

JUNE 2023

PROJECT WELLBEING

Dr Phu's research, funded by MS Australia, has focused on evidence-based physiotherapy interventions to improve impaired functions as a consequence of multiple sclerosis (MS). His current research project aims to develop an individualised, all-inclusive exercise program and use assistive devices to improve walking in people with MS.

If the research confirms the effectiveness of treatment strategies, it is expected that implementation of clinical interventions will contribute to reduced fall rates in people with MS and associated injury-related costs, diminished fear of falls and improved quality of life for people with MS.

This is the kind of advancement in clinical MS research that will be undertaken at the new MS Plus Wellbeing Centres through Project Wellbeing.

My name is Dr Phu Hoang. For 21 years, I have been working as a researcher and clinician specialising in the rehabilitation of movement and mobility for people with MS.

It is important to me to share what your support means to researchers and clinicians, like me. And what it means for people living with MS.

I've witnessed incredible results at the existing MS Plus Centre in Lidcombe. Many of my patients have improved their MS symptoms, including Alison, who can now walk up to four kilometres at a time unassisted.

Alison has regained mobility and even improved her MS symptoms. Before Alison arrived at the MS Plus Centre, she was told elsewhere that

she simply wouldn't improve. We both enjoyed proving them wrong.

Alison — *"After two years of treatment with Dr Phu the Centre, my MS symptoms have improved in ways I could have only dreamed."*

"I'm so grateful. It's thanks to people like you donating to support vital research that I've regained my strength and mobility. But it devastates me to know that there are other people like me in Australia who are missing out on this transformative care."

"Before I started my rehabilitation, I had lost use of my left arm and hand, and it was nearly impossible to lift my left leg. This all made my balance terrible. I had to use a

walker to get around, and I still fell with that, too."

"If you'd have seen me at my first assessment at the Centre, attempting a simple exercise that a toddler could manage, and sobbing uncontrollably because I couldn't do it, you would not believe where I am at today."

"But Dr Phu told me he could improve my walking. I'm happy to say, he was right."

My research at the MS Plus Centre focuses on mobility loss. It's one of the most devastating and common issues for people living with MS.

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FROM THE CEO

ROHAN GREENLAND



May was one very, very big month for the MS community. So big, it's worth recapping the key events that focus on MS Australia's core mission – taking us to a world free from MS through advocacy, research and – ultimately – a cure.

- May 1-31: The May 50K – our single most important fundraiser for MS research, attracting 13,000 participants and raising more than \$3m. I managed to hobble more than 250km (I tore an adductor) but doubled my fundraising target. Thanks to all who took part – you are simply amazing. And thanks to all those who generously sponsored our efforts. Every dollar makes a difference!
- May 1-3: Global MS Summit 'Pathways to Cures', with the world's leaders in MS research, including MS Australia, committing to align research priorities and work on agreed strategic objectives to get us on the pathways to cures further and faster. A landmark event.
- May 16-18: Australia and New Zealand Association of Neurologists conference. So good to hear from so many MS clinicians and researchers, including the Ian McDonald Memorial Lecture presented by Professor Jeannette Lechner-Scott reflecting on 30 years of progress in the treatment of MS. Inspiring presentation.
- May 21: Our patron, the Governor-General, and Mrs Hurley join us to take part in the Canberra MS Walk Run + Roll fundraising event around Lake Burley Griffin – a record turnout despite the cold and blustery conditions!
- May 25: MS Australia showcases our resources and advocacy work at the International Treatment and Research in MS (TriMS) online conference.
- May 26: The Menzies Institute for Medical Research MS Symposium in Hobart – delighted to speak at this empowering event bringing researchers and people living with MS together.
- May 29: The Medical Journal of Australia publishes a World MS Day interview with our talented Head of Research, Dr Julia Morahan – don't miss it!¹
- May 30: World MS Day, and we are at Parliament House in Canberra with the Parliamentary Friends of MS for a breakfast event to launch our MS Nurses campaign to reverse the alarming decline in MS Nurses in Australia – really pleased to have the Assistant Health Minister Ged Kearney – a nurse leader herself – lend her support to the cause. Don't miss our powerful MS Nurses advocacy video – a very fitting finale for a very big month!²

Rohan Greenland
CEO, MS Australia

¹ insightplus.mja.com.au/2023/19/the-road-ahead-for-multiple-sclerosis

² www.msaustralia.org.au/nurses

I've discovered the muscle weakness that causes this problem has a pattern, but nobody has really addressed this in research before.

I have seen that exercise can help people regain lost function and even improve lesions in the central nervous system. Researchers and clinicians like me are at the forefront of cutting-edge research taking place at the MS Centres - and **we need support from people like you to help more people with MS in Australia.**

You will help both people living with MS to live better lives, and the research to accelerate towards new MS solutions.

With support of wonderful people like you, Project Wellbeing will be able to build and expand MS Plus Wellbeing Centre rehabilitation facilities. With the latest, most helpful equipment, we will offer the best possible care and support to those with MS and conduct more cutting-edge research.

With the number of people in Australia living with MS increasing, we need MS Plus Wellbeing Centres to bring MS solutions to people faster.

I have seen tears of happiness in the eyes of people who have received treatment as well as other MS Plus specialist services. They have regained independence, mobility and confidence in the MS Plus Centre.

Your support is needed to continue and expand these remarkable results.

Please donate now to Project Wellbeing to help improve outcomes for more people with MS.

www.fundmsresearch.org.au/alisons-story
or call 1300 733 690.

Thank you for your support,

Dr Phu Hoang, PhD

Senior Physiotherapist and Clinical Researcher

WHAT IS MS?

NEW VIDEO LAUNCHED TO EXPLAIN AND DEMYSTIFY A DISEASE IMPACTING MORE AND MORE AUSTRALIANS

With the incidence of multiple sclerosis (MS) on the rise in Australia, an important new educational video resource launched nationally.

The 'What is MS?' video attempts to demystify and explain a complex, and often at times, invisible disease that now impacts more than 33,000 Australians.

Commissioned by MS Australia, the video, 'What is MS?', will educate the general public and people living with MS, especially those newly diagnosed, about the causes, different types of MS and common symptoms of a condition that currently has no cure.



WATCH THE 'WHAT IS MS?' VIDEO BY SCANNING THE QR CODE



WHAT TRIGGERS THE IMMUNE RESPONSE AGAINST MYELIN IN MS?

The myelin sheath is the fatty coating around the nerves in the brain and spinal cord that enables efficient nerve conduction.

In multiple sclerosis (MS), immune cells mistakenly attack and damage the myelin sheath. This disrupts nerve conduction and can result in many different neurological symptoms, depending on which part of the brain or spinal cord is affected.

We don't yet understand what triggers this immune attack on the brain and spinal cord.

What was the aim of the research?

To help understand what triggers brain autoimmunity in MS, Associate Professor Anthony Don from the University of Sydney and his team focused on studying the structure of the myelin, and how the immune system is activated when myelin is compromised.

In humans, 25-35% of the fats in myelin are 'sphingolipids' made by enzymes in the myelin-producing cells. Specific sphingolipids, called sulfatide

and galactoceramide, are unique to myelin and determine its stability.

In a new MS Australia-funded study, the team investigated the effect of subtly changing these sphingolipids in the myelin, to examine whether this could trigger an autoimmune attack on the brain.

What did the researchers do?

Using a laboratory model, researchers blocked one of the enzymes responsible for producing the myelin sphingolipids, galactoceramide and sulfatide.

By blocking the enzyme, the researchers created myelin with slightly shorter sphingolipids compared to the normal sulfatide and galactoceramide.

What did the researchers find?

Changing the sphingolipid length had several consequences. The myelin sheath was thinner, and fewer nerve cells were myelin-coated.

The researchers also found that the immune system was activated very early on in the

brain and increased over time. A specific type of immune cell called 'microglia', which can attack myelin, was activated. Over time, the myelin became damaged, causing neurological symptoms to develop.

In addition to the effects on myelin thickness and immune system activation, the team found that changing the sphingolipids damaged other myelin sheath proteins, such as myelin basic protein (MBP).

MBP is believed to be another target of autoimmunity in MS. These findings suggest that sphingolipids play an important role in the overall integrity of myelin.

What does this mean for people with MS?

This study has provided important new insights into the triggers and molecules involved in the immune sensing of compromised myelin. This is critical for our understanding of how MS develops.

The hope is that these studies will help to support the development of new therapies to prevent and repair myelin damage in people with MS.



DETECTING CHANGES IN WALKING EARLY IN MS COULD BE THE KEY TO PREVENTING PROGRESSION

Better ways are needed to detect disease progression

MS can cause a variety of symptoms attributed to the immune system mistakenly attacking and damaging the myelin sheath in the brain and spinal cord.

One such symptom is changed walking, or gait, which can occur even in the absence of clinical signs.

These subtle changes in gait cannot be detected using standard clinical measures (e.g. walking speed), particularly earlier in the disease course. This makes it difficult to monitor progression and make changes to current treatments to prevent further disease activity.

It has been proposed that the local divergence exponent (LDE), a sensitive measure of gait stability, better reflects the MS-related changes in walking, and may parallel changes in the brain and spinal cord detected on magnetic resonance imaging (MRI).

Research has shown that this measure is lower in people living with MS than those without MS, and is associated with falls and self-reported walking ability.

Previous studies have explored the use of LDE in clinical settings, but the data has been obtained from different body locations using various methods (e.g. treadmill walking vs overground walking).

It is not clear which approach would be best to assess walking stability earlier in the disease course when treatments may be more effective in preventing progression.

What did the researchers do?

MS Australia-supported researcher Professor Mary Galea from the University of Melbourne and her team recruited 49 people living with MS with an expanded disability status scale (EDSS) of ≤ 2.5 (no walking impairment), and 24 people living without MS to walk overground for 5 minutes while movement data was obtained from sensors placed on the sternum (mid chest) and lumbar (lower back) areas.

The data was used to develop models to identify gait impairment in people with MS at early disease stages.

What did the researchers find?

The researchers found that the LDE measures from the sternum were more sensitive to MS-related changes, which is in line with previous studies.

This suggests that this sensor location is better suited to monitor walking impairment in people living with MS earlier in the disease course.

What does it mean?

By focusing on people with MS with no impairment in walking, this study highlights the sensitivity of the LDE measurements in detecting progression at the early stages of disease.

While further research is required, the LDE may offer an alternative to currently insensitive tests of walking impairment in people living with MS at the early stages of disease.



leep

lived experience expert panel

MS AUSTRALIA STRENGTHENS ITS LIVED EXPERIENCE VOICE IN ITS WORK

MS Australia recently launched our Lived Experience Expert Panel (LEEP) to provide a formal process to receive advice from experts across the MS community and support the work of MS Australia. The LEEP will support MS Australia's advocacy agenda by providing lived experience advice and evidence. This will ensure that the MS community has a strong voice in MS Australia's governance, research, policy and advocacy and education and awareness. We want our work to be driven by the needs and experiences of people living with MS and their carers.

We put out a call for interested and qualified Australians to apply for membership of the LEEP. We have been overwhelmed with outstanding applications and are currently

undertaking a shortlisting process to determine the final makeup of the panel. Successful applicants will be selected for their capacity to assist in achieving the purpose of the LEEP and to provide meaningful feedback and input on MS Australia's policy, research and communications work.

The final LEEP membership will be determined by applicants' ability to provide input and advice on areas of expertise outlined in our terms of reference. This will include people living with MS and carers. We will also seek to ensure diverse representation, including younger people, older people, people living in rural, regional, and remote Australia and people who are members of vulnerable and/or

diverse communities, including the Aboriginal and Torres Strait Islander community, LGBTQI+ community, CALD community and people who are socially and economically disadvantaged.

We are also seeking expertise across areas including employment, training and the labour market; housing and assistive technology; government services, supports and policy processes; the social and economic barriers facing people living with disability; medical research and MS treatments and medications.

MS Australia will announce the final LEEP membership in August 2023.

www.msaustralia.org.au/leep



MS NURSES

LIFE-CHANGING CARE

NEW CAMPAIGN SHINES LIGHT ON LIFE-CHANGING MS NURSE CARE

MS Australia launched a new campaign at Parliament House on World MS Day (30 May) to raise awareness of the crucial role played by MS Nurses.

The *MS Nurses: Life-Changing Care* campaign features intimate interviews with MS Nurses and their patients, which showcase the incredible value of MS Nurse care; contributing to a range of health benefits for people with MS, such as lower disability levels, slower disease progression, less severe symptoms, improved mental health, and higher quality of life.

The number of people diagnosed with MS has risen rapidly in recent years, with over 33,000 Australians now living with the disease.

At the same time, the number of MS Nurses practising in Australia is in decline (around 90), with approximately only one nurse for every 370 individuals living with MS, highlighting a significant gap in access to specialised care.

Almost one in three Australians living with MS are being deprived of the necessary care and support to manage their condition effectively, impacting their overall wellbeing and quality of life.

Addressing a Parliamentary Friends of MS event, the Hon Ged Kearney MP, Assistant Minister for Health and Aged Care, acknowledged the immense value delivered by the MS Nurse workforce and pledged her Government's support and

engagement in identifying funding pathways to address the workforce shortage.

"We are absolutely focusing on [nursing workforce] – it's what our government is incredibly, absolutely, 100% committed to.

"We couldn't think of any partners better than MS Australia to work with as we pursue that agenda," Assistant Minister Kearney said.

Keynote speaker, President of MS Nurses Australasia (MSNA), Meaghan Osborne explained why MS Nurses are so critical.

"MS Nurses make a huge difference to people living with multiple sclerosis. Yet 31.5% of people with MS don't have access to MS Nurse care.

"Every single person living with MS should have equal opportunity to access an MS Nurse across this country, and the dignity and quality of life that such access can ensure," Ms Osborne said.

In addition to providing essential care and support to people with MS, MS Nurses are also a 'cost-dominant' (i.e. cost saving) healthcare solution.

MS Australia says a modest investment of \$6.5m a year would provide an extra 65 MS Nurses to support people living with MS and result in savings in excess of \$60m every year.

www.msaustralia.org.au/nurses

MEET THE RESEARCHER

ASSOCIATE PROFESSOR JENNIFER RODGER

UNIVERSITY OF WESTERN AUSTRALIA, WA



TELL US AN INTERESTING FACT ABOUT YOURSELF...

This is probably the hardest question... I speak fluent French because I was born in Quebec, and keep up my language skills by reading French novels and watching French movies.

WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

I am fascinated by the brain and how so many different cell types work together to produce such a complex organ. Multiple sclerosis (MS) is a devastating example of what goes wrong when normal communication and interactions between cells break down. I believe that my research will not only contribute to finding a cure for MS, but will also help us understand how our brains work, and make the world a better place.

WHAT WAS THE MOST EXCITING DEVELOPMENT IN MS RESEARCH?

In the last few years, there has been a real paradigm change in

the way that we understand the brain: it is not an isolated organ, but is deeply influenced by other systems (e.g. the microbiome, the immune system) and also by the environment. This means that there are many new and exciting strategies that can be tested to treat and potentially cure MS. The field of research has become incredibly creative, pushing the boundaries of current technology and knowledge.

TELL US ABOUT YOUR CURRENT RESEARCH PROJECT...

A key feature of MS is the death of oligodendrocytes, the myelinating cells in the brain and spinal cord that are crucial for normal brain activity. My colleague Professor Kaylene Young and I recently demonstrated that a form of brain stimulation, repetitive transcranial magnetic stimulation (rTMS) improves the survival of newborn oligodendrocytes and encourages remyelination. This is exciting because rTMS is non-invasive, has no serious side effects, and has shown promising

outcomes in a preliminary clinical trial. In this project, we carry out a series of experiments in brain cell cultures that will allow us to understand the mechanisms whereby rTMS promotes the survival of and myelination by oligodendrocytes. The results will guide the design and optimisation of treatment parameters that can be tested in a future clinical trial to improve outcomes for people with MS.

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

My research is important because it aims to understand how the brain works, and what goes wrong in MS. This basic knowledge is necessary if we are to understand, treat and eventually prevent MS. I believe that this will be possible in the future thanks to the excellent research going on around the world (especially the projects supported by MS Australia!)

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MS



DONATE (donations over \$2 are tax deductible)

To support MS Australia's vital work I would like to:

- ☐ Make a one-off donation of \$
- ☐ Make a monthly donation of \$
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