

# Polio Australia

*Representing polio survivors throughout Australia*

## Annual Report



July 2013 – June 2014

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**National Patron: Dr John Tierney PhD, OAM, Federal Senator for NSW 1991 – 2005**

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# About Polio Australia

## Vision

Polio Australia's Vision is that 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.



## The purpose of Polio Australia is to:

- ▽ Educate and inform polio survivors, their families and carers, and the community at large about the late effects of polio.
- ▽ Provide information, education and training to General Practitioners and a range of medical specialists and other health professionals to improve the diagnosis and management of the late effects of polio.
- ▽ Facilitate the provision of appropriate and consistent health, disability and aged care support services across all states and territories to improve the treatment and management of the late effects of polio.
- ▽ Provide outreach to culturally and linguistically diverse and Aboriginal and Torres Strait Islander polio survivors to ensure their diverse needs are being met in a culturally appropriate way.
- ▽ Advise governments on policy development and programs in relation to the late effects of polio.
- ▽ Stimulate research into the late effects of polio.
- ▽ Assist the state Networks to support polio survivors and their families, friends and carers at the local level.
- ▽ Facilitate and encourage the co-ordination and further development of activities within and between the state Networks.
- ▽ Support and promote polio immunisation at a national level, and provide assistance to the state Networks to do so at the local level.

## Management Committee

Established in 2008, Polio Australia is a national peak body governed by a Management Committee comprising representatives from the six state Polio Networks. 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) or Post-Polio Syndrome (PPS).



## Vale Neil von Schill



Neil von Schill was one of Polio Australia's founding members, and was an active part of the team until he suffered a major stroke in 2011. He passed away in May 2014. Neil's was a life cut short but his legacy will live on.

## Our Paid and Unpaid Team

### National Program Manager



**Mary-ann Liethof**

Mary-ann is the only full-time staff member employed by Polio Australia and is responsible for developing and implementing all program areas. Mary-ann was officially appointed as Polio Australia’s National Program Manager in early January 2010 on a part time basis, which increased to full time in January 2011 thanks to a 3 year donation from The Balnaves Foundation. This funding has now concluded, however Mary-ann’s contract has been renewed for a further 3 years through concerted fundraising efforts.

### Bookkeeper/Administration Assistant



**Shylie Little**

Shylie started volunteering one day a week at the Polio NSW Parramatta Office in 2007 and later increased her attendance to two days per week. From mid 2010 Shylie’s duties predominantly involved bookkeeping for Polio Australia. Following her second retirement in June 2013 Shylie is now employed by Polio Australia for one day a week. She is not only our bookkeeper but she also capably manages a myriad of administrative tasks

### Capacity Building Consultant



**Glenn Gardner AM**

We are very pleased to have received a private donation to enable the engagement of Glenn Gardner in a part-time consultancy to help Polio Australia build its capacity and develop sustaining financing strategies.

For almost 20 years until 2007, Glenn Gardner was Managing Director and CEO of Northcott Disability Services (formerly the NSW Society for Crippled Children). It was during his time with Northcott that Glenn learnt first-hand about Australia’s polio story and a mutually beneficial relationship was established with Polio NSW and, more recently, Polio Australia.

### Business Manager and Web Manager



**Gillian Thomas**

Gillian works day and night to ensure Polio Australia meets all its business and financial responsibilities. Using her considerable technical expertise, she designs, populates and manages Polio Australia's three websites, and provides input across all program areas based on her expert and personal knowledge of polio and its late effects. Gillian's passionate belief in the need for a national voice for polio survivors culminated in the highly successful meeting of all Australian State Polio Networks in May 2007 and the unanimous agreement to form Polio Australia. In 2008, she was elected Polio Australia's inaugural President.

### National Patron and Lobbyist



**Dr John Tierney OAM**

John Tierney is Polio Australia's National Patron, and was elected President in December 2012. Since 2007, John has taken a delegation to Canberra on a semi-annual basis to lobby for special funding for the half a million Australians experiencing the Late Effects of Polio (LEoP). John has done this in his capacity as a pro bono government relations consultant to Polio Australia. Thanks to John, Polio Australia has made substantial progress in making the government and the parliament aware of LEoP, although we still haven't received any dedicated funding. John's commitment is to continue lobbying until we do!

### Administration/Project Assistant



**Jill Pickering**

Jill commenced volunteer work one day a week with Polio Australia in February 2011. She assists with tasks including keying in data for the Australian Polio Register, and compiling and summarising feedback information from the Health and Wellness Retreats for reporting purposes. Previously, Jill worked in several roles using her Occupational Therapy skills before retiring in 2000 due to limitations caused by post-polio syndrome. She then volunteered for 10 years at Polio Network Victoria before joining Polio Australia. Jill is also the current President of Post-Polio Victoria.

The nature of not-for-profit charities is that there are numerous people and organisations quietly providing support in many, many ways, and we sincerely thank each and every one for their contributions.

# Strategic Priorities

At its 2011 Annual General Meeting and Strategic Planning Meeting, Polio Australia’s Management Committee decided on four priorities to work towards over the next three years, which this Annual Report reports against.

<h2>Priority One</h2>	<ul style="list-style-type: none"> <li>• <b>CAPACITY BUILDING</b> Securing a stable income stream to support Polio Australia and our key program areas into the future</li> </ul>
<h2>Priority Two</h2>	<ul style="list-style-type: none"> <li>• <b>EDUCATION</b> Promoting enhanced knowledge and management of the Late Effects of Polio across the Health and Community sectors</li> </ul>
<h2>Priority Three</h2>	<ul style="list-style-type: none"> <li>• <b>HEALTH SERVICE PROMOTION</b> Lobbying and advocating for recognition of and appropriate service provision for Australia's polio survivors</li> </ul>
<h2>Priority Four</h2>	<ul style="list-style-type: none"> <li>• <b>COLLABORATION</b> Working with and supporting state-based Polio Networks by producing resources and standardising polio information for use by the Networks and their members</li> </ul>



## The Year at a Glance

<b>July 2013</b>	<ul style="list-style-type: none"> <li>• Commenced discussions with Rotary International with a view to establishing a joint Polio Australia/Rotary Fund to support polio survivors</li> </ul>
<b>August</b>	<ul style="list-style-type: none"> <li>• Addressed students at Latrobe University's National Centre for Prosthetics and Orthotics on the needs of polio survivors</li> </ul>
<b>September</b>	<ul style="list-style-type: none"> <li>• "Walk with Me" participants in Victoria and New South Wales raised a total of \$13,755 in donations</li> </ul>
<b>October</b>	<ul style="list-style-type: none"> <li>• Polio Awareness Month</li> </ul>
<b>November</b>	<ul style="list-style-type: none"> <li>• Undertook 4 year program evaluation reviewing how the Polio Health and Wellness Retreats increase the 'health literacy' of participants</li> </ul>
<b>December</b>	<ul style="list-style-type: none"> <li>• Lobbying visit to meet with new government members at Parliament House in Canberra</li> </ul>
<b>January 2014</b>	<ul style="list-style-type: none"> <li>• New promotional posters produced</li> </ul>
<b>February</b>	<ul style="list-style-type: none"> <li>• Clinical Training Trial held in Victoria</li> </ul>
<b>March</b>	<ul style="list-style-type: none"> <li>• Parliamentary Friends of Polio Survivors launched at a Morning Tea in Canberra</li> </ul>
<b>April</b>	<ul style="list-style-type: none"> <li>• Work started on new clinical practice resource module</li> </ul>
<b>May</b>	<ul style="list-style-type: none"> <li>• 5th Polio Health and Wellness Retreat run in New South Wales</li> </ul>
<b>June</b>	<ul style="list-style-type: none"> <li>• Presented at International Post-Polio Conferences in St Louis, USA, and Amsterdam, The Netherlands</li> </ul>

## President's Report

Polio Australia continues to achieve great things with very few resources. Behind the scenes Gillian Thomas and Mary-ann Liethof's work continues on a daily basis to advance our vital work in support of Australia's 400,000 polio survivors, and the three of us have worked as a great team in managing the day-to-day program of Polio Australia. Even though so much time is given freely for Polio Australia, to be effective in the long term its programs and staff need a much more secure financial base.

### The End of Balnaves Foundation Funding

The year 2013 marked the third and final year of The Balnaves Foundation funding. I wish to publically acknowledge our thanks to the Foundation for providing funding over this period of \$180,000 dollars which supported Polio Australia's programs for three years. Now that this funding is finished, we need to redouble our efforts to raise additional funds for more staff to support Mary-ann as she continues to implement our Strategic Plan.

Since the end of the Balnaves Foundation funding, Polio Australia has made some progress in diversifying the funding base of the organisation through a range of initiatives. This has included: donations from Rotary Clubs; the annual "Walk with Me" fund raiser event; corporate and private donations, including one very large individual donation of \$30,000 for Late Effects of Polio (LEoP) education. More work needs to be done on building our Patron's Circle and more effectively publicising our bequests program.

### Re-Establishing Polio Survivors' Links with Rotary International in Australia

One of the most promising avenues of funding has been re-establishing our links with Rotary International over the last year. Worldwide, Rotary has done tremendous work helping to eradicate polio from the world. But Rotary's earlier work with polio survivors between the 1920's and 1960's in Australia is all but forgotten.

Polio Australia is now rebuilding this connection with our "We're Still Here!" message. We have had LEoP speakers going to Rotary Club meetings in Melbourne, Sydney, north Queensland and the Hunter Valley. Also, most of the Clubs that we go to provide us with a donation of up to \$1,000 dollars for Polio Australia's work. The President of the Rotary Club of Cessnock, David Clark, commented, "Wouldn't it be great if Rotary International and Polio Australia joined in a genuine partnership to expand the already unparalleled Rotary story of eliminating polio throughout the world with the addition of closing the loop by helping the many polio survivors?". This is a splendid vision and I think that we have found a new catch cry!

This Speakers' Program has laid the groundwork for developing links between Polio Australia and Rotary International at a higher level. Following a meeting with 28 Rotary District Governors at the Rotary Institute in Canberra in November 2013, a joint Polio Australia / Rotary International Steering Committee was established with the aim of creating a Polio Survivors Fund. Polio Australia is now being sponsored for 2014 and 2015 by the two Rotary Districts that cover all of metropolitan Sydney (Districts 9675 and 9685).

## **"Walk with Me" is Growing**

As a member of Ability First Australia (AFA), a very promising annual fundraiser for our organisation results from our participation in AFA's national *"Walk with Me"* activity. Starting from small beginnings in 2012, in September 2013 the two participating teams – the Melbourne Meanderers and the Parramatta Promenaders – raised \$13,755. Next year we look forward to more state Polio Networks joining in the Walks and fundraising, and we plan to divide the proceeds between the national and the respective state organisations, according to how much each state raises.

## **Another World-Class Health and Wellness Retreat in Sydney**

In early May 2014, we held our Annual Health and Wellness Retreat in Sydney. I would particularly like to thank Mary-ann Liethof for her tireless work in yet again putting together another world-class program. If you haven't attended one of these life-changing experiences, next year's Retreat will be in Torquay, Victoria, from 30 April to 3 May 2015.

## **"We're Still Here!" Returns to Canberra Halls of Power**

During the year, our centrepiece lobbying efforts were very prominent in the halls of power in Canberra as we wore our T-Shirts and lobbied nine key Members and Senators reminding the new Federal Government that *"We're Still Here!"*.

We continue to be ably supported in this lobbying by our five Parliamentary Patrons who have been chosen across Party lines. In this work we are still making great progress in raising the profile in the parliament and the media of both Polio Australia and the needs of the country's 400,000 polio survivors.

At a Parliamentary Friends of Polio Survivors morning tea, we presented special plaques to our five (bipartisan) Parliamentary Patrons and provided them with an opportunity to speak. So far in the federal parliament over the last six years, sixty-one members and senators (25%+ of all parliamentarians) have either joined our Parliamentary Friends of Polio Survivors group, or agreed to see us, or come along to one of our events or spoken in the Parliament about the needs of Australia's polio survivors. This is a far cry from when we first went to Canberra in 2007, when one MP said to us, *"Polio, didn't we fix that fifty years ago?"*.

Unfortunately, as yet, these efforts have not led to a direct funding commitment from Canberra.

## **A Disappointing Federal Budget in 2014**

Another Federal Budget (2014) has come and gone without any sign of specific government funding for our vital LEOp programs. The closest that we came this round was an indication from Health Minister Dutton that we were *"on his wish list"*, just before the 2013 election. Unfortunately, this didn't make it through the toughest Budget in 20 years. This underscores the point that for Polio Australia to be able to offer our information and self-management services to a much wider range of polio survivors, we need to diversify and intensify our fund-raising efforts.

## Building Bridges to the USA and Europe



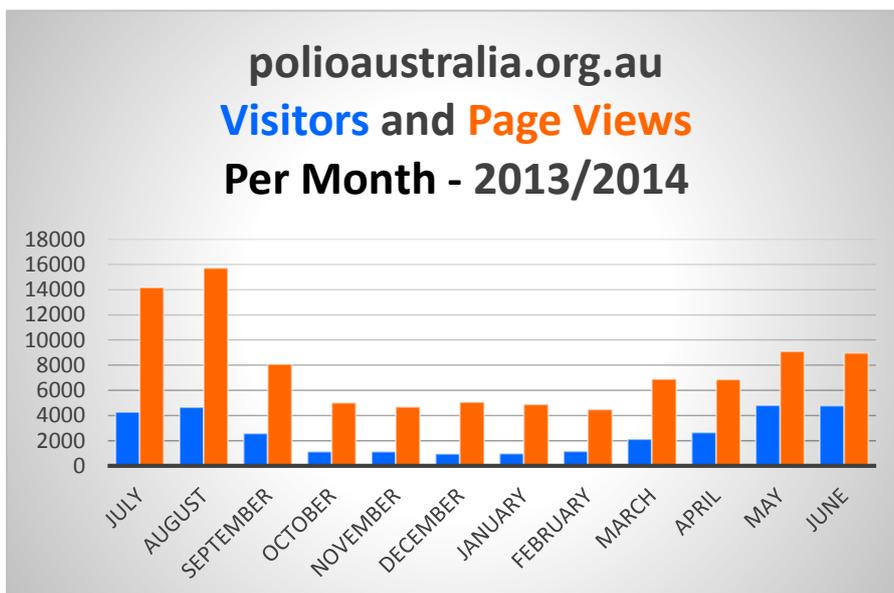
In June this year, Mary-ann and I attended international polio conferences in St Louis, USA (Mary-ann), and in Amsterdam, Europe (Mary-ann and John). Mary-ann presented in the USA on Polio Australia's world-class Health and Wellness Retreats and how they improve the health literacy of the participants. She also provided this presentation as a Poster in Amsterdam. I spoke in Europe about raising funds for the support of polio survivors from the community and government, with

a particular focus on our lobbying efforts in Canberra with the "We're Still Here!" campaign and our work with Rotary International. We plan to be at the next international conference in Stockholm in 2017 and, before that, we have started the preliminary planning for an Australasian-Pacific International Conference in Sydney in the spring of 2016. Put it in your diary.

**Dr John Tierney OAM**

## Online Update from the Vice President

Polio Australia consolidated its web presence with further development of its three websites during the year. Entries to the Australian Polio Register continued to grow steadily. Maintaining the Register, freshening the websites, and adding and updating content is a never-ending job. The graph below gives a snapshot of activity during the year on our main website.



Ella Gaffney (Mudgee, New South Wales) and Lyn Glover (Gold Coast, Queensland) have continued their good work as Polio Australia's social network 'champions'. Ella and Lyn keep Polio Australia's Facebook visitors and Twitter followers up-to-date with our latest news, together with other items of interest gleaned from around the world.

**Gillian Thomas**

## National Program Manager's Report

The 2013-2014 period has seen Polio Australia continue to move from strength to strength, which is a great source of pride and very rewarding for me. At the next Annual General Meeting to be held at the end of 2014, the Management Committee will be reviewing the three year Strategic Plan we developed in 2011. In spite of the ongoing issue of extremely limited resources, much has been achieved. More details on this can be found on Pages 21-25.

There is always so much more to be done, and the relentless need to seek and apply for project funding takes precious time away from developing and implementing them. I am still the only full-time, paid employee, so delegation is not an option. As mentioned in the President's Report, we are working on several strategies to secure a stable funding base. However, we are very grateful for the generous donations we receive from the community. As indicated on Page 13, these donations currently make up 43% of Polio Australia's income.

The 2014 Polio Health and Wellness Retreat held in Baulkham Hills, New South Wales, proved to be yet another successful event. We always have a core group of 'Retreat Junkies' who attend regularly, but there are also a larger percentage of 'new' polio survivors learning valuable self-management strategies from their participation. I was keen to determine the benefits to participants in relation to 'increased health literacy' and 'improved health outcomes', which was accomplished through a program review questionnaire sent out to all past Retreat participants. The resulting data was used in presentations I made at international post-polio conferences in June. More on Page 17.

I was also very pleased to be able to facilitate a pilot clinical workshop titled "*Understanding the Late Effects of Polio*" for 19 health professionals in January 2014. This three hour session provided an overview of the Late Effects of Polio and explored practical strategies to help post-polio clients stabilise their symptoms. We are seeking funding to facilitate a series of these workshops in future. See Page 17 for details.

Since attending the Copenhagen Post-Polio Conference in 2011, I have been interested in running an Australasian-Pacific Region Conference in Sydney. Holding this kind of professional international conference in Australia, with access to the North American, European, and Scandinavian post-polio specialists, would provide a unique opportunity for Australia's own health practitioners to enhance their knowledge and/or review their practises in line with the latest research into this little studied field.

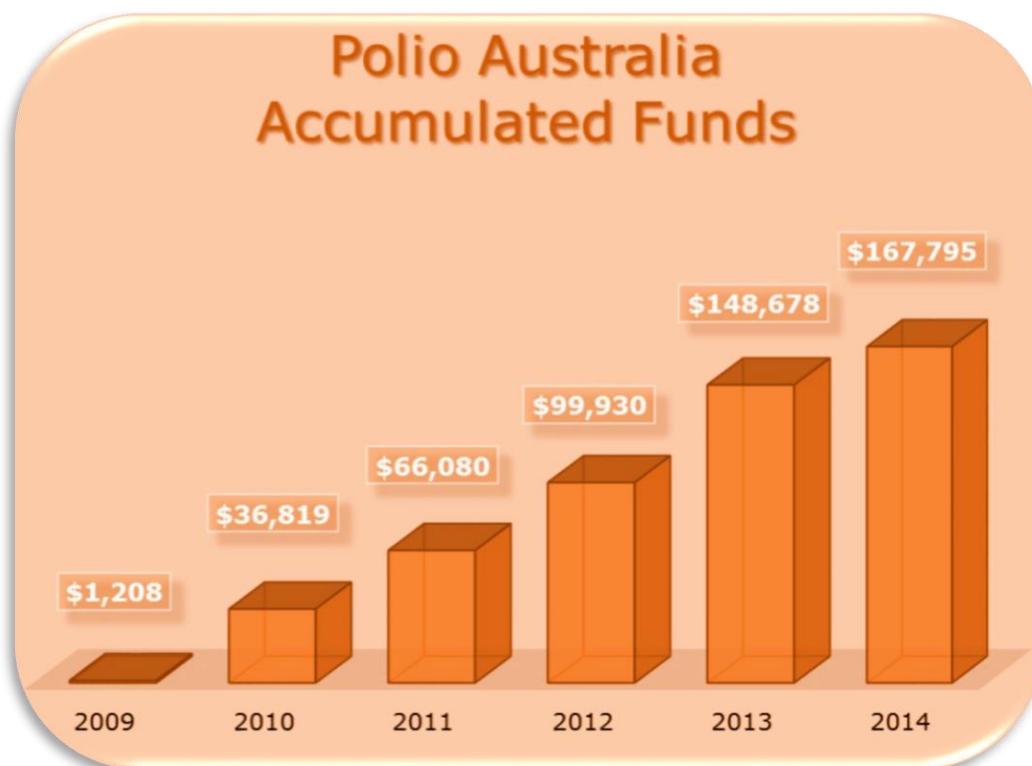
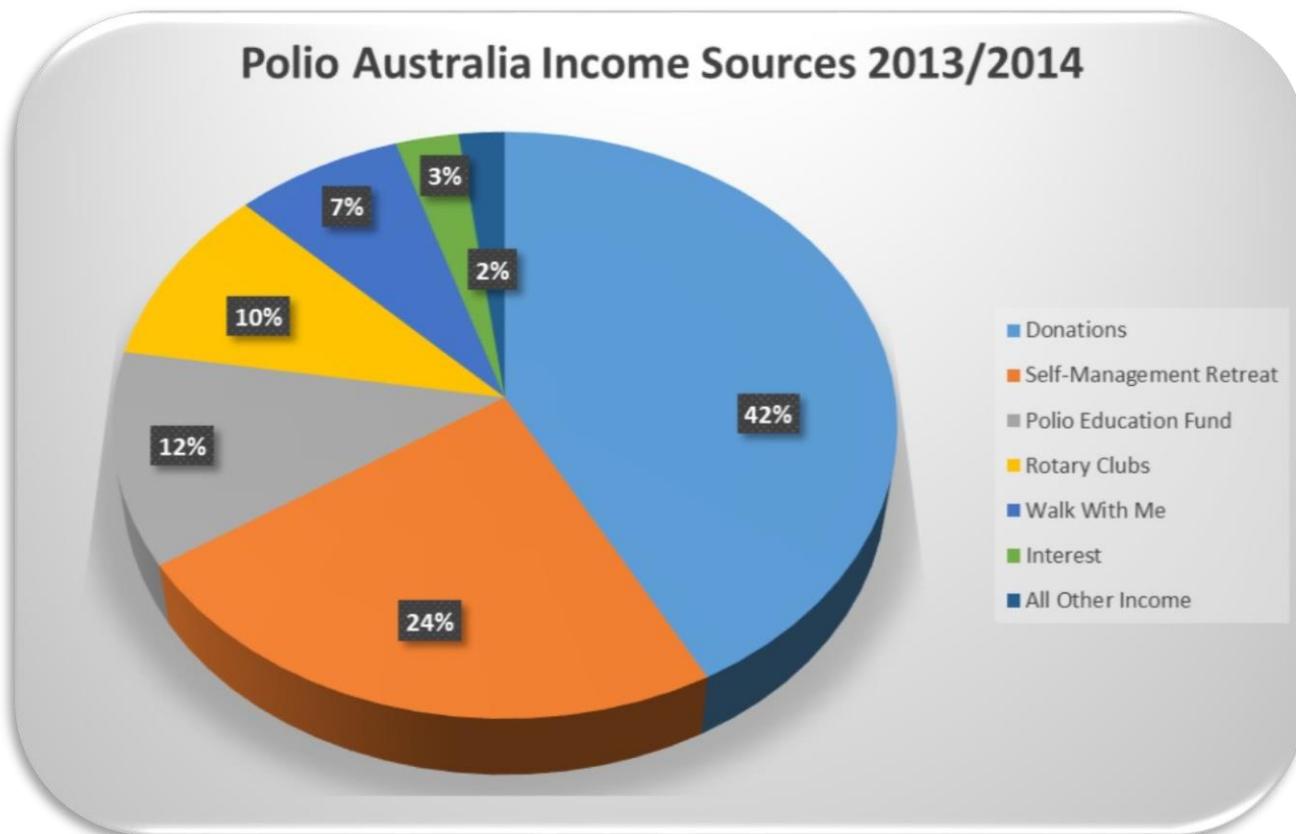
Polio Australia will now explore running the first 3 day Australasia-Pacific Region Post-Polio Conference in Sydney in October 2016. As with both the Post-Polio Health International and European Post-Polio Conferences, the target delegates would be a mix of health professionals and polio survivors, which is an ideal opportunity for everyone to learn from each other.

At both conferences, I was strongly encouraged by health professionals and polio survivors who all indicated that they would love to visit Australia, so there is the interest from the international community. The biggest challenge will be to secure partners and sponsors to invest in this conference. However, lack of resources hasn't stopped us yet, so we will give it a go.

**Mary-ann Liethof**

# Priority One

## Funding Sources 2013-2014



Intensive fund-raising efforts have resulted in increasing reserves through one-off donations, but Polio Australia’s long-term viability requires that we secure recurrent funding.

## Priorities One, Two and Three

### 2013 "Walk with Me" Events

Sunday 1st September was a lovely, sunny spring day as Polio Australia's "Melbourne Meander" team gathered at Birrarung Marr, on the banks of the Yarra River for an 11.00am start. We joined in with hundreds of individuals and families walking and wheeling for this year's "Walk with Me" fundraising event organised by Scope in Victoria.

The "Melbourne Meander" team comprised 18 polio survivors, their families and friends, with Fran Henke scootering 8 kms around Flinders in Westernport. All registered "Melbourne Meander" team members were busy finding supporters to sponsor them in the lead up to the event, achieving a total of \$5,290.

John Tierney and Gillian Thomas both 'walked' as members of Polio Australia's "Parramatta Promenade" team on Friday 13th September, which raised an impressive \$8,465. The New South Wales "Walk with Me" fundraising event was organised by Northcott.

The 2013 "Walk with Me" events raised a total of \$13,755 for Polio Australia, and we were delighted with the positive energy and generosity underpinning these activities. Thanks go to our post-polio community, families and friends, far and wide.

### Lobbying Activities

John Tierney, Gillian Thomas (with Peter Garde), and Mary-ann Liethof visited Canberra in December 2013 to lobby the new government. Two of Polio Australia's five Parliamentary Patrons (below), Mark Coulton and Jill Hall, generated sufficient interest to establish a formal "Friendship Group of Polio Survivors", with 21 parliamentarians signing up so far.



A morning tea was held in March 2014 for these parliamentarians at Parliament House to launch the Friendship Group. Four of our five Parliamentary Patrons spoke at the launch (Greg Hunt was unavailable) and were presented with plaques for their support of Australia's polio survivors. Together with the Polio Australia lobbying team, approximately ten polio survivors from the ACT polio support group attended, and three additional parliamentarians came to the morning tea.

The Polio Australia delegates met separately with an Advisor from Health Minister Peter Dutton's staff, once again to discuss our proposal to support Australia's polio survivors. Later in the afternoon, we met with two staff members of the Australian Medicare Locals Alliance (AMLA) to discuss their relationship with Pain Australia, and how Polio Australia and the AMLA might be able to similarly work together in future. An offer was made to include polio-related medical articles in AMLA publications which go to all doctors.

## Rotary Connections

As detailed in the President's Report (Page 8), Polio Australia has been actively working on building relations with Rotary International over the past 18 months. We are also very fortunate to have a champion in Jill Forsyth from the Rotary Club of Kew – the Melbourne suburb where Polio Australia has its office. On Sunday 22nd December, Polio Australia and Rotary Club of Kew volunteers joined forces for a Bunnings Sausage Sizzle fundraiser. The net takings at the end of the day amounted to \$1,091.50, and there was an additional \$46.10 worth of change in the 'charity box'.

Queensland-based polio survivor, Suzanne MacKenzie, ran her very own "We're Still Here!" fundraising campaign at Rotary Clubs up north. Sue raised more than \$10,000 in support of Polio Australia's work from the Rotary Clubs she has spoken to.

John Tierney, Glenn Gardner (Consultant), and Mary-ann Liethof also spoke at numerous Rotary Clubs, and we would like to thank the following Rotary Clubs for their generous donations (totalling \$17,750 this year) in support of Polio Australia's work on behalf of all Australian polio survivors.

### January to June 2014

- Rotary Club of Cairns (Qld)
- Rotary Club of Cairns Mulgrave (Qld)
- Rotary Club of Cessnock (NSW)
- Rotary Club of Charters Towers (Qld)
- Rotary Club of Goodna (Qld)
- Rotary Club of Kew (Vic)
- Rotary Club of Mareeba (Qld)
- Rotary Club of North Ryde (NSW)
- Rotary Club of Parramatta City (NSW)
- Rotary Club of Paterson (NSW)
- Rotary Club of Ross River (Qld)
- Rotary Club of Singleton (NSW)
- Rotary Club of Thuringowra Central (Qld)
- Rotary Club of Townsville Central (Qld)
- Rotary Club of Townsville South West (Qld)

### July to December 2013

- Rotary Club of Collingwood (Victoria)
- Rotary Club of Kew (Victoria)
- Rotary Club of Maitland Sunrise (NSW)
- Rotary Club of North Ryde (NSW)
- Rotary Club of Parramatta (NSW)
- Rotary Club of Parramatta City (NSW)
- Rotary Club of Sorell (Tasmania)
- Rotary Club of Williamstown (NSW)

# 2013/2014 Fundraising Campaigns Pictorial



**Canberra Lobbying March 2014**



**Rotary Connections**

## Priorities Two, Three and Four

### Understanding the Late Effects of Polio Clinical Workshop



On the 20th of February 2014, Polio Australia facilitated its first "Understanding the Late Effects of Polio" workshop for 19 health professionals at MS Australia's training facility in Blackburn (Victoria). This three hour session was designed to explain the Late Effects of Polio (LEoP) and Post-Polio Syndrome (PPS)

and to explore practical strategies to help post-polio clients to stabilise their symptoms and improve their overall health.

The session presenters were:

**Dr Stephen de Graaff, Senior Rehabilitation Physician and Director of Pain Services, Epworth Healthcare**

Dr de Graaff has been diagnosing PPS and working with post-polio patients since 1995. He provided a general introduction to the Late Effects of Polio and Post-Polio Syndrome including symptoms, diagnosis, cause, incidence, treatment options and current research.

**Louise Thomas, Senior Physiotherapist, NeuroMuscular-Orthotics**

Louise previously managed Polio Services Victoria at St Vincent's Hospital, Melbourne, and continues to consult with post-polio clients at NeuroMuscular-Orthotics. She presented practical strategies used by physiotherapists, orthotists, and various other allied health professionals to address key concerns such as managing pain and fatigue, and help with stability and avoiding falls.

**Natasha Layton, Occupational Therapist**

Natasha specialises in assistive technology and environmental interventions. She has worked with diverse populations in rehabilitation and community settings over the last 20 years. Natasha's research area is the use and outcomes of assistive technology and other enablers, and she works collaboratively with Victoria's Aids and Equipment Action Alliance conducting inclusive research in this field.

**Mary-ann Liethof, National Program Manager, Polio Australia**

Mary-ann has worked with the post-polio community since 2004 and currently facilitates annual Polio Health and Wellness Retreats for up to 70 polio survivors and their family member/carers in various states. She provided an overview of the role of Polio Australia, including support services available.

At the end of the workshop, participants were asked to complete an evaluation form. A summary of the responses follow:

- Professions represented were nearly half each physiotherapists and occupational therapists, with one nurse and a couple of case managers;
- The overwhelming response was positive to Polio Australia’s first PPS/LEoP training workshop, with all attendees saying they would recommend the session to other treating health professionals (THPs);
- Around 75% showed interest in being recognised as an informed/experienced LEoP and/or PPS practitioner;
- Virtually all attendees said that THPs need information on PPS/LEoP, and most said they would take follow-up action;
- All attendees said they could now better understand and recognise LEoP/PPS symptoms;
- Most participants said the session helped them to understand how LEoP/PPS exercise differed from neuro/ageing clients and provided polio management options;
- Three quarters of attendees said they now have better awareness of how Polio Australia supports polio survivors/THPs.

## International Post-Polio Conferences

Following the submission of Abstracts for the Post-Polio Health International Conference in St Louis, USA from 31 May to 4 June and the European Post-Polio Conference in Amsterdam from 25 to 27 June, Mary-ann was accepted as a panel presenter in St Louis, and did a Poster presentation in Amsterdam. John Tierney also put in an Abstract for Amsterdam and was accepted to do an oral presentation.

Mary-ann’s Poster presentation was based on the four year review of the Health and Wellness Retreats and focussed on the “increase in Health Literacy” and “improved Health Outcomes” of the participants. Responses to the program evaluation questionnaire clearly indicated that Polio Australia’s Health and Wellness Retreats are achieving these goals.

## Post-Polio Health International

Mary-ann was one of 212 survivors and their families and friends and health professionals with expertise in promoting healthy ideas who met in St Louis for PHI’s 11<sup>th</sup> Post-Polio Conference from 31 May to 3 June. Participants attended from 7 countries, 35 states and the District of Columbia. People participated in a wide variety of sessions learning new ideas and skills, participating in discussions and meeting new people strengthening their networks.



## European Polio Conference

Mary-ann continued on to the 2<sup>nd</sup> European Polio Conference held in Amsterdam from 25 to 27 June 2014, where she joined John Tierney and a number of other Australians: Jill Pickering, Merle Thompson, Robyn Aulmann, Sue and Graeme MacKenzie, Noella Joslyn and her daughter Alice.



John's oral presentation and Mary-ann's Poster presentation from the Conference were uploaded to Polio Australia's website, along with daily blog reports and photos.

In addition to the plethora of information disseminated across the days of the two conferences, the real importance of attending was the opportunity to observe:

- the undeniable benefit of having a forum where polio survivors can come together to discuss their issues with each other, and with informed health professionals;
- a forum for health professionals who are working with polio survivors to present their working practises and/or research;
- the fact that there are numerous health practitioners around the world who consider post-polio a significant enough issue to be working on;
- the cross-fertilisation of ideas, introduction to new practices, assistive technology, and/or other management techniques, thereby facilitating better care;
- the building of both local and international connections.

## Clinical Practice Module

Following a generous project-based donation from a polio survivor who has chosen to remain anonymous, Occupational Therapist and Researcher, Natasha Layton, was approached to write Polio Australia's next Clinical Practice Module, focussing on physio/OT intervention.

An expert reference group was contacted and engaged, consisting of: Margaret Petkoff (OT at Polio Services Victoria), GM Jegasothy (Jega) (WA physiotherapist), Melissa McConaghy (NSW physiotherapist), Louise Thomas (physiotherapist and previous Coordinator of Polio Services Victoria), Ann Buchan (SA physiotherapist), and Dr Mary Westbrook (NSW psychologist). Most are members of Polio Australia's Clinical Advisory Group.

In addition to the expert reference group, several polio survivors were asked to contribute their experiences of the health sector, to be inserted as "Lived Experience Expert" vignettes.

At year end work was progressing well, in line with our aim of launching the resource at Parliament House during the 2014 Polio Awareness Month in October.

## 2014 Polio Health and Wellness Retreat

The 2014 Retreat was run for sixty participants at St Joseph's Centre for Reflective Living in Baulkham Hill, NSW, from Thursday 8 to Sunday 11 May.



The format was the same as for previous years as this has proved very successful: Orientation on Thursday afternoon/evening; Body on Friday; Mind on Saturday; and Spirit on Sunday morning, before the closing Plenary after lunch. As the last NSW Retreat was four years ago, there were a number of different presenters at this one. The feedback was very good, with one participant summing it up as follows:

*While there is often a feeling that there may not be much more we can learn or do to assist in our daily lives and ongoing mobility, it was generally agreed that we were leaving the Retreat richer for not only the information gained but also for the new friendships forged and the old renewed.*

In April, Mary-ann and Jill Pickering visited two potential Victorian Retreat venues for 2015 in Geelong and Torquay. It was agreed that the Wyndham Resort in Torquay was much more suitable as far as accessibility, facilities, and location were concerned.

As discussed earlier, Mary-ann undertook a four year program review of the Health and Wellness Retreats and their impact on the “increase in Health Literacy” and “improved Health Outcomes” of the participants. The survey responses clearly indicate that Polio Australia’s Health and Wellness Retreats are achieving these goals. This can be summarised in the additional comments provided in response to the following two questions:

**Q1 - Overall my knowledge and understanding of the Late Effects of Polio and how it affects me – or family member/friend:**

*“I have a good understanding of the LEOp and how it affects me, and a reasonable grasp of the associated issues. However attending the Retreat, and its 4 day concentration of current information, plus exchanging views with many other polio survivors has expanded my knowledge and understanding of my LEOp/PPS and the different ways issues can be coped with by myself and other polio survivors, all of whom are uniquely impacted on.”*

*“I was able to extend my knowledge and receive valuable assistance which led to the upgrading of my respiratory support from a CPAP to a BiPAP. I also was able to develop a greater understanding of how to feel more comfortable accepting assistance from carers and other concerned family members.”*

**Q10 - Since attending the Retreat, my ability to achieve improved health outcomes, make healthy choices, and seek opportunities to continue learning has changed:**

*“I tended to avoid going to specialists, physios and others owing to bad experiences as a child. But having met many of them at the Retreats, I am now able to approach them more readily. I have since had two assessments at Polio Services Victoria and advocate same for other polio survivors I encounter at meetings and in the community.”*

*“Definitely – I do aqua aerobics three days a week. Sometimes I just couldn’t be bothered but I now know I MUST be bothered. I know I need to make healthy choices like eat the right food, don’t put on weight, do exercise, etc. I want to know more and I want others to know more. Going to the Retreat was one of the most rewarding things I have ever done. I wish I could go to more of them. Meeting so many others who, even though our conditions varied greatly - from people in wheelchairs, to others like me with no visible signs of having had polio - I knew everyone there knew how I was feeling. I enjoyed almost every session, but being able to chat with the others was so rewarding. It had a profound effect on my life. It was also such an emotional event for me too, learning that others had been shunned as children. Very emotional, but so good to be able to speak about it and know they understood.”*

## The Last Three Years

In November 2011, Polio Australia's Management Committee developed a three year Strategic Plan to take us through to the end of 2014. A key objective to come from this meeting was the need to establish a stable income stream to support staffing and programs:

- ▽ Staff: National Program Manager / Fundraiser / Project Officers / Administration Support
- ▽ Programs: Education Modules / Program for Health Sector / Retreats / Conferences

According to the Institute of Community Directors Australia, the strategic planning process enables organisations to think through and document what they are doing, for whom and why they are doing it. It aims to focus an organisation's vision and priorities in response to a changing environment and to ensure that members of the organisation are working toward the same goals.

The strategic plan documents for the organisation and its clients and supporters:

- ▽ Where they are going;
- ▽ What they need to do to get there;
- ▽ How they are progressing along the way; and
- ▽ That a full account of the results achieved will be delivered at the appropriate time.

At Polio Australia's 2014 Annual General Meeting, it will be time to review the 2012 to 2014 Strategic Plan. The table below provides a snap shot of our progress to date. In almost all instances, the only reason objectives have not been achieved is due to the lack of resources. Funding submissions were made for all these project areas but were not successful. However, Polio Australia will continue to seek ways of implementing these programs over the next 3 years.

### Report Against Strategic Plan: 2012 to 2014

#### Priority One: Capacity Building

Securing a stable income stream to support the organisation and key program areas into the future

<b>Key strategies undertaken in order to meet objectives</b>	<b>Activities for each strategy</b>	<b>Timeframe</b> <b>Achieved</b> <b>Not Achieved</b>
<b>1</b> Establish a community investors Polio Support Circle	<b>1.1</b> Develop investment prospectus and approach sources for potential Polio Support Circle Members	by end February 2012
	<b>1.2</b> Organise bi-annual investors networking/information luncheons	October 2012 March 2013

2 Work with Parliamentary Friends of Polio Survivors (PFoPs)	2.1 Develop investment prospectus and approach PFoPs to secure support and advice to promote networking/information luncheons	by end February 2012
	2.2 Organise bi-annual investors networking/information luncheons	October 2012 March 2013
3 Pursue Federal Government Funding	3.1 Lobby Parliamentary Patrons and PFoPs to ensure "Enquiry into Services for Polio Survivors in Australia" proceeds	by end February 2012
	3.2 Identify and apply for relevant Tenders and Grants via Department of Health and Ageing (DoHA) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)	Ongoing
4 Explore all philanthropic and corporate funding opportunities	4.1 Identify and apply for all relevant philanthropic grants via Philanthropy Australia and other sources	Ongoing
	4.2 Create listing of potential corporate investors such as mining companies, begin sending waves of investment prospectuses, and following up	by end January 2012, then ongoing

### Priority Two: Education

Elevating the level of knowledge and management of the Late Effects of Polio across the Health and Community sectors

Key strategies undertaken in order to meet objectives	Activities for each strategy	Timeframe  Achieved Not Achieved
1 Best Practice Clinical Modules for Health Professionals	1.1 Research available material in the various treatment modalities and solicit input from Clinical Advisory Group	January to December 2012
	1.2 Trial the 15 draft Modules with a variety of health professionals	January to December 2013
	1.3 Film a series of 10 to 20 minute practical demonstration videos of the 15 Best Practice Clinical Modules for training use by the medical sector	January to December 2013
	1.4 Liaise with relevant peak health professional bodies regarding promotion protocols for training videos	January to June 2014

<b>2</b> Fact Sheets for Consumers	<b>2.1</b> Prepare draft Consumer Fact Sheets adapted from the Best Practice Clinical Modules and solicit input from Post-Polio Networks and Support Groups	January to December 2013
	<b>2.2</b> Produce, print and distribute Consumer Fact Sheets to Post-Polio Networks and Support Groups and upload to website	January to December 2013
<b>3</b> Annual Polio Health and Wellness Retreats	<b>3.1</b> Continue to work on Program and promote Queensland Retreat	January to April 2012
	<b>3.2</b> Work with PolioSA and university students to source venue and program options for South Australia Retreat	by April 2013
	<b>3.3</b> Consider state options for 2014 Retreat such as Tasmania, Western Australia or return to New South Wales	by April 2014
<b>4</b> Three Day International / Asia-Pacific Post-Polio Syndrome Conference – March 2014	<b>4.1</b> Research venues, draft Program framework for Conference and solicit input from Clinical Advisory Group	January to December 2012
	<b>4.2</b> Call for Abstracts to populate Program	January to June 2013
	<b>4.3</b> Promote Conference through peak polio organisations worldwide	July 2013 to February 2014
<b>5</b> Annual Polio Awareness Month - October	<b>5.1</b> Coordinate a mass visit to Parliament House with at least 4 representatives from each State Polio Network meeting with their local MPs	January to October 2012 culminating on Wednesday 17 October
	<b>5.2</b> Work in coordinated manner with all Polio groups across Australia to identify and encourage state-based activities and assist in promotion of activities via Polio Australia publications and website	June to October each year
<b>6</b> Australian Polio Register	<b>6.1</b> Encourage periodic Australia wide push to promote its existence via State Polio Network publications to encourage more registrations	Monthly/Quarterly/Ongoing
	<b>6.2</b> Utilise accumulated data on Register for promotional and research activities	January 2012 - ongoing

### Priority Three: Health Service Promotion

Lobbying and advocating for recognition and appropriate service provision for Australia’s polio survivors

Key strategies undertaken in order to meet objectives	Activities for each strategy	Timeframe <b>Achieved</b> <b>Not Achieved</b>
<b>1</b> Polio Clinics	<b>1.1</b> Encourage all State Polio Networks to compile and submit ideas for polio clinic models in their own states	Achieved January to June 2012
	<b>1.2</b> Identify and liaise with appropriate government and/or health service providers to discuss possible options for implementation	Achieved July to December 2012
	<b>1.3</b> Develop the blueprint for a range of polio clinic models incorporating public and private sectors, rural satellites, and remote consultation for implementation across Australia	Not Achieved January to June 2013
<b>2</b> Research	<b>2.1</b> Identify list of potential Research projects with a view to seeking funding, such as: Burden of Disease, Indigenous Community Oral History, Treatments, other	Achieved January to June 2012
	<b>2.2</b> Work up projects and seek funding from relevant organisations including government, philanthropic and corporate, such as Mining Companies	Achieved July 2012 to June 2013
<b>3</b> National Policy Development	<b>3.1</b> Explore policy frameworks from similar organisations to Polio Australia and draft Policy Principles	Not Achieved by December 2012
	<b>3.2</b> Take every opportunity to respond to the federal government’s new health strategies and directives with relevant ‘position statements’ based on Polio Australia’s Policies	Achieved Ongoing

## Priority Four: Collaboration

Working with and supporting State-based Polio Networks by producing resources and standardising information for use by the Networks and their members

Key strategies undertaken in order to meet objectives	Activities for each strategy	Timeframe <b>Achieved</b> <b>Not Achieved</b>
<b>1</b> Resourcing Polio Community	<b>1.1</b> Continue monthly/quarterly publications, and maintain up-to-date and relevant website	Ongoing
	<b>1.2</b> Direct all new enquiries to relevant State Polio Networks	Ongoing
<b>2</b> Standardising Information	<b>2.1</b> Develop Polio Australia Medical Alert Card and distribute to all State Polio Networks	by end of September 2012
	<b>2.2</b> Develop Polio Australia Hospital Admission Information and distribute to all State Polio Networks	by end of September 2012
	<b>2.3</b> See Priority Two: 2 - Fact Sheets for Consumers	January to December 2013