



Impact Report

2022



SPINAL
RESEARCH
INSTITUTE

“

I know the huge difference
the right research can make
to people's wellbeing and
quality of life.

Associate Professor Doug Brown AM
Founder, Spinal Research Institute



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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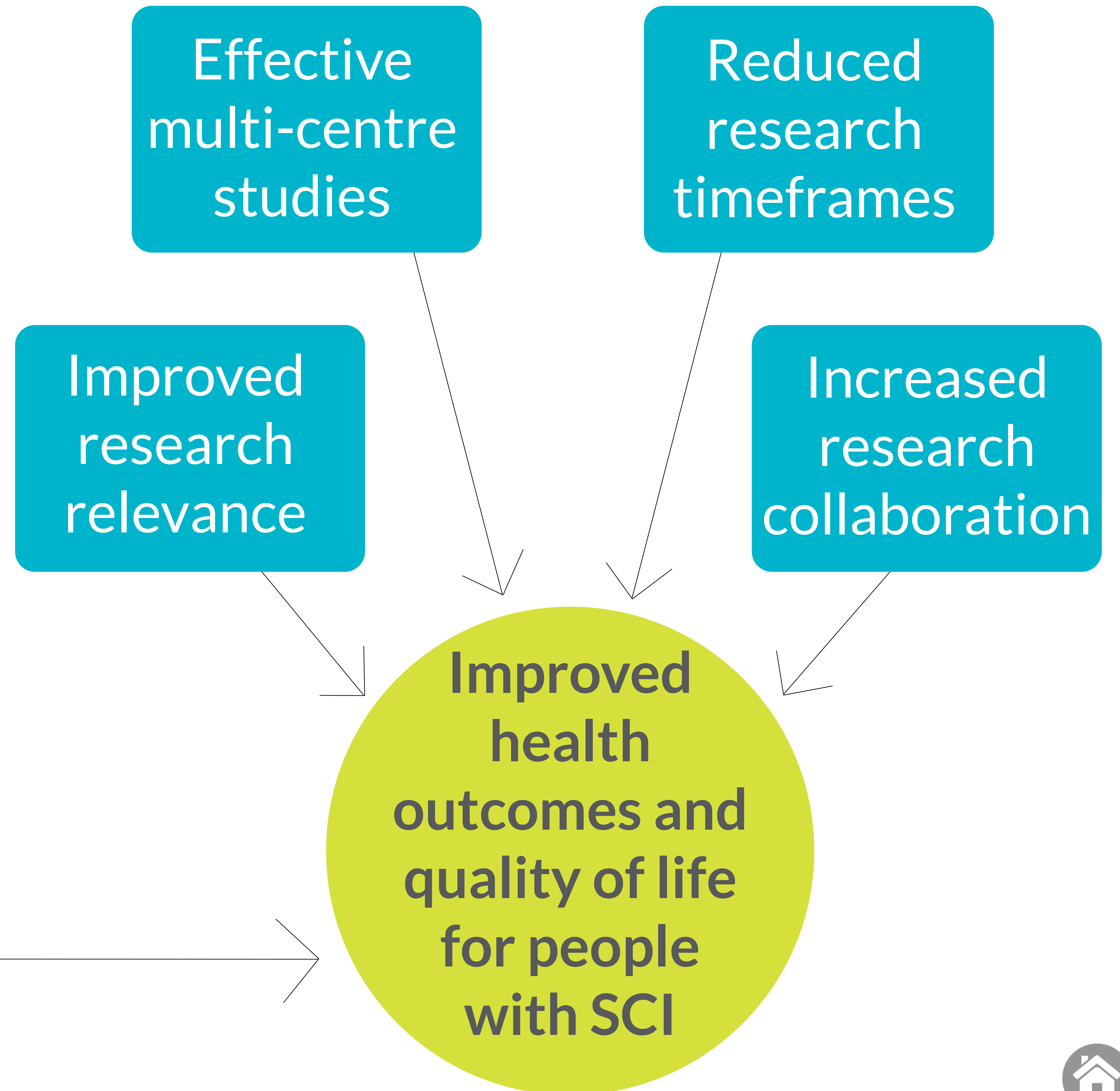
Our vision and mission

The vision of the Spinal Research Institute is to improve health outcomes and quality of life for people with spinal cord injury.

People with a spinal cord injury face many challenging secondary health complications that diminish their quality of life and capacity for independence. By building global collaboration in spinal cord injury research and clinical trials we aim to reduce the length of time it takes to achieve significant and translatable research outcomes.

Our work supports research collaboration and knowledge sharing, and actively involving people with lived experience of spinal cord injury in the research process to improve research relevance.

Our goal



Spinal Research Institute's history

2011

SPINAL RESEARCH INSTITUTE FOUNDED

Associate Professor Doug Brown AM founded the Spinal Research Institute to improve the lives of people with spinal cord injury through global research collaboration.

2013

BOARD OF DIRECTORS ESTABLISHED

The Spinal Research Institute's Board was established with Dr. Con Mylonas as Chair. This was a significant point in the evolution of the Spinal Research Institute as an organisation.

2015

LONG TERM FUNDING RECEIVED

We were incredibly fortunate to receive two long-term funding pledges from Shine On Foundation, and Bordo International. Also in 2015 we developed and published our first strategic plan.

2017

TRAVEL GRANTS LAUNCHED

The launch of the SCI Travel Collaboration grant enabled early career researchers to attend the International Spinal Cord Society's (ISCoS) Annual Scientific Meeting. Two grants were awarded and many researchers have since been supported through this program.

2019

NEW FACES AND PATRON'S PROGRAM

Funding from IOOF Foundation paved the way for the Consumer Engagement work to come in 2020. Our new Chair, Fi Slaven, was appointed and we welcomed new directors Dr Mario D'Cruz and Nick Morris, who bring the perspective of lived experience. Lady Southey AC launched our Patron's Program of annual giving at a supporter event at Cranlana.

2021

MENTOR PROGRAM LAUNCHED

2021 was the SRI's 10-year anniversary. We launched the Mentor Program to support early career researchers through collaboration, design, investigation and publication, and we supported 30 researchers to attend the virtual annual ISCoS meeting.

2012

FIRST FULL YEAR OF OPERATION

In this first full year of operation for the Spinal Research Institute we continued to receive support and encouragement from Austin Health and we held the inaugural Spinal Cord Injury Research Forum.

2014

BETTY AMSDEN AO BECOMES PATRON

Betty Amsden AO is remembered by the Board and staff of the Spinal Research Institute as an endlessly generous woman who cared deeply for disadvantaged and marginalised members of the community.

2016

FUNDING FOR SCORH DEVELOPMENT

A multi-year grant from Ian Potter Foundation supported development of the Spinal Cord Research Hub, an online platform facilitating collaboration between spinal cord researchers globally. This was further progressed with a multi-year grant from IOOF Foundation in 2017.

2018

LADY SOUTHEY AC BECOMES PATRON

We were delighted when Lady Southey AC accepted the request to become our Patron. We also gained a fantastic new CEO in Kristine Hendry. We launched the Spinal Cord Research Hub at the ISCoS/ANZSCoS combined conference held in Sydney.

2020

CONSUMER ENGAGEMENT FOCUS

Our Community and Consumer Engagement Manager was appointed, and we launched the *Consumer Engagement in Research* and *In Conversation* videos. We held the inaugural Spinal Cord Injury Research Writing prize and published 'Why Research Matters' showcasing research from around the world.

2022

WEBINARS AND COLLABORATIONS

This year we ran our consumer engagement webinar series. We're working with various collaborative research groups on the Spinal Cord Research Hub, and once again offered Collaboration Grants for attendance at the ISCoS Annual Scientific Meeting.



Chair of the Board's message

In 2019, I was extremely honoured to be appointed as the Chair of the Spinal Research Institute's Board of Directors. I would like to take the opportunity to acknowledge Dr. Con Mylonas as the first Chair of the SRI and thank him for all his efforts. I would also like to sincerely thank our patron, Lady Southey AC, for her ongoing involvement and support, as the SRI considers ourselves very fortunate to have someone so committed to helping us achieve our goals.

The last two years have seen much change and we were delighted to welcome Mr. Nick Morris OAM and Dr Mario D'Cruz to the Board. Both gentlemen have brought a depth of knowledge, skills and lived experience to the group and a commitment towards building research collaboration and consumer engagement to improve the lives of those with spinal cord injury.

This year the SRI also farewelled a founding member, Professor David Berlowitz, and we are very grateful for his years of service and commitment, and know he remains a key supporter of the SRI. In farewelling Professor Berlowitz, we also welcomed Associate Professor Marc Ruitenber.

Like so many during the past two years, the SRI team and our supporters were not able to meet and yet we found flexible and inventive ways to stay connected, support each other and continue to grow our programs. Many innovations were added throughout this time, including the Consumer Engagement Program, which has continued to go from strength to strength.

We have been very fortunate this year to have a face to face event and it was delightful and heartwarming to be surrounded by our supporters and donors. Your philanthropic patronage and passion is very much valued and appreciated.

In closing, I want to express my ongoing gratitude to the SRI team, supporters, volunteers, ambassadors, researchers and our Board, for your steadfast support of our mission and all that we have achieved together. There is still much to be done, as we work together towards improving the lives of those with spinal cord injury.

Fi Slaven
Chair
Board of Directors



Fi Slaven
Chair



Margaret Beattie
Company Secretary



**Associate Professor
Doug Brown AM**
Executive Director



Dr Andrew Nunn
Director



Tom Morris OAM
Director



Nick Morris OAM
Director



Dr Mario D'Cruz
Director



Craig Macaulay
Director



**Associate Professor
Marc Ruitenber**
Director



Board and team member changes

While it is sad to lose valued team members, it provides us with opportunities to celebrate their achievements and thank them for their contributions. It also paves the way for us to welcome new faces as we look to the future.

After nine years, **Professor David Berlowitz** has decided to retire from the Spinal Research Institute Board. David helped to establish the SRI in 2011 and joined the Board when it formed in 2013. David provided invaluable support in the development of the SRI's research collaboration programs and was a member of the Hub Advisory Group - 17 spinal cord injury research specialists from around the world - who helped inform the development of the SRI's Spinal Cord Research Hub (SCoRH). David's expertise, pragmatism and good humour will be greatly missed and we are incredibly grateful for his contributions to the SRI over the past 11 years.

Before David stepped down from the Board, he helped in the search for a new Director and we are very pleased to welcome **Associate**



Professor David Berlowitz

Professor Marc Ruitenberg to the SRI Board. Marc heads the Neurotrauma Research Group at the University of Queensland. His research focuses on the body's response to traumatic injury, including spinal cord injury, and the role of inflammation in the recovery from this trauma. Marc recognises the need for collaboration and consumer engagement in spinal cord injury research, and is excited by the opportunity to join the Board of a charity whose vision aligns with his own passions and research interests.

At the end of 2021 we farewelled two of our team members - **Jemma Altmeier** and **Liana Cross**.

As Marketing and Communications Manager, Jemma was instrumental in coordinating the launch of the Spinal Cord Research Hub in 2018. Jemma's marketing



Associate Professor Marc Ruitenberg



Jemma Altmeier

acumen and involvement across all of the SRI's programs has been invaluable.

Liana, Digital Communications Manager, established our digital strategy and made great strides ramping up our online presence, which led to significant increases in our social media audience and website traffic.

Jemma and Liana together also initiated the SRI's Spinal Cord Injury Research Writing Prize and related digital publication, 'Why Research Matters,' which has been a great success. We thank Jemma and Liana for the contributions they have made to the SRI and we wish them both well on their future paths.

In February, we welcomed **Claire Backhouse** in the role of Marketing and Communications Manager. Claire is a communications specialist with over 10 years' experience in Australia's higher education sector and in the not-for-profit sector in Vietnam and Cambodia.



Liana Cross



Claire Backhouse

Prior to joining the SRI, Claire spent more than two years in Cambodia, where she was Communications Manager for 'This Life,' a community development organisation focused on social justice issues such as gender-based violence, children's rights, and juvenile justice and diversion. Prior to this Claire was the Engagement and Development Communications Coordinator at the University of Queensland Graduate School, focused on the Higher Degrees by Research program and the Three Minute Thesis competition.

Another exciting addition to the team in 2021 was **Fiona Low**, taking on the newly created role of Office Administrator and Program Support, to help support the growth of the SRI's programs and operations. Fiona has extensive administration experience gained from working in corporate and non-profit organisations across Japan, UK, Australia and Hong Kong, and has held roles from Team Assistant to Executive Manager, supporting high-level Executive and Senior Management, Board Chairs and Directors, external consultants, government bodies, and teams both large and small.



Fiona Low



Chief Executive Officer's message

I am delighted to share with you, the Spinal Research Institute's inaugural Impact Report. Our vision is to improve the health and quality of life of people with spinal cord injury and this report highlights the recent outcomes of our work and the impact we are creating to help achieve this goal.

Our programs have grown and evolved significantly over the past couple of years, despite the challenges of the pandemic. The Spinal Cord Research Hub (SCoRH) proved its value as an enabler for online collaboration, when researchers were unable to meet face to face; we launched our Mentor Program for talented emerging researchers; conferences pivoted to an online model, meaning we could provide more Research Collaboration Grants for conference attendance than ever before; and our Consumer Engagement Program ramped up with the establishment of our Consumer Advisory Network and webinar series development.

We are incredibly proud to support and work with our local spinal cord injury community of consumers, researchers, and clinicians, while also recognising the importance of establishing international connections and collaborations that help to propel Australian research and consumer engagement forward. We know that collaboration is key to increasing the scale of spinal cord

injury research trials and in turn achieving results that can be translated into improved healthcare policy and practice.

The ability to create and deliver innovative programs is testament to the wonderful relationships we have built with our philanthropic community. I would like to thank our donors and recognise the commitment they have made to the SRI.

I would also like to thank and recognise the contribution of the SRI team and Board, our Patron Lady Southey AC, our Ambassadors, and Consumer Advisory Network. In particular, I would like to acknowledge two team members who departed the SRI in late 2021, Jemma Altmeier and Liana Cross, and thank them for their valuable contributions.

We are working hard to deliver on our mission. We firmly believe that by driving research collaboration, investing in the next generation of researchers, and transforming research through consumer 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



SRI team left to right

Associate Professor Doug Brown AM, Founder
Kristine Hendry, Chief Executive Officer
Deirdre Mori, Development Manager
Fiona Low, Office Administrator and Program Support
Antonio Vecchio, Community and Consumer Engagement Manager
Claire Backhouse, Marketing and Communications Manager
Emma Peleg, International Research Collaborations Manager



A word of thanks from our Patron, Lady Southey AC

Like many families around Australia mine has been touched by spinal cord injury. I am proud to be the philanthropic Patron of the Spinal Research Institute as I share their passion to improve health outcomes and the quality of life for people affected by spinal cord injury.

Since taking on the role of SRI Patron in 2018 from my good friend Betty Amsden AO, I am in the fortunate position of seeing what has been achieved and looking forward to the vision ahead. The SRI's exciting collaborative work with researchers, community members, and partnerships with key institutions around the world will make a tangible difference to the lives of those with spinal cord injury as they are transformed through better health and quality of life outcomes.

I am so pleased to be able to help one of the most vulnerable groups in the community through the power of philanthropy. I am also thrilled to be involved in one of the most exciting areas of research and to see how, with the help of philanthropy, we are driving ambition and innovation in SRI programs to increase more successful, translatable outcomes.

It is my hope that members of the spinal cord injury community receive the best treatment and care available, so that they can excel and thrive and live full and rewarding lives. Philanthropy makes this possible.

As Patron, I would like to thank the SRI donor community for your continuing commitment and wonderful support to the SRI and hope you can feel proud, as I do, of what we have achieved together. Thank you for your loyalty and I look forward to you being a part of our future as we continue to make a real difference to the lives of the many people with a spinal cord injury.

Lady Southey AC
Patron



Lady Southey AC, SRI Patron with Associate Professor
Doug Brown AM, SRI Founder and Executive Director



Ambassadors - championing the SRI in the community

The Spinal Research Institute 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 experiences of our Ambassadors in a range of settings has enabled us to talk about the impact of our work in meaningful ways.

We are very lucky to have Jason Ellery as one of our ambassadors. He's an inspiring person with a positive outlook and enthusiastic approach to life. His spinal cord injury occurred on a snowboarding trip in 2011, and while his injury was life-altering, he has shown a remarkable capacity for resilience and an unshakable determination to make progress in all areas of his life.

Since his injury, Jason has gone on to achieve further qualifications, and he has also represented Australia in wheelchair rugby, winning a World Championship.

It is obvious that Jason has a unique take on life, and he often talks about how challenging situations can help build resilience. "I think not dwelling on the bad things and not thinking about things that you can't control is the best

approach. Just control what you can by doing the best you can in that particular situation." Jason's achievements and management of his life after spinal cord injury show how effective this approach can be.

Jason is passionate about the impact that improvements in research collaboration can have. "Spinal cord injury research can dramatically improve the quality of life for me and the millions of people living with spinal cord injury across the world. That's why I support the SRI - the focus on improving lives, here and now, is what matters."

The SRI would like to take this opportunity to thank 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:

- Marc Brew
- Dr Mario D'Cruz
- Max and Stefania Di Paolo
- Jason Ellery
- Dr Gilleen Hilton

Jason & Nicole Ellery with their sons Ky and Jordy

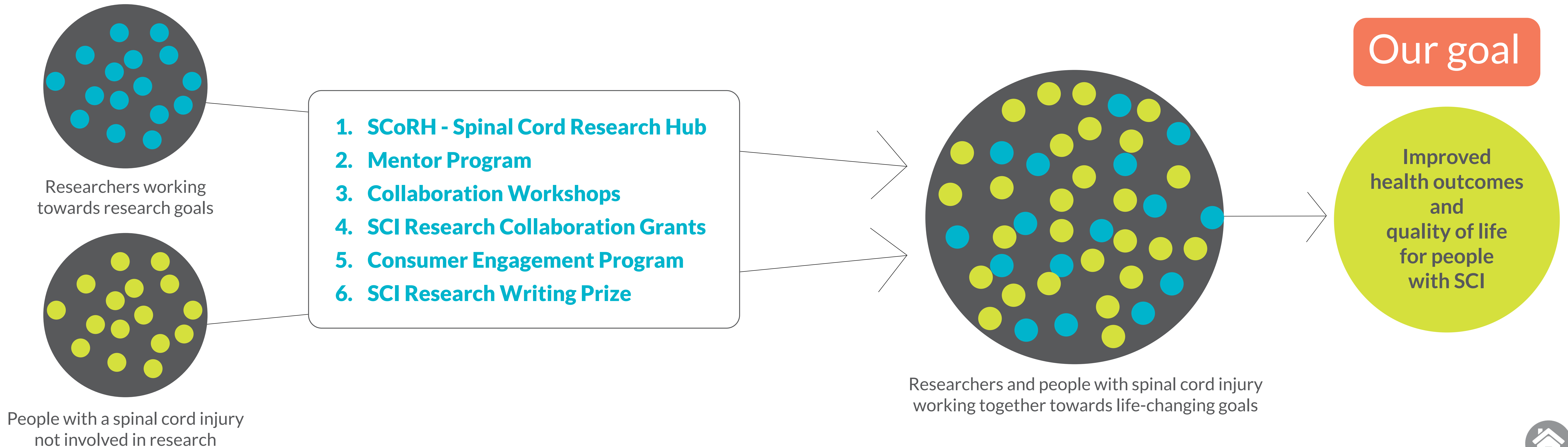


Our programs

The Spinal Research Institute has **six** programs. These programs support researchers working in the field of spinal cord injury, and consumers, or those with lived experience of spinal cord injury, to become involved in the research process.

When people with spinal cord injury and researchers work together to make decisions about research, the health outcomes and quality of life for people with spinal cord injury will be improved. **That's our goal.**

An overview of each program and its impact can be found on the following pages.



SCoRH - Spinal Cord Research Hub

The Spinal Cord Research Hub (SCoRH) is the world's first online platform for spinal cord injury research collaboration. This Australian innovation was developed by the Spinal Research Institute, with support from leading local and international experts in spinal cord injury research, and launched in 2018. 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.

The number of researchers and clinicians working on SCoRH has increased by 47% in the past 18 months, demonstrating its value as an enabler for collaboration when the pandemic closed many universities and research institutions and prevented face to face interaction.

Utilising SCoRH, the SRI can respond to the changing needs of researchers. Conversations with researchers and feedback sought through surveys reveal that being time-poor is the biggest challenge researchers face. We have provided support to meet this specific need of the research groups collaborating on SCoRH by facilitating meetings and workshops that will push their research forward.

SCoRH's new **Research Group Facilitation service, developed by the SRI's International Research Collaborations Manager, Emma Peleg**, 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.

Comments on the Research Group Facilitation service:

"I have thoroughly enjoyed our sessions, having the SRI encourage us to ensure we meet our objectives really has been the key to getting this group active."

"The session was an opportunity to bring a much wider group of people together and validate the value and importance of their work. It also highlighted the importance of collaboration and has led to new projects, ideas and joint learning. Thank you."

SCoRH Facts

336 members
from **37** countries

1/3 of members
are early career
researchers

36 key areas
of research
identified

22 research
groups
established

50% of SCoRH
research groups
using Research
Group Facilitation
service

SCoRH member Dr Camila Quel de Oliveira,
Lecturer and Physiotherapist, Graduate School
of Health, University of Technology Sydney



Mentor program

The Spinal Research Institute's Mentor Program was launched in 2021 having begun as a successful pilot program in 2019.

The program has four aims:

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

Mentoring in research equips individuals with skills that might not be available within their own organisation or institution. The mentor/mentee relationship is not bound by geographical limits, and supports growth beyond the mentee's physical location to help develop their networks for collaboration.

Participation in the program is through application, and applicants must define a specific research project to focus on during the mentorship. This ensures that applicants have carefully considered how their research will improve quality of life for people with spinal cord injury.

"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."

"I think the SRI mentorship program is a great platform to upgrade your skills, knowledge, confidence and collaboration opportunities. Moreover, it is facilitating multi-centre and cross-culture studies."

Participant surveys show

- **100% of mentees feel strongly connected with the SCI research field. (40% increase)**
- **100% of mentees agree that the mentor program has improved their research skills.**
- **100% of mentees feel confident that they can progress their research. (40% increase)**

Dr Sintip Pattanakuhar (right), a Rehabilitation Physician at the Faculty of Medicine, Chiang Mai University, applied to the SRI's pilot Mentor Program in 2019. Dr Pattanakuhar was paired with Dr Leslie Morse from the University of Minnesota Medical School. Working on a set of focussed goals, Dr Pattanakuhar and Dr Morse achieved the outstanding outcome of having a co-authored paper published in the highly regarded *Journal of Spinal Cord Medicine* about spinal cord injury-related osteoporosis and fragility fractures.

After a further successful application to our 2021 Mentor Program, Dr Pattanakuhar was paired with Professor Armin Gemperli of Swiss Paraplegic Research. With Professor Gemperli's support, Dr Pattanakuhar made a successful application for a Swiss Government Excellence Scholarship. In September 2022, Dr Pattanakuhar will commence a postdoctoral fellowship with Professor Gemperli and his research group.



Collaboration workshops

Collaboration workshops are all about connecting people, sharing practices, and disseminating information. These workshops provide the Spinal Research Institute with an opportunity to co-host with leading institutions in spinal cord injury research as well as connect with the international research community in an open discussion-style setting.

Outcomes from these workshops further our goal of building international research collaboration in a meaningful way for researchers, clinicians and consumers.

To the right is a list of the workshops co-presented by the SRI at the Annual Scientific Meetings of the International Spinal Cord Society (ISCoS) and the Australian & New Zealand Spinal Cord Society (ANZSCoS) since 2016.

2021

2021 ISCoS Workshop, virtual meeting: Knowledge Translation in SCI Research: Gaps and Bridges

Co-presented with: Prof Kim Anderson-Erisman (North American Spinal Cord Injury Consortium) and Gunilla Åhrén (The Gothenburg Competence Centre for SCI, Sweden).

2021 ISCoS Workshop, virtual meeting: Establishing Consumer Engagement Programs and the Impact for SCI Research Organisations

Co-presented with: John Chernesky (Praxis Spinal Cord Institute, Canada), Magdalena Skrybant (National Institute for Health Research, UK) and Harvey Sihota (International Spinal Research Trust, UK).

2021 ANZSCoS Presentation, virtual meeting: Exploring Different Ways of Integrating Consumer Engagement in Spinal Research

Co-presented with: Dr Johnny Bourke (Burwood Academy Trust, New Zealand).

2019

2019 ISCoS Workshop, Nice, France: From Concept to Practical Application: Meaningful Consumer Engagement in SCI Research

Co-presented with: Prof Kim Anderson-Erisman (North American Spinal Cord Injury Consortium), Kylie Cochrane (International Association for Public Participation (IAP2), Australia), John Chernesky (Praxis Spinal Cord Institute, Canada) and Dr Johnny Bourke (Burwood Academy of Independent Living, New Zealand).

2018

2018 ISCoS Workshop, Sydney, Australia: Developing Practical Tools for Global Research Collaborations in a Time Poor World

Co-presented with: Dr Keith Hayes (Ontario Neurotrauma Foundation, Canada) and Dr Jane Hsieh (Wings for Life, Canada).
Additional support from: Rick Hansen Institute, Canada.

2017

2017 ISCoS Workshop, Dublin, Ireland: SCI Clinical Research Engagement: Developing an Active Research Network

Co-presented with: Dr Keith Hayes (Ontario Neurotrauma Foundation, Canada), Dr Phalgun Joshi (Rick Hansen Institute, Canada), Prof Armin Curt (Balgrist University Hospital, Switzerland) and Dr Jane Hsieh (Wings for Life, Canada).

2016

2016 ISCoS Workshop, Vienna, Austria: International Collaboration on Clinical Research in Chronic SCI

Co-presented with: Dr Kim Anderson (University of Miami, USA) and Dr Harvinder Chhabra (Indian Spinal Injuries Centre).
Additional support from: Rick Hansen Institute, Canada; Ontario Neurotrauma Foundation, Canada; Institute for Breathing and Sleep, Australia; and International Collaboration for Repair Discoveries (iCORD), Canada.



SCI Research Collaboration Grants

The Spinal Research Institute was pleased to offer 30 Research Collaboration Grants to enable early to mid-career researchers to attend the 60th International Spinal Cord Society (ISCoS) Annual Scientific Meeting in October 2021. The objective of this grant, which we offer each year, 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 Meeting offers a unique opportunity to grow and garner fresh ideas and collaborate with international peers. Successful applicants must demonstrate they are working to pool expertise and obtain cross-fertilisation of research ideas through collaboration.

In 2021 the SRI also offered four grants to attend the Australian and New Zealand Spinal Cord Society meeting.

Dr Gillean Hilton, a local occupational therapist and spinal cord injury researcher, attended the ISCoS Meeting as a recipient of the first SRI grant in 2017. Attending the international conference as a PhD candidate enabled Dr

Hilton to build her professional network and seek opportunities for collaboration, critical for an early career researcher to be successful in her research and make a difference to the lives of those with spinal cord injury she was working with back home in Melbourne, Australia.

Recipients of the SCI Research Collaboration Grants share their positive experiences of attending ISCoS in 2021:

“Interest in our fields from clinicians has led to collaboration to enable the dissemination of our techniques into the clinical setting.”
Dr Elizabeth Bye (group), Australia

“This has already led to new experiments being hypothesised in our lab to apply our group research program to additional areas of research.”

Dr Ryan O’Hare Doig (group), Australia

“Attendance at ISCoS helped to expand our collaboration horizons beyond the national and regional levels.”
Dr Jimena Quinzanos (group), Mexico



34
Grants
awarded in
2021



79
Grants
awarded since
2017



5
Grantees with
lived experience
of SCI



49
Female
grantees since
2017



Supporting research in low and middle-income countries

In addition to supporting our local researchers, the Spinal Research Institute has been working with groups of researchers on the Spinal Cord Research Hub (SCoRH) who are dedicated to improving quality of life outcomes for people in low and middle income countries, where the incidence of spinal cord injury is often much higher than economically developed countries. The groups include researchers from South Africa, Tanzania, Bangladesh, Pakistan, India, Nepal and Brazil.

One of the groups is working collaboratively to improve quality of life outcomes for their communities via telehealth and telerehabilitation. In many low and middle income countries, rehabilitation services often do not exist. It is very common for patients to be sent home from hospital without rehabilitation, after being treated for their initial traumatic injury, resulting in poor quality of life outcomes.

The Telehealth/Telerehabilitation research group is working to change this, with the potential to impact the health of people with spinal cord injury across many low and middle income countries and globally.

Supported through our SCoRH Research Group Facilitation service, the Telehealth/Telerehabilitation group has accelerated their progress in the last year by:

- defining the objectives and the direction of the group,
- progressing actions and outputs,
- nominating leads for their project tasks,
- defining short and long-term actions, and
- beginning work on their first group task.

“Imagine yourself, if you are living in rural area and you are told to go to Ruwa (the NRC) next to Harare for rehabilitation. You don’t have money, you don’t have transport to Harare and sometimes you don’t even have a wheelchair for personal mobility, how could you possibly find your way to Ruwa?” (I11, rehabilitation professional, female)^

^Øderud T. Surviving spinal cord injury in low income countries. *Afr J Disabil.* 2014;3(2):80. Published 2014 Aug 26. doi:10.4102/ajod.v3i2.80

Dr Yumna Albertus, Member of the Telehealth/Telerehabilitation SCoRH research group, University of Cape Town



Consumer Engagement - bringing the lived experience to SCI research

In Australia, 20,800 people live with a spinal cord injury. They are key stakeholders in the research process and it is vital that their voice is heard to ensure that research meets their needs and priorities.

For the past two years the Spinal Research Institute has been actively progressing our innovative Consumer Engagement Program. This flagship program is working to transform the spinal cord injury research field by, for the first time in Australia, supporting people with lived experience of spinal cord injury ('consumers') to become involved in co-design and co-delivery of research projects. It does this by improving knowledge and understanding of the research process and upskilling members of the spinal cord injury community so that they can participate as partners in research.

The program also engages researchers, championing the inclusion of lived experience in research, and we aim to create a set of world first protocols to formalise and guide the consumer engagement process.

Increased collaboration between researchers and consumers will result in more relevant research, to improve outcomes for people

with spinal cord injury in areas such as: respiratory and cardiovascular health, bladder and bowel function, sexual function, pain management, upper limb function (for people with quadriplegia), treatment of pressure sores, and management of sleep apnea - all secondary health complications of spinal cord injury that can impact on quality of life.

The resounding success of the early stages of this program, including this year's webinar series *Your voice. Your research. Your future.*, has resulted in a suite of educational resources that the SRI has produced for on-demand learning.

The SRI's Community and Consumer Engagement Manager Antonio Vecchio says the lived experience is "a crucial element of the research process, and something that we are working hard to improve by bringing together those with a spinal cord injury and spinal cord injury researchers. When I ask people in the community what is more important to them right now, being able to wiggle a toe in ten years or seeing an improvement in their bowel and bladder function, nobody ever chooses the toe. This illustrates how important it is that the voices of the lived experience are heard."



Antonio Vecchio, SRI's Community & Consumer Engagement Manager with clinician and researcher, Leanne Rees.



Consumer Advisory Network

The Spinal Research Institute's Consumer Advisory Network was established to inform and help shape our Consumer Engagement Program. Membership of the Consumer Advisory Network currently consists of four people living with spinal cord injury, a family member/carer of a person with spinal cord injury, and a spinal cord injury researcher.

We developed a specific Terms of Reference for the Consumer Advisory Network, along with a Policy for Consumer Remuneration.

The inaugural Consumer Advisory Network meeting was held in early 2021. Candid round table discussions were held on the topics of: barriers to consumer involvement in research;

how we create better awareness of research within the consumer community; and the creation and dissemination of educational content.

The Consumer Advisory Network has played an important role in identifying key research awareness gaps, helping us to improve our education and awareness resources including the webinar series. The Consumer Advisory Network will also play an important role in the evaluation of our Consumer Engagement Program.

Establishing the Consumer Advisory Network has been imperative to including the voice of lived experience in our Consumer Engagement

Program and ensuring the program meets the needs and priorities of the spinal cord injury community.

We are fortunate to have a Consumer Advisory Network that is engaged, diverse and committed to improving levels of consumer engagement in research. Two network members share their thoughts:

Christine & Ben

Since Ben acquired a spinal cord injury and became paraplegic in 2012, we have worked as a team to ensure that our lives are as comfortable and fulfilling as possible. We have made many new friends who have enriched our lives. Joining the SRI's Consumer Advisory Network was an opportunity for us to give back and help the spinal cord injury community. It is important to have the



voice of people with lived experience, including the voice of family members, helping to shape the program, so it is relevant to community members. We are proud of what we have achieved so far and look forward to helping the Consumer Engagement Program continue to evolve, as ultimately this will provide all of us in the spinal cord injury community with a better quality of life - and that's good for our family, friends, and community.



Lachie O'Brien
Lived experience of SCI



Martin Heng
Lived experience of SCI



Christine Tripp
Family member / Carer



Leanne Rees
Clinician & SCI Researcher



Ben Gruter
Lived experience of SCI



Campbell Message
Lived experience of SCI



Webinar series

As part of the Consumer Engagement Program, this year the Spinal Research Institute held a series of four webinars. Under the title Your voice. Your research. Your future., the four webinars focused on two key areas. The first was to provide people with lived experience of spinal cord injury and their family members foundation knowledge about research. This included how research works, how to access information about upcoming research, and information about how to participate in the research cycle. The second focus was to increase awareness of the value of consumer engagement among researchers and the research community. This included providing strategies for incorporating consumer engagement into practice.

The webinar series was an Australian-first project in the spinal cord injury field, to inspire and educate people with lived experience to become involved in the co-design and co-delivery of research projects. Funding from our partners gave us the opportunity to deliver a relevant and engaging webinar series that received very positive feedback from participants. Viewers who interacted with the live webinars also provided valuable insights that will help inform future program development.

Here is some feedback from the webinars:

“Fantastic presentation. Thank you.”
“Thank you for the seminar! Really enjoyed it.”
“You are so aware of the research benefits of daily life. Wheelchairs, driving modifications etc. As an Occupational Therapist, this helps us move forward.”
“Thanks so much for this! It was great :)”
“Thank you Drs Palermo, Graco and Lakhani for sharing your work and how you are making a difference for the SCI community.”

Consumer involvement in research is vital, to help impact trial success and influence research direction to have more relevance and better represent the complex health needs of the spinal cord injury community, thereby improving health and wellbeing outcomes.

Recordings of the webinars live on as online learning resources and can be watched on-demand, creating ongoing impact.

[Watch webinar videos](#)

Pictured (right) are the Australian-based researchers who were interviewed for the webinar series.



Dr Annie Palermo



Dr Marnie Graco



Dr Ali Lakhani



Leanne Rees

Video series

In Conversation - connecting with the SCI community during the pandemic

When face to face contact wasn't possible during lockdowns, we knew we needed to stay connected to the SCI community, and in mid-2020 we launched our In Conversation video series. The videos share insights on the physical and mental health impacts of the pandemic, while also capturing fascinating stories and perspectives of the remarkable interview subjects. Topics included managing health and wellbeing during lockdown, developing resilience in difficult situations, and the potential health complications of COVID-19 for people with spinal cord injury. The videos were greatly received and to date have reached over 11,000 people on Facebook.

[View series](#)

Consumer Engagement in Research

In 2020, we launched a three-part video series about consumer engagement in research. Nick Morris, SRI Director, discusses this important topic with John Chernesky (Praxis Spinal Cord Institute) and Lynne Panayiotis (Royal Talbot Rehabilitation Centre). The videos discuss the benefits of consumer engagement in research, what meaningful engagement looks like, and how to get involved in research.

[View series](#)



Consumer Engagement in Research video featuring John Chernesky, Lynne Panayiotis and Nick Morris



In Conversation

WITH RHIANNON TRACEY



SCI Research Writing Prize: Why Research Matters

In 2020 the Spinal Research Institute launched its inaugural Spinal Cord Injury Research Writing Prize. We asked spinal cord injury researchers and clinicians 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 had to explain their research in 800 words or less, keeping in mind the question “Why does my research matter?”

The shortlisted entries were published in the first edition of ‘Why Research Matters.’ The objective of ‘Why Research Matters’ is to demystify and share the important work happening around the world in the field of spinal cord injury research.

The Writing Prize is open to all spinal cord injury researchers, whether their research is in progress or published. Entries are subject to a blind judging, where the writers’ names are not known to the judging panel.

Research with the potential to positively impact the quality of life for an individual with spinal cord injury should be made accessible. ‘Why Research Matters’ provides a forum for researchers to showcase their research

outside of traditional academic publications and enables engagement with the spinal cord injury community through an accessible, ‘storytelling’ format that demonstrates the diversity in spinal cord injury research.

The publication intrinsically supports our programs of research collaboration and consumer engagement, and we are excited to provide this opportunity to Australian and international researchers to share their work with both peers and the spinal cord injury community.

Pádraig Carroll, a PhD student and Research Assistant from the Royal College of Surgeons in Dublin, Ireland was one of the researchers whose writing we included in our 2020 publication.

Pádraig told us: “My spinal cord injury research project has gained much wider recognition and a huge amount of interest since being published by the SRI in ‘Why Research Matters.’ The response has been unprecedented, and I am truly grateful for this support.”

Why Research Matters: A collection of spinal cord research from around the world



2021

The 2021 edition of Why Research Matters contained 8 written pieces. Contributing researchers were from 5 countries.

[View Edition 2, 2021](#)



WHY RESEARCH MATTERS

A collection of spinal cord research from around the world



Winning submissions from the SCI Research Writing Prize



The 2020 edition of Why Research Matters contained 12 written pieces. Contributing researchers were from 8 countries.

[View Edition 1, 2020](#)



More achievements and highlights

SRI Founder Awarded OAM



Executive Director and Founder, Associate Professor Doug Brown, was made a Member of the Order of Australia in 2021 for his significant service to medicine, particularly spinal cord injury.

Poster: Consumer Remuneration



‘Consumer engagement in spinal cord injury research: Developing a policy and model for consumer remuneration,’ presented at ANZSCoS Scientific Meeting 2021.

ISCoS Partnership



In 2022, the SRI once again partnered with 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.

SRI 10 Year Anniversary



The Spinal Research Institute celebrated its 10th anniversary in 2021. In this video CEO Kristine Hendry shares some of the achievements and highlights from this important milestone year. She also talks about some of the exciting things planned for the future.



Vision & Impact virtual event

In September 2021, we brought together our incredible supporter network of individuals, community groups, businesses and foundations, to thank them and to share with them our vision to improve the lives of people with spinal cord injury and the impact we are making in the field of spinal cord injury research.

Our wonderful Patron, Lady Southey AC, hosted the online event and reminded everyone of how important and unique our work is in spinal cord injury research collaboration and consumer engagement.

Through live presentations and recorded messages, we shared stories of how the Spinal Research Institute is making a positive impact; always striving to improve the lives of people with spinal cord injury.

Kristine Hendry, SRI CEO, spoke to our future programs and goals, saying; “We are working hard to deliver on our mission, through programs demonstrating excellence and innovation.

“Our programs for the support of spinal cord injury early career researchers are unique and leading the way in Australia and

internationally, a position we’re proud to hold.

“Our vision for the Consumer Engagement Program is to transform the spinal cord injury research field, starting here in Victoria, by supporting consumers – people with lived experience of spinal cord injury – to be actively involved in the research process.”

The image to the right shows many of the guests who attended the event. Speakers included:

Fi Slaven, SRI Chair

Associate Professor Doug Brown AM, SRI Founder and Executive Director

Dr Mario D’Cruz, SRI Director

Dr Gillean Hilton, occupational therapist and researcher, Austin Health, Vic

Dr Diana Dorstyn, psychologist and researcher, Adelaide University, SA

Dr Marnie Graco, physiotherapist and researcher, Institute for Breathing and Sleep, Vic

Dr Vanesa Bochkezanian, lecturer in neurological physiotherapy, Central Queensland University, Qld

Antonio Vecchio, SRI Community and Consumer Engagement Manager



Morning Tea with our Patron

In May this year, the Spinal Research Institute welcomed guests to a morning tea generously hosted by SRI Patron, Lady Southey AC, at *Cranlana*, the Myer family home in Melbourne. It was a wonderful opportunity to connect and reconnect with many of the SRI's friends and supporters. Having not been able to meet face to face for more than two years, this event was long overdue.

As one element of the gathering, Kristine Hendry, SRI's CEO, conducted a Q&A with physiotherapist and spinal cord injury doctoral researcher Leanne Rees. Leanne gave us an insight into her research of the media's portrayal of spinal cord injury and disability. Leanne was joined by Antonio Vecchio, the SRI's Community and Consumer Engagement Manager, which made for an interesting and lively discussion about the importance of co-designed research and how this has positively impacted Leanne's study. Antonio explained how this study has in turn helped shape the SRI's focus on consumer engagement, by reinforcing the benefits of consumer input to make a study more relevant and beneficial to the spinal cord injury community.

Kristine spoke about how consumer engagement in research builds skills and confidence to enable people with spinal

cord injury to advocate for research that best meets their needs and priorities. She also mentioned our work in maintaining connections with the local spinal cord injury community throughout the pandemic, including creation of a series of health and wellbeing videos that are available online.

Lady Southey AC expressed her gratitude to the SRI's supporters, old and new:

"Our heartfelt thanks go to each and every one of you for your incredible support in 2020 and 2021. It has enabled the SRI to continue to move forward in its mission of improving health outcomes for people with spinal cord injury so that they may achieve their full potential in life."



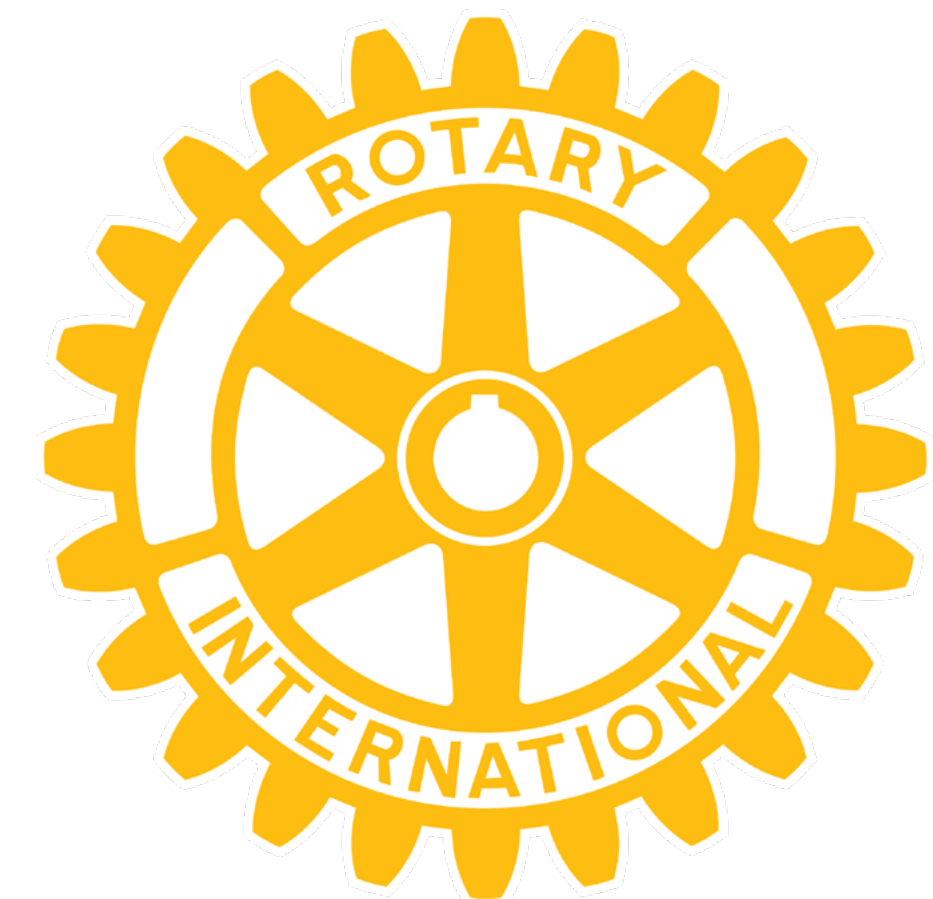
Thank you

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

Founding Donors

Ms Joanna Baevski
Mr Geoff Handbury AO
Dr Peter Kingsbury
Mr Irving Lenton
Mrs Rae Rothfield
Lady Southey AC
Mr Zich Woinarski QC

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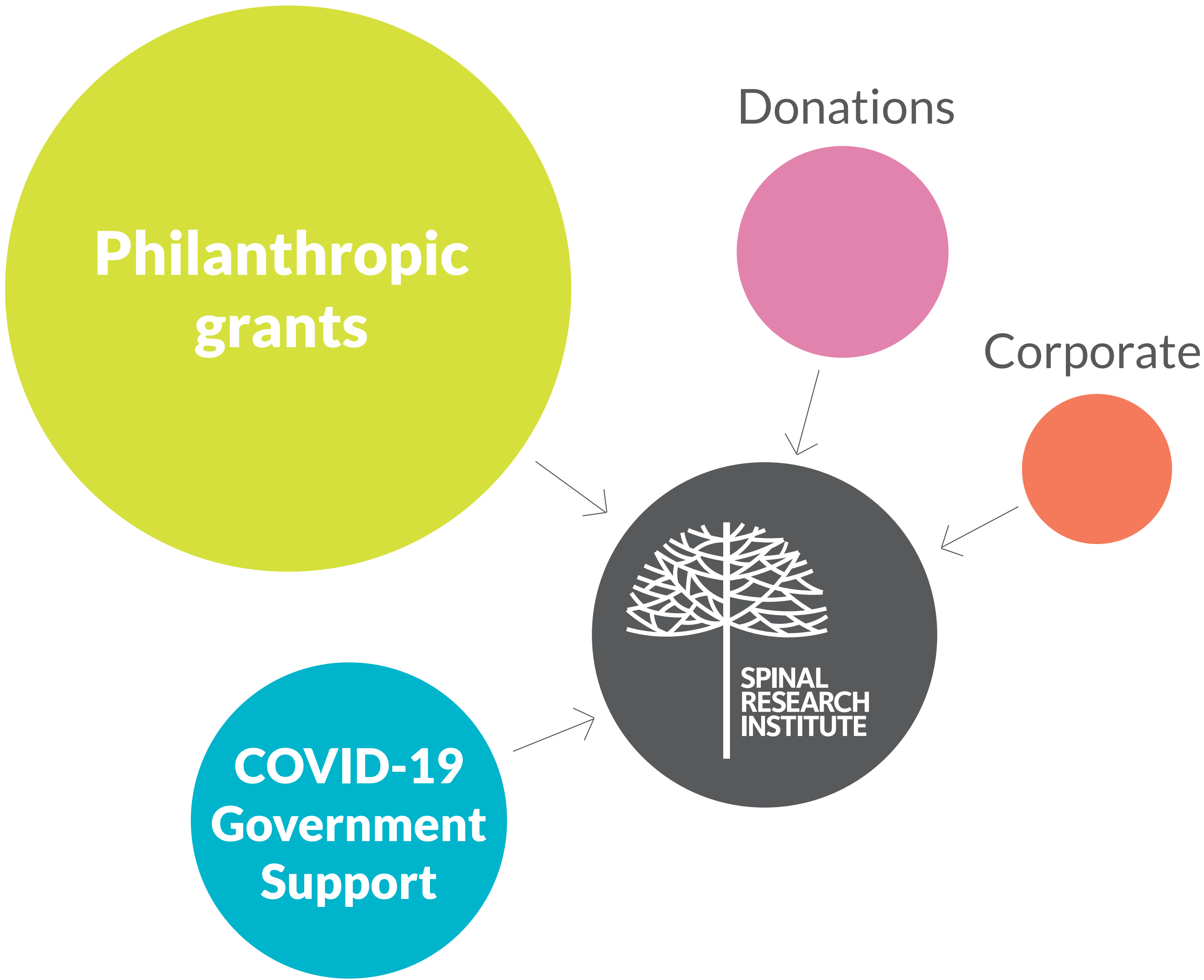
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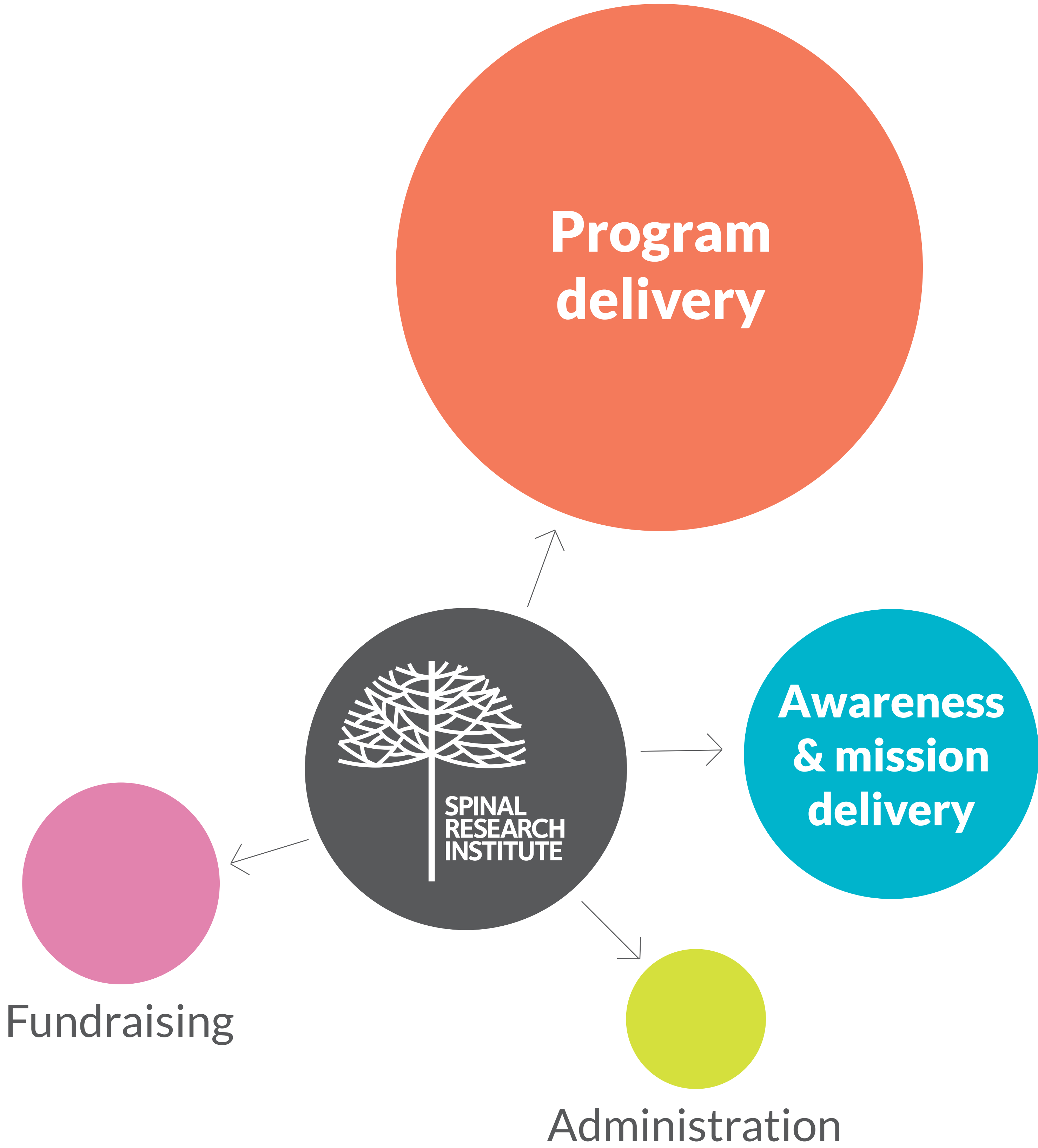
BETTY
AMSDEN
FOUNDATION



Funding sources



Expenditure



This information is based on figures from the 2021 financial year.
Our financial reports can be found on the [Australian Charities and Not-for-profits Commission website](#).



Where to next?

This report has focused on the recent achievements and impacts of the Spinal Research Institute; there are also many exciting things on the horizon.

In September, members of the SRI team will travel to Vancouver, Canada, to attend the 61st International Spinal Cord Society Annual Scientific Meeting. The team will be very busy presenting scientific posters, meeting with recipients of the 2022 SCI Research Collaboration Grants, establishing new relationships, and reconnecting with international colleagues.

We will be continuing our mentoring work and in 2023 we will put the call out for a new group of early career researchers to be assigned a mentor.

As always, we will continue to work with our SCoRH researchers and share their successes as they establish new research collaborations and publish new research. We will expand our Research Group Facilitation service as we know how time-poor researchers can be.

In the consumer engagement space, we will be developing the next phase of our program, including implementing the learnings from the webinar series. Our pioneering work

in Australian spinal cord injury consumer participation and remuneration is in its infancy and we will be working hard to develop it further.

The feedback from the 2020 and 2021 Writing Prize, and associated 'Why Research Matters' publications, was wonderful and we are running this again in the second half of 2022. It will be interesting to read the submissions and hear from researchers all around the world.

Excitingly, in 2023, we will be expanding our team to enable us to pursue new program opportunities in research collaboration and knowledge translation.

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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