

Polio Australia

Representing polio survivors throughout Australia



*Joint Polio SA and Polio Australia Information Session for Polio Survivors
Adelaide—May 2018*



Annual Report 2017-2018

Polio Australia

Polio Australia's Purpose

As the national peak body for polio survivors, Polio Australia's purpose is to:

- educate Australian polio survivors and their families and the community about the Late Effects of Polio (LEoP);
- source and provide best practice information, education and training to general practitioners, medical specialists and allied health professionals to improve the diagnosis/management of the LEoP;
- facilitate the provision of appropriate and consistent health and other support services, across all states and territories, to improve the treatment and management of the LEoP;
- advise governments on policy development and programs in relation to the LEoP;
- stimulate research into the LEoP;
- assist the State Polio Networks to support polio survivors and their families, friends and carers at a local level;
- facilitate and encourage coordination between State Polio Networks; and
- support and promote polio immunisation programs.

Vision

All polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed life choices.

Mission

Polio Australia is committed to standardising quality polio information and service provision across Australia for polio survivors.

Values

Polio Australia represents the needs of the post-polio community and works with passion and professionalism to educate, advocate and achieve recognition for polio survivors.

Governance

Our Board Members ensure the charity complies with legislation and has good governance.

In 2008 the six Australian State Networks signed a Memorandum of Understanding which in turn lead to the development of a Constitution for a national organisation, Polio Australia, and its incorporation later that year.

Two representatives from each state are appointed to the Board of Polio Australia, each for a two-year term. The Board also has capacity to appoint three Independent Directors for specialist roles.

Our Board 2017/18



Gillian Thomas
President 2018
(NSW)



Jenny Jones
Secretary (WA)



Brett Howard
Treasurer (SA)



Arthur Dobson
(TAS)



Tessa Jupp
(WA)



Susanne Mackenzie
Fundraising
Coordinator
(Independent QLD)



Gary Newton
Communications
Coordinator
(Independent VIC)



Michael Powell
(QLD)



Billie Thow
(TAS)



Dr Christine
Tilley (QLD)



Bev Watson
(VIC)



Peter Wierenga
(SA)

Incoming



Alan Cameron
(NSW)



Peter Freckleton
(VIC)

Outgoing



Dr John Tierney
President 2017
(NSW)



Ron Exiner
(VIC)

Our Team



Shylie Little
(NSW)



Jill Pickering
(VIC)



Left to Right: Rachel Ingram (VIC), Paul Cavendish (NSW), Maryann Liethof (VIC), Bonnie Douglas (VIC), Jake Malsbury (VIC), and Steph Cantrill (VIC)

All key members of the Polio Australia Team are knowledgeable about polio and its late effects. They demonstrate the ability to think analytically and work strategically to achieve Polio Australia's goals on behalf of Australia's polio survivors.

The key members have a range of career backgrounds and bring a diverse set of skills to Polio Australia.

Details are provided online here: www.polioaustralia.org.au/polio-australia-team.

Steph Cantrill

Polio Community Officer

Commenced May 2018, working 3 days per week to facilitate information sessions for polio survivors in Victoria. Funded by Jill Pickering—private donation.

Paul Cavendish

Clinical Health Educator

Commenced September 2017, working 5 days per week to facilitate Clinical Practice Workshops for health professionals throughout Australia. Funded by the Federal Department of Health for 3 years.

Bonnie Douglas

Financing Manager

Commenced January 2018, working 3 days per week to generate an income stream for Polio Australia into the future. Funded by Spinal Life Australia for 2 years.

Our Team



- Rachel Ingram** **Health Promotions Officer**
Commenced August 2017, working 5 days per week to facilitate awareness campaigns, social media activity, web maintenance, and project work across the full range of Polio Australia's activities. Funded 50/50 by the Department of Health and Spinal Life Australia.
- Maryann Liethof** **National Program Manager**
Commenced January 2010, working 5 days per week to oversee Polio Australia's Program areas. Funded by general donations.
- Shylie Little** **Administration/Bookkeeper**
Commenced January 2010, working 2 days per week to provide bookkeeping services, including accounts payable/receivable, and payroll. Funded by general donations.
- Jake Malsbury** **Administrative Officer**
Commenced May 2018, working 1 day per week to provide administrative and project support for the Clinical Practice Workshops Program. Funded by the Department of Health for 3 years.
- Jill Pickering** **Administration/Volunteer**
Commenced February 2010, working as required to provide data entry and to generate statistics and reports from the annual Health and Wellness Retreats.
- Gillian Thomas** **Business Manager/Volunteer**
Commenced August 2008, working as required to ensure Polio Australia meets all its business and financial obligations. She also provides guidance and input across all program areas.

*"Coming together is a beginning,
staying together is progress, and
working together is success."*

– Henry Ford

President's Report

By Gillian Thomas

A Watershed Year

As Polio Australia approaches its 10th anniversary, we are pleased to report that 2017-2018 was our most productive year yet. Funding success enabled the employment of additional staff and expansion of a number of program areas, together with a concerted focus on financing options to secure the future viability of Polio Australia. The outcomes of the grants from Department of Health and Spinal Life Australia and another substantial donation from Jill Pickering can be read in the Program Reports on pages 8-11. On behalf of the Board and Australia's polio survivors I express our gratitude for this funding.

Farewell and Welcome

At the Board's ninth Annual General Meeting, we said goodbye to outgoing members, Dr John Tierney OAM (NSW) and Ron Exiner (Vic). I would like to take this opportunity to thank John and Ron for their years of service on the Board, and wish them well in their future endeavours.

Over the five years that John was President of Polio Australia, his leadership, pro bono lobbying, and financial support through his Walk With Me fundraising efforts and donations were vital to our continuing success. We are also grateful that John continues as our National Patron, so his wisdom and advice is not lost.

As Polio NSW's second Board member, John was replaced by Alan Cameron, who has been the Polio NSW Treasurer since 2008. Post Polio Victoria's replacement for Ron is Peter Freckleton, whose main profession has been as a barrister at the Victorian Bar. Both have the credentials to be an asset to the Board.

Strategic Plan Development

John's work left us in a strong position to move forward. I was honoured to be elected as President at the 2017 AGM, leading Polio Australia into its next phase with an expanded team and programs. It was timely that a new three-year strategic plan was due following the AGM, and the Board and staff participated in a

lively session to map through to the end of 2020. The Strategic Priorities can be seen on page 14 of this report.

At our team meeting early in the year, the meat was put on the bones of the 2018-2020 strategic plan. The energy and enthusiasm displayed at this meeting, and the outcomes from it, confirm that exciting times are ahead for both Polio Australia and our post-polio community.

Priority One of our strategic plan is education. As such, our vanguard project for 2018 is the continued roll-out of the *Late Effects of Polio Clinical Practice Workshops* across Australia. The impact of the training on the lives of Australia's polio survivors is inestimable, as the information will assist health professionals to manage their clients' chronic post-polio health condition. As polio survivors, we should encourage our own health professionals to attend a workshop when it reaches our area. Details of upcoming workshops are online here:

www.poliohealth.org.au/workshops

Online delivery of the workshop material is also currently being explored, as a means of reaching even more health professionals, especially in remote areas, and as a reinforcement of the face-to-face training.

Governance

With the increase in both financial and human resources, Polio Australia's Board members will also be working on reviewing our Policies and Procedures in the upcoming year. It is anticipated that two sub-committees will be formed to oversee '*Finance*' and '*Governance and Risk Management*'. This work is intended to clarify the content of our constitution by making explicit the underlying principles of governance approved by the organisation.

In Conclusion

I thank the Board and staff, particularly our National Program Manager, Maryann Liethof, for their hard work and dedication over the last year towards achieving our goals. With our increased resources I look forward to further increasing our reach and impact over the coming year.

National Program Manager's Report

OPERATIONS OVERVIEW

By Maryann Liethof

This is a very different Annual Report to those of previous years, primarily due to the influx of crucial funding which has enabled us to employ staff! During the 2017-18 financial year, a great deal of my time was spent advertising and interviewing for these funded positions. I believe Polio Australia is very fortunate to have now secured a well-rounded, skilled, competent, and passionate team.

Having worked alone in the office for the past 7 years—apart from periodic visits from volunteer, Jill Pickering—I now have the enviable 'problem' of where to accommodate people! Of course, not everyone on the team works fulltime, nor are they all based at our small office in Kew, Victoria. As such, we have regular email exchanges, and schedule monthly telephone conferences to ensure everyone is kept in the loop with the various program areas.

Regular events held by Polio Australia such as the 2017 Polio Health and Wellness Retreat, the Annual General Meeting, and the Walk With Me activity in Canberra, were made so much easier with input from Rachel Ingram (Health Promotions Officer) and Paul Cavendish (Clinical Health Educator), who commenced in August and September 2017, respectively. Both have now progressed to managing and building on their own program areas, and their reports follow.

Bonnie joined the team in January 2018, taking on the challenge of exploring income streams that will enable Polio Australia to continue providing services into the future. She quickly realised that raising funds for our small charity is no easy feat, especially in the current economic climate. Nevertheless, Bonnie has been learning all she can about philanthropy, and following up on networking leads, which we hope will eventually bear fruit!

In May, we were able to employ Steph Cantrill,

which fulfilled another long-term goal of providing information sessions on the Late Effects of Polio for survivors and other general members of the community. This service is currently only funded to run in Victoria, but we plan to expand the program if more funding can be secured. Steph's role is classified as a community development worker, but her background in Occupational Therapy provides her with an excellent working knowledge of how the LEOp can impact on the body.

Our final appointment was Jake Malsbury, who is providing administrative support for Paul's Clinical Practice Workshops program. As Paul is on the road most of the time running the workshops, Jake researches and contacts the range of health professionals and practices in specific regions, and follows up with information on forthcoming training. This has ensured maximum promotion of and subsequent attendance at Paul's workshops.

One of our strategic goals for the forthcoming year is to engage with more 'younger' polio survivors, i.e. those born from 1975 onwards. We know there are hundreds, if not thousands, of this 'next generation' of Australian-based polio survivors accessing clinical services for orthopedic surgery and/or orthotics. We are now working up a program to assess and then develop the information services they need at this stage of their lives.

As an organisation, Polio Australia continues to align itself with individuals and organisations that support the needs of polio survivors, including: the international and state Polio Networks; Rotary International; peak allied health bodies; polio clinics and services; Global Citizen Australia; and the Assistive Technology for Older People Alliance, to name a few.

In the coming year, Polio Australia will continue striving to raise awareness of the needs of polio survivors through community and health service provider education, and government lobbying. I believe we finally have the right team balance to carry our strategic goals forward.

Program Reports

HEALTH PROMOTION

By Rachel Ingram
Health Promotions Officer

I began in the role of Health Promotions Officer in August 2017. I have a Bachelor degree in Science (Health Promotion), and was excited about the opportunity to tackle a health issue that was completely unfamiliar to me. In 2017-18, I have learnt nearly everything about post-polio, and coordinated a range of projects to support Polio Australia's mission.

Polio Awareness Month

The theme for Polio Awareness Month 2017 (October) was *Ageing With Dignity*. We used a variety of methods to spread the awareness of the Late Effects of Polio throughout the month:

- 'Myth Monday': a range of social media cubes featuring a common myth, followed by the facts. A separate myth was done for each Monday in October. For each of the other days throughout the month, I scheduled posts which were uniquely interesting and informative and most had a call-to-action (e.g. register on the Australian Polio Register or donate to Walk With Me events)
- We collected stories from polio survivors across Australia, and developed and distributed a media release to a range of media outlets nationally. We had articles in:
 - ~ Indy News (Hervey Bay, QLD)
 - ~ Midland Express (Kyneton, VIC)
 - ~ Ocean Grove Voice (Ocean Grove, VIC)
 - ~ The Senior (National)
 - ~ Medical Media (National)

Still Here Website Redevelopment

In 2017-18, Polio Australia's existing *Still Here* website was redeveloped. This is now a blog-style website which focuses on the activities of Polio Australia and media articles. Polio survivors can also submit their own story to the website.

Breathe Charity Screening

Polio Australia, with the help of Village Cinemas, was fortunate to secure the rights to two exclusive early-release screenings of the highly acclaimed movie "Breathe", a real-life story of tragedy and resilience. Polio Australia ran the screenings of "Breathe" in Geelong and Melbourne during November 2017 and raised almost \$8,000 from the two events.

Polio Australia thanks Independent Board Member, Gary Newton, for all his work in negotiating the two screenings—especially in his home town of Geelong, which attracted 100+ people. Gary was also able to secure sponsorship from a number of organisations, as well as donations from individuals who were unable to attend.

World Polio Day 2017

Polio Australia and Global Citizen formed an important partnership for World Polio Day 2017. World Polio Day was on the 24th October 2017, and focused on 'One Last Push' toward polio eradication. Although this is not a specific goal of Polio Australia, we do support ongoing immunisation to ensure polio does not return.

Global Citizen approached us with the idea of forming a partnership alongside Rotary International, Results and UNICEF Australia. The event idea was a barbeque and presentation at Parliament House on World Polio Day. We organised a delegate, Rohan Clark, to speak on behalf of Polio Australia and polio survivors at the event. The event was very successful with a large attendance and gained attention from various politicians.

Polio Health and Wellness Retreat 2017

I attended the Polio Health and Wellness Retreat in 2017, which was an integral learning experience. It was a fantastic opportunity to meet polio survivors from all walks of life, and to learn more about post-polio. I also gained great insight into the enormous effort that goes in to planning the Retreat!

www.stillhere.org.au

The screenshot shows the Polio Australia website. At the top, there's a navigation bar with a search bar and social media icons for Facebook, Twitter, and YouTube. Below that, the main header features the Polio Australia logo and the tagline "Honouring Australia's polio survivors - 'We're Still Here!'". A featured story by Ann South Australia is highlighted with a yellow background and the text "We're Still Here!". The footer contains a navigation menu with links for Home, Media, Campaigns, Events, Rotary, Stories, Share Your Story, Australian Polio Register, Our Other Websites, and Contact Us.

Program Reports



Photo: Hobart, Tasmania—Clinical Practice Workshop—February 2018

CLINICAL PRACTICE WORKSHOPS

By Paul Cavendish
Clinical Health Educator

The past year has been a very rewarding experience and one in which Polio Australia has commenced to establish greater networks and knowledge among health and medical professionals across Australia.

After commencing in mid-September 2017, there has been plenty of travel, and more to come! Following a two-week orientation at Melbourne, were two Polio Retreats (one in New Zealand and Polio Australia's Retreat in Queensland). The Retreats are an invaluable part of learning and connecting together for polio survivors, and certainly provided great support in getting to know the people who enable the education of health professionals to be successful. For the remainder of 2017, workshops were delivered at Noosa (QLD), Wagga Wagga, Canberra, Wollongong and Coffs Harbour (NSW). As the year started to draw to a close, planning for the rollout of workshops (and securing host venues) for the subsequent 6 months across Australia occurred.

The Clinical Practice Workshops have been delivered across all states of Australia during the past year. The plan remains to provide opportunities for health professionals to attend workshops in a community/private practice setting and in public hospitals so we have knowledge and skills across our health sector. This approach has largely been successful in each state of Australia. There have been some difficulties with reaching relevant health

professionals who are interested in The Late Effects of Polio. It often requires some education on the relevance of this topic to managers/heads of department in public health settings. It can be difficult in getting the opportunities to health professionals with small businesses. However, with continued efforts, positive feedback from attendees, and the work being performed by the rest of our team, it would be safe to say there is increasing awareness in the general community (along with health professionals) that will continue to assist all aspects of our organisation.

Overall, during the past 9 months we have trained 422 health professionals with our clinical practice workshop and delivered 3 specific sessions for aged care providers. Given the period of time to establish workshop venues, material for the delivery of the workshops, and the Christmas holiday period which reduced the period of time of workshops delivery, it is anticipated the next year will involve more education, and expanding our services to General Practitioners and the Aged Care industry. We are continuing to review our performance, seeking an independent review with [Research For Good](#), and are looking forward to finding valuable lessons from this exercise.

Within the Clinical Education role, we also trialled delivery of information sessions to polio survivors in Adelaide and Geelong during May. Both of these sessions involved media coverage. In particular, the Adelaide session was very successful with over 100 polio survivors in attendance. The development of further services and support information across Australia specific to the needs of polio survivors will continue to be an important complement to the delivery of our workshops next year.

Polio In The Media

seniors



Local News News Distribution Community Travel Health Lifestyle Entertainment

NEWS

Childhood polio virus catches up with seniors

8th Apr 2018 12:00 PM



by Tracey Johnstone

USE THIS CONTENT

AS WE age the natural cell degeneration has started to raise health issues that seem may inexplicable unless you unknowingly had polio as a child.

Australia was announced polio virus-free since 2000, but as we are ageing after experiencing the polio epidemics of the '30s, '40s and '50s and as late as 1962, there are residual effects from those earlier years that are surprising.

Whether you had polio or were living in a household where there was polio, the gastrointestinal virus could have had an impact on you.

Polio Australia's national program manager Maryann Liethof said if you are experiencing symptoms such as muscle weakness which doesn't seem the norm for you, particularly if you are 65 or 70, it's important you tell your GP and your physiotherapist about your family's history of polio.

Paralytic polio sufferer Eric Rushton, 72, suggests going even further, ensuring that any medical personnel you are working with know about any polio history you have.

During his late-50s Eric started to experience again gradual decline in muscle function, "I wasn't aware polio was something you could mostly recover from only to have symptoms return decades later," he said.

Eric found medical personnel from dentists to physiotherapists and even hospital surgical staff, were not aware of the Late Effects of Polio.

"It's not the polio virus you have got to worry about, it's what the polio virus did to your body," Ms Liethof said.

Could you have had non-paralytic polio?

Ms Liethof said if a baby had flu-like symptoms, they may have been diagnosed with encephalitis. "Everyone who contracted polio would have had some form of encephalitis or inflammation of the brain because that is what the disease does," Ms Liethof said.

"You may not have been diagnosed with polio, especially if you didn't have paralysis that lasted any length of time, but that doesn't mean that you weren't infected with the virus. You may not have had subclinical damage done."

Subclinical damage meant a child had minimal motor neuronal damage and if the child had anywhere between 10 and 30 per cent of their motor neurones killed off, there would have had some form of muscle weakness.

"As a child that may have looked like slow physical development without it appearing to be anything more sinister," Ms Liethof said. "Where the motor neurones were killed off they would have regrown little sprouts to take up the innervation of the muscle."

However, as cell degeneration starts to occur in older Australians, those who contracted the polio virus as a child may find themselves experiencing Post-Polio Syndrome where the sprouts retract from the muscles leading to muscle atrophy, muscle and joint pain and even respiratory problems.

There is also the biomechanical decline associated with late effects of polio which has pain attached, but of a different kind. While they may be obvious they are a lot harder to diagnose.

What is paralytic polio?

"You have to have had at least 50 per cent or more of your motor neurones killed off at the time of the viral infection for paralysis to have set in," Ms Liethof added.

Paralytic polio would have left a child with a residual disability such as slight limp, smaller foot or shorter leg, or with upper body conditions like a withered shoulder and possibly respiratory problems.

"Even polio survivors need to be told that the problems they are not just ageing; they are the by-products of their polio," Eric added.

Australia continues to vaccinate babies age two, four and six months and again at four years old. "We will continue to vaccinate forever," Ms Liethof said.

For more information, go to [Polio Australia](#).

For seniors diagnosed with Late Effects of Polio, they are invited to join the Polio Australia register to help the organisation collect further statistics.

Survivor 'still here'



BE THERE: Polio survivor Gary Newton has urged medical professionals to attend local workshops on treating the late symptoms of the disease. 181879 (Rebecca Hosking)

By Luke Voigt

Doctors are struggling to treat polio survivors as the largest physical disability group in Australia, according to a local campaigner.

"More health professionals need to understand my condition," Grovedale polio survivor Gary Newton told the Indy yesterday.

Gary contracted polio at 15 months in 1954, two years before a vaccine was available.

Despite the disease's Australian eradication in 1988, Polio Australia estimates the country still has 400,000 survivors.

"It's a very little known fact but we're still here," Gary said.

"We're not those cute, cuddly, little kids that got all that attention in the '50s and '60s anymore."

The late effects of polio could cause new muscle weakness and atrophy, chronic fatigue, pain and respiratory problems, he explained.

"We're still needing help and support and struggling with the disease that we've had all our lives."

Gary uses a wheelchair due to 80 per cent paralysis in his legs and 30 per cent in his arms.

But too often medical professionals did not understand his condition, he said.

"Medical training today... doesn't touch on polio apart from the fact there is a vaccine."

He urged local doctors to attend one of two workshops in Newtown and central Geelong next Thursday to expand their knowledge.

Gary travelled in January to promote awareness in India, where vaccinations have all but eradicated the disease.

"But they're next door to Pakistan, which is polio endemic," he said.

Polio was only "a plane ride away" from reappearing in Australia, given doctors diagnosed a Pakistani student here in 2007, he warned.

Gary encouraged local medical professionals to visit [polioaustralia.org.au](#) to find out more about the workshops.

Voice

OCEAN GROVE

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Disease beaten but effects live in

20 October 2017 10:37 AM

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Ocean Grove's Barbara Hamann was infected with polio in 1955, at 12 years of age.

She was put in an isolation ward due to fear of transmission, and her right arm and left leg were paralysed. After a near full recovery at the age of 15, Barbara lived an independent and productive life. She married, had four boys, worked in hospitals and as a bridal dressmaker, and was very active in her spare time. Now, the independence she fought so long and hard for is now being challenged by the debilitating effects of Late Effects of Polio (LEoP).

The LEoP can cause new muscle weakness and atrophy, chronic fatigue, pain, and respiratory problems. As polio is a disease of the past in Australia, there is little knowledge of the LEoP in the health sector today. Those living with the condition are often faced with exorbitant medical expenses to diagnose and manage the symptoms, as well as the cost of mobility aids and equipment to help maintain their quality of life.

Barbara's ability to age with dignity is compromised due to a lack of knowledge of the LEoP among health care professionals and lack of understanding from others. Barbara echoes the experience of many polio survivors.

"The hardest thing for me, personally, is that I don't have a 'visible disability', and people don't accept that I am struggling with the Late Effects of Polio," she said.

A recent grant from the Department of Health to fund a LEoP Clinical Practice Workshops Program has brought that goal much closer. Over the next three years, Polio Australia plans to upskill up to 3600 health practitioners across Australia in how to best manage the LEoP for their clients.



Ocean Grove's Barbara Hamann is a polio survivor.

The aftermath of surviving polio on Life Matters

Thursday 22 February 2018 by Rachel Ingram

Category: **I am a polio survivor, Media Coverage**

Australia was officially declared polio free in 2000, but that doesn't mean that the effects of the virus in this country have disappeared entirely.

Gillian Thomas and Paul Cavendish were interviewed by Amanda Smith on Radio National survivors for the program 'Life Matters':



Thank you to **Radio National** for the interview and audio recording.



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Polio Awareness Month Campaign 2017

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Polio victims still struggle

Tuesday, 17th October, 2017

Section: Health



STILL HERE AND STILL BATTLING - Jane Trengove is one of the 400,000 Australian polio survivors who want to be able to age with dignity.

FEW people will fail to remember the dreaded polio epidemic years of the 1930s, '40s, and '50s before vaccines relegated the infection to Australian history books - or so we thought.

Many years on, the survivors of those epidemics are facing another battle - the debilitating effects of a condition known as late effects of polio or, for others, post polio syndrome.

The catchcry "We're still here" has been chosen to highlight their ongoing struggle with their old adversary as well as an insidious new adversary - ageing.

October is Polio Awareness Month which focuses on the theme *Ageing With Dignity* - something that is proving difficult for some of the 400,000 Australians who survived the deadly virus last century but are now facing the effects of ageing compounded by their original disabilities and their later-age effects.

Many are locked out of help from the National Disability Insurance Scheme because of the age 65 cut-off, which leaves them reliant on a much less effective and generous aged care system.

While post polio syndrome causes further neurological damage and further disability, later effects of polio can result in new muscle weakness and atrophy, chronic fatigue, pain and respiratory problems. It is often caused by the strain on the body from years of disability.

Polio Australia lobbies government on behalf of survivors and has organised a series of events around the country to raise awareness that the legacy of polio still lingers. It also supports World Polio Day on October 24, promoting vaccination to prevent the disease world-wide.

- To find out what's happening in your state: (03) 9016-7678, www.polioaustralia.org.au/whats-on-in-your-state

Jane's story

JANE Trengove contracted polio as a baby in Melbourne in the mid-1950s.

The virus caused paralysis to her right arm and leg, and partial paralysis her left arm and leg. The paralysis has remained throughout her life.

While Jane's childhood experiences were positive thanks to strong support from her family and acceptance from her peers, her disability made for a traumatic adolescence.

Entering the workforce was also hard as Jane struggled to find a workplace that could accommodate her disability, and though she managed to find part-time work, this still meant financial hardship.

Now 64, Jane lives with late effects of polio. Everyday tasks and activities are becoming increasingly difficult. Even with her full leg brace and scooter, and though fiercely independent, she is looking at a future of increased needs.

As a "younger" polio survivor, Jane is eligible for the NDIS and hopes to get a motorised wheelchair. Being able to acquire the appropriate aids and equipment is vital to ageing with dignity.

Jane is fighting an uphill battle to remain independent but she fears that one day she will have to move into a nursing home.

Despite her best efforts, Jane's capacity to participate in recreational activities, maintain family and community interactions, and stay in the workforce is an ongoing challenge.

"I want to continue working and I want to remain in my own home, but I need support to achieve this," she said.

Polio Australia national program manager Maryann Leithof said the organisation's vision was for all polio survivors in Australia to have access to appropriate health care, assisting them "to age with the same dignity that we all aspire to".

A recent grant from the Department of Health will fund a program to upskill 3,600 health practitioners across Australia in how to best manage LEOp.

ADVERTISER.COM.AU MONDAY DECEMBER 11 2017



STANDING TALL: Ron Blackwell at 19, and inset, today at his Athelstone home. Picture: AAP/BRENTON EDWARDS

The modern fight against post-polio syndrome ramps up as sufferers fight misdiagnosis and rising costs

ABC Newcastle, By Nancy Notzon
Updated 10 Mar 2018, 10:46am



PHOTO: Rose Collins and her older sister Gloria contracted polio as children. (Supplied: Rose Collins)

Defeated polio strikes again

JILL PENGELLEY

RON Blackwell returned to primary school in Bordertown hiding a caliper on his right leg.

He had been yanked out of his community almost two years earlier, in 1947, and sent to the Somerton Crippled Children's Home to be treated for polio.

"My mother insisted on me wearing long trousers to cover the supports I wore," he says. "But now, if someone tells me I don't believe in vaccines, I'll pull my trousers up and show them."

Mr Blackwell, 78, of Athelstone, was just eight when diagnosed with polio. He is one of 2857 people on the Australian Polio Register.

PolioSA estimates more than 400,000 people living in Australia have had the disease but are not on the register.

Despite now being eradicated from most countries, polio continues to rear its head, usually decades later, in the form of post-polio syndrome, which can include weakness, fatigue and pain. A retired teacher, Mr Blackwell began to experience post-polio fatigue in his 40s.

He urges everyone who had contracted polio, no matter how mild, to join the register. "We've found over time that a lot of people are deniers," he says.

"It's particularly those who didn't have paralytic polio; they don't recognise that as strange things happen to them, it may be polio being revisited."

Mr Blackwell volunteered for a study by University of Adelaide and Queen Elizabeth Hospital, to understand how normal loss of muscle mass and strength associated with ageing affects people with post-polio syndrome.

Principal investigator Dr Kandiah Umaphysivam says progression of the frailty of ageing, known as sarcopenia, could be delayed with healthy diet and exercise.

"But where people have an existing neurological disability like post-polio syndrome, their capacity to exercise is reduced," he says.

"This (study) is the first step towards developing a screening tool, and identifying which types of exercise, dietary changes and other wellbeing interventions work best to keep people with PPS active and healthy for longer."

Polio SA president Brett Howard encourages people to add their names to the Australian Polio Register to reflect the unmet need for polio services.

"It's important for all people who've ever had polio to be counted," he says. "After the vaccines were introduced, many medical records about polio in Australia were destroyed. "It was assumed it was all over but we're still here."

FOR INFORMATION GO TO POLIOSA.ORG.AU OR CALL 0456 893 402. TO INQUIRE ABOUT JOINING THE STUDY, EMAIL KANDIAH.UMAPATHYSIVAM@ADELAIDE.EDU.AU OR CALL 0436 991585



weakness, fatigue and pain. A retired teacher, Mr Blackwell began to experience post-polio fatigue in his 40s. He urges everyone who had contracted polio, no matter how mild, to join the register. "We've found over time that a lot of people are deniers," he says.

If someone tells me they don't believe in vaccines, I'll pull my trousers up and show them

People also typically experience pain, chronic fatigue and muscle weakness.



PHOTO: Rose Collins only noticed her symptoms of post-polio a few years ago, more than half a century after having polio. (ABC Newcastle: Nancy Notzon)

Diagnosis can take years

Ms Collins did not know she had polio as a child.

Her older sister Gloria was seriously ill with a paralytic form of the virus when she was young, while Ms Collins merely had a fever.

Program Reports

COMMUNITY INFORMATION SESSIONS

**By Stephanie Cantrill
Polio Community Officer (Vic)**

Summary of work since commencing on the 8th of May 2018:

- Met with several relevant service providers, including Polio Services Victoria, Dr Stephen de Graaff, Anne Duncan at Victorian Respiratory Support Services, and Darren Pereira at Neuromuscular Orthotics.
 - Collected a number of names/contacts of other services providers in order to pass these on to support groups.
 - Met with a number of support groups, including Bayside, Mornington Peninsula, South-Eastern Region (Springvale), Bendigo, and Geelong.
 - Passed on information to the groups such as a research project being conducted by Deakin University, podiatrist contacts, MyAgedCare details and shared other material I have gathered along the way.
 - Have used the opportunity when speaking with the groups to learn about what to prioritise for information sessions and how to best reach out to polio survivors.
- Been in contact with a number of other key people, including former and current group convenors who are either too far from Melbourne for casual visits, or operate on days that I'm not working for Polio Australia.
 - Met with Polio Network Victoria members, and most members of the Post Polio Victoria committee, and plan to continue building relationships with these organisations.
 - Attended a meeting of the ATOP (Assistive Technology for Older People) Alliance, with the intention of continuing to support their advocacy efforts.
 - Helped to develop a multi-organisation flyer for information sessions and other gatherings, with the aim of providing information that explains the role of the Victorian organisations and Polio Australia.
 - Conducted the first polio community information session in Noble Park (Victoria) on Friday 27th July, with 18 people in attendance – received positive feedback.
 - Arranged to speak at LaTrobe University, national Podiatric Conference, and Polio Day event, later in the year.

Photo: Noble Park Community Information



Program Reports

FINANCING/REVENUE

By Bonnie Douglas
Financing Manager

I started my part-time role as Financing Manager with Polio Australia in January 2018. Having previously worked in corporate environments, primarily in information technology roles, I have certainly found this role challenging, and I look forward to developing it further over the next year as we roll out the "Splish, Splosh, Splash" campaign.

Grants

This table shows grants applied for between January and June 2018. Grants include an Expression of Interest (EOI) for the development of a multi-year relationship with the Ramsay Foundation. We applied for 7 grants and won one.

Purpose	# Grant Applications lodged	Total \$ Requested	# Won	\$ Received
Retreat	5	\$75,000	1	\$20,000 ³
Advertising	1	N/A ¹	0	0
CDW	1	N/A ²	0	0

¹ Advertising on Yarra Trams with no dollar value specified

² EOI no budget specified

³ Marian and E.H. Flack Trust

Retreat Sponsorship

We offered a variety of sponsorships to health professionals as well as disability product and service providers, to raise money to offset costs of the Retreat. Sponsorships included advertising in Polio Oz News, display of a banner at the Retreat, and including flyers in Retreat show bags.

- Secured sponsorship from 1 health practitioner for a Retreat workshop (\$400).
- Secured multiple donations of items for the Retreat raffle.

Donations and Bequests

Donations continue to be an extremely important component of revenue. This year we received \$91,850.75 in donations, and \$25,000 in bequests.

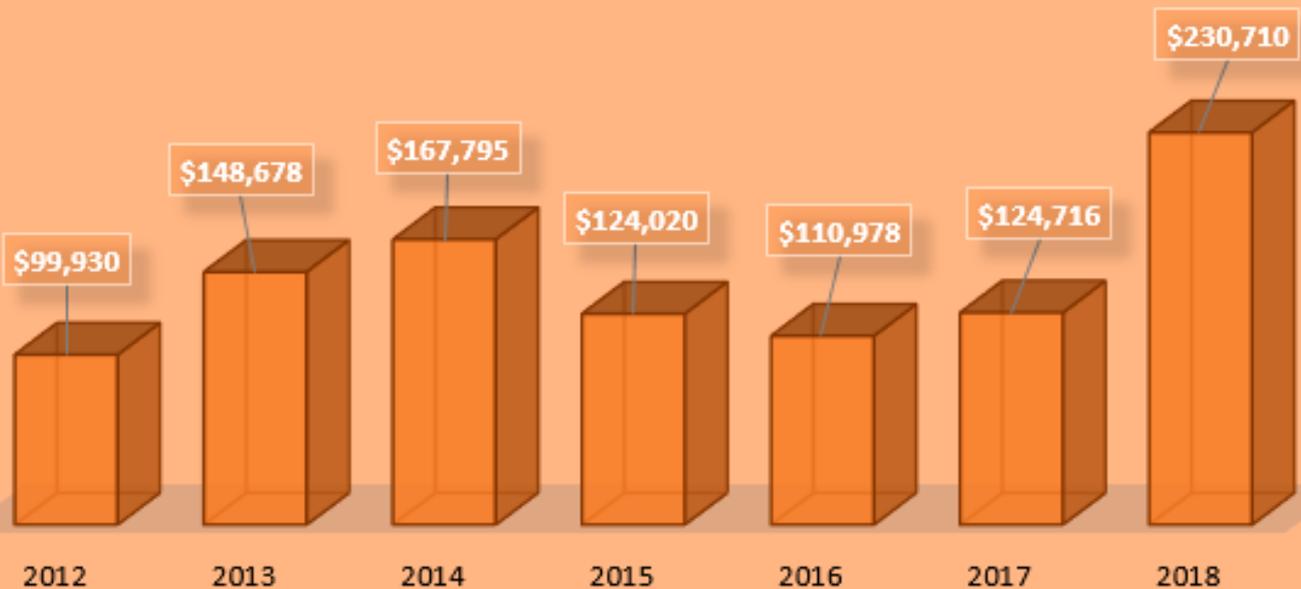
Other Activities

- Entertainment Book: This scheme provides groups with the opportunity to raise funds through the sale of digital and/or hard-copy Entertainment Books. The Entertainment Book contains coupons specific to a region (e.g., Sydney, Melbourne, Perth). Polio Australia receives \$14 from each book sold. Sold 4 Entertainment books (\$56).
- Ritchies IGA Community Benefit card. Ritchies' Community Benefit Card Program donates a percentage of the money spent by Ritchies IGA customers to their nominated club, school or charity.
- Listed on Australian Philanthropic Services, a not-for-profit organisation that administers private ancillary funds and aims to connect philanthropists with not-for-profit organisations.
- Launched our page on GiveNow, an online donations platform launched by OurCommunity.
- Attended ATSA Melbourne and contacted multiple suppliers regarding partnerships and corporate giving programs.
- Developed a fundraising campaign to be introduced to primary schools over the 2018-2019 financial year. The "Splish, Splosh, Splash" puddle jumping contest will challenge students to raise money for Polio Australia as they compete to jump over a large fabric "puddle".

Financials

Accumulated Funds 2012–2018

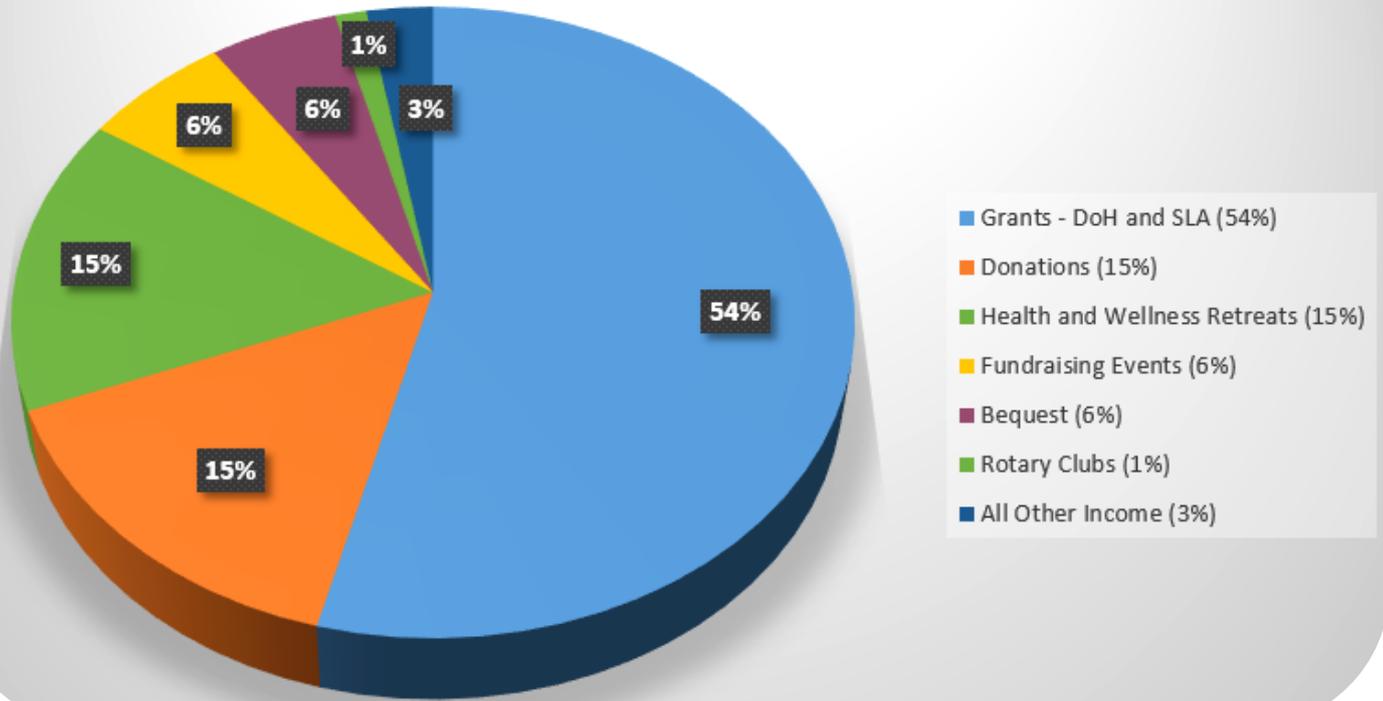
POLIO AUSTRALIA ACCUMULATED FUNDS



2017—2018

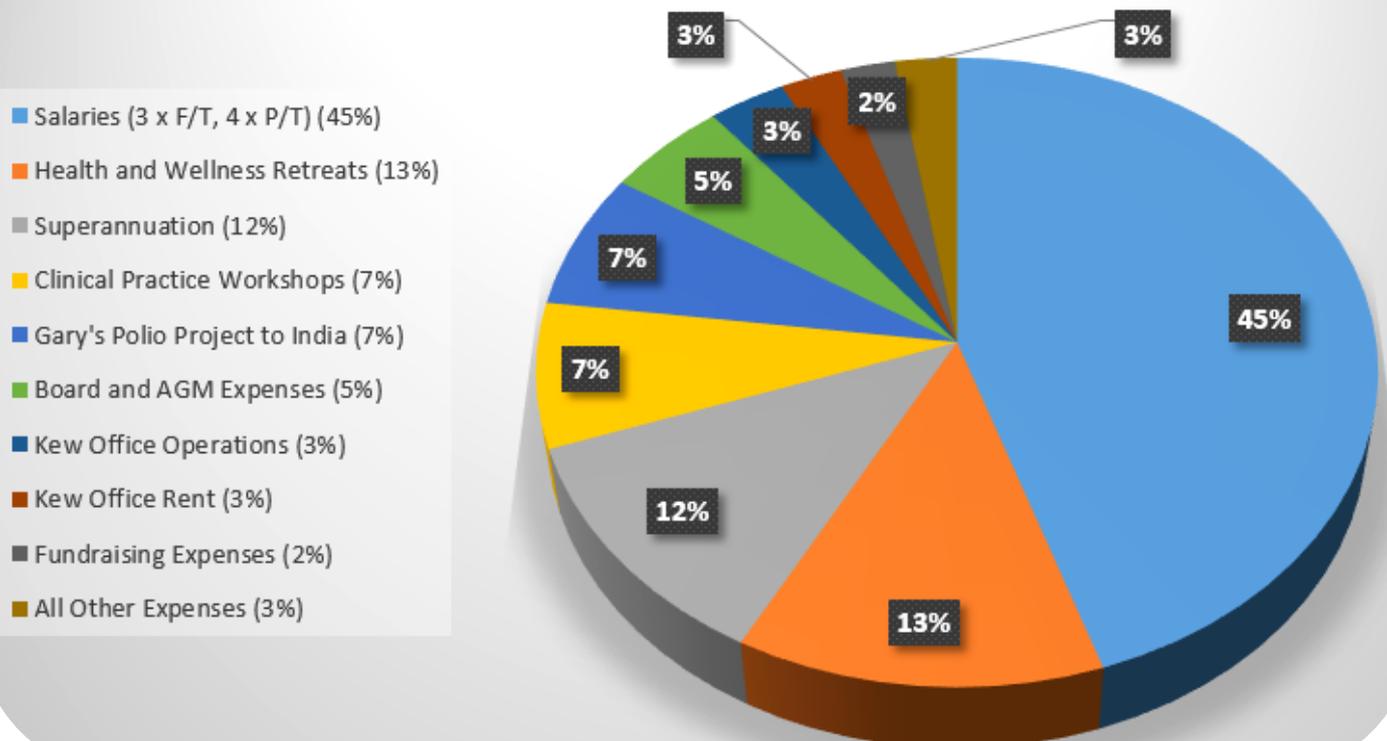
Income

Polio Australia Income Sources 2017/2018



Expenditure

Polio Australia Expenditure 2017/2018



Strategic Priorities

2018–2020

At its 2017 Annual General Meeting and Strategic Planning Meeting, Polio Australia's Board decided on four priorities to work towards over the next three years, which this Annual Report reports against.

Priority One

EDUCATION

Educating health professionals and polio survivors in the management of the Late Effects of Polio.

TRAINING



Priority Two

CAPACITY BUILDING

Future proofing Polio Australia to ensure sustainability beyond 3 years' funding.

Future proof



Priority Three

PARTNERSHIP DEVELOPMENT

Enhance external and internal relationships for mutually beneficial outcomes.



Priority Four

ADVOCACY AND VISIBILITY

Lobbying and advocating for recognition and appropriate service provision for Australia's polio survivors whilst creating positive visibility in the community, including reaching out to younger polio survivors.

ADVOCACY





Priority One

Parliamentary Patron, Mr Mark Coulton MP, launching the Clinical Practice Workshops Program at Parliament House, Canberra, November 2017

Priority Two
Walk With Me fundraising event held in Brisbane, September 2017



Priority Three

Independent Board Member, Gary Newton, with Rotary District 9780 Conference Delegates April 2018

Priority Four

Polio Australia representative, Rohan Clark (second from right) joined forces with Global Citizen Australia for Polio Awareness Day at Parliament House, Canberra, October 2017



Selected Highlights



2017 Retreat participants, Marcoola Beach, Queensland



Walk With Me Canberra 2017



Walk With Me Brisbane 2017

Walk With Me 2017
\$28,611.36
donated by 103 donors

Clinical Practice Workshop, Coburg, Victoria, 2018



A Special Thank You

Polio Australia has had much to be thankful for, with support from a number of individuals and organisations over the 2017-18 period. Some of our key benefactors are highlighted here:

Fundraisers and Major Donors

- Jill Burn
- Eastern Region Polio Support Group (Vic)
- Laurence Peter Gordon Bequest
- Margery Kennett
- Karin Kolenko and Gold Coast Benji
- Sue Mackenzie
- Gary Newton
- Jill Pickering
- Liz Telford
- Gillian Thomas

Major Sponsorship and Grants

- APCO Service Station
- Federal Department of Health
- Spinal Life Australia
- IRT Foundation
- The Marian and E.H. Flack Trust
- Rotary District 9640
- Rotary Club of Geelong (Vic)
- Rotary Club of Hamilton (Qld)
- Rotary Club of Thuringowa Central (Qld)
- Scooters Australia

Walk With Me Brisbane Donations = \$17,625.36

Walk With Me Canberra John Tierney Donations = \$7,100

Walk With Me Canberra Gillian Thomas Donations = \$2,985

Walk With Me Canberra Brett Howard and Peter Wierenga Donations = \$525



John holding up his 'Retirement Trophy', presented in Canberra, November 2017

Last Word From Dr John Tierney DPM

When I became Polio Australia's President in 2012, my main objective was to achieve both a proper funding base for Polio Australia and to employ sufficient staff with this money to run our world-class programs in support of Australia's 400,000 polio survivors. This was achieved last July, so it is now time for me to move on to full-time retirement.

I wish Polio Australia all the best for the future, although as National Patron, I am sure that I will be called on from time to time to assist with government affairs.

Polio Australia

Representing polio survivors throughout Australia

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Social Media



Page: www.facebook.com/PolioAustralia/

Group: www.facebook.com/groups/PolioAustralia/



www.twitter.com/polioaustralia



"We're Still Here!"