

JULY 2023

# MS + YOU

Connecting you to stories of your incredible impact

**“I am living proof that MS Plus Centres are improving people's symptoms.”**



## **Thank you for helping Alison live her dream in New York City.**

**When Alison started seeing Dr Phu Hoang at the Lidcombe MS Plus Wellbeing Centre, she was using a walker to get around.**

Sometimes she fell. Her leg was affected by drop foot and hyperextension, and Alison could not use her left arm or hand. Even speaking was a struggle at times. It's incredible to think she can walk five kilometres now!

Your support for MS Plus Wellbeing Centres means Allison can access expert advice on diet,

medication, and physical therapy. In April this year, her hard work paid off. She was able to achieve her dream of walking across the Brooklyn Bridge!

Alison says it feels amazing to be living without visible symptoms again, and she wants to share her message of hope with other people who live with MS.

**Thank you for helping make the Wellbeing Centre – and Alison's dream – a reality.**

---

*Wellbeing Centres use a whole-of-person approach to improve the lives of people living with MS.*

# This World MS Day, we celebrated your support.

World MS day is a wonderful opportunity to share stories, raise awareness, campaign for progress – and celebrate the impact of generous people like you.

It's incredibly important to recognise the progress we've made towards improving treatments, support and services for people who live with MS. So much of that is down to the kindness of people like you. Thanks!

This World MS day, we had a particular focus on celebrating our amazing MS Nurses. Your support means they can be there, with the advice, compassion, and expert care that helps people who live with MS bear their difficult days – knowing more good days will come.

In this issue of *MS + YOU*, we bring you stories of these brilliant nurses' compassionate care. We also update you on Project Wellbeing, and the latest research funded by you.

**Enjoy the newsletter!.**



**John Blewonski**  
CEO, MS Plus

**54.7%** of people reported that MS Nurses provided helpful advice on managing MS symptoms. Managing MS symptoms is complex and often takes time to work with people to personalise solutions.

**Over 50%** of people reported that nurses helped them stay on treatment. MS nurses are there when people need them to use their experience to share ways to overcome and relieve any side effects.

*"To touch that sand is the best feeling."*



## You helped this Iron Man get back to the beach – 16 years on!

It's been 16 years since Wayne touched the sand – and more than 30 since he competed in the Iron Man Australia triathlon. He's missed the beach so much.

MS brought mobility issues, and made it impossible to get to the beach. Then your kindness helped connect Wayne with his Support Coordinator, Lisa. She helped Wayne source the custom-made, off-road wheelchair that carried him back to the place he loves most.



*"Without the help of MS Plus, and without the help of my Support Coordinator Lisa and her advice of what was required to fund a chair like that, I wouldn't have that chair," Wayne says.*

The beach had always been a big part of Wayne's life. It was a joy he thought he had lost, but this incredible moment shows that no matter how far along in their MS journey a person may be, things can change for the better.

It is your generosity that helps enable Support Coordinators like Lisa to help people with MS live their best possible lives.

**Thank you for helping Wayne – and many others.**



# Thank goodness for nurses!



**This World MS Day, MS Plus celebrated the vital work of our MS Nurses.**

**Thanks to you, these compassionate staff help connect people impacted by MS with quality care and support through every stage of their journey.**

**MS Nurses provide expert clinical guidance in times of urgent need, to help assess symptoms and find the right people to assist.**

This is a vital service that can help people avoid unnecessary and stressful emergency hospital visits and provide solutions for managing symptoms. They are also a kind ear in lonely times to help share and lighten the load of the daily challenges of living with MS.



## **John and Margaret's search for answers.**

When their 17-year-old daughter Louise was diagnosed with MS, John and Margaret were overwhelmed, afraid, and unsure how best to support the person they love. Thankfully, they reached out to MS Plus.

An MS Nurse was able to give them advice on practical issues like treatment options.

She helped John and Margaret understand brain health, find the right specialist, and support for Louise to continue with school.

This expert advice has been essential for Margaret and John. It means they can support their daughter through a really challenging time, knowing they're doing everything possible to help her build a good life.

## **"Help, I think I'm having an MS relapse."**

Katie is used to occasional pins and needles in her hands – but she was frightened when it suddenly worsened. She tried contacting her medical team and neurologist, but couldn't get through.

Thankfully, an MS Nurse answered the phone. She helped Katie understand that her symptoms were likely to be a pseudo-relapse triggered by stress and a cold.

The nurse worked with Katie to make a plan for managing her symptoms until they resolved – and laid out the steps she could take if they did not.

**Thanks for helping Katie find expert advice, comfort and care during a scary time.**

Last year, you helped MS Nurses provide life-changing support to **1,155** people living with MS.

# Your support fuels the fire of Paul's hope.

## Thank you for helping him get through the hardest days.

Since Paul Gallagher was diagnosed with MS in 2016, he's had many bad days – but the journalist and writer always gets through them. This year, when he spoke at the People with MS Conference in Victoria, he shared how he maintains hope for better times ahead.

Paul emphasised the importance of connection with

the MS community, and reaching out for support. He described his outlook on hope as a fire that needs fueling, watching and guarding. Paul said:

*"For any human being, but especially those challenged with illnesses like ours, we need specific and therapeutic fuels. Like expertise from medical professionals, doctors, specialists, psychologists, allied health. We need and thrive with peer support, from this body, MS Plus Peer Support, Telegroups."*



Thank you for fuelling the hope, health and dreams of people like Paul, who live with MS.

## Better wellbeing is on its way!



## Thanks for transforming lives through Project Wellbeing.

Thank you for supporting Project Wellbeing – an ambitious push to build and expand MS Plus Wellbeing Centres across the country.

Your generosity is already helping more people live well with MS.

The Wellbeing Centre in Lidcombe is being transformed, with an improved and expanded centre set to open next year.

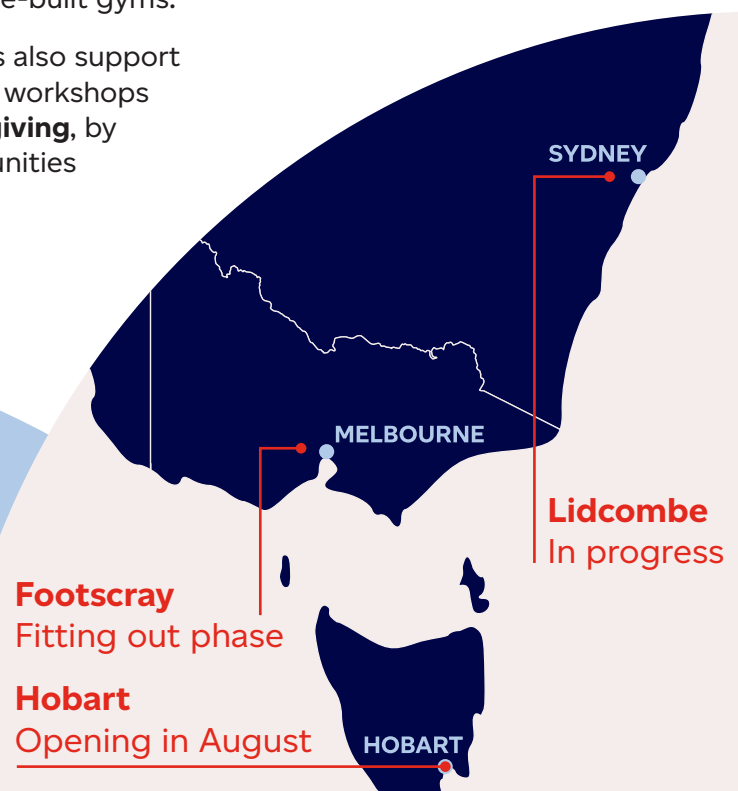
The Footscray Wellbeing Centre will also open its doors very soon, and the Hobart Wellbeing Centre is on track to open in August.

The Wellbeing Centres are underpinned by five 'paths to wellbeing'. They aim to facilitate **connection** with the MS community, as well as physical **activity** at purpose-built gyms.

Wellbeing Centres also support **learning**, through workshops and classes, and **giving**, by providing opportunities to volunteer.

Finally, they'll encourage people into **taking notice** of new research that can raise everyone's standard of care.

*Thanks for supporting this groundbreaking project that will transform lives.*



**Footscray**  
Fitting out phase

**Hobart**  
Opening in August

**Lidcombe**  
In progress



# MS Plus camps are a family affair

**MS Readathon is giving families a place to relax, recharge and reconnect.**

MS Plus camps are a fun way for people who live with MS, and their carers, to connect with others who share their experience. Both children and adults build lifelong connections while they are there.

The camps are an opportunity to share information about support services that can assist families in achieving their goals. They provide a normalising experience for children whose parents live with MS. And they are fun – a family holiday filled with adventure, activities, and community.

The MS Plus camps are a key part of our commitment to supporting carers of people who live with MS. Research has identified six focus areas – of which respite, outings and retreats like these are one.

All costs for the camps, including accommodation, meals and activities are covered by funds from MS Readathons – thanks to the support of people like you. **You are giving families the chance to relax, recharge and reconnect.**



Last year MS Readathon raised **\$2,274,120** nationally to help kids and families impacted by MS through Family Camps, Family Fun Days and vital support services.



## *A gift for the future*

**Nigel's giving more than a lifetime of support to others with MS.**

Since being diagnosed with MS in 1993, Nigel Caswell has been speaking to schools, community groups and politicians to help improve the lives of people who live with MS.

His advocacy has seen Nigel awarded the MS Plus John Studdy Award, and a Medal of the Order of Australia – and he wants to make sure his incredible impact continues even after he's gone. That's why he's decided to leave a gift in his Will to MS Plus.

Nigel knows the gift in his Will can help researchers find better treatments – and perhaps one day, a cure. He says:

*"It might not be there in time to help me, but my gift can help others receive a cure."*

If you'd like to know more about how to leave a gift in your Will to MS Plus, please contact **Laura** or **Rebecca** for a friendly chat, on **1800 443 867**. You can also email [futureplanning@ms.org.au](mailto:futureplanning@ms.org.au) or visit [www.mymslegacy.org.au](http://www.mymslegacy.org.au)





Associate Professor Piccio and her team hope their discoveries will lead to a way to repair myelin

# Thank you for taking us closer to a world without MS.

*Your generous support is helping fund world-class research projects to improve our understanding of MS and make strides towards finding a cure.*

## A new way to repair the damage of MS.

**Thanks to you, Associate Professor Laura Piccio is investigating a protein that could help reverse the effects of MS.**



Your support is enabling researchers to investigate ways to help the body replace damaged myelin. One day, this could allow doctors to reverse the effects of MS!

In people who live with MS, the immune system attacks myelin – a protective sheath covering nerves in the central nervous system. This damages the protective myelin sheath, disrupting communication between the body and brain, and causing MS symptoms.

Generally, the central nervous system can replace myelin – but first, it needs to clear out the ‘debris’ of damaged myelin. This is done by microglial cells.

In people who live with MS, these microglial cells are impaired. They can’t clear enough debris to fully replace damaged myelin.

That is the problem – and Associate Professor Laura Piccio is on the hunt for solutions.

Her team is studying the role of TREM2 – a protein located at the surface of microglia. Their initial research suggests TREM2 plays a key role in the process of clearing debris and helping replace myelin. They hope to activate TREM2 to remove the barriers to remyelination.

**Thank you for supporting this exciting research. It could hold the key to helping reverse the damage done by MS.**



# Does the NDIS work well for people with MS?



**With your support, Professor Bruce Taylor's team is working to help people living with MS navigate the NDIS.**

A new research project led by Professor Bruce Taylor is putting the National Disability Insurance Scheme (NDIS) under the microscope to see how well it supports people who live with MS.

**The team will conduct five discrete projects, each with different aims. They will:**

- 1 determine how many people with MS have NDIS plans
- 2 explore the average monetary value of plans, and factors affecting the extent of support
- 3 evaluate the impact of an NDIS plan on quality of life and workforce participation
- 4 explore the experience of applying for and administering an NDIS plan
- 5 evaluate the experience of preparing or contributing to an NDIS application among local area coordinators and healthcare providers to identify strengths and weaknesses in the application process.

The project will run for three years. After this, the research team will share their findings through a free online course, to help people who live with MS get the most from the NDIS.



## Will you help create a better NDIS?

MS Plus is supporting MS Australia's submission to the NDIS Review Panel that calls for essential reforms to improve the NDIS for the MS community.

**Scan the QR code** to add your name to the letter and help secure a better NDIS for people living with MS.



## Move well, live well!

**Clinical Physiotherapist Dr Phu Hoang is making strides with exercise.**

Thanks to your support for Project Wellbeing, Dr Phu Hoang is helping people who live with MS regain their strength and mobility to an amazing degree. While his focus is on physical therapy, Dr Phu takes a holistic approach.

*"I have learned that restoring functional loss requires a comprehensive approach that addresses the whole person, rather than just a single aspect, such as strengthening or balance," Dr Phu says.*

By working with thousands of people who live with MS, Dr Phu has discovered a pattern in the loss of muscle strength. This is the first time it has been recognised.



Now Dr Phu is investigating how this pattern works. He aims to enable any clinician to address muscle weakness directly by using exercises that target the correct muscles, rather than more general exercises.

**Thank you for helping Dr Phu build on 21 years of MS specialisation to transform people's lives.**



# Walk, Run, Roll!

This May, the **MS Walk, Run + Roll** saw over 7,800 people across Sydney, Melbourne, Canberra and Launceston move to make sure no-one faces MS alone.

**Participants have raised over \$1.1 million to help fight MS.**

Thank you for helping connect people living with MS to life-changing research, support and services.

*Thank you  
again*

