

IMPACT REPORT

December 2020 - November 2021

Funding groundbreaking research to cure spinal cord injury.



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A MESSAGE FROM

Thanks to your support, science may be on the cusp of making major breakthroughs.

SpinalCure had an incredibly successful 2021 despite the many challenges brought about by another year of the global pandemic.

It was heartwarming and encouraging to see our community pull together in the face of such challenges.

SpinalCure's mission is cure-related, not care, and we aim to achieve real life human outcomes by funding and supporting the most advanced, highest quality research projects.

"As many of us reading this know, a spinal injury can be absolutely devastating and also deeply impacts the families and surrounding communities of those injured."

It is also important to highlight the other cost to society. More than 20,000 people suffer a spinal cord injury in Australia with an estimated annual cost to the economy of \$3.7 billion.¹

This year SpinalCure has been focused on progressing neurostimulation, the world's leading experimental treatment for people with spinal cord injury.

"We believe this treatment can bring about profound change to people's lives in the very near future."

In March this year, our eWALK trial, at Neuroscience Research Australia (NeuRA) in Sydney, launched and received outstanding national media coverage. This worldfirst clinical trial aims to improve the ability of paraplegics to walk and has taken four participants through the program so far.

Working with the scientists this year, we have prepared a neurostimulation roadmap which aims to take this therapy out of the lab to mainstream adoption and are in the midst of a campaign to raise the much needed funds. How much we raise, and how quickly we raise it, will determine how soon treatments can be made widely available, giving people the chance of a better life.

These really are exciting times as we inch closer to bringing experimental treatments to more Australians on a scale and quality not achieved anywhere else in the world before. The SpinalCure team is excited to be playing a key part in such an important and innovative time in spinal cord injury research.

Kathryn Borkovic Chief Executive Officer

¹Spinal Cord Injuries in Australia—The case for investing in new treatments. Alpha Beta, December 2020)

Funding groundbreaking research

Thanks to your support, SpinalCure is Australia's most active and successful organisation in securing and distributing funds for research into finding a cure for spinal cord injury.

The organisation is now taking an active role in driving several of the most promising leads toward clinical translation under the enthusiastic and determined leadership of our new CEO, Kathryn Borkovic and Executive Director, Duncan Wallace.

In a general sense, there are 3 main areas of attack to overcome functional loss in SCI:

1. Minimising the damage caused by SCI

2. Electrically stimulating the remaining tissue to enhance or restore function

3. Promoting regrowth and repair of damaged neurons.

It is most likely that a combination of all three will be required to achieve the best outcomes.

"SpinalCure has provided significant funding to all three areas over the past 20 years, and I am excited by the fact that in each of these areas we now have identified a key line of research which we think is of sufficient promise to invest in significantly over the next five years or so."



A MESSAGE FROM THE SCIENTIFIC CHAIR, PROFESSOR PERRY BARTLETT AO FAA

CONTINUED...

1) Minimise the damage

It is now clear that much of the functional loss after injury occurs due to the inflammatory processes and while inflammation is also important in promoting repair, the aim is to reduce or eliminate its negative component.

In world-leading research funded in part by SpinalCure, Professor Marc Ruitenberg at the UQ, has been able to identify the key components of the inflammatory process that follows injury in mice and humans. Through a small preliminary trial, he has demonstrated that the anti-inflammatory agent intravenous immunoglobulin (IVIg) is able to significantly change the inflammatory profile of the patients.

SpinalCure is now excited by the opportunity to be behind the progression of this work into an expanded multicentre clinical trial and future therapeutic application.

2) Restoring function through stimulation

The next exciting opportunity initiated and backed by SpinaCure is the use of electrical stimulation of the spinal cord below the site of injury—to amplify the signals from the brain to stimulate the nerves below the lesion and improve function.

This technology builds on the fact that even with the most severe injury there often remains some intact nervous connections across the lesion.

We are excited by the opportunity to explore this technology with our partner NeuRA. I am especially delighted that one of Australia's foremost neuroscientists, Professor Simon Gandevia, and his group are undertaking the pioneering human studies to rigorously determine both the mechanism(s) by which neurostimulation exerts its effects and more importantly, conduct the world's first double-blind clinical trial to ascertain the effectiveness of the method to improve function.

3) Promoting regrowth of damaged neurons

Finally, I am happy to report that work from my own laboratory on a molecule EpHA4-Fc has reached the stage of Phase I clinical trials. This molecule has previously been shown to promote spinal cord repair in mice after injury and with successful completion of Phase I trial, will be available for advancement to clinical trials in human spinal cord injury.

"Thus, I am delighted to report that SpinalCure is now entering an exciting phase of translating the advances achieved by our investments in all three areas into the clinic over the next few years."

Emeritus Professor Perry Bartlett AO FAA, Scientific Chair

Launch of the report, Spinal Cord Injuries in Australia – The case for investing in new treatments

JAN 21

Penguin Bloom movie launch, World Premiere and impact campaign. Proceeds from charity pre-screening and exclusive behind-the-scenes photography exhibition donated to SpinalCure thanks to the Blooms and Roadshow Films



FEB 21

Charity screening of Penguin Bloom hosted by ASB Marketing and TAG Financial Group

OUR YEAR

MARCH 21

The eWALK trial begins, with media launch in June

Annual Lloyd's Golf Day



APR 21

Newport Bowling Club Anzac Day Raffle



JUNE 21

\$600,000 donated to the eWALK trial, thanks to The CatWalk Trust and SpinalCure supporters.

\$97,500 donated to A/Prof Marc Ruitenberg's research, University of Queensland (UQ)



MAY 21

Key supporter Kerr Neilson speaks to the AFR about his support.

Launch of our #HelpMeStand campaign for ongoing eWalk trial funding

JULY 21 - AUG 21

Working with NeuRA scientists on Project Spark roadmap

SEPT 21

Director of Prince Of Wales, Sydney Spinal Unit, Dr Sachin Shetty online update on spinal cord injury and the pandemic

OCT 21

Hosted VIP Webinar on Project Spark

Meeting with Federal Health Minister Greg Hunt

NOV 21

Lloyd's Golf day

David Prast Achievement Award announcement



OUR IMPACT

THE **IMPACT** OF OUR WORK IS VISIBLE AND HIGHLY MEASURABLE

TOTAL FUNDING INVESTED INTO RESEARCH THIS YEAR



4

THE EWALK TRIAL

Profs Simon Gandevia and Jane Butler, NeuRA Human studies aiming to restore walking ability begins March 2021

THE IVIG TRIAL

A/Prof Marc Ruitenberg, UQ Reducing the impact of new injuries. SpinalCure funded the pre-clinical work that led to this trial.

BIOMARKERS TO PREDICT RECOVERY

A/Prof Marc Ruitenberg, UQ Enabling clinicians and researchers to better gauge treatment effectiveness. Landmark paper published.

GAME-BASED ROBOTICS REHABILITATION STUDY

Dr Camila Quel de Oliveira, UTS Aims to improve hand and arm function in quadriplegics.

Thanks to our supporters, since inception we have directly funded over 30 research projects and secured funding for many more.

OUR RESEARCH PROJECTS

eWALK clinical trial at Neuroscience Research Australia (NeuRA)

The eWALK clinical trial, which aims to improve walking in paraplegics through spinal cord neurostimulation, commenced treating participants in March 2021. **Neurostimulation is the world's leading experimental therapy for people with spinal cord injury.**

It works by applying electrical currents over the skin to the spine to wake up neural pathways that survived the injury.

The eWALK trial is a double blinded sham controlled clinical trial—the scientific equivalent of a gold standard. It is led by the NeuRA scientific team in Sydney with additional global satellite labs taking part.

The trial is led by Professor Simon Gandevia FAA, acknowledged as the world's most cited neurophysiologist.



"I found it great to be able to participate in a research trial which will help people like myself with a cure one day."

~ eWalk trial participant

"Extremely worthwhile treatment program with benefits to health, social wellbeing, cardio, standing and walking."

~ eWalk trial participant

Sam Bloom tries neurostimulation at NeuRA.

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EWALK TRIAL CONTINUED...

The eWALK trial is the first in the world to apply this level of scientific rigour to neurostimulation. It aims to test and validate the promising findings of smaller studies, carried out globally, where participants have had function and feeling return after neurostimulation therapy.

While progress was delayed by the pandemic, the program has resumed and NeuRA is taking enrolments for additional participants for 2022.

The three international sites are due to commence treating volunteers early in the new year.

Why this research is important:

The eWALK trial enables Australians with a spinal injury to benefit from a promising experimental therapy. There are no other treatment options available in Australia. "There is enough evidence for us to believe this is the leading experimental treatment for people with spinal cord injury. In order for it to be developed for mainstream use it must first be tested and validated in an independent and high-quality, rigorous scientific setting. Simon Gandevia and his team are the best scientists globally to be working on the challenge."

Prof. Perry Bartlett AO FAA, Scientific Chair.

The trial is also the first important step towards gathering the evidence needed for use of this treatment by everyday Australians with a spinal cord injury.

Given that eWALK is a gold standard trial and the first of its kind globally, it's findings will be pivotal in the global quest for a cure.

"Improved neural pathway connections and mobility"

~ eWalk trial participant

Clinical research into acute injuries, UQ

SpinalCure has supported Associate Professor Marc Ruitenberg since 2011 when he was an early career researcher.

A/Prof Ruitenberg and his team are examining the 'inflammatory phase' of SCI, which is normally a crucial part of healing and injury recovery. However, in spinal cord injuries, it appears that there is excessive, non-resolving inflammation and scar tissue formation that hinders repair, and the reason why this happens isn't well understood.



"What we discovered in our animal studies is IVIg can reduce this harmful inflammation and, excitingly, significantly improve the recovery from serious spinal cord injuries."

~ A/Prof Marc Ruitenberg

ACUTE INJURIES CONTINUED...

The IVIg trial

A/Prof Ruitenberg has been trialling the anti-inflammatory drug IVIg, which is given to participants within hours of spinal trauma in an effort to reduce secondary damage caused by inflammation.

A/Prof Ruitenberg recently completed the initial clinical trial, treating 20 newly injured people with IVIg. The paper will most likely be published in 2022.

This trial has shown the treatment to be safe and feasible, and A/Prof Ruitenberg is excited about the results. Some patients, including two schoolboys injured playing rugby, have seen much greater recovery than would normally be expected from the severity of their injuries.

A/Prof Ruitenberg is now planning a much larger Phase 2/3 clinical trial, with sites across Australia. This will allow many more people to possibly benefit from the therapy, and provide the scientific evidence required to show that that IVIg treatment is as beneficial as the scientists believe it to be.

Biomarkers to predict recovery

The inability to predict injury outcomes is a major issue in the field of SCI research, hampering our ability to demonstrate the effectiveness of new experimental treatments.

In January 2021, A/Prof Ruitenberg and his colleagues released a groundbreaking paper detailing how changes in levels of certain molecules in the blood can be used to predict the degree of recovery a patient can expect.

Why this research is important

The biomarker research enables clinicians and researchers to better gauge treatment effectiveness and importantly makes statistical analysis of research results far more accurate and meaningful.

IVIg treatment, on the other hand, could mean many newly injured people will leave hospital in much better shape than previously thought possible. Further clinical trials will test the potential of this therapy on wider populations.



Art and original image by Faith H.

Brennan and Luke A. Hammond, UQ.

The next 1–5 years: Increasing community access to promising new treatments

Now, our focus is on key projects with a high chance of success and getting these promising technologies out to the people who need them as soon as possible.

Project Spark: sparking a revolution in the way spinal cord injury is treated

With the critical foundational eWALK trial up and running, we have developed a roadmap to take the research out of the lab and into mainstream use. To do so, we'll need to gather the evidence required for TGA approval of the device and therapy.

We've spent much of the year working with NeuRA scientists preparing a 5-year project plan, timeline and budget.

We've called it Project Spark, not only because the therapy uses electrical currents, but also because we believe it will **spark a revolution in the way spinal cord injury is treated.**

Project Spark involves a series of rigorous clinical trials and a national suite of community-based studies. We are also scoping a mobile therapy program to provide access to experimental therapies to people with SCIs in regional and rural areas.

Support needed: approximately \$46m in funding.

We are currently in the midst of a national campaign aimed at all levels of the community including philanthropy, business, state and federal government to raise the funds needed.

LOOKING FORWARD

CONTINUED...

Project Spark will begin with the first of three community studies, which will start treating people in the second half of 2022. Aiming to improve respiratory, hand and upper limb function, the program will treat 75 quadriplegics over 3 years.

Support needed: \$2.2m

Expanding anti-inflammatory trial nationally

The positive results of the initial IVIg trial have paved the way for A/Professor Ruitenberg to start planning a much larger trial making the experimental IVIg treatment available in trauma units nationally in the next 1–2 years.

Support needed: \$10m

Our goals are ambitious, but we believe they are achievable if governments, philanthropists and the community pull together.

We are laser-focused on achieving these goals. People with SCI should not have to wait and funding is the major hurdle.

Total research funding required

\$58m approx over the next 3-5 years

Release of Spinal Cord Injuries in Australia – The case for investing in new treatments report

In December 2020, SpinalCure released a new landmark report looking into the cost of spinal cord injury to the Australian economy.

Thanks to the iCare Foundation, SpinalCure commissioned the report from leading strategic economic consultants, Alpha Beta.

The report shows that spinal injuries cost the economy \$3.7 billion per annum and the total lifetime cost of SCI in 2020 is estimated at \$75.4 billion.

Further, if a treatment could improve muscle function in just 10% of people with SCI, it can offer \$3.6bn-\$10.3bn in cost savings. This report has been instrumental in our government advocacy plans as we expect, once made mainstream, spinal cord neurostimulation has the potential to reverse, not only some of the physical damage following an injury but also result in significant cost savings to government budgets, as injured people become more independent and healthier following treatment.



ADVOCACY AND AWARENESS





Project Spark

Establishing a national centre to develop and distribute neurostimulation treatments, changing the lives of people living with spinal cord injury and reducing SCI's cost burden to the Australian economy.

Federal advocacy

SpinalCure met with the Federal Health Minister Greg Hunt in October following submission of a lengthy and detailed Project Spark funding proposal. Minister Hunt is supportive of the project.

We now move to the next phase of our government advocacy strategy which will involve a nationwide campaign as we secure further support for the project.

We also hope to secure a number of philanthropic pledges in support of Project Spark which will help with our government fundraising goal.

SpinalCure is exceedingly grateful to Senator the Hon Linda Reynolds CSC, Minister for the NDIS, for her invaluable support.

Bloom movie premier and campaign

SpinalCure had the unique opportunity to work with Roadshow Films ahead of the launch of the Penguin Bloom movie to develop an impact campaign.

We were also invited to join filmmakers and the Bloom family at the Worldwide Premiere in January 2021, held at the Westpac OpenAir cinema, with stunning views of the Sydney Opera House - it was a truly magical evening.

Penguin Bloom tells the true story of SpinalCure Ambassador Sam Bloom, played by Naomi Watts, a young mother whose world is turned upside down after a near-fatal accident leaves her paralysed.

The film has helped to raise awareness and shone a spotlight on what life is like living with a spinal cord injury.

The Sam Bloom for SpinalCure research fund has raised over \$120,000 for spinal cord injury research.

Working with Sandra Sully on the VIP event

In October 2021, SpinalCure hosted an online webinar where our community had the opportunity to hear directly from the scientists we support and about our 5 year plans. Sandra was a standout MC for the event.

Sandra has been involved with SpinalCure for 20 years after interviewing one of our ambassadors, Janine Shepherd when she made her film "Never Tell Me Never". In 2009, Sandra became our Patron.

Sandra is a tireless and active advocate for a cure.







Trans-Tasman partnership going strong

Setting up and funding the eWALK trial was possible thanks to the help of our counterpart in NZ, the CatWalk Spinal Research Trust NZ.

Both organisations recognise the critical importance of neurostimulation and agreed to co-fund the eWALK's \$3.6m budget.

CatWalk was founded in 2005 by Catriona Williams MNZM, formerly one of New Zealand's leading international equestrian riders.

CatWalk and SpinalCure share the common goal of a world where people no longer need to live a life suffering a spinal cord injury.

David Prast Fellowship

SpinalCure and our partners Spinal Cord Injuries Australia, have come together to establish and fund an annual \$15,000 professional development scholarship for an outstanding & highly dedicated NeuroMoves therapist.

This award is in memory of the very remarkable Mr David Prast who was a Board member of both organisations and whose tireless advocacy saw the opening of the first NeuroMoves in 2008.

NeuroMoves is an evidence based exercise and therapy service for people with neurological conditions or physical disability.

There are now 11 NeuroMoves clinics across six states and these facilities will be integral to our planned neurostimulation community studies.

Despite most events being cancelled due to the global pandemic, funds secured by SpinalCure totalled \$1,744,000 over the December 2020 -November 2021 period.

To all our supporters, big and small, we send our heartfelt thanks.

Our Foundation supporters included:

- Neilson Foundation
- Farrell Family Foundation
- Roger Allen and Maggie Gray Foundation
- Howland Rose Foundation
- Swiss Re Foundation
- Profield Foundation

Funds secured by SpinalCure totalled \$1,744,000 Dec 20 - Nov 21

HOW OUR

SUPPORT

COMMUNITY

AND PARTNERS

SHOWED THEIR

Lloyd's annual golfing fundraiser - twice!

Long term partner Lloyd's Australia hosted two annual charity Golf Days this year held in March and November at Sydney's Concord Golf Club. A total of \$46,525 was raised across both events. **Our heartfelt thanks go to Lloyd's for their ongoing support.**



Raising a total of **\$46,525**







Billabong community fundraiser

We are often moved by the stories from our wonderful community of fundraisers and the story shared by Cindy Donohue, from Billabong head office on the Gold Coast, really touched us.

The office held a bake sale to celebrate what would have been a birthday for their dear late friend and colleague of 30 years, Marlene Wills.

"Marls, as she was affectionately known, was a beautiful person with a huge heart. Marls had read, enjoyed and was so inspired by the book Penguin Bloom that she shared it around her networks with the book touching the hearts of many, especially here in the office at Billabong. It was only fitting that any funds raised in her Birthday Bake Sale would be donated to the charity supported by Sam Bloom, SpinalCure Australia."



SPOTLIGHT ON SOME OF OUR SUPPORTERS



Business

We couldn't have achieved such a successful year without the support from the business community, donating their time, money and prizes. Some of our key supporters are:

Oroton, Bayfields, Headlands Distilling Co., Lloyd's Australia, Swiss Re, White Space Concepts, Res Publica, Sargood on Collaroy, GIANTS Foundation, Speed Agency, Mountain Service Co, Queen Charles, Gai Waterhouse Horse Racing Stables, Wild Nature Australia, TappON, PopInk.

Headlands, a Wollongong-based distillery, was founded with the community positioned as a fifth business partner, such that 20 percent of the profits are donated to charity. That charity is SpinalCure, and the profits are assisting with research efforts to find a cure for spinal cord injuries. And our wonderful ambassadors Rodger Corser, Ed Cummings, Sam Bloom, Emma Mickle, Dean Martelozzo and Tom Elphick as well as supporter, Kerri-Anne Kennerley, thank you for your support throughout the year.



Donor community

A big thank you to our donor community. You have helped us get to this important milestone.

We have two incredibly promising experimental therapies in the pipeline and believe we can develop them for mainstream use in a matter of 5 years with the right funding.

Donor honour board

All our donors are essential to our work. These donors have made outstanding contributions to the research over this year:

Suzette Gately, Helen Kirby, Randolph Clinton, Gillian Meecham, Cindy and Terry Lissiman, Shawn Koric, Jonathan McCauley, Shufen Wang, Keith Evans,

Peter Eliassen,

Gerard Payne,

Jo-Anne Wormald,

Ludvig Kerec,

E. Rorrison,

Francesca Portelli,

Thomas Wormald,

Emma Valentine, Geoffrey Crawford, Nicholas & Milla Brown, Sue Mackinnon, Rebecca Ratcliffe. It's been almost 2 years since I was squashed by a tree branch and left with a T-12 incomplete Spinal Cord Injury. It's hard to put into words the effect that the injury has had on my life other than it's immeasurable.

Add in the un-seen complications of having a SCI – loss of bladder and bowel function, loss of sensation, the pressure sores and neuropathic pain just to name a few – and all of a sudden it seemed like managing living with a SCI was a full time job. Of course, there is also the flow-on effect to your partner and family who suddenly find themselves in a carer's position.

Fortunately for me, I was lucky enough to regain motor function in my legs and the ability to walk. The fact that I walked out of a SCI rehab hospital after 3 months, after so much uncertainty, is something I still can't describe.

As happy and excited as I was, I struggled with seeing my new friends that I'd made in rehab not share in the same success. With complete injuries their prognosis was not as good as mine and to put it simply, it just didn't seem fair.

This led me to getting involved with SpinalCure. I desperately want to see a cure for SCI and I could sense SpinalCure share that passion and drive to fund research.

The research that SpinalCure funds and their 5 year plans give me hope. I am especially excited about the community studies they are planning to roll out next year including in Victoria, where I live. I hope I can be a participant and I hope the friends I made in the trauma unit can also participate.

Any improvement in functions such as bladder, cardiovascular, respiratory could make a huge difference to our lives. This hope for everyone with spinal cord injury drives my motivation to keep fundraising and supporting SpinalCure.

Emma Mickle, Community Ambassador

SPINALCURE'S WORK BRINGS ME HOPE





"In an instant, my career as a Paramedic, my sporting aspirations for ultra-running and triathlon, my passion for the outdoors and hiking, were gone."







spinalcure.org.au