

PPViews Post Polio Victoria Newsletter No 3 October

Hello everyone,

Thank you to all of you who participated in our consultation meeting on August 22nd. In spite of roadworks in High Street Northcote reducing the parking significantly, seventy people attended. We had some great coverage in *the Age* the previous week and on the *Red Symons Breakfast Program* on the day. Thank you to those of you who registered an apology. Many thanks to Cheryl Sullivan who facilitated and to our helpers Cathy Tolnai, Beth Exiner, Carol-ann Allen, Ron Exiner and Judith Bell. It was a wonderful day with lively discussion, sharing of stories, many suggestions and of course a tasty lunch. We have included a summary of our consultation meeting with this newsletter. Thank you also to those who have registered interest in being part of a working group, which will be discussed further after our forthcoming Annual General Meeting on the 26th November. We are now refining the Constitution which will be on the website soon, to be endorsed at the AGM and we hope you can make it. Before that though, we hope to catch up with you at Polio Day on October 22nd. *Regards Liz, for the PPV committee.*

EUROPEAN CONFERENCE ON POST POLIO SYNDROME

Liz attended this conference held in Copenhagen, Denmark August 31-September 2. To see the program go to www.poliocconference.com and to see videos of some of the presentations go to <http://www.poliocconference.com/Power%20points.php>. Mary-ann has written a comprehensive diary and report and I encourage you to visit the **Polio Australia website** www.polioaustralia.org under *Hot News*. There is also a link to view conference video presentations.



Blaise Doran (PSV), Liz Telford and Mary-ann Leithof (Polio Australia) at the reception at the Copenhagen City Hall.

POST POLIO VICTORIA'S FIRST ANNUAL GENERAL MEETING will be held at the Disabled Motorists Association 2A Station Street Coburg 1.00 Saturday November 26.

This venue has ample parking.

Please consider nominating for the committee.

Meetings are held monthly. If you would like to find out more about what is involved, please contact any of the interim committee management members.

A notice and nominations forms will be sent to members soon. If you haven't yet joined, please download the membership form from the website or contact us. Only members can nominate.

WORLD POLIO AWARENESS WEEK-COFFEE FOR POLIO October is **Polio Month**. Polio Australia invites us to **send in photos** of community awareness activities. Why not invite a friend or two for coffee to discuss local and global polio issues? If **orange** isn't their (or your) colour-why not get some fabric and create a ribbon?

PPV-OBSERVER STATUS ON POLIO AUSTRALIA
The Committee of Management of Polio Australia has agreed that PPV can attend their meetings in an observer capacity. Most meetings are held by teleconference. Next PA meeting -14 October.

**SUMMARY OF PROCESS AND KEY OUTCOMES
FROM THE COMMUNITY MEETING OF POST POLIO
VICTORIA Inc HELD AT NORTHCOTE TOWN HALL ON
MONDAY 22nd AUGUST 2011**

INTRODUCTION

This meeting's aim was to find out from people who have polio their issues of concern, and their ideas about what PPV can do. This information will help PPV set its goals. The Committee is developing a strategic plan document to guide the work of the PPV over the next three years. The meeting also provided an opportunity for the community to find out about Post Polio Victoria.

MEETING PARTICIPANTS

65 people who experience PP symptoms, 3 staff members (Independence Australia, The Council of Self Help Groups and Polio Services Victoria) and 5 people assisting with the organisation of the day. A number of the participants have not previously been involved with any Polio Support Groups or services.

GROUP PROCESS

Participants were sitting at 8 tables. The people at each table were asked to share with each other what the key issues are to them and to discuss priorities. These were then reported back to the entire group.

PRIORITY ISSUES

The priority issues which emerged are:

The need for better Information for post polio survivors, their families and medical and allied health services they use

Better education in polio and post polio for GPs and allied health staff

A register of all polio survivors (it was noted that Polio Australia is working on this and all participants were encouraged to register if they hadn't done so already)

More affordable and available Aids in the home

HOW CAN PPV ADDRESS ISSUES RAISED

The meeting believes that PPV can help address the priorities by:

Advocating to AMA, other professional groups and governments

Holding annual Awareness days

Disseminating research results and news about polio and post polio

Not duplicating or undercutting other groups

Representing polio survivors effectively when decisions are being made.

WHERE TO FROM HERE?

The outcomes of the meeting are being considered by the PPV Committee as it puts the PPV Strategic Plan together. The Plan will be publicised in the near future.

....FROM OUR COMMUNICATION OFFICER

Since the last newsletter I have participated in the Taxi Inquiry Forum. We emailed you the report that came out last week. I also represented PPV at the Annual General Meeting of the Aids and Equipment Action Alliance, whose vision is "That Aids and Equipment is readily and equitably available to all people who require it to enable full participation in society." Well worth our support! Peter Willcocks has joined the AEAA committee as Secretary.

All the best, Ron.

...FROM OUR TREASURER

Owing to the generosity of a few enthusiastic friends of Post Polio Victoria and some very worth while grants PPV has not been stressed financially during the evolving establishment process. For the future however, pretty much every idea people put forward as a worthy project has a dollar figure attached and we will only be as successful as the amount of money we can attract for distribution. I take this opportunity to point out to readers that we have successfully applied for "Gift Recipient Tax Deductibility" which is important because like most other not for profit charitable organisations any donation we receive is Tax Deductible.

Happy hunting—Geoff.



Participants at the PPV consultation meeting.

THE GLOBAL POLIO SITUATION

At the conference in Copenhagen we met polio survivors in their twenties and thirties who had contracted polio in countries such as Kadistan and India. We are part of a global "polio community" and we can each contribute to raising the awareness of others that polio is a current concern and not a thing of the past. Last week there were ten polio cases in western China, believed to have spread from Pakistan. China had been polio-free for ten years.

For more information go to :

<http://www.polioeradication.org/Mediaroom/Newsstories/Newsstories2011/tabid/408/iid/158/Default.aspx>

PPV Promotion

If you missed the Age article here is the link:

<http://www.theage.com.au/victoria/cruel-syndrome-brings-return-of-polio-symptoms-20110815-1iutt.html>