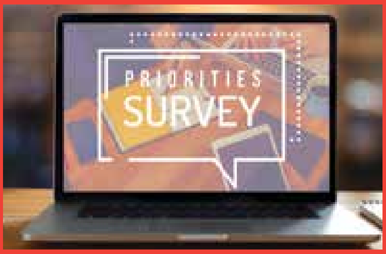
MS AUSTRALIA
RESEARCH
ADVOCACY
CURE
50 years of progress

MS WIRE

March 2022

2021 PRIORITIES SURVEY: THE RESULTS ARE IN!



MS Australia will use the data gathered in this survey to shape its future strategic direction.

We were overwhelmed by the response to our survey. We had 3,000 people participate, of which 1,544 were people living with MS. Of the 1,544 people with MS who took part in the survey, there were 990 people with relapsing remitting MS, 284 people with secondary progressive MS, and 128 people with primary progressive MS.

In addition, 16 people with clinically isolated syndrome and a small group of people that didn't know what type of MS they had also completed the survey. These proportions are equivalent to the whole MS population in Australia. This equates to approximately 1 in every 16 people in Australia with MS responding to the survey.

There were people from all over Australia, in remote areas, regional areas and urban areas. There were people recently diagnosed right through to those who have had MS for over 40 years. Therefore, this survey has been one of the most in-depth disease-specific surveys carried out by a disease organisation in Australia.

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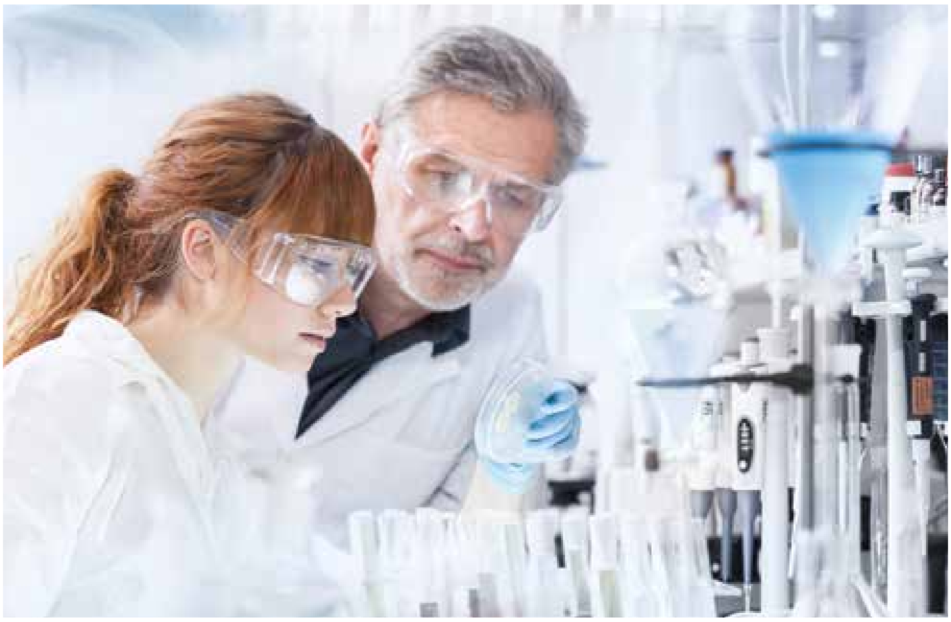

$6.9 MILLION FOR MS RESEARCH IN LARGEST-EVER FUNDING ROUND

Twenty-six new projects, ranging from one-year innovative studies to major three-year projects, have received grant funding from MS Australia in 2022.

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. This is MS Australia's largest–ever annual grant funding commitment – an outstanding achievement in the 50th year since the formation of this national organisation to drive awareness, research and support for people living with MS.

MS Australia has awarded four senior research fellowships to established MS researchers who are leaders in the MS research community, providing security and funding support for these individuals to guide and develop their research teams. Also awarded were three targeted call project grants, which aim to boost funding in the remyelination, neuroprotection and neurodegeneration space.

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PROGRESS IN MS RESEARCH
SCIENTIFIC CONFERENCE
3 – 5 APRIL 2022
Find out more here:
www.msaustralia.org.au/events/

A WORD FROM OUR CEO

It was way back in February 1972 that the state MS societies, after much deliberation, passed resolutions to establish a national body – the National Multiple Sclerosis Society of Australia – a body that eventually evolved into MS Australia.

We have come a long way in those 50 years, but the mission hasn't changed. We remain focused on finding a cure by funding the best research and supporting those living with MS through advocacy, education and awareness.

So, it's fitting that in our 50th year, we can make a record investment in MS research totalling almost $7 million. This has been made possible through your steadfast support, the support you give to our fundraising events, especially The May 50K, and the support of our Member Organisations.

With the advent of disease modifying therapies, the chances of leading a near normal life are better for people diagnosed today with the most common form of MS than ever before.

But there's a long way to go with repair and regeneration - the goal of much of the research we fund. And the more we learn, the more we know, the closer we are getting to repairing the damage wrought by MS. The more I talk to our world-class researchers, the more I am convinced that the breakthroughs we all seek are within reach.

We are also wholly committed to supercharging our advocacy for all those living with MS. We are currently recruiting our first ever Head of Advocacy to work in partnership with people living with MS and our Member Organisations across issues and programs ranging from the NDIS and aged care to adaptive technology and access to neurologists, MS nurses and allied health professionals.

Our 50th year is a time not only to take stock but to firmly push the pedal to the metal.

Best wishes

Rohan Greenland

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2021 PRIORITIES SURVEY: THE RESULTS ARE IN!

The survey asked various questions about research, clinical trials, symptoms, advocacy, and strategic priorities and the responses were all anonymous. We asked several anonymous demographic questions to determine both the demographics of the survey respondents and the priorities of different groups of people. For example, someone newly diagnosed with MS will likely have different priorities than someone who has experienced MS for a long time, and it was vital that we got feedback from the community as a whole.

The survey data revealed some very clear messages. As this was a modified survey from 2016, we also can see some changes in priorities over that time. The top research priority was a cure via repair and regeneration. This was also reflected in the preferred research stream, neurobiology, which includes looking at ways to repair damage in the central nervous system (the brain and the spinal cord).

The survey had a wide range of questions, which then drilled down into each area and asked specific questions within each research priority. We asked people what symptoms they thought should be prioritised for research and management. The results of this question did vary slightly when the respondents were separated into the different types of MS. Overall, people living with MS thought the top five priorities were:

1. Walking and mobility,
2. Cognitive function,
3. Fatigue,
4. Pain, and
5. Vision problems.

When this was further divided into those with relapsing remitting MS, the order of the top five priorities were:

1. Cognitive function,
2. Walking and mobility,
3. Fatigue,
4. Vision problems, and
5. Pain.

Those with progressive MS (either primary or secondary progressive MS) ranked the top priorities as:

1. Walking and mobility,
2. Balance and falls,
3. Fatigue,
4. Cognitive function, and
5. Pain.

People could also enter other priorities that may have been missed in open text fields, which were then subsequently considered when looking at the community's priorities.

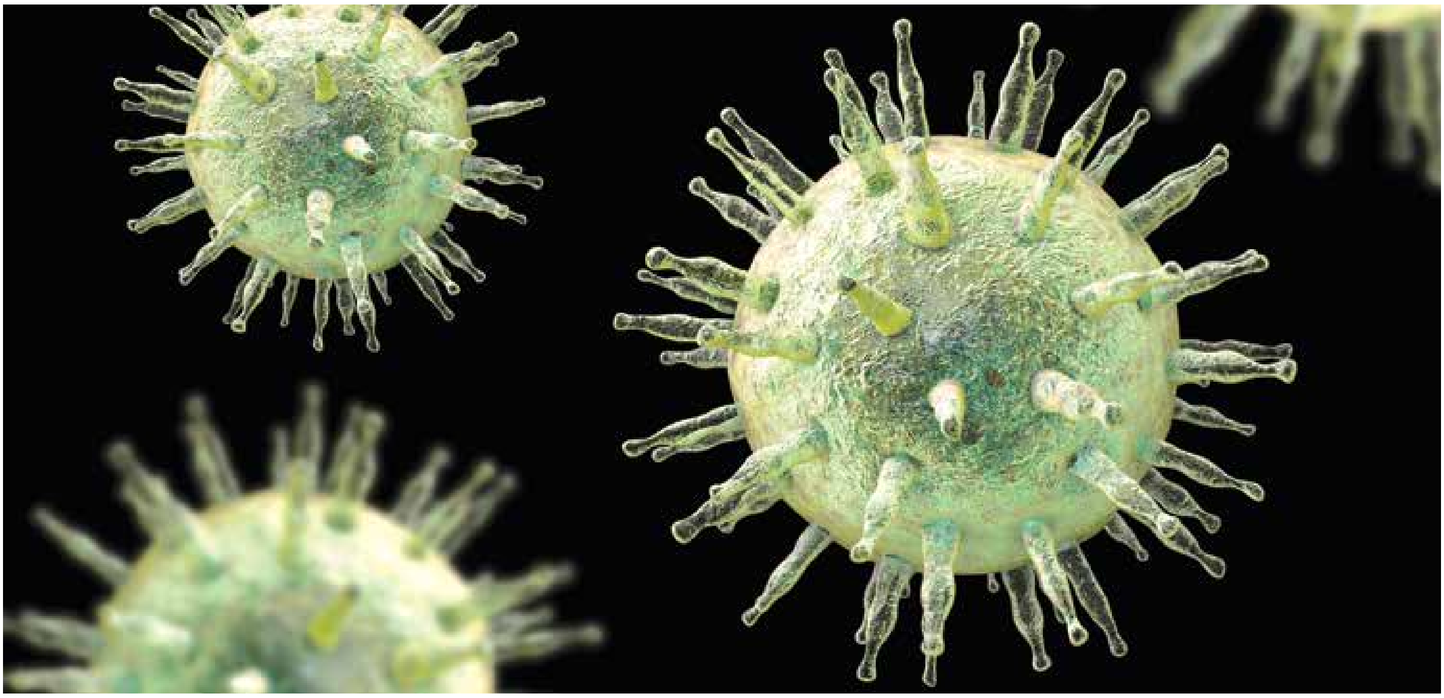
Another core function of MS Australia's work is to advocate on behalf of our MS Member Organisations, to represent the over 25,600 people in Australia diagnosed with the disease, their carers and the broader MS community. In this survey, we asked the MS community to rank their advocacy priorities. The top advocacy priority was additional funding for MS research.

The results of this question were largely uniform across the different sections of the MS community. The top five priorities for advocacy were:

1. Additional funding for MS research,
2. Approval of new MS medications, both for use in Australia and inclusion on the Pharmaceutical Benefits Scheme (PBS),
3. Meeting the disability needs of people who are not eligible for the National Disability Insurance Scheme (NDIS),
4. Better access to treatment, including disease modifying therapies and treatments for symptoms, and
5. Better access to specialist neurologists.

Once again, within this section, survey respondents were encouraged to fill in an open text field to report any areas that may have been missed. In this section, a number of people expressed frustration with navigating the NDIS and housing/care issues, highlighting the primary areas of concern for people with MS.

People with MS are a key pillar of MS Australia, this survey further helps us to receive feedback from a large sample of the Australian MS community. We would like to thank those who participated, your opinion is helping shape the future of MS Australia's research and advocacy priorities.



NEW EVIDENCE: DOES THE EPSTEIN-BARR VIRUS CAUSE MS?

MS is an autoimmune disease in which the immune system mistakenly attacks the insulating myelin sheath that surrounds the brain and spinal cord. While the individual causes of MS are not known, EBV, which causes glandular fever, has long been recognised as a risk factor. EBV infects B cells of the immune system and lives mostly in an inactive form in these cells for the rest of a person's life.

EBV has been suspected of causing MS based on several lines of evidence. For example, people who have had glandular fever have a higher risk of developing MS; and people with MS have higher antibodies to EBV in their blood. However, this evidence is not conclusive.

CAUSAL OR NOT?

Determining whether EBV actually causes MS has been a very difficult task, because around 95% of adults are infected with EBV, and yet MS is a relatively rare disease, affecting around 1 in 1,000 people. In addition, the symptoms of MS do not appear until around ten years after EBV infection occurs. This requires very large numbers of people to be studied over time, to determine the connection between EBV and MS.

In a new study from Harvard University, the researchers followed a group of more than 10 million young adults in the U.S. military, 955 of whom were diagnosed with MS during their period of service. Blood samples were collected at the start of service and two-yearly thereafter, so the researchers had access to multiple blood samples from the leadup to MS onset (for 801 of the MS cases).

WHAT DID THE RESEARCHERS FIND?

The researchers found that in this group, the overall risk of MS increased 32-fold after infection with EBV. The researchers found no increase in the risk of MS after infection with other viruses, including cytomegalovirus, which is transmitted in a very similar way to EBV. The sheer magnitude of this increase in risk in such a large cohort suggests that EBV is an important factor in the development of MS.

It is likely that the disease mechanisms underlying MS begin several years before the onset of symptoms. The time between conversion to EBV-positivity, and the onset of MS was around 7.5 years (range 2 – 15 years). To examine this further, the researchers looked at a blood marker of nerve damage in people who would later go on to develop symptoms of MS. This marker, called neurofilament light chain, can be elevated as early as 6 years prior to symptom onset. However, the team found that this marker only increased after EBV infection, consistent with a causal role for EBV in nerve damage in MS.

There was only one person in the study of the 801 MS cases who was EBV-negative in the blood sample taken prior to MS onset. It is possible that they became infected after the last blood collection, did not mount a detectable immune response to the virus, or were misdiagnosed with MS. It is also possible that MS is occasionally caused by other viruses.

WHAT DOES THIS MEAN FOR FUTURE RESEARCH?

"The hypothesis that EBV causes MS has been investigated by our group and others for several years, but this is the first study providing compelling evidence of causality," said Alberto Ascherio, Professor of Epidemiology and Nutrition at Harvard Chan School and senior author of the study in a Harvard University press release. "This is a big step because it suggests that most MS cases could be prevented by stopping EBV infection and that targeting EBV could lead to the discovery of a cure for MS."

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$6.9 MILLION FOR MS RESEARCH IN 2022 IN LARGEST-EVER FUNDING ROUND

These grants provide avenues to enhance repair and restore function in those with MS. The 2022 funding covers a range of different MS research priorities, 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, depression, diet, exercise, new drug candidates to treat MS and myelin repair. MS is a very complex disease making it necessary to address all of these areas to help gain a full understanding of the disease and come up with the best ways 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 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.

> “The 2022 funding covers a range of different MS research priorities, including causes and prevention, better treatments and cures via repair and regeneration of cells.”

One of the studies looking into causes and prevention of MS will be undertaken by Associate Professor Alexander Klistorner from the Save Sight Institute at the University of Sydney NSW. Associate Professor Klistorner will investigate what causes MS to progress, which remains poorly understood. He will study several potential mechanisms of disease progression using non-invasive imaging techniques in people with secondary progressive MS. Understanding the driving forces behind progression in MS is of paramount significance to hopefully pave the way for new treatments.

Many of the new projects and fellowships will focus on improving treatments for people with MS. Dr Milena Gandy from Macquarie University NSW will test a remotely delivered psychological treatment for people with MS who experience depression, anxiety and other functional difficulties.

Both Associate Professor Yasmine Probst from the University of Wollongong NSW and Associate Professor Lucinda Black from Curtin University WA will be studying diet and nutrition for the management of MS.

Dr Izanne Roos from the University of Melbourne VIC will use a statistical model that predicts the risk of developing aggressive MS at the earliest stages of MS. She will then determine whether the use of highly effective therapies can prevent aggressive disease in those people at high risk.

Ms Terry Purton from the University of Tasmania TAS will be investigating the effects of consuming probiotics on cognitive symptoms (thinking and memory), signs of inflammation and gut bacteria in people with MS.

Associate Professor Alexander Klistorner

Dr Milena Gandy

Associate Professor Yasmine Probst

Associate Professor Lucinda Black

Dr Izanne Roos

Ms Terry Purton

Dr Steven Petratos

Associate Professor
Kaylene Young

Professor Trevor Kilpatrick (left) and Professor Tomas Kalincik (right), studying together under a Paired Fellowship grant.

> “Several studies will be focusing on a cure for MS via the repair and regeneration of cells, one of the most significant areas of unmet need.”

Several studies will be focusing 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. These include Professor Tomas Kalincik and Professor Trevor Kilpatrick, who received the Paired Fellowship. This unique grant funds a researcher and clinician to collaborate on a shared program of research that will accelerate the translation of research outcomes into clinical practice. The team will first develop and validate a set of signs or markers that will be sensitive enough to detect subtle changes in people with seemingly well-controlled MS. They will then generate a new method for monitoring the activity of the immune system within the brain. Finally, the team will develop a promising treatment for progressive MS.

Dr Steven Petratos from Monash University VIC is looking at blocking the modification of a specific protein or interaction between this protein and another which leads to nerve fibre damage. This work will hopefully halt disease progression and provide recovery from disability.

Associate Professor Kaylene Young from the Menzies Institute for Medical Research TAS will progress her first potential myelin replacement therapy through a phase II clinical trial evaluating its effectiveness in people with MS, and investigate how myelin loss and replacement impact brain function in laboratory models. She will also study families with an unusually high incidence of MS, which may provide clues to the genetics of MS. Ultimately, her goal is to carry out laboratory research to identify signalling pathways that lead to the development of MS, learn how MS impacts brain circuit function, and design and translate treatments to protect and repair the brain.

We are very grateful to the MS community, our donors and funding partners, including MS Limited, MSWA, MS Society 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.

This is just a brief overview of some of the new research projects funded in 2022. The full details of these and the other projects we are funding in 2022 can be found here: www.msaustralia.org.au/projects.

RECOGNISING OUTSTANDING AND SELFLESS MERITORIOUS SERVICE TO THE MS COMMUNITY

The annual MS Australia John Studdy Award recognises outstanding, consistent, and selfless meritorious service of 10 or more years, by those making or who have made a tangible difference to the benefit of people living with multiple sclerosis (MS) and/or their families or carers.

MS Australia Board Member and Chair of the John Studdy Award panel, Sharlene Brown, is delighted to announce the winners of the 2021 John Studdy Award are **Mr Charlie Bennett** and **Mr George Pampacos**, for their unwavering work and loyalty to the MS cause over many decades.

Sharlene Brown said, "The Board would like to thank Charlie and George for their outstanding commitment and service to the MS community and notable contribution to the lives of many living with the disease."

Charlie Bennett receiving the award from Sharlene Brown.

Charlie Bennett has dedicated his life to supporting people with MS, fundraising to find a cure, and caring for his wife Jenny who lives with the disease. Charlie cycles and captains 'Team Jenny' to raise awareness and vital funds for MS, for research also care and support services, in his home state of Queensland.

Since 2013, Charlie, his wife (diagnosed with MS at 15) and the riding team have raised over $250,000. Treasured MS Queensland Ambassadors, the Bennetts speak at events and volunteer for other fundraising and community activities. Charlie educates politicians and others about MS, its impact and effect.

Charlie is a John Studdy Award co-recipient for his passion, commitment, and dedication to the MS community and working towards a world without MS.

Inspired by community, acceptance and togetherness, Charlie says, "I choose to get involved because since becoming Jenny's carer and making new friends with others in the MS community, I have seen how devastating this disease can be for people of all ages. It is a disease for life until a cure is found, a daily fight. They deserve better."

George Pampacos encapsulates the spirit of John Studdy and is an Award co-recipient for his stewardship, leadership, and tenacity to make a tangible difference for the benefit of people living with and affected by MS.

George has made a substantial difference to the benefit of people living with and affected by the disease. Under his leadership as Chair of MSWA, the organisation enjoyed accelerated growth and success in revenue, client service hours, premises, and funds for MS research.

George was also instrumental in preparing MSWA for the NDIS and generating new income streams. He has represented people with MS in Western Australia through media and public speaking while MSWA President and as the son of a mother and with friends living with MS. As Vice President of MS Australia, George provides expert strategic advice as a skills-based Director.

"When I was a teenager, my mum was diagnosed with MS. Seeing her live with MS for the past 30 years and her daily battles has made me want to help to improve the lives of all people with MS and do what I can with my skills to find a cure - so future generations do not have to live with MS."

To read about the John Studdy Award, including past recipients, visit: www.msaustralia.org.au/about-us/john-studdy-award/.

AMY STARTED 2022 FULL OF HOPE, THANKS TO YOU!

Late last year, we asked Amy about her hopes for 2022. She could barely get the words out without bursting into tears.

"My goal is to get my independence back. I want to rise above MS and be the best mum I can be," Amy told us.

Thanks to you, and the generosity of the whole MS community, Amy's dream could soon be a reality. With your help supporting the 2021 Christmas Appeal, MS Australia recently raised $104,220 to fund promising research in 2022. That research could give Amy her life back and change the world for everyone with the disease. Thank you for your kindness and support.

Before Amy had MS, she lived an energetic, busy life with her three young daughters. She helped at their sports days and was heavily involved in the community. MS took all that away.

Amy's terrifying symptoms began when she was in the shower.

"I got all dizzy and couldn't stand. I had to crawl to the lounge because I couldn't walk," Amy said.

Since then, Amy's MS has slowly progressed. Despite receiving the best treatments available, she now needs a wheelchair, struggles to leave the house, and lives in constant pain. Losing her independence has been tough on Amy; the hardest part is seeing the impact it has on her kids. Amy explained:

"My kids have to look after me now and it's not fair. I'm their Mum. It's my job to care for them."

Your support is helping fund exciting research in 2022 that could give Amy her life back and help her, once again, be the mum she wants to be.

One of the projects you're helping fund could perhaps solve one of the most debilitating symptoms of MS – loss of mobility.

Dr Phu Hoang leads this research. He will be analysing patterns of muscle weakness in thousands of people with MS, then developing a set of clinically proven exercises that could slow the progress of the disease and keep people active for as long as possible.

> "Words can't describe how grateful I am. To everyone who gives to fund MS research, no amount of thanks can ever be enough."

One day, Dr Hoang's research could even help Amy walk again.

Your support is also helping fund game-changing research led by Associate Professor Anthony Don. Associate Professor Don is investigating whether certain drugs could repair nerve damage caused by MS. These drugs could have the potential to reverse the symptoms of MS and restore physical and cognitive function in people with the disease.

This research could transform Amy's life and the lives of everyone affected by MS.

When we told Amy about it – and how the support from people like you is helping make it possible – she again choked up with emotion and asked us to share her personal message of thanks:

"Words can't describe how grateful I am. To everyone who gives to fund MS research, no amount of thanks can ever be enough."

Amy's three beautiful daughters also wanted to thank you. They think people like you are *'amazing'* and *'superheroes'* for helping their mum.

From Amy, her daughters, the researchers and everyone affected by MS, thank you for your kindness. Your generosity is helping transform the future of MS. This year, your support will bring us even closer to the day when MS no longer has power over people's lives.

MEET THE RESEARCHER

DR IZANNE ROOS

UNIVERSITY OF MELBOURNE, VIC

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

I completed my medical and specialty neurology training in South Africa, before moving to Melbourne to pursue a PhD in MS research.

WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

MS is a potentially debilitating disease, and a major source of non-traumatic disability. The MS treatment landscape has undergone a massive transformation over the past 20 years. I wanted to be a part of this change!

WHAT DO YOU THINK HAS BEEN THE MOST EXCITING DEVELOPMENT IN MS RESEARCH?

Each person with MS has a unique personal and social circumstance, and a unique MS experience. There are currently 15 licensed therapies for the treatment of relapsing MS. Clinicians therefore now have the opportunity to personalise treatment decisions so we can use the right drug, for the right patient, at the right time.

TELL US ABOUT YOUR CURRENT RESEARCH PROJECT...

6% of patients have an aggressive form of MS, and accumulate disability at an accelerated rate. The best treatment approach in these patients is however uncertain. In my project, I aim to validate a statistical model that can predict an individual's risk of developing aggressive MS at the earliest stages of MS. I will also establish whether early use of highly potent therapies can prevent aggressive disease in those patients at high risk.

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

This research will enable neurologists and people with MS to tailor the choice of treatment strategy to the predicted MS severity as early as the first year of MS symptoms. This will ensure that all people with MS receive treatment that will maximise their chance of a life without disability, while maintaining quality of life and employability.

WHAT DO YOU ENJOY MOST ABOUT WORKING IN THE LAB AND WHAT ARE SOME OF THE CHALLENGES YOU FACE?

As both a clinician and a researcher, I have the privilege of both researching a disease and managing the people affected by it. While it is a balance to ensure that both roles are given the attention they deserve, being able to work in both the clinical and research areas gives me a unique perspective about the issues important to people with MS, and unmet research needs.

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

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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:

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