





**JUNE 2021** 

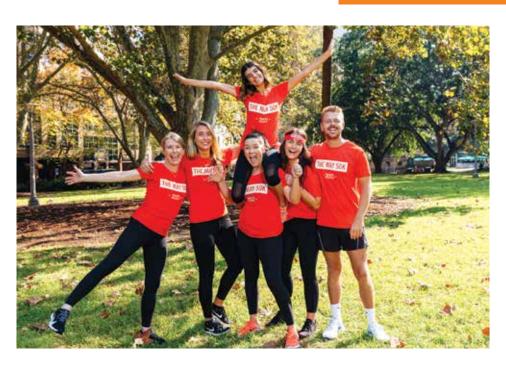
### **EXCITING PROGRESS IN** A CHALLENGING YEAR



Research Australia is currently funding 62 research projects covering a range of MS research priorities, including causes prevention, better treatments and reversal of disability through repair or regeneration of cells.

None of this research would be possible without the ongoing support of the MS partners and the MS state/ territory organisations. Each year, researchers funded by MS Research Australia provide a detailed report on their progress. Here are some of the research highlights – just a fraction of the incredible progress that you have made possible.

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## YOU'VE RAISED \$5.2 MILLION FOR LIFE-CHANGING MS RESEARCH

This year marked the third year of MS Research Australia's national fundraising campaign, The May 50K. The virtual fitness and fundraising movement challenges Australians and the MS community to run or walk 50 kilometres throughout the month of May, whilst raising funds to power world-class research into MS.

This May, we saw over 28,600 Australians leave their limits behind by taking on a range of inspiring activities including cycling, running, horse riding, arm cranking, walking and paddle boarding - nothing was off limits! Some even completed their 50 kilometres in one day, taking the challenge to a whole new level. Once again, we've had more people participating in The May 50K than there are Australians living with MS (25,600), highlighting the incredible MS community who continue to work towards stopping MS in its tracks.

Together, The May 50K community logged a monumental 1,273,899 kilometres as part of the challenge, which equates to doing 31 laps around the world!

The competition also heated up this year, with 498 workplaces participating in the challenge, including Atlassian, Coca-Cola Europacific Partners Australia, Nuzest, JBL and many more who fought for the top of the leaderboard, raising over \$841,000 to leave MS behind.

The combined efforts resulted in an impressive \$5.2 million raised for vital MS research - a remarkable outcome which will help to improve the lives of people living with the disease today and in the future!

Cont. on pg 2



### A WORD FROM OUR CEO



First and foremost, a heartfelt thank you to the entire MS community and the broader Australian public for your superb participation in, and support of, The May 50K.

Thanks to your fund-raising efforts, and your heroic walking, arm cranking, running, rowing, rolling, cycling – to name but a few – we have not only made our target, but exceeded it, by raising \$5.2 million for world-class and life-changing research into MS. There has been tremendous support from individuals – some 28,600 signed up to participate, along with 498 workplaces taking part in the challenge. I was able to visit a number of workplaces with internal teams this year and note that there has been fierce competition between them.

A big shout out to the teams at Merck (\$35,000 raised), Atlassian (\$34,000), Australian Clinical Labs (\$25,000), Coca-Cola Europacific Partners Australia (\$24,823) and Omni Executive (\$24,800). There has also been outstanding individual efforts, both in terms of fundraising and physical challenges completed.

They all made my efforts pale by comparison, but I did reach my fundraising target and got my 51km covered over three dedicated runs: two 15km runs and one Half Marathon – a big stretch for me and my arthritic joints. The fact that two of them were done in Canberra's subzero temperatures made it that much more invigorating. A huge thank you also to every participant – no matter how big or small the distance or the amount raised. Because every single dollar raised has helped us reach our target. Every. Single. Dollar. So thank you, one and all.

I also want to profusely thank our small but tireless The May 50K fundraising team so ably led by Tanja Voss. I have been associated with many fundraising activities in the not-for-profit sector over my career, but this has been by far the best, with palpable energy and enthusiasm for the mission – to improve lives of everyone living with MS and to find a cure.

I dedicated my The May 50K to my cousin, Claire, who lives with MS. But as I ran through the pain barrier in my Half Marathon, I was also thinking of a young 9-year-old in Perth – Connie – who is living with MS and very graciously lent her support to this year's The May 50K. Connie, we can't thank you enough for helping motivate us all, every step of the way. Thank you!

Together, we WILL leave MS where it belongs, behind us. Best wishes

Rohan Greenland

# CONTINUED FROM PAGE 1 YOU'VE RAISED \$5.2 MILLION FOR LIFE-CHANGING MS RESEARCH

We'd like to thank you for putting your trust in us each year and passionately believing in our mission – you truly are our biggest motivation and inspiration.

Since the inaugural launch of The May 50K in 2019, you've now raised a record-breaking \$13.9 million in Australia and \$17.3 million globally to accelerate MS research. We're still pinching ourselves!







#### THE MAY 50K TAKES ON THE WORLD

In 2021, The May 50K was also celebrated globally with participants from the US, Canada, Ireland, Netherlands and the UK leaving their limits behind. Across the globe, we saw over 11,130 people taking on the challenge, raising a collective AUD \$2.2 million for life-changing MS research and access to treatment.

Watching the international growth of our Australian born The May 50K campaign, makes us so proud and excited for the future. Our global collaboration and teamwork is helping to unravel the mysteries of MS faster, and shape a more certain and worry-free future for the 2.8 million people living with MS across the world.



#### THANK YOU - FROM THE BOTTOM OF OUR HEARTS

Reflecting on this year's The May 50K, we would like to say a massive thank you to our incredible fundraisers, their generous donors and supporters – we're so grateful to have you on our team. You've showed us once again just how determined you are to leave MS behind by funding life-changing MS research. Thanks to you, we can continue vital research into MS, ensuring earlier prevention, better treatments and ultimately a cure for people living with MS.

Thank you for changing the lives of people living with MS by continuing to be the driving force behind this movement and enabling our superpower – MS research.

Now rest up and recharge, because we're already getting ready for 2022! Together, each year, we're getting one step closer to leaving MS behind for good. To register your interest for The May 50K 2022, please head to: www.themay50k.org/register-interest-2022



## DMTS, VACCINES AND MS: WHAT DOES THIS MEAN FOR YOUR IMMUNE SYSTEM?

#### **EXPLAINING DMTS**

Disease-modifying therapies (DMTs) are used in multiple sclerosis (MS) to suppress immune responses that inappropriately attack the brain and spinal cord. But do these MS treatments also diminish a person's capacity to fight infection? Can people with MS on DMTs still make antibodies? These are fundamental questions to determine whether people with MS can develop effective immunity to COVID-19 either through infection or vaccination, while maintaining their MS treatment.

Research addressing these questions and other impacts of COVID-19 on people with MS is ongoing. Measuring the effects of DMTs on vaccine effectiveness isn't new because vaccinations are a regular part of routine healthcare for people with MS on DMTs.

DMTs are designed to dampen down immune responses in autoimmune diseases such as MS, to prevent the immune system from mistakenly attacking the body. They include therapies like ocrelizumab, which reduces the number of B cells; while others such as fingolimod trap the immune cells in certain parts of the body so they can't enter the brain and cause damage. Others, including cladribine, generally reduce the overall number of lymphocytes in the body. Early MS medications such as interferons worked on interfering with the normal chemical signaling between immune cells. Each DMT affects the immune system, so what happens when this DMT-altered adaptive immune system encounters the COVID-19 virus?

#### **RESEARCH INTO COVID-19 AND DMTS**

Interestingly, while scientists had never encountered COVID-19 before the current pandemic, they have for many years been looking at the effects of DMTs on the immune response and its ability to protect the body following vaccination. The evidence indicates that the different DMTs have different effects on vaccine response, and that medication timing has a significant impact, i.e. soon after taking some medicines, the immune system struggled to produce a response to vaccines, but even a couple of weeks post-treatment the adaptive immune response was better.

When scientists have looked at COVID-19 and the response of people with MS on DMTs, they have found different outcomes. Scientists in Sweden studied people who had therapies that targeted specific B cells, i.e. ocrelizumab and a similar medication rituximab. Their results indicate that people on these treatments who have previously had COVID-19-like symptoms were capable of developing antibodies against SARS-CoV-2 despite their numbers of B cells being reduced. In contrast, a study from Israel following widespread vaccinations suggests that people on B cell therapies have a reduced ability to produce antibodies against SARS-CoV-2. They found the same for people on fingolimod, but not for people on cladribine. Information about other MS DMTs has not been reported yet. These results are based on small numbers. and whether there is a difference in the antibody response to a natural infection and vaccination remains to be seen.

However, the results of the Israeli COVID-19 vaccination study align with previous studies showing a reduced ability to produce an immune response against various other vaccines (non COVID-19 vaccines) following B cell therapy. Despite this, these investigators concluded it was still worthwhile for people on these treatments to receive vaccines, as even though the response was lower, there was some protection expected.

A retrospective study also identified a small number of people who also received vaccinations during the clinical trials for cladribine, including vaccines for the flu and chickenpox (Varicella-zoster virus). The analysis showed protective influenza antibody levels at four weeks post-vaccination in people with MS taking cladribine. Additionally, both vaccines showed that protective antibody levels were maintained or increased regardless of the level of white blood cells in the blood. While this is a limited and early study presented at ACTRIMS (Americas Committee for the Treatment and Research in MS), it indicates that people taking cladribine can mount and maintain an effective vaccine response.

#### WHAT DOES THIS MEAN FOR PEOPLE WITH MS?

This research is ongoing, but work in other fields where B cells are reduced, such as cancer patients on B cell therapies, suggest in the absence of B cells, T cells might still be able to mount an effective response against pathogens. This is giving us fascinating insights into the amazing machine that is the human immune system. While there is more work to be done to understand the intricacies of vaccine response while taking B cell therapies, the take-home message is that vaccination is safe for people with MS on DMTs.

If you are taking a particular DMT, your specialist healthcare team might suggest delaying your vaccination for a short time after your MS treatment, not out of any risk, but to maximise your immune response against a vaccine. Visit our COVID-19 Vaccination Guidance page on our website for more information about specific DMTs and vaccination for people living with MS. As always, if you have any questions about your health, MS treatment or vaccination, please talk to your specialist healthcare team.

View our COVID-19 Hub: www.msaustralia.org.au/about-ms/ covid-19-and-ms for more information about specific DMTs and vaccination for people living with MS.

## CONTINUED FROM PAGE 1 MS RESEARCHERS MAKE EXCITING PROGRESS IN A CHALLENGING YEAR



#### MS PROGRESSION: YOUR GENES ARE NOT YOUR FATE

Over the last year, Dr Vilija Jokubaitis completed her 3-year project to see if a person's genetics can help predict whether they are likely to develop mild, moderate or severe MS.

This work was co-funded by MS Angels Melbourne, Charity Works for MS and the Industry Superannuation Property Trust.

Collaborating with neurologists and geneticists around the world, Dr Jokubaitis examined more than five million genetic variants in over 1800 people. She confirmed two genes were associated with the age at which people develop MS, but did not find any genes that influence MS severity.

What this suggests is that the severity of MS is not under strong genetic control. That is, your genes are not your fate as there are other factors involved.

It tells us that outcomes can be modified by appropriate use of MS therapies, and also likely, by various environmental factors.

DR JOKUBAITIS CONFIRMED
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WITH THE AGE AT WHICH PEOPLE DEVELOP
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INFLUENCE MS SEVERITY.

#### MAXIMISING BODY AND MIND HEALTH IN MS

Understanding the factors we can modify to optimise health and wellbeing in MS is an important goal of several current research projects.

#### **Smoking**

Dr Claudia Marck is exploring the experience of smoking in MS in a current MS Research Australia funded research project. She interviewed people with MS regarding smoking and their current health beliefs.

She identified that many people did not know that smoking can worsen their MS, in addition to exacerbating anxiety, depression and other health problems. Her findings have also attracted further funding from Quit Victoria and the University of Melbourne. This funding will help to develop better resources to educate people about the effects of smoking in MS and provide practical assistance to stop smoking and improve overall health and wellness.

#### Diet

Several researchers funded by MS Research Australia are working towards understanding how diet might play a role in how MS progresses, and in improving general health in people with MS.

Associate Professor Lucinda Black has found that while high amounts of highly processed food increase the likelihood of MS, an anti-inflammatory diet may help reduce the likelihood of MS in women. Associate Professor Black, whose project is co-funded by MSWA, is now examining dietary factors associated with disease progression.

Ms Alice Saul's PhD project, co-funded by the Penn Foundation, explores whether diet can reduce MS relapses and progression (measured by MRI) and other MS symptoms such as fatigue. Ultimately it is hoped that these projects will help us to better understand the role of diet in MS and the changes that can be made to improve health.

#### Mental health

Dr Lisa Grech is a psychologist and MS researcher, who also lives with MS. Her work aims to address the higher rates of depression in people with MS, which are two to three times that of the general population.

### IN SOME CASES, PEOPLE WITH MS DID NOT RECOGNISE THAT THEY HAD SYMPTOMS OF **DEPRESSION OR THAT EFFECTIVE HELP WAS AVAILABLE TO** MANAGE DEPRESSION.

Dr Grech's interviews with neurologists, MS nurses and people with MS have uncovered barriers to effective treatment. In some cases, people with MS did not recognise that they had symptoms of depression or that effective help was available to manage depression.

Going forward, Dr Grech is looking at whether a brief screening tool to be used by healthcare professionals might help with better detection of depression in the MS population, as well as developing recommendations to improve the outcomes for people with MS experiencing depression.

#### Gut bacteria

Recent years have seen a growing interest in the effect of the gut bacteria, or "gut microbiome", on the immune system, and the use of diet and probiotics to attempt to alter the microbiome in human health.

Associate Professor Laurence Macia has been studying the influence of gut bacteria in laboratory models of MS, with cofunding from the MS Angels. Gut bacteria can have a powerful effect on reducing inflammation in the body. Associate Professor Macia is studying a molecule made by gut bacteria, called butyrate, that binds to a sensor molecule on immune cells called GPR109A. She has shown that lack of butyrate or GPR109A reduces the severity of disease in the laboratory.

Her ongoing work is looking more deeply at how this happens, and whether targeting this pathway in immune cells might be a new option in treating MS. Her follow up project is examining how controlling diet components (such as carbohydrate, protein and fat) might reduce disease severity in laboratory models of MS.

#### **DEVELOPING AND TESTING NEW TREATMENT OPTIONS** FOR MS

Professor Sanjay Swaminathan is studying Epstein-Barr virus (EBV) infection. We currently know that infection with EBV is necessary for the development of MS and has been implicated in MS disease processes.

Professor Swaminathan has shown that EBV interacts with human genes that increase the risk of MS and can "hijack" these genes by switching them on or off. In this project, Professor Swaminathan has shown that EBV can be prevented from hijacking human genes, using a chemical that interferes with an EBV protein. He is now designing new molecules that has this same effect and could potentially be safe for use in humans in future.

Dr Jennifer Massey is researching autologous haematopoietic stem cell transplant (AHSCT) for MS in a clinical trial. MS Research Australia, with the MS Angels, is funding Dr Massey's Fellowship to look at how AHSCT alters the immune system. She has found that depletion of immune cells by chemotherapy stimulates regrowth of a particular type of immune cell that can suppress autoimmunity. The favourable changes to the immune system persist three years after the transplant, even once the immune cell numbers in the blood return to normal.

**C** DEPLETION OF IMMUNE CELLS BY CHEMOTHERAPY STIMULATES **REGROWTH OF A PARTICULAR** TYPE OF IMMUNE CELL THAT CAN SUPPRESS AUTOIMMUNITY.



Dr Lisa Grech

Associate Professor Laurence Macia Professor Sanjay Swaminathan

Dr Jennifer Massey



## SUPERCHARGING THE MS AGENDA

In the lead up to World MS Day (Sunday 30 May), MS Australia hosted a special multiple sclerosis (MS) research and advocacy update with the Parliamentary Friends of MS, live streamed from Parliament House on Tuesday 25 May.

At the event, Parliamentarians, MS researchers, advocates and people living with MS were joined by speakers from MS Australia, including CEO Rohan Greenland and President of the Board, Associate Professor Des Graham, Co-Chairs of the Parliamentary Friends of MS group, Senator Wendy Askew and Senator Deb O'Neill, and MS research experts Dr Julia Morahan and Professor David Tscharke. The speakers highlighted the work being done to improve the lives of people living with MS, as well as bringing to light the importance of connections within the MS community.

President of the MS Australia Board and Chair of its subsidiary MS Research Australia, Associate Professor Des Graham, hosted the event. As a person living with MS, and with over 35 years of experience in the health and human services sector, Associate Professor Graham is drawing on his vast expertise and experience and is determined to make a difference.

Associate Professor Graham reflected on the significance of the 2021 World MS Day "Connections" theme (www.msaustralia.org.au/news-blogs/latest-news/reflecting-world-ms-day-2021) and identified World MS Day as

the marker to supercharge the MS research agenda. Whilst doing so he called on and challenged the Parliamentary leaders to assist us to end MS once and for all.

In the area of MS research, MS Australia and MS Research Australia have made significant gains over the last 10 years, in particular the past five years, across both searching for a cure, and in improving the treatments and care available to people living with MS.

IT IS NOW

MORE THAN EVER

THAT OUR AIM AT

MS AUSTRALIA AND

MS RESEARCH AUSTRALIA
IS TO SUPERCHARGE THE

MS AGENDA.

MS Australia and MS Research Australia are better connected than ever before, providing greater capacity and support to each other, our members, research institutions and our highly engaged volunteers and community.

"Today we know so many of the moving parts of the biology that makes up the MS puzzle", says Associate Professor Graham.

"We have improved our disease modifying therapies monumentally. We

Photographed: Professor David Tscharke, Associate Professor Des Graham, Dr Julia Morahan, Rohan Greenland at Parliament House, Canberra.

have translated research findings into improved quality of life and improved daily outcomes."

However, as Associate Professor Graham stresses, the reality is also this:

- We still don't have a cure, and people with MS still do not enjoy the same quality of life as most Australians.
- In fact, some people living with MS have over a 40% reduction in quality of life than a person without a disability.
- For people with progressive MS, quality of life is similar to or worse than terminal metastatic cancer.
- The annual per person cost of MS is similar to a person with Parkinson's disease, or the first year following a stroke. And three times higher than for a person with Type 2 Diabetes.
- We still have young people (aged below 65 years) with MS living in nursing homes.
- We do not recognise the enormous physical and emotional burden carers carry in supporting their loved ones.
- The number of people living with MS in Australia increased by just over 20% from 2010 to 2017.
- The annual total costs of MS per person continues to rise at around 17%.
- Of the 25,600 people living today with MS, less than a third have gained entry into the National Disability Insurance Scheme (NDIS).
- The health economic impact of MS was \$1.75 billion dollars annually in 2017. A 41% increase from 2010.

Associate Professor Des Graham experiences this reality every day as a person living with MS, but he believes we are on the cusp of something great.

"We have a Prime Minister whose life has been touched by MS, we have two incredible Senators, our [Parliamentary Friends of MS] Co-Chairs, who have the lived experience of family members with MS and we are connected nationally and internationally to the wider MS community," says Associate Professor Graham.

"It is now more than ever that our aim at MS Australia and MS Research Australia is to supercharge the MS agenda".

MS Australia will continue to play its role in raising awareness, advocating, and prioritising our efforts into the treatment, prevention and ultimately a cure for people with MS.

Watch the recording of the live stream here: www.msaustralia.org.au/ms-research-and-advocacy-update-parliamentary-friends-ms



#### An MS diagnosis at any age can be life changing.

Whilst the average age of diagnosis is between 20-40 years old, children and teenagers can also develop MS - with some as young as two years old. It is thought that up to 10% of people living with MS either experience their first symptoms or receive a diagnosis in childhood - also referred to as paediatric MS.

Recently, we met a young girl called Connie Baker who took part in this year's The May 50K. Connie is 9-years old and was diagnosed with paediatric MS just six months ago.

Connie has always been a vibrant and enthusiastic child, enjoying school sports, playing the drums and she's even a little Math whiz!

However, despite her determination to throw herself into almost everything, Connie had been experiencing migraines for around five years. As the migraines got progressively worse, Connie's parents took her to a paediatrician who immediately sent Connie for an MRI, which sadly discovered lesions on her brain.

After a week of staying in hospital and undergoing multiple tests, Connie was diagnosed with MS.

Currently, Connie's MS symptoms are showing as migraines, but her mum Paula understands that this is only the beginning of her daughter's MS journey.

"Connie doesn't want to know about her disease and how it may progress in her lifetime. She doesn't like all the appointments and tests, but she knows she needs them to stay healthy."

Other than living with MS, Connie is just like any other 9-year-old with big dreams for her future. She wants to be a teacher when she grows up, have children and live in a two-storey house. Connie says that "just because you have MS doesn't mean you can't have fun."

Fortunately, the Bakers have received wonderful support from their friends and family throughout this challenging chapter. From school pick-ups and hand-made cards, to checking in on Connie at the hospital and offering emotional support - Paula says they are lucky to have a very caring network.

Despite the only recent diagnosis, the Bakers decided to take action and show Connie that they will support and love her through anything life throws at her. Connie and her family took part in The May 50K to help find better treatments and cures for MS, in support of other children, teenagers and adults who are also living with the disease.

Paula believes in research as the key to ensuring Connie can live a relatively normal and fulfilled life.

"What if the funds we raise enable the research that cures MS? We have to be passionate about research because this is our daughter's life. This is her future, and we will do whatever we can to make it better."

The strength and positivity Connie and her family have shown since her diagnosis is admirable.

We wanted to show Connie that she's not alone and that the MS community wholeheartedly supports her, so together with her parents Paula and Graham, we prepared a little surprise for her.

We created the 'Connie's Crew' team and asked The May 50K participants to join the team in support of Connie to help leave MS behind. The surprise was a huge success, with 848 participants joining Connie's Crew, who raised over \$314,000 for life-changing MS research together – a record-breaking effort!

Thank you to everyone who joined and showed Connie that she's not alone on her mission to Kiss Goodbye to MS. Together, we're accelerating vital research into MS to create a brighter future for people and children living with MS like Connie.

For any questions about The May 50K, please don't hesitate to call us on 1300 785 717 or email us at themay50k@msra.org.au.



#### LET'S GET STARTED! TELL US AN INTERESTING FACT ABOUT YOURSELF...

I have always wanted to be a neuroscientist. I began to think about it when I was in primary school, but received little encouragement except from one individual. It was my grandfather and he firmly believed that the pursuit of knowledge was for everyone. He made no distinction between his grandsons and granddaughters when it came to the right to education. If I'm here today it's, to a large extent, thanks to him.

## WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

It was while I was in the third year of my B.Sc. degree that I met, for the first time, a young person affected with MS. She was a good friend and suddenly developed severe symptoms and struggled to complete the year. It wasn't a hard decision to make as to which area of neuroscience to choose.

## WHAT DO YOU THINK HAS BEEN THE MOST EXCITING DEVELOPMENT IN MS RESEARCH?

From my perspective the vast improvements made in the understanding of the pathological processes underlying MS over the last 20 years have been among the most important game-changing developments in the field. This new vision has generated a better understanding of the disease evolution and the basis of progression. I have no doubt that the new focus on progression will lead to improved therapeutics aimed at early intervention.

## TELL US ABOUT YOUR CURRENT RESEARCH PROJECT...

I had the good fortune to meet Professor Karlheinz Peter, a cardiologist at the Alfred Hospital and Baker Institute, at a scientific meeting on imaging techniques. It was then that we decided to investigate the role of platelets in neuroinflammation using a combination of a platelet-targeting drug he had developed and my MS animal models.

After a few hiccups, we generated data that proved platelet targeting to be highly potent in blocking disease progression. Our current project aims to demonstrate that platelet targeting from early disease stage prevents neurodegeneration and entry into the progressive disease stage.

# WHY IS YOUR RESEARCH IMPORTANT AND HOW WILL IT INFLUENCE THE UNDERSTANDING AND TREATMENT OF MS?

The focus of the project is on mechanisms causing early tissue destruction. The new animal model generated as part of the research will allow measurements of spontaneous repair and the evaluation of adjunct therapies promoting repair. We believe that this research will lead to improved patient monitoring and new strategies for neuroprotection.

# WHAT DO YOU ENJOY MOST ABOUT WORKING IN THE LAB AND WHAT ARE SOME OF THE CHALLENGES YOU FACE?

The most exciting part of being a scientist is the feeling that every day, one is participating in the creation of new knowledge. The challenge is to find the time to devote enough attention to all aspects of the work: training junior scientists, reading, writing manuscripts, giving lectures and (sadly) administrative duties as well...Sometimes I feel like a juggler about to lose all my clubs.

## HELP MS RESEARCH AUSTRALIA FIND A CURE FOR MS

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To support MS Research Australia's vital work I would like to:				Cheque (made payable to MS Research Australia				MS
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