



15
year
anniversary

MS WIRE

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

\$2.1 million raised in record-breaking The May 50K campaign



LEAVE YOUR
LIMITS BEHIND.

THE MAY 50K

#KissGoodbyeToMS

This year MS Research Australia launched a new Kiss Goodbye to MS initiative – The May 50K!

The May 50K is a virtual fitness and fundraising challenge developed to encourage more people to get involved in raising funds for life changing MS research.

The MS community, their family, friends and colleagues were encouraged to get active and run or walk 50 kilometres in the month of May to help leave MS where it belongs, behind us. Over 9,200 participants signed up to take part, putting in love, sweat and tears to log a monumental 474,575 kilometres. The result of this incredible effort? A record-breaking **\$2.1 million raised for MS research!**

The virtual nature of the challenge set The May 50K apart from other events, as well as the unique flexibility it offered to ensure anyone that wanted to could take part regardless of their physical ability. Although most participants chose to walk or run, the challenge was also inclusive and adaptable for those

with mobility limitations to scale the distance down or up, or to modify their preferred approach.

The May 50K is a huge part of taking the Kiss Goodbye to MS campaign to the next level. Initially established to raise awareness back in 2012, Kiss Goodbye to MS has expanded internationally and been warmly embraced by 13 countries. It is the only campaign dedicated to globally increasing awareness and, in recent years, also raising vital funds for MS research.

In previous years Kiss Goodbye to MS operated as a successful “do-it-yourself” style fundraising campaign, where supporters created their own ideas of how they wanted to fundraise. This attracted some of our most creative and unique fundraising events including horse rides, car rallies, sky dives and gala balls. The Red Lab Coat Day – whereby researchers wear red lab coats and put together videos to showcase their MS research culminating in a Battle of the Labs winner – has also

(continued page 2...)



A WORD FROM OUR CHIEF EXECUTIVE OFFICER

As another financial year draws to a close I would like to take the opportunity to thank our many valued donors whose support helps MS Research Australia to continue to make advances in MS research.

I'd also like to reflect on what has been achieved over the preceding 12 months. The findings, the key impacts and most importantly how lives have been changed.

- We identified that people on high-efficacy disease-modifying MS therapies were 2-3 times more likely to report improved employment outcomes.
- Our Health Economic Impact of Multiple Sclerosis (MS) in Australia Report revealed that the burden of MS to Australia is \$1.75 billion per year, this is an increase of 41% since 2010.
- We funded an additional \$4 million per annum in MS research with \$1.75 million allocated to fund 20 new, high-quality, competitive grants to researchers from all over Australia.
- After holding a comprehensive modifiable lifestyles workshop, a team of experts are developing a guideline report addressing diet and other modifiable lifestyle factors in MS.
- Positive results received from Autologous Haemopoietic Stem Cell treatment (AH SCT) studies and an observational trial held in Australia for certain types of MS is leading to more AH SCT research and early discussions around centres of excellence.

- A unique assembly was held to identify how the MS community can work collaboratively to Stop and Reverse MS within 10 years.
- Research into long term outcomes in people with relapsing remitting MS has shown that treatment with the newer, more effective medications have slowed disability progression and also reduced the likelihood of people developing secondary progressive MS.
- Working to ensure Australians have access to two new therapies which have been approved and registered for use in the U.S. for active secondary progressive MS.
- Significant progress achieved whilst working with the three large global research networks of the International Progressive MS Alliance with promising new drug targets for primary and secondary progressive MS.

As you would have seen from our cover article, this year we introduced The May 50K, a Kiss Goodbye to MS campaign that has broken all records and expectations. A staggering \$2.1 million raised for Australian MS research, with over 40,000 donors, 9,200 active fundraisers and with a fundraising cost ratio of just 22 cents in the dollar. The global MS community has been watching closely and is already asking to know the secret to its success. Recently, we were thrilled to hear that our very own Tanja Voss, was nominated and recognised by the highly credentialed, Fundraising and Philanthropy Magazine, for creating and leading change in fundraising with The May 50K. This is a steeply competitive environment and we wish to congratulate Tanja for working tirelessly and going above and beyond.

Our national and global purpose has always been focussed and very clear. We facilitate, fund, educate, strategise, empower, leverage, innovate and advocate when it comes to MS research activities. We exist for two interconnecting and, hopefully, self-defeating reasons: 1) is because there are people affected by MS in Australia and the world, and 2) is because MS research is the key to change 1).

Dr Matthew Miles, CEO



**OVER
40,000
DONATIONS
RECEIVED**



**ON AVERAGE EACH
FUNDRAISER
RAISED OVER
\$350**

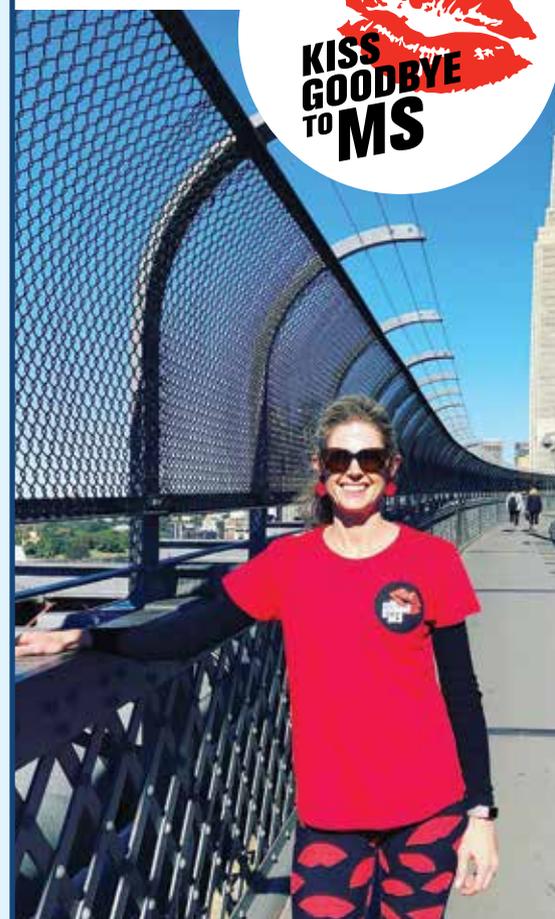


**APPROX
\$180,000
RECEIVED IN PRO BONO SUPPORT**

been a fantastic way of raising awareness and funds within the research community. Now, the exciting addition of The May 50K has made 2019 our biggest year yet...and we're only half way through!

The support for the MS research cause has been, and continues to be, awe-inspiring showing what a special, determined and supportive community there is in Australia. A huge thank you to everyone that took on The May 50K and we can wholeheartedly say that with more funding, it's not a matter of 'if', it's a matter of 'when' we will Kiss Goodbye to MS.

Find out more at:
kissgoodbyetoms.org





Healthy lifestyle, lower depression...SNAP!

People with MS who maintain a healthy diet experience lower levels of depression than those who don't according to new Australian research.

What is the link between MS and depression and anxiety?

Depression and anxiety are observed in up to 40% of people with MS, nearly double that of the general population. Both conditions may be considered symptoms of MS, as they can result from inflammation occurring in the brain and spinal cord. However, the psychological impact of a diagnosis of a chronic illness like MS can also contribute to these conditions.

Depression and anxiety have also been associated with increased inflammation, fatigue and disability, and contribute significantly towards reduced quality of life in people with MS. While interventions such as medications and psychological support can be effective, only a small proportion of those with MS seek medical help for such issues.

What are modifiable lifestyle factors?

Modifiable lifestyle factors are parts of a person's lifestyle that they may be able to change or influence in some way. Examples of this could include smoking, nutrition, alcohol consumption and physical activity. People with MS are often interested in how they can make changes to their lifestyle to help manage their condition, but the research evidence in this area is still growing.

Research into depression and anxiety and modifiable lifestyle factors

To explore whether modifiable lifestyle factors contribute to the severity of some of the symptoms of MS, Dr Claudia Marck from the University of Melbourne collaborated with Dr Ingrid van der Mei from Menzies Institute for Medical Research, who runs MS Research Australia's Australian MS Longitudinal Study (AMSLS).

Over 1,500 people with MS completed a survey via the AMSLS study on various lifestyle behaviours such as smoking, nutrition, alcohol consumption and levels of physical activity (consistent with the SNAP guidelines published by the Royal Australian College of General Practitioners). In addition, they also responded to survey questions to gather data on anxiety and depression. The data was then carefully analysed to explore if there was any connection between lifestyle behaviours and the occurrence and severity of anxiety and depression symptoms.

What did this latest research study discover?

- Most people with MS who participated in this study did not smoke (90%) and consumed alcohol within recommended levels (83%).
- However, only 10% of participants met the optimal daily intake of two serves of fruit and five serves of vegetables*. Just over half (53%) engaged in adequate amounts of physical activity and less than half (39%) had a healthy body mass index (a measure of body fat based on a person's height and weight).
- Overall, a mere 3% of people in this study met all five healthy lifestyle factor requirements (nutrition, physical activity, body weight, smoking and alcohol consumption).
- Findings showed that smoking (defined as more than one cigarette, cigar or pipe per day) and consuming more than the nationally recommended amounts of alcohol (two or more standard drinks per day) are linked to the increased occurrence of depression. Severity of depression also increased with increasing levels of smoking.
- Conversely, those who followed a healthy diet according to the Australian Guide to Healthy Eating (five or more serves of vegetables per day and two or more serves of fruit at least six days per week) were found to have lower severity of depression.
- This study also showed that with each additional healthy behaviour, the occurrence and severity of depression reduced proportionally.

The full results from this study have recently been published in the journal *Acta Neurologica Scandinavica*.

What do these research findings mean?

This study confirms previous studies suggesting there is a high prevalence of depression and anxiety in Australian people with MS, and is the first to provide evidence that many people with MS are not meeting healthy lifestyle recommendations.

While this research shows strong links between poor lifestyle and poor depression/anxiety outcomes, further research is needed to fully understand if modifying lifestyle factors can become a treatment option for people with MS experiencing these symptoms.

This study is a stepping stone towards developing a strong, evidence-based and holistic approach towards the management and treatment of MS and its symptoms, which includes factors that can be self-managed by people with MS.

* *Nutrition Australia – Australian Dietary Guidelines*



What are clinical trials?

Clinical trials are usually the final steps before new medical interventions are introduced to the clinic. They are the accumulation of extensive research and work, with many bright ideas failing to even reach this step.

Clinical trials are essential to prove that the new proposed intervention is more efficacious than what is currently used and to ensure treatments are evidence-based. Without such trials, there is no way to determine whether new interventions developed through research are effective or safe. In saying that, by the time an intervention gets to the trial stage a huge body of work has been done to try and ensure the safety of any procedure or treatment.

The pre-trial work consists of two stages of research. The first stage is the initial fundamental laboratory research, followed by the second stage that builds on fundamental scientific research to drive findings towards the clinic (translational research).

Trials can cover a broad range of treatment options or procedures. These can be a new diagnostic test, a new medication or a new intervention, such as psychological or physiotherapeutic treatments or new medical devices. There are four phases to clinical trials which are explained in more detail opposite.

PHASE 1

Phase 1 trials are the first time a new treatment or procedure is given to a person. This first step is to ensure there are no adverse effects in people, typically the treatment is trialled on small numbers of healthy volunteers (20-80 people) to confirm it is safe. Often the treatment is initially given at a low dose and then gradually increased. This is known as a Phase 1 trial.



PHASE 2

The next step is Phase 2 trials, which are also primarily focused on safety but the number of participants increases (100-300 people). These are designed to start teasing out any possible side effects and measure the effectiveness of the treatment.





So what are placebos, blinding and randomisation?

Placebos are a vital part of drug trials as it is well documented that doing anything in medicine can cause a strong, temporary, physiological response in the body – the ‘placebo effect’. In the placebo arm of a clinical trial, the placebo participants will undergo a procedure or receive a tablet that seems identical, but without the active ingredient. For an intervention to be considered effective, it must show a significant effect over and above that seen in the placebo group.

Blinding is when patients, doctors and assessors do not know whether the patient is taking medication or placebo. This means that the effects of the intervention, including side-effects, can be objectively identified.

Randomisation refers to a trial design where patients are randomly assigned to either the treatment or placebo group to avoid any bias in patient selection.

When the results are put together from several clinical trials that all rigorously follow these international ‘gold-standard’ methods, there can be a high level of confidence that a new treatment is safe and effective. All of the 12 currently approved MS medications in Australia have gone through this long and rigorous process. They are the successful ones which have all been shown to be effective in the treatment of MS. Unfortunately, there have been a number of trials of potential medications and procedures which – when put to the test despite anecdotal evidence and hype – have failed to be effective.

PHASE 3

Phase 3 trials are bigger again and can easily include over 1,000 participants. Side effects are measured and the research ensures that the new treatment is more effective than no treatment (against a placebo) or existing treatments (against an active comparator).



PHASE 4

Once a treatment has passed Phase 3 it is typically presented to the regulatory authorities for approval for use and made available to patients, however that doesn't mean the research stops. The intervention then enters Phase 4 in which the long term outcomes are continually monitored in people using it around the world. This ensures that anything not picked up during the Phase 3 clinical trial (which are usually over a shorter time period) can be identified and assessed.

Clinical trials are meticulous in design and implementation, with strict enrolment criteria and data collection to ensure that the results are accurate and free from bias and other influences which would mask the true effect of the intervention under investigation. The way trials are carried out is a field of study in itself, and has been developed over many years. Current trial methods use techniques such as placebo control, blinding and randomisation to guard against bias and ensure that the results can be accurately interpreted.



Want to get involved in a trial?

Visit mstrials.org.au to find out more about the clinical trials which are currently underway and recruiting here in Australia and New Zealand.



Jae Lee and Dr Steven Petratos from Monash University

Targeting nerve fibre damage

Multiple sclerosis (MS) is due to the body's own immune cells attacking the brain and spinal cord.

Usually this attack starts with the coating around the nerve fibres, which is made of myelin. Myelin can be repaired, but this is often incomplete and once myelin is permanently lost, the underlying nerve fibres start to be damaged. Damage to the nerve fibres themselves is not able to be repaired and it is this type of damage that leads to the disability accumulation seen in progressive forms of MS.

A group of researchers including Jae Lee and Dr Steven Petratos from Monash University, who are funded by MS Research Australia and The Trish MS Research Foundation, have been looking at the role of a particular protein in the damage to nerve fibres. In previous research, they have shown that when this protein is removed from cells, MS symptoms are less severe in laboratory models of MS. What is not clear from this earlier work however, is whether the reduced symptoms are due to the attack by immune cells on the nerve being blocked or whether there is something different about the nerve fibre that makes it less vulnerable to damage.

“In a series of experiments where they removed the protein from nerve cells and then added it back in, they showed that damage to the nerve fibre was linked to blockages in the transport of molecules along the nerve fibre.”

In their new study, published in the *Journal of Neuroscience*, the team used a laboratory model of MS to examine the molecular pathways related to this protein. In a series of experiments where they removed the protein from nerve cells and then added it back in, they showed that damage to the nerve fibre was linked to blockages in the transport of molecules along the nerve fibre. Nerve cells transport vital molecules related to energy production and other materials along the nerve fibre to keep the nerve cell healthy.

The results show that this protein seems to be linked to both the direct nerve fibre damage and the loss of myelin. This is the first time that experiments have shown that the nerve fibres themselves have a role to play in maintaining myelin in MS.

At the moment, medications for MS are based on blocking the attack of the immune cells on myelin and are ineffective against the nerve fibre damage seen in progressive MS. Understanding the details of how nerve fibres are damaged in MS and the molecules involved brings us one step closer to finding ways to block nerve damage in MS and ultimately provide blueprints for treatments that can reverse damage and treat progressive MS.

A close-up photograph of a person's hand holding a bright red, glossy heart. The hand is positioned on the left side of the page, with the palm facing upwards. The background is a soft, out-of-focus bokeh of light circles in shades of white and yellow.

Be a part of the change this end of financial year

The financial year is coming to an end and there is no better time to make a tax-deductible donation to MS Research Australia.

Your donation will help change the lives of people living with MS through supporting the effort to accelerate Australian MS research for prevention, better treatments and a cure for MS.

Over 15 short years, MS Research Australia has become the largest not-for-profit funder of MS research in Australia, with over \$44.3 million invested in funding and facilitating vital research.

With your support significant achievements have been made including:

- **Twenty new grants awarded in 2019 to outstanding Australian MS researchers, totalling over \$1.75 million.** Research focus areas ranged across exploring the role of nutrition and lifestyle factors in MS, targeting myelin repair, and the development of new ways to track disease progression.
- **The publication and launch of the Health Economic Impact of MS in Australia 2017 Report.** This report is an update of our original 2010 report and demonstrates the enormous burden of MS and its impact on quality of life, as well as updating prevalence figures for Australians with MS. The report showed that MS now costs Australia \$1.75 billion per year (an increase of 41% from 2010) and the number of people with MS increased to over 25,600 (an increase of just over 20% from 2010).
- **A new 'Stop and Reverse MS' in ten years initiative,** which brought together stakeholders from across the MS community including people living with MS, researchers, clinicians, industry, representatives from MS Societies, donors and philanthropic organisations. The Stop and Reverse Assembly has developed a strategy to accelerate research with an integrated approach to collaboration, funding and governance.
- **Over \$2 million invested in the last decade to research into Epstein-Barr Virus (EBV)** and the development of a vaccine – an extremely important area of research given that 100% of people with MS have been identified as being infected by EBV.
- **Seven major research platforms funded and coordinated** to bridge knowledge gaps, including the Vitamin D MS Prevention trial, the Australian MS Longitudinal Study (involving over 3,000 participants each year) and the Autologous Haematopoietic Stem Cell Transplant Registry.

Typically there is a 25% increase in donations received by charitable organisations in June in Australia. This is a wonderful time to lend support to causes that you care about as it is easy to track your donations and the time line for claiming your tax deduction is short. Over the coming year, the team at MS Research Australia will continue working hard to accelerate the effort to end MS. Your generous support will continue to play a vital role.

To be a part of the change this end of financial year, please consider donating to MS Research Australia at msra.org.au

Generic options now available for some MS treatments

When you go to the pharmacy and stock up on your favourite cold medication, or another type of over the counter medication, the pharmacist often asks if you want the generic option or not. You now may be asked the same question when it comes to some MS disease modifying therapies.

A generic medicine is defined by Australia's Therapeutic Goods Administration (TGA) as "an additional brand of an existing medicine. It contains the same active ingredient (the chemical that makes the medicine work) as the existing medicine." This means that they work the same way in the body and will have the same beneficial effects. The generic medication must demonstrate that it can meet the same standards of quality, safety and effectiveness as the original brand – this is known as bioequivalence. For MS medications, if the generic medicine is listed on the Pharmaceutical Benefits Scheme (PBS), the cost to someone living with MS is also likely to be the same as the original brand name version.

A generic medication may be packaged or presented differently (i.e. tablets may be different colours or shapes). Some brands may also have different patient support programs or services (such as blood tests) associated with the medication that may not be available with the generic version of the medication.

So why now? Well, the answer to that question comes down

to intellectual property laws. Basically, the inventor or developer of a medication has a period of time where no one can take their medication and copy it and sell it, but after an initial period has lapsed, other companies can produce and sell medications using the same active ingredient. Given that some of the disease modifying therapies for MS have been around for a number of years, their intellectual property is expiring, meaning that companies that produce generic medications can now replicate these medications.

Generic versions of MS medications are already available for some MS disease modifying therapies overseas and as of the 1 June 2019, intellectual property protection for teriflunomide (Aubagio) has expired, so it is expected generic versions of this medication will start arriving in Australia. This means you may be asked whether you would like the generic version when you visit the pharmacy – just as they do for some other medications. It is important to know whether you want the name brand or the generic version, and it is up to you. You will need to inform the pharmacist of your preference. It is important

to make an informed decision, so please discuss your decision with your treating neurologist or MS nurse if you have any questions or concerns about switching between brands of medicine.

More information about generic medications for MS can be found at msra.org.au.



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 \$
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Payment method:

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