

# Polio Australia

Representing polio survivors throughout Australia



## REPORT

### **Australasia-Pacific Post-Polio Conference**

### *Polio: Life Stage Matters*

20-22 September 2016

Four Seasons Hotel Sydney

Australia

# Contents

About Polio Australia.....	3
About Polio.....	3
Aim of the Conference.....	4
Timeline.....	5
Steering Committee.....	6
Scientific Committee.....	7
Fees.....	7
Accommodation.....	8
Keynote Presentations.....	9
Additional Presentations.....	10
Who Came?.....	11
Social Events.....	11
Sponsorship.....	12
What They Said.....	13
Acknowledgements.....	15
Summary.....	16

# About Polio Australia

Polio Australia was incorporated in 2008 to act as the peak national body representing Australia's polio survivors. It is committed to standardising quality information and service provision across Polio Australia is a self-funded charity governed by a [Board](#) who are all either polio survivors themselves experiencing the Late Effects of Polio and/or Post-Polio Syndrome, or people who work with polio survivors, their families and carers. Polio Australia represents all the [state Polio Networks](#), and the President, Dr John Tierney, and Vice-President, Gillian Thomas, are also both on the Board of [Polio NSW](#). Polio Australia and the state Polio Networks are the only organisations working exclusively with, and on behalf of, polio survivors in Australia.

The purpose of Polio Australia is to inform and educate polio survivors, their families and carers, and the community about the chronic, and often debilitating, condition known as the Late Effects of Polio and/or Post-Polio Syndrome. It assists state Networks to support polio survivors and facilitates the co-ordination of activities between states.

Polio Australia strives to provide quality information, education and training for doctors, specialists, and allied health professionals, to improve the diagnosis and management of the Late Effects of Polio/Post-Polio Syndrome. Polio Australia is well placed to advise government on [policy development](#) and programs and to stimulate research into the Late Effects of Polio.

Polio Australia also supports and promotes polio [immunisation](#) at a national level and provides assistance to states to do so at a local level.

Polio Australia facilitates an annual residential chronic condition self-management program for polio survivors and their partners/carers – also known as a [Polio Health and Wellness Retreat](#). Polio Australia has established information and educational websites for both [polio survivors](#) and [health professionals](#), including [resources for health professionals](#) and the [Australian Polio Register](#); it provides community education; and has the support of a multi-disciplinary [Clinical Advisory Group](#) to advise on [education for health professionals](#).

## About Polio

Post-Polio Syndrome is a diagnosable neurological condition experienced by approx. 50% of people who survived *paralytic* polio (only 0.5% of all polio infections-[WHO](#)). The broader description of the Late Effects of Polio (or Post-Polio Sequelae) covers both Post-Polio Syndrome and progressive biomechanical decline, which can be experienced by *anyone* who contracted polio. In Australia, the Late Effects of Polio potentially affects hundreds of thousands of people. This decline is due to consistent overuse of insufficiently innervated muscles, and may only become overtly apparent up to 50 years after poliomyelitis infection. As this timeframe coincides with advancing age, the symptoms are regularly misdiagnosed as 'general ageing' by uninformed treating health practitioners. As such, many polio survivors continue to struggle because of the lack of accurate information and clinical support to properly manage their health.

Symptoms associated with the Late Effects of Polio/Post-Polio Syndrome can include: unaccustomed fatigue unrelated to activity, new muscle weakness and atrophy, decreased strength and endurance, pain in muscles and/or joints, an inability to stay alert, respiratory and sleep problems, swallowing or speaking difficulties.

Common corresponding health concerns include: scoliosis/kyphosis, arthritis, osteoporosis, obesity-related diseases – such as hypertension and diabetes – due to increasing mobility restrictions, frequent falls, and subsequent depression. Currently, there are no pharmaceutical interventions to treat/relieve the Late Effects of Polio/Post-Polio Syndrome.

## Aim Of The Conference

As the world celebrates the highly successful polio eradication program, which has reduced the number of polio endemic countries to three – Nigeria, Pakistan, and Afghanistan - the challenge to maintain high vaccination rates around the world to prevent further outbreaks remains.

At the other end of the challenge continuum is the growing need for health professionals with the knowledge to adequately treat the estimated 20 million people worldwide who are survivors of polio. Polio survivors can be found in every country, although those in the western world tend to be an ageing demographic, whereas those in developing countries are across the age spectrum.

The health issues for ageing polio survivors and young polio survivors differ. In young polio survivors the challenge is to prevent and treat severe deformities, to reduce disability, and to improve social participation. In ageing polio survivors, management focuses on preserving independence and quality of life.

The aim of the Australasia-Pacific Post-Polio Conference is to exchange knowledge about the diagnosis and treatment of the post-polio condition in different age groups to best preserve functioning throughout life.

International post-polio conferences have previously been held in the USA by [Post-Polio Health International](#) (11 since 1981), and in Europe through the [European Polio Union](#) (2 held in 2011-Copenhagen and 2014-Amsterdam).

The first ever Australasia-Pacific Post-Polio Conference – “*Polio: Life Stage Matters*” held in Sydney in September 2016 was a forum to facilitate better care and build international connections by bringing together health care providers, researchers, polio survivors and their caregivers not only from the Australasia-Pacific region, but worldwide.

The aim of the Conference was to exchange knowledge about the diagnosis and treatment of the post-polio condition in different age groups to best preserve functioning throughout life.

# Timeline

August 2014	National Program Manager returned from PHI (USA) and EPU (Amsterdam) Post-Polio Conferences
August 2014	Referred to the Intermedia Group by ARATA (Australian Rehabilitation & Assistive Technology Association)
	Emailed Simon Cooper, Director of the Intermedia Group with conference proposal
	PA Executive team met with Simon Cooper and Marketing Manager, Melanie Robertson, in Sydney to discuss proposal
October 2014	Selected Four Seasons Hotel Sydney as Venue
February 2015	Signed Contract with Intermedia Group/ <a href="#">Interpoint Events</a>
	Selected and approached suitably qualified people to be on both Steering and Scientific Committees
	Selected and invited Keynote Presenters
May 2015	1 <sup>st</sup> Call for Abstracts – due 31 August 15
	<a href="http://www.postpolioconference.org.au">www.postpolioconference.org.au</a> website launched
November 2015	2 <sup>nd</sup> Call for Abstracts – due 31 March 16
December 2015	Conference Registrations open
July 2016	All Abstracts reviewed and sent to the Journal of Rehabilitation Medicine for printing
September 2016	Australasia-Pacific Post-Polio Conference held

## Steering Committee

Conference Chair  
Dr Stephen de Graaff  
Rehabilitation Physician  
Director of Pain Services  
Epworth Health (Victoria, Australia)

Joan Headley  
Executive Director  
Post-Polio Health International  
(St Louis, USA)

Mary-ann Liethof  
National Program Manager  
Polio Australia (Victoria, Australia)

John McFarlane  
President  
European Polio Union (Ireland)

Dr Margaret Peel PhD  
Microbiologist (Ret)  
Polio Australia Board Member  
(Queensland, Australia)

Jill Pickering  
Occupational Therapist (Ret)  
Polio Australia Volunteer  
(Australia, Victoria)

Dr Michael Summers PhD  
Evaluator/Senior Policy Advisor  
(Victoria, Australia)

Liz Telford  
Social Worker  
Post Polio Victoria Secretary  
(Victoria, Australia)

Gillian Thomas  
President, Polio NSW and  
Vice President, Polio Australia  
(New South Wales, Australia)

Dr John Tierney PhD OAM  
President  
Polio Australia  
(New South Wales, Australia)

## Scientific Committee

Sarah Anderson  
Prosthetist and Orthotist and Lecturer  
La Trobe University (Victoria, Australia)

Merete Bertelsen  
Physiotherapist  
Special Hospital for Polio and Accident  
Patients (Copenhagen, Denmark)

Dr Stephen de Graaff  
Rehabilitation Physician  
Director of Pain Services  
Epworth Health (Victoria, Australia)

Joan Headley  
Executive Director  
Post-Polio Health International  
(St Louis, USA)

Dr Ian Neering PhD  
Physiology and Pharmacology Researcher  
(Australian Capital Territory, Australia)

Dr Peter Nolan  
General Physician  
St Andrews Hospital Toowoomba  
(Queensland, Australia)

Dr Michael Summers PhD  
Evaluator/Senior Policy Advisor  
(Victoria, Australia)

Dr Mary Westbrook PhD  
Psychologist (Ret)  
(New South Wales, Australia)

# Fees

Registration Options	Early Bird Rate (Until Friday, 12 August, 2016) excludes GST of 10%	Regular Rate (From Saturday, 13 August, 2016) excludes GST of 10%	Refund & Cancellation Policy
<b>3 Day Conference</b> <i>includes a complimentary invitation to the Welcome Cocktail Party</i> <b>Special offer: buy 3, get the 4th free.</b>	\$1,200	\$1,320	Cancellations received in writing by the 19th August 2016 will incur a \$100 cancellation fee. Cancellations received after the 19th August 2016 will receive NO refund. A replacement delegate can attend with no penalty charge but must be advised to Post-Polio Conference by email.
<b>3 Day Conference</b> Carer <i>includes a complimentary invitation to the Welcome Cocktail Party</i>	\$375		
<b>3 Day Conference</b> Polio Survivor, Family, Friend, Student, Rotarian <i>includes a complimentary invitation to the Welcome Cocktail Party</i>	\$540	\$600	
<b>2 Day Conference</b>	\$900	\$990	
<b>2 Day Conference</b> Carer	\$250		
<b>2 Day Conference</b> Polio Survivor, Family, Friend, Student, Rotarian	\$405	\$450	
<b>1 Day Conference</b>	\$500	\$550	
<b>1 Day Conference</b> Carer	\$180		
<b>1 Day Conference</b> Polio Survivor, Family, Friend, Student, Rotarian	\$225	\$250	
<b>Gala Dinner Ticket</b> Wednesday 21st September 2016	\$100		



## Accommodation

The Conference was held at the [Four Seasons Hotel](#), a five-star luxury hotel in Sydney's CBD, located at 199 George Street Sydney NSW 2000.

The Four Seasons had a special rate for delegates of the Post Polio Conference @ \$265 per room per night for the first 50 rooms booked (including GST). Hotel Breakfast was an additional \$35 per person.





# Keynote Presentations

\* Members of Polio Australia's Clinical Advisory Group

Country	Name	Discipline	Keynote Presentations
1. Australia NSW	Bernard Badorrek *	Orthotist	The Legendary Walker and Unwitting Biomechanist
2. Australia NSW	Prof Robert Booy *	Microbiologist and Virologist	Advances in the surveillance, control and elimination of polio
3. Australia SA	Ann Buchan *	Neurophysiotherapist	Four decades of working with post-polio patients: What's changed? What works? What to avoid?
4. Australia Victoria	Dr Steve de Graaff*	Rehabilitation Physician	Pain management for polio patients
5. Australia Victoria	Anne Duncan *	Respiratory Nurse	Ventilation advancements for polio patients over the decades
6. Australia WA	(Jega) Gnaaletchumy Jegasothy *	Physiotherapist (Retired)	Developing a Late Effects Clinic: WA experience
7. Australia ACT	Kerry Highley	Medical Historian	Dancing In My Dreams: Confronting The Spectre of Polio
8. Australia Queensland	Jenny Horton	WHO/Rotarian	End Polio Now Campaign Update
9. Australia Victoria	Natasha Layton *	Occupational Therapist	Assistive Technology
10. Australia NSW	Dr Helen Mackie	Rehabilitation Physician	Attendee feedback review of Mt Wilga LEO P Clinic
11. Australia NSW	Melissa McConaghy*	Neurophysiotherapist	Demystifying treatment of the polio body
12. Australia Queensland	Dr Peter Nolan *	General Physician	Cough, split, and breathlessness: respiratory problems for post-polio patients
13. Australia Victoria	Darren Pereira *	Orthotist	Orthotic needs for younger polio survivors
14. Denmark	Merete Bertelsen	Physiotherapist	Physiotherapy for post-polio patients as part of an interdisciplinary rehabilitation program. How do we meet the needs of polio survivors in different life stages? A practical perspective.

15. Denmark	Dr Lise Kay	Urologist	Contenance issues for post-polio patients
16. Italy	Dr Antonio Toniolo	Microbiologist and Virologist	Post-Polio Syndrome as a viral disease: research results
17. Netherlands	Dr Frans Nollet	Rehabilitation Physician	Evaluation and improvement of functional abilities for post-polio patients
18. USA	Dr William DeMayo	Rehabilitation Physician	Telemedicine Opportunities: potential health service provision and educational options for remote and/or difficult to reach post-polio patients of all ages
19. USA	Dr Marny Eulberg	General Practitioner (Retired)	What polio causes, does not cause and might cause
20. USA	Joan Headley	Director of Post-Polio Health International	Post-Polio Research: Why and What
21. USA	Marmaduke Loke	Orthotist	A 21st Century approach to holistic bracing for neuromuscular disorders
22. USA	Dr Stephanie Machell	Psychologist	Case consultation: Psychotherapy with a Polio Survivor
23. USA	Dr Carol B. Vandenakker-Albanese	Rehabilitation Physician	Management of Spinal Issues in Polio Patients

## Additional Presentations

- 38 Additional Oral Presenters
- 8 Poster Presentations
- 85 Total Presentations
- 8 Clinical Practice Workshops
- Post-Polio Service Dreaming Workshop and Panel Discussion

## Who Came?

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

### 229 Delegates from 14 countries:

---

Australia - 168  
Canada - 1  
Denmark - 6  
India - 6  
Italy - 2  
Japan - 6  
Netherlands - 2

New Zealand - 16  
Spain - 1  
Sri Lanka - 4  
Taiwan - 1  
Uganda - 1  
United Kingdom - 3  
USA - 12

---

## Social Events

- Welcome cocktail Party at MCA with a performance by the Circular Keys Chorus
- VIP dinner for Invited Keynote Presenters, Polio Australia Board members, and Committees
- Gala dinner at the Four Seasons Hotel - 3 courses dinner for 123 paying delegates with Guest Speaker, The Hon Jillian Skinner, New South Wales Minister for Health



# Sponsorship

## Platinum Sponsor



\$24,000 NSW Health  
\$9,000 GSK  
\$6,000 ResMed\*  
\$5,000 Polio Australia  
\$4,000 Post-Polio Health International

\$2,500 Trade Stalls

- Mt Wilga Private Hospital
- Otto Bock
- ResMed\*

## Sponsors



## Supporters



POST-POLIO HEALTH INTERNATIONAL  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK



## What They Said

As an allied health practitioner, it was a great pleasure to attend the Australasia-Pacific Post-Polio Conference – Polio: Life Stage Matters. I particularly noted the high proportion of consumers present: truly, a 'nothing about us, without us' experience.

Many of the papers by consumers were high quality and 'cut through' to the core issues of equity, respectful co-management and a focus on the demands of daily living.

I would have liked to see a panel of consumers / service users evaluate and interrogate some of the more scientific papers: speaking as a presenter, it is important to be reminded to translate research findings into plain language and to always focus on the meaning and translation of any research.

I applaud the organisers and the scientific panel for pulling together the international and national speakers, and it was excellent to see the abstracts formally published.

*Dr Natasha Layton, PhD  
Occupational Therapist, Victoria, Australia*

Congratulations on the success of the conference. It was a pleasure to attend and to meet such an inspiring team all working towards a common goal!

*Dr Kelly Jones  
Senior Research Fellow, School of Public Health & Psychosocial Studies  
AUT University, New Zealand*

We really enjoyed the conference. The quality of the presentations was outstanding and the networking opportunities were so valuable. The venue, accommodation and catering were perfect. Thanks so much for your efforts, which I know must have seemed daunting at times.

*Dr Pat Dorsett  
Senior Lecturer, Honours Program Director  
School of Human Services and Social Work, Griffith Health Institute  
Centre for Population and Community Health, Griffith University  
Queensland, Australia*

It was great to be invited to be part of such wonderful conference. I attended the 2008 and 2011 conferences in Europe and I think ours was of equal if not better standard. I am planning to do a systematic review followed by a clinical study on osteoporosis in polio patients and hope to have some data to present at the next meeting in two years.

*Dr Nigel Quadros  
Senior Consultant Rehabilitation Medicine, The Queen Elizabeth Hospital  
Senior Clinical Lecturer Division of Medicine, University of Adelaide, Australia*

Thank you for the invitation, it was a great conference! I did not hesitate for a second when deciding to come. I do believe it was a very successful conference and people learned valuable nuggets of information from every presenter. I loved everything about the conference, location, venue, organization, staff, and presentations. Great job! For anything in life to look easy, a great deal of work must be accomplished, it showed. Thank you again for all your hard work.

*Marmaduke Loke  
Dynamic Bracing Solutions, California, USA*

Congratulations on putting together such a great conference. I found it really energising. I especially liked the mix of academics and "real people". The theory/practice intersection is just so important. The experience certainly validated for Pat and I the work we have been doing and inspired us to keep going even though our research has been mostly self-funded. Of course, none of it would have been possible without the in-kind support from a number of organisations and of course the post-polio networks and individuals. Once again, thanks again for a great conference. I look forward to attending in the future.

*Dr Sandra Woodbridge  
School of Human Services and Social Work, Griffith Health Institute  
Centre for Population and Community Health, Griffith University  
Queensland, Australia*

I was so very grateful to attend the conference. It was beneficial in so many ways with the vital information gained from the speakers and the friendships formed with the many other polio survivors attending. I was also very interested to hear the stories from the International polio survivors. And I was particularly saddened by the stories of the younger survivors who contracted polio from the early immunisation programs. What a cruel irony!

At the conference, for the first time I felt **one of the many** rather than **one of the very few**. It was a life-affirming experience as 'We're Still Here!' and we survivors talked and laughed together like old friends. Who knows we may have shared a ward somewhere so many years ago.

There were so many highlights for me: the Cocktail Party at MCA with the wonderful Circular Keys Chorus and the Gala Dinner were real treats. However, the absolute standouts were the presentations by the medical and allied health professionals. There is still so much more information to be absorbed on how to look after ourselves better so I will re-visit the many presentations on the Polio Australia website.

*Sylvie Sampson  
ACT*



# Acknowledgements

Polio Australia was inspired and encouraged to hold this Australasia-Pacific Post-Polio Conference: Polio – Life Stage Matters, after having participated in the 2011 and 2014 European Polio Union Conference in Copenhagen and Amsterdam, respectively, in addition to the 2009 and 2014 Post-Polio Health International Conferences held in the USA.

Both Polio Australia's President, Dr John Tierney, and National Program Manager, Maryann Liethof, spent time attending sessions and making several important acquaintances amongst the organisers and medical presenters. Everyone we spoke to appeared enthusiastic about attending a Post-Polio Conference in Australia, which was made even more evident when the majority of these people accepted invitations to attend as Keynote Presenters.

Polio Australia is extremely grateful to these international Keynote Presenters, who not only helped to raise the standard of expertise and prestige of this Post-Polio Conference to an unparalleled level, but all attended on a pro-bono basis.

We are also very thankful to Dr Steve de Graff for Chairing and expertly guiding the Conference, as well as Polio Australia's other Clinical Advisory Group Members, all of whom attended and presented on their post-polio speciality areas. Their selfless dedication to caring for Australia's polio survivors is greatly appreciated.

Apart from the invited Keynote Presenters, we warmly acknowledge the contribution of a host of additional Presenters from Australia, and world-wide, whose combined knowledge and skills helped enrich the Conference Program in interesting and sometimes unexpected ways.

However, none of this would have been possible without the backing of Interpoint Events, and we are honoured to have had the opportunity to work with consummate professionals, Melanie Robertson and Simon Cooper, to bring the whole Conference to life.

Polio Australia would also like to thank and acknowledge those who provided Sponsorship: NSW Health, the Dept of Social Services, GSK, ResMed, Otto Bock, Mt Wilga Private Hospital, and Post-Polio Health International. International Conferences are expensive to put on, and Sponsorship can be difficult to secure in such a competitive environment, so we are delighted that these organisations chose to invest in our event.

There are many others to thank from the Steering and Scientific Committees, Polio Australia's Board Members, and our volunteer Master of Ceremonies, Gary Newton. It is clear that a tremendous amount of good-will went into making this Australasia-Pacific Post-Polio Conference a success.

Last, but no means least, acknowledgment and appreciation goes to all the delegates: polio survivors, their family, and carers; and treating health professionals. All came to participate, connect, and learn from this event, and we trust the Conference delivered!

## Summary

Polio Australia is proud of its achievements over the last six years. We believe our programs have helped thousands of polio survivors improve their capacity to self-manage their condition, and for hundreds of health professionals to better understand and identify the late effects of polio.

Polio Australia's websites, resources, and publications have enabled us to share our knowledge and experience throughout Australia and overseas.

Our pursuit of best-practice information, and subsequent interaction with other peak post-polio organisations and health practitioners around the world, has been instrumental in bringing about this Post-Polio Conference.

The Australasia-Pacific Post-Polio Conference: Polio-Life Stage Matters has successfully achieved the goal of facilitating the exchange of knowledge pertaining to the diagnosis and treatment of the post-polio condition in different age groups to best preserve functioning throughout life.

Polio Australia would like to think that our programs, together with the information shared at this Conference, will leave a lasting legacy for future generations of polio survivors, both in Australia and overseas.