MS WIRE
JUNE 2024

FOR TOO LONG, THE STATUS QUO OF MS HAS RUINED LIVES AND TORN FAMILIES APART

Every five minutes, someone in the world learns that they have multiple sclerosis (MS). It's a cruel and pervasive disease which can affect so many aspects of life – taking away a person's strength, their quality of life and even impacting their mental health.

I know we can help research rise to a new level and ease the burden of MS on Australian lives.

My name is Dr Steven Petratos, Senior Research Fellow at the Regenerative Neuroscience and Development Group at Monash University. I'm currently leading a three-year research project developing novel therapies for treating MS and reversing disability.

Right now, MS researchers like myself are working feverishly to develop therapeutic interventions that can give back what MS takes away from far too many lives.

The sooner we can conduct research, the sooner we can translate it to life-changing results for people living with MS – and those who will be diagnosed in the future.

Ricky, was diagnosed with MS at 35. He is a man who lost his job, his family, his mobility and even his independence to MS.

Sadly, with 2.9 million people living with MS around the world, Ricky's story is an all-too-common tale.

But it doesn't have to be.

Research has the power to challenge the status quo and put a stop to MS, for good. But we urgently need your help to fund transformative research projects that can improve the way we treat, manage and one day cure MS.

Already, my research has linked a specific protein – known as NgR1 – to degeneration in the spinal cord and optic nerve following an MS attack.

Identifying this protein was a vital first step towards finding a cure to MS. It was only thanks to generous people like you that my work received the funding it needed to achieve this world-first discovery.

Right now, millions of people around the world are waiting for a cure – only research can help us find one.

But the truth is, our work simply isn't possible without you.

Unfortunately, funding remains one of the greatest barriers to the progress of MS research in Australia. Only around 10%

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MS AUSTRALIA IN PARTNERSHIP WITH *TAKE MY HAND*

MS Australia is partnering with Take My Hand, a powerful Australian feature film produced by Bronte Pictures and showing in cinemas nationally in late 2024.

With multiple sclerosis (MS) a central part of the storyline, Take My Hand provides a unique opportunity to grow awareness and understanding of MS and to support those living with MS in Australia and globally.

MS is the most common acquired chronic neurological disease affecting young adults, often diagnosed between the ages of 20 to 40 and, in Australia, affects three times more women than men. As yet, there is no cure. In MS, the body's own immune system mistakenly attacks and damages the fatty material – called myelin – around the nerves. This results in a range of symptoms, but no two people experience MS in the same way.

Capturing the essence of MS can be challenging, yet Take My Hand accomplishes this feat through a poignant script that authentically portrays both the characters' lives and the disease at the heart of the narrative.

Our Take My Hand hub offers exclusive behind-the-scenes footage, interviews with cast and crew and a heartfelt message from Executive Producer Claire Jensz, whose MS journey is depicted so beautifully in this film.

The hub also provides privileged access to pre-sale tickets for Q&A screenings scheduled for August 2024 at cinemas across Australia.

MS Australia is excited to be collaborating with Claire Jensz, Writer/Director John Raftopoulos (also Claire's husband) and the entire creative team behind Take My Hand, recognising early on the film's profound portrayal of MS, and its potential to spark meaningful awareness within the community.

Associate Professor Des Graham
President
MS Australia

Rohan Greenland
CEO
MS Australia

www.takemyhandthemovie.com

FOR TOO LONG, THE STATUS QUO OF MS HAS RUINED LIVES AND TORN FAMILIES APART

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of grant applications are successful. This means many high-quality research projects don't receive the funding they need to get off the ground.

Your support helps give projects like mine the opportunity to carry discoveries from the lab to the clinic – where they can have a real and measurable impact on the lives of people living with MS.

By supporting MS Australia you are helping fund innovative research projects, enabling us to continue making discoveries and developing novel therapies right here in Australia.

I can't help but think of all the people whose lives have already been turned upside down by MS.

People like Ricky, who despite all he has suffered, refuses to let MS keep him down. Ricky's story is an inspiring tale of humanity's power to rise above even the greatest of challenges.

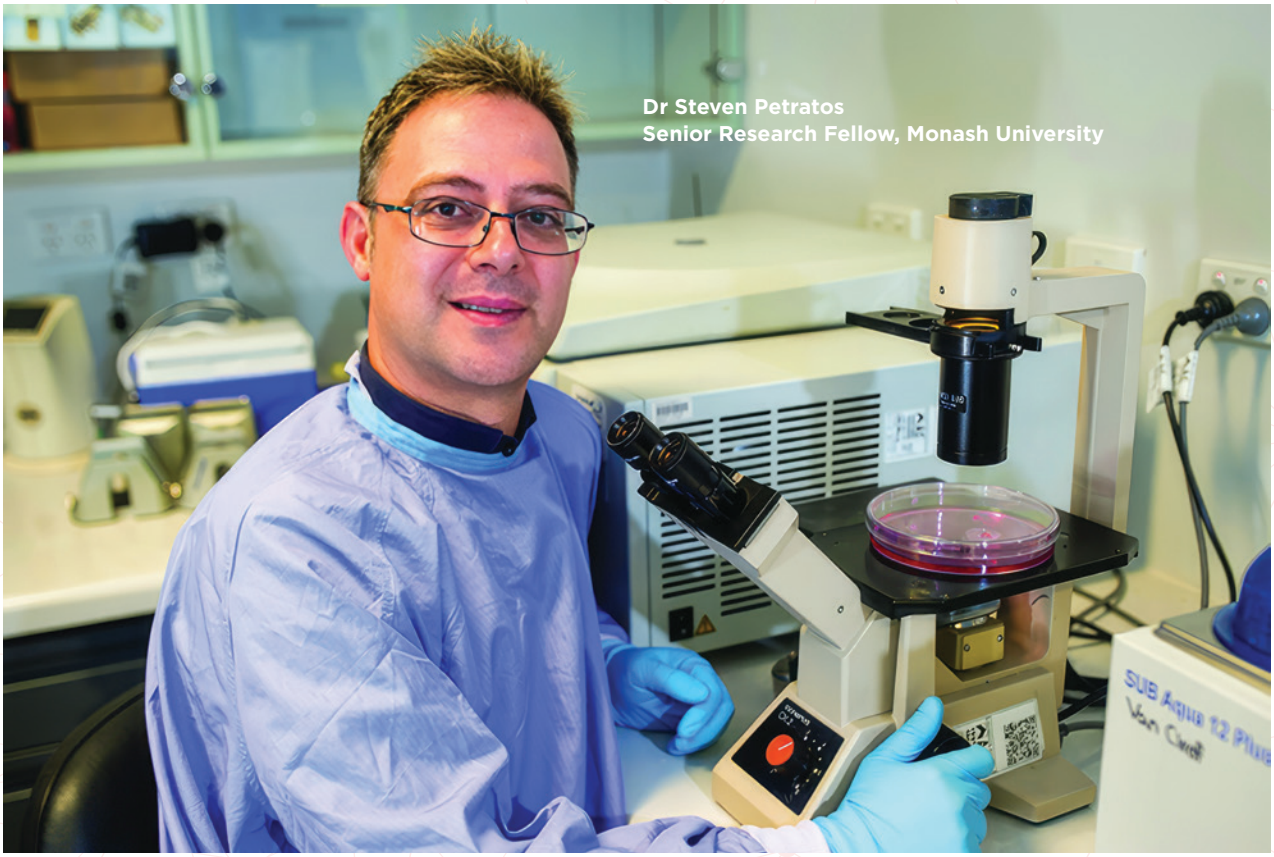
But it's also a tragic reminder of just how important it is that we conduct research now to stop more people like him from suffering tomorrow.

Together, I believe we can rise to the challenge.

Through hard work and determination, Ricky continues to rise above the challenges of his MS. But what he needs now more than ever is a cure. Today, your generous support of MS research can help drive the discoveries that could give him one.

Dr Steven Petratos

Senior Research Fellow, Monash University



Dr Steven Petratos
Senior Research Fellow, Monash University

To donate online - www.fundmsresearch.org.au/tax-appeal-2024

NEW REPORT CALLS FOR FASTER MS DIAGNOSIS IN AUSTRALIA ON WORLD MS DAY

A new report has revealed the prolonged time to diagnose multiple sclerosis (MS) and highlighted the urgent need for increased investment in MS research and enhanced awareness of the disease.

The 'My Diagnosis' report produced by MS Australia and released on World MS Day has revealed the average time from onset of symptoms to an MS diagnosis extends nearly four years.

The report draws on data from the Australian MS Longitudinal Study (AMSLS), a survey-based research study established in 2002 that collects patient-reported outcomes from 2500 people living with MS.

A review of that data by the Menzies Institute for Medical Research at the University of Tasmania examines trends in MS diagnosis over the past 25 years.

Since the introduction of the first disease-modifying therapies (DMT) for MS treatment in 1996, the average time to diagnosis has reduced from five years and almost four months in 1997-2000 to three years and almost 11 months in 2017-21.

While this reduction in diagnosis times is good news at a population level, there are still many people who experience a very long time to diagnosis.

To improve MS diagnosis time, the report details three key areas that need to be addressed:

- Improved funding for research to help identify methods for earlier detection and intervention of MS.
- Better education and awareness of MS among healthcare professionals.
- Better community understanding of early MS symptoms.

Dr Julia Morahan, Head of Research at MS Australia, says delays in receiving an MS diagnosis is critical lost time for people living with the condition, which can result in irreversible damage and profound mental distress.

"In MS, time is brain. We know that the longer it takes to get a diagnosis of MS, the greater the risk of damage occurring and disability accumulating, which can ultimately diminish a person's quality of life," Dr Morahan said.

Being able to accurately diagnose and halt MS at an earlier stage has enormous potential to significantly reduce the burden of the disease on people's quality of life and the economy.

More than 33,000 Australians are now living with MS, which is the most commonly acquired chronic neurological disease affecting young adults. Concerningly, the number of people diagnosed with MS has been increasing at an accelerating rate.

Associate Professor Vilija Jokubaitis from Monash University's Department of Neuroscience is confident that breakthroughs in earlier diagnosis are possible with better resourcing, the establishment of MS biobanks and more financial support for research in MS.

"Greater research investment will support efforts to uncover more accurate biomarkers that are specific to MS. These biomarkers might be in the blood or cerebral spinal fluid or imaging biomarkers that have a very specific signal that can differentiate MS from other neurological conditions," Associate Professor Jokubaitis said.

Associate Professor Jokubaitis says an improved understanding of MS among healthcare professionals through targeted awareness

campaigns would also ensure symptoms are recognised and acted upon earlier.

"Given MS affects about one in seven hundred Australians, many GPs are unlikely to see people with MS depending on where they practice. So if a person comes to them with those symptoms, it may not be the first thing they think of if the awareness isn't there."

MS symptoms may include severe pain, walking difficulties, debilitating fatigue, partial blindness and cognitive issues.

Not knowing the cause of one's symptoms can cause immense distress and anxiety for the person affected with MS.

Together with quantitative data from the AMSLS, the 'My Diagnosis' Report captures a number of lived experience diagnosis case studies.

Laura Birchall shared her experience of her first MS symptoms and the impact of waiting for a diagnosis.

"Waiting for a diagnosis had an enormous impact on me emotionally, my ability to focus and my ability to work," Ms Birchall said.

Ms Birchall believes she had years' worth of MS symptoms that she dismissed at the time because she felt they could be explained by something else, and encourages others in a similar situation to have a conversation with their doctor.

"I think if something feels a little bit off, even if it's not stopping you from doing your day-to-day activities. If there's been a change, if something doesn't feel right, talk to people in your life about it, and listen to them when they tell you to go to the doctor," Ms Birchall said.

The report's findings were released on World MS Day, a day that presents a unique opportunity for the global MS community to come together to discuss MS diagnosis and seek solutions.

MS Australia CEO Rohan Greenland says the report's findings demand action to reduce MS diagnosis times and has called on the government, healthcare professionals, and the public to take heed of the findings.

"Investing in MS research and building greater awareness among GPs and the general public of the condition will propel us towards a future where MS is detected earlier, and a future where its impact is significantly mitigated," Mr Greenland said.

RACHEL KERR

ANNOUNCED AS RECIPIENT OF 2023 JOHN STUDDY AWARD

Rachel has been an active ambassador for MS Queensland, fundraiser and advocate for people living with MS for over 13 years, featuring in countless local radio and TV interviews, speaking at numerous fundraising events and acting as a keynote speaker at education and awareness information sessions where she shares her story to support various MS awareness campaigns.

First awarded in 1999, MS Australia's annual John Studdy Award recognises outstanding, consistent, and selfless meritorious service of 10 or more years, by someone making or who has made a tangible difference to the benefit of people living with multiple sclerosis and/or their families or carers.

The late John Studdy was the former Chairman of the National Multiple Sclerosis Society of Australia, the forerunner of MS Australia. He was a tireless advocate for the MS community and dedicated to advancing the wellbeing of people living with MS and the search for a cure. This award is for individuals who, like John Studdy, have made a significant contribution to the MS movement in Australia.

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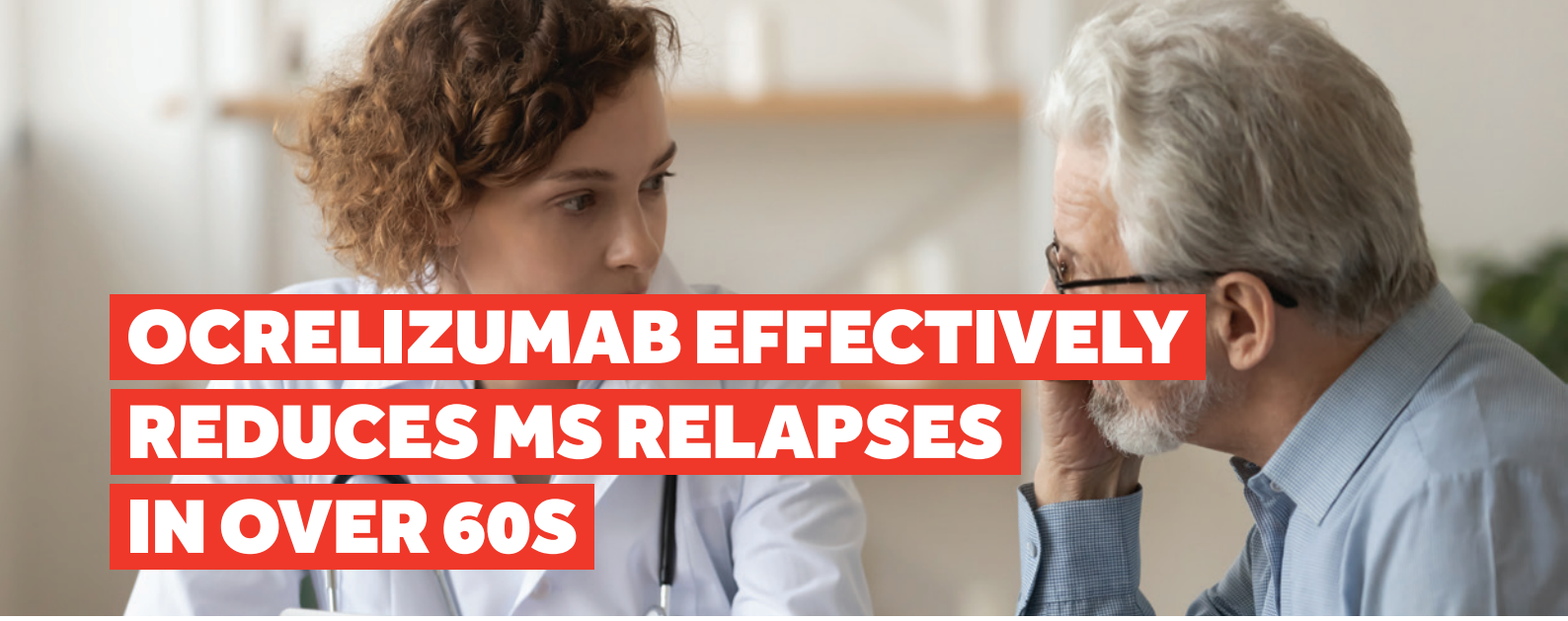

OCRELIZUMAB EFFECTIVELY REDUCES MS RELAPSES IN OVER 60S

Choosing the best treatment for MS in older people is complex, given their lower rates of MS relapse, but higher risk of therapy-related infections and side effects.

The effectiveness versus risk of disease-modifying therapies (DMTs) in this group has been unclear, partly because individuals over 60 have historically been excluded from major clinical trials. This lack of evidence complicates therapy decisions for older MS people with MS.

Real-world evidence from MSBase

To help address this question, researchers from Monash University turned to real-world data in the MSBase registry.

Rather than being a clinical trial (where a therapeutic intervention is formally tested head-to-head against other therapies or placebo), MSBase is an ongoing observational study where clinical information is collected from people during the course of their standard MS care.

From its inception in 2004, the Australian-based MSBase registry has been an incredibly powerful resource for answering questions about MS, now including over 90,000 patient records from people with MS in 45 countries.

What was the aim of the study?

In younger people with MS, ocrelizumab is a highly effective therapy, while interferon beta and glatiramer acetate have lower efficacy.

The aim of this study was to determine whether ocrelizumab (Ocrevus®) is more effective than interferon beta (e.g. Rebif®, Betaferon®) or glatiramer acetate (Copaxone®) in people with MS starting these therapies over the age of 60.

The study was led by Dr Yi Chao Foong and Associate Professor Anneke van der Walt, both recipients of research funding from MS Australia, as well as Professor Butzkueven and Dr Chao Zhu.

What did the researchers do?

Researchers compared outcomes of people with MS who had switched to or started on ocrelizumab, to those starting interferon beta/glatiramer acetate (IFN/GA) over the age of 60.

For each group, they determined the time to the first MS relapse, the average number of relapses per year, and the progression or improvement of disability.

What did the researchers find?

The researchers identified 248 participants commencing ocrelizumab and 427 receiving interferon beta or glatiramer acetate over the age of 60.

The rate of MS relapses and the time to first relapse were lower in those treated with ocrelizumab than with interferon beta or glatiramer acetate.

Overall, there was a low relapse rate in this age group.

However, there was no difference between the therapies in disability progression or disability improvement over 3.57 years.

What does this mean for people with MS?

This study highlights that ocrelizumab is effective in those over 60 with MS. Importantly, it also confirms the benefit of treatment in older people with MS and provides real-world data to guide treatment decisions in older people with MS.

For personalised MS treatment advice, please consult your neurologist and health care team.

EARLY HIGH-EFFICACY THERAPY IN PAEDIATRIC MS REDUCES RISK OF REACHING KEY DISABILITY MILESTONES

The Power of Registries

The study, published online in *The Lancet Child Adolescent Health*, investigated the effectiveness of high-efficacy DMTs on slowing disability progression in paediatric-onset MS by leveraging data from two MS registries.

Approximately 4–8% of people with MS have symptoms before the age of 18 years. Children are known to recover from relapses more effectively due to better remyelination capacities and stand to benefit significantly from high-efficacy treatments.

Registries are vital in advancing our understanding of MS across all age groups. They offer crucial insights into disease progression, treatment responses, and long-term outcomes.

What Did the Researchers Do?

MS Australia-funded researcher Dr Sifat Sharmin and her team analysed longitudinal data, tracking the same individuals over an extended period to observe changes, from the international MS registry, MSBase, and the Italian MS and Related Disorders Register, focusing on individuals under 18 with relapsing-remitting MS.

The study looked at 5,224 individuals with MS, out of which 70.6% (3,686) were female and 29.4% (1,538) were male. On average, these young people were about 15 years old when they first started showing signs of MS. The researchers tracked transitions across disability states using Expanded Disability Status Scale (EDSS) scores and assessed the impact of high-efficacy therapies (e.g., alemtuzumab, natalizumab) compared to low-efficacy therapies, and no treatment.

What Did the Researchers Find?

High-efficacy therapies significantly reduced the risk of disability worsening across all disability states, with the most substantial reduction observed in individuals with minimal disability.

Treatment benefits declined as disability increased. Even low-efficacy therapies showed benefits, particularly in reducing the risk of transitioning to mild disability in young people with minimal disability.

What does this mean for children with MS?

Early treatment with high-efficacy therapies in paediatric-onset relapsing-remitting MS substantially decreases the risk of reaching significant disability milestones. This effect is most pronounced when treatment begins in individuals with minimal or mild disability.

The findings suggest the importance of initiating high-efficacy therapy early to preserve neurological function in children with MS.

In Australia, there are currently only two DMTs approved for paediatric MS. This research is a significant step in broadening the range of treatment options for children with MS, aiming to support their journey towards living full and healthy lives.

MEET THE RESEARCHER

ASSOCIATE PROFESSOR JUSTIN RUBIO

THE FLOREY INSTITUTE OF NEUROSCIENCE AND MENTAL HEALTH, UNIVERSITY OF MELBOURNE, VIC

WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

My first post-doctoral studies were conducted at the Wellcome Trust Centre for Human Genetics (Oxford, UK), where I worked on gene discovery for a rare neurological disease. During this period (mid-late 90s), gene technology developments meant that similar work on common human diseases was becoming feasible. Two studies published in 1996, describing the first genome-wide scans for MS susceptibility genes, whetted my appetite for working on MS. In 1999, I moved back to Melbourne to get started. The rest is history!

TELL US ABOUT YOUR CURRENT RESEARCH PROJECT

This project brings together knowledge and capability my team has developed with MS Australia support, which enables us to detect and characterise DNA sequence changes (somatic mutations) on a genome-wide scale in single neurons and oligodendrocytes isolated from post-mortem MS tissue. From this work, we have observed increased numbers of somatic mutations in cells that reside in inflammatory demyelinated lesions, which we hypothesise have the potential to impact functionally important genes and drive MS progression. This project seeks to integrate somatic mutation data in brain cells with genetic data from large population-based studies (GWAS) and single nucleus RNA-seq to identify genes that may be potential drug targets for progressive MS. Functional studies of selected candidate genes in neural iPSC-derived brain organoids (disease modelling) will then be used to determine the impact of these genes on myelination and remyelination, with a view to providing early pre-clinical target validation evidence.

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

Of the 14 disease modifying therapies currently available for MS, all are immunotherapies and only two are approved for treating progressive MS. The proposed work is important because it seeks to address this clinical unmet need through the identification of therapeutic targets that may be translated into medicines for progressive MS. It is envisaged that potential medicines developed on the back of this research would impact neuroprotection and/or myelin repair, thereby slowing or preventing disease progression and improving the quality of life for people living with MS.

HELP FAST TRACK A CURE FOR MS

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

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PAYMENT METHOD

- ☐ **Cheque** $
  made payable to MS Plus Ltd
- ☐ **Direct Debit Request** $
  copy of service agreement can be provided on request

Financial institution

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Account holder's name

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Signature

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