



ANNUAL REPORT 2015

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INTRODUCTION

It has been a very active year and much has been achieved. 2015 saw a new President, Vice President and Secretary and a largely new committee. We are all volunteers which of course puts some limits on what we can do especially as most of us are grappling with the concept of pacing ourselves! However, we believe that there is a need for a polio specific advocacy group, just as there are groups for other disabilities and chronic health conditions and we are motivated to ensure that everyone has access to quality health care.

With the advent of the NDIS, next year is going to be very important in ensuring that the rights and interests of people with polio are protected. PPV will be pursuing this vigorously and we hope we can rely on the support of our members and community.

Our goals fall under these main headings:

Advocacy
Information and Communication
Education
Liaison

OUR MISSION

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

ANNUAL GENERAL MEETING 2015

Twenty five members and supporters gathered at the Disabled Motorists Australia in Coburg on Monday 23rd November 2015. This annual report was presented by President, Geoff Dean, with input from Vice President Margaret Cooper, Secretary Liz Telford and Committee member Fleur Rubens.

A change to the constitution that allows associate members take on any position on the committee apart from President, was voted in by the meeting. This change aims to provide a broader pool of members to take on executive positions. One of the challenges for PPV has been that most of the committee members are themselves struggling with post polio issues and need to carefully manage their commitments and energy levels, at times needing to take time out. The committee must still have a majority of committee members who have had polio themselves.

Geoff thanked the committee (Margaret Cooper, Liz Telford, Fleur Rubens, Jill Pickering, Susan Shaab, Ron Exiner and Fran Henke) for its work over the year and acknowledged that most of the committee are experiencing the ups and downs of living with post polio while continuing to make a significant contribution to PPV's activities.



PPV COMMITTEE 2016

The new committee for 2015/16 consists of:

President Geoff Dean, Vice President Margaret Cooper, Secretary, Ron Exiner, ordinary members Ron Bell, Judith Bell, Jill Pickering, Liz Telford, Susan Shaab, Fleur Rubens, Rosslyn Pickhaver and John van Delft.

We look forward to another productive year!



2015 ACHIEVEMENTS

1. Advocacy

Goal: To ensure the adequate provision of services for all people with post polio whether covered by the NDIS or not

The introduction of the NDIS and the Commonwealth Home Care Package mean significant changes in disability and aged care. Our focus is on how these changes impact on people with polio, and ensuring that these changes will be beneficial to, or at the least, not disadvantage our community.

As many people who have post polio will be over the age of 65 (the NDIS cut-off) when it is introduced over the next three years, we have been seeking to clarify how services and equipment to the over 65s will be funded.

- We have written submissions and letters to the Federal and State Governments
- We have held meetings with then Federal Minister Fifield, the State Parliamentary Secretaries for Disability and Health and State Government officials

Goal: To ensure that people with polio have access to the aids and equipment they require for optimum mobility.

We made a submission to the National Disability Insurance Agency concerning assistive technology

PPV participated in many meetings about Aids and Equipment

We have been active on promoting the needs of our members to the Multi Purpose Taxi program

Polio Services Victoria

We are liaising with and advocating to PSV re current service levels and quality.

2. Information and Communication

Goal: To promote awareness of polio specific health information

PPV is concerned about the reduction in polio specific information provision and is seeking to fill the gap which has been created.

Website

We have refined and developed our website as an important source of information. It contains resources and links to medical information, other websites and organizations. We have had the support of Keith Yates of Webfoot Design for the past three years and are grateful for his assistance. Reuben Endean of Backtoback Design has now taken over website management.

Newsletter

Our quarterly newsletter provides members and others with updates on the advocacy work and other relevant information. We don't seek to replicate support group newsletters, Polio Australia's newsletter or Polio Health International's bulletins which we forward on and provide links to on our website. Thanks to our editor, Susan Shaab, for all her work during the year.

Facebook

We have developed our Facebook page to link with groups and people not only in Victoria but around the world. Our thanks to Fran Henke, our social media expert.

Communication with members

We have regularly emailed on matters of importance and to circulate relevant publications such as the Polio Australia and PHI newsletters, and other information that we think is of importance our members.

Letter to the Editor

Our letter to The Age (Sep 2015, *The Age*) in response to an article on hospital mismanagement highlighted how lack of knowledge of post polio can have very serious consequences.

Polio alert is critical

“Julia Medew highlights errors in clinical management that have occurred in our hospitals with some devastating outcomes (“Hundreds of patients' deaths preventable”, 15/8). A lack of medical knowledge is another cause. Here is a real example. In 2011, a man died unexpectedly in a major hospital a month after surgery. He had a history of polio. A surgical error considered minor (as it is for someone without post polio) combined with inappropriate post-surgery care (due to hospital ignorance of post-polio management) resulted in respiratory failure. The cause of death was given as “post polio”, although it was not the disease process but clinical management that caused this man's preventable death.

Anyone who contracted polio, whether paralysed or not (an estimated 400,000 Australians) may develop post polio, a condition that may affect the central nervous and respiratory systems. One Victorian hospital now has a polio medical alert for patients known to have had polio. All hospitals need to do the same, and patients should alert staff if they ever contracted polio. Despite the successful global polio eradication campaign, post polio will be around for decades to come and hospital staff must be educated.”

Liz Telford and Fleur Rubens, Post Polio Victoria Inc.

3. Education

Goal: to ensure that protocols exist in hospitals to facilitate the safe and effective treatment of people with polio.

Post polio is a complex neurological condition that is not always well understood in the medical and allied health professions. A person with a history of polio may have particular drug sensitivities, respiratory needs,

positioning requirements due to muscular-skeletal issues and may recover more slowly from surgery or other procedures requiring anaesthesia.

A particular focus this year has been on care during anaesthesia and post surgery rehabilitation. We have advocated to the Austin Hospital, St Vincents Hospital and the Australian and New Zealand College of Anaesthetists (ANZCA) on the development of information for consumers and professionals.

As a result, Dr Anthony Tobin, assistant Director St Vincent's Hospital, wrote a referenced article 'Anaesthetists need to be wary of Post Polio Syndrome' which was published in the *ANZCA Bulletin* September 2015. This article was co-badged with the PPV logo.

Margaret Cooper has submitted an article "What is happening to Polio Survivors? The Role of the Patient in Assessment and Management' to the *Australian Family Physician*.

A polio alert is now in use at St Vincent's Hospital so that any in-patient who informs the hospital at intake of their polio history will have an alert attached to their file. We will be advocating for a similar alert to be introduced in other hospitals.

4. Liaising with other organizations and the community

Polio Australia

PPV is now a member of Polio Australia and represented on the PA Board and is represented on the Steering Committee of the International Post Polio Conference 2016, being hosted by PA

Polio Network Victoria

PNV is the network of the 14 support groups around Victoria, auspiced by Independence Australia, who is advised by the Polio Reference Group. When PPV established to fill the advocacy gap, it decided to incorporate as an independent body with no auspicings body.

With similar goals, we have worked hard to ensure that our work complements and supports the work of the support groups.

Representatives of PPV and the Polio Reference Group met this year to develop its working relationship.

We have also joined **People with Disabilities Australia (one of the five peak disability groups), Chronic Illness Alliance, and Ross House**

Outreach to people with polio

We contact and provide information to people who have registered on the PA Polio Register and requested information. In 2015 we have made contact with 14 people, many who were seeking information for the first time since the initial illness.

SOME HISTORY OF POLIO ADVOCACY

Established in 2011, PPV provides a focus on the specific needs of those who live with post polio, some estimated 5000 or more people in Victoria and over 70,000 Australia wide. Emerging at a time when polio services were being reduce PPV held a forum at the Northcote Town Hall which was promoted through an article in the Age and an ABC radio. 70 people attended to discuss polio health issues and these concerns and ideas helped form the PPV mission statement.

People with polio have long been active in disability advocacy, both fighting for polio services, and in generic disability activism. For example, when the health department closed Fairfield Hospital in 1998 plans for Polio Services Victoria were limited, despite growing understanding of post polio syndrome. A strong protest from polio survivors was heeded and the service was extended.



U.S President and polio survivor Franklin D. Roosevelt

What are the most important issues for PPV for the next year?

Following the formal meeting we had a brisk discussion and the following priorities were suggested:

- Acquiring funds for a community worker to support our work
- Clarifying the changes to the disability and aged system and their implications for people with polio
- Advocating for equity of services for those over 65
- Access to custom made aids and equipment



Pat Twomey, left, who has been actively involved with the polio community for decades celebrates her 90th birthday in December. With her is Mary-ann Liethof who spoke following the AGM, and Liz Telford, PPV committee member.

FINANCIAL SUMMARY 2015

Receipts		Expenditure	
General donations	1462	Brochure printing	547.80
Donation Leongatha RSL	500	Secretary expenses (admin)	338.50
Geelong Support Group donation	50	Postage	35
Walk with me fundraising	455.93	Banner	433.80
Raffle 2014/5 AGM	125	DMA Hall hire (2014/5 AGM)	55
Membership fees*	790	Catering (AGM)	235.95
Bank interest	54.30	Personal carer (AGM)	200
		Ross House membership	171.72
		Website upgrade	300
		Conference	113.30
		Consumer Affairs Victoria annual reg	53
		Misc	6

Bank balance @ 01 July 2014: \$4788.46

Bank balance @ 30 June 2015: \$5735.62

Notes

- PPV receives no government funding and relies on donations and fundraising. We have managed to improve our position slightly as a result of the generosity of our supporters and members and careful management of expenditure
- Three donors make monthly automatic bank transfers. This is very much appreciated.
- * PPV briefly introduced membership fees during 2014/5 but then reversed this decision as a result of the workload which was created. All those who paid membership fees agreed that PPV could retain them as donations, for which PPV is very grateful
- PPV's medium term sustainability requires sourcing of some level of funding. Currently approaches are being made to State Government and charitable foundations seeking this support.

Acknowledgements

We are grateful to the Collingwood Neighbourhood Justice Centre for providing us with the meeting space free of charge.

We thank Keith Yates for providing website hosting at no charge.

We have received donations from many members, including some who provide automatic monthly donations. We thank everyone for their support.

We thank Beth Exiner who provided assistance at the Annual General Meeting. We enjoyed your company and appreciated your contribution to the smooth running of the event.

Many thanks to Sophia Exiner for facilitating the formatting and layout of this report.