



2016 Committee:

Geoff Dean (President), Margaret Cooper (Vice President) Ron Bell (Treasurer), Ron Exiner (Secretary), Liz Telford, Fleur Rubens, Jill Pickering, Susan Shaab, Judith Bell, Rosslyn Pickhaver, John Van Delft.

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President's Report – Geoff Dean.

Following a busy 2015, and, re-elected for 2016, I am pleased to report that we have an enhanced 11 member Committee for 2016.



Margaret Cooper is Vice President, Ron Exiner is Secretary, Ron Bell is Treasurer, Liz Telford is our rep on the Steering Committee of the Australasia-Pacific Post Polio Conference in Sydney hosted by Polio Australia and Judith Bell, Jill Pickering, Rosslyn Pickhaver, Fleur Rubens, Susan Shaab and John Van Delft make up the committee.

As 2016 looks to be as hectic as last year, advocating, health policy and information sharing, I am pleased that the within this year's Committee there is a depth of returning expertise.

We have long been aware of Committee members struggling with post-polio issues and the needs to carefully manage their commitments, energy levels, and, to have recreation time. To ensure that we could co-opt volunteers who have not had polio (so cannot be Full Members), into some officeholder positions, an amendment to our constitution was voted on at the 2015 AGM on the 23rd of November 2015. The amendment to our Constitution reads as follows; "A minimum of two thirds of the Committee shall be made up of Full Members with the remaining places available to Associate Members.

The positions of President and Vice President must be held by Full Members." Formerly the positions of Secretary and Treasurer also had to be held by Full Members.

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PPV presentation at the Australasia-Pacific Post-Polio Conference 2016.

Important requirements in the provision of health care to people with post polio as seen by PPV will be presented to the Australasian Pacific Conference in September this year in a paper entitled Quality patient care-the polio survivor's perspective. Through discussions with fellow polio survivors and our research, we have identified five important areas. These are polio appropriate respiratory testing, relevant hospital protocols, the use of a collaborative model of rehabilitative care, improved polio awareness by doctors/allied health professionals and ensuring adequate funding for older people living with post polio (while the those under 65 will be catered for under the NDIS). Liz will make this presentation. Email or call PPV if you would like to share your experiences or thoughts on any of these areas. (See the abstract on page 2)



Is anyone aware of hospitals that have in-take questions about polio history? We would love to know, so please email us.



Conference Abstract : Quality patient care: the polio survivor's perspective

Polio requires the person to spend considerable time and effort to obtain the information they require, enabling them to adapt to the challenges of living with the condition of post polio. However, this knowledge and expertise is rarely used for the planning and provision of polio healthcare. For example, the risks for patients with a history of polio admitted to hospital for surgery are well documented (Lambert DA, Giannouli E, Schmidt, BJ 2005;103:638-44).

Despite this knowledge, the onus is on the patient to inform the hospital of their polio history, its effects and treatment implications. Brochures designed for the post polio patient to give to the surgeon and anaesthetist, are available through most polio support organizations but patients are not always aware of this. Even when armed with the brochure and other information, doctors vary in their receptiveness to information provided by patients. Post Polio Victoria (PPV) is advocating for improvements, which will reduce medical complications and encourage greater patient engagement with rehabilitation programs. PPV's research has drawn on current literature as well as anecdotal evidence from PPV members.

As a result we have identified five crucial areas that require health care improvements. This paper will identify these and make recommendations for how they could be addressed, complications avoided and recovery improved. These areas are polio appropriate respiratory testing, relevant hospital protocols, the use of a collaborative model of rehabilitative care, improved polio awareness by doctors and allied health professionals and ensuring adequate funding for older people living with post polio (while the those under 65 will be catered for under NDIS).

PPV will present this paper to the conference. To read other abstracts and to see the conference program go to the conference website www.postpolioconference.org.au



**2016 Australasia-Pacific
Post-Polio Conference**
Polio - Life Stage Matters

**20-22
SEPT
2016**

**FOUR
SEASONS
HOTEL
SYDNEY**

**SAVE
THE
DATE**

New resource on Anaesthesia and Surgery

Polio Service Victoria has developed an excellent new brochure on Anaesthesia and Surgery-a Guide for People with a History of Polio. We encourage you all to read it:

https://svhm.org.au/wps/wcm/connect/65b61596-7ff7-4680-865c-9d959aa240f5/Anaesthesia+and+Surgery+A4.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=65b61596-7ff7-4680-865c-9d959aa240f5

President's Report -cont.

2016 is an important year for all Polio Survivors; informing ourselves about how the introduction of the National Disability Insurance Scheme will affect each of us. Margaret, Liz, and Ros continue to meet with our State Ministers, and their advisors. Jill maintains a watching brief on Transport.

Liz and Fleur continue educating about respiratory issues and hospital care for Post-polio survivors, and will contribute to the September Sydney Conference (see abstract on page 2).

The 2016 Australasia-Pacific Post-Polio Conference will be held in Sydney 20th -22nd of September.

It's an important opportunity for research, clinical knowledge and health issues of the 20 million worldwide, polio survivors to be acknowledged and discussed.

The conference titled "Polio: Life Stage Matters" because the needs of ageing and younger survivors differ." The aim of the Conference, aimed mainly at health professionals, is to exchange knowledge about the diagnosis and treatment of the post-polio condition in different age groups to best preserve functioning throughout life.

PPV is endorsed by the Australian Taxation Office as a Health Promotion Charity and a Deductible Gift Recipient making all Australian donations over \$2 tax deductible

Donations to PPV enable us to print this newsletter, maintain the website, hold forums and support the many other costs associated with PPV's work and may be made by post to

PPV Ross House 247-51 Flinders Lane, Melbourne 3000 or by Electronic Funds Transfer to Post polio Victoria Inc Bendigo Bank BSB 633 108 Account number 142520766

Visit to Shepparton Polio Support Group March 2016.

Shepparton Polio Support Group invited PPV to its meeting to provide information on the impacts of the NDIS. The group was concerned to know what will happen after the NDIS rolls out which in the Goulburn region will be in January 2019.

Ron Exiner and Liz Telford attended this friendly and lively meeting, which was attended by approximately 25 people including some partners, daughters and other supporters both from Shepparton and surrounding areas.

We explained that those eligible under the NDIS should be much better off and that there is a "no-one will be worse off" government commitment which means that for those who are not eligible, the same level of service as currently received eg through HACC, SWEP or Disability Services, will continue. How this will be administered is not clear but we do know that it will be through the new Commonwealth Home Support Program (CHSP). Concerns were raised about how this will affect local service provider, Goulburn Valley Health.

We outlined PPV's advocacy goal of ensuring that the level of support for those receiving services under the CHSP matches the higher level available under the NDIS.

A vigorous discussion about changes in service provision over the past few years followed, with the group sharing their concerns about this.

On behalf of the group, Marilyn Grimme thanked us with a gift bag of beautiful local produce including apples and pears, dressing and her delicious home-made chutney. We enjoyed meeting everyone, and appreciated the warm welcome.



A Change of Season Holiday?

LOOK no further than Paynesville, East Gippsland.

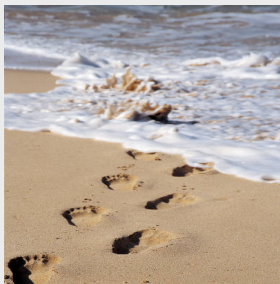
I am reliably informed that this is a beautiful part of our State for a holiday. During autumn and early winter it has milder weather than other holiday destinations because of the sheltered/temperate influence of the Gippsland Lakes.

Paynesville also has holiday rental houses specially set up for people with disability/accessibility issues.

These are: Eagle Point Cottages at 6 Tait St, Eagle Point, Victoria, run by Rose and Rob. Ph 0409 566 345

Wendy's HOUSE AT 42 Victoria St, Paynesville, Victoria run by Nancy Ph 0427 231 969; (brochures about Wendy's House are available with this posted newsletter)

At both houses there is enough room for all the family; children and grandchildren. Late Autumn/early Winter is also the ideal time for a less busy chill in/ chill out holiday.



Why become a member of Post Polio Victoria?

This is a personal segue to my review of Joan London's novel "The Golden Age."

I had polio in 1950, and spent 9 months at Yooralla, Fairfield. From there, I was taken twice a week to the Yooralla School, on the Pelham Street and Lygon streets' corner, Carlton. The school continued into the 60's.

My mother contracted polio about the same time. We lived in a house that backed onto Merri Creek in Thornbury. There were theories that polio was water borne disease.

Few services were treating adults. My father nursed my mother at home. My younger brother went to stay with our grandparents. When I was discharged from Yooralla, my parents arranged for me to stay with friends. There my real learning about society began. I was thoroughly spoiled by their older children, who took me everywhere they went.



1950 Susan at Yooralla, Fairfield. Masked, two; staff nurses, and my mother, on her weekly visit.

I wore a knee -high caliper on my left leg until I was 8. Soon after, Australians knew about the virus that causes polio. In 1956 Australian Governments introduced vaccinations to prevent it. As a child I was sent to swim, and learn ballet to strengthen my left leg. I walked or rode my bike everywhere.

I studied Social Work at Melbourne University between 1965 and 1968, getting there by motor- bike. In 1969, I had a spill while riding to work. The accident caused significant damage to my "good" right leg. Today I have some difficulty with my right knee, which has taken the weight load off the left leg.

Post Polio Syndrome is an increasingly debilitating condition as we age. Though I have no serious symptoms, I joined the PPV Committee, because of its work alerting the medical, and allied professions about PPS. This is important. I have been on the PPV Committee for 2 years. It has perturbed me, time, every medical/dental appointment I have attended, recently, that young practitioners have learned little about polio, let alone its Late Life Effects.

Though I haven't, many members of PPV have been assessed at the Polio Services Victoria, clinic at St Vincent's Hospital. It puts information of interest to Polio survivors on its' website. Geoff Dean has been asked to let everyone know that the PSV website has been improved, so that there is more material available. *By Susan Shaab*