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POLIO AUSTRALIA INCORPORATED

Representing polio survivors throughout Australia

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WE'RE STILL HERE!

On 30 March 2012 representatives from Polio Australia and State Polio Networks participated in a Roundtable Forum on the Late Effects of Polio / Post-Polio Syndrome conducted by the Federal House of Representatives Standing Committee on Health and Ageing. The representatives presented cogent arguments on the urgent need for comprehensive, consistent, adequately funded health, disability and peer support services for **all** Australian polio survivors.

On 4 July 2012 the Committee tabled a Discussion Paper resulting from the evidence taken during the Roundtable Forum. Publicity following the release of the Discussion Paper led the Australian Medical Association to report "**Polio survivors going undiagnosed**" in an Australian Medicine Online article on 16 July 2012 - this acknowledgement was a significant breakthrough for Australia's polio survivors.

As noted by the Committee in their Discussion Paper:

As already acknowledged, the impact of LEOP/PPS is significant, not only for sufferers but also for their families and carers. The peer support and advocacy provided by Polio Australia and the state-based polio networks assists those affected by LEOP/PPS by providing access to information and advice, and also importantly by providing social and emotional supports.

The Committee was impressed by the commitment and passion of roundtable participants and their supporters, some of whom came to observe the day's proceedings. 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.

In its comprehensive Report the Committee recognised the urgent need for Polio Australia to receive funding for its work:

The Committee notes the potential for awareness raising activities, and professional capacity building activities to be supported under DoHA's Chronic Disease Prevention and Service Improvement Flexible Fund. Therefore, the Committee encourages Polio Australia, either in its own right as an incorporated entity or in partnership, to investigate options of applying for funding under this initiative to promote awareness of LEOP/PPS.

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DoHA's Chronic Disease Prevention and Service Improvement Flexible Fund may provide support to extend Polio Australia's peer support activities and the Committee encourages Polio Australia to investigate options of applying for funding under this initiative.

Invitations for the Flexible Funds were opened in November 2011, with submissions due by 24 December 2011. Even before the Committee's advice was known, Polio Australia had submitted two applications to the Department of Health and Ageing (DoHA) - one each for the Chronic Disease Prevention and Service Improvement Fund ("*The Prevention, Early Intervention and Management of the Late Effects of Polio*") and the Health System Capacity Development Fund ("*The Late Effects of Polio Best Practice Clinical Recommendation Modules*").

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In May 2012, Polio Australia was advised that neither of these Flexible Fund applications was successful which was an extremely disappointing result. **Yet again Australia's polio survivors miss out on government support and services.** Brief written feedback on the applications has been received and Polio Australia will be holding further discussions with the Department of Health and Ageing as a matter of urgency. In the meantime, Polio Australia struggles on and does what it can with only one philanthropically-funded staff member and polio-survivor volunteers.

Clearly, to date the efforts of Polio Australia and its member State Polio Networks to obtain government funding for our work in support of Australia's hundreds of thousands of polio survivors, their families, and the health professionals who care for them, is not deemed sufficient. The fight must continue, even though polio survivors grow weary of the battle after many have spent well over 20 years at the front.

The Committee concluded its Discussion Paper with the following:

To support its aim of raising the profile of LEOP/PPS further, the Committee undertook to produce this discussion paper for presentation in Parliament and to the Minister for Health for consideration. Importantly, this discussion paper not only outlines the key issues raised during discussion, but at various points the Committee has clearly expressed its views in Committee comment. However, and while acknowledging the limits of inquiry conducted by a single roundtable, on further consideration the Committee concluded that some key issues warrant specific recommendation. In particular, the Committee considered recommendations should address the need to determine the potential size of the population at risk of developing LEOP/PPS and options for raising awareness.

These are the three recommendations made by the Committee:

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.

I am one of Australia's hundreds of thousands of polio survivors who needs access to polio-specific services. I want to see not only the above recommendations turned into action, but also the work being done on my behalf by my state and national polio support networks receive long-overdue funding. Show your support for the post polio community by taking this to your Party Room or Caucus for discussion.

We are still here - and we still have a lot of fight in us yet!

POLIO AUSTRALIA

Background, Achievements, Key Projects and Finances

Background

Polio Australia was incorporated in 2008 as the peak, national organisation representing and advocating for polio survivors in Australia, and opened an office in Melbourne in January 2010.

Polio Australia's members are the six state-based Polio Networks, and its Management Committee is made up of two representatives from each member.

As the majority of Polio Australia's member Polio Networks are volunteer organisations, in the main entirely self-funded, their capacity to pay Membership Fees is very limited. The annual subscription is therefore pegged at \$100 per member.

Overview of Achievements

Polio Australia's achievements since the office was opened in January 2010 include:

- Lobbying of the Federal Government for polio-specific services, achieving a House of Representatives *Standing Committee on Health and Ageing Roundtable Discussion* in March 2012, and a resulting *Discussion Paper On the Late Effects of Polio/Post-Polio Syndrome*.
- Organising and running a highly successful *Polio Health and Wellness Chronic Condition Self-Management Residential* program in New South Wales (2010), Victoria (2011), Queensland (2012), with South Australia (2013) currently under preparation.
- Developing and launching Polio Australia's fact-filled website.
- Launching the *Australian Polio Register* to capture important data about our polio community.
- Running annual Polio Awareness Campaigns each October.
- Producing and widely distributing Polio Australia's monthly e-Bulletin *Reflections* and quarterly electronic Newsletter *Polio Oz News*.
- Establishing a Clinical Advisory Group to advise on the development of Clinical Practice Recommendations for the diagnosis and management of the Late Effects of Polio.
- Attending and presenting at the 2011 European Post-Polio Conference in Copenhagen, Denmark.
- Keeping up to date with international developments in the management of the Late Effects of Polio and reporting to stakeholders through the Polio Australia website and publications.

Federal Government funding is URGENTLY required to ensure Polio Australia's work can continue with sufficient resources to do it justice.



Overview of Key Projects

- Website:** Polio Australia's website is solely managed by polio survivor, volunteer, and President, Gillian Thomas. This includes administration of the **Australian Polio Register**.
- Residentials:** Annual best-practice **Polio Health and Wellness Self-Management**.
- Publications:** **Reflections** and **Polio Oz News** are produced by the National Program Manager and are only available electronically. We appreciate that there are many polio survivors who are not on-line but we have no staff or funds for printing, collating or posting. Nevertheless, these publications are currently emailed to nearly 2,000 people in Australia and overseas.
- Resources:** Polio Australia commissioned an on-line resource for health professionals called **Late Effects of Polio: Clinical Practice Introduction** which was professionally written and reviewed by entirely volunteer labour. This initial module will be promoted to a range of health service providers following its launch on Wednesday 31st October 2012. Although Polio Australia applied to numerous sources, including the Federal Government, to fund this and other related resources, we have been unable to secure any funding to date.
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Overview of Finances

- Staff:** Polio Australia has a three-year grant from The Balnaves Foundation which funds the National Program Manager's salary. The National Program Manager is Polio Australia's **only paid staff member**. This grant concludes in 2013.
- Office:** Polio survivor and volunteer administration worker, Jill Pickering, provides an annual donation which funds the rental of Polio Australia's small one-room office.
- Projects:** Polio Australia applies to numerous philanthropic organisations for each individual planned 'project' such as the annual Polio Health and Wellness Residentials. Although Philanthropic Trusts rarely contribute towards 'operational' funding such applications as are possible are also submitted.
- Donations:** Polio Australia is a Health Promotion Charity with DGR status so all donations over \$2 are tax deductible. We welcome any donations – no matter how big or small – to help build our reserves to pay for operational expenses such as staff, promotional material, travel reimbursement, and program costs. With little ability to run large fund-raising campaigns, total donations to date have been minimal.
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Despite Polio Australia's extremely limited financing to date, we have been able to achieve an impressive amount with only one paid staff member and a small number of volunteers.

However, after 2013, there is currently no guaranteed funding for the employment of the National Program Manager, let alone any other staff, or for operational expenses. It is clear that Polio Australia is doing vitally important work as it strives to standardise quality information and service provision across Australia to ensure that polio survivors have access to appropriate health care and the support required to maintain independence.

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