

PPViews

Post Polio Victoria Newsletter, No 7, December, 2012

2012 President's Report

Liz Telford's, 2012, President's Report, is attached.

From the New President

by Jill Pickering

Our second PPV AGM was held at the Disability Sport and Recreation (DSR) Office at 241 George St, Fitzroy, on Saturday November 17th, 2012, at 2:00pm.

After nominations and voting there were changes to the PPV Committee for 2013 with Ian Paroissien and Joan Smith joining us and Martin Grillo, Bob Slater, Angela Bruzzese, Peter Willcocks and Bernard Peasley departing. However, Martin Grillo and Peter Willcocks will continue to work with Margaret Cooper on the Advocacy Working Group, and Bernard Peasley will manage PPV's website and produce our quarterly Newsletter. PPV acknowledges the contribution from previous Committee members, and is very pleased that several departing Committee members will continue to support us in key PPV work. The new Committee, elected at the November 2012, PPV AGM, are:

Office Bearers:

Jill Pickering – *President*
Ron Bell – *Vice President*
Joan Smith – *Secretary (new)*
Geoff Dean – *Treasurer*

Ordinary Members:

Maree Jongkryg – *Chair*
Liz Telford
Ian Paroissien (new)

NB: Bernard Peasley will remain interim secretary until Joan Smith takes over in February 2013.

Additional PPV Support:

Margaret Cooper – *Advocacy Working Group Convenor*
Bernard Peasley – *Website and Newsletter Editor*

New Committee Member Introductions

by Jill Pickering

- Joan Smith retired early due to Post Polio problems and is involved in a range of voluntary roles, including being convenor of the Knox-Yarra PSG and a member of the Knox City Council, which enables her to keep the municipality aware of Post Polio and general disability issues. Joan will take over as Secretary in Feb, 2013

- Ian Paroissien is 76 yrs old, married for 43 years, a goldsmith for 58 years, and is still working 2 days/week. He is also a member of the Australian Labour Party & Jenny Macklen's electoral team. Ian contracted Polio in 1945, used crutches for 55 years and has used a wheelchair for the past 15 yrs.

The PPV Committee will start the New Year with a Planning Day in early February to identify key priorities for action during 2013. It will provide a chance for the new Committee to develop productive, working relationships for 2013. There is so much to be done, but with a full committee of active members, we could achieve more. So if any other PPV members would like to offer their skills, please contact Jill Pickering by phone – (03) 9428-4709, or email – pickjill@hotmail.com.

London Paralympics: two perspectives

by Liz Telford

At our AGM, held at DSR on Nov 17th, we were treated to two fascinating insights into the London Paralympic Games, by our guest speakers Brian McNicholl (OAM & ex-paralympian) and team orthotist, Darren Pereira.

Brian told us how his childhood experiences started him on the path to becoming a Paralympic champion. To deal with childhood bullying, Brian developed some pretty persuasive self-defence strategies. In addition, with support from his family who recognized that he would need to develop his upper body strength to compensate for lower limb issues, he got involved in athletics and power-lifting. A Gold, Silver and Bronze Medallist, he had to retire before the 2000 Sydney Games due to an injury but continues his involvement and attended the London Games as a Technical Assistant.

Darren went to London as the Australian team orthotist. His main role was to assist the athletes to move more efficiently around the Olympic Village as in previous Games some were tiring because of the size of the Village. Competitors did not wear these orthotics during competition. Darren explained some of the rules regarding the wearing of orthotics and it was surprising to hear that while amputees wore expensive equipment, orthotics were not allowed to be worn in competition. Darren described how confronting it was to watch a

competitor who would normally wear a brace, fall near the finish line.

The Australian Team is supported by some of the world's the best technologies. A PPV member asked Darren whether any of these resources were being used for the general (disability) community, and his answer was that this hasn't been the case to date. Perhaps this needs some follow up, as the "technologically more advanced" orthotics are out of reach for many people. Darren's professional association is campaigning for orthotics to be listed under Medicare, as it is one of the few allied health services that is still not covered.

PPV Members join Polio Australia for the "We're Still Here" Campaign in Canberra

On Wednesday 31st October 2012, 60 polio survivors and their supporters from around Australia attended the "We're Still Here!" Campaign at Parliament House Canberra. These campaigners comprised: 35 polio survivors, 14 partners, and 11 friends or family members.

The photo below shows the Victorian PPV delegation meeting with Federal Greens Member, Adam Bandt.



Victorian Taxi Industry Inquiry

The Taxi Industry Inquiry's Final Report, *Customers First: Service, Safety, Choice* was tabled in State Parliament on 12/12/12. Over the course of the Taxi Industry Inquiry more than 1,500 written submissions were received from many hundreds of taxi users, industry

participants and community business groups across Victoria who engaged with the inquiry and provided input. PPV prepared and presented a submission.

The Final Report can be viewed at:

<http://www.taxiindustryinquiry.vic.gov.au/final-report-customers-first>

Tips for booking a Wheelchair Accessible Taxi (WAT) on Christmas Day

Christmas Day is a busy day for taxis and particularly wheelchair accessible taxis (WATs). To help you to book a WAT on Christmas Day, the VTD has been in contact with both **Silvertop Taxis** and **13CABs**. Both companies will take bookings for the outward and the return trip (if applicable). If a booking can't be covered on Christmas Day by Silvertop Taxis or 13CABs they have an arrangement in place to work with each other to cover the booking as quickly as possible. Their arrangements for booking a WAT, in Metropolitan Melbourne on Christmas Day, are below.

Silvertop Taxis

Christmas Day Bookings for WATs open on 3rd December and close on 22nd December. After advance bookings close, passengers are still able to ring on Christmas Day and book for "the next available WAT". The Silvertop Taxis WAT number is: **8413 7202**

13CABs

Christmas Day bookings are now open. Depending on demand, bookings for Christmas Day may close in the week before. If bookings do close, customers will be encouraged to ring on the day to request a WAT and will be advised of any delays at the time. The 13CABs WAT number is: **136294**

Mobile Phone Handset Needed

With the change in Secretary, PPV needs a second-hand mobile phone handset. If any member knows of a simple (smart phone not needed) handset that could be donated to PPV, could they contact Bernard Peasley at the PPV phone number - 0431 702 137.

May all PPV members and their families have a safe and happy Christmas, and may 2013 bring you all health, wellbeing and peace.

– PPV Committee

The "We're Still Here" campaigners in the foyer of New Parliament House, Canberra, 31st October, 2012



PRESIDENT'S REPORT TO THE PPV ANNUAL GENERAL MEETING, 2012

I am pleased to present the Annual Report for 2012. Consistent with the Three Year Strategic Plan (presented to the Association last year), we have focussed on five key objectives, which are to:

- establish a viable committee structure,
- advocate on issues that specifically affect people with post polio,
- increase community awareness,
- develop relationships with other organisations; and
- promote post-polio research at a national level.

While our activities have been guided by the Strategic Plan we have also been able to respond to the needs and opportunities that have arisen during the year. I will list some highlights of the year.

Early in the year, we had the opportunity to host Canadian polio survivor, polio eradication and post polio rehabilitation campaigner Ramesh Ferris. We saw great value in this as providing a focus and energy to attract others to work with us on some community awareness raising and educational events. This was very successful and during his week here we participated in six events and in conjunction with Polio Australia we worked with GlaxoSmithKline, Disability Sport and Recreation, World Health Organisation, General Practice Victoria, Dr. Stephen De Graaf, Rotary Carlton and held our own event which attracted a broad audience and generated much interest.

The GP Education evening, which was part of the above program, was a first of its kind and generated an article that was distributed to the 22,000 GPs in Victoria in their online newsletter. We hope that there will be more such events and preliminary discussions with GPV staff and PA have begun. Misdiagnosis is such a serious issue.

Another key achievement was our appearance before the Parliamentary Standing Committee on Health and Ageing Inquiry into Post Polio. Our selection to appear indicates how PPV has come to be recognised as a legitimate representative of polio survivors. The resulting report highlighted many of the concerns that we raised. The voices of members of PPV were definitely heard in that report as the examples that I raised were all drawn from the examples members sent to us in response to our call.

One of the matters we raised to the inquiry and highlighted in the report is the lack of hospital protocols for hospital management of people identified as having post polio. The unnecessary death last year of Victorian polio survivor, Vivian Endene, highlights this need. PPV supports Vivian's partner Fleur Reuben in her attempts to have his case files independently reviewed and I hope that we will see the development of effective protocols, the absence of which we feel contributed to Vivian's death.

Ensuring that Victoria has services to meet our needs is an important advocacy goal for PPV. We met with Blaise Doran of Polio Services Victoria to discuss the current state of the service and to help us develop our advocacy targets. We were informed of the waiting times (4 months or longer for regional clinics), the increase in younger overseas born patients and we shared some of our views, concerns and hopes about PSV. From our initial meeting we have identified the need for funding for community education and case-work support for polio services. The conversation between PSV and PPV will be on going, and we appreciate the support indicated by Blaise and the PSV staff towards PPV.

We have actively advocated to Independence Australia and the Polio Reference Group about the appropriate and transparent use of the Special Purpose Post Polio Fund, a fund established by donors to provide education and community awareness.

We have also advocated to the Taxi Inquiry, the Accessible Public Toilet Inquiry and to the Federal Government about the Essential Medical Equipment Program.

The Advocacy Working Group has been established and is convened by Dr. Margaret Cooper OAM. A major focus for the Advocacy Working Group has been the development of a PPV policy on the NDIS and advocating to a number of key politicians and advisory groups. We believe we are the only polio group working to ensure that the NDIS meets the needs of people with polio. We are advocating to remove the age limit which will discriminate against those with conditions such as post polio which can lead to disabilities develop later in life.

I would like to acknowledge and thank members of this group. Particular thanks to Margaret for convening and guiding it so well. Thank you also to the other members - Wayne Slattery, Peter Willcocks and Lyn Lillicrap for their participation.

Publicity for PPV has been strong with a number of exposures in the media including the Leongatha local newspaper, the Geelong Advertiser, Seniors magazine (which is distributed Australia wide both Ion-line and in hard copy) and an interview on ABC Gippsland.

Our website has been well managed by Bernard Peasley and is well used. The website has a growing number of links, key PPV documents and ours and others newsletters. We also actively promoted Polio Australia's register on our website. We see this as the best way for us to promote research at a national level.

Our fundraiser screening of the film "The Sessions", initiated and coordinated by Shirley Glance was a great success in a number of ways. Not only did it raise over \$1500 but it also provided the excuse to send hundreds of flyers out to organisations, family, friends and colleagues, around Melbourne with information about post polio and PPV. There was a wonderful atmosphere at the Como Cinema in the foyer with 160 attending. Many thanks to Shirley for the idea, her enthusiasm and for coordinating this with me. Her positive approach and organising skills were greatly appreciated.

There are a number of other people and organisations I'd like to thank for their support in various ways of PPV during the year. Polio Australia, on which we have Observer Status, Disability Sport and Recreation for providing this venue and the Collingwood Neighbourhood Justice Centre where the committee meets, and also to Jen Sykes of Polio Network Victoria. I'd also like to mention the quiet on going support provided by Keith Yates from the Blackburn North Lions Club, whose company Web Foot Technologies sponsors our website. The Victorian Local Government Association (VLGA) has done the printing of all the material we have mailed out to members who don't have email, and we thank them for this support.

This is our first year as a full Management Committee and there have been some challenges along the way. I have outlined the highlights, but there is also a lot of administration involved in operating as an incorporated association. We are all volunteers and affected by post polio in various ways. This is why it is important that as many people as possible get involved to share the load. I would like to thank all this year's committee members: Our Secretarial team lead by Bernard Peasley included Jill Pickering and also Maree Jongkryg (who looks after membership applications), our Treasurer Geoff Dean, Ron Bell who has kept us in touch with the polio support groups, and Peter Willcocks who has kept us in touch with the Aids and Equipment Alliance and other relevant groups and Rotarian Bob Slater. I would also like to thank Angela Brusseze who connected us to Diversity and Disability, and founding member Martin Grillo who introduced us to number of advocacy groups, including Disability Resource Centre both who left the committee during the year. I would like the contributions of each of these 2012 committee members to be acknowledged.

The partners and family members of the Committee members deserve a special mention and I would like particularly to thank my husband Ron Exiner (an Associate Member of PPV) for supporting and enabling my work with PPV. He has also facilitated our printing at the VLGA. The partner's and families of the other committee members have also been important contributors to PPV's success and this is greatly appreciated.

Finally, I'd like to thank all PPV members for their participation and interest. PPV now has well over 100 members and this demonstrates the need for a group like this.

After two years in the position, I am not re-nominating for President and it is time for someone else to take the leadership role. However, I am standing for the committee because I think our work is so important and will continue to work on the advocacy issues. I think we can all be proud of what we have achieved in our first full year of operation.

Liz Telford

17 November 2012