



MSWIRE

June 2022



MS AUSTRALIA WINS GLOBAL MS BRAIN HEALTH AWARD



The MS Brain Health initiative has launched an annual series of awards to illustrate the global impact of lifelong brain health and showcase the ongoing progress in this area.

The awards showcase the work of healthcare professionals, multiple sclerosis (MS) societies and individuals in addressing the importance of brain health in MS.

MS Australia is delighted to announce it has been successful in winning the patient organization category, with our submission titled, "At MS Australia, Brain Health is integrated into all of our work".

We believe that since the launch of the *Brain Health: Time Matters in MS* report in 2015, Brain Health has become part of our DNA.

We haven't had just one single Brain Health project but a multitude of projects and activities to progress the Brain Health initiative over the past five years.

We use the Brain Health report to champion systemic improvements in health, disability, aged care and social services across the wider Australian community.

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THANK YOU - YOU'VE RAISED OVER \$3.4 MILLION FOR LIFE-CHANGING MS RESEARCH!

May has been a fun-filled month with 19,467 people mostly across Australia getting active to raise money to accelerate research into the prevention, treatments and ultimately a cure for multiple sclerosis.

So far, the national movement has raised \$3,434,124 to leave MS where it belongs, behind us.

One of our youngest participants in The May 50K was 10-year-old Connie, who was diagnosed with paediatric MS just 18 months ago.

Being diagnosed so young, Connie and her family don't know what the future holds, so it's a very uncertain time for them. While other kids are enjoying their childhood, young Connie is struggling with fatigue and her MS is slowing her down from doing the things she loves.

But Connie is one tough little lady and did not let MS stop her from being involved in The May 50K. She got active with her family, and we went out to The May 50K community

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FROM THE CEO



It feels as if we have been on a rocket for the last three months, with major events propelling our research and advocacy work forward at a record rate.

In February, we announced a record investment in Australian MS research, a shade under \$6m, all made possible by the rock-solid support of the MS community, generous donors and our hard-working Member Organisations - MS Limited, MSWA, MS South Australia and Northern Territory, and MS Queensland.

Following advocacy by MSA, in March, the Australian Government announced a record \$18m for MS research with a focus on the Epstein-Barr Virus.

In April, we held our first MS research conference since the beginning of the pandemic, with a record number of delegates gathering in Hobart for three days of superb presentations and discussions on the latest in MS research.

We launched a critically important report on MS Nurses and the incredible health and economic benefits they bring to people living with MS and the broader community. It also highlighted the urgent need for another 50 MS Nurses to address unmet need.

Also in April, we unveiled our election policy statement, with seven key points we wanted all major parties and candidates to address ahead of the federal election to improve the lives of all people living with MS, their families, friends and carers.

In May, we kicked off our major research fundraising event for the year, the iconic May 50K and prepared a major report and survey on the employment challenges faced by people living with MS, ready for launch on World MS Day on May 30.

Leading up to World MS Day, we were honoured to receive a global MS Brain Health Award for our comprehensive work in promoting brain health, developing resources and working towards the implementation of the landmark MS Brain Health: Time Matters Report.

All this achieved in the past three months. But we will not rest on our laurels with plans in place to make the next three months equally energetic. We will not rest until we have put MS where it belongs - behind us.

Best wishes

Rohan Greenland

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MS AUSTRALIA WINS GLOBAL MS BRAIN **HEALTH AWARD**

Here are just a few examples:

- a suite of health and wellbeing resources on our website and social media channels with a particular focus on how to keep your brain healthy.
- allocation of brain healthfocused research grants to address smoking behaviours, exercise, and promote explore dietary factors that reduce progression and MRIs for predictions.
- engagement with the Australian pharmaceutical benefits process SO that people with MS have access to subsidised disease modifying therapies (DMTs) and increased choice. There are now at least 15 subsidised DMTs available to people with MS in Australia.
- news items and treatment sheets that assist people with MS with decision-making.

At the request of the former Minister for Health, Greg Hunt, we created a series of Roadmaps including a Roadmap to Defeat MS in Australia.

Together with budget submissions and policy platforms, these Roadmaps are used to negotiate with relevant Minsters, politicians, officials departmental and key decision-makers to seek government funding and support for Brain Health-related initiatives.

This year, Australia's Medical Research Future Fund has, for the first time, made significant MSspecific allocations for research.

We have promoted the Brain Health GP Guide to enable an integrated and comprehensive approach to MS management in various GP publications.

Recently, the Royal Australian College of GPs published a special MS-focussed edition of their iournal with a number of articles from Australian MS researchers and many references to the MS Brain Health initiative.

We collaborate with other web-based directories like The Better Health Channel to ensure MS-specific information is shared widely across the Australian community.

And we provide an online list of all MS clinics across Australia to improve access to MS specialist care.

We've recently launched our new MS Nurse Care in Australia Report. Actioning the report recommendations to raise awareness of and increase access to MS Nurses will, in turn, advance many of the recommendations of the Brain Health initiative.

A simple test of the effectiveness of our Brain Health work is feedback from the MS community. Responses from people with MS are always positive and encouraging.

Winning this award will spur us on to increase the breadth and depth of our MS Brain Health work and to share our successes with other MS Brain Health champions. MS Australia congratulates all individuals, teams and organisations who submitted a nomination to the first Brain Health Awards.

Our shared vision is for a world without MS. We are determined that the Brain Health: Time Matters in MS recommendations will be used widely among those committed to creating a better future for people with MS, their families, carers and friends.

Visit the MS Australia YouTube channel www.youtube.com/ watch?v=bW3fM1Je5X8 for an explanation by Rohan Greenland, CEO of MS Australia of how Brain Health is integrated into all of our work.

To read more about the MS Brain Health initiative, please visit the MS Brain Health website www.msbrainhealth.org and go to 'recommendations' then 'brain health report'.

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THANK YOU – YOU'VE RAISED OVER \$3.4 MILLION FOR LIFE-CHANGING MS RESEARCH!



Team 'Berlin Boys & Galz' with Rohan Greenland, Jeremy Henderson, Dr Jo Lane, Kim Sullivan, Jen Ramsay and Sally Coyle. Mario McDonnell – on the camera.

encouraging people to join her team 'Connie's Crew'. We received a fantastic show of support with a whopping 890 people joining Connie's team! This not only put a big smile on Connie's face, but united everyone towards making MS a thing of the past. So far, Connie's Crew has raised over \$283,000 and has clocked 44,962km.

Connie and her family are still just at the beginning of her journey living with MS and like all our participants living with MS, they have enjoyed being involved with The May 50K as they too want to create a future free of MS.

Every dollar raised during The May 50K helps stop MS in its tracks.

With sufficient funding, MS researchers are 10 years away from stopping MS.

The May 50K is a virtual fitness and fundraising challenge to run or walk 50km (or more!) during the month of May while raising funds for life-changing research into MS. During The May 50K, you can pick your distance. While most people stick with 50km, some passionate people challenge themselves to walk 500km!

One in three Australians will be directly impacted by multiple sclerosis.

Since 2000, the treatment options for MS have increased from only 1 to 15 available treatments today, and that's all thanks to research. MS researchers are certain that with more funding, it's not a matter of 'if' we can stop and reverse MS, it's a matter of 'when'. Research not only gives hope but confidence. Confidence that there will be a future where MS no longer has an impact on peoples' lives like it does today.

With sufficient funding, MS researchers are 10 years away from stopping MS.

If you didn't have the chance to join in The May 50K this year, there's always next year and it's never too early to start training!

Fundraising for The May 50K is open until the end of June and donations over \$2 are tax deductible.

You can donate here to help leave MS in the past, where it belongs **www.themay50k.org.**

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MS EXPERTS MEET IN HOBART TO PRESENT LATEST RESEARCH

On April 4 and 5, MS researchers, MS Nurses, clinicians and allied health professionals gathered in Hobart to discuss their latest work and most exciting findings.

This was our eighth Progress in MS Research Scientific Conference, with close to 50 oral presentations and over 80 poster presentations, making this one of our largest scientific programs.

The conference is designed to help boost collaborations and stimulate innovative research into the causes, prevention, improved treatments and ultimately a cure for MS. These are ambitious goals and to achieve this we need to collaborate and work together. As Steve Jobs said, "great things in business are never done by one person, they're done by a team of people". The conference delegates truly embraced this notion and there was a high level of exchange of scientific thought and investigation among neurologists, researchers and allied healthcare professionals.

In addition to the 180+ Australian scientists, we had three fantastic international experts from the US and Switzerland who shared their research.

The main themes of the conference were:

- Digital Research (digital biomarkers, virtual clinics, digital labs)
- Lifestyle Factors
- Imaging
- Innate Immunity.

Many other fascinating and important research developments were shared diverse fields including autologous haematopoietic stem cell therapy (AHSCT), cognitive behavioural therapy, repair of the damaged myelin sheath in MS, and more.

DIGITAL RESEARCH

Advances in technology are providing amazing new tools to allow researchers to see even the most subtle changes in MS. From computerised tests to wearable sensors to artificial intelligence (AI), all are paving the way towards improved clinical care.

Dr Daniel Merlo from Monash University presented his latest work on how long-term worsening of reaction time detected by a computerised test can predict disability progression. Most cognitive (thinking and memory) tests used in the clinic are not suitable for routine use due to the length of time required to complete them. The computerised test that Dr Merlo presented only takes ten minutes and can be completed at home or in the clinic. Using a specific model, he was able to classify test participants into specific groups based on their change in reaction time. Using this model, he identified a group of participants with relapsing remitting MS who were likely to experience continued reaction time worsening and a group who had an increased probability of

The conference is designed to help boost collaborations and stimulate innovative research into the causes, prevention, improved treatments and ultimately a cure for MS.

confirmed disability progression. The development and validation of these tests could provide neurologists with more information to make better mutual clinical care decisions. This test could also be an important biological marker in clinical trials of new medications for progressive MS, which are urgently needed to accelerate and enable trials for this MS type.

Dr Mava Panisset from the University of Melbourne talked us through her research on using wearable sensors to measure walking stability. There are many measures of walking stability, such as the timed walk, but these cannot detect specific aspects of walking that are affected in MS, nor measure subtle changes. Her latest research shows that wearable sensors could distinguish between people with MS and those without MS, and that placement of wearable sensors on the chest was more sensitive to subtle changes in walking stability than placement on the lower back. This work demonstrates the potential capacity of wearable sensors to be used as a digital biomarker (medical sign) for detection of early functional changes in MS and could potentially be used to monitor disease via a smartphone.

LIFESTYLE FACTORS

Lifestyle factors are aspects of life that can influence MS disease progression and disability, such as diet, exercise, gut health, or smoking. We know that this is an important area for the MS community as it provides a mechanism for people with MS to take control and potentially minimise the impact of MS on their lives. While there is evidence that these factors can affect disease course, this is a complex area of research with so many variables to be considered.

Professor Bruce Taylor from the Menzies Institute for Medical Research presented his work on the prevalence of MS in the greater Hobart region and how this has changed over time. Hobart has the highest level of MS in Australia, and there is a latitude gradient of MS incidence observed in Australia as in other parts of the world, such that the percentage of people with MS is higher the further people live from the equator. This is likely due to lesser exposure to UV radiation and/ or the associated vitamin D availability.

Professor Taylor's work shows that the incidence and prevalence of MS has increased over the years in the greater Hobart region. It is possible that lifestyle factors may have caused this shift, such as obesity, smoking, use of sunscreen (reducing UV exposure) or reduced numbers of or later pregnancies, but this requires further investigation.

Associate Professor Yasmine Probst

from the University of Wollongong presented an overview of the current state of play in nutrition in MS and provided advice to healthcare professionals to help guide their response to diets.

Currently, there is single no recommended diet proven in MS to prevent or slow progression, and although some nutrients may influence the immune system, nothing is absolute.

Associate Professor Probst highlighted that that everyone is different and has an individual gut microbiome, and as such there is no single "quick-fix" for everyone. The only diet recommendation at this stage is to follow the Australian Dietary Guidelines.

IMAGING

Development of cutting-edge technologies for imaging the brain has provided new insights into MS, helping with the development of biomarkers for disease diagnosis and monitoring.

Professor Michael Barnett from the University of Sydney presented his exciting research on the use of MRI coupled with AI to try and get a complete picture of what is happening in the brain of people living with MS. Traditionally, counting the number of lesions on an MRI scan would give us an idea of progression, but Professor Barnett spoke about how slowly expanding lesions may impact the health of people living with MS and may potentially be the driver of progression. The slow expansion of lesions can be quite difficult to detect between two time points but using specialised imaging and AI over multiple time points, the team has developed a method for measuring this. In fact, these slowly expanding lesions may correlate with loss of brain volume and disability progression. It is hoped these measures can be deployed in the clinic and tracked in MSBase, an international database of MS clinical outcomes.

INNATE IMMUNITY

Another important area of focus was innate immunity, the first line of defense of our immune system. This appears to be an important role in the development and progression of MS.

Dr Wei Yeh from Monash University presented his work on the effect of vitamin D supplements on the immune system in people who have experienced a first demyelinating event. Vitamin D deficiency is a risk factor for MS, with vitamin D thought to dampen the immune response. Dr Yeh has found that three months of high dose vitamin D supplementation caused various genes to be turned on or off in immune cells, as well as changes to various biological processes.

Dr Yeh also found this to be dependent on the dose of vitamin D. These results provide insight into the effect of vitamin D on the immune system in



Associate Professor Desmond Graham addresses delegates Photographer Stacey Baker

people who are yet to be diagnosed with MS and may inform future vitamin supplementation studies.

Mr Jason Turner from the University of Tasmania talked about the link between the immune system and social cognitive difficulties. Social cognition refers to the processing of social information, such as the ability to recognise facial emotions. Mr Turner looked at the link between several proteins of the immune system that promote or reduce inflammation and social cognition functioning in people living with MS. He found higher levels of immune system proteins that promote inflammation was associated with poorer social cognitive function in people living with MS. The opposite was also true in that anti-inflammatory immune system proteins were associated with better social cognitive functioning. Overall, this research showed that disease inflammatory processes, distinct from the inflammation that occurs during relapses, may partly be a driver of the difficulties in social cognitive abilities in people living with MS.

INVOLVEMENT OF PEOPLE LIVING WITH MS

We know that involvement of people living with MS in research is absolutely vital and it was wonderful to hear about this from someone with first-hand experience.

Ms Katrina Chisholm, who lives with MS and is part of the Our Health in Our Hands initiative at the Australian National University, presented her experience as someone living with MS involved in MS research. People with MS involved in research contributed to research question development,

data analysis, preparation of peer reviewed papers, creation of a toolkit for collaboration between people living with MS and researchers. and production of conference presentations. People with MS felt supported and that their contributions valued throughout were experience. Ms Chisholm explained that being involved in research can be empowering and provide a meaningful way to contribute to both the research community and the broader MS community.

LIVE UPDATE

Following on from the first two days of the conference, the Live Update took place on the final day where people could hear directly from the experts on the progress of global MS research in real-time. Topics discussed included MS gene hunting, rewrapping nerve fibres, how MS Nurses improve the lives of people living with MS as well as a neurologist's insight.

You can watch the Live Update on demand via our website at www.msaustralia.org.au/events/liveupdate2022/livestream2022.

BEYOND THE CONFERENCE

It was fantastic to see researchers, clinicians and allied health professionals presenting their latest research and networking face-to-face after delays due to the pandemic.

Additionally, there were many young up-and-coming researchers presenting world-class work, a clear indication that MS research in Australia is only going to continue from strength to strength.

CONCERNS AND PRIORITIES OF THE MS COMMUNITY DURING TIMES OF CRISES

The 2019/2020 summer saw one of the most devastating bushfire seasons on record. Shortly afterward, the COVID-19 pandemic began, having a huge effect on the wellbeing of people, as well as healthcare systems worldwide.

Recent research has shown that people with MS negatively changed their health behaviours due to the Australian bushfires and the pandemic.

Royal Commission reports have been important to highlight needs of people with disability, however they have not focused on a specific disease group. It is important that people with MS actively participate in emergency preparation programs and are included in community disaster risk management.

WHAT DID THE RESEARCHERS INVESTIGATE?

MS Australia-funded researchers. Dr Yvonne Learmonth and Dr Claudia Marck and their team, aimed to understand the needs of people with MS during times of crises, focusing on the black summer bushfires and the early stages of the COVID-19 pandemic. This study involved people with MS, carers, healthcare professionals and disability advocates who completed a survey, interviews and a workshop.

WHAT WAS THE MS COMMUNITY'S EXPERIENCE WITH THE BUSHFIRES?

The survey revealed that most people with MS affected by the bushfires had at least one concern. These included leaving home, exposure to smoke, mood change, symptom change, and health in general, with the impact of smoke causing the highest concern. People with MS also found bushfire financial assistance, isolation from their community and reduced access to healthcare to be concerning. The wider MS community indicated that maintaining power in the home where people with MS lived and feeling helpless to assist their clients were concerns.

People with MS indicated in the interviews that, they experienced increased levels of anxiety, and despite MS organisations supporting people with MS through phone calls, many felt that more support was needed.

Few people with MS had a bushfire preparation plan, and if they did, it worked for one type of natural disaster but had little relevance to another, or it was not current. Healthcare providers reported difficulties in helping people with MS prepare an emergency bushfire plan and highlighted the importance of considering the person's disability when preparing for future crises.

WHAT WAS THE MS COMMUNITY'S EXPERIENCE **DURING THE EARLY STAGES OF THE COVID-19 PANDEMIC?**

The survey revealed the main concerns of people with MS were COVID-19 severity in MS and the effects of MS medication on susceptibility to COVID-19. The wider MS community was also concerned about the reliability of information.

In the interviews, about half of the people with MS experienced increased anxiety and confusion due to loss of family interaction, changes in access to amenities, and worries about not understanding the restrictions. They were also concerned that illnesses could worsen their MS and how their anxiety was influenced by the external stresses they were exposed to. However, there were also participants who found that they could monitor and manage their symptoms better due to the restrictions.

People with MS mentioned they experienced social anxiety and a fear of returning to work once restrictions were eased. However, employers supported participants to allow them to isolate and feel safe in their work environment. Overall, the transition to different workplace practices was difficult for people with MS and resulted in unwillingly disclosure of personal health information.

WHAT IS REQUIRED TO SUPPORT OPTIMAL **HEALTH IN PEOPLE WITH MS DURING CRISES?**

The views of participants who attended the stakeholder workshop echoed those who completed the survey and interviews. This group decided on priorities for preparing for and managing MS care during bushfires and through the COVID-19 pandemic.

Bushfire-related priorities included:

- Accurate, timely, consistent information, from MS organisations and major stakeholders
- Central phone or chat service for people with MS
- Central online information source
- More MS Nurses in rural areas
- One-to-one education on creating a bushfire plan specific for people with disability
- National registry of people with MS to expedite communication
- Communication from MS organisations to restate the importance of maintaining appointments/ management.

Pandemic-related priorities included:

- Localised information
- Central phone or chat services for people with MS
- Better access to MS Nurses through increased telehealth staffing numbers
- Instructions on how people with MS and clinicians can use telehealth better
- Focus on home-based exercise and consider carer involvement.
- Accessing information coordination of multiple information sources, easy to understand with multiple dissemination formats.

WHAT DOES THIS ALL MEAN?

The researchers recommend that MS healthcare professionals are acknowledged communicators of health information and that high priority is placed on meeting the needs of people with MS to support them to maintain their health and, employment at times of crises.

TO STOP MS SOONER, WE NEED YOU

Cheryl, 48, is such a strong woman, and she tries to stay positive despite the debilitating, unpredictable pain, muscle spasms and extreme fatigue she endures.

She has multiple sclerosis (MS), a chronic disease that attacks the central nervous system, for which there is currently no cure.

Cheryl's particular experience of MS means her vitality and strength are slipping further away each year. She is losing her vision and independence. Cheryl can no longer play hockey with her daughters like she used to. She has always given 100% to her job, but she now struggles to keep up in the hospital kitchen where she works. Even driving to the shops has become impossible at times due to her temporary vision loss.

Above all, Cheryl hates asking for help – but now she can't get by without it. Despite the progress made thanks to MS research, the key to a cure is yet to be found for people like Cheryl.

One leading Australian scientist is taking a fascinating new approach to try and unlock the secrets of MS, and you can help accelerate research like his.

Associate Professor Brad Sutherland – an expert in vascular biology – is pursuing a theory on MS which has been "understudied" until now. The research project he is leading is focused on blood flow to the brain and how it links to the fundamental mechanics of MS development.

"My research opens up new opportunities. If we can better understand what causes MS, we can find ways to prevent this disease or achieve the goal of a cure."

Associate Professor Sutherland's ambition is to uncover new information about cells on blood vessels at the blood-brain barrier,



and how they may trigger the onset of MS. As he explains:

"Our blood vessels are like pipes that carry blood and nutrients to the brain. We need a constant flow through those pipes for healthy brain function.

"The pipes are held together and supported by a network of nuts and bolts (which are our cells). Sometimes, when those cells are faulty, they can cause leaks. Those leaks can allow harmful molecules to enter the brain and cause damage to important tissue.

The potential for his research findings could be life-changing.

"It's the foundation we need to learn how to prevent the disease, develop ways of improving treatment and achieve our ultimate goal of finding a cure and stopping MS altogether."

Donations will help fund vital research projects that will build critical knowledge of MS, aiming to prevent and ultimately cure MS.

These projects will help to build on the progress already made through investment in MS medical research, to bring a final and complete end to

My research opens up new opportunities.
If we can better understand what causes
MS, we can find ways to prevent this
disease or achieve the goal of a cure.

Associate Professor Brad Sutherland

"My research is focusing on these nuts and bolts of the pipe - cells found on capillaries called pericytes - to see if the structure and function of the blood vessels is impaired in MS, and whether this is a trigger for the disease."

the distress and limitation MS inflicts on lives

And ultimately, your gift could give back people like Cheryl with MS control over their lives – and futures.

Please support MS research -

www.fundmsresearch.org.au

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MEET THE RESEARCHER

ASSOCIATE PROFESSOR LUCINDA BLACK

CURTIN UNIVERSITY



TELL US ABOUT YOUR CURRENT RESEARCH PROJECT...

While diet appears to be linked to MS onset, the role of diet in the disease progression of MS remains unclear. My vision is to remove the confusion surrounding diet for people with MS. I will use a combination of research methods, including: interviewing people with MS, carers and health professionals about diet; using blood samples and dietary intake data from large, multicentre studies of people with MS to test whether diet might influence disease progression; and developing an online dietary education program for people with MS, codesigned by people with MS.

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

I began working with MS researchers

in relation to vitamin D. When I started engaging with the MS community, many people asked me about diet in general. I assumed that the research had already been done, but instead found a significant knowledge gap in the scientific literature and a lot of confusing information online.

Since I couldn't answer the questions I was being asked by people with MS, I was inspired to help fill the knowledge gap in the field of diet and MS.

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

I enjoy supervising and mentoring nutrition students in the field of diet and MS. The students I support are passionate and motivated and are keen to make a difference to the lives of people with MS. Some of these students may go on to have successful research careers, and it is a privilege to be part of their journey.

My current challenge is common to many people - a lack of time. I can only do so much, which is why I am focusing on building a team so that together we can help fill the knowledge gaps in diet and MS and bring the evidence to the MS community more quickly.

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

There are many exciting developments happening all over the world in MS research. I have seen the benefits that a healthy diet can bring to people's lives, so naturally I'm excited that people with MS are keen to learn more about diet.

Since diet is a high priority for people with MS. the research field of diet and MS is growing, both nationally and internationally, and we are starting to see more high-quality evidence emerging about diet and MS.

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

The impact of this research is substantial because dietary changes, including food choices and supplementation, are lifestyle practices that people can change.

By developing evidence about diet and MS disease progression, and providing information on diet to the MS community through an online education program tailored for people with MS, this research will help all people with MS make informed dietary decisions.

HELP MS AUSTRALIA FIND A CURE FOR MS

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To support MS Australia's vital work I would like to:			Cheque (made payable to MS Australia)	MS
Make a one	e off donation of \$		Direct Debit Request (copy of service agreement can be provided on request)	
Make a mo	onthly donation of \$		Financial institution:	USTRALIA 151 008 515 508
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