

MARCH 2023

# MS + YOU

Connecting you to stories of your incredible impact

“I am  
more  
than  
my MS.”



## Eliza Middleton's journey from diagnosis to STEM superstar

**When Eliza was diagnosed with MS, her first child was just three months old.**

“Crippling fear overtook me for what my future would look like,” Eliza explains. “Rather than seeing myself as a mother, partner, artist, athlete and scientist, I suddenly felt defined by MS.”

But the kindness of people like you helped connect Eliza with the support she needed to thrive.

“The Employment Support Program has been incredible. My support worker, Jeff, has

advocated for me and helped me adjust my expectations in line with any potential limitations MS may present – to the point where I now see them as opportunities to be flexible,” she says.

Since being diagnosed, Eliza has welcomed her second child and built a successful career – even being named a ‘Superstar of STEM’ by Science and Technology Australia.

*Thank you for helping people like Eliza break down barriers and live their best lives.*

Last year, you helped connect **17,740** people like Eliza to a life-changing support worker.

# You're at the heart of our MS Plus community. Thank you.

As CEO of MS Plus, I feel it's such a privilege to connect with supporters, clients, researchers and staff as part of our wider MS community.

I've been reflecting a lot on connection this month, and believe it is the beating heart of MS Plus.

I see the connection between generous donors and the breakthroughs we are making in MS research; connection within the relationships between Key Support Workers and people who live with MS are absolutely life-transforming; and there's never a day that goes by when I don't feel or witness the connection and compassion within our community as we work to bring an end to MS.

I hope you enjoy the stories of connection in this edition of MS + YOU.

Together, they paint a clear picture of the enormous impact your kindness has, and show what we can achieve by working together. **Thank you as always for your support.**



**John Blewonski**  
CEO, MS Plus



Pauline always has a smile for her clients

*"I let people know we're always here for them."*

## Key Worker Pauline shares how your kindness helps her lighten the load for people with MS.

As a Key Support Worker, Pauline provides a bridge between MS Plus clients and the world of support and services – whether they're delivered by MS Plus or external agencies.

"We offer support to access the NDIS, and our employment team, nurses, and social workers. We also have an allied health team with physios, dieticians, and occupational therapists," Pauline explains.

A friendly and familiar voice, Pauline checks in with clients on a regular basis to help them overcome barriers connected with their diagnosis.

Recently, Pauline helped a client access lifechanging help through the NDIS after her partner passed away and she was left to raise her 10-year-old child alone with no family support.

"Our client was physically unable to leave the house; then they both ended up in hospital with COVID-19.

"We lodged an NDIS application, and she now has support with transport and household tasks.

"I was so touched when she told me, 'We've been having take-away for 12 months. This is the first normal meal in a year for myself and my son.' Those types of wins are the reason I love my job."

**Donations to MS Plus ensure Pauline can help people live their best lives with MS. Thank you - on behalf of every person and family you help.**



Last year, generous and caring supporters like you funded **40,168** hours of Support Coordination – to help people with MS navigate and access government services.

# Lisa started a support group that will change dozens of lives.

Thanks for helping make her dream a reality.



Lisa wants a life filled with laughter and friendship – not just MS

Lisa knows better than most how MS can challenge your identity and independence.

Before being diagnosed she lived an active life, but 14 years on, her mobility is not what it was.

It's been confronting - and Lisa really felt she needed to connect with others who 'get it'.

When she discovered there was no MS Plus Support Group nearby, Lisa decided to start one.

It was the kindness of people like you that ensured she could undergo training, become a facilitator, and start her local group. Now she belongs to a community of people who share experience, encourage each other, and connect with support.

"There are 43 people with MS just in my local area – that's a lot of people who felt as isolated, lonely, and scared as I did," Lisa says.



Last year, you helped **800** people like Lisa find understanding, care and friendship in 80 local MS Plus Peer Support groups.

## Where there's a Will, there's a ... lot of progress!

### Deidre and Lin's legacy of care and compassion

Deidre was an astute, eloquent and caring woman. She was dedicated to supporting her MS community, as well as others with neurological conditions, so she became a volunteer counsellor at Royal Melbourne Hospital when she retired.

**Sadly, after entering palliative care in the same hospital where she'd been a popular volunteer, Deidre died in 2020 – but her legacy of care and compassion will live on through a gift in her Will.**

"Deidre wanted to plan for the future," says her husband Lin. "We didn't have kids, so she suggested we leave money to charity and give back to MS Plus. It was a great idea."



*Could you be like Deidre and Lin, and leave a legacy of love for those living with MS?*

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



This state-of-the-art Wellbeing Centre will open its doors next year

# A place to call home

## A new Wellbeing Centre will help people with MS thrive.

Construction of the new MS Plus Wellbeing Centre in Lidcombe is underway!

When it opens in 2024, the centre will represent a massive step forward in our ongoing efforts to help people with MS live life to the fullest, on their own terms.

The Centre has been designed as a supportive and healing community space, capable of offering holistic care to fill some of the gaps in a failing system.

The sad reality is that many people who live with MS and other neurological conditions don't have access to accommodation that is appropriate to their needs and life stage.

**Now, thanks to you, the Wellbeing Centre in Lidcombe will help provide the right kind of care, including residential care for people of all ages.**

- There will be 20 apartments with two bedrooms each, so families can be included.
- Accommodation will be split between short and longer term stays.
- A wide range of services will be on hand to help young people with MS live independently.

The centre will include a specialised gym, so clients with MS can work on their strength and movement. There'll be eight therapy spaces, a café, gardens, kids zone, and large communal areas for classes, workshops and group events. It will be a vibrant hub and social space.

It will be staffed by a team of caring and highly-trained professionals, to improve community access to physiotherapists, continence nurses, dieticians, and employment support workers.

This Wellbeing Centre will deliver much-needed support and services for people who live with MS, and young people with MS in particular.

*Please continue to support breakthrough facilities like this – and help change lives.*

**2,934** Australians who have a disability and are under the age of 65 living in aged care.

Last year your support provided **106,550** hours of specialised accommodation care to people living with MS.



Ricky's trainer is helping him build back strength and mobility

*"Rise, move, heal, feel better."*

**How the MS Plus Gym and supporters like you are helping Ricky find his strength.**

After 47-year-old Shushrik aka Ricky was diagnosed with MS, his taxi driving license was medically cancelled. Despite the challenges of using a wheelchair, and the loss of his job and mobility, Ricky is building a new life on his own terms.

The MS community helped Ricky connect to a support worker who transports him to the old MS Plus Gym at Lidcombe two days a week. There, physiotherapists and trainers – and his newfound friends – are helping him work towards his big goal of walking a whole block independently.

**"The gym is such a positive, happy environment.**

**It gave me the mental strength to go ahead and live with MS. Thank you for making this possible."**

- Shushrik



Last year your support provided **4,213** hours of vital exercise physiology to people like Shushrik.

## Building up muscles – and hope.

**Caitlin shares why working out, and your care, helps people live better with MS.**


Getting active is one of the five pathways to wellbeing for people who live with MS, and through her work at the MS Plus Gym in Lidcombe, Caitlin sees the amazing benefits it brings every day.

"Our exercise services combine targeted exercise programs with social engagement so our clients are improving their physical and mental health to build an overall sense of wellbeing," she says.

Your support for these programs helps people who live with MS feel safe – physically, and in the knowledge they're being supported by professionals who understand their individual needs.

*Thank you so much.*





You're helping MS researchers make life-changing discoveries

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

**Last year, your generous donations helped to fund \$1 million towards world-class research projects that are improving our understanding of MS and making strides towards finding a cure.**

A world without MS is closer every single day that researchers can keep searching and working.

Every dollar fuels momentum, and could lead to a breakthrough which transforms lives. Last year alone, our wonderful community raised one million dollars!

That's a huge boost towards better treatments, deeper understanding, and one day, a cure.

The funding will go towards four major projects, two of which are featured here.

By kindly contributing support for this vital research, you've helped give hope to our

**22 new projects** ranging from one-year innovative studies to major three-year projects, have received grant funding from MS Australia in 2023 so far.

This would not have been possible without the determination and generosity of the MS community – **including you!**

MS community, and we want you to know what a tremendous difference that makes.

MS Plus is now responsible for coordinating research fundraising from MS organisations across the nation, and we'll keep you updated on exciting medical breakthroughs as they come through.

**Medical research is a long game, but history shows we make huge breakthroughs if we persist.**

It was only in the late 19th century that MS was identified as a condition. Since then, ground-breaking treatments have been developed that can help to slow down the disease's progression.

Researchers have developed more and more treatments thanks to the support of people like you. We've come a long way, but there is still more to do.

*Thanks again for your generosity, and having the vision to look forward to a future free of MS.*



# Catching the “slow burn” signs of MS progression.

**With your support and a state-of-the-art camera, Professor Alexander Klistorner hopes to detect secondary progressive MS sooner.**

Your generosity has helped launch innovative new research investigating which mechanisms in the brain and spinal cord cause the development of secondary progressive multiple sclerosis (SPMS).

Professor Alexander Klistorner and his team will use state-of-the-art neuroimaging techniques, partly developed in their own lab, to enhance our understanding of what drives the progression of MS.

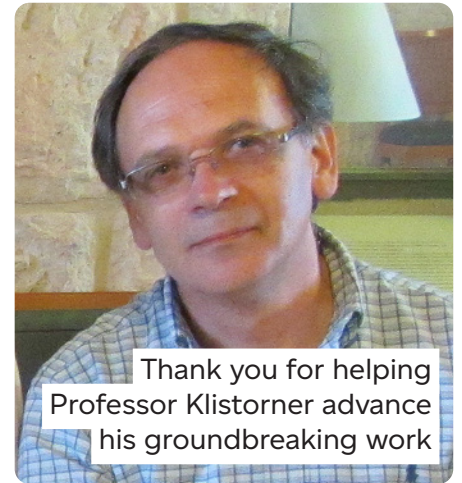
Their research focuses on permanently demyelinated nerve fibres inside chronic lesions and “slow burning” – or low-grade inflammation – around the lesion edge.

“Slow burning” inflammation significantly damages normal brain tissue over time. And it has been suggested that permanent demyelination makes some nerve fibres more vulnerable to physiological stress.

This is an understudied area of MS research. By supporting

it, you could help build our knowledge of the role of “slow burning” inflammation in the progression towards SPMS, which could lead to exciting new treatments that could slow down disease progression.

We will keep you updated as it unfolds.



Thank you for helping Professor Klistorner advance his groundbreaking work

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# Protect and repair: how myelin could help turn MS around.

**Thanks to this community, Professor Kaylene Young and her multidisciplinary team are close to realising a groundbreaking new MS therapy.**

A new therapy replacing myelin lost to MS is coming closer each day thanks to the generosity of people like you.



It takes a team to find a new MS treatment!

**Such a treatment has the potential to protect and repair the brain and spinal cord, which is the greatest unmet need for people living with MS.**

The treatment is being pioneered by a multidisciplinary team led by Professor Kaylene Young. It includes laboratory scientists, clinicians, biostatisticians, epidemiologists, geneticists – and importantly, MS advocates and people living with MS.

The goal is to identify the ‘signalling pathways’ that cause people to develop MS, and investigate how the disease impacts brain circuit function, to help create treatments that protect and even repair the brain.

The researchers are running a phase II clinical trial that could replace myelin in people with MS and evaluate the impact on their brain function.

Beyond this, they plan to study families with an unusually high incidence of MS in an effort to improve our understanding of the role genetics might play in cell behaviour.

This exciting research could pave the way for the next big breakthrough.

*Thanks for making it possible!*

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The Ride to Fight MS. In 2022, 10,000 riders, including MS Ambassador Carol Cooke AM PLY (pictured right) raised \$2,764,919 on the 40<sup>th</sup> MS Gong Ride event.

# Riding high!

## MS Gong Ride raises \$2.7M

After two false starts due to COVID-19, the iconic **MS Gong Ride** was back with a bang last year.

To every participant, donor, and MS supporter – **thank you.**

Your kindness connects people living with MS to lifechanging research, support and services.



*Thank you again*

