nd, 2010, the inaugural Stem Cell Global Blueprint Conference was held to discuss barriers to the advancement of stem cell technologies from the lab to the clinic and to take the first steps towards a blueprint for stem cell innovation, translation, and commercialization for spinal cord injury and related degenerative disorders of the central nervous system.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Over 100 international stem cell expert stakeholders expected to attend. Publication of an international stem cell agreement in a peer-reviewed publication.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
More than 80 international stakeholders attended this conference, including scientists, clinicians, funding agencies, regulators, media and advocacy groups.

The conference focused on increasing cross-communication between stakeholders and between countries, and establishing best practices for stem cell translation that are applicable on a global scale. Several working groups were formed. The Delphi working group will work towards building consensus around solutions and conveying this knowledge to policy-makers; the website working group will translate the knowledge gained at the conference through an informational website for consumers and their families and caregivers.

STRATEGY 2
Supporting multi-centre clinical trials in acute care, rehabilitation and community, fostering global collaboration where possible; supporting pre-clinical research imminently ready for translation.
The Canadian Multicentre CSF Pressure Monitoring and Biomarker Study (CAMPER)

Grant number: 2009-35 (in Strategy 1) and 2011-165
Project status: Ongoing

DESCRIPTION

CAMPER is a multi-centre acute spinal cord injury clinical research study that aims to: 1) characterize the changes in intrathecal pressure, in order to provide more advanced practice guidelines on the management of blood pressure in acute SCI, and 2) obtain and analyze CSF samples to validate a series of biomarkers (specific proteins produced during SCI) and to independently confirm their ability to predict injury severity and neurologic outcome.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011

If funded, this study will be expanded to four additional sites across Canada and could begin as early as the fourth quarter of 2010.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011

The expansion of the pilot project to a multi-site study has experienced some delays due to ongoing sub-site contract negotiations between UBC-UlO and each site’s institution, as well as delays within RHI of hiring a new project manager for the project.

The pilot project, undertaken in Vancouver and entitled “Cerebrospinal Fluid (CSF) Pressure Monitoring and Biomarker Validation in Human SCI”, will be concluded in June 2011. Based on a review of lessons learned to date from this pilot, the three-year, multi-centre CAMPER study was designed and implemented in fiscal year 2010-2011, and will be rolled out to RHSCIR sites across Canada in the upcoming fiscal year. The following activities have been completed for this multi-centre study, as of March 31st 2011:

- The study protocol and budget have been finalized.
- The study manual, case report forms and consent forms have been developed in draft.
- A contract template for engaging the sites has been developed in draft.
- Six sites have been identified for the study: Vancouver (which will only take part in the multi-centre study once the pilot has concluded), London, Halifax, Ottawa, Calgary and Montreal. Applications for ethics review have been made for all of these sites. Some sites have received approvals from their ethics review boards.
- Staffing needs have been identified and recruitment processes for staff have begun in some sites.

Publications: 1
**Minocycline**  
*Grant number: N/A  
*Project status: Ongoing*

**DESCRIPTION**  
Minocycline is a tetracycline derivative that has shown neuroprotective effects in animal models of several neurological conditions including spinal cord injury. This study expands upon a single-centre human double-blind randomized placebo controlled pilot study examining the use of intravenous Minocycline in acute spinal cord injury within 12 hours after injury. This study indicated promise with respect to improving outcomes during the acute stage of SCI, particularly in incomplete cervical injuries. If successful, this study holds the potential to yield the only neuroprotective drug intervention for acute SCI (the efficacy and safety of methylprednisolone remains equivocal and controversial).

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**  
A multi-centre study was developed in 2010-2011 in response to the early promise shown by the single-centre study. However, this larger study encountered some challenges in assessing the sample size needed for adequate statistical power to establish the drug’s efficacy in SCI applications. Once the sample size has been determined, a decision will be made on the feasibility of continuing with the study.

The pilot study data has been submitted to the Lancet for publication.

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**Restoration of Upper Limb Function in Individuals with Sub-Acute Spinal Cord Injury**  
*Grant number: 2010-925  
*Project status: Ongoing until April 2013*

**DESCRIPTION**  
This multi-centre randomized control trial evaluates the efficacy of upper limb therapy based on functional electrical stimulation (FES) for persons with sub-acute tetraplegia.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**  
This multi-site, phase II randomized control trial is in the early stages of implementation. Ethics approvals have been received for one site, with reviews pending in the other two.

In fiscal year 2010-2011, the project team wrote the datasets for the study, created a data warehouse, and developed site contracts. Patient enrollment has just begun, with two patients recruited to date.
Working Group to Develop an Online Physical Activity & Nutritional Counseling Proposal

Grant number: 2010-52
Project status: Completed

DESCRIPTION
This project supports the creation of a working group charged to identify ways to enhance access to specialized fitness information and services by incorporating an Internet-based strategy that facilitates uptake of these services in the home of participants.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Completion in mid-2010. The proposal will be submitted to RHI’s Community Partnerships Program.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
This project was completed and has been successful. The proposal was submitted to RHI’s Community Partnerships program and is now being funded.
Coordination of IHT Activities Across Canada Directed Towards Persons with SCI
Grant number: 2010-02
Project status: Ongoing

DESCRIPTION
This project provides support for a lead and assistant to conduct the following activities: prepare final in-home telehealth (IHT) proposals (Pressure Ulcer Internet Clinic, Online Physical Activity Service, SCI eLearning), coordinate potential participants and seek leveraging and partnership opportunities.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Project deliverables include preparation of other IHT proposals (pressure ulcer internet clinic, online physical activity service, and SCI-I eLearning), and seek leveraging and partnership opportunities for future funding.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
All three proposals developed as part of this project were successful; two of the resulting projects commenced this fiscal year: Feasibility of an Internet Pressure Ulcer Clinic (see grant #2010-79S), and the Online Physical Activity project (see grant #2010-52).

As proposal development activities came to an end, the support provided with these funds evolved into support for implementation of each of these projects.

Within the ambit of this project, the team is working on developing another proposal, for bladder self-management. The project team is engaged in discussions with a private sector technology firm, and will make a decision shortly on the feasibility of this initiative.
Rejoyce: Additional Sites

*Grant number: 2010-55*

*Project status: Ongoing until October 2011*

**DESCRIPTION**

This project supports the extension of the previous, RHI-supported study of the Rejoyce device to a third site.

The aims of the project are: 1) To evaluate improvements in hand function in stable, C5-6 SCI subjects treated with FES-assisted exercise on a ReJoyce workstation, telesupervised over the Internet; 2) To compare the efficacy of 5 days/week versus 1 day/week treatment; 3) To correlate the information obtained from hand function tests with measures of social utility and subject satisfaction; and 4) To identify the efficacy, costs and obstacles of a fully functional, nation-wide IHT system.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**

This project has experienced some delays. The start-up phase of the project was protracted due to challenges in establishing the multi-centre site in Toronto. Initial equipment testing and patient recruitment commenced Jan 2010. A total of 20 patients were recruited in the three sites of this study (Toronto, Montreal and Vancouver), of which 9 have completed the study to date.

The double-blind study is still ongoing, but some results have been achieved in the process of carrying out this study. For one, the study highlighted some technical problems with the Rejoyce device, which led to the manufacturing firm introducing a more rigorous quality control system. The device is now compliant with international regulatory requirements. Secondly, out of necessity the project team developed an internet-based communications technology. This application, similar to Skype, is tailored to the needs of telesupervised physiotherapy, and may have applications beyond the current study.

RHI developed a video on the Rejoyce study in November 2010, which is available on Youtube (http://www.youtube.com/watch?v=YI8JDGh4Hw8).

The Rejoyce project team demonstrated the device at RHI’s booth at the 2011 ASIA/ISCoS conference in Washington, DC in June.
Sitting Pivot Transfers in Individuals with a Spinal Cord Injury: Minimizing Upper Extremity Risk Exposure and Maximizing Performance
Grant number: 2010-825
Project status: Ongoing until March 2012

DESCRIPTION
Most individuals with a spinal cord injury (SCI) who use manual wheelchairs as their primary source of mobility perform sitting pivot transfers (SPTs) numerous times per day. This comprehensive biomechanical study aims to identify the most effective and safest SPT technique(s) for individuals with a SCI.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
In 2010-2011, the start-up phase of the project was completed in advance of the project schedule. As of Mar 31 2011, 26 individuals were enrolled. The team anticipates that this project will present the largest sample size ever studied during a comprehensive biomechanical assessment of sitting pivot transfer.
Abstracts: 1

Phase I Trial of Riluzole in Patients with Acute Spinal Cord Injury
Grant number: 2008-16
Project status: Ongoing until December 2011

DESCRIPTION
The purpose of this study is to evaluate safety and pharmacokinetic profiles of Riluzole in patients with acute spinal cord injury.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
The study is designed as a multi-site, single arm active treatment pilot study involving 36 subjects. RHI supported implementation of the study at the Canadian site (Toronto).

To date this site has received ethics approval and screened eight patients.

A North American Clinical Trials Network (NACTN) meeting was held in Toronto March 17-19, 2011, to perform a mid-trial review of the phase I trial of Riluzole as a neuroprotective agent. The meeting also discussed potential collaboration between the Christopher and Dana Reeve Foundation (CDRF) and the Ontario Neurotrauma Foundation (ONF).

Grant number: 2008-16
Project status: Completed January 2011

DESCRIPTION
This study examines whether early (<24 hrs from the time of injury) surgical decompression of the spinal cord results in a better neurologic outcome than later (>24 hrs from the time of injury) decompression in patients sustaining an acute cervical SCI.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Final results are to be published in 2011.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
The optimal timing for intervention in acute spinal cord injury has long remained a source of debate and controversy within the field of spine surgery. STASCIS is one of the most extensive and rigorous analyses performed on this topic to date.

The STASCIS study was a multicenter, international, prospective controlled study on the impact of time into decompressive surgery. A total of 313 patients with acute cervical SCI were enrolled, of which 182 underwent “early” surgery (less than 24 hours after injury), with the remaining 131 having “late” surgery (24 more hours after injury).

This study revealed significantly better results for patients undergoing early decompression surgery than late decompression surgery, even when controlling for a number of factors such as age, pre-operative impairment and steroid administration. It also demonstrated the safety of early surgery.

A manuscript has recently been submitted to the New England Journal of Medicine and is currently under review.
**Acute Practice Network Systematic Reviews**

*Grant number: 2008-16  
Project status: Completed January 2011*

**DESCRIPTION**

The ACT-PN Systematic Reviews (SRs) represent a collection of unbiased research evidence applicable to acute medical interventions for spinal cord injury, as well as preclinical therapeutic options. Clinical chapters of this work address a complete set of topics relevant to acute SCI clinical care medical regimens spanning from the initial point of injury through to the patient’s exit to receive rehabilitative care.

These systematic reviews involve a collaboration of subject matter experts with expertise in the clinical management and preclinical research of SCI from centres of excellence in Halifax, Montreal, Ottawa, Toronto, Calgary and Vancouver.

**ANTICIPATED RESULTS, FISCAL YEAR 2010-2011**

Two reviews (out of 14) are remaining to be published in J. Neurotrauma.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**

A further four reviews have been published in fiscal year 2010-2011, for a total of 16 systematic reviews for this project as a whole. This represents two more reviews than originally anticipated.

A special issue of the Journal of Neurotrauma, encompassing all systematic reviews, is anticipated later in 2011.

Publications: 4
The Graded and Redefined Assessment of Strength, Sensibility and Prehension (GRASSP)

Grant number: 2008-14 & 2008-16
Project status: Ongoing until December 2012

DESCRIPTION
The Graded Redefined Assessment of Strength Sensibility and Prehension (GRASSP) is a multi-centre study with seven sites, six in Ontario and one in Quebec, which captures data after cervical SCI for any level at any point during recovery (acute, sub acute, chronic). The focus of this work is to establish methods to diagnose and quantify hand dysfunction in traumatic SCI with greater sensitivity and discreteness than existing methods.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Web-based data collection is underway in multiple sites with early peer-reviewed publications expected in the first quarter of 2010-2011.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
Ethics approval have been obtained for all Ontario sites and all are recruiting patients. An ethics application has been submitted for the Quebec site.

To date 25 patients have been enrolled in the study.

The team is working with European investigators engaged in a similar study to potentially merge data as well as with American investigators who are considering participating in the study to increase sample size.

GRASSP Tool Kits have been standardized for all centres and are now available to order online for those sites wishing to use GRASSP as an upper limb assessment approach (www.sci-grassp.org).
Publications: 1
Feasibility of Internet Pressure Ulcer Clinic

Grant number: 2010-795
Project status: Ongoing until February 2012

DESCRIPTION
This project is a multi-site pilot investigation to assess the feasibility of integrating several information technologies, each deployed over the internet, within the practices associated with clinical management and prevention of pressure ulcers in persons with SCI.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
The project team has been working in collaboration with Telus to develop self-management tools for pressure ulcer prevention and management. The products are undergoing beta testing, and will undergo a privacy impact assessment in 2011.

The design phase of the protocol for the study is being undertaken across the four sites of the project (Calgary, Winnipeg, Fredericton and London). Agreements for all sites are expected to be signed shortly.

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STRATEGY 3
Supporting the development of a Best and Brightest program to nurture new SCI researchers.

Best & Brightest Program
Grant number: N/A
Project status: Ongoing

DESCRIPTION
RHI supported the Ontario Neurotrauma Foundation’s (ONF’s) Best & Brightest Program, which in fiscal year 2010-2011 supported nine Mentor-Trainee awards for two years to build capacity for doctoral and post-doctoral students and young investigators to do research with well-established investigators.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
The investments supported Principal Investigators to facilitate the development of work in the areas identified. The impact of this funding will be realized over a two year period.
STRATEGY 4
Collecting and analyzing data on SCI in Canada, including acute, rehabilitation and community components and supporting research and multi-centre trials, utilizing a web-based national technology platform and collaborating globally where appropriate

**Rick Hansen Spinal Cord Registry (RHSCIR) Study**
*Project status: Ongoing*

**DESCRIPTION**
The Rick Hansen SCI Registry (RHSCIR) is an unprecedented, nationwide project that is collecting critical information on SCI at 27 major Canadian acute care and rehabilitation facilities across the country. RHSCIR will create a truly Canadian database of information about SCI that will benefit all Canadians with SCI and every professional involved in the SCI continuum of care far into the future. RHSCIR will be an invaluable resource for researchers and clinicians seeking to better understand SCI and the effectiveness of specific treatments, practices or programs for improving functional outcomes and quality of life after SCI.

**ANTICIPATED RESULTS, FISCAL YEAR 2010-2011**
The group is confident that approval can be gained for the project from the two outstanding eastern provinces (NFLD & NB) and are focused primarily on finalizing agreements with TRI as soon as possible.

National team is focusing on operation of the project at each site, working towards standardizing data collection procedures, improving consent rates, ensuring data quality and preparing for centralization of the data. Active and regular communication with site coordinators are helping to build relationships between sites and national and providing a good sense of capacity at each site. Test transfers of data collected to date are being conducted with all the RHSCIR pilot sites; once privacy protection framework is approved, regular live transfers can begin.

During 2010/11, RHSCIR national team will be engaged in preparation of peer-reviewed publications on baseline data collected to date. They will be working toward consensus on the dataset, will standardize data definitions, outcomes measures and collection points for all data elements.
RESULTS ACHIEVED, FISCAL YEAR 2010-2011

RHI continues to expand the RHSCIR network. In fiscal year 2010-2011, RHI added one more hospital to the network (Lyndhurst, in Toronto), for a total of 27 facilities, located in 12 cities and seven provinces, encompassing almost all of Canada’s major SCI trauma units and rehabilitation hospitals. Data sharing agreements for another three facilities are expected to be signed shortly. In addition, in the fiscal year, the sites enrolled an additional 634 individuals to RHSCIR, for a total of 1,753.

RHI sustains existing RHSCIR sites through capacity building on measurement and good clinical practice, monitoring and other activities. In October 2010, RHI brought all RHSCIR Site Coordinators together in Vancouver for the first of what will become an annual Coordinator’s meeting. This meeting was very well received, and led to improved understanding and engagement among the attendees.

RHI has taken steps to assess the percentage capture of patients at sites, aiming to improve its enrollment rate to 100% of new SCI patients. We instituted a reconciliation process in Vancouver with hospital records, resulting in 100% coverage of SCI patients at that site. This process will be rolled out to other sites over the year, so that percent coverage will be identified and the reconciliation made to improve this coverage.

RHI has also undertaken research to identify factors affecting consent of SCI to be enrolled in RHSCIR. Strategies will be developed based on this research to increase the consent rate.

The RHI RHSCIR national team has been engaged in the preparation of peer-reviewed publications based on RHSCIR data. To date, they have developed three manuscripts in draft, with five more in development. These are expected to be published in the coming fiscal year.

Publications: 3
Book chapters: 1
Presentations: 1
Rick Hansen Institute Global Research Platform (RHI GRP)
Grant number: N/A
Project status: Ongoing

DESCRIPTION
In carrying out the RHSCIR study described above, RHI recognized the need for an IT platform robust and flexible enough to collect, store and analyze the large datasets needed for this unique study. In fulfillment of this need we have created our own, in-house technology to suit this purpose.

The RHI Global Research Platform (RHI GRP) is a state-of-the-art, web-based data collection platform for spine-based research, developed in 2010-2011 and officially launched in January 2011. This platform allows for real-time data collection and offers enhanced privacy and security features that comply with all privacy legislation in Canada. The RHI GRP is designed to be truly universal and portable— for example, it will be possible for a clinician to enter data on a smart phone or tablet while exiting the operating room. The platform also provides unprecedented information sharing and collaboration potential for participating RHSCIR sites, in all major jurisdictions across Canada.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Beta testing of the RHSCIR data collection platform will commence in 2010.

The support platform will facilitate the imminent launch of the TRP sponsored multi-site clinical studies.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
RHI GRP platform developed & launched January 2011. It is being prepared for use with the RHSCIR Study as well as for other studies including CAMPER and CSS.
STRATEGY 5
Facilitating the adoption and implementation of validated best practices as identified by the Translational Research Program and through properly evaluated public policy and community-based programs aimed at improving treatment, care and support and communicating these best practices directly to Canadians with SCI

Accreditation Canada
Grant number: N/A
Project status: New

DESCRIPTION
RHI has partnered with Accreditation Canada to develop standards and an accreditation program for spinal cord injury. All hospitals and rehabilitation facilities providing care to people with SCI across Canada are potential recipients for these standards.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
As of March 31st 2011, the following activities have been completed towards the creation of this accreditation program:

- An initial literature review has been completed;
- The internal project team and advisory committee have been established;
- A news release describing the project and the partnership with Accreditation Canada has been issued; and
- The first Advisory Committee meeting was held in March in Ottawa, to review the scope of standards.
CMA Education Credits  
*Grant number: 2010-56 and contract  
Project status: Mixed (grant is ongoing, intramural implementation phase is new)*

**DESCRIPTION**
Rick Hansen Institute’s Best Practices Implementation (BPI) Program is supporting the implementation of Actionable Nuggets, with Continuing Medical Education credits available through the Canadian Medical Association (CMA).

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 spinal cord injury (SCI). This project will use a tool called “actionable nuggets” to provide knowledge on current best practices for specialized patient populations for primary care physicians. Physicians will receive an electronic invitation to review short focused care guidelines related to the management of care for people with SCI.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**
Guidelines were developed in the first stage of this project. In the past fiscal year RHI has identified a strategy to implement these guidelines. RHI partnered with the Canadian Medical Association (CMA) to deliver the content to broader audience through Continuing Medical Education Microcredits.

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Rehabilitation E-Scan  
*Grant number: N/A  
Project status: Ongoing*

**DESCRIPTION**
The Rehabilitation E-Scan is an ongoing project to obtain information about current SCI rehabilitation care and treatment practices in Canada. The first phase of this project involves development of an atlas showing the status of SCI rehabilitation service delivery, care providers and research capacity at RHSCIR sites across Canada. Once finished, the atlas will be freely available to the public via the RHI website.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**
Data collection began in fiscal year 2010-2011. Analysis is expected to begin by July 2011, and a draft report produced by early 2012.
Physical Activity Guidelines and Guides for Canadians Living with SCI
Grant number: 2010-51
Project status: Ongoing

DESCRIPTION
In 2010, RHI provided support to a project to develop physical activity guidelines and guides for both acute and chronic spinal cord injury patients that would promote physical activity and improve physical function, fitness and quality of life, using the same series of steps that were employed for the development of Canada’s existing physical activity guides.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
The Physical Activity guidelines were released on March 17, 2011, with systematic dissemination and awareness campaigns. RHI and SCI Action Canada have engaged with media and social media outlets to promote the guidelines.

Evaluation of SCI-U
Grant number: 2010-77
Project status: Ongoing

DESCRIPTION
The pilot project of SCI-U is intended to develop and validate five streaming video modules designed to be accessed online for people with SCI interested in learning validated self-management techniques.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Delivery [of modules] is expected to start Sept 2010.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
As of fiscal year 2010-2011, all five of the planned SCI-U modules (bowel, bladder, skin, nutrition, and an introductory module) have been developed. The development team included both clinicians and consumers at different sites across Canada. A preliminary evaluation, for development purposes, has been completed, which has provided useful insights into areas for improvement. The team is now in the midst of a formal post-hoc evaluation. This blinded study, which will involve 10 people with SCI and 10 healthy participants, is expected to be completed in the summer of 2011.

In June 2011, an abstract was presented at the ASIA/ISCoS meeting in Washington, DC.
SCIRE
Grant number: 2010-01, 2010-57, & 2010-67
Project status: Mixed (2 new, 3 ongoing)

DESCRIPTION
SCIRE is a web-based synopsis and critical review of existing scientific literature on a broad range of topics in SCI rehabilitation, the result of the combined efforts of expert scientists, clinicians, consumers and stakeholders across Canada. It is expected that the pre-appraised, synthesized research from SCIRE will translate into improved health for Canadians with SCI by increasing the accessibility of up-to-date, quality information to health care professionals, scientists, policy-makers, and individuals with SCI.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
The SCIRE project has involved 69 researchers and clinicians across Canada. In fiscal year 2010-2011, SCIRE resulted in 8 publications in refereed journals, 38 presentations at conferences, 1 workshop and approximately 295,000 hits on the SCIRE website.

SCI Home Ventilation Guidelines
Grant number: 2008-20
Project status: Ongoing to 2012

DESCRIPTION
This project aims to develop guidance to individuals requiring ventilatory assistance, their caregivers, and health care teams on the role of mechanical ventilation in the home setting. Despite rapid development of home ventilation, no recent guidelines have addressed the issues of who, when, how, and even why such support should be offered.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Guidelines are expected to be published November 2010, followed by uptake activities through Neurological Health Charities Canada.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
Guidelines submitted to the Canadian Thoracic Society. Review scheduled for 2011 Q1 with publication anticipated by 2011 Q2.
Get in Motion: Physical Activity Counseling for Canadians Living with Spinal Cord Injury

Grant number: 2010-04
Project status: Completed December 2010

DESCRIPTION
Get in Motion is a free, physical activity counseling service for Canadians living with spinal cord injury, designed to provide information and support to help people achieve their personal physical activity goals. RHI supports the expansion of this service to a greater number of clients, greater community involvement, and expanded partnerships.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
The project is complete.

89 individuals with SCI have received customized physical activity counseling since the inception of the program in 2009. The Get in Motion service is available in English and French.

A best practice model for delivering physical activity counseling to adults with SCI was developed.

Clients of the Get in Motion service who engaged in more leisure time physical activity were more autonomous outdoors and had greater life satisfaction and motivation to exercise in the future.
Contribution Analysis to Assess the Performance (Planning, Monitoring and Evaluation) of the Discovering the Power in Me Project
Grant number: 2010-45
Project status: Completed December 2010

DESCRIPTION
The objective of the project was to pilot the “Discovering the Power in Me” (DPM) program in a tertiary care rehabilitation setting.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Completion in August 2010 in order to allow for post-workshop follow-up with the study participants.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
18 individuals with SCI participated.

The outpatient group did not show any change in the outcome measures used. The inpatient group showed promising trends toward improved scores in self-efficacy, self-esteem and participation measures immediately following the workshop and at six months post workshop.

Evaluation of the Power in Me NB
Grant number: 2011-34
Project status: New, ongoing to July 2012

DESCRIPTION
To pilot a multi-media based education program, entitled “Discovering the Power in Me” to people with SCI and other mobility disabilities in New Brunswick.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
This project was launched in November 2010 and is currently ongoing.
Autonomic Dysreflexia, and Abnormal Cardiovascular Control Following Spinal Cord Injury: Translating Knowledge into Best Practice for Health Practitioners

Grant number: 2009-42
Project status: Completed August 2010

DESCRIPTION
This project evaluates the effect of education on issues of management of chronic secondary cardiovascular conditions in SCI population: autonomic dysreflexia, orthostatic hypotension by the medical personnel of ER and paramedics.

ANTICIPATED RESULTS, FISCAL YEAR 2010-2011
Completion in August 2010.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
133 individuals attended a one-hour educational workshop including 113 ER personnel (physicians, nurses, medical students and staff) in Vancouver, Toronto and Winnipeg and 20 paramedics from BC. Post-course follow-up with participants indicated that knowledge retention was high (e.g., 73% of ER respondents were able to correctly recognize the three main causes of AD).

Based on this project, RHI produced a video on AD in November 2010, entitled “Best Practices - Diagnosis and Management of Autonomic Dysreflexia” (http://www.youtube.com/watch?v=iau-G2DHVtA).

The project is ongoing post Mar 2011 as the team is refining course content and coordinating course administration and knowledge evaluation in Canada and the US.
Incorporation of Physical Activity into the Rehabilitation Process after SCI
Grant number: 2010-80
Project status: Ongoing until April 2012

DESCRIPTION
The initial research plan outlined a study including three phases performed at multiple research facilities. Phase one is to be carried out at three separate research sites with phases two and three being conducted at four sites.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
To date, the primary site (McMaster) is furthest along; it has almost reached its recruitment goal of 20 participants, and is testing individuals in study Phases one and two. The second site (UBC) has completed ethics, has all required equipment in place and is recruiting subjects. The third site (Queen’s) has run into ethics delays and is not likely to begin for another month.

Due to the delays at some sites mentioned above, this project is anticipated to overrun its original end date of April 2012 by a few months.

STRATEGY 6
Working with RHI partners to enhance service delivery through the full implementation of the Solutions Model (solutions team, navigators)

Ontario Solutions Model
Grant number: 2011-09
Project status: Ongoing

DESCRIPTION
To fund coordinator positions for the Ontario Alliance, and three regional Alliances (in Hamilton, Ottawa and London).

The Ontario SCI Solutions Alliance is a province-wide collaborative network working toward optimal integration of health care and community service elements, eliminating duplication of services, identifying and addressing service gaps, and ensuring the needs of individuals with SCI are met efficiently and effectively.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
The funds were used to fund coordinator positions for the Ontario Alliance, and three regional Alliances (in Hamilton, Ottawa and London).
STRATEGY 7

Working with RHI partners to enhance capacity and develop initiatives that respond to the priority needs of people with SCI, utilizing collaborative funding mechanisms such as Scotiabank Wheels In Motion (S-WIM), and provincial/territorial 20th Anniversary investments, etc.

Provincial & Territorial Partnerships
Project status: Ongoing

DESCRIPTION
RHI partners with a number of organizations in each of the provinces and territories of Canada in support of its Community Partnerships objectives. These initiatives are of vital importance to RHI’s work for the following reasons:

- They help recruit researchers and clinicians into the national SCI network;
- They facilitate collaborations by accelerating provincial participation in RHI’s national projects (for example, Manitoba’s involvement in the online pressure ulcer clinic);
- Capacity building and researcher development initiatives (scholarships, fellowships, research coordinator positions, travel funds, grants to new researchers) help ensure skills exist to carry on SCI research in the future.
- While each province is able to set their own research priorities, they are encouraged to align their priorities with RHI’s national priorities, thereby maximizing opportunities for collaboration, leveraged funding, and research impact.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
RHI-Provincial & Territorial partnerships resulted in far-reaching impacts on research. Examples:

In Ontario, RHI partnered with the Ontario Neurotrauma Foundation (ONF) to develop capacities for research, through leadership chairs and secondments.

In BC, RHI partnered with ICORD to foster scientific collaboration and to implement an international exchange program for post-doctoral fellows.
The Provincial/Territorial funding agreements also resulted in:

- Recruitment of researchers and clinicians into the national SCI network.
- Collaborations that facilitated provincial participation in national projects, and augmented Health Canada funding (for example, Manitoba’s involvement in the online pressure ulcer clinic).
- Capacity building and researcher development through scholarships, fellowships, research coordinator positions, travel funds and grants to new researchers.

The partnerships also helped deliver services that directly or indirectly met the priority needs of people with spinal cord injuries and furthered their quality of life.

In several provinces, RHI supported peer support programs, and collaborative development and implementation of provincial/territorial SCI Strategies and Enhancing Active Living opportunities for people with SCI.

In the NWT and Yukon, RHI supported client services and funded solutions customized to overcome unique geographical challenges.

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**Wheels in Motion Grants**

*Grant number: N/A*

*Project status: Ongoing*

**DESCRIPTION**

Using funds raised from the Rick Hansen “Wheels in Motion” campaigns, RHI provides support to individuals with SCI and to communities in the form of grants for targeted, small-scale projects to help improve their quality of life and better integrate into their communities.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**

In fiscal year 2010-2011, RHI awarded 103 grants totalling over $1.25 million. Including amounts leveraged from other sources, the total amount of these projects is estimated to be nearly 13 times greater.

According to reports on these grants received this fiscal year, 95% of the projects are reported as successful. 80% of the projects are reported to have had a strong impact on self-care.
**Let’s Play**
*Grant number: 2010-15, 2011-19, 2010-24, 2010-33*
*Project status: Completed December 2010*

**DESCRIPTION**
In 2010-2011, RHI provided four Let’s Play grants: one for a public park and three for public schools.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**
Based on statistics from report-back forms, Let’s Play has had a large impact on the accessibility provided at supported play spaces. For example, 98% percent of respondents described as “absolutely true” that the play space design encourages shared and inclusive play. 93% percent of respondents described as “absolutely true” that a significant majority of play elements are accessible to children with mobility impairments. And 84% percent of respondents reported that the number of children with mobility related impairments accessing the play space has increased relative to usage prior to construction/renovation.


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**STRATEGY 8**
Providing excellence in leadership, coordination and program support at the national and international level

**Canadian SCI Conference: SCI Treatment Strategies for SCI**
*Grant number: 2010-965*
*Project status: New, completed May 2010*

**DESCRIPTION**
This project supported the 3rd Canadian meeting on Spinal Cord Repair: Treatment Strategies for SCI: From Biology to Clinical Reality, which was held April 20th to 22nd 2010 at the Banff Centre in Banff, Alberta.

**RESULTS ACHIEVED, FISCAL YEAR 2010-2011**
The conference attracted 89 registered participants including clinicians, scientists and students.

The conference included a panel discussion on the translation of basic research and enabled clinicians and scientists to better understanding each other’s challenges when taking treatments to clinical trials. Participants agreed on the value of the meeting; the fourth conference will be held in Halifax in 2013.
ICORD
Grant number: 2011-185
Project status: New

DESCRIPTION
In order to strengthen its relationship with ICORD, RHI provided support for the development of international linkages within the SCI research community and the identification, development, validation, and acceleration of the translation of new knowledge and best practices in SCI.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
This project supported various seminars and meetings held by ICORD, Trainee international travel costs and the ICORD International Exchange Program.

CPA Atlantic Summit
Grant number: 2011-20
Project status: Completed

DESCRIPTION
RHI supported CPA PEI in hosting the 2nd annual “Atlantic Summit” in Charlottetown, drawing participation from provincial CPAs, CPA National, provincial government departments, Queen Elizabeth and Prince County Hospitals, the Council of the Disabled, Parasport and Recreation, Quality Tourism of PEI and Lawtons Home Health Care.

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
At the Atlantic Summit, CPA affiliates from across Canada developed measurable outcomes that will assist in standardization of services and development of best practices.

Strong relationships were developed/reinforced with community, provincial and national partners, which increased CPA-PEI awareness of what organizations look for and the services they provide. This information ensured that appropriate services can be provided for everyone with SCI or other mobility disabilities on PEI, resulting in a greater number of easy and successful transitions from the hospital into the community.
Sponsorship of Conferences, Meetings and Events

Grant number: N/A
Project status: Completed

DESCRIPTION
RHI supported a number of conferences, meetings and other events related to SCI in Canada and abroad:

- ICORD 49th Annual Meeting Workshop, Vancouver, BC, Feb 2011
- Provincial Spine Lesions Conference (Colloque lésions médullaires 2010), Montreal, QC, Nov 2010
- Jive Sponsorship, Toronto, ON, Jun 2010
- United Way of Saskatoon, Saskatoon, SK, Nov 2010
- Moelle Epiniere-Rock&Roule Fundraising Event, Montreal, QC, Nov 2010
- Toronto Rehab Institute-Travel grant to SCI conference, Toronto, ON, Oct 2010
- American Spinal Injury Association-Founding Partner Sponsorship, Atlanta, GA, ongoing
- ConnecTra Society Celebration Event, Montreal, QC, Mar 2011
- BC Paraplegic Association event, Vancouver, BC, July 2010
- 2010 NWBC - Saskatchewan Wheelchair Sports Association, SK, May 2010
- 2010 MOBILITY CUP - Disabled Sailing Association of British Columbia, Vancouver, BC, May 2010

RESULTS ACHIEVED, FISCAL YEAR 2010-2011
These events helped accelerate collaboration and awareness around disability issues in Canada.