

Welcome to the quarterly update of the Spinal Cord Research Hub (SCoRH), an initiative of the Spinal Research Institute (SRI). In this newsletter, discover ways that the SCoRH platform can assist you, and find out more about other SRI programs.

## **SCI Research Collaboration Grant recipients** attend ISCoS 2024

The SRI was delighted to support eight early career researchers to attend the International Spinal Cord Society's Annual Scientific Meeting in Antwerp, Belgium in September. Over the course of the conference, the grant recipients presented posters, made valuable connections, and strengthened their growing networks. We look forward to hearing more about their progress in spinal cord injury research in the future.

The grant recipients shared their experiences from the conference.

"Learning about global advancements in SCI research has been inspiring and will significantly contribute to my ongoing work on spinal cord graft development." Leena Chaudhari, India

"It (attending ISCoS) allowed me to establish valuable connections with fellow researchers and clinicians, fostering potential collaborative opportunities that will enrich my PhD project." Maria Cunha, Portugal

"The knowledge I gained about emerging practices in SCI care will directly inform my efforts to improve health outcomes for individuals with SCI." Laura Stendell, Australia

Read more about their experiences at the conference.



Left to right: Angela Hanks Philippus, Laura Stendell, Ryan Dorrian, Kanishka Gambhir, Srisankavi Sivasankar, Leena R Chaudhari, Maria Cunha, Natalia Padula

## **Congratulations, Dr Haleluya Moshi!**

We are delighted to share the news that Dr Haleluya Moshi was awarded The 2024 Paul Kennedy Legacy Award for Psychology cosponsored by NSIC Psychology Service, The National Spinal Injuries Centre, Buckinghamshire Healthcare NHS Trust, University of Sydney, and Stoke Mandeville Spinal Research. The SRI supported Dr Moshi's attendance at ISCoS in 2023, and one of his aims at the time was to improve his



professional network with a view to developing future collaborations. Winning this award is a fantastic acknowledgement of the progress he has made in this area.

Dr Haleluya Moshi is a senior physiotherapist and lecturer at the Kilimanjaro Christian Medical University College in the faculty of Rehabilitation Medicine. He has more than 17 years experience offering rehabilitation services to persons with traumatic spinal cord injury. Dr Haleluya is interested in disability prevention and rehabilitation in resource-constrained areas. He is currently developing a database for traumatic spine and spinal cord injury at the Kilimanjaro Christian Medical Centre (KCMC), the only hospital in Tanzania with a spinal cord injury unit.

We asked Dr Moshi about his experiences at ISCoS 2023.

Participating in ISCoS 2023 introduced me to a more extensive network of potential collaborators, more than initially anticipated. I had the opportunity to meet and connect with several scientists specialising in spinal cord injuries (SCI), each with diverse interests. Engaging with the psychosocial special interest group expanded my perspective on the needs of individuals with SCI, prompting me to consider a broader range of factors. I established contacts with individuals interested in collaborating on addressing psychosocial needs, an area that has received limited attention in my home country. Moreover, I gained insights into the possibilities of applying for both small and large grants dedicated to SCI treatment and rehabilitation.

Listen to Dr Moshi discuss <u>accessibility struggles for SCI patients in rural Africa</u>, recorded at ISCoS 2024.

# Low and middle income country researchers benefit from Research Group Facilitation service

Low and middle income countries (LMIC) experience a higher burden of SCI-related complications due to limited healthcare resources. These difficulties led a number of researchers from LMICs to create a research working group on SCoRH. Initially, working towards a unified goal presented challenges stemming from disparities in healthcare quality, resource availability, as well as time differences between countries. However, SCoRH's Research Group Facilitation service played an instrumental role in mitigating these issues.

The research group comprises members from Bangladesh, India, Nepal, Pakistan, and South Africa. Together, they have developed a draft to examine the COVID-19 response and the management of individuals with SCI in LMICs. Their objective was to expand their efforts by engaging and collaborating with interdisciplinary professionals in the field of SCI.

Building local capacity through collaboration can foster more sustainable and autonomous research practices within LMICs, ensuring that the benefits of research are disseminated more broadly.

It is fantastic to see the group's progress stemming from their beginnings on SCoRH, and we look forward to hearing more about their progress. If you're an SCI researcher working in a LMIC, email us at <a href="mailto:admin@scorh.org">admin@scorh.org</a> and we will put you in contact with the group.

### What is Research Group Facilitation?

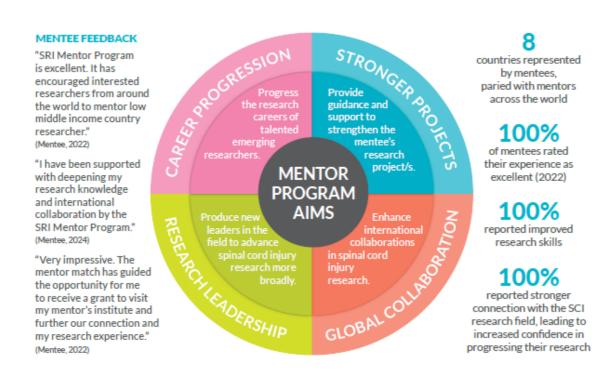
This service supports established groups to overcome obstacles that prevent or hinder their progress. Researchers globally are time-poor, and administrative tasks such as organising meetings with group members in a range of international locations can be prohibitively time-consuming. Additionally, as group members are concurrently working on other projects and managing conflicting priorities, it can be difficult to maintain momentum, leading to a lack of clarity about group actions and goals. Research Group Facilitation provides structure and focus that can assist with these issues. If you are interested in the Research Group Facilitation service, please email us at <a href="mailto:admin@scorh.org">admin@scorh.org</a>.

## **SCoRH** - new platform update

We are currently redesigning the <u>SCORH</u> platform to improve user experience and provide enhanced functionality. The improvements will provide a more streamlined and intuitive experience for our members. We look forward to sharing the upgraded platform with you in 2025!

## **Mentor Program - get involved in 2025**

The SRI offers a Mentor Program for early career researchers with the aim of improving global collaboration in the field of spinal cord injury (SCI) research. In 2025, we will be putting a call out for new participants in this program. We will advertise this opportunity through our SCoRH mailing list, so if you have colleagues who you believe might be interested in participating in this program, please forward this email and encourage them to join SCoRH.



The SRI's Mentor Program continues to grow and we work hard to set up meaningful pairings that will benefit our mentees into the future. If you've ever considered being a mentor in a program like this, please <u>contact us</u> so that we can keep your details on file for future rounds. Mentees are from a wide range of SCI disciplines and research areas, so your expertise and willingness to work with an emerging researcher could make all the difference.

### Work with us!

We're looking for a Research Program Officer who will be responsible for developing and delivering research-related projects and programs; providing a researcher's perspective and input to support the development and growth of the SRI's current programs including Collaboration Grants, Mentor Program, the Spinal Cord Research Hub (SCoRH) and Consumer Engagement Program. It's a part time position (15 hours per week), and applications close on 15 December. View the position details and apply.



## **International Day of People with Disability**

Every year, on December 3rd, we acknowledge and promote International Day of People with Disability. This year's official theme is "Amplifying the leadership of persons with disabilities for an inclusive and sustainable future."

The theme this year reflects the current international political and policy context, in particular the Pact for the Future and the upcoming 2025 World Summit for Social Development, and the need to create momentum for achieving the 2030

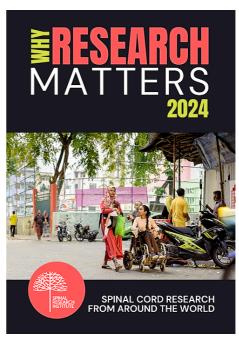
Agenda. The theme seeks to amplify the centrality of the leadership role of persons with disabilities, in all of these efforts - from the global to the local.



## **2024 Why Research Matters**

We're very pleased to bring you the 2024 edition of Why Research Matters, a collection of spinal cord injury research from around the world. It is a compilation of the top twelve entries from the Spinal Research Institute's 2024 Spinal Cord Injury Research Writing Prize. The entries presented showcase a wide range of research interest areas and their authors are working in six different countries.

For the first time since we began holding this competition five years ago, the judges' scores were tied, so we have two winners of the Judges' Choice Award! One discusses the impact of technology and specialty nurse



counsellors on urological outcomes in SCI patients in India, and the other follows the development of a low-cost manual standing wheelchair. Congratulations Dr Dinesh Suman and Shovan Parvez!

We hope you enjoy reading this year's edition.





Dr Dinesh Suman is the Director. Neuro-Urology and SCI Andrology at the Indian Spinal Injury Centre, New Delhi. With qualifications including M.Ch. (Urology) and a fellowship in Neurourology from the National Hospital for Neurology and Neurosurgery, London, he has led the department since 1999. He is a founder member of the Spinal Cord Society of India, with over 28 publications and ongoing research in SCI healthcare. He has received multiple awards, including the ET Times Now Award as one of India's "Promising Urologists."

Shovan Parvez is a Rehabilitation Engineer at the Centre for the Rehabilitation of the Paralysed (CRP), specialising in assistive technology and robotics. He earned his bachelor's degree in Electrical and Electronic Engineering from Daffodil International University and has been working with close guidance from Dr. Monzurul Alam on developing numerous opensource assistive devices, including Standing Wheelchair, Standing Frame, and Exoskeleton Walker which aims to increase the accessibility of assistive devices in low economic settings through freely sharing their design.

# Reminder: Consumer Engagement Consultation Service available through SCoRH

This service supports researchers who would like to know more about how to include consumers in the design and implementation of their research. Including the perspectives of consumers is best practice in SCI research and is increasingly required in order to secure funding through grants. However, it is not always clear how researchers might approach this in their own projects. The Consumer Engagement Consultation service provides guidance about the ways in which consumers might be involved in different stages of the research process.

Visit SCoRH to access more information about this service or email us at <a href="mailto:admin@scorh.org">admin@scorh.org</a>.

## The Landscape of Spinal Cord Injury Research in Australia 2018 - 2023

In case you missed it, the Spinal Research Institute (SRI) recently published its report, The Landscape of Spinal Cord Injury Research in Australia (2018-2023). The aim of the report was to gain a clear understanding of the SCI research being undertaken within Australia. We hope this will inform and support efforts to minimise duplication of research, reduce financial waste, and help make strategic decisions around investment, thereby maximising the use of the limited resources available.

Two approaches were used to identify as much current and recent research as possible. These were: a comprehensive web-based search to identify research currently in progress (commenced during or since 2018), and a scoping literature review to identify recently completed research (literature published between January 2018 and May 2023).

- The total amount of overall funding identified in this search was \$48,662,255. 87.5% of funding was allocated to clinical research, and 12.5% to pre-clinical research.
- Associate Professor Linds Barchy
  Research and Knowledge Translation, Lead Spinal
  Research and Knowledge Translation, Lead Spinal
  Research Institute Associate Professor, Monash University

  Dr Marnie Grace
  Implementation Scientist, Institute for Brentling and
  School Scientist, Institute for Brentling and
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- The literature review included 196 eligible publications, the majority of which reported clinical research (87.2%), consistent with funding patterns.
- Of the 196 publications, only nine engaged people with lived experience of SCI other than as research participants.

This report identifies several opportunities for new approaches to advance the reach and impact of SCI research in Australia. Models that integrate pre-clinical, clinical and community-based research involving multidisciplinary teams, in consultation with SCI consumers and key stakeholders, could maximise impact and return on investment. In addition, stronger incentives for multi-state collaborative projects are needed from funding agencies.

# Are you seeking participants for your research study or clinical trial?

The SRI regularly receives requests to promote research to potential participants for research projects. We now have an <u>online form</u> where these requests can be submitted for consideration. Studies and trials currently seeking participants are below.

### BREATHE: The Spinal cord injury, Mind and HeART (SMART) Study

Researchers seek adults living with #SCI in Sydney to trial a non-invasive therapy that may improve heart & brain function, which in turn may lead to a decrease in blood pressure, sleep problems, brain fog, pain, and fatigue. It may even improve mood!

The SMART trial aims to investigate the effect of a self-regulated slow paced

breathing technique in adults with a spinal cord injury. In other populations, this technique has demonstrated promising results, such as reduced pain and depression and improved cognitive function and cardiovascular health. No published study has investigated the effect of this intervention in a population with spinal cord injury. The study is being conducted at Royal North Shore Hospital, St Leonards, Sydney.

https://bit.ly/SMART-trial

## The SMART trial

Spinal cord injury, Mind and heART

We are testing a promising new therapy for Adults with Spinal Cord Injury.

This non-invasive therapy will likely improve heart and brain function. So, it will possibly lead to improved blood pressure and mood in addition to less cardiac issues, sleep problems, brain fog, pain and fatigue.

This study is conducted at the Royal North Shore Hospital at St Leonards, Sydney.

#### Are you eligible to participate?

- Are you 18 years or older?
- Have you had your spinal cord injury for longer than 12 months?

#### What will the therapy involve?

 Breathing exercises and techniques for remaining focused under demanding situations



#### Time commitments:

- **Assessment**: 4 sessions over 12 months (2.5 hours per session)
- Therapy: 10 treatment sessions (4 hours per week, including homework)

You will receive a gift voucher for your time.

If you are interested, please contact us or scan the QR code:

Mob (**Jacob**): 0420 378 157 Email: smart.trial@sydney.edu.au







Master SMART Trial Advertisement Type A Version 3.0 dated 15 April 2022

### **Events and dates**

2025 International Spinal Cord Society Annual Scientific Meeting

8-11 October 2024 in Gothenburg, Sweden

More information

## **SCoRH** member publications

Ullah, S., Qureshi, A.Z., AlWehaibi, T.A. et al. Functional priorities of individuals with spinal cord injury: a Saudi Arabian perspective. Spinal Cord 62, 539–545 (2024). https://doi.org/10.1038/s41393-024-01018-0

Watson, P.K., Stendell, L., Quel de Oliveira, C. et al. Leisure-time physical activity motives and perceived gains for individuals with spinal cord injury. Spinal Cord

62, 546–552 (2024). https://doi.org/10.1038/s41393-024-01013-5

Dorey, T.W., Nightingale, T.E., Alrashidi, A.A. et al. Effects of exercise on autonomic cardiovascular control in individuals with chronic, motor-complete spinal cord injury: an exploratory randomised clinical trial. Spinal Cord 62, 597–604 (2024). <a href="https://doi.org/10.1038/s41393-024-01019-z">https://doi.org/10.1038/s41393-024-01019-z</a>

Hesam-Shariati, N., Alexander, L., Chen, K.Y. et al. A home-based self-directed EEG neurofeedback intervention for people with chronic neuropathic pain following spinal cord injury (the StoPain Trial): description of the intervention. Spinal Cord 62, 658–666 (2024). <a href="https://doi.org/10.1038/s41393-024-01031-3">https://doi.org/10.1038/s41393-024-01031-3</a>

Sweet, S.N., Shi, Z., Pastore, O. et al. The spinal cord injury (SCI) peer support evaluation tool: the development of a tool to assess outcomes of peer support programs within SCI community-based organizations. Spinal Cord (2024). <a href="https://doi.org/10.1038/s41393-024-01033-1">https://doi.org/10.1038/s41393-024-01033-1</a>

Bojanic, T., McCaughey, E.J., Finn, H.T. et al. The effect of abdominal functional electrical stimulation on blood pressure in people with high level spinal cord injury. Spinal Cord (2024). <a href="https://doi.org/10.1038/s41393-024-01046-w">https://doi.org/10.1038/s41393-024-01046-w</a>

## **Opportunities**

NHMRC Grants and funding
Various opportunities and closing dates
Read more

Medical Research Future Fund
Various opportunities and closing dates
Read more

## Got something you'd like to share?

Please email us with the details including any relevant links and closing dates. Our email address is <a href="mailto:info@thesri.org">info@thesri.org</a>. You can also tag us on Twitter, LinkedIn or Facebook. Links to our profiles on these platforms are in the footer of this email.

The Spinal Research Institute (SRI) is a not-for-profit organisation building research collaboration and consumer engagement to improve the lives of people with spinal cord injury.

The Spinal Cord Research Hub (SCoRH) is an initiative of the SRI.

SCoRH is a free online platform uniting the international spinal cord injury research sector.

Anyone with an interest in spinal cord injury research is welcome to join - it's quick, free, and easy!

Join SCoRH

The Spinal Cord Research Hub is supported by Freemasons Foundation Victoria.



### Follow the SRI for more updates











Our address is
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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.