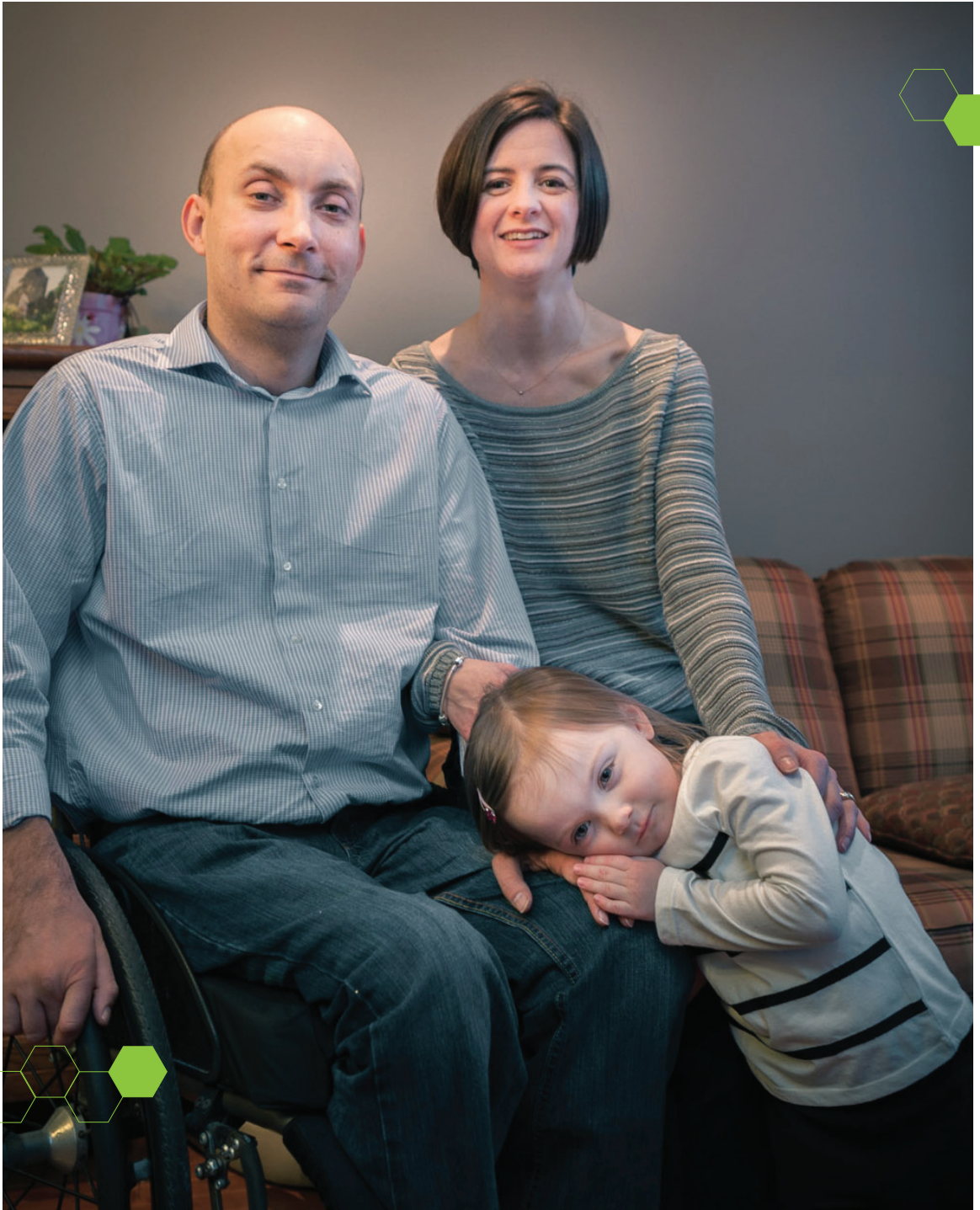




**SPINAL CORD INJURY:
A MANIFESTO FOR
CHANGE**



LET'S

CONNECT

NOW

“Living with a spinal cord injury is challenging enough. But being paralyzed also means dealing with complications, like pressure ulcers, fractures and cardiovascular problems. These problems can have a significant impact on your daily life. I’ve fractured my leg, and experienced first-hand the perils of osteoporosis at a young age. I’m prone to sudden and potentially dangerous spikes in blood pressure. It can become overwhelming, trying to lead a ‘normal’ life while dealing with these problems – or trying to avoid them. And I worry they will get worse as I grow older.”

*– Paul Peer, 38
husband, father, quadriplegic*

SPINAL CORD INJURY: A MANIFESTO FOR CHANGE



This is a call to action. A plea for change. A pledge to make life better over the long term for people whose complex needs are not being adequately served.

Spinal cord injury (SCI) can be devastating. Imagine having limited or no voluntary movement of your legs, arms or hands. Eating, dressing, bathing, even breathing – these are things many people with SCI can't do without help.

People with SCI may require as much as two years in acute and inpatient rehabilitation hospitals and outpatient rehabilitation services of one type or another. Then, after rehab is finished, the long, hard battle to maintain health and wellbeing continues. In the wake of their injury, they must deal with a whole range of 'secondary' health conditions' – for the rest of their lives.

If you have a SCI, there's a good chance you'll develop a pressure ulcer, fracture or heart disease, among other health issues. You'll see a physician and be rehospitalized three times more often than people in the general population.¹

Shockingly, a decade after injury, most people with SCI report having seven concurrent secondary health conditions.² One in four of these people is hospitalized each year while others visit emergency rooms on multiple occasions, seeking urgent care.^{3, 4}

We can do better. And, as a society, we must.

We're not starting from zero. We've already done some groundbreaking work. In 2012, the Canadian rehabilitation community produced a landmark report, known as the E-Scan Atlas,⁵ which described the state of Canadian rehabilitation services for people living with SCI. The E-Scan provided a blueprint of what needs to happen to transform SCI rehabilitation practice across Canada.

And that's what we're going to do now: move from blueprint to action.

A few months ago, 23 experts from Canada and abroad gathered to create a plan of action. It's laid out in this Manifesto – an unprecedented document that contains concrete action items to transform SCI health-care delivery over the next five years. Simply put, this plan will help ensure that people with SCI can access vital services, when and where they need them. We can make this happen. Let's connect now.

In this document, we outline four distinct steps that must be taken to address three major health problems that plague people with SCI: pressure ulcers, fractures and cardiovascular disease. The measures we suggest can significantly reduce the enormous burden SCI places on individuals, their families, our health-care system and society as a whole.

A COMPLEX, COSTLY CONDITION

SCI is one of the **1%** of conditions in Ontario with the highest health care spending.⁶

SCI costs Canadian society an estimated
\$3.6 billion
per year.⁷

The estimated total lifetime economic burden of a SCI in Canada ranges from about

\$1.5 million
for incomplete paraplegia to

\$3 million
for complete tetraplegia.⁷

The direct health-care costs in the first year following a traumatic SCI are estimated at over

\$100,000⁸



Canada is home to recognized clinical and scientific leaders in these three areas: 1) pressure ulcers, 2) fractures, and 3) heart disease.

We need to leverage this expertise to set new standards for preventing and managing these health problems.

Why the urgency?

Many Canadians don't have a family doctor. Think how serious this is if you are living with a SCI. Family doctors play a key role in recognizing developing conditions before they become serious and costly medical problems.

Even those with a family doctor are not always sent to the right specialist for their specific needs. And then, in addition to long specialist wait times, there's just the challenge of physically getting into the physician's office in a wheelchair, or onto an examining table. Amazingly, these issues are major barriers to provision of the best care for Canadians with SCI.

The wider picture is one of serious regional disparities and gaps in care. In some parts of Canada, people with SCI may not have access to specialized SCI health-care professionals, outpatient services – such as skin and wound management clinics – or funding for assistive devices, like a wheelchair cushion to help prevent pressure sores.

These gaps are troubling because people with SCI must manage these complex and costly secondary health conditions throughout their lives. Whether the injury was caused by trauma (e.g., car crash) or disease (e.g., cancer), people with SCI commonly need far more services than people with other chronic diseases.

What needs to happen?

We know there are silos of excellence in SCI services, wound management, heart disease and fracture care across Canada. But we need to connect these services and create a coordinated network of health-care providers that people with SCI can quickly access, wherever they are. An organized system of expert services would ensure the right diagnosis, the best therapy based on acuity and severity, in the proper setting – whether the problem is skin, bone or heart-related.

This Manifesto presents four directives for action. Each contains specific actionable items, including groups we will work with to achieve our intended outcomes. This game-changing approach will significantly improve the health and well-being of people with SCI, and reduce the challenges associated with navigating our health-care system and the burden of illness for people living with SCI. It's time to draw together our many strengths in rehabilitation and health-service delivery across Canada.

Let's Connect Now.

It's time to do better, to make treatment of spinal cord injury a public priority. And this is the way to do it.

THE CHALLENGE:

PRESSURE ULCERS

Decreased skin sensation and reduced mobility are among the reasons people with SCI develop pressure sores. Just sitting improperly, or not changing position, can bring one on in as little as an hour.



Pressure ulcers affect 95% of individuals with SCI over the course of their life.⁹

\$5K

Pressure ulcers increase frequency and length of hospitalization.¹⁰ In Ontario, the cost of treating pressure ulcers is estimated at \$4,745 per month for each patient living in the community.¹⁰

Pressure ulcers can get in the way of work, school and social activities. In extreme cases, pressure ulcers can be deadly.

Annual incidence and prevalence rates remain high at 30%,^{11,12} but use of prevention best practices can reduce treatment-related costs by 90%.^{13,14}

90%



1

Invest in specialty outpatient rehabilitation services to markedly reduce the number of inappropriate SCI-related emergency room (ER) visits and unnecessary hospital admissions for pressure ulcers, fractures and cardiovascular disease in five years.

To achieve this goal, we will:

- Communicate our findings and plan for action, using multiple modalities, directly to provincial health ministries, Local Health Integration Networks (LHINs), Community Care Access Centres (CCACs), centres locaux de services communautaires (CLSCs), health authorities, health networks and health-care administrators to fund and support a network of primary-care physicians and community-service providers that can efficiently resolve SCI-related health problems currently managed through ER visits and hospital admissions.
- Establish partnerships with provincial health ministries and health-care professionals/administrators to provide resources to develop an interprofessional team specializing in SCI secondary complications, and establish a prevention-oriented outreach program that supports existing services.
- Engage actively with health-care researchers and economists to understand why people with SCI use the ER and/or require hospitalization, and then develop a tracking system that will monitor the quality of care and health outcomes.
- Implement targeted educational programs that provide clinicians and consumers with preventative strategies, and help people with SCI to connect with existing services when they, themselves, spot early signs of complications.

Benefits:

Fewer inappropriate ER visits and hospital admissions; **greater support** for primary-care physicians and community-service providers; **coordinated networks** of care; **better informed** clinicians and consumers.

2

Reduce the incidence and severity of pressure ulcers, fractures and cardiovascular disease among people with SCI.

To achieve this goal, we will:

- Promote action among rehabilitation centres of excellence and key national SCI organizations to establish a Canadian Association of Spinal Cord Injury Rehabilitation Professionals (CASCI RP). This group will integrate and coordinate services, promote information-sharing and implementation of best practices, and support the translation of research into new approaches.
- Assist provincial health ministries and rehabilitation centres of excellence to help people with SCI better manage their health through coordinated, systematic and ongoing education, awareness, and feedback programs.
- Coordinate with Telehealth agencies and their industrial partners to develop evidence-informed SCI-specific training programs and care ‘algorithms’ that can be used by national and provincial call centre hotlines.
- Use social media platforms and traditional media to create Internet-based forums where people can share knowledge and experience about living with SCI.

THE CHALLENGE:

FRACTURES

Bone loss is a big challenge for people with SCI. It leads to an increased risk of lower-extremity ‘fragility’ fractures. These breaks can result from something as simple as being transferred to a car.

1 in 10 people with SCI get a lower extremity fracture each year.¹⁵ These injuries increase the risk of other problems, such as cellulitis, pressure ulcers, blood clots, and depression.

Studies show that lower-extremity fractures are associated with increased risk of mortality up to **5** years post-fracture.¹⁶

7X Patients who are hospitalized for fractures stay seven times longer than those who don’t have fractures.¹⁷

Best practices in fracture management strategies are essential to reduce morbidity.¹⁸

Benefits:

More effective, timely and appropriate **access to care**; earlier **recognition** and detection of SCI-related complications; **reduction** in incidence and severity of secondary problems; less reliance on front-line **health-care resources**; **fewer** ER visits and hospital admissions.

3

Accelerate access to new technologies and advanced rehabilitation therapies.

To achieve this goal, we will:

- Actively solicit venture capitalists, angel investors, technology incubators, and governmental organizations to rapidly move promising new technologies into the clinic for evaluation and implementation.
- Mobilize researchers, clinicians, hospitals, research ethics boards (REBs), and clinical trial finders to make it possible for every Canadian with SCI to take part in interventional studies.
- Work with non-governmental organizations (e.g., Ontario Neurotrauma Foundation and Rick Hansen Institute) and industry partners to make funding available for the creation of new software applications for people with disabilities.
- Partner with the Rick Hansen Institute (RHI), SCI Canada and other relevant SCI stakeholders and advocacy groups to create an implementation network that will speed the dissemination of new knowledge and best practices.
- Engage with the SCI Knowledge Mobilization Network and other SCI advocacy groups to measure implementation of best practices and the level of professional competence related to evidence-based therapies.

Benefits:

Faster dissemination of new knowledge and best practices; tracking health-care **improvements** and patient quality of care; **speedier evaluation** and delivery of new technologies; **rapid implementation** of self-management and assessment tools at **minimum cost**.

4

Create a widely-accessible national dataset to track the diagnosis and management of pressure ulcers, fractures and cardiovascular disease in Canadians with SCI.

To achieve this goal, we will:

- Seek out agencies such as Health Quality Ontario to create quality improvement plans that will enable the development and analysis of SCI-specific indicators and benchmarks.
- Work with specialists in pressure ulcers, fractures and cardiovascular disease to map the 'episodes of rehabilitation care' for people with SCI, and develop health-care quality indicators.
- Partner with public agencies to develop 'algorithms of care' to ensure people with SCI who lack insurance or cannot pay for services outside provincial health plans get appropriate care at the right time.
- Utilize available information technology platforms (e.g., Google resources) to develop a real-time system that will inform people with SCI about where and how to get specialized services (including accessible transit and alternative modes of care delivery).

THE CHALLENGE:

CARDIOVASCULAR DISEASE

The prevalence of symptomatic heart disease in people with SCI is 30-50%.¹⁹

30-50%

60-70%

For asymptomatic heart disease, it's as high as 60-70%.²⁰

Heart disease is the leading cause of death in both the acute and chronic stages after spinal cord injury.²¹



Routine heart disease screening is crucial for primary and secondary prevention improved quality of life, well-being and survival.¹⁸

- Specifically engage with Canada’s Top 100 Employers to develop a workplace ‘flextime system’ that can maximize productivity and minimize sick days and employee attrition by understanding daily activities of employees with SCI.
- As a model for other jurisdictions, assist Ontario’s Assistive Devices Program (ADP) in reviewing a wider range of new devices and technologies to predict usage and potential costs (compared to existing or emerging interventions).

Benefits:

Development of health-quality **indicators** and **benchmarks**; decrease in practice and service-delivery variations; reduction in inappropriate ER visits due to adverse events; better long-term health for people with SCI; optimization of **health resources**; better access to resources in the community; improved **workplace productivity**; decreased reliance on disability pensions; funding for a wider range of **new devices and technologies**, and reduction in inappropriately prescribed devices.

Moving Forward

Here in Canada, we have the expertise and the capacity to provide better care for people with SCI throughout their lives. When 23 experts in SCI care met to come up with this plan at the consensus meeting, "E-Scan: Moving from Blueprint to Action", the passion in the room was palpable. We cannot lose that spirit. We must not be deterred.

But we will need partners and allies to translate the Manifesto objectives into successful outcomes. Governments, granting agencies, health-care providers and professionals, industry, consumers and other stakeholders are all vital players.

Let’s move quickly – for the sake of 86,000 Canadians who live with a SCI, their families and their caregivers. They deserve to feel that change is imminent.

Join us in putting this plan into action. Together, we can transform lives.



Catharine Craven, BA, MD, FRCPC, MSc
Physical Medicine and Rehabilitation
On behalf of the E-Scan Investigative Team

Christina Balioussis, PhD
Dalton L Wolfe, PhD

Jane Hsieh, MSc
Molly Verrier, MHSc, Dip (P&OT)

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Expert Contributors to the Fall 2013 Consensus Meeting: E-Scan Moving from Blueprint to Action

These expert clinicians, scientists, administrators and consumers participated in the two day consensus process to derive the content and priority setting reflected within this document.

Christina Balioussis, PhD

Research Analyst
Toronto Rehabilitation Institute -
University Health Network

Fin Biering-Sørensen, MD PhD

Professor, Chief Physician
Clinic for Spinal Cord Injuries,
Copenhagen University Hospitals

Karen Campbell, RN PhD

Wound Project Manager
ARGC, Parkwood Hospital

Catharine Craven, MD FRCPC MSc

Scientist, Associate Professor
University of Toronto / Toronto
Rehabilitation Institute - University
Health Network

Dany Gagnon, PT PhD

Associate Professor
Université de Montréal

**Chantal Graveline, BSc PT MSc PhD
MBA CHE**

Director, Client Services
Spinal Cord Injury Ontario

**Shaun Gray, MD PhD CCFP FCFP
FRCPC**

Division Director and Associate
Professor
PMR University of Alberta

James Guest, MD PhD FACS

Professor
University of Miami

Sara Guilcher, PhD

Affiliate Scientist
Li Ka Shing Knowledge Institute,
St. Michael's Hospital, Toronto

Kristina Guy, PT MSc

Professional Practice Leader
Toronto Rehabilitation Institute -
University Health Network

**Stephanie Hadi, MScOT OT Reg.
(Ont.)**

Research Associate
Toronto Rehabilitation Institute -
University Health Network

Keith Hayes, PhD

Chair SCI Committee
Ontario Neurotrauma Foundation

Pamela Houghton, HBSc BScPT PhD

Professor
Western University

Jane Hsieh, MSc

Associate Scientist
Lawson Health Research Institute

Susan Jaglal, PhD

Toronto Rehabilitation Institute Chair
University of Toronto

Andrei Krassioukov, MD PhD FRCPC

Associate Director and Scientist
International Collaboration on Repair
Discoveries (ICORD)

**Sonja McVeigh, MD FRCPC Dip.
Sport Med.**

Physiatrist
Nova Scotia Rehabilitation Centre

Nicole Mittmann, MSc PhD

Executive Director
Health Outcomes and
PharmacoEconomic (HOPE) Research
Centre, Sunnybrook Health Sciences
Centre

Vanessa Noonan, PhD PT

Director, Research & Best Practice
Implementation
Rick Hansen Institute

**Arnold Noyek, OC MD FRCSC FACS
Officer**

The Order of Canada

Chelsea Pelletier, PhD

Postdoctoral Fellow
Toronto Rehabilitation Institute -
University Health Network

Milos Popovic, PhD

Professor
University of Toronto / Toronto
Rehabilitation Institute - University
Health Network

Molly Verrier, MHSc Dip P&OT

Senior Scientist
Toronto Rehabilitation Institute -
University Health Network

Dalton Wolfe, PhD

Scientist
Lawson Health Research Institute

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