

JULY 2022

# MS + YOU

How you're powering up MS research – and lives

## Emma feels lucky to live a good life with MS.

### Like you, she's determined to help others do the same.

Emma is a devoted parent of two children, a committed volunteer for MS Plus, and a keen yoga student. She attends regular physiotherapy to help keep her body as strong and mobile as possible. She also has MS and another neurological condition called functional neurological disorder (FND).

Unfortunately, there are too many people living with MS and other

neurological conditions who just aren't getting the support they need and deserve. That's why MS Plus, and supporters like you, are working hard to connect them to appropriate, professional and timely care.

Happily for Emma, your generosity is helping her access to specialist MS services. You are helping her live life on her terms, and to the best of her ability.

At MS Plus, we believe people can be more than their condition.



With your help, we're working to deliver more services, more expertise, more awareness, and more research.

We want the MS community to thrive and we want to help people living with neurological conditions to do the same.

# A big 'thank you' from our CEO

When I look at the MS community, I see a vibrant organisation.

I see our MS Plus support workers advocating for clients and connecting them to the services they deserve.

I see the strength, determination and courage of Australians who have MS, and who continue to strive and achieve.

I see how our continuing investment in research is speeding up the pace of discovery, and leading us to more effective treatments for MS.

I look forward to the development of our first Wellbeing Centre which will provide a base for delivery of exceptional services.

**None of this would happen without you! I encourage you to read more about the wonderful things you are supporting and creating.**

**Thank you for all that you do for people who live with MS.**



**John Blewonski**  
CEO, MS Plus

## We're better together!

30 May was **World MS Day** – a day that brings the global MS community together to celebrate solidarity and hope for the future.

This year, as part of the theme **#msconnections** we're continuing to focus on building a support crew by shining a light on the importance of connecting with quality care, including the role of empathy in forging deeper and stronger connections.

Watch the **World MS Day 2022 – In my shoes** video on YouTube.



Stuart's new chair – and your care – has been life-changing.

## When times are tough, you can always ask for help!

**And Stuart and Wenda's lives are better for it.**

During difficult times it can often be hard to ask others for help. Stuart, whose MS has deteriorated rapidly over the last couple of years, reached a point where he was unable to get up from his recliner chair.

Stuart's wife Wenda, who herself has stage IV cancer and is wobbly on her feet, was helping Stuart into a sitting position. Both of them found the task physically exhausting.

However, there was a simple solution. It came when Stuart courageously reached out for help from MS Plus.

He was put in contact with a social worker – a role entirely made possible thanks to the kind and generous donations from supporters like you.

The social worker connected Stuart and Wenda to Plus Financial Assistance Program, and they made a purchase which Stuart describes as "life-changing".

An automatic reclining chair was shipped to their home, and Stuart can now relax in comfort, and get out of the chair without needing Wenda's help or enduring excruciating pain.

**A simple, practical solution has given them both greater dignity and confidence.**

**"In the space of a few hours, our lives have changed dramatically. I am now independent when it comes to moving from my chair.**

**I would like to express my gratitude to MS Plus, and all your donors, for the part everyone has played in making this life-changer possible."**

- Stuart





## MS doesn't stop Cheryl from living independently

When Cheryl was diagnosed with MS, she thought it might mean she would have to give up all the things she loved. She misses some activities, but thanks to supporters like you, she still has her independence.

**"I'm Cheryl, I'm 48 and a mother of two teenage daughters.**

**I was first diagnosed with MS when I was 42.**

**I've spent the last 10 years working in a hospital, cooking, and delivering food for some of the most vulnerable people in the country.**

**Working with MS is difficult, and I often end shifts with pain across the right side of my body.**

**MS is not going to stop me from doing the things I love.**

**I'm frightened for the day I'll no longer be able to manage, but what gives me hope is all the good work and research MS Plus is doing.**

**With your continued support, I believe we can find a cure for MS." - Cheryl**



A recent longitudinal study in Australia showed that those who had support from an MS nurse experienced less severity of MS symptoms, less depression and anxiety and a higher quality of life.

To connect with an MS nurse, phone **MS Plus** on **1800 042 138**

*"It's incredibly satisfying to see clients thrive."*

**Jodi is a Plus Advisor team leader. Here's why she loves her work.**

Jodi spends her workdays helping her clients with MS and other neurological conditions live their best possible lives.

She says there's nothing more satisfying than knowing a client is getting the care they need and deserve.

Jodi has lots of stories with good outcomes, but there's one that really sticks in her mind.

Jodi had picked up the phone to a very distressed lady. The woman's GP had just told her that she might have MS, and referred her to a neurologist. There'd be a six month wait to see the specialist, leaving the woman in a frightening state of uncertainty.



It was Christmas Eve, but Jodi was able to get in touch with a local MS clinic and get the lady a priority appointment.

It's still difficult for some people with MS to get appropriate, timely care. **But your support for MS Plus and team leaders like Jodi is helping change that.**

# Could a new drug reduce nerve damage?

**Dr Rash and his team may have found a way to protect the brain and slow the progression of MS.**

Brain inflammation appears to be a significant contributor to nerve cell death – and subsequent disability – for people who have MS.

**If we can stop brain inflammation, could we stop, slow or prevent the progression of MS?**

A three year study is investigating those questions. Lead researcher, Dr Lachlan Rash, says his team is focused on the protein 'ASIC1', which found in nerves throughout the body. The activation of ASIC1 proteins in inflammatory cells increases their ability to damage tissue, leading to nerve cell death.

Dr Rash's team have several leading drug candidates which may block the activation of ASIC1, and ultimately help reduce the disabling effects of MS progression.

Resources for this ground-breaking research have been made available through the generosity of you and others in the MS community.



Dr Rash has been studying the ASIC1 protein for 25 years.



The **MS Australia Clinical Trials Network** was established to encourage high quality clinical MS research in Australia and to increase awareness of clinical trials and clinical research for people.

Find out more at [www.mstrials.org.au](http://www.mstrials.org.au)

# You've put immunity molecules under the microscope

**Thanks to an incubator grant and your support, Dr Hugh Reid hopes to better understand the immune response in MS patients.**

Dr Hugh Reid wants to know why the myelin sheath – a protective material preventing nerve damage – is recognised as a foreign agent by the immune systems of people with MS.

Thanks to the generosity from supporters like you Dr Reid and neurologist, Professor Roland Martin, will examine a group of molecules called the



Dr Reid hopes his lab discoveries will become MS breakthroughs.

HLA-DR15 which they believe plays a role in immune response. The findings may uncover opportunities to prevent nerve damage in people with MS.

**Your support for MS Plus will continue to fund pioneering research like this – as we work together to stop MS.**





"This study will improve our understanding of how myelin loss affects neuron communication.

We hope to reveal how new treatments could target brain circuit communication to restore brain function, protect neurons from damage and halt disease progression in people with MS."

- Dr Kalina Makowiecki

## With your help, this researcher could unlock the mystery of MS progression

**Dr Kalina Makowiecki's groundbreaking research into myelin repair offers new hope to people living with MS.**

Thanks to the support from donors like you, MS Plus is funding a 3-year, \$428,000 dollar project, that will allow Dr Makowiecki to investigate the role of myelin in the progression of symptoms in people who have MS.

As you may know, myelin is an insulator that wraps around nerve cells, and is suspected to be crucial in the body sending electrical signals to the brain. MS appears to strip the myelin sheath away, making it difficult for neurons to communicate, and eventually leading to neuron death. It's the loss of

nerve or neuron communication that causes disability in people with MS.

Dr Makowiecki wants to understand exactly why and how. Greater understanding of this process may lead her and her team to treatments which could protect nerve cells, slow down the progression of MS symptoms, and potentially halt the process altogether.

**It is your support for MS Plus which is fuelling this and other vital MS research projects. Your kindness and generosity could be the key to finding a cure for MS.**



## Stay in the loop of MS research

Progress in MS Research Live Update On Demand. Hear the latest on MS gene hunting, Rewrapping nerve fibres, How MS Nurses improve the lives of people living with MS, A Neurologist's insight.

Find out more at: [www.msaustralia.org.au/events/liveupdate2022](http://www.msaustralia.org.au/events/liveupdate2022)

# Rod did something extraordinary for his wife – and other people with MS.

Rod saw first-hand how MS affected his wife Lynette, and saw how helpful the MS nurses were. He's giving back by leaving a gift to MS Plus in his Will.

Rod knew something was wrong when his wife Lynette – a highly qualified accountant – was struggling to hold down a single job. She was fired for incompetency 17 times.

When Lynette received her MS diagnosis, this all started to make sense. But she



deteriorated very quickly, developing epilepsy two years after her diagnosis, and required frequent trips to the hospital.

MS Plus stepped in to help Lynette find suitable accommodation with the support of professionally trained nurses.

The experience has inspired Rod to include a gift in his Will to MS Plus. He has seen and felt the difference that the right kind of support can make to a person who has MS.

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If you would like to know more about how to leave a gift in your Will to MS Plus, please contact **Laura Henschke** on **1800 443 867** or **Laura.Henschke@ms.org.au**

## Making memories and friendships

### How MS family camps, and your kindness, are connecting people for life.

It can be tough being a parent who has MS. That's why, through the funds raised from the MS Readathon, MS Plus supports families living with MS.

Our MS Family Camps bring parents, partners and kids together with other families who 'get it'. There are MS-friendly facilities, and opportunities to take a break from everyday life and share experiences.

Here's just one parent on the difference the camp experience made for her:

**"Camp is something my kids will talk about for some time. I did not know how much I needed the emotional support until after the camp. I cried all the way home! It's amazing to feel you have an extra support network of people who really know exactly how you feel."**



Camp is all about lifting each other up.

**MS** Readathon

MS Readathon funds MS Family Camps and Family Days across the country, along with other support services for families living with MS, starts August, sign up today visit [www.msreadathon.org.au](http://www.msreadathon.org.au) or call **1300 677 323**





Connie, The May 50K participant and champion fundraiser.

*A drum roll please...*

## You helped raise over **\$3.5 million** in **The May 50K**

**All your hard work has really paid off. Thanks for taking part and helping to put MS behind us.**

One of the youngest participants in The May 50K was 10-year-old Connie. Connie was diagnosed with paediatric MS just 18 months ago, so she had extra motivation to complete The May 50K. She wanted to help raise funds and awareness, and she also wanted to prove that MS isn't going to stop her from taking on the world – and achieving her goals.

The result? Connie smashed the challenge and 'Connie's Crew' raised over \$283,000. (Insert wild applause here!)

But it wasn't just Connie who contributed. The MS community, including 19,493 people like you, ran, walked, cheered, encouraged and supported. Friends and family pitched in generously. Those wonderful efforts raised over \$3.5 million to accelerate MS research, and we couldn't be prouder.

Head to **@KissgoodbyetoMS** on Facebook and Instagram to see how your fundraising efforts are changing lives.



Get together with your friends, family, workmates, clients and suppliers, and experience all the excitement and camaraderie the MS Gong Ride has to offer!

Visit [www.msgongride.org.au](http://www.msgongride.org.au) to register for the November 2022 event

## A place to be well, thanks to you.

**The first Wellbeing Centre opens in Footscray soon.**

Ever wanted a one-stop shop where you could get personalised exercise classes, physiotherapy and a purpose designed gym for people who have MS?

**If you live in the Footscray area, you're in luck.**

The very first Wellbeing Centre opens there soon – thanks to the hard work and generosity of the MS community.

The Wellbeing Centre will also be a place where you can access other important services like NDIS



Gym, physio and more. It'll all be available at our Wellbeing Centres.

support coordinators and employment specialists.

It's part of MS Plus's long-term goal to open wellbeing centres all across the country. **So stay on the lookout for news on centres near you!**



Two teams raised an incredible **\$135,065** for MS support services when they challenged themselves to **Conquer Cradle Mountain to Beat MS** in early 2022!

Your support empowers people across the MS community to conquer their challenges.

*Thank you!*

