

## Four new incubator grants awarded for 2015

**MS Research Australia incubator grants are awarded to specifically provide seed funding for the early stages of new research efforts, with the aim of generating the preliminary data needed to support future grant applications. In the first of two rounds to be held in 2015, four new incubators have been awarded totalling \$95,350 in funding.**

Incubator grants were introduced to provide a mechanism for funding new ideas or ideas for which there was no preliminary evidence. It is the forum for blue sky ideas and the opportunity for researchers to follow-up unusual findings where full project applications are not yet warranted.

Dr Peter Crouch working with Mr James Hilton at the University of Melbourne will determine whether a functional copper deficiency exists in a laboratory model of MS and also in the brains of people with MS. This incubator grant, among others, was made possible by a generous grant from The Silbercher Family Foundation. While the role of copper in MS has been looked at before, Dr Crouch will be using sensitive measurement techniques optimised as part of his other research interests to assess the specific activity of multiple copper dependent enzymes for the first time in MS.

Biomarkers, such as molecules that could be measured using a simple blood test, would be valuable to track clinical outcomes and response to therapies in MS as well as to measure the effect of new treatments in clinical trials. Associate Professor Michael Buckland from the Brain and Mind Centre at the University of Sydney, will be researching the potential for exosomes in the blood as a biomarkers

for MS. Exosomes are normally present in the blood and contain molecules from their cells of origin. Associate Professor Buckland will profile a specific type of molecule in exosomes known as small non-coding RNAs in people with MS to see if they could be useful as biomarkers.

Associate Professor Judith Greer, from the University of Queensland, is aiming to make a mouse with the capacity to be a much better laboratory model of the human disease than the models that are currently available. Current laboratory models of MS have a number of limitations in terms of mimicking the human immune response in MS. Associate Professor Greer is attempting to overcome these issues by building the model using cells from people with MS.

Interferon-beta was the first licenced therapy for MS and is still a common

treatment choice worldwide. However, some people can experience serious side effects on this therapy. Dr Markus Hofer from the University of Sydney will be attempting to improve interferon beta treatments by investigating a specific gene that is activated as part of the molecular cascade in response to interferon therapy.

'We are very pleased to announce the new round of incubator grants for these novel ideas in MS research,' said Associate Professor Mark Slee, Chair Incubator Grants, MS Research Australia Research Management Council, 'I would like to congratulate the researchers involved and look forward to hearing about their results.'

For further information about the current incubator grants and all the research currently funded by MS Research Australia visit [www.msra.org.au](http://www.msra.org.au) ■





## A word from our Chief Executive Officer

**MS Research Australia is continually striving to increase awareness about the important MS research being conducted nationally and globally, and increasing the amount of research directed to the prevention, better treatments and a cure for MS. We are proud to be an integral part of many of the global MS research collaborations that are gaining incredible traction worldwide.**

In 2014/5 we committed more funds to MS research than ever before in our history and we recently announced another four Incubator grants to begin mid-year. This brings our total for 2015 to 26 new research projects totalling over \$2 million. Our incubator projects are an important source of funding for researchers with 'out of the box' ideas to explore new research directions.

In February, MS Research Australia's Kiss Goodbye to MS campaign was highly commended in the Fundraising Institute Australia National Awards for Excellence. More recently, MS Research Australia has been recognised as the 2015 Charity of the Year. It is a huge honour to receive this Award and testament to the hard work of the small MS Research Australia team, and the wider MS community, who are all dedicated to supporting MS research. Performance, operational excellence, impact and transparency were the pillars to which we were measured.

Together with your continued support, we can keep the momentum going and continue to not only increase the awareness but also increase the funding for the vital MS research and the impact of that research. ■

**Dr Matthew Miles**



WE ARE PROUD TO BE RECOGNISED AS

# THE AUSTRALIAN CHARITY OF THE YEAR

**MS Research Australia has been recognised as Charity of the Year in The Australian Charity Awards 2015.**

The Australian Charity Awards were introduced in recognition of the dedication and achievements of non-profit organisations, charitable funds and charitable institutions. As a partner program of The Australian Business Awards, the Awards highlight charitable organisations with outstanding results through initiatives that have significantly benefited charitable causes. Previous winners have been JDRC and The Fred Hollows Foundation.

In 2004, MS Research Australia was established to change the way MS research is funded in Australia. There are 2.5 million people worldwide and 23,000 within Australia affected by the disease. In just ten years, MS Research Australia has greatly increased the total funding and the number of research programs focusing on multiple sclerosis throughout Australia. Since 2004 the organisation has contributed over \$24 million to fund the best MS research in Australia, and now, also internationally via the International Progressive MS Alliance.

In 2006 there were only a couple of therapies available to treat the disease. Now, thanks to the work of the international and Australian MS research community, there are 11 treatments available for MS. MS Research Australia is one of only 12 not-for-profit medical research organisations in Australia that award prestigious category 1 competitive grant funding. The charity is the largest national MS organisation in Australia dedicated to funding and coordinating MS research.

MS Research Australia's Kiss Goodbye to MS campaign raised over

\$800,000 for MS research in 2014 and created widespread awareness and empowerment about the disease.

'It is a great honour to be awarded Charity of the Year. This award is a culmination of over ten years of very hard work by many people. The support of people with MS, donors, state based MS societies, allied organisations and corporates has been critical to this success' said Dr Matthew Miles, Chief Executive Officer of MS Research Australia.

Ms Tara Johnston, Program Director of the Australian Charity Awards says, 'The initiatives of charitable organisations are dedicated to transforming the lives of individuals, inciting social change and creating a positive impact on the broader community. We are proud to honour MS Research Australia for its achievements.'

Megan Healey is a mother of three children and was diagnosed with MS 17 years ago. She says 'As someone who is living with MS, it gives me hope to see the ground breaking achievements of MS Research Australia. It is imperative that we continue to work towards a cure for this disease not only for the individuals living with MS, but also for their family members and the community. National awards such as this are wonderful for the recognition of the hard work and also to increase awareness about MS.'

The 2015 Australian Charity Awards program received a significant number of nominations, with five organisations shortlisted and recognised for Outstanding Achievement and MS Research Australia announced as the overall winner for The Australian Charity of the Year. For more information on The Australian Charity Awards go to [www.charityawards.com.au](http://www.charityawards.com.au) ■



Category 1 funding helps researchers to leverage further infrastructure and research funds for their universities, boosting the overall funding available.

## Accelerating MS research through high quality grants

**The 2015 meeting of the MS Research Australia Research Management Council is fast approaching. At this meeting all new research applications will be assessed to identify the projects that will receive MS Research Australia funding beginning in 2016.**

MS Research Australia grants are classified as 'Category 1 funding' on the Australian Competitive Grants Register (ACGR), but what does this mean for MS research in Australia?

The Register is a centralised listing of nationally competitive grant schemes, and includes government funding agencies such as the National Health and Medical Research Council (NHMRC). It also includes a number of not-for-profit organisations that award competitive research grants, with MS Research Australia being one of twelve medical research charity organisations included on the list. All funding bodies must meet strict criteria to be included on the Register, including providing grants on a national basis, with a robust peer review and grants governance process. MS Research Australia funds only the best quality MS research applications in order to further the mission to accelerate Australian MS research towards the

prevention, better treatments, and a cure for MS.

Professor Anne Kelso, Chief Executive Officer of the NHMRC, explains that 'The ACGR ensures that all competitive grants on the list, including grants from the NHMRC as well as grants from not-for-profit organisations, follow a stringent protocol for rigorous assessment of all applications. This ensures that only the best quality applications receive funding.'

Grant programs that are recognised as category 1 funding are considered more prestigious and more competitive in the academic research field. Professor Peter Smith, Dean of Medicine at the University of New South Wales until mid-2015, explains why these grants are so important to universities: 'Category 1 funding for medical research is the most prestigious of all funding available to researchers, and offers many benefits to universities, not least its ability to attract and retain high-quality researchers from all over the world. Category 1 grants also help to bring additional Commonwealth Government funds to the university, increasing overall research productivity.'

They also provide additional 'bang for their buck' as they are used as a metric by which researchers and universities

measure academic productivity, and help leverage additional funds to ensure the continuity of research. University of Sydney researcher, Associate Professor Scott Byrne, a recipient of a MS Research Australia Project Grant, says 'Being awarded category 1 funding is so important for researchers to help leverage follow-on funding from a range of sources, to allow the continuity of research that is necessary for real progress to be made. Category 1 grants are also one important measure of a researcher's track-record. They are often a critical factor in decisions surrounding academic appointments and promotions.'

Through the rigorous Research Management Council process and by offering Category 1 grants MS Research Australia ensures that supporters' funds are not only going towards the highest quality MS research in Australia, they are offering the best return on investment. The grants mean that Australian MS researchers can keep working in the field of MS, can attract even further funding support and can consistently work towards a better understanding of MS. Ms Renee Steenstra, a person with MS and ambassador for Kiss Goodbye to MS, explains why this matters: 'Knowing that MS Research Australia grant awards are going to the highest quality research projects gives me confidence that this work will bring us closer to finding a cure for MS.' ■



## Gene activity studied using MS Brain Bank tissue

Since 2008 people with MS have been able to make a very special gift to MS research by donating their precious brain and spinal cord tissue to research via the MS Research Australia Brain Bank after their death.

In 2015, the MS Research Australia Brain Bank has provided tissue to a number of research projects investigating different aspects of MS biology.

One of these projects is being run by Associate Professor Jeannette Lechner-Scott, from the Hunter Medical Research Institute in NSW, and her PhD student Katherine Sanders, who is being supported by a MS Research Australia Postgraduate Scholarship.

It is known that damage to the brain tissue in MS begins in the normal-appearing tissue before progressing further into the more obvious MS lesions. This project will explore whether changes in the activity of genes within this normal-appearing white matter brain tissue

could help to understand or predict the 'triggers' of this damage.

Associate Professor Lechner-Scott and her team will be looking specifically at the role of microRNAs (miRNAs) in the onset and progression of MS. miRNA are molecules which are used by cells to control gene activity. miRNAs are known to play roles in cell growth, cell death and in the development of different tissue types. They are also known to play a role in many disease processes.

In this project, the researchers are investigating how miRNAs are involved in MS. Since miRNA function differs between cell types, they will look directly at the miRNA profile in MS lesions taken from the brain tissue of people who had MS, something that has only been done in a limited capacity before. Since miRNA molecules are remarkably stable, there is great potential for them to be used as biomarkers to diagnose and predict disease outcome in MS.

To profile the samples, they will be using a novel method in MS miRNA research called NanoString technology. This technique employs fluorescent barcodes that very specifically tag particular miRNA. Microscope images are then taken of the sample and the exact number of molecules counted, thus giving very detailed data whilst limiting the amount of precious brain tissue used.

Brain donation is an incredibly valuable gift that people with MS can make to enable new breakthroughs in medical research. Associate Professor Lechner-Scott's project will help us to understand what may trigger the disease, how lesions develop, and possibly identify markers that could be used to monitor treatment response or disease progression. This work highlights the value of studying human tissue to deepen our understanding of the genetics of MS and how this affects the structure and function of the brain and spinal cord.

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

# Helping the work live on

During September, MS Research Australia and over 140 other charities across Australia, will be working together with the Include a Charity campaign to highlight the vital role that bequests play in benefiting all communities in need.

Donna Bradley-Robinson explains what motivated her to include MS Research Australia in her Will. 'In 1994, just one year after getting married, at the age of 29. I was diagnosed with relapsing-remitting MS.'

'MS changed the course of my life – my marriage ended and my career in the Police force changed from patrol duties to a desk job. I then became determined to learn as much about the disease as I could and also what research was being done to help people living with MS. In 20 years I have seen so much progress with treatments and it is this ongoing effort and the incredible commitment to supporting important MS research projects that has inspired me to leave a bequest to MS Research Australia.'

'I encourage people with MS to be aware of the efforts being made to support their needs for a better life. MS Research Australia provides a vital role in keeping us informed on all of the latest research findings as well as funding MS projects that will someday find a cure.'

'Whilst there is ultimately only one priority and that is to find a cure, research must continue to explore all avenues to discover the causes and better treatments so future generations can be prevented from being affected by MS.'



Donna Bradley-Robinson

Gifts left to charities in wills are made by people from all walks of life, not just the wealthy. Often, gifts are left by ordinary, hard working individuals who want to know they'll be contributing to a better society after they're gone.

If you would like more details about leaving a bequest to MS Research Australia, please call **1300 356 467** or visit [www.msra.org.au/bequest](http://www.msra.org.au/bequest) ■

## Partner Profile – ISPT

**Founded in 1994 by four leading industry superannuation funds, ISPT is one of Australia's largest unlisted property fund managers. ISPT manages over \$11 billion of funds through investments in office, retail, industrial and residential properties. More than 50% of Australian workers have their retirement savings invested in property through ISPT.**

In 1999, ISPT established a Staff Community Program in a drive to give back to the community. Through this

Program, ISPT staff are able to support community initiatives that they are most passionate about.

When staff member Diana Bell was diagnosed with MS, ISPT strove to not only provide support in the workplace for Diana, but also looked for ways that a donation to MS Research Australia could make the biggest difference for people with MS. They made a significant contribution in 2006 to support a new research project focusing on understanding the genetics of MS.

This important work later developed into a national collaborative research platform called ANZgene – the Australian and New Zealand MS Genetics Consortium. By working together, the researchers involved in ANZgene were able to achieve much greater results and contributed to the discovery of over 110 genes associated with MS risk. Since then, ISPT has continued to support MS Research Australia, providing funding towards additional research projects such as research into methods to predict vision loss in people with optic neuritis.

Betty Shallard, Portfolio Services Manager said 'MS Research Australia has provided us with regular updates on the projects we have supported and presented information at our staff meetings. It is interesting to consider that the influence of vitamin D, sunlight and genetic history may all be contributors to the disease. We believe that early diagnosis of MS is very important and through the work of MS Research Australia we hope that a cure is soon found.'

MS Research Australia is very grateful to ISPT for their ongoing and generous support. ■



# SUPER PROPERTY



# Ambassador stories

Kiss Goodbye to MS ambassadors play a fundamental role in executing a successful and engaging campaign. They dedicate their time to build the public face of our campaign, educating Australians on the ongoing research projects being funded by MS Research Australia, as well as enabling the community to raise money to support these programs.



## SARAH DONALDSON: BLOGGER

**Tell us about yourself:** I run a fashion, beauty and lifestyle blog, Harper and Harley, which focuses on wardrobe essentials for women and adhering to a minimal colour palette. I'm also a core cast member of the Fashion Bloggers reality show which airs on E!

**How has MS touched your life?** My mum was diagnosed with MS in 2004. I still remember when it happened, we were holidaying as a family on Stradbroke Island and one morning my mum was violently ill and couldn't move her body. I was only 15 years old and didn't know

what was happening, I had never heard of multiple sclerosis before.

Over the last 11 years my mum went from using a walking stick, to a frame and now she needs a scooter. Her car has been transformed with hand controls as she lost the ability to use her feet to control the pedals. Fortunately, my mum is a strong and positive woman and has a very supportive network around her. She constantly surprises me by doing things I thought she would never do, like flying down to Sydney to visit me or taking a cruise to New Zealand and the Pacific Islands.

**Why did you decide to accept the offer to be an ambassador for Kiss Goodbye to MS?** With my mum bound to a scooter as a result of her MS, I know first hand how terrible the disease can be. Learning that three out of four people diagnosed with MS will be women, and that the average age of diagnosis is just 30 years of age, were huge factors in driving my passion to raise awareness for this important cause.

As a young woman I can't imagine what it would feel like to have my vision for the future suddenly upended – and this is exactly how my mum must have felt. I have been fortunate to build an

online presence with my career and am determined to use my influence to help raise funds for a cure.

I am really inspired by the work that MS Research Australia do, and I believe that there isn't enough funding going towards finding a cure for MS. With some PR and media attention I believe we can continue to build on the work that MS Research Australia are already doing.

**What does being a Kiss Goodbye to MS ambassador involve?** Using the Harper and Harley platform, I committed to posting about Kiss Goodbye to MS every day throughout the month of May. I did a series of beauty posts that featured a different red lipstick every day, raising awareness and funds for MS Research Australia. I was really touched by the beauty and fashion industry's support of my campaign, with the story being picked up by numerous media outlets during the month, as well as having friends, family and followers donate to the cause.

**Who is your biggest inspiration?** My parents. My mum, for never giving up and my dad for standing by her and supporting her. ■

## What's it like to take part in a research study?

We interviewed Mira Carney from Sydney, about her experiences of being part of a physiotherapy research trial with Dr Phu Hoang from Neuroscience Research Australia.

**Please tell us about your experience of MS.** In 2004 I started experiencing tingling in my left hand. My GP thought it was Carpal Tunnel Syndrome but the test returned negative. I was later sent for an MRI of the brain and was diagnosed with Primary Progressive MS (PPMS) in 2006. My symptoms stayed fairly stable until I broke my left leg in 2008 and I started experiencing weakness and foot drop

on my left side, which slowly progressed. There are no disease modifying medications for PPMS but I take a drug called Fampyra to help nerve conduction and I participate in an exercise program at the Australian Catholic University twice a week and do an Iyengar yoga class once a week for people with MS through the MS Society.

**Can you tell us a bit about the research study you were involved in?** I was involved in a trial over many months to see if using a dance mat every day could improve balance and mobility and decrease the incidence of falls in people

with MS. The dance mat was plugged into my TV at home and for about an hour a day I followed a sequence of arrows on the screen with my feet on the mat. At the end of each session I would get a score as to my accuracy.

**Why did you choose to take part in research? Why did you particularly choose that study?** I think it is important to keep up with and try anything new especially when there is no cure for MS. I feel that exercise is very beneficial for my MS and my health in general and I was keen to trial the dance mat that could improve my mobility and balance.



**RENEE STEENSTRA:  
PROJECTS DIRECTOR**

**About yourself:** I have been a senior leader at the Australian Indigenous Education Foundation for over five years, and am presently working as the Projects Director. Alongside this, I am a wife, and a mother to two wonderful children. And one of my proudest roles to date – I am an ambassador of MS Research Australia’s national fundraising campaign, Kiss Goodbye to MS.

**Can you share your journey with MS?** In 2011, I had just moved down to Sydney from Brisbane to take up an exciting career opportunity. One afternoon in the office, I felt something very lightly touching me on my ribs. At first I thought it was a loose thread on my shirt. Within days that sensation turned to an insatiable itching, then by

the end of the week it was an intense constricting feeling. During this time I was referred to a Sydney neurologist who specialises in MS, where I discovered I had two sizable lesions on my spine.

The 12 weeks that followed were difficult. My husband and I were adjusting to a new city, I was managing a large team at work and battling the ever changing symptoms that come alongside MS. But I got through those weeks with my family, friends’ and colleagues’ support and by taking each day as it came.

In early 2015 a follow up MRI revealed more disease activity, confirming my diagnosis with MS.

**You were recently nominated for a Pride of Australia Award:** I feel humbled and honoured to be nominated for the Pride of Australia Award. I also feel a little uncomfortable because there are people who choose to do incredibly courageous things. I feel I’ve been dealt a bad hand and for me there’s no choice but to do something good with it.

**Your decision to become an ambassador for Kiss Goodbye to MS wasn’t a decision you made lightly?** When I was diagnosed with MS I decided that I didn’t want MS to define me, and in no way did I want it to become an integral part of my identity.

I had worked hard in my career and at most I wanted MS to be a small footnote in the story of my life.

In early 2014, three years after my initial diagnosis, MS Research Australia invited me to become a Kiss Goodbye to MS ambassador. I knew that taking on this role would mean that my MS would be somewhat elevated out of the footnotes of my life. Ultimately, my decision to publicly support Kiss Goodbye to MS was to petition for myself, to stand for my children and to stand on behalf of the 23,000 Australians with MS. I hope that by speaking up I can make a difference.

**Why do you choose to support MS Research Australia?** The scariest part of MS is the not knowing. Not knowing when the next episode will be, how bad it will be or what it will affect next. My dream is a world where a diagnosis with MS is followed by an explanation of what the cure is. But research into MS will not continue simply because is it right or fair or needed. It takes all of us in the community to demand that we make finding a cure a priority. I am counting on our scientists and know that it is not a question of ‘if’ we can eliminate this disease – it is a question of when. ■

For more information about the Kiss Goodbye to MS campaign please visit [www.kissgoodbyetoms.org](http://www.kissgoodbyetoms.org)

**Do you have any advice for other people considering taking part in a research study?** I would definitely recommend the study to others. I found the process easy and worthwhile especially when you know that new developments could make a difference to the lives of many people. My goal in living with MS is to stay as fit and mobile as possible as I hope and wait for a cure someday. Using the dance mat every day definitely improved my fitness.

Mira took part in a pilot trial of this intervention for balance and falls prevention. Based on promising preliminary results from this study, the researchers will soon be rolling out a large-scale clinical trial across multiple sites. This study forms part

of Dr Hoang’s MS Research Australia Fellowship, and will examine the full potential of this innovative program to reduce falls risk in people with MS. For

more information on this and other MS research studies currently recruiting participants please visit [www.mstrials.org.au](http://www.mstrials.org.au) ■





Hear from worldwide experts on the latest findings in MS research, including an overview of presentations from the 2015 Progress in MS Research Scientific Conference.

**Date:** Saturday 31 October 2015

**Time:** 9.30 am – 12.30 pm

**Venue:** Royal Melbourne Hospital Function Centre,  
300 Grattan Street, Parkville, VIC

**Speakers:**

- Associate Professor Helmut Butzkueven, University of Melbourne
- Professor Robert Motl, University of Illinois, USA
- Dr Jia Liu, Icahn School of Medicine at Mount Sinai, USA
- Dr Lisa Melton, MS Research Australia

This public lecture is **FREE**, however registration is required to secure your seat. Register online [www.msra.org.au/public-lecture](http://www.msra.org.au/public-lecture)

## Kiss Goodbye to MS Campaign Manager

Richelle King has recently joined the MS Research Australia team, taking a 15 month maternity leave contract as Campaign Manager of Kiss Goodbye to MS. Taking ownership over the campaign, Richelle is responsible for developing and implementing the 2016 strategic direction, and taking the Kiss Goodbye to MS Campaign to new heights.

With over five years of experience in the not for profit industry, Richelle is passionate about using her skills to make a difference. With a Bachelor of International Communications, Richelle has a strong background in communications and marketing, as well as experience in overall project management.

'I am determined to use my skills to make a difference in Australia. I am very proud of the work that MS Research

Australia do, and am excited to see new developments and research outcomes that are a result of the fundraising efforts of all of our wonderful Kiss Goodbye to MS supporters. The MS Research Australia team is dynamic and hands on and I am excited to be working with them to find a cure for MS.'

'One of the perks of my role as Campaign Manager of Kiss Goodbye to MS is that I have the opportunity to interact with our community on a daily basis. I find it so rewarding to speak with each of our fundraisers, hear the passion and determination that they have and know that MS Research Australia is doing everything that we can to put an end to MS. I am so grateful to have the opportunity to interact with our fundraisers and supporters and see firsthand the difference that your efforts make.'



Richelle King

## Help MS Research Australia find a cure for MS

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

To support MS Research Australia's vital work I would like to:

- Make a one off donation of: \$
- Make a monthly donation of: \$
- Learn more about leaving a bequest in my Will
- I have already made a bequest to MS Research Australia in my Will

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**Thank you for supporting MS Research Australia with your generous donation.**

Please return by post to:  
**PO Box 625, North Sydney NSW 2059**

You can also donate online at:  
**[www.msra.org.au](http://www.msra.org.au)**

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