

MARCH 2024

# MS + YOU

Connecting you to stories of your incredible impact

## Lorraine's looking forward to a new MS gym – and making little kids laugh!



**When Lorraine was diagnosed with Primary Progressive MS a few years ago, a call to MS Plus changed her life.**

Despite losing her ability to walk or drive, expert support, and the generosity of people like you, gives Lorraine a positive outlook on her life with MS.

*“When I’m having a bad day, I think of everything I did that week,” she says. “And I think ‘okay, that’s pretty good. Let’s see what next week brings.”*

And with a positive mindset keeping her mentally healthy, Lorraine is focussed on the future and improving her physical health at the new Footscray Wellbeing Centre.

*“Ultimately, I’m a person first, not just a disability,” Lorraine says. “I’ve put a license plate on my wheelchair which makes people have a laugh with me. Little kids love it and I feel like people really see me, not just my chair.”*

*Thanks for giving people with MS more to look forward to.*

# You give me so much cause for optimism.

**An MS diagnosis can really knock a person for six.** I often hear people describe feeling blindsided, shocked, scared, and lonely.

But in this issue of *MS + YOU*, I hope you'll see that, with the right support, life with MS can be one of hope and joy too.

Every day I am inspired by people like Deanna who share their MS stories through art, generous partners like Annemarie who created hope through a gift in her Will, and the incredible researchers like Dr Jennifer Massey who are helping us get closer to the cure we know is out there.

And most of all, I am inspired by compassionate people like you who are making a better future for people with MS possible.

**Thank you for everything you do to give them so much to look forward to.**



**John Blewonski**  
CEO, MS Plus

Deanna uses art to express her feelings about living with MS.



*"It really butters my biscuit knowing that despite my MS, anything is possible."*

**Deanna thought she was going to die when she was diagnosed with MS at just 17.**

*"The news was delivered to my mum over the phone and she kept crying," Deanna says. "We didn't fully understand what MS was and I was offered very little support or education. I wish there were positive MS representations back then."*

Thanks to support from MS Plus and generous people like you, Deanna hasn't just learned to live well with MS – she's gone on to achieve some amazing things.

In 2022 she raised almost \$8,000 for MS research and support services, participating in the MS Walk, Run + Roll and MS Tuscany Trek, and curating a charity art show featuring artists with invisible illnesses.

And her own art project that transformed an MRI into a colourful, flowery representation of hope won first prize in the 2022 MS Plus Art Show.

*"My journey with MS hasn't always been the most pleasant, but I am happy to say it does get better," Deanna says. "Medication has improved, support groups and representation have improved."*

**There are more good things to come for Deanna – and you help make them possible. Thank you.**



**"MS Plus services are a game changer. Now I tell people to please reach out, get help, and ask for support."**

Our **events, gifts in wills, appeals and community fundraising** enables MS Plus to continue funding better treatments, ongoing services and research that will empower people to better manage their condition and one day **make MS a thing of the past.**



*'The Girl I Once Knew'*  
by Aimee Rowland.  
Winner of the 2023  
MS Plus Virtual Art Show.



*"I painted 'The Girl I Once Knew' shortly after my MS diagnosis – it felt as if I was being stripped of my identity as I struggled to connect to the world and more importantly myself."*  
– Aimee Rowland

## Introducing the winners of the 2023 MS Plus Virtual Art Show.

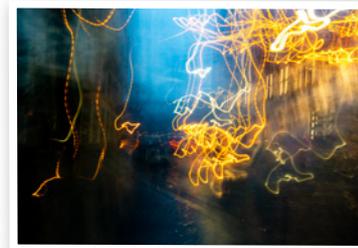
The 2023 Art Show featured 171 works submitted by artists who are living with or caring for someone with a neurological condition like MS. Entries included paintings, illustrations, sculptures, craft, digital artwork, and photography.

The Barry Allen Art Award for first prize was awarded to Aimee Rowland for *'The Girl I Once Knew'*, a self-portrait in oil painted on the discarded clothing of strangers.



*'Happy Autumn'*  
by Jana Morgan.  
Highly Commended  
Paintings/Illustrations.

*'The Counsellor'* by Sally Waterford.  
Highly Commended  
Sculptural/Craft Artwork.



*'Distraction'* by Stephen Ellis.  
Highly Commended Digital  
Artwork and Photography.

*'Seashore'*  
by Anne Fritz.  
Carers Award.



## People with MS were supported with more services in 2023 – thanks to you.



### Plus Peer Support

**220** volunteers

**82** face to face peer groups

**22** virtual peer groups

**81** people provided with more than **500** hours of support via one-on-one phone calls

**11** Peer Link wellbeing programs, providing over **264** hours of support.



### Plus Connect

**16,328** connections made through Plus Connect



### Health Promotion & Education

**1,778** people registered for a webinar

Podcasts: **9,446** downloads,  
**7,358** unique listeners

Client and health professional views of our on-demand YouTube webinars: **18,207**



### Plus Advisor

**1,203** clients supported by a MS Plus nurse or social worker

*"Since calling MS Plus my life has changed for the better. Without the services available to me and others with MS, I wouldn't be where I am today."* – Lorraine, Footscray Wellbeing Centre client.

The 2023 Sydney Mega Swim saw teams of all ages complete a 24-hour relay to support people living with MS.



## MS Mega Challenge is passing the good stuff forward.

It's not surprising this great fundraising event is loved by teams – because if there's anything the MS community knows, it's that we can do more when we work together.

The MS Mega Challenge sees teams tackle 12 or 24 hours of their favourite activity, relay style.

From swimming to triathlons, and even badminton, the events raise money for the MS Go for Gold scholarship program, to help people living with MS chase a personal dream, and the Plus Financial Assistance Program.

Last year, 1,579 participants raised nearly \$500,000 in MS Mega Challenge events.

**To register for the 2024 MS Mega Challenge or to find out more, visit [msmegachallenge.org.au](https://msmegachallenge.org.au) or scan the QR code:**

**MS MEGA**  
CHALLENGE



Sally, who wishes she'd joined an MS Peer Support group sooner.

*"Without doubt, peer support has enriched my life."*

**Sally describes being diagnosed with MS as being "inadvertently thrown into the 'MS club'".**

*"Both carers and people living with MS are automatically connected," she says. "Straight away there's a bond."*

For nearly 10 years, Sally has nurtured her bonds with other people living with MS through Plus Peer Support.

This free service connects people living with MS with others who've been where they are to share knowledge, experience, and even tips on how to manage their condition.

**And it's possible because of generous people like you.**

Sally's only regret is that she didn't join a peer support group sooner.

*"Had I gone before I retired I probably would have learned about adjustments so that I could have stayed longer or received assistance transitioning to alternative work," she says.*

*"But without a doubt, peer support has enriched my life. Your peers can truly help you learn to live well with MS."*

**Thank you for helping more people access the life-changing connection of Plus Peer Support.**

# A gift for the future

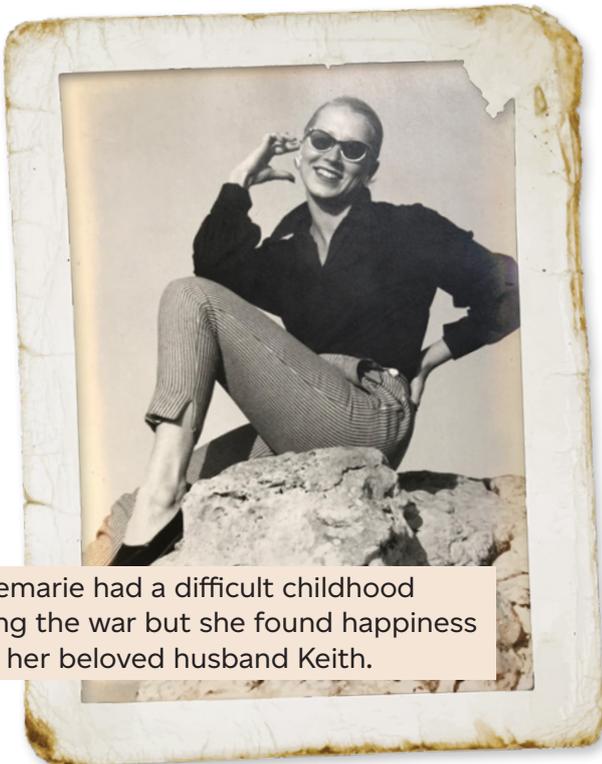


## Annemarie wanted to transform Keith's experience with MS into help for others.

It's been many years since Annemarie lost her husband Keith to complications from MS. But her promise to help others like him lives on through a gift in her Will.

Annemarie was devoted to Keith throughout his MS journey. As the daughter of German immigrants, she'd had a difficult childhood when her father was interned during World War II. But when she met Keith in the 1950s she finally found happiness in their marriage and overseas travels.

And when Keith was diagnosed, Annemarie stood by him with unwavering support. By his late 60s he was in a wheelchair but despite his declining health she cared for him at home so he wouldn't need to move into residential care.



Annemarie had a difficult childhood during the war but she found happiness with her beloved husband Keith.

Annemarie outlived Keith by many years but she kept her promise to help others like him who live with MS.



Sadly, Keith passed away at age 69, 40 years after his initial diagnosis. Before he died, he and Annemarie agreed that their estates should give hope to other people living with neurological conditions.

*"Annemarie didn't want others to suffer as Keith did," says Annemarie's cousin Annele. "She wanted to find a cure."*

Annemarie found more joy later in life with a second marriage, extensive travels and a busy social life. She lived until a few weeks after her 90th birthday.

In her Will, she remained true to her commitment to supporting people like Keith and helping find a cure for MS, leaving most of her estate to MS Plus.

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If you have questions about making or changing your Will to include MS Plus, we can probably help answer them in a friendly and confidential conversation. Email [futureplanning@msplus.org.au](mailto:futureplanning@msplus.org.au) or call **1800 443 867** to get started today.

Gifts in Wills give the MS community so much more to look forward to. Last year, 66 Trusts and Estates donated a total of **\$3,500,000** to MS Plus.



# Thank you for supporting continual advances in MS research.

*There are more and more excellent treatments for MS becoming available – and that simply wouldn't have happened if people like you had not donated so generously in the past. Better still, the best is yet to come!*

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## Dr Jennifer Massey wants to know more about the links between MS and Epstein-Barr virus.

Researchers have long suspected a link between Epstein-Barr virus (EBV) and MS. But if EBV is so common, affecting 95% of the adult population, and MS is relatively rare, what could that connection be?

### **With your support, Dr Jennifer Massey wants to find out.**

Her research project is investigating the impact of a highly effective MS therapy known as AHSCT (autologous haematopoietic stem cell transplant) on an individual's immune response to Epstein-Barr virus.

AHSCT helps to 'grow' a new immune system that is less reactive to the brain and spinal cord. For some people with MS it's proven to have incredible benefits.

But it's possible the treatment leaves the immune system weakened and allows hidden viruses like EBV to reactivate.

By learning more about how Epstein-Barr virus behaves after stem cell transplants, Dr Massey hopes to learn more about its role in MS and how it affects progression of the disease.



**“By understanding how different therapies modulate a patient's immune system, we may be able to develop targeted cellular therapies in the future,” she says.**

**“It's an exciting time to be working in MS research.”**

# Research gives people with MS more options, and more hope for a cure.

MS Australia's research program supports research activity in areas where Australian scientists will have the greatest impact on MS research worldwide.

It funds investigator-led projects like Dr Jennifer Massey's and:



Postdoctoral Fellowship:

## Dr Nicholas Blackburn (TAS)

*'How does genetic variation contribute to multiple sclerosis?'*

Project Grant:

## Associate Professor Justin Rubio (VIC)

*'The impact of inflammation on DNA damage in brain cells in primary progressive MS'*



Postdoctoral Fellowship:

## Ms Alice Saul (TAS)

*'The role of pain in multiple sclerosis.'*



## What is MS?

A new video answers the question.

MS affects more than 33,000 Australians, but too few people understand a disease that is often 'invisible'.

This video, created by MS Australia, will help change that. Scan the QR code to watch the video:



## Challenge yourself with The May 50K and leave MS where it belongs – behind us!

Leave your limits behind with The May 50K. Run, walk, or move 50 km in May and raise vital funds to leave MS exactly where it belongs, behind us!

The May 50K is a virtual fitness and fundraising challenge to help you achieve your health and fitness goals. You can take part in your own time, at your own pace, and in and around your local area.

Register now at [themay50k.org](https://themay50k.org) or scan the QR code:

**THE MAY 50K**



*"My mum, my sister and I have all been diagnosed with MS. I don't want this for my daughters.*

*Thank you for helping fund the research and support that could change my life and ensure tomorrow will be better than today for me and my girls.*

*Your kindness gives me hope for the future."*

– Bronwyn, mum of two living with MS.

Scan the QR code below to see Bronwyn share more of her story.

