



2014 Committee:

Jill Pickering (President), Maree Jongkryg (Vice President), Joan Smith (Secretary), Geoff Dean (Treasurer), Graeme Smith, Fleur Rubens, Rod Hysted.

PO Box 6, Clifton Hill, VIC, 3068

Email: postpoliovictoria@gmail.com

Web: www.postpoliovictoria.org.au

Facebook: <http://on.fb.me/1gtxUFT>

Phone: 0431 702 137 ABN: 98 441 126 864

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Post Polio Victoria Newsletter

Nº 11, January 2014

President's Annual Report 2013

Jill Pickering's annual report on the activities and challenges of Post Polio Victoria during 2013

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Advocacy Working Group Annual Report

A report from Margaret Cooper on the work of the Advocacy Working group in 2013.

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Annual Financial Report

Geoff Dean's Report on the financial activities of Post Polio Victoria for the 2013 calendar year.

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Reader smoke haze tip

With bushfires raging over Victoria in recent weeks, how a member coped with the effects of the smoke haze.

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Bushfire planning leaves behind people with disabilities

An interesting article on issues for people with disabilities during the fire season.

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Accessibility and inclusion in Victoria's national parks

Something for the more adventurous in us all. Bush walking for people in wheelchairs.

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President's Annual Report 2013

Committee Members

I would like to thank the committee and our Advocacy Working Group (AWG) for their valuable contributions to PPV. Although we lost two committee members during the year - Ian Paroissien, due to major health problems & Liz Telford our Inaugural President, for family reasons, Rod Hysted joined and

now produces our newsletter *PPViews*. The AWG group, coordinated by Margaret Cooper has been joined by Wayne Slattery and Gayle Hennessy.

Planning Day February 2013 identified four Key Goals for 2013 which were that PPV:

- Be a strong & sustainable voice for Victorian Polios,
- Demonstrate NDIS accountability to political parties this election year,
- Increase Committee and AWG members to maximise our advocacy potential, and
- Continue raising community awareness of Polio Survivor's unique needs.

1. Be a strong & sustainable voice for Victorian Polios

Work Smart - After major achievements last year and subsequent committee changes, we focused on working at levels we could realistically maintain. We collaborated where possible with like minded groups to reach wider audiences and minimise operational costs such as insurance for public events. We are grateful that Disability Sport & Recreation have provided this venue free of charge for the second year. *(Continued next page)*

Funding - Thanks to Liz Telford we received a \$1650 grant from DHS for general operating costs, such as producing the newsletter, correspondence and attendant carer help for forums and



committee meetings as needed. However with more on the committee we could provide an even stronger advocacy voice for Victorians.

Membership Fees – We surveyed members this year and found around 90% would pay an annual fee between \$10 - \$20. The final figure will include a hardship clause safety net and apply from July 2014. Non-financial members will not have voting rights.

PSV – Met twice with Blaise Doran, until he resigned in July this year (2013. Ed) and will re-commence regular meetings with PSV's new co-ordinator Russell Anbiah shortly.

Polio Australia – We represented PPV on Polio Australia's Committee to which we have observation rights.

Polio Network Victoria (PNV) – Jen Sykes and I met quarterly to ensure both organisations play an effective complementary role for Victorian Polios.

2. Demonstrate NDIS accountability to political parties this 2013 election year

Ian Paroissien spoke to Jenny Macklin several times during his short time on the committee.

PPV received positive feedback on the quality of our submission to the NDIS Parliamentary Committee.

PPV has joined Polio Australia in lobbying to ask how Polios already 65yrs old or over, can access the same level of services provided by the new NDIS system up to the age of 65yrs.

3. Increase Committee and AWG members to maximise our advocacy potential.

There are 12 positions on the PPV committee. We need a full committee to spread the work & skill base to operate at our most effective level. We still have 5 vacancies and urge everyone to canvas members, friends and others to join this worthwhile cause.

Advocacy Working Group – Has held regular email meetings and recently a face-to-face meeting convened by Margaret Cooper. Points raised included:

- Wayne Slattery will represent PPV on the All Aboard Transport Action group,
- Need to discuss assessment, equipment and swimming programs issues with PSV, and
- Ability for other culture needs to be met by PSV

4. Continue raising community awareness of Polio Survivor's unique needs.

Survey - Conducted a Survey on PPV member needs (Reported on in previous PPViews. Ed)

Newsletter – Ongoing production of a quarterly newsletter PPViews.

Website – Reviewed the content, structure and updating process with Bernard, our website manager recently. Additional ideas included information on; government subsidies, social needs, heating and medical cooling, home renovations on our web page titled "Financial Assistance", NDIS and AWG developments.

Facebook - Rod Hysted has started a Face Book page. <http://on.fb.me/1gtxUFT>

Information to Members - Circulated on an ongoing basis.

PPV Presentations - Two presentations about PPV activities to Rotary and Probus clubs

International Polio Month October - Helped Polio Australia (PA) run the Bunnings display table, and joined PA on the "Walk with Me" awareness fund raiser campaign.

Canberra Lobbying - PPV members travelled to Canberra in June 2013 to support Polio Australia's "We're Still Here!" campaign.

In summary I thank the committee, AWG and members support for PPVs achievements and urge you to consider joining our committee. Together we can stay energised and deliver our full potential.

Jill Pickering

14 November 2013

ADVOCACY Working Group report

Appendix to PPV President report AGM 16 November 2013

Advocacy is about translating Post Polio Victoria's mission statement into action. It involves the Post Polio Victoria Committee, the Advocacy Working Group and all members.

The AWG has the benefit of input by several people by email or phone. We had our first face to face meeting 12/10/13. Liz Telford, Emilio Savle, Wayne and Rav Slattery, Margaret Cooper, Margaret Kinsella, Gayle Hennessy, Peter Willcox, Martin Grillo and Lyn Lillecrapp. Peter Willcox is an individual member of the Aids & Equipment Action Alliance, secretary of the AEAA Wait times project, and represents our polio perspective. Martin Grillo is on the Board of Disability Action Victoria and is able to alert us to relevant issues. Wayne represents Post Polio Victoria on the All Aboard Transport Action Group.

Our actions this year concerned:-

Monitoring NDIS

www.ndis.gov.au and Aged Care Reforms www.myagedcare.gov.au

The latter were introduced on 1/7/13. At this early stage the cutoff remains at 65, unless the individual was receiving disability support prior to that age. If so that person can elect to go with aged care or stay with disability services. Some concerns are that we don't know what disability services will remain

available to ageing clients and we don't know what funding Victoria will grant to clients and what the impact will be when there will be economic pressure to cost shift ageing people to the Federal Department of Health & Ageing budget.

The survey of members' experiences and wishes

Rod Hysted has collated the results and developed pie charts of interesting results.

Polio Services Victoria

There have been some concerns raised by members about service issues.

We need to continue the discussions begun this year with Blaise Doran, with the new coordinator about how this service might be developed.

St Vincent's Hospital and associated services

Liz has continued to work with Fleur Rubens to determine what factors were involved with Vivian Endean's death and seeking better processes for dealing with patients with a history of polio. This has involved trying to seek a case review and discussions with the Office of the Health Commission.

On behalf of Post Polio Victoria Liz assisted Fleur to meet with senior St V's medical and legal representatives. Liz and Fleur

took the opportunity to discuss the need for better education of medical staff about post polio issues and the development of protocols for patients living with polio and the possible increased role of Polio Services Victoria. A positive development has been that all known patients who have a history of polio have a "polio medical alert" attached to their file.

Safe train stations

Post Polio Victoria has written to the Minister for Transport Terry Mulder, about fire safe lift access at remodeled and future stations. We hope to meet with him or senior staff soon.

Financial assistance

Post Polio Victoria's website now carries information.

Employment

There are anecdotal and some survey reports of younger people having difficulty getting work.

Centrelink

A member has suggested there needs to be education of staff about post polio syndrome and late effects of polio

Cultural awareness

From the survey and anecdotal reports we have concerns around cultural awareness of service providers.

Margaret Cooper, Convenor.

PPV Financial Statement 2013

POST POLIO VICTORIA Inc.

STATEMENT OF RECEIPTS & EXPENDITURE

01.07.2012 to 30.06.2013

Cash Management Trading Account—BENDIGO BANK.

RECEIPTS		EXPENDITURE	
Bank Balance @ 01.07.2011	3,147.37	Consumer Affairs	43.90
Donations	2,530.00	L.E.P. Booklet	300.00
Interest	56.27	Brochure Printing	510.00
Taxi Refund	34.75	Taxi	393.45
		Secretarial	294.61
		P.O. Box	99.00
		C.O.S.H.G. Membership	15.00
		P.P. Health International	30.00
		Bank Transaction Fee	3.35
		Bank Balance 30/6/2013	4079.08
TOTALS	\$5768.39		\$ 5768.39

Reader smoke haze tip

"I had been distressed this week and didn't know what was causing these extra problems. More sweating, struggling with breathing, feeling weak physically, not able to do much at all, forgetting to eat, etc. until my son pointed out the smoke haze over Melbourne, and that I was struggling to breathe. This improved when I shut the windows and only had the air conditioner on." **As always, we recommend that you discuss this with your GP or medical specialist.**

Photo courtesy of: [Emmanuellives](#) at [en.wikipedia](#)



Bushfire planning leaves behind people with disabilities

When bushfires start, no one should be more worried than people with disabilities. Recent [research](#) shows people with disabilities are [twice as likely](#) to die or be injured than the general population during a disaster. They are also less likely to receive aid and less likely to recover in the long-term.

Jo Ragen, a senior research associate at the University of Sydney, describes her experience of a bushfire evacuation in the [1994 fires along Australia's eastern seaboard](#):

We had over 100 young people with physical disabilities at a recreational camp, and I told the [State Emergency Service] we can't be leaving on trucks. Even though they thought we had enough time to get out, in the end, that's what happened: young people were loaded onto the back of trucks and utes and we left behind what was really essential equipment for those being evacuated – wheelchairs, ventilators.

It taught me that people with disabilities need to be involved right from the planning stage. Thinking that someone is going to turn up and 'rescue' a person with a disability means someone is going to be forgotten and a catastrophic outcome is real.

As Australian authorities urge the general community to prepare and plan for bushfires, the early warning systems and public awareness campaigns are often failing to consider the needs of persons with disabilities.

Advice on the ground specifically for people with disabilities is pretty slim, and for bushfires is centred on the message of "leave early". But recent research by the [Bushfire Collaborative Research Centre](#) finds many people instead choose the "wait and see" option. In fact, less than 1% would leave their house on days of extreme or catastrophic fire danger.

This may be compounded for a person with a disability, as leaving early can be difficult as it means leaving behind essential equipment at home that is needed for daily living.

How we could be better prepared

For people with disabilities, significant gaps exist in current approaches to bushfire risk reduction.

Communications about bushfire preparedness are often not in accessible formats. There are assumptions that people with disabilities are living in households

dependent on others, when many are either living independently or are heads of households.

As Jo Ragen says:

Plans that lump all people with disabilities together are like plans that say 'all people with blond hair must do this in a bushfire'. In my experience, when you wait for others to plan, or think someone else will evacuate you, you'll either get evacuated in a way that is not safe or appropriate, or you'll get left behind.

There are various measures being done to improve this situation in Australia.

For example, a recent report on ["Increasing the Resilience of the Deaf Community in NSW to natural hazards"](#) found that while none of the natural hazard preparedness programs or tools cater specifically to deaf people, there were communication tools that could be considered "deaf-friendly" or required only small alterations.

A recent [United Nations survey](#) consulted nearly 6,000 people with disabilities in 126 countries, and found a high proportion of people with disabilities die or suffer injuries during disasters because they are rarely consulted about their needs and governments lack adequate measures to address them.

In cases where they need to evacuate - such as during floods or earthquakes - only 20% of respondents said they could evacuate immediately without difficulty, 6% said they would not be able to evacuate at all, and the remainder said they would be able to evacuate with a degree of difficulty.

So where does that leave Australians during what is proving to be [another dangerous bushfire season](#)?

The only way we will ensure that no one is left behind is if people with disabilities are actively included in the consultation, planning and preparedness stages of thinking about disasters. Specific input and ideas from people with disabilities is essential for identifying risks and increasing the chance of survival if disaster does strike.

[Sarina Kilham](#)

[Research Fellow, Centre for Disability Research and Policy at University of Sydney](#)

Sarina Kilham is a research fellow on a project funded by Australian Aid on "Promoting the Inclusion of People with Disability in Disaster Management in Indonesia".

Accessibility and inclusion in Victoria's national parks

Accommodation

Wilsons Promontory National Park and Cape Conran Coastal Park are now equipped with modified cabins and all-terrain wheelchairs to make it easier for people with a disability to stay and enjoy the spectacular natural beauty.

Specially modified cabins have entrance ramps, accessible bathrooms and parking close by to make it much easier for people with a disability, families and carers to enjoy their park stay.

A personal hoist and specialised bathroom equipment, such as a shower commode chair, are also available to visitors free of charge.

For photos and further information about the equipment available go to:

[Wilsons Promontory National Park](#)
[Cape Conran Coastal Park](#)

All-terrain wheelchairs

All-terrain wheelchairs are now available in a number of Victoria's parks for visitors with significant physical disabilities to explore the great outdoors.

The chairs are suited for sandy and semi rough tracks, making it easier to access the many stunning trails in the [Grampians](#) and [Lysterfield Park](#) and beaches at [Cape Conran](#), [Wilsons Promontory](#) and [Point Nepean](#).

Beach access wheelchairs especially for children are also available at Wilsons Promontory National Park and Cape Conran Coastal Park. An all-terrain wheelchair called a Hippocampe is available at [Coolart Historic Area](#).

All-terrain wheelchairs easily disassemble and fit in the back of a station wagon and with the help of operators, you can experience Victoria's parks like never before. Please supply your own bike helmet at the Grampians and Wilsons Promontory.

Chairs can be booked free of charge.

To book or for more information contact:

- Cape Conran Coastal Park Cabins and Camping on (03) 5154 8438
- Grampians National Park, Katherine Dyson on (03) 5361 4000
- Lysterfield Park, Trailmix on (03) 8790 4402

- Point Nepean National Park Information Centre on (03) 5984 6014
- Wilsons Promontory National Park Information Centre on (03) 5680 9555.

All-terrain chairs (TrailRiders) can also be booked and borrowed for free at selected local Shires. They are:

Surf Coast Shire

Surf Coast Sport & Recreation Centre located on Beach Road, Torquay, next to the Visitor Information Centre and Surf World Museum.

Phone: (03) 5261 4606 Fax: (03) 5261 4756b

Email: surfcoastersrc@surfcoast.vic.gov.au

Website: www.surfcoast.vic.gov.au



Hepburn Shire

Daylesford Regional Visitor Information Centre
 98 Vincent St, Daylesford

Phone: (03) 5321 6100

Email: events@hepburn.vic.gov.au

Website: www.visitdaylesford.com.au

Moorabool Shire

Lerderderg Library

Bacchus Marsh

215 Main St, Bacchus Marsh

Phone: (03) 5366 7100

Email: info@moorabool.vic.gov.au

Website: www.moorabool.vic.gov.au

Parks Victoria won the National Disability Award in 2011 under the Health and Wellbeing category and is implementing more access strategies for people with disabilities across the state. Parks Victoria is progressively updating accessibility information for visitors on this website. [Keep in touch with us for updates.](#)

[This article was taken from the Parks Victoria website.](#)