



Participant and Family Information Package



Rick Hansen Spinal Cord Injury Registry
www.praxisinstitute.org



You are being invited to participate in the Rick Hansen Spinal Cord Injury Registry (RHSCIR) because you have sustained a spinal cord injury (SCI). This information package has been created to help you better understand the purpose and goals of RHSCIR. The information has been organized into a series of questions and answers. A member of the local RHSCIR team will follow-up with you to answer any questions that you may have after reading this. If you would like to contact the local RHSCIR team at any time, you can find their contact information at the end of this package.

“What is this all about?”

The Rick Hansen Spinal Cord Injury Registry is operated by the Praxis Spinal Cord Institute (formerly the Rick Hansen Institute).

The Praxis Spinal Cord Institute’s vision is:

A world without paralysis after spinal cord injury.

And its mission is:

To lead collaboration across the global SCI community by providing resources, infrastructure, and knowledge.

To identify, develop, validate, and accelerate the translation of evidence into best practices to reduce the incidence and severity of paralysis after SCI, improve health care outcomes, reduce long-term costs, and improve quality of life for those living with SCI.

Praxis is the process by which a theory, lesson, or skill is applied practically – moving knowledge into action. Its founder, Rick Hansen, epitomizes this paradigm and inspires the Institute to continue the work he started close to 30 years ago.

“Who is Rick Hansen?”

In the summer of 1973, Rick Hansen was a free-spirited, athletic fifteen year old who had a life-altering automobile crash that left him with paraplegia. His new reality came with a lot of challenges, but with determination, a sense of humour and a lot of heart, he found a way to keep doing the things he loved, and began to make new dreams. He went on to become a world-class athlete, winning 19 wheelchair marathons, three world titles, and 15 medals, 6 at the Paralympic Games and 9 at the Pan Am Games.



In the spring of 1985, he embarked on his biggest dream yet and wheeled the circumference of the earth to raise awareness and funds for spinal cord injury. Two years and 40,000 km later, Rick and his team returned to Vancouver, B.C., having raised over \$26 million dollars.

Today, as the founder of the Rick Hansen Foundation, Rick remains committed to improving the quality of life for people with a spinal cord injury. Rick's vision continues to endure and is the inspiration that drives the work of the Institute every day.

"What is a registry?"

A registry is a computer database used to store information about one thing – in this case, spinal cord injury (SCI). By collecting this information, we can better understand how a SCI affects a person.

For instance, if you keep track of all SCIs that happen in Canada in a single year, you are creating a very simple registry. If you collect more information, such as whether the patients are male or female, you will know how many people were injured that year and how many were men, and how many were women. The greater the amount and variety of information, the more detailed and useful the registry will be. As time goes on, the registry will be filled with all kinds of information like:

- **How SCIs happen** (car accidents, sports, fall, tumours, degenerative changes etc.)
- **What kinds of treatments are given** (the kind of surgery or medications used)
- What kinds of changes are necessary, if any, in the home, workplace or community (a wheelchair ramp, equipment in the bathroom etc.)



"Why create a registry?"

A registry holds a lot of information that can be used to better understand how a spinal cord injury affects a person and his/her whole life. By knowing this, health care professionals and researchers can work to improve how bedside care is given, which rehabilitation therapies work best, what kinds of research are most effective, and how people with SCI can best manage in their everyday life – at work, at home, and at play.



- Researchers
- Doctors
- Health Care Planners
- Nurses
- Rehabilitation Therapists
- Community Organizations and others

“How does a registry work?”

A team of people who want to improve an aspect of health care, (for example, the quality of life for people with a spinal cord injury) comes together and decides what information is needed and how to collect it. Tools such as computer programs, information collection forms, and education booklets are created. Then, people who have had a SCI are asked if they will take part in the project. If they agree, information about them and their injury is collected and stored in the registry. As information builds up in the registry, researchers and other health care professionals can use it to decide how to best help people with a spinal cord injury.

“Are there other registries?”

Yes. The idea of a registry is not new; other registries have been created for similar reasons and have been successful. For example, the information collected by the Canadian Stroke Network and the Canadian Trauma Registry has been helpful in supporting research and improving the care related to those areas.

“What will this Registry do?”

This registry will be the one place in Canada that holds detailed information about spinal cord injuries. One of the realities of SCI is that it is not very common compared to something like heart disease. Although SCI happens all over the world, there are actually not enough people in any one area to collect enough information to plan the best care and do the best research. The hope of RHSCIR is to involve all Canadians with SCI, and all SCI health care professionals and researchers (across Canada, and eventually around the world) in improving bedside care, advancing research, and improving the quality of life for people who have had spinal cord injuries.

The registry provides annual reports describing SCI in Canada, as well as reports to clinicians and hospitals about their patient care. Researchers have also used data from the registry to answer specific questions about SCI. Publically available reports and information about research can be found at www.praxisinstitute.org.

“Will the Registry help find a cure for SCI?”

We hope so. One of the long-term goals of the people who created the registry is to help scientists search for a cure. The information in RHSCIR will help create a database of information that will be used by health researchers, clinicians, and organizations providing community support. RHSCIR will also allow researchers

to link with individuals across the country interested in participating in future research studies. If you would like, the Praxis Spinal Cord Institute or the RHSCIR team will contact you about future research studies that you may be eligible for.

Finding the answers needed to be able to repair an injured spinal cord will take many years. Many things are happening already; this registry is a tool to help with this work. In the meantime, people with SCI need to live a good life.

During this long-term process of searching for a cure, more immediate goals include:

- Measuring how well current treatments work;
- Developing better treatments and therapies;
- Planning directions for future research;
- Improving the health care system for people with SCI;
- Understanding gaps in care and services & gathering information to help advocate for resources to fill these gaps

“If I agree to participate, what does that really mean?”

Participating really means allowing us to collect information about you, your injury, and the type of care and therapies you receive. Most of this information will be taken from your chart. In some instances, you will be giving the information by answering questions and filling out questionnaires. You will be followed up with in the community and information will be collected starting now and continuing throughout your life (unless you later decide you no longer wish to participate):

- At 18 months after your injury
- At 5 years after your injury;
- Every 5 years after that.

“What kinds of information do you want to collect?”

We would like to collect information about:

- You;
- The type of spinal cord injury you had;
- The kinds of treatments and therapies you receive;

- Your quality of life and community participation;
- Your overall health throughout your life.

“How will you collect the information?”

- In the beginning, a local RHSCIR staff will visit you two to three times in the hospital to start collecting information. Each visit will take about 10-30 minutes and will not get in the way of your regular care.
- We will also collect information directly from your chart and from other local hospital databases that already have information about your injury. This is to minimize the amount of your time that is required by using information that has already been collected about your injury.
- In the future, a local RHSCIR team member will contact you by email, mail, telephone, or in person to complete questionnaires; this will take on average 45 minutes each time.



“How do I know RHSCIR is acting in my best interest?”

Everything about RHSCIR has been closely examined by people who are separate from the Rick Hansen Institute and experts in the field of ethics, privacy, and the collection of patient information.

“What about my privacy?”

Protecting your privacy is **very important** to us. We will make sure that all of your information is properly protected and will not be released without your consent. The national RHSCIR team has developed a number of practices to ensure patient confidentiality is maintained, which includes the following:

- ✓ Your ‘identifiable’ data will be securely stored and available only to the local RHSCIR team(s) at the hospital(s) where you receive treatment and specific authorized staff at the national RHSCIR office.
- ✓ All RHSCIR staff (both local and national) have signed a confidentiality agreement and must adhere to strict privacy policies and procedures.
- ✓ The national RHSCIR team has a Privacy Officer who oversees the data that is housed in the national registry. The Privacy Officer ensures that your data is safely guarded and held in a secure, protected environment.
- ✓ RHSCIR has a Data Use and Disclosure policy governing any request for access to the national data. Nothing that could directly identify you will ever be disclosed.
- ✓ RHSCIR meets legislative provincial and federal standards.

“How will participating in RHSCIR benefit me?”

The number one benefit to you is that you will be helping health care professionals and researchers collect better information about what happens to people after they have a spinal cord injury. This can lead to better care and, eventually, a better life for all people with SCI. The information you share will also be used by researchers to speed up the pace of discovering real solutions for spinal cord injury, and improve the quality of life for people with SCI and their families.

“Who can I contact?”

You can always talk to somebody about your participation in RHSCIR. It doesn't matter when, or what you would like to talk about.

If you have any questions, please contact:

National RHSCIR Office:

Phone: (604) 827-2421 | Email: RHSCIR@praxisinstitute.org

For more information on the Rick Hansen SCI Registry, please visit:

www.praxisinstitute.org.