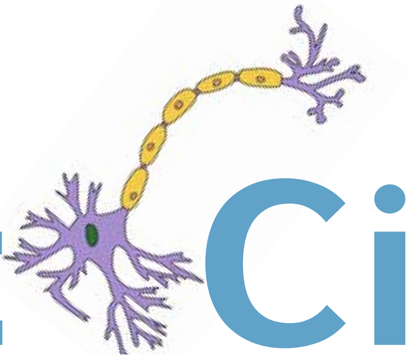
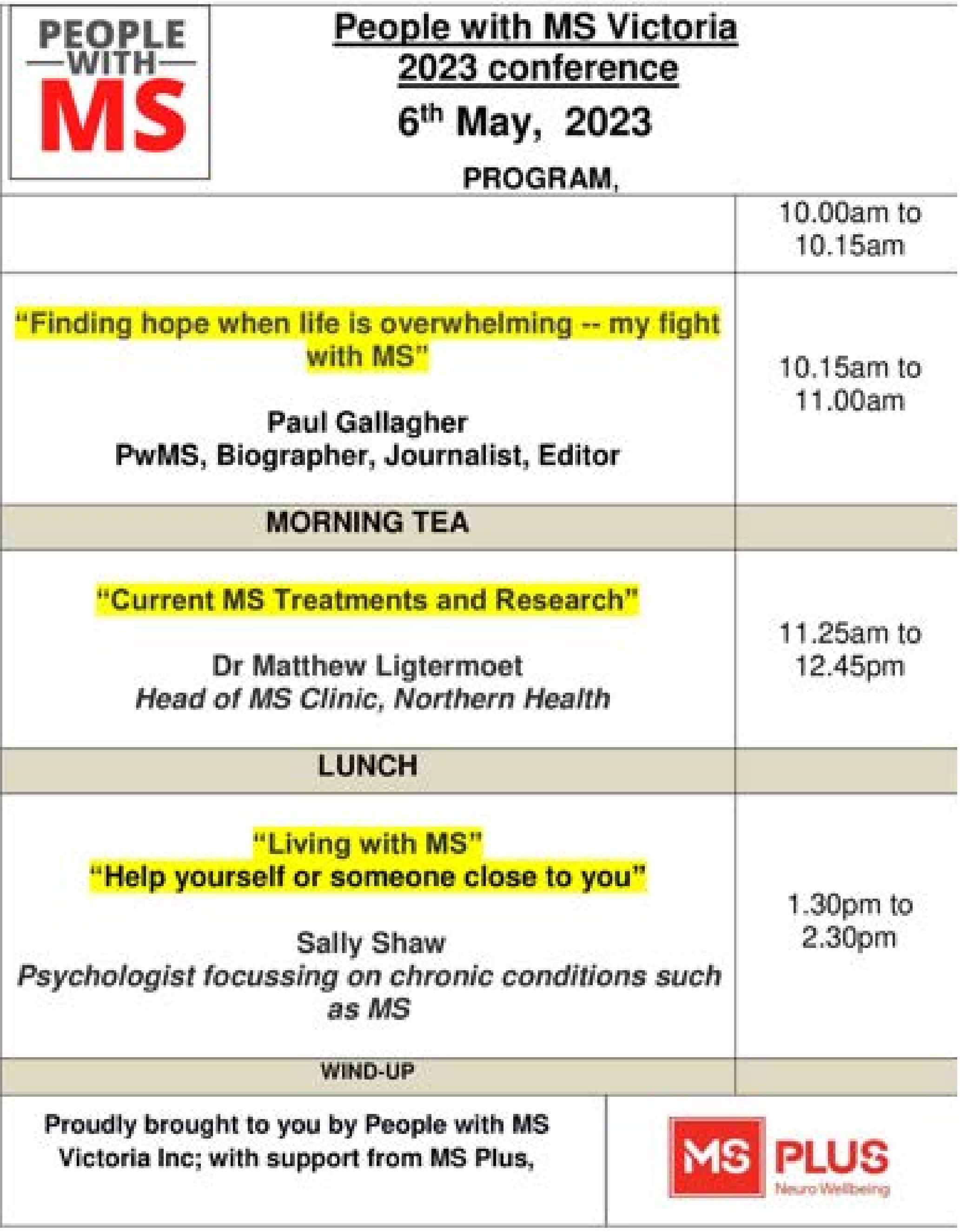
Autumn Edition 2023

Short Circuit





People with MS Victoria
2023 conference
6th May, 2023
PROGRAM,

	10.00am to 10.15am
"Finding hope when life is overwhelming -- my fight with MS" **Paul Gallagher** **PwMS, Biographer, Journalist, Editor**	10.15am to 11.00am
MORNING TEA	
"Current MS Treatments and Research" **Dr Matthew Ligtermoet** ***Head of MS Clinic, Northern Health***	11.25am to 12.45pm
LUNCH	
"Living with MS" **"Help yourself or someone close to you"** Sally Shaw *Psychologist focussing on chronic conditions such as MS*	1.30pm to 2.30pm
WIND-UP	
Proudly brought to you by People with MS Victoria Inc; with support from MS Plus,	MS PLUS Neuro Wellbeing

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HURRY UP!

$250 Power saving bonus is still available. Applications are open, until the 30 June 2023. The Bonus to all Victorians households who visit the Victorian Energy Compare website.

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People with MS Victoria 2023 conference BOOKING FORM

Only $10 per head; Light lunch included; and Transport, assistance maybe available Phone: 0435 085 827 To book your seat please complete and return this form

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Updated facts and figures about Multiple Sclerosis

MS Research Australia has just published new updated facts figures about MS.

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Letter from Nigel Autmn 2023

A belated welcome to 2023. I hope that not many of you were affected by last year's floods or by other disasters and if you were, I hope you are well on your way to recovery. And I hope that for all of you this year brings you something that you really desire.

The team here at PwMS-Vic are getting ready to present this years "Living with MS" conference which will be held on May 6th and will feature three top class speakers. Paul Gallagher, an author and journalist, living with MS; Dr Matthew Ligtermoet Head of the MS Clinic, at Northern Health, Melbourne who will talk about new and emerging treatments and current research; and Sally Shaw, a psychologist focussing on chronic conditions including MS; who will talk about how you can help yourself, or someone close to you, cope with the mental and emotional strain of MS.

The conference will be held at the MS-Plus Nerve Centre in Blackburn. Parking is easy, but audience numbers will be limited to 50, and these three speakers will attract a wide audience so get your booking in quickly. Booking details are provided later in this newsletter.

Now for some general news; and there has been some welcome news recently about the NDIS. Two NDIS providers and five people associated with them have been permanently banned, from providing services to people with a disability. This was after a fraud taskforce found evidence of fake and inappropriate claims. It is good to see that fraudulent operators can expect to be found out and prosecuted.

Secondly; a big – yet barely publicised – change to NDIS access came last year from a Federal Court decision known as NDIA v Davis. The Court clarified the meaning of two words – "available" and "remedy" – as they relate to accessing the NDIS.

The NDIA's "Rules for Becoming a Participant" require the NDIA to confirm that "there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy (an applicant's) impairment". The court decided that in this context, "remedy" means not merely relieving but "something approaching removal or cure of the impairment.

The court also clarified that that "available treatment" means "treatment(s) which are not merely theoretically available but which an individual can, in reality, access".

The impact of these decisions should not be underestimated. They have the potential to significantly expand the population eligible for NDIS support because the court has indicated access should be based on the real effectiveness and availability of treatment.

People with MS Victoria should like to offer hearty congratulations to Dr Therese Burke, MS Australia's Clinical Platform Coordinator, who was made a Member of the Order of Australia (AM) in the 2023 Australia Day Honours List.

Dr Burke was honoured for her significant service to medicine, particularly multiple sclerosis research, and to nursing. She started her journey in nursing in Sydney and with the establishment of the first MS clinic at Westmead Hospital, Dr Burke assisted on projects in ground-breaking genetic research. This is where her love of research began.

Having enthusiastically agreed to work with neurologists in the establishment of the MS clinic, and with no formal training available in Australia at the time, Dr Burke undertook certified training in MS nursing overseas. This later led to a master's degree and a PhD (exploring the lived experience in MS), at the University of Notre Dame, Australia. Dr Burke is now an Adjunct Senior Research Fellow at the University of Notre Dame, Australia, and in 2020, joined MS Australia to develop educational modules for clinical trial staff working in MS and to assist in expanding the research world for people living with MS. Her award is truly well deserved.

Let me finish by reminding you that COVID is still with us. In fact it shows every sign of becoming a permanent part of our environment. So; I trust that all of you are keeping your anti-COVID vaccinations up to date and are taking precautions to avoid catching COVID such as wearing masks in crowded spaces. You will need to be fully vaccinated to attend our conference and we will most likely encourage participants to wear masks.

Keep well and keep fighting MS; Nigel Caswell O.A.M., President.

The world mourns the death of disability rights activist Judy Heumann (1947-2023)

Judy Heumann, widely regarded as one of the world's greatest advocates for equity and rights, for the disabled, died March 4 at the age of 75. You, most likely, have never heard of Judy Heumann. she's not Australian and she has no direct connection to the multiple sclerosis (MS) community. However, you should know about her. Everyone who lives with a chronic disability owes her a great deal.

Born in 1947 in Philadelphia and raised in Brooklyn, New York, Judy contracted polio at age two. Her doctor advised her parents to institutionalize her when it was clear that she would never be able to walk. (Institutionalization was the norm 1949.) When Judy attempted to enter kindergarten, the principal refused her entry, labelling her a "fire hazard." However, her parents, particularly her mother, fought back and demanded that Judy have access to a classroom. She eventually was able to attend a special school, although according to The New York Times, this wasn't until she was 9, and "even then she took her classes with other disabled students in a basement.

Remarkably she went on to high school, and Long Island University, and the University of California, Berkeley. She earned a B.A. in 1969 and a master's in public health six years later. The New York Board of Education then refused to give Judy a teaching license because she used a wheelchair. She sued and went on to become the first teacher in the state to use a wheelchair. It seems nothing would stop her; again and again, she fought and won.

Judy's role as a disability advocate started with a place called Camp Jened, a summer camp for people with disabilities that operated from the 1950s to the '70s. There, campers discovered what they could do and confronted what they couldn't; as shown in the 2020 Oscar-nominated documentary film, *Crip Camp: A Disability Revolution.* Judy was a camper, and then a counsellor, at Crip Camp.

The campers didn't forget their sense of achievement or the connections they made with one another. Several reconnected later and planted the seeds that grew into the disability rights movement.

In 1977, Heumann led more than 100 protesters during a sit-in at a federal building in San Francisco, part of a broader nationwide disability rights protest. She later testified at a congressional hearing into the 1973 Rehabilitation Act. This was the first piece of legislation in the U.S. to address equal access for people with disabilities. However, four years after it was signed into law, it still hadn't been enforced, which prompted the protests. The Act was eventually enforced.

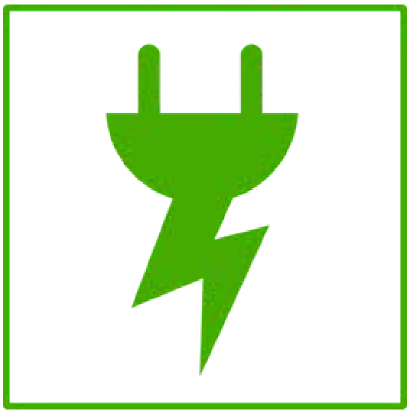
Over the years, Judy went on to help found the World Institute on Disability. She served as the first adviser on disability and development at the World Bank, as assistant secretary of the office of special education and rehabilitation services in the administration of President Bill Clinton, and as the first special adviser for international disability rights at the US State Department during the administration of President Barack Obama.

These are amazing achievements for a woman who once, as a child, risked being institutionalized because of her disability. Just two years ago she is quoted as having said; "We need to continue to educate people, until they understand, disability is a normal, valuable part of human life,"

It has been suggested that a movie about her life might be in the works. To me, that would be the perfect tribute to a woman whose name deserves to be known by everyone.

Nigel Caswell

The $250 Power Saving Bonus for Victorian households is now available to every household which uses the Victorian Energy Compare website



Applications are open between 1 July 2022 and 30 June 2023. The Bonus is available to all Victorians households who visit the Victorian Energy Compare website; or if you are not a computer user then contact Victorian Energy Compare at 1800 000 832.
The $250 Power Saving Bonus for Victorian households is now open. Before submitting an application for the bonus, please read the eligibility requirements.
Eligibility requirements:
You must be a Victorian residential energy consumer (i.e. have a residential electricity account).
You must be the account holder
Only one payment is available per household
As part of the Power Saving Bonus application process, we will present you with information about the best priced electricity offers available in your area. You are not required to switch offers or retailers.
The application process will take five to ten minutes of your time, and you will need to have a recent electricity bill with you.
compare.energy.vic.gov.au
1800 000 VEC (832)

MS AUSTRALIA
RESEARCH
ADVOCACY
CURE

KEY FACTS & FIGURES ABOUT

MULTIPLE SCLEROSIS

Multiple sclerosis (MS) is a chronic disease that attacks the central nervous system (the brain, spinal cord and optic nerves). The progress, severity and specific symptoms of MS cannot be predicted. MS is a lifelong disease for which a cure is yet to be found; however, doctors and scientists are making discoveries about the treatment and management of MS every day.

GENERAL FACTS ABOUT MULTIPLE SCLEROSIS

More than 33,300 Australians live with MS

Over 2.8 million people are living with MS worldwide

1-2 Australians are diagnosed with MS every day

Average age of diagnosis is between 20-40 years

MS affects more young adults than any other acquired chronic neurological disease

3 out of 4 Australians diagnosed with MS are women

FORMS OF MS AT DIAGNOSIS

85% RELAPSING REMITTING MS (RRMS)

12% PRIMARY PROGRESSIVE MS (PPMS)

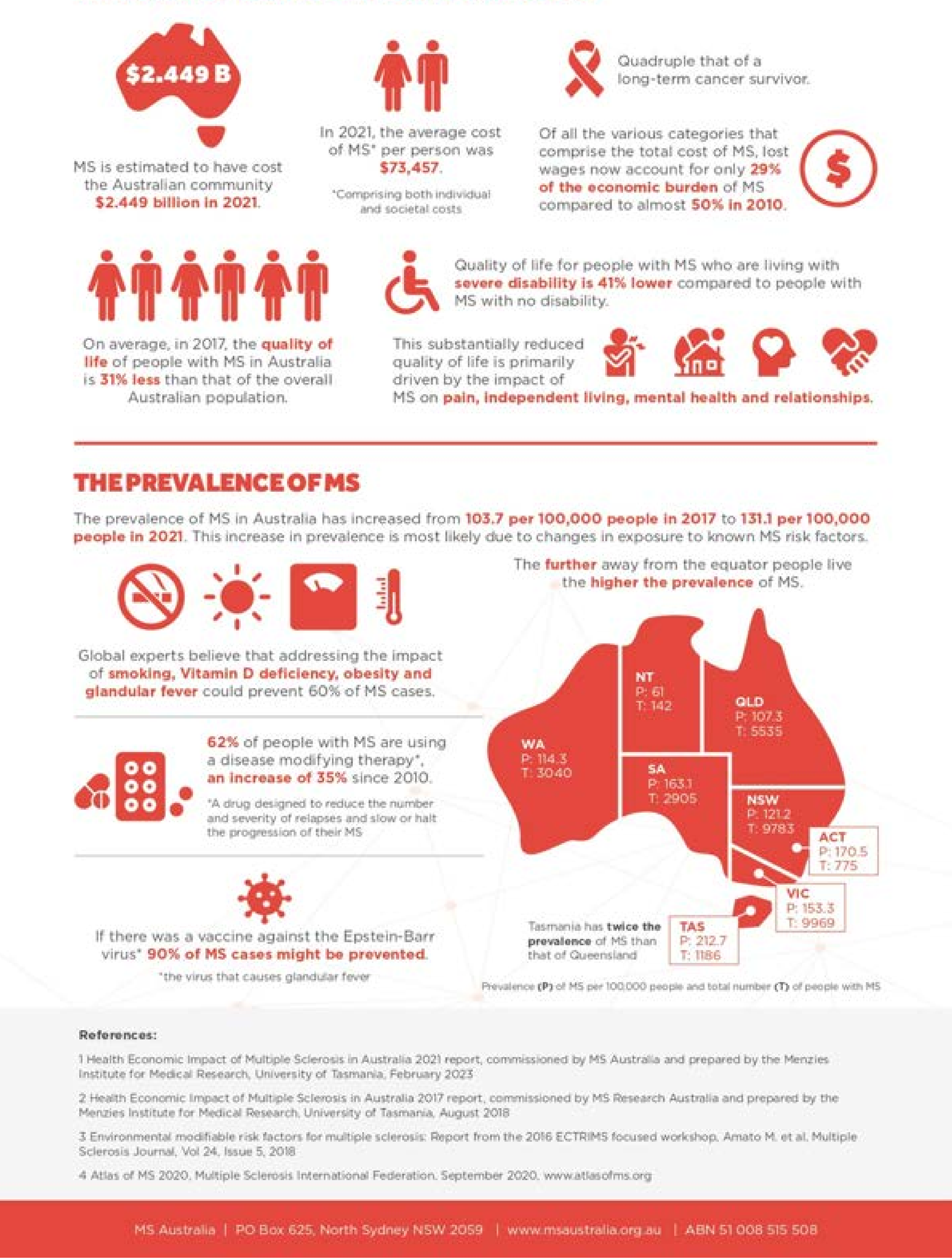
3% UNKNOWN MS DISEASE TYPE

Many people diagnosed with RRMS will eventually develop secondary progressive MS (SPMS).

COMMON SYMPTOMS OF MS

The symptoms of MS can be both visible and invisible to others, are unpredictable and vary from person to person and from time to time in the same person.

- CHANGES IN MEMORY, CONCENTRATION OR REASONING
- DIZZINESS AND VERTIGO
- SLURRING OR SLOWING OF SPEECH
- VISUAL DISTURBANCE, SUCH AS BLURRED OR DOUBLE VISION
- EXTREME TIREDNESS (UNUSUAL FATIGUE)
- EMOTIONAL AND MOOD CHANGES
- ALTERED SENSATION, SUCH AS TINGLING, NUMBNESS OR PINS AND NEEDLES
- PAIN
- SEXUAL CHANGES
- ALTERED MUSCLE TONE, SUCH AS MUSCLE WEAKNESS, TREMOR, STIFFNESS OR SPASMS
- BLADDER AND BOWEL CHANGES
- DIFFICULTIES WITH WALKING, BALANCE OR COORDINATION
- SENSITIVITY TO HEAT AND/OR COLD



$2.449 B

MS is estimated to have cost the Australian community **$2.449 billion in 2021**.

In 2021, the average cost of MS* per person was **$73,457**.

*Comprising both individual and societal costs

Quadruple that of a long-term cancer survivor.

Of all the various categories that comprise the total cost of MS, lost wages now account for only **29% of the economic burden** of MS compared to almost **50% in 2010**.

On average, in 2017, the **quality of life** of people with MS in Australia is **31% less** than that of the overall Australian population.

Quality of life for people with MS who are living with **severe disability is 41% lower** compared to people with MS with no disability.

This substantially reduced quality of life is primarily driven by the impact of MS on **pain, independent living, mental health and relationships.**

THE PREVALENCE OF MS

The prevalence of MS in Australia has increased from **103.7 per 100,000 people in 2017** to **131.1 per 100,000 people in 2021**. This increase in prevalence is most likely due to changes in exposure to known MS risk factors.

Global experts believe that addressing the impact of **smoking, Vitamin D deficiency, obesity and glandular fever** could prevent 60% of MS cases.

62% of people with MS are using a disease modifying therapy*, **an increase of 35%** since 2010.

*A drug designed to reduce the number and severity of relapses and slow or halt the progression of their MS

If there was a vaccine against the Epstein-Barr virus* **90% of MS cases might be prevented.**

*the virus that causes glandular fever

The **further** away from the equator people live the **higher the prevalence** of MS.

NT
P: 61
T: 142

QLD
P: 107.3
T: 5535

WA
P: 114.3
T: 3040

SA
P: 163.1
T: 2905

NSW
P: 121.2
T: 9783

ACT
P: 170.5
T: 775

VIC
P: 153.3
T: 9969

TAS
P: 212.7
T: 1186

Tasmania has **twice the prevalence** of MS than that of Queensland

Prevalence **(P)** of MS per 100,000 people and total number **(T)** of people with MS

References:

1 Health Economic Impact of Multiple Sclerosis in Australia 2021 report, commissioned by MS Australia and prepared by the Menzies Institute for Medical Research, University of Tasmania, February 2023

2 Health Economic Impact of Multiple Sclerosis in Australia 2017 report, commissioned by MS Research Australia and prepared by the Menzies Institute for Medical Research, University of Tasmania, August 2018

3 Environmental modifiable risk factors for multiple sclerosis: Report from the 2016 ECTRIMS focused workshop, Amato M. et al, Multiple Sclerosis Journal, Vol 24, Issue 5, 2018

4 Atlas of MS 2020, Multiple Sclerosis International Federation, September 2020, www.atlasofms.org

MS Australia | PO Box 625, North Sydney NSW 2059 | www.msaustralia.org.au | ABN 51 008 515 508

BOOKING FORM

People with MS Victoria Inc

2023 “Living with MS” Annual Conference

Sat 6th May, 10.00am – 3.00pm
The Nerve Centre, 54 Railway Rd, Blackburn
Enquiries; cplatfor@bigpond.net.au; Mobile: 0405 755 113

SPEAKERS

Paul Gallagher-- PwMS, Biographer, Journalist, Editor; topic
“ Finding hope when life is overwhelming -- my fight with MS”

Dr Matthew Ligtermoet- Head of MS Clinic, Northern; Talking about
“Current MS Treatments and Research”

Sally Shaw - Psychologist focussing on chronic conditions including MS; topic
“Living with MS” - “Helping yourself or someone close to you”

Only $10 per head;

Light lunch included; and Transport, assistance maybe available Phone: 0435 085 827

To book your seat please complete and return this form
by email to: cplatfor@bigpond.net.au or
by mail to; PO Box 658 Eltham 3095;

Dietary needs[if any]	*Vegetarian*		*Vegan*		*Gluten Free*	
Access needs [if any]	*Wheelchair*		*Walker*		*Scooter*	

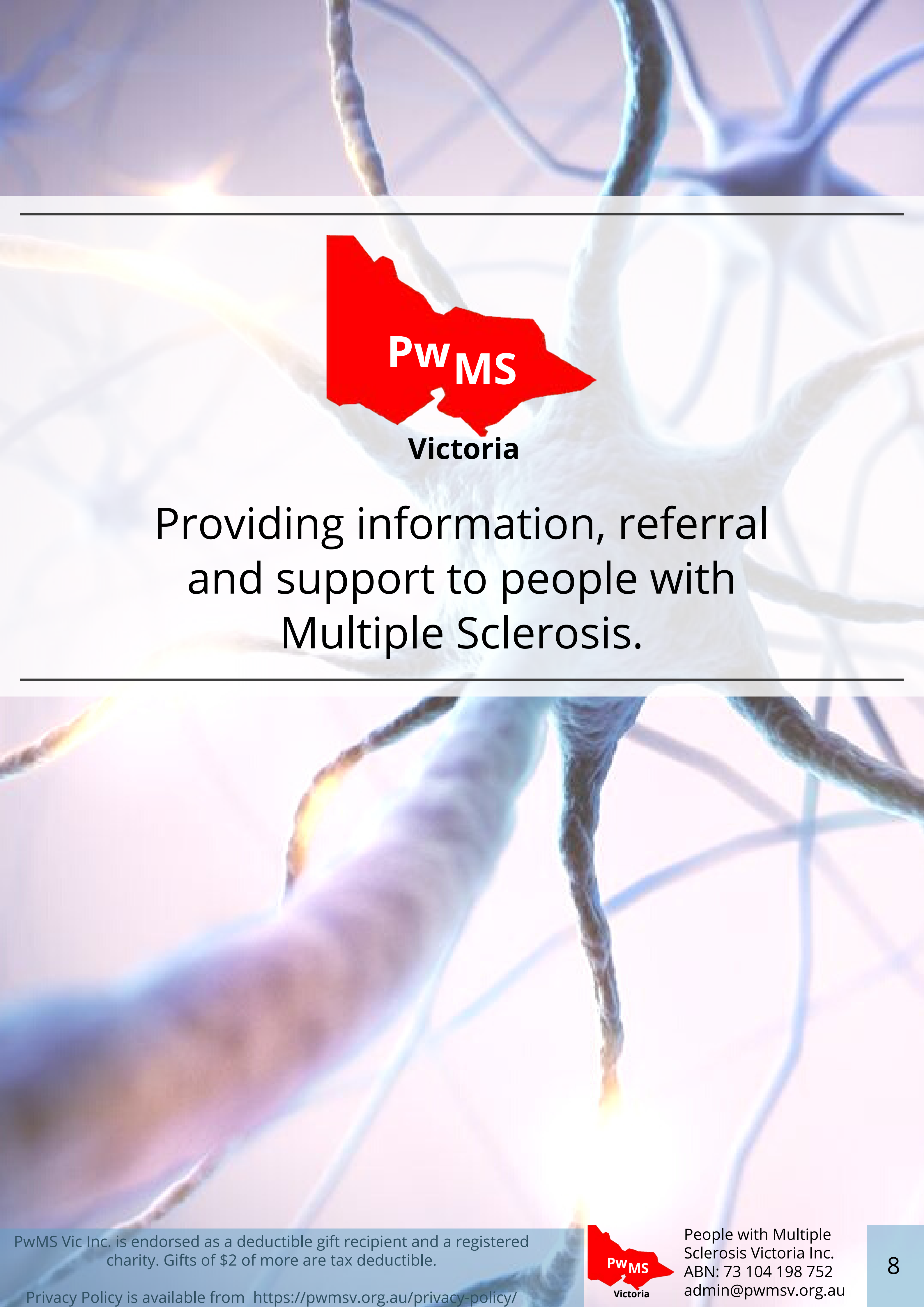
Enclose payment of $10 per attendee (Please tick payment method)
[ ] Cheque payable to PwMS Victoria, Inc. or
[ ] Direct payment to PwMS Vic Inc, BSB 083-004, Acct 04-636-6841(include name)

BUY YOUR TICKET TODAY!
NUMBERS ARE LIMITED

SEE THESE AMAZING SPEAKERS

AT THE NERVE CENTRE

ON THE 6TH OF MAY



Victoria

Providing information, referral and support to people with Multiple Sclerosis.