

# Polio Australia

*Representing polio survivors throughout Australia*



**2014 Annual General Meeting**

## **Strategic Plan 2015-2018**



## We're Still Here!

### Polio Australia's Board

as at November 2014

- President: Dr John Tierney OAM (NSW)
- Vice President: Gillian Thomas (NSW)
- Secretary: Jenny Jones (WA)
- Treasurer: Brett Howard (SA)
- Tessa Jupp (WA)
- John Mayo (Qld)
- Dr Margaret Peel (Qld)
- Deanna Varney (Vic)
- Bev Watson (Vic)
- Peter Wierenga (SA)

### Observers

- Billie Thow (Tas)
- Arthur Dobson (Tas)
- Geoff Dean (Post Polio Victoria)

### Staff

- National Program Manager:  
Mary-ann Liethof (Vic)
- Administration Officer/Bookkeeper  
(Part-time): Shylie Little (NSW)
- Fundraising Consultant (Casual):  
Glenn Gardner (NSW)

### Regular Volunteer

- Jill Pickering (Vic)

## Introduction

Australia experienced waves of polio epidemics throughout the 20<sup>th</sup> century. However, with the introduction of the Salk and Sabin vaccines, polio was an uncommon infection in Australia by the early 1960s. Thankfully, Australia is now free of new cases of polio although, years after contracting the infection, increasing numbers of Australia's 400,000 polio survivors are developing a range of new symptoms, collectively identified as the Late Effects of Polio or Post-Polio Syndrome (LEoP / PPS).

In the late 1980s, Polio Networks were formed in every state of Australia, predominantly governed and managed by volunteer polio survivors, to provide information about the LEoP / PPS for their brethren. Most were funded through membership; others attracted small amounts of state government funding.

In 2007, these Networks came together to discuss the need for a national body, as the volunteer polio survivors became increasingly more debilitated by the LEoP / PPS. The result is that Polio Australia was incorporated in 2008 to represent polio survivors throughout Australia.

Most of those affected by LEoP / PPS are now over 60 years of age, limiting this potentially debilitating chronic disease to an ageing – and therefore finite – population.

Although not a new condition, federal government support for people living with the LEoP / PPS has been nonexistent, resulting in widespread issues including, but not limited to:

- misdiagnosis due to lack of awareness of the LEoP / PPS across the health sector;
- lack of awareness of polio survivors' own condition;
- the exacerbation of motor neuron damage;
- a significant increase in falls leading to the need for expensive acute care; and
- extraordinary costs relating to health and disability.

Following intensive lobbying by Polio Australia, a federal House of Representatives Standing Committee on Health and Ageing Roundtable was held on the 30<sup>th</sup> of March 2012. Three recommendations were proposed in the resulting "*Discussion Paper on the Late Effects of Polio / Post-Polio Syndrome*".

The federal government has taken no action to progress these Recommendations since the Discussion Paper was released. Although Polio Australia has the expertise, programs and strategies to achieve these Recommendations—and more—lack of necessary financial and human resources poses an ongoing challenge.

It should also be noted that apart from younger migrants, most polio survivors are not eligible for the National Disability Insurance Scheme (NDIS) due to the 65 year cut-off.



## Our Vision

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

## Our Mission

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

## Our Values

As the national peak body, 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.



## Our Purpose 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.

*Campaigners with Federal Health Minister Sussan Ley*



## Objective One: Education

*Promoting enhanced knowledge and management of the Late Effects of Polio across the Health and Community sectors*

### Strategies



#### HEALTH SECTOR

- Facilitate at least one professional development workshop for allied health practitioners per year
- Produce at least one professional development webinar and / or clinical practice training video to be hosted on website per year
- Coordinate, promote, and run the 2016 Australasian-Pacific Post-Polio Conference in Sydney
- Source and maintain a list of trained / informed health professionals to be hosted on website, who are available for referral / consultation
- Secure funding to produce two clinical practice resources addressing specific aspects of the Late Effects of Polio
- Continue to develop health professional website

### Strategies



#### COMMUNITY SECTOR

- Develop strategies to engage and inform 'new' polio survivors who don't identify as disabled and / or don't recognise their symptoms as relating to the Late Effects of Polio
- Produce and promote a video documentary highlighting the positive aspects of living with polio
- Produce standardised information resources for use by the state Polio Networks and their members, eg. Fact Sheets
- Expand polio awareness campaigns to include and target the general public
- Continue facilitating annual Polio Health and Wellness Retreats
- Continue producing and distributing quarterly "Polio Oz News" e-magazine

## Objective Two: Advocacy

*Lobbying and advocating for recognition of and appropriate service provision for Australia's polio survivors*

### Strategies



- Instigate annual "We're Still Here!" media campaign each October
- Visit key parliamentarians in Canberra once a year
- Continue informing six Parliamentary Patrons about Polio Australia's activities
- Engage individual federal government Members and Senators in campaigns and activities
- Submit applications for government funding for Polio Australia's program areas as they arise
- Produce Position Statements and provide feedback and responses on proposed government policies and initiatives that impact on the post-polio community

## Objective Three: Capacity Building / Resources

*Building resources—financial and human*

### Strategies



#### FINANCIAL

- Pursue a range of options to secure a stable income stream to support Polio Australia and our key program areas into the future, e.g. clinical workshops and webinars, and clinical practice resource sales
- Continue developing sponsorship-based relationships with organisations such as Rotary International
- Generate opportunities to promote Polio Australia and increase visibility to attract investors and in-kind support

### Strategies



#### HUMAN

- Actively identify and recruit three new, skilled / well-connected Board Members
- Source and recruit a skilled pro-bono fundraiser
- Devise a targeted campaign to engage younger polio survivors in succession planning to ensure sustainability and relevance

## Objective Four: Visibility

*Creating positive visibility in the community*

### Strategies



#### EXTERNAL

- Actively publicise the Australian Polio Register using opportunities such as speaking engagements, campaigns, media interviews, blogs, and social media such as Facebook and Twitter to raise awareness and increase statistical data
- Produce and submit regular articles and / or notices for external newsletters and magazines (hard copy and online) targeting seniors and younger migrants who may have a connection to polio, as well as health professionals
- Source and approach relevant organisations to request links to Polio Australia on their websites (and reciprocate accordingly)

### Strategies



#### INTERNAL

- All state Networks to regularly publicise the Australian Polio Register through respective websites and newsletters to their members
- Devise positive publicity messages to attract younger / less-affected polio survivors, e.g. stories of successful lives lived, and how contributing their own statistical data can assist others in the post-polio community
- Pursue opportunities to engage with local media (print and radio), e.g. article submissions and / or Letters to the Editor re immunisation, and contacting talk back radio to promote positive messages



## Objective Five: Partnership Development

*Enhance external and internal relationships for mutually beneficial outcomes*

### EXTERNAL

- Actively seek out and follow up opportunities to develop partnerships, joint ventures, and affiliations with other organisations and individuals for mutually beneficial outcomes. These include:
  - International peak polio organisations—for up-to-date and best-practice resource and information exchange to assist in the support of our respective post-polio populations
  - Parliamentary Patrons—to keep them informed about Polio Australia's activities and remind the federal government that "We're Still Here!"
  - Rotary International—to promote the 'closing the circle' concept of Rotarians starting Crippled Children's Associations, to polio eradication, to supporting polio survivors potentially leading to a Post-Polio Trust
  - Health professionals—to ensure they are informed and / or trained in working with polio survivors, as well as possibly contributing time / knowledge to Clinical Advisory Group activities
  - Peak health bodies—to assist with information exchange and dissemination
  - Philanthropic organisations and corporations—which may decide Polio Australia's projects and activities a suitable match with their funding criteria
  - Universities—which may be interested in research projects in the areas of post-polio treatment, statistics, and / or history
  - Aids and Equipment suppliers—to negotiate paid advertising opportunities in newsletters and / or events



### INTERNAL

- Polio Australia and state Polio Networks to work synergistically to achieve priorities by:
  - Continuing to meet quarterly via teleconference and face-to-face AGM / Strategic Plan Review
  - Further developing joint fundraising campaigns such as the annual "Walk With Me" activity in each state
  - Polio Networks regularly keeping their state membership base informed about Polio Australia's activities and initiatives via newsletters, website, and / or meeting updates
  - Polio Networks regularly informing Polio Australia about their activities for promotion in Polio Oz News and / or website
  - Sharing statistical data and resource material between Polio Networks and their membership bases
  - Continuing to refer potential new members to their respective state Polio Networks

## Programs

**Polio Australia strives to develop programs and services to assist both polio survivors and health professionals to achieve effective management of the Late Effects of Polio including:**

### **AUSTRALIAN POLIO REGISTER**

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today.

### **CLINICAL ADVISORY GROUP**

The aim of the group is to advise on quality information and best-practice service provision across Australia, incorporating appropriate diagnosis and management of the LEO/PPS.

### **EDUCATIONAL PRESENTATIONS**

Polio Australia facilitates Professional Development Workshops for health professionals as opportunities and resources permit.

Speaking engagements are also organised at a variety of service clubs, including Rotary, as a source of promotion and potential funding revenue.

### **CLINICAL PRACTICE RESOURCES**

Polio Australia has produced two in a series of proposed Clinical Practice Resources: *LEoP: Introduction to Clinical Practice* (2012), and *LEoP: Managing Muscles and Mobility* (2014)

### **LATE EFFECTS OF POLIO SELF-MANAGEMENT RESIDENTIAL PROGRAM**

Polio Australia holds an annual Late Effects of Polio Self-Management Residential Program (also known as "*Polio Health and Wellness Retreats*") for up to 70 polio survivors and their families/carers addressing self-management strategies for the post-polio body.

### **POLIO AWARENESS MONTH**

Each October, Polio Australia coordinates awareness-raising through its annual Polio Awareness Month campaign.

### **PUBLICATIONS**

Polio Australia publishes its e-Bulletin, "*Reflections*", eight times a year and a quarterly e-Magazine "*Polio Oz News*", both of which are available online.

### **WEBSITES**

Through volunteer efforts, Polio Australia has produced five websites which have been created to promote specific activities:

[www.polioaustralia.org.au](http://www.polioaustralia.org.au)—general information  
[www.poliohealth.org.au](http://www.poliohealth.org.au)—for health professionals  
[www.stillhere.asn.au](http://www.stillhere.asn.au)—campaigns and stories  
[www.polio.org.au](http://www.polio.org.au)—event promotion  
[www.postpolioconference.org.au](http://www.postpolioconference.org.au)—2016 Australasian-Pacific Post-Polio Conference



Kew Junction Tower  
Suite 119C, 89 High Street South  
Kew Victoria 3101  
PO Box 500  
Kew East Victoria 3102

**Phone:** +61 3 9016 7678

**E-mail:** [office@polioaustralia.org.au](mailto:office@polioaustralia.org.au)

**Websites:** [www.polioaustralia.org.au](http://www.polioaustralia.org.au) ● [www.poliohealth.org.au](http://www.poliohealth.org.au) ● [www.stillhere.asn.au](http://www.stillhere.asn.au)  
[www.polio.org.au](http://www.polio.org.au) ● [www.postpolioconference.org.au](http://www.postpolioconference.org.au)