



# Polio Australia

Representing polio survivors throughout Australia



"We're Still Here!" Campaign October 2012

**European Polio Conference: Post Polio Syndrome, a condition without boundaries**  
Amsterdam - The Netherlands - June 2014

Free Papers Session FS1 – Polio Survivors Coping and Exchange of Experiences

***Self-Management of the Late Effects of Polio (LEOP)***

***Seeking Government and Private Funding Support: The Australian Experience***

**Dr John Tierney OAM PhD MED**  
**President and National Patron Polio Australia**  
**Former Australian Federal Senator**

# My story . . .



POLIO AUSTRALIA

# Challenges . . .



2009  
*Polio Australia  
delegates with  
current  
Health Minister,  
Peter Dutton*

# Educating Politicians . . .

The Hon Julia Gillard MP  
Prime Minister of Australia 2010-13



L-The Hon Bill Shorten MP,  
Leader of the Opposition  
R-The Hon Greg Hunt MP,  
Minister for the Environment



Senator The Hon Mitch Fifield,  
Assistant Minister for Social Services  
(Disabilities)



The Hon Christopher Pyne MP,  
Minister for Education and  
Leader of the House



Mark Coulton MP,  
National Party Chief Whip

# Back story . . .

2007 Designing a Future Conference



# Polio Australia Programs . . .

Over the last six years Polio Australia has developed:

- 3 information-specific websites
- Australia's unique "National Polio Register"
- Post-polio clinical resource modules, and
- Specific programs such as our annual three day intensive Health and Wellness Retreats

**Touched by**



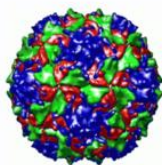
**Polio**

**Please register today!**



**Australian Polio Register**

**All about the**



**Late Effects of Polio**

**Polio Australia**



**Lobbying for Services**

**We're Still**



**Here!**

**Resources for**



**Polio Survivors**

**Resources for**



**Health Professionals**

**Polio Health & Wellness**



**Self Management**



**POLIO AUSTRALIA**



2012  
Polio Health  
and Wellness  
Retreat  
Sunshine Coast,  
Queensland



# Lobbying in the Australian Parliament . . .



Parliament House, Canberra – “We’re Still Here!” Campaign October 2012

Jill Hall MP  
(ALP)

Mark Coulton MP  
(Nat)

The Hon Greg Hunt MP  
(Lib)

The Hon Catherine  
King MP (ALP)

Senator Rachael Siewert  
(Greens)



With Our Parliamentary Patrons

# Polio survivors call for fair go



Polio victim Margaret Maroney is calling on the government to provide funding for survivors.  
Picture: Elesia Lee

By Naomi Fallon

MARGARET Maroney's earliest memories of her childhood battle with polio are of being left lonely and afraid in a big cold place as she waved goodbye to her parents.

The farming family had been forced to send their three-year-old daughter to a children's home in Sydney while she recovered from the debilitating viral disease that can affect nerves and lead to partial or full paralysis.

The 61-year-old Holt resident remembers spending about 12 months there, before returning to her home in Young, NSW.

"From there I was taken home wearing boots and callipers on my left leg," she said.

"My father used to massage my leg every night ... with this horrible

cream, I can remember the smell. We recaptured some of the muscle in the calf of my left leg where some other polio survivors didn't."

Ms Maroney underwent two surgeries at the age of five and 10 - neither of which completely corrected the mobility issues with her left leg.

"My foot has had ongoing pain - but I just got used to it - because the bones are not set properly," she said.

As a result of her illness Ms Maroney fatigues easily, has poor circulation in her left leg and is susceptible to infection in the limb.

Despite her troubles she considers herself to be "one of the lucky ones".

She went on to marry, have six children and has spent the past 15 years working as a nurse.

"There's so many of us out there that have actually developed post-polio syndrome that's put them back into

wheelchairs and walking aids," she said. "Who's to know, that could be me in 10 years' time. I can see that slowly happening to my body."

Tomorrow Ms Maroney will join more than 50 campaigners at Parliament House to talk to politicians about the need for government funding to boost services for polio survivors.

President of Polio Australia Gillian Thomas said the government needed to stop relying on volunteers to do all the work. "It is way past time that polio survivors received funding for best-practice services, including those that Polio Australia delivers," she said.

"Polio survivors don't complain. We have quietly carried on with our lives. "But now, more than ever, we need support and it's time to give us a fair go by funding the health and support services we need. We're not asking for a handout, just a fair go."



## October

**Did you know that polio survivors today form the largest single physical disability group in the country?**

**Yes, We're Still Here!**

Tens of thousands of Australians contracted paralytic polio between the 1930s and 1960s and as they head into their senior years, the development of new symptoms can occur, commonly known as the 'Late Effects of Polio'.

**Symptoms include . . .**

- ~ unaccustomed fatigue unrelated to activity
- ~ decreased strength and endurance
- ~ pain in muscles and/or joints
- ~ weakness and muscle atrophy
- ~ muscle spasms/twitching
- ~ respiratory and sleep problems
- ~ swallowing or speaking difficulties

Find out more and sign up to the  
**Australian Polio Register**  
[www.polioaustralia.org.au](http://www.polioaustralia.org.au)  
Ph: 03 9016 7678

## NEWS DESK



**Orange appeal:** Fran Henke and other polio survivors wore orange when explaining their needs to MPs in Canberra, including Bruce Billson.

## Survivors lobby MPs

FRANKSTON-based MP Bruce Billson was among politicians lobbied by a 60-strong delegation of polio survivors in Canberra to raise awareness of their "We're Still Here!" campaign.

Mr Billson spoke with Fran Henke, of Hastings, a committee member of Mornington Peninsula Post Polio Support Group and chair of Polio Reference Group Victoria.

The polio survivors converged on Parliament House on 31 October,

coinciding with the launch of a new online resource module by Ballarat MP Catherine King.

The module, The Late Effects of Polio: Introduction to Clinical Practice, provides health professionals with the latest information on the treatment of patients with late effects of polio, or post-polio syndrome.

The module is available at [www.polioaustralia.org.au/Resources/HealthProfessionals](http://www.polioaustralia.org.au/Resources/HealthProfessionals)

**WE'RE  
STILL  
HERE!**



**POLIO AUSTRALIA**

# Government support . . .

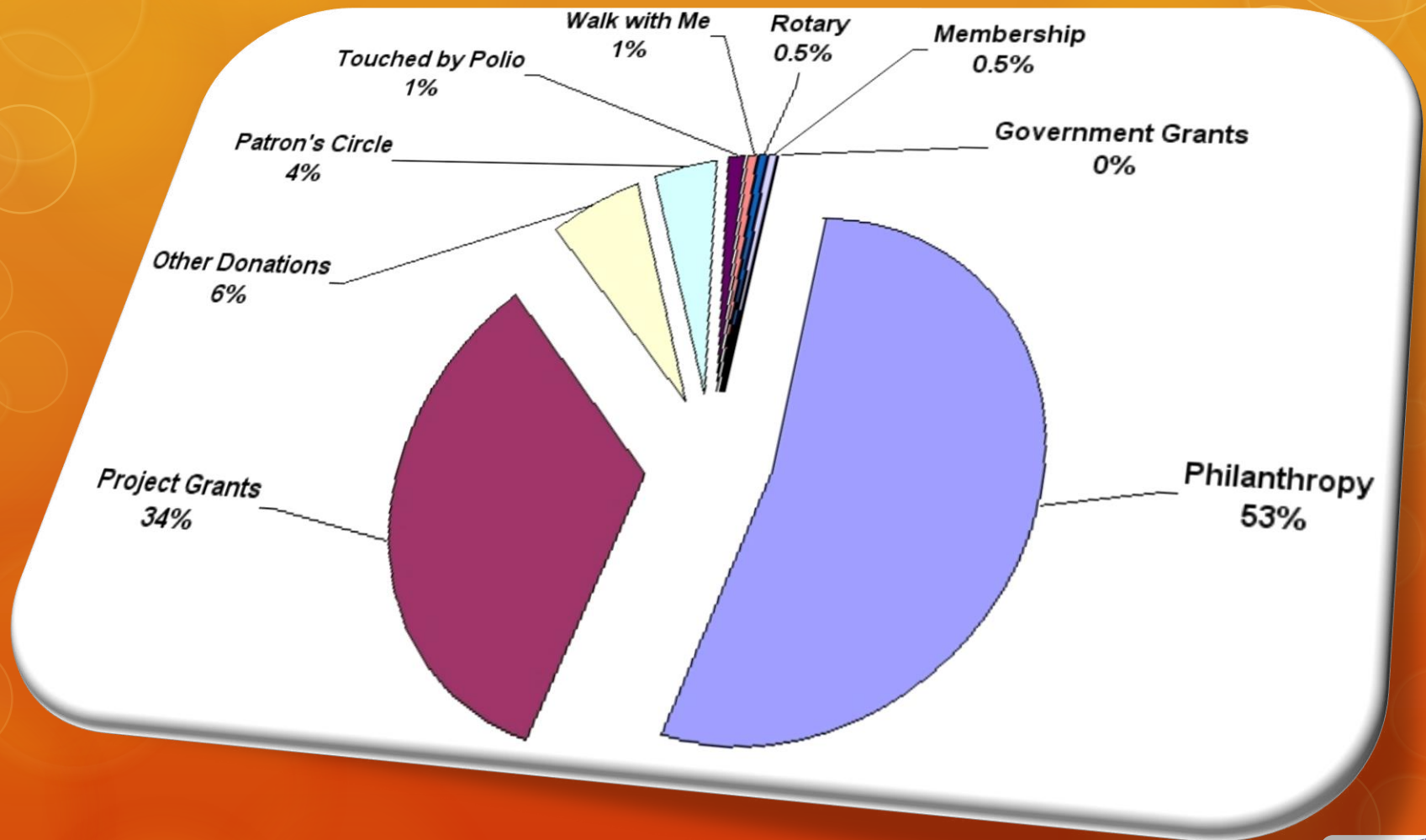


March 2012 – House of Representatives  
Standing Committee on Health and Ageing Roundtable Forum  
on the Needs of Polio Survivors

# Other funding alternatives . . .



# Current funding sources



**Funding Sources**  
~ 2010 to date ~

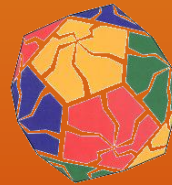
# In summary . . .



**Thank you!**

# Polio Australia

Representing polio survivors throughout Australia



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