

## THE MAY 50K IS BACK!



**THE MAY 50K**

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[WWW.THEMAY50K.ORG](http://WWW.THEMAY50K.ORG)

Your favourite fitness and fundraising challenge is back for another year! Last year we were blown away by the support for The May 50K and we are once again challenging you this May to raise funds for life-changing MS research by running or walking 50 kilometres throughout the month.

This year marks not only the second year of The May 50K, but also a new decade in which we are determined to raise even more funds to accelerate research into prevention, better treatments and finding a cure for MS. It's time to test your limits, get fit, and join over 10,000 Australian runners and walkers in The May 50K challenge to help leave MS where it belongs, behind us.

Together we are unstoppable! The inaugural launch of The May 50K in 2019 was a testament to what the Kiss Goodbye to MS community can achieve when we work towards the same goal – freedom from MS.

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## WEARABLE TECHNOLOGY: THE NEW DISEASE PROGRESSION DETECTIVE

### THE NEED FOR EFFECTIVE, REAL TIME MEASUREMENT OF DISEASE PROGRESSION

It is vital that we come up with new ways to measure disease progression. We need cheap, fast, reliable ways to be able to detect real time changes in disease activity. This is especially important for progressive MS, where reliable measures are needed to be able to carry out clinical trials in an expedited manner. It is also important for relapsing remitting MS, where early detection of disease progression might lead to a rapid switch of medications, and thus prevent a relapse and accumulation of disability.

Currently, ways to detect disease progression take time, such as following someone and monitoring obvious changes in disabilities combined with MRIs, neither of which are rapid nor in real time. Researchers are investigating alternatives such as subtle changes in gait.

### MEASURING WALKING STABILITY IN PEOPLE WITH MS

New research has shown that measuring walking stability in people with MS using relatively inexpensive technology, could open the door to a quicker, more reliable way to monitor disease progression. Walking manner, also known as gait, can be affected by balance issues that people in the early stages of MS may experience.

Cont. on pg 2

### COVID-19 AND MS

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## CONTINUED FROM PAGE 1

Even in the absence of obvious disabilities, many people with MS use strategies to improve their stability and reduce the risk of falling, such as taking shorter steps.

Current ways to measure walking stability in the clinic are not sensitive enough to detect the subtle changes in gait that people with MS may experience. This makes it difficult to monitor progression and make changes to current treatments to prevent further disease activity. Therefore, there is a need to better monitor the advancement of disease and the effectiveness of medications in people with MS.

### HOW DID RESEARCHERS USE WEARABLE SENSORS TO MEASURE GAIT?

Professor Mary Galea, a MS Research Australia funded researcher, has found that using wearable sensors can provide information on subtle movement changes that were previously only available as

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an expensive movement analysis in a Movement Laboratory. Her research has focused on using these sensors to measure walking and balance in people with MS during their appointments at the clinic. By doing this, the results can be immediately provided to the neurologist

to determine whether a person's treatment is effective in preventing disease progression, or whether changes need to be made. Since these sensors can detect the most subtle changes, disease progression can be monitored closely, and any changes can be acted on quickly to prevent further progression.

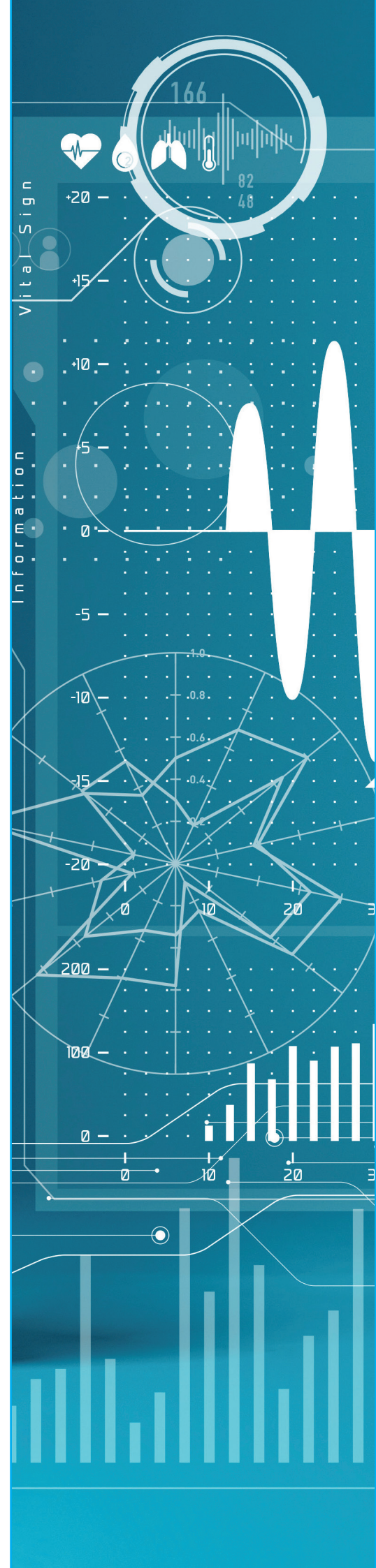
Part of this work has been published in *Gait and Posture*. In this study, Professor Galea and her team compared gait stability between 30 people with MS with no gait impairments and 15 people without MS using different sensor locations and data sources. The participants walked on a treadmill at 1.2 metres per second and movement data was obtained from sensors on the sacrum (base of the spine), shoulder and cervical markers (base of neck), as well as an accelerometer placed at the sacrum. The researchers used these to calculate the local divergence exponent (LDE), a new, simple and sensitive measure of gait stability, which is believed to match up with changes in the brain and spinal cord based on magnetic resonance imaging (MRI).

### WHAT DID THE RESEARCHERS FIND?

The researchers found that people with MS, despite not showing any obvious signs of gait instability, walked with a less steady gait than people without MS based on all four measurements. However, the accelerometer placed on the sacrum appeared to underestimate gait instability compared to the sensors, with the LDE being about 18% higher in people with MS based on the sensors compared to only 7% from the accelerometer. Therefore, the LDE, as calculated by the sensors and accelerometer, was effective in detecting subtle changes in gait stability in people with MS who show no obvious signs of disability.

### WHAT DOES THIS ALL MEAN?

This means that measuring gait can detect subtle physical changes and may determine the effectiveness of the treatment regimen early in the disease course, allowing clinicians to act upon this quickly to prevent further progression.



# WHY DOES THE IMMUNE SYSTEM ATTACK ITSELF?

**Why in some immune-mediated diseases does the immune system mistake parts of the body as foreign invaders? What triggers it?**

These are important questions, and they are being asked not just for MS, but for a number of different diseases, including diabetes, arthritis, Graves' disease and lupus, to name just a few.

MS arises when the immune system attacks the myelin sheath, an insulating coating on nerve fibres. This attack damages the insulating coating which disrupts or halts the signals travelling down the nerves, interrupting the signaling between the brain and the body. Given that the brain controls everything we do, this disruption can result in a wide range of symptoms.

Every second you are alive your immune system is constantly making decisions. Most of the time when it encounters something new, it is likely to be harmless, but there is a small number of times when it will come across something that is very dangerous. The immune system must be able to discriminate between the two scenarios while also distinguishing between self and non-self. Most of the time it gets it right and we can survive in an environment full of bacteria and parasites. But unfortunately, sometimes this goes a little askew.

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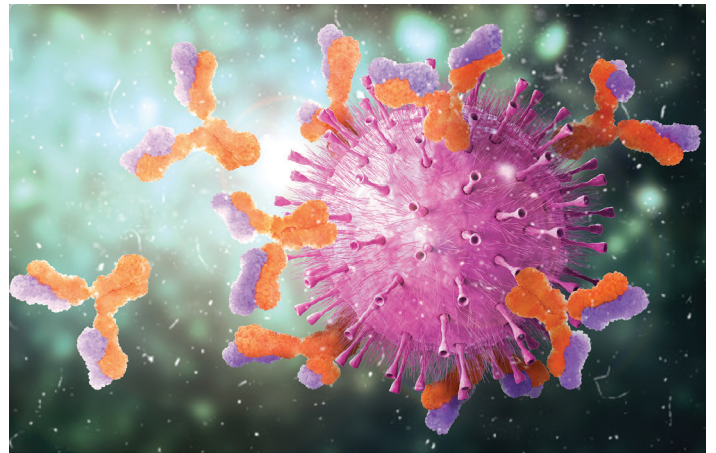
Australia has led the way in terms of research into understanding some of the environmental risk factors that might lead to MS. If these factors influence our risk, they must also influence the immune system. These factors include genetics, vitamin D levels, UV light exposure, EBV infection and some others (for a more comprehensive article on risk factors, visit [msra.org.au/news/unravelling-causes-ms](http://msra.org.au/news/unravelling-causes-ms)).

While a number of risk factors have been identified, the actual molecular mechanism has not been discovered. We know that events occur that cause the immune system in MS to go awry and hence many of the successful medications used to treat MS target the immune system. However, despite a number of attempts, an autoantibody has not been discovered in people with MS, which means that MS doesn't meet the criteria to be classified as an autoimmune disease, but rather falls under the category of immune-mediated diseases. An autoantibody is an antibody (a protein) produced by the immune system that is directed against one or more of the individual's own proteins.

Scientists at the Garvan Institute of Medical Research in Sydney have recently published a scientific study in the prestigious journal *Cell* which might help unlock some of the mysteries behind the molecular mechanisms generating auto-reactive immune cells.

Using cutting edge genetic technologies, the researchers looked at a small number of people with Sjogren's syndrome. Sjogren's syndrome is an autoimmune condition that mainly affects the eyes and salivary glands. They analysed some of the autoantibodies in these individuals and traced them back to the B cell (a type of

immune cell) that made these antibodies. They then analysed the genetic makeup of those cells to try and determine why they exist and how they had gone awry.



What they found was that the cells that produced a response against the body had accumulated mutations in their DNA, which shared similarities to mutations found in lymphoma (a type of cancer arising from immune/blood cells). It is important to note that these cells weren't cancerous, but they probably had lost some of their ability to control their rate of growth and also lost some of their ability to repair mistakes in their DNA. These mutations turn these cells rogue, allowing them to evade immune tolerance checkpoints that should destroy any cells that attack the body. It also allowed them to multiply unchecked, leading to a small number of out of control immune cells, producing some of the auto-reactive antibodies in these people with Sjogren's syndrome.

While this study has been carried out in a different autoimmune condition, it may be similar to what occurs in MS. MS Research Australia works closely with other organisations in other disease areas to ensure we can leverage off each other's understanding and research.

“ THE CELLS THAT PRODUCED A RESPONSE AGAINST THE BODY HAD ACCUMULATED MUTATIONS IN THEIR DNA. ”

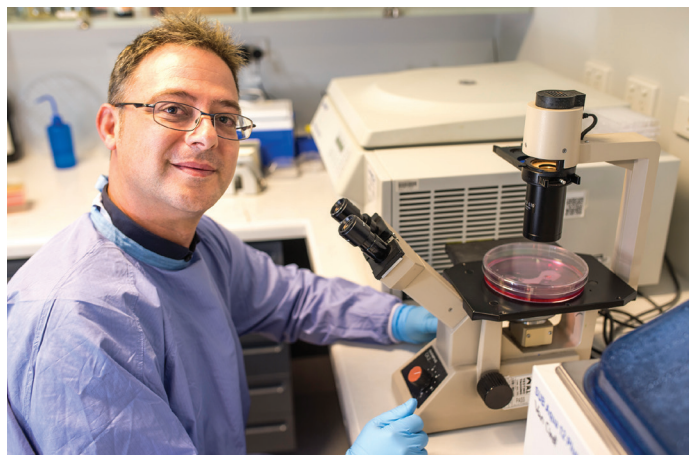
To date, studies like this have been technically unfeasible, as these rogue cells are rare, possibly only 1 per 500 normal immune cells. Traditionally, the only way these studies could be done was via collecting pools of cells which would have masked the rare cells. It is only through advances in DNA technologies that has allowed the analysis of individual cells. It is an exciting time in research that such things can be discovered, and we look forward to similar studies being carried out in MS.

# REPURPOSING AN EXISTING DRUG TO REPAIR DAMAGE CAUSED BY MS

**MS results from the loss of myelin, the insulating sheath around nerve fibres, in the brain and spinal cord. The body has limited abilities to repair myelin (a process called remyelination), and myelin repair is often incomplete in people with MS.**

Currently, all the available therapies target the immune system, and there are no treatment options capable of repairing the damage. Repairing myelin is thought to be very important as it may reverse some symptoms of MS and could provide protection against further damage to the nerves.

MS Research Australia funded researcher, Dr Steven Petratos from Monash University VIC, and his team are currently working to repurpose an existing drug to encourage the body's repair mechanisms to remyelinate the nerves in the brain and spinal cord. The drug, called DITPA, mimics the action of a thyroid hormone and has been used in clinical trials to treat a rare disorder called Allan-Herndon-Dudley syndrome (AHDS), which severely affects movement.



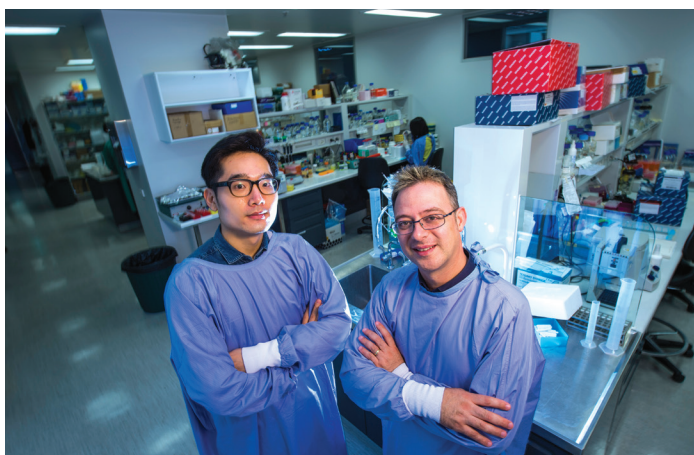
Dr Petratos' work has shown that this drug has the ability to encourage precursor cells within the brain to become myelin producing cells, and these then might enhance the ability of the body to repair areas of damaged myelin in the brain and spinal cord. He has shown that this has promising effects on laboratory models of MS and it may reverse some symptoms of MS.

Additionally, DITPA has the advantage of being able to cross the blood-brain barrier to directly target affected areas in the brain. This is one of the biggest barriers for any potential treatment of MS. If successful, this study may have important implications for people living with MS due to its potential to reverse some of the damage caused by the disease, as well as provide protection from further damage. It may be beneficial for people with both relapsing and progressive forms of MS. This is exciting because while MS affects over 25,600 people in Australia, treatment options are mostly limited to people with relapsing remitting MS (RRMS) and unfortunately there are currently very few options for those with progressive forms of the disease.

DITPA is currently in the pre-clinical stages of research, with Dr Petratos and his team hoping to move this potential treatment option into clinical trials in a few years. He has recently been awarded a patent on the drug and is also in discussions with a major pharmaceutical company to develop the drug for trials in people with MS. While this is still in early stages of research, if successful it may have a big impact on MS.

Dr Petratos was recently awarded a MS Research Australia and Trish MS Research Foundation Project Grant to support this work.

“ DR STEVEN PETRATOS AND HIS TEAM ARE CURRENTLY WORKING TO REPURPOSE AN EXISTING DRUG TO ENCOURAGE THE BODY'S REPAIR MECHANISMS TO REMYELINATE THE NERVES IN THE BRAIN AND SPINAL CORD. ”



“ WHILE THIS IS STILL IN EARLY STAGES OF RESEARCH, IF SUCCESSFUL IT MAY HAVE A BIG IMPACT ON MS. ”

# HAVING OTHER CONDITIONS AS WELL AS MS IMPACTS EMPLOYMENT

**Comorbidities, which are medical conditions that occur simultaneously with another disease, are common in people with MS.**

A growing body of information suggests that in order to improve treatment outcomes and quality of life of people with MS, comorbidities must also be factored into our research efforts and the clinical management of MS. Research has shown that people of working age who are living with MS and comorbidities are more likely to be on a disability pension. However, for employed people with MS, the impact of comorbidities on work productivity is not known.

## INVESTIGATING THE IMPACT OF COMORBIDITIES ON EMPLOYMENT

To provide further information on the prevalence and impact of comorbidities on work-related outcomes in people with MS, researchers from the Menzies Institute for Medical Research in Tasmania led by Associate Professor Ingrid van der Mei conducted investigations on a nationally representative sample of working age people with MS. Findings from their studies have recently been published in *Multiple Sclerosis Journal*.

For this study, 929 working age people with MS from MS Research Australia's long-running survey-based *Australian MS Longitudinal Study*, which is managed by the Menzies team, provided information on specific comorbidities. Information included whether each comorbidity assessed was present or not, had been diagnosed by a doctor, whether it was treated and the extent to which it limited their daily activities. The severity of 13 MS symptoms and the work productivity of these participants were also assessed using a well-established rating scale and MS specific Work Productivity and Activity Impairment Questionnaire, respectively.

## WHAT DID THE RESEARCHERS FIND?

90% of people with MS who participated in this survey reported having at least one comorbidity, with 65% receiving treatments for them at the time. The most common comorbidities were identified as depression (45%), anxiety (42%), allergies (38%), migraines (30%) and high blood pressure (25%).

They also found 38% of people had one or more comorbidities that limited their activities. The comorbidities that were said to most limit daily activities were osteoarthritis (51%), migraines (40%), anxiety (33%), depression (29%) and allergies (18%). Some comorbidities, such as osteoporosis and inflammatory bowel disease, were rarer, but limited activities greatly.

“ THE DATA SHOWED THAT THE AVERAGE NUMBER OF DAYS LOST IN WORK PRODUCTIVITY IN THE 4 WEEKS PRIOR TO THE COLLECTION OF DATA WAS 1.3 DAYS FOR THOSE WITH MS WITHOUT COMORBIDITIES AND 2.5 DAYS FOR THOSE WITH COMORBIDITIES. ”

The data also showed that the average number of days lost in work productivity in the 4 weeks prior to the collection of data was 1.3 days for those with MS without comorbidities and 2.5 days for those with comorbidities. This confirms the significant impact comorbidities have on work attendance in people with MS.

When these researchers looked at the total number of comorbidities for each person and their severity, they saw a proportional increase in the likelihood of not working in people with MS who participated in this study. This did not change even when age, gender and education levels were accounted for in the analyses. MS symptom severity also showed a clear link with the loss in work productivity of participants experiencing comorbidities.

## WHAT DOES THIS ALL MEAN?

These findings have shown that comorbidities are not only prevalent in people with MS, but also negatively impact the work status and work productivity of working age people with MS. It highlights the importance of simultaneously managing comorbidities and MS symptoms, which could in turn improve employment outcomes and quality of life.

This body of work contributes significantly towards improving our understanding of the comorbidities experienced by people with MS and how they add to the burden of the disease. The recent *Health Economic Impact of MS Report*, commissioned by MS Research Australia, showed that lost wages now accounts for just 32% of the economic burden of MS compared to almost 50% in 2010, which is an improvement possibly due to the increasing use of disease modifying therapies.

However, these new findings show that we can do even better to support people with MS in employment by also paying attention to the other health conditions experienced alongside MS.





Over 9,200 people took on the challenge across Australia and raised a record-breaking \$2.1 million for life-changing MS research!

This achievement goes beyond what we could have ever hoped for.

In 2020, we want The May 50K to go further. We want you to bring your colleagues! The May 50K is your chance to look after your workplace's health and well-being, whilst encouraging some healthy competition between colleagues this May. Whether it's a lunch run with the entire team, or a walk to your next meeting – you decide

when, where and how to complete your 50 kilometres. Your team will feel energised, happier and is guaranteed to have a lot of fun – all in the name of vital MS research!

Register yourself or a team today and commit to leaving your limits behind by running or walking 50 kilometres this May! Every step you take, every kilometre you clock, takes us closer to finding a cure for MS.

Together we will change the future of MS.

**Find out more about The May 50K at: [www.themay50k.org](http://www.themay50k.org)**



## THE MAY 50K WINS HIGHLY COMMENDED AT THE FIA AWARDS FOR EXCELLENCE IN FUNDRAISING



**MS Research Australia is proud to be recognised as 'Highly Commended' for The May 50K campaign in the 'Impact Through Events' category at the Fundraising Institute of Australia Awards for Excellence in Fundraising.**

The Awards recognise the outstanding initiatives and innovative efforts of professional fundraisers, volunteers and organisations and we were thrilled to be nominated alongside MS Limited who took home the win for their initiative The All New MS Readathon.

It's great to see The May 50K being celebrated alongside its peers, and we are looking forward to what's to come in 2020.

“ THE AWARDS RECOGNISE THE OUTSTANDING INITIATIVES AND INNOVATIVE EFFORTS OF PROFESSIONAL FUNDRAISERS ”

# FREEFALLING TO RAISE RESEARCH FUNDS



**Every day we're thankful to the MS community – dedicated supporters like you. Dedicated supporters like Maureen, who for her 80th birthday jumped out of a plane to fundraise for Kiss Goodbye to MS!**

Maureen Hillman was inspired to support MS Research Australia after hearing a fellow church member talk about his fundraiser in memory of a friend who had lived with MS. From that point on, Maureen wanted to learn more. She wanted to help however she could.

She's since met several people living with MS and listened to their stories.

“ THE SENTIMENT OF THOSE WHO SUPPORT US IS ALWAYS THE SAME – ‘I WANT TO MAKE SURE NO ONE ELSE GOES THROUGH THIS’.

Maureen's certainly not alone. Over 7 million people in Australia know someone living with MS. And the sentiment of those who support us is always the same – ‘I want to make sure no one else goes through this.’

More recently, her desire to help others led to her decision to leave a gift to MS Research Australia in her Will.



“ DO IT – DON'T HESITATE – DO IT. THERE IS SO MUCH SATISFACTION AIDING SOMEONE IN THIS WORLD AND I'M SURE PEOPLE LIVING WITH MS GET GREAT COMFORT KNOWING THE WORK THAT IS BEING DONE ON THEIR BEHALF. ”

Encouraged by the progress already made in MS research, Maureen wanted to ensure this continues. She wanted to provide a future where the secrets of MS have been unlocked. And she knows that powering medical research is the only way to discover the causes of MS and find a cure.

Asked what she'd say to someone considering such a generous gift, Maureen told us, “Do it – don't hesitate – do it. There is so much satisfaction aiding someone in this world and I'm sure people living with MS get great comfort knowing the work that is being done on their behalf.”

Over the last 15 years, generous donations and gifts in Wills have enabled us to fund MS research and keep the momentum of breakthroughs and discoveries going. The number of available treatments for people living with MS has increased six-fold and we understand more about MS than ever before. Maureen made this happen. You made this happen. We simply can't do what we do without the support of the MS community, so we thank you.

If you'd like to understand more about how to make a gift in your Will, please feel free to reach out to our friendly Gifts in Wills team. You can reach Nicki Grant, Gift in Wills manager, during business hours on 02 8413 7927 or via [nicki@msra.org.au](mailto:nicki@msra.org.au)



# MEET THE RESEARCHER

## DR STEPHANIE TREND, TELETHON KIDS INSTITUTE



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

I grew up in a musical family, so karaoke is very competitive in our household!

### WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

I have always been interested in science and the world around us. During my university studies I became fascinated by the human immune system and the

differences between immune responses in healthy people and those with different health issues. After I completed my PhD an opportunity arose to become involved in MS research as part of Professor Prue Hart's team at the Telethon Kids Institute. That was 3 years ago, and I've never looked back. Meeting with the study participants who take part in our research has been invaluable in helping me to understand the impact of MS on people's lives. It is highly rewarding to be involved in research that aims to better understand MS so that it might be more easily treated or prevented in the future.

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

The development of therapies that deplete immune cells (such as ocrelizumab) has benefitted patients greatly and has provided important insights for researchers trying to understand the contributions of those immune cells to MS.

### TELL US ABOUT YOUR CURRENT RESEARCH PROJECT...

Antibodies are small proteins that are made by some immune cells that allow the immune system to identify and respond to substances detected in the body. Antibodies are found in the brain and spinal fluid of people with MS, however it isn't clear what effects they might be having

in those locations. We are investigating whether the immune cells from people with MS or clinically isolated syndrome (pre-MS) respond differently to antibodies compared with cells from healthy people, and are measuring the amounts of proteins on the immune cells that bind to antibodies and initiate immune responses to them.

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

This research will help us to better understand what causes inflammation in MS - a key driver of the condition - and whether responses to antibodies are involved. Since we are testing samples from people with pre-MS and MS, we will also gain better understanding of how immune responses might change as the disease progresses and whether the same treatments are appropriate for both groups of people.

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

There is nothing more exciting than analysing your latest data and realising you are the first person in the world to know something new. Ensuring new research projects have adequate funding is probably the biggest challenge for all scientists.

## HELP MS RESEARCH AUSTRALIA FIND A CURE FOR MS

### Donate (Donations over \$2 are tax deductible)

To support MS Research 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 Research Australia

### Contact details

Title:  First name:   
 Surname:   
 Address:   
 Suburb:  State:  Postcode:   
 Phone:  Mobile:   
 Email:

### Payment method:

- Cheque (made payable to MS Research 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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