

# The Spinal Cord Injury Strategy for Alberta

The Spinal Cord Injury Community Working Together  
to Make a Difference

JUNE 2021



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# Executive Summary

Spinal cord injuries are complex and varied, often having significant and lifelong impacts on people's physical and mental health, social well-being, employment and family. Challenges range from the urgency of immediate care and recovery, to living with chronic health conditions well after the initial injury, to dealing with socio-economic changes, to accessing needed resources and supports.

For every individual living with a spinal cord injury, countless more family members, friends, employers and others are also impacted. This means that the consequences and high costs associated with a spinal cord injury can be measured in both dollars and in lives.

In 2016, people with lived experience of spinal cord injuries and representatives from more than 12 different organizations — comprising researchers, academic institutions, health care professionals and leaders, and government — came together to determine how these diverse people and groups could work together to address the complex issues of spinal cord injury. They recognized that by working as partners and across disciplines, much more could be accomplished than by working independently.

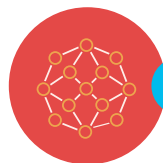
The stakeholder group formalized to become the Spinal Cord Injury Partner Committee and articulated a clear vision: to improve the lives of people living with spinal cord injuries. Its first priority was to develop a provincewide strategy to serve as a roadmap.





## Creating a guide for the future: the Spinal Cord Injury Strategy for Alberta

Collaboration lies at the heart of the Spinal Cord Injury Strategy for Alberta, which was built with and will be implemented through partnership. The Strategy will facilitate collaboration and connection among core stakeholders to provide concrete and measurable recommendations, identify clinical and social best practices and services, and support research for innovative medical, technological and social interventions. It articulates three primary goals:



1

**Strengthening the spinal cord injury network;**



2

**Supporting a holistic approach to daily living; and**



3

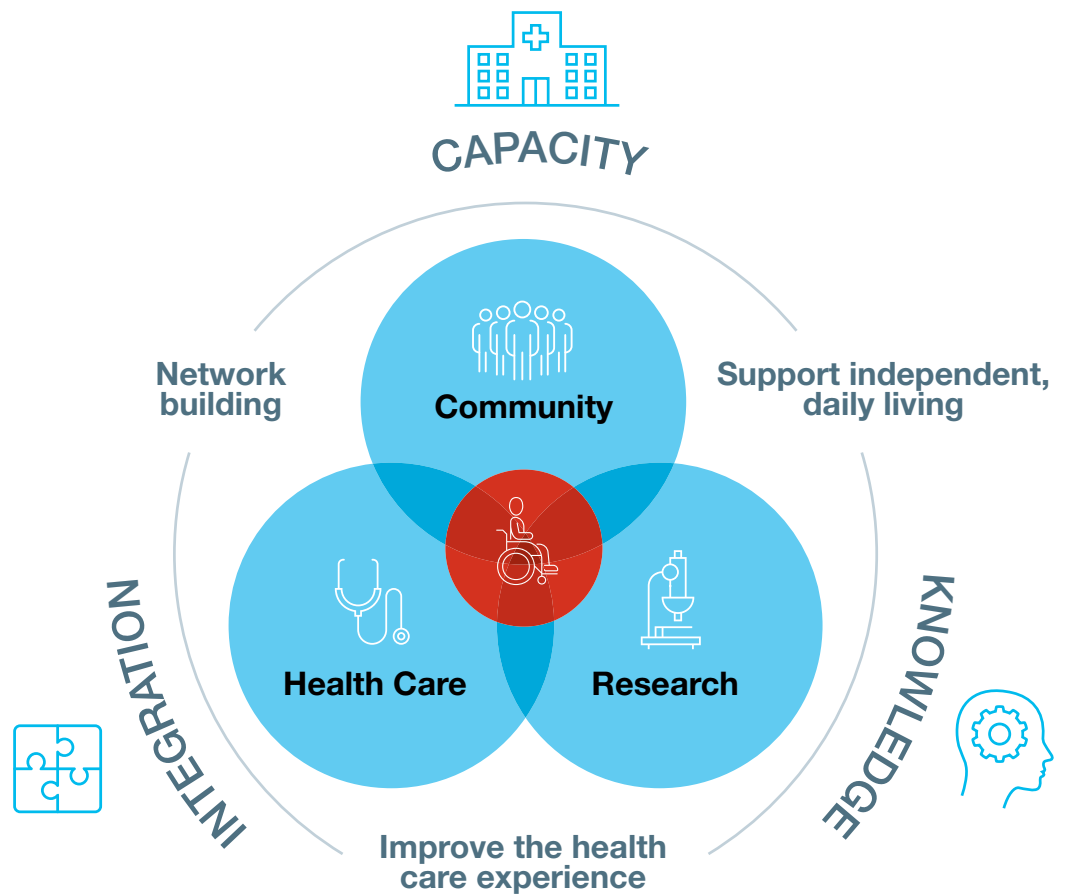
**Creating an improved health care experience.**



This document will be evaluated and amended as new priorities and recommendations are identified over the long term.

Strategic priorities centre on building capacity, knowledge and integration.

Figure 1 describes the relationship between the Strategy's priorities and goals which will be accomplished by the key sectors – community, research and health care. At the centre, the focus remains on those living with spinal cord injuries whose lives the Strategy aims to support and improve.



**FIGURE 1**  
Connecting it All Together





## Making a difference in lives, families and communities

The Strategy's inclusive and collaborative approach will not only integrate expertise across the community, health care system and research, but also create opportunities for advocacy and for raising the voices of people living with spinal cord injuries. With its emphasis on collaboration, the Strategy will play a pivotal role in improving quality of life by enabling and accelerating the cooperative development of best practices and resources for enhanced recovery, increased independence and active living, and an improved health care experience for Albertans living with spinal cord injuries. Over the short and long term, the Strategy is expected to:

- create greater capacity to develop initiatives to address gaps and challenges in daily living, health care and research. Collaborate on more-informed projects to bolster stakeholders' ability to translate information and treatments for end users;
- build on and better utilize existing knowledge and support the creation and translation of new knowledge from preclinical research to clinical and community-based research; and
- integrate the expertise, resources and knowledge sharing between the core stakeholders to improve the lives of those living with a spinal cord injury

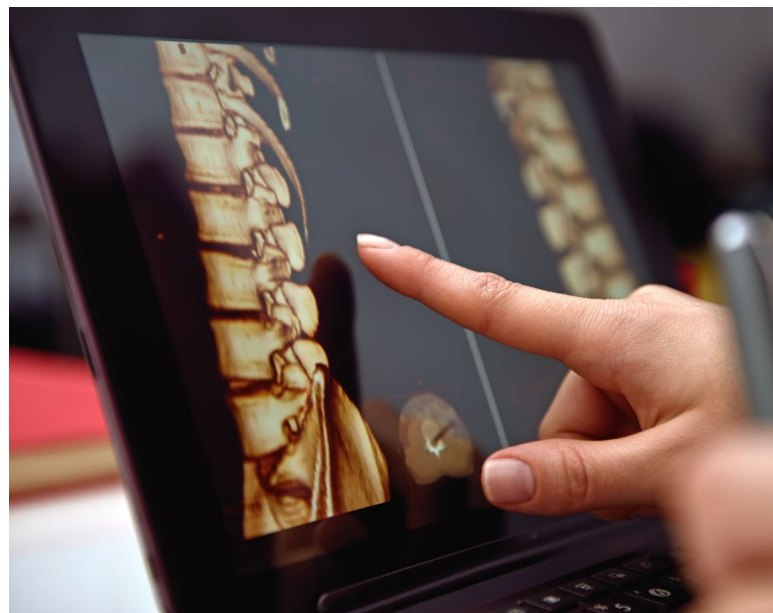
Ultimately, the Spinal Cord Injury Strategy for Alberta is expected to be a major step forward toward improving the lives of people living with a spinal cord injury. Facilitating and supporting initiatives that lead to evidence-based care, resources and treatments will improve daily, independent living and improve the health care experience for Albertans.

# Introduction

## What is a Spinal Cord Injury?

From the physiological perspective, a spinal cord injury is the result of damage to the spinal cord that causes temporary or permanent changes to muscle function, sensation and/or autonomic function to the parts of the body below the level of injury. The impacts of a spinal cord injury on physical function are diverse, and are influenced by location and severity of the injury, and whether it is traumatic or non-traumatic. This diversity of injuries is reflected in the many varieties of support, rehabilitation and resources needed throughout life by each individual living with a spinal cord injury. While therapies exist to help combat many of the ongoing effects (e.g., pain, blood pressure), none are able to fully restore function and there are many secondary health complications (e.g., bladder infections, pressure sores), which require continuous care.

Spinal cord injuries can have a significant and lifelong impact on a person's physical and mental health, social well-being, employment and family, requiring people to make numerous changes in their lives. Challenges range from the urgency of immediate care and recovery, to living with chronic health conditions well after the initial injury, to dealing with socio-economic changes (e.g., employment), to accessing needed resources and supports.



## Why do we Need a Provincial Spinal Cord Injury Strategy?

More than 5,200 Albertans<sup>1</sup> are directly affected by spinal cord injury, and with an aging population and the increasing number of falls generally associated with aging, the number of people who experience a spinal cord injury is expected to increase in coming years. For every individual living with a spinal cord injury, countless more family members, friends, employers and others are also impacted. This means that the consequences and high costs associated with a spinal cord injury can be measured in both dollars and in lives.

From an economic perspective, the health care system, individuals, their families and caregivers all experience major financial realities in providing the care needed to address all aspects of spinal cord injury.<sup>2</sup> The lifetime economic impact of a traumatic spinal cord injury in Canada, for example, including direct and indirect costs, ranges from \$1.5–\$3 million depending on the type of injury. This does not include the impact of the rising number of non-traumatic spinal cord injuries associated with an aging population.<sup>3</sup>

<sup>1</sup> Alberta Health Services Data Analytics

<sup>2</sup> Krueger H., et al. 2013. Chronic Diseases and Injuries in Canada

<sup>3</sup> Fasset D. R., et al. 2007. Journal of Neurosurgery: Spine



Concurrent with economic impact is the day-to-day impact on overall quality of life, especially for those who have inequitable access to care and resources including people living in rural locations, and vulnerable populations<sup>4</sup> such as people under the age of 65 who live in long-term care facilities, anyone from a lower socio-economic group, Indigenous Peoples and people from marginalized communities.



While the many challenges of transitioning back into community living following a spinal cord injury are difficult at the best of times, they are compounded by inequities in access to resources and supports, among them mobility needs, adapting to work and home environments, socializing supports and numerous other modifications. Meeting these needs can be even more challenging for people with limited access to resources. For example, something as simple as finding a gym to stay active, social and healthy can be almost impossible, because gyms with equipment adaptable for wheelchair users do not exist in every community and, when they do, are often highly expensive. Appropriate and accessible programs and resources to support employment, education and vocational training aids in financial stability, security and independence. This in turn also helps with affordability of necessary equipment, housing and transportation resources, which altogether affect a person's quality of life and ability to live independently and on their own terms in their community.

Given the many complexities of spinal cord injury, improving the lives of people living with spinal cord injuries is a considerable, yet essential, challenge. Finding answers is clearly beyond the scope of one discipline or one system. A focused, coordinated joint response — bringing together Albertans living with spinal cord injuries, clinicians, researchers, government, policy makers, caregivers and community — holds the potential to deliver meaningful results. Working together, treatments, care and supports can be developed and improved, in the clinic and in the community, to better the lives of people living with spinal cord injuries.

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<sup>4</sup> Fyffe D. C., et al. 2011. Topics in Spinal Cord Injury Rehabilitation





## A strategic response to an urgent need

The considerable and lifelong impacts on and costs to people directly and indirectly affected by spinal cord injury point to a critical need for a provincial strategy to create collaborative, innovative and novel solutions to address the many impacts on function, health and other facets of life faced by people living with a spinal cord injury every day.

Leveraging Alberta's well-recognized strength in research to deepen our understanding of spinal cord injuries and develop novel treatment approaches will lead to new therapies and technologies that will improve the lives of those living with a spinal cord injury. Knowledge and research — and mobilizing both in practice — is the key to creating informed, evidence-based solutions.

This can include optimizing the use of existing data sources (e.g., academic and health care databases) to answer research questions or generating new knowledge to increase understanding and develop new therapies. Because of the current lack of treatments and the complexity of spinal cord injuries, it is important to support research and translation, from early foundational and preclinical studies, to clinical trials and community-based research, through to implementation and application. It is also important to support community driven initiatives that address the current gaps in care, resources and supports for greater independent living and improved well-being. Integrating expertise and resources across community, research and health sectors, along with other academic disciplines (e.g., engineering, computer sciences) and partners, will expand Alberta's strengths and build the capacity to more effectively develop and implement novel, informed research and innovations and clinical and community initiatives.

An effective provincial strategy would use a multi-pronged approach, blending community support, research and health care to work together to improve the quality of life of people living with spinal cord injuries. In order to be successful, this strategy must address the myriad challenges in health care and community living, and strengthen research efforts.

# The Spinal Cord Injury Strategy for Alberta

The Spinal Cord Injury Strategy for Alberta brings together clinicians, researchers, government, policy makers and community in partnership with Albertans living with spinal cord injuries in shared purpose: to improve the lives and well-being of people living with spinal cord injuries.

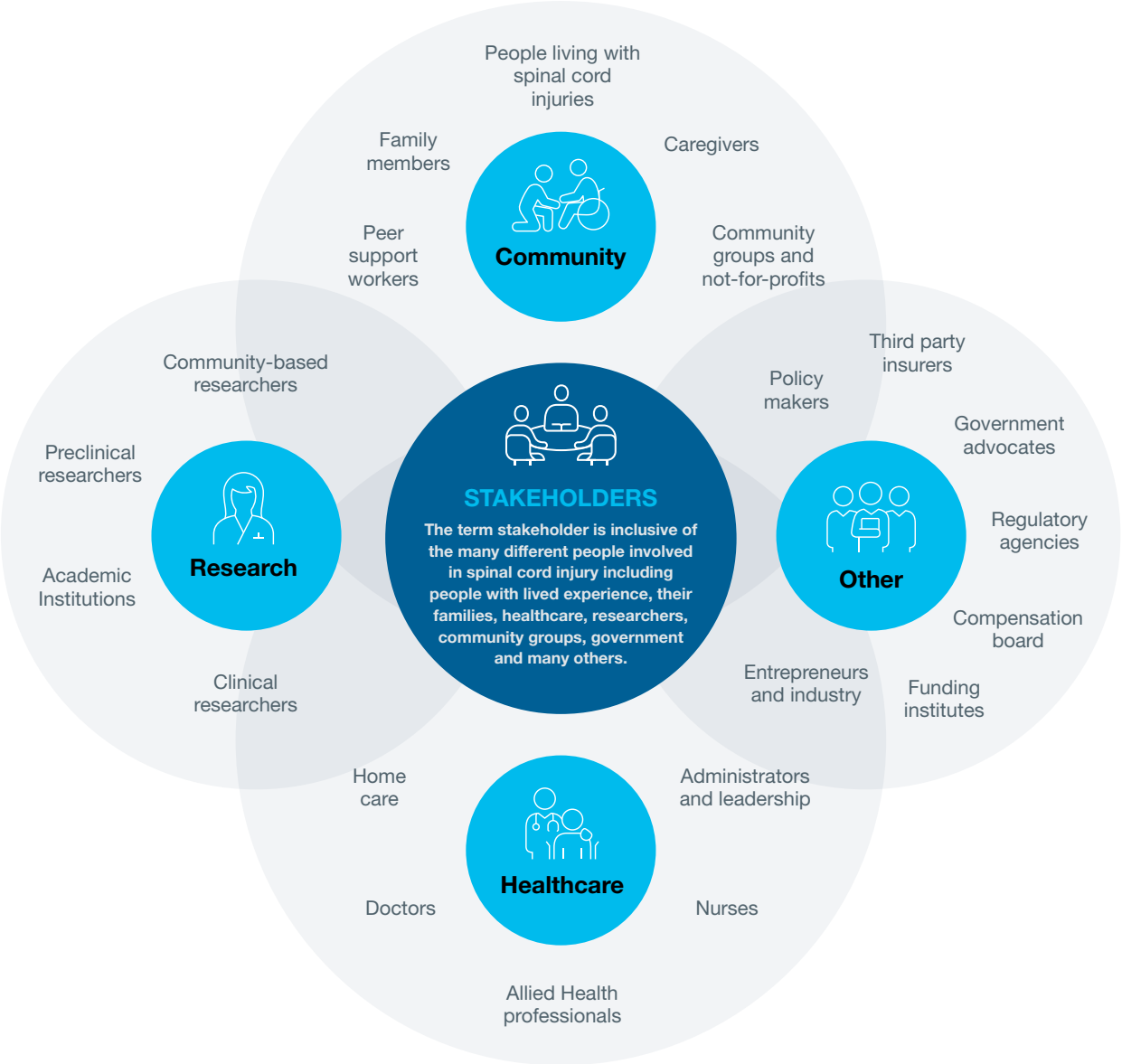
The Strategy will facilitate collaboration and connection among these core stakeholders to provide concrete and measurable recommendations, identify clinical and social best practices and services, and support research for innovative medical, technological and social interventions. An inclusive and collaborative approach will not only integrate expertise across the community, health care system and research, but also creates opportunities for advocacy and for raising the voices of people living with spinal cord injuries. With its emphasis on collaboration, this Strategy will play a pivotal role in improving quality of life by enabling and accelerating the cooperative development of best practices and resources for enhanced recovery, increased independence and active living, and an improved health care experience for Albertans living with spinal cord injuries.

The collaborative approach embedded throughout the Strategy was also integral to its development and the determination of its vision, mission, goals and priorities (see Appendix C for a list of participating individuals and groups). This Strategy was built through the cooperative support and sharing of expertise from people living with spinal cord injuries, those working for spinal cord injury not-for-profit organizations, clinical and preclinical researchers, government policy makers and advocates, and health care professionals and leaders, demonstrating the impact that is possible when many work together in a common cause.



The Strategy will facilitate collaboration and connection among these core stakeholders to provide concrete and measurable recommendations, identify clinical and social best practices and services, and support research for innovative medical, technological and social interventions. As represented in Figure 2 below, together these core stakeholders can work together to strengthen the network of spinal cord injury stakeholders in Alberta and beyond.

An inclusive and collaborative approach will not only integrate expertise across the community, health care system and research, but also creates opportunities for advocacy and for raising the voices of people living with spinal cord injuries. With its emphasis on collaboration, this Strategy will play a pivotal role in improving quality of life by enabling and accelerating the cooperative development of best practices and resources for enhanced recovery, increased independence and active living, and an improved health care experience for Albertans living with spinal cord injuries.



**FIGURE 2**  
Spinal Cord Injury Stakeholders



# Vision, Mission and Values

## Vision

Improve the quality of life of those living with spinal cord injuries in Alberta.

## Mission

Provide an inclusive, person-centred strategy that supports evidence-based practices, treatments and services to improve the lives of Albertans living with spinal cord injuries. Integrate knowledge and expertise for greater community, health care and research capacity province-wide.

## Values

1. Equitable and respectful inclusion of all stakeholders<sup>5</sup> with acknowledgement of the diversity among and within each system
2. Cultivate discovery and curiosity for innovation
3. Empower cross-sector collaborations

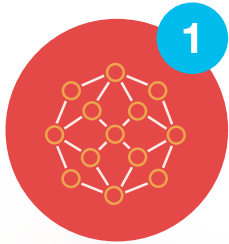
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<sup>5</sup> The term *stakeholders* is inclusive of people with lived experience, their families, and healthcare, research, community group and government stakeholders.



# Strategy Goals

The Strategy will play a pivotal role in improving quality of life by working toward the following three goals. These goals are ambitious but necessary and will require cooperative effort from all stakeholders.



## Strengthen the spinal cord injury network

- Increase sharing and integrating of expertise, knowledge and resources among all stakeholders
- Identify provincial initiatives and collaborative partnerships, particularly partnerships in rural and remote communities, Indigenous communities, and government partnerships at the municipal, provincial and federal levels
- Identify opportunities for national and international partnerships and initiatives



## Support a holistic approach to daily living

- Enhance health and social recovery for improved daily living in both urban, rural and remote communities and for vulnerable populations, including greater support and access to equipment, community rehabilitation and resources
- Increase independence and community participation through a person-centred approach to supporting physical and mental well-being and addressing environmental and infrastructure factors in the community
- Build community and support people living with spinal cord injuries and their families through social and community programs and services which promote and support independent living



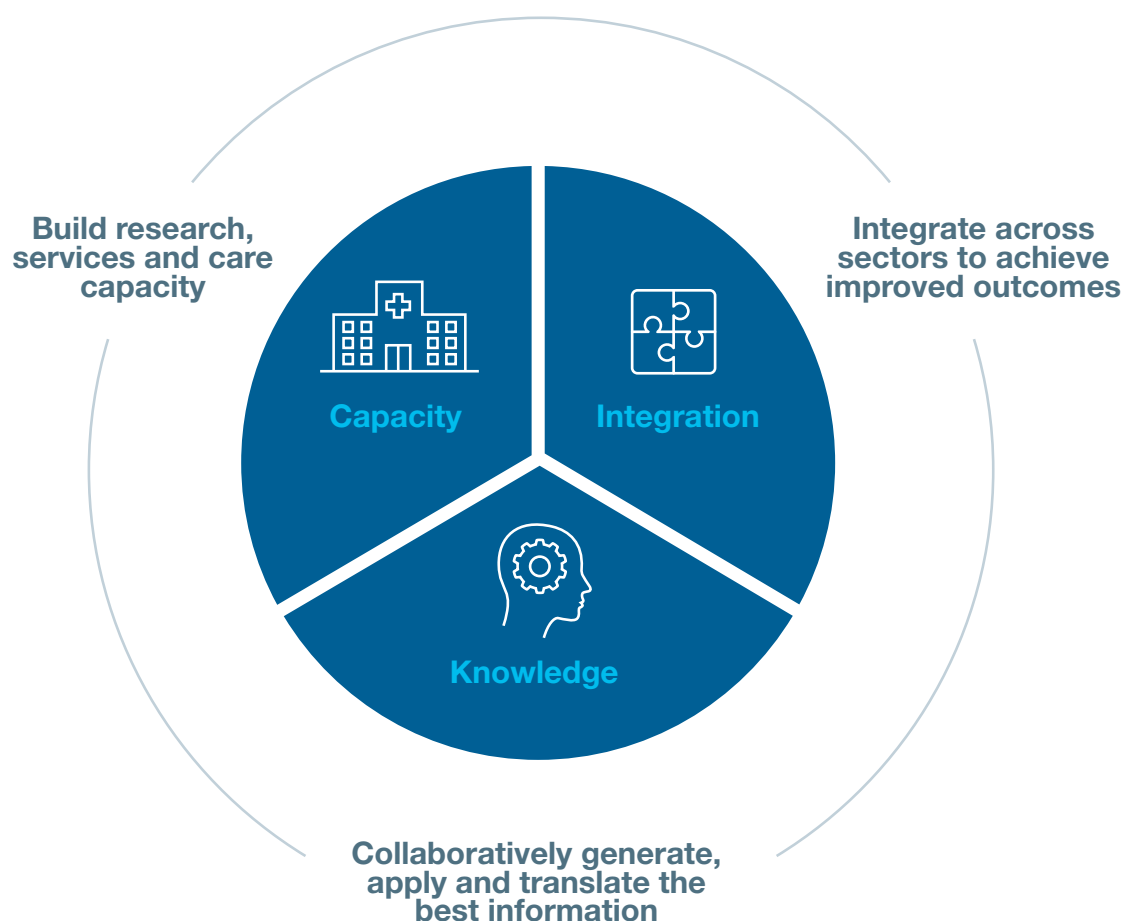
## Create an improved health care experience

- Foster compassion, without false pessimism or false hope, in diagnosis and rehabilitation planning in acute care, with life-long support for achieving health and functional goals and community participation
- Streamline support and increase access for out-patients obtaining supports, services, vital equipment and resources to support their physical and mental health, including for rural and vulnerable populations
- Reduce health-related complications and hospital readmissions
- Reduce health care costs for individuals and the overall health care system
- Implement novel, evidence-based treatments and therapies into practice by supporting research and translation from bench to bedside

# Priorities

To achieve its stated goals, the Spinal Cord Injury Strategy for Alberta focuses on three main priorities: Capacity, Knowledge and Integration.

Each priority includes a series of recommendations, with the basic assumption that the work be evidence-based, co-generated with persons with lived experience and subject matter experts, and evaluated regularly for informed and ongoing adaptability and improvement. These priorities and recommendations, outlined in Figure 3, support the Strategy's higher-level goals. The recommendations are meant as a guide, open to the network of spinal cord injury stakeholders in Alberta to tackle individually and/or collectively.



**FIGURE 3**

Inclusion and integration of the community, clinical and research activities







## PRIORITY 1 Capacity

Build capacity and momentum in Alberta for the strategic development and alignment of research, services and care.

### Key Recommendations

**1.1.** Establish leadership and accountability to support the mission and goals of the Strategy. This governance would strengthen the spinal cord injury network of stakeholders, support novel collaborations, seek out funding and investing opportunities, support knowledge integration and encourage resource sharing. Leadership should reflect the collaborative approach outlined in the Strategy and include representation from all stakeholders, including people with lived experience.

Leadership would implement or support collaborative implementation of the Strategy's Key Recommendations in all priority areas; however, establishing a leadership structure is not required to implement all recommendations.

**1.2.** Identify novel connections and strengthen existing partnerships. Encourage and support provincial collaborations to strengthen connections among the network of spinal cord injury stakeholders of health care, research and community partners, as well as expand the network to include national and international partners, as well as government partners (municipal, provincial and federal).

Capacity building should be an inclusive process with outreach efforts made to connect with rural and remote communities and specific populations (e.g., people living in long-term care facilities). Virtual and in-person methods should be used to build inclusive communication.

**1.3.** Recognize that Indigenous Peoples living with spinal cord injuries, and their communities, face unique circumstances and have distinct cultural approaches to health care, community living and well-being that must be appreciated and respected. A better understanding of how spinal cord injuries impact Indigenous Peoples is needed and will help inform the development of a framework for building collaborations and supporting Indigenous Peoples who are living with spinal cord injuries to appropriately address their needs and challenges. A systems and grassroots approach that aligns with existing collaborations, is led by and in partnership with Indigenous Peoples, and which honours Indigenous ways of knowing and cultural traditions, will ensure meaningful collaborations result in positive outcomes for people living with spinal cord injuries.

**1.4.** Identify current gaps in resources, services, practice and research to address the needs of people living with spinal cord injuries and their families. Conduct regular provincial environmental analyses and ongoing stakeholder engagement, as well as ongoing evaluation of existing programs and services. Work with and use existing environmental scans and information from national and international partners when possible (e.g., engagement activities by the Praxis Spinal Cord Injury Institute).

**1.5.** Identify and secure funding opportunities, such as grants, investments, partners (e.g., Alberta Innovates) and others to support strategic initiatives, innovations and commercialization, as well as activities that contribute to increasing collaborations among research, care and the community, and supporting knowledge translation and implementation.

Secure support for sustainability of the administration and governance of the Strategy to ensure implementation of the recommendations for capacity, knowledge and integration.

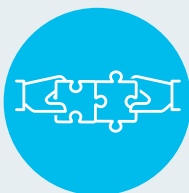
**1.6.** Continually adjust the Strategy using an evidence-based approach to identify and incorporate changes over the long term.

**1.7.** Develop and implement a support structure to aid and direct Albertans living with spinal cord injuries during local, provincial and national emergencies. This support structure would need to be easily accessible and widely recognized.

## Projected Key Results



**Increased number of provincial, national and international partnerships**



**More new gaps or challenges identified per year**



**Increased investor funding for innovations and research**



**Increased support for start-ups and companies**





## PRIORITY 2 Knowledge

Collaboratively generate, apply and translate the best information and knowledge to inform community resources, practice, service delivery and future research.

### Key Recommendations

**2.1.** Collectively define the information needed to ensure data and knowledge important to all stakeholders is collected, including clinical and academic endpoints, and also information important to the community and people with lived experience of spinal cord injuries.

**2.2.** Support and develop new data collection efforts and partner with existing data consolidation efforts provincially, nationally and internationally. This includes improving access to administrative health data and spinal cord injury registries and collaboratively strengthening data collection efforts.

Standardize data collection and consolidation, where appropriate, using provincial, national and/or international guidelines (e.g., the International Standards for Neurological Classification of Spinal Cord Injury).

**2.3.** Support preclinical and clinical research to increase the understanding of the impacts and injuries to the spinal cord and the development of novel innovations. Develop a research-driven strategy that builds on Alberta's research strengths and integrates collaborations across sectors to inform research, aid in translation and implementation, and better connect the community with current research projects.

**2.4.** Increase awareness and accessibility of existing information and databases to best use existing data and expertise, reduce redundant data collection, improve efficiency of research recruitment and ease the burden of participation in research studies.

**2.5.** Collectively use data, tools and lived experience perspectives to inform the design and implementation of evidence-based community, clinical and research initiatives. Consolidate data, when possible, and use innovative technologies, machine learning and artificial intelligence to aid in regular evaluations of large data sets to identify gaps. Use knowledge from other regions (provincial, national and international) to inform and adapt evidence-based services and care to Alberta's needs and to inform future research.

**2.6.** Support translation of initiatives, innovations and information to end-users (e.g., clinical staff, people with lived experience) and decision-makers (e.g., policymakers). Translation includes moving information and evidence across the spectrum of preclinical research, clinical and community research, and into the hands of end-users. Translation should be incorporated within initiatives and activities to streamline the implementation process.

Encourage all stakeholders to take part in translational and dissemination activities. These activities must address barriers and differing levels of access to information and technology by using multiple information channels (e.g., social media, newsletters, brochures and print materials, public seminars, community meetings, media relations, etc.).

### Projected Key Results



**Greater awareness of existing information, resources and expertise**



**Increased use of existing data from registries, health data bases and research repositories**



**Increased number of new research projects enabled by spinal cord injury grants**



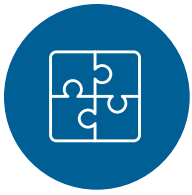
**Greater number of innovations brought to market**



**Increased number of new companies and entrepreneurs**



**Greater number of translational activities (e.g., information-sharing seminars)**



## PRIORITY 3

# Integration

Integrate knowledge, practice and research to achieve improved outcomes for people living with spinal cord injuries and their families.

### Key Recommendations

- 3.1.** Identify and develop initiatives that connect clinical, community and research activities and expertise. Involve organizational leaders (e.g., at hospitals, different levels of government, academic institutions) and support new and existing partnerships and personnel devoted to translational collaborations to ensure cross-sector integration. Encouraging and supporting translational activities and knowledge dissemination is important and requires dedicated people and resources.
- 3.2.** Develop a framework that can be used as a tool for engaging with different stakeholders to create novel collaborations, inform evidence-based activities and support advocacy work. This includes greater participation by and raising the voice of people with lived experience, as well as community and not-for-profit groups, to identify gaps and develop research and clinical initiatives. This framework should include supporting connections with rural communities, vulnerable populations and Indigenous communities. This framework could also be used to develop a stakeholder advisory process to inform ongoing activities of the Strategy.
- 3.3.** Integrate knowledge and expertise in developing standardized educational materials which can be tailored to different stakeholders.
  - For people living with spinal cord injuries and their families, education is needed to support their journey, particularly early after injury, to aid in planning, expectation setting and accommodations. This should include connecting with a trained and appropriately matched peer who can help navigate the health system and community resources.
  - For people working in the health care system, whether in emergency or acute care centres or in home care, develop educational materials that improve the understanding of spinal cord injury-specific health issues (e.g., bowel care, autonomic dysreflexia, etc.). This will improve care and help prevent secondary health issues that typically occur as a consequence of spinal cord injury.
  - For those in academia, support education, including using existing resources (e.g., the Alberta SPOR Patient Engagement Platform), on collaborating and working with community partners and people with lived experience.



**3.4.** Host an annual event that focuses on information sharing and promoting collaboration and integration across the research, community and health care sectors. This event could be a combination of presentations on current spinal cord injury projects in research, the community and health care, as well as an opportunity to pitch new ideas and identify new collaborations and opportunities. This event would need to be engaging and accessible to all stakeholders and feature a diversity of topics and interactive sessions across platforms.

**3.5.** Develop a robust evaluation mechanism to assess integration and impact across clinics, researchers, communities and government. This mechanism should include a sharp focus on impact in rural and remote communities and within specific populations (e.g., Indigenous communities, long-term care residents) and be used to inform future initiatives and communication strategies.

### Projected Key Results



**Increased stakeholders engagement informing project development, design and implementation**



**Improved health care outcomes**



**Increased person-reported improved quality of life**



**Increased number of people returning to work after injury**



**Increased person-reported participation in meaningful life**



**Reduced long-term costs related to the health care system and personal costs to those with lived experience**



**More access to standardized care and resources in spinal cord injury centres**



**Greater number of cross-sector collaborations and initiatives**



## Strategy in Action

The cross-sector collaborative approach outlined in the Strategy is already being used in the development of provincial initiatives to increase innovation and translation, build connectivity and address inequitable access to clinical care and supports. These early initiatives provide a proof-of-concept that these types of partnerships are not only possible but also valuable. They each are working to address one or more of the recommendations of the strategy (i.e., 2.3, 3.2, 3.3). For more information on these early initiatives please see Appendix A.

# Implementation and Action Plan

The actions in the plan will be developed based on the Introduction and Implementation meeting in June 2021. This meeting will provide the necessary input from the spinal cord injury community on how best to pave a path forward and implement the Strategy.

## Evaluation Framework

An evaluation framework to monitor the successful implementation of the Strategy, the impact on the integration across sectors and improvement of the daily lives and health care experiences of those living with spinal cord injuries is in development. The Introduction and Implementation meeting in June 2021 will help inform the framework's development.

# Appendix A

## Demonstrating Success: Building the foundation for a strong Spinal Cord Injury Strategy

Three early initiatives that align with the Strategy's mission demonstrate proof-of-concept that this approach of cross-sector collaborations is not only possible, but strengthens Alberta's overall capacity to work together and accomplish initiatives that will better the lives of those living with spinal cord injury.

These initiatives, **Increasing Innovation and Translation, Building Connectivity** and **Addressing Inequitable Access** – one each in the sectors of research, community and health – address current challenges faced by the spinal cord injury community. Each initiative has its own focus and outcomes, and each involves connection across the community, research and clinical stakeholders to increase capacity, knowledge and integration. Two of these initiatives, **Increasing Innovation and Translation** and **Addressing Inequitable Access**, were developed prior to the implementation of the Strategy, and are connected to the Strategy through collaboration and cooperation.

### 1. Increasing Innovation and Translation

**Challenge:** Currently there are no cures for spinal cord injuries and despite the implementation of many clinical and social best practices, many people living with spinal cord injuries continue to experience lifelong challenges. There is an urgent need to innovate and improve clinical, technological and social interventions that lead to enhanced care, independence and eventually, cures. Preclinical and clinical research and development, and their translation into real-life applications, are essential for driving innovation forward.

**Research Initiative:** Alberta researchers are committed to better understanding spinal cord injuries and developing novel treatments for those living with spinal cord injuries. Research occurs along a translational spectrum from understanding the mechanisms of injury, to developing therapies and clinical studies, to finally implementing therapies in care. Creative problem-solving is needed to develop and translate innovative ideas and technologies that can address the complex challenges of recovery and community living. Developing new academic (e.g., machine learning, engineering) and non-academic partnerships (e.g., industry partners) to advance novel research and technologies is crucial for increasing innovation. It is recognized that to effectively promote and translate research from the lab to the clinic, and ultimately to the community, collaboration among multidisciplinary partners is necessary.



## 2. Building Connectivity

**Challenge:** The community, including people living with spinal cord injuries, can often be disconnected from health care and research initiatives as well as from knowledge. This is not because the community cannot provide value to these projects, but because relationships often do not exist to support these types of collaborations.

**Community Initiative:** Growing the spinal cord injury network within Alberta involves strengthening the connections among the various stakeholders across the province. These encompass a wide range of individuals and organizations, including, but not limited to: the public, community groups, researchers, health care professionals, government, Indigenous partners and, most importantly, those with lived experience. This diverse network of stakeholders is essential in developing and implementing the Strategy, as well as the ongoing evaluation of priorities and activities. Care needs to be taken to include connection with vulnerable populations such as those under 65 years of age living in long-term care, those living in a lower socioeconomic standing, etc.

Recent progress in building connections includes the Alberta Spinal Cord Injury Community Interactive Learning Series, hosted by Spinal Cord Injury Alberta, Alberta Health Services and the Praxis Spinal Cord Institute, and the coalition of several neurological-focused community groups in the Alberta Neuroscience Network. Building on these successes, the Spinal Cord Injury Strategy for Alberta is committed to further developing collaborations through an engagement framework to ensure the Strategy, its initiatives and future projects are informed by, and align with, the needs of the spinal cord injury community.

## 3. Addressing Inequitable Access

**Challenge:** Specific clinical and social best practices are proven to have a positive impact on people living with spinal cord injuries. However, identified best practices are not available equally to all who would benefit from them. This may be due to a variety of factors, including discrepancies in the availability of rehabilitation technologies or lack of expertise and education in health care practices. It may also reflect regional issues of distribution, or the availability of or access to resources for community living, such as peer support, in rural areas. Additionally, the defining of clinical and social best practices should be evidence-based and involve discussions with people living with spinal cord injuries.

**Clinical Initiative:** Access to care, including community resources and support, can have a significant impact on the quality of life of people living with spinal cord injuries. People living outside major metropolitan areas must often travel long distances to access care, such as specialists, resulting in increased complications, emergency room visits and more-frequent hospital readmissions. There is a critical need to develop and implement an integrated care model with a particular focus on ensuring access to specialized, lifelong care for patients living in rural and remote areas and long-term care facilities. This initiative aims to create a model of standardized and equitable care for all Albertans with spinal cord injuries, while lowering overall health care costs to both individuals and the health care system.

# Appendix B

## Partnerships & Alignment for Building a Provincial Spinal Cord Injury Network

This is a list of provincial, national and international groups and organizations that work within the field of spinal cord injury.

### **Advocate for Persons with Disabilities**

The advocate's role is to enhance the wellbeing and quality of life of Albertans living with disabilities; as well, represents the rights, interests and viewpoints of Albertans with Disabilities.

### **Alberta Aids to Daily Living**

Assist Albertans who suffer from a long-term disability, chronic or terminal illness to pay for basic medical equipment and supplies

### **Alberta Health Services**

Provide a patient-focused, quality health system that is accessible and sustainable for all Albertans.

### **The Alberta Neuro Network**

A network of not-for-profit and community organizations working within the realm of neurological disorders and diseases in Alberta.

### **The Alberta Paraplegic Foundation**

Benefiting the lives of Albertans who are disabled, principally from spinal cord injury by funding worthwhile scientific and community development projects related to spinal cord injury.

### **Canadian Primary Care Spinal Cord Injury Network**

A national network of primary care providers focused on spinal cord injuries.

### **Campus Alberta Neuroscience**

Campus Alberta Neuroscience empowers Alberta's neuroscience and mental health community of researchers, entrepreneurs and industry, community groups and other partners to improve brain health through collaborative research, education, implementation and innovation.

### **Foothills Medical Centre**

One of Canada's largest hospitals providing advanced healthcare services to more than two million people from Calgary, southern Alberta, southeastern British Columbia and southern Saskatchewan.

### **Glenrose Hospital**

The largest free-standing, comprehensive tertiary rehabilitation hospital in Canada, serving patients of all ages who require complex rehabilitation to enable them to participate in life to the fullest.

### **Neuroscience, Rehabilitation and Vision Strategic Clinical Network**

A clinical network that brings together neuroscience, vision and rehabilitation academics, health professionals, policy-makers and community members to support development and implementation of health solutions.

### **The North American Spinal Cord Injury Consortium**

A collaboration of spinal cord injury organizations, individuals and groups to improve research, care, cure and policies that affect those living with spinal cord injuries, their families and community.

### **Praxis Spinal Cord Institute**

Lead global collaboration in spinal cord injury research, innovation and care using spinal cord injury knowledge translation to bridge health evidence with real-world delivery.

### **Premier's Council on the Status of**

### **Persons with Disabilities**

An advisory council for creating opportunities for persons with disabilities to participate equally and fully in society.

### **RESTORE Network**

REsearching STRategies fOr Rehabilitation (RESTORE).

A multi-institute initiative to support research into clinical neurorehabilitation aiming to enhance recovery for those living with neurological disorders by evaluating and discovering novel therapeutic interventions.

### **ReYu Recovery Centre**

Promoting neurorecovery through intense activity based training for improved function for those with spinal cord injuries.

### **SMART Network**

Provide a well-equipped and comprehensive interdisciplinary, multi-sector environment to foster innovation and create solutions to improve patient outcomes and quality of life while minimizing costs.

### **Spinal Cord Injury Alberta**

Empowering and supporting those living with spinal cord injury through five core services: client support and service coordination, community development and systemic change, peer program, information services, and active living.

### **Spinal Cord Injury Canada**

Assist Canadians with spinal cord injuries and other physical disabilities to achieve independence, self-reliance and full community participation.

### **Spinal Cord Injury Treatment Centre**

To promote awareness and create opportunities for people affected by spinal cord injuries to enhance their quality of life.

### **Steadward Centre for Personal and Physical Achievement**

Support community and individual achievement and excellence in Adapted Physical Activity and Para Sport by applying innovative research, sharing our expertise, and delivering quality programs, with and for, individuals experiencing disability.

### **Synaptic Health**

Reducing barrier and providing community-based rehabilitation for those living with neurological conditions.

### **Tetra Society of North America**

Empower people with physical disabilities by find solutions to overcome environmental barriers and access resources and opportunities.

### **University of Alberta – The Neuroscience and Mental Health Institute**

A multi-faculty, interdisciplinary teaching and research community dedicated to discovering how the brain and nervous system functions, understanding the basis for disease and translating discoveries into improved prevention and treatment options for people worldwide.

### **University of Calgary – The Hotchkiss Brain Institute**

Inspire discovery and apply knowledge towards innovative solutions for neurological and mental health disorders through six core values: excellence, collaboration, integrity, impact, creativity, and relevance.

### **Voice of Albertans with Disabilities**

Actively promote full participation in society and provides a voice for Albertans with disabilities. Guided by the principles of full participation, accessibility and equality.

### **Wheels of Change**

A peer group of Albertans living with spinal cord injuries who provide input and feedback on clinical and academic projects and initiatives.

### **The Wheels Girls**

A peer group of women in Alberta living with spinal cord injuries.

### **Wheelchair Sports Alberta**

Facilitate sporting opportunities for Albertan's living with physical impairments and/or wheelchair athletes to develop and compete at all levels from club to national.

# Appendix C

## Acknowledgements

The Alberta Spinal Cord Injury Partner Committee, who guided the development of the Strategy, recognized that through collaboration, specific and unique activities can be successfully developed to overcome the challenges of living with, caring for and researching spinal cord injury. The Alberta Spinal Cord Injury Partner Committee is composed of representatives from several different spinal cord injury stakeholder groups. Together, these groups represent the community, health care, academic and government partners involved in the spinal cord injury network in Alberta.

Along with the input from the Spinal Cord Injury Partner Committee, several other individuals representing people with lived experience, government, health care and research provided their time, knowledge and input in developing the Strategy through interviews and focus groups. The Spinal Cord Injury Strategy for Alberta would not have been possible without the invaluable expertise and support of several groups and individuals, including:

- Advocate for Persons with Disabilities
- Alberta Health
  - Alberta Aids to Daily Living
- Alberta Health Services
  - Clinical Quality Metrics
  - Foothills Medical Centre
  - Glenrose Rehabilitation Hospital
  - Provincial Research Data Services
- The Alberta Neuro Network
- The Alberta Paraplegic Foundation
- Campus Alberta Neuroscience
- Neuroscience, Rehabilitation and Vision Strategic Clinical Network
- Praxis Spinal Cord Institute
- Premier's Council on the Status of Persons with Disabilities
- The RESTORE Network
- ReYu Recovery Centre
- Spinal Cord Injury Alberta

- Spinal Cord Injury Treatment Centre Society
- University of Alberta
- University of Calgary
  - Spinal Cord and Nerve Injury NeuroTeam, Hotchkiss Brain Institute
- University of Lethbridge
- Wheels of Change Peer Group

Current and past members of the Spinal Cord Injury Partner Committee include: Gail Aguilon, Bill Barrable, Dr. Pamela Berg, Dr. Steve Casha, Dr. Rebecca Charbonneau, Teren Clarke, Penny Clarke-Richardson, Dr. Dave Collins, Jennifer Dotchin, Shaun Dyer, Dr. Karim Fouad, Dr. Chester Ho, Dr. Brad Jacobs, Dr. Katharina Kovacs-Burns, Jason Knox, Dr. Olle Lagerquist, Dr. Grant McIntyre, Louise Miller, Vance Milligan, Jennifer Moore, Dr. Vivian Mushahwar, Dr. Vanessa Noonan, Dr. Aaron Phillips, Dr. Ian Rigby, Dr. Carlyn Volume-Smith, Michelle Wallace, Dr. Patrick Whelan, Dr. Shannon Wowk.





