



# PPViews

No. 19, April 2018

## PRESIDENTS' REPORT

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**APRIL 2018** marks 5 years since the Federal Government recruited dozens of Australian scientists and academics to end the spread of polio throughout the world.

In 2017, the World Health Organization reported just 22 cases of infection. The difficulty of providing immunisation in besieged parts of the world, where civilians have little access to food and water, cannot be underestimated. Polio is also still being reported some of our neighbouring countries of the Pacific Rim.

Although no case of polio has been reported in Australia for more than a decade, polio-virus was found in the Melbourne sewerage system in December last year. This shows that current Australian immunisation rates are adequate to give us herd protection. A 2014 study, found some parents were failing to have their children vaccinated on time or to completion. Australian schools, at all levels, now require parents to provide documentation that their children's vaccinations are up-to-date, before they can be enrolled, showing the success of scientific advice on the efficacy of mass immunisation programmes.

Unfortunately, the same cannot be said about the understanding of scientists and health workers about the Late Effects of Polio (PPS). Last November, the British Polio Fellowship, wrote that the level of awareness of PPS, was "unacceptable," as "120,000 people in the UK are living with PPS, a neurological condition for which there is no cure." see PRWEB UK 7 November 2017.

In the English-speaking world, Postpolio-victoria was the one of the earliest established groups to raise awareness of the problem.

We also want to ensure that our Health Departments contribute to programmes to diagnose PPS and maximise their better health. In November 2017, 4 members of PPV met with the Advisor and research assistant to the Victorian Health Minister. As a result, we were encouraged to apply (and have done so) for a Health Condition Support Grant of \$5000 per year over 2 years.

On 22nd March 2018, we were told our first year of funding has been approved (see related article Page 3). Since our 2017 AGM, your PPV Committee has met 3 times; the Committee has sent representatives to Polio Services Victoria, and Polio Network Victorias' meeting at Independence Australia.

Our focus is to support networking to polio survivors, advocating for their rights to the same services available to all other Victorian residents, and keeping our members informed of the latest research on post polio syndrome and keeping well and controlling PPS symptoms.

For PPV members who may have missed the ABC radio programmes focussing on health there are 2 about polio that are worth downloading; February 22nd 2018. The aftermath of surviving polio-Life matters –ABC Radio National Gillian Thomas, polio survivor- President of Polio Australia, and the state branch in New South Wales, and Paul Cavendish an exercise physiologist and clinical educator talk with Amanda Smith, about Post Polio Syndrome

and on [www.abc.net/new/2018-03-18/The-modern-fight-against-post-polio/9544276-full-story](http://www.abc.net/new/2018-03-18/The-modern-fight-against-post-polio/9544276-full-story); <http://ab.co/2pkcZQz>

### 2018 Committee

- Geoff Dean (President)
- Ron Bell (Treasurer)
- Margaret Cooper
- Ron Exiner
- Peter Freckleton
- Shirley Glance
- Jill Pickering
- Liz Telford
- Susan Shaab

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# Continuity of Support Program

This program is printed in full because it is very relevant for polio survivors over the age of 65 who also currently receive State funded in-home support. This support enables people to get out of bed in the morning, shower and dress, participate in family and other activities, and go to bed at night. Along the way there may be food preparation, shopping assistance and help with minor domestic chores.

From 1 April the Commonwealth government will fund the Continuity of Support Program with some contributions from State governments. People will receive the same hours they received under the State government programs, however, there doesn't appear to be any way of getting a reassessment.

As polio survivors get older we need more assistance but it is very unclear of how to get extra time funded. It is also unclear about who will fund aids and equipment. Most State governments already have programs to fund essential equipment and this may continue for a year or two.

Of course those of us who need more care now may well be outlaying significant funds to buy the care privately. This is unfair as people without private savings will not be able to purchase the care they need.

We hope these are teething problems with the Continuity of Support Program and that polio advocacy organisations will be able to convince policymakers of the need for improvement.

## Continuity of support for older people receiving specialist disability services in Victoria

Information for Service Providers June 2017

### Key messages

- Responsibility for managing continuity of support arrangements for older people receiving specialist disability support services will transition from the Victorian Government to the Commonwealth Government (the Commonwealth) on 1 April 2018.
- The Commonwealth has established a new Commonwealth Continuity of Support Programme administered by the Department of Health.
- This programme will ensure older Victorians who are currently receiving state administered specialist disability services are supported to enable them to achieve similar outcomes to those they were aiming to achieve before the introduction of the National Disability Insurance Scheme (NDIS).
- Your existing clients should continue to receive services without disruption to their existing arrangements and should not be disadvantaged.
- The majority of clients will transfer to Commonwealth on 1 April 2018 across the state. A very small number of 64 year old clients will remain under state arrangements following this date and will transition by 30 June 2019.
- Victorian service provider agreements will cease or be varied as at 31 March 2018 and replaced by new contracts to be negotiated between the Commonwealth Department of Health and service providers.
- The Commonwealth Department of Health will contact you separately about these changes.

### Eligibility

Clients aged 65 years of age or over who are not eligible for the NDIS will continue to receive services under a new Continuity of Support Programme administered by the Commonwealth Department of Health.

### Changes for Service Providers

The Victorian and Commonwealth governments have agreed to work closely with service providers in executing the transition arrangements, including the transition to new Commonwealth contracts.

Older people who are ineligible for the NDIS will transfer to the Continuity of Support Programme or alternatively may choose to transfer to other aged care arrangements administered by the Commonwealth.

Service providers who support a small number of clients who reside in areas that are yet to transition to the NDIS will continue to be funded by the Victorian Department of Health and Human Services after 1 April 2018 until their eligibility to move to Commonwealth continuity of support arrangements has been established.



To ensure a smooth transition, the Commonwealth Department of Health has been provided with de-identified information about your clients who may be eligible for the Continuity of Support Programme. Authority to release this information to the Commonwealth is provided under Section 39 (4) of the Disability Act 2006.

### What do the changes mean for older people accessing specialist disability services on 1 April 2018?

Older people accessing specialist disability services should continue to receive services without disruption from 1 April 2018 as a direct result of the transfer of funding responsibility and should not be disadvantaged. Prior to this, older people will continue to receive their supports under existing arrangements with the Victorian Department of Health and Human Services.

A small number of clients who are 64 years and who reside in areas where the National Disability Insurance Scheme (NDIS) has not commenced operation will need to test their eligibility for the NDIS before being considered for the Commonwealth Continuity of Support Programme. All of these remaining clients will transfer by 30 June 2019.

Aboriginal and Torres Strait Islander people who are aged 50-64 years of age who have been determined ineligible for the NDIS are also able to access the Commonwealth Continuity of Support Programme.

### Further information

The information available here complements information on the [Department of Health and Human Services National Disability Insurance Scheme](#) web page and information already available to service providers, and people with a disability and their family members about the roll out of the NDIS.

If you require further assistance from the Department of Health and Human Services please contact your Local Engagement Officer or Program and Service Advisor.

Information on Commonwealth continuity of support arrangements can be found on the Department of Health website at [Continuity of support](#)

To receive this publication in an accessible format phone 9096 5111, using the National Relay Service 13 36 77 if required.

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Available at [www.dhhs.vic.gov.au/home](http://www.dhhs.vic.gov.au/home)

## New Community Worker for Victoria

Thanks to a donation from Jill Pickering, Polio Australia will be employing a community worker for the Victorian polio community. This will be part time for one year starting as soon as someone is employed!

With aims to strengthen the polio groups and help us develop good consistent information out to those already linked in but also the many others who are not, this is an out reach position. The worker will be seeking to connect with people who are not already connected in the networks.

Working with a steering committee, which will include PPV and PNV, this is a great opportunity to strengthen, focus and coordinate how support is provided to people with polio in Victoria.

We wish to acknowledge the generous donation by Jill Pickering, making this project possible.

Jill has been a great financial supporter of Polio Australia since its inception and her generosity has benefitted the polio community, not just in Victoria, but, throughout Australia.

Thank you Jill!

## Polio Services Victoria (PSV) update

This is a summary of the update on the PSV website.

The PSV team consists of:

- . Rehabilitation Physician
- . Physiotherapist
- . Occupational Therapist
- . Social Worker
- . Orthotist
- . Allied Health Assistant

During 2018, PSV will continue to provide specialist health and management for people who have had polio. These clinics will take place at St Vincent's Hospital and at clinics in regional Victoria. Referrals for an appointment with PSV's medical consultant require a referral from a patient's GP.

Post Polio Victoria has been providing feedback to Polio Services Victoria about patients' clinic experiences. Polio Services Victoria now has its' own feedback mechanisms, which include an interview with a PSV staff member, online feedback and post box in the hospital clinic.

## ...also Good News on Funding!

In November last Year, 4 members of Post Polio Victoria met with the Advisor and research assistant to the Victorian Health Minister.

Resulting from that meeting, we were encouraged to apply for a Health Condition Support Grant of \$5000 per year over 2 years.

In February, Post Polio Victoria made an immediate application.

In March, Margaret Cooper received a letter from the Assistant Director of Primary and Community Health that our application had been **"successful. Post Polio will receive \$5000 for 2017-18 and \$5000 for 2018-19."**

The letter also stated **"The Department of Health and Human Services recognises the vital role of peer-led support groups in the health service system.** The aim of the Health Condition Support Grants program is to assist small groups to continue their valuable work in providing mutual support and information exchange for their members."

# Post Polio Victoria and Polio Australia

Many of our members understand the relationship between Post Polio Victoria (PPV) and Polio Australia (PA).

To explain the relationship; PA is a federation of the various State polio organizations. In Victoria, the two State organizations that make up Polio Australia's (PA) membership are PPV and Independence Australia, represented by Polio Network Victoria (PNV), the umbrella organization of the Support Groups.

PPV's previous representative to Polio Australia was Ron Exiner, who attended PA's AGM in November 2017.

Ron reports: "There was a celebratory feel around this AGM. We normally spend most of our time trying to work out how to raise funds for the important work we do.

However this year, we were able to hear about successes, having received funding which has enabled PA to significantly extend its professional education activities throughout Australia and also seek to secure a sustainable financial future."

Subsequent to the AGM, PA has also received a separate substantial donation to employ a community worker to work with PPV and PNV. This will provide some much needed support to PPV to help us with our advocacy, education, information provision and support to our members and the polio community.



The PPV representative on the Polio Australia Board for the current year is Peter Freckleton.

## Our 2017 Annual General Meeting

Another small but enthusiastic gathering was held at the Disabled Motorists last November.

Fleur Rubens stepped down from the committee and we thanked her for her great work over the past three years, especially in instigating changes at St Vincent's Hospital around respiratory care. Largely through Fleur's dogged work there is greater awareness of the risks to post-polio patients and there is a Polio Alert system at St Vincent's.

We welcomed new committee members Shirley Glance and Peter Freckleton. Both are members of Bayside Group.

Shirley has already made her presence felt taking on some of the administrative role, and helping with grant writing. Peter is our new Polio Australia representative.

Shirley and Peter join the ongoing committee members;

Geoff Dean, President  
Ron Bell, Treasurer  
Margaret Cooper  
Liz Telford  
Ron Exiner  
Susan Shaab  
Jill Pickering



Margaret Cooper



Shirley Glance

Natasha Layton speaking at our AGM on "getting smarter about aids and equipment" She gave us hints. Here are some;

- Approved for SWEP we must be wiser spending our \$'s
- Remain with a physio, OT who understands your needs and can recommend the best equipment for you
- Disability groups start showing governments that timely supply of equipment saves money and community diversity because we have fewer falls, fractures, hospitals admissions, joint replacements, and rehabilitation hours and we stay in the community happier in our familiar community that thrives with our involvement

## Virus shown to be likely cause of mystery polio-like illness

22 JAN 2018 | UNSW MEDIA

**A major review by UNSW researchers has identified strong evidence that a virus called Enterovirus D68 is the cause of a mystery polio-like illness that has paralysed children in the US, Canada and Europe.**



Photo: Shutterstock

A major review by UNSW medical researchers has identified strong evidence that a virus called Enterovirus D68 is the cause of a mystery polio-like illness that has paralysed children in the US, Canada and Europe.

The study, by a team led by UNSW Professor Raina MacIntyre, Director of the NHMRC Centre for Research Excellence in Epidemic Response, is published in the journal *Eurosurveillance*.

"In 2014, children in the US began to be diagnosed with a mystery illness that caused a polio-like paralysis," says Professor MacIntyre.

"More than 120 children developed the condition, known as acute flaccid myelitis, in the US alone but experts were baffled as to the cause."

That same year there were also unusually large outbreaks of infection with Enterovirus D68, or EV-D68 – a virus known since the early 1960s to cause runny noses, coughs, muscle aches, fever and difficulty breathing.

About 2280 people in the US, Canada and Europe were infected with the virus, many of them children, and their respiratory symptoms were more severe than usual.

Clusters of the paralysing illness, also mostly in children, were reported in the same regions.

"This raised the possibility of a link between EV-D68 and acute flaccid myelitis. However, the virus had never been known to cause paralysis before," says Professor MacIntyre.

For the new study, the UNSW team analysed the scientific literature on acute flaccid myelitis. They applied the Bradfield Hill criteria – a set of nine principles developed to determine causality that are named after the two researcher who used them to settle the debate about smoking causing lung cancer.

"The scientific method Bradfield Hill used to prove that smoking caused cancer is now an accepted tool to determine causality," says Professor MacIntyre.



## About Breathe

PPV was given some double movie passes to "Breathe" to give away. One of the recipients, Robyn Abrahams writes;

Thanks to PPV I had the pleasure of seeing Breathe recently with a friend.

It is a very thoughtful and considered story of Robin Cavendish, by his filmmaker son, Jonathon.

Robin contracted polio in 1958 in his twenties. He had recently married, and had a baby son.

Despite using Cavendish equipment in my working life (a wheelchair with a built in respirator designed by Robin and his friend Teddy Hall who features in the film), I was not familiar with the brave man's life. So I was in for an emotional ride.

The cast was excellent and each played their roles very well. Paralysis and polio is not easy to pretend, however.

I contracted polio at the age of 4, and spent time in the Royal Children's Hospital and then long term in Fairfield Infectious Diseases Hospital, as did many of us.

For me the movie was very difficult.

It made me recall things about being a polio survivor that I would have preferred to have never remembered. I found the scene in the German iron lung ward particularly distressing.

The ward I was in at Fairfield was near the iron lung ward. From my bed, I could hear as clear as day, the whoosh- clang noise the machines made as they assisted so many to breathe.

This made me so sad, and I remembered many things about my hospitalization and years of ongoing treatment, mostly dreadful and shameful in terms of health care; probably best forgotten.

Talking about it afterwards with Liz Telford I was able think about and process those memories, but not easily. When I remember being in the hospital I also remember the emotional experience of it. That's the hard part.

The story is three fold for me.

It is the story of polio and its' treatment or should I say so-called management. Plus our seemingly instinctive will to survive, do our best and achieve as did Robin Cavendish.

Second, it's about the wonders of love, an exceptional marriage, coupled with love and support of amazing family and friends.

Thirdly, it's about the complexities of assisted suicide and dying with dignity.

Set in hospitals, then idyllic country UK this is an incredible story of a brave, independent, clever man plus his amazing, supportive wife. But it also reflects something more universal about the experience of having polio.



## Tribute to Mexican artist, Frida Kahlo, Polio Survivor and disability rights advocate.

*Mexicans love to celebrate, so Frida's art is celebrated at all national events. Around the world, she has also become a cult figure, long after her death. Her continuing popularity is a testament to her stand for Equal Human Rights, and, ordinary people yearning for it.*

*By Susan Shaab*

Frida Kahlo died aged 47 on the 13th of July 1954. She remains the most well known of all Mexican female artists. In Mexico, her works are listed as heritage items. Thus, her original work cannot be sold to foreigners, nor taken out of the country.

Frida contracted Polio when she was 6. For her, the long-term effects of polio, were a shortened, thinner right leg with curvature and deterioration of the spine.

When she was a teenager, Frida was badly injured when her school bus collided with a street-car. She was badly injured. It took months for her to recover, wearing a plaster cast corset. Her time spent recovering was a reflective time when she decided on art as her career. Subsequent months she spent drawing and painting herself using a reflective mirror, and, family, and friends. Painting became Kahlo's expressions on identity and existence.

In the 1950's her health declined rapidly. She could not stand or sit for more than a few minutes. She took a huge amount of painkillers, and after complications for gangrene in her injured right leg, it was amputated just below the knee.

Frida's work is best known for its subject matter; women, disability, folklore, amorphous gender assignment, and the bright, natural pigments she used.

*Her work is copied onto T-shirts, leather goods, and ceramic items, all of which create work for small artisans and clothing companies, and sold in tourist shops all around Mexico.*

# Polio Australia

Representing polio survivors throughout Australia



## Polio Health and Wellness Retreat Body / Mind / Spirit

Stamford Grand in Glenelg, South Australia  
Thursday 11, Friday 12, Saturday 13 and Sunday 14 October 2018

*Expression of Interest Only*

Polio Australia will once again be facilitating its 4 day / 3 night Polio Health and Wellness Retreat for polio survivors and their partners/family members from Thursday 11 to Sunday 14 October, 2018 in the beautiful seaside suburb of Glenelg, South Australia. The Stamford Grand has **9 wheelchair accessible rooms** available.

The holistic 'Body / Mind / Spirit' theme will continue and include sessions such as:

- ◆ Interactive group sessions and one-to-one consultation opportunities with a variety of allied health professionals
- ◆ Hydrotherapy and exercise options
- ◆ Latest orthotics, aids and equipment displays
- ◆ Chair Dancing and Meditation Sessions
- ◆ Activities To Keep The Mind Active
- ◆ Creative Workshops

See details of previous Retreats at [www.polioaustralia.org.au/retreats](http://www.polioaustralia.org.au/retreats)

### Polio Australia's Health and Wellness Retreat

11th—14th October 2018

*Cost of Registration Fees for 3 nights accommodation, all meals and most activities  
\$450 pp double and twin / \$500 single*

Please provide me with more information on the Polio Health & Wellness Retreat when available.

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Phone/s:** \_\_\_\_\_ **Email:** \_\_\_\_\_

**Return to:** Polio Health & Wellness Retreat, Polio Australia, PO Box 500, Kew East, VIC, 3102 or  
Email: [office@polioaustralia.org.au](mailto:office@polioaustralia.org.au)