

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

\$150,000 awarded to 'outside of the box' research ideas

MS Research Australia has funded six new MS studies totalling almost \$150,000 in the first round of incubator grants for 2019/20.

MS Research Australia is delighted to announce the outcome of the first incubator funding round of 2019/20 – six new grants have been awarded totalling to almost \$150,000. Incubator grants provide seed funding for the early stages of innovative new research, with the aim of generating preliminary data needed to support future grant applications from a range of funding sources. Historically, for every dollar invested in this funding scheme, the scientists have managed to secure an additional 27 dollars in additional funding, really accelerating their areas of research.

The successful studies are:

Professor Julie Henry from the University of Queensland, QLD will use the grant to determine the best way to measure changes in social cognition, which can predict longer term quality of life in people with MS. Social cognition is the ability to process social information, such as recognising facial emotions, and impairment of this can be evident in the early stages of MS. Professor Henry will compare conventional tests with more true to life social cognitive tests and look at how well these tests predict real world outcomes. The study aims to advance the understanding, treatment and management of MS.

Dr Diana Dorstyn from the University of Adelaide, SA will develop and test an online information and discussion forum, MSJobSeek. People with MS can experience significant challenges in finding and maintaining employment, but peers who share their experience of living and working with MS can promote self-management, empowerment, and help other people with MS move into work. The forum will be led by employed peers with MS and overseen by a health psychologist. The study will determine whether MSJobSeek is an effective tool in supporting people with MS and enhancing their employment.

Dr Claudia Marck from the University of Melbourne, VIC will determine the best way to guide MS clinicians to assess smoking behaviour and help people with MS to quit smoking.



Mr Stephen Schibeci, Westmead Institute for Medical Research

Tobacco smoking is associated with worse health outcomes for people with MS, however up to 30% of people with MS smoke. It is not known whether people with MS are routinely asked about their smoking behaviour and whether they get the help they need to quit. Also, it is not known whether people with MS are aware that smoking worsens their MS. Dr Marck will answer these questions by interviewing people with MS who smoke or have recently quit, as well as neurologists and MS nurses. The goal is to bring smoking rates down and maximise health outcomes in people with MS.

Dr Nasser Bagheri from the Australian National University, ACT will assess all MS services providing care for people with MS in the ACT region. Due to the high complexity care that can be required for people living with MS, there is a need for a detailed description of all the MS resources available and how they are used. Dr Bagheri aims to develop a new local decision-making tool that can be used by people with MS and health professionals for monitoring, reviewing and improving MS care in the ACT region. The aim of the study is to eventually extend this nationally.

(continued page 2...)



A WORD FROM OUR CHIEF EXECUTIVE OFFICER

Our 15th year has been another encouraging and impactful one for people affected by MS.

We had some positive breakthroughs this year and we had the chance to (very briefly) reflect on all that we have achieved during the last 15 years. As the largest Not-For-Profit funder, educator and coordinator of MS research in Australia, we have committed over \$4.1 million to MS research for the 2020 financial year. A part of this has come about due to an additional \$700,000 in further funding for translational research and the stellar success of Kiss Goodbye to MS' new fundraising campaign The May 50K, which raised \$2.1 million in its first year. However, we gratefully thank all of our donors, no matter how large or small. We also very much thank the MS state societies who contributed to some of the funded research in the last financial year.

From a personal point of view, it was terrific to see **The May 50K** recently shortlisted by The Fundraising Institute of Australia (FIA) for a major national award. It is satisfying to see our fundraising experts, who work so hard to raise the funds that support our competitive and prestigious MS research, being appropriately recognised. All of the MS Research Australia team contributed to its success but I would like to acknowledge that our Head of Relationships, Fundraising and Development, Susan Williams and Community Fundraising Manager - Kiss Goodbye to MS, Tanja Voss, did an

incredible job with The May 50K and I thank them for all of the late nights, early mornings and weekends to bring this to fruition. The May 50K is one of the most successful inaugural-year digital fundraising campaigns in our sector over the last decade and work is already underway to make year two even more successful.

Recently, we had another of those milestone moments for those affected by MS and those who have dedicated much of their lives to finding solutions to it; the first ever approval in Australia to register a treatment for secondary progressive MS. It wasn't long ago, that I was told by an MS expert, that he didn't think we would ever have registered and approved treatments for progressive MS. Hopefully, by the time we come back to you in early 2020, we will have three!

But very far from this being an end point or a "job nearly done", it reminds us that:

- a) Less than 30% of people living with primary or secondary progressive MS have an effective treatment for their type of MS.
- b) People living with MS are prioritising not only stopping or halting the disease but reversing or repairing the damage done (which the new therapy doesn't do).
- c) The incidence and prevalence of MS in Australia is increasing, despite some experts believing that up to 90% of cases of MS may be preventable.

Much work is yet to be done but the exciting thing is that it's all now very feasible, with your help.

Forty years ago, the interferons became the first ever registered treatment for relapsing-remitting MS across the globe. They revolutionised our approach and our thinking about MS. These "world firsts" gave hope and belief to what is possible and what might lie ahead. Much has now changed in the armoury against relapsing MS but I firmly believe this recent announcement will be as important and as pivotal a point for people living with progressive MS as it was all those years ago for relapsing disease.

Dr Matthew Miles, CEO

\$150,000 awarded to 'outside of the box' research ideas continued...

Mr Jeremy Keane from the Westmead Institute for Medical Research, NSW has found that certain immune cells infected with Epstein-Barr Virus (EBV) express MS risk genes differently in men compared to women. He will use the grant to determine if these differences are caused by different responses to sex hormones. There are three times more women than men diagnosed with MS in Australia. Women are protected from MS relapses during pregnancy when oestrogen levels are high, but they are at increased risk of a relapse after delivery when oestrogen levels drop. The findings from this study will indicate how sex hormones may affect MS, which may be used for therapeutic benefit.

Mr Stephen Schibeci from the Westmead Institute for Medical Research, NSW (pictured front cover) has found that a protein made by EBV hijacks immune cells and manipulates some of the genes within those cells, including the genes known to increase the risk of MS. He will use this funding (with thanks to the Trish MS Research Foundation) to determine whether this protein can be blocked. Findings from this work may support new approaches to control EBV infection, which could lead to the development of new treatment options for people with MS.

The standard of application was extremely high, reflecting the high calibre of science happening in Australia. It is through the generosity of our fundraisers and donors that we are able to fund these innovative projects and ideas, so that we can Stop and Reverse MS in the next 10 years.

More information about these grants and other research currently funded by MS Research Australia can be found at www.msra.org.au/projects



Paired fellowship recipients closing the gap on myelin repair

An innovative funding scheme generates ground-breaking progress in understanding the genetic changes in MS as well as myelin repair.

The MS Research Australia Macquarie Group Foundation Paired Fellowship is a novel scheme where a senior laboratory-based research fellow and a clinician work together to 'fast-track' research breakthroughs and improve outcomes for people living with MS. The inaugural Paired Fellowship was awarded in 2017 to Associate Professor Kaylene Young and Professor Bruce Taylor from the Menzies Institute for Medical Research in Tasmania. They have made some exciting progress so far.

MS Translation Centre and the MS Research and Translation Network

Associate Professor Young and Professor Taylor have established the MS Translation Centre at the Menzies Institute for Medical Research and the MS Research and Translation Network. One of the projects they have been working on, along with members of the Network, is the production of a Massive Open Online Course (MOOC) called Understanding MS.

The course launched internationally in April with almost 4,000 people enrolling and close to 2,000 people completing it. The launch was a success with 97% of participants recommending the course and 61% stating they would implement what they've learnt into their lives. Of those that completed the course, 40% had MS, 40% were carers or family members of people with MS, and 20% had no link to MS. This is a great initiative to educate people about MS while also raising awareness of the disease.

Genetic changes in families with MS

In his clinical research, Professor Taylor has identified families with an unusually high number of people with MS. His research has identified a genetic change that occurs only in the family members who have MS. In collaboration with Associate

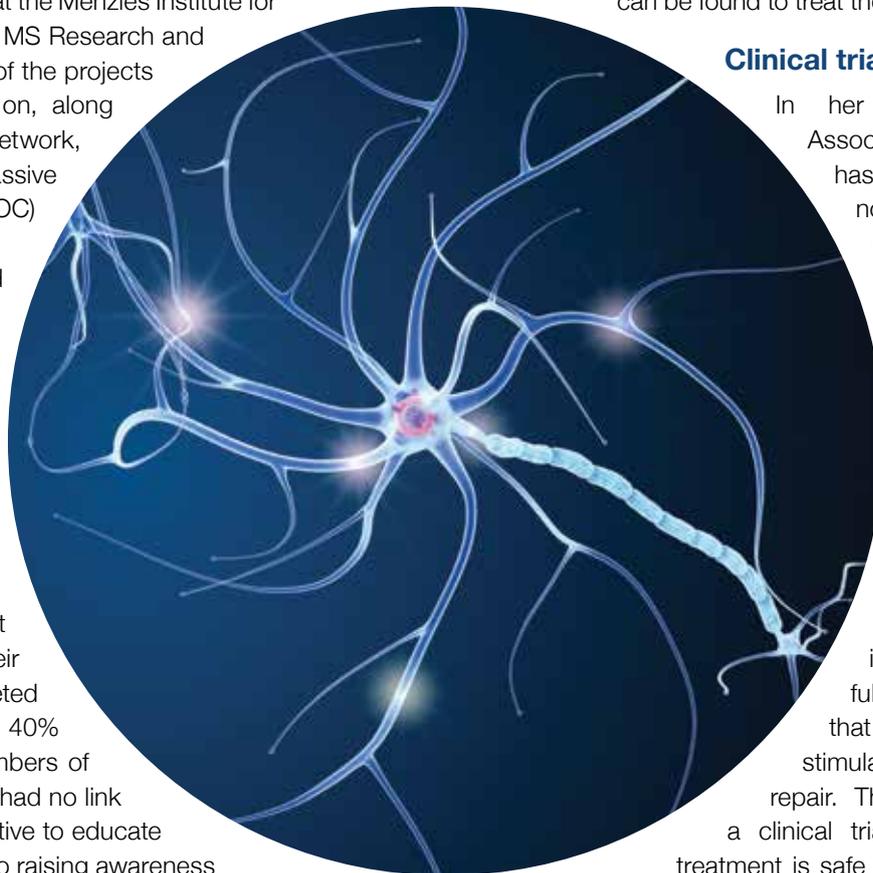
Professor Young, they are now working to determine the role this genetic change plays in cell health using cells derived directly from the people with MS.

Associate Professor Young has used a cutting-edge technique with international collaborators to generate stem cells and then myelin-producing cells directly from blood cells of the family members affected by MS. These cells will form part of a wider stem cell repository called MS Stem. Currently, they have blood samples from 70 people with the aim of having stem cells generated from all samples by early 2020. The ultimate goal of this study is to determine how the genetics of these cells are causing biological differences and to see if any existing drugs can be found to treat those differences.

Clinical trial into myelin repair

In her laboratory research, Associate Professor Young has found that a form of non-invasive transcranial magnetic stimulation can promote myelin growth in laboratory models of MS. To complete this work, Associate Professor Young and her team have developed new models of MS that more accurately mimic what is happening in human disease, to fully investigate the way that transcranial magnetic stimulation leads to myelin repair. They are now launching a clinical trial to determine if this treatment is safe and effective for people with MS. Participants have been recruited for the trial, and 30 are expected to complete the trial by early 2020.

The progress that has been made on these studies is huge and exciting, and we look forward to the outcomes. This work will provide a greater understanding of the genetics of MS, and importantly, will hopefully lead to the treatment of people with progressive forms of MS.



Top MS researchers meet in Melbourne

On the 31st October and 1st November, MS researchers, MS nurses, clinicians and allied health providers gathered in Melbourne to discuss their latest work and most exciting findings.

This was our seventh Progress in MS Research Conference which was held over two very full days. There were close to 50 oral presentations and over 70 poster presentations, making this one of the largest scientific programmes we have ever had.

The conference is designed to help boost collaboration and stimulate innovative research into the causes, prevention, improved treatments and ultimately cures for MS. These are ambitious goals and to achieve this we need to collaborate and work together – as the saying goes, “alone we can do so little; together we can do so much”. The delegates at the conference truly embraced this notion and there was a high level of exchange of scientific thought and investigation among neurologists, scientists, biologists and health researchers.

In addition to the 150+ Australian scientists, we had three fantastic international experts from the US and Sweden who shared their research and built relationships with our researchers here in Australia.

The main themes of the conference were:

- Smarter clinical trials
- Deep characterisation of MS
- Patient reported outcomes
- Accelerating the drug development pipeline

However, many other fascinating and important results were shared across diverse fields including diet and causes of MS, autologous hematopoietic stem cell therapy (AHSCT), immunology, physiotherapy and more.

Smarter Clinical Trials

All MS treatments need to go through clinical trials to prove that they are safe and effective. Traditionally, clinical trials in MS have used the number of relapses a person has as a sign of whether the treatment being trialled has been successful or not. However, as our treatment options get better and the number of relapses are being reduced, we need additional indicators to show whether a treatment option is superior to current treatments.

We also need robust indicators for disease progression in people with progressive MS, as one challenge hampering the development of new medications is the lack of a readily available robust and objective measures of disease progression. A number of different researchers are busy trying to develop such measures and presented their

progress at the Conference.

Dr Eduardo Cofre Lizama from the University of Melbourne explained his latest discovery – that certain ankle muscles activate in order to compensate for various changes in gait due to MS – which could potentially be used as a measure of disease activity.

Daniel Merlo from Monash University presented his work involving the use of online tools to determine changes in cognition, with these changes then being used to predict the trajectories of a person’s MS.

Up-and-coming researcher Kira Groen from the Hunter Medical Research Institute at The University of Newcastle shared data looking at a type of genetic material in the blood, known as RNA, and showed how it changed at different times in the MS disease course.

The work of these researchers is diverse, tackling the challenge from very different angles. However, all of these approaches could help us come up with a range of new measures to track and predict the direction of someone’s MS, as well as monitor how they are responding to existing medication or novel therapies.



Conference scientific organising committee and the 3 international speakers

Deep Characterisation of MS

Advances in technology are providing amazing new tools allowing scientists to see further and further into MS.

Exciting research presented from an early career researcher, Dr Felix Marsh-Wakefield from the University of Sydney, showed analysis of blood from people with and without MS. He looked at up to 37 proteins on the surface of cells simultaneously, providing an even deeper understanding of what is happening to a type of immune

cell called 'B cells' in people with MS.

Dr Scott Kolbe from the University of Melbourne explained his work using cutting edge magnetic resonance imaging (MRI) technologies to measure the density of nerve fibres in the brains of people with MS. He has discovered that this measurement is nearly seven times more sensitive than measuring changes in brain volume, and is a good indicator of changes in a person's cognition such as thinking and memory.



Conference welcome and opening address

Technology also enables very detailed analysis of the genetic composition of individual cells – something which was previously unobtainable.

Associate Professor Justin Rubio outlined his research investigating changes in DNA of single brain cells affected by MS. This study fitted nicely with the work of one of the international speakers, Associate Professor Gonçalo Castelo-Branco, who is also using some of the latest genetic technologies to decipher which genes are activated in individual brain cells. He showed that some of the cells which coat nerve fibres in myelin, may also have a function within the immune system. These cells make up a small portion of myelin producing cells and without our ability to look at cells individually they would have remained hidden. Now they have been uncovered, this raises the next question – what role might these cells play? The answer may revolutionise the way we think MS develops.

Patient Reported Outcomes

Technology and wearables (e.g. fitness trackers and smart devices) were also mentioned in research looking at patient reported outcomes. Scientists are finding new ways to systematically collect patient reported outcomes – a vital area of research considering that the person living with MS is the one with the most insight into their own journey with the disease.

We heard from Associate Professor Ingrid van der Mei from the Menzies Institute for Medical Research, about her

plans in conjunction with MS Research Australia to build a platform to combine clinical data with patient reported outcomes, as well as other data. The aim of this is to help develop a fully integrated picture of a person's MS, known technically as 'deep phenotyping', to improve treatment decisions.

To collaborate with and leverage off other areas of health, Professor Chris Bain from Monash University presented what is happening in the digital health sector, which aligned well with what people are investigating in the MS research arena

Dr Jo Lane from the Australian National University presented her work, which includes collaboration between a range of scientists, health care providers and people living with MS to develop integrated genetic and digital medical technologies for disease monitoring.

All of these projects share the goal of developing an integrated system for people with MS to be well informed and empowered to actively manage their health and wellbeing.

Accelerating the Drug Development Pipeline

Another important area was translating fundamental biological research (the first stage in the research process) out of the laboratory into the clinic faster.

Dr James Hilton presented his research looking at a drug which helps redistribute copper in the brain and spinal cord which is potentially contributing to the death of nerve cells, not just in MS but also motor neuron disease (MND).

Additionally, Dr Steven Petratos from Monash University showed promising results of a treatment option which involved using stem cells as a drug delivery tool. His work showed that these cells can migrate to the brain where they can then help with the repair of myelin in laboratory models.

These were only two of the novel therapies described at the conference, but it is vital that these treatments are rapidly translated to the clinic. The pathway from the lab to the clinic is a long and arduous path, and one of the sessions at the conference specifically tried to address this. A panel discussion included contributors with experience in taking fundamental research into clinical development. In Australia there is a depth of talent to make this happen but at the moment the process can be fragmented and this session aimed to bring people together to accelerate important fundamental research into the clinic.

Onwards and upwards

Overall it was amazing to see such dedication, commitment and quality of the scientists in the room. Additionally there were a number of young up-and-coming scientists presenting their work which was world class – a clear indication that MS research in Australia is only going to go from strength to strength.

Fundraising in focus

I'm so thankful to be able to write this article for you today. In 2019, fundraising has reached new heights and this is because of you and supporters just like you.

You have made an enormous difference to the lives of people with MS. Here are just a few of the fundraising highlights from the year...

The May 50K

In May this year over 9,200 people signed up for The May 50k to raise life changing funds for MS research. Don't tell anyone, but I initially thought around \$500,000 would be raised. Sometimes it's just so wonderful to be wrong! As you might know by now, the MS community well and truly stepped it up and raised a record breaking \$2.1 million. A wonderful example of supporters like you moving the dial on MS research.

Gifts in Wills

Leaving a gift in your Will to MS Research Australia is one of the most effective and enduring ways to express your deepest values, protect future generations and play a pivotal role in helping accelerate MS research both locally and globally.

Once again this year we were humbled by the thoughtful and generous actions of supporters who left a gift in their Will. One such supporter, Sally Anne, was motivated to leave a gift in her Will to MS Research Australia after watching her life-long friend battle with progressive MS over many, many years. It was her firm belief that supporting research will end MS and her deeply held desire to help make sure others do not have to endure as her dear friend did.

Thousands of everyday Australians choose to support causes closest to them in this way. You don't have to be wealthy. We are immensely grateful for any gift, no matter the size, as each one adds up and helps create a better future for people living with MS.

This year more than \$380,000 was provided to MS Research Australia through gifts in Wills. Truly transformative, these legacies help ensure the next generation can realise a world where MS no longer has the power to interrupt and limit their lives.

We're almost there but we simply can't do it alone. Your legacy can be part of the solution to end MS.

Trusts and Foundations

Support from Trusts and Foundations to MS Research Australia has long played a role in increasing the funds available for MS research. The Trish MS Research Foundation and MS Research Australia have worked in partnership for many years and this year have together been able to fund a new Translational Research Grant round. This was made possible as a direct result of the Trish MS Research Foundation receiving two gifts in Wills. Both The Trish MS Research Foundation and all of us here at MS Research Australia would like to acknowledge the thoughtfulness and generosity of both the Deputy Headmistress of Trish Langsford's school, Ravenswood School for Girls, and Mia Polykarpou, an inspirational person who lived with MS, for their gifts. Special thanks to all of our Trust and Foundation partners, we are very appreciative of your ongoing support.

Thank you for taking a moment out of your day to hear about the wonderful achievements of the MS community. The fundraising team here at MS Research Australia will be back again next year, working tirelessly to make sure we can fund even more research in 2020 and beyond.

You can donate today by visiting our website: www.msra.org.au/donate



Susan Williams, Head of Relationships, Fundraising and Development

Kiss Goodbye to MS is celebrating its biggest year yet

\$2.5 million raised for MS research!

Looking back on what has been the biggest year for Kiss Goodbye to MS ever, let's take a moment to acknowledge and celebrate your endless passion, determination and enthusiasm to raise life-changing funds for multiple sclerosis research – you have swept us off our feet!

Your incredibly hard work raised a record-breaking \$2.5 million for MS research in 2019 – thank you!

Historically, Kiss Goodbye to MS has been run as a “do-it-yourself” fundraising campaign only, encouraging the MS community to raise funds for MS research with their activity of choice.

This year, we decided it was time for a change! We took a leap of faith and revamped our beloved campaign to raise substantially more funds for vital MS research, fast-tracking our way to Kiss Goodbye to MS. It's still the same campaign that that we all know and love, just with a little more attitude and determination. True to form, you embraced it!



The May 50K was born

This new virtual fitness and fundraising challenge, encouraged people beyond the MS community to raise funds for MS research. Over 9,200 people took on the challenge and left their limits behind by running or walking 50 kilometres throughout the month of May. We're still pinching ourselves, as together you logged 474,575 kilometres and raised over **\$2.1 million** for life-changing MS research! An outstanding accomplishment that will make a long lasting difference to the 25,600 Australians living with MS and the future landscape of MS.

A global movement

Kiss Goodbye to MS continued to inspire people across the world to join the movement and come together to raise funds for MS research. Our Australian campaign was again celebrated in **13 countries**, enabling MS researchers to continue their invaluable work to help find better treatments and a cure for MS. Watching the international efforts and funds raised increase in 2019, we know that it's no longer about hope. We know that our combined efforts will stop and reverse MS.

The Great Wall of China Trek

Another highlight of the year was our first 'fundraising adventure', which saw 19 dedicated supporters travel to China and trek the Great Wall. Our passionate team challenged themselves, made unforgettable memories, overcame every obstacle thrown their way and collectively raised over **\$70,000** for MS research. Registrations for our next 'fundraising adventure' are already open, with Tuscany announced as the next adventure destination! However, the China trek will certainly go down as one of the most special experiences in Kiss Goodbye to MS history.



A huge thank you to the Kiss Goodbye to MS community

These are just a small selection of our 2019 highlights. We see and appreciate everything you do for MS research. Thank you for taking on The May 50K, holding fundraising events, donating, sharing your #KissGoodbyeToMS snaps on social media, purchasing merchandise, attending events, trekking the Great Wall of China, donating your time, skills or products and volunteering. We are in awe of your support!

Every dollar you raised will help MS Research Australia to continue funding the brightest MS researchers and most innovative projects in Australia. Every project we fund could lead to the next breakthrough for the prevention, better treatments and a cure for MS.

Thank you for an unforgettable 2019 which exceeded all our expectations! We can wholehearted say that this year will always have a very special place in our hearts.

Stay tuned for 2020 – we've got even bigger plans for The May 50K and are looking forward to taking on Tuscany with you. And as always, we also have a few surprises in store!

LIVE Update



MS research in cyber space

A great way to stay up-to-date on the latest progress in MS research is by joining us in cyber-space for our live streamed events.

True to form, almost 900 of you tuned in to our Live Update on Saturday 2 November to hear the latest from a selection of international and home-grown MS research experts.

You joined us from all over Australia and around the world with people live streaming from as far afield as the UK, Spain, Mexico, Kuwait, Singapore, South Africa and the USA.

This was the first time that the fantastic Breony Heanue joined us as co-host alongside MS Research Australia's Dr Hamish Campbell. Breony was diagnosed with MS three years ago and earlier this year used the new Kiss Goodbye to MS fundraising campaign, The May 50K, as a way to tell friends about her diagnosis while raising funds for MS research.

Breony and Hamish interviewed our four expert speakers on topics including:

- Deciphering environmental enigmas: MS risk factors explained
- Repairing MS damage – remyelination research
- Integrating patients with research – self reported outcomes
- Evolution of the Australian MS treatment landscape: where to next?

It was really insightful to get the experts' views on your questions too. We had over 300 questions submitted prior to and during the live stream with the MS experts answering as many as possible.

We know you're busy people and can't always live stream on the day, so we made a recording of the event available straight away so you don't miss out. There have been 9,000 views since the event so if you haven't had chance watch yet, simply visit msra.org.au/events/liveupdate2019/livestream



Live Update interview panel

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