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MS RESEARCH AUSTRALIA

NEXT

THE AUSTRALIAN CHARITY AWARDS CHARITY OF THE YEAR 2015

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

Kiss Goodbye to MS on the world's stage

Many countries all over the world face the same problem as Australia: the prospect of an even smaller amount of funding being allocated to essential MS research, across numerous sectors.

With Kiss Goodbye to MS experiencing continued growth and success for MS Research Australia, the campaign is now set to become a global initiative. Initially an awareness campaign, the enthusiasm and desire to 'do more' shown by our community saw the growth of Kiss Goodbye to MS into a fundraising initiative, with now all nett money raised funding critical MS research initiatives around Australia.

The success of the campaign has not gone unnoticed, with the MS International Federation (MSIF) and associated countries taking a keen interest in Kiss Goodbye to MS.

MSIF have officially adopted Kiss Goodbye to MS as an important initiative in the federation's global fundraising strategy. They have been drawn to the positivity and empowerment of Kiss Goodbye to MS and the hope that it brings to people who are living with MS. It is particularly popular with younger people affected in some way by MS and the age range 25-55, many of whom have not played an active part in fundraising for MS before.

'From the day I first joined MSIF, the Kiss Goodbye to MS campaign stood out as one of the most exciting things happening around the world. Whenever we've talked to our members and people involved in MS there has been a real excitement about it, and it is now going to be our first major international fundraising campaign,' said Luke Thomas, Head of International Fundraising, MSIF and based in London.

Kiss Goodbye to MS is going global.

MSIF is a unique network of MS organisations from around the world that exists to help fight for a world free of MS. In 2016 member countries will be encouraged to adopt Kiss Goodbye to MS in their own organisations and tailor the campaign to promote MS awareness and fundraising worldwide.

'People love this campaign because it's got so much energy and they can get involved in any way they like. The success of the campaign in Australia is a sign of great things to come for all of the countries coming on board in 2016 and 2017,' Mr Thomas said.

The introduction of Kiss Goodbye to MS internationally has received a very positive response with eight countries committing to implement the campaign next year. Among those countries are New Zealand, Denmark, Ireland, USA, Sweden, Argentina, Mexico and France. Additionally, 14 other countries are considering this opportunity for a 2017 roll-out.

'Ongoing funding for MS research is paramount to further understand the disease. While research in this sector has come a long way over the last 10 years, there is still a way to go. Research projects rely on funding which is facilitated through campaigns such as Kiss Goodbye to MS' said US-based, Mr Weyman Johnson III, President MSIF.

'We are proud to see Kiss Goodbye to MS reach new heights. We hope that this will facilitate the growth of MS research funding not only in Australia but worldwide. We will work closely with the countries adopting the campaign to ensure a smooth collaboration, maximising this exciting opportunity' said Richelle King, Kiss Goodbye to MS Campaign Manager.

Of course, there will be no changes to Kiss Goodbye to MS in Australia. All of the nett funds raised will go to funding critical MS research in Australia. ■

A word from our Chief Executive Officer

In 2015 MS Research Australia has continued to strive to make significant contributions to the MS research landscape both nationally and globally. This year, we are proud to have increased awareness of the need for greater funding and investment in MS research.

The biennial Progress in MS Research Conference has become an integral event for MS researchers as it fosters collaborations and learnings between the research community. Special thanks to the local and International keynote speakers, event attendees and the Conference Scientific Committee.

We have recently partnered with JDRF to fund an innovative research fellowship which will investigate the overlap between type-1 diabetes and MS. This project holds substantial promise and will allow us to build on this critical area of immunological research. This cross- disciplinary approach targeted towards the genetic and immune pathways of people with immune-based diseases like MS has the potential to benefit hundreds of thousands of people. Speaking of collaborations, our focus on progressive MS via the global Alliance continues to function very well with over 500 MS researchers from around the world coming together to be involved and research this area of paramount importance.

Additionally this year we have been honoured to have received several prestigious awards. The Australian Business Awards, Charity of the Year 2015 was, of course, the big one! Both the Public Relations Institute and Fundraising Institute of Australia awarded us highly commended awards. A number of our staff also received prestigious fellowships or scholarships in 2015. Not only does this recognise the performance and high standards upheld by our organisation, it heightens the awareness and importance of MS research in the community. ■

Dr Matthew Miles

Investigating the overlap between type 1 diabetes and multiple sclerosis

MS Research Australia and JDRF Australia have come together to jointly fund an innovative research fellowship to investigate the overlap between the two diseases. JDRF Australia is the national funding body for research into type 1 diabetes, an autoimmune disease which has much in common with MS.

We are pleased to announce that following a competitive process the fellowship has been awarded to Dr Grant Parnell, from The Westmead Institute for Medical Research. Funded via a generous grant from the Macquarie Group Foundation, the fellowship will provide $150,000 over one year, that will go towards salary plus other costs associated with this research.

Dr Parnell will benefit from mentorship from leading researchers in the fields of MS and type 1 diabetes. Professor Graeme Stewart AM and Associate Professor David Booth, from The Westmead Institute are both experts in MS and Professor Christopher Goodnow, from the Garvan Institute of Medical Research is an internationally recognised researcher in type 1 diabetes.

The fellowship will begin with a focus on the role genetics plays in both diseases and investigate the common genes which have been identified to increase the risk of developing MS and type 1 diabetes.

Another aim is to broadly develop a range of research projects which jointly examine both diseases. This part of the fellowship will allow MS Research Australia and JDRF Australia to further develop the research potential of this cross-disease space.

'This funding partnership is unique for MS Research Australia, in that it has allowed us to partner with a high impact charitable research organisation working in another disease', said Dr Matthew Miles, Chief Executive Officer. 'The fields of MS and type 1 diabetes research both have much to learn from each other, and we are pleased that this fellowship will allow us to formally recognise and build this area of research'. ■

Dr Grant Parnell, Westmead Institute for Medical Research.

Identifying the MS research resources in Australia

MS Research Australia recently published the second of two reports which take stock of how far the MS research field has come in the past 10 years.

Launched at the recent Progress in MS Research Conference, the *Resource Landscape Report* is a tool for MS researchers to promote wider awareness of the excellent research resources that are available in Australia. This document follows on from the *Research Audit 2004 – 2014* published in late 2014, which took a detailed look at all research outcomes arising from MS Research Australia funding over the last 10 years.

The *Resource Landscape Report* provides an overview of research resources and infrastructure from around Australia. It includes details of professional networks and societies, funding opportunities, specialised equipment and facilities, and general research infrastructure that is available to MS researchers. The report aims to improve resource utilisation while also encouraging collaboration and non-duplication of major resources.

Supported by a grant from the Macquarie Group Foundation, this document is a key tool for the MS community to identify Australia's key research strengths and reveals opportunities and gaps where further development is needed. In conjunction with the *Research Audit* and with ongoing public consultation on research priorities, the *Resource Landscape Report* will help to inform MS Research Australia's research strategies from 2016 onwards.

'Capitalising on Australia's research strengths is vital for progress to be made in our understanding of MS,' said Dr Lisa Melton, Head of Research. 'We hope that the *Resource Landscape Report* will assist Australian MS researchers to access the full range of resources available, and support them in their important work. This Report will continue to evolve as new resources become available, and we welcome feedback or new submissions from researchers to ensure this tool is kept current.'

The *Resource Landscape Report* is available to view online at **www.msra.org.au** ■

The Resource Landscape Report was launched at the recent Progress in MS Research Conference. All delegates received a copy including Dr Elizabeth McDonald, Associate Professor Jennifer McGinley and Professor Mary Galea.

Bringing research closer to the community

Following the recent Progress in MS Research Conference, a public lecture was held to share the exciting MS research progress with the community.

This year, the public lecture was fully booked in a matter of hours. It was held at Royal Melbourne Hospital and was attended by 150 people with MS, and their family and friends.

Dr Lisa Melton, Head of Research at MS Research Australia presented an overview of the research discussed at the conference and was followed by Assistant Professor Jia Liu from The Icahn School of Medicine at Mount Sinai in New York, who generously stayed on beyond the end of the conference to share her research on myelin and the psychiatric symptoms of MS.

Associate Professor Jennifer McGinley, Head of Physiotherapy at the University of Melbourne talked about the importance of maintaining physical activity throughout life, and some of the ways that people with MS can achieve this to improve overall health. Professor Helmut Butzkueven, neurologist and researcher at the University of Melbourne, provided insights into emerging treatments, including for progressive forms of MS.

This public lecture is the first of a series to be coordinated by MS Research Australia, to bring updates on MS research to the community. Public lectures are planned for Sydney, Hobart, Adelaide, Perth, Brisbane and Canberra with dates to be announced early next year. The presentations held in Melbourne were filmed and will be available on the MS Research Australia website **www.msra.org.au** ■

Mingling of minds and expertise – the 2015 Progress in MS Research Conference

The 2015 Progress in MS Research Conference, held recently in Melbourne, was a resounding success with researchers and clinicians from all over Australia coming together to discuss results and ideas. They were joined by an outstanding group of international keynote speakers who travelled from the US and Italy to share their expertise.

The biennial Progress in MS Research Conference is coordinated by MS Research Australia with a Scientific Program Committee to showcase the latest results of investigators from all fields of MS research.

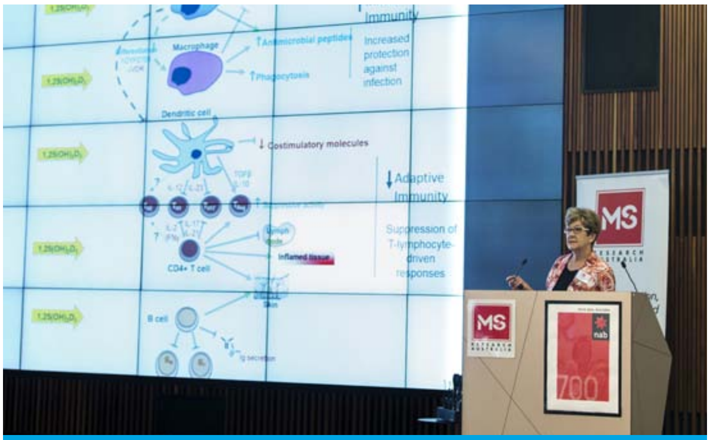
This year's conference revealed an impressive array of young talent in Australia, particularly in the areas of myelin repair, genetics and clinical research. These inspiring researchers represent a promising future which will benefit people with MS in Australia and worldwide.

Feedback on the conference from researchers has been very positive. Keynote speaker Professor Prue Hart, from the University of Western Australia said, 'It was a wonderful conference with a very positive, exciting atmosphere, I have come back with lots of new ideas for MS research'.

Visiting keynote speaker, Professor Luca Battistini from Italy, commented that the conference showcased the impressive breadth of Australian MS research. He said, 'It has been excellent to see the collegiate atmosphere here, and enjoy the discussions with researchers from so many different fields.'

Congratulations to all of the young investigators who presented their work at this conference, but in particular, to Mr Nathaniel Lizak from Monash University for his 'Best Oral Presentation' on the role of MS treatments in slowing disability progression, and to Dr Lucinda Black from the Telethon Kids Institute, WA, for her 'Best Poster' on the accurate measurement of vitamin D concentrations in clinical and research settings.

Professor Helmut Butzkueven, MS Research Australia Conference Convenor.



Professor Prue Hart, Telethon Kids Institute, WA.

Vitamin D and UV

Dr Annette Langer-Gould from Kaiser Permanente Research and the University of Southern California, USA, spoke about her research on the role that vitamin D plays in people from different ethnic backgrounds. Her work suggests that while low ultraviolet (UV) light exposure is universally associated with a greater risk of MS, low levels of vitamin D are not a risk factor for people from an African American background, confirming that these two MS risk factors work independently. Her presentation was complemented by Professor Prue Hart from the Telethon Kids Institute WA who discussed her work on the direct effects of UV light and vitamin D on the immune system. There were also several presentations from emerging researchers on their findings on vitamin D and immune cells.

Genetics

The sessions on the Genetics of MS really showcased the multiple strengths of Australian MS researchers in this area and revealed the enormous body of work that is going on to unpick the exact function of the more than 100 MS risk genes in modifying the immune system in MS. This included presentations on the next wave of genetic research, such as understanding the chemical tags that regulate genes and can alter the function of immune cells.

Myelin repair

Assistant Professor Jia Liu from the Icahn School of Medicine at Mount Sinai in New York kicked off an inspiring session on myelin repair and regeneration. She outlined her work investigating the role that myelin damage and repair plays in the psychiatric symptoms of MS such as depression. She was followed by an impressive series of young Australian researchers who are working on understanding the biology of myelin growth and repair – together their work reveals great potential that molecules and drugs will ultimately be found to enhance the natural myelin repair mechanisms in the brain.

Pathology and immunology

Professor Luca Battistini from the Fondazione Santa Lucia in Rome, shared his experiments to physically sort the immune

MS Research Australia Conference Scientific Committee: Dr Lisa Melton, Dr Kaylene Young, Professor Helmut Butzkueven (convenor), Associate Professor Jenny McGinley and Professor Robyn Lucas. Missing from photo is Dr David Nolan.

cells in the blood of people with MS and reveal the cells involved in managing the response to the Epstein Barr Virus (EBV), another strong risk factor for MS. His work and that of Australian researcher, Professor Michael Pender, confirms that people with MS have a deficient response to EBV and confirms the important role that B cells of the immune system play in the disease.

Microparticles and platelets

A very intriguing session revealed that platelets, traditionally only thought to play a role in blood clotting, play an active role in inflammatory diseases including MS. Dr Jacqueline Orian from La Trobe University, presented results from her collaboration with Professor Karlheinz Peter from the Baker IDI Heart Research Institute. Together they have revealed that platelets infiltrate the brain and spinal cord before immune cells in animal models of MS-like disease. This may be a useful method to track disease activity over time, using specialised imaging techniques. Other researchers in this session presented work on the smaller cousins of platelets, known as microparticles, which are also active in the MS disease process. This is an emerging area that has great potential for improving MS diagnosis and monitoring as well as revealing clues about the biology of MS.

Physical activity and optimising health in MS

Professor Mary Galea from the University of Melbourne discussed the factors that present both barriers and enablers for physical activity for people living with disability. She shared learnings from an extensive program designed to increase the uptake and persistence of physical activity in people with spinal cord injuries which was conducted at various gyms in the community. Increased 'incidental' physical activity as well as more formal planned exercise, have both been shown to have health benefits in rehabilitation, and improving depression and anxiety.

Mr Nathaniel Lizak, Monash University was awarded the Young Investigators Best Oral Presentation.

Clinical outcomes and epidemiology

Predicting disease course in MS and assisting the treatment decisions that doctors and people with MS must make, was the focus of one of the final sessions in the conference. 'Real-world' clinical data from people with MS collected over many years, has identified personal and genetic factors that predict disease progression, and the benefits of both early treatment and treatment continuation.

Progressive MS

The final session of the conference showcased current and future work into progressive forms of MS, including work towards a much needed, accurate measure and definition of progressive MS to facilitate clinical trials and treatment, a project to investigate the risk factors for primary progressive MS, and the work of the International Progressive MS Alliance (of which MS Research Australia is a managing member) in funding and focussing attention on progressive MS research. ■

Dr Jerome Staal, University of Melbourne, Dr Tobias Merson, Florey Institute of Neuroscience and Mental Health and Dr Stan Mitew, University of Melbourne.

Professor James Wiley, Florey Institute of Neuroscience and Mental Health and Dr Matthew Miles, CEO MS Research Australia.

Researcher and Philanthropist

Professor James Wiley is a supporter of MS research in more ways than one. Having had a long and distinguished career as a clinical haematologist and researcher, Professor Wiley was prompted to take a turn into MS research when his daughter was diagnosed with the disease. He has also been a consistent and generous donor to MS Research Australia over many years.

Currently a Principal Research Fellow at Florey Institute of Neuroscience and Mental Health, Professor Wiley has worked and studied worldwide including the University of Oxford in the UK and the University of Pennsylvania USA during his career.

In 2008, Professor Wiley was approached by Professor Graeme Stewart to chair the ANZgene MS Genetics Consortium, one of the national collaborative platforms coordinated by MS Research Australia. This highly successful collaboration has contributed enormously to the international discoveries of the more than 100 genetic variations that increase the risk of developing MS.

Professor Wiley has also contributed to the understanding of the genetics of MS through the work of his own laboratory into the role of the P2X7 gene in MS biology and risk.

As a haematologist, Professor Wiley was also a natural choice to assist in the development and guidance of the Autologous Haematopoietic Stem Cell Transplant Registry for MS, which is tracking the outcome of patients receiving this form of treatment for MS in Australia.

He says ‘MS is an unpredictable disease but MS Research Australia is an important resource for patients and their carers to access the latest information on research from around the world.’

‘Progress in MS research over the past decade has been rapid due in large part to the international collaborations in areas such as genetics, in clinical trials and focussed research meetings.’

Dr Matthew Miles, CEO MS Research Australia, highlights the importance of Professor Wiley’s philanthropy being directed towards young researchers. These researchers will be the future of MS research in Australia. ‘We are very grateful to Professor Wiley for his generosity; his support has been perfectly aligned with one of our key strategies - to ensure we are actively supporting young MS researchers.’

‘Research into new treatments for MS has great value and I am proud to be a supporter of the positive contribution which can be made by a dedicated organisation such as MS Research Australia.’ Professor Wiley added. ■

A passion for finance

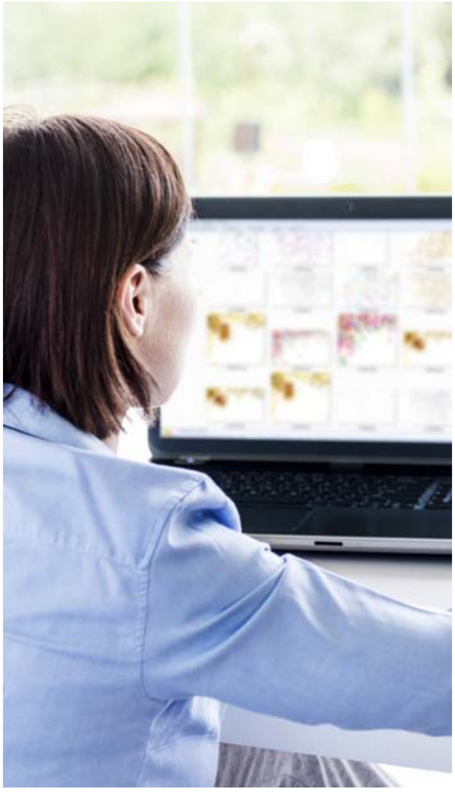
Patrick Foong started with MS Research Australia in 2014, and as the Head of Finance is responsible for managing the strategic financial direction of the organisation.

With a Bachelor of Business and as a certified practicing Accountant, Patrick has a strong background in business and accounting with over 17 years’ experience in a corporate environment, and seven years in the not-for-profit sector. Patrick’s desire to use his past experiences to help a not-for-profit organisation was the driving force behind his move from the corporate sector to the charity space.

Patrick says, ‘I always had a vision that working with a charity would give me a better insight into the research being undertaken in MS.’ As someone who is passionate about the not-for-profit industry, Patrick says what he enjoys most about working for MS Research Australia is that it allows him to help the community and make a difference.

‘I feel privileged to work with such a dynamic and passionate team who are committed to finding a cure for MS. As my role is stretched across a range of portfolios, I am lucky to have the opportunity to work with various team members and gain valuable insight into all facets of the organisation.’ ■

Participating in MS research survey research – how you can get involved



There are many ways to get involved in MS research including survey-based research studies. Genevieve, a person with MS, was asked about her motivation for taking part in MS research surveys and how she has found the experience.

Please tell us about your experience of MS? For several years I suffered from the MS symptoms of bad balance, dizziness, weak/uncoordinated legs, and some bladder problems, all of which gradually got worse. I had no idea what was causing them and put them down to just getting older and did not discuss them with my GP until they were seriously impacting on my everyday life. My first MRI showed numerous brain and spinal lesions.

I already have a significant level of disability, especially with my mobility, but am lucky that so far there has been no impact on my cognitive function. I'm not able to work full time anymore and having been a self-sufficient person all my life, the limitations MS imposes on me on a daily basis can be very frustrating.

Can you tell us a bit about the research studies you are involved in? I have registered with the Australian MS Longitudinal Study (AMSLS), the HOLISM study, and the North American Research Committee on Multiple Sclerosis study, which is a worldwide study, with over 37,000 PwMS participants. In addition, I participate in occasional short surveys conducted by other researchers.

Why did you choose to take part in research and in particular, survey-based research? The rise of the internet and IT technology has massive power – both good and bad. The capacity to gather and store huge amounts of data which is easily shared has incredible potential to accelerate research capabilities and outcomes. I cannot do very much about my MS, but I can contribute to the data pool for the benefit of researchers and other MS patients.

How did you get involved with these research studies? I had a very long period off work due to my MS, and like many others spent a lot of time on the internet trying to find out more about this horrible disease. It was through this that I found the various studies I have registered with.

What has been your experience taking part in research? The studies I am registered with are long term and ongoing. They will be worthwhile, maybe not directly for me as an individual, but for people with MS around the world and into the future as the data that's being gathered has the potential to produce valuable research outcomes. I have found, though that some of the assessment tools used do not always reflect some of the realities of living with MS and sometimes focus too much on relapses, which don't affect everyone with MS.

Do you have any advice or recommendations for other people considering taking part in a research study? As far as registering for surveys goes – the more data that is collected the greater the potential benefits. Given that registering for studies has no side effects and doesn't cost anything except a bit of time given occasionally, I encourage every person with MS to get involved – it may not directly benefit them here and now, but will help others in the future. ■

The Australian MS Longitudinal Study supported by MS Research Australia has been running since 2001 and now has over 3000 people regularly completing research surveys. The AMSLS gives people with MS a voice in matters of importance to them, through scientific surveys designed by professional researchers. Anyone aged over 18 years with a diagnosis of MS can join the study. To find out more www.msra.org.au/amsls ■

How to become involved in Multiple Sclerosis Research

Australian MS Longitudinal Study

The Australian MS Longitudinal Study started in 2001 and has over 3000 people completing research surveys each year.

Data are gathered on areas such as employment, the cost of living with MS, medication usage and disability.

These data are used for improving services, treatments and advocacy to improve the quality of life for people living with MS.

The study is a partnership between MS Research Australia and the Menzies Institute of Medical Research at the University of Tasmania.

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Studying the genes that are switched on and off in the brain

In March this year we wrote about Dr Cheryl Li, an early career researcher from the University of Sydney who received the Ian Ballard Travel Award, to collaborate and learn from experts at King's College London in the UK.

Having recently returned from her twelve week visit, Dr Li has provided MS Research Australia with an update.

Dr Li visited the laboratories of Professor Jonathon Mill, a world-renowned expert in the genetic study of post-mortem tissue samples at the Institute of Psychiatry. This trip was an opportunity for Dr Li to learn specialised skills in the analysis of DNA extracted from brain tissue so that she can continue her investigations using tissue donated to the MS Research Australia Brain Bank.

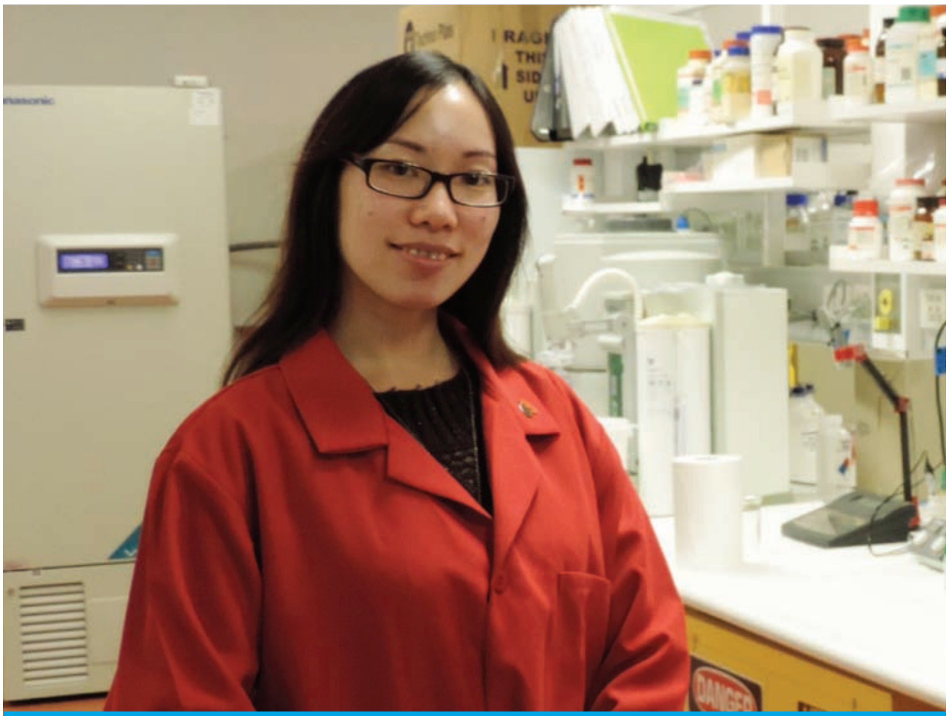
Dr Li has been studying the genes that are switched on and off in the brains of people with MS, and comparing this with brain tissue donated by healthy individuals.

Whilst at the laboratory of Professor Mill, Dr Li was trained in a number of specialised analysis techniques and was able to work on a collaborative project using tissue collected at the Institute of Psychiatry including brain tissue from individuals who had MS and also from people who did not have MS.

In particular, Dr Li was studying the tissue from a region of the brain called the thalamus, which has been shown to be important in MS. She was looking for specific differences in a measure called DNA methylation. DNA methylation refers to the 'bookmarking' of DNA with chemical tags. This process helps to regulate the level of gene activity, by identifying which genes are switched on or off.

She found that in the DNA from the MS brain tissue, there were differences in the level of methylation compared to the same regions in healthy controls, and in particular, found important differences in several genes that play a role in the immune system. These genes will be a target for further study to understand if they play a role in the development of MS. This work highlights the value of studying human tissue to deepen our understanding of the genetics of MS. Better understanding of how genes can control the interaction between the brain and immune system may lead to the development of targeted new therapies.

To register your interest in becoming a donor with the MS Research Australia Brain Bank, visit **www.msbrainbank.org.au/register** or call **1300 672 265**. ■



Dr Cheryl Li, University of Sydney.

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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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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:

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