



ANNUAL REPORT 2018-2019

Gillian Thomas, President ♦ ABN 53620 396 311 ♦ ABRN 142 977 053 Suite 605A & B, Kew Junction Tower, 89 High Street South, Kew Vic 3101 PO Box 500, Kew East Vic 3102

Phone: +61 3 9016 7678 ♦ Mobile: 0466 718 222 ♦ office@polioaustralia.org.au www.polioaustralia.org.au • www.poliohealth.org.au

www.australianpolioregister.org.au • www.stillhere.org.au

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2018-19 HIGHLIGHTS

10 Years Representing Australia's Polio Survivors

August 2018 marked Polio Australia's 10 year anniversary. A <u>timeline</u> featuring highlights of our achievements over the past decade has been uploaded to our website.

The Next Generation

Polio Australia is committed to supporting all Australian polio survivors, including the 'Next Generation' who were born from 1975 onwards in countries other than Australia. We conducted a focus group comprising five of these younger polio survivors to discuss issues they are currently facing, and what Polio Australia could do to help this demographic. Their stories can be viewed on our website.

Fact Sheets For All

Data gathered from both the Next Generation focus group and various online surveys conducted by Polio Australia, identified that there was a gap in providing accessible, practical information to polio survivors. In response, a new series of Fact Sheets have been developed, covering a broad range of post-polio related issues. There are four categories - Health, Lifestyle, Services, and Providers - encompassing 29 topics. These can be found on the "Living With Polio" information hub on our website.

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

Mission Statement

Looking Ahead

The Federal Department of Health has confirmed that they will be extending Polio Australia's contract for 3 years through to 2022. The grant provides us with the resources necessary to continue educating health professionals on the Late Effects of Polio. Polio Australia can also confidently and actively develop stronger partnerships with universities, peak bodies and providers across aged care, health, and disability.

PRESIDENT'S REPORT



August 2018 marked the 10th Anniversary of Polio Australia. Up until 2017, Maryann Liethof (National Program Manager), Dr John Tierney PhD AM (President 2013-17 and National Patron), Shylie Little (bookkeeper), and myself were the 'Team'; and John and I work on a purely volunteer basis. Thanks to consistent lobbying and much hard work, we received funding from the Department of Health to run Clinical Practice Workshops across Australia, and an additional 2 year grant from Spinal Life Australia; all of which resulted in an expanded 'Team'.

Apart from being President of Polio Australia, I am also the Business Manager, and I am delighted to report that our Financial Report reveals that we are in the strongest financial position we've been in since we were incorporated in 2008. Apart from the two funding grants mentioned above, we have also had another incredibly generous personal donation from Jill Pickering (polio survivor and volunteer), which pays for our Community Engagement Officer, Steph Cantrill. We also received an unexpected but very welcome donation from St George Association for People with Physical Disabilities for \$10,000, being the balance at the cessation of their operations. With the increased funding enabling the Polio Australia team to be expanded, our programs in support of polio survivors across Australia have likewise been extended.

These additional resources mean that, as an organisation, we are in the best position we have ever been to fulfil our original Mission "to standardise quality polio information and service provision across Australia".

Changes to the Board (see page 12) include the recruitment of a new Independent Board Member, Noel Will, who, prior to retirement, was a teacher for 16 years, and in the financial services industry for 22 years. Brett Howard moved from Treasurer to the position of Vice President (vacant since the 2017 AGM). Alan Cameron is the new Treasurer, a role he also fulfills for Polio NSW. Having completed a 2 year term, Spinal Life Australia's representative, Michael Powell, stood down, nominating Ross Duncan as his

We believe these changes will assist Polio Australia in strengthening its Governance role and ensuring the charity continues to comply with relevant legislation. With increased staff members, Polio Australia reviewed its governance functions and has established two Board Sub-Committees for: 1) Governance and Risk Management, and 2) Finance. These Sub-Committees have prepared three new Policies covering these areas, and will now be working on related Procedures.

The Board is sometimes amazed that so much is able to be achieved so fast by such a small team, especially with our resource constraints. The team members who have joined us over the last couple of years not only each work very effectively in their individual program areas, but together they encourage, support and extend each other. An example of what they can achieve collaboratively is the new information hub about "Living With Polio". Everyone contributed to and critiqued the work, and the outcome is a resource that we are justly proud of.

As Maryann notes in her report, she is now only working 3 days a week as she eases into planned full retirement at the end of the year. It seems hard to believe that when Maryann leaves Polio Australia she will have worked with us for 10 years. I will be both personally and professionally very sorry to see Maryann go - without her vision, drive and enthusiasm (and occasional badgering!) Polio Australia would not be the strong and thriving organisation it is today. She will have much to look back on with pride, and has certainly earned her upcoming retirement.

Following the Federal election in May 2019, we were very pleased that our five Parliamentary Patrons remain in the Parliament. In the House of Representatives, Greg Hunt, Catherine King, Steve Georganas and Mark Coulton all retained their seats, while Rachel Siewert continues her term in the Senate. Greg Hunt remains as Health Minister; Mark Coulton has been appointed as the Minister for Regional Services, Decentralisation and Local Government; Catherine King leaves her role as Shadow Health Minister and has taken on the Infrastructure, Transport and Regional Development portfolio in Labor's Shadow Cabinet. The end of the caretaker period also means the Department of Health finalised the contract for our 3-year funding extension to conduct Clinical Practice Workshops, thus giving certainty to our staff working in this Program area, and facilitating our longer-term planning.

All in all, a satisfying year for Polio Australia.

NATIONAL PROGRAM MANAGER'S REPORT



The 2018-19 period has been the most productive year for Polio Australia to date. The Team has really settled in and have made great inroads in their respective programs.

All this increase in staff activity has enabled me to take more of a back seat regarding my own workload, and adopt more of a mentoring and overview role.

In consultation with Gillian, the Board, and the Team, I also decided it would be opportune to decrease my working days. Consequently, I started working 3 days a week at the beginning of 2019. This enabled the organisation to save on salary and free up some office space.

I am genuinely excited about the increased scope of education sessions, information dissemination, and systemic advocacy that Polio Australia has been able to accomplish over the past year. Many new partnerships have been forged and existing relationships strengthened, thanks to dedicated staff allocating the time needed to reach out.

This has opened up many more opportunities for collaborating with similar organisations on, for example, joint submissions in support of our mutual demographic; people ageing and/or with a disability. This was the case during the Royal Commission into Aged Care Quality and Safety.

Another example of this is Polio Australia's membership of the Assistive Technology for Older People (ATOP) Alliance. ATOP is working on an advocacy campaign to lobby for a nationally consistent assistive technology program for people with a disability who are not eligible for the National Disability Insurance Scheme (due to the 65 year cut off).

Many require funding for equipment, which is not always sufficiently covered as part of an aged care package.

I'm sure this is only the tip of the iceberg, and that awareness and understanding of the issues impacting on the lives of polio survivors will continue to be expanded throughout the wider community.

Another long-held ambition that was launched during the year is the "Next Generation" project, which aims to provide information and support for younger polio survivors who have not been accessing existing support services. As this cohort was born overseas, our Team has been contacting and exchanging information with numerous community service providers that work with migrants, refugees and asylum seekers. This has been a time consuming, but also rewarding outreach exercise.

The 2018 Polio Health and Wellness Retreat was held in Glenelg, South Australia, and attended by 65 participants: NSW 14; NZ 6; QLD 5; SA 12; Taiwan 2; TAS 7; VIC 18; WA 1. There were 21 workshops to select from, as well as one-to-one consultations with health professionals, and massage therapy.

It was decided to combine our annual <u>Walk With</u> <u>Me</u> fundraising activity with the Retreat to make the most of the number of people who would be attending. It was a glorious, sunny day for a stroll or wheel along the Glenelg beachfront, and we managed to raise over \$10,500. Whilst this was down from previous years, it is still a vital injection of funds for Polio Australia's programs.

Another exciting development was working with Polio SA's Board to future-proof services by helping them employ a part-time Community and Membership Officer. Polio SA received bequest funding, enabling them to pay for dedicated staff for the first time. The services provided by Polio SA will now be able to evolve in ways that would not have previously been possible. Active state Polio Networks are an important 'local knowledge' information source for polio survivors, making this an excellent outcome for all concerned.

PROGRAM REPORTS: HEALTH PROMOTION



Health Promotions Officer

The 2018-19 period has been a very exciting time in my role, as now in my second year, my role has really evolved and I have gained significant knowledge and confidence when working towards health promotion activities for polio survivors.

Polio Awareness Month 2018

The theme for Polio Awareness Month 2018 was "Life stages of post-polio", highlighting that we support polio survivors from their 20s right up to their 90s and beyond. This allowed us to profile polio survivors from our "Next Generation" group. We use October to drive home the "We're Still Here!" message. We sent out a range of media releases, and used social media to increase awareness of the late effects of polio.

Living With Polio - New Information Packages In 2018, we identified the need for more refined information on the late effects of polio for polio survivors and the wider community. We decided to design a new information package featuring fact sheets, short videos, clinical research, additional links and any other relevant information. We identified 31 different topics segregated into four categories: "Health", "Lifestyle", "Services" and "Providers".

Fact Sheet Development

We worked in partnership with Swinburne University to engage with a group of students - "The Bureau" - who undertook the graphic design component of our new information system and fact sheets.









We then recruited the expertise of more than ten health professionals, as well as our in-house skills, to write the fact sheet content for the 31 topics. We also focused on ensuring all of our fact sheets were at a reading level appropriate to our target audience.

Video Production

We also partnered with Swinburne University to engage a *Student Intern* to complete the video production for our information packages. We were very lucky to have Charlotte Lynge Laursen, a Masters of Media and Communication student, join our team as a Professional Intern. Over a three month period, we filmed 13 videos with six different health professionals. During this time, we also took the opportunity to film 'biography' style videos of three of our "Next Generation" polio survivors.

New Marketing Materials

Polio Australia developed a new organisational brochure, which better explains Polio Australia's resources and how we fulfil our mission to help polio survivors access appropriate health care and support.

Digital marketing and social media

As a part of my role, I consistently work to improve the profile of Polio Australia through digital marketing and social media, including:

- Google AdWords: Google grants eligible notfor-profits \$10,000 USD in free advertising each year. Polio Australia utilised Google Ad Grants' Online Challenge Program, which gave us an account volunteer through Google's partner universities.
- Facebook Page: I have been working on increasing our reach across our Facebook page, and providing polio survivors with upto-date engaging content. We have increased our page following by 163 people over this 12 months.

Woman In Leadership Course

In preparation for Maryann's retirement at the end of 2019, I enrolled into an Executive Ready Leadership course with *Women And Leadership Australia*. This course has been very insightful into leadership, communication, strategic thinking and organisational learning. I look forward to using these newfound skills in years to come.

HEALTH PROMOTION EVENTS



World Polio Day

Polio Australia partnered with Global Citizen, Rotary International, Results and UNICEF Australia for World Polio Day. The event was held on 24th October 2018 at Parliament House in Canberra. Gillian Thomas, Alan Cameron and Paul Cavendish attended this event, and Gillian spoke on behalf of Polio Australia. The event was very successful with a large attendance and gained attention from a number of politicians. We hope to continue this very important partnership into the future.



Polio Health and Wellness Retreat

I was tasked with the responsibility of organising and running the 2018 Retreat. I had very big shoes to fill after a very successful seven Retreats run by Maryann in previous years. The Retreat held in Glenelg, South Australia was very successful, and a valuable and enjoyable learning experience for me.



Next Generation Project

Our "Next Generation" project aims to outreach to polio survivors who were born overseas and contracted polio more recently. Alongside the new information systems, we also established a Next Gen Facebook Group for this cohort to connect on a more personal basis. Our contract Administration Officer, Jake Malsbury, worked on developing connections with refugee support groups in Melbourne that are possibly working with Australia's 'next generation' of polio survivors who were born overseas.

PROGRAM REPORTS: CLINICAL PRACTICE **WORKSHOPS**



Clinical Health Educator

The second year of delivering workshops on the Late Effects of Polio (LEoP) has been very rewarding. We have secured Department of Health (DoH) funding extension over a threeyear period. This signifies the achievements we have made, and also recognises our plans to develop knowledge and skills among professionals working with polio survivors.

Workshop Delivery

539 health professionals were trained in the LEoP during this financial year. This is in addition to presentations at GP, Pedorthic and Occupational Therapy national conferences. endorsed Primary Health Network sessions, and to a range of hospitals and community settings. Feedback from the first half of 2019 comprised:

- 100% stating the workshop content was clear and well communicated
- 100% stating the presenter had good or very good subject matter knowledge
- 99.5% stating they would recommend or strongly recommend this workshop to their colleagues

Expansion Of Education Delivery

The DoH accepted our request to vary our existing contract by expanding education to professionals working in disability and aged care. This recognises polio survivors require people in these areas to have necessary awareness of LEoP. We also expanded education to specific health professional disciplines, in line with feedback from attendees during 2018. We have delivered to GPs and medical professionals, physiotherapists, occupational therapists, nurses and aged care providers and assessors.

Increasing Understanding Of LEoP

Polio Australia coordinated two studies during this period. One on user satisfaction with orthotics (127 participants) and another on fatigue and impairment (293 participants). The results have been incorporated into our workshops and were presented at the Pedorthic National Conference in September 2018 and secured a presentation at an upcoming Assistive Technology conference in August 2019.

The surveys bring us one step closer to developing greater links with universities as we show there is still a polio survivor base with unresolved questions regarding health management. In addition to increasing our profile by presenting at conferences, we have also supplied material to university course coordinators of disability and neurological conditions for Semester 1, 2019.

Identifying Relevant Health Professionals And **Local Contexts**

We are still learning from our growing health professional network and polio survivor population on the appropriate format and context of education. There are areas where community workshops are needed to support polio survivors using private practice services. There is also greater need to develop connections with aged care providers to support polio survivors as they transition away from private practice services to different support.

Future Direction And Partnerships

Polio Australia and Polio New Zealand have agreed to develop a combined Clinical Advisory Group to help advocate and support clinical understanding and research undertakings. With secured funding, we are also able to explore opportunities to develop university partnerships to stimulate greater research on the LEoP.

The expansion of a clinical service at Griffith Rehabilitation Hospital, Adelaide, who now offer a specific post-polio clinic was very pleasing. We aim to increase these opportunities as we develop networks with health professionals and organisations in the public and private setting. This will not replace our ongoing aim of expanding the listings on the Health Professionals Register.

PROGRAM REPORTS: COMMUNITY INFORMATION AND ENGAGEMENT



Community Engagement Officer

At the start of the 2018-19 financial year, I was employed part-time as a Polio Community Officer and only for Victoria. Now, I am working as a full-time Community Engagement Officer, and my role has expanded to include South Australia, New South Wales and Tasmania.

In the last year, I held 22 community information sessions for polio survivors and their families and carers. While most of these were in Victoria as this was my initial area of focus, there have also been sessions in Berri, Naracoorte and Mt Gambier in SA, and Broken Hill in NSW. A session in Hobart will be conducted in early July 2019.

While attendance at these sessions has been variable, there have been over 250 people in total. Many of these have been people who hadn't had prior contact with Polio Australia or their state network, and the sessions have answered a lot of questions for them. It's really encouraging and rewarding to get feedback like this:

"Thank you for giving me more understanding of myself and just what post-polio is"

"So helpful for polio survivors"

"Always interesting to talk to other people with same problems and share information"

It has been a privilege to give these polio survivors, and their family members, the information and resources that can help them better manage their condition. Many of them are also very pleased to know that our Clinical Educator is also making his way around the country, as everyone has a story about health professionals who need to know more about how to work more effectively with the post-polio body.

Another benefit to come out of these information sessions is the awareness it has raised in the community. Through promoting the sessions, I have had the opportunity to get the word out through social media, radio and print media that there are thousands of polio survivors in Australia, many of them experiencing the Late Effects of Polio. I have also been able to raise some awareness (and a small amount of funds) through speaking at Rotary clubs, often with a polio survivor co-presenting with me.

Below is a summary of some of the other activities I've been engaged in over the past year:

- Met with other non-profit organisations to learn more about how they connect with their communities;
- Worked with Carers Victoria to co-deliver three information sessions;
- Continued to be part of the Assistive
 Technology for Older People Alliance, to
 address the gaps in funding for equipment for
 people with disability over 65 years of age;
- Worked with the Polio Australia team on advocacy activities such as the submission to the Royal Commission into Aged Care Quality and Safety.

In the next financial year, I look forward to:

- continuing to provide information and resources for polio survivors and their families;
- working with the Clinical Educator to develop and deliver education sessions for care workers;
- building a network of organisations working with migrants and refugees, and ensuring they are aware of the resources available to migrant polio survivors; and
- continuing to raise awareness of, and advocate for, the needs of polio survivors.

PROGRAM REPORTS: FUNDRAISING



Financing Manager

From 1 July 2018, we applied for nearly \$2 million in funding through more than 20 grant applications. We were successful in receiving a grant from the Marian Flack trust for \$20,000 for the 2018 Retreat, and \$10,000 from the John Kirby Foundation in support of an Outreach Project in NSW. As of the end of June 2019, we were still waiting to learn the outcome of four of applications. The competition for funds is fierce and experts in the field recommend that organisations only rely on grants for 10% of their needs. For an organisation like Polio Australia, donations and bequests should make up the bulk of revenue.

We tried to launch a fundraising initiative called *Splish! Splosh! Splash!* which involves gumboot throwing competitions at primary schools. *Splish! Splosh! Splash!* is loosely based on Alan Marshall's book, *"I can jump puddles"*. Unfortunately, this effort has been slow to get off the ground as it does require volunteers to assist with contacting and negotiating with primary schools.

In addition to working on bringing revenue into the organisation, I implemented Salesforce for Polio Australia. Salesforce is a well-known CRM (Customer Relationship Management database) used by not-for-profit organisations to manage their relationships with their constituents.

My contract concludes at the end of July 2019. The past 18 months with Polio Australia have been a steep learning curve for me. Fundraising is not as easy as I think it should be. I have learned a lot and developed some key skills that I can take into the future.

I would like to thank Polio Australia, as well as Spinal Life Australia, which funded the position, for giving me this opportunity. I wish Polio Australia all the very best in the future.











SYSTEMIC ADVOCACY



Polio Australia has been increasing its systemic advocacy efforts to ensure polio survivors are better represented on important national health, ageing, disability and service provision issues.

Alliances

We have been working with two integral *Alliances*:

Assistive Technology for Older People (ATOP) Alliance is a group of peak disability organisations who strategise systemic advocacy to address the gaps in funding of aids and equipment for people with disability who are not eligible for the NDIS.

Neurological Alliance Australia: an alliance of national not-for-profit peak organisations representing adults and children living with progressive neurological or neuro-muscular conditions in Australia. The Neurological Alliance aims to promote improved quality of life for people living with these conditions and funding to support research.

Royal Commission into Aged Care Quality and Safety

Polio Australia developed a draft submission, which was distributed to polio survivors and the wider community requesting feedback. The key issues we identified were:

- Aged care funding is insufficient for the complex needs of older Australians living with a disability.
- A lack of recognition of disability and the disability-related needs of older people within the aged care system.
- Inappropriate and inadequate level of assessment for people with disability and specific health conditions.
- A lack of available support and funding for assessed care needs.
- A lack of funding, and funding consistency, in relation to assistive technology.
- A lack of knowledge and/or training by aged care workers regarding disability and specific health conditions.
- There is inconsistency in the level of care available between different geographical regions.

Other 2018-19 Submissions

Below is a list of submissions Polio Australia has made:

- Shaping the future of disability policy for 2020 and beyond survey (copy of this survey submission is not available)
- Submission to MyAgedCare on Streamlined Consumer Assessment for Aged Care
- Commitments For The 2019 Federal Election (as part of Neurological Alliance Australia)
- Submission to the Terms Of Reference for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability *(copy of this submission is not available)*
- Submission to Australian Building Codes Board Statement of support for accessible housing
- Assistive Technology for Older People (ATOP) Alliance communique Equal access to assistive technology for older people with disability

YOUR SAY

Understanding the LEoP

In addition to conducting workshops, we have run surveys on satisfaction with orthoses, self-reported impairments, and physical function and fatigue. Thanks to polio survivor's contributions, we have stimulated greater interest among academics and health professionals as a cohort (yes, "We're Still Here!").

The Orthotics and Prosthetics User Survey

The key findings from this survey were that polio survivors acknowledged the complexity of orthoses, generally feeling satisfied with the efforts of their health professional. However, health professionals are amazed that 81% of polio survivors have difficulty balancing while standing with their orthosis!

The self-reported impairments and fatigue

This survey identified polio survivors rated muscle weakness and muscle fatigue as the top impairments they experienced, followed by general fatigue. Perhaps no surprise to polio survivors, but the muscular effects were still the most strongly identified difficulty. It highlights the need for Polio Australia to continue asking academics and health professionals to identify the best strategies to positively influence weakness and fatigue.

A key finding for us is recognising that a third of respondents were unaware if they had been diagnosed with Post-Polio Syndrome, or had not sought diagnosis.

Figure 1. The self-reported impact of muscle weakness and muscle fatigue

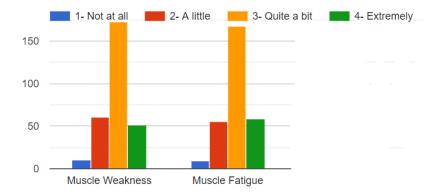
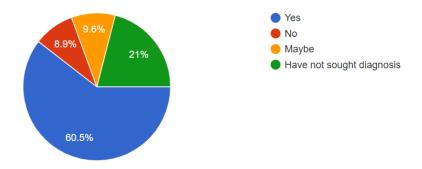


Figure 2. Polio survivors who have had a diagnosis of Post-Polio Syndrome



SPREADING THE WORD

Iris and Yu-ching attended <u>Polio Australia's Polio Health and Wellness Retreat in 2018</u>. Iris is a polio survivor and Yu-ching is a physiotherapist, both living in Taiwan. There is limited information about post-polio in Taiwan, so they attended the Retreat to gather information to provide to survivors in Taiwan. When Iris and Yu-ching returned to Taiwan, they held a meeting to present what they had learnt. Iris provided the following account.

"On 1st December, Yu-ching and I held a meeting, hosted by a senior physiotherapist, referred to as a 'polio expert', on a sunny Saturday morning in Taiwan. In attendance, were around 30 polio survivors, including four younger polio survivors (36 – 69 years), physiotherapists and a neurologist.

During my presentation, I spoke to the audience about our experience travelling in Australia and what I learnt from the Retreat. I explained the benefits of using a wheelchair and crutches and after the meeting, some of the polio survivors were interested in using them too.

In Yu-ching's presentation, she introduced Polio Australia's staff and highlighted some key health issues among polio survivors including sarcopenia and osteoporosis and the importance of muscle strength testing.

Some of the polio survivors I spoke to after the meeting, told me it was the first time they had attended a meeting about polio, and the first time they had met other polio survivors who are open-minded and willing to learn more about Post-Polio Syndrome (PPS). They also discussed their problems with finding a 'polio expert', their refusal to use mobility aids and their concerns about ageing.

The attendees had many questions, and we knew this was just the beginning – we will be able to learn more about PPS together.

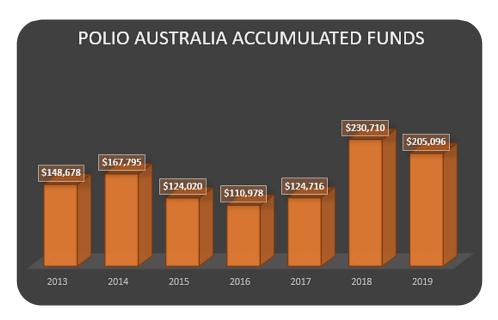
Before attending Polio Australia's Retreat, I didn't think much about polio, as I am the youngest polio survivor in Taiwan. But now I know there are people all over the world advocating for polio and I am not alone. I am now starting to spread awareness for other polio survivors – amazing!!

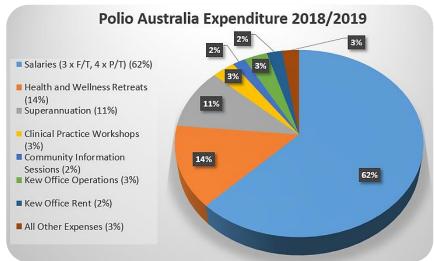


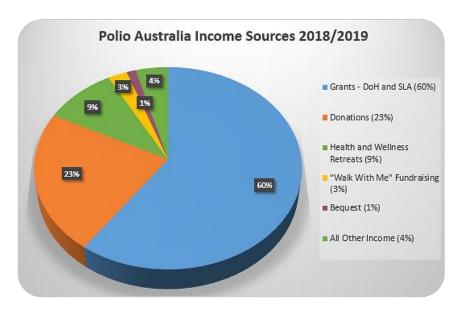
Iris and Yu-ching at the Retreat



FINANCIALS







OUR BOARD 2017/18

Polio Australia Board Members ensure the charity complies with legislation and has good governance. Two representatives from each state Polio Network are appointed to the Board for a two-year term. There are also three Independent Directors appointed for specialist roles.



Gillian Thomas President (NSW)



Brett Howard Vice President (SA)



Alan Cameron Treasurer (NSW)



Gary Newton Secretary and Communications Coordinator (Independent VIC)



Arthur Dobson (TAS)



Dr Peter Freckleton (VIC)



Jenny Jones (WA)



Tessa Jupp OAM (WA)



Susanne Mackenzie Fundraising Coordinator (Independent QLD)



Billie Thow (TAS)



Dr Christine Tilley (QLD)



Bev Watson (VIC)

Incoming



Peter Wierenga (SA)



Noel Will (Independent Vic)



Ross Duncan (QLD)

Outgoing



Michael Powell (QLD)

PICTORIAL HIGHLIGHTS

Paul Cavendish's Clinical Practice Workshop

Steph Cantrill's Polio Information Session





2018 Walk With Me and Polio Health and Wellness Retreat Participants







2018 Walk With Me Event

2018 Retreat - Chair Dancing Session