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The Parliament of the Commonwealth of Australia

# Discussion paper on the late effects of polio/post-polio syndrome

House of Representatives  
Standing Committee on Health and Ageing

June 2012  
Canberra

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*Extracts from*  
**House of Representatives Standing Committee on Health and Ageing**  
***Discussion paper on the late effects of polio / post-polio syndrome***

***Raising awareness and education – Committee comment***

**2.87** The importance of raising awareness of LEOP/PPS was raised frequently during discussion. As outlined above, raising awareness amongst clinicians and allied health professionals is critically important to ensure timely diagnosis and treatment that is based on best practice. ... the Committee believes that more should be done to ensure that curricula for medical students, and for other relevant health professionals, include information on LEOP/PPS as a possible diagnosis and on best practice treatment and management.

**2.88** ... the Committee commends the work of Polio Australia's Clinical Advisory Group which has been tasked to produce standardised, quality information on LEOP/PPS to inform health professionals, as well the wider community. **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.**

**2.89** While some state government health departments already have web-based resources which provide information on LEOP/PPS, the Committee notes that there is no information available on the DoHA website. The Committee considers that DoHA should take action to address this deficiency by providing a nationally co-ordinated web-based repository of information on LEOP/PPS.

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***Peer support and advocacy***

**2.130** Frequently during discussion, participants emphasised the importance of peer support for people with LEOP/PPS, as well as for their families and carers. Participants explained how many polio survivors, and families and carers benefited by being connected with others in similar situations, sharing experiences and information. **Polio Australia, the national peak body established in 2008 through collaboration of existing state post-polio networks, is the principle provider of peer support. Polio Australia assists polio survivors, and their families and carers, through nationally-focussed advocacy, the provision and dissemination of information and support for educational and networking activities to improve health and well-being. The state post-polio networks also continue to play a vital support role at local level.**

**2.132** Since 2010, Polio Australia has also offered an annual self-management residential to assist people with LEOP/PPS and their families and carers. According to Ms Thomas, the aim of the residential is to help sufferers and their families to take a holistic approach to managing LEOP/PPS by focusing on body, mind and spirit.

**2.133** Although a small amount of funding has been available from state and territory governments to fund programs provided by some of the state-based post-polio networks, participants noted that **by and large the supports provided by Polio Australia and the state-based post-polio networks are funded by philanthropic donations. Polio Australia and the state-based networks are also heavily reliant on the contribution of the volunteer labour of their members and others to support their activities.**

#### ***Peer support and advocacy – Committee comment***

**2.134** 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.**

**2.135** 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.** As noted elsewhere in this discussion paper, **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.**

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#### ***Research – Committee comment***

**2.144** ... The Committee suggests that Polio Australia, through its Clinical Advisory Group, seek to engage with the research community to encourage those with relevant expertise to seek NHMRC funding (or alternative funding available, for example through DoHA's Chronic Disease Prevention and Service Improvement Flexible Fund or from philanthropic sources) to support research into LEOP/PPS.

***Recommendations contained in***  
**House of Representatives Standing Committee on Health and Ageing**  
***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.