A WORLD WITHOUT PARALYSIS
AFTER SPINAL CORD INJURY

AN INTRODUCTION TO THE RICK HANSEN INSTITUTE
Our Vision

A world without paralysis after spinal cord injury.

Our Mission

To lead collaboration across the global spinal cord injury (SCI) community by providing resources, infrastructure and knowledge; and to identify, develop, validate and accelerate the translation of evidence and best practices to reduce the incidence and severity of paralysis after SCI, improve health care outcomes, reduce long-term costs, and improve the quality of life for those living with SCI.

Who We Are and What We Do

As a catalyst, our organization brings together the best and brightest minds in SCI research, clinical care and related services.

We are designed to influence all elements of SCI treatment and care, developing new therapies and decreasing the time for research to be translated into real-life benefits.

Research must lead to action. For this reason, Knowledge Translation is integrated into everything we do.

This model – a national network with common goals, supported by infrastructure, resources and knowledge dissemination – is already making a difference and will result in better outcomes for individuals with SCI.

It has also attracted international attention, further establishing Canada's reputation as a leader in SCI care and research, and will lead to substantial cost savings for our health care system here in Canada and potentially around the world.

Pillars

Acknowledgments: The Rick Hansen Institute would like to thank the following funders and partners: Health Canada, Rick Hansen Foundation, Western Economic Diversification, the Governments of Alberta, British Columbia, Manitoba, Ontario, and Saskatchewan, International Collaboration on Repair Discoveries (ICORD) and Vancouver Coastal Health.
THE REALITY OF SCI

Spinal cord injuries have a devastating impact on the health and well-being of individuals. Many would categorize SCI as one of the greatest survivable catastrophes experienced by a human being. Health care needs for people who sustain a SCI are highly specialized and complex. Regardless of cause or age at injury, SCI has far reaching consequences for individuals and their families.

Some facts on SCI in Canada:

- There are an estimated 86,000 PEOPLE LIVING WITH SCI IN CANADA, and millions more worldwide
- An estimated 4,300 NEW CASES of SCI occur each year IN CANADA
- Traumatic SCI occurs most commonly in males between the AGES OF 16–30, ALTHOUGH AS THE POPULATION AGES MORE INJURIES WILL OCCUR FROM FALLS AND ILLNESSES
- The economic cost of traumatic SCI is estimated at $3.6-BILLION A YEAR in Canada
- The economic cost over a lifetime for each individual can vary from $1.6-MILLION FOR A PERSON WITH PARAPLEGIA to $3 MILLION FOR A PERSON WITH QUADRIPLEGIA
- This financial burden is further compounded by the fact that the UNEMPLOYMENT RATE FOR THOSE WITH SCI IS AS HIGH AS 60%

Compared to the general population, Canadians with SCI:

- Are re-hospitalized 2.6 TIMES more often
- Require 3 TIMES more contact with a physician
- Require 30 TIMES more hours of home care services
- And have a far shorter life expectancy, from 15 TO 30 FEWER YEARS
The Power of Partnerships

The Rick Hansen Institute (RHI) was established in 2007, with a mission to foster greater collaboration across the SCI community and to accelerate progress towards a cure for paralysis after SCI.

Our Anticipated Outcomes

While there are many institutions working in SCI, RHI’s focus is on the following outcome-based objectives: reduction in the incidence and severity of permanent paralysis resulting from SCI; increased restoration of physical function following SCI; and reduction in the incidence and severity of secondary complications associated with SCI.

Our Funding Model

RHI manages investments on behalf of the Rick Hansen Foundation and our funding partners, and strategically invests those funds in areas and projects that can have the greatest impact in relatively short order.

Our Core Work Areas

To achieve our goals, RHI is focused in three core work areas:

- **Translational Research** – moving basic discoveries into new treatments and approaches that tackle the most pressing needs of Canadians with SCI

- **Best Practices Implementation** – based on existing and emerging evidence, identifying best practices in SCI treatment and care, and promoting their wide-scale adoption

- **Global Clinical Research Platform** – developing a global web-based registry to collect and analyze valuable data on SCI, which in turn will support our translational research, clinical research studies and best practices implementation efforts

These core areas – leading edge translational research with direct links to clinical best practice – function together to create greater integration across the research and health care continuum as projects progress from research to clinical implementation.

Our Funders and Partners

To serve and support our three main client groups – scientists, clinicians, and ultimately, individuals with SCI – leveraging partnerships are key. Our funders include Health Canada, Western Economic Diversification, various provincial governments and the Rick Hansen Foundation.

Our colleagues and partners include the International Collaboration on Repair Discoveries (ICORD), Accreditation Canada, the Canadian Medical Association, Ontario Neurotrauma Foundation, Canadian Paraplegic Association, China Rehabilitation Research Center, Peking University Third Hospital, the Institute for Medical Research Israel Canada and Brisbane’s Princess Alexandra Hospital, to name just a few.
Progress to Date in SCI Research

In 1973, Rick Hansen, then 15 years old, shattered his spine after being thrown from a truck. He spent seven months in recovery and rehabilitation in Vancouver. Most of the first two months was spent in a bed to hold his spine in place in the hope it would heal. He soon learned he would never walk again. Returning home to Williams Lake, BC he found a home and community with many accessibility barriers.

Today, new research is revolutionizing the treatment of SCI both in the hospital and in the community. In addition, new breakthroughs and discoveries, progressive drug therapies, and advanced surgical techniques are helping people to better manage quality of life issues associated with SCI, such as chronic pain, bladder and bowel complications, pressure ulcers, sexual dysfunction, and increased susceptibility to respiratory problems.

We now know that:

- **Timely and early intervention after injury is a critical success factor.** A Canadian clinical trial, the RHI-supported Surgical Treatment for Acute Spinal Cord Injury Study (STASCIS), is showing 20% improvement in outcome and reduction in impairment after early surgical intervention.

- **The damaged central nervous system has the potential to rewire and adapt.** Rehabilitation strategies that utilize electrical stimulation can improve functional recovery. For example, University of Alberta Professor Arthur Prochazka, with funding from RHI, has developed technology that will allow individuals with quadriplegia to maximize their hand function in the comfort of their own homes.

- **Better understanding of underlying mechanisms is enabling development of new drugs and treatments.** Reducing the incidence and severity of secondary complications such as neuropathic pain will improve quality of life. For example, recent research has identified the importance of evaluating new treatments for SCI-related pain syndromes, such as pregablin, which acts as a preventative measure reducing pain signals that are sent out by damaged nerves in the body.

Despite the progress, there is still a long way to go, and there are several significant challenges to overcome before the impacts of injuries and their costs can be drastically reduced.
RICK HANSEN INSTITUTE AT A GLANCE

**ROBUST DATA**

To maximize results, both translational research and best practices implementation require access to a robust source of data on individuals with SCI. A data set such as this becomes increasingly useful as more individual patients are included and followed over time. RHI has established a Canadian registry of SCI patients as well as a web-based data collection and research management platform (the Rick Hansen Institute Global Research Platform), with 27 Canadian facilities currently contributing data and aggressive plans to expand the number of sites internationally. An international registry will allow researchers and administrators to make informed decisions based on common data sets around the world.

**THE BUSINESS CASE FOR BETTER CARE**

RHI is collaborating with the Centre for Operational Excellence at the Sauder School of Business, University of British Columbia, on a pilot project to improve the access and timing to health care for individuals with traumatic SCI from the moment of injury until they are discharged. This multi-phase project will build computer simulation models of the health care system to illustrate the direct and indirect impact of hypothetical changes, and the many indirect impacts, and will offer key decision-makers the evidence they need to recommend operational changes in the delivery of care for individuals with SCI as they move through the healthcare system. This novel approach to conducting health services research was first piloted in Vancouver and mapping is currently taking place in six acute and rehabilitation locations across Canada and in all Rick Hansen SCI Registry sites.
Autonomic dysreflexia (AD) is a potentially life-threatening response to pain below the level of injury in the spinal cord that is not felt by the individual. Vancouver’s Dr. Andrei Krassioukov, a world-renowned expert in AD and Principal Investigator at International Collaboration on Repair Discoveries (ICORD), developed and validated the curriculum for a course that improves the knowledge of emergency room personnel and paramedics of this condition. Over 130 emergency staff in Vancouver, Toronto and Winnipeg, have taken the course and can now recognize the symptoms and manage the treatment of AD for patients with SCI, helping to decrease SCI-related emergency room and hospital admissions and improve the quality of care provided to individuals with SCI.
Canada’s Emergence as a Global Leader in SCI Research and Care

Canada has taken a leading role in many of the advancements that have been translated from discovery into improved clinical treatment and services. The Rick Hansen Foundation and its partners have worked closely with government to build this leadership position, culminating in SCI expertise, technological innovation and a unique, inter-disciplinary approach that is widely admired around the world.

This leadership – through multiple investments in capacity and infrastructure – has resulted in:

- The creation of the Rick Hansen Institute in 2007. Acting as a catalyst, RHI combines leading-edge translational research with direct links to clinical best practice.

- The implementation of the Rick Hansen SCI Registry, the first and only Canadian database of information to collect and share standardized SCI data. It is a truly national network following the same protocols and clinical practices, representing all of Canada’s major SCI trauma units and rehabilitation hospitals and more than 2,000 participants.

- The development of the Rick Hansen Institute Global Research Platform (RHI GRP), a state-of-the-art, web-based, secure data collection and research management platform that enables easy and efficient capturing of data that can be readily accessed. The RHI GRP is highly adaptable: it can be used as a spine data collection tool and can run multi-centre clinical trials. The RHI GRP is now being rolled out internationally.

- The establishment at the University of British Columbia and Vancouver Coastal Health of International Collaboration On Repair Discoveries (ICORD) as one of the largest interdisciplinary SCI research programs in the world. With 43 faculty and more than 300 trainees and staff, ICORD is leading numerous regional, national and international initiatives, including the establishment of the international guidelines for SCI clinical trials.

- The opening of the Blusson Spinal Cord Centre (pictured in background), an 11,000 square metre state of the art facility housing ICORD, the Rick Hansen Institute, the Vancouver Coastal Health Spine Clinic and other service providers all under one roof. There are only two other facilities like it in the world.
BUILDING A GLOBAL NETWORK

The contributions that have been made to date by Canadian researchers and healthcare professionals have been critical to positioning Canada as a leader in SCI care and treatment around the world.

However, the collaboration of like-minded international organizations is critical in accelerating the translation of the most promising global discoveries into day-to-day clinical practice.

Participation in a global registry is seen by many as one efficient way to obtain a large enough dataset to expand the number of clinical studies that can be conducted, and serve as a means to measure the implementation of best practices.

Registry sites in international locations will increase the number of SCI-related clinical trials and translational research projects that can be implemented.

RHI is working to establish sites in Brisbane, Australia at Queensland University of Technology, and the Hebrew University and University of Tel Aviv in Israel. Cooperative agreements have also been established with the China Rehabilitation Research Centre and Peking University Third Hospital in Beijing, China as well as with organizations in the United States.

Leveraging expertise, knowledge, infrastructure and resources, the RHI global network encompasses organizations working towards common goals of scientific and clinical advancements in SCI research and care.

“Collaboration, and in particular international collaboration, is the best way to invigorate new ways of thinking, share ideas and coordinate the precious resources that we have in the area of Spinal Cord Injury.”

— Dr. Ben Goss,
Senior Research Fellow in the AO Spine Reference Centre,
Queensland University of Technology,
Australia
A Vision for a Better World

To bring Rick Hansen’s vision of an inclusive society and a world without paralysis after SCI to life, we are inviting other committed leaders to join us on a journey of determination, courage, and leadership. Together, we can help build on Rick’s past achievements, extend the impact of his leadership and forge ahead in making a fundamental difference in Canada and around the world.

The Rick Hansen Institute is eager to continue working with its existing and new partners to help shorten the discovery time for new treatment methods; to develop a shared data platform and clinical trials network; and to further identify and promote best practices.

The 25th Anniversary of the Man In Motion World Tour marks a time to celebrate Rick’s journey of inspiration and hope, and to create tremendous momentum for the future vision of the Foundation and Institute that bear his name, as well as for individuals living with SCI and related disabilities.

Just as his global tour established Rick’s place in Canadian history, so will the 25th Anniversary campaign set the stage for all of us to participate in creating a healthy, inclusive and sustainable world.

We invite you to be part of history.
“I truly believe we are standing on the threshold of an exponential expansion of the boundaries of our knowledge — progress that will have a positive impact on thousands of lives for many years to come.”

- Rick Hansen