



WHY RESEARCH MATTERS

A collection of spinal cord research from
around the world



Winning submissions from the SCI Research Writing Prize



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MESSAGE FROM THE CEO



It is with great pleasure that I welcome you to 'Why Research Matters', a compilation of the top-12 entries from the Spinal Research Institute's (SRI) inaugural Spinal Cord Injury Research Writing Prize. We were thrilled with the large number of submissions received, from across 14 countries and a wide range of research interest areas, and I would like to thank all the researchers for taking the time to submit their writing.

The objective of this publication is to demystify and share the important work happening around the world in the field of spinal cord injury (SCI) research. Researchers were asked to present their work for a non-scientific audience in an easy to understand and compelling manner, keeping in mind the question "Why does my research matter?". The Writing Prize was open to all SCI researchers, whether their research was published or not, in the midst of trials or paused due to the COVID-19 pandemic. Entries were subject to a blind judging, where the writers' names were not known to the judging panel.

This publication supports the SRI's programs of research collaboration and consumer engagement, by disseminating information to members (researchers and clinicians) of the Spinal Cord Research Hub, our online research collaboration platform, and importantly, to people with lived experience of SCI. Our Consumer Engagement Program aims to actively involve people with lived experience of SCI in all aspects of the research process and we want to connect the SCI community to the broad range of research that is being undertaken, from functional recovery to physical exercise, assistive technology to vocational rehabilitation.

I would like to acknowledge and thank the judging panel, who volunteered their time and expertise to assess the Writing Prize submissions, and offer my congratulations to the winning entries.

Happy reading,

Kristine Hendry
CEO, Spinal Research Institute

The Spinal Research Institute has a vision to improve the health and quality of life of people with spinal cord injury (SCI).

Our work supports world class SCI research and clinical trials by building much needed tools for research collaboration and knowledge sharing, and actively involving people with SCI in the research process.

DID YOU KNOW?

Every year, around the world, between 250,000 and 500,000 people suffer a SCI.

People with a SCI are two to five times more likely to die prematurely than people without a SCI, with worse survival rates in low- and middle-income countries.

SCI is associated with lower rates of school enrolment and economic participation, and it carries substantial individual and societal costs.

The majority of SCIs are due to preventable causes such as road traffic crashes, falls or violence.

SCI can also occur due to medical reasons such as tumours, bleeding into the spinal canal and some infections.



Secondary Health Conditions

SCI affects much more than a person's ability to walk; there are many secondary health conditions that can impact a person's life.

The broad range of SCI research presented in this publication shows just how important diverse research is in the pursuit of improving the lives of people living with a SCI.

DEPRESSION AND ANXIETY

RECURRENT BRONCHITIS
AND PNEUMONIA

BOWEL DYSFUNCTION

IMPOTENCE AND
INFERTILITY IN MEN

SEVERE OSTEOPOROSIS

SOCIAL MARGINALISATION
AND PRESSURE ON FAMILY
RELATIONSHIPS

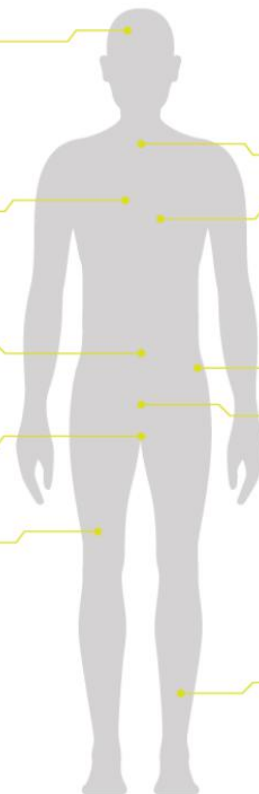
SLEEP APNOEA

BLOOD PRESSURE
FLUCTUATION

PRESSURE SORES

RECURRENT
URINARY
TRACT INFECTIONS

MUSCLE WASTING



SPINAL CORD INJURY RESEARCH WRITING PRIZE

To help share the important research that is happening in the field of SCI, we launched the Spinal Cord Injury Research Writing Prize, whereby the winning entries would have their written piece published in a non-scientific publication; available and accessible for everyone.

We asked researchers around the world to write about their (or their group's) research in a creative and compelling way, considering the question "Why does my research matter?"

Judging panel

- A/Prof. Doug Brown, SRI Executive Director
- Dr Mario D'Cruz, SRI Director and Ambassador
- Dr Jo Nunnerley, Academy Director Burwood Academy of Independent Living
- Brigid O'Connell, Health Reporter Herald Sun and Deakin University Journalism Tutor
- Benoit Gruter, Peer Support Volunteer at AQA Spire

Assessment criteria

- Convincingly answers the question 'Why does my research matter?'
- Explains the research in a way that is easy to understand
- Is compelling to read

Prize

All winning entries won a place in an online workshop that explores research translation and impact, facilitated by renowned course provider Research Impact Academy (researchimpactacademy.com).

Winning entries are featured in this publication showcasing international spinal cord research.

THE JUDGING PANEL

We are proud to introduce our broad-based judging panel. They represent diverse perspectives and expertise, knowledge and interest areas.



A/Prof. Doug Brown
Executive Director, Spinal Research Institute

Doug is the Founder and Executive Director of the Spinal Research Institute.

He is a Physician with over 30 years of experience in the management of spinal cord injury and has contributed to a wide range of research projects throughout his career. A leader in his field, Doug is passionate about improving the treatment and care of people with spinal cord injury globally, and has held positions at national and international organisations. He is former director of the Victorian Spinal Cord Service, Past President of the International Spinal Cord Society, and is recognised internationally for his contribution to the field.



Jo Nunnerley, PhD
Academy Director, Burwood Academy of Independent Living

Jo is the Academy Director at the Burwood Academy of Independent Living (BAIL), Christchurch, New Zealand, where she leads a team of clinical and lived experience researchers. She also has a research role in the Department of Orthopaedic Surgery and Musculoskeletal Medicine, University of Otago, Christchurch. Her research combines her clinical experience as a physiotherapist in spinal cord injury, and interests in lived experience research and knowledge translation.



Dr Mario D'Cruz

Director, Spinal Research Institute

Since his surgical training was interrupted by a road accident in 2001, Mario has been both a quadriplegic and a medical practitioner. Advancing spinal academic and clinical research is as important to Mario at a personal level as it is scientifically. He conducts a medical practice focused on people living with spinal and mobility impairment. A medical educator, he teaches university and secondary students in biological sciences, medicine, surgery, clinical practice and spinal research.

Mario collaborated with the University of Melbourne and Stem Cells Australia in developing and publishing a comprehensive internet directory and information resource for all the major stem cell research trials in all the medical specialties being conducted globally.

Mario has been an Investigating Officer with the Victorian & Australian Medical Boards and is a committee member at AQA Spire.



Brigid O'Connell

Health Reporter, Herald Sun

Brigid has been a journalist for 17 years at various print media outlets in Australia. Since 2008, she has been the health reporter for the Herald Sun.

She has won a Melbourne Press Club Quill Award for best Suburban Reporting, and Special Commendation in the United Nations Media Peace Awards.

Brigid also teaches journalism at Deakin University and is a co-author of 'The Baker IDI Wellness Plan: Scientific secrets for a long and healthy life', published by Penguin in 2017.



Benoit Gruter

Peer Support Volunteer, AQA Spire

Benoit worked for many years as an academic teaching philosophy. Later he worked as a policy adviser in both multicultural and Aboriginal affairs for the Victorian Government. His major interests in these roles were strategies for opposing racism and the ways in which the mental health system caters to the needs of cultural and linguistic minorities. In 2012 he became a paraplegic as the result of a spinal bleed. In 2015 he retired from the paid work force. In retirement Benoit's time is taken up by grandchildren and his continuing academic interests in philosophy and psychology. Benoit also volunteers as a peer support worker with AQA Spire, assisting others with a recently acquired spinal cord injury adjust to their changed circumstances.

READING BETWEEN THE LINES - MEDIA PORTRAYAL OF SCI

Written by Leanne Rees



PhD Candidate
LaTrobe University
Australia

This entry received the highest combined score from the judging panel.

JUDGES'
CHOICE

When was the last time you read a media story on spinal cord injury (SCI)? Perhaps it was this recent headline in The Sydney Morning Herald, 'Scientists flag cure for paralysis to get sufferers 'back on their feet,' (23 July, 2020).

For Susie, who has paraplegia, these kinds of headlines make her 'grumpy'. Why? Because in her words,

"Language is powerful,
and it sets the pace ... I've been
described as suffering from
paraplegia, but I haven't suffered
... I'm just doing normal things
with my life."

People with SCI live long active lives thanks to advances in knowledge, improved technology, and better access to services. Despite this progress, people with spinal cord injury continue to face barriers to gaining employment, forming relationships, and participating in the community.

They also continue to face society's negative attitudes and misunderstanding of SCI.

Media is everywhere and shapes our attitudes and understanding of many things, including what we think about SCI. As a physiotherapist working in SCI for nearly 20 years, I've seen the effect media stories can have on people with SCI and want to know more. So, in 2019 I started a PhD that focuses on answering two related questions, how the media portrays SCI and how this portrayal impacts those living with SCI.

This research is the first of its kind and is being done in consultation with people with SCI. This research will be conducted over four years, and here is what I have found so far.

How is SCI reported?

An analysis of 70 years' worth of newspaper coverage found that SCI is reported as either 'tragedy' or 'over-achievement'. Tragedy included descriptions of loss, dependence, and helplessness, such as the inability to work, described in this article

from the The Canberra Times, 'Invalid pensions threatened' - 'Among those declared ineligible were paraplegics, people who were bedridden and those who had been told by their doctors that they would die if they attempted to work again,' (1980).

Over-achievement included stories on the Paralympic Games or other physical achievements like pushing a wheelchair from Sydney to Melbourne (1979) or canoeing the length of the Murray River (1981). Rarely was the voice of someone with SCI included, however this did improve slightly in recent years.

What do people with SCI think?

I've interviewed people with SCI and they too confirm that the media portrays SCI in two very different ways, you're either 'a sufferer or inspirational', or 'really stuffed or heroic'. More importantly, these interviews revealed that what affects people with SCI the most are the stories and images that are missing; there is 'nothing in between'. People with SCI have told me that they would like to be seen as members of our community – business owners, workers, dads, mums, and mates. As Doug explained, "we are just like everyone else," and Michelle, "it would be great if in media [coverage] we're portrayed as active members of the community, because that's how I would like to feel."

People interviewed also reported that the media tends to focus on recovery and walking, with concern for the misreporting of facts around SCI. This includes the lack of explanation around incomplete and complete SCI, which many felt misled the public, captured in this quote, "Very, very rarely have I heard that differentiation between what a complete SCI is and what an incomplete SCI is, and there is a very big difference."

As explained by Tom the negative impact of this is, "Having to justify yourself. Why didn't you recover? Did you not work hard enough?"

What's next?

The next stage of my research will focus on how it is that media coverage is created in these ways. This will include talking to people who work in mainstream media such as television and newspapers, and people who work in communication and public relation roles in health services and insurance companies. My aim is to examine the attitudes and understanding of SCI from people who help deliver media content, with opportunity to simultaneously raise awareness of the potential negative impact.

We are all engaged in media, one way or another. This research will raise awareness of how SCI is understood by society, in a way that has never been looked at before. By unravelling the facts and promoting the voice of people living with SCI, this research will not only help break down barriers faced daily by people with SCI, but all people living with disability.



FINDING A NEW PATH IN LIFE

Written by Annette Halvorsen



Senior Consultant and PhD Candidate
St Olavs Hospital / Norwegian University
of Science and Technology
Norway

“Will life ever go back to normal?” the 30-year-old woman asks me. She looks anxious and overwhelmed. Her 32-year-old husband suffered a spinal cord injury during a vacation in the Alps. A crash during a mountain bike trip with his friends damaged his spine and left him paralysed and wheelchair dependent. He was just transferred to our rehabilitation clinic, after acute surgery was performed abroad, at the Hospital Pasteur in Nice. This is my first meeting with the couple.

While I am thinking how to handle her question, I observe that she is holding her left hand on her pregnant belly. I take a seat between the patient bed and beside the pregnant woman. “Your life is going to be different from what you are used to” I start slowly and before I can say some more the next question comes up, this time from the patient himself “Can I return to work?”.

A spinal cord injury (SCI) often drastically disrupts the lives of affected patients and their relatives and caregivers. Caregiving for a loved one with SCI involves both physical and emotional investment. This may be overwhelming and result in strained relationships, less choice and control over life, increased stress, and financial difficulties for the family.

Despite standards of SCI rehabilitation care being high in Norway, my impression after 18 years in the clinical field is that many patients and family members feel insufficiently prepared to live in this new reality. During rehabilitation, the main focus is on medical problems and physical challenges, with only little attention for adjustment to living with a SCI.

My ongoing research project will provide new knowledge on how patients and their family caregivers cope in the first years after injury in terms of work inclusion, participation, caregiver burden and quality of life.

The research will focus on understanding areas central to most people's life. The results will be very useful for me and my colleagues in counselling situations as described above.

One area is the importance attached to employment as the primary means of participation in society. We know that the economic impact of a SCI is very high. Many people suffering SCI at working age end up with disability pension. However, we know only little about which factors promotes or inhibits labour market participation for people living with a SCI.

Even more surprising, how being a caregiver for a person with SCI affects labor participation, is a knowledge gap! Is the sickness absence higher for caregivers compared to the general population? Are caregivers more often working part time compared to the general population? No such data exists for caregivers of people with SCI. Knowing that family caregivers are central in giving support to our patients, knowledge about the burden of care and the consequences for employment, will be studied as well.

In addition to self-reported data from people with SCI and family caregivers in Norway, we utilise data from several other data sources in our research project. In Norway, we have the unique opportunity to link data from different data sources by using the personal identification number. Data from SCI patients, caregivers and the general population, provided by Statistics Norway, The Norwegian Labour and Welfare Administration and the Norwegian Spinal Cord Injury registry are extremely useful in finding the answers to our research questions.

But how can I be sure that I investigate the topics most relevant to this young couple and their unborn child? We have invested heavily in the involvement of three user representatives as members of our research team. SCI affects many aspects of their life.

One caregiver and two people with SCI share their insights in the research team. They are using their personal experience in all research phases wherever possible, from the study design to reporting the results. This will ensure that the results of this project are relevant and useful for other people living with a SCI and their caregivers.

Back to the conversation in the patient room. We talked for at least one hour. Most of the time I was listening. Many questions came up and it was hard to answer all. This young couple is currently standing at their start point of a new path in life, adjusted to life with SCI. On my bike on my way home from the hospital, I am thinking about the couple. While waiting before the red light, divorce rates following SCI are flashing through my mind. During rehabilitation, we are helping people find the direction of their new path. But what's happening afterwards? We have to ensure that our patients and their caregivers stay on the path and do not lose their way after discharge! We need new knowledge to make this possible.

Coming home, I know my research matters.



Image (L to R): Professor Aslak Steinsbekk (Supervisor), Steinar Mikalsen (User representative), Anders Nupen Hansen (User representative), Monica Engelsjord (User representative caregivers), and Annette Halvorsen (Project Leader, PhD Candidate, PMR specialist).

This research project was made possible by Dam Foundation and Liaison Committee between the Central Norway Regional Health Authority (RHA) and the Norwegian University of Science and Technology (NTNU).



NEW HOPE FOR THOSE SUFFERING A SPINAL CORD INJURY

Written by Elizabeth Bye



Postdoctoral Research Fellow
Neuroscience Research Australia
Australia

It was like any other day for Samantha. She had been skiing since she was a child and felt at peace on top of the mountain. As she started the descent, she noticed her ski binding felt loose but thought nothing of it. Samantha sped up as the mountain became steeper, feeling herself ride the wave of adrenaline. Suddenly she started losing control and, rather than perform a parallel stop, her binding snapped and she tumbled down the mountain for what felt like an eternity.

Samantha came to and found herself lying with her limbs resting at unnatural angles. Instinctively she tried to move her legs. Nothing. Her limbs were lifeless dead weights, unable to be shifted. In the blink of an eye her life would change forever.

Samantha awoke in a hospital bed, staring at the ceiling. A doctor entered and confirmed her absolute fear, she had a serious spinal cord injury (SCI). Weeks in intensive care passed, where every bodily function required a tube, a machine, a nurse. Eventually, tubes were extracted, machines turned off and she was transferred to a rehab ward. Here she faced the reality of her disability, her new life, nothing would ever be the same again. She spent hours in the physiotherapy gym every day coming to grips with her new body. After weeks she could wriggle her toe

ever so slightly and a few days later she could lift her ankle. With these tiny movements came hope.

This is the reality for more than 15,000 people in Australia who have suffered a SCI.

Each day, someone, somewhere in Australia sustains a SCI. Like Samantha, their world will be shattered when they are told they may never walk again.

For decades, people with SCI have been told there is no cure for paralysis. A hard reality to accept. More recently, however, new developments offer hope for people suffering from this devastating injury.

“Neuroplasticity” is a term referring to the changes that occur throughout the spinal cord and brain following a neural injury. Such changes can be beneficial like restoring the ability to move or feel, but can also be damaging by triggering involuntary movements or spasms.

The tantalising goal for rehabilitation is to harness the positive effects of neuroplasticity. Many interventions have been trialled to promote neuroplasticity, unfortunately with very little



Image: The new Spinal Cord Injury Research Centre at NeuRA.

success. However, there is one exciting new development, neurostimulation, which uses electrical currents to increase the activity of damaged nerves via implanted or surface electrodes. A simple analogy likens the neurostimulation to a deaf person's hearing aid. The stimulation amplifying the messages sent from the brain to the spinal cord to help promote movement that would otherwise be impossible. The small weak signals allowing Samantha to wriggle her toe, will be strengthened leading to more movements in her legs, with the hope that one day she will walk again.

Many regard neurostimulation as a promising therapy to bring lasting benefits to those with SCI. In fact, experts in the field have said that neurostimulation may be the first steps in a revolution for people with SCI. However, clinicians and researchers can believe passionately that neurostimulation works, a preconceived bias, but until it is rigorously assessed through a randomised, sham-controlled trial and proven to be effective, people like Samantha will not reap the potential benefits.

Scientists at Neuroscience Research Australia are conducting the first international clinical trial involving 50 people with SCI. Participants will be recruited from all over the world, including sites in Sydney, Perth, Chicago, Glasgow and Toledo. Each participant will be randomly allocated to receive neurostimulation or sham-stimulation in combination with an intense physiotherapy program of three one-hour sessions per week, over 12 weeks.

The main outcome measuring the effectiveness of neurostimulation will be the participants' walking ability. This will be measured on a 21-point scale, ranking the ability of a person to walk 10 metres, taking into account the amount of assistance, braces or other devices required.

Samantha regained some movement in her legs after a year of intense rehabilitation. She still spends 80% of her time sitting in a wheelchair, viewing the world from a new angle and constantly meeting barriers which limit her ability to access her world. She can now walk short distances in her home with a frame and assistance.

Samantha dreams of the day she can walk without reliance on others. She dreams about feeling the sand between her toes and the sunshine warming her legs. Neurostimulation provides hope to people like Samantha that a cure is possible. The potential impact of this novel therapy is huge as it may offer a better life for those living with SCI.

A world without paralysis is a world I want to live in.



PATIENT AND PUBLIC INVOLVEMENT IN SPINAL CORD RESEARCH - HOW DO WE DO IT BEST

Written by Pádraig Carroll



Research Assistant
Royal College of Surgeons in Ireland
Ireland

Dublin, Ireland 9.15pm

Jack is a software engineer. He has used a wheelchair since a rugby-related spinal cord injury (SCI) resulted in tetraplegia 15 years ago. Scrolling through his Twitter feed, he notices a research article trending. 'Ground-breaking intervention for spinal cord injury trialled in mice shows promise in recovering leg movement,' he reads. "I hope that's not all the researchers are doing," he thinks. "There are so many things I'd rather have back before walking again," he says to himself sighing.

Melbourne, Australia 6.15am

Xi-wang is a research fellow. He works in a busy laboratory developing novel scaffolds to repair SCIs. Commuting to the university he hears the radio headlines '... in latest science news, a ground-breaking treatment for SCI shows promise in recovering leg movement. Stay tuned for more!' He finds the research paper on his phone. Noting that the study is in mice, he hopes the findings will have relevance to his own work and help improve chances of securing funding so that an effective treatment can be progressed.

New York, USA 4.15pm

Isabella is an attending physician in rehabilitation medicine. She leads a busy clinic specialising in traumatic SCI. Checking her emails at the end of the day, she sees a message from one of her colleagues and a link for a news story. "What do you think of this – one of the patients just saw this online? – 'Promising results in spinal cord trials on mice, is a cure on the way?'" I wonder if they have replicated the complexity of the acute injury in their model. The risk/benefit balance is going to be critical for people with existing injury," she types back.

'It is the spectator, and not life, that art really mirrors.' Oscar Wilde's words (from *The Picture of Dorian Gray*) resonate here. Like Jack, Xi-wang and Isabella, our backgrounds and expertise frame our reactions when viewing research developments. In our example, three people interested in SCI research respond differently to the same piece of news. Each reaction forms a part of a story and reveals different priorities. How might we combine these perspectives to develop an inclusive, unified approach to SCI research that reflects the needs and priorities of all stakeholders?

In 2019, Royal College of Surgeons in Ireland and the Irish Rugby Football Union Charitable Trust, supported by Advanced Materials and BioEngineering Research (AMBER), launched a research partnership. This research aims to develop an advanced platform for spinal cord repair combining novel biomaterials, stem cells, and gene therapy in animal models. To maximise the potential impact of this partnership, the project team wanted to include perspectives and insights of seriously injured players in the research process using 'Patient and Public Involvement (PPI)' approaches. PPI ensures research is carried out 'with' or 'by' members of the public rather than 'to', 'about', or 'for' them, and incorporates their priorities in research. PPI approaches include patients/public collaborating as advisory panel members, identifying future research areas, or contributing to the design of research materials. PPI is well established in clinical research, for example where treatments are being evaluated, but PPI in laboratory research is comparatively new. We are aiming to establish how best to do this through our project on PPI in preclinical SCI research.

We have formed a PPI panel consisting of researchers, clinicians and seriously injured rugby players to help guide the scientific work necessary for the regeneration and repair of spinal cord lesions. In parallel, we are researching how to conduct PPI in an evidence-informed manner to generate a safe common forum to collaborate productively. Readers may be interested to find that our ongoing review of over 10,000 scientific research papers on PPI has

found less than 10 examples of patient involvement in preclinical and spinal cord research, highlighting a significant area of interest. To address this, we are interviewing people affected by SCI, spinal cord researchers and clinicians to develop our own set of guidelines on how best to do PPI, and develop a shared list of priorities for our current and future work.

Jack, Xi-wang and Isabella exist only as characters in our story, but their experiences are reflective of many worldwide. We write their perspectives to reflect the thousands of people who are involved in research in different ways. We hope that through our PPI activities, we can create an open forum to discuss and share responses of seriously injured players, clinicians, and scientists. This will mean our scientific research programme is informed by a shared understanding, reflecting the priorities of all stakeholders, particularly patients and the public who are ultimately most affected. This research is important to all researching SCI, as it ensures that findings impact people's lives in relevant ways. Furthermore, it gives people affected by SCI the chance to shape and impact research that affects them.



THE SPINAL CARDIO-PROTECTIVE STUDY

Written by Priya Iyer



Professional Leader Dietetics
Royal Rehab
Australia

Have you ever heard people saying, “I ate calcium and protein for breakfast today” or “I had beans, bread and dairy for my breakfast?” Well, we do not eat single nutrients or single food groups, do we?! The breakfast meal probably would have been baked beans on toast with a tub of yoghurt or a glass of milk. Yes, we eat a combination of foods plated in appealing forms based on recipes and dietary patterns. Therefore, we, researchers, here at the Spinal Rehabilitation Centre are looking at the impact of eating practices and dietary patterns on health rather than just nutrients and single food groups.

The most common cause of death for Australians is cardiovascular disease, including heart disease and stroke. Individuals with spinal cord injury (SCI) are at particular risk of cardiovascular disease, due to a decrease in muscle bulk and inactivity. Poor diets also increase the risk of cardiovascular disease. Research indicates that the Mediterranean diet (with olive oil and lots of fruit and vegetables), DASH diet (Dietary Approaches to Stop Hypertension [high blood pressure] with lots of fruit and vegetables) and Nordic diet (including lots of fish) may help decrease

risk factors for cardiovascular disease. Our research investigates how nutrition education and provision of a health-promoting diet can lower the risk of cardiovascular disease in individuals with SCI.

Traditional hospital menus focus on treating specific diseases (e.g. diabetes diet, low energy diet, malnutrition, etc.) and food choices are based on meeting nutrient requirements following guidelines mandated by external groups. But at home and in the community, meal choices are not regulated by an external system. Rather, food is an integral component of being human, affecting our psychology, social lives, and health.

As an intrinsic facet of the human experience, food/dietary patterns offer a holistic approach to improving health and quality of life. Good nutrition knowledge fosters healthier food choices. The value of educating individuals with SCI to inform their food choices both in hospital and beyond hospital walls is often overlooked. There exists an unmet need to challenge traditions and remove the negative connotation of disease and treatment-focused approaches to meal planning in health facilities, especially in rehabilitation settings.

Our research is rooted in the belief that menus mimicking health promoting dietary patterns solidify nutrition knowledge and promote its lifelong application. Therefore, our current intervention study explores the benefits of a Mediterranean style eating pattern in individuals admitted to spinal rehabilitation. We are also examining the association of this dietary pattern with body composition, cardiovascular disease risk factors and eating behaviours.

To the best of our knowledge, no nutrition intervention programs, which use knowledge translation techniques and environmental manipulation, exist in SCI rehabilitation. This is a world-first study modifying the environment (hospital menus/food service delivery) as a health promotion approach to lower cardiovascular disease risk in individuals with SCI.

With this, we hope to equip individuals with solid nutrition knowledge to inform food choices and enable adapting their usual eating pattern with elements of the health promoting Mediterranean diet. This study will offer useful information about the association of the Mediterranean dietary pattern with the heart health of adults with SCI. Additionally, this study will also encourage redesigning the rehabilitation menu and dining model with a focus on preventative health and wellness. Watch this space for fascinating facts from this study!

Image credit: Unsplash, Brooke Lark.



WORK IS POSSIBLE, WORK IS DOABLE: EARLY VOCATIONAL SERVICES AFTER SCI

Written by Julia Bloom



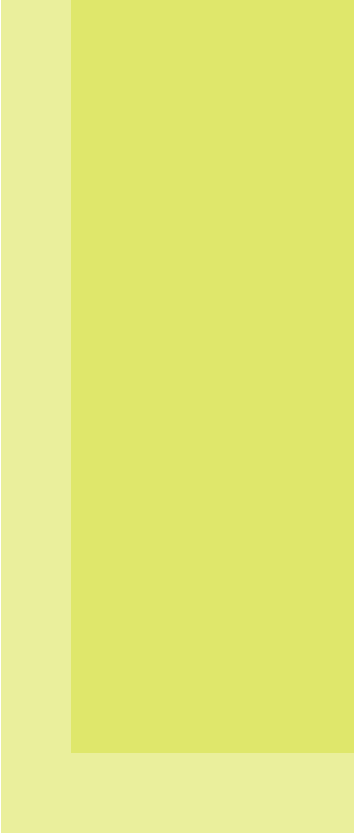
Lecturer
Griffith University
Australia

Research has consistently shown that working is important for a person's wellbeing. Think about your work. Think about your projects, your co-workers, your customers. Think about how important your work is to you. Maybe you identify yourself by what you do. Are you a carpenter, engineer, butcher, academic? Imagine that, from one day to the next, you became unable to do your work. The tasks themselves are very difficult, or impossible. Or the place that you work is now inaccessible. How do you support yourself, and your family? What do you think about, talk about, and strive towards? Has your identity changed?

Although not every person with a spinal cord injury (SCI) is prevented from returning to work, a substantial proportion find that this is their reality. Physical changes, inaccessible work environments, the increased logistics of getting around, and the attitudes of others can be barriers to returning to work after SCI.

So perhaps it is unsurprising that work has not historically been a large part of initial rehabilitation for people with SCI. Common wisdom says that we should wait for people with SCI to recover physically before even thinking about work. A developing body of research challenges this idea. A substantial number of people are ready to think about, talk about, and prepare for return to work soon after the injury – many while they are still in hospital. Early intervention vocational rehabilitation programs are emerging, which capitalise on this readiness to preserve careers in the long-term.

However, there are questions about how soon vocational rehabilitation should commence after injury and what sort of support people actually need in this situation. To date, there has been limited information about what happens straight after discharge; whether thoughts about work change when faced with settling back into the community.



To address this information gap my research involved undertaking interviews with people who have participated in an early intervention vocational rehabilitation program and are currently settling back into the community after discharge from hospital. I followed these people for six months after discharge to see how their thoughts about work changed, what factors impacted their readiness to return to work, and whether their support needs changed.


Results showed that, interestingly, readiness to return to work does seem to change after discharge from hospital. It does not improve in a linear way over time – readiness can fluctuate in response to physical rehabilitation gains, and because goals and plans set in the hospital can turn out to be unsuitable in the community.

Just having a plan though, even if the plan changed, granted a feeling of confidence which seems to lead to readiness. And the plan will change – in response to new gains in rehabilitation or because of adjustments made when returning to the community. So returning to work is a constant process of setting small goals and being prepared to throw them out the window and reassess.

Unsurprisingly, the best kind of support when returning to work seems to be work-related – supportive employers, rehabilitation counsellors, return to work coordinators, employment services, and HR. The knowledge of processes, barriers and the world of work seems to add clarity which participants find very valuable.

Having these conversations early on is said to inspire the hope that work is possible. But with detailed and flexible planning, and the support of vocational rehabilitation professionals, readiness to think about, prepare for, and return to work can be more than inspired – it can be actively supported. This thinking can move forward from “work is possible”, to “work is doable”. Even when working is prevented by physical rehabilitation needs or other factors beyond the person’s control, early vocational support can assist them towards the ‘starting line’ of returning to work much earlier, preserving careers, and identity, in the long-term.

“This is who I am, this is how I support myself, and this is what I’m striving towards.”



OF AGEING AND SPINAL CORD INJURY

Written by Theresa C. Sutherland



Postdoctoral Research Associate
Texas A&M Health Science Center
United States

Age brings wisdom, but it also brings challenges. Your body starts to give out and things don't work as well as they used to. Take your nervous system, for example: as you get older your brain loses flexibility, your neurons' ability to grow and regenerate damaged branches decreases, and the cells supporting your neurons lose functionality. This leads to the decreases in memory and cognition that we associate with advancing age. It also leaves the central nervous system more vulnerable to the effects of neurodegenerative diseases and trauma.

Spinal cord injury (SCI) is typically regarded as having two phases: the primary and secondary injuries. The primary injury encompasses the immediate damage to the spinal cord, the disruption of neuronal axons and functional connections between neurons, and the death of neurons; very little can be done to treat it. The secondary injury includes a broad spectrum of pathologies that exacerbate the damage. It is ongoing and constantly evolving, making it difficult to identify a simple solution to alleviate its effects. Many of the cellular and molecular processes involved in the secondary injury are also detrimentally altered in normal ageing, compounding the impact of SCI in older people.

The lack of functional recovery that is associated with SCI is linked to the degeneration of severed axons, the abnormal growth of what remains, and the failure of axons to regrow. Axonal growth inhibitors are also present in the central nervous system after injury; these are associated with elements of the secondary injury. In the last decade, axon growth has received a lot of attention in SCI research. Studies have investigated the mechanisms behind it, how it is affected by injury and, most significantly, how can we promote growth and regeneration after injury. Despite rapid progress in understanding and manipulating the regulation of axon growth post-injury, a major gap exists in our knowledge: how does ageing impact axon growth and regeneration in the central nervous system after a SCI?

Why is this such a significant problem?

The demographic of SCI patients is changing. The incidence of SCI has two peaks: the highest is in younger adults (20–30 years old), with the dominant cause being motor vehicle accidents, and the second is in older people (65 and over), resulting largely from falls. The average age at which SCI occur is increasing (it is currently approximately 43 years in the USA), and patients are living longer with their injuries.

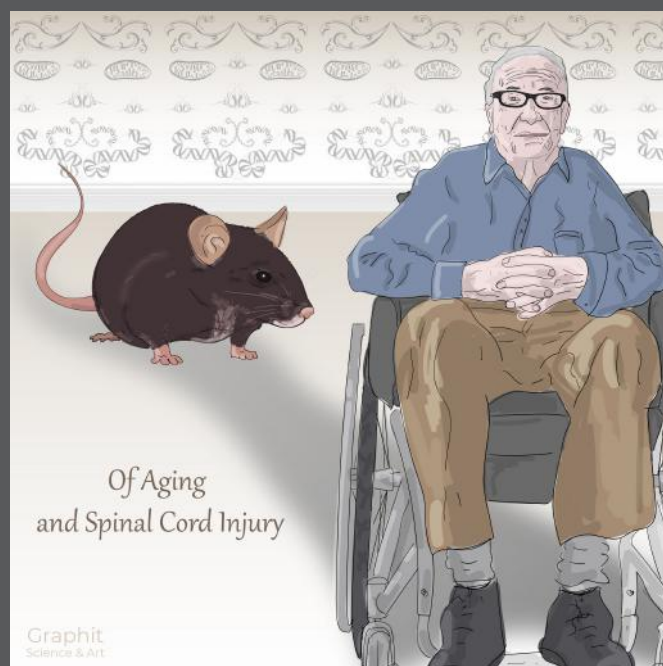
According to a survey conducted by the Christopher & Dana Reeve Foundation, approximately 80 per cent of people with a SCI in the USA are aged 40 years and over.

This represents a challenge for SCI research. The average age of the rodents commonly used in pre-clinical SCI studies is around three months. To put this in perspective, a six-month-old mouse is roughly equivalent to a 20-year-old human; a 12-month-old mouse is representative of a 40-year-old human. Despite the increasing incidence of SCI injuries in middle-aged and ageing individuals, less than 0.35 per cent of the rodents used in SCI research are 12 months or older. There is currently a lack of scientific literature and pre-clinical studies examining the effects of age on SCI. This area is highly relevant to clinical treatment but has received very little attention.

This is where our work in the Geoffroy Lab at Texas A&M Health Science Center comes in. Our current research is two-pronged. One of our studies seeks to understand, and combat, the age-related decline in axon growth potential using genetic and molecular techniques. In the second project, we are examining how the non-neuronal elements of the secondary injury change with age. The ultimate goal of both projects is to find a therapy that can help patients recover from SCI, regardless of age.

Image supplied by Theresa C. Sutherland and created by Graphit Science & Art.

To date, we have confirmed the ongoing decline in ageing neurons' ability to regrow axons and highlighted the manipulation of specific molecules within the neuron as a promising avenue towards restoring growth in neurons of any age. We also have developed a keen interest in the manipulation of the mitochondria – commonly called the “powerhouse” of the cell. Mitochondria are vital to axon growth and are also known to decrease in efficacy and functionality with age. Our observations suggest mitochondria play an important role in the age-related decline in axon growth and indicate that targeting mitochondria may be a promising approach in SCI research. These projects and observations are good steps down the long road towards a SCI therapy for all patients.



HANDBIKEBATTLE

Written by Ingrid Kouwijzer



PhD Student

Helimare Rehabilitation Center /
University of Groningen
The Netherlands

"The summit is what drives us, but the journey is what matters."



Physical inactivity is defined as a global public health problem by the World Health Organization. Individuals with a physical disability have a lower physical activity than the general population. Among individuals with a physical disability, wheelchair users with a spinal cord injury (SCI) have the lowest level of physical activity. This is a problem because it is associated with a high prevalence of cardiometabolic disease, which is the leading cause of mortality in this population. An increase in physical activity, and more specifically exercise, has shown to have a positive association with decrease in risk factors for cardiometabolic disease. In addition, a higher fitness level as a result of physical activity and exercise, makes activities of daily living easier and is associated with a higher life satisfaction. Therefore, exercise interventions are very important.

That is easier said than done. Everyone knows that physical activity and exercise are important. Numerous studies have shown that exercise interventions work. But if we are honest, we know that adhering to exercise in the long term and really integrating it into daily life, is very hard for the general population, let alone for people with SCI.

How to solve this problem?

In the Netherlands, they came up with the HandbikeBattle to solve this problem; a challenging handcycling event in the mountains of Austria. The time trial is 20.2 kilometres long with more than 800 metres of elevation. That sounds extreme to complete in a handcycle, and it is! However, the event is not created for elite athletes, but for untrained wheelchair users with no sports background. The mission of the HandbikeBattle is threefold: 1) to encourage wheelchair users to initiate or keep training after the rehabilitation period, 2) to learn from others and gain confidence to achieve other goals in life, and 3) to show that not only elite able-bodied athletes are capable of incredible performances, but recreationally-active wheelchair users as well.

From previous studies, we know that handcycling is an ideal training mode for wheelchair users because it is physiologically more efficient and is less straining on the shoulders compared to wheelchair propulsion.

Each year, 12 Dutch rehabilitation centres form teams of four to six former rehabilitation patients each, to participate in the HandbikeBattle. They train four to five months. During the training period some guidance is provided by the rehabilitation centres. The participants train together with their team members, but they are also supposed to take initiative and train independently at home or with family and friends. The rationale is that handcycling will be incorporated into their daily life and participants will be self-motivated to keep handcycling for the long term. In addition, during training and the week in Austria they will encounter new situations during activities of daily living and learn from peers how to overcome these barriers. In June 2013 the first edition of the HandbikeBattle with 49 participants was a fact. The HandbikeBattle became an annual event. In 2019 the event had grown to 112 participants.

Since 2013 an observational cohort study has started to investigate the affects of participating in the HandbikeBattle. Before and after the training period, and one year after the event, participants are asked to fill out questionnaires about activities of daily living, self-efficacy and quality of life. In addition, they undergo several incremental peak tests to evaluate the effects of training on fitness.

The results tell us that participants show an increase in fitness of 16–22%. These fitness levels remain stable one year after the event. In addition, the increase in fitness level during the training period is associated with an increase in life satisfaction. Several years after the event, most participants report that they experience benefits in fitness (90%), handcycling (87%), personal development (81%), activities in daily life (66%) and health (64%). With the study we gain valuable insights in testing and training of people with a SCI and it shows us the positive effects of training on physical and mental health. Training with peers towards a challenging goal makes the difference!

“Crossing the finish line is a very emotional moment. Through the HandbikeBattle I re-lived my whole rehabilitation period. It took me weeks after the Battle before I had processed everything. I am another person now. My self-image is more positive and I gained confidence. I deal with setbacks different than before. And these are only the mental aspects. Because I started training for the HandbikeBattle I became aware of my (unhealthy) lifestyle. Now I eat healthier and I do a lot of exercise. I notice that my body has a higher capacity and that I recover faster from illnesses”. Male participant, 39 years old, spinal cord injury, Th9.



Images supplied by Ingrid Kouwijzer.

REVERSING PARALYSIS AFTER SPINAL CORD INJURY

Written by Monzurul Alam



Research Assistant Professor
Department of Biomedical Engineering,
The Hong Kong Polytechnic University
Hong Kong SAR

If you were born in the early 80s like me, you might have remembered the exciting TV series called *McGyver*. I was very inspired and fascinated by such science and technology shows at my early age, which led me to pursue my early degrees in physics and electronic engineering. I soon realised that there was more to this fascinating science, and further pursued my higher degrees in bioengineering and neuroscience focusing on rehabilitation after paralysing spinal cord injury (SCI). When I look back, I realise that I was very lucky to have had such an interdisciplinary background of physics, engineering, neuroscience, and rehabilitation. I also feel extremely lucky to have undergone my postdoctoral training under the renowned professor in the SCI field, Dr Reggie Edgerton from the University of California, Los Angeles to study different neurorehabilitation therapies. Finally, I returned to the Hong Kong Polytechnic University where I'm currently a Research Assistant Professor in the Department of Biomedical Engineering working on different spinal cord repair strategies.

Our goal is to reverse paralysis—simple, yet ambitious. I truly believe that reversing paralysis after a SCI is possible, and we are working hard towards this goal. Recent electrical neuromodulation studies, where the inactive spinal cord is activated by electrical stimulation, have demonstrated restoration of walking function in several severely injured individuals, while the doctors did not have any hope that they would walk again! This treatment, however, requires major surgery to implant an electrical stimulator inside the body. The surgery involved in this treatment—as with any other invasive therapy—can cause various complications and risks. Our strategy, in contrast, is to develop a non-surgical (non-invasive) pain-free treatment where no such surgeries are required! This will not only save the patient from having to undergo critical surgery and its associative costs, but also increase its access to a larger SCI population worldwide. The technique we use is called transcutaneous electrical stimulation (tES), similar to TENS (transcutaneous electric nerve stimulation) but targeting the spinal cord by simply placing the sticky electrodes onto the skin above the spine.

In our latest study, we provided the first evidence of permanent recovery of voluntary movements using non-invasive tES treatment. Our study participant, a 48-year-old woman who had been paralysed for over 21 years from a cervical injury resulting from a motor vehicle accident, regained significant muscle control and mobility in her legs after 16 weeks of tES treatment. The tES treatment was combined with physical training sessions such as standing and treadmill stepping training, three to four times a week.

What we found far exceeded many others' expectations: after only four months of treatment, our study participant regained significant voluntary movements in her paralysed leg, allowing her to stand on her own and stabilise her knee without assistance. In fact, she even managed to squat without the assistance of a holder which she had never been able to do over her two decades of paralysis! She also regained significant sensation of her previously paralysed body parts. This is the first non-invasive treatment that has resulted in such

dramatic improvements of sensorimotor functions in a paralysed individual. We also noted that as the training progressed, the patient became less dependent on the stimulation to control her legs. Furthermore, we observed no loss of function in the weeks following the treatment, which suggests permanent recovery of the neural circuits in the spinal cord.

The overwhelming success of this study sheds light on the future of paralysis treatment. Our study participant is now working hard every day (doing sit-ups, standing, and locomotor training with tES) aiming towards the next steps—regaining over-ground walking. We look forward to the day when she can independently walk out of our lab! This should inspire many other SCI individuals to work harder on their rehabilitation because we believe that it is not just a hope—it is going to be a reality that paralysis after a SCI is reversible. We all look forward to that day and are working hard to further improve the neuromodulation techniques to improve efficiency and functionality. With our knowledge of engineering, we are also working on developing a small, affordable neuromodulation system which can be easily used at home to boost the rehabilitation of SCI. We wish to publish our design as open source (free to copy) so that the benefits can reach to all the SCI individuals around the world.



Image:
This image shows an experimental training session of a patient with Asst/Prof Monzurul using the technology described.

SPINAL CORD INJURY AND FAT

Written by David McMillan



Clinical Researcher

The Miami Project to Cure Paralysis,
University of Miami School of Medicine
United States

My research aims to understand and treat obesity, or the unfavourable accumulation of fat within the body, that is common after spinal cord injury (SCI). Due to the “neurogenic” origins of obesity in SCI this underlying health condition cannot simply be willed away, and after an injury fat accumulates in a manner quite different than in people without paralysis. Fat infiltrates into paralysed muscle, causing the muscle to become “marbled” like a fine steak. It encroaches into paralysed bones, causing the marrow to become “yellow” and viscous. It bunches up around the organs in the abdomen and, most important for health, it accumulates in the blood. Fats that circulate in the blood are known as triglycerides (TGs), and TGs are of great interest because certain types of TGs have a tendency to damage the blood vessels they travel in. This damage leads to cardiovascular disease, and cardiovascular disease is one of the leading causes of death in all people, including those with SCI. The type of TGs with the greatest potential for harm are those that enter our blood immediately from a meal.

Recently I studied the phenomenon of ‘postprandial lipemia’ in people with SCI. Postprandial means literally ‘after lunch’, and lipemia refers to a swelling of fat. After consuming any meal (it doesn’t only happen after lunch) circulating TGs increase as external fats come in from the meal. At the same time, eating also causes TGs to be released from internal sources within our body (this is

counterintuitive and admittedly frustrating, but is likely due to evolutionary factors that no longer apply to modern life). Then, slowly, the TGs exit the blood as they are taken up into tissues such as muscle or fat cells to be used as fuel or stored. Because TG metabolism involves complex crosstalk between different organs, postprandial lipemia can last for some time, and it is during this time that the harmful TGs can damage the blood vessels. Previous research showed that people with SCI likely have exaggerated postprandial lipemia, but we do not yet know why this is the case.

To determine the cause of postprandial lipemia in SCI I had people with and without SCI consume a special liquid meal and I measured the rise and fall of TGs in their blood for 6.5 hours after the meal. There are two important components of my study that were not included in previous studies. First, we used a body scan to determine the precise amount of fat and lean (muscle, bone, etc.) tissue in everyone’s body, and each meal was made relative to the person’s lean tissue. This approach accounts for the fact that, due to atrophy of paralysed muscles, persons with SCI simply have less muscle to take up TGs from the blood. Second, we mixed a special “lipid tracer” chemical into the meal that allows us to start to tease out the source (external vs internal) of the postprandial TGs in the blood. The results of my study show that people with paraplegia had a similar rise in postprandial TGs as people without injury.

These findings are encouraging as they demonstrate that people with thoracic injuries can avoid postprandial lipemia if they practice proper nutritional control. Despite the similar rise in total TGs, however, the lipid tracer revealed that the TGs were coming from different sources, with more TGs from internal sources in the paraplegics. This unique finding could help us learn about how neurological signals help coordinate the complex postprandial TG metabolism, something that is otherwise very difficult to measure and often overlooked.

Our brains are multitaskers, at once allowing us to consciously move and feel, while also silently conducting a biological orchestra in the background. As those living with SCI know, these “autonomic” background processes can quickly be pulled into the forefront of our lives when they are not running so smoothly. Fat metabolism is one of the silent orchestras that changes after SCI, and while it is difficult to observe fat metabolism at work the results of its dysfunction has a very real impact on people’s lives.

My study provides some of the first evidence that in people with paraplegia proper nutritional control helps keep TGs from rising too high after a meal. However, not everything was normalised by meal control, and the observed difference in sources of TGs in SCI is teaching us about the role that neurological signals play in coordinating fat metabolism.

My testing has been postponed due to the COVID-19 pandemic, but we are ready and eager to test people with cervical injuries. I thank you for reading about my project and the results so far, and I invite you to follow this space.

Special acknowledgement: Jazzmin Peluchette co-editor of written piece.



Image credit: The Miami Project to Cure Paralysis (Media Department).

PREVENTING LIFESTYLE-RELATED DISEASES IN PEOPLE WITH SCI - TIME TO RAISE THE TEMPERATURE?

Written by Sven Hoekstra



Postdoctoral Researcher

The Peter Harrison Centre for Disability Sport, Loughborough University
United Kingdom

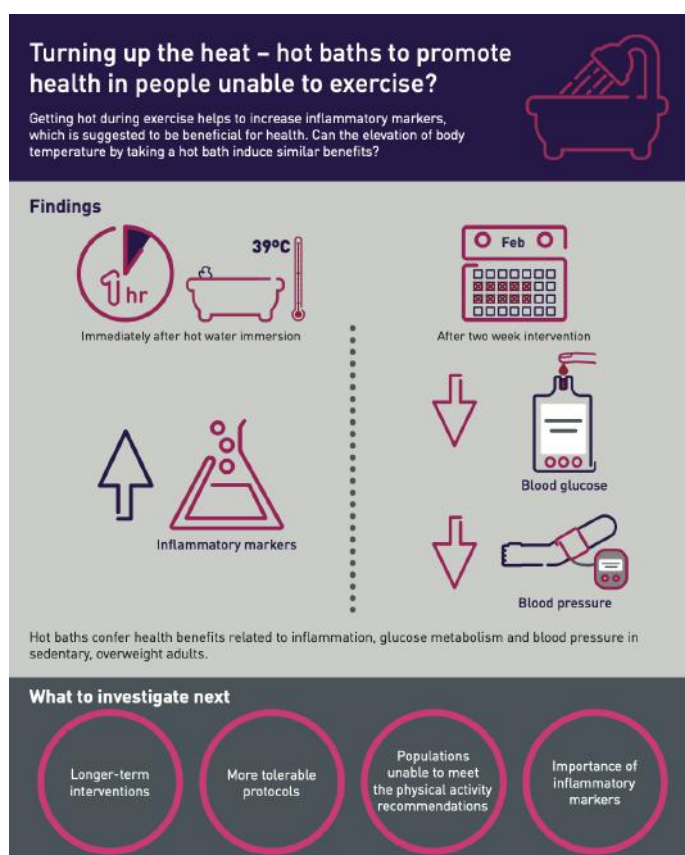
As a result of advances in medical care, life expectancy has increased dramatically among people with a spinal cord injury (SCI) in the past decades. This can only be described as a truly positive thing. However, it has further uncovered the secondary complications associated with a spinal injury. Notably, while the prevalence of type 2 diabetes (T2D) and cardiovascular disease (CVD) is increasing at an alarming rate in the able-bodied population, such lifestyle-related diseases are even more prevalent in people with SCI. This could be related to the changes that occur in the nervous system, the loss of muscle mass resulting from paralysis, but also the low levels of physical activity that individuals with SCI generally engage in. Luckily, there are ways to help prevent the development of lifestyle-related diseases. Indeed, exercise has rightly been referred to as a panacea for a wide range of health issues. For instance, it can improve vessel health and the way in which the body processes glucose, while it can also reduce so-called chronic low-grade inflammation. The latter is increasingly recognised as a risk factor for both T2D and CVD and is an aspect of health our research group has focused on in the past years.

Although an immune response following infection is crucial to remain healthy, it is evenly important that the activation of the immune response is lowered following such a response. Chronic low-grade inflammation, on the other hand, is a state in which the immune system is constantly slightly overactive. This is usually characterised by elevated concentrations of inflammatory markers in the blood. Perhaps somewhat counterintuitively, a bout of exercise also elevates the concentration of these markers. However, this response is short-lasting and most importantly, it stimulates the production of anti-inflammatory markers. As a result, many researchers believe that repeated stimulation of this acute inflammatory response by exercise can reduce chronic low-grade inflammation in the long run. Promisingly, our research has shown that arm-cranking induces a similar inflammatory response compared with cycling, despite the use of a much smaller muscle mass during arm-cranking.

Thus, exercise can reduce chronic low-grade inflammation, and this seemingly also holds true for upper-body exercise. So far so good. However, there

may be a caveat. In a study conducted in collaboration with our colleagues from the Wakayama Medical University, we collected blood samples from wheelchair racers with a tetraplegia (spinal injury at the cervical level) and those with a paraplegia (spinal injury below the cervical level) before and after the wheelchair half-marathon in Oita (Japan). Interestingly, we found a much lower inflammatory response after the race in the athletes with a tetraplegia. The same has been reported in studies investigating other forms of upper-body exercise, such as arm-cranking. Although it is important to note that these are results from acute studies, investigating only a single exercise bout, it suggests that exercise for people with a tetraplegia, as opposed to persons with a paraplegia, may be less effective to reduce chronic low-grade inflammation. As such, additional strategies to combat this condition and help prevent lifestyle-related diseases may be needed. One such strategy is closer than you might think and can be found in your own bathroom: taking hot baths, also called hot water immersion.

The idea of using hot water immersion to induce an inflammatory response stems from exercise studies, which showed that exercise in the heat results in a much larger inflammatory response compared with exercise in neutral conditions. Thus, there may be something related to the elevation of body temperature per se that can stimulate this response. And sure enough, when increasing the body temperature of our participants by letting them sit in a hot bath for 60 minutes, we observed an increase in the concentration of inflammatory markers. Crucially, this was not only the case in able-bodied participants, but also in participants with a tetraplegia. Hence, while it may be difficult for people with a tetraplegia to induce that important acute inflammatory response through exercise, hot water immersion may be an alternative strategy to do so. It should be noted, however, that there are currently no studies that have investigated whether regular hot water immersion sessions actually reduce chronic low-grade inflammation in people with SCI. However, in preparation for such a study, we exposed able-bodied individuals to a hot water immersion intervention, in which they underwent 10 sessions in two weeks. The main finding was a reduction in fasting glucose and insulin concentrations, potentially contributing to a reduced risk for T2D and paving the way for studies in people with SCI. Therefore, while the wide-ranging benefits of exercise training cannot be denied, when it comes to preventing lifestyle-related diseases in people with SCI, and in particular those with a tetraplegia, it may be time to raise the temperature ...



Reference
Hoekstra SP, Bishop NC, Faulkner SH, Bailey SJ, Leitch CA (2018). Acute and chronic effects of hot water immersion on inflammation and metabolism in sedentary, overweight adults. *Journal of Applied Physiology*, 125(6), 2008–2018.

Acknowledgements
Bathrooms modified "Fast Awesome Social Bath" - Fast Awesome Free 5.2.0 by Bloorbourne - <https://bloorbourne.com>

Loughborough University
Peter Harrison Centre for Disability Sport



Infographic: An infographic outlining the findings of a study investigating the acute and chronic effects of hot water immersion in sedentary, overweight males (Hoekstra et al., 2018; *J. Appl. Physiol.*).

Image: An example of how hot water immersion may be implemented in the rehabilitation setting.

LIFE GOALS

Written by Adele Snyman



Occupational Therapist
Zithulele Hospital
South Africa

“Good morning, my name is Adele. I’m your occupational therapist,” I started and then leaped into my explanation of how I’d help her to problem solve ways to do the things that she’d previously done, “... like being able to wash and dress yourself and get into a car ...,” I ended.

“What’s the point?” she replied. I stopped. She was a beautiful, well spoken, 21-year-old woman with striking dark eyes. It’d been one week since her car accident, and she’d been paralysed from the waist downwards. I recognised her despondency and hopelessness, a common emotion following such a tragedy, but I was desperate to connect with her.

“What are you most worried about?” I asked, a feeble attempt at asking her where she would like us to start in rehabilitation and what her goals may be.

“I’m worried about my grandmother, what is she eating?” she replied. She went on to explain her context. She’d grown up in an informal settlement, only one of the harsh reminders of South Africa’s history of apartheid. She’d faced a difficult childhood and by the time she had completed her schooling she was the only person left who could care for the grandmother who had raised her. She had moved to the city where she’d worked as a domestic worker for a family. The family had a room in their garden where she could live and they had been kind enough to

allow her grandmother to move in with her. She gratefully explained that they had allowed her grandmother to stay on in the room whilst she was in hospital. “But,” she added,

“I might not walk again. I won’t be able to go back to work. My grandmother and I will lose our accommodation and our income. And what’s my grandmother going to eat whilst I’m in rehabilitation?”

The next day I went back. She didn’t want to get up out of bed and was definitely not going to be persuaded to try achieve any of the goals I had set for her, no matter how much I tried to convince her that getting out of bed, even if only to wheel herself out into the sunshine in the garden, would help her to feel better. I went and fetched my laptop. I explained the plan. She didn’t need to get out of bed and in my hourly sessions with her we’d work on compiling a CV and start looking for a job that she could do in a wheelchair. Hopefully by the time she left she’d have the means to look after her grandmother. She looked at me and for the first time I saw a glimmer of hope in her eyes.

I got to know her as we typed out her CV, in the first session. We spent the second session looking for and applying for positions. She worked tirelessly, and kept my laptop to continue working at it for much of the day. South Africa has a high unemployment rate, and I hoped that she wouldn't be disappointed. But I was confident that she stood a good chance. Companies received tax breaks and earned what's known as 'BEE' points by employing people with disabilities. To top this off she was educated, professional and charismatic.

The next day I was walking to my office when I heard someone calling out to me. It was her. She was out of breath from pushing herself as hard as she could. "Adele," she said, "I got a call back, I'm going for an interview tomorrow, please teach me how to transfer myself into a taxi and fold up my chair." I smiled at her. She was out of bed, had bathed and dressed herself and hadn't needed me to facilitate any of it.

It got me thinking about how we set rehabilitation goals; how different the rehabilitation process is when the client initiates the goal, and how much easier these goals are achieved when the client is driven to achieve them. It made me wonder how we could best facilitate client led goal setting in a country like South Africa with such great language, cultural and socio-economic diversity. How are therapists currently setting goals and are the goals

client initiated? How do we ask the right questions to find out what would really make the person 'tick'?

She went for the interview and was given the job. She was discharged from the rehab centre by the end of the week, fully independent and on her way to ensure that her grandmother was well taken care of and having a warm, homely meal.

PS. This is a true encounter, as remembered by the author.



MEET THE RESEARCHERS

Want to know more about the researchers featured in this publication and their studies? Please contact us at info@thesri.org



Monzurul Alam

Research Assistant Professor
Department of Biomedical Engineering, The Hong Kong Polytechnic University, Hong Kong SAR

Monzurul Alam is a researcher with an interdisciplinary background in engineering and neurorehabilitation. He received a Masters in Bioengineering from Miguel Hernandez University and PhD from the Department of Rehabilitation Sciences at Hong Kong Polytechnic University. He also received Postdoctoral training in neuromodulation from Dr Reggie Edgerton's laboratory at the University of California, Los Angeles. Currently, he is a Research Assistant Professor at the Department of Biomedical Engineering of the Hong Kong Polytechnic University. Monzurul's research is grounded in fundamentals in the field of system neuroscience with applications to prosthetics and rehabilitation following neurological injuries. Electrophysiology, pharmacology and neurostimulation are the common techniques applied in his research.



Julia Bloom

Lecturer
Griffith University, Australia

Julia Bloom is a lecturer and PhD candidate at Griffith University, whose work focuses on emerging early intervention vocational rehabilitation approaches for people with SCI.



Elizabeth Bye

Postdoctoral Research Fellow
Neuroscience Research Australia, Australia

Elizabeth Bye completed her Doctorate of Philosophy at the University of Sydney. She is a physiotherapist who has worked at the Spinal Injury Unit at Prince of Wales Hospital for the last eight years. Elizabeth's research is in rehabilitation medicine. She is currently working at Neuroscience Research Australia as a Postdoctoral Research Fellow examining the effects of transcutaneous spinal cord stimulation on walking ability in people with SCI. Elizabeth is passionate about improving the lives of people with SCI.



Pádraig Carroll

Research Assistant

Royal College of Surgeons in Ireland, Ireland

Pádraig Carroll is a research assistant working on a patient and public involvement (PPI) study as part of a larger spinal cord repair group. His work is placed within the Tissue Engineering Research Group (TERG) in the Royal College of Surgeons in Ireland (RCSI) in collaboration with Advanced Materials and BioEngineering Research (AMBER) Centre. Pádraig has a background in health psychology, where he developed an interest in PPI and qualitative research methods. Prior to moving to academia in 2020, he worked as an assistant clinical psychologist.



Annette Halvorsen

Senior Consultant and PhD Candidate

St Olavs Hospital / Norwegian University of Science and Technology, Norway

Annette Halvorsen studied medicine and graduated in 1999. She became a specialist in physical medicine and rehabilitation in 2004. Thereupon she has been working as senior consultant at the SCI unit, at Trondheim University Hospital in Norway. She was strongly involved in the establishment of the Norwegian Spinal Cord Injury Registry (2012) and the Nordic Spinal Cord Injury Registry (2017) and she is today's leader of both registries. She is currently a PhD candidate at the Department of Public Health and Nursing at the Norwegian University of Science and Technology. She is the secretary/treasurer of the Nordic Spinal Cord Society.



Sven Hoekstra

Postdoctoral Researcher

The Peter Harrison Centre for Disability Sport, Loughborough University, United Kingdom

After the completion of an MSc at Groningen University in The Netherlands, investigating the effects of training for an event called the HandbikeBattle on health and fitness in people with SCI, Sven Hoekstra went on to pursue a PhD with the Peter Harrison Centre for Disability Sport at Loughborough University (UK). During this project, he investigated the immune and metabolic response to health promoting strategies suitable for people with a disability, such as arm-cranking and passive heating by hot water immersion. Currently, Sven is a Postdoctoral researcher at Loughborough University, aiming to implement the findings from his previous research into clinical settings, such as the inpatient rehabilitation phase following SCI.

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MEET THE RESEARCHERS



Priya Iyer

Professional Leader Dietetics
Royal Rehab, Australia

Priya Iyer is an accredited practising dietitian with extensive experience in clinical dietetics. Priya is passionate about improving nutrition care and outcomes in individuals with SCI. With a vision to contribute visibly to enable policy and practice changes, Priya is actively involved in research in the field to ensure optimum outcomes for people with SCI. Currently, Priya is pursuing her PhD as just a start to work towards strengthening evidence in the area of nutrition in SCI.



Ingrid Kouwijzer

PhD Student
Heliomare Rehabilitation Center / University of Groningen,
The Netherlands

Ingrid Kouwijzer is a human movement scientist and medical doctor. She has clinical work experience in the field of rehabilitation medicine and neurology. Currently she works as a PhD student at Heliomare Rehabilitation Center. Her study involves the HandbikeBattle project, which is a Dutch multicentre handcycling initiative. The main interests of the study are physical capacity testing, handcycling training, and physical and mental effects of participation.



David McMillan

Clinical Researcher
The Miami Project to Cure Paralysis, University of Miami
School of Medicine, United States

In 2010, David McMillan was serendipitously involved in a community research project involving exercise and people with SCI. This experience set David on a trajectory, and he is now a clinical researcher using metabolic science to learn about SCI and identify low-tech / low-cost strategies for targeting obesity in people with SCI. Outside the laboratory David is an avid purveyor of adaptive outdoor recreation, including being a seasoned adaptive scuba dive buddy. His love of inclusivity and nature has also led him to advocacy pertaining to the disproportionate effect that climate change has on people with disability.



Leanne Rees

PhD Candidate
LaTrobe University, Australia

Leanne Rees is a PhD candidate at LaTrobe University and physiotherapist with the Victorian Spinal Cord Service, both in Melbourne, Australia. In 2018, she completed a Masters of Public Health which fostered an interest in the social and environmental determinants of health and wellbeing for people with SCI, and the role media has in the public health space. In 2019, Leanne commenced a PhD investigating media portrayal of SCI and its impact on people with SCI.



Adele Snyman

Occupational Therapist
Zithulele Hospital, South Africa

Adele Snyman is an occupational therapist who works in a deeply rural village in the former Transkei in South Africa. She is passionate about SCI and neuro rehabilitation and has recently completed a Masters in Occupational Therapy in Neurology. Adele considers herself privileged to share in so many people's brave and resilient journeys towards independence.



Theresa C. Sutherland

Postdoctoral Research Associate
Texas A&M Health Science Center, United States

Theresa C. Sutherland completed a Bachelor of Forensic Biology from the University of Technology Sydney, followed by a Bachelor of Science (Honors) studying the acute cellular response to SCI. From there Theresa obtained her PhD in Neuroscience in the lab of Dr Catherine Gorrie, studying differences in injury progression and neuro-inflammation after SCI between adult and paediatric rats. Theresa joined the Geoffrey lab at Texas A&M in 2019 for her first postdoctoral position. Here she continues working on the themes of age and SCI, trying to understand the age-dependent decline in axon growth with the eventual goal to restore regenerative potential to aged axons, and find strategies to enhance axon growth and functional recovery after SCI irrespective of age.

Spinal Cord Research Hub (SCoRH)

The global collaboration platform for SCI researchers and clinicians.

Join today at www.scorh.org



ABOUT THE SPINAL RESEARCH INSTITUTE

We provide opportunities for SCI researchers and clinicians to build multi-centre collaboration. By building global collaboration and consumer engagement in SCI research and clinical trials, we aim to reduce the length of time it takes to achieve significant and translatable research outcomes.

Through our programs we meaningfully engage a broad audience of people with lived experience, SCI researchers, clinicians and like-minded supporters.

Our Programs

Spinal Cord Research Hub (SCoRH)

Connecting researchers and clinicians internationally

Consumer Engagement Program

Actively involving those affected by SCI in research

Travel Grants

Facilitating research collaboration

Mentor Program

Supporting research careers

Conference Workshops

Sharing best practice with the SCI community

Our Impact

- 1** Increased research collaboration
- 2** Effective multi-centre studies
- 3** Reduced research timeframes
- 4** Research that meets the needs and priorities of the SCI community
- 5** Improved health outcomes and quality of life for people with SCI



Support research collaboration

Your support will help us improve the lives of people with spinal cord injury through global research collaboration and consumer engagement.

There are many ways to support the Spinal Research Institute including corporate partnerships, fundraising, donations and bequests. You can also join our Patron's Program of annual giving.

Contact our Development Manager at info@thesri.org

Visit www.thesri.org to find out more about the work we do.



GET IN TOUCH

Spinal Research Institute

Royal Talbot Rehabilitation Centre
1 Yarra Boulevard
Kew VIC 3101
Australia

info@thesri.org
www.thesri.org



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