

Overview

In 2017-18, PPV has continued to advocate, provide information and work in the interests of people with polio. Highlights have included our participation on a committee investigating the provision of aids and equipment under My Aged Care and facilitating and chairing the Quarterly meetings involving Polio Services Victoria and other polio stakeholder groups. We continue to provide information to our members and the polio community about the NDIS.

We were fortunate enough to receive a small grant from the Department of Health and Human Services which, together with a generous donation from Jill Pickering, has enabled us to employ Ruben Rubens as a part time Administrative Officer. This has enabled PPV to improve its systems and upgrade its website.

Mission Statement

We aim to

- Advocate on Issues related to Post-Polio to health professionals, services and government authorities.
- Raise awareness and educate people on issues that surround polio to the broader community.
- Build positive relationships with Victorian Polio Support groups.
- Foster relationships with "Polio Australia", "Polio Services Victoria", "Polio Network Victoria" and other relevant services and community groups.
- Provide information and advice on Post-Polio and its late effects to people who have had polio, and who may now be experiencing, or starting to experience, the complications associated with this condition.
- Assist people who have had polio, along with their families, carers and networks to support each other and stay connected to their community.
- Be aware of and support current appropriate research into the effects of poliomyelitis.
- Promote the eradication of poliomyelitis

PPV's 2018 Annual General Meeting was held on Monday 26 November 2018 at the Disabled Motorist's Association. It was great to see some familiar and some new faces!

Apart from our normal business, the significant feature of our AGM was the tribute paid to Dr Margaret Cooper OAM who was a member of our Committee up to her death in October 2018. Liz Telford and Geoff Dean led a tribute to Margaret, highlighting her long history of advocacy in the disability field as well as her contribution to PPV and the polio community. Liz read out a series of tributes to Margaret from a



wide variety of prominent disability advocates and leaders.

These tributes have been published on our website at <u>www.postpoliovictoria.org.au/</u> <u>tributes-for-margaret-cooper-oam/</u>

There was a feeling sadness in the room but also appreciation for all Margaret had achieved in her life.



Guest speaker - Speaking up for herself

Antonet Pavilupillai is 31, an accountant who likes to go out with her friends, curl up on the couch and binge on her favourite TV show (Grey's Anatomy for example!) and volunteers with The Life You Can Save, the organisation focused on ethical giving set up by Philosopher Peter Singer. She also had polio as a baby.

When the NDIS rejected a brace that enabled her to wear a more dressy shoe saying it wasn't "reasonable or necessary" and an NDIS worker told her "she only wanted to look good", Antonet was angry. The NDIS was set up to provide people with disabilities the same opportunities as those without.

"Is wanting to look good only the privilege of the able bodied?" she asked. She was aware that for many people, women in particular where dress shoes are not just lace ups, having to wear braces made it difficult to dress up. This causes emotional stress and embarrassment, especially for young women (and some not so young!)

To defend the rights of people with disabilities, Antonet has taken the NDIS to the Administrative Appeals Tribunal. The case is not yet resolved. By speaking up for herself, Antonet is also speaking up for others. We will follow with interest and all wish her luck with the case!

PPV Committee 2019

Thank you to the committee of 2017/18. Thank you to Geoff Dean for taking on the role as President this past five years, and it is great that we will still have your continued contribution on the committee.

Thanks to Ron Exiner for being in the role of Secretary for the past two years. Ron is standing down from the committee. Thanks for all your help Ron! Bringing the coffees especially! Ron will continue involvement with PPV, particularly as chair of the Quarterly meetings.

The PPV Committee for 2018-19 will consist of:

Ron Bell (President)	Liz Telford	Robyn Abraham
Shirley Glance OAM	Jill Pickering	Aruna Prasad
(Secretary)	Geoff Dean	Barbary Clarke
Tilly Srinivasan (Treasurer)	Susan Shaab	Rangan Srinivasan

Facilitating Quarterly Meetings

One of PPV's important activities is to advocate for better services for people with Polio. One of the ways we do this is by facilitating quarterly meetings between Polio Services Victoria, PPV, Polio Network Victoria and Polio Australia. The aim of these meetings is to provide feedback to PSV about the nature and quality of services and to work together to identify ways in which services can be improved. Ron Exiner , PPV Secretary for 2017-18, chaired these meetings

During the 2017-18 Quarterly Meetings, we discussed and provided feedback on a wide range of issues including the staffing levels and structure of PSV, Regional Clinics, b waiting periods and telephone triage, information exchange and ways in which we can work together to improve outcomes for people with polio. PPV also provided significant feedback to PSV based on the experiences of our members, with a view to improving the focus on clients' needs and abilities.

Liaison with other polio groups

PPV has a representative on Polio Australia's Board and as such we participate fully in the governance of PA. Peter Freckleton was PPV's representative in this year. We also attend PNV meetings with a view to improving communication and opportunities to work cooperatively in the interests of all people with polio. Shirley Glance is our current representative.

Advocacy on Aged Care and Aids and Equipment

While PPV is very supportive of the National Disability Insurance Scheme, many of our stakeholders are not eligible to participate because they are over the age of 65. People with polio, who are over 65 when the NDIS is introduced in their area, are reliant on My Aged Care for their services and aids and equipment. One of our goals is to ensure that people who get their services through My Aged Care are able to access what they need, particularly with regard to aids and equipment – orthotics, wheelchairs etc in the same way that NDIS recipients can. We don't think that My Aged Care is operating in a way which ensures that expensive equipment is available to people with polio when needed.

During 2017-18, the late Dr Margaret Cooper (who very sadly died in October 2018) and Peter Wilcocks represented PPV on a committee which is investigating how to provide for aids and equipment needs under My Aged Care.

Information provision

PPV gets a regular stream of queries and requests for information via email and occasional letters. During the year, we responded to all information requests from individuals as well as providing information by email to our members. This information includes Polio Health International Bulletins and other items of interest. Liz Telford, with assistance from our new Administration Officer, Ruben Rubens was primarily responsible for this work.

Newsletters

PPV produced 2 newsletters, containing news and items of interest during 2017-18. These newsletters are distributed by email where possible and by hard copy to those members who don't have email addresses. Production of the newsletters was coordinated by Susan Shaab. We also acknowledge Rebecca Jahr from Nest Therapies who did great work on the design and layout at minimum cost to us.

PPV Facebook Page

During 2017-18, we continued to administer and update our Facebook page. Fran Henke and Liz Telford both contributed to ensuring that our Facebook page is up to date, newsworthy and interesting. Check it out if you haven't done so already.

Website

PPV's website, <u>postpoliovictoria.org.au</u> was maintained during the year by Liz Telford and R uben Rubens. Our website contains information about PPV, information about polio and post polio.

A Shared Brochure

A shared project with Polio Australia, we have produced a <u>brochure</u> giving information about the three the polio organisations in Victoria , PA, PPV and Polio Network Victoria.

Thanks Ruben, who did much of the technical work, in collaboration with Steph Cantrill from PA.

A summary of our finances during the 2017-18 financial year shows:

Opening balance:	\$9018.45
Income:	\$7113.60
Expenditure:	\$2259.80
Closing balance:	\$13782.25

CONGRATULATIONS!

We were all very excited that our secretary Shirley was awarded this honour in this year's Queen's Birthday list, for her contribution to community service particularly her in disability and with the Council of Jewish Women. Our warm congratulations to Shirley!

