

Committee:

Liz Telford (*President*), Martin Grillo (*Vice President*), Bernard Peasley (*Secretary*), Geoff Dean (*Treasurer*), Ron Bell (*Support Group Liaison*), Angela Bruzzese, Maree Jongkryg, Jill Pickering, Bob Slater, Peter Willcocks

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PPViews

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From the President

“Nothing about us without us” is an old motto used by many different advocacy groups and it stresses the importance of participation in service development. *PPV*'s main focus this last few months has been participating in inquiries and discussions with government, service providers and politicians to put forward our concerns and our views and raising awareness of post polio wherever possible. *PPV* aims to ensure that services and programs meet the diverse needs of people with polio.

Below you will read about a few of these activities. Some of the documents referred to will be on our website shortly, but email us or phone, if you would like more information about any of these items, or would like to be more involved. All the best and hoping you are managing to keep warm this chilly winter! - Liz

Polio Australia Mass Canberra Gathering

We are heading off to Canberra for the *We're Still Here* October Polio Awareness Month campaign. (See attached flyer for details). Some are going for the day, others for a night or two. If you can get away, it would be great if you can join us! Liz has booked a meeting with Adam Bandt who is her local member and also the member for the Independence Australia office, so Liz and Jen Sykes and any others who want to join them, will be having a chat with Adam Bandt about post-polio. A draft letter that you can use to make an appointment with your local member in Canberra was emailed to you recently. Contact us if you would like a copy sent to you.

Contact Jill Pickering: (03) 9428-4709
pickjill@hotmail.com

Released: The Post Polio Parliamentary Roundtable Discussion Paper

The discussion paper on the late effects of polio/post-polio syndrome House of Representatives Standing Committee on Health and Ageing 29 June 2012 can be downloaded from:

http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/leop%20pps/report.htm

What a day this was! It was a great sign of recognition that *PPV* was asked to participate in this important event. The committee has published their finding and full details are available on the parliamentary website and we recommend that you take a look. In essence the committee arrived at three recommendations:

- Aust. Bureau of Statistics should conduct a count/estimate by of the people with Late Effects of Polio/Post Polio Syndrome;
- Education and training of health professionals and allied support services needs to be improved; and
- Boards of Medicare Locals should liaise with Polio Australia and the State Networks.

You might suggest that this is pretty obvious, but this is the first time that the above recommendations are supported by an Australian Government Initiative. We are sure that the recognition and report is only a beginning. What a fantastic outcome for all those who put in so much work.

The NDIS and polio - how will we fare?

PPV strongly supports the NDIS, but seeks to have the benefit available throughout life, rather than ceasing at aged sixty when the aged care system (not well equipped to deal with disability) is to take over.

The *PPV* Advocacy Working Group, convened by Dr. Margaret Cooper A.O., has developed a position paper on the NDIS and this will be on the website soon. *PPV* is organising meetings with relevant politicians such as the Minister for Disability Reform, (and Minister for Families, Community Services and Indigenous Affairs), Jenny Macklin.

Breaking news: As this newsletter was being prepared The Victorian Premier announced that Victoria would participate in the NDIS trial. Good news for people with disabilities! *PPV* will continue to voice the needs of people with post polio and work towards an NDIS that is relevant to us all.

Victorian Taxi Industry Inquiry

As well as being represented at the VCOSS consultation forum by Maree Jongkryg, PPV put in a submission based on the concerns raised by PPV members and other polio survivors who have spoken to us.

PPV members report that some wheelchairs have been rejected as unsuitable for travelling seated in the wheelchair, causing great distress. We would like the Department of Transport to work with relevant departments and services to identify and make public a list of wheelchairs in which people can remain seated during travel. Guidelines on wheelchairs/mobility aids acceptable for travel on wheelchair accessible taxis need to be brought into line with international standards.

For those not in wheelchairs, getting in and out of taxis can be difficult. PPV believes that all taxi vehicles should be accessible. As identified in the report, it is preferable for taxis to be universally accessible, as are London taxis.

Our members have experienced unwillingness by drivers to take short fares, difficulties hailing taxis and a lack of driver sensitivity to issues of disability. PPV believes that improved driver competency, training, remuneration and work conditions are relevant to this problem. It is important to include training in safely securing wheelchairs in Wheelchair Accessible Taxis, disability awareness and sensitivity to passenger needs. *(Full submission available on the website soon).*

Did you know...?

Essential Medical Equipment Payment

To offset costs that may arise from the carbon tax, the Commonwealth Government has introduced a payment of \$140 for people whose disability requires the use of certain medical equipment eg ventilators, CPAP machines, motorised wheelchair and heating and/or cooling in the home to regulate body temperature. (You need to hold a Commonwealth Concession or Veteran's Affairs card to be eligible).

PPV has received clarification that Post Polio Syndrome is included as one of the medical conditions that would receive the Essential Medical Equipment Payment, under the classification "neurodegenerative disorders".

The Medical Practitioner completing the claim form is responsible for determining whether the symptoms are due to post polio and fall into the neurodegenerative disorder category. *(Full response from Martha McHugh,*

Assistant, Section Manager Carer Payments, Disability and Carer Families, Housing, Community Services and Indigenous Affairs available on the PPV website soon and will be published in Polio Australia's next "Reflections")

For more information on the Essential Medical Equipment Payment phone Disability Sickness and Carers on 132 717 or refer to the DHS Website:

<http://www.humanservices.gov.au/customer/services/centrelink/essential-medical-equipment-payment>

PPV sponsored place at the Queensland Post Polio Health and Wellness Retreat

Pauline Corrigan from Traralgon was the recipient of this special PPV offer, which was made possible by the generous donation of the North Blackburn Lions Club. Pauline said that she left the Retreat feeling very positive.

"I came away feeling tired but refreshed with the hope of more good things to come" and "I can't recommend the Retreat more highly", Pauline wrote, thanking everyone concerned.

(Full article in the winter edition of Independence Australia's Inform/Polio Perspectives).

Vale Joan Gillespie (1937 -2012)

Joan Gillespie contracted polio at five months and was cared for by a number of hospitals (the Royal Children's, Austin, Mt. Macedon, Frankston Orthopaedic and Lady Duggan) and then at Yooralla until her early teens. Later, she lived at Deva Hostel, Angus Mitchell House and later became a resident of Fairfield Hospital until she went to live with her partner in 1980.

She worked full time for 23 years until post polio made this impossible in the late 1980's. However she continued to work tirelessly for the community visiting the Fairfield, Repatriation and Austin hospital wards.

For many years she was accompanied by her little dog, Charlie perched on her wheelchair (as those that attended the PPV Forum at Northcote Town Hall last year were delighted to see).

Joan's community work was recognised in 2011 with Veteran Community Award as part of the Victorian Senior of the Year Awards for her exceptional contribution to the veteran community. Joan served on the Polio Advisory Committee from 2002 to 2005. Joan will be truly missed by all and our condolences go out to her partner John and their many friends.

PLEASE KEEP SATURDAY 17 NOVEMBER FREE FOR OUR ANNUAL GENERAL MEETING
It will be held at 2.00 at Disability Sport and Recreation (formerly Wheelchair Sports) 341 Gore St Fitzroy.
More information will be available soon. Your support and input is important for our success!