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MS WIRE
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DEB'S STORY SHOWS THE NEED FOR RESEARCH INTO EARLY MS DIAGNOSIS

Someone who knows about the importance of an early diagnosis is Deb. Unfortunately for Deb, she didn't get one.

Deb's symptoms started appearing when she was in her teens, as she began to struggle with incontinence — something she now admits she was too embarrassed to talk to anyone about at the time.

Then in 1980, she started experiencing bouts of fatigue, so much so that she needed time off from school.

Four years later, during a netball match, she lost all feeling in her right leg and was rushed to hospital. The medical team there performed a series of scans but were unable to identify the cause of the issue.

A year after meeting her late husband — who lived with a disability himself — Deb started experiencing difficulties with her vision, which led to her being signed off work for more than a fortnight.

"I can remember my husband and I walking to the doctor. We must have looked so weird, because I was hanging onto his shoulder as I stumbled across the road. I couldn't see anything. They didn't do any further exploration at that time. And I rested for two weeks. Then bingo, I was fine again. So, you forget about it and you go on," remembers Deb.

In 1992, a clicking knee led to Deb being referred to a neurologist, who investigated a potential arthritis diagnosis.

"It took months to get an appointment. Then I remember being hooked up to machines with a bunch of electrodes on my head. The results came back as normal, and I started thinking the problem was that there was something wrong with my mind," recalls Deb.

In 1995, Deb and her husband had a baby boy. A year later, whilst working as a teacher, her leg gave way again.

"I started seeing a physio. I was able to do the exercises she asked me to do but still ended up limping out of each session. I found out later that she told my GP that she thought I was faking it," recalls Deb.

An uncomfortable theme began to emerge. Not only did Deb have to deal with her symptoms, but also the sense of mutual distrust these experiences created between herself and the medical professionals who were supposed to help.

In 1997, after years spent questioning her own sanity, Deb finally received her diagnosis.

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FROM THE CEO

ROHAN GREENLAND

First, an enormous thank you to all who undertook or supported someone undertaking the iconic May 50K, our single most important fundraising event for multiple sclerosis (MS) research. Your support – as a participant, donor or supporter – is critically important for Australian MS research.

Your dollars help propel us further and faster down the pathways to cures, with cutting-edge Australian research increasingly globally linked and aligned to the international effort to drive prevention, early detection, improved treatment and ultimately a cure.

Second, we have been busy in this post-election period, congratulating newly appointed ministers, asking for early meetings and extending our appreciation for a new portfolio alignment across the health, ageing and disability disciplines.

While it was no surprise that the accomplished health minister, Mark Butler, was reappointed, it was a surprise to find his responsibilities extended to include the NDIS and disability.

While some in the disability sector see this as a detrimental move, I support it, especially as it aligns with a key policy priority supported by MSA and the Neurological Alliance Australia, calling for better alignment across the disability, health and aged care portfolios.

While this is a welcome alignment, it is still just that – an alignment. We will move heaven and earth to see that the better integration of services and improved access to care is realised as a result of this reshuffle of responsibilities.

But it's a good start, and we look forward to an early meeting with ministers new and old in this super-ministry.

We also look forward to early meetings with cross-bench and opposition health spokespersons, including the re-elected independent member for Kooyong, Monique Ryan, a paediatric neurologist.

We will be pushing the case for a national action plan for neurological conditions, sustained funding for neurological research – including MS research – under the Medical Research Future Fund, a national neurological data set – because we still haven't got one – and support for an MS Biobank.

The election may be over, but our advocacy mission continues with fresh passion. Because people living with MS and other neurological conditions are still not getting the support they so desperately need.

Rohan Greenland
CEO, MS Australia

DEB'S STORY UNDERPINS THE NEED FOR RESEARCH INTO EARLY DIAGNOSIS

CONTINUED FROM PAGE 1

"I felt strangely happy that my symptoms had a cause beyond me losing my mind," recalls Deb, "My husband, who was in hospital himself at the time for kidney stones just said we would work through it. And we did."

Without better diagnostic tools, people can endure years of uncertainty, unnecessary treatments, and miss out on an early intervention. A misdiagnosis can mean taking the wrong medication with serious side effects, while a delayed diagnosis can result in irreversible damage.

Without research into better diagnostic methods, this cycle will only continue. With an early diagnosis it is possible to receive medical support, therapies and other treatments that help ease the burden of MS as soon as possible.

Someone who's passionate about finding new ways of diagnosing multiple sclerosis (MS) early is Dr Xin Lin. Along with his team of researchers, he is working tirelessly to minimise the impact of MS.

"The average time from onset of symptoms to MS diagnosis is nearly four years. We're getting better, but four years is still a long time," says Dr Lin.

Dr Lin's work focuses on developing biological markers for MS, aiming to create a faster, more reliable diagnostic process.

"One of the big challenges that remains is that we still don't have a good set of blood-based markers for MS. If we did, we'd be able to potentially diagnose via a simple blood sample. And given that blood tests are less invasive and more clinically accessible, this could dramatically speed up the diagnosis process.

The current process of diagnosing MS remains time-consuming, and it presents a barrier to treating MS from the earliest stages," says Dr Lin.

Dr Lin and his team are working on a way to diagnose MS via a blood test. If successful, doctors will be able to identify MS much sooner and with greater accuracy, ensuring people receive the right treatment earlier, improving outcomes and enhancing quality of life.

The biological markers of a disease can be used to reflect or capture the complexity of that disease's processes.

Being able to identify the biological markers of a disease like MS gives us a set of molecules, which are easy to identify through blood testing, and is generally very targetable using drugs.

"Aside from this making diagnosis faster and easier, I think one of the most exciting things about what we're doing is the benefits and application could extend way beyond early diagnosis. It could also help with treatment development, as well as just translational research in general. By finding a new set of biomarkers, we can both repurpose existing, approved therapies and potentially dramatically speed up the development process of new ones.

"All of which has the potential to transform patient outcomes, putting valuable time on the side of everyone living with MS.

"We simply wouldn't be able to do this expensive and time-consuming work if it were not for the continued generous support of donors. Complex procedures like measuring molecules from blood samples mean we need very specialist equipment, and this all costs a lot of money.

"So, my team and I are grateful every single day for the life-changing support that every donor provides." says Dr Lin.

While we can't change what Deb went through, we can ensure fewer people face the indignity and frustration of a delayed or misdiagnosis. Your generosity means researchers can spend more hours in the lab. And those hours will one day create a solution that puts time on the side of everyone living with MS.

Please help fund vital research into new ways of diagnosing MS earlier – so that people like Deb don't have to wait to receive effective treatment, care and support. Thank you.

You can help change the story for people like Deb. Your tax-deductible gift can support faster diagnosis, better treatments, and a future free from MS.

DONATE TODAY

GLOBAL MULTIPLE SCLEROSIS PREVENTION INITIATIVE UNDERWAY

A new international effort to prevent multiple sclerosis (MS) is now officially underway. Researchers, clinicians, people living with MS, and MS organisations from around the world met in Lisbon, Portugal in April for the inaugural Global Prevention and Early Detection Initiative workshop.

Over a five-year period, MS Canada is contributing $5m and MS Australia, a further $2.5m to support this global initiative. Together, we will work with international collaborators and the Global MS Research Strategy Group to fund research focused on the window of risk and preclinical stages of MS.

Delivering her opening remarks at the workshop, Dr Pamela Valentine, President and CEO of MS Canada, reflected upon the momentum of MS research catalysed by the strength and collaboration of the global MS community.

“We have an unprecedented opportunity given the progress that has been made in better understanding MS. We believe this global initiative will allow for better understanding of risk factors and ultra-early detection that will help us move towards preventing MS for future generations,” Dr Valentine said.

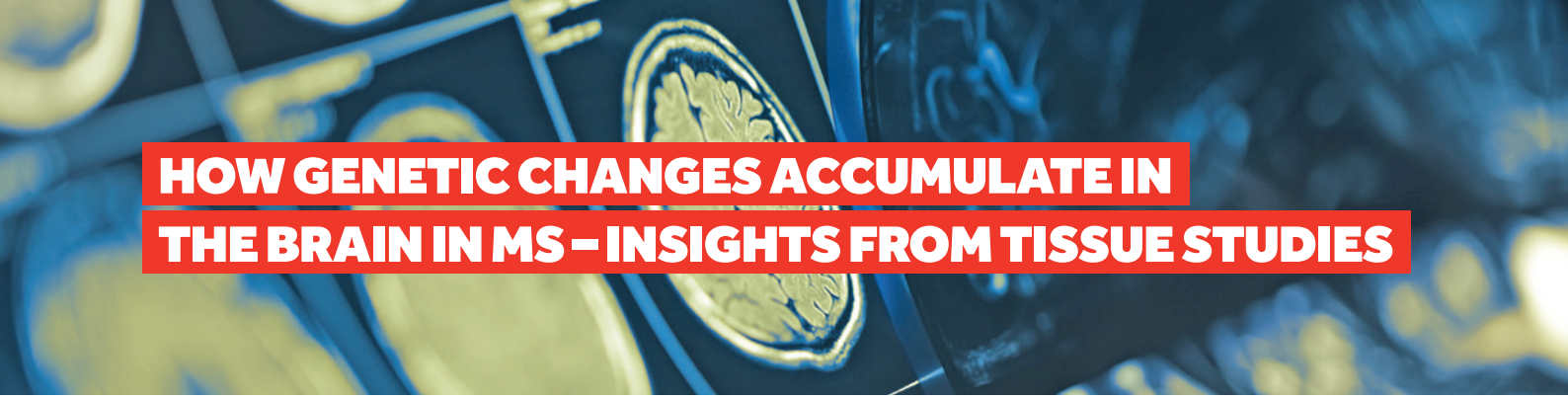
The global prevention initiative builds on the strong foundations of existing international research initiatives and partnerships and comes in response to the latest iteration of the Pathways to Cures Roadmap, which outlines research areas with the greatest potential to stop MS, restore function and repair damage from the disease, and end MS through prevention.

In response to this report, MS Canada and MS Australia led a proposal that their next global priority would be prevention, early detection and early intervention.

Addressing the workshop delegates, Rohan Greenland CEO of MS Australia, reaffirmed the organisation’s commitment to the Pathways to Cures strategy, a vision focused on stopping progression, restoring function, and ultimately preventing MS from occurring in the first place.

“Prevention is a cornerstone of this strategy, and it underscores the critical importance of identifying risk factors of MS, improving early detection of MS, and investing in research that could one day eliminate MS altogether,” Mr Greenland said.

“The potential of this new global initiative into the prevention and ultra-early detection of MS efforts to transform lives is truly inspiring. I encourage each of you to remain engaged and actively support these endeavours. Your involvement is essential to achieving our shared vision of a world free from MS.”



HOW GENETIC CHANGES ACCUMULATE IN THE BRAIN IN MS – INSIGHTS FROM TISSUE STUDIES

Genetic changes – what are they and why are they important in MS?

Genetic changes occur when there are alterations to DNA in the cells of the body. When these changes occur in genes which are important for a cell's function or survival they can contribute to the development of diseases.

Over 200 genetic changes have been linked to the development of multiple sclerosis (MS). These are inherited genetic changes, which are present from birth and may increase a person's risk of developing MS. However, genetic changes also occur naturally in cells after birth due to normal biological processes, environmental factors or disease processes. These genetic changes are referred to as somatic mutations.

Unlike inherited genetic changes, somatic mutations are not passed down from parents but instead might develop in response to inflammation and other cellular stressors. This could contribute to disease progression, particularly in progressive MS, where ongoing damage to neurons (nerve cells) plays a key role.

What did the researchers do?

Applying innovative laboratory techniques, MS Australia-funded researcher Associate Professor Justin Rubio and his team studied somatic mutations in the brain tissue of people with MS donated through the MS Australia Brain Bank and UK MS and Parkinson's Tissue Bank. The researchers also analysed brain tissue from 16 people without MS.

The researchers looked at brain areas with older MS lesions (regions of chronic inflammation) and areas without lesions, comparing the number and patterns of somatic mutations in their neurons.

What did the researchers find?

Published in Nature Neuroscience, the researchers found the rate at which somatic mutations accumulate is two-and-half times faster in neurons located in chronic MS lesions compared to those in normal-appearing MS tissue and tissue from people without MS. This accelerated rate of mutation in neurons occurred from around 40 years of age. Additionally, neurons in normal-appearing MS tissue had significantly more genetic changes than those in the brain tissue of people without MS.

The researchers also found distinct patterns of somatic mutations in neurons within MS lesions compared to normal-appearing MS tissue and tissue from people without MS, which suggests that chronic inflammation in MS is associated with specific processes that may contribute to nerve damage (neurodegeneration) and disease progression.

Why is this important for people with MS?

These findings indicate that, beyond being an immune-mediated disease, processes involved in MS also damage neurons at the genetic level. This research shows that inflammation in MS can lead to genetic changes in neurons, which may contribute to disease progression.

While further research is needed, these insights bring us closer to understanding how inflammation drives genetic changes in neurons. This could help in developing treatments that protect nerve cells and support their repair, particularly in progressive MS, where ongoing damage to neurons plays a major role.

Associate Professor Rubio said, "Our work identifies a previously unknown mechanism that may cause neurons to get sick and die as MS progresses. This discovery is not a treatment, but a clue to a process that could be targeted by new treatments. Learning more about the processes involved in causing the accelerated mutation rate in neurons in lesions is a first step towards developing new treatments for progressive MS."

"We are extremely grateful to donors to the MS Australia Brain Bank and their family members for making this work possible, and to MS Australia for contributing to the funding of this project."

ONLINE FATIGUE INTERVENTION PROGRAM SHOWS PROMISING RESULTS FOR PEOPLE WITH MS

Addressing fatigue in multiple sclerosis (MS) remains a significant unmet need that profoundly impacts the quality of life and daily functioning for People with MS (PwMS). The debilitating nature of fatigue for many PwMS is such that the international research community has discussed a need to rename this symptom, to reflect its full impact.

The lived experience of MS fatigue

Paralympian Janine Watson, a member of MS Australia's Lived Experience Expert Panel (LEEP) explains:

"MS fatigue is completely misunderstood with the general public. When I say I am tired, what I really mean is: My body is shutting down and I cannot function. My arms and legs are becoming paralysed. I am losing my sight. I am losing the ability to think and speak. It is difficult for me to even remember my own name."

"As an athlete, I repeatedly get shamed as lazy or not dedicated to my sport as I only do one hour of training per day when other athletes do 5. What people don't understand with MS fatigue is that every hour of activity, whether it be sports training or simply showering and dressing, results in at least 4 hours of recovery and bed rest to become functional again. That is not laziness."

Traditional treatment options for MS-related fatigue are limited, highlighting the importance for PwMS to find ways to manage and cope with their fatigue.

What program was used in the study and how does it work?

Elevida is an online program, designed to help PwMS manage fatigue. To date, this program has only been prescribed in Germany, and in German. It is based on cognitive behavioural therapy (CBT), a psychological approach that helps individuals understand and change patterns of thinking, feeling and behaviour.

The program includes structured exercises, educational materials, and practical strategies to help users identify and modify thoughts and habits that can contribute to fatigue. It encourages self-reflection and gradual behaviour changes to improve energy levels and overall wellbeing.

The program is self-guided, meaning users can go through it at their own pace without needing direct guidance.

The German version of Elevida has been shown to be effective in reducing MS-related fatigue.

What was the aim of the research?

This study aimed to assess how well an English translation of Elevida is accepted and to gain information on the potential effectiveness of the program in PwMS in Australia.

What did the researchers do?

Researchers, supported by MS Australia, recruited 15 PwMS with self-reported fatigue to trial the translated version of the Elevida

program. Participants included 9 individuals with relapsing-remitting MS and 6 with progressive MS.

The program consists of 9 modules involving online questions in the form of conversations, each taking approximately 60 minutes to complete. Participants were required to complete all 9 modules and were asked to allow 3 to 5 days between modules to reflect on the content, practice the skills they learnt, and complete the homework. The program follows a think-aloud protocol, which allows participants to provide their thoughts and experiences verbally while completing the task.

At the end of the program participants were asked to provide feedback on the program to determine if participants found Elevida useful (acceptable) and if it was practical for them to use. The study measured how participants engaged with the program, whether they thought it was helpful, and what challenges they faced. Feedback was gathered on ways to improve the program.

To test the effectiveness of the program in reducing MS-related fatigue, participants completed the Chalder Fatigue Scale (CSQ) questionnaire prior to starting the program, on completion of the program and at 2 months after program completion.

What did the study find?

Published in International Journal of MS Care, the study found the English version of the program to be highly acceptable among those who took part. Over 90% of participants rated acceptability as good or very good, and approximately 70% reported that they found the program helpful. 80% of participants said they would recommend the program to others with MS-related fatigue.

The study also found that people with MS-related fatigue who participated in the program experienced a statistically significant decrease in their fatigue levels by the time they finished. Two months after completing the program, their fatigue levels remained lower than before they started.

What does this mean for people with MS?

This study adds to the growing evidence that CBT can help reduce fatigue in PwMS. By addressing the thoughts, emotions, and behaviours that can make fatigue worse, PwMS can experience an improvement in their fatigue levels. Used in combination with other therapies such as medication and physical therapy, CBT offers a more wholistic approach to managing fatigue related symptoms.

A program like Elevida offers particular promise. The program is made specifically for people dealing with MS-related fatigue, so the strategies are tailored to the unique challenges of the condition. The program is online, so is particularly convenient for those who have difficulty accessing in-person support. The program has been shown to be effective in reducing MS-related fatigue in a large randomised clinical trial in Germany and now in a small cohort in Australia.

Based on outcomes from this study, the next step is to optimise the English version of Elevida so it can be trialled in larger studies of people living with MS-related fatigue in Australia. The ultimate goal is to provide an intervention that can offer a meaningful relief of MS-related fatigue symptoms that may improve the quality of life of people living with MS in Australia.

MEET THE RESEARCHER

DR IAIN COMERFORD

THE UNIVERSITY OF ADELAIDE

TELL US AN INTERESTING FACT ABOUT YOURSELF?

I ran my first marathon in 2013 to raise money for MS Australia and since then have completed seven marathons.

WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

As I learned more about how the immune system is controlled, it became clear that there were lots of potential ways that we could devise to control immune responses. Multiple sclerosis (MS) can be such a devastating disease, so I have always been interested in identifying ways to control immune responses so that MS could be treated better or even stopped entirely.

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

The development of disease modifying therapies for MS patients that can block immune cell migration into the central nervous system. These amazing therapies stemmed from findings from basic research into the molecular mechanisms of cell migration in model systems and seeing them successfully translated into clinically important immunotherapies for MS patients has been incredible.

TELL US ABOUT YOUR CURRENT RESEARCH PROJECT

We have been investigating how different cell types involved in the immune response work together to promote inflammation in responses that are relevant to MS. We have found that a cell type called neutrophils interacts with cells called T cells to promote inflammatory functions of the T cells in a model of MS. This was an unexpected finding as we do not normally expect neutrophils to control T cell function. We now want to find out how neutrophils are doing this and identify the molecules and mechanisms involved. We hope that this will lead to us identifying ways in which we can block neutrophils from promoting inflammatory T cell responses and that this might be a way to switch off inflammation in MS.

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

I most enjoy the daily process of discovery and testing ideas in the lab. The days when we find out the answers to the big questions we have been asking are the most rewarding. The biggest challenges are juggling all the commitments involved and obtaining funding for the research.

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