

NEW DATA SHOWS MULTIPLE SCLEROSIS RISING & ACCELERATING IN AUSTRALIA

The number of Australians living with multiple sclerosis (MS) is increasing at a significant and accelerating rate.

The latest data showed that 33,335 Australians were living with MS in 2021, an increase of 30% (7,728) over the four years since the previous update in 2017 (25,607).

The increase of MS in Australia has more than doubled from the previous period, which identified an increase of 4,324 people over eight years from 2010 to 2017.

Consequently, the prevalence of MS in Australia has also risen considerably. In 2021, 131.12 Australians per 100,000 people lived with MS, up from 103.7 per 100,000 in 2017.

The latest MS figures were published in the interim report, *Health Economic Impact of Multiple Sclerosis in Australia in 2021*, commissioned by MS Australia and prepared by the Menzies Institute for Medical Research at the University of Tasmania.

Principal Research Fellow at the Menzies Institute for Medical Research and Clinical Neurologist

at the Royal Hobart Hospital and one of the report authors, Professor Bruce Taylor, says that while the rise in prevalence is a concern, the results were not unexpected.

"Increasing MS numbers are not what any of us want to see, however, the data is consistent with what we have been witnessing both domestically and internationally.

"Many lifestyle and behavioural risk factors contribute to a person developing MS, including obesity and insufficient sunlight exposure.

"If we can narrow down more precisely what risk factors are driving this escalation through further research, we could significantly reduce the risk of MS in Australia and globally," Professor Taylor said.

The Interim Report also examined the economic impact MS has on Australian society by looking at the per person costs and the total cost of illness.

In 2021, the annual per person cost of a person living with MS in Australia was \$73,457, an increase of \$5,075 from 2017.

The annual per person costs of MS in Australia are higher than other comparable complex chronic diseases such as Parkinson's disease (\$53,318), Type 2 diabetes (\$5,209) and long-term cancer (\$17,401).

Head of the Health Economics Research Unit at Menzies and lead author of the report, Professor Andrew Palmer, says the total costs for all people with MS in Australia have increased substantially, from \$1.75 billion in 2017 to \$2.5 billion in 2021.

"The rising costs of MS in Australia are significant, reflecting the increasing number of people with the disease, as well as CPI increases," Professor Palmer said.

"Due to the current climate of inflationary pressures, it is expected that MS cost estimates will continue to escalate even further from 2022 onwards."

MS Australia CEO Rohan Greenland says the latest MS numbers were concerning, but believes it is clear what must be done to turn this around.

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FROM THE CEO

ROHAN GREENLAND



It's hard to believe that it's March already...and that means we are gearing up for our most important research fundraising event of the year, The May 50K! I'm in training already and will – if all goes well – include a Half Marathon in my attempt to run 200km during the month of May. That's 8km a day. A tall ask for my arthritic joints, but I am determined to do it and raise as much as I can to support our world-class MS researchers.

And it's more important than ever before, as we find that the number of people living with MS in Australia has dramatically jumped, rising from 25,607 in 2017 to more than 33,000 today.

But there's another reason why we should be re-doubling our fundraising efforts, and that's based on hope.

In early May, MS Australia will be sending a delegation to a global summit that is looking to better align global research efforts and drive closer collaboration to take us further and faster towards the cures that we are all striving for. And we're not just participants – we are among the leaders of this initiative, working closely with the American, Canadian, UK and Italian MS societies in particular – the largest of the international research funders – to drive into operation an internationally agreed research framework – Pathways To Cures.

This research roadmap holds much promise, as we work to strengthen collaborations and partnerships that focus on three objectives:

- Stopping MS through early detection and treatment
- Restoring lost function and ending MS by reducing risk factors
- Providing guidance for those most at risk.

There's another reason we should all be running, walking, rolling or moving in some way to support The May 50K. Physical activity is important for brain health and remyelination! One clinical trial in the US, now recruiting participants, is looking at whether aerobic exercise could be the ideal complement to remyelinating medications because aerobic exercise improves walking function in people living with MS, and, the researchers note, promotes remyelination in animal models both independently and synergistically with medications.

Thank you to all who will participate in The May 50K this year. And please, help promote it to your family, friends and work colleagues. It's for an incredibly great cause, it will make a big difference and it's a whole lot of fun as well.

Rohan Greenland
CEO, MS Australia

New data shows multiple sclerosis rising & accelerating in Australia

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"The latest data shows an obvious urgent need for further government investment in MS research, so we can first put the brakes on this acceleration, and ultimately stop MS in its tracks," Mr Greenland said.

MS Australia is also calling on the Australian Government for:

- Greater investment in MS research, particularly through the Medical Research Future Fund
- Regular data collection through the Australian Institute of Health and Welfare
- Better access to care including MS Nurses
- Better understanding of MS and other neurological conditions within the NDIS via a neurological advisory group
- Better investment in broader preventative health measures, including healthy weight, tobacco control, nutrition and physical activity, all of which contribute to brain health.

MS Australia is committed to working with the Australian Government to address these issues, as well as increasing investment in MS research, and working collaboratively with other MS organisations across the world to align and accelerate research that will lead us faster and further down the pathways to cures.

MS Australia will also commission further research into the reasons behind this sharp surge in prevalence.

Mr Greenland says people living with MS in Australia have good access to efficacious disease modifying therapies, which can be life-changing for people who are newly diagnosed but says with prevalence on the rise more must be done.

"A recent study found that MS prevalence had increased in every world region from 2013 to 2020, with a person diagnosed with MS every five minutes. Now we are seeing that same alarming trend in Australia and must act to both better understand what is driving this increase and to support everyone in our MS community," Mr Greenland said.

To help curtail rising MS costs, MS Australia is also calling on the federal, state and territory governments to invest in the MS Nurse workforce.

Mr Greenland says specialised nurse care is also a highly cost-effective model of MS care, reducing the need for emergency visits, hospitalisations, and other more costly health professionals such as general practitioners and neurologists.

"Access to MS Nurses provides a better quality of life for a person with MS and significantly reduces

the costs to our health system. MS Australia stands ready to work with governments across Australia on measures to increase the MS Nurse workforce," Mr Greenland said.

MS Australia President, Associate Professor Des Graham, says it will take the full might of a global collaborative effort to get ahead of the escalating rates of MS across the world.

"MS Australia has joined forces with leading international MS organisations to share knowledge, resources and expertise to ensure we are throwing everything we've got to put MS behind us," Associate Professor Graham said.

MS Australia and Menzies Institute for Medical Research would like to thank the people with MS who participated in the Australian MS Longitudinal Study (AMSLS) surveys that informed this Interim Report and the dedicated AMSLS team.

View the *Health Economic Impact of Multiple Sclerosis in Australia in 2021: An Interim Update of Prevalence, Costs and Cost of Illness from 2017 to 2021* and Media Release on MS Australia's website www.msaustralia.org.au



More than 33,300
Australians live
with MS



1-2 Australians are
diagnosed with
MS every day



3 out of 4 Australians
diagnosed with MS are women



MS is estimated to have cost the
Australian community
\$2.449 billion in 2021.

In 2021, the average cost of
MS* per person was **\$73,457.**

*Comprising both individual
and societal costs

MS AUSTRALIA FUNDS OVER \$3 MILLION FOR MS RESEARCH GRANTS IN 2023

MS Australia is delighted to announce over \$3 million of funding towards MS research in 2023. The twenty-two new projects address MS Australia's priorities for MS research, including causes and prevention, better treatments and cures via repair and regeneration of cells.

- MS Australia has funded over \$3 million towards MS research grants commencing in 2023.
- The twenty-two new projects address MS Australia's priorities for MS research, including causes and prevention, better treatments and cures via repair and regeneration of cells.
- The grants focus on various areas within these themes, such as the mechanisms underlying progressive MS, the role of different immune cells in MS, pain, diet, and new ways to treat MS and repair brain function.

Twenty-two new projects, ranging from one-year innovative studies to major three-year projects, have received grant funding from MS Australia in 2023. The new grants also include fellowships and scholarships that help support and grow the Australian MS research workforce and promote global collaborations to stop MS in its tracks.

The 2023 funding covers a range of different MS research priorities, including cures via repair and regeneration of cells, better treatments and causes and prevention. The grants focus on various areas within these themes, such as the mechanisms underlying progressive MS, the role of different immune cells in MS, pain, diet, and new ways to treat MS and repair brain function.

MS is an extraordinarily complex disease making it necessary to address all these areas to help gain a full understanding of the disease and devise better approaches to combat it.

As always, these grants were selected following a rigorous external expert review of applications overseen by our Research Management Council. This process ensures that the projects and researchers funded are of the highest quality and have the most significant potential to make a difference for people living with MS.

Unfortunately, due to limited resources, not every high-quality project could be funded, and we continue to strive to find ways to extend the funding envelope each year.

Several studies will focus on a cure for MS via the repair and regeneration of cells, one of the most significant areas of unmet need. This will hopefully pave the way towards halting progression completely.

Many of the new projects and fellowships will focus on improving treatments for people with MS.

Other new projects will be investigating causes and prevention of MS.

Visit page 8 to read about five of these exciting new projects and to meet the lead researchers.

To meet all the newly-funded researchers visit MS Australia's website at "Research We Fund" and select 2023.

We are incredibly grateful to the MS community, our donors and funding partners, including MS Plus, MSQ, MSWA, MS Society of SA & NT and the National Health and Medical Research Council, for making it possible to fund these amazing researchers as they work towards stopping MS in its tracks.

A summary of the current and ongoing research projects funded by MS Australia can be found in our Snapshot Document which can be found on MS Australia's website under "Resources".

MS Australia's media release, *MS Australia boosts Multiple Sclerosis research with over \$3 million in grants*, can be found on our website under "News".

ADVOCATING FOR PEOPLE LIVING WITH MS

MS Australia has undertaken a range of advocacy activities over the last six months, including advocating for an improved National Disability Insurance Scheme (NDIS), disability employment, housing and assistive technology, aged care and better funding to meet the challenges of MS.

In November 2022, we provided a submission to the Department of Health and Aged Care on the proposed new Program for In-Home Aged Care. Our submission focused on the importance of the program meeting the needs of older people with disability, including those people living with MS who are not eligible for the NDIS.

We also provided a submission on the Treasury's Employment White Paper Consultation with a focus on improving labour market outcomes for those who face challenges in employment, including people with disability. Our submission focused on the need to improve disability employment programs, create more employment opportunities for people with disability and a national awareness campaign on the value of employing people with disability.

In December 2022, we provided our first submission to the NDIS Review, which provided a broad overview of the issues facing people living with MS and recommended solutions for the NDIS Review Panel. This included a focus on improving the National Disability Insurance Agency's (NDIA) understanding of disability (including MS), making the NDIS more accessible and easier to navigate, the value of early access and access to the most appropriate supports, and a greater emphasis on participant choice and control. The submission outlined six essential areas for reform, which are the focus of our renewed NDIS campaign effort.

In December, we also lodged a submission to the Joint Standing Committee on the NDIS on the culture and capability of the NDIA. Building on our recommendations to the NDIS review, we called for the NDIA to improve their understanding of people living with progressive, degenerative, neurological and neuromuscular conditions such as MS and ensure they improved staff training, knowledge and engagement. We also called for establishing an NDIA neurological

advisory group to better represent the nearly 1.6 million Australians living with progressive neurological or neuromuscular conditions.

In January 2023, we provided a 2023-24 pre-budget submission that sought commitments from the Australian Government through the 2022-23 Federal Budget to:

- Prevent and defeat MS in Australia through a significant investment in research funding for better treatments, prevention and ultimately, a cure for MS
- Improve access to MS Nurses
- Improve support for people with MS living with disability
- Improve support for people ageing with MS

We also provided a submission to the Senate Standing Committee on Community Affairs on the extent and nature of poverty in Australia. This submission focused on the impact of poverty on people living with MS and aligned with the recommendations of our White Paper submission regarding employment for people with disability. It also sought improved access to social and affordable housing, reduced healthcare costs, assistive technology and energy concessions and a more person-centred focus on the delivery of income payments for people with disability.



To read MS Australia's submissions, please go to www.msaustralia.org.au/advocacy/submissions



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A LEGACY FOR COMPASSION AND COURAGE

IN MEMORY OF JUDITH - A BRAVE WOMAN

Judith Webb was a much-loved primary school teacher, volunteer, wife and mother. Her husband Bob says she was “outgoing with a terrific smile,” who always put others first.

“She loved helping people. In Canberra, she ran a popular church kids club, organised a drop-in centre and food parcels for needy people, and was a visitor at local aged care homes. When we were in London, she cooked Christmas dinner for homeless people,” recalled Bob.

Judith and England-raised Bob met at a youth hostel in Wales in 1966 and married the following year in London.

Back in her native Sydney, Judith returned to teaching and community volunteering, and Bob pursued a PhD in astrophysics.

As they entered their 60s, Bob and Judith looked forward to retirement.

But in 2007, Judith started having unexpected falls. She undertook several tests, but it wasn't until two years later the family learned that Judith, 66, had late-onset primary progressive multiple sclerosis (PPMS), a relatively unusual form of the disease.

“Judith encouraged her students to do the MS Walkathons and Readathons to support people with multiple

sclerosis (MS). Otherwise, we knew little about the disease. There was no family history, and we didn't know anyone else who had it,” said Bob.

Gloria McKerrow House, an MS support centre in Canberra, provided practical tips on managing MS, and Judith attended MS-tailored exercise classes.

But within a few years, she lost all mobility in her legs, the normal use of her arms and hands, and her eyesight deteriorated.

“There were no available treatments for PPMS then. Judith was brave and didn't complain. But she found it hard that she became the one who had to be cared for instead of helping others,” said Bob.

Despite a valiant 10-year fight, Judith died in 2020 from an MS-related infection.

Motivated by a desire that others not face the same

experience, and as a tribute to Judith's generosity and courage, Bob decided to allocate a portion of his Will to MS Plus for research.

Their daughter Kate supports their charitable intentions, and Bob believes their son Andrew, who sadly passed away in 2016, would have liked the plan too.

Today, Bob keeps abreast of international PPMS research developments, including those undertaken by MS Australia. Recently, the first-ever treatment for PPMS was TGA approved.

“It came too late to help Judith, but it should give hope to others,” he said.

“I hope further research will improve MS treatments and maybe even reverse this mean disease. That's why part of my Will is going to MS Plus for research — to remember a brave and loving woman and the people she would have wanted to help.”



To learn how to support people with MS through a gift in your Will, contact Laura or Rebecca on 1800 443 867, email futureplanning@ms.org.au or visit www.myslegacy.org.au.

MEET THE RESEARCHERS

As reported on page 4, MS Australia has funded over \$3 million for MS research grants in 2023.

The twenty-two new projects address MS Australia's priorities for MS research, including causes and prevention, better treatments and cures via repair and regeneration of cells.

Read about five of them here.

TOWARDS CURES

Associate Professor Jennifer Rodger

from The University of Western Australia and the Perron Institute, WA, studies repetitive transcranial magnetic stimulation (rTMS), a non-invasive method that uses a rapidly changing magnetic field to generate small electrical pulses in the brain. Her team have shown that rTMS can improve the survival of myelin-producing cells in the brain. This project will help to understand the precise factors involved in survival of these cells, and design treatments to rescue brain function in people with MS.



IMPROVING MS TREATMENTS

Ms Olivia Wills

from the University of Wollongong, NSW, is exploring the role of diet in a brain-healthy lifestyle for people living with MS. This project will rationalise dietary choices and may lead to targeted nutrition approaches for brain health including recommendations for people living with MS, their carers and their families.



Ms Alice Saul from the Menzies Institute for Medical Research, University of Tasmania, TAS, aims to improve our understanding of the nature of pain associated with MS, to develop advice on pain management for people living with MS and health practitioners, and to design treatment intervention studies for specific types of pain.



Dr Jennifer Massey

from St Vincent's Centre for Applied Medical Research, NSW, will be investigating whether the Epstein-Barr virus (EBV) may be the cause of MS by studying the effect of Autologous Haematopoietic Stem Cell Transplant (AHSCT). This project will also help clinicians alter the way in which AHSCT is performed (e.g., with anti-viral or cellular therapies) to better control EBV if it is shown to be relevant to disease remission.



CAUSES & PREVENTION OF MS

One study will be led by

Dr Nicholas Blackburn

from the Menzies Institute for Medical Research, University of Tasmania, TAS.



Genetics can influence the risk of developing MS, however, it is currently unknown which genes and what changes to these genes cause MS or worsen MS symptoms. Dr Blackburn aims to identify rare MS-associated genes by studying families where multiple members have MS.

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MS



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