



2016 Committee:

Geoff Dean, Margaret Cooper, Ron Exiner, Jill Pickering Susan Shaab, Fleur Rubens, Liz Telford, John Van Delft..

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Have you got any questions about POST POLIO SYNDROME?

Go to our website which will take you to our Facebook page. **Like** the articles you find most informative.

The NDIS

While we have been advocating strongly for equity of service for the over 65s, we also want to encourage everyone who is eligible to register when it becomes available in their area.

The NDIS is in the process of rolling out in the municipalities of Banyule, Darebin, Whittlesea, Nillumbik or Yarra from July 1st this year.

So if you are under 65 and live in the above municipalities, are an Australian citizen and use equipment and/or require supports because of your disability, you should register now.

Next year the NDIS will roll out in Central Highlands and Inner Gippsland from 1 Jan 2017 and Inner East and Outer East Melbourne from 1 Nov 2017. **Call the NDIS on 1800800100 if you have any questions or to ask for an access.**

The President's Report

Since my April report, some of us on the PPV committee have been ill. Many of our members have been busy attending to consultations in the area they live in as part of their local Governments submission to the State Disability Plan 2017 -20.

In July, your PPV Committee submitted an official response. We have also been busy with advocacy, strengthening polio health services, and applying for research grants.



We are waiting an answer to our submission for funds from the State Disability Plan for a Post Polio Victoria pilot project. "Breathe Safely; Live Well," is a pilot research project. Before the 2016 Federal election, the Federal Health Minister announced that funds would be set aside for research likely to improve health outcomes for people with ongoing health issues. Each State would select projects for funding through the State Disability Plan. Read our full submission in this newsletter. It is also available on the Post Polio Victoria website. Margaret Cooper has been untiring in her efforts to reach and monitor the experience of Polio survivors outside Oz. This year, she travelled to Malaysia and India, making connections with people who are living with severe disability following untreated polio infections. Many of us were lucky enough to attend her picture/ video presentation of this. This opened our eyes to how disabled people viewed/ignored/ challenged by those holding power in other countries.

Margaret's article; "What is happening to patients who have had polio? The Role of the patient in assessment and management", was published in the Royal Australian College of General Practitioners' Journal; "Australian Family Physician" Vol 15 No 7 July 2016.



**CPAP Machine
Phillips Respironics
C-flex with
humidifier**

Yours for a kindly donation to Post Polio Victoria

Older style but very comfortable to use with variable pressure relief. Advise a maintenance check and will require adjustment to your settings. This machine has been used by three of our members and has been well looked after. So if you are a PPV member needing a CPAP machine, you could be the fourth.

Contact Liz Telford (9486 5905) for more details

Choice Investigation

Is it better to buy a wheelchair or other equipment on line from overseas or have it tailor fitted from a supplier in Australia?

Read Kate Browne’s analysis in [Choice Magazine](#) of 22/6/2016.

President’s Report (cont).

We are continuing work with letters to Health Insurance Funds that publish a Members’ Newsletter, offering to provide articles about polio.

Notice of our AGM on Monday 28th November 2016 appears in this newsletter. Everyone is welcome. Think of joining the Committee. The more of us there are the better the representation of our members.

PPV attend en masse at the Australasian Pacific Post Polio Conference

Polio Australia’s conference was a great success with over 200 delegates from many countries including India, Canada, Japan, America, Britain, New Zealand and more. There were so many topics of interest.

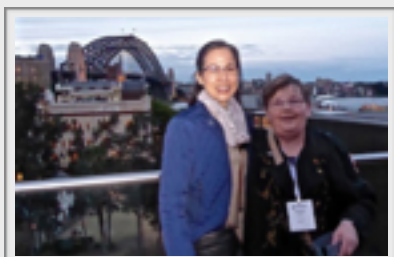


The committee of PPV was well represented with Margaret Cooper, Ron Exiner, Liz Telford, Jill Pickering, and Fleur Rubens all present and actively involved.

Jill and Ron contributed to the smooth running of the conference sessions, as time-keepers for sessions and supporting the organizers in various ways, as well as liaising with delegates on our many issues.

Fleur was actively making contacts and furthering our interests by discussing our projects and concerns with practitioners from

Fran Henke Blogs from Sydney



This has been the biggest thing Polio Australia has done in its 10 year history. There have been delegations, retreats held around the country, clinical studies published, clinical practice workshops. But inviting more than 20 health professionals from USA and Europe (at their own expense) to come to Australia for an Australasia-Pacific Conference in a five star hotel, was huge.

Follow her story at <http://fhenke.wixsite.com/blog-pointsofview>



Post Polio Conference (con.)

interstate and overseas. Fleur’s creative mind was actively engaged and a new resource idea is being developed out of one of these meetings.

Liz presented “Quality Patient Care-the Patient’s Perspective”, outlining PPV’s views on the need for hospital protocols, respiratory standards and client-centred rehabilitation (the abstract was in the April PPV newsletter) . It was pleasing that two researchers, one from Italy and one from New Zealand, as well as many others were there to hear our concerns.

Liz also participated in a master class panel with Dr. Stephanie Machell Psychologist, discussing the psychological and emotional issues of working with patients with post polio. Liz found it a great experience to work with Stephanie who many of you will recognize from the PHI’s newsletter.

Margaret was seen the day before the conference began finding a prominent piece of wall space and setting up her poster presentation. During breaks conference delegates spoke to Margaret about her study and the implications. Margaret had this to say about her conference experience:

“My poster, long windedly titled “The Experience of Ageing for People with Physical Impairments- with particular reference to polio survivors” prompted some comments from others who had noticed, but not written in detail about, the emotional reactions and adaptive competence of survivors. Like many other participants, I was caught up in the whirlpool of new theories, new service models and discussions. I was excited about Dr Toniolo’s painstaking detection of fragments of poliovirus found in certain cells of people experiencing post polio syndrome, <https://www.poliohealth.org.au/antonio-toniolo/>, and the possibility of antiviral treatments. The presentations made by several Asian and Pacific survivor groups about their struggles to develop services will continue to challenge us for decades. For more information from the conference, read Fran’s blog, go to the Polio Australia website and come along to our AGM to hear Mary-ann speak.

Polio services – meeting with St Vincent’s hospital

Since our last newsletter, an important meeting has been held with St Vincent’s Hospital (as host body for Polio Services Victoria). It was hosted by Bayside Polio Support Group and



ANNUAL GENERAL MEETING

will be held on

Monday 28 November 2016

1.30 PM

At: the Disabled Motorists Association

2A Station St Coburg 3058

The formal Annual General Meeting will be followed by a presentation by Mary-ann Liethoff: "Highlights of the 2016 Australasian Pacific Post Polio Conference" and an opportunity to discuss the issues that arise.

Afternoon tea will be provided

RSVP by Friday 14th November to PPV Secretary Ron Exiner

9486 5905 or

postpolio victoria@gmail.com

If you will need carer assistance on the day and/or would like PPV to provide some financial support (50%) for the taxi or public transport cost, please let us know. We would like you to come!

took place on 2 August 2016. Fiona McKinnon, Group Manager, Allied Health and Community Services and Kathryn Bailey, Sub-Acute Ambulatory Care Services Manager represented St Vincent's.

Members from Bayside, the Polio Reference Group, Polio Australia, and Post Polio Victoria represented the polio community.

The meeting was significant in that it was an opportunity for all key polio related organisations to provide feedback to senior St Vincent's staff on the services which are provided by Polio Services Victoria. We were also briefed by St Vincent's on the current status of polio services and the changes which are being implemented. It should be noted that the meeting took place in the period following the departure of the previous Coordinator and before a new Coordinator has been appointed, which was why there was no PSV representative there. In fact, we have been recently contacted by Claire Formby who will be acting Coordinator until February 2017, by which time it is planned to make a permanent appointment.

There was considerable discussion around service levels and approaches, resources and the needs of people with polio. We also took the opportunity to raise issues around the needs of people with polio for suitable, affordable orthotics and the difficulties people are having in accessing these in an increasingly privatised market and given the inadequate levels of funding under the Statewide Equipment Program (SWEP). The impact of the NDIS and its current policy of applying only to those people who are under 65 years of age were also discussed.

The importance of regular client feedback for PSV was also an important topic of conversation. It was agreed to institute quarterly meetings to promote this feedback and also to enable St Vincent's to keep us abreast of service developments and issues. PPV has taken on the responsibility of coordinating these meetings. The first such meeting is currently being organised and will take place in November.

If you have any comments about Polio Services Victoria services, could you please send us an email to postpolio victoria@gmail.com or write to our postal address - Ross House, 247-251 Flinders Lane Melbourne VIC 3000. All the feedback we receive helps us to reflect back to PSV what its clients experience. Of course we wouldn't use people's names.

All in all, it was a very constructive and cordial meeting and PPV looks forward to continuing to represent and advocate for Victorians with polio in the future.