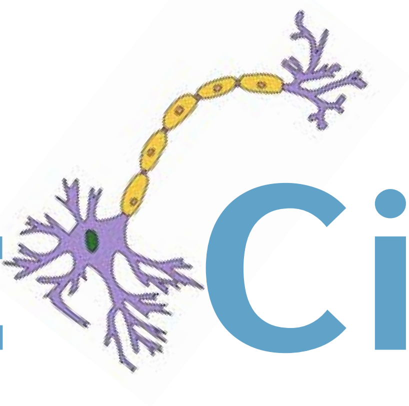
Spring Edition 2024

Short Circuit



People with MS Vic. Inc. Spring Seminar

and ANNUAL GENERAL MEETING

MONDAY 18TH NOVEMBER 2024, 10.00AM. AT THE NERVE CENTRE 54 RAILWAY RD BLACKBURN

Keynote presentation by **Kylie Osborne**;

Senior Mgr, Community & Partnerships, MS Plus:

PEER SUPPORT for PEOPLE with MS

Enquiries to; cplatfor@bigpond.net.au

-THE NEW ARRANGEMENTS -

WHAT ARE THEY? HOW DOES IT WORK?

Light refreshments will be served after the presentation -----------------------------------

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Don’t tell Carol what she cannot do! This paralympian and fundraiser sets example

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Empower Golf

Exciting Golf and MS (NDIS supported)

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VERY SUCCESSFUL CONFERENCE FOR PEOPLE WITH MS IN VICTORIA

People with MS Vic, as usual held its annual one day conference “Living Better with MS” on the first Saturday of May, and once again we had three excellent speakers:

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PwMS Vic Inc. is endorsed as a deductible gift recipient and a registered charity. Gifts of $2 of more are tax deductible.

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People with Multiple
Sclerosis Victoria Inc.
ABN: 73 104 198 752
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President's report Spring 2024/25

G'Day all. Welcome to spring/summer 2024/25. I don't know about where you are but here in Melbourne it has been an unpleasantly cold start. Yes, I know cold weather is appreciated by most people with MS but this September seems to have been unfriendly.

Apart from the weather the other topics on the lips of people with MS have been the success of people with MS at the Paris Olympics, the new NDIS Act, and the recent redundancies at MS Plus. There is an article about people with MS in the Olympics in this newsletter read it and be inspired.

Some of the staff you have been used to working with, at MS Plus, have gone, like Kim Repcak who used to be the go-to person for the Peer Support Program in Victoria. Kim was made redundant in mid-July. The whole Peer Support Program is now managed by Katarina Moujjall, based at Lidcombe, Sydney; and who reports to Kylie Osborne, senior manager based at the Nerve Centre, Blackburn.

MS Plus says it is committed to continuing to deliver the Peer Support Program—including face-to-face groups, which will continue across Victoria, NSW, ACT and Tasmania. However, the recent changes have resulted in a review of peer support processes and administrative arrangements. And they believe that with ongoing support they will be able to continue to offer a quality national peer support program.
They say they have, however, made some minor changes to the way peer group referrals are managed, to simplify the process and improve response times for clients. Also to support clients in better identifying the availability of their local face-to-face groups, MS Plus has developed an interactive map of groups which will be made available on its website.
It is hoped these improvements will eliminate previous double handling of requests by MS Plus staff and enable them to focus on developing and maintaining the very best Peer Support Program possible.
We have invited Kylie Osborne from MS Plus to be the keynote speaker at our AGM and spring seminar at the Nerve Centre on Monday November 18th, Kylie will describe the changes in detail and answer any questions you may have.
Come along and hear what is planned and meet some of the people who convene the peer support groups around Victoria. (See page 7 for details)

New NDIS laws start
From 3 October 2024, new laws for the NDIS came into effect. Many changes will come through new NDIS rules. Some changes will happen right away, while others will start later. The government says these changes will help return the NDIS to its original intent and improve the experience for all participants.

For most people, there should not be big changes to the way you experience the NDIS.However, A key change is a new definition of NDIS supports. This makes clear what NDIS funding can and cannot cover. Participants can only use their NDIS funds for items listed as approved NDIS supports. In some cases participants may be able to request a substitution from the replacement support list. View the NDIS supports lists .

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Please note that PwMS-Vic is once again looking for new members for its executive committee.
If you are willing to join us you can be certain of playing a useful role supporting and advocating for people living with MS.

PwMS-Vic runs two seminars every year, maintains an informative website and FaceBook page, and it lobbies government and service providers on behalf of people living with MS.
If you are interested in joining us or would like some more information
contact admin@pwms-v.org.au, and I will get back to you.

Nigel Caswell O.A.M. President

VERY SUCCESSFUL CONFERENCE FOR PEOPLE WITH MS IN VICTORIA

People with MS Vic, as usual held its annual one day conference “Living Better with MS” on the first Saturday of May, and once again we had three excellent speakers: Andrew Potter, (National Advocacy Coordinator, MS Australia); Helmut Butzkeuven, (Head, of Neuroscience, at, Monash University, and Foundation Director of Neurology, at Alfred Health); and Andrew Giles, (Executive Officer(The Neurological Alliance Australia)

Helmut was the keynote speaker and as usual was very interesting. He started by speaking about vitamin D and the Epstein Barr Virus (EBV). How higher vitamin D levels do appear to reduce the occurrence of MS but do not impact on its progression. And although most people who show EBV antibodies don’t develop MS, EBV appears to be an essential precursor to MS. However, its role in or impact on MS progression is unknown, and MS Australia is supporting two trials examining whether treating MS sufferers with EBV medication, might reduce MS fatigue levels or slow MS progression.

He then spoke about the discovery of a type of MS lesion, (SEL), which goes on growing years after it first appears, and which may be the reason why some patients’ MS continues to progress even though they show no new lesions. Also these SEL lesions could prove valuable biomarkers and a trial treating patients with SELs could be an efficient way of testing the impact of drugs on progressive MS. SELs may also prove useful biomarkers for other research for example looking for re-myelination candidates.

Helmut also spoke about new approaches to research called OCTOPUS and PLATYPUS which would enable two or more drugs to be trialled simultaneously to eliminate those which offer no prospects. Thereby reducing the cost of trials. Finally Helmut spoke about the fact that people with MS are living longer which needs to be taken into account in trials, and he emphasised the importance of patients ensuring they get vaccinated against pneumonia, influenza, and shingles all of which become more prevalent with age.

Andrew Potter and Andrew Giles both spoke about the work they and MS Australia do lobbying for improved services and facilities for people with MS. Andrew Potter has MS and coordinates a group of “advocates”, volunteers who also have MS, who strive to build relationships with their members of parliament to ensure that politicians of all persuasions are well aware of the costs and impact of MS and the needs of people living with the disease.

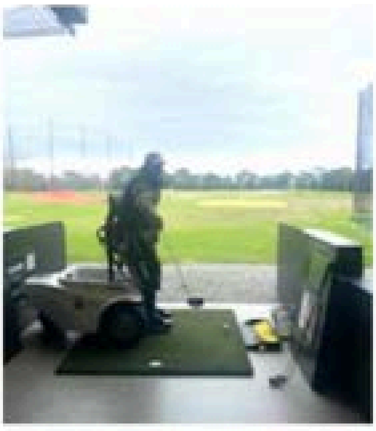
Andrew Giles spoke about the work of the Neurological Alliance, the peak body representing many neurological disease specific organisations and about MS Australia (one of the driving forces behind the Alliance. The Alliance primarily targets the Federal Government and its agencies, trying to address areas of common interest; (1)Increasing funding for research, (2)Strengthening the NDIS and ensuring its staff understand the nature and patterns of neurological disorders; (3)Ensuring equitable access to assistive technology for those not on the NDIS; (4)Ending the discrimination against people over 65 caused by their exclusion from the NDIS; and (5)Improving integration between the Health-care, Disability-care, and Aged-care systems.

Audience members had the opportunity to ask questions and chat with the speakers during the breaks. Videos of the presentations are available via our website or on U-Tube at Helmut https://youtu.be/vPAz8twc1xI; Andrew Giles https://youtu.be/EA5AhbmNF0g
Andrew Potter https://youtu.be/j8ETASIkdf8

Nigel Caswell.
President, PwMS-Vic

Referred to article https://www.abc.net.au/news/2019-04-12/living-and-fishing-with-multiple-sclerosis/10989574 12 of April 2019

Empower Golf



Exciting Golf and MS (NDIS supported)

Celebrating ten years in 2024, Empower Golf was founded by James Gribble, one of the only quadriplegic golfers in the world, to make golf accessible to people of all abilities. Now the number one provider of inclusive services for golfers, adaptive equipment, and accessible golf facilities across the country, the organisation helps over 5,000 Australians living with disabilities experience and enjoy one of the world's oldest and most inclusive games.

"Golf is a sport that can be enjoyed for life and making it accessible to people who had not had the opportunity to experience its many benefits was a driving factor in establishing Empower Golf"..

Margaret McIntyre (known as Meg) is a physiotherapist who was diagnosed with MS at an early age and requires the use of a para golfer to enjoy the game of golf. After meeting with James Gribble in 2021, she went to her first clinic and was hooked. "I cried after the first ball I hit!" She has now helped set up multiple introductory golf clinics and is passionate about the benefits of getting out on the golf course.

"Time is not on your side for anyone with MS. You have to seize on opportunities as they come".

When asked why she loves golf so much, Meg explains, "I love the challenge, being outdoors, and the community that is a golf club. I have met so many of the other members who I now call friends." As a physiotherapist, she is conscious of maintaining her fitness, mobility, and psychological and social well-being.

When asked for her advice for others contemplating golf, "Definitely give it a go"

Given the severity of her MS, Meg uses a Para-Golfer—a purpose-built all-terrain wheelchair that raises the user into a standing position. The NDIS also funds these revolutionary devices and they are available at many of Empower's facilities nationwide.

With 20% of the Australian population living with a disability, golf is a life game that feeds the benefits of competition, well-being and, most importantly, human connection.

As the only nationally registered NDIS provider, Empower Golf runs regular golf clinics. It provides coaching, caddying, and adaptive equipment across Australia to support individuals with disabilities returning to or wanting to improve their golf. All services are provided by Australia's most experienced team of all abilities-accredited PGA coaches.

For anyone interested in attending these events, click the link below to find a nearby clinic: *https://empowergolf.com.au/events/*.

For all other information about this provider, visit their website: *https://empowergolf.com.au/.*

The regional manager in Victoria is Richard Yann, and you can reach him on 0451 876 609. Happy Golfing!

Article provided by Martin Skoneczko, PwMS. (pictured above using a Para-Golfer).

Snap Send Solve

When you are out on your daily walk and you see something which needs to be reported the Snap Send Solve app makes it very easy. All you need to do is snap a photo of the issue on your phone, add a title and brief description, and send it via the Snap Send Solve app. The exact location of the item photographed will be automatically recorded and the report will go to the responsible authority. AND ITS FREE.

The Snap Send Solve app sends reports of local issues to 850+ authorities across Australia and Aotearoa New Zealand. This includes all local councils, water authorities, power companies, government organisations, telcos, universities, and retailers with shopping trolleys. The sort of things reported are abandoned cars or trolleys, dumped rubbish, graffiti, pot-holes or broken footpaths, and burst water mains. What's more your local council is a subscriber to the scheme.

To load Snap Send Solve on your phone simply go to the App store or Google Play, search for Snap Send Solve, and follow the instructions.

Nigel Caswell.

Need an Occupational Therapist?

An Occupational Therapist can be an extremely helpful support in your journey with MS. If you find your situation getting harder, an OT can help to identify assistive technology or other ways of making life a little easier. However, experience from many people with MS who have been through the process of looking for an OT shows that finding the right OT for you when you need one can be very difficult. Given this, we highly recommend you please start to look for an OT as early as possible, and to feel comfortable switching between OTs until you find someone you feel able to talk to and who understands your needs.

Finding the right OT is well worth investing the time and effort involved. Your Dr or health professional may be able to refer you to a suitable OT. Some resources you can consider include:

§ The OT Association in Australia: has a very comprehensive nationwide service available for locating occupational therapists for neurological conditions.
Website: https://www.otaus.com.au/find-an-ot

§ MS Plus may also be able to assist in Victoria and NSW;
Website: https://www.msplus.org.au/support-services/allied-health-services/occupational-therapy

§ If you are on the NDIS a first point of contact might be your Local Area Coordinator (LAC) for feedback and guidance as they may be across other people in similar situations and be aware of good OTs in the local area.

Don’t tell Carol what she cannot do!

This paralympian and fundraiser sets example for others to follow

Being told you’ve got an incurable illness — and that life is over as you know it — is a bad day in anyone’s life. For Carol Cooke, though, her memory of a neurologist’s gloomy prediction had the opposite effect.

She remembers the neurologist saying it was time to go home so she could “put (her) affairs in order” before being “incapacitated.” Already an active person, the next prediction felt about as bad as the first: “I would have to quit doing sport, quit work and go on a whole bunch of drugs,” Carol recalls.

Instead, she turned the prediction into reality, of a different sort. “It just made me more determined,” she adds. “I wasn’t going to let MS dictate what I was going to do.”

New heights and different goals

What followed was a celebrated life as an international athlete and Paralympian and an inspiring example of what can happen when people with MS keep moving forward, opting for new heights and different goals.

One prediction came true when Carol Cooke was told she had multiple sclerosis, but not in the way she remembers it being said. Sitting in a neurologist’s office, she recalls the specialist telling her life “as I knew it, was over.”

What the neurologist had said became a spur that Carol remembers to this day. “He was thinking negatively,” she explains, “and I think of it positively, because my life has been awesome and given me opportunities I never would have had.”

Originally from Canada, Carol had been a rising star in the swimming world, aiming for the 1980 Moscow Olympics Games. Her hopes were dashed when boycotts closed the door, and she instead put her attention squarely into her work with the Toronto Police Force.

Moving to Australia, she would be ultimately diagnosed with multiple sclerosis in 1998.

Never one to accept the negative predictions of others, Carol tried her hand at an Australian Paralympic Talent Search Day in 2005. While unable to reach the Beijing games, she gained sixth place in the 2009 World Rowing Championships before considering a switch to cycling. By 2012, she finally competed for Australia, in the London Paralympic Games. Carol scored gold in the Time Trial and bagged another two golds at Rio (2016) before a silver in Tokyo (2021). As for the World Titles, Carol has nine titles to her name and finished 2022 as third-ranked in the world.

Other achievements include leading the operation of the 24-Hour Mega Swim fundraiser for 17 years, raising more than $11 million since 2001. Carol has also authored two books, and become a “Member in the General Division of the Order of Australia” (AM).

Having a goal

It hasn’t all been clear sailing. “This year in particular has been very bad,” she says, “being in ICU 4 months ago and fighting for every breath.” Eying a new horizon, Carol is hoping to reach the World Championships in September. “No one thought this would be possible, but I believe having a goal has helped me overcome my health challenges.”

Carol is one example of what people can achieve with multiple sclerosis rather than despite it. Other high-achieving athletes with MS include Emily Petricola (cycling) and Janine Watson (taekwondo).

For anyone interested in trying their hand at Paralympics, you can check out the “Bupa Try Para-Sports Days” via the website: ticketing.humanitix.com/tours/bupa-try-para-sports

Article provided by Paul Gallagher

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Light refreshments will be served after the presentation

Peer Support Group Co-ordinators especially welcome Come along and meet and chat with some of your fellow peer support group leaders

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Some assistance is available towards transport or accommodation costs. For Information, or to let us know you intend to attend, and if you have any special dietary needs; please contact; Chris Platford; cplatfor@bigpond.net.au

PwMS
Victoria

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