



People with MS Vic Inc Committee Meeting – Minutes

2020 Annual General Meeting

Via Zoom

Monday 16th November 2020 – 10.30 - 11.30am

Committee: Nigel Caswell (President PwMS), Chris Platford (Secretary), Michelle Raymond (Treasurer), Zsolt Kovacs (Committee Member), Andrea Badlee (Committee Member), Raylene Carnie (Committee Member),

Volunteers: Sue Platford,

Apologies: Adolfo Gianni (I.T Committee Member); Mary Murphy, Tim Ryan (Short Circuit Ed.), Allen Maher (Fundraising) Alison Reece, Roger Reece (Vice President), Martin Skoneczko, Marilyn Simmonds

The meeting was chaired by Nigel Caswell (President PwMS)

No	Agenda Item
1.	<p>Welcome Nigel extended a welcomed all attendees in what an extraordinary year. Nigel gave recognition of NADOC week acknowledging the Wurrundjerri people, the history, culture, and elders both past and present. During the year, our meetings were on Zoom. We successfully applied for a deferral of funding for the Annual Conference.</p>
2.	<p>Confirmation of minutes of AGM 18th November 2019</p> <p>Motion: That the minutes of the meeting be accepted as an accurate record of that meeting with one change that being the removal of the financial designation for Raylene Carnie under note 7 – Election of Committee Members Moved: Chris Platford Seconded: Michelle Raymond All in Favour: Motion passed</p>
3.	<p>Matters Arising Nil</p>
4.	<p>Correspondence The correspondence as outlined by Chris</p> <p>July 2019</p> <ul style="list-style-type: none"> • We received a request from ING for additional signatory information • A reminder that submissions for the 'Inquiry into the Conduct of the 2018 Victorian State Election' close on 30/08/19 • Appointment of Garry Whatley to the MSL Board <p>August 2019</p> <ul style="list-style-type: none"> • The Financial Acquittal for 2018-19 National Disability Conference Initiative was submitted and was accepted • The Combined Liability Insurance Renewal documents were submitted to Cowden's • There was a Disability Royal Commission Update • We were advised there is a GSNV Mental Health First Aid Course in October • A quote was received from DMC for the Short Circuit mailout • The National Disability Conference Grant 2019/20 was received <p>September 2019</p> <ul style="list-style-type: none"> • Email was received from Andrew Giles (MSA) regarding focus groups to assist people searching for stem cell therapies • Position was advertised: Executive Manager Consumer Directed Care by MSL • We received the GSNV Newsletter • The latest Pensioners and Seniors Information Kit was received from Maria Vamvakinou MP

	<p>October 2019</p> <ul style="list-style-type: none"> Public & Products Liability, Management Liability and Professional Indemnity insurances certificates receive <p>November – Nil</p> <p>December & January; -- No meetings</p> <p>February 2020</p> <ul style="list-style-type: none"> Confirmation of Tim’s appointment Grant Funding was received for \$10,000 from the Victorian Government Disability Self Help Grant program 2019-2021 Application was been made for a Grant through the Federal National Disability Conference Initiative <p>March 2020 No meeting</p> <p>April 2020</p> <ul style="list-style-type: none"> Request was made for variation to grant to carry over until Nov <p>May 2020</p> <ul style="list-style-type: none"> Signed copy of the executed letter of variation for extension of time for the National Disability Conference Initiative was received <p>June 2020</p> <ul style="list-style-type: none"> National Disability Conference Initiative 2020-21 grant was approved \$9,000 GST exclusive Restructure of MSL - Maree Maher and Esis Tawfik were made redundant as a result of a restructuring of Client Engagement and Wellbeing portfolio. Appointment of Jodi Haartsen, ex Eastern Health, MS Nurse. Three areas were created Community Connection, Linkage and Learning. <p>Moved: Chris Platford Seconded: Nigel Caswell All in Favour: Motion passed</p>
5.	<p>Treasurers Report</p> <p>The bank balance as of 30 June 2020 was \$34,599.05 comprised of \$2,580.60 NAB, \$7,018.45 ING Business Optimiser, and \$10,000 ING Term Deposit and \$15,000 in Term Deposit</p> <p>We received two Grants one from DSS for \$9,240 and one from DHHS for \$5,500 total \$14,740.</p> <p>Michelle mentioned that financially it was a successful year. The financials have been signed off by the auditor and the audit report was clear.</p> <p>Moved: Michelle Raymond Seconded: Chris Platford All in Favour: Motion passed</p>
6.	<p>Presidents Report</p> <p>I will start by thanking my fellow committee members and volunteers for their invaluable support.; (Roger Reece, Michelle Raymond, Chris Platford, Tim Ryan, Aldo Gianni, Raylene Carnie, Andrea Badlee, Allen Maher, Zsolt Kovacs, Alison Reece, and Sue Platford). Their contributions are vital to the operation of PWMS-V. I would particularly like to welcome Tim Ryan the new editor of Short Circuit. We are very lucky to have Tim join our small team. Tim has MS but this hasn’t stopped him building a career. He is currently CEO of Lord Somers Camp and Powerhouse. He has taken up his editorial role with real gusto and has made a huge difference to the look of Short Circuit.</p> <p>I would also like to thank John Blewonski, CEO, and the excellent team at MSL for the ongoing support we receive, particularly with our newsletters, meeting venue and insurance cover.</p> <p>PWMS-V has had a relatively quiet year because of the COVID19 crisis which prevented us running our annual conference in May. We had excellent speakers lined up and hopefully they will be available for 2021. As an alternative we delivered an on-line conference on the 14th</p>

November with two exciting speakers: Dr Julia Morahan, Head of Research at MS Research Australia, and Debbie Roberts, Founder and CEO of "DFI".

- Dr Morahan, spoke on current research into the cause, cure, and management of MS, with emphasis on the exciting research being carried out in Australia.
- Debbie Roberts whose company, DFI, specialises in developing products to support people with differing abilities, spoke about exciting new technology which is affordable and can really make life easier for people with disabling conditions like MS.

During the year thanks to Tim, and the many contributors, we also produced four editions of Short Circuit. And thanks to Aldo we maintained our website which continues to be regarded as a very valuable source of practical advice for PwMS. And we were invited to provide comments to MS on a number of new information initiatives.

We have been watching with interest the activities of the **Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability** which was established on 4 April 2019. People with disability and their advocates have worked hard to get this Commission established and, in some respects, it is fortuitous that it has coincided with the COVID crisis. A large amount of evidence has been reported to the Royal Commission and in the media regarding the lack of support for people with disabilities during the crisis; losing support or being left without support for days. It would appear that people with disabilities were virtually overlooked in initial planning for COVID response.

It is good to see the Australian Government has launched a pilot of a new **National Disability Information Gateway** available at www.disabilitygateway.gov.au. I support the idea of putting information about all disability support services in one place but I have some reservations because the pilot seems to put more emphasis on information for those on the NDIS than on information for older people on "Aged Care" or those under 65 but not eligible for the NDIS.

It is also good to see **The NDIA has launched its 2020-2024 corporate plan** with a commitment to its Participant Service Improvement Plan and Participant Service Guarantee which sets timeframes which it commits to meet in making decisions about access, plan approvals, implementation, plan reviews and nominee changes. Hopefully, this will shift the NDIS further towards meeting its goals of being transparent, responsive, respectful, empowering, and connected to its clients.

When **COVID19** first struck there was considerable concern in the MS community that MS medications because of their impact on one's immune system might make one more at risk if one contracted the virus. The good news is that there are an increasing number of studies which suggest that the medications mostly do not increase susceptibility and, in several cases, may actually reduce susceptibility.

On a lighter vein we were delighted to read that a study reported drinking coffee each day appears to help people with MS and with milder disability and fatigue. Researchers at the university of Regensburg in Germany suggested that "for selected patients" regular coffee consumption could be a way of easing MS-related fatigue! The study was published in the journal [Nutrients](#)

Finally, we noted with pleasure the ongoing exciting developments in MS research, especially here in Australia where the research is greatly aided by the efforts of MS Research Australia and the many many people who support its fundraising efforts. I feel increasingly certain that within my lifetime we will have reached the point where doctors will be able to say "Well you have MS but don't worry we ought to be able to stop it from getting worse".

Moved: Nigel Caswell **Seconded:** Roger Reece **All in Favour:** Motion passed

The meeting closed at 11.30am.