

# AUSTRALIA'S POLIO HEALTH AND WELLNESS RETREAT



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**Improvements in self-management strategies for people living with the Late Effects of Polio following a 3 day residential program**



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Representing polio survivors throughout Australia

# BACKGROUND



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# WARM SPRINGS POST-POLIO WELLNESS RETREAT



**Warm Springs Retreat Organising Committee** *(left to right)*

Sue Jones - Polio Canada; Kathy Maynard; Dr Fred Maynard; Barbara Duryea - John P. Murtha Neuroscience and Pain Institute; Dr William DeMayo - John P. Murtha Neuroscience and Pain Institute; Sunny Roller (seated) - University of Michigan; Dr Werner Rink - Reha Zentrum Passauer Wolf; Christy Osborn - Bay Cliff Health Camp



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# AUSTRALIA'S POLIO HEALTH AND WELLNESS RETREATS



**Australian contingent at Warm Springs Retreat:**  
*(left to right)*

*Dr John Tierney* – Polio Australia's National Patron

*Shirley Glance* – Polio Support Group Convener

*Fran Henke* – Polio Support Group Member

*Mary-ann Liethof* – Polio Australia's National Program Manager

*Liz Telford* – Post Polio Victoria's President

*Suzie* – guide and child patient at Roosevelt Warm Springs Rehabilitation Institution



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# NEW SOUTH WALES 2010

## *St Joseph's Baulkham Hills*

CENTRE FOR REFLECTIVE LIVING

СЕНТРЕ ЛОВ РЕФЛЕКТИВЕ ЛІВІНГ



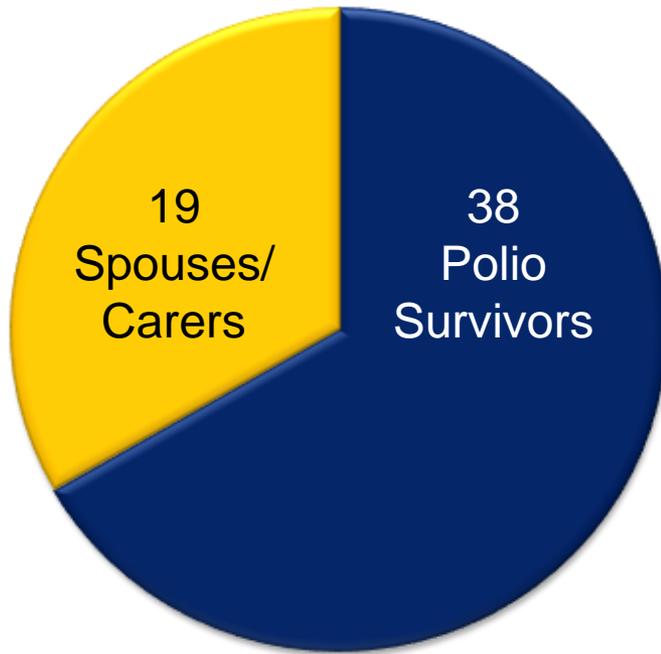
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# NEW SOUTH WALES 2010

## Population by State/Territory

NSW – 7.23 million	SA – 1.64 million
VIC – 5.55 million	TAS – 507,600
QLD – 4.51 million	NT – 220,700
WA – 2.29 million	ACT – 6,300

## 57 Participants



## Regional Demographic



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# THE POLIO BODY



Bracing



Pain Management



Physiotherapy & Exercise Options



Scooter Demonstration



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# THE HEALTHY MIND



Bridge



Early Memories



Origami



Sudoku



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# SPIRITUAL HEALTH



Seated Yoga and Meditation



Life Balance



Awakening the Spirit Within



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# ADDITIONAL ACTIVITIES

Massage



Spouse/Carer Discussion

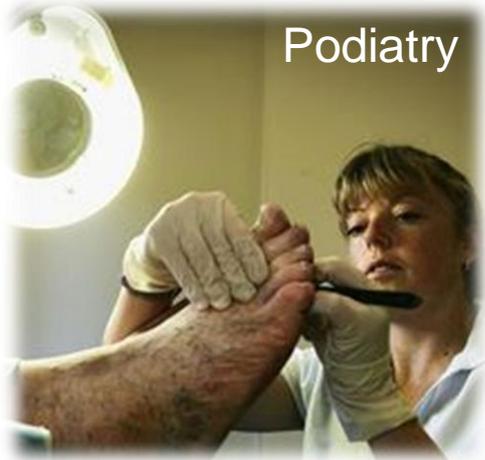


Acupuncture



Trivia Night

Podiatry



Group Singing



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# FEEDBACK

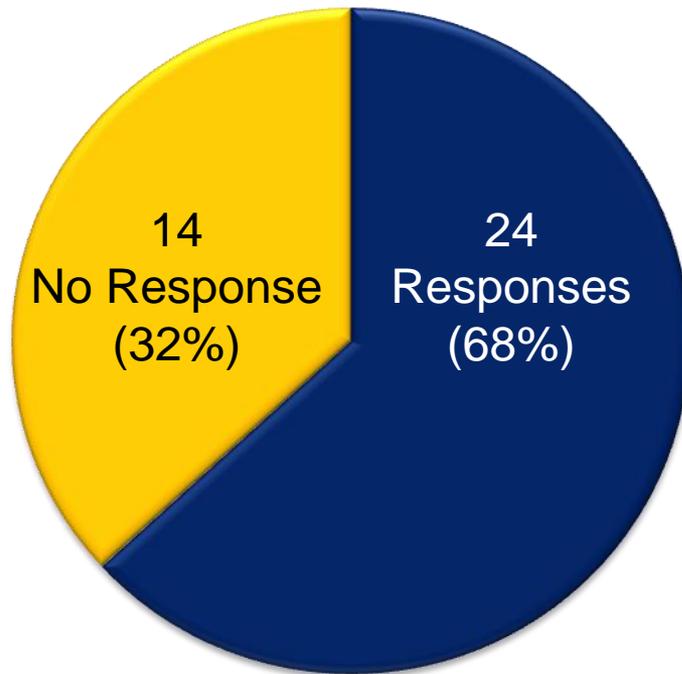
*"Thanks for all you put into the retreat. For me it was a life-changing experience! It seemed to offer everything we needed: great plenary sessions, excellent small group discussions and one-to-one opportunities with [health] professionals, and the chance to share all these experiences with one's partner.*

*Beyond that, there was the informal chance to make connections and share experiences with other polio survivors. Congratulations to everyone involved. I've already made three important follow-up appointments...."*

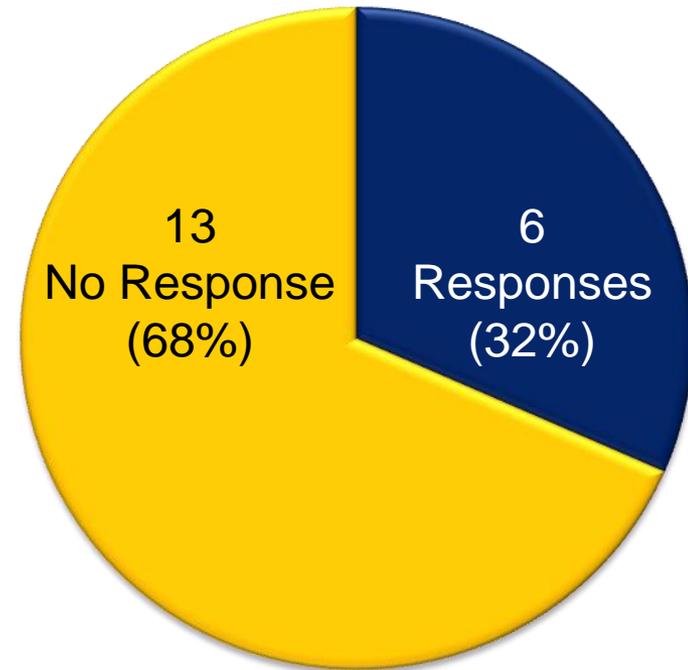


# SIX MONTH FOLLOW UP

## Polio Survivors



## Spouse/Carers



# KEY COMMENTS

*"Just knowing it is in our power to better manage our condition and being prepared to put strategies in place to assist has greatly helped."*

*"I see the importance of talking to polio survivors and to stop denying I was disabled and in need of help."*

*"Vanity and pride stopped me going out - now I have a scooter and go for hours - it's great!"*



# KEY THEMES

## Interaction with Health Professionals *(65 comments)*

- ✓ Feel better through exercising more and being more physically active *(13 comments)*
- ✓ Appointments made for orthotic assessments *(10 comments)*
- ✓ Considering the new and different types/styles of braces currently available *(6 comments)*
- ✓ Understand the need for individually tailored exercise *(6 comments)*
- ✓ Understand the value of a good podiatrist *(6 comments)*
- ✓ Appreciate the importance of diet in maintaining a better weight level (one person lost 5 kg) *(6 comments)*
- ✓ Understand the need for a full physiotherapy assessment *(4 comments)*
- ✓ Walking has improved after being prescribed orthotics *(3 comments)*
- ✓ Made follow up appointments with health practitioners knowledgeable in the LEOP *(3 comments)*
- ✓ Increased understanding of the: healthy mind, who is on the PPS 'team', effect of medicines, and information and services available *(8 comments)*



# KEY THEMES

## Acceptance of 'Polio Self' / Wellbeing *(45 comments)*

- ✓ Great to feel “normal” and with people who understood what is happening to us *(12 comments)*
- ✓ Benefits of sharing polio experiences and how other polio survivors deal with them *(11 comments)*
- ✓ Inspired by the incredible goodwill and enthusiasm shown by polio survivors *(9 comments)*
- ✓ Greater acceptance of self; I love my life; feel better *(4 comments)*
- ✓ Need to accept help graciously when it is offered *(3 comments)*
- ✓ Realised I was better off than others with disabilities *(3 comments)*
- ✓ Continuing to learn about all aspects of the polio body *(2 comments)*
- ✓ Still able to enjoy my life – it may be different but it's mine *(1 comment)*



# KEY THEMES

## Pacing *(19 comments)*

- ✓ Went “easy” and paced my activities *(13 comments)*
- ✓ Now realise it is possible to remain active and positive *(6 comments)*



# KEY THEMES

## Pain *(17 comments)*

Prior to the Retreat these participants felt depressed and unable to improve their situation as pain and fatigue caused confusion, frustration, and sleeplessness.

Learning new pain management techniques including:

- reducing workloads
- accepting the need for a caliper or scooter
- medication, and
- pacing

are enabling them to cope better and improve their quality of life.



# KEY THEMES

## Aids and Equipment *(16 comments)*

- ✓ Physical benefits of using a walker including walking better and straighter *(6 comments)*
- ✓ Recognise value of using mobility aids *(4 comments)*
- ✓ Purchased a scooter and used it on holidays *(3 comments)*
- ✓ Psychological benefit using walker, opened up my life *(2 comments)*
- ✓ Other aids purchased: boot hoist and car support cushion *(1 comment)*



# KEY THEMES

## Spiritual Health *(8 comments)*

- ✓ The serenity of prayer helps difficult times to pass *(5 comments)*
- ✓ Helping others is therapeutic *(2 comments)*
- ✓ Started gentle yoga exercise previously thought harmful *(1 comment)*



# KEY THEMES

## Spouse/Carers

My husband previously minimised my polio issues – he now realises this is not helpful to our relationship.



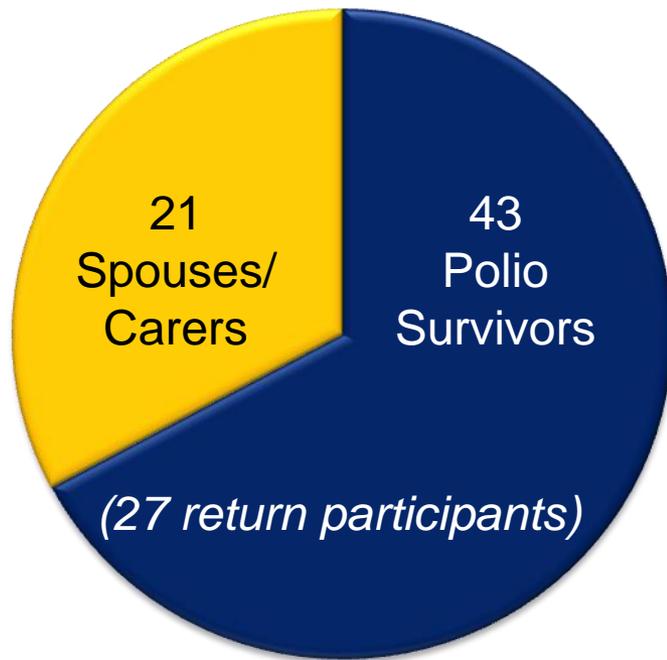
# VICTORIA 2011



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# VICTORIA 2011

## 64 Participants



## Regional Demographic



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# FEEDBACK

*"I would like you to know just how much I enjoyed the weekend at Mt Eliza. For most of my life I just got on with it. Now I am finding the information about polio and the way it has affected me in later years very useful for helping me maintain my independence." (polio participant)*

*"I just wanted to thank you for the wonderful experience this weekend. I have come away a different person. I met so many amazing people and was privileged to hear parts of their stories. These touched my heart and I came away humbled by the courage, fortitude and positive attitudes that they all had. There was much shared laughter and gratitude for families and supports such as yours." (massage therapist)*



# THE AUSTRALIAN WAY

## The Venue

- ✓ reasonably-priced, purpose-built conference facility
  - ✓ on-site accommodation with ensuite bathrooms
  - ✓ single, double and twin share sleeping configuration
  - ✓ in-house catering and table service
  - ✓ within one hour from a capital city
  - ✓ pleasant surroundings
  - ✓ accessible for people using mobility aids
- ? exercise options / recreational activities



# THE AUSTRALIAN WAY

## Cost

- ✓ Polio Australia receives no government funding
- ✓ grant employs one full time worker for three years
- ✓ office rent paid by a private donor for two years
- ✓ no organisational 'sponsorship'
- ✓ philanthropic grants supplement cost of Retreats
- ✓ participant pays less than half of cost to Polio Australia
- ✓ goodwill of the health professionals and specialists



# THE AUSTRALIAN WAY

## Program Content

- ✓ Retreat organisers are not health professionals
- ✓ assisted by Clinical Advisory Group
- ✓ local polio community make recommendations which:
  - engages the potential participants in the process;
  - ensures specialists are known as having some experience with polio survivors;
  - keeps the program 'fresh' for repeat participants;
  - introduces new specialists for wider professional networking opportunities



# CONCLUSION

**The Polio Health and Wellness Retreat format has proven to be an effective self-management tool due to:**

- ✓ the shared experience of the participants
- ✓ the 'open circle' Question and Answer forums which fully engage participants
- ✓ a clearer understanding and better retention of the management strategies being presented
- ✓ the depth of the process making it different from a 'conference' format
- ✓ participant feedback regarding follow up on a range of self-management strategies



# CONCLUSION

- ✓ education of polio survivors and their family/carers in self-management techniques enabling people to achieve general wellbeing and ensuring that they remain as mobile and independent as possible in their own homes
- ✓ information and strategies being shared with the participants' local health service providers helping to facilitate improved care for other patients presenting with the LEOP
- ✓ the 'Mind, Body, Spirit' theme being an holistic framework towards effective Self-Management for polio survivors, their families and carers



# THANK YOU

Thank you for your interest in Polio Australia's Health and Wellness Retreats. We continue to seek funding so they can be run throughout Australia.

Full details of the Retreat programs and session presenters can be found on Polio Australia's website:

[www.polioaustralia.org.au](http://www.polioaustralia.org.au)

[What We Do / Self Management](#)

If you would like a copy of this presentation, a copy will be uploaded onto Polio Australia's and possibly "The Informed Scientist" websites after the conference.



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