



A BETTER NDIS FOR ALL AUSTRALIANS



There is not much, if anything, that has beaten me in this lifetime.

Certainly not my multiple sclerosis (MS).

I wish I could say the same for the National Disability Insurance Scheme (NDIS).

I take pride in my resilience, my independence, my intelligence, and my above-average health literacy.

I should be expertly positioned to navigate the NDIS, to advocate and negotiate on my behalf to secure the support I require.

I have spent my entire professional career in healthcare; as a nurse, a passionate advocate, a senior administrator and policy maker, and in more recent years in senior leadership roles with MSPlus, MS Research Australia and the Multiple Sclerosis International Federation.

Now, as the current Chair of MS Australia and as a person living with MS, I am extremely proud

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IS MULTIPLE SCLEROSIS ON THE RISE?

LATEST FUNDING FOR NEW AND INNOVATIVE RESEARCH ANNOUNCED BY MS AUSTRALIA

MS Australia has announced its new round of incubator grants for 'out-of-the-box' Australian research projects that will explore innovative ways to prevent and treat multiple sclerosis (MS), including new research that will further explore the prevalence and incidence of MS in different parts of Australia.

This latest round of funding for the new MS research projects will see \$180,000 distributed across four research projects and a postgraduate scholarship for an outstanding young researcher in the field of MS.

MS Australia's Head of Research Dr Julia Morahan says the grants are both an investment into the research and in the researchers.

"They allow new and important questions to be asked that will lead us closer to the answers we need to ensure multiple sclerosis is where it needs to be – behind us.

"In this our 50th year, our mission is to supercharge MS research and advocate with vigour, to achieve our ultimate goal, a world without MS," Dr Morahan said.

2022 INCUBATOR GRANT RECIPIENTS

Incubator grants support novel ideas, and the subsequent generation of preliminary data that may enable researchers to apply for larger grants in the future.

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FROM THE CEO



'Reminder: Each day brings us closer to a cure.'

This was both a comforting and challenging tweet from the American National MS Society that arrived in my social media feed.

Comforting, because we can often lose sight of the many small but significant scientific advances that are made day-in, day-out by the hard-working researchers we collectively fund.

Challenging, because there is still so much to be done before we break the back of the confounding disease that is MS.

Yes, we have come a long way since MS Australia was created 50 years ago. But it's time to redouble our efforts as - study by study, we are indeed turning the tables on MS.

Much is happening.

We will soon release the results of a much-anticipated study on Vitamin D that is likely to be of global significance.

We are seeking funding to enable Australia to be a major international player in clinical trials to assess existing drugs, to see if they can be repurposed to help change the quality of life for people with progressive MS.

We are ramping up our campaign to ensure that people with MS and other neurological conditions have a voice within the NDIS advisory structures.

We are getting ready to assess the many high-quality MS research grant applications we get each year.

And we are asking the Australian Government to plug gaps that see neurological conditions shamefully left behind in national health data collections.

This is, of course, just a glimpse of the activity that is underway to achieve our ultimate goal - a world free of MS.

As long as we can keep raising the funds so desperately needed by our researchers, we will fulfil the claim that each day will indeed bring us closer to a cure.

Best wishes

Rohan Greenland

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and humbled to be a contributor to a better future for Australians living with MS, their families, loved ones, carers and friends.

Proud, but also exasperated.

Exasperated because it's clear that if I can't successfully navigate the NDIS and secure the assistance I require, despite my knowledge, connections, and understanding of government bureaucracy and health systems, the NDIS is fundamentally broken.

But while the NDIS may have beaten me, please be assured I am far from defeated. In fact, there are many reasons for us all to be hopeful.

Not the least of which is that the architect of the NDIS, Minister for the NDIS, Bill Shorten, is now back at the helm and promising to rebuild trust, ensure fairness and restore the scheme to its original intent.

Another reason for optimism - a review of the NDIS, recently brought forward to the latter half of this year, will provide the formal mechanism to recommend much-needed improvements.

Importantly, we know what is broken and have already identified solutions.

MS Australia is actively campaigning for **A better NDIS for people living with MS**, by calling for three major changes to the NDIS.

Changes that would benefit not only the 25,600 Australians living with MS, but all Australians living with a disability that might find themselves in need of support from the NDIS.

And while these changes are simple and straightforward, their impact should not be underestimated.

Hear our voice: Firstly, we're calling for effective representation

within the NDIS. We're calling for the 1.6 million Australians living with degenerative neurological or neuromuscular conditions to be heard, understood and effectively represented in the NDIS.

Understand MS: Secondly, we're calling for better understanding, awareness and education about MS in the NDIS. It's simple really. How can the NDIS assess what it doesn't fully understand?

Don't discriminate: Finally, we're calling for an end to age discrimination by removing the age 65 cut-off.

Chronic disease doesn't care about your age and nor should the NDIS.

Very simply, all Australians with MS should be entitled to register with the NDIS if and when they need it.

At their heart, these are universal changes to the NDIS that will ultimately deliver better support to all Australians who need it.

As a client of the NDIS, I am all too aware of the enormous burden placed on my family and thousands of other families and carers, that occurs every time the NDIS makes ill-informed and inconsistent decisions.

Rest assured, as the Chair of MS Australia and as an individual living every day with a chronic, debilitating, and progressive disease, I stand ready to work with the NDIA and the Minister for the NDIS, to advocate for **A better NDIS for people living with MS**, and to bring to fruition improved quality of lives for thousands of Australians.

**Associate Professor Des Graham
Chair
MS Australia**

SLEEP IN MS: MORE IMPORTANT THAN WE THOUGHT

Poor sleep quality is common in people with MS and has been associated with lower quality of life and even higher mortality in previous studies.

Some of the risk factors for poor sleep include a greater level of disability and specific MS symptoms, including fatigue, depression, anxiety and cognitive difficulties.

However, it has been unclear whether poor sleep itself is associated with reduced quality of life in people with MS, or whether this is due only to the effects poor sleep has on other symptoms of MS. This is important because it has implications on whether treating poor sleep is likely to make a clinically meaningful difference to the health of people with MS.

A new study from the University of Tasmania's Menzies Institute for Medical Research has examined this question in people with MS in Australia through the Australian MS Longitudinal Study (AMSLS). The AMSLS is one of MS Australia's collaborative research platforms and is a survey-based research study that has been running since 2001 and now has approximately 2500 people completing research surveys each year.

WHAT DID THE RESEARCHERS DO?

The major aim of the study was to determine whether poor sleep is associated with reduced quality of life in people with MS, independent of their other MS symptoms.

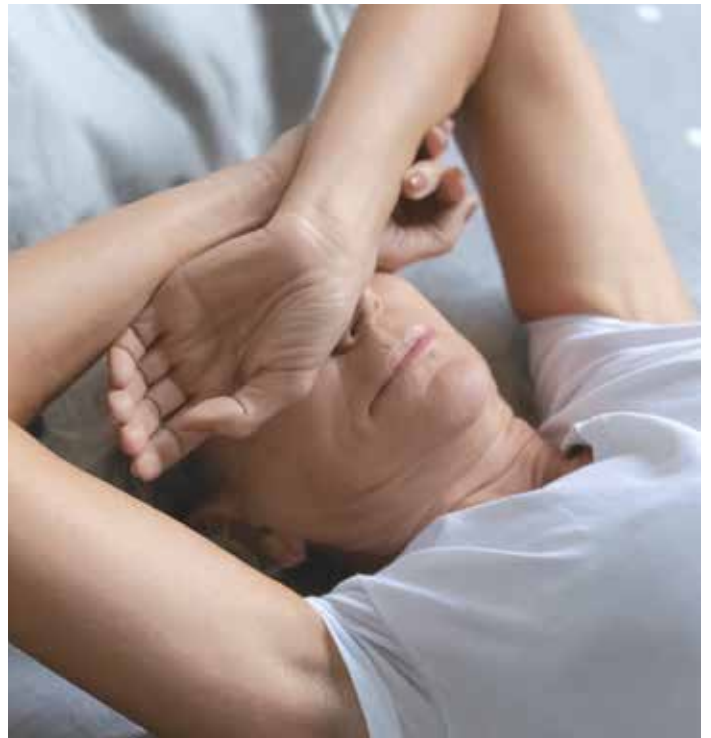
To examine this, researchers surveyed 1717 people with MS within the AMSLS. They investigated how common sleep problems were, how sleep problems related to 13 common MS symptoms, and whether poor sleep affected health-related quality of life, even after other MS symptoms were taken into account.

Health-related quality of life was measured using a survey encompassing independent living, mental health, coping, pain, senses, self-worth and happiness.

WHAT DID THE RESEARCHERS FIND?

More than two-thirds of people with MS (68%) experienced poor sleep. This is up to twice the rate of sleep problems in the general community (33%-45%).

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Poorer sleep was associated with being younger, overweight or obese, having a recent MS relapse, higher disability levels and three groups of MS symptoms ('pain and sensory', 'feelings of anxiety and depression' and 'fatigue and cognition'). The effect of sleep and MS symptoms on quality of life were also measured.

Study author Dr Laura Laslett says, "Interestingly, sleep dysfunction stood out as being strongly associated with health-related quality of life, independent of other symptoms of MS."

She added, "I think the most important take-home message from this research is that both sleep and MS symptoms are independently related to quality of life, and that effects of sleep on quality of life are not just secondary to MS symptoms."

WHAT DOES THIS MEAN FOR PEOPLE WITH MS?

We don't yet fully understand what drives poor sleep in MS. Changes in the brain in MS are present in people with MS who have sleep disorders and likely also impact sleep.

The study also showed that specific MS symptoms, including anxiety, fatigue, depression and cognitive issues, were associated with poorer sleep. These could be impacting sleep, and vice versa. Further research is needed to find the most effective ways to address sleep problems in MS. If you are experiencing sleep problems, please consult your MS healthcare team.

Head of Research at MS Australia, Dr Julia Morahan, says, "This is such an important study because it gives us another potential lever to improve health in MS. We are so grateful to the AMSLS participants who generously give their time and information to help others with MS."

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Professor Bruce Taylor



Dr Vivien Li



Dr Belinda Kaskow

Professor Bruce Taylor from the University of Tasmania will measure the prevalence and incidence of MS at three locations in Australia at different latitudes and build on Professor Taylor's recent findings that found an increase in the total number of people being diagnosed with MS in the Hobart area.

This research will also inform whether further study of modifiable lifestyle factors, such as sun exposure, is required.

Professor Taylor noted that low sunlight exposure and low vitamin D levels may be important drivers of MS risk.

"This may explain why the disease is more common in Tasmania than in locations closer to the equator. If we could identify the risk factors and reduce them by just 50%, we could significantly reduce the risk of MS globally," Professor Taylor said.

Dr Vivien Li from the Royal Melbourne Hospital VIC will study how pausing treatment affects MS disease activity using new MRI technologies.

Dr Li will use one of two 7-Tesla MRI scanners in Australia, which have over twice the magnetic strength of standard hospital scanners, to assist in making more informed treatment decisions.

"This research will study how brain inflammation is affected by stopping or pausing treatment using new MRI technologies, which provide better images, comparing them to routine hospital scans, to see if smaller and subtler changes of MS activity can be identified," Dr Li said.

Dr Belinda Kaskow from Murdoch University WA will investigate specific components of the immune system that may be involved in early signs of MS.

Dr Kaskow says this will help identify how early this immune imbalance occurs and give critical insight into how the disease begins.

"Understanding immune system dysfunction at the earliest clinical time point to study MS allows us to better understand the disease course, so that we can develop therapies to halt disease progression," Dr Kaskow said.

Incubator grants support generation of preliminary data to apply for large

2022 POSTGRADUATE SCHOLARSHIP RECIPIENT

MS Australia postgraduate scholarships support students with an outstanding track record who are undertaking a postgraduate degree in MS research.



Dr Alistair Govier-Cole

Dr Alistair Govier-Cole from Monash University VIC aims to understand how cells that normally repair the protective sheath around nerve fibres known as 'myelin', may be involved in perpetuating the autoimmune reaction against myelin in people with MS.

"Knowing that every scientific contribution we can make to better understanding MS is one small step closer to the dream of eventually curing MS, or at least making it more treatable and improving the quality of life of people with MS, provides a lot of motivation," Dr Govier-Cole said.



Mr Samuel Klistorner

Mr Samuel Klistorner from the University of Sydney will investigate better ways to monitor the degeneration of the nervous system caused by MS and the potential effects of therapies in preventing damage to brain tissue around chronic lesions.

Mr Klistorner is passionate about the future opportunities that technology brings to MS and the research field in general.

"My research, in collaboration with neurologists, scientists and fellow researchers, will help to develop biomarkers that can one day be used in drug trials for treatment," Mr Klistorner said.

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novel ideas, and the subsequent data that may enable researchers to secure grants in the future.

A TIRELESS ADVOCATE FOR BETTER MS TREATMENT

As a Nurse Practitioner, Jodi Haartsen remembers the many stories she heard of people experiencing MS symptoms and them being dismissed.

The symptoms may have resolved, or delays were experienced in accessing specialist care. However, while people were waiting, their brain health was worsening, and damage was occurring.

There was also often the surplus emotional suffering of feeling like they weren't being heard and struggling to get what they needed.

"We now have a greater understanding in MS care of the importance of timely access to care and treatment, of keeping a healthy lifestyle for brain health and the need to ensure we have standards that support all healthcare providers to be aware of these," Jodi said.

Jodi has worked for many years as a passionate advocate for the MS community, pushing to ensure everyone with MS has fast access to the best possible treatments.

For the past 20 years, Jodi has worked as a nurse in the neurology field in various roles, including surgery, stroke research, as an educator (teacher) and nurse practitioner, before joining the MS Plus team as Executive Manager, Client Engagement and Wellbeing, where she supports education and wellbeing initiatives for the MS community.

Her recent role with MS Brain Health, which creates policies and guidelines to empower healthcare providers and people with MS to live their best lives, has also given Jodi a prime opportunity to change how people receive MS treatment.

"I became involved with MS Brain Health seven years ago because it was apparent to me that some people were receiving high standards of care in MS, while others were not afforded the same opportunity due to their location and resources. There was a gap in a globally recognised set of standards that guided services delivery and helped people understand what to expect," Jodi said.

“ There was a gap in a globally recognised set of standards that guided services delivery and helped people understand what to expect,” Jodi said. ”

When Jodi first joined MS Brain Health the organisation had just published recommendations for best practice MS care. Jodi was on the steering committee to find the best way to share the information and make sure the policy was put into practice.

"One thing we focused on was, how do we encourage people to act quickly? For instance, in other areas of



Jodi's top 3 tips for brain health

1. When you're worried, speak up
2. Keep active physically and mentally
3. Get the right people around you – not just health services but family and friends

neurology, there is an awareness of time sensitivity, but in MS, it is still lacking. We had to ask ourselves, how do we communicate this urgency of referrals to the GP community? To have doctors say, "This is a new diagnosis. You need to see someone within one month, six months is too long, and damage is occurring."

Jodi worked to communicate the brain health message nationally, as well as in her work in the MS clinic. Using the subsequently developed Brain Health Standards, she was able to make changes in clinical practice that included developing better practices for people to achieve a brain-healthy lifestyle and improve access to services.

"Through auditing our clinical activities against globally recognised standards, we were able to reduce our urgent clinic wait times from four weeks to two days."

"We all have a role to play to create change and action for people with MS to improve brain health, no matter how you are involved with MS.

"Brain health is all about acting now. It matters."

FROM DIAGNOSIS TO A DIRECTIVE TO HELP OTHERS: AN INTERVIEW WITH TREVOR BOLLAND

When his daughter Monique was diagnosed with MS at 22, Trevor Bolland changed careers and founded the nutritional supplement company Nuzest to help support his daughter.

Trevor wasn't satisfied with the bleak prognosis they were given, so together they looked to health experts all over the world for advice and turned a diagnosis into a directive to help others.

What started as a father and daughter looking for answers is now a global team, formulating supportive nutrition for whatever life throws at you.

Here, Trevor shares his MS Gong Ride experience, supporting MS research and his daughter's diagnosis.

WHAT IS THE REASON YOU REGISTERED FOR THE MS GONG RIDE?

My daughter has MS. She was diagnosed 18 years ago, and ever since then I have actively supported MS through participation in various charity events, corporate sponsorship, and fundraising activities for research.

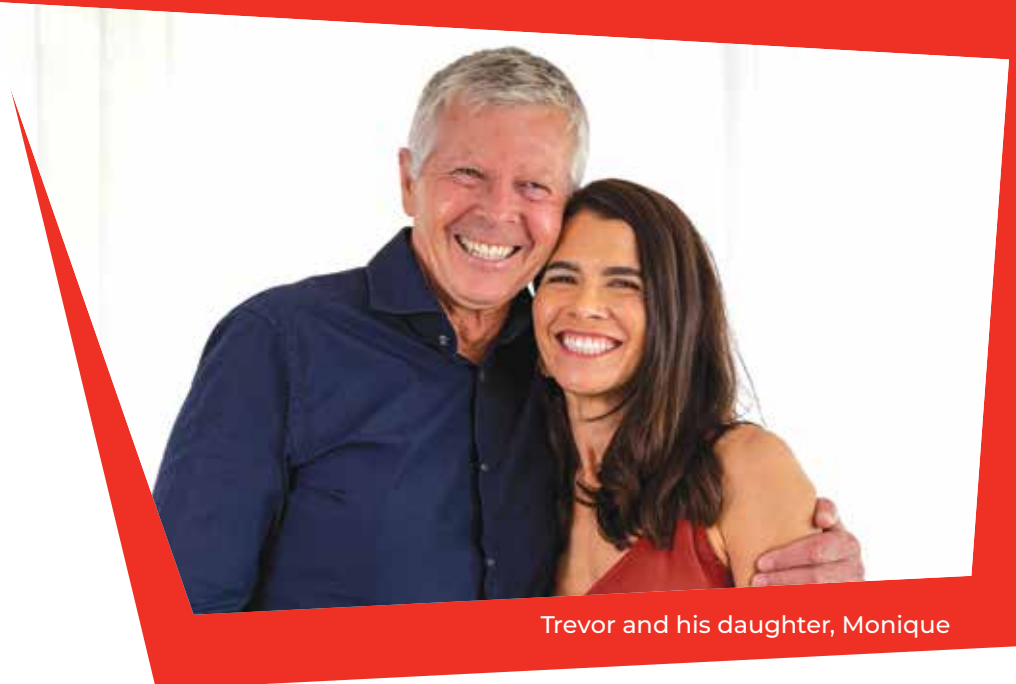
WHAT IS THE IMPACT OF MS ON YOUR DAUGHTER AND FAMILY?

Monique's diagnosis resulted in me selling out of the business I was then in to focus on helping Monique deal with the situation.

Trevor taking part in the MS Gong Ride



MS AUSTRALIA



Trevor and his daughter, Monique

Due to the severity of her lesions and the physical effect MS had on her in the early stages, the initial impact was significant, obviously for Monique, but also emotionally for Christine and me as parents.

However, it brought us all even closer as a family, put a perspective on life, and made Monique herself a stronger person. Her positive approach and determination are reflected in her career and motherhood.

DOES MONIQUE USE THE SERVICES OF MS PLUS?

We have not needed to. However, it is a great service, especially for people who do not have the financial and emotional support required to manage life with MS, especially in the early stages.

ARE YOU EXPERIENCED CYCLISTS?

I would call myself an 'enthusiastic amateur', but I have certainly covered a few kilometres and experienced the pain and pleasure of the sport, including my share of tumbles and scars.

WHAT HAVE YOU GOT OUT OF YOUR MS GONG RIDE EXPERIENCE TO DATE?

Apart from enjoying any excuse to get out on the road, I do enjoy the

experience of participating in large group events. There is an atmosphere of excitement and anticipation which enhances the pleasure of the ride. However, the Gong Ride is special because the charity is so close to home.

HOW ARE YOU FUNDRAISING?

I have not even started yet, but Facebook and email will be used to a limited extent. However, I have participated in many charity rides and am conscious of the number of such events that are out there. I feel there is an element of charity fatigue out there so my fundraising efforts will be cautious. However, I will make up for that with a decent personal donation.

ANYTHING ELSE YOU'D LIKE TO SHARE?

It is extraordinary how much more knowledge has been gained over the past 10 years and how far research has come in developing new treatments to manage the disease. It is comforting to know that the MS research community is confident that a cure will be found in the next few years.

The MS Gong Ride takes place on 6 November 2022.

You can join Ride to Fight MS by visiting: www.msgongride.org.au

Find out more about Nuzest at: www.nuzest.com.au/kiss



MEET THE RESEARCHER

DR STEVEN PETRATOS

MONASH UNIVERSITY



**Dr Petratos,
Monash University**

***Finding a cure via repair and regeneration – Neurobiology Project 2022
Investigator led research***

LET'S GET STARTED! TELL US AN INTERESTING FACT ABOUT YOURSELF.

When I was a younger post-doctoral researcher I could recite the specific manuscript, author, journal and year of publication of research studies in my field which some of my colleagues would be amazed at.

WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

As an undergraduate student, I was always intrigued by how the immune system interacted positively and negatively with the brain.

Since the start of my research career, I have been driven by a desire to provide a better quality of life for people living with MS.

I have always promised myself that I will never give up investigating the devastating disease that my grandfather lived with for most of his life.

TELL US ABOUT YOUR CURRENT RESEARCH PROJECT.

The research team, headed by Dr Steven Petratos, has shown that a modified version of a specific protein is present within active MS lesions in a laboratory model of MS.

This modified protein then interacts with another protein to cause nerve fibre damage.

The scientists are now proposing a new method to block either the modification or the interaction between the two proteins, to halt disease progression and provide recovery from disability.

The goal of this project is to limit the nerve fibre damage in MS and thereby prevent disability in individuals living with this condition. This project will address this key unmet medical need by delivering a potential new drug directly into MS plaques through the patient's own 'blood stem cells', thereby promoting repair of the nervous system.

WHY IS YOUR RESEARCH IMPORTANT AND HOW WILL IT INFLUENCE THE UNDERSTANDING AND TREATMENT OF MS?

MS commonly occurs due to the specific destruction of the protective sheath of nerve fibres, known as myelin, by immune cells, which mistakenly attack this structure.

If this project is successful, and in particular, the drug delivery method is shown to be safe and efficacious in repairing the damaged brain, then the fact that it has already been tested in clinical phase trials means that a company can immediately design studies to be tested in MS patient groups that are not responding to other therapies.

Therefore, this project will provide the proof-of-principle studies necessary for a new cellular therapy to enter clinical phase trials in MS patients.

HELP MS AUSTRALIA FIND A CURE FOR MS

DONATE (donations over \$2 are tax deductible)

To support MS Australia's vital work I would like to:

- Make a one off donation of \$
- Make a monthly donation of \$
- Learn more about leaving a gift in my Will
- I have already left a gift in my Will to MS Australia

CONTACT DETAILS

Title: First name:

Surname:

Address:

Suburb: State: Postcode:

Phone: Mobile:

Email:

PAYMENT METHOD

- Cheque** (made payable to MS Australia)
- Direct Debit Request** (copy of service agreement can be provided on request)
Financial institution:
BSB number:
Account number:
Account holder's name:

CREDIT CARD

Mastercard Visa Amex

Credit card number:

Exp: CVV:

Name on card:

Signature:



ABN 51 008 515 508



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