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Post Polio Victoria Newsletter

Nº 10, October 2013

“Walk with me” Fund-raiser

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Vale Beth Brodribb

Beth worked at Paraquid during the genesis of the polio network. She worked tirelessly for polio survivors.

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Membership Survey

When PPV was founded in 2011, it was decided not to charge a member fee. PPV has consulted with members to assist in decision making. **Page 3**

User Friendly Trams

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PPV AGM and Open Forum Invitation

Details of AGM and Open Forum on Saturday 16th of November at Disability Sport and Recreation. **Page 5**

President’s Report

We seem to be experiencing wide swings of warm and cold days as Spring settles in. Luckily we also had nice bursts of rain well timed for my garden lawn rehabilitation. After removing weeds, and seeding new grass I can now watch it grow.

Since our last newsletter your committee has worked on:

- PPV Membership Advocacy needs survey.
- Medical/Clinical Alert Issues – currently in contact with Polio Services Victoria (PSV) new coordinator who was due to start last month to continue this project.
- Keeping up to date with NDIS developments thanks to Margaret Cooper, PPV Advocacy working Group (AWG).

- Lobbying with Polio Australia to ask how Polios already 65yrs old or over, can access the same level of services the new NDIS system provides to people diagnosed with disability before the age of 65yrs.
- Written to The Honourable Terry Mulder, Minister for Public Transport to request his urgent attention to install lifts at train stations not situated at level crossings and call for all underground stations to have at least one fire safe lift.
- Supported Polio Australia’s “Walk with Me” fund raising campaign (page 2)

In conclusion, our key focus now is the next PPV AGM and Open Forum on Saturday 17 November 2013. We have two very interesting and relevant speakers for the day and ask members to spread the word to attend both the short AGM

and Open Forum. We have made gains this year, but could achieve even more with all committee vacancies filled. For Polio Survivors the key issue is how to pace and prioritise our activities. A viable PPV needs all Committee positions filled to spread the load and expertise. I urge you to consider nominating for the Committee. Together we can stay energised and deliver our full potential.

Warm regards, Jill Pickering



“Walk with me” fundraiser



Sunday 1 September dawned as a balmy, sunny start to Spring. As we assembled at Birrarung Marr we caught up with some familiar faces. ‘Walk With Me’ Campaign was organised by SCOPE, and allowed Polio Australia to join in for its own much needed fundraising.



Post Polio Victoria had a few participants with their sponsors to encourage us on our walk or ‘scoot’. Jill, Joan, Graeme, Ron, Judith and Liz were among

those who supported Mary-ann from Polio Australia. We helped to raise the wonderful total of over \$5000. Perhaps next year we can aim even higher.

Vale Beth Brodribb

Jen Sykes, Community Officer at Polio Network Victoria, a service of Independence Australia, recently advised she had received a phone call from Rod Harris advising that his mother, Beth Brodribb, passed away yesterday. Beth worked at the then named ParaQuad at the genesis of the polio network. Following is an excerpt from “Iron Wills’ that explains Beth’s involvement.

“Beth Brodribb, who had been working with ParaQuad’s sheltered workshop, was asked to help with the network. Beth was given the names of polio survivors and the network grew quickly. Her job was to gather and disperse information. Copies of material Edith (Hall) brought back were sent interstate in the hope of encouraging establishment of self-help groups all over Australia.

Within a year networks of polio survivors were formed in each state and territory. In Victoria, Beth had managed to contact 400 polio survivors, publish the first newsletter and organise a seminar that attracted people from all over the country.

The aim of the seminar was to discuss the needs of post polio survivors and to share information. Recommendations from the seminar were taken up with the Health Department.

In 1989 the network changed its name to the Australian Polio Network and began a social program for members, numbering well over 500. Beth Brodribb went to St Louis for an international polio conference and also visited the British Fellowship in the UK. Like Edith, she returned with valuable resources and information.”

We have a lot to thank Edith and Beth for – Jen Sykes

Mary-ann from Polio Australia has a free ‘as new’, height adjustable shower stool looking for a new home. It was bought for her mum who has since moved into an aged care facility. (Ed. Sad news, Mary-ann’s mum has passed away and we extend our profound sympathies to her and her family.)

Contact details for Mary-ann are: PO Box 500 Kew East Vic 3102
Suite 119C/Level 1/89 High Street Kew Vic 3101
Phone: 0466 718 222 / (03) 9016 7678 / Email: mary-ann@polioaustralia.org.au



PPV's Advocacy Survey

Earlier this year, PPVs Advocacy Group produced a survey to inform it of future directions that advocacy could take for the organisation.

The survey was released in July, and we have been delighted with the response. Over seventy people completed the survey, both online and in paper form.

Following is an initial report on the findings. A further more complete discussion will be reported in future editions of PPViews.

About two thirds of the respondents were female and over 80% of respondents were born in Australia. The majority of respondents were in their 60s and 70s. However, it was interesting to see people in their 40s and 50s also. As can be seen from the pie chart above, over 84% of respondents have some symptoms of LEOP or PPS, possibly up to 99% if the unsure people are included. (See Diagram 1)

I was surprised to see that nearly half of the respondents funded aids and equipment themselves.

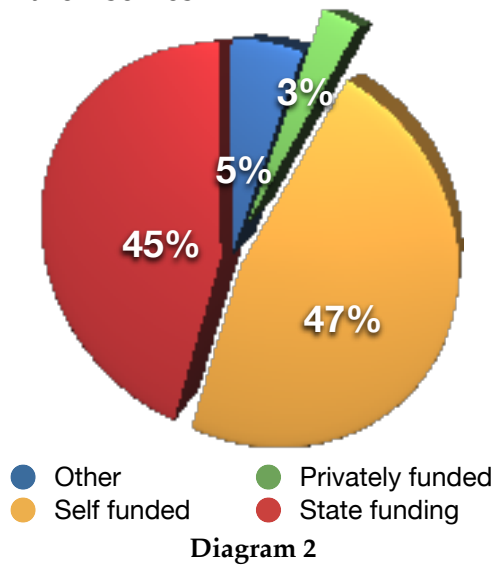


Diagram 2

Some respondents were able to find assistance through private funding such as Lions etc. (See Diagram 2)

A point of concern is that 45% of respondents felt that health practitioners were not aware of

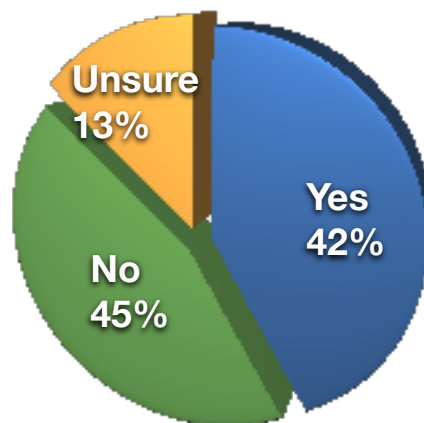


Diagram 3

the health and treatment implications of PPS, a further 13% were unsure. (See diagram 3)

Also of concern is that medical staff failed to discuss treatment management issues related to polio such as anaesthesia, medication and rehabilitation in nearly two thirds of the respondents. (See Diagram 4)

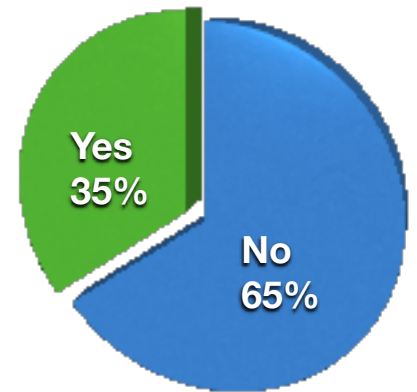


Diagram 4

This strongly reinforces the need for further training of health professionals to better meet the needs of the Polio community.

Most of the respondents were aware of organisations supporting the Polio community such as Polio Services Victoria, the Victorian Respiratory Service, Polio Network Victoria, Polio Australia and polio support groups.

Membership Fee Survey

When Post Polio Victoria was founded in 2011, it was decided not to charge a membership fee. It was also decided to review this decision in 2013.

At its May meeting, the PPV Committee of Management moved to survey members for their opinions on whether there should be a membership fee.

This was a chance for members to have a say about this policy change.

Over 90% of the respondents said they would consider paying a membership fee, and 100% of respondents said it would not effect their continued membership. Most of the respondents felt a fee of between \$10 and \$20 would be reasonable.

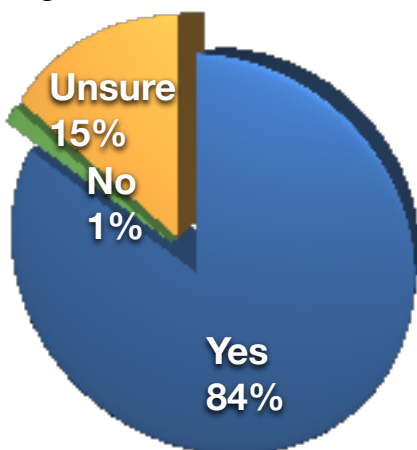


Diagram 1



AGM and Open Forum Day

Official Invitation

Saturday 16th November 2013
Time – 10.30am for an 11.00am start

To be held at
 Disability Sport & Recreation Centre.
 341 George Street, Fitzroy.
 Melways 2C C8.
 Loads of parking and trams nearby.

Please RSVP by Friday 8th November
 By Email – postpolio victoria@gmail.com
 OR by phone to the Secretary – 03 9763 8401
 so that we can provide seating and catering.

TIMETABLE

10.30am for an 11.00am start	- Arrive and register – Have a cuppa
11.00 – 11.30	AGM as per Agenda
11.30 – 12.00	Guest Speaker – Mary-ann Liethof (Polio Australia)
12.00 – 1.00	Lunch
1.00 – 1.45	Guest Speaker – Gary Ferguson (COTA – Council of the Ageing)
1.45 – 2.30	NDIS Political perspective from:- Hon Kelvin Thompson (ALP)
2.30	Afternoon Tea



Lunch and tea/coffee provided
A Carer will be available to assist

Super Stops – Melbourne Wheelchair Accessible Tram Stops

The AQA Peer Support/ Information Department has located all the Tram Super Stops on their AQA website. To access the Super Stops and their locations' just enter the AQA website and on the left column click onto the 'Information Service' section then proceed to the 'Melbourne Wheelchair Accessible Tram Stops' section. The Super Stops are shown through Google Maps for easy reference.

There are over 330 super stops throughout metropolitan Melbourne with more set to open. With 50 new low floor trams on order, the total number of low floor trains on the network will increase to 150. Each super stop has a raised platform to allow easy access to the new low floor trams, and can include a number of additional features, such as touch screen information, Metcard ticketing machines, passenger information displays and next tram announcements.

Using accessible stops

Melbourne's tram network has a growing number of accessible stops, each built to suit the environment around it and to consider the needs of tram passengers, motorists, cyclists and pedestrians. Each stop has its own unique characteristics.

Centre Island Platform

A Centre Island Platform stop is located in the centre of the road. Trams approach the stop on the left side of the platform and passengers get off and on from the right hand side of the tram.

As the doors open on the opposite side to a 'normal' stop it is important for passengers not to stand in the off-side step-well of a tram when entering these stops as it can interfere with the operation of the doors. Some centre island stops are limited to trams only, while some also allow road traffic to pass through when trams are not using it. Examples: Flinders St / Swanston St, Melbourne University.

Kerb Extension Stop

A Kerb Extension Stop allows level access for tram passengers, but also a path for cyclists or motorists. In addition to tram passengers, cyclists may also use designated cycle path on the stop. In some locations cars are permitted to drive over the raised area of the Kerb Extension Stop, but must stop when a tram stops and give way to passengers getting on and off the tram. Pedestrians should wait behind the yellow line until the tram has arrived and its doors have opened. In Swanston St, Melbourne - motor vehicles are not permitted to travel across the Kerb Extension Stops. Example: Bourke St / Swanston St, Northcote Town Hall.

Platform Stop

A Platform Stop provides level access to low floor trams. Unlike a Central Island Platform Stop, the trams open their doors on the left side and there is a dedicated platform for each direction of travel. Passengers should stand behind the yellow

line until the tram has arrived at the stop and opened its doors. Cars and cyclists are not permitted to follow the tram tracks at Platform Stops. For pedestrians - crossing between the two platforms is prohibited other than at the designated crossings provided. Example: Federation Square, St Kilda Rd / Commercial Rd.

Easy Access Stop

Easy Access Stops provide level access to low floor trams while also allowing road traffic to operate separate from tram tracks. Cars and cyclists must stop when a tram enters the stop, but passengers should wait clear of the roadway until the tram has stopped and opened its doors. Example: Harold St / Danks St, Middle Park (above), Macarthur St / Spring St, Melbourne.

For more information please visit:

- AQA Victoria - http://www.aqavic.org.au/information_melbourne_accessible_tram_stops.html.
- Yarra Trams - <http://www.yarratrams.com.au/using-trams/accessible-journeys/making-your-accessible-journey/>.
- Public Transport Victoria - <http://ptv.vic.gov.au> or call on 1800 800 007 (6am – 12am daily)

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Website: www.aqavic.org.au

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Introducing Rod Hysted, the new editor of PPViews

G'day, I am Rod Hysted. I have been asked by the PPV committee to take on the role of "producing" PPViews. I hope that members will provide feedback as to how our newsletter can best meet your needs. My email address is rhysted@mac.com, for any suggestions. The newsletter will evolve over the coming months as I get used to producing it.

So here is a bit about me: I contracted polio early in 1964, when I was 7. I was in grade 2, and have no real memories of the time polio began effecting me. Apparently, I was beginning to dislike school, which was very unusual, as I had loved school. I had increasing difficulty walking to and from school. Mum began to worry one afternoon, when I hadn't arrived home. She searched for me, and found me lying, crying in the gutter, unable to walk.

I was eventually diagnosed with polio. According to my mum, it was an unusual case, as I had received my 'polio shots', and it was at the very end of the polio epidemics.

I spent the rest of the year at Lady Duggan during the week, and went home on weekends. I was fortunate to have an excellent physiotherapist, Carolyn Goldberg, who had recently returned from studying polio treatment in

the USA. I remember with great fondness nurse Calder, who made our days great fun. I also remember with equal fondness Mona Tobias, who was a pioneer in special education, and instituted many creative solutions to help educate the kids at Lady Duggan.



From an article in The Sun, 2nd Dec 1964

I hated Friday lunches with fish and chips because the fish was horrible, destroying the magic of Friday fish and chip nights for years afterwards. I intensely disliked the bodice that strapped me to my bed each night and the plaster casts my legs were banded into. It took many years for me to be able to use a sleeping bag without feeling claustrophobic.

I had monthly visits to the Royal Children's Hospital. I was very excited after one of my final visits, because I was told I would walk again. When I had my next physio session I declared to Miss Goldberg that I was going to

walk then and there. She suggested that I should take it slowly. Surprisingly, it was almost successful as I tried walking in great imitation of a drunken sailor across the room, before falling down as my under-exercised muscles gave up. I was on top of the world! I had walked again. Apparently, I had been adamant since contracting polio that I **would** walk again, and had no hesitation letting everyone know it.

After returning home, just before Christmas that year, life slowly returned to normal. I went back to school the following year, in year 4.



Discharge letter from Miss Goldberg, 1964

I was fortunate to retire, at the beginning of last year, after 35 years as a teacher in primary and secondary schools, and more recently as an assistant principal. I am extremely grateful to be married to Heather and have two wonderful boys.

I am delighted to be associated with Post Polio Victoria, and am looking forward to taking up my new role of bringing PPViews to members.