



# RICK HANSEN INSTITUTE

Strategic Plan for Fiscal Years 2016-2023



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# Table of Contents

The Reality of Spinal Cord Injury .....	3
Barriers to Further Progress .....	6
The Need for Standardized Treatment of SCI in Canada.....	6
Moving Research into Practice .....	8
Developing & Commercializing New Innovations for SCI.....	9
Economic and Sustainability Considerations .....	10
Strategic Plan F2016-2023 .....	11
Going Forward .....	12
Objectives F2016-2023 .....	13



As of October 2019, the Rick Hansen Institute has officially renamed to Praxis Spinal Cord Institute. This Strategic Plan was developed under the former name. To learn more about the name change, please visit our website at [www.praxisinstitute.org](http://www.praxisinstitute.org).

# The Reality of Spinal Cord Injury



Spinal cord injury (SCI) is one of the greatest survivable catastrophes experienced by a human being. Just imagine what it is like to have a spinal cord injury, to have your mobility restricted, and your independence limited, to know that your life will be cut short by 15 to 30 years.

Regardless of cause or age at injury, SCI has a devastating impact on an injured person's health and well-being, and far reaching consequences for individuals, their families and the healthcare system.

In 1973, a 15 year old Rick Hansen shattered his spine after being thrown from a truck. He spent seven months in recovery and rehabilitation. Most of the first two months was spent in a bed to hold his spine stationary; in the hope it would heal. He soon learned he would never walk again.

**Today that outcome would be very different.**

During the past 25 years, significant progress has been made in rallying the scientific and medical research communities to generate improvements in spinal cord injury care that are minimizing damage to the spinal cord, maximizing physical function of the individual, and reducing long-term healthcare costs. Research collaboration, evidence-based best practices and an increasingly coordinated healthcare system have greatly improved outcomes for people with SCI.

**But there is still much work to be done.**

## Now, imagine a not too distant future where....

A newly-injured individual with a traumatic spinal cord injury in Canada has a greater chance of some neurological recovery than today and certainly far greater than when Rick Hansen suffered his SCI in 1973.

As soon as his or her injury occurs, he will be triaged to an accredited Rick Hansen Institute (RHI) SCI network site which adheres to national SCI standards of care and he will have access to leading-edge SCI research. His treatment will consist of best practices that are agreed upon by international experts to ensure he has access to early surgery, that guidelines are in place to minimize pain and that programs are available to maximize physical function such as reaching, grasping and walking. He will be provided with an opportunity to enroll in international clinical trials that can promote neurological recovery within his lifetime. And throughout the continuum of care, he will be a participant in his own treatments and will receive information in a personal and timely manner to ensure he can actively manage his injury and health issues. Productive and satisfying community living will be facilitated by innovative technical aids, assistive devices along with individualized long-term medical and social supportive services.

Data on clinical practice will be collected in the Rick Hansen SCI Registry (RHSCIR) using internationally agreed upon data standards; this data will be aggregated with other Canadian and international sites. This state-of-the-art information technology platform will also collect imaging and biomarkers, paving the way for an era of personalized medicine.

In this not too distant future, using RHSCIR, decision-makers in government and health authorities will be able to evaluate improvements in SCI patient care, outcomes and cost savings, serving as a model for other complex, chronic health conditions.



## It is within our reach...

Since 2007, the Rick Hansen Institute has connected scientists, researchers, surgeons and practitioners to acquire and translate research findings into practical solutions. Through this work, Canada is now a leader in medical research, treatment and care for people living with spinal cord injuries.

Thanks to the support of our federal and provincial governments, RHI remains focused on galvanizing the world's best researchers and clinicians to collaborate on accelerating the translation of the most promising research into practical solutions for individuals with SCI.



## The Facts on SCI in Canada

- There are an estimated **86,000** people living with SCI in Canada.
- This total includes over **48,000** people with paraplegia and over **37,000** people with quadriplegia.
- An estimated **4,300** new cases of SCI occur each year.
- About half of all new cases are due to traumatic injury – most sustained from **falls or motor vehicle accidents**.
- The economic cost of traumatic spinal cord injury is estimated at **\$2.7 billion a year** for healthcare, equipment and modifications and long-term care. Costs are even greater when including those with chronic injuries.
- The lifetime medical costs for quadriplegia exceed **\$3 million**; for paraplegia, **\$1.5 million**.

# Barriers to Further Progress



## The Need for Standardized Treatment of SCI in Canada

At this time, although there are no known regenerative cures for the restoration of neurological function in people with chronic SCI (those currently living with paralysis from a previously sustained injury), the newly-injured have a greater chance of recovery due to advances in surgical interventions, the timing of receiving these interventions after injury and advances in rehabilitation efforts.

However, not all newly-injured Canadians can benefit from these advances as they are not universally available across the country. This disparity in care is due to a lack of institutional standards for SCI care across the country, limited clinical practice guidelines and limited consensus on the outcome measures necessary to evaluate the impact of treatment for people with SCI.

The success of translating research findings into future treatments and interventions will be limited if care across the country is not standardized with outcomes that are validated and mechanisms that disseminate new knowledge.

Treatments to minimize paralysis will need to be provided hours following injury and evaluated in multi-centre clinical trials. Providing optimal treatment will require a

detailed understanding of the current healthcare system and the changes needed to provide treatments 'out in the field' hours following the injury. Increasing our ability to understand, measure and standardize the clinical environment will enable us to provide improved care for individuals with SCI and ultimately prepare them for curative treatments as they become available.



## Ensuring Equitable Care for All Canadians

In 2012, RHI partnered with Accreditation Canada to develop comprehensive, evidence-based standards for SCI care in acute and rehabilitation settings. These standards were developed to become a vehicle for advancing the consistency and reliability of SCI care across Canada, while utilizing the same accreditation process in which most hospitals and rehabilitation centres already participate. The SCI Standards were developed with the intent to provide content that is specific to the work that clinicians do every day, tailored to reflect the unique needs and journeys of care of SCI patients, and to incorporate current evidence-informed best practices in SCI care. At a broader level, the SCI Standards will help standardize and optimize care for people with SCI as more and more organizations across Canada adopt them, helping to establish Canada as a global leader in the field.

## Moving Research into Practice

On average, it takes 17 years for new knowledge to be translated into practice and even when knowledge is translated, the utilization of the knowledge is inconsistent<sup>1</sup>.

As we strive towards developing curative treatments for SCI, it is important that the knowledge generated along the way is translated into practice.

As described by the 'knowledge to action model' (Graham et al), knowledge translation (KT) is a dynamic and iterative process. It includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the healthcare system<sup>2</sup>. All of this takes place within a complex system of interactions between researchers and knowledge users. Knowledge users include other researchers, practitioners, administrators, policy makers and people with SCI. Implicit is the notion that evaluation and monitoring of KT initiatives, processes and activities are key components of the KT process. This overarching framework is critical to moving research into practice and will set the stage for the dissemination of cure(s) for SCI when they are ready to be implemented. Furthermore, it enables the impact of research initiatives to be evaluated and the successes and barriers to implementation to be identified.

Moving research into practice can also be impeded without adequate and appropriate engagement of consumers. RHI is committed to actively engage consumers in all of its activities and to ensure they receive optimal care.

At RHI, the approach of incorporating KT and consumer engagement throughout the continuum of research and best practice implementation will shorten the 17 year timeframe to achieve translation of knowledge into practice. This will ensure that all newly-injured Canadians with SCI will have access to cures as soon as they become available.

<sup>1</sup> Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. 2001. Available at [http://www.nap.edu/catalog.php?record\\_id=10027](http://www.nap.edu/catalog.php?record_id=10027). Accessed June 2011.

<sup>2</sup> Graham ID, Logan J, Harrison MB et al. Lost in Knowledge Translation: time for a map? The Journal of Continuing Education in the Health Professions. 2006; 26(1): 13-24.

## The Art of Implementation Science

Comprised of researchers, clinicians and KT experts and funded in partnership with RHI and the Ontario Neurotrauma Foundation, the SCI Knowledge Mobilization Network is a community of practice that evolved out of a national best practice implementation effort. The goal of the network is to improve health outcomes for individuals with SCI with demonstrated economic impact through implementation science leading to innovations in clinical practice. SCI KMN has established a multi-province initiative to accelerate the identification and adoption of evidence-based SCI care best practices in healthcare facilities. An independent assessment of SCI KMN showed that the majority of respondents (81%) believe that implementation of best practices to improve outcomes among SCI patients is effective at improving patient care.

*"SCI consumers are individuals with lived experience; including persons with SCI, their family and friends, as well as consumer-focused community organizations and advocacy groups"*



## Developing & Commercializing New Innovations for SCI

To directly benefit people with SCI, the delivery of new products, such as therapeutics and medical devices, requires that they are successfully brought to market, or commercialized. Commercializing such innovations through traditional models is challenging due to the complexity of SCI and the relatively low incidence and prevalence as compared to other chronic health conditions. For potential investors, the view of high scientific risk combined with a small addressable market can lead to the perception that SCI is an unattractive area to invest in.

However, there are several benefits for investors to commercializing innovations for SCI:

- People with SCI have clear unmet medical needs.
- There are numerous incentives to commercialize products for SCI by regulatory authorities such as the Orphan Drug Designation and the Humanitarian Use Device programs in the United States, which have specific guidance for rare diseases and conditions.
- Innovations that address the secondary complications following SCI such as pressure ulcers, neuropathic pain and urinary tract infections, may be applied to other health conditions; providing access to larger markets.
- People with chronic SCI are stable and represent a baseline against which the effectiveness of a therapy can be assessed. Stable baseline data enables investigators to more accurately measure the efficacy of a given intervention.

RHI's most valuable resource is its network. Great potential value exists between linking this global network of collaborators in SCI research and care with those developing and commercializing innovations to benefit people with SCI.

## Economic and Sustainability Considerations

In Canada, limited government resources are available for providing essential services to Canadians. Financial constraints in the healthcare system continue to be a major area of concern for healthcare providers and patients, particularly for SCI stakeholders where the annual economic burden of traumatic SCI is about \$2.7 billion<sup>3</sup>. Although improvements in care for people with SCI may become available through research, uptake of these improvements may be limited if they do not offer cost-savings to the healthcare system. It is critical that economic sustainability be addressed for all research and best practices implementation (BPI) endeavors at the onset; to ensure uptake by stakeholders while providing benefit to people with SCI.

Economic sustainability of our BPI efforts is an important and necessary consideration during the design phase of all research studies that could lead to best practices. Economic sustainability is also a major criterion for assessment of potential projects for RHI investment.

Through the generosity and leadership of the Rick Hansen Foundation and the Canadian federal and provincial governments, funding has been provided to enable the establishment of RHI and the implementation of its national and provincial programs.

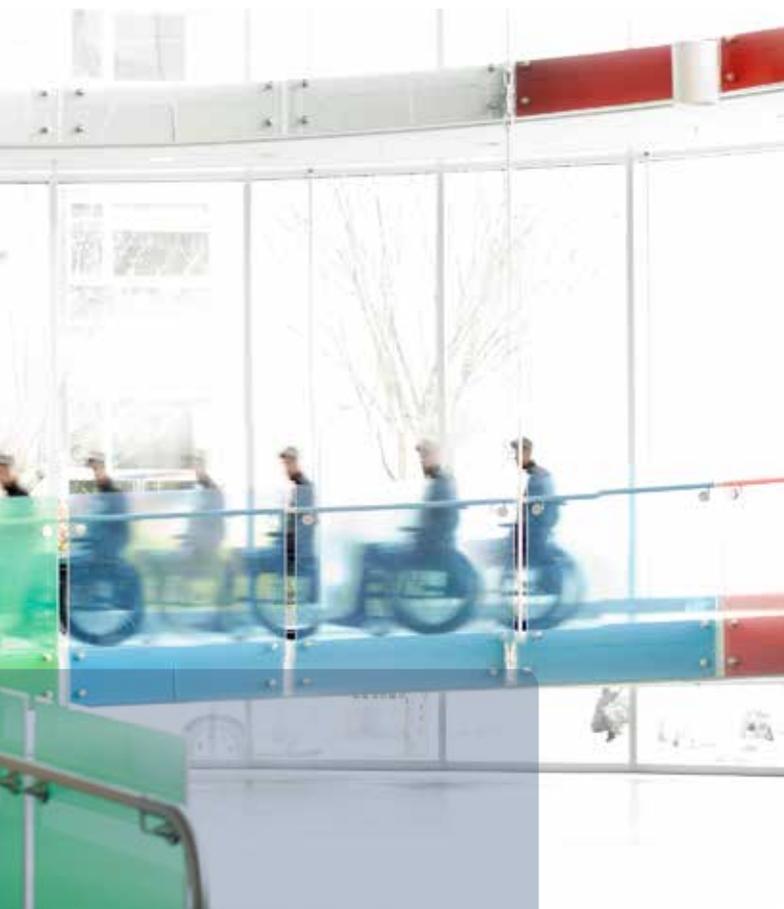
RHI is committed to continuing to demonstrate the value and alignment of its activities to government and public priorities to ensure continued support. To leverage the support received to date RHI is committed to identifying a broad base of national and international funding sources, and securing a diversified, sustainable revenue flow.

## Better Patient Outcomes

Providing expert and timely specialized care results in better patient outcomes and improved healthcare efficiencies, but knowing how to make this a reality remains a constant challenge in healthcare management. This is why RHI embarked on the Access to Care and Timing (ACT) project, which is a national, multi-centre research study describing the processes of healthcare delivery for individuals sustaining a traumatic SCI in Canada. The model was designed as a tool to inform clinical and administrative decisions in traumatic SCI care. It is able to simulate traumatic SCI patient flow through the healthcare system and test various “what-if” policy scenarios to predict both short- and long-term outcomes such as life expectancy, health service utilization, costs and health utilities following traumatic SCI.

<sup>3</sup> H. Krueger & Associates Inc. The Economic Burden of SCI: A Literature Review and Analysis. 2010. Available at <http://www.krueger.ca/index.asp?Page=Projects>. Accessed June 2011.

# Strategic Plan F2016-2023



## VISION

A world without paralysis after spinal cord injury.

## MISSION

To lead collaboration across the global spinal cord injury 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.

## VALUES

Teamwork

Global collaboration and partnerships

Innovation for impact

Integrity and trust

Exceptional patient-oriented outcomes

To advance our mission and vision, our work is based on the Praxis Model<sup>4</sup> in which RHI's activities are based on four key program areas (Cure, Care, Consumer and Commercialization) and six supporting strategies (translational research, best practices implementation, informatics, network development, consumer engagement and supporting the next generation of the "Best & Brightest" researchers).

<sup>4</sup> Barrable B, Thorogood N, Noonan V, Tomkinson J, Joshi P, Stephenson K, Barclay J, Kovacs Burns K. Model for bridging the translational "valleys of death" in spinal cord injury research. *Journal of Healthcare Leadership*, April 2014 Volume 2014:6 Pages 15—27.

# Going Forward

## Roadmap Towards the Cure: A 25-year Plan

In consultation with our stakeholders, RHI developed three ambitious milestones to work towards our vision of a world without paralysis after spinal cord injury.

### 25 YEAR MILESTONES (2038)

By 2038, RHI envisions that all newly-injured Canadians with traumatic and non-traumatic SCI will have access to novel therapies that will reduce paralysis and restore physical function in specific types of spinal cord injuries. There will be ongoing international collaboration on other potential therapies investigated through the RHI International Clinical Trials Network.

In addition, all newly-injured Canadians with SCI will receive comprehensive personalized treatments for their injury to minimize paralysis and facilitate productive and satisfying community living.

### 10 YEAR MILESTONES (2023)

By 2023, RHI envisions that there will be international collaboration on five promising neuro-restorative novel therapies (i.e., neuro-regeneration, neuro-protection or neuro-plasticity such as stem cells) in clinical trials utilizing the RHI International Clinical Trials Network that have been approved by the international SCI community. In Canada, 75% of all newly-injured persons sustaining a traumatic SCI will receive standardized care in SCI Centres that are part of the RHI Network.



### 5 YEAR MILESTONES (2018)

By 2018, RHI envisions that there will be global collaboration among the international SCI community towards identifying cures for SCI. As part of this effort, RHI will participate in two or more existing or new international clinical studies in neuro-restorative therapies. In Canada, 50% of all newly-injured persons sustaining a traumatic SCI will receive standardized care in SCI Centres that are part of the RHI Network.

By taking an integrated program approach and with ongoing consultation with our stakeholders, RHI is working towards achieving these milestones so that one day, a world without paralysis after spinal cord injury will no longer be our vision. It will be our collective reality.

# OBJECTIVES F2016-2023



In consultation with national and international stakeholders, RHI identified eight organizational goals for the fiscal period 2016-2023 that will work towards our mission and vision. RHI will continue to review progress to date and develop strategic plans every five years.

In order to achieve these goals, we have identified specific organizational objectives which are described in greater detail in our **business plans** (plans developed for our primary funders) and **Program roadmaps** (developed in consultation with our Program Advisory Committees: [www.rickhanseninstitute.org/work/programs](http://www.rickhanseninstitute.org/work/programs)). These objectives help prioritize RHI's organizational activities on an annual basis and support the activities described in the annual operating plans. The section below describes the organizational goals, their alignment to RHI's four programs (Cure, Care, Commercialization and Consumer) and the corresponding tactic and impact.



## Organizational Goal #1

Further our understanding of the biology and physiology of SCI.

### Alignment to Program

Cure, Consumer

### Tactic

Support promising cure-related preclinical and clinical research and evaluation that enable the molecular and cellular understanding of SCI.

### Impact

SCI research is accelerated toward cures.



## Organizational Goal #2

Support the development of promising therapies for neuro-restoration in acute and chronic SCI.

### Alignment to Program

Cure, Care, Commercialization, Consumer

### Tactic

Participate in new or existing neuro-restorative therapies in acute and chronic SCI and complete two existing clinical studies.

### Impact

SCI research is accelerated toward cures.



### Organizational Goal #3

Achieve evidence-informed equitable care for Canadians sustaining a SCI in Canada and address gaps in knowledge that will advance SCI care and facilitate future SCI cure(s).

#### Alignment to Program

Care, Consumer

#### Tactics

Support the accreditation of SCI acute and rehabilitation centres in Canada.

Support research and implementation of best practices in the prevention and management of secondary complications such as pressure ulcers, pain and urinary tract infections in SCI centres across Canada.

Support and lead activities related to improvement of neurological outcomes which includes: pre-hospital triage, acute care management and rehabilitation to maximize recovery.

Develop supporting tools and environment to promote long-term health, self-management, wellness and participation.

#### Impact

Improved and standardized delivery of care across Canada and internationally.



## Organizational Goal #4

Bring a greater number of innovations to market that will directly benefit people with SCI.

### Alignment to Program

Cure, Care, Commercialization, Consumer

### Tactics

Increase the pipeline of potential innovative therapeutics and medical devices for SCI and secondary complications.

Accelerate the commercialization process for innovative therapeutics and medical devices for paralysis and secondary complications following SCI.

Facilitate the implementation of innovative therapeutics and medical devices into the delivery of healthcare for people with SCI through advocacy and policy change.

Increase investor and industry engagement and participation in SCI research and development.

### Impact

Promising innovations in SCI technologies are brought to market in Canada and internationally.



## Organizational Goal #5

Inform, empower and engage people with SCI to seek opportunities to participate in clinical research and their own health decision-making.

### Alignment to Program

Cure, Care, Commercialization, Consumer

### Tactics

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

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

### Impact

People with SCI and their families and caregivers are more empowered to participate in research and in their own care.



## Organizational Goal #6

Continue to nurture and expand RHI's network locally and internationally and to include consumers, investors, industry and policy makers.

### Alignment to Program

Cure, Care, Commercialization, Consumer

### Tactics

Sponsor and participate in national and international conferences that bring together SCI researchers and clinicians in order to foster collaborations.

Host Praxis 2016 to discuss barriers for traversing the 'valleys of death' in the research-to-practice continuum.

Actively engage investors and policy makers in RHI's efforts for commercialization and policy change.

### Impact

A more responsive, effective and inclusive network.



## Organizational Goal #7

Demonstrate value and return on investment to RHI funders.

### Alignment to Program

Cure, Care, Commercialization, Consumer

### Tactic

Integrate economic and impact evaluations in key RHI projects.

### Impact

Validation of RHI's mandate and increased confidence resulting in funding renewal.



## Organizational Goal #8

Ensure sustainability of RHI operations and programs.

### Alignment to Program

Cure, Care, Commercialization, Consumer

### Tactic

Ongoing efforts to renew funding from existing sources and identify and secure funding from new and innovative sources.

### Impact

Assured and long term sustainability of RHI operations and programs.



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