



Australasia-Pacific Post-Polio Conference—Polio: Life Stage Matters Sydney—20-22 September 2016



Annual Report 2016/2017

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.



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.



Maryann Liethof National Program Manager (VIC)



Samantha O'Meara Community Engagement & Bequest Officer (VIC)



Shylie Little Administration/ Bookkeeper (NSW)



Jill Pickering Regular Volunteer (VIC)

Our Board

Established in 2008, Polio Australia is a national peak body governed by a Board comprising two representatives from each of the six State Polio Networks, and up to three specialist independent members. Polio Australia is a consumer founded, consumer focused, not-for-profit, incorporated organisation representing hundreds of thousands of polio survivors who are now living with the Late Effects of Polio (LEoP).



Dr John Tierney President National Patron Government Lobbyist (NSW)



Arthur Dobson (TAS)



Gillian Thomas Vice-President Business & Web Manager (NSW)



Ron Exiner (VIC)



Jenny Jones Secretary (WA)



Brett Howard Treasurer (SA)



Tessa Jupp (WA)



Susanne Mackenzie Fundraising Coordinator (Independent QLD)



Gary Newton Communications Coordinator (Independent VIC)



Billie Thow (TAS)



Bev Watson (VIC)



Peter Wierenga (SA)

Incoming



Michael Powell (QLD)



Dr Christine Tilley (QLD)

Outgoing



John Mayo (QLD) (resigned Nov)



Dr Margaret Peel (QLD) (resigned Nov)

Our Wins

2016 Australasia-Pacific Post-Polio Conference

Walk With Sue

Brisbane



Fundraising Events





Raised \$12,385

\$4003

In 2016-17



Launched Health Professional Register



Seven new videos on our website



Polio Survivors Talk About LEoP Video length: 2 mins 22 secs



Partnership with Spinal Life Australia

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President's Report

Introduction

I am pleased to report that 2016-2017 has been Polio Australia's most successful year to date, encompassing not only our highly acclaimed Australasia-Pacific Post-Polio Conference in Sydney but also the establishment of a sound funding base for Polio Australia, with federal government program funding, and organisational support funding from Spinal Life Australia. My special thanks again this year go particularly to Maryann Liethof and Gillian Thomas who continue to give their all to our vital work in support of Australia's 400,000 polio survivors.

Australasia-Pacific Post-Polio Conference

The highlight of the 2016-2017 year was the highly successful Conference held in Sydney in September. Over three days, 229 participants and 61 pro-bono speakers from 14 countries took part. Our special thanks go to Maryann Liethof whose drive and determination made this all come together so well. I would also like to especially thank the Chair of our Conference Steering Committee, Dr Steve de Graaff; webmaster extraordinaire, Gillian Thomas; MC, Gary Newton; and *Interpoint Events*, the conference organising team, whose skills in managing such an event were invaluable.

A jewel in the crown of this Conference was the agreement by NSW Health Minister, the Hon Jillian Skinner MP, to host and speak at the Conference Gala Dinner. Also, the funding for our Conference received a terrific boost with a sponsorship of \$24,000 from her NSW Department of Health.

At the end of the Conference one enthusiastic participant asked "Where are you putting the conference on next year?". Given this event was two years in the making and consumed so much of Polio Australia's time, effort and resources over that time frame, I am afraid that such a Conference will not be happening anytime soon.

For those who attended, I hope that you learned a lot about how to manage your post-polio condition; I certainly did! If you were unable to attend, Polio Australia's websites, in particular *Polio Health*, is a gold-mine of information from the Conference to assist with the management of the LEoP.

Walk With Me In Canberra and Brisbane

During Polio Awareness Month in October, we returned to Canberra for our second *Walk With Me* event at Parliament House. We invited the Members and Senators to *Walk With Us* from the front entrance of Parliament House to either the Senate door or the House of Representatives door and back. We were joined on the walk by parliamentarians, the Polio Australia Board and a number of other polio survivors and supporters. My special thanks go to Brian Wilson for organising members of the ACT Post-Polio Support Group to attend. We were all very prominent in the parliament wearing our *Walk With Me* T-shirts.

A morning tea preceded the walk with our Parliamentary Patrons and the Parliamentary Friends of Polio Survivors, where we launched our updated Australian Polio Register and our new Post -Polio Health Professionals Register, which enables polio survivors and health professionals to search for practitioners who actually know something about the LEoP. These wonderful resources were put together by Gillian Thomas.

Also in 2016, we had a Queensland *Walk with Me* for the first time, which was organised by Sue Mackenzie, our Events Coordinator extraordinaire and Independent Board Member. Sue had a great event on the Brisbane River to support her fundraising efforts, with many taking part.

Walk with Me this year was a great financial success with 150 donors contributing \$16,388 dollars.

Queensland-based Bill Peacock worked with his local Rotary Club of Bribie Island to host a Fashion Parade and Lunch. This was held on the International Day of People With Disability, with all proceeds going to Polio Australia.

We are greatly indebted to Sue and Bill for their efforts in organising their respective activities, as well as everyone who so generously supported these fundraising campaigns.

Federal Government Health Funding-At Last!

For the last nine years, Polio Australia has been lobbying the federal government and parliament

for recognition and support for Australia's 400,000 polio survivors. On the one hand, we have had stunning success in raising the profile of polio survivors, especially through lobbying, *Walk with Me* and *We're Still Here!* campaigns.

On the other hand, our attempts to access federal funding over the years had not been successful. We did, however, almost get over the line in 2014, but fell at the last hurdle when there was a change in Health Minister. In 2017, we were finally successful.

This year, Gillian Thomas, Maryann Liethof, and myself were joined by Michael Powell, a Polio Australia Board member and the CEO of Spinal Life Australia *(SLA)*, which auspices the Queensland Polio Network. We were the Polio Australia Canberra lobbying team, successfully lobbying in June for financial support for the needs of polio survivors. Earlier in the year, a meeting took place between Fran Henke (a former independent member of the Polio Australia Board), Dr Margaret Cooper, Maryann Liethof and the Hon Greg Hunt MP, Minister for Health, in his Victorian seat office. This greatly helped Polio Australia secure the critical Canberra meeting in June.

We have now secured, from the Federal Department of Health, \$150,000 per annum funding for three years for a series of nation-wide *Clinical Practice Workshops*. These proposed workshops are based on Polio Australia's highly successful program trialed a year ago in northern Sydney in partnership with Rotary District 9685.

Spinal Life Australia Support Funding For Polio Australia

At the AGM in November, our new Queensland based Board member, Michael Powell, signaled that SLA, under his leadership, is keen to develop more services for their polio survivors and to further develop the support group network across Queensland. Part of this change would also be to provision of resources for the work of Polio Australia.

The executive of Polio Australia and SLA then met in Brisbane to explore how the two organisations could develop a productive partnership to support our polio survivors. Given our challenges with government and other community-based organisations in the past, this offer was a breath of fresh air. The Board of SLA agreed to fund Polio Australia at \$100,000 dollars per annum for the next two years (2017–2019), with a focus on developing self-sustaining funding strategies into the future.

In the meantime Polio Australia had to make budget for 2016–2017. This became possible because of some excellent fund-raising work by our Independent Board member, Gary Newton, who secured for us a very large philanthropic donation of \$50,000.

Our Rotary Partnership

In November, I addressed the Rotary Zone 7B / Zone 8 Conference in Penrith (NSW). This Zone covers Australia and New Zealand. This was a gathering of 400 Rotary Governors, past, present and future, and other Rotary leaders. They had asked me to speak on the Late Effects of Polio (LEoP).

One of the matters that I covered in my address was Polio Australia's highly successful partnership with Rotary District 9685 in 2015 / 2016, to train health professionals in the LEoP. Neurological physiotherapists Melissa McConaghy from ARC Health and Catriona Morehouse from Mt Wilga Private Rehabilitation Hospital conducted the eight workshop training sessions for health professionals. They were very well received by the participants who scored the workshops very highly on all measures. In my talk I pitched for supported central funding at the Rotary Zone level. Even though Rotary did not take this up, the feedback data from the District 9685 health professional workshop program was an excellent springboard for convincing the federal government to fund this pilot program nation-wide between 2017 and 2020.

Our Developing Partnership With Polio New Zealand

The very strong link that has been forged between Polio Australia and Polio New Zealand continued over the last year. In October, I headed across the ditch again to take part in their second Health and Wellness Retreat in Rotorua at the OE2 rehabilitation facility, which has two thermal pools (hot and very hot). In recent times, a number of executive members of Polio NZ have attended our Health and Wellness Retreats in Australia, and this year sent the largest international contingent to our Australasia-Pacific Post-Polio Conference in Svdnev.

Farewell

At the Board's Canberra AGM, we said goodbye to outgoing members, John Mayo and Dr Margaret Peel, both from Queensland. I would like to take this opportunity to thank John and Margaret for their years of service on the Board, and wish them well in their future endeavours.



Our online presence continued to expand over 2016-2017.

By year end, increased social media activity saw our Facebook page pass the 1,000 "likes" milestone, the membership of our related Facebook group almost doubled, and our Twitter feed had attracted over 500 followers.

Work on Polio Australia's websites also continued apace with several important developments being released.

Health Professionals Register

earch:								
Profession	Title	First Name	Surname	Suburb / Town	State / Territory	Practice Type	Wheelchair Access	More Information
Case Manager	Mr	Dean	Goyne	West Footscray	Victoria	Community Health Service	Yes	Full Details
Chiropractor	Mr	Mark	Trbojevich	Pearce	ACT	Private Clinic	Yes	Full Details
Exercise Physiologist	Miss	Susanna	Cheng	Eastwood	New South Wales	General Practice	Yes	Full Details
Massage <mark>Therapi</mark> st	Mr	John	Kirkwood	Nairne	South Australia	Private Clinic	No	Full Details
Massage Therapist	Ms	Andrea	Schadeberg	Pymble	New South Wales	Private Clinic	No	Full Details
Neurophysiotherapist	Mrs	Ann	Buchan	Unley	South Australia	Private Clinic	Yes	Full Details
Nurse	Mrs	Tessa	Jupp	Floreat	Western Australia	Community Health Service	Yes	Full Details
Nutritionist	Ms	Melinda	Overall	Summer Hill	New South Wales	Private Consultant	No	Full Details
Occupational Therapist	Mrs	Rosemary	Franzsen	Eastwood	New South Wales	Public Hospital	Yes	Full Details
Occupational Therapist	Mrs	Maria	Fruin	Mona Vale	New South Wales	Private Consultant	Not Applicable	Full Details
Occupational Therapist	Mrs	Sybbi	Georgiou	Lawson	New South Wales	Other	Yes	Full Details

Database of health professionals created with sorting and searching functionality

Australian Polio Register



Add Your Details Today! Polio Australia encourages every polio survivor living in Australia (regardless of the country where you contracted polio) to add your details to the Australian Polio Register.

Read More



entry on this page. Be sure to let us know of any errors. Read More



Explore All Entries To Date The publishable data in the Register can be browsed in various ways - by family name, maiden name, given names, birth year, polio year, polio age, or polio location.

Read More 💛

Refined and updated in time for the Conference





By the closing date for donations on 31 December 2016, the five 2016 Walk With Me teams had raised: \$16,388.00 donated by 150 donors

In-house fundraising platform established to simplify donating, improve reporting, and reduce costs

Conference Videos

11 Conference videos generously provided by Post-Polio Health International were made accessible through our Polio Health website

Ivig as a treatment for Post-Polio Syndrome: trial results Prof. Frans Nollet, MD, PhD	Physiotherapy for post-polio patients as part of an interdisciplinary rehabilitation program Merete Bertelsen, PT
Video length: 19 mins 47 secs	Video length: 26 mins 36 secs
Master class in physiotherapy assessments and exercise therapy Catriona Morehouse, PT Gnanaletchumy Jegasothy, PT (Ret) Ann Buchan, PT Merete Bertelsen, PT	Post-Polio Syndrome as a Possible Viral Disease: results from an Italian PPS cohort Antonio Toniolo, MD
Video length: 1 hour 50 mins 17 secs	Video length: 33 mins 24 secs

National Program Manager's Report

Polio Australia is proud of its achievements over the last six years, particularly with such limited resources. The 2016-17 period included numerous activities and 'wins', a selective few of which are highlighted in this report.

Australasia-Pacific Post-Polio Conference

Our pursuit of best-practice information, and subsequent interaction with other peak post-polio organisations and health practitioners around the world, was instrumental in bringing about the first ever Australasia-Pacific Post-Polio Conference: *Polio-Life Stage Matters* in September 2016.

Over the two years of negotiations and planning, we appreciated the support of Dr Steve de Graaff, who Chaired the Conference Committee, Simon Cooper and Melanie Robertson from Interpoint Events who, quite literally, made the Conference possible, and all the Australian and international presenters who so generously invested their own money, time, and expertise to make the Conference a world class event. The combined forum of polio survivors together with health professionals, provided important interaction and learnings for all delegates.

Proposal to Support Polio Survivors: LEoP Clinical Practice Workshops Program

In March, I joined polio survivors and advocates, Frances Henke and Dr Margaret Cooper, for a meeting with the (then) recently appointed Minister for Health and Minister for Sport, the Hon Greg Hunt MP. Greg has been a long time Parliamentary Patron of Polio Australia, and it was a great opportunity for us to visit his electoral office in Hastings, Victoria, to present him with a *Proposal to Support Polio Survivors*. Polio Australia's Executive followed this up with a visit to Canberra in June, where we were ecstatic to be advised that our Proposal had been successful! The coming year will see the development of a national LEOP Clinical Practice Workshops Program across a 3 year funding period.

Fundraising

Without regular income, fundraising plays a vital part in enabling the work of Polio Australia to continue. Three key events were run in October, November, and December, which helped raise nearly \$20,000 for Polio Australia's work.

Two Walk With Me events – one in Brisbane and the other in Canberra – were led by Independent Board Member, Sue Mackenzie, and Polio Australia's President, Dr John Tierney, respectively. Polio Australia sported a brand-new logo for our 'Walk With Me' activities, and we thank freelance artist, Angela Casabene, for designing the logo pro -bono. A Fashion Parade and Lunch was also held on Bribie Island on the International Day of People With Disability. The Fashion Parade was organised by Bill Peacock and his team, Peter Sheehan and Tom Dutton, together with the Rotary Club of Bribie Island, led by Anne Matthews. The event attracted 70 participants.

We are greatly indebted to John Tierney, along with Polio WA, PPV and PNSW Board representatives, Sue Mackenzie and Bill Peacock for their efforts in organising their respective activities, and everyone who so generously supported these fundraising campaigns.

Relocation of Polio Australia's Office

In February, I moved Polio Australia's office from Level one to Level six, still at 89 High Street, Kew, Victoria. This was a result of changes to our rental agreement. Fortunately, the new office has proven to be far more satisfactory, with more space, wonderful views, and very reasonable rent. We thank Jill Pickering for her ongoing donation which pays for the office.

Video Production

To assist in the delivery of Polio Australia's messages, we produced seven short promotional videos for our websites, some specifically for health professionals. These focussed on how to assess and manage the post-polio body, and have enabled us to quickly demonstrate the issues facing polio survivors, and the efficacy of our Clinical Practice Workshops. We are grateful to Mt Wilga Private Rehabilitation Hospital for providing the venue and organising staff to be involved.

Human Resources

In June 2017, Sam O'Meara joined Polio Australia in the new role of Community Engagement and Bequest Officer. This position is being funded through a new partnership with Spinal Life Australia. Sam's role involves contacting members of our post-polio community to have a friendly chat about how they're travelling, and to provide an update on Polio Australia's current and upcoming programs and activities, including the fledgling Bequest Program.

With new funding from both Spinal Life Australia and the Department of Health, Polio Australia will be seeking to employ additional staff in the areas of: Clinical Practice Educator, Fundraising Officer, and Administrative Officer. With this unprecedented boost to our resources, I anticipate the 2017-18 Annual Report looking very different!



At its 2014 Annual General Meeting and Strategic Planning Meeting, Polio Australia's Board decided on five priorities to work towards over the next three years, which this Annual Report reports against.

Strategy Dne: Education	Promoting enhanced knowledge and management of the Late Effects of Polio across the health and community sectors	
Strategy Two: Advocacy	Lobbying and advocating for recognition of and appropriate service provision for Australia's polio survivors	
Strategy Three: Capacity Building & Resources	Building resources—financial and human	Walk With Me
Strategy Four: Visibility	Creating positive visibility in the community	
Strategy Five: Partnership Development	Enhance external and internal relationships for mutually beneficial outcomes	

16ALA

Financials

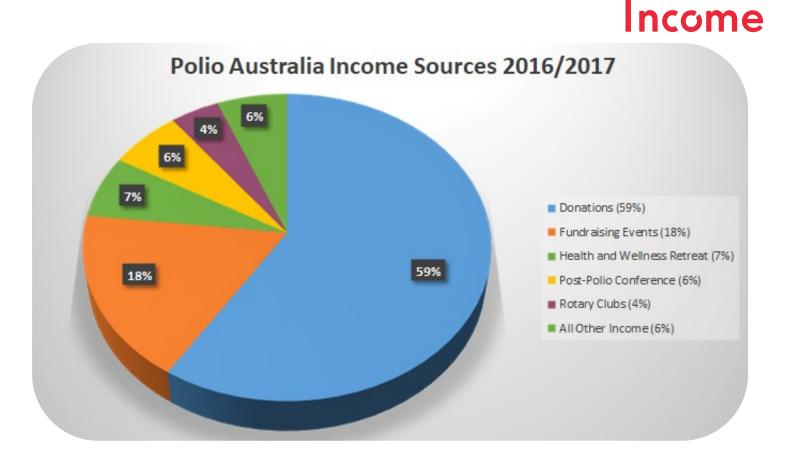
Accumulated Funds 2011—2017

POLIO AUSTRALIA ACCUMULATED FUNDS

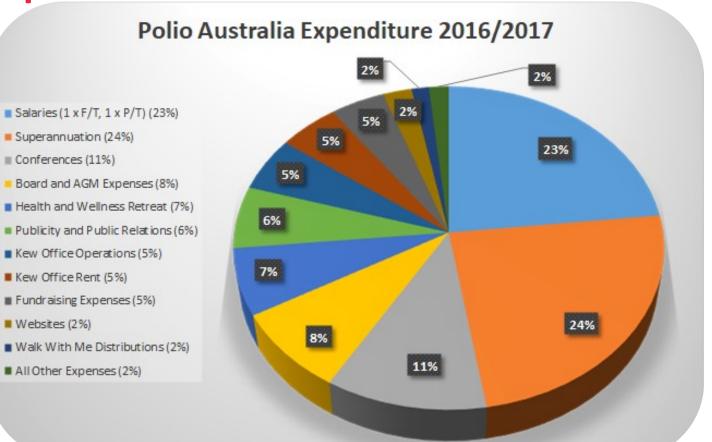




2016-2017



Expenditure



2016 Australasia-Pacific

The first ever Australasia-Pacific Post-Polio Conference was held between 20th and 22nd September 2016 at the Four Seasons Hotel, Sydney. In attendance was a total of 229 delegates from 14 countries.

The proceedings included 23 keynote presentations, 38 additional oral presentations and 8 poster presentations. Overall, a total 85 stimulating presentations across a broad spectrum of post-polio issues.

The aim of the Australasia-Pacific Post-Polio Conference was to exchange knowledge about the diagnosis and treatment of the post-polio condition in different age groups to best preserve functioning throughout life. It was a forum facilitate better to care and build international connections by bringing together health providers, care researchers, polio survivors and their caregivers not only from the Australasia-Pacific region, but worldwide.

Future Proofing Polio Services Panel Discussion

"We really enjoyed the conference. The quality of the presentations was outstanding and the networking opportunities were so valuable."

- Dr Pat Dorsett



Japanese Polio Delegation at Welcome Cocktail Party

"For the first time I felt one of the many rather than one of the very few. It was a lifeaffirming experience as 'We're Still Here!' and we survivors talked and laughed together like old friends."

Sylvie Sampson (ACT), Polio Survivor

229 delegates

- 153 Survivors/Family/Friends
- 7 Carers
- 60 Professionals (some also polio survivors)
- 3 Students
- 6 Others

Post-Polio Conference

Objectives 1, 2, 3, 4 & 5

"Polio—Life Stage Matters"



Gary Newton







Neena Bhandari

Jenny Horton





Sai Padma



Maryann Liethof



Marmaduke Loke



Dr Nigel Quadros



Prof Antonio Toniolo



Dr Steve de Graaff





Gayle Kennedy

The Australasia-Pacific Post-Polio Conference: Polio—Life Stage Matters, provided much food for thought, and even some life-changing strategies for the post-polio delegates. This was all made possible thanks to the huge pool of Australian and international expertise which provided a total 85 stimulating presentations across a broad spectrum of post-polio issues.

Many important connections, as well as new friendships, were made in the 3 days of the Conference, which is the true mark of a successful Conference.

Post-Polio Health International recorded 11 Presentations at the Conference, and all the Abstracts were published in The Journal of Rehabilitation Medicine and distributed to the delegates.

Fundraising Events

Walk With Me Canberra

Walk With Me Canberra was held on 10th November 2016 and involved a 1km walk/wheel/ride around Parliament House. Polio Australia's Board, along with members of the ACT Polio Support Group, participated the event, which raised \$12,385 from 111 donors.

Walk With Sue Brisbane

Walk With Sue (Mackenzie) Brisbane was held on 29th October 2016 and involved a 1.5km walk/wheel/ride along the Brisbane River. The event raised \$4003 from 39 donors.





International Day for People with a Disability

On Saturday 3rd December, a lunch and fashion parade fundraiser was held on Bribie Island, Queensland. Local representative, Bill Peacock, and the Rotary Club of Bribie Island hosted the event. The event raised \$2,747, with all proceeds going to Polio Australia.



New Walk With Me logo!





Funding From Government

Following a meeting in March 2016, with the (new) Minister for Health, The Hon Greg Hunt, Polio Australia's Executive Team visited Parliament House on 15th June 2016, to discuss a proposal requested by and submitted to the Health Minister.

The proposal encompassed the need for a national health professional education program on the Late Effects of Polio (LEoP). Polio Australia was granted funding of \$150,000 pa across a 3 year period for the LEoP Clinical Practice Workshop Program.

The need for this program developed from a great many accounts from polio survivors over the decades, citing uninformed, expensive, and inappropriate treatment by a range of practitioners. The project follows the successful pilot program in 2015-16 of eight LEoP Clinical Practice Workshops in the Northern Sydney suburbs for 140 health professionals. The funding and workshops will begin 1st July 2017.

After nine long years of lobbying, this Federal Government funding is a major victory!

Dijectives, I, 2, 3, 8, 5 Parliamentary Patron, The Hon Greg Hunt House on 31 October 2012 The Hon Greg Hunt reacting with (I-r): Dr Margaret Prances Henke on 17 March 2017

Other Achievements

Polio Australia Captured on Film

Polio Australia commissioned and uploaded seven videos to the websites, each covering a different aspect of the work being done by Polio Australia to achieve our commitment of standardising quality polio information and service provision across Australia for polio survivors.

NB: 'Walk With Me' video not pictured.

Objectives 1 & 4

Me' video not





Polio Australia in

Profile

LEoP Clinical Practice Workshops



Future Proofing Polio Services



Best Practice Management of LEoP



Bequest Program

Health Professional Register

29

registered health professionals . . . and growing! Polio Australia developed an online interdisciplinary listing of willing practitioners who have an interest in treating polio survivors. In the absence of best practice management of people with LEoP, this register assists survivors in accessing appropriate care to analyse and minimise symptoms, maximise function, and support participation. Health professionals and polio survivors can access the register via the www.poliohealth.org.au website.

Objectives 1,2 & 3

Spinal Life Australia Partnership

Spinal Life Australia (SLA) proposed a partnership with Polio Australia to support polio survivors through helping the organisation thrive. The board of SLA agreed to fund Polio Australia at \$100,000 dollars pa for the next two years (from 1st July 2017), with a focus on developing self-sustaining funding strategies into the future.

This funding will be used to enhance Polio Australia's existing fund-raising programs such as *Walk with Me*, Rotary links, and the Bequest program, as well as exploring wider philanthropic and corporate sponsorship opportunities.

Spinal Life

\$100,000 pa Sustainability Funding

A Special Thank You

Polio Australia has had much to be thankful for, with support from a number of individuals and organisations over the 2016-17 period. Some of our key benefactors are highlighted here:

Fundraisers and Donors

- Jill Burn
- Karin Kolenko and Gold Coast Benji
- Sue Mackenzie
- Gary Newton
- Bill Peacock
- Jill Pickering
- Joan Smith
- Liz Telford
- Dr John and Pam Tierney

Notable Contributors

- Dr Margaret Cooper
- Frances Henke

Sponsorship and Grants

- Department of Social Services
- GSK
- Simon Cooper and Melanie Robertson, Interpoint Events
- Mt Wilga Private Rehab Hospital
- NSW Health
- Post-Polio Health International
- Rotary Clubs across Australia
- Scooters Australia
- Danica Knezevic
- All Conference Presenters

The Long Lived Story Of Florence Jean Barber

Was Florence Jean Barber "Australia's Longest Living Polio" Survivor" at 102 years of age? This was the question Florence's nephew contacted Polio Australia at the end of 2016 to find out.

Although we didn't really know, Polio Australia did feel that this milestone certainly warranted recognition by way of a plaque.

Board Member and volunteer National Communications Coordinator, Gary Newton, visited Florence on Monday the 13th of February, together with Winnie Teo, Coordinator of the Geelong Polio Support Group, where they presented her with a plaque acknowledging Florence Jean Barber as "Australia's Longest Living Polio Survivor".

Florence passed away peacefully a few months later, having lived a full and satisfying life.





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Websites

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Social Media



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

www.twitter.com/polioaustralia

