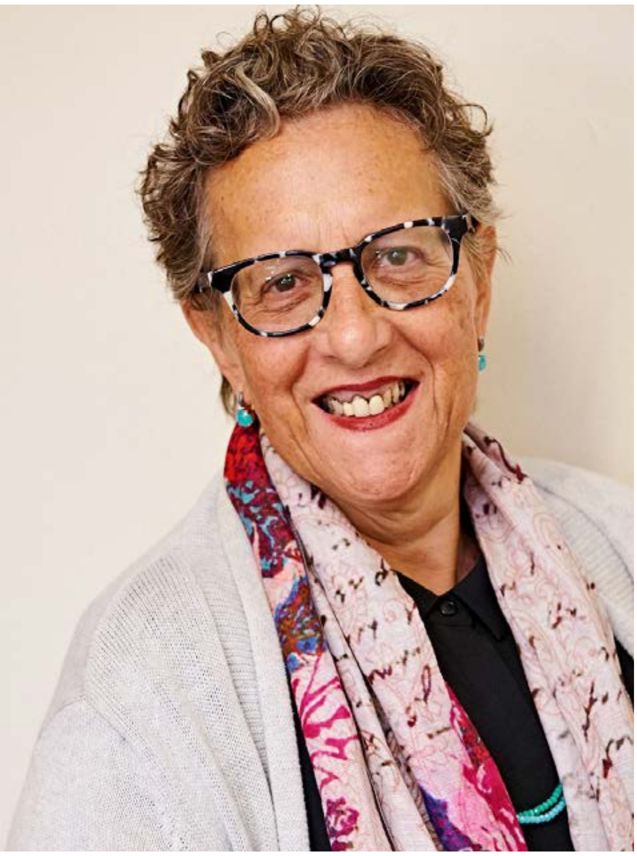
# POST POLIO VICTORIA - ANNUAL REPORT 2019 -2020

*Post Polio Victoria Inc. (PPV) was formed in 2011 and has now over 200 members. PPV is managed by a Management Committee made up largely of people with polio. We are a volunteer managed advocacy and information group.*



## President's Report

I am pleased to present to you our Annual Report for 2019/2020 for Post Polio Victoria Inc. At our Annual General Meeting in November 2019 we welcomed four new members to the Committee. No one could have predicted what would happen in the next few months with Covid-19 however we did manage to meet face to face in March 2020 to work on our Strategic Plan. This new Plan will set the course for PPV over the coming years as we work to fulfilling our vision of **"People and polio, Uniting and thriving".** I would like to thank Anne Wright for facilitating and all the committee for participating in the process.

In April 2020 Peter Freckleton and I were interviewed by an ABC regional reporter on the sticking similarities between the polio epidemic and the coronavirus. This brought back terrible memories for Polio survivors of such similarities. We wrote to the Prime Minister Scott Morrison and other health ministers regarding our concerns that we would be given full treatment if infected with Covid-19, including ventilator access.

The committee have worked tirelessly this year, to end the exclusion on polio survivors over 65, with recommendation that ALL people with a disability over 65 be included in the National Disability Scheme (NDIS). We have sent in submissions to the Royal Commission, and spoken to Local MP's and Federal MP's including The Hon Bill Shorten.

Hence polio survivors' interests have been furthered by disability groups pulling in the same direction. It is very encouraging that the Disability Royal Commission has expressed keenness to have further submissions on the NDIS exclusion.

This is important for the future of all polio survivors in the years ahead, to ensure they get the assistance they need to live with dignity. It would be undesirable and tragic for us to be isolated into a separate system which would lack the strength provided by being in the growing and ever more powerful disability mainstream.

Given all the Royal Commissions and other high-level activities now on foot. This is our moment to raise awareness of polio survivors and establish policies which will be of benefit across the board in the years ahead. PPV has been striving hard to make the best of the opportunities on many fronts, and we are optimistic that good things may be achieved.

We advocate for fair treatment in health crises, and health services, and access to life enhancing possibilities.

**Quarterly Meetings** with Polio Services Victoria, Polio Australia and Polio Network Victoria. This is a perfect platform for working collaboratively on issues that have been brought to our attention and ways to resolve them. I would like to thank Ron Exiner for chairing these meetings for the past four years. We shall miss his input and support during this time, Ron's full report is included in the Annual Report.

In 2018 the late Margaret Cooper OAM contacted Melbourne University, Prof Keith McVilly about her concerns of the needs of polio survivors. As a legacy to Margaret the University of Melbourne and PPV collaborated in a study. Petra Quinlan-Turner MD took on the research. Our thanks to Prof. Keith McVilly and Dr. Phyllis Lau for their assistance and to Petra for taking on the project. We hope to continue working with the university to follow through the recommendations.

Even though the year has been hard on all of us, we have something to celebrate as well. Liz Telford, PPV's inaugural President, was awarded an OAM in the 2020 Queens Birthday Honours list for services to people with polio and the community. PPV is delighted that Liz's years of contribution and service have been accordingly recognised in this way.

After many years of advocacy regarding possible complications from anaesthesia, we have had an article published in the Australian New Zealand College of Anaesthetists (ANZCA), *"Patients with a polio history – what anaesthetists need to know"* Thank you to Liz Telford OAM for writing this article.

I would like to thank the committee and sub committee members for their work and commitment during this year. In particular I would like to thank Peter Freckleton, Robyn Abrahams and Barbary Clarke for their contributions and keeping me on my toes. It has been somewhat challenging but we have managed to meet monthly via Zoom, which in itself has been a blessing in many ways, enabling those who live far away to be involved in our meetings. I am grateful to each and every one of you for working together, sometimes at short notice. Without your support all that we have achieved would not have been possible during this tumultuous year. The present committee was elected at the last Annual General Meeting held in November 2019.

# OUR COMMITTEE OF MANAGEMENT

To better tell the story of who we are, we published all our committee members full biographies on our website at postpoliovictoria.org.au/about-us. If you'd like to share your story of how you came to be a member of PPV and the polio community, email us at info@postpoliovictoria.org.au to include a new page showcasing our members.

**Shirley Glance** is the current President of PPV. She is also active in the community as a member of the National Council of Jewish Women, and as a community advocate for Breast Screening Victoria.

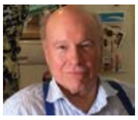
**Susan Shaab** is PPV's Vice President, editor in chief, and passionate advocate for public housing and social justice.

**Nimo Hersi** is our Secretary. She  was three years old when she caught polio in Mogadishu, the largest city of Somalia. She now works in the community sector and is developing resources to help people parenting with polio.

**Lan Huynh** is our Treasurer, when she's not busy being a dentist and accounting student!

**Nanette Morel,** AKA Ms Chocolate Frog, is a retired child-psychologist, and active community member.

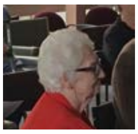
**Robyn Abrahams** is a Registered critical-care nurse, and midwife, and worked as a management consultant.



**Peter Freckleton** is a barrister, expert in legal translation, and frequent letter to the editor on issues of disability rights.

**Ron Bell** is our former president. His story was published in the book 'The Calliper Kids' on page 130

**Anne Wright** is a leader in health care and has had more than 20 years' experience in the public health sector.



**Judith Bell** is a long standing committee member of PPV and active community member

**Geoff Dean** was a founding member of PPV and our  former President and Treasurer.

# FINANCIAL SUMMARY

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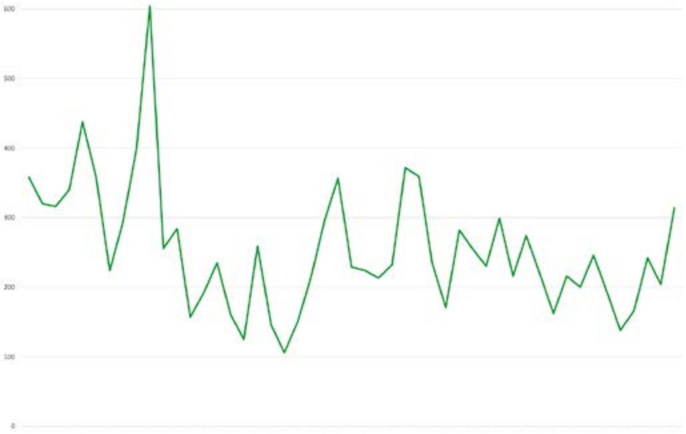
|---|---|---|
| Opening balance: | $ | 12,827.12 |
| Income: | $ | 1,701.98 |
| Expenditure: | $ | 4,772.89 |
| **Closing balance:** | **$** | **9,756.21** |

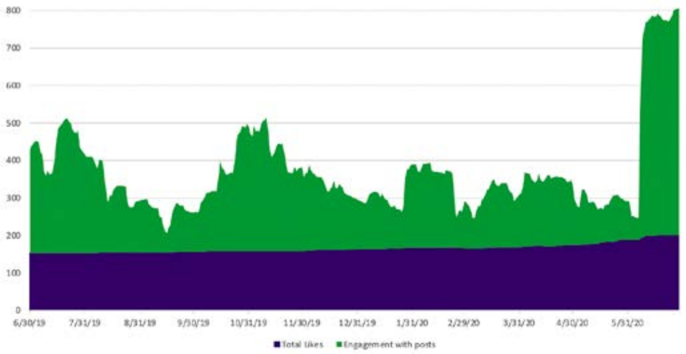
Thank you to our regular and new donors over the year, we really appreciate your support!

# MEDIA AND COMMUNICATIONS

### Monthly Website Visits 2016-2020

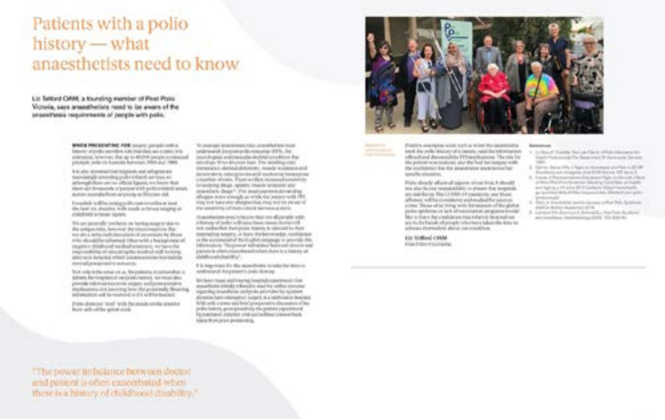


### Facebook likes and engagement 2019-20



PPV uses online communications to reach out to members and people with polio across the state. While our websites content has grown, we haven't attracted a larger audience over time. Our Facebook page continues to slowly gain followers. We encourage members to use the resources and information on our website and facebook page, and let us know any events, news and information you would like us to share.

Liz Telford OAM had a piece published in the Australia and New Zealand College of Anaesthetists Bulletin, a major breakthrough in our advocacy for better medical knowledge and training! **postpoliovictoria.org.au/patients-with-a-polio-history-what-anaesthetists-need-to-know/**



Patients with a polio history — what anaesthetists need to know

Liz Telford OAM, a founding member of Post Polio Victoria, says anaesthetists need to be aware of the anaesthesia requirements of people with polio.

"The power imbalance between doctor and patient is often exacerbated when there is a history of childhood disability."

Liz Telford OAM

# ADVOCACY

## Submissions & Endorsements

- Women with a Disability Australia – petition for equal access to acute care and human rights for all Australians during Covid-19
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. ‘Against the Exclusion of Polio Survivors from the National Disability Scheme.
- Submission to the Disability Royal Commission ‘Against the Exclusion of Polio Survivors from the National Disability Scheme.
- Submission to the National Disability Strategy Governance and Engagement
- Joint submission with AFTA – Aged Care and Quality and Safety
- Second Submission to the Regulation Impact Statement Proposal, to include minimum accessibility standards for housing in the National Construction Code
- PPV Response to the Final Recommendations of Counsel Assisting the Aged Care Royal Commission, in which we called for interim access to the NDIS pending implementation of the Final Recommendations.

## Membership survey during COVID-19

During the lockdown in Victoria, we surveyed our members to find out more about how coronavirus has been affecting people with histories of polio.

For most of us, the lockdown made it a lot harder to keep in touch with family and friends – but others are used to staying home, or have learned to use technology to keep in touch. Some people had a chance to let the world catch up to their slower pace of life. Others felt used to it and had survived worse, but for many there were added challenges, especially the difficult memories of childhood polio.

A great concern for many people with polio is regular exercise, and just over half of respondents were having difficulty with that, with access to hydrotherapy, pools, gyms and other sports facilities interrupted.

Getting medical treatment has also become significantly more difficult. Of great concern are three respondents who are had increased difficulties paying the bills and keeping a roof over their head. Thankfully, family, friends, carers, neighbours have all come to our assistance. Other responses were food deliveries, nurse on call, and ‘husband’ also came in handy a couple of times.

Read more detailed results of our membership survey at **postpoliovictoria.org.au/survey-results**

# NETWORKS AND AFFILIATIONS

## Polio Australia

PPV has a representative on Polio Australia's Board (PA) and as such we participate fully in the governance of PA. Peter Freckleton was PPV's representative this year, and has been liaising with PA Board members formulating arguments for inclusion of polio survivors in the NDIS.

## Polio Services Victoria (PSV)

Steph Cantrill represents Polio Australia at our Quarterly Meetings with Polio Services Victoria and Polio Network Victoria.

## Affiliation Assistive Technology for All ( ATFA)

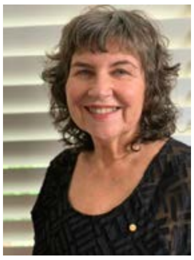
We have representation on the Assistive Technology for All (ATFA) which consists of peak bodies, consumer representatives from across the health, ageing and disability sectors. The current campaigns, seeking to secure equitable access to assistive technology for people with disability not eligible for the National Disability Insurance Scheme (NDIS) through the establishment of a funded national assistive technology program. This aligns with PPV's raison d'etre.

## Other Affiliiations

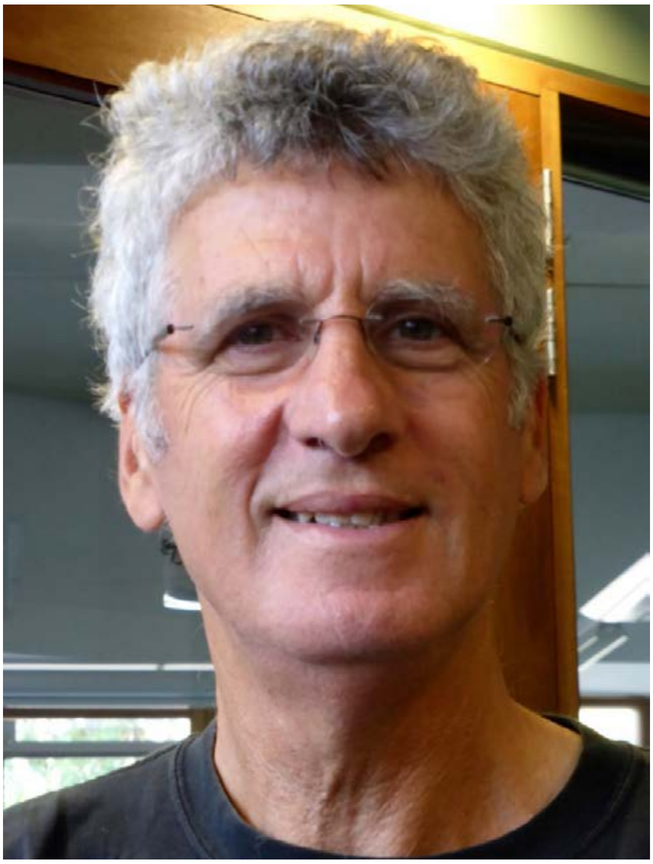
- Affiliation of PWDA – People With Disability Australia
- Affiliation of PHI – Post-Polio Health International
- Affiliation of WWDA – Women with Disability Australia
- Polio Network Victoria

# LIZ TELFORD, OAM

We were delighted that Liz Telford, former President and founding member of PPV was awarded the Order of Australia Medal (OAM) in the June 2020 Queen's Birthday Honours list, for her dedication and commitment to Post Polio Victoria. Due to COVID-19 there hasn't been a good photo opportunity to show Liz recieving her medal, but here is a big congratulations for Liz!



# QUARTERLY MEETINGS WITH POLIO SERVICES VICTORIA



For the past four years, Post Polio Victoria (PPV) has run this advocacy forum.  It aims to advocate to Polio Services Victoria (PSV) on behalf of people with polio, for services which are client focussed and meet peoples' needs.  Polio Australia (PA) and Polio Network Victoria (PNV) also attend and the meetings provide a forum for all of us to communicate and liaise.

The service culture at PSV was the original impetus for this forum and in 2020 there was considerable discussion about the progress which PSV has made and what remain as ongoing challenges.  This should remain a focus of these meetings.

Safety of people with polio in the hospital system is another important issue.  PPV believes it is very important to have a polio alert included in the admission procedures in all hospitals in Victoria.  St Vincent's currently has such an alert and the meeting has been able to review the strengths and weaknesses of its approach as a basis for more advocacy to be done during 2021.

The Quarterly Meetings (QM) was also used a reference point for the preparation of an article on the need for anaesthetists to understand the issues for people with polio around anaesthesia. This article, prepared by Liz Telford, has just been published in the Victorian College of Anaesthetists Bulletin.

The QM is the only regular forum for the four polio organisations to meet and the groups involved have shown considerable commitment to participating and communicating and I would like to acknowledge this.

Finally, I am announcing that after four years I am stepping down as Chair of the QM.  I would like to thank all involved for their support over this period.

Ron Exiner
Chair

## Post-polio Syndrome: knowledge transfer and professional development for GPs and other health professionals

*Presented by the University of Melbourne Researchers: Petra Quinlan-Turner MD, Dr. Phyllis Lau and Prof. Keith McVilly*

*The late Dr. Margaret Cooper OAM (1943-2018) initiated a research collaboration with the University of Melbourne and Prof. Keith McVilly in 2018 to address the needs of people with a history of poliomyelitis. The University of Melbourne is pleased to be continuing Dr.Cooper's legacy in this joint study with Post-polio Victoria Inc. (PPV).*

There are ongoing concerns about a lack of awareness of post-polio syndrome (PPS) and the late effects of polio (LEoP) among Australian health professionals. There is need for both information and professional development in this area. While some resources are available, the reasons for the lack of their uptake by health professionals has been unclear.

This study investigated views of Australian and New Zealand health professionals on learning about polio related effects. It also explored the limiting and enabling factors for professional learning about PPS and LEoP management.

The study addressed two research questions:

1. What are Australian and New Zealand health professionals' views on learning about polio and its sequelae?

2. How can knowledge transfer and translation about PPS and LEoP be enhanced for Australian and New Zealand health practitioners to better inform clinical practice and improve patient outcomes?

### Methods

Interviews were conducted with a mix of health professionals with experience in working with polio survivors. There were eleven participants (4 GPs, 3 physiotherapists,1 occupational therapist, 1 orthotist, 1 social worker and 1 anaesthetist) interviewed.

All participants were of the view that learning about PPS was important for the competent management of patients and fostering effective patient-practitioner relationships.

Critical issues that health professionals needed to be aware of included falls risks in people with PPS, the psycho-social wellbeing and quality of life for polio survivors, and issues pertinent to immigrant populations and younger women of childbearing age. Anaesthesia in particular was a procedure that carries particular risks for polio survivors, such as aspiration or abnormal respiratory function. Polio survivors therefore require special considerations and management before, during and after anaesthetics.

A range of enabling and limiting factors affecting the uptake of professional development in the areas of PPS and LEoP were identified. Time available to practitioners, workforce and funding constraints, a lack of information about the prevalence (including among younger immigrant populations), and a lack of recent research about the clinical management of PPS contributed to a lack of awareness of the relevance of PPS to health professionals' practice and subsequently low levels of engagement with learning about PPS. Health professionals also seemed not to be aware of some of the existing resources on PPS and LEoP, such as the LEoP module in the on-line HealthPathways resource.

Health professionals in general preferred flexibility and a mix of face-to-face and online delivery in their learning opportunities. Promoting multi-disciplinary learning groups that include professionals from fields such as physiotherapy, occupational therapy, social work, orthotics and general practice may be a potential solution to improve ownership of learning and is consistent with the multidisciplinary nature of PPS management. The co-design and facilitation of these groups with polio survivors could enhance the relevance and quality of the learning experience.

## Recommendations:

- The HealthPathways' specialist module on LEoP should be evaluated with the view to supporting its uptake by health professionals.

- Professional and academic organisations including the Royal Australian and New Zealand colleges of GPs, physiotherapy boards, schools of social work and relevant allied health disciplines should collaborate to develop multidisciplinary peer learning materials on PPS and LEoP and embed them in health professional continuing professional development.
- Polio survivors should be involved in the co-development of educational materials to improve the relevance to all stakeholders involved.
- Strategies need to be developed to raise the awareness of health professionals concerning the significance and relevance of having knowledge about PPS and LEoP, particularly with respect to its prevalence in younger immigrant communities, and to dispel the misconception that because Australia has been declared polio free it is no longer an issue of clinical and social concern in our community.

## Acknowledgements

The research team thanks PPV and their reference group consisting of Shirley Glance OAM, Liz Telford OAM and Dr. Peter Freckleton, the Bayside Polio support group, and Polio Australia for their support and sharing their expertise throughout this project.

Post
Polio
a voice for people with polio
Victoria Inc.

| | |
|---|---|
| Purpose: | We act with purpose in all our activities |
| Openness: | We are open to all thoughts, ideas and possibilities to achieve excellence and best practice outcomes for individuals with polio, both young and old |
| Learning: | We will promote and utilise learning in all activities |
| Integrity: | We will conduct all aspects of PPV with integrity |
| Originality: | We will promote originality in our advocacy and problem solving to achieve best practice outcomes. |

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