



NEXT



THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

Celebrating ten years of accelerating MS research

2014 marks the tenth anniversary of MS Research Australia and a decade of accelerating, enabling and funding Australian research as part of the worldwide effort to solve MS.

Some of the world's leading researchers are now stating that a cure for MS is not a question of 'if', but of 'when'. In the meantime the quality of life for many people with MS has improved dramatically, due to better treatments, earlier diagnosis and improved symptom management.

The progress made in such a short space of time is remarkable and Australian researchers are certainly among the best in the world. More hard work is necessary, however, particularly in funding and treatment for progressive MS.

This article reflects on what MS Research Australia has achieved so far and – more importantly – what this means for people with MS. It will also give an exciting insight into the new discoveries and initiatives on the horizon that provide hope for an even brighter future, and ultimately for a world free from MS.

Our history

The first known Australian MS society medical research grant was in Sydney in 1963. For much of the first 30 years of the state MS societies' existence, they individually contributed small, ad hoc amounts to medical researchers in their respective states.

In 2003, due to their important focus on providing services for people with MS, the MS societies' collective contribution to research was being too thinly spread over an increasing number of projects to have a major impact on MS research in Australia.

Pressure was mounting from both Australians with MS and the US National MS Society, then and now a very large funder of Australian MS researchers, for MS Australia to increase its research funding.

Several state societies' directors and CEOs at the time discussed the overdue need to recommit to research funding via a new business model. As a result, MS Research Australia was incorporated in

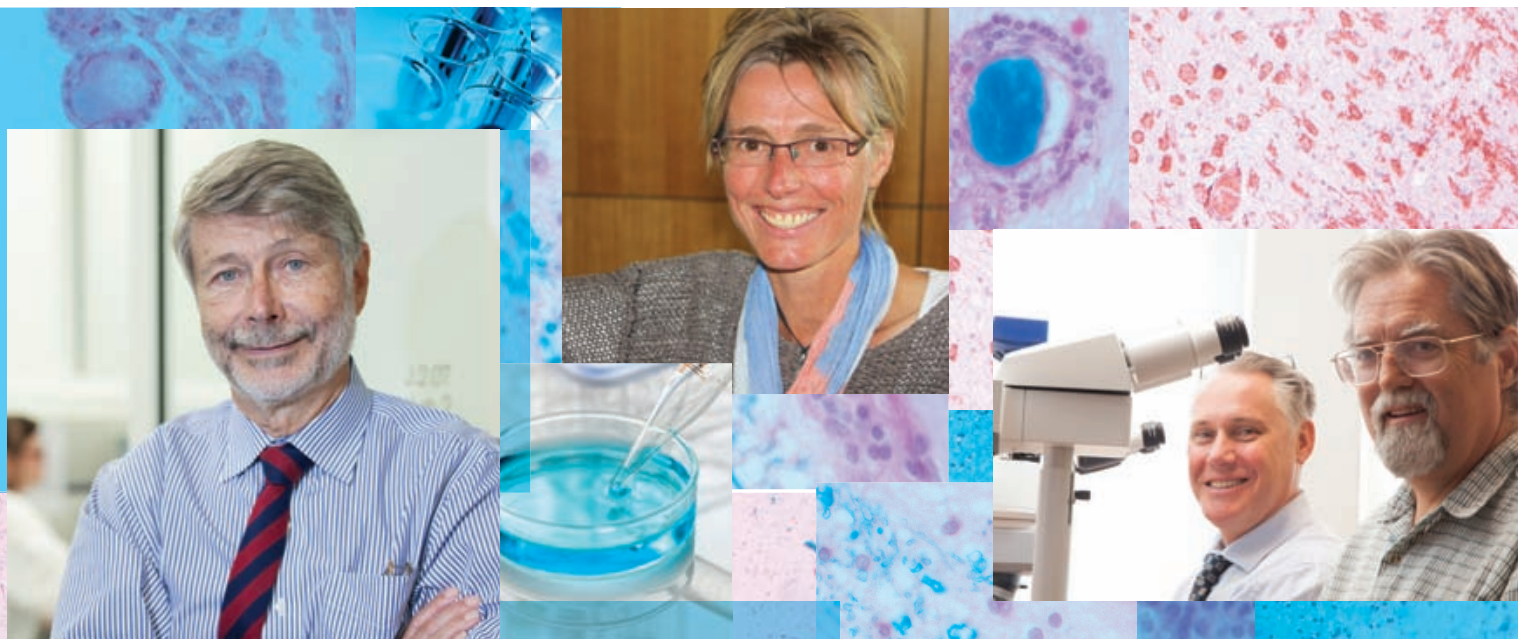
early 2004 as an independent national MS research funding organisation.

Over the past ten years, MS Research Australia has vastly increased the amount of funding available to researchers all around Australia. It has also been an important catalyst for increased funding of MS research from key Australian research funding bodies such as the National Health and Medical Research Council and the Australian Research Council.

How we work

MS Research Australia's mission is to accelerate Australian MS research as part of the worldwide effort towards the prevention, better treatments and a cure for MS.

We work in close partnership with leading medical research institutes and scientists around Australia and New Zealand, encouraging collaboration and focussing our efforts on where we can make the greatest impact within the global context.





RESEARCH AUSTRALIA

Celebrating 10 years 2004 - 2014



MS Research Australia coordinates several major collaborative research platforms, such as the Vitamin D MS Prevention Trial and the MS Research Australia Brain Bank, as well as funding a range of individual MS research projects led by talented scientists around the country.

MS Research Australia seeks financial contributions to support the research strategy by engaging support from public donors, trusts and foundations, private philanthropists, State and Federal government, corporate partnerships, key relationship fundraising, bequests and the state MS societies.

Key research achievements

The role of vitamin D in MS

Researchers funded by MS Research Australia identified a latitudinal gradient in Australia and New Zealand, which indicates the risk of developing MS is seven times higher for people in Tasmania compared to Far North Queensland. This research indicated a link between lack of sunlight, vitamin D, and the development of MS.

Another group of researchers supported by MS Research Australia discovered that genes involved in vitamin D metabolism are implicated in MS risk, reinforcing the role vitamin D could play in contributing to a solution.

These two studies led to MS Research Australia launching the world first trial of vitamin D supplementation as a preventative measure for people at risk of MS.

MS Genetics

Ten years ago only two of the genes associated with MS were known. Now, due to the work of the International MS Genetics Consortium, in which MS Research Australia-funded researchers play an important part, well over 100 genes have been identified. Each of these genes is now being investigated to find the exact mechanisms behind what is causing MS.

The MS Research Australia Brain Bank

Examining brain tissue from people with MS is crucial for advancing our scientific understanding. MS Research Australia has established a Brain Bank to collect tissue donated by people in Australia who had MS and consented for their brain tissue to be used in MS research.

Tissue donated by people with MS gives far more detailed information on the human condition than using animal models of MS and the MS Research Australia Brain Bank has become a vital program for furthering innovative research studies.

The Australian MS Longitudinal Study

The Australian MS Longitudinal Study is a nationwide study that surveys people with MS over time on issues of importance to them.

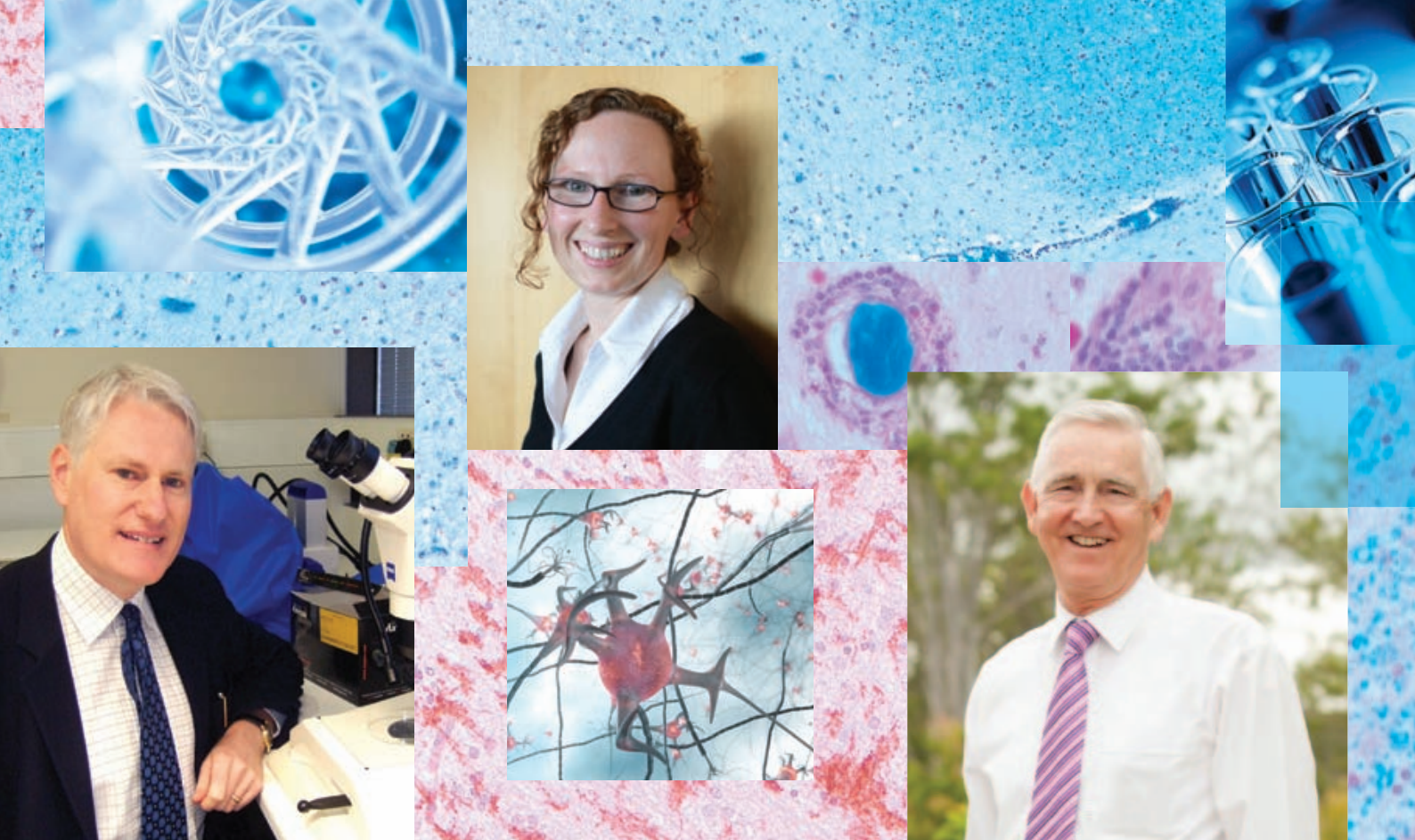
The survey provides vital data on the economic impact of MS, the effect of MS on employment, and other practical life issues. Data from the Longitudinal Study was pivotal in achieving air conditioning rebates for people with MS who are much more affected by heat than the general population.

The state MS societies have used the data from this study to guide service provision and advocacy for people with MS, leading to positive improvements in quality of life.

Attracting talented researchers to the MS field

Through the provision of competitive postgraduate research scholarships, MS Research Australia has an outstanding track record of attracting promising young scientists to a long-term career in MS research. This is vital in keeping talented researchers in the field of MS and providing the boost they need to get their careers off the ground.

Each year MS Research Australia also funds several small incubator grants for 'outside the box' ideas. These allow



researchers to prove a novel principle in their research and launch a promising new line of investigation, which frequently goes on to attract significant further funding, at a rate of 27 times the initial commitment.

New therapies and improved outcomes for people with MS

Ten years ago, the only disease modifying treatments available for MS were injectable. Today, people with relapsing remitting MS have ten treatment options including taking a daily tablet or receiving an infusion taken in just two treatment courses one year apart.

The newer treatments are showing benefits for a great many people, and the increasing choice and efficacy of treatments, together with earlier diagnosis and improved management strategies mean that the outlook for many people with MS has improved significantly in a relatively short time.

Providing hope for the future

The future may be brighter for many people with MS, but there is still much more work to be done. In particular, people with progressive forms of MS have no treatments currently available to them.

It is vital that the research momentum continues so that all people living with MS

can benefit. Outlined below are just a few of the exciting new discoveries and initiatives on the horizon, which we hope will result in a better future for people with MS.

International Progressive MS Alliance

Together with other leading MS organisations around the world, MS Research Australia has joined the International Progressive MS Alliance – the most ambitious collaborative project the global MS research movement has ever embarked upon.

This innovative collaboration, coordinated by the MS International Federation, is dedicated to fast-tracking discoveries to improve outcomes for people living with progressive MS. Specifically it will increase our understanding of disease progression; design shorter, faster trials that measure patient outcomes; conduct trials to test new therapies; and develop new approaches to symptom management and rehabilitation.

Clinical trials

A wide range of clinical trials for MS treatments are underway around the world. This includes new targeted methods for modulating the immune system, protecting nerves from MS damage, repurposing therapies already approved for other

disorders, and novel approaches for treating all forms of MS, including progressive MS. Clinical trials enable people with MS to have access to the latest treatments and to play a direct role in contributing towards the search for better treatments and a cure. For more information on the clinical trials currently recruiting in Australia, visit www.mstrials.org.au

Reversing the damage

Scientists are continually discovering new information about how MS damages the nervous system, as well as the factors involved in the body's ability to recover from injury. Early human trials are underway to investigate new therapies aimed at repairing or regenerating myelin.

Studies are also providing new evidence that exercise and rehabilitation can improve many functions and even help rewire areas of the brain. Researchers are pursuing these leads to find the best ways people with MS can maximise their quality of life.

Preventing MS

In addition to genetic research and the discovery of the role of vitamin D in MS, studies are underway to uncover other factors that may reduce the risk of MS for future generations. ■



A word from our Chief Executive Officer

In this very special ten year anniversary issue of NEXT, we reflect on the incorporation of MS Research Australia in 2004 and the significant achievements it has made.

It is without doubt the vision and determination of many who worked for many years to establish the organisation as we know it today. Based on the best medical research industry models, MS Research Australia developed a rigorous and robust fundraising and funding model which has seen an increase in MS research investment from just under \$500,000 per annum in 2004 to over \$3 million per annum in 2013.

MS Research Australia has made a significant contribution to the landscape of MS research in Australia over the past 10 years and we are determined to continue this momentum with both local and global collaborations to ensure we find even better treatments, prevention and the cure for MS.

I am also privileged to announce two nominations we submitted for very prestigious awards were successful: Research Australia awarded Carol and Roy Langsford OAM the 2014 Lifetime Achievement Award, which honours individuals who have demonstrated a significant lifetime commitment to supporting and promoting health and medical research in Australia. MS Australia awarded the John Studdy Award to Mike and Katrina Hemingway in recognition of their efforts and contributions to the MS community over the past 10 years.

Lastly, I would like to introduce you to another member of our dedicated team, Joanne Hunter, who is our Administration and Campaign Coordinator. ■

Dr Matthew Miles

Research audit 2004 – 2014

As part of our ten year anniversary, MS Research Australia has taken a detailed look at all research outcomes arising from our funding since 2004. This research audit provides an extremely important report card against the original strategic goals set out at our inception.

Since 2004, MS Research Australia has awarded over \$14 million in funding for investigator-led research via 154 grants, in addition to over \$8 million dedicated to collaborative research platforms.

The research audit took the form of an internal evaluation as well as a survey completed by grant recipients. The results have been brought together in a comprehensive Research Audit Report highlighting the achievements of the past ten years. Supported by a grant from the Macquarie Group Foundation, this document is a key benchmark for MS Research Australia to evaluate our progress, and will be a crucial guide to future areas for development.

The report reveals that we have been extremely successful in achieving our original strategic goals. Since 2004, MS Research Australia has increased the nationwide research investment into MS research projects by more than five times the original spend.

In this time, we have built a fully peer-reviewed portfolio of research funding with Government category one accreditation for competitive funding schemes. We found that for every \$1 invested in MS research, recipient researchers were able to obtain around five times this amount in subsequent external funding, such as from the National Health and Medical Research Council to continue their research.

MS Research Australia grants have contributed to many exciting breakthroughs and achievements in the MS field. With over 200 publications, four patents and many biomarkers, clinical assessment tools, and novel research methodologies, developed and in use. MS Research Australia-funded

researchers are clearly making tangible progress in the effort to solve MS.

The audit also identified that MS Research Australia grants help build capacity in the MS research field. Around 94% of MS Research Australia-funded researchers continue in the MS research field, establishing extensive collaborations both nationally and internationally, and training, on average, a further four researchers.

‘Tracking the outcomes of our research funding is an important part of what we do at MS Research Australia,’ said Dr Matthew Miles, Chief Executive Officer. ‘Due to the long term nature of a lot of research, outcomes from funding ten years ago are still ongoing as initial findings are built upon. We feel that the results of the audit confirm MS Research Australia is funding the best and most valuable research for people with MS in Australia.’

The research audit document was launched at the tenth anniversary event in November 2014, and is available online from the MS Research Australia website www.msra.org.au

The next step in our planning is to develop a national resource map. This document will be interactive and updatable to ensure it retains relevance year upon year. ■



Pulling together the threads to understand MS

Imagine a cat's cradle – a network of threads running to and fro, crossing over and diverging again – now imagine that the clues to MS lie at the points where all the threads cross over.

Researchers in Australia and around the world are working hard to pull together huge 'threads' of data on the genes and the environmental factors associated with susceptibility to MS, as well as data on the behaviour of the immune system in MS, and how it responds to the current treatments for MS. Identifying the common threads between all of these factors will ultimately help to stop the disease in its tracks.

Recently a group of international researchers published a major analysis of the networks of genes that are switched on or off in people with early MS, relative to their vitamin D levels and in response to treatment with interferon-beta. Drawing

in a third 'thread' of data, they also looked at the number of active MRI lesions in the brains of these individuals and determined the gene activity patterns that were associated with either high or low numbers of lesions. By looking at the three patterns of gene activity and how they overlapped, the researchers were able to show that vitamin D directly controls a large system of genes, regulating immune system functioning and MS lesion activity. Importantly, they also showed that the effects of interferon-beta treatment and vitamin D levels on this gene network were added together to have a larger impact on reducing MS disease activity. These findings suggest an important relationship between genes and environmental factors such as vitamin D that may work together to influence not only MS severity but also a person's response to MS treatment.

Dr Steve Simpson Jr, a researcher at

the Menzies Research Institute Tasmania and currently funded by MS Research Australia, is part of another team of researchers trying to pull the threads together. Using valuable data from the Southern Tasmanian Longitudinal MS Study they have been looking at how genes, vitamin D, and aspects of diet and lifestyle impact on relapse rates and brain lesions. Most recently the team have focused on one particular gene known as WT1 that has previously been implicated in MS susceptibility. They have revealed that variations in this gene can also influence the response of the body to both sunshine and interferon-beta treatment to increase levels of vitamin D in the blood stream. These findings show that for some people, their treatment response may be optimised in certain environmental conditions.

More research is needed to continue to pull these threads together. Research around the globe is providing vital information on how existing interventions work and how genetics may ultimately be used to help choose the right therapy for an individual.

While this data supports a potential role for vitamin D in preventing and treating MS, direct evidence is still required to show that vitamin D supplementation is a safe and effective therapy, and the most appropriate doses. This is what we are trying to achieve with the MS Research Australia-funded Vitamin D MS Prevention Trial (PrevANZ) currently underway in Australia and New Zealand. ■



Administration and Campaign Coordinator

Joanne Hunter graduated in 2009 with a Bachelor of Health from Macquarie University, majoring in International Aid. Since then, Joanne has worked in the not-for-profit sector for over 6 years, with the last three of those spent at MS Research Australia.

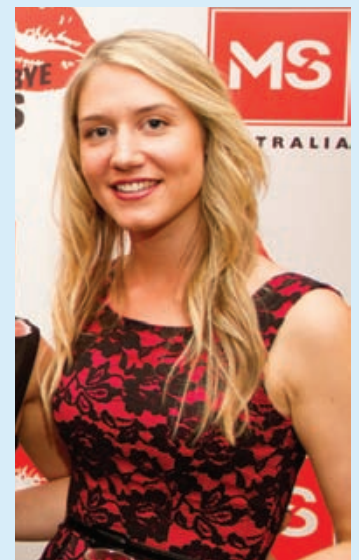
Before joining MS Research Australia, Joanne gained significant experience working with various charities both in Australia and in the UK. Her passion to help others led her into sponsorship and campaign roles for organisations such as the Oaktree Foundation in Sydney and local community initiatives in London, UK.

Joanne is the Administration and Campaign Coordinator at MS Research Australia. Her role includes providing administrative support, handling enquiries, managing the organisations database and coordinating events, including the Sydney MS Angels – a corporate female networking group who fundraise for MS research.

Joanne says, 'I really enjoy my role here at MS Research Australia, no two days are ever the same. It is an ever changing, ever evolving organisation that is both challenging and rewarding'.

'There is a real sense of achievement knowing that I am a part of a small organisation which is achieving real research results. Even after just three years I can see how much has changed in the MS research world and it makes me so excited to see what can be achieved in the future!'

'The best part of my job is how closely I get to work with the MS community. Whether it's assisting someone on the phone or volunteering at an MS fundraising event. I get to meet some wonderfully inspiring people who have the same passion as I do – to find a cure for MS.' ■



Joanne Hunter

Harnessing the brain's natural capacity for myelin repair

Researchers from the Florey Institute of Neuroscience and Mental Health in Melbourne have revealed exciting new possibilities for the development of therapies to promote the repair of myelin in MS.

They have shown that a specialised type of stem cell present in adult brains makes a significant contribution to the repair of myelin in mice with MS-like disease.

The results, published in the *Journal of Neuroscience* in October, are the culmination of several years of meticulous research by the team led by Dr Tobias Merson.

Dr Merson was the recipient of a prestigious Betty Cuthbert Postdoctoral Fellowship, co-funded by the National Health and Medical Research Council (NHMRC) and MS Research Australia from 2007-2010 as well as a Project Grant in 2009. Since then, Dr Merson has gone on to win further funding from bodies such as the NHMRC and Stem Cells Australia and now leads a growing team of MS researchers.

Neural Precursor Cells (NPCs) are specialised stem cells that reside in a small area of the adult brain. NPCs have been shown to be capable of generating new neurons and other support cells

of the brain – their original discovery overturned the long-held belief that there were no stem cells in the brain that could aid its repair.

Following some early evidence that NPCs may also be involved in myelin repair, Dr Merson and his team set out to investigate just how important these cells were in myelin repair and how they might be stimulated to enhance repair in diseases such as MS.

The team used elegant genetic techniques to label the NPCs with coloured markers so that they could track their movements in the brains of mice who have suffered a demyelinating injury that mimics MS.

Following the injury the researchers could see that the NPCs moved in very large numbers into the damaged white matter areas and converted, or differentiated, into myelin-producing oligodendrocyte cells. The contribution of the NPCs to restoring myelin greatly exceeded that of the oligodendrocyte precursor cells that normally sit throughout the brain ready to repair and maintain myelin. They were also able to show that the new myelin produced was thick and healthy.

Crucially, the team also showed that although the NPCs contributed



Dr Tobias Merson

enormously to repair in the areas closest to their resting niche, they were unable to differentiate to produce myelin in parts of the white matter further away. Further investigation of this finding may provide vital clues as to why myelin repair stalls in some parts of the brain in MS.

The team is now continuing to investigate the mechanisms that control the movements and differentiation of NPCs into myelin producing cells. They hope to harness this knowledge to develop new treatments that will stimulate and enhance repair in MS. ■

Brain donation provides hope for a cure

Brain imaging techniques such as magnetic resonance imaging (MRI) are useful for diagnosing MS and monitoring disease activity, but recent studies have found that many changes in the brain and spinal cord due to MS are not detectable in MRI scans. To fully understand MS, researchers need to study the cells, genes and proteins at the microscopic or molecular level in MS tissue.

Since human tissue is not available for study during life, researchers can only use post-mortem tissue donated by people with MS who consented to their tissue being used for research

before they passed away.

Anyone in Australia who has been diagnosed with MS is eligible to register as a brain donor for MS research. Many people write in their Will that they would like to become a brain donor, however, from a legal point of view it is very important that the official Brain Bank Donor Consent Form is completed and signed. Signing the Consent Form and notifying your next of kin enables the donation process to happen smoothly when a person passes away, and ensures that the donated tissue is the best possible quality for researchers to use.

The MS Research Australia Brain

Bank encourages people with MS to sign up as a MS brain donor as early as possible in life. There is no upper age limit on becoming a brain donor and we welcome all people with MS regardless of the stage or subtype of disease. Even people with mild or early stage disease should consider signing up to donate.

Each brain donation is a precious and invaluable research resource that can bring us one step closer to curing MS.

To register your interest in becoming a brain donor, complete the registration form at www.msbrainbank.org.au/register, or call MS Research Australia at **1300 672 265** ■

Awards for MS research inspiring advocates

MS Research Australia is proud to have nominated four very inspiring individuals for prestigious awards which recognise their tireless efforts for MS research and the MS community.

Roy and Carol Langsford OAM, co-founders and directors of the Trish MS Research Foundation have been awarded the highly prestigious Research Australia 2014 Lifetime Achievement Award. This Award honours individuals who have demonstrated a significant lifetime commitment to supporting and promoting health and medical research.

Mike and Katrina Hemingway, founding members of Foundation 5 Million and leading Kiss Goodbye to MS fundraisers have been awarded MS Australia's highest accolade, the John Study Award. This award formally recognises their years of service improving the lives of people affected by MS and their ongoing contribution to MS research.

On behalf of MS Research Australia and the MS community, congratulations on these well-deserved awards. ■



Katrina and Mike Hemingway



Professor Christine Bennet AO, Chair Research Australia, Carol and Roy Langsford OAM and Col Reynolds OAM

Partner Profile – National Australia Bank

Whether through major sponsorships, workplace giving, specialist volunteering or employee fundraising, National Australia Bank (NAB) and its employees have an excellent track record of supporting the Australian community. In 2013, NAB contributed \$66.7 million to charitable projects and its employees generated over \$2 million in workplace giving donations. Over 27,000 staff days were spent volunteering on community programs.

NAB's relationship with MS Research Australia exemplifies this commitment to the community. Over the past ten years NAB (and its subsidiaries, MLC and JBWere) have been ongoing supporters of our work, sometimes going to extreme lengths to ensure sufficient funding is generated; for example, in 2010, a team of energetic cyclists took on the MLC Risk Ride – a 400km, ride from Mt Gambier to Lorne – and generated over \$80,000 for MS Research Australia. Most recently a team of walkers, led by ex-NAB Executive, Mike Hemingway and his wife Katrina, trekked over 300km across the width of the UK.

In 2013 NAB generously provided over \$50,000 in funding from their Community Endowment for a specific MS research project, investigating how sunlight

protects the central nervous system from an autoimmune attack. This project, led by Dr Scott Byrne at the University of Sydney, will be completed in 2015 and, if successful, will be an important proof-of-principle study, which could form the basis of a new preventative treatment option for autoimmunity. We could not have funded this important work without the support of NAB.

NAB staff have already started to plan their Kiss Goodbye to MS

fundraising initiatives for 2015. NAB is also providing the venue for a meeting of our Melbourne MS Angels (a female networking group who provide financial support for MS research) in Melbourne later this month and JBWere kindly hosted our Sydney MS Angels earlier this year.

MS Research Australia is very grateful to NAB, MLC, JBWere and their staff for their wonderful ongoing support of vital Australian research into MS. ■



MLC cyclists participating in the Risk Ride from Mt Gambier to Lorne

Kiss Goodbye to MS in 2015

Taking part in fundraising is a powerful way for people with MS, their friends, family and colleagues to make a difference in contributing to MS research, moving us closer to a time when MS is a thing of the past. Thanks to your fantastic support this year, the Kiss Goodbye to MS campaign alone has raised over \$816,000! This is a huge achievement and we thank each of you for your generosity and support.

The campaign is in its third year and we are proud to announce that corporate sponsorships covered majority of the running costs. This in turn allows the fundraising done by you to be channelled directly to MS research where it is most needed.

Kiss Goodbye to MS is now looking for people who would like to hold a

fundraising activity in 2015. We are regularly surprised and impressed with the fantastic ideas fundraisers come up with when holding their own events. From high teas and dinners with friends, to river walks, amazing races, treks across the UK and to the top of Mount Kilimanjaro – the sky is the limit!

Please join us in our quest to find a cure by participating in a fundraising activity next year. It could be as simple as wearing red lipstick in May and getting sponsored to do so. Or, you can be sponsored to participate in a sporting event, challenge or hold your own event! For fundraising ideas or to register as a fundraiser, visit our website.

With the 2015 plans already in motion, be sure to like us on Facebook to keep up to date with the latest news, or visit www.kissgoodbyetoms.org ■



Regan Trask and family raised over \$7,800 and are pictured here Kissing Goodbye to MS from Mount Kilimanjaro

Workplace giving made easy

Already for next year, we have businesses and workplaces signing up to hold Kiss Goodbye to MS fundraising events in May. They are a fantastic way for you and your colleagues to have fun and support a great cause!

Get in touch with us today to order your Corporate Kit – with everything you need to hold a Kiss Goodbye to MS fundraising event in your workplace. ■



Fastway Couriers held a state wide fundraising BBQ and encouraged staff to purchase merchandise to support MS Research Australia

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:

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