



NEXT

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

New MS fellowship to fast track breakthroughs

A new MS Research Australia fellowship in partnership with the Macquarie Group Foundation will enable a senior research fellow and a clinician to work together to 'fast-track' research breakthroughs and improve outcomes for people living with MS.

The MS Research Australia-Macquarie Group Foundation Paired Fellowship addresses one of the key recommendations made in the 2013 McKeon Review into Health and Medical Research, which was for clinicians to participate in the research process. This is to break down the barriers between the lab and the people-based research done in the clinic to ensure faster translation of research discoveries into better health outcomes in the community. The Review also recommended that 1,000 practitioner fellowships be funded within 10 years.

The Commonwealth Health Minister, the Hon Greg Hunt MP said, 'Australia's status as a health and medical research powerhouse depends on the talent of researchers. MS Research Australia is leading the way with this new initiative.'

Dr Matthew Miles, CEO, MS Research Australia adds that, 'Our new grant program launches a unique initiative, identified in this country as a strategic goal of great importance. We believe this to be the first ever research practitioner/researcher fellowship fully funded by philanthropic means.'

'The leadership shown by the Macquarie Group Foundation in co-funding this fellowship with MS Research Australia will hopefully lead other philanthropic supporters to do the same,' Dr Miles said.

'The Macquarie Group Foundation is pleased to support this important initiative

in collaboration with MS Research Australia, which addresses a clearly demonstrated gap in medical research in Australia,' said Lisa George, Head of the Macquarie Group Foundation. 'We hope this paired fellowship will provide great outcomes for many people with MS.'

In a competitive process, the inaugural recipients of this fellowship are Dr Kaylene Young and Professor Bruce Taylor from the Menzies Institute for Medical Research at the University of Tasmania.

'Australia's status as a health and medical research powerhouse depends on the talent of researchers. MS Research Australia is leading the way with this new initiative.'

– Hon. Greg Hunt, Health Minister

Currently, there is no treatment that can prevent nervous system damage in people with MS. Dr Young (laboratory based MS researcher) and Professor Taylor's (clinical MS researcher) clear objective is to expedite new treatments that can protect and repair the nervous system. The two are also leading Australia's first MS Translation Centre at the Menzies Institute which aims to



focus on moving discoveries along the pathway to change clinical practice.

Over the next three years, Dr Young and Professor Taylor will work in tandem to accelerate Dr Young's laboratory findings into clinical practice and take Professor Taylor's clinical discoveries into the laboratory to help develop targeted new treatments that aim to prevent or halt nervous system damage.

Professor Taylor said 'Through my clinical research I have been able to link a particular genetic change with the development of MS. I am looking forward to working with Dr Young to move this clinical finding into the laboratory in order to identify how we can develop a drug that can protect the nervous system against MS-related injury.'

Dr Young further explained that 'by working with Professor Taylor, I will be able to determine whether the treatment I have been investigating in the lab is safe for people with MS by progressing the treatment into a clinical trial.'



The 2017 Telstra National Business Awards held in Sydney was the culmination of thousands of detailed and intensive applications and multiple interviews from all over Australia.

A team of Telstra judges debated on the finalists in each category long into the night with the coveted winners announced at a gala dinner event held at the Sydney Convention Centre.

We are so very proud to announce that MS Research Australia took out one of the top awards, the 2017 Telstra Australian Charity Award Winner. An amazing achievement for our small team.

We would like to acknowledge the incredible work of our fellow finalists including Big hART and Youngcare who are outstanding organisations.

We were also thrilled to have been a finalist for the overall Telstra Business of the Year Award, after winning the NSW Business of the Year. In what was an incredibly close contest, we salute and admire the eventual winners, GenWise.

Award programs of this calibre provide a number of benefits. For MS Research Australia and the MS community, programs like the Telstra Business Awards and the Australian Business Charity Awards help to build awareness of a misunderstood disease. They help to reinforce credibility and validate the organisation in the eyes of prospective donors and philanthropists. Winning these awards demonstrates to the community that MS Research Australia has gone through rigorous analysis and our transparent operations and financials are always willingly open to scrutiny.

Consistently being recognised by your peers and experienced judging staff in this metric conscious world, reinforces the professionalism of MS Research Australia and most importantly continues to attract much needed attention for our laser focussed mission to cure MS.

We have the plan, the expertise, the people and the dedication to achieve that goal - the only thing that is lacking is the dollars. We very much hope you can help us fill in the missing part.

Dr Matthew Miles, CEO

Boardroom observer

MS Research Australia is thrilled to be asked to participate in The Sydney Observership Program for the second consecutive year.

The Sydney Observership Program was initially started by Jonathan Gavshon with assistance of well-known businessman, David Gonski AC. It provides unique opportunities for young talented individuals, to gain experience on Boards in the not-for-profit sector. All successful candidates are mentored and trained before and throughout their twelve month placement. During that time, Observers attend all Board and Committee meetings as a non-voting member, in order to learn about the fundamental principles and functions of non-profit boards, the role of board members, the processes and other governance priorities.

‘I feel particularly lucky to have been paired with MS Research Australia because in my view not only is it a fantastic cause, but a very well run organisation with an experienced Board.’

Last year MS Research Australia’s Board observer was JB Were’s Head of Philanthropic services, Shamal Dass. This year, Fleur Wright, Executive Director at UBS has commenced the program. Fleur has 15 years’ experience collaborating with global banking and investment companies. Under the Program, she has represented MS Research Australia at the inaugural Sohn Hearts and Minds conference and fundraising events for research into Osteogenesis Imperfecta. We believe her experience and knowledge will be extremely beneficial to our organisation.

‘Fleur is an enthusiastic, smart and well-connected young leader. Among other things, we believe she will be a great contribution to our

team, particularly in the areas of data analysis, business processes and organisational contacts. We look forward to developing this working relationship throughout the year’ said Chairman, Paul Murnane.

Fleur said ‘The Observership Program has provided me with a robust framework and network to be able to provide support in the not-for-profit sector. I feel particularly lucky to have been paired with MS Research Australia because in my view not only is it a fantastic cause, but a very well run organisation with an experienced Board. I have already witnessed hugely valuable outcomes towards prevention, treatment and a cure for MS’.

Our increasingly diverse Board experience, skill set, tenure and gender balance, are ensuring that we continue to improve and grow our strengths and keep in line with AICD recommendations. Paul also mentioned ‘I am incredibly proud of our transparent processes and the fact that we can provide such an opportunity to a young up and coming professional’.



Fleur Wright, Executive Director, UBS



Dr Kaylene Young and Professor Bruce Taylor awarded the inaugural MS Research Australia-Macquarie Group Foundation Paired Fellowship

Science with a purpose

Following the announcement of the MS Research Australia-Macquarie Group Foundation Paired Fellowship, MS Research Australia Advocate and Kiss Goodbye to MS Ambassador, Jillian Kingsford Smith spoke to Professor Bruce Taylor and Dr Kaylene Young on what this grant means for the MS community.

Anyone living with MS has a different perspective or indeed a heightened sense of both the significance and value of time.

In what is believed to be a world first, the MS Research Australia-Macquarie Group Foundation Paired Fellowship program provides hope to people living with MS by putting laboratory and clinical science side-by-side. It potentially fast tracks ground breaking research, translating it into reality for the benefit of the MS community.

'One of the things this fellowship has done, which is very important, is brought a clinical researcher and a research scientist together,' explains Professor Taylor. 'Kaylene and I both realised when we started talking about the development of our project that because our lines of enquiry and interests in MS coalesced, that we could, in fact, enhance what each other was doing.'

'Kaylene is committed to taking my clinical findings and giving it a significant scientific underpinning and I can take what Kaylene has discovered and bring that into the clinical environment,' continued Professor Taylor. 'This has been a major move forward for both of us. It would be easy to stay rooted in our own silos but instead we're bridging a gap, enhancing the work of one another and accelerating the outcomes. That in itself is groundbreakingly important.'

For a research scientist, security is something they unfortunately learn to live without. However, the three-year grant has inspired the pair to envisage loftier, long-term goals.

'They want to see science with a purpose; science where they can see an outcome that may potentially change the way they live with the disease.'

'Without the fellowship, I would still be carrying out research, but it would likely be far more fragmented,' explained Dr Young. 'This fellowship allows me to commit to my goal and also work with Bruce to be able to achieve better outcomes for people with MS. I can be more ambitious with my planning and goals because I have that guarantee of support.'

As a clinician, Professor Taylor speaks to people living with MS on a daily basis. 'The MS community are seriously supportive of research, but what they want to see is research that is not completely unrelated to their own situation in life,' said Professor Taylor. 'They want to see science with a purpose; science where they can see an

outcome that may potentially change the way they live with the disease.'

Any major medical or scientific advancement will be riddled with dead ends but a paired fellowship program such as this allows for a shortened time between making a discovery and being able to say 'yes that's worth pursuing; that's worth bringing into a clinical environment to progress.' Obviously, shortening that timeframe is incredibly valuable to the MS community.

All too often wonderful scientific discoveries are announced, but with the caveat that a potential benefit may be ten, fifteen or even more years away from realisation.

Professor Taylor and Dr Young are focussed on developing pathways to shorten that timeframe, expediting the translation of their research into reality.

The pair aim to take their ideas and bring them into a clinical trial setting within two to three years. And whilst that may sound like a long time, in science that's an exceptionally short time span. Following that research phase, the goal is to spend only three to five years on the clinical evaluation phase. In a nutshell, the paired fellowship will enable the translation of research into practice within five to eight years, rather than ten years plus.

'This fellowship will absolutely change the way I operate clinically. It will make me think about aspects of my work from a different perspective and I daresay make me chase things harder,' explained Professor Taylor. 'It will make me want to really understand findings more extensively and then also show how they are translated into better outcomes for people living with MS.'



Jillian Kingsford Smith

Jillian Kingsford Smith has worked internationally as a journalist, turning her hand to writing books in 2012 when she was diagnosed with MS at the age of 42. She is a Kiss Goodbye to MS Ambassador, MS Research Australia Advocate and best-selling author.

Unlocking the genetics of MS relapses

Australian researchers discover a gene which might influence MS relapse rates.

Our genes influence everything about us, including the way we look, the way we act and of course they play a significant role in our susceptibility to diseases, including MS.

Previously a considerable amount of research has gone into identifying genes that contribute to the risk of developing MS. MS Research Australia has supported scientists in the Australia New Zealand MS Genetics Consortium (ANZgene) who have contributed to this work with the international discovery of over 110 genes that play a role in the development of MS.

The majority of these earlier studies have compared the genes of those with MS and those without, this is very useful in discovering the genes associated with the development of MS. However, as we know, the course of MS, the number of relapses and the severity of symptoms is hugely variable between individuals with MS. None of these genetic studies have been able to tell us why.

Now an Australian study, led by PHD student Yuan Zhou and overseen by Professor Bruce Taylor at the Menzies Institute for Medical Research at the University of Tasmania, has carried out one of the largest genetic association studies to look at whether genes determine relapse rates in people with relapsing MS.

In this study which was published in the *Journal of Neurology, Neurosurgery, and Psychiatry*, the researchers investigated three different populations, the Tasmania MS longitudinal study, the MS Research Australia-supported Ausimmune/Auslong longitudinal study and the US Paediatric MS longitudinal study. Each of these studies followed people with MS for at least six years, and the Ausimmune study also included people from the very first onset of the disease.

‘They identified differences in one gene in particular, the LRP2 gene, that was significant in predicting relapses in both paediatric and adult MS.’

A total of 449 DNA samples were analysed and compared to the clinical history, including relapses and treatments, to see whether there were genetic differences between those who had more relapses than those that had fewer relapses.

They identified differences in one gene in particular, the LRP2 gene, which was significant in predicting relapses in both paediatric and adult MS. With one version of the gene even leading to a doubling of the risk of a relapse.

Interestingly, while most of the previous genes linked with the development of MS are associated with the immune system, this gene is thought to be involved in the development of the brain. Genetic studies like this are important because they can potentially



be used to help doctors and patients better understand their prognosis, i.e. what to expect from the disease. However, they may also shed light on the molecular causes of relapses, which will lead to a better understanding of the drivers of relapses, and ultimately to more targeted treatments.

MS Research Australia is also funding research by Dr Vilija Jokubaitis at the University of Melbourne, who is looking into the inherited differences between people with either mild or severe MS with the hope of determining which genes can predict disease severity.

We have learnt a lot about MS through genetic studies but our genes have not revealed all their secrets yet.

First treatment for primary progressive MS approved in Australia



MS Research Australia has been reporting on every step that Ocrevus a new MS medication, has taken on its journey to become the first ever approved treatment for progressive MS and relapsing MS in Australia. In July, Ocrevus reached another milestone, it was listed on the PBS for relapsing MS. MS Research Australia is continuing to advocate for Ocrevus's inclusion on the PBS for progressive MS, and is calling on the MS community to add its voice in the call for its inclusion.

Australia has moved swiftly and positively for people with MS in regards to Ocrevus (ocreluzimab) and is the second country in the world, after the U.S, to approve this very important therapy.

Ocrevus has been recommended for listing on the Pharmaceutical Benefits Scheme (PBS) for relapsing MS. Now we await with great anticipation the outcome of the Pharmaceutical Benefits Advisory Committee meeting in November this year where Ocrevus will be considered for listing on the PBS for primary progressive MS. Affordable access to all MS treatments is paramount, but most intensely so for those with progressive forms of MS who, have no treatment options available. Members of the MS community can have their voice heard by making a submission to the PBAC via the pbs.gov.au website before 4 October.

Primary progressive MS is a form of MS in which there is a gradual worsening of symptoms and disability right from the start, without the periods of attack and recovery that characterise relapsing remitting MS. 10-15% of people diagnosed have primary progressive MS.

The reasons why some people develop primary progressive MS rather than relapsing remitting MS are still not clear. There is a huge research effort underway to shed light on why this is, with significantly more work needed.

Up until now, all of the treatments that have worked for people with relapsing remitting MS have sadly failed when they have been tested in clinical trials for primary progressive MS, leaving researchers, clinicians and people with MS disappointed and frustrated.

Ocrevus has shown very good results in clinical trials for relapsing remitting MS, significantly suppressing relapses and delaying the development of disability. In the trials for primary

progressive MS, the effect size was more modest, slowing down disability progression by around 25% in people who received Ocrevus compared to those who received the placebo.

Ocrevus won't completely stop progression in people with primary progressive MS, but it can be expected to preserve physical function and quality of life for longer.

Most importantly, it also provides vital clues as to what is happening and where to go from here. This is just the beginning of a renewed and targeted push to develop highly effective treatments that will put a stop to disability progression altogether.

‘Ocrevus won't completely stop progression in people with primary progressive MS, but it can be expected to preserve physical function and quality of life for longer.’

Ocrevus belongs to a class of drugs known as monoclonal antibodies. It recognises and binds to just one molecule in the body.

This molecule is called CD20 and is only found on the surface of a specific type of immune cell known as B cells. It binds to CD20 on the B cell, triggering the destruction of this cell. This then depletes the number of these immune cells in a person's body.

Traditionally, B cells have not been the primary focus of research in MS. The success of Ocrevus, and other treatments that target B cells has however refocused researchers' attention. The Ocrevus trials have not only been a success in terms of

treatment, they are also a success in helping us understanding the biology of MS.

This has given new impetus to the researchers working on progressive MS and to the pharmaceutical industry – opening up the field and providing new incentives to re-double efforts.

The International Progressive MS Alliance, of which MS Research Australia is a managing member, is playing a central role in this effort.

The Alliance has brought together, not only MS organisations and researchers, but also industry representation and regulators. This is to ensure that all of the right expertise is in the room to speed up progressive MS treatments and information, from the laboratory, pre-clinical testing, clinical trials and, finally, through the regulatory approvals process.



How your legacy to MS Research Australia can make a difference

Many of Australia's greatest medical research institutions have led wonderful discoveries and medical breakthroughs thanks to the support that has eventuated via bequests. Some institutes, such as the St Vincent's Institute of Medical Research and the Walter and Eliza Hall Institute of Medical Research in Melbourne were only built in the first place, due to incredibly generous bequests.

In the world of multiple sclerosis, why should you leave a bequest to MS research? When bequestors were asked about their motivations they often said that one of the major factors that compel them to leave a bequest to MS research, is that they 'don't want others to go through the same thing that I did'. It is often seen as changing the landscape for people with MS, creating a large impact or 'significantly moving the dial'.

One of our roles at MS Research Australia is to further develop and maintain mutually beneficial partnerships between ourselves and the MS community. We gain financial support for research projects that are funded now and in the future for the national and international benefits for people living with MS.

Independent research conducted by Galaxy Research in early 2017 highlighted that the vast majority of people with MS in Australia prioritise research as the most important area of need for their philanthropic dollar. Other research conducted by the philanthropic unit at Swinburne University showed that 55% of all bequests given to health-related initiatives, on average, are directed to medical research.

‘Medical research is a natural and obvious choice as it is a way to make a tangible difference to the world.’

Over the last 14 years, the vast majority of bequest income (over 97%) from people affected by MS has gone to the state based MS societies to primarily provide vital care and services for people with MS. MS Research Australia has received around 4% of the total bequest income. Most recently however MS WA has announced they will allocate 50% of their non-restricted bequests to MS research through MS Research Australia.

MS Research Australia is launching a new bequest initiative to grow the bequest funding that can be allocated to important MS research. This initiative is about leaving a legacy to MS Research Australia and being able to make a significant difference to people with MS now and in the future. These changes will lead us closer to the vision of a “world free of MS”.



Paul Murnane, Chairman, MS Research Australia with his daughters Stephanie and Joanna

The **bequest** initiative will now encompass 3 main opportunities for anyone wanting to leave a bequest to **MS Research Australia**:

- **A general bequest to MS research;** to help fund our growing gap in the annual funding of MS research. This year we had over \$4 million in high potential MS research projects that remained unfunded.
- **A priority bequest to MS research;** highlight in your Will that you would like to ensure your funds go to one of the top 3 priority categories for people affected by MS in Australia (a) Research in to a cure for MS (b) Research in to the prevention of MS (c) Research to find better ways to treat MS.
- **A targeted bequest to MS research;** you can highlight that you may wish to leave a bequest to an emerging or targeted area of MS research.

Former investment banker, now corporate advisor, and Chairman of MS Research Australia, Paul Murnane has seen first-hand the desperate need for medical research funding here in Australia after his wife Annie was diagnosed with MS.

Paul said 'My wife Annie and I, along with our two daughters are all in favour of leaving a bequest to MS Research Australia. Medical research is a natural and obvious choice as it is a way to make a tangible difference to the world after you are gone.'

'Since I first became involved over 20 years ago, the landscape of MS has completely changed, people are now being diagnosed far quicker, there are better and substantially more treatment options available to manage the most common form of MS, the overall quality of life for people living with MS is much better, as well as a universal increase in hope for a cure within our lifetime. This is all a credit to the fantastic medical research that has been done.'

MS Research Australia welcome the opportunity to discuss with you the difference a bequest will make. We also ensure that the families and loved ones of the bequestor are fully updated on where their funds have gone and the impact made.

To start a discussion please call Neil Robertson on **1300 356 467** or visit **www.msra.org.au/bequest/**

A school rallies behind a student diagnosed with MS



When a year 12 student at SCEGGS Darlinghurst was recently diagnosed with MS the school community were shocked.

The student, Niamh was confused and, as would be expected, scared. But over the last few months Niamh has transitioned on from her initial shock, to become a young woman who is brave and determined not to let a diagnosis with MS stand in her way.

The school community have not only supported Niamh, they have rallied around her. The school invited MS Research Australia's Research and Development Coordinator, Dr Hamish Campbell to address the school assembly, educating the entire school on what a diagnosis with MS means, and the incredible progress we have made in better understanding this disease over the last 10 years.

Year 12 can be tough for anyone, let alone for someone who has just been diagnosed with a chronic disease that currently has no cure. But Niamh, with the support of her family, teachers, friends and school community has been so brave on her journey. Her diagnosis with MS has raised questions that any other 17 year old wouldn't need to consider. And while

our team at MS Research Australia can't answer all of those questions, she is able to speak directly to our research team at any time.

The school's year 12 cohort have committed to raising funds for research into MS, determined to make a difference that will impact their friend's future. They have raised \$7,792 (and counting) for Kiss Goodbye to MS so far, surpassing their original goal of \$3,000 within weeks!

‘The school community at SCEGGS Darlinghurst have not only supported Niamh, they have rallied around her.’

In a true show of support 100 students, and a few teachers, from the school joined the Kiss Goodbye to MS City2Surf team on the 13th August. They all proudly wore their Kiss running singlets walking, running and jogging 14km on a chilly Sunday morning. A pretty great effort for anyone, especially 100 teenagers!

The fundraising efforts of this year 12 group have overwhelmed our Kiss

Goodbye to MS team. But equally important to raising funds is that the school has supported and uplifted a student with care and compassion. The idea to raise funds for Kiss Goodbye to MS came directly from the students. They worked with their teachers to come up with fundraising ideas, hold activities and organised the City2Surf team on their own accord.

The funds raised by SCEGGS Darlinghurst through Kiss Goodbye to MS will contribute to the ongoing work of MS Research Australia. MS Research Australia is funding research projects to better understand MS, to develop treatments and to ultimately find the cures for all types of this disease. Kiss Goodbye to MS allows passionate young people like the entire year 12 cohort at SCEGGS Darlinghurst to make a difference to the future of one of their peers.

On SCEGGS Darlinghurst's website the banner reads "What sort of person do you want your daughter to be?" The 2017 year 12 students are compassionate, determined and kind. And what incredible qualities to demonstrate at any age, let alone as young women.

12 years of collaboration between Perpetual and MS Research Australia

At MS Research Australia, we rely on the generous support of our major funding partners to fund the best quality MS research in Australia.



One of our long-term partners is Perpetual, whose philanthropic clients have greatly contributed to Australian MS research. Long term support is absolutely essential to realise the full extent of benefits from funding medical research.

Perpetual connects their clients who want to donate to specific causes to highly reputable not-for-profits working in those areas. MS Research Australia, has had a long-term relationship with Perpetual dating back to 2005.

One way Perpetual distribute funds from the charitable trusts they manage on behalf of their clients is through their IMPACT Philanthropy Application Program where charities can apply for support for causes. In a highly competitive process, MS Research Australia has been awarded various grants to carry out our vital MS research through these funding rounds.

‘Importantly, our funding program allows NFPs to demonstrate how they improve outcomes for the communities

and sectors in which they operate, which is vital. We encourage high quality outcomes by identifying organisations that can maximise their impact through strong strategy, solid leadership, good governance and with an outcomes focus.

‘It’s a rigorous application program, but ultimately it matches our clients’ wishes with suitable organisations, and that can only be a good thing’, said Jane Richmond, Perpetual’s Senior Philanthropy and Non Profit Services Manager.

Funding from Perpetual’s clients has been pivotal for a number of MS projects. Back in 2006, funding was provided for The Australian MS Longitudinal Study (AMSLS) which is an ongoing project, following over 3,000 people with MS, and has provided vital information on the challenges facing people with MS in Australia, including employment issues and economic burden.

Other projects funded include three studies that investigate the role of MS

risk genes, genetics and vitamin D in the development of MS. With help from Perpetual’s clients, MS researchers have discovered a link between the genetics of a specific type of immune cell and vitamin D, and discovered how this might alter the function of immune cells in the central nervous system. They have also discovered rare genetic changes which can either enhance or lower a person’s risk of developing MS.

These projects are essential as understanding the mechanisms that underlie the genetic susceptibility of MS will improve understanding of disease progression, which in turn will allow development of better treatment approaches.

‘MS Research Australia has always been focussed on clear, measurable outcomes and strong governance principles as has Perpetual, I believe that this has been an integral part of the strong and long-term relationship, said Matthew Miles.



HELP MS RESEARCH AUSTRALIA FIND A CURE FOR MS

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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 bequest in my Will
- I have already made a bequest to MS Research Australia in my Will

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