



Polio Australia Incorporated

Representing polio survivors throughout Australia

www.polioaustralia.org.au



Reflections

*"We're Still Here!" Campaign Summary
November 2012*



The **"We're Still Here!"** campaigners definitely made their presence felt at Parliament House on Wednesday 31st October 2012, and succeeded in raising overall awareness of the needs of Australia's polio survivors with their respective Members of Parliament (MPs). Heartfelt thanks go to all these **self-funded** Campaign Heroes, their supporters, and well wishers who made the **"We're Still Here!"** Campaign the success that it was. This is a summary of the day and where-to-from-here.

The Campaign Heroes

On Wednesday 31st October 2012, 60 polio survivors and their supporters from around Australia self-funded their attendance at the **"We're Still Here!"** Campaign at Parliament House in Canberra, organised by Polio Australia. These campaigners comprised: 35 polio survivors, 14 partners, and 11 friends or family members. They represented the following states:

26 – New South Wales (NSW)	4 – Queensland (Qld)
15 – Victoria (Vic)	3 – South Australia (SA)
9 – Australian Capital Territory (ACT)	3 – Western Australia (WA)

On arrival, each campaigner was provided with a **"We're Still Here!"** T-shirt, a Polio Australia badge and orange ribbon, a pen, and a handout kit to give to their MP. Group photos were taken in the reception hall at Parliament House (*above*). A short video of Polio Australia's President, Gillian Thomas, can be viewed [here](#) and more photos and videos will be uploaded on to Polio Australia's website soon.

Messages of Support

Polio Australia set up a dedicated webpage for the [Campaign Heroes](#) and [Messages of Support](#). As at the 31st October, 31 messages of support were received – with a number of later messages still to be uploaded. It is obvious from the sample messages below that the **"We're Still Here!"** Campaign not only resonated with the post-polio community, but also their families and public supporters:

- **To the Polio Australia Team and all Campaign Heroes**
Congratulations to all who will be in Canberra on the 31st! As a survivor of polio since the age of 18 months and now suffering the late effects of polio - my spirit, heart and soul will be with you as you support all of us in the same situation. I have always believed that "together we can all make a difference in this world!"

- [To the Polio Australia Team](#)
I fully support the sufferers of polio in their efforts to highlight the lack of support they receive in trying to cope with their disabilities. Many of the "polio era" are now reaching their elder years. This presents two major problems. Not only are they trying to cope with the natural aging process but the degenerative effect of their earlier polio infection is now becoming apparent. Their lifestyle is now manifestly inferior to their peers. These people deserve a special effort from us to help them. In most cases they have coped with their disability during their life but now at a tender age, their burden is nearly too great to bear. Please raise the awareness of this problem.
- [To Margaret Maroney](#)
Dear Mum, We have all been aware of the effects polio has on your body and yet you never complain. Your fighting spirit is to be admired and for that we are all lucky and grateful you survived such a horrible thing so you could be our wonderful mother.
- [To the Polio Australia Team and all Campaign Heroes](#)
I really hope all goes well in Canberra on the 31st. I was born in September 1949 in Kent, England. I was only three weeks old when I got polio. I have lived in Perth WA for 31 years. Late effects of polio has really taken its toll on me. My muscles are very weak now, I live with pain every day and have to use a roller walker. Good luck for the 31st. I will be thinking of you on this day.

Publicity

We were fortunate to have the volunteer assistance of a 4th year Bachelor of Business (Marketing) student from Monash University, Denton Trieu, to prepare, distribute and follow up Media Alerts profiling various Campaign Heroes. Denton was recruited and mentored by GlaxoSmithKline's Manager Corporate Affairs and Patient Advocacy. This activity resulted in 3 radio interviews with; ABC Riverina, ABC Perth Breakfast, and RPH Adelaide, and articles appearing in 8 local newspapers:

[ABC Online News](#) (NSW)
[Brimbank Leader](#) (Vic)
[MPNews](#) (Vic)
[Mudgee Guardian](#) (NSW)

[Southern Courier](#) (NSW)
[The Chronicle](#) (ACT)
[The Coffs Coast Advocate](#) (NSW)
[Wentworth Courier](#) (NSW)

Follow up articles (*not online*) appeared in 2 local newspapers; the Mudgee Guardian (NSW), and the Frankston Times (Vic).

One of the campaigners also uploaded information about the day on her blog [here](#). However, despite 2 Media Alerts being sent to a wide range of state and national media outlets, there was no media representation on the day to interview the campaigners or photograph history in the making.

Denton was also responsible for social media activity on Polio Australia's [Facebook](#) page and [Twitter](#) account, as well as instigating and tracking the online Petition (*more details follow*).

The [Australian Polio Register](#) was given a substantial boost during September and October following an article which appeared in the nationally distributed "The Senior" newspaper (*unsolicited but much welcomed*), titled "Polio back to bite its victims: Better health training essential". Polio Australia received an additional 300+ registrations which confirms that there are untold numbers of polio survivors who have been unaware of their condition and are now keenly seeking information and support.

Launch of a New Resource



The Hon Catherine King MP and Gillian Thomas, President, Polio Australia

Morning Tea at Parliament House (*courtesy of Dr John Tierney, Polio Australia's National Patron*) was also the occasion for the Hon Catherine King MP, Parliamentary Secretary for Health and Ageing (*and one of Polio Australia's 4 Parliamentary Patrons*) to launch Polio Australia's new online resource Module "[The Late Effects of Polio: Introduction to Clinical Practice](#)". Campaigners also met and mingled briefly with Members and Senators who accepted an invitation to attend the Launch, including:

- | | |
|------------------------------------|-----------------------------------|
| • Senator Sue Boyce (Qld/Lib) | • Nola Marino MP (WA/Lib) |
| • Senator Carol Brown (Tas/ALP) | • Senator Claire Moore (Qld/ALP) |
| • Mark Coulton MP (NSW/Nat)* | • Graham Perrett MP (Qld/ALP) |
| • Jill Hall MP (NSW/ALP)* | • Senator Lisa Singh (Tas/ALP) |
| • Greg Hunt MP (Vic/Lib)* | • Senator Anne Urquhart (Tas/ALP) |
| • Senator Gary Humphries (ACT/Lib) | * <i>Parliamentary Patrons</i> |

Online Petition

Another strategy of the "We're Still Here!" Campaign related to an [online Petition](#) addressed to the Hon Tanya Plibersek, Minister for Health and Ageing, highlighting the urgent need for Federal funding to provide support and specific health services for Australia's polio survivors.

By October 29, the Petition had been signed by 1,416 supporters and has since increased to over 1,500. In the Minister's absence, the Petition was presented to the Hon Catherine King MP, to hand over to the Hon Tanya Plibersek MP. Senator Claire Moore, a valued and long-time Parliamentary Friend of Polio Survivors, offered to present the Petition in the Senate.

Paying Homage

During the launch proceedings, short speeches were also made by Gillian Thomas, President of Polio Australia, Dr John Tierney, and the Hon Greg Hunt, a strong supporter and Parliamentary Patron of Polio Australia. All spoke about the tenacity of polio survivors and their propensity to get on with their lives without complaint – until now. The Late Effects of Polio were acknowledged as affecting many people in significant and life-changing ways.

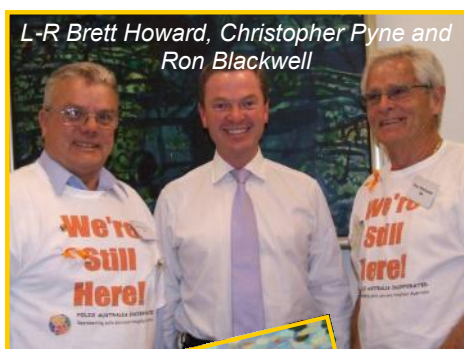
Although the "The Late Effects of Polio: Introduction to Clinical Practice" (which was produced by GlaxoSmithKline's Vaccines Medical Department as a volunteer project because Polio Australia was unable to secure sufficient funding for it) will go some way towards introducing many health professionals to the complex symptoms of polio's late effects, it is not a substitute for adequate and appropriate health and support services for Australia's polio survivors. This level of support requires Federal funding.

We were also very pleased to receive a [Media Release](#) issued from the Hon Catherine King's office (via the Department of Health and Ageing's Ministerial and Departmental Media Releases), reporting on the launch of the online resource Module.

Delivering the Message

Either prior to arriving, or whilst in Canberra, the "We're Still Here!" campaigners set up meeting times with their local Members of Parliament, being:

- Adam Bandt MP (Vic/Greens)
- Bruce Billson MP (Vic/Lib)
- Russell Broadbent MP (Vic/Lib)
- John Cobb MP (NSW/Lib)
- Mark Coulton MP (NSW/Nat)
- Peter Dutton MP (Qld/Lib)
- Joel Fitzgibbon MP (NSW/ALP)
- Josh Frydenberg MP (Vic/Lib)
- Barry Haase MP (WA/Lib)
- Luke Hartsuyker MP (NSW/Nat)
- Greg Hunt MP (Vic/Lib)
- Ed Husic MP (NSW/ALP)
- Sussan Ley MP (NSW/Lib)
- Russell Matheson MP (NSW/Lib)
- Michael McCormack MP (NSW/Nat)
- Scott Morrison MP (NSW/Lib)
- Judi Moylan MP (WA/Lib)
- Shayne Neumann MP (Qld/ALP)
- Julie Owens MP (NSW/ALP)
- Christopher Pyne MP (SA/Lib)
- Michelle Rowland MP (NSW/ALP)
- Philip Ruddock MP (NSW/Lib)
- Alex Somlyay MP (Qld/Lib)
- Kelvin Thomson (Vic/ALP)



Lunch, Question Time and Beyond

The Hon Mark Coulton MP (*a Parliamentary Patron*) joined the campaigners at a buffet lunch in the Members and Guests Dining Room, which was provided courtesy of Polio Australia as a thank you to everyone who attended. This was made possible thanks to the funds raised by Dr John Tierney and Fran Henke from their participation in Polio Australia's "[Walk With Me](#)" activity in September.

After lunch, the campaigners sat in on Question Time and were acknowledged by the Speaker as [distinguished visitors](#) (*Page No. 50 of Hansard-bottom right*), which elicited a cheer that almost had the delegation ejected from the gallery. (*There are strict rules of behaviour for people in the public gallery.*) Apparently there was some footage of this shown on ABC Canberra News as part of their scheduled Question Time program but we have been unable to locate a copy of this.

After Question Time, many campaigners took a tour of Parliament House before departing for the day. One third of the campaigners were staying the night in Canberra, and several met for a wind-down dinner at a local hotel restaurant where it was generally agreed that the campaign had been worthwhile.



The Bottom Line

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. On 4 July 2012 the Committee tabled a [Discussion Paper](#) resulting from the evidence taken during the Roundtable Forum which noted:

"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 recommended Polio Australia apply for the only funding available through the Department of Health and Ageing (DoHA). These applications had already been submitted but neither was successful:

- The Chronic Disease Prevention and Service Improvement Fund submission was for "*The Prevention, Early Intervention and Management of the Late Effects of Polio*", costed at \$2,044,905 across 3 years;
- The Health System Capacity Development Fund submission was for "*The Late Effects of Polio Best Practice Clinical Recommendation Modules*", costed at \$830,455 across 3 years.

Both submissions incorporated a suite of strategies, with an emphasis on health sector and community education in multimedia formats. There are no further rounds scheduled for this funding, which renders this avenue closed for the foreseeable future.



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.”

It is important to note that there are no other organisations are doing the work of Polio Australia, which means that if any of these recommendations are to be progressed, it would be done by Polio Australia – which requires urgent funding to continue its work.

Currently, all programs provided by Polio Australia, such as the annual Polio Health and Wellness Retreats, are funded through a variety of ad hoc philanthropic grants, all of which need to be applied for through multiple funding submissions. Initiatives such as Polio Australia’s website, the important Australian Polio Register, the two electronic publications “*Polio Oz News*” and “*Reflections*”, and “*The Late Effects of Polio: Introduction to Clinical Practice*” online resource, are only made possible through thousands of volunteer hours.

What Do We Want?

Polio Australia urges the post-polio community and their supporters to write to their MPs asking them to support the need for Federal funding to maintain and build on the services Polio Australia provides as the only national peak body representing polio survivors in Australia. Please use this document and this [handout](#) for funding facts and details.

When Do We Want It?

Funding for Polio Australia’s sole paid employee, the National Program Manager, Mary-ann Liethof, is currently being generously provided by [The Balnaves Foundation](#) (whose founder, Neil Balnaves, is also a polio survivor), but this runs out at the end of 2013. As there are very few philanthropic trusts/foundations that fund operational costs (such as staff), Polio Australia’s capacity to continue providing services is provisional unless funding is forthcoming.

Polio Australia is a registered charity, with [donations](#) over \$2.00 being tax deductible. We welcome all donations*, irrespective of the amount, and very much appreciate the generosity of Jill Pickering and Dr John Tierney, who have provided funds to pay for integral operational costs such as office rental, equipment, etc.

This campaign attracted 4 donations totalling \$1,500 from the Lioness Club of Dromana (Vic), J Eitzen (SA), NW & PA Allen (Qld), and M Maroney (ACT).

***Note:** As a national body comprised of the state Polio Networks, Polio Australia does not receive membership fees from individuals.

Polio This Week

Source: [Polio Global Eradication Initiative](#) - as of Wednesday 7 November 2012

Wild Poliovirus (WPV) cases

Total cases	Year-to-date 2012	Year-to-date 2011	Total in 2011*
Globally	181	505	650
- in endemic countries	176	226	341
- in non-endemic countries	5	279	309

Case breakdown by country

Countries	Year-to-date 2012				Year-to-date 2011				Total in 2011*	Date of most recent case
	WPV1	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total		
Pakistan	45	2	1	48	134	2		136	198	09-Oct-12
Afghanistan	27			27	47			47	80	01-Oct-12
Nigeria	83	18		101	33	9		42	62	15-Oct-12
India					1			1	1	13-Jan-11
Chad	5			5	114	3		117	132	14-Jun-12
DR Congo					86			86	93	20-Dec-11
Angola					5			5	5	07-Jul-11
Niger					1	1		2	5	22-Dec-11
CAR					2			2	4	08-Dec-11
China					18			18	21	09-Oct-11
Guinea						3		3	3	03-Aug-11
Kenya					1			1	1	30-Jul-11
Côte d'Ivoire						36		36	36	24-Jul-11
Mali						7		7	7	23-Jun-11
Congo					1			1	1	22-Jan-11
Gabon					1			1	1	15-Jan-11
Total	160	20	1	181	444	61	0	505	650	
Total in endemic countries	155	20	1	176	215	11	0	226	341	
Total out-break	5	0	0	5	229	50	0	279	309	

Data in WHO as of 8 November 2011 for 2011 data and 06 November 2012 for 2012 data.



POLIO AUSTRALIA INCORPORATED

Representing polio survivors throughout Australia

Please pass this e-Bulletin on to friends and colleagues who have an interest in the late effects of polio

- ◆ If you are not the original recipient of this e-Bulletin and would like to receive it directly in future, please email us [here](#).
- ◆ If you do not wish to receive any further communication from Polio Australia, please email us [here](#).

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