

Polio Australia

Representing polio survivors throughout Australia

Report

2014 Polio Health and Wellness Retreat



5th Annual Polio Health and Wellness Retreat

St Joseph's Centre for Reflective Living, Baulkham Hills, New South Wales

Thursday 8, Friday 9, Saturday 10 and Sunday 11 May 2014

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1. Executive Summary

Polio Australia's vision is to ensure that all polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.

Since it commenced active operations in January 2010, Polio Australia has run five “*Residential Chronic Condition Self-Management*” programs – also known as “*Polio Health and Wellness Retreats*”. In line with our Strategic Plan, it is the goal of Polio Australia to run these Retreats annually for polio survivors and their partners/carers/family members in every state in Australia.

The ongoing theme of these annual Retreats is based on “*The Healthy Body/Mind/Spirit*”, which takes a holistic approach towards effective self-management of the Late Effects of Polio (LEoP) and Post-Polio Syndrome (PPS), and associated behavioural change for polio survivors, their families, carers and family members.

In April 2010, the inaugural Retreat was held at St Joseph's Retreat for Reflective Living in Baulkham Hills, New South Wales, for 59 participants. In April 2011, the second Retreat was held in the tranquil setting of the Melbourne Business School in Mt Eliza, Victoria, and was attended by 64 people. In April 2012, the third Retreat was held at the Ramada Hotel and Conference Centre Marcoola Beach on the Sunshine Coast in Queensland, and was attended by 73 people. Last year, in 2013, the fourth Retreat was held at Stamford Grand, Glenelg, South Australia and was attended by 70 people.

According to feedback received, we are very pleased to report that Polio Australia's 5th Annual Polio Health and Wellness Retreat was yet another unmitigated success, thanks to the 63 participants who made their way to St Joseph's Retreat for Reflective Living in Baulkham Hills, New South Wales, and the wonderfully generous efforts of the 21 session presenters, most of whom provided their services pro-bono.

There were also one-to-one sessions booked with: Dr Helen Mackie for a discussion on Lymphoedema; Dr Steve de Graaff for self-management strategies; and foot care with Podiatrist, Rudo Makuyana.

Many participants took advantage of the 3 massage therapists, Carol Gridley, Aruna Ellis and Reena Haikar, who were onsite for remedial sessions.

Partners/carers/family members are always encouraged to attend these Retreats as it is vital for the polio survivors to have this support and understanding in order to achieve their own self-management goals. It is equally important for the partners/carers/family members to have scheduled and informal opportunities to meet and discuss their own specific concerns which is accommodated in the “*Partnering Polio*” sessions.

A lot of networking was done during the four days/three nights and people agreed to having their names on a Contact List so they could keep in touch with each other following the Retreat.

A survey based on feedback from these Retreats provided a rich vein for oral and poster presentations at 2 Post-Polio Conferences being held in the USA and Amsterdam in June 2014. The subject title is: *Polio Australia's Annual Health and Wellness Retreats Review: the implications for participants on Health Literacy and Health Outcomes*

The 10 Health Literacy and Health Outcomes survey questions were based on Professor Don Nutbeam's conceptual model of 'health literacy as an asset'. In addition to questions about changed health behaviours and practices as a result of having attended the Retreats, the survey also sought to identify any improvement in people's capacity to advocate for both themselves and others in relation to getting support to manage the late effects of polio, and their participation in changing social norms and practices such as raising awareness about physical access issues within their communities. The results of this survey provide essential statistical data for use in reports, funding submissions, lobbying government, health related publications, and further research.

The Retreats have become a flagship program for Polio Australia, supporting its vision of ensuring that all polio survivors have access to adequate support and information together with comprehensive, consistent health care from a range of well-informed and educated professionals.

Day 1

The “*Healthy Body*” day began with an overview of “*Challenges in Post-Polio*” by Dr Steve de-Graaff, Director of Pain Services and Senior Rehabilitation Physician, Epworth Healthcare, Victoria followed by sessions on:

- Post-Polio Exercise Options
- Functional Footwear
- A Breath of Fresh Air
- Pain and Fatigue Management
- Swollen Polio Legs
- Managing Arthritis and Osteoporosis
- Osteopathic in Self Care
- Partnering Polio
- Mindfulness
- Optimal Nutrition
- Avoiding Falls
- Taking Charge of Your Own Health
- Aids and Equipment Display
- Footwear Display
- Guided Deep Relaxation

concluding with “*The Circular Keys Chorus*” entertainment after dinner. There were also opportunities for one-to-one consultations with a variety of the presenting health professionals, as well as appointments with massage therapists.

Day 2

The “*Healthy Mind*” day commenced with a presentation on the “*Healthy Brain Ageing*” by Dr Loren Mowszowski, Healthy Brain Ageing Clinic, University Of Sydney. This was followed by sessions on:

- Chair Yoga
- Early Polio Memories
- Mind Matters
- Telling Your Story
- A Family History Taster
- Travel Options
- Partnering Polio
- Card Making
- Making the Most of Our New Reality
- Laughter: The Best Medicine
- AutoMobility Display
- Guided Deep Relaxation

concluding with a presentation from the Comedian, Tommy Dean, after dinner. This day also included the opportunity of appointments with a podiatrist, and massage therapists.

Day 3

The “*Healthy Spirit*” day commenced with a presentation by Sister Annie Bond, previous Director for St Joseph’s Centre for Reflective Living. This was followed by concurrent sessions on:

- Awakening the Creative Spirit Within
- Philosophically Speaking
- Meditation

Evaluations

By way of demonstrating how this Retreat has ‘changed people’s lives’, a sample of the evaluation comments follows:

- Now understand why my head turns left when I swallow, why I choke, and how to prevent it.
- Practical hands-on demonstrations and risk evaluations and where to look for help to manage disability and paperwork in our final days.
- Helped understand difference between pain and fatigue and how to manage them.
- Learnt what causes swelling and how to relieve it.
- Every human is different – polio attacks in different areas, thus each polio survivor is an individual with their own special problems and requires individual help.
- How to breathe the right way and save your voice.

Acknowledgements

We are extremely grateful to all the session facilitators and therapists for sharing their time, knowledge and expertise, especially as the majority of these presenters provided their services at no charge.

Polio Australia warmly thanks The Marian and E.H. Flack Trust and GlaxoSmithKline for their ongoing and generous support for these Retreats.

This financial support provided the opportunity to provide the 4 day/3 night Retreat at a greatly reduced cost, starting from \$350 per person twin share, which included all meals, accommodation and most activities.

2. Demographics

Participants Year of Birth Range: 1925 to 1965

Years Polio Contracted: 1929 to 1965

Who Came?

Polio Survivors	Spouse/Carers	Total Participants
40	21	61

Gender Representation

Female	Male
38 Total (31 polio survivors)	23 Total (9 polio survivors)

States

NSW	QLD	SA	TAS
43 (17 male / 26 female)	9 (3 male / 6 female)	0	0
VIC	WA	NZ	
8 (2 male / 6 female)	2 (1 male / 1 female)	1 (1 female)	

Assistive Devices Used

Mobility Aids	Equipment
Walking Sticks = 21	Shower Stool = 11
Electric Scooters = 7	Toilet Raiser = 9
Electric Wheelchairs = 5	Commode = 1
Walker Frames = 3	Respirator/bi-pap = 1
Elbow Crutches = 2	
Manual Wheelchairs = 1	

3. Program

Day 1 - Orientation - Thursday 8 May

Time	Activity
2.00 to 6.00 pm	Retreat Check In Registration and facility orientation
6.30 to 7.30 pm	Dinner in Dining Room
7.30 pm	Welcome by Dr John Tierney <i>President, Polio Australia</i> and Gillian Thomas <i>Vice President, Polio Australia and President, Polio NSW</i>
7.45 pm	Guest Speaker: Paul Galy on his book " <i>The 4th of May: The Memories of Paul Galy OAM</i> "
8.15 pm	Program Overview and Brief Announcements
8.30 pm	Participant Introductions
9.00 pm	Relax and Mingle

Day 2 – The Healthy Body - Friday 9 May

Time	Activity and Facilitator
7.30 to 9.00 am	Breakfast
9.15 to 10.00 am	Plenary: The Polio Body Dr Steve de Graaff <i>Director of Pain Services and Senior Rehabilitation Physician, Epworth Healthcare, Victoria</i>
10.00 to 10.25 am	Morning Tea
10.30 am to 12.00 pm	Post-Polio Exercise Options Gilly Davy <i>Clinical Educator and Senior Neurological Physiotherapist Advance Rehab Centre</i>
	Functional Footwear Paul Galy <i>Footwear Practitioner, David Winsor Shoemakers</i>
	A Breath of Fresh Air Colleen Kerr <i>Speech Pathologist, Optimal SP</i>
	Pain and Fatigue Management Dr Steve de Graaff <i>Director of Pain Services and Senior Rehabilitation Physician, Epworth Healthcare, Victoria</i>

3. Program – cont'd

12.15 pm	Lunch
12.15 pm to 2.00pm	Independent Living Centre NSW Display
	Barefoot Freedom Footwear Display
	Rest / Deep Relaxation
2.00 to 3.30 pm	Osteopathic in Self Care Anne Cooper and Dr Stiofan MacSuibhne <i>Osteopaths, Central Sydney Osteopathy</i>
	Swollen Polio Legs Dr Helen Mackie <i>Rehabilitation Physician, Mt Wilga Private Hospital</i>
	Managing Arthritis and Osteoporosis Jenny Ly <i>Senior Health Promotion Officer, Arthritis and Osteoporosis NSW</i>
	Partnering Polio Graeme Smith, <i>Partner of Joan Smith</i>
3.30 to 3.55 pm	Afternoon Tea
4.00 to 5.30 pm	Mindfulness: Resilience, Performance and Positive Mental States Dr Stiofan MacSuibhne <i>Osteopath, Central Sydney Osteopathy</i>
	Optimal Nutrition Melinda Overall <i>Nutritionist</i>
	Avoiding Falls Rachael Morris <i>Occupational Therapist, Advance Rehab Centre</i>
	Taking Charge of Your Own Health Mary Potter <i>Consumer Health NSW</i>
6.30 to 7.30 pm	Dinner
8.00 pm	Circular Keys Chorus

3. Program – cont'd

Day 3 – The Healthy Mind - Saturday 10 May

Time	Activity and Facilitator
7.30 to 9.00 am	Breakfast
9.15 to 10.00 am	Plenary: Healthy Brain Ageing Dr Loren Mowszowski <i>Healthy Brain Ageing Clinic, Clinical Research Unit Brain and Mind Research Institute, Sydney University</i>
10.00 to 10.25 am	Morning Tea
10.30 am to 12.00 pm	Chair Yoga Heena Rakar, <i>Yoga Teacher</i>
	Early Polio Memories Joan Smith <i>Convenor, Knox-Yarra Ranges Polio Support Group and Secretary, Post-Polio Victoria</i>
	Mind Matters Gillian Thomas, <i>Vice President Polio Australia</i>
12.15 pm	Lunch
12.15 pm to 2.00pm	AutoMobility Display
	Rest / Deep Relaxation
2.00 to 3.30 pm	Telling Your Story Gale Kennedy <i>Author</i>
	A Family History Taster Rhonda and John Gaffey <i>U3A Tutors</i>
	Travelling Options Mathew Hennig <i>Manager, Flying Wheelies</i>
	Partnering Polio Graeme Smith. <i>Partner of Joan Smith</i>
3.30 to 3.55 pm	Afternoon Tea
4.00 to 5.30 pm	Card Making Joan Smith <i>Convenor, Knox-Yarra Ranges Polio Support Group, and Secretary, Post-Polio Victoria</i>
	Making the Most of Our New Reality Gale Kennedy <i>Author</i>
	Laughter: The Best Medicine Usuff Omar <i>Newtown Laughter Club</i>
6.00 to 7.00 pm	Dinner
8.00 pm	Comedian - Tommy Dean

3. Program – cont'd

Day 4 – The Healthy Spirit - Sunday 11 April

Time	Activity and Facilitator
7.30 to 9.00 am	Breakfast
9.15 to 10.00 am	Plenary: The Healthy Spirit Sister Annie Bond <i>Previous Director, St Joseph's Centre for Reflective Living</i>
10.00 to 10.25 am	Morning Tea
10.30 am to 12.00 pm	Awakening The Creative Spirit Within Sister Annie Bond <i>Previous Director, St Joseph's Centre for Reflective Living</i>
	Philosophically Speaking Margot Taverne <i>U3A Tutor</i>
	Meditation Leanne Huet <i>Sahaja Yoga Practitioner; and</i> Lene Jeffrey <i>Solfège Music Therapist</i>
12.15 pm	B-B-Q Lunch
1.15 to 2.30 pm	Closing Plenary Mary-ann Liethof <i>and</i> Gillian Thomas <i>Polio Australia</i>

4. Evaluations

4.1 Plenary Sessions

4.1.1 Presenters

1 = Below standard to 5 = Excellent	1	2	3	4	5
Day 2 (Body) Dr Steve de-Graaff	0	1	1	6	29
Day 3 (Mind) Dr Loren Mowszowski	0	0	2	7	26
Day 4 (Spirit) Sister Annie Bond	0	0	3	9	15

4.1.2 Comments

Lymphoedema Discussion with Dr Helen Mackie

- Great to talk specifically on your problem
- Consultant listened, understood and gave useful advice
- Learning more about the lymph glands
- Did not know lymphoedema needs attention
- Useful information for self-management of my LEOp **x2**
- Needs a 'do's and don'ts' handout

Self-Management Discussion with Dr Steve de Graaff

- Consultant listened, understood and gave useful advice **x2**
- Suggested things I should see my local doctor about
- Practical help and tips **x2**

Foot Care with Rudo Makuyana

- No comments

4.2 Day 2 Polio Survivors Sessions Feedback

10.30am to 12.00pm

Session	Most useful aspects	What other information would have liked
<i>Post-Polio Exercise Options</i>	<ul style="list-style-type: none"> • Distinction between exercise and daily activities x2 • Need for cardiovascular exercise • Very positive, comprehensive and appropriate • Practical approach to neurophysiology • Short bursts of exercise are as beneficial as long exercise sessions • Useful ideas but asked more questions than gave information • Right way to exercises numbers / speed 	<ul style="list-style-type: none"> • Sample exercise demonstrated x2 • Being asked about what we wanted to learn • Wanted problems addressed
<i>Functional Footwear</i>	<ul style="list-style-type: none"> • Choice of custom made footwear x2 • Practical advice on footwear • Understanding my gait better • One-on-one interaction • Made appointment for custom orthotic shoes 	<ul style="list-style-type: none"> • Information on changes over time

4. Evaluations – cont'd

Session	Most useful aspects	What other information would have liked
<i>A Breath of Fresh Air</i>	<ul style="list-style-type: none"> • Well-presented and knows her subject x8 • Practical, interactive, useful demonstrations x3 • Practical breathing exercises and the importance of swallow function • Great content • Exercises and explanation • How to breath the right way and save your voice • Cheerful presenter, makes learning fun • Now understand why I choke and how to prevent it - thank you • Exercises to improve voice and breathing • Why my head turns left when I swallow • Breathing/voice and swallowing / dysphagia 	<ul style="list-style-type: none"> • N/A
<i>Pain and Fatigue Management</i>	<ul style="list-style-type: none"> • Practical daily management advice x5 • Interesting basic polio information x3 • Q and A x2 • Management of the body • Pain levels • Targeted medication • Improve if possible – keep using it but don't overdo it • Adapt and keep pain and fatigue under control 	<ul style="list-style-type: none"> • More on medication, i e pain killers, sleep issues, what help to get and where

2.00pm – 3.30pm

Session	Most useful aspects	What other information would have liked
<i>Osteopathic in Self Care</i>	<ul style="list-style-type: none"> • Holistic, easy to understand explanations and exercises demonstrated x6 • Happy with presentation x2 • How to find a local osteopath • Osteopath is right for me • New aspects and how to help the body to heat itself 	<ul style="list-style-type: none"> • Uncomfortable to hear physiotherapists being degraded • More discussion/examples on case histories
<i>Swollen Polio Legs</i>	<ul style="list-style-type: none"> • Knowledgeable/experienced presenter with in-depth knowledge - good PowerPoint x2 • Why it happens and how to deal with it x2 • What to watch for – i e. seek advice, be more aware of swelling x2 • Listening to others with similar problems x2 • Q and A's • Toilet visits increase at night as the edema clears with elevated legs • Can treat lymphoedema by scuba diving 	<ul style="list-style-type: none"> • Over technical, prefer user friendly information x2 • How to identify where the edema is • Medication

4. Evaluations – cont'd

2.00pm – 3.30pm

Session	Most useful aspects	What other information would have liked
Managing Arthritis and Osteoporosis	<ul style="list-style-type: none"> • Different aspects of arthritis, arthritis exercises and their importance x9 • Balanced intake of nutrition, calcium and vitamin D helps manage osteoporosis x4 • Useful way to help us and what may not • Q and A's • Bone density testing advice • Stressing muscles helps bone strength and delays osteoporosis • Keep moving to slow arthritis 	<ul style="list-style-type: none"> • Little knowledge of LEOp - presentation was more general x2 • Some advice was not helpful for people with LEOp
Partnering Polio	<ul style="list-style-type: none"> • Helping participants talk about what they were struggling with 	<ul style="list-style-type: none"> • N/A

4.00pm – 5.30pm

Session	Most useful aspects	What other information would have liked
Mindfulness	<ul style="list-style-type: none"> • Mind exercises and relaxation x4 • Simple, well founded meditation examples x2 • Very restful but finished early • How mindfulness generates loving kindness • Session calmness 	<ul style="list-style-type: none"> • Almost inaudible! • Little time for discussion as presenter left early • Ways to improve mindfulness techniques and positive mental states • Broader perspective on resilience and performance
Optimal Nutrition	<ul style="list-style-type: none"> • Everything covered, great, very alive x3 • I eat and drinking incorrectly • Food samples • Helpful in a general way • Will try nutrition supplements • Melinda was informative, knowledgeable and great at answering questions - we had some laughs • Best session of the day 	<ul style="list-style-type: none"> • Samples of how breakfast / lunch/ dinner menu should look like and the amount
Avoiding Falls	<ul style="list-style-type: none"> • Very interesting and useful information x3 • Practical hands-on demonstrations and risk evaluations x3 • Overview of all things relating to falls • Q and A's • Balance and being aware of all pitfalls • Handouts supplied to follow the talk • Need to see specialist about my leg • Need an eyesight test 	<ul style="list-style-type: none"> • More time to discuss environmental exercise, prevent falls and fill in a falls risk document x3 • People were talking amongst themselves • Attendee introductions too long • Longer session for Q and A's
Taking Charge of Your Own Health	<ul style="list-style-type: none"> • Where to look for help to manage our disability and paperwork for our final days • Learning about different websites available on-line on health issues 	<ul style="list-style-type: none"> • N/A

4. Evaluations – cont'd

4.2.1 Follow-up actions

- Be more aware of need to pace myself **x5**
- Low impact exercise **x4**
- Optimal nutrition for myself **x4**
- Follow-up swollen feet and legs **x4**
- See local osteopath **x3**
- See Steve de Graaff **x2**
- Treatment ideas from Dr de Graaff
- Learn to relax
- Benefits of posture regime
- Magnesium for restless legs
- Review layout of home to minimize risks
- Physiotherapist assessment
- Several follow-up plans for prevention program, bone density tests, swallow test, lymphoedema, speech pathology, massage, gait re-training, sleep assessment and mindfulness
- Placed shoes order from lunchtime display
- Pass information to local physiotherapist
- Web search for information

4.2.2 Comments

- Excellent program, all sessions informative and well balanced topics - well done! **x15**
- Circular Quay Choir was perfect finish to the day **x3**
- Helpful advice from Steve de Graaff
- All participants have amazing stories to tell
- Initially frustrated by people telling their story, but helpful information did come out
- Basic good health strategies with special emphasis on ways to learn and improve
- Each presenter gave different perspectives and aware of the LEOp
- Very hard making choices of topics – could have gone to all sessions
- Good food with every effort to provide for special needs
- Have decided to come again and bring my partner / carer
- Mary-ann is an excellent organizer and always very quick to respond to our needs
- Would like access hard / electronic copy of sessions
- Some attendees dominated sessions with interests not relevant to the discussion
- Few rooms were stuffy, airless and dark - one a/c is noisy and blocked out the presenter

4. Evaluations – cont'd

4.3 Day 2 Spouse/Carers Sessions Feedback

10.30am to 12.30pm

Session	Most useful aspects	What other information would have liked
Post-Polio Exercise Options	<ul style="list-style-type: none"> • Whether to use it or lose it • The need to have 'out of breath' exercises • Very good presentation • Q and A's 	<ul style="list-style-type: none"> • Some basic exercises to get started
Functional Footwear	<ul style="list-style-type: none"> • Speaker's polio specific knowledge and expertise • Made an appointment during the session • All very interesting • Technical side of making shoes for polios 	<ul style="list-style-type: none"> • Approximate costings • Details of shoe making companies in other states
A Breath of Fresh Air	<ul style="list-style-type: none"> • Excellent - every bit smaller or larger is helpful! x2 • Videos on swallowing and exercises to improve voice and breathing • Swallowing and voice care advice • Practical exercises demonstrated • Session well covered 	<ul style="list-style-type: none"> • Exercises to try • Information on asthma
Pain and Fatigue Management	<ul style="list-style-type: none"> • Information from Dr de Graaff and the attendees input • Helped understand difference between pain and fatigue and how to manage them • Causes of fatigue and how to handle the situation • Simple but helpful • Q and A's and content of Steve's talk 	<ul style="list-style-type: none"> • Some written information

2.00pm – 3.30pm

Session	Most useful aspects	What other information would have liked
Osteopathic in Self Care	<ul style="list-style-type: none"> • Exercises that help loosen muscles • Treatment demonstration on 3 polios 	<ul style="list-style-type: none"> • Written information explaining osteopathy
Swollen Polio Legs	<ul style="list-style-type: none"> • Very informative, detailed presentation • Learnt what causes swelling and how to relieve it 	<ul style="list-style-type: none"> • N/A
Managing Arthritis and Osteoporosis	<ul style="list-style-type: none"> • Good presenter, great information x4 • Provided useful websites • Osteoporosis section, supplements and diet • Simple exercises 	<ul style="list-style-type: none"> • N/A
Partnering Polio	<ul style="list-style-type: none"> • Sharing in partnering polio • I'm pretty well off comparatively • Good interactive session • Covered everything 	<ul style="list-style-type: none"> • N/A

4. Evaluations – cont'd

4.00pm – 5.30pm

Session	Most useful aspects	What other information would have liked
Mindfulness	<ul style="list-style-type: none"> • Was told name of a good book 	<ul style="list-style-type: none"> • Not sure what it was about • Session was not what I expected
Optimal Nutrition	<ul style="list-style-type: none"> • Good session, plenty of information • Butter not margarine, natural muesli, not toasted, sugar is bad, no chips, less beer – good session • Information on the different food diet components • Ratio of parts in a good diet 	<ul style="list-style-type: none"> • N/A
Avoiding Falls	<ul style="list-style-type: none"> • Things to watch out for • Risk factors and how to improve management 	<ul style="list-style-type: none"> • N/A
Taking Charge of Your Own Health	<ul style="list-style-type: none"> • Good Information and handouts • Useful information on consent for hospital treatment • Sharing personal problems and possible solutions • Website information and services available • Information was complete 	<ul style="list-style-type: none"> • More helpful websites

4.3.1 Follow-up actions

- Will follow-up Dr de Graaff's useful information
- To constantly monitor our capabilities
- Managing arthritis and exercise
- To watch my diet
- Exercise to achieve 'out of breath' status daily
- More effective exercise plan to progress, not regress
- More on arthritis and speech therapy
- Improve nutrition, have a bone density test
- Consult partner's doctor for change to new painkiller

4.3.2 Comments

- Wonderful, informative day organised efficiently **x2**
- All sessions provided new information to act upon
- Recommendation to walk
- Great entertainment
- Tiring but informative and enjoyable
- Shoe making contacts in other states would be good
- Every human is different – polio attacks in different areas thus each polio survivor is an individual with their own special problems and requires individual help
- Little disappointed some important sessions ran concurrently
- Dinner was cold, the rest excellent

4.4 Day 3 Polio Survivors Sessions Feedback

10.30am to 12.30pm

Session	Most useful aspects	What other information would have liked
Seated Yoga	<ul style="list-style-type: none"> • Techniques of exercise with yoga mindfulness and relaxation x7 • Gentle stretching, breathing, movement and meditation x4 • All of it - very good practitioner x3 • Releasing the mind by recognising and not judging the body • Stopped my back pain • Hope to follow this program at home 	<ul style="list-style-type: none"> • N/A
Early Polio Memories	<ul style="list-style-type: none"> • Sharing stories, experiences with those who understand x6 • Great session • My aunt cared for me after hospital - saved me going to rehabilitation home • All joined in discussions openly and listened to others, brought back good and bad memories 	<ul style="list-style-type: none"> • Impact on self and others • Start with brief outline - how and where begin your story
Mind Matters	<ul style="list-style-type: none"> • Benefits of computer based games • Tools to improve/retain good mind function • Nice to hear, had to do my whole life • Accessing and trialing various brain challenges • How to find computer mind games • Bit of fun, like to do puzzles so will try the locations out 	

2.00pm – 3.30pm

Session	Most useful aspects	What other information would have liked
Telling Your Story	<ul style="list-style-type: none"> • Useful tips to write my story, e.g. finding you own voice x3 • Excellent 	<ul style="list-style-type: none"> • N/A
A Family History Taster	<ul style="list-style-type: none"> • Advice on how/what research to do x4 • Very well presented x2 • Hearing other peoples stories x2 • More interesting than expected – especially the myth stories 	<ul style="list-style-type: none"> • How to use history websites
Travelling Options	<ul style="list-style-type: none"> • Very informative travel session with firsthand experience x3 • Good to see a business to assist disabled travelers x2 • Great ideas on ways to plan travel x2 • Interesting to hear of others' travel experiences • Pamphlets 	<ul style="list-style-type: none"> • User friendly travel destinations / companies • Needed more than negative wheelchair experiences
Partnering Polio	<ul style="list-style-type: none"> • Went to find out more about it – thought Graeme handled it very well 	<ul style="list-style-type: none"> • N/A

4. Evaluations – cont'd

4.00pm – 5.30pm

Session	Most useful aspects	What other information would have liked
Card Making	<ul style="list-style-type: none"> • Creative and well presented • Loved card making • Seeing how proud participants were of their achievements 	<ul style="list-style-type: none"> • N/A
Making the Most of Our New Reality	<ul style="list-style-type: none"> • Learning from others' experiences and sharing stories x2 • Reinforced that I must get a wheelchair and make the most of life • Useful sharing, helped to navigate my way forward • Put my experiences into perspective with others • That there is life after polio • Excellent, interesting speaker 	<ul style="list-style-type: none"> • More from other participants x2
Laughter: The Best Medicine	<ul style="list-style-type: none"> • Excellent fun!! Wonderful experience, must follow – very good x2 • Good insight into the structure and benefits of laughter • Meditation and learning how good laughter is for the soul • I believe that laughter is the key to life • Have been to others, each one different, but good 	<ul style="list-style-type: none"> • Genuine laughter techniques – not just change of facial expressions • Thought it was a joke telling / comedian based session – wrong

4.4.1 Follow-up actions

- Find a local seated yoga **x5**
- Continue yoga and family tree **x2**
- Exercises
- Check our family history, write my polio story **x4**
- Contact Flying Wheelies next time we travel **x2**
- Keep my brain active **x2**
- Must tend the mind as much as the body
- Computer mind games
- Laugh more - join a laughter club **x2**
- Buy an electric wheel-chair
- Check medical, car, aids
- Be more considerate of my partner

Assessments

- Have a physiotherapy assessment
- Get hearing checked
- See a doctor about my back

4.4.2 Comments

- Great day **x7**
- First session speaker Dr Loren Mowszowski was fascinating **x2**
- Chat to others for helpful hints to overcome problems **x2**
- Tied the mind, body relationships in together well
- Very happy with my chosen sessions
- Loren's talk was really helpful and reassuring
- Pleased to have Gayle 'on our team'
- Neuroscience and importance of maintaining optimum cognitive function
- Enjoyed massage with Aruna
- Great accommodation, food, company, etc.

4. Evaluations – cont'd

4.5 Day 3 Spouse/Carers Sessions Feedback

10.30am to 12.30pm

Session	Most useful aspects	What other information would have liked
Seated Yoga	<ul style="list-style-type: none"> • How simple seated yoga is for all 	<ul style="list-style-type: none"> • N/A
Early Polio Memories	<ul style="list-style-type: none"> • How polio is an individual experience • Listening to other stories was good 	<ul style="list-style-type: none"> • N/A
Mind Matters	<ul style="list-style-type: none"> • More mind games sites to check • Websites to keep the mind active • Very stimulating and enjoyable • Navigating websites and where payments are required • Great to get a list of websites for mind games and training 	<ul style="list-style-type: none"> • Something other than computer games x2

2.00pm – 3.30pm

Session	Most useful aspects	What other information would have liked
Telling Your Story	<ul style="list-style-type: none"> • N/A 	<ul style="list-style-type: none"> • N/A
A Family History Taster	<ul style="list-style-type: none"> • N/A 	<ul style="list-style-type: none"> • N/A
Travelling Options	<ul style="list-style-type: none"> • Excellent session, very informative, will use this source • Information on what is available • Learning how to talk to facilities, etc., was priceless • Valuable source of information 	<ul style="list-style-type: none"> • Expected more on different modes of travel, not just speakers' experiences - will check website
Partnering Polio	<ul style="list-style-type: none"> • Sharing problems and solutions with other carers x2 • Lots of help from other carers • Where to ask for help - presenters personal advice sheet • Great presenter 	<ul style="list-style-type: none"> • N/A

4. Evaluations – cont'd

4.00pm – 5.30pm

Session	Most useful aspects	What other information would have liked
Card Making	<ul style="list-style-type: none"> • Very creative and enjoyable, could have gone all day • Great for chatting as you work • Preparation beforehand was excellent 	<ul style="list-style-type: none"> • N/A
Making the Most of our New Reality	<ul style="list-style-type: none"> • Excellent session for both survivors and significant others • Outstanding - mirrors my partner's journey through life with PPS • Wonderful session • Inspiration from speakers' experiences - showed things in a new light 	<ul style="list-style-type: none"> • More about speakers' hard-won advice
Laughter: The Best Medicine	<ul style="list-style-type: none"> • Great fun, very relaxing • Everything well presented, good participation 	<ul style="list-style-type: none"> • N/A

4.5.1 Follow-up actions

- Access travel website and service
- Will make the most of our new reality
- Get information on companion card, NICAN and taxi vouchers
- Design my own exercise program
- Continue to use internet brain and training sites
- Do card making
- Pass new information to my support group
- See problems from a different angle
- Mind games good when I have time
- Inspired to do more family history
- See the doctor

4.5.2 Comments

- Great day, stimulating and invigorating **x2**
- 'New reality' session was the best
- Good to see AutoMobility vehicle modifications, could suit our needs
- Inspired by how polios deal with increasing health concerns
- Tommy Deans performance a high point, very enjoyable, good choice
- Dr Loren fantastic - refreshing to see a young women who knew her subject and presented it well
- Disappointed with no media coverage

4. Evaluations – cont'd

4.6 Day 4 Polio Survivors Sessions Feedback

10.30am to 12.00pm

Session	Most useful aspects	What other information would have liked
<i>Awakening the Creative Spirit Within</i>	<ul style="list-style-type: none"> • Peaceful exercise on getting in touch with your inner self and letting go x2 • Entire session great, very meaningful • Calming, feel ready to start again • Remember to feed your Spirit 	<ul style="list-style-type: none"> • N/A
<i>Philosophically Speaking</i>	<ul style="list-style-type: none"> • The challenging discussion x2 • Very interesting, charming lecturer, • Nice way to end the Retreat • Learned more on philosophy • Information handouts • U3A sounds OK 	<ul style="list-style-type: none"> • N/A
<i>Meditation</i>	<ul style="list-style-type: none"> • Excellent, interesting, peaceful, relaxing x4 • Different approach to meditation – yoga philosophy and music • Must practice more • Interesting but bit wafy 	<ul style="list-style-type: none"> • Longer session • Prefer more 'down to earth' meditation

4.6.1 Follow-up actions

- Find time to meditate and search local options **x2**
- Meditation and reflection
- Remembering 'balance' in life
- Practice, practice, practice!
- Using music handouts and knowledge learnt when meditating at home
- Take time to get in touch with my creative spirit
- Scheduling time for the spirit
- Calm down, look after yourself
- More exercise

4.6.2 Comments

- Brilliant speakers, full of knowledge
- Much needed time for centering
- Learned more on condition and coping strategies

4. Evaluations – cont'd

4.7 Day 4 Spouse/Carers Sessions Feedback

10.30am to 12.00pm

Session	Most useful aspects	What other information would have liked
<i>Awakening the Creative Spirit Within</i>	<ul style="list-style-type: none"> • Very interesting, thought provoking x2 • Most useful • Spiritual encouragement 	<ul style="list-style-type: none"> • N/A
<i>Philosophically Speaking</i>	<ul style="list-style-type: none"> • N/A 	<ul style="list-style-type: none"> • N/A
<i>Meditation</i>	<ul style="list-style-type: none"> • Very relaxing • Not useful to me but informing 	<ul style="list-style-type: none"> • N/A

4.7.1 Follow-up actions

- Consider, revise relevant information

4.8 Booked Sessions Feedback

Session	Most useful aspects
<i>Massage – Carol</i>	<ul style="list-style-type: none"> • Has a good interest in PPS treatment • Enjoy massage x2 • Helped me relax my muscles • Massage was very calming
<i>Massage – Aruna</i>	<ul style="list-style-type: none"> • Aruna was gentle and good
<i>Massage – Heena</i>	<ul style="list-style-type: none"> • Useful information for self-management of my LEOp condition
<i>Lymphoedema Discussion Dr Helen Mackie</i>	<ul style="list-style-type: none"> • Useful information for self-management of my LEOp x2 • Great to talk on my specific problem • Consultant listened, understood and gave useful advice • Learning more about lymph glands • Did not know lymphoedema needs attention • Needs a do's and don't's handout
<i>Self-Management Discussion Dr Steve de Graaff</i>	<ul style="list-style-type: none"> • Consultant listened, understood and gave useful advice x2 • Practical help and tips x2 • Suggested things I should see my local doctor about
<i>Foot Care Rudo Makuyana</i>	<ul style="list-style-type: none"> • N/A

4. Evaluations – cont'd

4.9 General Feedback

4.9.1 Venue

1 = Below standard to 5 = Excellent	1	2	3	4	5
Standard of Venue	0	0	3	5	30
Standard of Room Accommodation	0	1	1	8	29
Standard of Meals	1	1	7	9	29
Met any special requirements	1	0	1	7	23

4.9.2 Organisation

1 = Below standard to 5 = Excellent	1	2	3	4	5
Organisational Standard	0	0	1	3	36
Standard of Retreat activities	0	1	0	15	24
Standard of Retreat entertainment	0	0	1	10	27

4.9.3 Future Retreats



Would you recommend this type of Polio Health and Wellness Retreat to others?		Would you attend another Polio Health and Wellness Retreat in future?	
Yes	No	Yes	No
38	0	36	0



4.9.4 Comments

- Outstanding organization and choices
- Glad I came, good spirit
- Valued networking and sharing ideas
- It was great – see you in 2015
- Wonderful venue and sessions
- Need to conserve energy better
- Don't like to miss anything, all interesting, enjoyable - but exhausted by the end of the day
- Little more exercise and rest
- Totally great weekend, wonderful presenters
- Some activities need longer sessions, e.g. card making
- Fewer options per day, have longer exploring activities
- Encouraging and inspirational meeting kindred spirits on the same journey
- Great team effort by organizers
- Thoroughly enjoyable, informative time
- Fabulous 4 days, time passed quickly
- Quality sessions all weekend
- Brilliant speakers, full of knowledge
- Thoroughly enjoyed the Retreat, learned plenty
- Much needed time for centering
- Excellent programs
- Learned more on condition and coping strategies
- Good to meet/learn from survivors/carers experiences
- Thank you, another fabulous, refreshing, informative Retreat
- Roll on next year!
- Mary-ann has boundless enthusiasm and focus
- Food was better last time we were here





5. Presenters (in order of presentation)




Thursday 8 May






	<p>Welcome</p>	<p>Dr John Tierney OAM President and National Patron Polio Australia</p> <p>From 1991 to 2005 John Tierney gave 14 years of distinguished service to the Australian Parliament, where he served as Senator for NSW. During his time in Parliament, he was a Parliamentary Secretary to the Deputy Leader in the Senate and Shadow Parliamentary Secretary for Communications, Information Technology and the Arts. John also chaired a number of Senate Standing and Select Committees over a range of portfolio areas, with a particular focus on education, employment, industrial relations, communications, information technology, health and welfare issues. John has taken a passionate interest in the area of disability, having contracted polio at birth, and was a special parliamentary adviser to the Minister for Community Services on disability matters from 1998 to 2001.</p> <p>In 2005 John became a Partner at Government Relations Australia Advisory, a position he retired from in 2011. However, he found it hard to completely retire and is now working part-time as Special Counsel at 1st State Government and Corporate Relations. John provides strategic advice on government matters to corporate clients across a wide range of industries at both a federal and state level in NSW. Additionally, he has undertaken pro bono advisory work for Lifeline Australia, Polio Australia and the Australian Association for the Education of the Gifted and Talented.</p> <p>In the 2012 Australia Day Awards John was awarded a Medal of the Order of Australia (OAM): For service to the Parliament of Australia, to education, and to the community.</p> <p>John was elected President of Polio Australia at the 2012 Annual General Meeting. In addition, John continues as Polio Australia's National Patron.</p>
	<p>Welcome and Mind Matters</p>	<p>Gillian Thomas Vice President Polio Australia</p> <p>For over 25 years I have worked for Polio NSW on a voluntary basis. I was a member of the original Working Party set up in 1988 to establish the Network, was subsequently elected as Secretary, and in 1997 became the Network's President.</p> <p>From 1989 until 2012 I was the Editor of the Network's highly regarded quarterly newsletter <i>Network News</i>. In 2002 I was honoured to receive an inaugural <i>David Bodian Memorial Award</i> from the International Post-Polio Task Force in recognition of my work for polio survivors, while in 2004 I was invited to serve on Post-Polio Health International's <i>Consumer Advisory Committee</i>. In January 2009 I was delighted to be awarded an <i>Australia Day Community Service Award</i> from Randwick Council for my outstanding service to polio survivors and the community. I passionately believe in the need for a national voice for polio survivors and my efforts culminated in the highly successful meeting of all Australian State Polio Networks in May 2007 and the unanimous agreement to form Polio Australia. Polio Australia is now a reality and in 2008 I was elected its inaugural President.</p> <p>In accordance with Polio Australia's Constitution, I stepped down from the role of President at the 2012 AGM and now serve as Vice President.</p>


	<p>Guest Speaker: <i>"The 4th of May: The Memories of Paul Galy OAM"</i> and Functional Footwear</p>	<p>Paul Galy OAM Footwear Practitioner David Windsor Shoemakers</p> <p>Born in Hungary, Paul was amongst the first Hungarian refugees to arrive in Australia after the Hungarian Revolution of 1956.</p> <p>Paul comes from a long family line of corrective footwear manufacturers. The family business dates back at least to the early 1880s when a factory was established in Budapest Hungary that became one of the largest manufacturers of orthopaedic shoes, artificial limbs and callipers in pre-WWII Hungary.</p> <p>As Guest Speaker, Paul will be discussing his book "The 4th of May: The Memories of Paul Galy Oam" which has been described as follows:</p> <p><i>"The author keeps the reader intrigued as to the outcomes of all the characters as they made their entrances into the story of his memoirs. He explores their frailties and their strengths, and the fight for survival that must never be forgotten! This truly wonderful chain of events is further enhanced with the authors own drawings which graphically interpret the emotional roller-coaster ride that is his story."</i></p> <p>Paul Galy's main line of business is making hand-made orthopaedic shoes for people with disabilities, including polio survivors and sufferers of vascular and arthritic conditions. Many of his clients are elderly. He takes great pride in helping and enabling these individuals to walk in comfort and grace. He also makes orthotics for those with conditions such as flat feet, diabetes, overlapping toes, and bunions. Many of his clients are referred from the major Sydney teaching hospitals.</p> <p>In June 2007 Paul was awarded a Medal of the Order of Australia (OAM): For service to the community as a medical grade footwear practitioner and manufacturer.</p>
	<p>Program Overview and Announcements and Guided Deep Relaxation and Choir</p>	<p>Mary-ann Liethof National Program Manager Polio Australia</p> <p>I worked as the Coordinator of Polio Network Victoria from 2004 to 2009, which included being one of the Victorian representatives on the Management Committee for Polio Australia. I was officially appointed as Polio Australia's National Program Manager in early January 2010 on a part time basis, which increased to full time in January 2011 thanks to a three year grant from The Balnaves Foundation.</p> <p>In 2008, I visited 10 post-polio related services across North America on a Churchill Fellowship Study Tour grant, the purpose of which was <i>"To identify techniques to better manage the late effects of polio"</i>. In 2009, I travelled to Roosevelt Warm Springs in Georgia, USA for Post-Polio Health International's 10th International Conference: <i>Living with Polio in the 21st Century</i> and Wellness Retreat to learn the benefits of the holistic chronic condition self-management model. With this experience, I was able to put together Polio Australia's first Late Effects of Polio Self Management Residential Program (also known as a Polio Health and Wellness Retreat) in April 2010 in Sydney, and four subsequent Retreats across Australia. In September 2011, I gave a presentation on our Retreats at the European Post Polio Conference in Copenhagen, where there was considerable interest expressed in this Program.</p>

Friday 9 May



	<p>The Polio Body <i>and</i> Self-Management Discussion <i>and</i> Pain Management</p>	<p>Dr Steve de Graaff Senior Rehabilitation Physician and Director of Pain Services Epworth Healthcare</p> <p>Dr Stephen de Graaff is a Fellow of the AFRM (RACP). His areas of research interest include Stroke Rehabilitation, Spasticity Management, Pain Management, Post-Polio Sequelae and Continuing Professional Development. Steve is currently Chairman of the Education Committee of the Australasian Faculty of Rehabilitation Medicine (RACP).</p>
	<p>Swollen Polio Legs <i>and</i> Lymphoedema Discussion</p>	<p>Dr Helen Mackie Rehabilitation Physician Mt Wilga Private Hospital</p> <p>Dr Helen Mackie is a Consultant in Rehabilitation Medicine who has been the medical director of the Mt Wilga Private Hospital Lymphoedema Service since its commencement in 1991. She is the current President of the Australasian Lymphology Association and is a member of the International Society of Lymphology.</p>
	<p>A Breath of Fresh Air</p>	<p>Colleen Kerr Speech Pathologist Optimal SP</p> <p>Colleen has worked as a Speech Pathologist for more than twenty five years with extensive experience in adult communication and swallowing disorders in acute, rehabilitation and community settings. She specialises in neurological disorders including Parkinson's, Multiple Sclerosis and Post-Polio Conditions. Colleen has been Director of Optimal Speech Pathology for twelve years and is driven to integrate research findings into clinical practice. Colleen considers it a great privilege to work with clients and their families, and is firmly committed to giving clients the skills to self-manage their recoveries.</p>
	<p>Post-Polio Exercise Options</p>	<p>Gilly Davy Clinical Educator and Senior Neurological Physiotherapist Advance Rehab Centre</p> <p>Gilly qualified as a physiotherapist in the UK in 2004 and worked in the National Health Service before moving to New Zealand where she worked for 5 and a half years. Gilly has specialised in neurological physiotherapy since 2007 and worked as a private community based therapist in Auckland for 3 and a half years before moving to Sydney. She has experience working with a wide range of neurological conditions and is particularly passionate in treating spinal cord injury, multiple sclerosis and Parkinson's disease. Gilly is an internationally qualified Nordic Walking instructor and uses Nordic Walking to help with gait re-training and cardiovascular exercise in the neurological population. She is based full time at the ARC Clinic and is the lead clinical educator of the Macquarie University and Australian Catholic University student program. Gilly is the lead clinician in the PD Warrior program, hydrotherapy service, falls and balance groups and Nordic Walking.</p>




	<p>Massage Therapy</p>	<p>Carole Gridley Massage Therapist HealthTouch Massage Therapies</p> <p>Carole has 15 years' experience as a remedial massage therapist and aromatherapist and has worked with a wide variety of people. Her qualifications include: Diploma Remedial Massage / Diploma Aromatherapy / Cert. I and II Oncology Massage / Australian Traditional Medicine Society (ATMS) Member 7810 / Registered as a provider with most private health funds.</p> <p>For the past five years she sub-contracted her therapeutic massage services to Advance Rehab Centre, a neuro physiotherapy facility, during which time she worked with many clients managing acute and chronic medical conditions as well as those recovering from stroke, rehabilitating from serious injury or being treated for, or recovering from, cancer.</p> <p>A few years ago, Carole undertook further training in oncology massage. This invaluable training has helped considerably with implementing appropriate massage techniques, positioning and session duration, not only for those being treated for, or recovering from, cancer but also for those managing chronic medical conditions and/or injury rehabilitation.</p> <p>Carole provided massage therapy treatments at the Polio Retreat held in 2010 and is looking forward to returning for the 2014 event.</p>
	<p>Massage Therapy</p>	<p>Aruna Ellis Massage Therapist Massage In Care</p> <p>I am a Registered Nurse and Massage Therapist, with more than 20 years' experience in the field of massage. I combine my skills and love of nursing and massage therapy to care for my clients. I specialise in working with adults and children with major illness and/or various physical conditions. I run my own practice, and cater for this population, along with providing specialised massage treatment for post-operative patients. We provide massage in any care facility, hospital, nursing home, palliative care, etc.</p>
	<p>Osteopathic in Self Care <i>and</i> Mindfulness for Health</p>	<p>Dr Stiofan MacSuibhne Osteopath Central Sydney Osteopathy</p> <p>I am a registered osteopath in Australia and registered in the general osteopathic and Western Medical Acupuncture scopes of practice in New Zealand. I treat patients from across the lifespan. I have a number of areas that I am particularly interested in:</p> <ul style="list-style-type: none"> • The management of complex/chronic pain conditions such as post stroke pain, headache, atypical facial pain and TMJ dysfunction • Occupational injuries/overuse and postural strain patterns and vocational rehabilitation • Pre-habilitation/post-surgical rehabilitation for joint replacement surgery in older patients with osteoarthritis • Patients with chronic disease / long term conditions • Stress management <p>My practice of acupuncture is largely restricted to musculoskeletal conditions, complex pain presentations and functional disorders such as irritable bowel and bladder syndromes.</p> <p>I teach mindfulness as a technique to help patient manage chronic health conditions, pain and palliative care contexts or as a resource for resilience in management / occupational health settings.</p>





	<p>Osteopathic in Self Care</p>	<p>Anne Cooper Osteopath Central Sydney Osteopathy</p> <p>Osteopath Anne Cooper has been practising in Sydney since 1989. She is President of the NSW Osteopathy Council, a Life member of the AOA and one of 5 osteopaths in her family. Anne's clients are mostly much stressed professionals who work very hard - and while they savour the finer things in life, they are time poor, with limited ability to fit in an exercise and fitness regime.</p>
	<p>Managing Arthritis and Osteoporosis</p>	<p>Jenny Ly Health Promotion Officer Arthritis and Osteoporosis NSW</p> <p>Jenny Ly is the Senior Health Promotion Officer at Arthritis and Osteoporosis NSW. She is also a pharmacist and has previously worked in community pharmacy before moving into health promotion and education.</p>
	<p>Avoiding Falls</p>	<p>Rachael Morris Occupational Therapist Advance Rehab Centre</p> <p>Rachael Morris is an experienced Occupational Therapist, qualifying in 2003. She has a breadth of experience and has worked in South Africa, the UK and now Australia since 2007. Her specialist skills and knowledge have helped many individuals to identify and achieve their rehabilitation goals. She has worked with a diverse client group with complex orthopaedic and neurological injuries. Rachael is passionate to implement evidence-based research into her occupational therapy practice.</p>
	<p>Optimal Nutrition</p>	<p>Melinda Overall JP Nutritionist</p> <p>Melinda Overall is a fully qualified Nutritionist, practicing in Sydney's inner-west, whose aim and passion is to help people obtain their best health and well-being through education, diet and lifestyle coaching. Melinda works with clients of all ages on a range of health issues from a holistic, lifestyle and nutrition perspective. She is always mindful to support and work with any treatment plans prescribed by medical practitioners and other complementary therapists in order to provide the best integrated and holistic healthcare for individuals. She is also a member of the Australian Traditional Medicine Society. Melinda's mantra is that good health is about balance not denial.</p>
	<p>Taking Charge Of Your Own Health</p>	<p>Mary Potter Consumer Representative Consumer Health NSW</p> <p>Mary Potter has been actively involved in health consumer advocacy for a number of years. Much of her understanding stems from the need to advocate for herself and her family. After graduating with a science degree she has worked in research and routine hospital laboratories. After many years out of the paid workforce she retrained in community welfare and hospital pastoral care. Her passion is continuity of care which covers a huge territory.</p>

	<p>Partnering Polio</p>	<p>Graeme Smith Spouse/Partner/Carer</p> <p>As the husband of a polio survivor, I have learned about a whole new part of my wife's childhood. I have also learned to share and partly understand her current issues dealing with post-polio and recently cancer. Being a carer created many new issues for me. I found that sharing with others who understand can be very helpful.</p> <p>Through my membership of our polio support group I have been able to meet with other partners of polio survivors and talk about our experiences and challenges. It has also given me the opportunity to gain more information about the condition and how I might be able to help, for example, by modifying our lifestyle and living arrangements. Sharing with trusted friends can also allow a good measure of humour to ease the way.</p>
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Saturday 10 May




	<p>Healthy Brain Ageing</p>	<p>Dr Loren Mowszowski Healthy Brain Ageing Clinic Clinical Research Unit Brain and Mind Research Institute The University Of Sydney</p> <p>Dr Loren Mowszowski is a Clinical Neuropsychologist, Research Associate and Postgraduate lecturer at the Brain and Mind Research Institute, University of Sydney. She is a Member of the Australian Psychological Society. Her clinical and research interests focus on older adult neuropsychology, including mild cognitive impairment, neurodegenerative disorders, late-life depression and Parkinson's disease. She is experienced in developing and facilitating cognitive training and psychoeducation programs, in a research context as well as in her neuropsychology practice. She has published several peer-reviewed journal articles and presented at conferences and community forums on these topics. Loren hopes to continue to investigate the effectiveness and mechanisms of cognitive training and 'healthy brain ageing' strategies as therapeutic techniques for managing cognitive decline in older adults, with a view to translating research findings into evidence-based practice accessible to the wider community.</p>
	<p>Seated Yoga Therapy <i>and</i> Aromatherapy</p>	<p>Heena Raikar Yoga Therapist</p> <p>Heena Raikar was born in India. Her great grandfather was a sadhak of nada yoga (disciple of classical music). Heena was introduced to yoga at the age of 17 and trained in India at the Yoga Institute, Mumbai and at the Kaivalyadham Institute, Pune, both well known for teaching therapeutic use of yoga. Heena has developed her own unique style of teaching yoga which includes therapeutic use of yoga in combination with psychotherapies giving it a holistic health perspective. She aims to spread the message '<i>Yoga is not only for people who can twist themselves in a knot inside out, but for common individuals who have their daily responsibilities and who are not in their best health</i>'.</p> <p>Heena aspires to teach yoga for a therapeutic purpose to benefit people coping with chronic health conditions like cardiac conditions, depression, anxiety and are struggling to manage their health.</p>

	<p>Foot Care Appointments</p>	<p>Rudo Makuyana Podiatrist Blacktown Podiatry</p> <p>I have been working as a Podiatrist for the last 3 years in Blacktown. As a Podiatrist, I strive to achieve the best health care outcomes for my patients. I believe that it's more than treating individual foot complaints but the patient as a whole, bearing in mind that their podiatric conditions can affect their general health. I am committed to the advancement of my profession so therefore think it's crucial to always practice evidence based medicine. In 2010 me and my friends at The Global Poverty Project, ran a campaign called <i>The End of Polio</i> where we successfully raised \$118 million for global polio eradication efforts. I truly believe and I am committed to seeing a world where we eradicate polio forever.</p>
	<p>Telling Your Story <i>and</i> Making the Most of Our New Reality</p>	<p>Gayle Kennedy Author</p> <p>Gayle Kennedy is a member of the Wongaiibon clan of South West NSW. She was Indigenous Issues Editor/Writer for Streetwise Comics from 1995-1998. In 2005 her book of poetry 'Koori Girl Goes Shoppin' was shortlisted for the David Unaipon Award. Gayle went on to win the award in 2006 with her book 'Me, Antman and Fleabag.' That book was shortlisted for a Victorian Premier's Literary Award and Deadly Award and was also commended in the Kate Challis RAKA Award. Her children's books for the Yarning Strong series were nominated for 2011 Deadly Award for Achievement in Literature. She has had articles and short stories published in publications as diverse as 'The Australian Women's Weekly', 'Readers Digest', 'Australian Author', 'Phoenix Educational Review', 'Australian Writer', 'The Sydney Morning Herald', and the 'Edinburgh Review.'</p> <p>Gayle has presented at various writers festivals and NAIDOC events as well as speaking both nationally and internationally on her experience with polio and disability in general. Gayle also worked with the Red Room Company on a poem to celebrate the 'Carved Trees' exhibition at the NSW State Library. Gayle speaks at schools and also runs writing workshops. Gayle published 6 new graphic novels with OUP in February 2014.</p>
	<p>Early Polio Memories <i>and</i> Card Making</p>	<p>Joan Smith Convener, Knox-Yarra Ranges Post-Polio Support Group, Victoria and Secretary, Post Polio Victoria</p> <p>As a polio survivor I have been committed to advocating for the rights and dignity of people with disabilities. That was a strong focus for me as Principal of a school for children with severe to profound disabilities.</p> <p>After early retirement, due to post-polio syndrome, I embarked on writing my life story for my grandchildren. That developed into the further project of producing and publishing "The Calliper Kids" – a book detailing life stories of eleven polio survivors living in our area. The book has proved a useful tool in educating our medical practitioners, aged-care providers and wider communities across the State. The outcomes of the project have also been very powerful for our story tellers. I continue in the role as Convenor of the Knox-Yarra Ranges Polio Support Group, where we continually receive and share very positive feedback about our stories.</p>

 	<p>A Family History Taster: Catching The Bug!</p>	<p>Ronda Gaffey and John Gaffey U3A Tutors</p> <p>Ronda and John are a sister and brother team who have an abiding passion for Family History – a passion which began with a curiosity engendered by the many stories told at family gatherings over the years.</p> <p>They are currently leading a U3A course in Family History called, “Catching The Bug”, sharing their experience and knowledge as well as supporting others in the thrill of the “ancestor hunt”, the historical, social and political context of their lives and the satisfaction such a journey of discovery brings.</p>
	<p>Travelling Options for People Ageing with a Physical Disability</p>	<p>Matthew Hennig Manager Flying Wheelies</p> <p>As a vision impaired, wheelchair traveller himself, Matthew has personally experienced the difficulties people with disabilities face every day. Whether it's poor access, careless service or inadequate facilities, one bad experience can mean that businesses lose the impaired travellers, their carers, their family and work colleagues as customers. Matthew started up <i>Flying Wheelies</i> to help their business partners keep their customers feeling that they are truly well cared for so they return next time.</p>
	<p>Laughter: The Best Medicine</p>	<p>Usuff Omar Newtown Laughter Club</p> <p>Usuff Omar has been a laughter leader for ten years. He trained under the founder of laughter clubs, Dr Madan Kataria. Usuff has led laughter sessions in Sydney, Hong Kong and USA. He currently leads two weekly laughter clubs in Sydney.</p>

Sunday 11 May

	<p>The Healthy Spirit <i>and</i> Awakening the Creative Spirit Within</p>	<p>Sister Annie Bond Previous Centre Director St Joseph's – Baulkham Hills</p> <p>Annie is a Sister of St Joseph and has ministered in schools and parishes in the Queensland Province. The majority of her time in ministry has been spent working in parishes first as a Pastoral Associate and then as Pastoral Co-ordinator where she exercised leadership of a parish.</p> <p>She holds a Master of Arts in Pastoral Studies and in May 2008 she received the Doctor of Ministry Degree from Catholic Theological Union in Chicago. Annie's studies have focussed in the area of liturgy.</p> <p>Annie was appointed the Director of St Joseph's Baulkham Hills Centre for Reflective Living in July 2008, although in April 2014, she will be commencing a new position as Assistant Director at Mary MacKillop Place in North Sydney.</p>
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 	<p>Meditation</p>	<p>Leanne Huet Sahaja Yoga Practitioner</p> <p>Leanne Huet has been practising and teaching Sahaja Yoga meditation for the past 30 years. Sahaja yoga meditation is a simple technique that anyone can do. It has immediate benefits in stress relief and a feeling of peace and contentment. Physically, it has been scientifically demonstrated that regular meditation can reduce the severity of certain illnesses.</p> <p><i>and</i></p> <p>Lene Jeffrey Solfège Music Therapist</p> <p>Lene Jeffrey RMT is a certified music therapist and meditation instructor. Lene has been developing musically supported methods for achieving and enhancing a thought-free meditative state of “mental silence”. With a particular interest in youth mental health, she has been implementing her programs in mainstream schools, examining the level of improvement in the mental health risk of participants. She currently works as a music therapist at Giant Steps School Sydney - a specialised public school for children with autism, where music therapy is an integral part of programs across all key learning areas. Lene also works with individual clients in private practice.</p>
	<p>Philosophically Speaking</p>	<p>Margot Taverne U3A Tutor</p> <p>Margot was born in Indonesia and spent three years in a POW camp on Java during WW2. She married at eighteen and spent the next thirty years being a wife and mother.</p> <p>Margo discovered Philosophy at forty and ‘resigned’ from motherhood at fifty to study Philosophy, Ancient History and Education at Macquarie University. She achieved a BA Hon Dip Ed, then resigned from study to be a better grandmother.</p> <p>Following her discovery of U3A, Margo joined the Upper North Region committee and became Leader in Philosophy groups. She went on to mentor gifted year five and six pupils in Ancient History, Mythology and Philosophy.</p> <p>Although now a great-grandmother, Margot has no intention on giving up her Philosophy courses.</p>

6. Articles

6.1 An Oasis In The Middle Of Suburbia by Nola B (NSW)

On Thursday, 8th May, I set out for the [St Joseph's Centre for Reflective Living](#). This Centre is not far from where I live and each time I visit it, I think of it as an oasis in the middle of suburbia. Its smooth expansive lawns, interspersed with trees, its beautiful gardens brightened by roses and tubs of Spanish Jasmine, could not help but lift the spirit, sharpen the mind and focus the body away from its deficiencies. It is an ideal venue for a Retreat concentrating on the Body, Mind and Spirit, especially the Spirit, as it is a former Convent of the Sisters of St Joseph and reminders of their founder, St Mary of the Cross MacKillop, (Australia's first saint) are everywhere.

Sixty people, the majority of whom had contracted polio, were gathered to hear many speakers and engage in various activities. Some were 'Retreat Junkies', a title they have given themselves as they have attended several Retreats, others were at their second retreat and others their first. Each person absorbed the Retreat in a different way, and this article will be how I absorbed the Retreat with information gleaned from others during the final session.

On Thursday afternoon, after getting our bearings (the building has many floors, passages, small rooms and comfortable bedrooms), we gathered for a meal. Later in the evening we were welcomed by Dr John Tierney, President of Polio Australia, Gillian Thomas, Vice President of Polio Australia and President of Polio NSW, and Mary-ann Liethof, National Program Manager, Polio Australia. We then heard from Paul Galy, whom many of you may know as the maker of your shoes. Paul spoke about his book "[The 4th of May](#)". This book was reviewed in Network News Issue 83, and it is a story of a family's survival during a dark age of our history. Paul stated he felt so relieved after the events in his family's life had poured from him in his writing but he felt strangely exposed in revealing so much of the family's (and his) experiences. Following Paul's talk, each attendee introduced her/his self and spoke about what she/he expected from the Retreat.

At the Retreat were John and Faye Powell. Faye had written a book, "[Matthew Pearce and The Howlong Connection](#)". John is a descendant of Matthew Pearce, a pioneer of The Hills district and who once owned the land on which St Josephs had been built. Matthew built Bella Vista, a beautiful home maintained by Baulkham Hills Shire Council and also an oasis in a mixed residential and industrial area.

On Friday the hard work began, learning about the Healthy Body. As in each section of the Retreat, there was one Plenary session at the beginning, "[The Polio Body](#)", presented by Dr Stephen de Graaff, Senior Rehabilitation Physician, Epworth Healthcare, Victoria. Dr de Graaff spoke on the initial polio infection and what occurred in the body, the advent of post-polio syndrome and the late effects of polio, and the difference and the management of both. His talk will be on the [Polio Australia website](#), along with other Retreat presentations.

Following the Plenary session were concurrent sessions, all based on the Polio Body. This was the format for the rest of the Retreat. Interspersed between sessions, were massage sessions, displays from the Independent Living Centre NSW of assistive technology, a Barefoot Freedom Footwear Display and, of course, meals. The day concluded with a performance from the "[Circular Keys Chorus](#)", proponents of the art-form of barbershop harmony.

Saturday, The Healthy Mind, commenced with a Plenary session titled, "[Healthy Brain Ageing](#)", by Dr Loren Mowszowski from the Brain and Mind Research Institute, University of Sydney. This was one of the best sessions, probably because most of us could relate to it. She gave examples of incidents, losing our car keys and forgetting that word. She assured us that this is quite normal, because as the body ages, so does the brain, but it could also indicate something else is going on and to seek help if one is concerned about it. She gave us little exercises to illustrate her statements. By request, this presentation will not be on Polio Australia's Website.

Again, there were sessions such as Seated Yoga, Early Polio Memories, Telling Your Story and a Family History Taster, with more massages and consultations, interspersed between them. There was also a session for partners of a person who has had polio.

The day concluded with a visit from the comedian, [Tommy Dean](#). This was a very enjoyable segment of the Retreat, made more so because of a discussion as to whether Tommy had contracted polio or [Guillain Barre Syndrome](#) as a child. After much discussion and advice to Tommy, we still don't know what he contracted, but he is certainly one of us - he has a disability.

Sunday - the final day of the Retreat. This day is always different. People are often sad to be leaving newly found friends, they are hurrying to pack and get their bags away, and they are distracted by the impending return to normality. The Healthy Spirit is not an easy topic, but it was well illustrated by Sr Annie Bond, previously Centre Director at St Joseph's, in her Plenary session.

Sr Annie spoke of how the spirit is intangible but an integral part of the body. She spoke of how beauty takes a person beyond mundane things – that is spirit. She spoke of the joy when she returns to St Joseph's, the beauty of the place, and the spirits which have been here – both the spirits of early pioneers and those of the religious order.

The day concluded with a closing Plenary where everyone spoke on what they had gained from the Retreat. To the first-timers, the knowledge they had gleaned from the various speakers and how that knowledge could assist them in managing their new symptoms was invaluable. To the Retreat Junkies and others there was always something new to learn, but also the making of new friends and renewing friendships was also of high importance. We left on a high and looking forward to the next [Retreat at Torquay](#), Victoria in 2015.

6.2 New Friendships Forged and the Old Renewed by Jan W (Qld)

From 08 to 11 May 2014, I had the pleasure of joining an eclectic group of 60 or so polio survivors (some with carers) at St Joseph's Centre for Reflective Living, Baulkham Hills, NSW to participate in a diverse interactive program exploring avenues available to assist and enhance the lifestyle of those of us experiencing PPS (Post-Polio Syndrome) and LEOp (Late Effects of Polio). Participants travelled from near and far, and included one delegate from New Zealand.

Thursday evening saw Welcome to the Retreat by Dr John Tierney OAM, President and National Patron of Polio Australia and Gillian Thomas, Vice President of Polio Australia followed by Guest Speaker Paul Galy OAM, Footwear Practitioner. Whilst Paul spoke briefly on his profession as a Footwear Practitioner and his involvement with clients requiring specialised footwear, he went on to speak about his escape from the Hungarian Revolution and subsequent arrival in Australia. His book *"The 4th of May: The Memories of Paul Galy OAM"* a recommended read. Mary-ann Liethof, National Program Manager, Polio Australia then provided a Program Overview which was followed by self-introduction by Retreat participants.

And so, the work began: Friday morning saw the day begin for all participants with an informative, helpful and interactive session with Dr Steve de Graaff, Senior Rehabilitation Physician and Director of Pain Services, Epworth Healthcare, Victoria. His areas of research interest include Stroke Rehabilitation, Spasticity Management, Pain Management, Post-Polio Sequelae and Continuing Professional Development. Areas discussed included Self- Management and Pain Management.

For the next two days participants attended sessions covering a wide variety of topics: "Swollen Polio Legs" / "A Breath of Fresh Air" (covering communication and swallowing resulting from neurological disorders) / "Post-Polio Exercise Options" / "Massage Therapy" / "Osteopathic in Self Care" / "Managing Arthritis and Osteoporosis" / "Avoiding Falls" / "Optimal Nutrition" / "Taking Charge of Your Own Health" / "Partnering Polio" / "Healthy Brain Ageing" / "Seated Yoga Therapy" / "Foot Care" / "Telling Your Story" / "Early Polio Memories" / "A Family History Taster: Catching The Bug" / "Travelling Options for People Ageing with a Physical Disability" / "Laughter: The Best Medicine" / "The Healthy Spirit" and "Awakening the Creative Spirit Within" / "Meditation" / "Philosophically Speaking".

The Retreat was not 'all work and no play' – Friday evening we were treated to an amazing musical performance by the Circular Keys Chorus, a group of 80 ladies and on Saturday evening comedian, Tommy Dean gave us a dose of that 'best medicine' – laughter.

While there is often a feeling that there may not be much more we can learn or do to assist in our daily lives and ongoing mobility, it was generally agreed that we were leaving the Retreat richer for not only the information gained but also for the new friendships forged and the old renewed.

6.3 A Most Worthwhile and Inspiring Retreat by MaryAnn H (NSW)

What a most worthwhile and inspiring retreat! I said to you prior to the retreat that I had never attended any of the functions mainly due to the demands of life/career and the fact that one just 'gets on with it'. I am really pleased to have attended and was more than impressed with all that unfolded. Many of the sessions provided vital information and yes I appreciated the one-to-one with Dr de Graaff, the massage, etc., and above all else meeting and relating to a most remarkable and courageous group of individuals. Mary-ann there were varying manifestations of the effects of polio but really in the truest sense of the word the retreatants are not disabled at all! I feel very blessed to have had the opportunity to be part of the retreat. There is a sense that we are all family!

You have a real flair for lifting people, Mary-ann, and your positive manner and your drive united us all. Nothing was too much trouble for you and your organisation was superb! You are indeed a blessing for Polio Australia!

A point! I really responded to the performance of the Circular Keys and was delighted that the Centre allows the choir to sing in the chapel. I have belonged to a choir for many years and we toured the south of Germany and Austria some years ago, often singing in old churches/cathedrals. Our repertoire was mainly sacred music, but I recall on one occasion prior to one performance, a member of a holy order made sure that the reserved sacrament was removed from the chapel!! She must have been worried that we were going to launch into some 'colourful' singing!!

6.4 Nancy's Ozzie Polio Retreat by Nancy B (New Zealand)

"Wow what an event!", says Polio NZ delegate Nancy Blackstock after attending Polio Australia's fifth Health and Wellness Retreat. *"It was a very participatory experience",* she reports. *"Mary-ann Liethof, Polio Australia National Program Manager, who organised all the retreats, is full of vitality and fun, and it showed."*

Everyone was asked at the outset what they expected to get out of the retreat, and at the end, what they had gained. "It made you think about the reasons you had come!"

Although there were speakers in daily plenary sessions, everyone sat round tables with plenty of room, then the rest of the day was given over to 90-minute small group sessions with 4-5 options per slot. All participants were actively involved in these, learning and asking questions. Choices had been made at pre-registration, and goody bags contained individualized programs.

"I never felt like I was being lectured to." This open format made it possible to meet all the 65 or so people (aged early 50s to 80s) who attended. Most of those Nancy spoke to had contracted polio at less than six months old, two in 1961 and 1965 respectively, and one in Malaysia. At the initial meet-and-greet Nancy introduced herself as the Kiwi on reconnaissance to gather as much information about retreats and their organisation and talk to as many people as possible.

"For a girl from across the ditch I had a great time. Everyone was very friendly and eager to share information." Making contacts began even before leaving Auckland: Nancy found one of the air hostesses on her flight had worked on the Duncan farms in shearing gangs in her earlier career.

Displays by the likes of the Independent Living Centre were available over a leisurely two-hour lunch break, and the evenings delivered a program of inspiring speakers and entertainment. The venue was relaxing, the food yummy (starting with breakfast from 7am). There was even good shoe shopping (see later), though Nancy gave herself some extra adventure by heading out shopping in free time after arriving, forgetting how much distance she had already taken herself around airports that day. Fortunately her wheelchair batteries didn't quite peter out on the long driveway back to the retreat centre.

Retreat venue was St Joseph's Centre for Reflective Living at Baulkham Hill, Sydney, operated by the Sisters of St Joseph whose founder, Mother Mary McKillop, also worked in New Zealand. They open their centre to people who seek a supportive space to pursue their particular dreams and all that seek the quiet of time apart.

Dr Loren Mowszowski, Healthy Brain Ageing Clinic, Brain and Mind Institute, University of Sydney, spoke about the ageing brain, what to expect and what we can do about it. She discussed strategy-based memory training, based on: External strategies: Using a diary, writing things down, lists and checklists for multi-step tasks, keeping things in consistent places. Internal strategies: concentration, repetition, chunking/grouping, visual imagery. (“I could have listened to her for another hour,”)

Optional interactive session choices included opportunities for a massage, and/or personal 20-minute sessions with Dr Steve de Graaff (polio) and Dr Helen Mackie (swollen legs).

Barefoot Freedom Footwear display: People tried shoes on and ordered what they needed, i.e. left small, right larger, to be made up and sent. One woman said it had cost her \$2000 to have to have a pair of shoes made to suit, but now she could buy four or five pairs from Barefoot for the same money! www.barefootfreedom.com.au

Automobility displayed a vehicle that would take a wheelchair. It was not self-drive but could be adapted and their website www.automobility.com.au is well worth a look if you are hunting for a suitable vehicle. They are based on a Kia Carnival which is the vehicle Nancy drives but the Australian conversion is different.

“Would I go to another retreat in Australia? I most certainly would!”

6.5 Thank You Letter from Rosemary C (NSW)

I just wanted to write and thank you for putting together such a wonderful program for this year’s Polio Retreat. Being my first, I was a little apprehensive about attending, but I’m so glad I did. I met a great bunch of people, learnt a lot, and really enjoyed myself along the way.

I know it must involve a massive amount of work – these events don’t come together without a great deal of work. I hope you feel that the effort was worthwhile – I think the success of the event speaks volumes and I only heard good things – people were very buoyed by the time there.