

IMPACT REPORT



SPINAL
RESEARCH
INSTITUTE

2023



Supporting research and consumer engagement to improve health outcomes and quality of life for people with spinal cord injury.

“

The right research can make a huge difference to people's wellbeing and quality of life.

Associate Professor Doug Brown AM
Founder, Spinal Research Institute

Right: **Elin Salmiranta** is a PhD candidate at the Research School of Health and Welfare at Jönköping University, Sweden. Her son suffered a spinal cord injury in 2014 prompting a career change. Her research seeks to improve the health of children with spinal cord injury by focusing on the caregiver role.

Cover: **Dr Anne E Palermo** with research participant Andres Morochz. Dr Anne E Palermo is a physical therapist, researcher, and Research Fellow at Neuroscience Research Australia (NeuRA). Her research focuses on secondary complications of spinal cord injury, specifically respiratory and balance function. She is currently investigating interventions that enhance trunk muscle function to restore breathing and balance post-SCI, with the goal of improving the evidence base for clinical practice.

Elin Salmiranta and Dr Anne E. Palermo are both authors in the SRI's *Why Research Matters 2022*.





The Spinal Research Institute acknowledges the
Traditional Owners of the land on which we work, the
Wurundjeri People of the Kulin Nation.
We pay our respects to Elders past and present.

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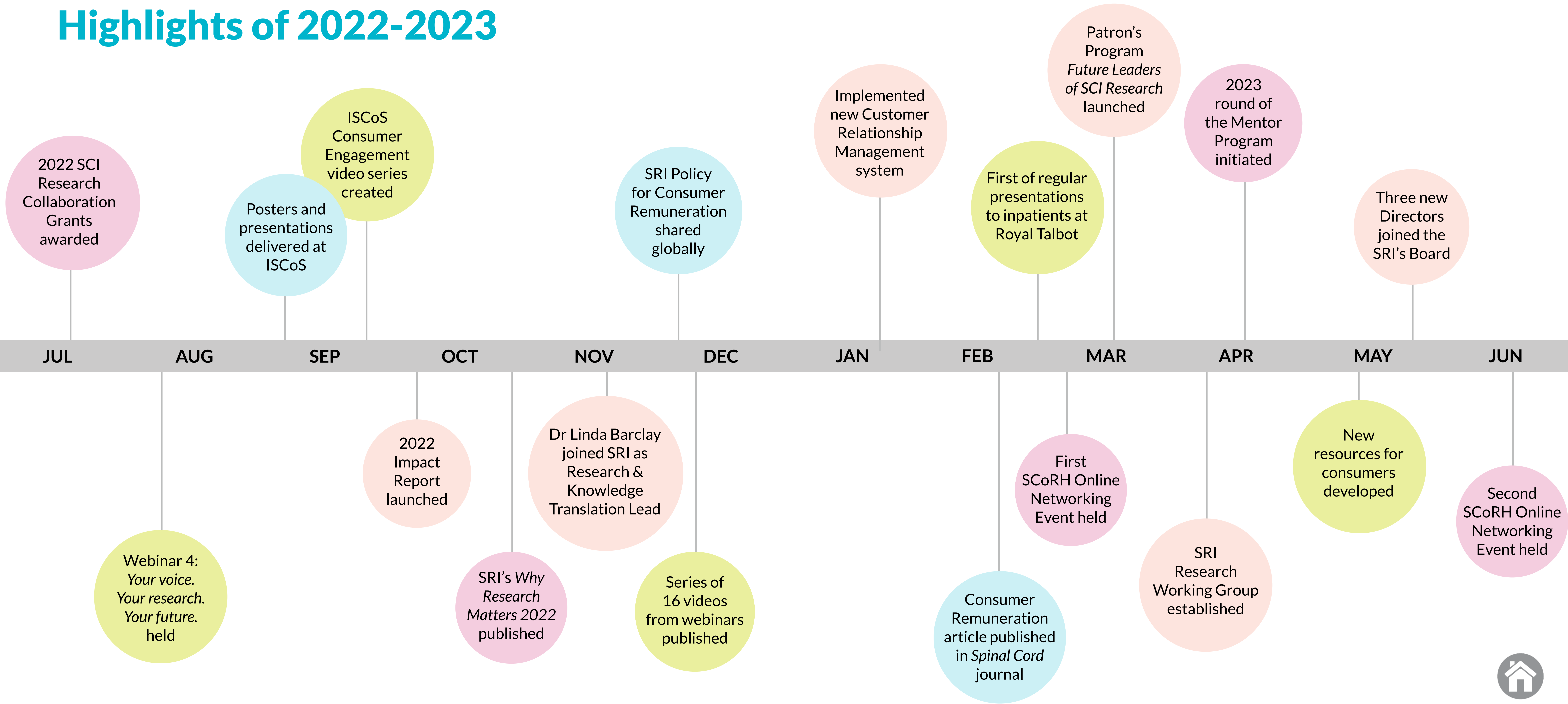
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Highlights of 2022-2023

● Programs for researchers ● Consumer engagement ● SRI research ● Operational



Chair of the Board's message

I remain extremely honoured to be the Chair of the Spinal Research Institute's (SRI) Board of Directors. This year we were delighted to welcome Grant Norton, Frank Nigro and Dr Caroline McFarlane to the Board. All three bring a diverse depth and range of skills, knowledge and experiences.

The SRI also farewelled Directors Margaret Beattie, Tom Morris, Kate Williams and Dr Andrew Nunn. All have played significant roles within the SRI and I would like to thank them and acknowledge their efforts. I am delighted that they remain great friends and advocates of the SRI.

Associate Professor Doug Brown AM has now moved to a non-executive Board role, so that we can continue to leverage his amazing wealth of knowledge, skills, networks and kindness. Doug is an original founder of the SRI and worked in the capacity of Executive Director.

I sincerely thank our Patron, Lady Southey AC, for her ongoing commitment and involvement, particularly with the Patron's Program - Future Leaders of SCI Research. This program supports the next generation of spinal cord injury researchers.

This year we implemented a new strategy that will drive innovative developments, growth in our programs, and broaden our international reach. The organisation as a whole has grown, which sees an increase in our research outputs and international standing. Leading by example, Kristine Hendry, CEO, and Antonio Vecchio, Community and Consumer Engagement Manager, co-authored a paper in the publication Spinal Cord, titled 'Involving people with lived experience of spinal cord injury in research: a policy for consumer remuneration'. This is the SRI's first journal publication and has raised awareness and discussion both nationally and internationally.

My aim is to give you a small taste of the impact that the SRI is having and I encourage you to read more about the SRI's far reaching work in this report.

However all of these achievements would not be possible without the commitment of our SRI team and the contributions of our donors, volunteers, ambassadors and Board. I am so grateful for your dedication to working together towards improving the lives of those with spinal cord injury. Thank you and please know, you are making a difference.

Fi Slaven
Chair, Board of Directors



Fi Slaven
Director & Chair



**Associate Professor
Doug Brown AM**
Director



Nick Morris OAM
Director



Dr Mario D'Cruz
Director



Craig Macaulay
Director



**Associate Professor
Marc Ruitenber**
Director



Grant Norton
Director



Dr Caroline McFarlane
Director



Frank Nigro
Director



Board and team member changes

Over the past year, the Spinal Research Institute (SRI) has seen a number of changes, particularly within the Board of Directors. These changes allow us to reflect on the significant contributions of departing Directors, and look to the future as we introduce three new Directors and a new staff member.



Associate Professor
Doug Brown AM

In June 2023, **Associate Professor Doug Brown AM**, resigned from his role as Executive Director of the SRI. He steps away from his involvement in the day-to-day operations of the organisation, which have evolved and matured in the years since Doug founded the SRI in 2011. Doug remains on the SRI Board as a dedicated non-executive Director.

Over the past year a number of long-term SRI Directors have decided to retire from the Board after many years of dedicated service. We are incredibly grateful for the contributions



Margaret Beattie

of **Margaret Beattie** (6-years service), **Tom Morris OAM** (8-years service), and **Dr Andrew Nunn** (10-years service) who has been involved with the SRI since its inception. Their knowledge, experience and acumen have been invaluable to the SRI and we offer them our sincere thanks.



Tom Morris OAM



Dr Andrew Nunn

Kate Williams, who joined the Board in late 2022, has needed to step down. We are very thankful to Kate for her contributions during her time with the SRI, especially in her role as Company Secretary.

We are delighted to welcome three new Directors, who all joined the Board in May 2023:

Dr Caroline McFarlane is a spinal consultant at the Victorian Spinal Cord Service. She has 20 years of clinical experience with a focus on rehabilitation in diverse settings around Victoria. Caroline has a commitment to

excellence in practice and is actively involved in women's leadership and supervision of registrars.



Dr Caroline McFarlane

Grant Norton is a degree-qualified mechanical engineer, holds an MBA, and is a Fellow of the CEO Institute of Australia. He brings a wealth of corporate experience having held senior leadership roles for almost 30 years. Grant's past roles include General Management within an Australian listed public company and country leadership roles within global organisations.



Grant Norton

Frank Nigro completed his Degree in Pharmacy at the Victorian College of Pharmacy. He was involved in the launch of Chemist Warehouse, where he remains actively involved in business development and professional culture. Frank is passionate about guiding new pharmacy graduates and junior pharmacists.



Frank Nigro

In November 2022, we welcomed **Dr Linda Barclay** in the newly created role of Research and Knowledge Translation Lead.



Dr Linda Barclay

Dr Linda Barclay is an Occupational Therapist with extensive clinical experience working with people with spinal cord injury. Most recently she has worked as a Senior Lecturer in the Department of Occupational Therapy at Monash University in a teaching and research role.

Linda provides a researcher's perspective and input to support the development and growth of the SRI's current programs. She is also establishing and developing new research-related projects and knowledge translation ideas and programs.

Linda's PhD and ongoing research focuses on improving the community, social and economic participation outcomes of people living with spinal cord injury. She is passionate about consumer engagement in research, and disseminating research findings to consumers and users of research in accessible formats including social media. Linda is excited to use her skills to contribute to the SRI's goal of facilitating impactful research.



Chief Executive Officer's message

I am very proud to share with you, the Spinal Research Institute's (SRI) 2023 Impact Report. This report highlights the impact of our work over the past year, as we strive to improve the health and quality of life of people with spinal cord injury.

In late 2022 the SRI Board and Team came together to create our new strategy for the coming three years. The new strategic plan (shown on the following pages) reflects the maturity and ambition of the organisation. It sets out a framework for the impact we aspire to, the outcomes we seek to achieve, and the tools we use to create change.

In addition to our continued work to facilitate collaboration and build research capability and capacity, the strategic plan also creates opportunities to inform research investment and influence health outcomes. In support of this, we created a new role within the SRI team to lead our research and knowledge translation activities, and we welcomed Dr Linda Barclay to this position at the end of 2022.

Of course, we could not create and deliver our innovative programs without the support of our donors and philanthropic partners, and I thank you for your continued commitment to the SRI.

I would also like to thank and recognise the dedicated contributions of the SRI team and Board, our Patron Lady Southey AC, our Ambassadors and Consumer Advisory Network, and the members of the research and spinal cord injury community who generously act as judges, reviewers, advisors, and mentors for our programs.

Lastly, on behalf of the team, I wish to express our gratitude to Associate Professor Doug Brown AM, who resigned from his role as Executive Director of the SRI in June 2023. While Doug will no longer be involved in the SRI's daily operations, he will continue working with the team in an advisory capacity and as a non-executive director. It is our privilege to continue the work that Doug commenced when he founded the SRI in 2011. By scaling research collaboration, capacity, and community engagement, we will achieve our vision to improve health outcomes and quality of life for the 20,800 Australians, and those around the world, living with spinal cord injury.

Kristine Hendry
Chief Executive Officer



Kristine Hendry
Chief Executive Officer



Deirdre Mori
Development Manager



Emma Peleg
International Research
Collaborations Manager



Dr Linda Barclay
Research and Knowledge
Translation Lead



Antonio Vecchio
Community and Consumer
Engagement Manager



Fiona Low
Office Administrator and
Program Support



Claire Backhouse
Marketing and
Communications Manager



Spinal Research Institute strategy for impact 2023 - 2026

Our purpose and vision

- Building research collaboration and consumer engagement, to improve the lives of people with spinal cord injury.

Our role

- Facilitate collaboration and cooperation within national and international spinal cord research to drive innovation and scale.
- Build consumer participation within research through understanding, confidence and experience.
- Influence and advocate for more research with an agenda shaped by the voices of lived experience.

Our beliefs

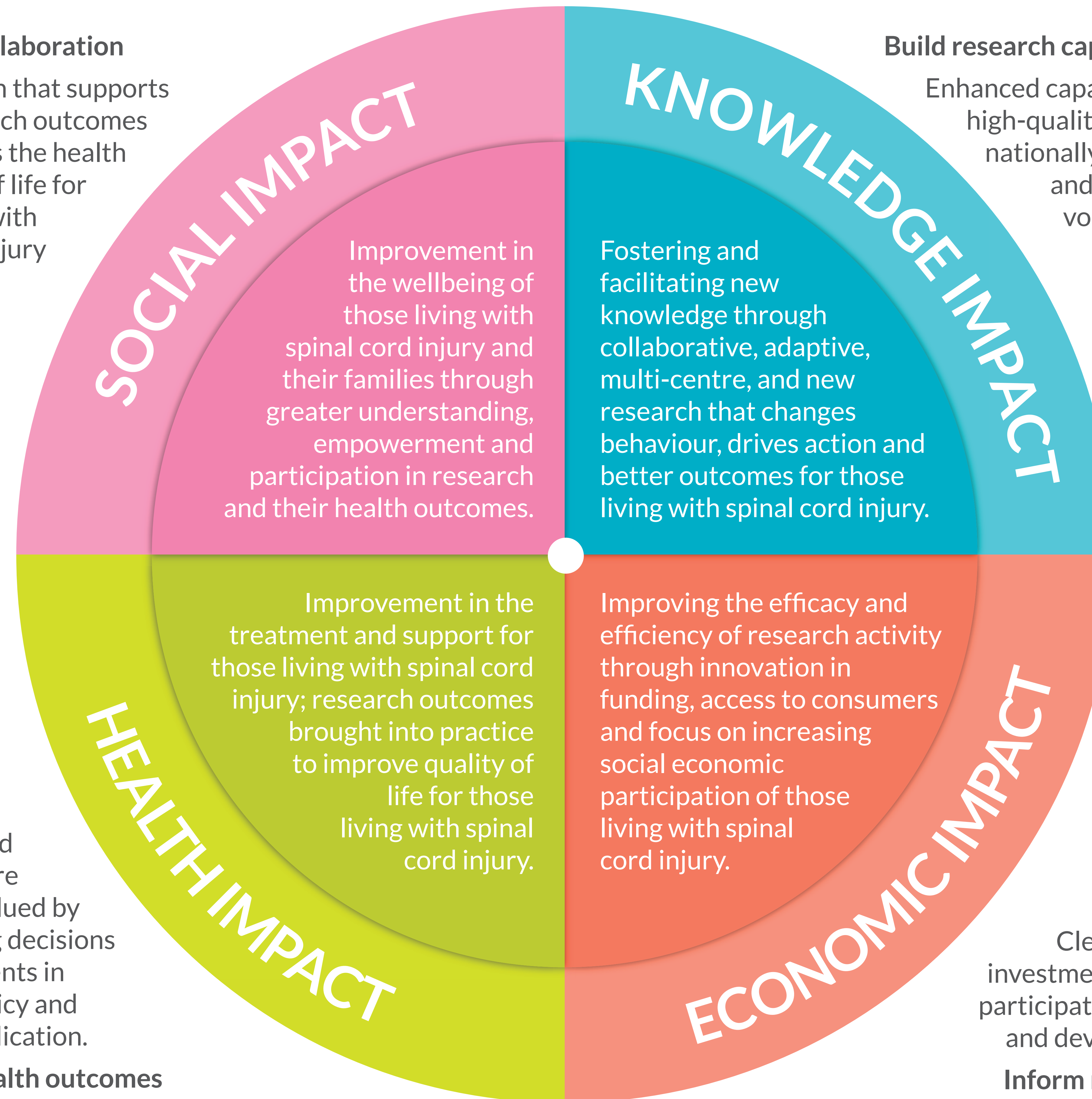
- We believe in the value and power of research to drive better health outcomes and improve the lives of people with spinal cord injury.
- We believe in the critical importance of collaboration from discovery to translation, and that alone we will not be as successful.
- We believe in the value of bringing together the voices of lived experience, researchers, clinicians and funders to drive relevance and better results.

Facilitate collaboration

Collaboration that supports better research outcomes and improves the health and quality of life for those living with spinal cord injury (consumers).

Voices of lived experience are heard and valued by those making decisions and investments in research, policy and practical application.

Influence health outcomes



Build research capability and capacity

Enhanced capability that generates high-quality research outcomes nationally and internationally; and capacity to scale the volume of research and the researchers in the field.

Clear economic case for investment to grow consumer participation, research activity and develop research talent.

Inform research investment

Our strategic framework

1. Invest in people

The organisation identifies, retains and develops its talent; is prepared for succession and provides the support needed to excel.

2. Secure programs

Existing programs have secured funding and can be scaled for impact; and new program opportunities through partnership are explored and realised.

3. Build resilience

Financial diversification through new funding sources, supported by investment in operational support to keep pace with action and support impact.

4. Strengthen partnerships

Developing and nurturing two-way and values aligned partnerships within the research sector and across the spinal cord field to support programs, investment and outcomes.



A word of thanks from our Patron, Lady Southey AC



This year has been very exciting for the Spinal Research Institute (SRI). With the support of philanthropy, our impactful programs are helping us

achieve our vision of improving the day-to-day lives, health and wellbeing of people living with spinal cord injury.

I was pleased to launch the Patron's Program - Future Leaders of SCI research, at 'Cranlana' earlier in the year. This philanthropic program is fostering a cohort of talented emerging researchers who will drive new advances in treatment and care, both locally and internationally, to help change the story for those living with spinal cord injury and their ability to reach their full potential in life.

I was delighted to welcome two new Foundations to the SRI this year and I wish to personally acknowledge Freemasons Foundation Victoria and Brian M. Davis Charitable Foundation for their generous and visionary support.

Freemasons Foundation Victoria is supporting the first phase of our new initiative on the Spinal Cord Research Hub (SCoRH), to connect and incorporate people with lived experience of spinal cord injury into the research process, as critical stakeholders.

The Brian M. Davis Charitable Foundation joined IOOF Foundation, The Marian & E.H. Flack Trust, and William Angliss (Vic) Charitable Fund this year in supporting our Consumer Engagement Program. This funding allowed us to make great progress in raising the awareness of community members about research co-design and their vital involvement, to help ensure research is meaningful and impactful to the needs of the spinal cord injury community.

With heartfelt gratitude, I thank each and every donor and our partners for your invaluable support and I look forward to continuing this exciting journey with you into the future.

Lady Southey AC
Patron



Professor Richard Sinnott (Melbourne eResearch Group), Deirdre Mori (SRI), Fi Slaven (SRI), Lady Southey AC (Patron, SRI), Rodney Lavin JP (Freemasons Foundation Victoria), Philip Mayers AM (Freemasons Foundation Victoria), Kristine Hendry (SRI)



Launch of the Patron's Program, Future Leaders of SCI Research at 'Cranlana' in March 2023

Ambassadors

The Spinal Research Institute (SRI) is fortunate to work with a group of Ambassadors who champion our cause in the spinal cord injury community and beyond. Being able to draw on the diverse and rich lived experiences of our Ambassadors, in a range of settings, has enabled us to talk about the impact of our work in meaningful ways.

The SRI thanks all of our Ambassadors for the work they have done in promoting our work and raising awareness of the importance of collaboration and consumer engagement in research.



Jason Ellery



Dr Mario D'Cruz



Dr Gillean Hilton



Max Di Paolo



Stefania Di Paolo



Marc Brew

Consumer Advisory Network

The Spinal Research Institute's (SRI) Consumer Advisory Network was established to inform and help shape our Consumer Engagement Program. It plays an important role in identifying key research knowledge gaps, helping us to improve our education and awareness resources. The Network also plays an important role in the evaluation of our Consumer Engagement Program to ensure that it meets the needs and priorities of the spinal cord injury community.

We are grateful to have a Consumer Advisory Network that is engaged, diverse and committed to improving levels of consumer engagement in research.



Lachie O'Brien



Martin Heng



Christine Tripp



Dr Leanne Rees



Ben Gruter



Campbell Message



Our programs

Spinal Cord Research Hub (SCoRH)

SCoRH is a unique online hub developed by the Spinal Research Institute (SRI) to foster and facilitate collaboration between researchers and clinicians working in spinal cord injury around the world. SCoRH also offers a research group facilitation service for members.

Mentor Program

The Mentor Program nurtures talented emerging researchers by matching them with an experienced mentor. Mentors are carefully selected according to the needs and research aims of participants. To date, all participants have reported improvement in their research skills.

SCI Research Collaboration Grants

These grants support researchers and clinicians to attend the International Spinal Cord Society Annual Scientific Meeting. Recipients have created global networks, generated opportunities for research collaboration, and presented their research to new audiences.



Consumer Engagement Program

This innovative program supports people with lived experience of spinal cord injury to co-design and co-deliver research that is relevant to their needs and priorities. Impact is achieved in a range of ways including creation and dissemination of educational resources.

SCI Research Writing Prize

Each year, we ask spinal cord injury researchers and clinicians to write about their research in a creative way. This provides an opportunity to present their research to a broad-ranging, non-scientific audience. Successful entries are featured in our publication, *Why Research Matters*.

Research & Collaboration

This program is all about connecting people, sharing practices, and disseminating information. It provides the SRI with an opportunity to collaborate with leading institutions in spinal cord injury research as well as connect with the international research community.



Spinal Cord Research Hub (SCoRH)

The Spinal Cord Research Hub (SCoRH) is an online platform for spinal cord injury research collaboration. This world-first Australian innovation was developed by the Spinal Research Institute (SRI), with support from leading local and international experts in spinal cord injury research. SCoRH enables researchers and clinicians to connect, share and collaborate in one easy-to-use online space, and to work across health disciplines and geographic boundaries to impact greater numbers of health outcomes for spinal cord injury.

In the last 12 months, the SRI has welcomed 40 new researchers and clinicians to SCoRH. This continued growth year-on-year demonstrates the value of the platform, and the community that has emerged through SCoRH continues to progress collaborative research opportunities.

To further facilitate engagement between SCoRH members, two SCoRH Online Networking Events were held in the first six months of 2023. These events, facilitated by the SRI, provided opportunities for members to network with other research colleagues across the globe, outside of the usual conferences and scientific meetings. Attendees were from a range of disciplines,

career stages, and geographic locations, and event feedback has been very positive.

“I have loved both of these events. I’ve told people about them and look forward to them happening again. It’s a great format too. I like the breakout groups and facilitated, simple questions that everyone can answer.”

“It’s a great forum and I loved being part of it because working with SCIs is rare in each country. When we come together in this forum, it is really enjoyable and we learn from one another’s experience.”

Another challenge that researchers consistently highlight is the lack of time they have available across an ever-growing number of competing priorities. The Research Group Facilitation Service offered through SCoRH seeks to alleviate this pressure by assisting with meeting and workshop facilitation. This service has accelerated research progress by helping to refine group objectives, identify project leads, define short and long-term actions, and advance these actions and associated outcomes.

Right: SCoRH member Dr Camilla Larsen

SCoRH Facts

Connecting Australian researchers to international collaborators.

376 members from **40** countries: Argentina, Australia, Bangladesh, Belgium, Brazil, Canada, Congo, Czech Republic, Denmark, Egypt, England, Finland, France, Germany, Greece, Hong Kong, India, Ireland, Italy, Japan, Kenya, Malaysia, Mexico, Nepal, Netherlands, New Zealand, Nigeria, Norway, Pakistan, Philippines, Qatar, Scotland, Singapore, South Africa, South Korea, Sweden, Switzerland, Tanzania, Thailand, USA.

The Spinal Cord Research Hub is supported by Freemasons Foundation Victoria



Freemasons
Foundation Victoria



Mentor program

The Spinal Research Institute's (SRI) Mentor Program is now in its fifth year. It began as a pilot program in 2019 and was run as a full program in 2021. The third round of the program opened for applications in March 2023 with double the amount of applications submitted, from seven countries. Thorough consideration is given to the matching process, and time is taken to match the successful mentees with a suitable mentor.

The program has four aims:

- Progress the research careers of talented emerging researchers.
- Provide guidance and support to strengthen their specific research projects.
- Produce the next generation of leaders in the field to advance spinal cord injury research more broadly.
- Enhance international collaborations in spinal cord injury research.

The impact of structured mentoring over an extended period of time provides significant benefits to those who participate. Mentoring in research equips individuals with skills that might not be available within their own organisation or institution. The mentor/mentee relationship has great potential to be successful because it is not bound by geographical limits, meaning that the SRI can

facilitate matches across the globe based on the needs of the mentee and any deficits faced in their particular locations.

As a result of the Mentor Program, our mentees have had many successes including: gaining new knowledge and skills, establishing new collaborative research relationships, improving the design of their research studies, obtaining research ethics approval, progressing their research projects, and successfully completing and publishing their research.

We asked participants from the 2021 round who completed the program in late 2022 to provide their feedback. All participants said that participation in the program was valuable for them. They also agreed that the quality of the mentoring they received was very high. In addition, all participants stated that the Mentor Program had improved their research skills and helped them define clear goals for their future research.



Dr Raju Dhakal is a clinician and researcher in Nepal where there is a lack of research and coordinated care, from prevention to acute care, rehabilitation and community reintegration. Through research, Raju aims to reduce fragmentation in care, increasing the quality of life for those with spinal cord injury.

Raju's objectives for mentor support were to further develop his skills in proposal writing and grant funding opportunities, all of which support him to establish a very important study on the prevalence of violence against women with spinal cord injury in Nepal. Raju aims to increase his skills to be a strong mentor for others in the future.

Raju was matched with a senior researcher from the UK, Professor Ravi Thiara, who has an extensive research career looking at violence against women with disability. They have been a strong match with progress in study design, although limited options for funding in Nepal continues to be a challenge.



Dr Jackie McRae is a clinical academic Speech and Language Therapist working in critical care in the UK. After 10 years of working in a specialist spinal injury unit, she undertook a PhD focused on the clinical management of dysphagia (difficulty swallowing) in cervical spinal cord injury.

Jackie was looking for mentor support to grow her skills in writing research proposals and learning about running multi-site studies and barriers in this type of research.

Being matched with Professor David Berlowitz from Australia produced stronger cross-country connections and relationships.

"It has been incredibly valuable and very stimulating. There is little SCI rehab research in the UK so the connections that my mentor provides are invaluable," Jackie stated.



SCI Research Collaboration Grants

Each year, the Spinal Research Institute (SRI) offers SCI Research Collaboration Grants to enable early and mid-career researchers to attend the Annual Scientific Meeting of the International Spinal Cord Society (ISCoS). In 2022, the meeting was held in hybrid style, allowing delegates to attend either in person in Vancouver or online. The SRI supported a total of 16 researchers with six attending in person and ten attending in a virtual capacity. The 2022 grant recipients were from nine countries: Malaysia, Pakistan, Thailand, United Kingdom, Australia, Bangladesh, Nigeria, Denmark, and Canada.

The objective of the grant is to support researchers to build their collaboration networks and develop our future leaders for the next generation of researchers. The grant enables recipients to facilitate the exchange of knowledge, and to build relationships with other researchers, institutions and countries involved in spinal cord research. Attendance at the ISCoS Annual Scientific Meeting offers a unique opportunity to grow and garner fresh ideas and collaborate with international peers.

Successful applicants demonstrated that they are working to pool expertise and obtain cross-fertilisation of research ideas through collaboration. Some of the 2022 recipients

highlight the impact of their grant below:

Discussing directly with a senior colleague the practical limitations of some of the measures we routinely collect guided the implementation of new outcome measures for my current study.
Dr Antonio Capozio, United Kingdom

The conference helped me to collaborate with other researchers, especially in Africa. I was able to connect with a researcher from South Africa and we promised to undertake joint research with data from Nigeria and South Africa.
Dr Bashir Kaka, Nigeria

Attending ISCoS was a transformative experience for me. I had the opportunity to meet researchers whose work I read and was inspired by for years. This allowed me to form relationships for future collaborations.
Merna Seliman, Canada

Attending the conference gave me the chance to introduce myself to people who have greatly influenced my early PhD studies and direction in scientific research. I gathered numerous contacts from around the world with whom I hope to engage further.
Paul Watson, Australia



24
countries
represented



91
total grants
awarded
since 2017



40
grant recipients
from low and
middle income
countries



“I really think that this is one of the best bang-for-the-buck grant programs in the SCI field.”
Professor Graham Creasey
Professor of SCI Medicine, Emeritus,
Stanford University, USA



54
women
since 2017



16
grants
in 2022



Supporting research in low and middle-income countries

The Spinal Research Institute's (SRI) programs for researchers aim to remove barriers that hinder collaboration and access to professional activities, which can be difficult in low resourced settings. Program participants consistently report positive impact as a result of participation in our programs, and participants from low and middle income countries often report significantly greater impact compared to those who have better access to resources within their everyday professional environment.

In recognition of this increased benefit, the SRI strives to ensure that each program supports a proportion of researchers from low and middle income countries. Consideration of this is incorporated into the assessment of applications for the SCI Research Collaboration Grants and the Mentor Program, and also elements of the Spinal Cord Research Hub (SCoRH) such as the Research Group Facilitation service. For the first time, this year, the SRI offered additional language support to researchers from low and middle income countries who entered the SCI Research Writing Prize. As a result, the 2022 Why Research Matters publication is a truly

global representation of current spinal cord injury research.



Margaret Mungai is Deputy Director of Nursing at the Moi Teaching & Referral Hospital in Eldoret, Kenya. As a wound care specialist she encounters spinal

cord injury patients with extensive pressure injury wounds that are very challenging for her multidisciplinary team. There is no dedicated ward and the neurosurgical ward is overcrowded meaning many patients are sent home to await surgery, or are treated conservatively and discharged. Many patients return to hospital with infections, pressure injury wounds, and joint and ligament contracture.

In 2021, Margaret received an SCI Research Collaboration Grant that supported her to attend the Annual Scientific Meeting of the International Spinal Cord Society (ISCoS). Margaret used this opportunity to expand her professional network and make as many

connections as she could. As a direct result of connections made at ISCoS, Margaret was invited to speak at the International Council of Nurses about her experience as a nurse/researcher in a low and middle income country, and specifically, in her region of Africa. That meeting was held in July 2023 in Montreal, Canada.

“ISCoS 2021 brought me to realize the need more than ever to harness a multidisciplinary health care team with interest in spinal cord injury care and research. I was so encouraged to complete the current case study we are doing with four other nurses highlighting the plight of spinal cord injury patients in Kenya as we look forward to collaborating with researchers interested in undertaking collaborative research with developing countries as we have many spinal cord injury patients in our hospitals and in the communities.



Faizan Jameel (left) is a Pakistani occupational therapist who is currently completing a Master in Health Sciences (Occupational Therapy) at Universiti Teknologi MARA

under the supervision of **Dr Ahmad Zamir Che Daud** (above right). Faizan is investigating functioning and quality of life among people with spinal cord injury in Pakistan and



Malaysia. Dr Ahmad Zamir Che Daud is an occupational therapist by background and a senior lecturer at the Centre for Occupational Therapy Studies, Faculty of Health Sciences,

Universiti Teknologi Mara, Malaysia. His research interest is upper limb rehabilitation for people with spinal cord injury.

Faizan and Ahmad attended ISCoS virtually in 2022 and were able to join many sessions on a wide range of research topics. They got to know prominent scholars in the spinal cord injury field. During the meeting, they used the online meeting networking feature to connect with researchers from other countries, including Bangladesh, the United Kingdom and Australia, who have similar research interests.

“The session that captured our interest a lot was sexual rehabilitation. In our occupational therapy practice, we did not tackle sexual issues as it is taboo in Malaysian and Pakistani culture. The session taught us how to approach and tackle if our clients raise sexual issues as part of their concerns. The meeting allowed us to share and disseminate the findings of our study on participation issues among clients with spinal cord injury in Pakistan and Malaysia.”



Consumer Engagement Program

The Spinal Research Institute (SRI) is committed to facilitating an ongoing paradigm shift that places people with lived experience of spinal cord injury ('consumers') at the forefront of research to help generate improved health and quality-of-life outcomes for the spinal cord injury community. Over the past 12 months, we have continued to raise awareness of the benefits of research, and educate consumers to equip them to partner in research co-design and co-delivery.

We launched a new consumer engagement focused newsletter that provides consumers with valuable insights and information regarding the importance of research and how to access relevant research information.

Early in 2023, we were invited to partner with Austin Health to deliver regular education sessions to spinal cord injury inpatients and their families at the Royal Talbot Rehabilitation Centre. This early intervention equips patients with an understanding of the research landscape and how to get involved in spinal cord injury research.

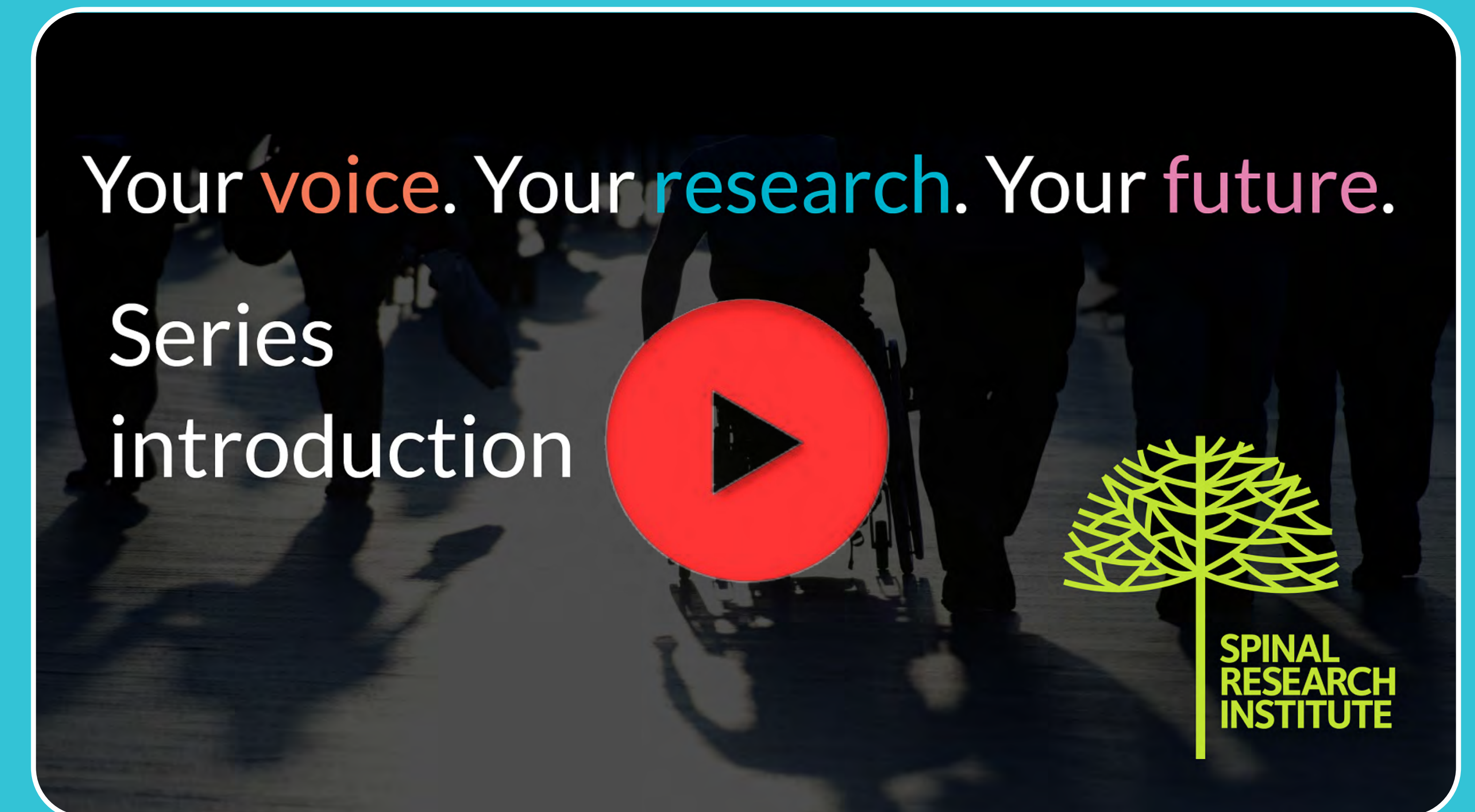
We were also invited to provide professional development to peer support mentors at AQA, the largest spinal cord injury peer support and service organisation in Victoria. The

information imparted has armed the peer mentors with knowledge that can be shared in their conversations with the spinal cord injury community, furthering the reach of the SRI's work.

Our program is also gaining international recognition, and international requests to collaborate speak to its relevance. Our development of a remuneration program was acknowledged with the publication of an SRI-authored article about our Consumer Remuneration Policy in the International Spinal Cord Society (ISCoS) Spinal Cord Journal in early 2023. This endorsement reinforces the direction the program is taking and validates the work we are doing to ensure consumers are adequately represented in research and fairly compensated for their input.

The program is also taking a leadership role by leveraging digital media to raise awareness and deliver education. A series of short videos we made during the ISCoS Annual Scientific Meeting 2022 in Vancouver were very successful, with over 3,200 views within one week of the meeting. These videos will be the subject of our presentation at the 2023 ISCoS Annual Scientific Meeting in Edinburgh.

Watch videos from the webinar series *Your voice. Your research. Your future.* (16 videos)



Watch the International Spinal Cord Society Annual Scientific Meeting Series (10 videos)



Research & Collaboration

SRI Policy for Consumer Remuneration - International Recognition

To establish spinal cord injury consumers as partners in research programs, the value of the skills, expertise, and knowledge they contribute must be acknowledged appropriately and supported with resources, including remuneration. To provide guidance on this matter, in 2021, the Spinal Research Institute (SRI) developed a Policy for Consumer Remuneration.

The policy was presented at the International Spinal Cord Society Annual Scientific Meeting in 2022 and is shared under a creative commons license as a resource for researchers.

The SRI Policy for Consumer Remuneration sets a standard for the spinal cord injury research field, which can serve as a model for Australia and as a template for other countries. The SRI's Kristine Hendry and Antonio Vecchio co-authored a paper about the development of the policy and the importance of consumer engagement in SCI research and consultation. The paper was published in March 2023 in the highly-regarded Spinal Cord journal.

[Read the article](#)

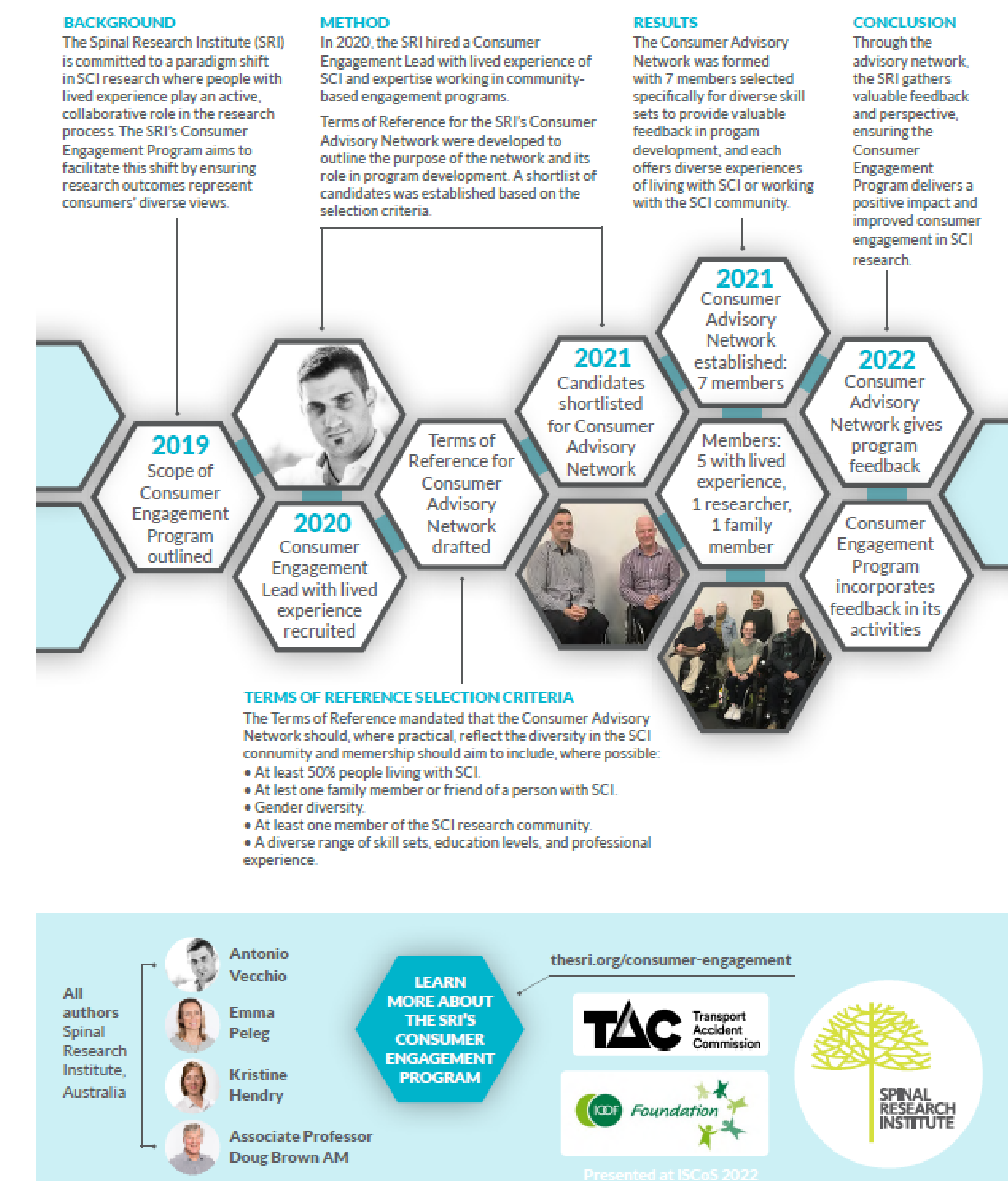
OUTCOMES AND IMPACTS OF THE SPINAL RESEARCH INSTITUTE'S COLLABORATION GRANTS PROGRAM



FACILITATING SCI RESEARCHER GROUPS TO DEVELOP RESEARCH IDEAS AN INITIATIVE OF THE SPINAL CORD RESEARCH HUB



VALUING DIVERSITY IN THE SCI COMMUNITY IN SHAPING CONSUMER ENGAGEMENT PROGRAMS



A full list of the SRI's publications is available on our website.

Visit website

These three posters were presented at the 61st Annual Scientific Meeting of the International Spinal Cord Society held in Vancouver, Canada in September 2022. Click the poster to see or download a larger version.



SCI Research Writing Prize: Why Research Matters

The Spinal Research Institute's (SRI) 2022 Spinal Cord Injury Research Writing Prize asked entrants to write about their research in a creative way that would resonate with, and be easily understood by, a broad-ranging, non-scientific audience. Entrants must explain their research in 800 words or less, keeping in mind the question "Why does my research matter?" Shortlisted entries are published in an annual anthology called *Why Research Matters*.

Exciting research is being conducted in Australia and globally, in both developed and developing nations. We understand that writing in English may be challenging for many researchers, so for the first time in 2022, we provided additional support for entrants for whom English is an additional language.

We are pleased to have published a truly global anthology that provides a snapshot of spinal cord injury research occurring around the world. *Why Research Matters 2022* contains the top thirteen entries from the 2022 Spinal Cord Injury Research Writing Prize. The entries presented showcase a diverse range of research interest areas and their authors are working in eleven different countries. They cover topics ranging from gene therapy to oral health, from electrical

stimulation to respiration and improving quality of life.

Why Research Matters provides a forum for Australian and international researchers to showcase their work outside of traditional academic publications and enables engagement with the spinal cord injury community through an accessible, 'storytelling' format. Some of the 2022 authors shared their thoughts on social media.

It's a huge honour to not only have my piece on *Why My Research Matters* published by @The_SRI, but also to be selected as the judges' choice! I am speechless and extremely grateful. The booklet is filled with many interesting, engaging and easy to read entries on #SCI research. **Martyna Stasiewicz**

Thank you to the @The_SRI for highlighting the importance and impact of respiratory research in people with #SCI. I'm honoured to have been included in this group of incredible researchers and clinicians. **Anne E Palermo**

I'm so grateful for this opportunity to present my research together with amazing researchers across the world who perform research that matters in the field of spinal cord injury research. **Elin Salmiranta**

WHY RESEARCH MATTERS 2022

13
authors

11
countries



A COLLECTION OF SPINAL CORD
RESEARCH FROM AROUND THE WORLD



Funded projects

In the past year the Spinal Research Institute (SRI) has co-funded two important spinal cord injury projects.

The first is the Spinal Cord Injury Service Module Project, a collaboration between the World Health Organisation (WHO) and the International Spinal Cord Society. The project stems from the WHO's 'Rehabilitation 2030' initiative, which draws attention to the profound unmet need for rehabilitation worldwide. The main objective of the project is to develop a practical resource ('toolkit') for spinal cord injury stakeholders in low and middle income countries that will be used to guide their efforts to strengthen spinal cord injury services in their country. The Spinal Cord Injury Service Module will focus on rehabilitation, taking into consideration the broader healthcare context and the full continuum of care including pre-hospital, trauma and acute care, as well as community integration.

The other project is the 5-year follow up to the International Spinal Cord Injury Survey, the first international community survey that focuses both on the lived experience of people with spinal cord injury and the societal response to their needs. The SRI is co-funding the Australian arm of the survey

(Aus-InSCI). Aus-InSCI represents the largest and most comprehensive survey of health-related issues, functioning, social inclusion, economic participation and support needs of people with spinal cord injury ever conducted in Australia. Results from the survey will be used to improve clinical practice, increase community support and change policies and systems to enhance the lived experience of people with spinal cord injury in Australia.

The SRI is proud to support these leading collaborative national and international initiatives to help improve the health and quality of life of people with spinal cord injury.



World Health Organization



International Spinal Cord Society (ISCoS) partnership

In 2022, the Spinal Research Institute (SRI) continued its partnership with the International Spinal Cord Society (ISCoS). This partnership enabled streamlined facilitation of the SCI Research Collaboration Grants, cross-promotion of a range of activities, and sharing of resources relating to spinal cord injury research.

Partnering with ISCoS provided an opportunity to add more value to the conference experience for our 2022 SCI Research Collaboration Grant recipients. Merna Seliman and Nattha Boonthanakorn were invited to participate in the SCI Care: What Really Matters podcast series, discussing their experiences as first time attendees at ISCoS, and the importance of the SRI's grants program in supporting their attendance.

[Listen to the podcast \(7 min\)](#) 

Several other grant recipients acted as social media ambassadors at the conference, allowing them to tap into a wider audience through association with ISCoS. They were able to gain experience through working with ISCoS at the Media Corner, and with Dr Jennifer Coker, ISCoS's Social Media Lead.



SRI CEO Kristine Hendry and International Research Collaborations Manager Emma Peleg were also interviewed by Dr Jennifer Coker for the podcast series. They discussed the importance of the partnership with ISCoS and offering grants to early career researchers to attend ISCoS meetings throughout the years including ISCoS 2022.

[Listen to the podcast \(11 min\)](#) 

Top: The Media Corner at ISCoS 2022. Right: Dr Jennifer Coker interviews SCI Research Collaboration Grant recipient Merna Seliman for the ISCoS Podcast series *SCI Care: What Really Matters*.



Patron's Program Future Leaders of SCI Research

In March, we launched our Patron's Program - Future Leaders of SCI Research. With this new focus, we continue our support of early career researchers through programs such as Mentoring, the SCI Research Collaboration Grants, and the Spinal Cord Research Hub.

Over the last decade, the Spinal Research Institute (SRI) has nurtured a number of talented spinal cord injury early career researchers. Each year the quality of applications for our programs increases.

Our current cohort of young researchers collaborate globally, resolve challenges with innovative solutions, and engage with new ideas. We are passionate about supporting our Future Leaders - the next generation of spinal cord injury researchers.

Across a multi-year program, we will support our Future Leaders in their personal and professional development, helping them to build their networks, and providing resources and guidance as they progress their research.

We will welcome emerging researchers from Australia and around the world, creating a mutually beneficial pool of collaborators, vital for achieving translatable research results.

To the right you will see some of the best and brightest researchers who have participated in our programs. Through generous support from our donors, the SRI has assisted these exceptional researchers to further their work in transforming the field of spinal cord injury research. We are pleased to introduce them:

Paul Watson, PhD Candidate

Nishu Tyagi, PhD Candidate

Arifa Jahan Ema, Occupational Therapist & Lecturer

Dr Sintip Pattanakuhar, Rehabilitation Physician & Researcher

Dr Raju Dhakal, Medical Director & Consultant Rehabilitation Medicine Physician

Merna Seliman, PhD Candidate

Pádraig Carroll, PhD Candidate

Dr Matthew Farrow, Research Associate

Learn more about the important work these researchers are currently undertaking, and find out how you can support emerging researchers in the field of spinal cord injury by joining our Patron's Program.

[Visit the Patron's Program](#)



“Supporting future leaders is the focus of the Patron's Program in 2023. I hope you will join me by investing in our next generation of spinal cord injury researchers to help them achieve their ambitions, and empower them to lead life-changing research.”

Lady Southey AC
Patron
Spinal Research Institute



Acknowledgements

The Spinal Research Institute (SRI) relies on external expertise to ensure our program selection processes are robust and transparent. We would like to thank all of our reviewers for their generosity in providing their time, guidance and knowledge. We would also like to thank the researchers who have shared their experience and insight as mentors in the Mentor Program.

We would like to particularly acknowledge the following contributions: Professor Graham Creasey (top right) for his guidance and ongoing support of the SCI Research Collaboration Grants since their inception in 2017, Dr Marnie Graco (centre right) for her generosity in working with us to realise and shape the Mentor Program since its inception in 2019, and Dr Farooq Rathore (bottom right) for his ideas and professional judgement in helping us to ensure that the SCI Research Writing Prize is a truly global competition.

SCI Research Collaboration Grants reviewers

- Professor Graham Creasey, Stanford University, USA
- Campbell Message, Melbourne Disability Institute, Australia
- Dr Colleen O'Connell, Stan Cassidy Centre for Rehabilitation, Canada

Mentor Program reviewer and mentors

- Dr Marnie Graco, Institute for Breathing and Sleep, Austin Health, Australia (reviewer)
- Professor Leslie Morse, University of Minnesota Medical School, USA
- Professor David Berlowitz, University of Melbourne, Australia
- Professor Armin Gemperli, Swiss Paraplegic Research, Switzerland
- Associate Professor Ravi Thiara, University of Warwick, United Kingdom
- Dr Vanette McLennan, Griffith University, Australia

SCI Research Writing Prize judges

- Dr Farooq Rathore, Armed Forces Institute of Rehabilitation Medicine, Pakistan
- Dr Ali Otom, King Hussein Medical Center, Jordan
- Emily Quattrocchi, Film maker, Australia (far right)
- Shivjeet Singh Raghav, Spinal Cord Society Consumer Committee, India
- Dr Christine Migliorini, The University of Melbourne, Australia



Professor Graham Creasey



Dr Marnie Graco



Dr Farooq Rathore



Emily Quattrocchi

Thank you

The Spinal Research Institute (SRI) would not exist without the philanthropic support from generous individuals, organisations and foundations.

Founding Donors

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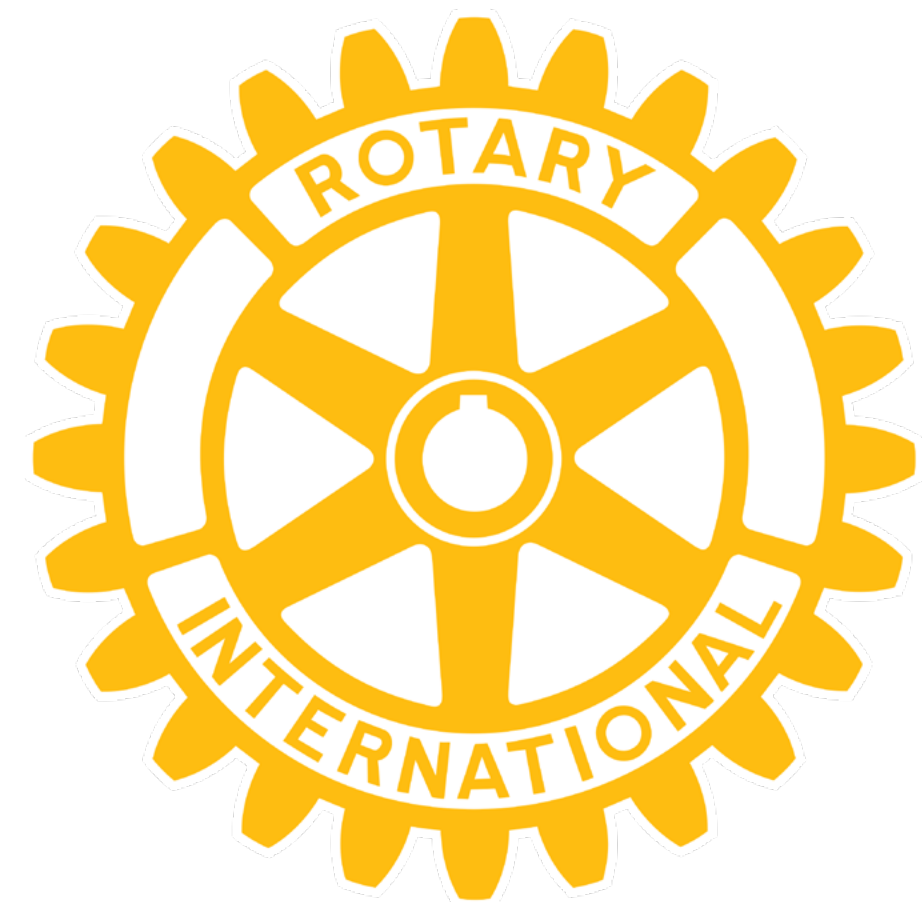
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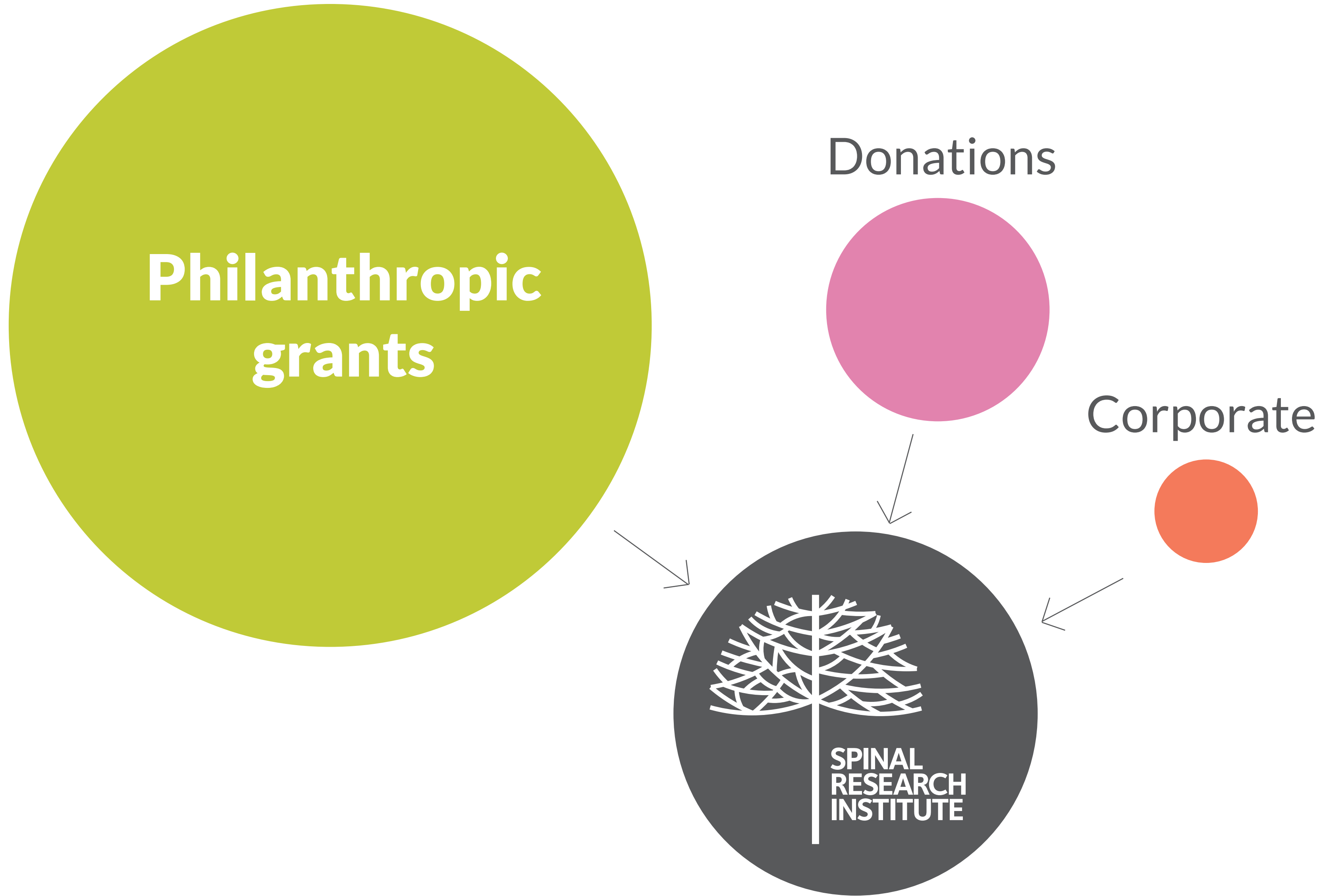


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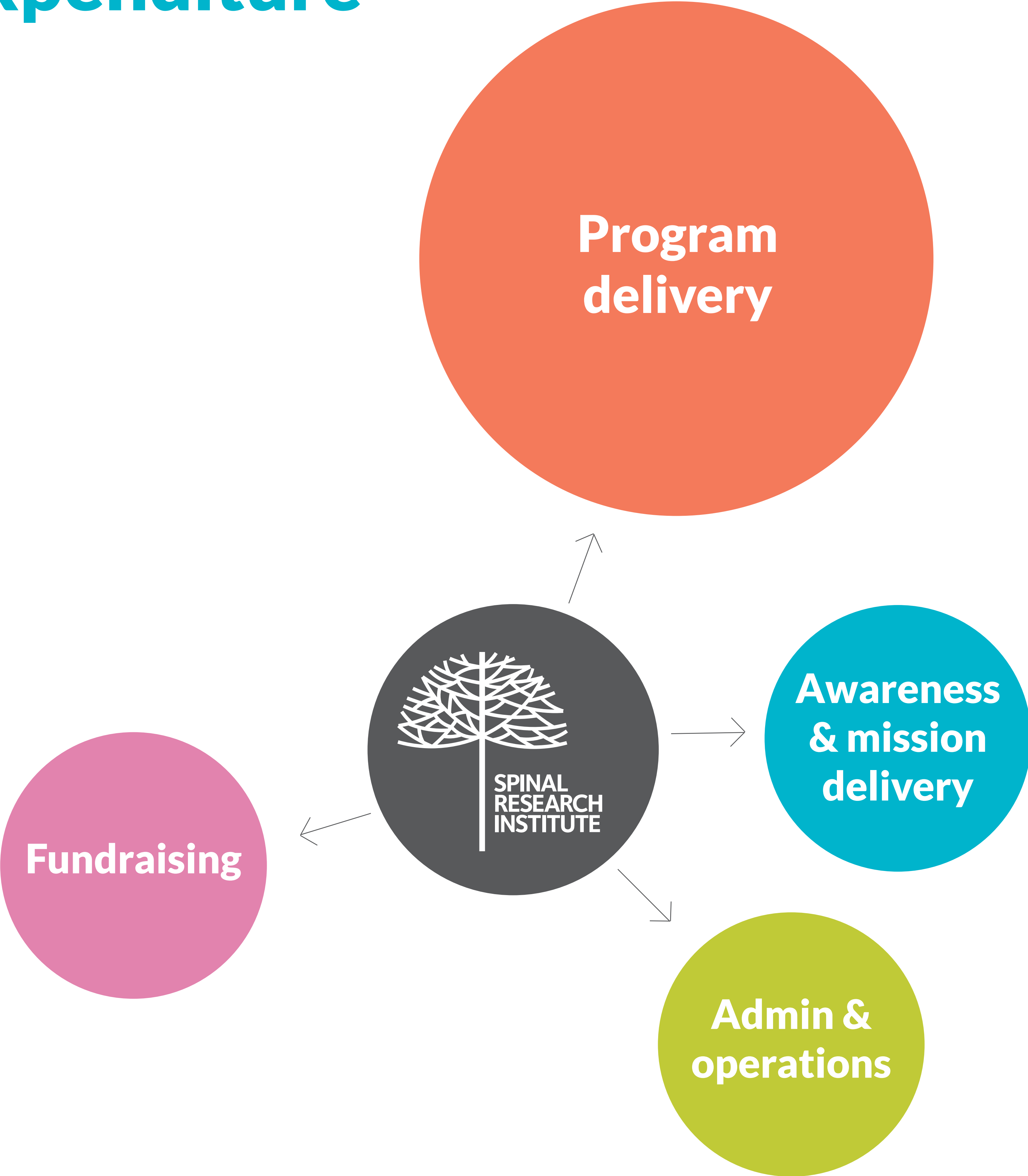
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Funding sources



Expenditure



This information is based on figures from the 2022 financial year.
Our financial reports can be found on the [Australian Charities and Not-for-profits Commission website](#).



Where to next?

While this report has focused on the recent achievements and impact of the Spinal Research Institute (SRI) there are also many exciting things on the horizon.

In October, members of the SRI team will travel to Edinburgh, Scotland, to attend the 62nd International Spinal Cord Society Annual Scientific Meeting. The team will be very busy presenting scientific posters, meeting with recipients of the 2023 SCI Research Collaboration Grants, establishing new relationships, and reconnecting with international colleagues.

Exciting work has commenced to enhance the Spinal Cord Research Hub (SCoRH) and take the first steps to incorporate consumer engagement on SCoRH. This will include a consumer engagement service offering to sit alongside our Research Group Facilitation service. We will also offer more SCoRH online networking events following the successful pilot of this concept in 2023. We have received some great feedback and will incorporate this so that future events are even more beneficial for attendees.

In addition to the new consumer engagement element on SCoRH, we are also working to develop new resources that will assist

consumers to participate in all stages of the research cycle. Our pioneering work in Australian spinal cord injury consumer participation and remuneration is progressing and we will be working hard to develop it further.

We will be continuing our mentoring work and our new group of mentees will begin working with their mentors. It will be great to see these pairings commence and the mentees make progress towards their research goals.

Work is currently being undertaken by the SRI on a project to map current and recent Australian spinal cord injury research, and we look forward to sharing the findings as soon as we can.

In the longer term we are focused on increasing our impact year on year, helping us achieve our goal of improving health outcomes and quality of life for people with spinal cord injury.

If you want to hear about these developments as they happen, follow us on social media or subscribe to our Plexus mailing list. All the links you need are on the right hand side of this page.

Stay in touch

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This list is for people with lived experience of SCI, although everyone is welcome.

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SCoRH

Everyone who is a member of SCoRH will receive the SCoRH newsletter.

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SRI Team at the launch of the inaugural Impact Report in October 2022



SRI Team and Board members at the strategy planning day in October 2022



