



# NEXT

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

## Priceless Angels have raised \$1 million for MS research

**“Angels are like diamonds. They can’t be made, you have to find them. Each one is unique.”**

**- Jaclyn Smith**



At MS Research Australia, there is barely a day that goes by that we don't see or hear from people asking us 'what more can we do?' It is a wonderful display of prevailing human spirit and from this community that is quite small in comparison to others, we have witnessed many amazing accomplishments.

But the MS Angels are particularly special to our organisation. It was less than a decade ago that Lynn Ralph and Lisa Pettigrew were both touched by multiple sclerosis in different ways. Both prominent Australian business women, Lynn and Lisa felt very strongly that they wanted to create something that would truly make an impact on MS research, whilst advocating for increased corporate philanthropy and equality in the workplace. This was not only for their loved one's living with MS, but the 23,000 Australians also diagnosed with the disease.

And thus, the MS Angels floated into our world! Recognising that there was tremendous power in harnessing the minds and hearts of other women who wanted to make an impact and contribution, Lynn and Lisa and many others created the charter 'chorus' in a select group of well-connected women from the Australian business community, dedicated to helping find a cure for MS through research.

The MS Angels are now operating in Sydney, Canberra, Melbourne and Brisbane. It is an invitation-only forum for accomplished women who are able to make a significant financial contribution towards MS research each year.

In eight short years, the Angels have quietly gone from strength to strength. Each state group has attracted an impressive calibre of women to advocate for research into MS and have hosted an equally impressive array of guest speakers at their events, again demonstrating their influence in the corporate and philanthropic spheres.

And not once has an angel allowed their halos to become dusty or their wings to lose any feathers. In fact, since the Angel's inauguration in 2009, 170 MS Angels have contributed

to the \$1 million-dollar milestone. These funds have directly supported 24 researchers at 11 of Australia's leading research institutions. What is important to note about the contributions from the Angels is that for every dollar donated, the researchers are able to leverage that donation five fold to attract follow-on funding from other sources. Quite critically, this follow-on funding enables continuity of research and progress into finding a cure, better treatment options and unravelling the many mysteries of MS.

**‘In fact, since the Angel's inauguration in 2009, 170 MS Angels have contributed to the \$1 million-dollar milestone.’**

Recently Dr Edwin Lim from Macquarie University, who was sponsored by the Sydney MS Angels in 2014, had a research breakthrough that looks set to revolutionise the MS fight.

Dr Lim and Professor Gilles Guillemin discovered the first-ever blood biomarker to distinguish the three recognised types (or stages) for MS. This discovery has now been translated into a potential blood test with hopes that a clinical test could be available within two years. This would not have been possible without the funding support of the MS Angels and other generous donors.

The outstanding women around Australia who are proud to call themselves Angels are attracted to the group for a number of reasons. Some have loved ones living with MS; some are living with MS themselves. Others are keen to embark or expand on their journey of philanthropy, acknowledging that they are receiving a great dose of camaraderie along the way. Others still are inspired to build their professional network and meet like-minded hearts and minds. Or maybe it's a little bit of all of those reasons.

If you would like to learn more about the MS Angels, visit [www.msra.org.au/ms-angels/](http://www.msra.org.au/ms-angels/)



# Why everyone affected by MS is talking about the Alliance

By Matthew Miles

**There is a saying “If you want to go fast, go alone. If you want to go further travel together.” But how do we go faster AND further together?**

That very essence is the key ethos of the International Progressive MS Alliance. How do we collaborate seamlessly with multiple countries and stakeholders and make rapid progress at the same time?

Convening the global stakeholders to help unravel the complexities of the most frustratingly complex part of MS was never going to be easy. Bringing the greatest scientific minds from all over the world to concisely agree on the research direction wasn't either. Research leaders from the member organisations had to be in lockstep with each other. Industry and regulators had to begin a new era of sharing knowledge and working together. However, in a relatively short period of time, all of these things have been achieved.

## Why is it important for people affected by MS?

People with primary or secondary progressive MS have not had many of the incredible benefits that successful MS research has brought to those with relapsing disease. Many have felt that all of this success was great but when would similar attention be turned to progressive MS? When was “my MS going to be addressed?” These were fair and valid questions. So, to help answer that, the global “Alliance” was formed. Now 14 countries strong with 6 managing member organisations (including Australia), this collaborative is now positioned to make some real impact.

It is also often said to us by people with relapsing disease, even if their MS is currently well controlled, that the Alliance provides a great deal of comfort should their MS take a turn for the worst or progress with time.

## The Alliance's 4 priority research areas?

- Better understand progression in MS
- Design shorter, faster clinical trials
- Conduct trials to test agents
- Develop and evaluate new therapies to manage symptoms

## How are people affected by progressive MS involved in the priority setting and grant-making?

The Alliance has three integral members of the scientific steering committee who have been or are affected by progressive MS. They are Jonathan Strum (USA) who was a carer for his wife who sadly passed away from progressive MS, Alexis Donnelly (Ireland) who has primary progressive MS and Caroline Sincock (England) who has secondary progressive MS. The three were chosen by a selection panel from over 500 international applicants for the roles and all play an important part in guiding the Alliance.

## What has it achieved so far?

- Focussed the minds of the best MS researchers on progressive disease – over 550 MS researchers already involved
- Built a strongly governed initiative with aligned “shared values” and solid processes around grant applications and grant making
- Leveraged an impressive €23 million in total research funding globally for progressive disease
- In collaboration with MSIF and member countries' own advocacy, assisted the approval of the world's first licenced therapy for progressive MS in the US, Australia and Europe
- Provided a vehicle for many countries to fundraise for research, some of whom had not done so before
- Expertly identified the barriers to success as well as prioritising what needs to be done next
- Built a strong culture of “kinship” and “working better together” amongst the countries that significantly fund MS research as well as giving smaller countries the opportunity to be involved.

## How is it governed?

It is governed by an Executive Committee made up of the CEO's of the six managing organisations: Cynthia Zagieboylo (Chair) (USA), Matthew Miles (Vice-Chair) (Australia), Peer Baneke (CEO MSIF), Mario Battaglia (Italy), Michelle Mitchell (UK) and Sylvia Leonard (Canada).

## Who runs and guides the scientific direction and research activities?

The Scientific Steering Committee consists of 20 scientific staff, volunteers and people affected by MS. It is chaired by Professor Alan Thompson (UK). Australian members are Professor Bill Carroll, Neurologist and Chair of MS Research Australia's International Research Review Board and Dr Lisa Melton, MS Research Australia's Head of Research. Other experts are brought in to scientific review committees as needed. The scientific steering committee set the strategic priorities and review the proposals that are submitted to the Alliance for their scientific merit and alignment with priorities.

The National MS Society (USA) is providing great leadership and substantive financial investment for the operations of the Alliance. But the true success of this collaborative lies in the way it has been able to inspire, galvanize and engage many, many countries in our effort to help the 1 million+ people worldwide living with progressive MS.

Visit [www.progressivemsalliance.org](http://www.progressivemsalliance.org) for more information

# Seed funding gets exciting new research off the ground

**MS Research Australia funds two rounds of incubator grants each year. These grants are designed to provide seed or blue sky funding to help researchers generate preliminary data around new research ideas. This data can then help researchers get further, large grants to more deeply explore these new lines of research.**

From the first round of applications received in early 2017 four new incubator grants have just been awarded, totalling \$90,000. These research projects have the potential to be developed into therapies and treatment options for people with MS, and to help our understanding of the risk factors for the disease.



**Dr Natalie Payne**, from the Australian Regenerative Medicine Institute, will research the potential of stem cell-based therapies for people with MS. In the future, specialised cells grown in the laboratory may be injected into a person with MS, where they would release molecules that can help fight the disease. With this incubator grant Dr Payne will develop these cells and test them in a laboratory model of MS. This clinically relevant project will determine if this approach can limit the effects of MS, but also validate that cell-based therapies are a feasible option for MS. This incubator grant was made possible by the generous support from the Trish MS Research Foundation.



**Dr Claire McCoy**, from the Hudson Institute of Medical Research, will determine if a particular molecule, called miR-155, may help switch support cells in the brain from destroying the myelin that protects the nerves in the central nervous system, to promoting repair and remyelination. Her work will help identify whether this molecule could become a useful therapeutic option in MS. This project is supported by the Trish MS Research Foundation.



**Dr Yvonne Learmonth**, from Murdoch University, will be engaging with the MS community to find ways to better support exercise and physical activity in people with MS. She will focus on people living in non-metropolitan areas of WA to identify how the delivery of physical activity and exercise services, regardless of where people live, can be improved through research. We are grateful to MS WA, whose contribution to MS Research Australia helps to underpin this grant.



Previously, **Dr Mary Tolcos**, from RMIT University, and her colleagues have shown that a lack of oxygen whilst in the uterus can delay the maturation of cells that make myelin in the brain. This results in a slower formation of myelin in early brain development. During this incubator grant, Dr Tolcos will gather preliminary evidence to determine if this affects the adult brain's ability to repair myelin damage, and whether it may play a role in MS.

Many excellent applications from the full 2017 grant application rounds were reviewed in November at our Research Management Council meeting and we look forward to bringing you the outcomes early in 2018.

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).

# Heat sensitivity in MS

**Dr Ollie Jay from the University of Sydney provides an update on his research into why heat sensitivity occurs in MS and strategies to help people manage it. Dr Jay's research is supported by MS Research Australia.**



Heat sensitivity is a major issue for 90% of Australians living with MS. It is characterised by a temporary but reversible worsening of MS signs and symptoms. One of the most commonly exacerbated symptoms experienced in the heat is fatigue, which often limits a person's ability to complete physical exercise and even perform day to day tasks, especially in summer.

Our research team at the Thermal Ergonomics Laboratory at the University of Sydney, in association with international collaborators, conducts research to develop a better understanding of the physiology of heat sensitivity in MS, and identify the most effective strategies that people can use to help prevent heat-related fatigue during physical activity.

## What do we know about heat sensitivity with MS?

It is unclear exactly what causes heat sensitivity (also known as Uhthoff's phenomenon). It is thought that even a 0.2 to 0.5°C increase in body temperature can lead to a worsening of MS symptoms. However, the exact increase in temperature needed or even whether an increase in body temperature is actually needed to induce Uhthoff's phenomenon still needs to be confirmed. Our work has recently shown that people with MS exercising in 30°C temperatures stop because of exhaustion when their core temperatures have increased by as little as 0.2°C or as much as 1.0°C. Our American colleagues have also shown that at 40°C people with MS display an increase in postural sway (the movement of the body during standing – an indicator of disability status), and that this occurs without the core body temperature increasing at all. Their results suggest that even increases in skin temperature, without core temperature increasing, may worsen symptoms.

We have also found that people with MS may also not be able to control their body temperature as efficiently as people without MS, as they only start sweating at a higher body temperature than people without MS. Additionally, the ability of people with MS to sense the temperature of the environment may also be altered. For example, we have found that the capacity to distinguish between different cold temperatures is blunted with MS, whereas the ability to sense warm temperatures remains unaltered.



Research team at the Thermal Ergonomics Laboratory at the University of Sydney.

## Ways to prevent heat sensitivity when indoors

When indoors during hot weather, one of the primary methods to cope with heat sensitivity is the use of air conditioning (AC). Australians with MS run their AC approximately 15 times more than a regular household. However, despite the fact that some people with MS can get medical energy rebates, its use can still prove costly and is vulnerable to potential power outages during extreme heat events.

One alternative is using a fan. Fans move air across the skin instead of chilling the air, and they use far less electricity. The same amount of heat loss can be achieved with an electric or battery operated fan as with AC because air flow also accelerates the evaporation of moisture on the skin, which further cools the body. Our research team has recently demonstrated that in a simulated heat wave, using a fan can deliver a cooling effect on the body equivalent to a reduction in air temperature of at least 6-7°C in healthy young men. This benefit is further enhanced if the skin is wetted with a damp cloth while using a fan.

## Ways to prevent heat sensitivity when physically active and/or outdoors

In everyday life, remaining indoors in an air-conditioned environment is highly restrictive and unrealistic. Many jobs require physical activity or outdoor exposure and it is important to try and incorporate physical exercise in your lifestyle. Physical exercise is well known to have profound health benefits including positive impacts on psychological wellbeing. Unfortunately, these essential activities put people with MS at a much greater risk of heat related problems, especially in summer.

‘...emerging evidence from studies in our lab indicate that reducing the core temperature may not be necessary to reduce the effects of heat sensitivity in people with MS.’



To date, it has been assumed that heat sensitivity is due to an increase in core body temperature and nearly all recommendations or strategies for people with MS planning to be physically active in the heat focus on reducing core temperature. These strategies include immersing the lower half of the body in 20°C water for 30 minutes prior to exercise. This has been shown to reduce core temperature by 0.5°C and enable people with MS to exercise in a warm environment with fewer side effects.

Another recommendation is to wear a cooling vest, (vests with ice or cold gel packs built in). These have been shown to improve movement and relieve fatigue. However, as these vests tend to be heavy, they can result in higher physical exertion and therefore increased internal heat production. Additionally, once the ice packs have melted the vests tend to be heavy and can instead act as an insulating barrier trapping the body heat in.

It has also been suggested that cooling the neck or the head can be beneficial, but more evidence is needed for this method.

However, emerging evidence from studies in our lab indicate that reducing the core temperature may not be necessary to reduce the effects of heat sensitivity in people with MS. Drinking

250 ml of cold (1.5°C) water every 15 minutes was found to increase the capacity of people with relapsing-remitting MS to continue exercising in a warm (30°C) environment by about 30%. This increased exercise capacity was observed despite no reductions in core or skin temperature with cold-water compared to drinking body temperature (37°C) water. We think that stimulating cold sensitive receptors in the mouth and throat may blunt the development of MS related fatigue, despite the increase in core body temperature.

Given that the majority of these temperature sensors along the gastrointestinal tract are located in the mouth and tongue, it seems likely that a similar reduction in heat sensitivity could be achieved by simply swilling cold water in the mouth, without swallowing. This approach would be particularly beneficial for people with MS who may prefer to limit how much they drink due to bladder symptoms (although staying hydrated is still really important).

Through our ongoing research we hope to help people with MS manage heat sensitivity through evidence-based practical methods.

**By Dr Ollie Jay, University of Sydney**

### Top tips on how to reduce heat sensitivity without Air Conditioning

	How does it work?	Anything else I need to know?
<b>Use a fan</b>	<ul style="list-style-type: none"> <li>• Promotes convective heat loss</li> <li>• Promotes evaporative heat loss when skin is wetted with damp cloth</li> </ul>	<ul style="list-style-type: none"> <li>• Evaporation is the most powerful way to cool the body</li> <li>• Fans use 50-times less electricity than AC</li> </ul>
<b>Precool in a cold bath</b>	<ul style="list-style-type: none"> <li>• Cools limbs delaying an increase in core temperature</li> </ul>	<ul style="list-style-type: none"> <li>• Helps slow development of fatigue</li> <li>• Recommended immersion time is 30 min</li> </ul>
<b>Ice vest</b>	<ul style="list-style-type: none"> <li>• Promotes conductive heat loss</li> </ul>	<ul style="list-style-type: none"> <li>• Blunts natural physiological cooling responses</li> <li>• Can be heavy and increase metabolic rate</li> </ul>
<b>Drink cold water</b>	<ul style="list-style-type: none"> <li>• Stimulates cold-sensitive receptors in the mouth and throat</li> </ul>	<ul style="list-style-type: none"> <li>• Can improve exercise tolerance in heat by ~30%</li> </ul>

# Understanding the effects of cognitive impairment

**Cognitive impairment in MS is common, but often overlooked. This is the clear message that journalist Jillian Kingsford Smith heard from several of the clinicians and medical researchers at the recent MS Research Australia Progress in MS Research Conference. This part of the conference was fascinating for Jillian and she reports on it here, including insights from both Dr. Anneke van der Walt and Associate Professor David Darby.**

Cognitive disability in MS can be loosely described as a fault in the neural networks in the brain and it can be present at any stage of the disease, from paediatric and clinically isolated syndrome (CIS), right through to progressive stages. Behavioural neurologist, Associate Professor Darby says that whilst cognition is a very complex area, it can best be described as our 'human thinking. Current research along with MRI data is showing that the level of cognitive impairment can be predictive of later MS disease outcomes.

So how does cognitive impairment present? Dr van der Walt explains that the traits of cognitive impairment can be subtle in the early stages of MS, but that identifying deficits in information processing speeds (i.e. how fast you de-code and process incoming information) can be useful.

It is changes in your processing speed that will greatly influence other types of cognitive processes, such as attention and concentration, working memory and retrieval, social cognition and importantly, executive functions.

Associate Professor Darby explains that many things can interact to influence cognition at its very base. These include fatigue, overall motivation, mood and exercise, not to mention individual physical MS symptoms.

Dr van der Walt describes cognitive impairment in people with MS as a preventable dementia.

"I understand that many people would hear the word 'dementia' with negative connotations but I consider it an interesting way to view the fact that we could potentially prevent some of the impairment problems."

Clearly monitoring cognitive symptoms is critical to being able to intervene. Annual tests are suggested as a minimum, ensuring a baseline is established and subsequent

changes are noted and reported.

For Associate Professor Darby, measuring cognition can be as simple as asking his patients how THEY think they're going. He believes this is important because how a person feels about their own thinking can also influence the way they think.

Cognition forms the basis of your self-esteem and how you relate to other people and understand what is going on around you. It's important to reinforce that cognitive impairment in MS generally relates to the way information is processed, but intellect and long-term memory can remain unaffected. Despite van der Walt's reference to dementia, interestingly, the issue of rapid-forgetting (often experienced in people with Alzheimer's) is not overly common in people with MS.

All of this leads to the question – how can people living with MS preserve or protect their cognitive ability?

"It's okay to do things a bit differently," explains Dr Van der Walt. "You can't always change your abilities but you can enhance the way you function."

She advocates for a suite of compensatory techniques, explaining that many memory problems can be solved with better organisation (see box).

Dr Van der Walt recounts several case studies of how some of these small adjustments to our everyday habits can mitigate a great amount of frustration, guilt, embarrassment, anger, decline in self-esteem and worry – for not only the person living with MS but also their support network of family or friends.

Associate Professor Darby also encourages maintaining a healthy lifestyle, explaining that exercise (particularly aerobic) has been linked with improvements or marked slowing in loss of cognitive abilities. Keeping socially active



Dr Anneke van der Walt (left) and Associate Professor David Darby

will also go a long way in treating mood and motivation which also influence cognition.

Dr van der Walt believes that early and escalated treatment with MS medications is important to prevent cognitive dysfunction in MS and cognitive rehab can also start in the MS clinic with the neurologist and MS nurse. Combining this with a number of things that a person can control in their own environment and everyday living can really make a difference to quality of life.

**By Jillian Kingsford Smith**

## PRACTICAL TECHNIQUES

**many memory problems can be solved with better organisation!**

**Consolidate and centralise!** Designate one place in your home as the information centre. Include your master calendar, mail, bills, phone messages, to-do lists, keys, wallet, shopping lists and more.

**Plan:** Post a calendar large enough to display everyone's appointments, activities, and reminders! Keep pens hanging beside it. Or use a computer program set up with reminders for routine tasks (synchronise it with your mobile device to have your appointments with you while on the go).

**Record:** Dictate your to-do list, notes or other things to remember on a digital voice recorder (available on many phones).

**Remind:** Use checklists, the alarm on your watch or phone, your kitchen timer, and more.

**Eliminate or remove yourself from distractions.** Turn off the TV, music and whatever else is "on" when speaking with someone in person or on the phone. Background visual and noise distractions can make learning or remembering more difficult. If you can't eliminate the distraction (for example, people talking at a party) then ask, "Can we talk in a quieter place?"

**Take a break.** If you are having difficulty concentrating, take a breath and refresh.

**Do one thing at a time.** Avoid switching back and forth from one topic or task to another. Finish or find an appropriate stopping place in what you're working on before you switch to something else.

# Kiss Goodbye to MS

## *Celebrating our biggest year ever*



**In 2017 the Kiss Goodbye to MS community has raised a huge \$1,150,000 for research into MS!**

Our Kiss Goodbye to MS campaign, which aims to bring hope to people living with MS, has become a passionate and driven community. We simply couldn't fund the amount of MS research we do without the community support. Whether you have raised funds, donated, volunteered or supported us on social media – thank you!

Kiss Goodbye to MS began raising funds in 2012. In our short 6 year history you – our community – have contributed

\$5,151,602 million for research into MS. Over \$5 million in 6 years is an incredible achievement and we are so grateful to have you on this journey with us.

Each year we wonder how we could possibly top the year we've just had. And each year you prove that you've got more in you! So 2018, we can't wait to see what you've got around the corner. But before we close the book on 2017 we are remembering some of our favourite 2017 moments.



The MS Charity Ball, organised by twin sisters Sarah and Millie Horton raised \$517,762 for Kiss Goodbye to MS – our biggest ever fundraising event!

Our ambassador, Emma Giunti wore an entire outfit of red for 31 days straight in May.



The pride our team felt when MS Research Australia won the 2017 Telstra Business Awards Charity of the Year.



When Tanya and Ro Calder trekked through Nepal flying our Kiss Goodbye to MS flag to support their best friend Loz who is living with MS.

Working with our incredible pro bono PR company Cube who achieved more media coverage for Kiss Goodbye to MS than we have ever seen before.



Megan Healey added to her fundraising tally again in 2017 – she has raised \$76,500 for us over the last 5 years.

# *Thanks for being there right alongside us in 2017!*

# Our greatest gift, an expression of love

Whether it's because we're careening fabulously fast into the festive season or simply pondering a gift to mark a special occasion throughout the year, we all experience a range of emotions in how we choose to give.

Let's take you on a journey of a wonderful relationship that started with MS Research Australia just over 5 years ago. It all began with a very simple phone call enquiry asking about the difference between our organisation and several others in the same MS community. After a satisfactory explanation, the caller hung up.

Further conversations with that caller were to follow over time; discussions about research projects and the progress that was being made. Gradually, that bond between the caller and MS Research Australia strengthened. So much so that in May this year it culminated in a significant donation well in excess of \$1 million - the highest ever donation received from an individual in our history.

Quite simply this gift was the action of a woman who wanted to commemorate the love for her husband who had bravely battled MS over 22 years. Her compassionate gift was in hope of preventing somebody else going through what her beloved husband had. When asked why she decided to make such a generous gesture, she replied "because it makes me happy."

*Donation, in memory  
of my darling husband*



We all know giving helps others, whether we volunteer, offer emotional support to those around us or donate to charities. But studies show that giving is also good for the giver – boosting physical and mental health. The Cleveland Clinic in the USA recently published a study that found the health benefits associated with giving were lower blood pressure, increased self-esteem, less depression, lower stress levels, longer and life and greater happiness.

The bond you have with the recipient of any gift – be it a friend, family member or organisation such as MS Research Australia – is critically important and we strive to make a connection with our supporters on many levels. Through information, awareness and of course finding that emotional and communal connection. As Winston Churchill said, "you make a living by what you get, but you make a life by what you give."

We are proud that we can transparently assure you that your financial support contributes towards our goal to accelerate research: into the cause, better treatments and prevention, with the aim of ultimately finding a cure for MS.

By Neil Robertson and Jillian Kingsford Smith



## 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

### Contact details

Title:  First name:   
Surname:   
Address:   
Suburb:  State:  Postcode:   
Phone:  Mobile:   
Email:

### Payment method:

- Cheque (made payable to MS Research Australia)
- Direct Debit Request (copy of service agreement can be provided on request)

Financial institution:  ABN 34 008 581 431

BSB number:

Account number:

Account holder's name:

- Credit Card

Mastercard  Visa  Amex

Credit card number:

Exp:  CVV:

Name on card:

Signature:



ABN 34 008 581 431