Minimizing disability. Maximizing quality of life.

Annual Report
2008 – 2009
SCISN At a Glance

The Spinal Cord Injury Solutions Network (SCISN) is a Canada-wide collaboration of people with spinal cord injuries (SCI), researchers, health care professionals, and service providers committed to minimizing disability and maximizing quality of life for Canadians with SCI.

Where We’ve Come From

Since his Man In Motion World Tour more than 20 years ago, Rick Hansen has nurtured a dream of true collaboration across the SCI community. In the past decade, his dream began to be realized with the formation of the International Collaboration On Repair Discoveries (ICORD), followed by the Rick Hansen Spinal Cord Injury Registry (RHSCIR), the Rick Hansen Wheels In Motion fundraising event, the SCI Translational Research Network (SCI-TRN), and the SCI Solutions Alliance (SCISA).

The SCI-TRN, SCISA and RHSCIR, created through investments by Health Canada and Western Economic Diversification (WED), shared a common goal of improving the quality of life of Canadians with SCI. In April 2008, a decision was made to combine these three entities into a single organization, which is more effectively and efficiently addressing priority needs and generating solutions for people with SCI. This merger represents an integrated approach that strives for synergy and best use of the approximately $70 million that has been invested in our work.

In addition to Health Canada and WED, several provincial/territorial governments have since made targeted investments through the Rick Hansen Foundation (RHF) to support the SCI Solutions Network vision in their respective jurisdictions.

Our Objectives

Approximately 41,000 Canadians live with a SCI, and approximately 1,200 new injuries occur every year. The SCI Solutions Network strives to minimize disability and maximize the quality of life of these Canadians. We have six primary objectives that all of our work is focused on achieving:

- a significant reduction in the incidence and severity of permanent paralysis resulting from SCI
- a significant increase in restoration of physical function following SCI
- a significant reduction in the incidence and severity of secondary complications associated with SCI
- a significant increase in level of satisfaction with quality of life and community participation among people with SCI
- ensuring that customized responses to priority unmet needs are available to 100% of individuals with SCI throughout their journey to full participation
- establishing a world class Canadian SCI registry and data management platform.

Our Work

To achieve its six objectives, SCISN works in five primary areas:

- conducting translational research that moves discoveries into new treatments and approaches that tackle the most pressing needs of Canadians with SCI—and those most demanding on our health care system
- developing a Canada-wide registry to collect and analyze valuable data on SCI
- promoting validated treatment and care approaches as best practices
- creating solutions to meet the priority needs of Canadians with SCI, through partnerships at the community level
- national leadership and facilitating collaboration across the SCI continuum

Acknowledgement

SCISN would like to express gratitude to Rick Hansen and RHF, who created the vision to minimize disability and maximize the quality of life for people with SCI. SCISN would also like to gratefully acknowledge Health Canada and WED, which recognized the value of SCISN’s vision for the Canadian SCI community, and provided financial support to make this vision a reality.

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Spinal cord injury (SCI) results in the most devastating of disabilities. Each year, SCI forever alters the lives of some 1,200 or more Canadians who sustain a SCI—and the lives of their friends and family members. Meanwhile, the economic burden of SCI on our society, in the form of health care costs and lost productivity over the course of the lifetimes of people with SCI, is staggering.

An outright cure for SCI remains an elusive dream. Nevertheless, Rick Hansen and the Rick Hansen Foundation (RHF) have long believed that much could be done in the absence of a cure—investments could be made that would minimize disability and maximize the quality of life for people with SCI. Entering the 21st century, RHF’s view of SCI research and care in Canada was that the essential expertise, structures and supports were in place, but collaboration and coordination were lacking across the entire continuum. In recent years, Health Canada, Western Economic Diversification (WED), and several provincial/territorial governments have aligned their thinking with RHF and made significant investments through RHF to support the creation of the SCI Solutions Network—SCISN for short.

It hasn’t happened overnight. As you can see from the timeline below, SCISN is the product of many years of work and evolution. Most recently, the Spinal Cord Injury Translational Research Network (SCI-TRN), the Rick Hansen Spinal Cord Injury Registry (RHSCIR) and the SCI Solutions Alliance were amalgamated into SCISN in 2008.

This melding of the three organizations is entirely logical. Working with its funding partners, RHF had created these organizations and given them the same ultimate goal: minimize disability and maximize quality of life for people with SCI. Only the path to success differed. SCI-TRN was to achieve the goal through focused translational research, while SCISA’s route was to work with community partners to create solutions at the service delivery level, and RHSCIR was to compile critical data on SCI and its treatments.
from across the country. But a fundamental principle for all of these entities was to engage across the continuum—researchers, clinicians, service providers, and Canadians with SCI all working together in an unprecedented spirit of collaboration. Why not work as one organization?

In principle, it looks uncomplicated. In reality, it required a massive amount of work and energy: for example, business planning, determining information technology (IT) and human resource requirements and filling those needs, and adjusting our thinking to see the power of widening our vision beyond our own immediate areas of focus. Add to this the fact that we moved into a new facility at the newly-built Blusson Spinal Cord Centre in Vancouver, and you can begin to appreciate how much work was required. All the while, we continued to work on projects already initiated by each former organization.

At year end, we find ourselves finally settled with key infrastructure in place and distractions finally receding. Consequently, results are beginning to emerge from our work pipeline. In other words, we are really getting down to the business of minimizing disability and maximizing the quality of life for Canadians with SCI.

What does this really mean? How do you minimize disability associated with life with SCI? What can be done to improve the quality of life of Canadians who live with a SCI?

People with little or no knowledge of SCI or similar disabilities might be tempted to think that the only way to improve quality of life for people with SCI is to outright “cure” or reverse paralysis.

As I already stated, an outright cure for SCI remains elusive and is, therefore, far from the only goal. And while measuring one’s quality of life is subjective and differs from individual to individual, we do know that significant improvements in quality of life often come from even modest breakthroughs in research or improvements in the way care and services are provided to people with SCI.

For example, we know that small gains in hand function can make a big difference in the lives of people with tetraplegia who are seeking more independence or to rejoin the workforce. We know that finding better ways to prevent and treat pressure sores would benefit the majority of people with SCI (and many others in the process). We know that reducing SCI-related chronic pain and spasticity would result in a huge improvement in the lives of many. And there are countless changes that can be made in our society that would improve the quality of life for Canadians with SCI—from improving basic accessibility to creating better access to care and support services.

There are avenues of research and emerging best practices that promise to yield progress in all of these areas. SCISN is committed to supporting this type of work, thanks to financial investments from Health Canada, Western Economic Diversification, the Rick Hansen Foundation, and many provincial governments.

These investments have also allowed SCISN to foster a powerful new spirit of cooperation and hope in Canada between people with SCI, researchers, clinicians and other health care workers, and people and organizations who support people with SCI at the community level. Together, we’re changing the way that people with SCI are viewed, treated and supported in Canada. The return on these investments, in terms of maximizing both human capacity and health care savings, are potentially enormous and just beginning to be realized.

You can read about our accomplishments in this year of change in the pages ahead.

I would like to express my sincere gratitude to the volunteers and staff across the country who have worked tirelessly to bring us to where we are today. This includes the many individuals who committed their talents and energies to the former SCI-TRN and the former SCI Solutions Alliance. My thanks as well to all of our hardworking staff, and the staff and volunteers of RHF who went above and beyond to help us in our time of need. And, of course, my thanks to Rick Hansen and the funders who have bought into our vision and mission of minimizing disability and maximizing quality of life for Canadians with SCI.

Yours truly,

Eric Boyd, CEO
SCI Solutions Network
Organizing to Meet the Objectives

**Six Primary Objectives**

Six clear objectives, developed in consultation with our primary funders, form the cornerstone of SCISN’s business planning, governance, and daily operations. All of SCISN’s work in translational research, SCI registry development, community partnerships, and best practice promotion is determined by its potential and measured against its ability to make progress against these objectives:

1. A significant reduction in the incidence and severity of permanent paralysis resulting from SCI
2. A significant increase in restoration of physical function following SCI
3. A significant reduction in the incidence and severity of secondary complications associated with SCI
4. A significant increase in level of satisfaction with quality of life and community participation among people with SCI
5. Ensuring that customized response to priority unmet needs are available to 100% of individuals with SCI throughout their journey to full participation
6. Establishing a world class Canadian SCI registry and data management platform

**Five Work Areas**

To meet the six primary objectives, SCISN carries out work in five critical areas:

- conducting translational research that moves discoveries into new treatments and approaches that tackle the most pressing needs of Canadians with SCI—and those most demanding on our health care system
- developing a Canada-wide registry to collect and analyze valuable data on SCI
- promoting validated treatment and care approaches as best practices.
- creating solutions to meet the priority needs of Canadians with SCI, through partnerships at the community level
- national leadership and facilitating collaboration across the SCI continuum

These five work areas represent the continuation of work originally undertaken by the former SCI-TRN and the former SCI Solutions Alliance.

Originally, each of these five areas were further broken down into a large number of strategies. At fiscal year end, in consultation with RHF and our funders, SCISN distilled these into eight clear strategies which are being pursued to reach our six objectives and, ultimately, minimize disability and maximize the quality of life of Canadians with SCI.

**Strategies for the Translational Research Program:**

- assessment and development of best practice guidelines for emergency response, treatment and access to primary health care
- supporting clinical trials in acute care, rehabilitation and community, fostering global collaboration where possible
- supporting the development of a Best & Brightest program to nurture new SCI researchers

**Strategies for the SCI Registry:**

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

**Strategies for our work in Best Practices:**

- 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
- communicating these best practices directly to Canadians with SCI

**Strategies for our Solutions work:**

- working with SCISN partners to enhance service delivery through the Solutions Model (solutions team, navigators).
- working with SCISN partners to enhance capacity and develop initiatives that respond to the priority needs of people with SCI, utilizing collaborative funding mechanisms such as Rick Hansen Wheels In Motion, and provincial/territorial 20th Anniversary investments

Our Network Leadership & Coordination team will provide critical support services for implementation of these strategies, including finance, accountability, and human resources management; as well as communications support and resource development expertise.

This entire SCISN structure and operational activity is illustrated in the organizational chart on the facing page. The chart also provides clarity about how SCISN is supported operationally (Network Leadership & Coordination) in the areas of finance, accountability/reporting, human resources, communications, and resource development. It also explains how all work activities are or will be overseen by the CEO working in concert with a National Advisory Council, with ultimate governance provided by a Board of Directors, to be appointed in the 2009 – 2010 fiscal year.

The remainder of this annual report tracks our progress in 2008 – 2009 in the context of this organizational structure.
SCISN Organization, Strategies & Objectives

National Advisory Council

SCISN Board of Directors

SCISN Chief Executive Officer

Network Leadership & Coordination

Translational Research Program

SCI Registry/IT

Implementation of Best Practices

Solutions Program

Reduced incidence and severity of permanent paralysis (1)

World Class Registry (6)

Reduced incidence and severity of permanent paralysis (1)

Reduced secondary complications (3)

Increased physical function (2)

Increased physical function (2)

Reduced secondary complications (3)

MINIMIZATION OF DISABILITY

MAXIMIZATION OF QUALITY OF LIFE

• Assessment and development of Best Practice Guidelines for Emergency Response, Treatment and Access to Primary Health Care
• Supporting Clinical Trials in Acute Care, Rehabilitation and Community, fostering global collaboration where possible
• Supporting the development of a Best & Brightest Program to nurture new SCI researchers

• Collecting and analyzing data on SCI in Canada, including Acute, Rehabilitation and Community components; supporting research and multi-centre trials, utilizing a web-based national technology platform and collaborating globally where appropriate

• 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
• Communicating these best practices directly to Canadians with SCI

• Working with Network Partners to enhance service delivery through the Solutions Model (solutions team, navigators)
• Working with Network Partners to enhance capacity and develop initiatives that respond to the priority needs of people with SCI, utilizing collaborative funding mechanisms such as Wheels In Motion, provincial/territorial 20th Anniversary investments, etc.

• Providing network leadership and coordination services such as Finance, Accountability & Reporting, Human Resources, Communications, and Resource Development

Increased Quality of Life (4)

Enhanced Responses to Priority Needs (5)

Enhanced Responses to Priority Needs (5)
Translational Research Highlights

- Twenty-nine research projects have been funded to date—investigating acute care interventions to minimize disability, rehabilitation interventions to restore function and minimize secondary health complications, and approaches that speed community reintegration and maximize independence after SCI.
- While the majority of projects are multi-year term and remain underway, SCISN has supported several projects which have yielded impressive results, such as the ReJoyce system shown on this page.
- Part of our translational research work is in the identification of best practices, which are subsequently earmarked for adoption and promotion via our Best Practices component. For example, we have supported SCIRE (SCI Rehabilitation Evidence), the only summary of worldwide best practices in rehabilitation for people with SCI.
- Research earmarked for support in the immediate future includes two promising multi-centre acute care clinical trials, including the minocycline trial referred to on the facing page.
- Comprehensive business planning and accountability documents to guide our investments in translational research have been completed.
- Key teams have been deployed—our work is guided by our Research Management Team (RMT) and a Research Advisory Committee (RAC).
Overview

Many people assume that research successes are automatically translated into medical practice. In reality, this hasn’t always been the case. There is a growing focus worldwide on resolving this disconnect by emphasizing translational research. A simple definition of translational research is applying discoveries generated during research and studies to the development of trials and studies in humans, and, where success has been determined, readying that knowledge in preparation for implementation into practice (more detailed definitions of translational research appear in Appendix II). In Canada, SCISN is playing an important role in making this happen with its Translational Research Program—translating into practice discoveries that hold the promise of meeting the priority needs of Canadians with SCI and easing the burden on our health care system.

To illustrate the need and potential for translational research, consider the common antibiotic minocycline, long-used as a treatment for various bacterial infections such as acne. In the early 2000’s, researchers—many of them Canadian—carried out animal experiments that suggested that minocycline can reduce inflammation and maximize functional recovery, when administered immediately following a SCI. Yet these results have never been exhaustively tested in humans with SCI. SCISN will explore the possibility of supporting a multi-centre minocycline human trial in 2009, led by Dr. Steve Casha of Calgary’s Foothills Hospital.

With SCI translational research, it’s important to remember that even modest improvements in function or incidence of secondary health complications can lead to enormous quality of life gains for people with SCI. For example, improvements in hand function can allow individuals to regain a great deal of independence or rejoin the workforce. Perhaps more dramatically, preserving or restoring the function of a single cervical level can mean the difference between breathing independently and being dependent on a ventilator to stay alive for the rest of one’s life. Similarly, developing prevention strategies and better treatments for pressure sores, which are a devastating and even life-threatening complication of SCI, could also make an incredible difference in thousands of lives. Meanwhile, breakthroughs in these three areas alone hold the potential for enormous health care cost-savings.

With $30 million funding from Health Canada, and with significant complementary investments made by several provincial governments, the SCISN Translational Research Program is carefully investing in work that promises to make progress against the first three of our six objectives listed on page 4:

1. A significant reduction in the incidence and severity of permanent paralysis resulting from SCI
2. A significant increase in restoration of physical function following SCI
3. A significant reduction in the incidence and severity of secondary complications associated with SCI

This work falls within three key strategies:

- assessment and development of best practice guidelines for emergency response, treatment and access to primary health care
- supporting clinical trials in acute care, rehabilitation and community, fostering global collaboration where possible
- supporting the development of a Best & Brightest program to nurture new SCI researchers

Research Project Selection

During the first half of 2008, the SCISN Translational Research Program worked to establish the specific areas of research focus within the three key strategies described above. This process relied on expertise from our Research Management Team (RMT), composed of four members who have specific expertise in one of the three distinct but inter-related disciplines of SCI acute care and treatment, rehabilitation, and community integration (see next section for more information on the RMT). Also contributing to the process were the larger Canadian community of SCI researchers and clinicians working within the three disciplines.

Together, they worked to understand translational research needs, and balance these needs with factors that could yield greater success, such as research expertise and capacity in Canada, and opportunities for leveraged funding and collaboration across the provinces and involving multiple institutions. Various participatory methods including Delphi, expert panels, and literature reviews were used to achieve this consensus. In the latter half of the year, smaller focus groups that included stakeholder representatives from SCI community organizations and provincial partners worked together to ensure that resources, expertise and capacity issues were aligned with the identified areas of translational research focus.

The resulting work formed the basis for SCISN’s business plan and for the initial Translational Research Program research project selections. A complete summary of funded projects as of March 31st, 2009, as well as those earmarked for funding in 2009 – 2010, and those being considered for funding in the new fiscal year or beyond, can be found in Appendix III.
Activity Report

Planning & Accountability
Immediately following the amalgamation of the SCI-TRN and the SCI Solutions Alliance, SCISN undertook an extensive business planning process which predominantly focused on the Translational Research Program. The SCISN Business Plan sets out in detail how our funders’ investments in translational research are to be managed, allocated and evaluated. Shortly after that, a Results-based Management and Accountability Framework (RMAF) was completed which allows us to comprehensively track progress for funders.

Staff
Jane Hsieh assumed the role of Executive Director of the Translational Research Program effective July 2008. She is supported with administrative staff and other operational components of SCISN, including accountabilities and communications.

Research Management Team (RMT)
SCISN’s overall translational research focus is guided by our RMT. The RMT ensures all Translational Research Program activities are aligned with SCISN objectives and priorities. The RMT encompasses expertise in acute care and treatment, rehabilitation, and community integration. The RMT has four members who are prominent members of Canada’s SCI research and health care communities.

- Dr. Anthony S. Burns, MD, MS, is the Medical Director of the Spinal Cord Rehabilitation Program at Toronto Rehabilitation Institute, and an Associate Professor in the Division of Physiatry, Department of Medicine at the University of Toronto. Dr. Burns leads SCISN’s translational research work in rehabilitation. He replaced Dr. Armin Curt in December 2008.

- Dr. Marcel Dvorak is the Medical Director of RHSCIR. Dr. Dvorak is Associate Professor and Head of the Academic Division of Spine, Department of Orthopaedics, University of British Columbia; and Medical Director of the Combined Neurosurgical and Orthopaedic Spine Program at Vancouver General Hospital.

- Dr. Michael Fehlings, MD, PhD, FRCSC, FACS, is Medical Director of the Krembil Neuroscience Centre and head of the Spinal Program at the Toronto Western Hospital. He is also a Professor of Neurosurgery at the University of Toronto. He leads SCISN’s translational research work in the acute care field.

- Dr. Luc Noreau, PhD, is a professor at the Rehabilitation Department, Laval University, and associate researcher at the Centre for Interdisciplinary Research in Rehabilitation in Social Integration (CIRRI), Quebec City. Dr. Noreau leads SCISN’s translational research work in the community reintegration field.

The Translational Research Program Executive Director and the SCISN CEO also hold positions on the RMT. In addition to focusing research within their specific areas of expertise, the team members meet on a scheduled basis throughout the year to guide the overall SCISN research agenda.

Research Advisory Committee (RAC)
To ensure impartiality and objectivity, our RAC was established in November 2008 to provide guidance and recommendations regarding research investments made by the SCISN Translational Research Program. The RAC is an international panel of distinguished, expert clinicians and researchers who independently, as a committee, provide scientific guidance to the RMT. RAC members provide expertise ranging from neuroscience, neurology, neurosurgery, SCI medicine, rehabilitation medicine, outcome measurement, quality of life issues, epidemiology and evidence-based health policy.

- Charles Tator, MD, PhD, FRCSC, FACS (RAC Chair), is a Professor, Department of Surgery, University of Toronto; and Senior Scientist at the Division of Genetics & Development, Toronto Western Research Institute (TWRI)

- Kim Anderson, PhD, is Assistant Adjunct Professor, Department of Neurological Surgery, University of California, Irvine; and a core faculty member of the Reeve-Irvine Research Center.

- Daniel P. Lammertse, MD, is a Principal Investigator and former Medical Director, Craig Hospital, Denver, Colorado; and Past President, American Spinal Injury Association (ASIA).

- Ivar Mendez, MD, PhD, is Chair of the Brain Repair Centre; Head of the Division of Neurosurgery in the Department of Surgery at Dalhousie University and Capital Health; and member of the Department of Anatomy & Neurobiology at Dalhousie University.
• Richard J. Riopelle, MD, FRCPC, FCAHS, is a Professor and Chair, Department of Neurology and Neurosurgery, McGill University.

Note: Branko Kopjar, MD, PHD, Associate Professor, Department of Health Services Program Affiliations, University of Washington, held a position on the RAC but resigned to avoid a conflict of interest due to engagement in a research project funded by SCISN.

**Business Case Development**

SCISN’s Translational Research Program is committed to employing a business case approach to justify research investments and best practice recommendations. The ultimate goal is to be able to predict the human and economic consequences of various treatments and interventions. Dr. Marcel Dvorak and Dr. Michael Fehlings of our RMT are heading efforts to utilize the business case development approach for the Translational Research Program.

**Data Collection Platforms**

The Rick Hansen SCI Registry (RHSCIR) is one of SCISN’s primary objectives and is reported on within its own section in this annual report on page 10. But it’s important to note that the Registry is also envisioned as a cornerstone of the SCISN Translational Research Program. Data collected through RHSCIR will help guide the Translational Research Program’s future focus and research investment choices. And, as RHSCIR will be based in 13 cities (35 institutions) across Canada with a state-of-art web-based platform, RHSCIR sites will form the initial membership of the Canadian SCI Clinical Research Network, the development of which is being led by Dr. Michael Fehlings and Dr. Marcel Dvorak of the RMT.

The Translational Research Program and its funded researchers will also collaborate and share information on our Sharepoint intranet/collaboration platform, due to be launched in mid-2009.

**Collaboration**

From inception, the Translational Research Program has recognized that true collaboration yields success. There is powerful synergy created by the mixture of different perspectives in specific areas of research—perspectives of different researchers working toward the same goals, and perspectives of people with SCI who stand to benefit from the research. Similarly, when breakthroughs are achieved and validated, transferring the resulting knowledge to action is greatly enhanced through the understanding and sharing of information across jurisdictions at the institutional, provincial and national levels.

SCISN is able to able to play a key role in expanding major initiatives into additional institutions within a province and across provinces. In turn, provincial partners contribute by investing in provincial capacity in the areas of national focus that extend the collective Canadian body of expertise. This body of expertise is being recognized by national organizations such as the Department of National Defense (DND) and is the basis of an evolving best practice partnership.

As we continue to increase our capacity and expertise within Canada, the obvious next step is to partner with like-minded countries with similar SCI research interests. Already, we have contributed to multi-centre initiatives originating in the USA (STASCIS, Riluzole). Australia and New Zealand, with similar population demographics and culture, are interested in learning from our Network model. In turn, we are interested in learning from their experiences—some Australian innovations are already aligned with our current research priorities. Shared bonds between citizens of Canada and Israel have also led to partnering opportunities that will contribute to our common goal. Provincial, national and global partnerships will certainly hasten our efforts to minimize disability and maximize quality of life for people with SCI.

**Looking Forward**

The collaborations established to date, our planning processes, and our early research projects are the building blocks of exciting translational research work set to launch in 2009. Upcoming clinical trials will capitalize on the clinical research network formed by the RHSCIR sites. Not only will we be collecting prospective SCI data consistently across the country, but we will ensure that there is no duplication of data collection efforts between projects requiring the same data for different reasons.

In 2009, we anticipate the launch of at least one or two clinical trials in the acute care and treatment segment of SCI. These innovative studies will be unique, totally Canadian and will likely have a high impact in the global SCI community.

Elevating the current standard of upper limb rehabilitation related to hand function will also be a focus for 2009 through a multi-centre randomized controlled trial of inpatients and through an additional Canadian site for a global in-home telerehabilitation project (ReJoyce) that is another totally Canadian innovation from Alberta.

Also coming into fruition in this next fiscal year is enhanced community service delivery to people with SCI—through provision of key services via a virtual internet clinic, and by providing targeted, evidenced-based findings and care guidelines directly to primary care providers who have not, until this point, had good access to this knowledge. Simultaneously, we will continue to search for innovative translational research and best practice implementation projects through directed and non-directed open calls for proposals. All of these efforts are placing SCISN on target to minimize disability and maximize quality of life for people with SCI.
Translational Research Highlights

• completion of comprehensive business planning and accountability documents to guide our investments in translational research.
• Key teams have been deployed—our work is guided by our Research Management Team (RMT) and a Research Advisory Committee (RAC).
• Twenty-six research projects have been funded to date—investigating acute care interventions to minimize disability, rehabilitation interventions to restore function and minimize secondary health complications, and approaches that speed community reintegration and maximize independence after SCI.
• While the majority of projects are multi-year term and remain underway, SCISN has supported several projects which have yielded impressive results, such as the ReJoyce system shown on this page.
• Part of our translational research work is in the identification of best practices, which are subsequently earmarked for adoption and promotion via our Best Practices component. For example, we have supported SCIRE (SCI Rehabilitation Evidence), the only summary of worldwide best practices in rehabilitation for people with SCI.
• Research earmarked for support in the immediate future includes two promising multi-centre acute care clinical trials, including the minocycline trial referred to on the previous page.

RHSCIR Highlights

• RHSCIR is actively enrolling patients in nine locations, and SCISN is positioned to receive data on 1,000 patients as soon as all data sharing agreements are in place.
• In 2009, RHSCIR completed an in-depth analysis of privacy legislation across Canada that has since guided our negotiations with institutions and development of our web-based data collection platform. RHSCIR’s entire approach to privacy has been praised by Ontario’s Privacy Commissioner.
• Data-sharing and funding agreements are now in place for sites in Calgary, Halifax, London, Saskatoon, Winnipeg, Hamilton, Ottawa, Vancouver and St. Michael’s Hospital in Toronto. Discussions are well underway in Edmonton, Montreal, Quebec, St. John’s, and three other institutions in Toronto.
• Development of the state-of-the-art, web-based data collection platform is being led by SCISN’s own highly qualified and experienced IT team. The platform will be truly universal and portable—for example, it will be possible for a clinician to enter data on a Blackberry while exiting the operating room. The platform also provides unprecedented information sharing and collaboration potential for participating sites, in all major jurisdictions across Canada.
Rick Hansen SCI Registry: Critical Data Collection

Overview
How many SCIs take place in Canada each year? How many of these are in the form of tetraplegia or paraplegia? How many are complete or incomplete? What are the results of the different methods used to treat and support people with SCI? How does a person’s financial or social status play a role in recovery or adjustment to SCI? Up until this point, we could only make educated guesses at the answers to these questions. The Rick Hansen SCI Registry (RHSCIR)—an unprecedented, Canada-wide project that is collecting critical information on SCI at 35 major Canadian acute care and rehabilitation hospitals—will give us answers based on real data.

RHSCIR supports the SCISN Translational Research Program and work towards meeting the SCISN objectives. It will also provide the larger community of Canadian researchers, clinicians and health care professionals, as well governments, other funders, and industry with a powerful research and reporting tool. It will promote collaboration and research, demonstrate flexibility and adaptability in helping partners achieve their SCI information goals, ensure data quality, and remain current with changing trends and issues in health care management.

The power of such a registry can’t be understated. For the first time, pure Canadian data is being recorded through the acute, rehabilitation and community integration phases of patient care in a high quality, prospective observational database—data that will ultimately reveal a picture of the incidence and severity of SCI, along with the types of various interventions and treatments employed at the acute care and rehabilitation stages and their corresponding success rates. When complete, rolled out across Canada, RHSCIR will provide unparalleled insight into SCI for clinicians, researchers, government funding agencies and industry leaders seeking to validate and employ best practices in care and support. And it will become an important tool for people with SCI and the community organizations that represent them. Additionally, RHSCIR will provide support and capacity for SCISN’s entire Translational Research Program, as it has the potential to be the backbone of important multi-centre clinical trials.

History and Context
RHSCIR was launched in 2003. Early development was spearheaded by members of the care delivery team in the Spine Unit at Vancouver Coastal Health, led by Dr. Marcel Dvorak, Dr. Vanessa Noonan, Lise Belanger and John Cobb. Specialists were consulted both within Canada and internationally to ensure the dataset would meet a wide range of interests, and be compatible with international datasets.

During the pilot implementation in 2003, newly minted privacy legislation coupled with a lack of funding to resource the Registry sites proved to be significant barriers to a successful pan-Canadian implementation. This restricted development and limited active Registry sites to just four—Vancouver, Calgary, Edmonton and Hamilton.

In the last two years, significant progress has been made, thanks in large part to Health Canada funding via the Rick Hansen Foundation, specifically highlighting the importance of and providing funding for the development of a “national knowledge, analysis data and technology network, including the coordination and management of SCI-Translational Research network databases to facilitate research.” In 2008, further momentum was gained with the formation of SCISN, into which RHSCIR was folded. At this point, RHSCIR gained the resources and infrastructure that are key for success of a national registry.

Activity Report
Privacy
The most critical task for RHSCIR in 2008 – 2009 was establishing a national privacy and security framework and developing a supporting privacy governance structure that needed to be independent from, but complementary to, the existing privacy regimes already in place at participating local sites.

We commissioned a national cross-jurisdictional privacy report from Anzen Consulting group, specialists in privacy related to the handling of personal health information. This report analyzed the privacy statutes directly applicable to participating sites that currently collect and store SCI data locally across each of the provinces and territories in Canada. To ensure a “gold standard” of privacy compliance, the privacy requirements found in these statutes were benchmarked against the 10 privacy best practices advocated by the Canadian Institutes for Health Research (CIHR), the prevailing source of guidance for clinical trials and epidemiological studies involving humans. The statutes were also benchmarked against other relevant privacy and security best practices and guidelines.

The resulting recommendations made in the report provided the framework for development of the SCISN’s own privacy and security policies and procedures which will support the management of the data resulting from SCISN-sponsored translational research.

It’s important to note that, at the moment, RHSCIR only deals with identifying personal health information at the local level; the national RHSCIR database does not collect or store
identifying health information. However, SCISN envisions the use of the national SCISN data repository and its web-based platform as an information management system to support the collection and centralized storage of national identifying SCI data—a system that will have the capacity to permit Canadian and, eventually, international researchers and other authorized users to access such data. To accomplish this, SCISN must develop and maintain a privacy and security framework that meets the highest standard of compliance to satisfy the various institutional, provincial, national and international laws and best practices in the conduct of research and sharing of personal health information.

**RHSCIR Sites**

The deployment of RHSCIR is being spearheaded by SCISN using a phased approach that relies on partnerships with participating sites—SCI acute care and rehabilitation centres across Canada—to achieve status as a pan-Canadian Registry program.

With the privacy framework established, the national rollout of RHSCIR was resumed, supported by industry standard Data Sharing Agreements integrated with agreements providing each of 13 participating sites with funding to resource the RHSCIR project with a research coordinator for a period of two years. Execution of the Data Sharing Agreements between SCISN and participating RHSCIR sites ensures an appropriate accountability framework is in place for the sharing of personal health information among RHSCIR sites.

At fiscal year end, RHSCIR is operational in several provinces, including Alberta, BC, Manitoba, Saskatchewan, Ontario and Nova Scotia. In the new fiscal year, it will be expanded to sites in Quebec and Newfoundland, and we will explore new partnerships in the Atlantic provinces and the northern territories.

**Data Collection**

The data collection process as outlined in the RHSCIR Research Protocol requires the collection of SCI patient information by the local RHSCIR team. Data collection begins from
the time of injury (pre-hospital), through acute interventions and rehabilitation procedures, through to follow up questionnaires at one, two, five and ten years, and every five years from that point until the participant withdraws from the study.

Participating RHSCIR sites are currently installing a local version of the RHSCIR database where SCI data is linked and de-identified by local RHSCIR staff before it’s transmitted to the national RHSCIR database located in Vancouver.

In the future, RHSCIR will capture all Canadian SCI cases, both new and chronic injuries, into its national database using a state-of-the-art, real-time, web-based data collection and reporting platform. This information, along with other SCISN-sponsored research datasets, will be stored in the SCISN national data repository, with SCISN becoming the ultimate data custodian of the national SCI information.

Development of the web-based data collection platform was well underway by year end, led by our inhouse IT development team and guided by a team of end-users who are defining the system’s functional requirements. The system will use web-based forms using a browser-based application for a co-ordinated data collection and transmission process using secure network via RHSCIR and role-based security access procedures. This system will be truly portable, allowing physicians and clinicians to enter data from wireless devices, and allowing participants with SCI to enter and view their data in their hospital rooms.

**Staff**

Health Canada funding and operational support from SCISN has allowed RHSCIR to elevate staff levels to meet the emerging needs of rolling out a national registry.

The Medical Director of RHSCIR since its inception in 2003 has been Dr. Marcel Dvorak. Dr. Dvorak is Medical Director of the Combined Neurosurgical and Orthopaedic Spine Program at Vancouver General Hospital, and has had a long-standing interest in using observational data as a means of minimizing disability and maximizing the quality of life for his patients and all people living with SCI.

This year, Catherine McGuinness was appointed to the position RHSCIR Managing Director. Other personnel working directly for RHSCIR include a national site coordinator, a statistician, a privacy officer, and a three-member IT team. Further support is provided by SCISN administrative and operations staff. Last fiscal year we also contracted clinical consultants in physiotherapy, acute care nursing, occupational therapy and legal consulting support.

**Looking Ahead**

The upcoming year is expected to see the Registry become fully operational in all 13 participating sites. In addition to moving forward with data collection, the RHSCIR national operations team is preparing to support multi-site translational research projects that will leverage the expertise and qualifications of the network of Registry sites. A full dataset review by the Translational Research Program leadership teams will focus RHSCIR data collection on elements that are acceptable to multiple stakeholders and complement SCISN-sponsored clinical research.

At the national office, the Registry program will further develop its operations to ensure all SCISN research is conducted to the highest standards of acceptable practice—for both the ethical conduct of research using humans, and for maintaining the privacy and security of the personal health information entrusted with us by the persons with SCI participating in SCISN's programs.
Best Practice Highlights

- SCISN developed a Knowledge Translation/Knowledge Mobilization Implementation Guide to provide a basic reference for researchers to assist with understanding of knowledge to action activities in the health care system.

- Many of the activities within our Translational Research Program focused on validating and identifying best practices in the SCI care continuum—we have started the process of preparing to promote these and other best practices.

- We provided grants for two knowledge mobilization workshops, including a Wheelchair Skills Training Program “train the trainer” session held in Vancouver. The event was well-attended by occupational and physical therapists from across BC, who can now, in turn, train colleagues and people with SCI throughout the province, who are the ultimate beneficiaries of the program’s low-cost, high impact approach.

Ian Dennison and Darryl Caves, physiotherapists at Vancouver’s GF Strong Rehabilitation Centre, were among those who took part in the recent Wheelchair Skills Program “train the trainer” event at Blusson Spinal Cord Centre. Ian learns a technique for negotiating stairs with Darryl’s assistance. Improving wheelchair skills is an excellent but often overlooked method of maximizing mobility and independence for people with SCI.
Best Practices: Knowledge Into Action

Overview

Just as many clinical discoveries aren’t always effortlessly translated into human research, many validated treatments and care approaches fail to be universally implemented across the SCI care continuum. For example, strong evidence exists to support the use of low molecular weight heparin in patients with SCI to reduce the likelihood of dangerous blood clots and associated side effects. But we still need to ensure that this best practice is well disseminated across institutions and practitioners serving SCI.

The SCI Solutions Network is committed to promoting widespread adoption of practices in care, treatment and policy that have clearly been demonstrated to minimize disability and maximize the quality of life of people with SCI. The process of promoting best practices is often called Knowledge Translation/Knowledge Mobilization (KT/KM) in the research and medical fields. Our work in moving knowledge into action will help us meet five of our six primary objectives:

1. A significant reduction in the incidence and severity of permanent paralysis resulting from SCI
2. A significant increase in restoration of physical function following SCI
3. A significant reduction in the incidence and severity of secondary complications associated with SCI
4. A significant increase in level of satisfaction with quality of life and community participation among people with SCI
5. Ensuring that customized response to priority unmet needs are available to 100% of individuals with SCI throughout their journey to full participation

A best practice is a technique or method that, through experience and research, has been proven to be more effective than other methods in addressing a problem. Note that best practices relating to SCI extend beyond the world of medical treatment—for example, promoting a best practice for making our streets and sidewalks fully accessible is entirely consistent with the fourth of our six objectives.

SCISN will support the promotion and adoption of best practices in the SCI field by:

- translating knowledge validated from our own work in Translational Research and Solutions programs
- seeking out and promoting approaches that are already best practices in parts of Canada or around the globe but have yet to be adopted universally across our country
- transferring knowledge and promoting adoption of best practices among SCI practitioners, institutions, organizations, funders and policy-makers.

Activity Report

At this early stage, our work in translational research and solutions has taken priority. Nevertheless, we have moved our best practices agenda forward with preliminary projects.

SCISN KT/KM Implementation Guide

This set of guidelines was developed by Jane Hsieh, SCISN Translational Research Program Executive Director, and Dr. Richard Riopelle, Professor and Chair of McGill University’s Department of Neurology and Neurosurgery, and member of the SCISN RAC. This SCISN Knowledge Translation/Knowledge Mobilization Implementation Guide provides a basic reference for researchers to assist with understanding of knowledge to action activities in the health care system.


SCISN provided a $10,000 knowledge mobilization grant to allow Dr. Lee Kirby of Dalhousie University to offer a “train the trainer” version of the Wheelchair Skills Training Program in Vancouver on March 26, 2009. The event was well-attended by occupational and physical therapists from across British Columbia, who can now, in turn, train colleagues and people with SCI throughout the province. The Wheelchair Skills Training Program is viewed as a validated best practice and has the potential to greatly improve the mobility and quality of life of people with SCI with its low-cost, high impact approach.

SCIRE (Spinal Cord Injury Rehabilitation Evidence)

The SCIRE project is essentially the identification of global best practices in SCI rehabilitation. Last year, SCISN provided funding to support the release of SCIRE 2. This support can be viewed as both helping identify the best practices (a stage of translational research) and promoting widespread adoption of best practices—our funding has contributed to the SCIRE team being able to publish their work to a wider audience, and we will continue to support future versions.

Looking Ahead

Over the course of the new fiscal year, our pipeline of work is expected to yield an increasing number of best practices validated and identified for promotion. We also recognize that it is critical to seek and promote validated best practices from the larger SCI community and care continuum, both in our country and abroad. To ensure we are able to meet the demand, we will develop protocols, processes and staff resources that will allow us to ramp up our work in promoting best practices, with a strict eye to ensuring that all work we do in this critical area is of the highest credibility and quality.
Solutions Highlights

- With funds raised by Rick Hansen Wheels In Motion, SCISN provided 115 solutions grants totalling more than $660,000 across Canada that helped address the priority unmet needs of hundreds of Canadians with SCI.
- Through our Access to Clinical Trials and Research Studies program, SCISN provided funding that allowed 51 individuals with SCI to participate in promising SCI research projects across Canada.
- In partnership with CPA Manitoba and other community stakeholders, SCISN helped to secure $3 million in funding for SCI Leadership from the Government of Manitoba.
- Working closely with the Canadian Paraplegic Association in Ontario, Nova Scotia and Alberta, the Solutions Program was able to enhance the Solutions Model of service delivery by creating and funding three solutions coordinator positions, as well as enhancing Regional/Local Solutions Teams.
- Working with the Government of British Columbia Ministry of Education, we created a standard for best practices for accessible play spaces for children age 0 – 6 years (or caregivers with disabilities) and allocated funding to support the construction of 21 accessible play spaces across BC.
Solutions Program: Meeting Unmet Needs

Overview

SCISN recognizes that minimizing disability and maximizing quality of life can’t be accomplished by research and medicine alone. Our Solutions program strives to address the priority, unmet needs of people with SCI in practical, tangible ways and, where possible, with an immediate impact. The two central strategies of our Solutions program are:

• working with SCISN partners to enhance service delivery through the Solutions Model, consisting of a solutions team, and navigators
• working with SCISN partners to enhance capacity and develop initiatives that respond to the priority needs of people with SCI, utilizing collaborative funding mechanisms such as Rick Hansen Wheels In Motion, and provincial/territorial 20th Anniversary investments

Work accomplished against these strategies is helping SCISN fulfill three of our six national objectives:

1. A significant reduction in the incidence and severity of secondary complications associated with SCI
2. A significant increase in level of satisfaction with quality of life and community participation among people with SCI
3. Ensuring that customized responses to priority unmet needs are available to 100% of individuals with SCI throughout their journey to full participation

Activities Report

Deploying the Solutions Model

For decades, CPA and many other organizations have provided a range of community-based services that make a real difference in the lives of people with SCI—adjustment counselling, information provision, peer support, vocational counselling, and access to recreation and active living opportunities.

Overall client case management, in which an individual is offered these services and also given coordinated support to navigate the myriad of health and government support services necessary after SCI, has been a desirable goal but one that has been difficult to achieve on a wide scale. Organizations such as CPA have attempted to offer this type of coordinated case management with marginal funding assistance and limited buy-in from the medical communities.

SCISN is working with CPA to change this. Our concept is to implement a “Navigator/Solutions Team Model” in major centres across Canada. This model of service delivery has been developed to ensure newly injured Canadians and their families have the help they need to access necessary services, care and support during an incredibly traumatic time of their lives.

Such a model would ensure every newly injured Canadian would be supported by both a navigator and an interdisciplinary team of experts representing acute, active rehab and community support services—a team committed to creating a customized solution when priority needs are not being met and to facilitating seamless coordination along the complex continuum of SCI services.

This same team would also be dedicated to identifying any gaps or flaws in current treatment, care and support systems; responding to immediate needs; and aggressively moving toward longer term systemic solutions based on
allocated $660,367 in funding resulting in 115 grants provid-

ing solutions to the unmet priority needs of hundreds of 

Canadians. Ongoing engagement with WIM organizers and 

local solutions teams enabled alignment of WIM funding 

with SCISN priorities. SCISN staff collaborated with organiza-

tions who serve people with SCI, including Canadian Para-

plegic Association, Canadian Wheelchair Sport Association, 

Canadian Wheelchair Basketball Association, Tetra Society, 

Abilities Foundation, Neil Squire Foundation and others, to 

courage participation in WIM both as an organization and 

to encourage their members to participate.

National Solutions: This year, two national solutions pri-

orities were funded based on priority needs identified by 

people with SCI:

- Solutions Model (SCI Navigator and Solutions Team): This 

  is essentially funding for the first strategy of the Solutions 

  program. Funding this year was allocated to support 

  key staff positions in Ontario and Nova Scotia to further 

  implement and validate the Solutions Model approach.

- Access to Clinical Trials and Research Studies: A portion 

  of funds raised by Wheels In Motion can be accessed by 

  people with SCI who are interested in participating in valid 

  research studies but can’t afford the travel and related ex-

  penses associated with doing so. SCISN has developed and 

  implemented guidelines and a process to allocate these 

  funds. To date, 51 individuals with SCI have accessed grants 

  totalling $211,433. Examples include support for a woman 

  with SCI to be able to travel from Hamilton, ON to Van-

  couver, BC to receive a diaphragmatic pacer implant as part 

  of the “Electrical Activation of the Diaphragm for Ventila-

  tory Assist” clinical trial. Other examples include travel for 

  pressure ulcer detection and prevention, and ReJoyce upper 

  extremity rehabilitation trials.

Provincial/Territorial Collaboration

The development of positive, collaborative relationships 

with our partners at the provincial/territorial level in order to 

maximize the quality of life of people with SCI is the corner-

stone of the Solutions program. Through provincial and 

territorial government funding received through the Rick 

Hansen 20th Anniversary campaign and the development of 

Secretariats and Provincial Solutions Teams (PSTs), SCISN 

seeks to provide support that meets the specific needs of 

people with SCI in every province and territory across Can-

ada. Here are developments that took place this year:

- Alberta, Manitoba and PEI all have PSTs. New Brunswick 

  recently had its first meeting with community stakehold-

  ers to begin the process of forming a PST. Ontario stake-

  holders have been meeting as a provincial alliance for a 

  year and are collaborating on a regular basis with SCISN.

- SCISN supported Solutions Teams in the Northwest Ter-

  ritories, Yukon, Nunavut, New Brunswick, Prince Edward 

  Island, Alberta and Manitoba to align business plans and 

  strategies with the SCISN business plan.
• SCISN provided support to Rick Hansen Foundation government relations personnel for announcements or follow-up meetings with governments of NWT, Yukon, Newfoundland, Manitoba and Canada.
• SCISN collaborated with Saskatchewan stakeholders to develop a provincial strategy for SCI and submit a proposal to the Saskatchewan government.

Please see table above for a summary of provincial government funding commitments raised during the 20th Anniversary by RHF in partnership with provincial stakeholders. Funds raised are targeted for expenditure in the respective provinces.

Other Initiatives

Let’s Play: The Let’s Play program allocates funding for the creation of inclusive, accessible public play spaces for children age 0 to 6 years in British Columbia. Highlights of the first year of the program are listed below:

• Twenty-one accessible play spaces were funded across BC for a total of $829,425.
• The second round of grant applications were distributed with 128 grant applications received.
• Three grants of $50,000 each are planned to be directed to new state-of-the-art accessible play spaces being built as a legacy of the 2010 Olympics and Paralympics. The $150,000 will be leveraged at least ten fold.
• Let’s Play hosted a workshop for BC play space equipment dealers/suppliers to introduce the principles and best practices that have been identified through the Let’s Play program related to accessible play spaces.

A key deliverable of this program is the development of standards for best practice in the design and construction of accessible play spaces. These standards do not currently exist in Canada. This project will take place in the new fiscal year. To date, two other provinces have shown interest in replicating the Let’s Play program and would like to utilize the guidelines and example of best practice in accessible play spaces created through the Let’s Play program.

Wheelchair Accessibility: RHF and SCISN have engaged wheelchair accessibility experts in BC to help establish a wheelchair accessibility team. The first priority was to work with Vancouver Olympic Organizing Committee (VANOC) to complete an assessment of the 2010 Olympic site, and subsequently work collaboratively with VANOC and 2010 Legacies Now to promote accessibility at all venue sites. To better assess the venue sites and make it easy to understand the level of accessibility and continued challenges, an assessment report has been developed by VANOC with input from SCISN and RHF.

Individual Requests: SCISN received and addressed more than 300 requests for information and/or assistance from individuals living with SCI and their families, and others. RHF defers all requests from individuals for equipment, information and support to SCISN.

Staff

Nancy Thompson was appointed as Director, Customized Solutions, immediately following the amalgamation of the SCI-TRN and the SCI Solutions Alliance. She is supported by three Solutions Coordinators who liaise with Wheels In Motion staff and share coordination of provincial partnerships. The entire program is also supported by a Community Grants Coordinator and by elements of the SCISN operations team, including accountabilities, communications, and information technology. As well, the Let’s Play program has its own Project Coordinator.

Looking Forward

Our primary focus in the new fiscal year and beyond is to increasingly focus on partnerships and opportunities at the provincial and community level to build capacity and ensure that those best suited to provide support to individuals have the resources they require. Further deployment of the Solutions Model of service delivery and partnering on other national solutions initiatives, in our view, rests with our ability to work with the provinces and territories with the goal of creating sustainability. To this end, we will explore many avenues, including collaboration on seeking new or renewed funding commitments from provincial and territorial governments, and ensuring that Wheels In Motion becomes an even more relevant and beneficial fundraising vehicle across the country.
SCISN Operational Highlights

- A comprehensive business plan was developed, along with plans in other key areas: communications, information technology, accountabilities and finance
- Significant progress has been made in achieving the goals and objectives of our planning documents
- SCISN completed establishment of an integrated and independent operations team and developed all necessary policies and procedures to guide SCISN operations
- SCISN offices were moved to the Blusson Spinal Cord Centre located at Vancouver General Hospital—we are proud to be a partner in a facility that exemplifies collaboration and partnerships in the SCI community
- SCISN is well on its way to independence as a Canadian non-profit corporation—incorporation has been completed, non-profit status is pending, and an independent Board of Directors has been elected and will convene in the new fiscal year
- SCISN is pursuing many exciting partnership activities, both here in Canada and around the globe.
Network Leadership & Coordination

**Overview**

SCISN operates in a challenging environment: it serves a diverse Canadian constituency comprised of different cultures and communities, and has key personnel and collaborators located across Canada. From an operational perspective, it needs to work in synch with partner organizations, including RHF, while continuing to establish itself as an independent organization set up to achieve the outcomes and impacts for which it is accountable.

**Human Resources**

As noted earlier in this report, SCISN came into existence in this fiscal year and represents the amalgamation of the former SCI-TRN, the SCI Solutions Alliance and RHSCIR. In August 2008, Dr. Chris McBride, Managing Director of the ICORD SCI research centre at the University of British Columbia, was hired as Managing Director to oversee SCISN operations of this unified entity.

The SCISN operations team provides operational support to all of our four program areas in translational research, Rick Hansen SCI Registry, best practices, and solutions. Initially, the SCISN operations team was focused on development of a shared service model with RHF to manage finance, human resources, and resource development. Later, SCISN shifted to establishing its own independent operational structure—a result of a mutual agreement with RHF. The composition of the SCISN personnel and the governing policies and procedures of the SCISN were shifted to reflect this development.

By the end of the fiscal year, the senior directors, managers and support staff were largely in place to fulfill the operational requirements of SCISN. Many of these positions were filled by existing personnel from the SCI Solutions Alliance and SCI-TRN, others were newly created positions. The operations staff has been kept as small and efficient as possible and has only expanded in response to clearly identified need. The senior positions include a Managing Director, Director of Finance, Director of IT, Manager of Accountabilities, and Manager of Communications. Each of these program areas will report on their own activities and highlights.

Technical and administrative positions were also filled to support operational activities, including three members of the IT development team, an operations manager, accountant, grants coordinator, Translational Research Program/Registry coordinator, and operations administrator. The Registry team also brought on support that will serve SCISN as a whole, including a privacy officer. Further support positions will be developed and filled in the coming year to support the activities of the CEO and our Board of Directors, as well as for the Translational Research Program and RHSCIR.

Through the creation of a joint SCISN/RHF steering committee and dedicated working groups, the SCISN operations team has developed a set of policies and procedures that guide the operations of the SCISN as a whole. While work on this area is ongoing and will be reported within various program areas, critical policies, plans and procedures relating to finance, reporting/accountabilities and communications were established.

We have also established key operational working groups for communications platforms (website, collaboration platform, contact management—see communications update in the following pages), grants and accountabilities, finance, and human resources. Working groups define the requirements for SCISN-related operations and how to operationalize these programmatic elements in a coordinated and efficient manner.

**Blusson Spinal Cord Centre**

In November 2008, SCISN moved from the offices of RHF to its home within the newly opened Blusson Spinal Cord Centre, which houses the ICORD research centre and will soon be the location of the Brenda and David McLean Integrated Spine Clinic.

The opening of the Blusson Spinal Cord Centre, coordinated by RHF, ICORD, UBC and Vancouver Coastal Health, was attended by BC Premier Gordon Campbell, former Vancouver mayor Sam Sullivan, cabinet ministers, donors, and supporters. The event garnered significant media attention.

Since then, it has been recognized as a unique symbol of collaboration across the SCI community, and in partnership with ICORD, the operations team has hosted tours of the building for several high profile and strategic partners and potential partners, including federal Minister of Health Leona Aqlukkaq; BC Premier Gordon Campbell; then BC Minister of Trade, Technology and Economic Development, Ida Chong; Australian trade commissioner and former Premier of Queensland, Peter Beattie; management from our two primary funders, Health Canada and WED, and a number of partners and collaborators from the health, service and research fields.

The move to the Blusson Spinal Cord Centre was a key step in establishing SCISN as a national hub for all of its programmatic activities. However, this did require dedicating time and resources relating to the true start-up phase of SCISN, which adopted the principle that efficiency and needs-based infrastructure were critical. Significant to SCISN oper-
ations, an independent IT infrastructure was put in place that leverages the network capacity of the University of British Columbia as established for the Blusson Spinal Cord Centre. Further details on the IT infrastructure and systems are provided in the IT section of this report.

**Governance**

With the blessing of RHF, SCISN is moving towards independence. Approval of SCISN application for incorporation as a national not-for-profit organization was received from Corporations Canada in February 2009. Application for Charitable Status is in progress with Canada Revenue Agency—we anticipate approval in late 2009. An inaugural core Board of Directors of SCISN has been nominated and approved by RHF Board in January 2009:

- One member from RHF Board of Directors (TBD)
- Dr. Armin Curt – Professor & Chairman, Spinal Cord Injury Center, University of Zurich, former ICORD Chair in Rehabilitation, former member of SCISN RMT
- Rajiv Das – former Chair of the SCI Solutions Alliance Board of Directors, businessman and former analyst with CIBC World Markets, individual with SCI
- Gary McPherson – former President of CWSA; former Chair of Alberta Premier’s Council on the Status of Persons with Disabilities; Executive Director, Canadian Centre for Social Entrepreneurship, University of Alberta School of Business; individual with SCI
- Harley Nott – former prosecutor with Ontario Ministry of Justice, former SCI Solutions Alliance Board Member, Member of Ontario LHIN Health Board, individual with SCI
- Daryl Rock – former Program Manager with HRDC; Associate Director of Knowledge Transfer for Canadian Council on Learning; Chairperson, ONF Board of Directors; individual with SCI
- Sam Sullivan – former Mayor of City of Vancouver, disability advocate, individual with SCI
- Marie Trudeau – former SCI Solutions Alliance Board Member, former Director with HRDC, former Executive Director with APQ, individual with SCI
- Dr. David Williams – former astronaut with Canadian Space Agency, Director of the Space and Life Sciences Directorate at the Johnson Space Center, trauma physician, researcher, Associate Professor at McMaster University

The SCISN Board of Directors will convene for the first time in April, 2009 with an inaugural Board meeting and orientation, and selection of the Chairperson. A draft governance policy is in development and will await approval by the Boards of RHF and SCISN. A draft memorandum of understanding between RHF and SCISN is in progress.

**Rick Hansen Foundation**

While SCISN is working toward independence, SCISN is a RHF innovation, and RHF remains ultimately responsible for SCISN funding from Health Canada, WED and several provinces. As such, our futures will remain intertwined. We will continue to work in close partnership in critical areas including resource development, communications, accountabilities and overall achievement of joint objectives.

For example, a joint SCISN/RHF Steering Committee was created in December 2008 and has met weekly to ensure smooth transition of key operations to the Network. This committee has jointly prepared details of the transition of RHF staff to SCISN (currently being finalized) and a SCISN employee policy handbook, along with non-disclosure agreements, notices and letters of offer. Similarly, a joint SCISN/RHF communications committee has been established to ensure coordinated and synergistic messaging, and many of our accountability efforts are jointly coordinated.

As RHF prepares for the 25th Anniversary of Rick Hansen’s Man In Motion World Tour, SCISN will continue to assist RHF in defining and implementing all efforts to seek renewed funding and investment commitments that will provide sustainability and an expansion of SCISN into an even more relevant entity in the global quest to minimize disability and maximize the quality of life for people with SCI.

**Leveraging**

Through the development of an integrated business model and plan resulting from the amalgamation of the SCI-TRN, RHSCIR, and SCI Solutions Alliance, SCISN has been able to leverage the investments made by WED and Health Canada through the development of provincial partnerships. SCISN worked diligently with provincial partners to align provincial resources with SCISN’s national strategies relating to translational research, solutions models, knowledge to action and leadership and coordination and RHSCIR. Through these efforts, an additional $23,780,500 was leveraged in support of the SCISN’s goals of reducing disability and maximizing quality of life for people with SCI. Additional leveraging of the Health Canada and WED funding will continue. This includes the development of additional partnerships and collaborative opportunities, which are described in the section below.

**Other Collaboration/Partnerships**

The move to the Blusson Spinal Cord Centre has facilitated many partnership opportunities and activities.

Development of formal linkages and partnership opportunities with UBC and Vancouver Coastal Heath were initiated and continue; discussions began about supporting an e-resource centre hosted by the Toronto Rehabilitation Institute and CPA Ontario; a collaborative research exchange was initiated with Queensland, Australia; a memorandum of understanding with the Department of National Defence is underway; and several resource development opportunities have been created.
For example, in partnership with RHF, SCISN has been working on potential partnership with Israel’s Hebrew University, UBC and RHF.

**Accountabilities**

Via RHF, SCISN stewards significant funds from multiple investors, with the most notable being Health Canada and WED. The reporting and accountability requirements for our investors necessitates a comprehensive evaluation approach. Central to this has been development of a Results-Based Management and Accountability Framework or RMAF, which tracks out all of our activity as it relates to Health Canada funding. SCISN also has made excellent progress in satisfying the accountability requirements of WED, as well those of the provinces/territories which have invested, via RHF and SCISN, in complementary strategies within their own jurisdictions.

The key benefits of this approach include:

- an enhanced ability to tell the SCISN’s performance story in a consistent and integrated way that focuses on tangible impacts and outcomes for people with SCI, and which will provide a compelling fundraising case for support.
- creation of monitoring and evaluation systems that will better inform and support management decision-making processes and strategy.
- a significantly streamlined process for managing numerous separate government evaluation and accountability requirements within one document, thus minimizing workloads for both Board and staff.

A critical component of the RMAF is the logic model (see Appendix I). It provides a simple means of describing and communicating the essence of a program’s design by displaying its key elements and the causal relationships among those elements. It is an illustration of how the inputs, activities and outputs of a program are expected to lead to the achievement of the expected outcomes.

As one moves down the logic model from immediate to intermediate to ultimate outcomes, the amount of control and influence that one initiative has on the outcomes diminishes. Ultimate outcomes are particularly difficult to attribute to any one program or factor, because a number of programs and initiatives are involved across various groups and other stakeholder organizations are contributing to changes in the health care system. There are also many environmental factors that affect SCI health care and support system change. However, initiative and project monitoring should reveal a progression from inputs/activities/outputs to immediate, intermediate and ultimate outcomes. SCISN seeks to contribute to changes in the health care system and delivery with regard to the treatment and support services related to SCI.

**Finance**

Late in the fiscal year, a Director of Finance was appointed, who worked diligently with RHF to reconcile SCISN accounts. Other achievements include development and implementation of a budget process, internal reporting and key policies and procedures for purchasing, including contracts and expenses. Standard templates for grants and grant budgets have been developed and implemented in partnership with RHF, and work continues on the implementation of the Navision accounting system.

All of these efforts will help to ensure that SCISN remains transparent and fully accountable in administering the investments made in our work by our funders.

**Communications**

Communications is viewed as a vital component of SCISN operations as we seek to publicize the work we’re doing, in order to leverage funding, generate collaboration and partnerships, and provide value for our funders. At fiscal year end, we have completed a comprehensive internal/external communications strategy and plan, and have worked hard to meet the objectives of this plan.

SCISN branding is well underway, with key messaging and corporate identity completed; letterhead, business cards, and other collateral in place; and a graphics, language and documents standards manual in use.

An interim public website is fully operational, with planning underway for a fully bilingual, interactive multimedia portal website employing a content management system.

Ongoing delivery of newsworthy SCISN messages and developments is taking place with electronic and print publications. These include Solutions newsmagazine, which has been developed to showcase SCISN work, raise awareness, and attract people to the solutions movement. Quarterly production and distribution commenced in March, with initial distribution of 3,000 per issue expected to exceed 8,000 by end of 2009. Media outreach has also been initiated, with articles and ads in several partner newsletters and websites, credible source participation in various research and medical journals, and cultivation and creation of media database.

Internal communications processes have been established, with major emphasis on development of SCISN-branded SharePoint collaboration site, which, when completed in the new fiscal year, will become the primary work platform for all of SCISN (document management, document collaboration, calendar/scheduling, work/project progress and management, and photo archives). We are also offering communications support to SCISN-funded researchers where opportunities for mutual benefit reside.
We continue to work with RHF, other RHF programs, and other partners, to achieve common communication goals aimed at leveraging and Network expansion opportunities. This includes ongoing work with Rick Hansen Wheels In Motion staff to achieve common goals and standardized messaging.

**Information Technology**

Information technology (IT) plays a critical role in determining the success of SCISN. Early on, it became clear that our IT focus would be in two areas: successfully building out the web-based data collection platform necessary for RHSCIR, as well as the information management of the planned Canadian SCI Clinical Trial Network and the individual multi-centre studies it will support; and deploying and maintaining all of SCISN’s network, servers, and communication infrastructure.

At year end, we had realized many significant accomplishments and milestones:

- IT infrastructure for our offices within the Blusson Spinal Cord Centre was completed, which resulted in total separation of SCISN and RHF computer and email systems.
- All SCISN staff were equipped with new user systems and updated with new hardware and software.
- The Registry project moved forward with a requirements-based, user-first approach. The development team was hired, with software architect, senior developer, and quality assurance position. Development methodology was chosen and adapted for the Registry; optimizing for best results and demonstrating early progress. User requirements and design phase is underway, involving interviews of user-experts from multiple disciplines.
- Low-cost, Internet-based Video conferencing solutions were chosen for two of three scenarios (Webex for internal meetings up to 25; Skype for one-on-one meetings).
- A collaboration platform for the entire SCISN organization was chosen (Sharepoint MOSS); the process is underway for installation and license transfer from Risk Analytica.

Looking ahead, we look forward to first completing the Registry requirements analysis and design, and then moving on to completing development of Registry release 1.0 within fiscal year 2009 – 2010. Other priorities will be to work with the SCISN privacy officer to review industry standards on data privacy and security, and develop policies and procedures to meet or exceed these standards.
## Financial Statement

2008 – 2009 Financial Information For All Funding Sources by Strategy

<table>
<thead>
<tr>
<th>SOURCE OF FUNDING</th>
<th>Health Canada</th>
<th>WED</th>
<th>Gov’t. of Ontario</th>
<th>Gov’t. of Alberta</th>
<th>Gov’t. of BC</th>
<th>Gov’t. of Manitoba</th>
<th>Other Provinces</th>
<th>Wheels In Motion</th>
<th>Other</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>REVENUE BALANCE</td>
<td>25,917,427</td>
<td>-</td>
<td>-</td>
<td>8,104,392</td>
<td>2,398,697</td>
<td>-</td>
<td>40,000</td>
<td>904,931</td>
<td>-</td>
<td>37,365,447</td>
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<tr>
<td>NET ADDITIONAL REVENUE RECEIVED/INCOME/FEES/GAINS &amp; LOSSES</td>
<td>733,573</td>
<td>1,000,000</td>
<td>2,614,052</td>
<td>621,255</td>
<td>55,715</td>
<td>-</td>
<td>170,000</td>
<td>1,232,764</td>
<td>1,293</td>
<td>6,428,652</td>
</tr>
</tbody>
</table>

### Translational Research Program

1. Develop and validate best practices——ER, Acute, Rehab, Community
   - 869,319 | - | 364,000 | 264 | - | - | - | - | 89 | 1,233,672
2. Supporting clinical trials——Acute, Rehab, Community
   - 364,015 | - | 250,000 | 188 | - | - | - | - | 64 | 614,267
3. Best & Brightest
   - 68,030 | - | 750,000 | 38 | - | - | - | - | 13 | 818,080
Sub Total | 1,301,364 | - | 1,364,000 | 490 | - | - | - | - | 166 | 2,666,019

### SCI Registry/IT

4. Collecting and analysing data using a national web based platform
   - 1,266,758 | - | 500,000 | 75 | - | - | - | - | 26 | 1,766,859
Sub Total | 1,266,758 | - | 500,000 | 75 | - | - | - | - | 26 | 1,766,859

### Best Practices

5. Facilitating adoption and implementation of validated best practices
   - 112,272 | - | - | 38 | - | - | - | - | 13 | 112,322
Sub Total | 112,272 | - | - | 38 | - | - | - | - | 13 | 112,322

### Solutions

6. Working with partners to enhance service delivery to people with SCI
   - 159,925 | - | - | 75 | - | - | - | - | 26 | 160,026
7. Working with partners to enhance capacity to respond to priority needs
   - 383,820 | - | 656,454 | 789,426 | - | 190,684 | 990,710 | 37 | 3,011,132
Sub Total | 159,925 | 383,820 | - | 656,529 | 789,426 | - | 190,684 | 990,710 | 63 | 3,171,158

### Network Leadership & Coordination

8. Finance, Accountability, HR, Communications, Resource Development*
   - 1,460,206 | 616,180 | - | 8,534 | 115,488 | - | - | - | 1,026 | 2,201,433
Sub Total | 1,460,206 | 616,180 | - | 8,534 | 115,488 | - | - | - | 1,026 | 2,201,433

### TOTAL EXPENDITURE

- 4,300,524 | 1,000,000 | 1,864,000 | 665,666 | 904,914 | - | 190,684 | 990,710 | 1,292 | 9,917,791

### REVENUE CARRY FORWARD

- 22,350,476 | - | 750,052 | 8,059,981 | 1,549,498 | - | 19,316 | 1,146,986 | - | 33,876,308

Appendix I: SCISN Logic Model

SCI Registry/IT

Translational Research

Solutions

Best Practices

Leadership

Network Leadership and Coordination

Network Mgmt Strategies

Partnership Development

Engagement and support of DM and Registry by key system actors such as acute care hospitals, rehabilitation centres, researchers and clinicians, people with SCI

Engagement and support of key researchers in Working Groups, Escans, white papers, reviews (literature, Delphi, systematic) and evaluations RFAs, RFPs, clinical trials, Universities, Hospital, Rehabilitation Centres, Local Solutions Teams, People with SCI

Projects completed

Engagement and support of key stakeholders in network functions, including governance.

Engagement and support of potential funding partners such as government, foundations and granting agencies, corporate and private donors

Projects completed

Validated science, approaches, therapies, protocols, policies, practices and measures (knowledge creation)

Cooperation, coordination and collaboration across the innovation spectrum

Network capacity built for ‘knowledge translation

Adoption of technology infrastructure/standards/measures (e.g. SCIRE) enabling improved innovation system performance

Adoption and adaptation of validated approaches, therapies, protocols, policies, practices, measures, and the necessary supports and services by care and service providers and use of these by consumers

Enhanced customized response to priority unmet needs available to Canadians with SCI

Increased community participation among Canadians with SCI (active living, education, employment)

Improved (Maximized) quality of life for those with SCI

Disability minimized for people with SCI:

Reduced incidence and severity of permanent paralysis

Increased recovery of function following injury

Reduced incidence and severity of secondary complications associated with SCI

Optimized personal, community and system burden

Supportive public policy for the adoption of good (best) practices

SCISN is designed to influence all elements of the innovation system for SCI treatment, care and services.

Increased access to SCI research and practices, and improved collection, management and use of evidence by all key system actors

Entrepreneurship and innovation: activities

SCISN 2008–2009

Aug 18, 2009
Appendix II: Translational Research Definition

A simple definition of translational research is “applying discoveries generated during research and studies to the development of trials and studies in humans, and, where success has been determined, readying that knowledge in preparation for implementation into practice.” While this definition helps explain the concept of translational research to the neophyte, it is sometimes necessary to use a more indepth description.

There are many more robust definitions of translational research. SCISN prefers the definition provided by the Canadian Institutes of Health Research (CIHR): “the exchange, synthesis and ethically-sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.”

Additionally, translational research is divided into three categories (T1, T2 and T3) as outlined by US National Institutes of Health, or NIH. T1 research activity is the translation of basic research into human studies. The new tests and treatments that lead from T1 research and result in improvements in clinical practice are known as T2 research activities. Identification of gaps in care also fall into the T2 category. Dissemination, implementation, incorporation of recommended care and impact measurement collectively fall into the category of T3 research activities.

The Translational Research program of the SCI Solutions Network invests in all three types of research activities, in the fields of SCI acute care, rehabilitation and community integration. In principle, the SCI Solutions Network does not fund basic discovery research unless there is a strong case that it is essential for translation into clinical trials. In these special cases, consideration may be given to “back-translational” pre-clinical projects that are intended to prepare or improve a potential clinical study design, and have primary and secondary outcome measures aligned with the national priorities of the SCI Solutions Network, along with clearly identified potential translational research partners for an imminent clinical trial.
Appendix III: Translational Research Summary

The SCISN Translational Research Program invests in translational projects that hold significant promise to help us reach our objectives and that are aligned with our three translational research strategies.

During the first half of 2008, the SCI Translational Research Network worked to establish the specific areas of research focus within these three research strategies. This exhaustive process consisted of balancing identified translational research needs with factors that could yield greater success, such as research expertise and capacity in Canada, and opportunities for leveraged funding and collaboration across the provinces and involving multiple institutions. The resulting work formed the basis for SCISN's business plan and for the initial Translational Research Program research project selections. A complete summary of awarded projects as of March 31st, 2009, as well as those earmarked or considered for funding in 2009 – 2010 or beyond, can be found below.

### Strategy 1: assessment and development of best practice guidelines for emergency response, treatment and primary health care

#### Projects Awarded

**Acute Care and Treatment Systematic Review of the Literature**
- PI: Dr. M. Fehlings et al | Institution: Toronto Western Hospital | Date awarded: Jan/08 | Amount: $194,332
- Overview and Status: An initial survey of Canadian hospitals has shown there are inconsistencies in the care of acute SCI. This project seeks to systematically review thousands of scientific and clinical peer-reviewed articles dealing with promising pre-clinical therapies ready for translation and many additional areas of SCI care, from pre-hospital, ICU, and acute care and treatment. Consensus on best practice recommendations will complete each area under review. The overall goal is to create a set of evidence-based recommendations for a standard of care that results in consistent and maximum outcomes for Canadians who sustain a SCI. The review began in 2008 and is expected to be completed in 2009 – 2010.

**ABC Course on AD (Autonomic Dysreflexia)**
- PI: Dr. A. Krassioukov et al | Institution: University of British Columbia | Date awarded: Jan/09 | Amount: $96,558
- Overview and Status: Autonomic dysreflexia is a dangerous and potentially life-threatening secondary complication of SCI. It is well understood in the realm of SCI-specific medicine, but not so well recognized or understood in the general medical community. Dr. Krassioukov, one of Canada's leading experts in the field, has been provided funding to translate knowledge into best practice guidelines for dissemination to health practitioners across Canada, including emergency room and paramedic personnel, so that AD can be diagnosed as early and as accurately as possible, and treated appropriately. This project is underway.

**SCI Chronic Pain Self-Management – A Clinical Demonstration Study**
- PI: Dr. K. Boschen et al | Institution: Toronto Rehabilitation Institute | Date awarded: Jan/09 | Amount: $97,238
- Overview and Status: Chronic pain, often excruciating, is a secondary complication of SCI that is difficult to manage and can lead to depression and inability to function in daily life. This project seeks to modify a successful pain self-management program designed for the general population to one that is specifically intended for people with SCI. This work is currently underway.

**The Rehabilitation Environmental Scan: A Pan-Canadian Atlas of Rehabilitation Service Delivery**
- PI: Ms. J. Hsieh et al | Institution: SCISN | Date awarded: Jan/09 | Amount: $135,000
- Overview and Status: How SCI rehabilitation services are delivered in various institutions and jurisdictions in Canada is not well understood. This pan-Canadian atlas of rehabilitation service delivery will assist the mapping of current rehabilitation practices and patient outcomes against current clinical issues to determine future SCI care and treatment priorities. Among the areas this atlas will seek to understand are patient demographics, clinical practices, and assessment and outcome measurement tools in use in various institutions and jurisdictions. Rehabilitation sites wishing to participate have access to web-based data collection, which is anticipated to begin by the third quarter of 2009.

**Delphi Process to Identify Priorities to Translate to Rehabilitation Practices**
- PI: Drs. J. Eng & D. Wolfe et al | Institution: UBC & Lawson Health Research Institute | Date awarded: Dec/08 | Amount: $48,100
- Overview and Status: This research initiative incorporated health professional practice, policy-maker, researcher expertise, and consumer experience with the available research evidence to achieve consensus on which areas are ready for translation into SCI rehabilitation practice. Several of the top priorities identified confirmed the relevancy of current SCISN best practice translation efforts. The remaining top priorities will be addressed through a call for proposals for knowledge translation and mobilization teams for each area, in parallel with the SCISN Evidenced-Based Practice (EBP) White Paper completion.
**SCI Home Ventilation Guidelines**  
Pl: Dr. J. Road | Institution: Canadian Thoracic Society | Date awarded: Mar/08 | Amount: $10,000  
Overview and Status: This research project is a partnership with Canadian Thoracic Association and aims to develop, and make widely available, guidelines to assess the need for and optimize ventilatory support for all people, including individuals with SCI, who require mechanical ventilation in the home. This award allowed for the systematic review and compilation of the evidence for best practice guideline development. The next steps include two interactive sessions to achieve consensus for best practice recommendations are currently underway. Thereafter, the guideline will be published and followed by innovative and traditional uptake activities occurring through Neurological Health Charities Canada.

**Projects Earmarked for Funding in 2009 – 2010**

**SCI Rehabilitation Evidence (SCIRE)**  
Pl: Dr. J. Eng, Dr. R. Teasell et al | Institution: UBC & Lawson Health Research Institute | Date awarded: TBA | Amount: TBA  
Overview: Published in 2006, SCIRE 1 was an unprecedented evaluation of the vast amount of knowledge specific to SCI rehabilitation from around the globe, and a summary of “the best of the best” into a single document made available for free online for front line clinicians and consumers. SCISN funding will allow for production of version 3 of SCIRE, which will be significantly enhanced from previous versions. This document will be a focal point for our best practices “knowledge into action” work, which has an anticipated release date of late 2010.

**SCIRE Case-Based Continuing Medical Education for Rehabilitation Health Care Providers in SCI**  
Pl: Dr. R. Teasell et al | Institution: LHRI | Date awarded: TBA | Amount: TBA  
Overview: This funding will allow the researchers to build on the foundation of SCIRE and use case-based scenarios to illustrate the use of SCIRE in clinical practice. It’s also allowing reframing of the knowledge or evidence for specific audiences—for example, remote/rural SCI health care providers—with the goal being knowledge translation, adoption of best practice and, ultimately, more consistent provision of rehabilitation services for people with SCI.

**SCIRE Outcome Measurement Toolkit**  
Pl: Dr. B. Miller et al | Institution: UBC | Date awarded: TBA | Amount: TBA  
Overview: Accurately measuring the outcomes of various rehabilitation interventions is critical. Using the SCIRE Outcome Measurement (OM) chapter as a platform, a SCI OM Toolkit will be identified through a Delphi process, with the goal of ensuring consistent use of the best OM tools in SCI rehabilitation clinical practice.

**Evidence Based Management Of Secondary Complications After SCI – Interactive Workshop**  
Pl: Dr. J. Eng et al | Institution: UBC | Date awarded: TBA | Amount: TBA  
Overview: In our continuing efforts to disseminate SCIRE findings, SCISN will fund an interactive workshop, adjudicated and accepted for presentation at the ISCoS (International Spinal Cord Society) conference in 2009, titled “Evidence-based management of secondary complications after SCI: What, when, and how?”. Spasticity, sexual health and cardiovascular complications following SCI will be the covered through evidence review, case presentations and audience/panel discussions. This interactive workshop aims to inform clinicians from around the globe on evidence-based decision-making and to enable future self-updating through this online free resource.

**Translating Research Findings on SCI into Family Practice**  
Pl: Dr. A. Aiken, Dr. M.A. McColl | Institution: Queen’s University | Date awarded: TBA | Amount: TBA  
Overview: Funding will be provided to prepare focused pieces of evidence-based information (“nuggets”) for direct translation into the primary care setting—25 nuggets will be translated/disseminated bi-weekly over one year and followed by a post-test survey in year two. Here is a sample nugget: “Begin screening for osteoporosis among people using wheelchairs at 30 years of age instead of at 50.” The goal is to see Canada-wide implementation for many common yet poorly understood best practices in health care for people with SCI. This work will begin in 2009.

**Best Practice Guidelines for Department of National Defence (DND)**  
Pl: Dr. M. Dvorak, Dr. M. Fehlings | Institution: SCISN | Date awarded: TBA | Amount: TBA  
Overview and Status: As part of a collaboration with DND, SCISN will provide a set of best practice guidelines for the treatment and care, from point of injury through community integration, of Canadian soldiers who sustain an SCI. This work will commence in 2009.
Strategy 2: supporting clinical trials and research in acute care, rehabilitation and community participation, and fostering global collaboration where appropriate

Projects Awarded

**STASCIS (Surgical Treatment for Acute Spinal Cord Injury Study)**

**PI:** Dr. M. Fehlings et al  |  **Institution:** Toronto Western Hospital  |  **Date awarded:** Jan/08  |  **Amount:** $100,000

**Overview and Status:** This funding is being contributed to Dr. Fehling's Canadian site of this multi-centre trial sponsored by the North American Clinical Trials Network (NACTN). The study is based on preliminary results showing a significant improvement for patients receiving decompressive/stabilization surgery within 24 hours of injury compared to those who received surgery after 24 hours. Final results are to be published in 2011.

**Safety & Pharmacokinetics of Riluzole in Patients with Traumatic Acute SCI**

**PI:** Dr. M. Fehlings et al  |  **Institution:** Toronto Western Hospital  |  **Date awarded:** Jan/08  |  **Amount:** $125,000

**Overview and Status:** Dr. Fehlings has been awarded funding to further the coordination of a Canadian site of a multi-centre North American trial to determine the safety and efficacy of riluzole, an anticonvulsant sodium channel blocker. The study is based on observations that suggest riluzole has some neuroprotective capabilities (it limits inflammation and neural damage, maximizing the preservation of function) in patients who have sustained a traumatic acute cervical SCI. Study enrolment is scheduled to begin in the third quarter of 2009.

**Economic Evaluation of Early Surgical Decompression for Traumatic Cervical SCI**

**PI:** Dr. J. Furlan et al  |  **Institution:** Toronto Western Hospital  |  **Date awarded:** Jan/09  |  **Amount:** $94,825

**Overview and Status:** Using a combination of Ontario-based health costing data with analysis of the Surgical Treatment for Acute Spinal Cord Injury Study (STASCIS) database, this project will strive to answer the key question of whether early surgical decompression of spinal cord (<24 hours post injury) is more cost effective than the late surgical intervention (>24 hours) in the management of patients with acute cervical SCI. In addition this study strives to determine ideal timelines for early surgical decompression, and the potential barriers that prevent these ideal timelines from being achieved. Results are anticipated in Dec/09.

**Cerebrospinal Fluid (CSF) Pressure Monitoring and Biomarker Validation in Human SCI**

**PI:** Dr. B. Kwon  |  **Institution:** UBC  |  **Date funded:** Jan/09  |  **Amount:** $96,774

**Overview and Status:** This study has three goals. The first is to establish new guidelines for managing hemodynamics (blood circulation and flow) of acute SCI patients. The second is to validate the use of biomarkers in the cerebrospinal fluid immediately following injury as a means of determining the severity of the injury and the ideal therapeutic strategy. The third is to describe the cellular constituents of the human inflammatory response to SCI (currently only known in animals). This work is currently underway at Vancouver General Hospital.

**Functional Magnetic Resonance Imaging of the Human SCI**

**PI:** Dr. P. Stroman et al  |  **Institution:** Queen's University  |  **Date awarded:** Jan/09  |  **Amount:** $97,015

**Overview and Status:** This study seeks to validate the clinical usefulness of spinal fMRI following SCI. While traditional MRI reveals great detail of the injury and its location in the spinal cord, fMRI provides insight into neuronal activity above and below the injury site. As such, it may be very useful in predicting outcomes and determining the effectiveness of new and existing treatments at a cost of only 15 additional minutes in an MRI for each patient. This work is now underway.

**The Graded and Redefined Assessment of Strength, Sensibility and Prehension (GRASSP)**

**Lead(s):** Ms. S. Kalsi-Ryan  |  **Institution:** Toronto Western Hospital  |  **Date awarded:** Jan/09  |  **Amount:** $150,000

**Overview and Status:** Small improvements in hand function can have significant impact on functional independence for people with tetraplegia, and so measuring these subtle changes becomes important, particular in determining the success of emerging therapies. SCISN funding is allowing for verification of the responsiveness of GRASSP, a very sensitive outcome measurement tool for hand function. Web-based data collection is underway in multiple sites.

**Can Pregabalin prevent the development of neuropathic pain following SCI?**

**PI:** Dr. C. Short  |  **Institution:** Dalhousie University  |  **Date awarded:** Jan/09  |  **Amount:** $96,125

**Overview and Status:** Neuropathic pain is a serious secondary complication of SCI. There is existing evidence to support the use of Pregabalin, an anticonvulsant drug, in the treatment of neuropathic pain. There is also evidence that there may be a small window of time post-SCI where the development of neuropathic pain can be prevented by administering an agent like Pregabalin. This randomized controlled trial hopes to confirm this to set the stage for a new standard of care for neuropathic pain. This study will commence in 2009.
<table>
<thead>
<tr>
<th>Project Title</th>
<th>Principal Investigator(s)</th>
<th>Institution(s)</th>
<th>Date Awarded</th>
<th>Amount</th>
<th>Overview and Status</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lower Extremity and Gait Rehabilitation White Paper</strong></td>
<td>Dr. T. Lam et al</td>
<td>UBC</td>
<td>Jan/08</td>
<td>$30,000</td>
<td>Canadian researchers are among the leaders in the scientific study of gait and lower extremity rehabilitation as means of improving walking function and reducing secondary complications of SCI. The SCISN Lower Extremity and Gait Rehabilitation White Paper is an outline of steps to be undertaken to build upon current research capacity, enhance clinical capacity, and facilitate multi-centre collaborations in this field. After the current internal review is completed, peer-reviewed publication will be sought for eventual dissemination amongst SCI stakeholders. SCISN will solicit proposals for gait and lower extremity rehabilitation research opportunities identified in the White Paper.</td>
</tr>
<tr>
<td><strong>Physical Activity White Paper</strong></td>
<td>Dr. A. Hicks et al</td>
<td>McMaster</td>
<td>Jan/08</td>
<td>$30,000</td>
<td>Physical deconditioning and its effect in magnifying subsequent secondary health complications of SCI and reducing life expectancy speak to the urgency for promoting physical activity in people with SCI. Steps required to help overcome the physical inactivity issue have been identified in the SCISN Physical Activity White Paper, with recommendations for potential collaborative projects. Proposals for these projects are currently under review. After the current internal review is completed, peer-reviewed publication will be sought.</td>
</tr>
<tr>
<td><strong>Development of an In-Home Telecare/Telehealth/Telerehabilitation Toolbox and White Paper</strong></td>
<td>Drs. D. Wolfe &amp; A. Prochazka</td>
<td>Lawson Health Research Institute &amp; U of Alberta</td>
<td>Mar/08</td>
<td>$40,000</td>
<td>Telehealth solutions appear to hold much promise for enhancing the health of persons with SCI in a small but geographically dispersed population, as exists in Canada. This grant allowed for production of a plan to evaluate delivery of pressure ulcer prevention and treatment, online physical activity services, SCI U for self-management, and other in-home telerehabilitation services, via the internet. The implementation details are to be published in a SCISN White Paper and the subsequent pilot projects are to be rolled out beginning in 2009.</td>
</tr>
<tr>
<td><strong>The Canadian Pressure Ulcer Initiative White Paper</strong></td>
<td>Dr. K. Hayes et al</td>
<td>LHRI</td>
<td>Mar/08</td>
<td>$30,000</td>
<td>Pressure ulcers are a secondary complication of SCI that greatly compromise the health and quality of life of individuals with SCI and represent a huge cost to the Canadian health care system. This White Paper outlines a strategic approach to prevent and reduce the impact of pressure ulcers. Projects to address the specific recommendations of the White Paper will be sought through a combined directed and open call for proposals. A Canadian SCI-specific pressure ulcer clinical practice guideline with a plan for implementation is currently under review as a first step in the strategic approach.</td>
</tr>
<tr>
<td><strong>Evidence-Based Practice (EBP) White Paper</strong></td>
<td>Drs. J. Eng&amp;D. Wolfe</td>
<td>UBC &amp; Lawson Health Research Institute</td>
<td>Jan/08</td>
<td>$30,000</td>
<td>Evidence-based practice (EBP) integrates the best available research, clinician expertise, and client characteristics into clinical practice guidelines. The goal of this White Paper is to prioritize the knowledge translation and mobilization needs of the Canadian SCI community based on EBP. Delphi participants, including regional representation of health professionals, consumers and policy-makers, contributed to the process. The results of this Delphi will be combined with efforts to identify the most effective knowledge translation strategies to complete the SCISN EBP White Paper.</td>
</tr>
<tr>
<td><strong>FES Therapy Restoring Voluntary Grasping Function In Chronic SCI</strong></td>
<td>Dr. M. Popovic</td>
<td>Toronto Rehabilitation Institute</td>
<td>Jan/09</td>
<td>$97,238</td>
<td>The main objective of this study is to determine the effectiveness of a new treatment regime that uses functional electrical stimulation (FES) for the improvement of hand function in persons with chronic SCI. In the study, FES is used as a therapeutic intervention that will help individuals with tetraplegia recover voluntary grasping function, rather than a permanently-used assistive device. It’s hoped that patients who undergo FES therapy should be able to grasp objects without stimulation once the treatment is completed. Results will be compared to those from a control group who receive conventional occupational therapy. This study is currently underway.</td>
</tr>
<tr>
<td><strong>Effect of Locomotor Training on Children with Incomplete SCI</strong></td>
<td>Dr. M. Radhakrishna et al</td>
<td>McGill University</td>
<td>Jan/09</td>
<td>$73,488</td>
<td>This study deals with how children living with a SCI respond to Body-Weight-Assisted Treadmill Training (BWATT). Numerous trials indicate that BWATT does improve human walking patterns in adults with incomplete SCI. The researchers involved theorize that, as a child’s nervous system is still developing, it is by definition more capable of changing and should respond well to BWATT. This study is currently underway.</td>
</tr>
</tbody>
</table>
### Strengthening Residual Cortico-Spinal Connections after SCI
**PI:** Dr. R. Stein | **Institution:** University of Alberta | **Date awarded:** Jan/09 | **Amount:** $68,067

**Overview and Status:** The purpose of the project is to determine the best method for strengthening residual connections between the brain and spinal cord in people with incomplete SCI to maximize functional ability. Electrical stimulation, Transcranial Magnetic Stimulation (TMS), Paired Associative Stimulation (PAS), and voluntary exercise will be tested individually and in various combinations with each other, to determine the most effective approach. This project is currently underway.

### Upper Limb Rehabilitation in Acute SCI – Piloting a Novel Computer and Robotic Assisted Rehabilitation Device
**PI:** Dr. J. Steeves et al | **Institution:** ICORD | **Date awarded:** Jan/09 | **Amount:** $97,238

**Overview and Status:** The aim of this project is to investigate the incorporation of the Armeo assistive device in existing rehabilitation programs to improve arm and hand function in individuals with sub-acute tetraplegia, maximizing independence in the process. During traditional approaches to upper limb rehabilitation, it’s difficult for many patients to maintain posture and stability during wrist exercise, and assistance is often required. The Armeo allows a patient to perform these exercises independently by combining completely adjustable weight bearing support of the arm with a grip sensor, in an advanced virtual reality environment. This project will take place in Vancouver and Toronto.

### Cognitive Behaviour Therapy Intervention to Improve Quality Of Life for Individuals With SCI
**PI:** Dr. C. Bradbury et al | **Institution:** Toronto Rehabilitation Institute | **Date awarded:** Jan/09 | **Amount:** $97,238

**Overview and Status:** Cognitive behaviour therapy is a psychotherapeutic approach that aims to manage mental health through a goal-oriented, systematic procedure. This randomized controlled trial will compare outcomes from a 12 session cognitive behaviour therapy group to a waitlist control group to investigate the potential for enhanced emotional wellbeing and improved quality of life after SCI. The study is currently underway.

### In-Home Tele-rehabilitation of Upper Extremity (ReJoyce)
**PI:** Dr. A. Prochazka | **Institution:** University of Alberta | **Date awarded:** Jan/08 | **Amount:** $226,000

**Overview and Status:** Dr. Prochazka’s study of In-home tele-rehabilitation for maximization of hand and arm function in people with tetraplegia has shown that use of his ReJoyce system/program, which can be carried out by a patient in their own home, results in clinically significant improvements. SCISN funding leverages funding from many global sources for this promising project, and is allowing the system to be evaluated at two Canadian sites (Montreal and Vancouver).

### A Telehealth Physical Activity Support Program for People with SCI (Get In Motion)
**PI:** Dr. K. Martin-Ginis | **Institution:** McMaster University | **Date awarded:** Mar/08 | **Amount:** $18,073

**Overview and Status:** Funding was provided for design, implementation and evaluation of the Get In Motion physical activity pilot program. Get In Motion offers physical activity support and programming via telephone consultation to participants with SCI living across Canada. The pilot was completed in the fall of 2008. Results suggest that providing specialized exercise consultations via the telephone is an effective way of promoting fitness to Canadians with SCI, who are often not able to access mainstream services because of geographic distances and lack of availability. Full results will be published in 2009.

### Development of a Research Famework to Maximize Wheelchair Mobility
**PI:** Drs. B. Miller & L. Kirby | **Institution:** UBC/Dalhousie University | **Date awarded:** Mar/08 | **Amount:** $15,000

**Overview and Status:** The objectives of this grant include proposing a research agenda to unify Canadian stakeholders in the field of wheelchair mobility. The resulting Wheeled Mobility Group meets regularly through yearly face-to-face meetings and a listserv to disseminate information for the purpose of white paper creation and research proposal submissions.

### Wheelchair Skills Training for Manual Wheelchair Users: Practical “Boot-Camp” for Trainers
**PI:** Dr. L. Kirby et al | **Institution:** UBC/Dalhousie University | **Date awarded:** Mar/09 | **Amount:** $10,000

**Overview and Status:** The Wheelchair Skills Training Program is a simple yet highly effective program for improving the skills of wheelchair users and thus enhancing mobility and independence. The funding allowed the researchers to provide hands-on training in the Wheelchair Skills Training Program to OTs and PTs in British Columbia, as well as give a presentation on this successful program to a broad stakeholder audience. Very favourable workshop feedback has encouraged partner funders to facilitate this workshop for at least two additional jurisdictions in 2009.

### Scoping Review of Disability Policy in Canada
**PI:** Dr. M.A. McColl | **Institution:** Queen’s University | **Date awarded:** Mar/08 | **Amount:** $10,000

**Overview and Status:** This survey provides a clear view of federal and provincial disability policies that have the potential to affect community integration for people with SCI. The work was carried out throughout 2008 and a final report was completed in early 2009. It is available online at http://chspr.queensu.ca, and may serve as a basis for an analysis of which policies lead to better outcomes and community participation.
Survey on Needs/Service Utilization and Outcomes of People with SCI
PI: Dr. L. Noreau | Institution: Laval University | Date funded: Mar/09 | Amount: $428,000
Overview and Status: This comprehensive survey will seek to interview 3,000 plus participants with SCI from across Canada to determine their needs, what care and support services they access, to what extent those services meet their needs, and what their health and participation outcomes are. All data collection is scheduled to be completed in 2009 – 2010.

Projects Earmarked for Funding in 2009 – 2010

In-Home Tele-rehabilitation of Upper Extremity (ReJoyce)
PI: Dr. A. Prochazka | Institution: University of Alberta | Date awarded: TBA | Amount: TBA
Overview: Dr. Prochazka’s study of In-home tele-rehabilitation for maximization of hand and arm function in people with tetraplegia has shown that use of his ReJoyce system/program, which can be carried out by a patient in their own home, results in clinically significant improvements. Funding for this project was granted in 2008. Additional SCISN funding leverages funding from many global sources for this promising project, and is allowing the system to be further evaluated in 2009 at an additional Canadian site (Toronto).

Access to Care – Patient Flow Pilot Study
PI: Dr. D. Atkins et al | Institution: University of British Columbia | Date awarded: TBA | Amount: TBA
Overview and Status: This pilot study is intended as an initial stage of a long term project to study the method(s) of improving the timeliness and quality of acute and rehabilitation care for SCI patients. This pilot study brings together an interdisciplinary team of health services researchers and professionals. A final report in Aug/09 will serve as the foundation for a long-term multi-year project to improve timeliness and quality of care for SCI patients.

Upper Extremity Rehabilitation White Paper
PI: Dr. C. O'Connell et al | Institution: Stan Cassidy Rehabilitation Centre | Date awarded: TBA | Amount: TBA
Overview and Status: Effective upper limb rehabilitation can lead to greater independence for many people with tetraplegia. The Upper Extremity Rehabilitation White Paper will outline the current state of upper limb rehabilitation and next steps required to enhance the field by engaging multiple centres across Canada to conduct randomized controlled interventional trials and translating new knowledge. Two such proposals are currently under review and the White Paper will be peer-reviewed for publication and dissemination.

Online Physical Activity and Related Educational Materials Through Video Consultation
PI: Dr. D. Wolfe et al | Institution: Lawson Health Research Institute | Date awarded: TBA | Amount: TBA
Overview and Status: This IHT project recognizes the importance of achieving cardiovascular health for Canadians with SCI, and seeks to validate the use of online fitness counselling and consultation via a live online video service such as Skype to promote home-based fitness programming. This operational grant will help determine roles, responsibilities and information technology needs.

Coordination of IHT Activities Across Canada Directed Towards Persons with SCI
PI: Dr. D. Wolfe | Institution: Lawson Health Research Institute | Date awarded: TBA | Amount: TBA
Overview and Status: Building on the work to produce the IHT White Paper (see page 30), this project will seek to coordinate all SCISN-funded projects aimed at exploring the provision of in-home tele-rehabilitation services, using telephone or internet, to Canadians with SCI. Given Canada’s geographic challenges, IHT represents a method of providing excellent care and support to people with SCI, and impressive cost savings to our health care system. Funding has been requested for two fiscal years (2009 – 2011).

A Telehealth Physical Activity Support Program for People with SCI (Get In Motion)
PI: Dr. K. Martin-Ginis | Institution: McMaster University | Date awarded: TBA | Amount: TBA
Overview and Status: Funding will be provided to further develop the Get In Motion physical activity pilot program, developed with SCISN funding in 2008. Building on the success of the pilot program, the current request will seek to increase the number of clients using the service; increase consumer involvement in program delivery; and expand partnerships towards future program sustainability. Preliminary results suggest that providing specialized exercise consultations via the telephone is an effective way of promoting fitness to Canadians with SCI, who are often not able to access mainstream services because of geographic distances and lack of availability.
Development of a Guideline on Exercise and Physical Activity

**PI:** Drs. K. Martin Ginis & A. Hicks  
**Institution:** McMaster University  
**Date awarded:** TBA  
**Amount:** TBA

**Overview and Status:** Information on physical activity and its benefits are much desired but not readily available to Canadians living with SCI. This project is aimed at the development and implementation of physical activity guidelines for both acute and chronic SCI patients, following the methods used for Canada’s existing physical activity guidelines for the general population. SCISN funding will support the scientific review, preliminary market research and prototype development. Partnership funding will be sought to test the concept and launch the final guidelines.

Global Blueprint for SCI Stem Cell Therapies

**PI:** Dr. M. Fehlings  
**Institution:** Toronto Western Hospital  
**Date awarded:** TBA  
**Amount:** TBA

Funding will be provided to host an international stakeholder conference that will allow Canadian researchers to lead development of a global blueprint for conducting human research in promising SCI stem cell therapies. The goal of this project is to culminate in a phase I study to evaluate the safety of stem cell transplants in patients with SCI in Canada through the SCISN Clinical Research Network. The conference is being planned for May, 2010.

Contribution Analysis to Assess the Performance of the Discovering the Power in Me Project

**PI:** Dr. A. Townson et al  
**Institution:** G.F. Strong Rehabilitation Centre  
**Date awarded:** TBA  
**Amount:** TBA

**Overview and Status:** Discover the Power in Me (DPM) is a program developed to teach people to manage change, set and achieve goals, lead more effectively, and think in ways to create success. SCISN has contributed funding along with stakeholder partners to evaluate and validate the program for implementation in the SCI rehabilitation setting.

Minocycline in Acute SCI—A Canadian Multicentre Study (MASC)

**PI:** Drs. S. Casha & J. Hurlbert  
**Institution:** University of Calgary  
**Date awarded:** TBA  
**Amount:** TBA

Minocycline is a common antibiotic that has been demonstrated to minimize inflammation and many other types of secondary damage that follow immediately after SCI in animal studies. A safety and feasibility study of 52 subjects randomized to IV minocycline vs placebo within 12 hours of injury has provided promising evidence for minocycline’s neuroprotective properties in humans. Funding is now being sought to conduct a randomized control trial to confirm the efficacy of IV Minocycline in improving neurological and functional outcome in humans after a SCI. This study, if funded, will commence in early 2010.

Cerebrospinal Fluid (CSF) Pressure Monitoring and Biomarker Validation in Human SCI

**PI:** Dr. B. Kwon  
**Institution:** University of British Columbia  
**Date awarded:** TBA  
**Amount:** TBA

This proposed multi-centre study will build on the work currently funded by SCISN to establish new guidelines for managing hemodynamics (blood circulation and flow) of acute SCI patients; to validate the use of biomarkers in the cerebrospinal fluid immediately following injury to determine the severity of the injury; and to describe the cellular constituents of the human inflammatory response to SCI (currently only known in animals). If funded, this study will be expanded to four additional sites across Canada and could begin as early as the fourth quarter of 2009.

Canadian Pressure Ulcer Prevention and Treatment Best Practice Guidelines

**PI:** Dr. P. Houghton  
**Institution:** University of Western Ontario  
**Date funded:** TBA  
**Amount:** TBA

There are many practices, some effective and some ineffective, being employed across Canada to treat pressure ulcers, an expensive and potentially life-threatening secondary complication of SCI. As well, new developments are now available for pressure ulcer prevention and treatment. This work, which will commence in 2009, involves updating nine-year-old best practice guidelines for mobilization across the Canadian healthcare system.

Feasibility of an Internet Clinic for Treating and Preventing Pressure Ulcers

**PI:** Dr. D. Wolfe  
**Institution:** Lawson Health Research Institute  
**Date awarded:** TBA  
**Amount:** TBA

Pressure ulcer prevention and treatment appear to be particularly amenable to a telehealth strategy. The intention of the initiative is to test the feasibility of delivering these services directly into the home of participants via the internet. The project will include consultation and education related to wound management and prevention; assessment of wound status and healing; and assessment of risk factors for the development of pressure ulcers, including a seating assessment with interface pressure mapping.

Incorporation of Physical Activity into the Rehabilitation Process after SCI

**PI:** Dr. A. Hicks  
**Institution:** McMaster University  
**Date funded:** TBA  
**Amount:** TBA

This proposal aims to address the need for including physical activity as an integral part of the rehabilitation process following SCI. This would begin during inpatient rehabilitation with valid and reliable exercise screening tests to determine level of physiological and psychological readiness for exercise upon discharge, and continue with an automatic referral to an exercise program upon discharge from rehabilitation to community. Following the cardiac rehabilitation model, the goal is to provide a direct flow from inpatient to outpatient exercise rehabilitation with 16 weeks of follow-up post-discharge.
**Sitting Pivot Transfers in Individuals With SCI: Minimizing Upper Extremity Risk Exposure and Maximizing Performance**  
PI: Dr. D. Gagnon et al | Institution: University of Montreal | Date funded: TBA | Amount: TBA  
People with a SCI who use manual wheelchairs as their primary source of mobility perform sitting pivot transfers many times each day. The excessive mechanical and muscular stress to the arms and shoulders results in secondary complications that compromise health, mobility and community participation. This project seeks to better understand sitting pivot transfers to identify the best technique and predictors of performance, which will contribute to the development of clinical practice guidelines.

**Pilot Efficacy Testing for SCI Self Management E-Learning Modules**  
PI: Dr. D. Wolfe, Mr. J. Shepherd | Institution: Lawson Health Research Institute | Date awarded: TBA | Amount: TBA  
Overview and Status: The pilot project of “SCI-U” is intended to develop and validate six streaming video modules designed to be accessed online for people with SCI interested in learning validated self-management techniques. SCI-U was developed by John Shepherd with initial funding provided by Ontario Neurotrauma Foundation and Toronto Rehabilitation Institute. Development of modules was underway at year end.

**Strategy 3: encouraging development of the “best and brightest” within Canada’s SCI research community.**

**Projects Under Consideration for Funding in 2009 – 2010**

Researcher Development – Best and Brightest: Ontario and Alberta have established grants to facilitate researcher development and capacity building within the respective provinces that will promote collaboration with SCISN strategies. SCISN is working with these provinces to maximize these opportunities.
## Access to Clinical Trials and Research Studies

<table>
<thead>
<tr>
<th>Clinical Trial/Research Study</th>
<th>Principal Investigator</th>
<th>Location</th>
<th>Participants</th>
<th>Amount (s)</th>
</tr>
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<tbody>
<tr>
<td>Electrical Activation of the Diaphragm for Ventilatory Assist</td>
<td>Dr. Rob McMaster</td>
<td>Vancouver Coastal Health Authority</td>
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<tr>
<td>Outcome Evaluation of FES-Assisted Exercise Therapy for Hand Function in Quadriplegic People</td>
<td>Dr. Arthur Prochazka</td>
<td>University of Alberta</td>
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<tr>
<td>Prevention of Pressure Sore Formation Using Electrical Stimulation</td>
<td>Dr. Vivian Mushahwar</td>
<td>University of Alberta</td>
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<td>$1,960, $1,700, $2,600, $72,000</td>
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<td>Retraining Walking after SCI</td>
<td>Dr. Jaynie Yang</td>
<td>University of Alberta</td>
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<tr>
<td>The effects of upper extremity FES exercise training on upper limb function in individuals with tetraplegia</td>
<td>Dr. Dave Ditor</td>
<td>Brock University</td>
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<td>Measuring Reduction in Interface Pressure in a Tilt-In-Space Wheelchair Among Persons with SCI</td>
<td>Dr. Karen Ethans</td>
<td>Health Sciences Centre/University of Manitoba</td>
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## Wheels In Motion Solutions Grants

- **Alberta 2008 WIM/Solutions Distribution by PST**<br>  Alberta Communities $89,786
- **SCI Programs (Active Living, Youth in Action, Peer Program)**<br>  Grande Prairie $5,2101
- **Wheelchair curling facility upgrade**<br>  Abbotsford $5,460
- **Peer event - Abbotsford Air show**<br>  Abbotsford $1,000
- **Support for Wheelchair Curling Team**<br>  Armstrong $800
- **Emergency Travel Funds**<br>  BC Undesignated $7,500
- **2008 Canada Cup International Wheelchair Rugby Tournament**<br>  Burnaby/New Westminster $2,500
- **Wheelchair Basketball Developmental City League**<br>  Burnaby/New Westminster $1,250
- **Spinergy Wheels for Wheelchair Basketball Program**<br>  Burnaby/New Westminster $700
- **Neil Squire - Computer Comfort Program**<br>  Burnaby/New Westminster $12,309
- **TrailRider**<br>  Campbell River $4,558
- **Wheelchair Rugby Chairs**<br>  Duncan $6,177
- **8-way power base for van seat**<br>  Fort St. John $2,035
- **V4 Mattress**<br>  Fort St. John $2,631
- **Power Chair for Individual with SCI**<br>  Kelowna $2,000
- **Power Mobility and Seating for SCI Individual**<br>  Kelowna $4,391
- **Varna 2 Handcycle for SCI Individual**<br>  Langley $3,250
- **Home renovation for SCI Individual**<br>  Langley $3,517.14
- **Lift for individual with SCI**<br>  Maple Ridge/Pitt Meadows $4,184
- **Chi Machine for individual**<br>  Maple Ridge/Pitt Meadows $336
- **Elevator and Ramp for Curling Rink**<br>  Nanaimo $2,637
- **Adjustable Rotec Bed for SCI Individual**<br>  North Vancouver $4,457
- **Wheelchair Access to Lake Okanagan**<br>  Peachland $1,927
- **Cheslakees School Play Ground for Disabled Children Access**<br>  Port McNeill $3,170
- **Outdoor Recreation Program**<br>  Prince George $6,000
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<tr>
<th>Program</th>
<th>Location</th>
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<td>2009 National Wheelchair Rugby Championships</td>
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<td>Wheelchair Curling Bonspiel</td>
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<td>Therapeutic Horseback Riding for People with SCI</td>
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<td>2008 BC Junior Wheelchair Basketball Challenge</td>
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<td>Adaptive Fitness Equipment</td>
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<td>Junior Wheelchair Sports Club</td>
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<td>Fishing Forever</td>
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<td>BCMOS Soaring</td>
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<td>Bridging the Gap - Getting Physically Active</td>
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<td>Adaptive Paddling and Canoeing Programs</td>
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<td>BCPA - Community Response Team</td>
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<td>Prometheus Project</td>
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<td>Funding for West Coast Adaptive Rowing Program</td>
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<td>Scooter for individual with SCI</td>
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<td>The Glass Box</td>
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<td>Outdoor Adventure Program</td>
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<td>Victoria/Vancouver Island Wheelchair Curling Development</td>
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<td>Wheelchair Rugby Chair for SCI Individual</td>
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<td>Airpulse PK Wheelchair Seating System for SCI Individual</td>
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<td>Whistler Adaptive Sports Program: “Have a go at Kayaking”</td>
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<td>Argo Trailer</td>
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<td>Fitness Equipment for SCI Individual</td>
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<td>Ramp at Local Church</td>
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<td>Pressure Relief Mattress for individual with SCI</td>
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<td>Moncton Area Solutions Fund</td>
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<td>Van Adaptations for SCI Individual</td>
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<td>Wheelchair Handi-Bus Lift</td>
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<td>Transportation Passes for People with SCI</td>
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<td>Upper-Tone System for SCI Fitness</td>
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<td>Home rehab Equipment for SCI Individual</td>
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<td>Equipment Loan Program (pressure relief mattresses)</td>
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<td>Aid-To-Para fund</td>
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<td>Paddle All program (accessible floating docks)</td>
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<td>Halifax Heat Wheelchair Basketball Team (facility rental costs)</td>
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<td>Accessible Seating at the Savoy Theatre</td>
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<td>Aid-to-Para Fund</td>
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<td>Junior National Wheelchair Basketball Team</td>
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<td>Portable Pool Lift</td>
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<td>Motor-assisted movement therapy trainer for SCI individual</td>
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<td>Power Wheelchair for SCI Individual</td>
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<td>Accessible Entrance at Meaford Museum</td>
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<td>SCI Summer Employment Program</td>
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<td>Fitness Centre Equipment Campaign</td>
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<td>Educational Endeavour and Vehicle for Person With a SCI</td>
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<td>SCI Individual Participation in Wheelchair Track and Field</td>
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<td>Inspiration Flight Program – Total Access</td>
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<td>Equipment and Support for Sledge Hockey Team</td>
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<tr>
<td>Lyndhurst Recreational Equipment</td>
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<td>SCI Individual Request</td>
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<tr>
<td>Enhancing Access to Translational Clinical Research Trials</td>
<td>Toronto</td>
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<tr>
<td>Equipment Fund (Wheelchair for SCI Individual)</td>
<td>Borden-Carleton (Albany)</td>
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<td>Equipment Fund (SCI Individuals)</td>
<td>Charlottetown</td>
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<td>Quebec QOL Distribution by Provincial Solutions Team</td>
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<tr>
<td>Bridging the Gap - Saskatoon City Hospital Rehabilitation Unit</td>
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**Let’s Play Grants**

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<thead>
<tr>
<th>Project Description</th>
<th>Location</th>
<th>Amount</th>
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<tbody>
<tr>
<td>100 Mile Elementary Playground</td>
<td>100 Mile House</td>
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<tr>
<td>Beckwith Park</td>
<td>Saanich</td>
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<tr>
<td>Brent Kennedy Elementary School</td>
<td>Crescent Valley</td>
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<tr>
<td>Cates Park/Whey-ah-Wichen</td>
<td>North Vancouver</td>
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<tr>
<td>Cedar Grove Accessible Play Park</td>
<td>Gibsons</td>
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<td>Cheslakees School Playground Renewal</td>
<td>Port McNeill</td>
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<tr>
<td>Deverill Square Park Accessible Playground</td>
<td>Nanaimo</td>
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<td>Kinnikinnick Adapted Playground</td>
<td>Sechelt</td>
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<td>K-Play ReCreate</td>
<td>Nanoose Bay</td>
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<td>Linwood Park Playground</td>
<td>Langley</td>
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<td>McLean Neighbourhood Park</td>
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<td>Parkinson Recreation Centre Let’s Play</td>
<td>Kelowna</td>
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<td>Pine Park Accessibility Project</td>
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<td>Prince Rupert Accessible Playgrounds</td>
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<td>Salt Spring Elementary School Playground Upgrade</td>
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<td>West Richmond Community Association Play Space</td>
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