



Polio Australia



"We're Still Here!" Campaign October 2012

Proposal to Support Australia's Polio Survivors June 2013

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Executive summary

Australia experienced waves of polio epidemics throughout the 20th 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).

Most of those affected by LEoP/PPS are now over 50 years of age, limiting this potentially debilitating disease to an ageing – and therefore finite – population. However, it is clear that its origins date back several decades.

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 become increasingly more debilitated by the LEoP/PPS. The result is that Polio Australia was incorporated in 2008 to represent polio survivors throughout Australia.

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 neurone 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 30th 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 in the 12 months since the Discussion Paper was released. Polio Australia already has the expertise, programs and strategies to realise these Recommendations. However, what Polio Australia lacks is the necessary financial and human resources to realise the Recommendations at the level required to adequately benefit the population experiencing the LEoP/PPS.

In terms of support through disability programs, it should be noted that apart from younger migrants, most polio survivors will not be eligible for the National Disability Insurance Scheme (NDIS) due to the 65 year cut-off.

A commitment of federal government support is required to strengthen Polio Australia so it can properly service Australia's polio survivors. Adequate resources would not only allow Polio Australia to run its current programs more efficiently, it would also facilitate the development of a raft of other innovative programs, further underpinning the Recommendations proposed in the *"Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome"*.

Polio Australia recognises dependency solely on federal funding is not sustainable and has planned a number of funding revenue wells to carry the service through its projected thirty year service requirement.

Polio Australia

Our *Vision*

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



Our *Mission*

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



Our *Values*

are encompassed in the following statement:

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.

Photos taken at the Health and Wellness Retreat in Queensland

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.



Our strategic priorities

Polio Australia was incorporated in 2008 and is governed by a Committee of Management made up of two representatives from each state Polio Network:

- Post-Polio Network (NSW) Inc
- Spinal Injuries Association Inc (QLD)
- Post Polio Support Group of SA Inc
- Post Polio Network - Tasmania Inc
- Polio Network Victoria (a service of Independence Australia)
- Post Polio Network of WA Inc

At its 2011 Annual General Meeting and Strategic Planning Meeting (*right*), Polio Australia's Committee of Management decided on four priorities to work towards over the next three years.

Priority One

Capacity Building: Securing a stable income stream to support Polio Australia and our key program areas into the future

Priority Two

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

Priority Three

Health Service Promotion: Lobbying and advocating for recognition of and appropriate service provision for Australia's polio survivors

Priority Four

Collaboration: Working with and supporting state-based Polio Networks by producing resources and standardising polio information for use by the Networks and their members



Polio Australia's
National Program Manager,
Mary-ann Liethof, speaking to
Post-Polio Victoria members

Polio Australia's existing programs

Community / Patient Education

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 which have addressed self-management strategies for the post-polio body, the healthy mind and the spirit. These Retreats are held in a different state each year to ensure polio survivors around Australia have access to this vital information.

Since 2010, 4 Retreats have been run in NSW (2010), Vic (2011), Qld (2012), and SA (2013). For each of the 4 days of the Retreats, several local health and other practitioners were sourced and invited to facilitate presentations. Most required additional education on the LEOP/PPS, but were all well acquainted with the issues by the completion of their sessions, thanks to exposure to so many polio survivors in one place. This 'crash course' in the LEOP/PPS now provides them with more effective strategies to assist other patients/clients.

Polio Awareness Month

Each October, Polio Australia coordinates awareness-raising through its annual Polio Awareness Month campaign. Known polio survivors are contacted and their stories are provided to the print media and radio stations to broadcast the message that "We're Still Here!" and that there is information and support from Polio Australia and Networks for people who are experiencing the LEOP/PPS and may not be aware of the condition.

In 2012, the campaign culminated in a mass visit to Parliament House with 60 polio survivors and their family members and friends from across Australia met with their local MPs to discuss their needs.

In addition, all state-based Polio Networks are encouraged and supported to generate local

media interest during October, with the aim of potentially reaching new members. Polio Awareness Month activities are also promoted via Polio Australia's publications and website.

Educational Presentations

Polio Australia currently organises speaking engagements at a variety of service clubs, such as Rotary, as a source of promotion and potential funding revenue. Polio Australia also seeks opportunities to speak to groups within the community who might be experiencing the LEOP/PPS.

Publications

Since October 2010, Polio Australia has published its e-Bulletin, "Reflections", eight times a year.

In February, May, August and November, "Reflections" is incorporated into our subsequent quarterly e-Magazine "Polio Oz News", which was introduced in June 2011.

Both these publications are a rich source of information for readers, which is obtained from a wide range of sources including material from health professionals, stories, reports on Polio Australia's activities, government initiatives, current affairs, and more.

Both "Reflections" and "Polio Oz News" are compiled, edited, published and distributed electronically by the National Program Manager.

Email distribution of these newsletters is currently at 1590 (and growing), including 200 international organisations and individuals. All editions are also uploaded to the website for general viewing.

Websites

Through volunteer efforts, Polio Australia launched its main website in 2010, following several unsuccessful attempts to secure government or philanthropic funding. The website has been promoted through Polio Australia's publications and has a high rating with Post-Polio Health International. The website attracts an average of 235 views per day. Two additional websites have since been created to promote specific activities.

Polio Australia's existing programs

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, whether or not they contracted polio in this country. Despite limited resources to promote the Polio Register widely in the community, Polio Australia has achieved remarkable results to date.

It complements Recommendation 1 of the "Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome".

Education for health professionals

Clinical Advisory Group

To help achieve its goals, Polio Australia has established a Clinical Advisory Group (CAG) comprising open-minded health care professionals who are experts in their field and have knowledge about polio and its late effects.

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.

The Clinical Advisory Group provides recourse to Recommendation 2 and 3 of the "Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome".

Late Effects of Polio: Introduction to Clinical Practice Resource Module

In October 2012, Polio Australia launched a new online resource module at Parliament House, Canberra titled "The Late Effects of Polio: Introduction to Clinical Practice".

With no funding forthcoming from government or philanthropic sources, this module was developed and produced thanks to GlaxoSmithKline (GSK) Australia's corporate volunteer program. The reference sources, content and structure of the resource module was guided by Polio Australia and written by GSK's Vaccine Department's Medical Team.

Potential program development

Polio Australia has plans, dependent on additional resources, to develop further mechanisms and services to enable health professionals to perform best practice in the management of their polio patients. These include:

- the establishment of a website specific to health professionals to be used as a resource for widening the range of health professionals accessing information on diagnosing and managing the LEO/PPS for their patients;
- the production and distribution of videos for health professionals via the website as part of their professional development and/or continuing medical education;
- the publishing of articles in discipline-specific Professional Journals, widening the range of health professionals accessing information on diagnosing and managing the LEO/PPS for their patients;
- formulating and providing blueprints for model polio clinics to be established in each state and territory, incorporating public and private sectors, rural satellites, and remote consultation for implementation across Australia; and
- Identifying and stimulating research projects in to the management of LEO/PPS.



Clinical Advisory Group

Program limitations and future development

Retreats



Limitations

Due to limited resources, Polio Australia is only able to hold these Retreats annually and in only one state per year. As a consequence, polio survivors may only benefit from this experience once or twice in their lifetime because of the geographical and financial restrictions.

Enablers

Ideally, Polio Australia would engage state based community development workers to source venues and session facilitators, and oversee logistics and operational procedures. A Project Officer based at head office would generate funding revenues. As a result, not only would this service remain viable, it could operate annually in every state and territory, thus providing accessible, up to date community/patient education.

Presentations

Limitations

This approach is restricted to the Melbourne region, the home base of the National Program Manager.

Enablers

A more efficient method would be the use of state based community development workers conducting educational presentations about the LEO/PPS to groups within the community as a source of promotion and funding revenue nationwide.



Program limitations and future development

Publications

Limitations

Due to lack of funding, Polio Australia is unable to print copies of these publications or distribute to anyone without email/internet access. This means approximately 50% of Australia's polio survivors miss out.

Because these publications are produced totally by the National Program Manager, work pressure and priorities sometimes mean editions are delayed.

Enablers

An additional staff member to compile and prepare information for these publications would ensure timely distribution. Funding to print and distribute copies to polio survivors who are unable to access these publications via email or on the internet would double the support available throughout the community. Subscription to these publications would also provide a modest revenue.

Australian Polio Register

Limitations

Polio Australia acknowledges there are many thousands of polio survivors not registered. This, again, is due to the reality that the National Program Manager is also responsible for the promotion of the Register.

Enablers

The ideal scenario would be to appoint six community development workers, one in each state, to promote the Australian Polio Register and liaise with relevant health professionals and key stakeholders, thereby capturing thousands of polio survivors yet to be registered.

Clinical Advisory Group

Limitations

Although this group is in place, it has been unable to become fully engaged due to a lack of resources, namely in the form of a Health Project Officer, to co-ordinate their efforts. As previously stated, lack of staff means that the dedicated time required to fully utilize the group is beyond current capacity.

Enablers

With the appropriate personnel employed, the Clinical Advisory Group would be engaged to develop a framework for informing a range of health professionals who will, in turn, go on to educate their polio patients in the comprehensive set of management strategies suitable for their complex condition. This intervention will assist in keeping people out of acute care facilities as a result of imprudent practices, thereby further reducing healthcare costs.

The LEOP: Introduction to Clinical Practice Resource Module

Limitations

Although it provides a thorough overview of the LEOP/PPS, the resource module does not provide in-depth detail on clinical recommendations for treatment in each of the specific areas relating to the symptoms of the LEOP/PPS. Without funding, it is also difficult to promote this resource effectively throughout the health sector—or provide printed copies, when requested.

Enablers

With the appropriate resources, every section of the module could be expanded to create a series of resource modules, thereby enabling greater clarity and knowledge for health professionals on how best to diagnose, treat and rehabilitate people with the LEOP/PPS. They could also be printed, promoted and distributed widely throughout the health sector.

No access to the NDIS

The Disability Sector

Disqualification from the National Disability Insurance Scheme: Most polio survivors will not be eligible for the National Disability Insurance Scheme (NDIS) due to the 65 year cut-off. By the time the national rollout happens in 2018, approximately 85% of Australia's polio survivors will be too old to apply.

The current financial impact of the LEO/PPS for the most part involves disability support such as home and personal care, mobility aids and other assistive devices, and ancillary costs such as home and vehicle modifications.

"The costs include assistive devices, braces, back braces, wheelchairs, scooters, CPAP [Constant Positive Airway Pressure] machines—you may need all of these things at the same time. People in our group, including me, have a number of different assistive devices. I walk with crutches and I have a brace. I have \$3,000 on my right leg. I also have a scooter, which was about \$3,000, and a wheelchair. I have all these different things to enable me to continue to do the things that I did before. I have a brace to enable me to swim in the water, which was \$1,500."

- Elizabeth Telford, Post-Polio Victoria
"Discussion Paper on the Late Effects of Polio/
Post-Polio Syndrome"



Dr Margaret Peel (left) and Elizabeth Telford at the Standing Committee on Health & Ageing Roundtable Forum

Disability Funding Barriers

Access to disability funding involves a number of barriers. Covering the costs of mobility aids and devices, and processes for accessing government funding to assist with these costs, can also add to delays in getting support needed by people with the LEO/PPS.

The following excerpts are from the "Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome":

"... it took me 10 months to obtain a new calliper and medical grade shoes when I first moved to Queensland. In those 10 months I was experiencing increasing pain ... I have another friend in Queensland with post-polio, and she has had to undertake the business of getting new callipers and medical grade shoes three times in the last 17 years. Each time it has taken her longer than one year to get them."

- Dr Margaret Peel, Polio Australia

"We have SWEP—the state-wide equipment program—in Victoria, which allows up to \$2,200 for devices. Most of the stories that I have are about people being on the waiting list in a public system because there is no ability or funds for it. People are often referred because [Polio Services Victoria] is a consultation service often referred to private orthotists. We can spend up to \$10,000 or \$15,000 in a year and get maximum \$2,200 back. The point I want to make about that is that it has a huge impact on us socially and emotionally and on our ability to connect and maintain a level of independence, which is what we are all trying to do".

- Elizabeth Telford, Post-Polio Victoria

Current funding sources

Polio Australia receives no funding from government sources

Key Contributors

(approx. \$265,000 from 2010-2014)

Balnaves Foundation

3 years funding for full-time National Program Manager (Jan 2011 to Dec 2013)

Jill Pickering

Personal donations towards the cost of operating expenses for 2010-2014

Dr John Tierney OAM

National Patrons Circle Donation and personal donations to support lobbying activities

Project Funding Grants

(\$170,500 from 2010-2013)

Fred P Archer Charitable Trust

Financial contributor to the 2010 operational costs

GlaxoSmithKline Australia

- Financial contributor to the 2010-13 Late Effects of Polio Self-Management Residential Programs (Polio Health and Wellness Retreats)
- Financial contributor towards Late Effects of Polio education events
- In-kind contribution to the 2011/12/13 Polio Awareness Month media campaigns
- In-kind contribution to the "Late Effects of Polio: Introduction to Clinical Practice" resource module launched in 2012

The Marian and EH Flack Trust

Financial contributor to the 2010/2012/2013 Late Effects of Polio Self-Management Residential Programs (Polio Health and Wellness Retreats)

Ian Potter Foundation

Financial contributor to the 2011 Late Effects of Polio Self-Management Residential Program (Polio Health and Wellness Retreat)

RE Ross Foundation

Financial contributor to the 2011 Late Effects of Polio Self-Management Residential Program (Polio Health and Wellness Retreat)

Mary Mackillop Foundation

Financial contributor to the 2012 AGM/ Strategic Planning Meeting

James N Kirby Foundation

Financial contributor to the distribution of the "Late Effects of Polio: Introduction to Clinical Practice" resource module launched in 2012

Fundraising Activities

(\$31,700 from 2010-2013)

2010-13 - Rotary International = \$2,800

2012 - Walk With Me = \$3,600

2012/3 - Patron's Circle = \$21,000

2013 - "Touched by Polio" Art Exhibition = \$4,300

General Donations

(approx. \$7,500 pa)

Membership

(\$600 pa)

Membership fees are paid annually by the six state-based polio networks on Polio Australia's Committee of Management

In Kind Support

Peter Roebuck (FCA)

Pro bono auditing of Polio Australia's accounts

Genuine Print

Pro bono production of business cards, brochures and posters

Rob Foster (UK) and Michael Simpson (USA)

Pro bono assistance with website in 2011 and 2012

What is needed

A better equipped organisation in the form of financial and human resources would not only allow Polio Australia to run its current programs more efficiently in regards to community/patient education, it would also facilitate the development of a raft of other innovative programs to ensure Australia's polio survivors are well supported.

Government funding is required to strengthen Polio Australia so that it has adequate resources with which to fully realise the Recommendations proposed in the *"Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome"*.

Future revenue plans

Polio Australia recognises dependency solely on federal funding is not sustainable and has planned a number of funding revenue wells to carry the service through its projected thirty year service requirement.

These include:

- Offering in-service training to a variety of medical and allied health professionals in the recognition and best practice treatment of people with the LEO/PPS by suitably qualified professionals, such as members of Polio Australia's Clinical Advisory Group.
- The establishment of a community investors' 'Patron's Circle'. This entails sourcing and approaching potential Patron's Circle members. Follow up will include bi-annual investors' networking/information luncheons. Currently, there are 4 members.
- Pursuing federal government funding for projects by identifying and applying for relevant Tenders and Grants via the Department of Health and Ageing (DoHA) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).
- Exploring a range of philanthropic and corporate funding opportunities by identifying and applying for all relevant philanthropic

grants via Philanthropy Australia and other sources. In addition, create a listing of potential corporate investors and distribute investment prospectuses.

- Raising revenue through an alliance with Rotary Clubs across Australia.
- Stimulating donations through various activities such as the annual "Walk With Me" day instigated by Ability First Australia, bequests, and periodical donation drives.

DoHA Flexible Funding

Polio Australia submitted two applications to the Department of Health and Ageing's newly released Flexible Funding in Dec 2011:

- **Chronic Disease Prevention and Service Improvement Fund** for *"The Prevention, Early Intervention and Management of the Late Effects of Polio"*; and the
- **Health System Capacity Development Fund** for *"The Late Effects of Polio Best Practice Clinical Recommendation Modules"*.

Neither application was successful and no further funding rounds are scheduled to date.

Funding outcomes

Dedicated Resources Enabling Polio Australia to Provide Adequate Services	Projected Outcomes for Australia's Polio Survivors
<ul style="list-style-type: none"> • Greater capacity to devise and drive new strategies to achieve the organisation's Vision and Mission • Greater capacity to develop and implement innovative projects to further the health and well-being of polio survivors • Capacity to work on collaborative projects with medical practitioners and the health sector to develop and produce best practice protocols, documentation and resources • Capacity to liaise with local community health service providers and negotiate polio-related in-service training • Capacity to identify opportunities with universities to stimulate research into areas such as: the burden of disease, statistics, the impact of polio on indigenous and linguistically diverse (CALD) communities, and managing the late effects of polio • Capacity to facilitate more state-based Late Effects of Polio Self-Management Residential Programs • Greater capacity to generate opportunities to raise awareness of the LEO/PPS, including Polio Awareness Month, throughout Australia • Capacity to organise and run community education sessions across Australia • Greater capacity for Polio Australia representation on various committees and at other professional meetings and events • Capacity to produce, print and distribute Polio Australia's publications and promotional material • Capacity to further develop and maintain Polio Australia's online presence including websites and social media • Greater capacity to source new funding and revenue opportunities for both operational and project-based activities 	<ul style="list-style-type: none"> • Polio survivors having access to appropriate health care and the support required to maintain independence and make informed lifestyle choices • Improved self-management and longer-term prognosis, and subsequent reduction in the need for acute care admission, further reducing costs to the health system • Enhanced engagement with health professionals resulting in wider acceptance of the LEO/PPS and improved diagnosis, treatment and management of the condition • Community health practitioners provided with specific treatment options and regimes resulting in informed and appropriate interventions • Research undertaken to identify the impact of polio on the community, incorporating the younger migrant polio survivors and the indigenous population, and the possible identification of new treatment options • Greater numbers of polio survivors, their families and carers having access to this intensive, comprehensive, and life-changing program • 'New' polio survivors identified, added to statistics, and provided with vital information regarding self-management and local services • 'New' polio survivors identified and linked in with state Polio Networks and support groups • The issues being faced by Australia's polio survivors being expressed in a range of forums providing acknowledgement and validation of their condition and a vehicle to voice concerns • The 50% of Australia's ageing polio survivors who don't have access to email or the internet are provided with vital information • The 50% of polio survivors who do access information electronically, as well as international researchers, are regularly updated • Continually evolving and improved services and reduced reliance on government funding

Four year budget

EXPENSES	YEAR 1	YEAR 2	YEAR 3	YEAR 4
Existing programs enhancement	\$157,187	\$155,226	\$159,845	\$164,415
New programs development	\$40,000	\$42,000	\$44,100	\$46,305
Consumer health projects	\$79,337	\$83,628	\$88,225	\$93,018
Health professionals projects	\$50,910	\$53,701	\$56,693	\$59,817
Community development projects	\$225,960	\$233,253	\$242,309	\$251,271
Awareness raising projects	\$61,837	\$64,378	\$107,050	\$113,726
Online information projects	\$112,000	\$37,200	\$40,920	\$45,012
Travel and communications	\$29,184	\$32,103	\$35,313	\$38,843
Insurances, accounting, audit, reporting	\$15,022	\$16,015	\$17,090	\$18,240
Year 1 setup costs	\$32,226			
SUB-TOTAL	\$803,663	\$717,504	\$791,545	\$830,647
	\$80,366	Plus 10% GST \$71,750	\$79,155	\$83,065
TOTAL PROGRAM COSTS	\$884,029	\$789,254	\$870,700	\$913,712

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Poliomyelitis

What is polio?

Polio (poliomyelitis) is a highly infectious disease caused by a virus. It invades the nervous system and can cause irreversible paralysis in a matter of hours. Polio can strike at any age, but it mainly affects children under five years old.

Polio is spread through person-to-person contact. When a child is infected with wild poliovirus, the virus enters the body through the mouth and multiplies in the intestine. It is then shed into the environment through the faeces where it can spread rapidly through a community, especially in situations of poor hygiene and sanitation.

Most infected people (90%) have no symptoms or very mild symptoms and usually go unrecognized. In others, initial symptoms include fever, fatigue, headache, vomiting, stiffness in the neck and pain in the limbs.

One in 200 infections leads to irreversible paralysis, usually in the legs. This is caused by the virus entering the blood stream and invading the central nervous system. As it multiplies, the virus destroys the nerve cells that activate muscles. The affected muscles

are no longer functional and the limb becomes floppy and lifeless – a condition known as acute flaccid paralysis (AFP). Paralysis occurs when 50% or more of the nerve cells are killed off or damaged.

Source: www.polioeradication.org

Eradication of polio

Major polio epidemics occurred in Australia throughout the last century, with 40,000 cases of paralytic polio recorded between the 1930s and 1960s.

With the introduction of effective vaccines in the 1950s (Salk) and 1960s (Sabin), together with a comprehensive immunisation program, Australia was declared polio free by the World Health Organisation (WHO) Western Pacific Region in 2000.

Polio, remains endemic in 3 countries (Nigeria, Pakistan and Afghanistan) where international efforts have not yet achieved the total eradication of the virus. However, countries which have stopped transmission of indigenous wild poliovirus can be affected by importations of the virus at any time.



The Late Effects of Polio / Post-Polio Syndrome

Australia's Polio Survivors

Although Australia is now free of new cases of polio, years after contracting the infection, increasing numbers of polio survivors have developed a range of new symptoms classified as post-polio sequelae. The post-polio sequelae cause a range of potentially debilitating health effects, manifesting primarily as biomechanical and/or neurological symptoms. The condition is referred to broadly as the late effects of polio (LEoP) or where specific clinical diagnostic criteria are satisfied, as post-polio syndrome (PPS).

The symptoms experienced by those with the LEoP, which are primarily biomechanical, vary considerably both in range and severity. The added neurological symptoms of PPS provide further health concerns. The symptoms experienced by those suffering from the LEoP/PPS commonly include:

- chronic fatigue;
- pain in muscles and/or joints;
- muscle weakness and atrophy;
- muscle spasms/twitching;
- respiratory and sleep problems;
- difficulties with swallowing and speaking;
- cold and heat intolerance.

Although there is no accurate data on the actual number of people experiencing the LEoP/PPS in Australia, it is estimated that hundreds of thousands of individuals are either affected or at risk of developing the condition.

These numbers are extrapolated from WHO's data that only one in every 200 cases of polio infection leads to paralysis due to 50% damage to the motor neurons – although everyone infected had some level of nerve damage, which may manifest as the LEoP/PPS in later life.

An ageing population

Most of those affected by LEoP/PPS are over 50 years of age, reflecting the fact that polio was an uncommon infection in Australia by the early 1960s.

However, migrants to Australia from countries where polio was eradicated more recently means that there is also a cohort of younger polio survivors. This younger group of polio survivors means that LEoP/PPS is a condition that needs to be addressed now and for many years to come in Australia.



The impact of the LEO/PPS

What is the impact on the Survivor, the Community, the Health Sector, and the Disability Sector?

The Survivor

There are a number of problems arising due to the current lack of support for polio survivors experiencing the LEO/PPS. These include:

- misdiagnosis;
- awareness of their own condition;
- the exacerbation of motor neuron damage;
- the high incidence of falls;
- co-morbidities;
- cost of disability;
- lack of family/community support; and
- mental health problems associated with loss of independence.

"There is also a lack of community awareness and that includes polio survivors. I did not know what was going on with me. We do not turn up to the GP and say, 'We are having post-polio problems.' It was not what I was thinking."

– Elizabeth Telford, Post-Polio Victoria
"Discussion Paper on the Late Effects of Polio/ Post-Polio Syndrome"

"... everybody is used to dad or mum being able to operate at a certain level and now dad or mum cannot operate at that level anymore. It can really affect relationships. It obviously can affect your independence and your self-esteem."

"It is not only the polio survivors but the carers and the families—the whole range of people involved—who need to be supported. If you do not manage your post-polio properly, you put excess strain on your family relationships and on the people who are helping you. We are ageing, and our carers are ageing as well."

– Gillian Thomas, Polio Australia
"Discussion Paper on the Late Effects of Polio/ Post-Polio Syndrome"

The Community

Polio continues to influence the community often to the detriment of health resources and human rights. This influence crosses boundaries into the lives of individuals and health professionals. However, the following factors may be considered community specific. They are the need for:

- continued immunisation;
- inclusion;
- community awareness; and
- migrant support.

Polio Australia knows of one Melbourne-based orthotist who specialises in making orthotics for polio survivors who has more than 150 polio customers aged 30 years or younger. This is just one orthotist in one state of Australia.

The Health Sector

The current health status in terms of care and support for polio survivors may be considered dire. Polio survivors often encounter malpractice, negligence, and ignorance from their health practitioners, possibly resulting in serious injury or even death. There is an urgent need for:

- specialised health practices;
- empowerment for polio survivors to self-manage;
- focus on a multi-disciplinary approach;
- awareness raising of the LEO/PPS in Australia;
- a focus on undergraduate training;
- ongoing training for health professionals;
- education in the health sector; and
- specialised post-operational procedures and protocols for polio survivors requiring acute care.

"I still hear reports from patients who come to see our service who say, 'My GP just does not believe me. My GP does not believe in post-polio syndrome.' I could understand that if it was a contentious diagnosis but I cannot say that it is. It has been established for a very long time."

– Blaise Doran, Coordinator, Polio Services
 Victoria

"Discussion Paper on the Late Effects of Polio/ Post-Polio Syndrome"

House of Representatives Standing Committee on Health and Ageing Roundtable - 30 March 2012

Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome (excerpt)

House of Representatives Standing Committee on Health and Ageing

"The Health and Ageing Committee, which I Chair, expressed interest in learning more about LEOP/PPS and its impact on polio survivors, their families and carers. Accordingly, on 30 March 2012 the Committee held a roundtable discussion in Melbourne. Participants at the roundtable included representatives of Polio Australia and associated state-based post-polio networks, which between them provide support and advocacy for Australia's polio survivors. A number of roundtable participants identified themselves as polio survivors directly affected by LEOP/PPS. The roundtable also included representation from health professionals involved with the treatment and clinical management

of LEOP/PPS, as well as a representative of the Australian Government Department of Health and Ageing. The roundtable discussions have formed the basis of the Committee's discussion paper, which I trust adequately reflects the range and scope of issues considered.

On behalf of the Committee I wish to thank all of the roundtable participants. The commitment of participants to providing support and advocacy for polio survivors was evident. In particular the Committee appreciates the contribution made by those directly affected by LEOP/PPS. Despite struggling by the end of the day with LEOP/PPS associated fatigue, the knowledge and experience of this group of individuals provided the Committee with invaluable insights. The Committee also acknowledges and thanks the observers who attended the day's proceedings, including polio survivors, their family members and carers."



**Steve Georganas MP
Chair**

"It was evident to the Committee that Polio Australia and the state-based polio networks are a cohesive and unified group dedicated to improving the lives of polio survivors, their families and carers."

The House of Representatives Standing Committee on Health and Ageing:

(l-r) The Hon Steve Irons MP – Deputy Chair, House of Representatives Standing Committee on Health and Ageing;
The Hon Steve Georganas MP - Chair, House of Representatives Standing Committee on Health and Ageing;
Dr Alison Clegg – Secretary, House of Representatives Standing Committee on Health and Ageing;
The Hon Mark Coulton MP – Member, House of Representatives Standing Committee on Health and Ageing;
The Hon Jill Hall MP – Member, House of Representatives Standing Committee on Health and Ageing

House of Representatives Standing Committee on Health and Ageing Recommendations

Three recommendations were proposed by the House of Representatives Standing Committee on Health and Ageing which were highlighted in the resulting "Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome":

Recommendation 1

The Committee recommends that the Australian Bureau of Statistics and/or the Australian Institute of Health and Welfare establish mechanisms through inclusion of appropriate questions in existing health and/or disability surveys to estimate and report on the size of the population of polio survivors living in Australia, and the proportion of that population experiencing the late effects of polio/post-polio syndrome.

Recommendation 2

The Committee recommends that the relevant National Boards, in consultation with key stakeholders including peak professional bodies, medical/health educators and training providers, seek to ensure curricula for students includes information on the late effects of polio/post-polio syndrome, to raise awareness of the condition as a possible diagnostic outcome and of best practice for treatment and management.

Recommendation 3

The Committee recommends that Medicare Locals actively engage with Polio Australia and the state-based post-polio associations, with state and territory government departments of health, and with general practitioners to promote activities which will raise awareness of the late effects of polio/post-polio syndrome: among practicing health professionals through continuing professional development; and in the community through patient education, noting the need to tailor communication to enhance engagement with specific population groups taking into account demographic factors such as age and cultural background.

The federal government has taken no action to progress these Recommendations in the 12 months since the Report was released.

Polio Australia is the only organisation with the expertise, programs and strategies to realise these recommendations but must be adequately resourced to do so.



(l-r) Gillian Thomas-then President, Polio Australia, Maryann Liethof-National Program Manager, Blaise Doran-Coordinator, Polio Services Victoria

Polio Australia's Response

Polio Australia already has the expertise, programs and strategies to fulfill these Recommendations.

However, what Polio Australia lacks are the necessary resources to realise the Recommendations at the level required to adequately benefit the population experiencing the LEOp/PPS.

Only a commitment of government funding will enable these Recommendations to be realised.

Our Committee of Management



John Tierney NSW
President



Gillian Thomas NSW
Vice President



Brett Howard SA
Treasurer



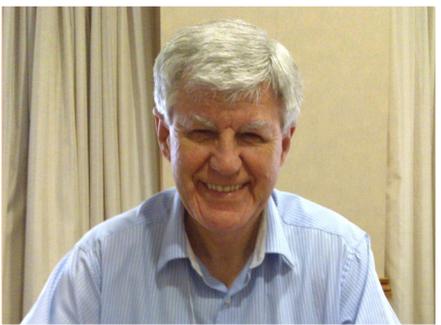
Jenny Jones WA
Secretary



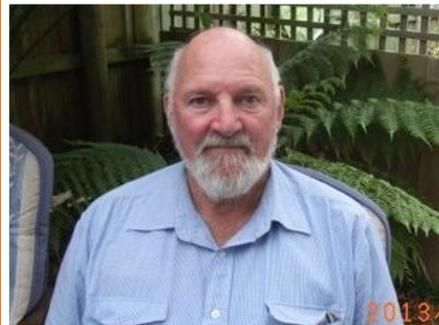
Arthur Dobson TAS



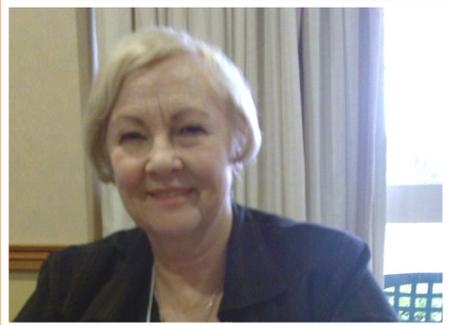
Tessa Jupp WA



John Mayo QLD



Gordon McKinnon VIC



Margaret Peel QLD



Jen Sykes VIC



Billie Thow TAS



Peter Wierenga SA

Our paid staff

National Program Manager



Mary-ann Liethof
(Kew, Victoria Office)

Following a small philanthropic grant and a private donation, Mary-ann was officially appointed as Polio Australia's National Program Manager in early January 2010 on a part time basis, increasing her hours to full time in 2011 following a second grant - **which runs out at the end of 2013.**

As the only paid employee, Mary-ann has been fully responsible for practically all aspects of devising and implementing Polio Australia's Programs strategies including: liaising with a range of health professionals, community consultation and advocacy, health promotion, media and public relations, research, producing and disseminating newsletters and reports, government lobbying, campaign management, public presentations, and organising Retreats.

Mary-ann's qualifications include a Diploma in Community Development as well as a Graduate Diploma in Education (Careers). She has worked in the community sector for more than 25 years in various positions including counselling, training, coordinating volunteers, conference co-ordination, health promotion, community education, and liaising between community members and GP's for a Division of General Practice.

Mary-ann worked as the Coordinator of Polio Network Victoria from mid 2004 to December 2009. During that time, she produced a DVD titled "*Post Polio Syndrome: The Australian Experience*" and was one of the Victorian representatives on the Management Committee for Polio Australia.

In April/May 2008, Mary-ann visited 10 post-polio related services across North America on a Churchill Fellowship Study Tour, "*To identify techniques to better manage the late effects of polio*".

On her return, Mary-ann produced a Report and series of videoed interviews titled "*Post Polio Syndrome: Shades of Grey*". Both were distributed widely to polio networks and support groups both nationally and internationally, and are available on-line on Polio Australia's website.

In April 2009, Mary-ann travelled to Roosevelt Warm Springs in Georgia, USA for Post-Polio Health International's 10th International Conference "*Living with Polio in the 21st Century*" and four day Wellness Retreat to learn the benefits of this self-management model. With this knowledge, she facilitated Australia's first Late Effects of Polio Self-Management Residential Program (also known as the Polio Health & Wellness Retreat) for 60 polio survivors and their family/carers in April 2010 in New South Wales, followed by 3 subsequent Retreats in Victoria (2011), Queensland (2012) and South Australia (2013).

In August/September 2011, Mary-ann attended the "*European Polio Conference: Post Polio Syndrome – a challenge of today*" in Copenhagen where she gave an oral presentation on the benefits of Polio Australia's Late Effects of Polio Self-Management Residential Program.

Administrative Assistant/Bookkeeper



Shylie Little
(Parramatta, Polio NSW Office)

Shylie worked as a volunteer with Polio Australia for two years, two days a week. She is soon to be employed one day a week to assist with banking, scheduling payments, bookkeeping, and a myriad of administrative tasks. Her salary is **funded through donations from July 2013 to June 2014.**

Our volunteers

From time to time, Polio Australia co-opts volunteers with particular expertise for special projects.

Business 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 has also volunteered at Polio NSW for 25 years, and was elected the Network's President in 1997, a position she still holds. Gillian was Editor of the Network's quarterly newsletter *Network News* from 1989 to 2012.

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. At the 2012 Annual General Meeting, having served two consecutive terms as President and being constitutionally ineligible to re-stand at that time for this position, she was elected as Vice President.

Lobbyist



Dr John Tierney OAM

Dr John Tierney OAM 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 LEOP. John has done this in his capacity as a pro bono government relations consultant to Polio Australia.

Previously John gave 14 years of distinguished service to the Australian Parliament, where he served as Senator for NSW. In the parliament, as a polio survivor, he took a passionate interest in the area of disability. John was a special parliamentary adviser to the Minister for Community Services on disability matters. Prior to entering Parliament, John was a Senior Lecturer in Education at the University of Newcastle until 1991.

Thanks to John, Polio Australia has made substantial progress in making the government and the parliament aware of the late effects of polio, although we still haven't received any dedicated funding. John's commitment is to continue lobbying until we do!

Administration



Jill Pickering

(Kew, Victoria Office)

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.



Brian O'Reilly

(Kew, Victoria Office)

Brian began volunteering one day a week in May 2013, and assists with the preparation of funding applications.

Brian has worked and studied in the public, private, health, and education sectors, and is currently studying Health Promotion.