



RESEARCH
ADVOCACY
CURE



MS WIRE

November 2022



FUNDING RESEARCH FOR A BRIGHTER TOMORROW

Bronwyn spent her childhood watching her mother live with advancing multiple sclerosis (MS). Her relationship with her family had changed overnight, and she'd become 'little mum' to her younger sister Kylie. Then Bronwyn was diagnosed with MS when she was just 25. ...continued on page 4



A BETTER NDIS FOR MS: *Kelly's story*

Kelly Engelhardt, 41, was first diagnosed with MS in July 2001, while studying teaching at university. Her teaching career was cut short as her condition worsened.

Married with two children, Kelly has been receiving support from the National Disability Insurance Scheme (NDIS) for five years, after her first application was denied.

While enormously grateful for the support, Kelly is frustrated by the NDIS's lack of understanding about her condition.

"I was out at the shops, and I just burst into tears. And I spoke to my neurologist, and he was like, 'Are you kidding me? They are asking you for proof that you can't be cured?' So it was really deflating. If they (the NDIS) don't understand about it not being cured, how are they going to understand what help I need."

"We all have different types of MS, within those different types we all have different degrees of disability and you need to understand everybody's case is completely different for what we need to make our lives better." ...continued on page 2

A BETTER **ndis**

FOR PEOPLE
LIVING WITH





FROM THE CEO

It has - by any measure - been a big year for MS. Yes, it has been MSA's 50th year, with a number of events held to mark the occasion. These have included our Research Roadshows, a 50th Anniversary Research Oration and - still to come - a commemorative dinner with members of the Parliamentary Friends of MS. But we have also reached some big milestones:

- In January, we released our new 2022-26 Strategic Plan, the first for the combined MSRA/MSA organisation, with our combined goals, encompassed in our tagline: *Research, Advocacy, Cure.*
- In February, we announced our largest investment ever in MS research, almost \$7m including a targeted call for myelin repair, neurorepair and regeneration.
- In March, a record investment of \$18m was announced in the Federal Budget to support MS research, particularly for research into the Epstein-Barr virus (EBV), a result of our advocacy.
- In April, we held our largest ever Progress in MS Research Conference, also launching our major report on MS Nurse Care in Australia.
- In May, we released the results of a major survey revealing the employment challenges of people living with MS and our updated employment resources for consumers and employers.
- In June, we partnered with key research organisations to lodge two proposals to the Medical Research Future Fund, one seeking funds for our major clinical trials platform for progressive MS, PLATYPUS and the second seeking support for Brain Bank infrastructure nationally.
- In July, we launched our #betterNDISforMS campaign with three clear aims, including a call for a consultative group to be established giving people with MS and other neurological conditions a voice within the NDIA advisory structure.
- In August, we joined other leading global MS research organisations - The Big Five - to develop a world-first research roadmap framework to help accelerate the pathways to cures.
- In October, we plastered Canberra Airport with our NDIS campaign messages on electronic advertising boards as federal politicians flew in for Budget week.
- Also in October, at the world's largest MS research conference - European Committee for Treatment & Research in MS (ECTRIMS) - we released the results of our major, seven-year Phase IIb clinical trial on whether vitamin D can prevent the development of MS.

The year, of course, is far from finished and we won't rest as we seek to supercharge both our research and advocacy work.

I will pause, however, to profusely thank you all - our hard-working Board Directors and staff, our MS Member Organisations, our research community, our fundraisers and May50K participants, our Parliamentary Friends, our generous donors and - most importantly of all - everyone living with MS, your carers, friends and families. Our lives are dedicated to you.

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A BETTER NDIS FOR MS: KELLY'S STORY

Kelly's mobility has dramatically declined in the last three years, and she requires the use of a wheelchair when leaving the house. Four months ago it was hard to go to the local shopping centre but she could do it. Now it has become too challenging and the impact on her health too great.

"I'm fatigued all the time, always so tired. It's the fatigue, the pain...I forget things easily."

In her most recent NDIS assessment, Kelly was left disappointed and baffled that her request to increase her access to an exercise physiotherapist from one hour a week to two hours a week was knocked back this year.

"I never wanted to stop working, I never wanted to rely on the government to help me with things. I am exceptionally grateful that the NDIS exists, more than I could ever explain, because it helps me. But I need help in some ways that are missing from the NDIS. To give

me hope that the decline can slow down, that I can be a better mum and wife for as long as I possibly can."

Kelly's story highlights how the NDIS has failed to support the needs of many people living with MS.

The NDIS Review is a significant opportunity to build a better, fairer scheme.

MS Australia is advocating for three key priorities to be implemented in the revised NDIS:

HEAR OUR VOICE: Include people with MS and other progressive neurological conditions in the decision-making structures of the NDIS to ensure fair representation and better support for our community.

UNDERSTAND MS: Improve awareness and understanding of MS within the NDIS to provide better support for people living with MS.

...continued on page 3



CONCEPT OF SELF IN MS

What is self-concept and what challenges it?

“Self-concept” is the way that people see themselves, often related to what they see as their characteristic traits, such as being hardworking, smart, or outgoing. A person’s sense of self can be dramatically impacted if there are changes or disruptions to their roles. A new study from the researchers at the University of Tasmania has examined self-concept in people with MS.

What did the researchers investigate?

Sixteen people with MS were interviewed on what they considered to be the most important aspect of themselves and about meaningful life events, as well as changes in how they perform roles and the impacts of these on self-concept.

Three major themes were interwoven through the narratives. These were how MS had *changed their life*, the *changing concept of self* with MS, and how their *thoughts had changed* with MS.

Changed Life

Many people identified particular events or instances that were defining moments for their self-concept. The time of diagnosis and symptom escalation were often referred to, such as for participant James who felt *“like I was about to just melt away really, like the person I was, was gone now.”*

Among changed roles, people described changed work roles, social life and family and partner relationships, such as participant Jeffrey: *“I don’t know what (my wife) thinks about me now... whether she thinks that I’m less of a person...”*

Changing Self

The impact of MS on self-concept was often widespread and profound. All participants referenced how much they thought MS had impacted their current perception of self, often by describing the magnitude, like participant Mary: *“Oh it’s changed, it’s changed tenfold.”*

While some people experienced this impact across many aspects of self and life, others felt they had maintained a stable sense of self after diagnosis amidst the changes. Some described a more determined and resilient belief in themselves: *“I’m a survivor, you know, that’s it. You keep getting knocked down, you keep getting back up again, that’s it.”*

Changing thoughts

Some people saw a clear need to adjust the things that were important to their sense of self, to accommodate their MS. For Sharon, it was work: *“I’m like, I’ve got to look after myself a little bit more and not work full-time because, obviously, I’m not the person that I want to be when I’m so focused on work.”*

Appreciation for small, personal victories was associated with more positive self-concept: *“So I guess I’ve tried to turn the negatives into positives now... So really, in a way MS is a good thing for me. Ok, it’s not a good thing but when I look back on my life it was shit for a long time until I got diagnosed.”* – Robert.

What does this mean for people with MS?

It is hoped this new understanding will help the development of more targeted supports, especially during times likely to challenge self-concept. If you need help with any of the issues raised in this article, please contact your MS health team or State or Territory Organisation.

(Names changed for privacy)

DON'T DISCRIMINATE: Remove the discriminatory age 65 cut-off for inclusion in the NDIS. All Australians with MS should be entitled to support from the NDIS regardless of age.

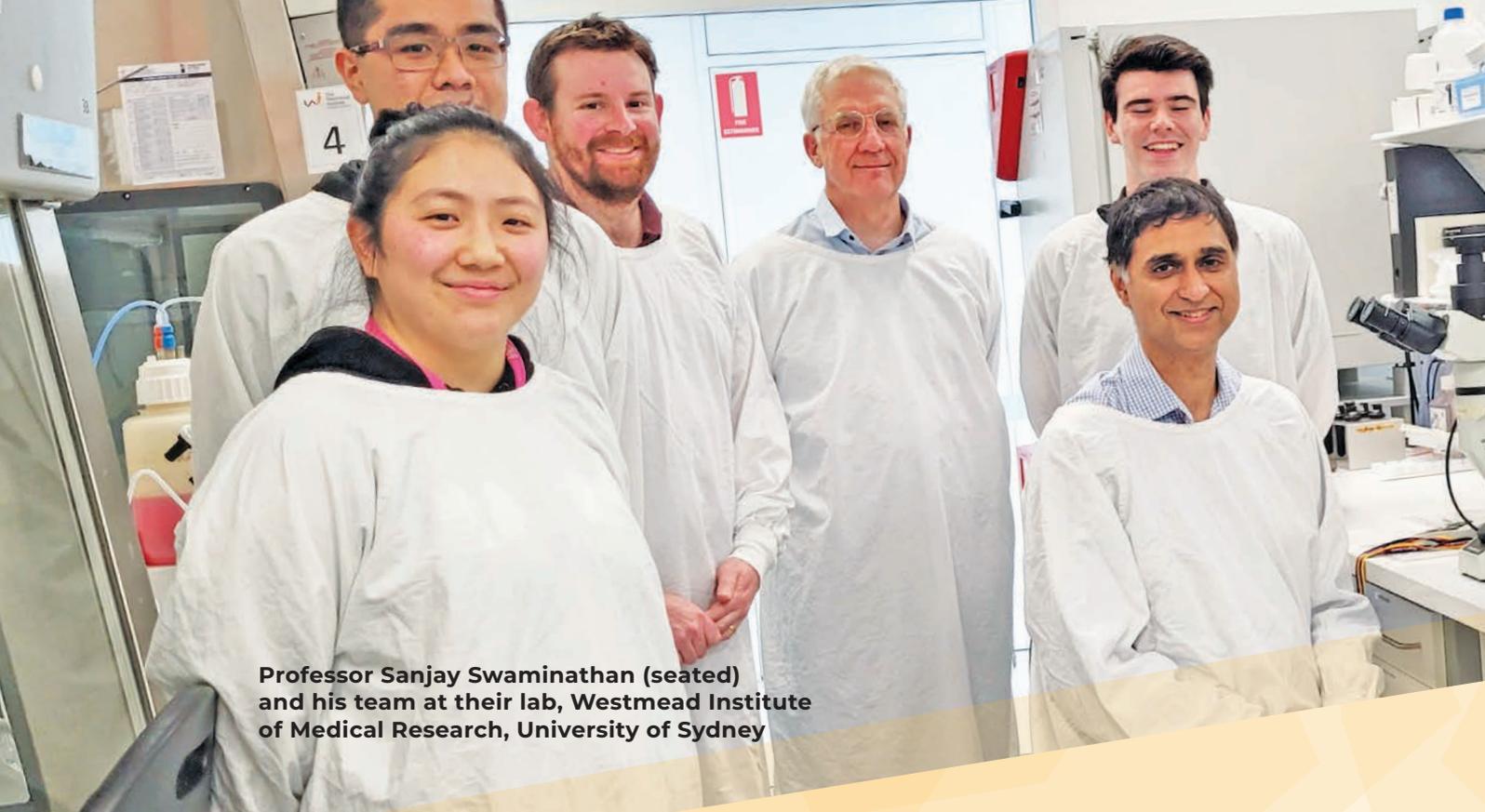
MS Australia will continue to ensure these priorities are kept front of mind during the NDIS Review.

At the beginning of the October 2022 parliamentary sitting week and with the NDIS Review underway, Kelly was featured in a billboard campaign at Canberra Airport, to ensure the campaign was front and centre with decision-makers as they arrived in the nation’s capital.

To learn more about MS Australia’s campaign, A better NDIS for people living with MS, visit www.msaustralia.org.au/advocacy/ndis

More information about the recently announced NDIS Review can be found here www.ndisreview.gov.au





Professor Sanjay Swaminathan (seated) and his team at their lab, Westmead Institute of Medical Research, University of Sydney

FUNDING RESEARCH FOR A BRIGHTER TOMORROW

continued from page 1...

"MS hit and it frightened me," shares Bronwyn. Since then, Bronwyn has learned her sister has MS too.

Now, as a mother of two daughters, 10-year-old Xanthe and 12-year-old Astrid, Bronwyn is equally concerned for their future.

"MS is so cruel. I don't want this for my daughters. It frightens me," she shares.

It wasn't until after leaving the family home that Bronwyn learned of her own MS. Her boyfriend Rod had proposed and asked her to follow him to Canberra to start their life together. Shortly after she moved in with him, Rod noticed Bronwyn had started having seizures in her sleep.

"I thought the worst thing that could happen to me in my 20s was needing glasses," shares Bronwyn. "I was so relieved when I got the diagnosis of nocturnal epilepsy because it wasn't MS!"

"I could cope with epilepsy, but I couldn't cope with MS. Not after what it had done to my mum - my whole family's life."

But the worst news was yet to come for Bronwyn. A few weeks after her diagnosis of nocturnal epilepsy, Bronwyn visited her neurologist following a routine MRI.

"My neurologist simply said to me, 'You also have MS'. He didn't see at the time that I was falling apart," shares Bronwyn. "That I'd lived through my mother's journey with MS."

"After I left his office, I sat at the bus stop for more than three hours and cried."

"Rod had just proposed six months prior to my diagnosis. He had no idea what my life was going to be like now - how hard I thought it was going to be for him as a carer for someone with MS. So, when I told him I had MS I suggested we break off our engagement."

Luckily, Rod's love for Bronwyn was greater than his worry for what their life with MS would be like.

Rod contacted MS Plus and support worker Sue Donaldson came to their home that same week.

"Why are you leaving Rod and your job? This isn't going to stop you from doing the things you love. Your MS could be completely different to your mother's," Sue explained.

"It was only then that I realised that I had treatment option; something that my mother never had," says Bronwyn.

After Bronwyn and Rod married, they were told they wouldn't be able to fall pregnant while she was taking injections for her MS.



Bronwyn (pictured) says MS research is about hope.

“MS research has always given me a next step, an option that if this treatment doesn’t work or my MS progresses, then we can always try something else.”

But researchers were soon able to offer a new treatment that would allow them to start a family.

“I stopped my daily injections and started taking this itty-bitty little pill. I was so grateful,” recalls Bronwyn.

Eight years after her initial diagnosis, Bronwyn and Rod welcomed the first of their two baby girls.

“MS research has always given me a next step, an option that if this treatment doesn’t work or my MS progresses, then we can always try something else. My mother didn’t have that.”

But not everyone with MS will respond to the same treatments as Bronwyn.

An Australian researcher who is investigating one of the possible causes of MS is Professor Sanjay Swaminathan.

“I’m looking at how viruses interact with genes to cause MS, in particular the Epstein-Barr virus (EBV),” shares Prof Swaminathan.

“If we understand that interaction, then we can target the disease with personalised medicines in those people who have that specific type of MS. It may also allow us to develop preventative treatments like vaccines for the virus and reduce the risk of MS.”

Prof Swaminathan is quick to note that it is complex work, and he is only looking at one of many environmental factors that are associated with MS.

“We need more researchers focused on MS so that we can collaborate and understand all the environmental factors and how they interact with a person’s genes. Such as looking at Vitamin D in MS, which is very important too,” states Prof Swaminathan.

Bronwyn says, “The more researchers that are focused on MS research, the faster we’ll get to the answers. Research for me is about hope. I hope tomorrow will be better than today, for my daughters’ sakes as much as mine.”

It will take a team to fast-track MS research and we need you to be part of this team.

Please give generously this Christmas, so researchers can deliver more effective treatments for those living with MS like Bronwyn - and ultimately find a cure for MS.

Together we can make a difference and change the lives of people living with MS.

To donate  fundmsresearch.org.au/donate-now  1300 733 690



CHANGES IN GUT BACTERIA ARE LINKED TO MS

What is known about the gut microbiome in MS?

We know that multiple risk factors are involved in MS onset and progression, including genetic and environmental/lifestyle factors (e.g. vitamin D, smoking, Epstein-Barr virus exposure), but what combination of risk factors contribute to MS onset and progression and what role gut bacteria play remain elusive.

The composition of bacteria found in the gastrointestinal tract, or the gut microbiome, is known to play an important role in regulating the immune system and brain function.

Changes to the gut microbiome have been linked to several inflammatory diseases, and is emerging as a potential environmental contributor to MS.

While there have been studies on the gut microbiome in people living with MS, these have been limited by small numbers of participants and other factors which could be influencing gut bacteria, like different diets or different geographic locations.

What did the researchers do?

The International Multiple Sclerosis Microbiome Study (iMSMS) has brought together a team of relevant experts from the US, UK, Argentina, Germany and Spain to perform a large-scale and detailed study of how the gut microbiome affects MS disease susceptibility and progression.

Published in the prestigious scientific journal, *Cell*, the iMSMS consortium sought to overcome the limitations of previous studies by recruiting 576 people living with MS and for every person with MS, a household member without MS.

Recruiting people without MS from the same household reduced the differences in environmental factors such as diet and geographic location.

What did the study find?

Of the people living with MS, 76% had relapsing remitting MS and 24% had progressive MS (primary or secondary). Nearly two-thirds of people living with MS were treated with disease-modifying therapies (DMT).

The study found that the gut microbiome composition and function were substantially different between disease subtypes and were modestly associated with diet.

The gut microbiome was also affected by DMTs – this suggests that DMTs have considerable effects on the gut microbiome, which may be part of their therapeutic action.

To a lesser extent, age, sex, and body mass index impacted gut microbiome composition, which is in line with previous studies.

The study identified 16 different species of bacteria that were increased, and seven different species that were decreased in people with untreated MS compared to people without MS. Similar trends

were observed between relapsing remitting MS and progressive MS.

Interestingly, there was a larger decrease in several bacterial species in progressive MS compared to relapsing remitting MS, suggesting that further alteration in these species may be linked with progressive disease.

Some of the species of bacteria that were found to be altered in people with untreated MS have certain properties that may contribute to MS. In a university press release, the lead author of the study, Professor Sergio Baranzini, stated “We were surprised by the number of species that were differentially present in MS when compared to controls.”

What is the take home message from this study?

Overall, the researchers found a depletion of potentially beneficial bacteria in people with untreated MS compared to people without MS, which in turn may affect key metabolic processes that can worsen the inflammation in MS.

The findings could lead to the development of new therapies that involve either manipulating the microbiome or dietary interventions that may restore the healthy composition and function of the gut microbiome.



IN HONOUR OF MY BELOVED MUM JUDE...

“When my mum Jude was diagnosed with Multiple Sclerosis (MS), it changed both our lives forever.

“Mum passed away in 2012, so I am channeling my grief into good; I am determined to help others who live with MS, and support research to find new treatments and a cure.

“MS is something so incredibly close to my heart. I’ve been involved with raising money for MS for close to 20 years. It was something I decided to do when my mum was diagnosed. At the time, there was so little known

about the disease,” remembers Bek.

“Back then, there were no treatments available for MS. Not one. People like my mum Jude were simply told they’d have to let the disease run its course.

“For me that simply wasn’t good enough. I became a passionate volunteer and began fundraising for MS research.

“I wanted to do as much as I could. I volunteered at the MS Nursing Home in Brisbane for six years and participated in events to raise funds for MS including

the MS Moon Walk, MS Mud Run and the Point to Pinnacle – to name just a few! I also do individual fundraising events every year for World MS Day in May.

“I’ve also had the pleasure of running the MS Peer Support Group in Hobart South, and met some amazing people,” said Bek.

“I have seen great progress in care and treatment for people with MS. I want that to continue – for the sake of people like my beautiful mum Jude.”

— Bek Thorpe

Over the past 20 years, donations from people like Bek have funded breakthrough research and helped improve the quality of life for Australians with MS. It’s working! A person diagnosed with MS today has access to more and better treatments than Bek’s mum did. There is more support for carers and families.

But the job is far from done, and Bek is determined to keep pushing. She continues to raise money for MS in honour of her mum. She wants to see a future where MS no longer has power over people’s lives. Where nobody has anything to fear from an MS diagnosis.

“MS is my passion. As long as I am around, I will continue to raise awareness and funds towards a cure!” says Bek.

Bek has dedicated her life to helping people with MS, and there’s a way she can continue making a powerful difference even after she’s gone – by including MS Plus in her Will.

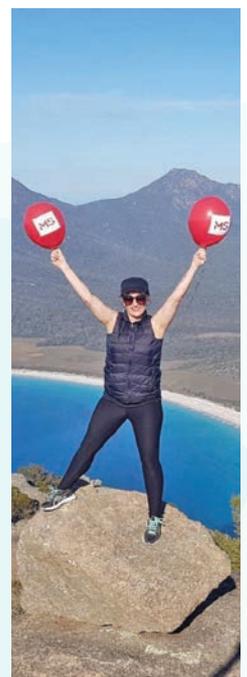
Gifts left in Wills will be crucial to the speed of MS research discovery, and improvements to quality of life for people who have MS.

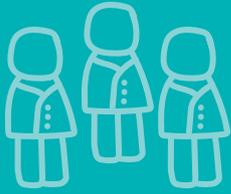
Every gift helps bring us closer to a day where no one loses their quality of life

because of MS. Every gift helps spare loving family members like Bek from the loss of someone they love and need.

If you’d like information about including MS in your Will in honour of someone you love, or want to make a difference in the lives of people living with MS, contact MS Plus.

For a no-obligation chat, please contact MS Plus Gift in Wills Manager Laura at futureplanning@ms.org.au or visit mymlegacy.org.au





MEET THE RESEARCHER

DR STEPHANIE TREND

TELETHON KIDS INSTITUTE AND PERRON INSTITUTE



Let's get started! Tell us an interesting fact about yourself.

Before starting my PhD, I worked in a pathology laboratory and as a clinical trial coordinator in a busy oncology clinic. I believe these experiences helped me to understand patient experiences within the Australian medical and research systems and allowed me to facilitate better research projects.

What inspired you to get involved in MS research?

I have always been interested in science and understanding the world around us. During my university studies I became fascinated by the human immune system and the differences between immune responses in healthy people and those with different health issues. After I completed my PhD, an opportunity arose to become involved in MS research. Meeting with the study participants has been invaluable in helping me

to understand the impact of MS on people's lives. It is highly rewarding to be involved in research that aims to better understand MS so that it might be more easily treated or prevented in the future.

What do you think has been the most exciting development in multiple sclerosis (MS) research?

The development of therapies that deplete immune cells (such as ocrelizumab) has benefitted patients greatly and has provided important insights for researchers trying to understand the contributions of those immune cells to MS.

Tell us about your current research project...

Our team has a focus on investigating the immune cells that are involved in MS very early in the disease, with an aim to better identify triggers and future therapies to prevent MS. We have shown that

in females with early or pre-MS (clinically isolated syndrome), an immune cell known as B cells may not have enough of an important regulating factor to prevent immune responses to their own body (known as autoimmunity). In this new study, we will investigate whether another immune cell known as neutrophils, which can produce proteins that stimulate B cells, might be behind this observation. If there is a link between neutrophils and B cell activation, this might offer another target for disease-modifying therapies in future.

What do you enjoy most about working in the lab and what are some of the challenges you face?

I feel very privileged to work with the wonderful community of people with MS, clinicians and other scientists to tackle the disease. There are always new and important advances in science and I love being able to contribute with our work.

HELP FAST TRACK A CURE FOR MS

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

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- Learn more about leaving a gift in my Will
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