



POLIO AUSTRALIA INCORPORATED

Representing polio survivors throughout Australia

An initiative of the Australian State Post-Polio Networks

Polio ... forgotten, but not gone



Report on the

Polio Health and Wellness Retreat 15 - 18 April 2010

Polio Australia Incorporated

▣ Suite 119C 89 High Street Kew Victoria 3101 ▣

▣ PO Box 500 Kew East Victoria 3102 ▣

▣ P: (03) 9016 7678 E: office@polioaustralia.org.au ▣

Website: www.polioaustralia.org.au

Table of Contents

1.	Executive Summary	3
2.	Demographics	5
3.	Program	7
4.	Evaluations	13
4.1	Day 1 – Polio Survivors	
4.2	Day 1 – Spouses/Carers	
4.3	Day 2 – Polio Survivors	
4.4	Day 2 – Spouses/Carers	
4.5	Day 3 – Polio Survivors	
4.6	Day 3 – Spouses/Carers	
4.7	General Activities	
4.8	Miscellaneous Feedback	
4.8.1	Attendance at Future Retreats	
4.8.2	Overall Experience Ratings	
4.8.3	Grouped Themes	
4.8.4	General	
5.	Polio Network Newsletter Reports	36
5.1	Tasmania	
5.2	Victoria	
6.	Conclusion	42

1. Executive Summary

Polio Australia was incorporated in 2008 and is governed by a Committee of Management made up of state Polio Network representatives who are all working with people living with the late effects of polio (LEOP).

Symptoms of LEOP include unaccustomed fatigue unrelated to activity, decreased strength and endurance, pain in muscles and/or joints, an inability to stay alert, weakness and muscle atrophy, muscle and joint pain, muscle spasms/twitching, respiratory and sleep problems, swallowing or speaking difficulties. There is also evidence of emotional distress, especially if assistance and support is inadequate

Many polio survivors who have emerging symptoms still report difficulty in obtaining correct diagnosis and treatment. As time passes, an increasing number of previously 'stable' persons with a history of polio infection report unexpected new symptoms. The large number of survivors who are now experiencing new symptoms has transformed the problem from an individual predicament to a considerable social concern.

In April 2010 Polio Australia, with input from the Post-Polio Network (NSW), conducted Australia's first three day "*Polio Health and Wellness Retreat*" in Baulkham Hills, New South Wales. The purpose of the Health and Wellness Retreat was to provide a holistic approach to managing LEOP and finding life balance. This Retreat model is to be used as a chronic condition self management technique in future Polio Australia activities. Each day focussed on a different aspect of health and wellness: Body, Mind and Spirit.

Polio Australia and Post-Polio Network (NSW) were successful in joint funding applications to both GlaxoSmithKline and the Flack Trust. This gave us the financial flexibility to provide the 3 day Retreat at an affordable \$370.00 per person/single or \$280.00 per person/twin share/double which included meals, accommodation and all activities. We are most grateful to these two funding bodies for their support of the post polio community.

The Retreat was held at St Joseph's Centre for Reflective Living and was a fully residential program attended by 57 people comprising polio survivors and their partners/carers, plus Polio Australia's National Program Manager, Mary-ann Liethof and Dr Steve de Graaff, Rehabilitation Specialist and Director of Pain Services at Epworth Rehabilitation, Camberwell, Victoria.

A number of health professionals familiar with the issues associated with LEOP were involved in facilitating question and answer forums which enabled a broad spectrum of concerns to be raised within a group of people with similar conditions. This format was highly successful insofar as people discussing their own experiences of what worked, supported by the knowledge and expertise of the respective health professionals.

Sessions addressing the 'Body' included an overview of 'The Polio Body' by Neurological Physiotherapist Melissa McConaghy, such as how the polio virus initially affected the motor neurons, and what is happening with the late effects of polio; scooter demonstration and tryout; exercises for people with limited ability; ventilation options; foot care for polio feet, pain management, bracing, dietary advice; and a range of personal therapeutic services were available.

The 'Mind' sessions commenced with a presentation from Dr Diane Bull who is a GP, psychologist and polio survivor. She covered 'emotional health' and taking care of yourself. This was followed by sessions on seated yoga; strategies to keep the mind active; early memories of having polio; finding your story; as well as a variety of activities such as Sudoku, Bridge, Origami, Bonsai, Art and Singing which were introduced as techniques to keep the 'mind' active.

Sessions for addressing 'spiritual health' included meditation, life balance, complementary health, and specific workshop on "Awakening the Spirit Within" by Sister Annie Bond.

Another aspect of the Retreat was to give polio survivors a safe environment to discuss their early memories of having had polio, as well as offering suggestions and techniques for finding and writing their stories. A lot of informal networking was done during the three days and people agreed to having their names on a Contact List so they could keep in touch with each other.

As there were a number of partners/carers participating, there were also scheduled and informal opportunities for them to meet and discuss their own specific concerns.

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

“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 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....”

In order to verify any positive changes in the participant’s self-management practices as a result of attending the Retreat, people agreed to receive and complete a follow up questionnaire reporting on their progress in six months time (October).

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

Steve Maccagnan of Moving Planet Productions generously donated his time and expertise to film a variety of activities and interviews over a two day period. We anticipate compiling an instructional video with the edited footage and uploading it to YouTube for general viewing and as inspiration for other organisations who may be considering running their own Wellness Retreats.

We would also like to thank the Lions Club of Mount Druitt for their generous donation of \$500 which paid for our evening entertainment – and included Lions’ volunteers to assist with the logistics – as well as funding the Bonsai and Origami sessions.

We thank the Rotary Club of Castle Hill whose members kindly volunteered to assist participants with their luggage on arrival and departure. This was very much appreciated.

Polio Australia’s vision is to ensure 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. The fact is that at this point in time, we have no formal funding to achieve these aims although we continue to explore every funding avenue.

This Retreat shows what can be done with a lot of good will and a small purse. Sufficient funding would ensure these Retreats can be facilitated in each state in order to inform and educate at least some of the tens of thousands of polio survivors, their carers, and the health professionals who work with them how to effectively manage the late effects of polio.

*“Tell me, and I will forget. Show me, and I may remember.
Involve me, and I will understand.”
– Confucius*

Photos have been uploaded to Polio Australia's Picasa Web Album

<http://picasaweb.google.com/PolioAustralia>

Polio Health and Wellness Retreat - April 2010

2. Demographics

Who Came?

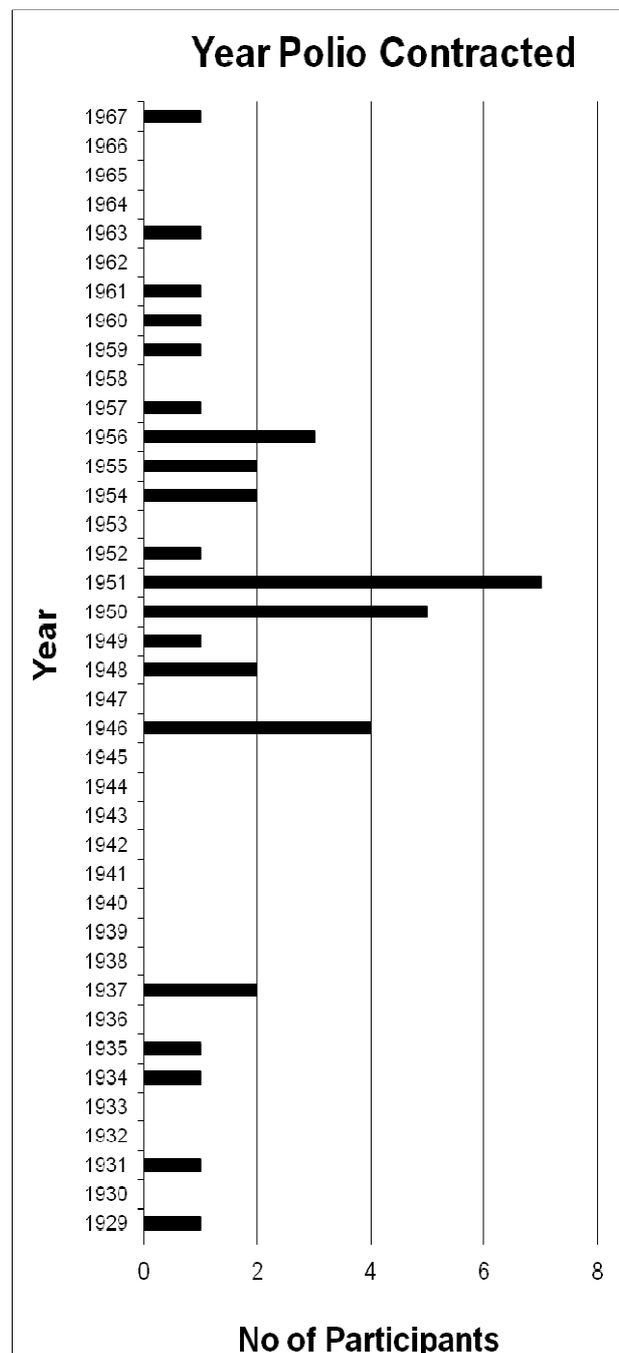
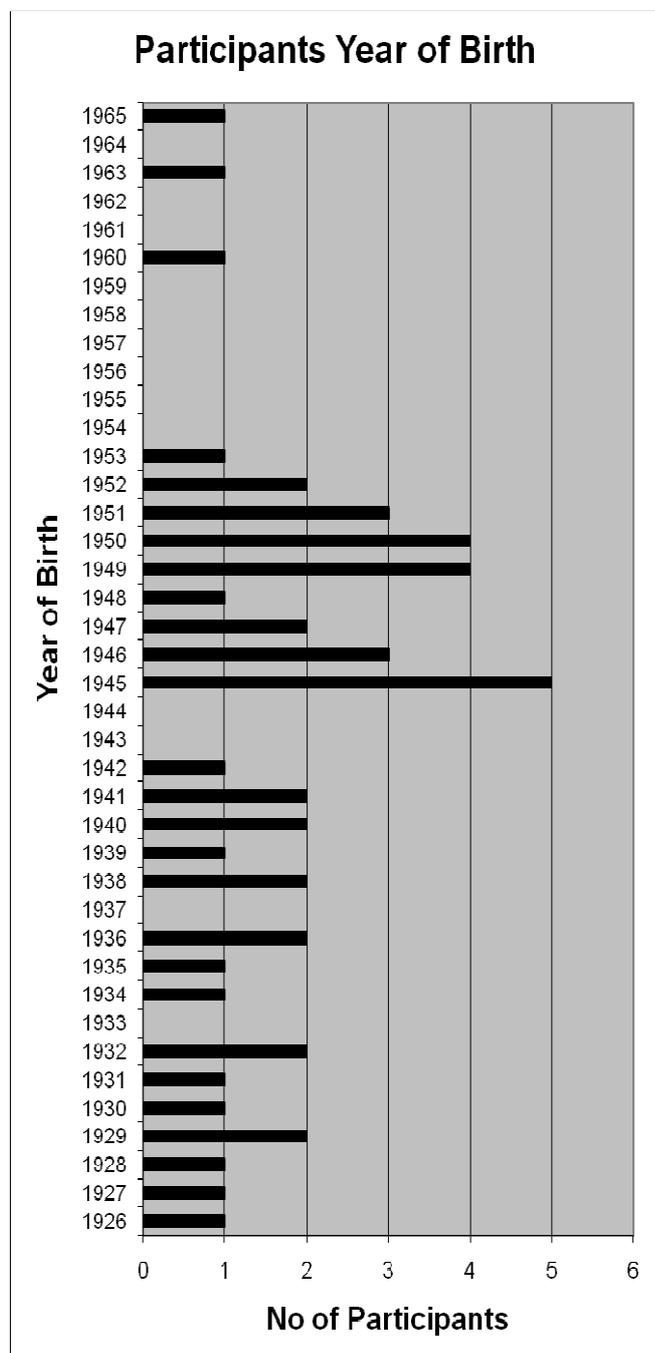
Polio Survivors	Spouse/Carers
38	19

Gender Representation

Female	Male
38 Total - 27 Polio Survivors	19 Total - 11 Polio Survivors

States

ACT	NSW	QLD	TAS	VIC
3	39	1	6	8



Participants using Mobility Aids = 28 or 73.6%

- Electric Wheelchair = 2
- Elbow Crutch = 2
- Elbow Crutch + Manual Wheelchair + Scooter = 2
- Manual Wheelchair = 2
- Walking Stick = 10
- Walking Stick + Manual Wheelchair = 1
- Walking Stick + Calliper = 1
- Walking Stick + Elbow Crutch = 1
- Walking Stick + Elbow Crutch + Scooter = 1
- Walking Stick + Electric Wheelchair + Scooter = 1
- Walking Stick + Scooter = 2
- Walking Stick + Scooter + Walker = 1
- Walking Stick + Segway = 1
- Walking Stick + Walker = 1

Scooter Demonstration



3. Program

Polio Health and Wellness Retreat Body / Mind / Spirit Program

A joint activity offered by Post-Polio Network (NSW) Inc and Polio Australia Inc

Thursday 15, Friday 16, Saturday 17 and Sunday 18 April 2010

at

St Joseph's Baulkham Hills
Centre for Reflective Living

64 MacKillop Drive Baulkham Hills NSW 2153

Website: www.stjosephscentre.org.au

Thursday 15 April

Time	Activity	Facilitator
2.00 to 5.30pm	Registration, room allocation and facility orientation	
6.00 to 7.00pm	Dinner (BYO wine)	
7.15pm	Welcome	Gillian Thomas <i>President, Polio Australia and PPN</i> and Neil von Schill <i>Treasurer, Polio Aust and Secretary, PPN</i>
7.25pm	Guest Speaker – My Warm Springs Experience	Dr John Tierney <i>Member, PPN Management Committee</i>
7.45pm	Program Overview	Mary-ann Liethof <i>National Program Manager, PA</i>
8.00pm	Participant Introductions	Mary-ann Liethof
8.25pm	Brief Announcements	Mary-ann Liethof
8.30pm	Relax and Mingle	
8.30 to 10.30pm	Warm Springs Movie	

Friday 16 April

Time	Activity	Facilitator
7.30 to 9.00am	Breakfast	
9.15 to 10.00am	Guest Speaker – The Polio Body	Melissa McConaghy <i>Physiotherapist, Mobile Rehab Innovations and Advance Rehab Centre (MRI&ARC), St Leonards, NSW</i>
10.00 to 10.25am	Morning tea	

10.30am to 12.00pm	All about scooters: <ul style="list-style-type: none"> • The selection process • Getting the scooter fitted to meet your needs • Safety in the community • Practical try-outs <i>1 hr session / ½ hr try-outs</i>	Vicky Fowler <i>Hurstville Store Manager Scooters Australia</i>
	Practical exercise session for people with limited mobility	Melissa McConaghy <i>Physiotherapist, MRI&ARC</i>
	Choices for people with breathing problems: discussion and display of various ventilation equipment	Sherrill Burden, ANZ <i>Clinical Director, ResMed</i>
	Foot Care for Polio Feet	Paul Musarra <i>Podiatrist</i>
	Booked/paid Acupuncture appoint	David White <i>Acupuncturist, MRI&ARC</i>
12.15pm	Lunch	
1.00 to 2.00pm	Rest and Relaxation	
	20 min Guided Deep Relaxation Session at 1.30pm	Mary-ann Liethof <i>National Program Manager Polio Australia</i>
	Booked/paid Podiatry appointment	Paul Musarra <i>Podiatrist</i>
	Booked/paid Acupuncture appoint	David White <i>Acupuncturist, MRI&ARC</i>
2.00 to 3.45pm	Pain Management – interactive Q & A session	Dr Steve de Graaff <i>Rehabilitation Specialist and Director of Pain Services Epworth Rehabilitation, Camberwell, VIC</i>
	Getting the best out of allied health professionals – interactive Q & A session	Melissa McConaghy <i>Physiotherapist, MRI&ARC</i>
	To brace or not to brace – interactive Q & A session	Darren Pereira <i>Orthotist NeuroMuscular Orthotics, Mount Waverley, VIC and MRI&ARC</i>
	Carers Cuppa and Discussion	Pam Tierney <i>Carer</i>
	Booked/paid Acupuncture appoint	David White <i>Acupuncturist, MRI&ARC</i>
4.00 to 5.45pm	Pain Management – interactive Q & A session	Dr Steve de Graaff <i>Rehabilitation Specialist and Director of Pain Services, Epworth Rehabilitation, Camberwell, VIC</i>

	Food for wellbeing and practical weight management strategies – interactive Q & A session	Lily Noviana <i>Dietitian</i>
	To brace or not to brace – Q & A session	Darren Pereira <i>Orthotist NeuroMuscular Orthotics, Mount Waverley, VIC and MRI&ARC</i>
6.00 to 7.00pm	Dinner (BYO wine)	
7.30 to 9.30pm	Trivial Pursuit	<i>(Proudly sponsored by Lions Club of Mount Druitt)</i>

Saturday 17 April

Time	Activity	Facilitator
7.30 to 9.00am	Breakfast	
9.15 to 10.00am	Guest Speaker – The Healthy Mind	Dr Diane Bull Psychologist <i>Member, PPN</i>
10.00 to 10.25am	Morning tea	
10.30am to 12.00pm	Practical Yoga Session / Seated	Heena Raikar <i>Yoga Instructor</i>
	Strategies and exercises to keep the mind active – interactive Q & A session	Zeina Merhi <i>Occupational Therapist, MRI&ARC</i>
	Early memories of having polio – interactive discussion group	Merle Thompson <i>Vice President, PPN</i>
	Booked/paid Therapeutic Massage	Carole Gridley <i>Massage Therapist, MRI&ARC</i>
	Booked/paid one-to-one orthotics appointment	Darren Pereira <i>Orthotist NeuroMuscular Orthotics, Mount Waverley, VIC and MRI&ARC</i>
	Booked 20 minute one-to-one self-management discussion (<i>free</i>)	Dr Steve de Graaff <i>Rehabilitation Specialist and Director of Pain Services Epworth Rehabilitation, Camberwell, VIC</i>
12.15pm	Lunch	
1.00 to 2.00pm	Rest and Relaxation	
	20 min Guided Deep Relaxation Session at 1.30pm	Mary-ann Liethof National Program Manager Polio Australia
	Booked/paid Therapeutic Massage	Carole Gridley <i>Massage Therapist, MRI&ARC</i>

	Booked/paid Occupational Therapy appointment	Zeina Merhi <i>Occupational Therapist, MRI&ARC</i>
	Booked/paid 30 min one-to-one Orthotics appointment	Darren Pereira <i>Orthotist NeuroMuscular Orthotics, Mount Waverley, VIC and MRI&ARC</i>
	Booked 20 minute one-to-one self-management discussion	Dr Steve de Graaff <i>Rehabilitation Specialist and Director of Pain Services Epworth Rehabilitation, Camberwell, VIC</i>
2.00 to 3.45pm	Finding your story – interactive discussion group	Margaret Bennie and Neil von Schill <i>Members, PPN</i>
	Introduction to the Internet – hands on experience	Ella Ross <i>Computer Pals for Seniors</i>
	Origami: Craft your own beautiful pieces to take home – interactive participation	Michael and Etsuko Clonaris <i>The Origami People</i>
	Anyone for Bridge? An introduction to this popular card game – interactive participation	Gillian Thomas President, PPN
	Challenge your mind with Sudoku – interactive participation	John Sattler <i>Volunteer, PPN</i>
	Booked/paid Therapeutic Massage	Carole Gridley <i>Massage Therapist, MRI&ARC</i>
	Carers Cuppa and Discussion	Ron Exiner <i>Carer</i>
4.00 to 5.45pm	Finding your story – interactive discussion group	Margaret Bennie and Neil von Schill <i>Members, PPN</i>
	Explore your inner artist: Pastels and Charcoal – interactive participation	Fran Henke <i>Member, Polio Network Vic (PNV)</i>
	Bonsai: Create your own mini garden to take home – interactive participation	Ray Nesci <i>Ray Nesci Bonsai Nursery (Proudly sponsored by Lions Club of Mount Druitt)</i>
	Singing is good for your health! – interactive participation	Mary-ann Liethof National Program Manager Polio Australia
	Booked/paid Therapeutic Massage	Carole Gridley <i>Massage Therapist, MRI&ARC</i>
6.00 to 7.00pm	Dinner (BYO wine)	
7.30 to 9.30pm	Roezone and Raffle Draw – Entertainment by Roe and David	<i>(Proudly sponsored by Lions Club of Mount Druitt)</i>

Sunday 18 April

Time	Activity	Facilitator
7.30 – 9.00am	Breakfast	
9.15 to 10.00am	Guest Speaker – The Healthy Spirit	Sr Annie Bond <i>Centre Director, St Joseph's Centre for Reflective Living</i>
10.00 to 10.25am	Morning tea	
10.30am to 12.00pm	Awakening the Creative Spirit Within – interactive discussion group	Sr Annie Bond <i>Centre Director, St Joseph's Centre for Reflective Living</i>
	2 x 45 min Meditation Sessions	Fran Henke <i>Member, PNV</i>
	Herbal and nutritional options for managing pain and fatigue – interactive Q & A session	Alison Mitchell <i>Naturopath Health Dimensions</i>
	Balancing your life – interactive discussion group	Liz Telford <i>Member, Polio Advisory Committee, PNV</i>
12.15pm	Lunch	
1.15 to 2.30pm	Choir Performance and Closing Plenary	Mary-ann Liethof



Dr Steve de Graaff – Pain Management



Paul Musarra – Foot Care



Darren Pereira – To Brace or Not To Brace



Heena Raikar – Yoga



Clockwise from top right: Choir Practice, Introduction to Bridge, Balancing Your Life, Sudoku, Dinner, The Healthy Mind, Saturday Night Entertainment, Origami

4. Evaluations

4.1 Day 1 Polio Survivors

Which sessions did you attend today?

10.30am to 12.00pm

Session	Most useful Aspects	What other information would have liked
Scooters	<ul style="list-style-type: none"> • Clear evaluation of different types • Trying out the scooters • Details and options and advise re scooters excellent • Being able to try out mobility aids • Having the types and benefits of different scooters explained and being able to try them – GREAT! • I was pleased to try the scooters and the walker seat impressed me • Basic info on scooters and what to expect and where to start if you need one. A good session of info and trial ride – right amount of info for an introductory session. • Very informative – cleared up a few things • Although this session was ‘scooters’, my opinion is it would be better called ‘mobility’ with all forms of aids presented. 	<ul style="list-style-type: none"> • Bigger variety of equipment and brochures would be better
Exercise	<ul style="list-style-type: none"> • Individual mini assessments/seeing how the picture is put together • Melissa was very easy to follow with her information. I felt I was coping well. • Personal assessment • The personal hands-on experience most helpful and informative. Melissa was extremely giving of herself and her expertise. • Reinforced prior knowledge/reminded me of pelvic floor! • The personalised approach to exercise need and planning • Types of exercise e.g. pilates, yoga, swimming. Time frame of when to stop overall. Overall very informative and excellent. • Hearing of others with very similar problems and the most appropriate exercise required • Practical advice and tips given as Melissa examined a few participants and discussed their cases • Melissa did a quick assessment of me and others. Her conclusions were very interesting and helpful – good suggestions 	<ul style="list-style-type: none"> • Handouts re exercise options especially for wheelchair users • I had expected a more specific description of exercise but the approach taken was actually better • Stick figure type exercise sheets for various environments, e.g. hydro, Swiss ball, weights, etc. • Nothing of benefit to me now but may be necessary later

	<ul style="list-style-type: none"> • By going through people's history she came up with new exercise • Information very useful. Technique of people sitting discussing limited exercising 	
Foot Care	<ul style="list-style-type: none"> • The models of feet were helpful visual aids. The whole session was useful, although I make regular visits to a podiatrist. • Talking about walking to prevent falls • The use of orthotics to alleviate pressure pain on your feet • Learned that I had a bunion and that I need to see a podiatrist to avoid pain • Wearing the correct orthotics, the importance of shoes, finally finding out what plantar fasciitis actually is • Details of feet how to look after and support – latest materials used • The different types and uses of aids • What services are provided by a Podiatrist. Paul was very informative – gave me confidence to say what I need to my own Podiatrist. • Use of orthotics 	<ul style="list-style-type: none"> • More diabetes care • Foot massage, shoe manufacturers, odd feet, specialist shoes
Breathing Problems	<ul style="list-style-type: none"> • Discussion and causes of sleep apnoea and associated remedies • Useful information on what is available • How to control my breathing • Latest designs and equipment 	<ul style="list-style-type: none"> • Q & A at end of session

2.00pm – 3.45pm

Session	Most useful Aspects	What other information would have liked
Pain	<ul style="list-style-type: none"> • Dr Steve's information on medications and their different application and how to best use them. Fabulous session Steve - thank you. • Confirmation of what I am currently doing and about some side effects of medication. • Discussion on drugs and also on alcohol. Hearing others' issues. • Excellent information, particularly side effects of medication and general information • Types of drugs, what to use and how much • Discussion on pharmaceuticals and neuralgia • The types of pain management • Medication and explanation • Like the questions and answers • Being able to share with others 	<ul style="list-style-type: none"> • Too much focus on pharmacology. Alternative strategies to control and reduce pain. • Maybe a little more on the actual 'workings' or not of our polio bodies. • More natural methods of pain management, i.e. acupuncture, massage, meditation • More on contribution of mood to pain management • Alternative pain management such as massage, meditation

	<ul style="list-style-type: none"> • Steve is so informative – a pleasure to listen to • Medication for pain – covered all aspects of this including side effects • It was all good – great shared discussions 	
Allied Health Professionals	<ul style="list-style-type: none"> • Programs available • Learning about the range of different AHP's • Addressing aspects of polio well • It was interesting to hear that Vic is more progressive than NSW • I found out I was over exercising and I would need to stop going to the gym • Providing an overview but also clarifying the roles of Occupational Therapists and Speech Therapists. Very comprehensive information was given and all questions well dealt with. • Indication of the various roles of health professionals and how they may help • Having others experiences. Also speech pathology explained, i.e. swallowing, etc. • What Occupational Therapists do. Finding out about Speech Pathology. • Exchanging info with others' about their experiences • Guidance as to which professional to use for what and as to how each may be of help • Listening to all the questions and finding what they are doing about getting help • Useful information about who I should see • Good coverage but did not add much to my knowledge • Listening to what others have found successful. This session was very open and inclusive 	<ul style="list-style-type: none"> • Handouts/online resources
Bracing	<ul style="list-style-type: none"> • Much useful information about the possibilities of supporting my weak knee • Braces available for viewing and Darren's knowledge • Good overview of what is available and personal consideration of our need • Very informative for future use • Darren's presentation was excellent - viewing the various types and understanding the process of finding the most appropriate orthotic and then making the orthotic • All – different type of orthotics demonstrated • Darren was full of all the new info - easy to listen to 	

Session	Most useful Aspects	What other information would have liked
Pain	<ul style="list-style-type: none"> • The thorough knowledge of Dr de Graaff on pain management and his patience in dealing with all the questions • Listening to the problems of other people and the possible solutions • Other people's questions • Discussion of various pain levels and methods for alleviation • The entire session was entirely useful • Understanding of medications and general health issues • The explanation of the types of pain and the types of medication and levels of pain medication • Discussing the various options available for pain relief • Round room discussion • Very good information and suggestions • Steve's detailed knowledge of the drugs available and their effects and suitability – many different problems dealt with 	<ul style="list-style-type: none"> • Some other concepts of non-medication dealings • Descriptive information of the various types of medication and their use, also the pro's and con's of each type
Food	<ul style="list-style-type: none"> • Handouts excellent. Q & A good. • The way Lily explained the entire food preparation and distribution of information made for a very thorough and informative session. Great Lily. Thank you. • Learning about the new 'plate' proportions for food categories • Info about portion size and proportions of food groups • Portions! We already know what we should be doing but it was helpful. • Good information on cooking food and portion size. Again excellent. • Most informative – the planning of meals very helpful • Very clear illustration of portion management • The 'plate' was really good and excellent handouts • Looking at portion sizes • How to cook healthy • It was all good – excellent presentation by Lily 	<ul style="list-style-type: none"> • Info specific to polio survivors. It didn't address mobility limitations, or specific needs. • Lily may have benefited from having discussions with Melissa first as she kept emphasising exercise beyond what most polio's were capable of. We were left feeling a bit confused, especially those of us who had been to the previous session on Allied Health, as we had been told that for our level of mobility, even housework could be considered exercise. • Perhaps a little more on relationship of exercise/effort to food intake
Bracing	<ul style="list-style-type: none"> • As I have very little pain and am going to see Darren about bracing later, I think I got enough • The different types of braces and where to go for an orthotic assessment in Brisbane 	<ul style="list-style-type: none"> • Please – film demonstrations, time permitting

	<ul style="list-style-type: none"> • Latest devices and materials they are made from and different uses of these devices • The new light weight braces • Comprehensive info on bracing for a person who never thought about or had experience with bracing • The new orthotics available now were shown, plus new materials • Clear, concise and well paced information 	
--	--	--

Follow-up action from today's information

Physio/Exercise

- I want to attend/have an assessment done by Melissa McConaghy's MRI&ARC at St Leonards
- Work more on core muscle control
- Will make appointment to see Melissa McConaghy and Darren Pereira
- Will try to see physio about pain in back
- I will certainly find ways to increase exercise and hydro
- Appointment with physio and orthotist
- Follow up with physio re my exercise program
- Visit Advance Rehab Centre for assessment and exercise
- Plan on making appointments for complete assessment – podiatry, orthotics and physio
- Make an appointment at Advanced Rehab Centre for individualised exercise program and other advice re polio management
- Might attend MRI and ARC Clinic
- Particularly in field of exercise, core muscles and balance
- Stop going to the gym

Food/Nutrition

- Changes in our kitchen/meal habits, for sure
- Structure my eating better to help with my weight loss
- Eat smaller portions

Orthotics

- Get an orthotic assessment
- Will go to have a consultation with Darren Pereira
- I intend to get a good review of my case as I now think I can do more to improve walk/gait and have less falls
- Go back to my orthotist to follow up with Darren
- To revisit orthotics now I have more info
- Visit to presenters when need of brace is required in the future – if practical at the time
- Just what new materials are available and costs, etc.

Pain Management

- Request pain relief for low level 'aches' due to fatigue
- Feel far more confident re my medications!
- See Steve tomorrow then go back to my GP and sort out better level of medication
- Have decided to change what pain management I will use based on Dr de Graaff's information
- Use of Panadol Osteo
- Change medication

Podiatry

- Find a reliable podiatrist to rebuild and/or alter the orthotics in my present shoes
- Regularly see a podiatrist

- Get orthotics and shoes checked
- Will have better questions and requests from my podiatrist
- Will take notes the podiatrist gave me to the company he recommended
- Would like an appointment to see Paul Musarra in his Albury practice

Misc

- Reactivate speech therapy
- Possibly buying a scooter
- Visit sleep clinic
- I would like to hear the info again with the latest in the future

Other Comments

- Some dominant participants tend to take over sessions. Facilitators need to be skilled in ensuring the quieter ones get the opportunity for input. It was good having Mary-ann as a floater between sessions to add input and to learn firsthand what is working well and what could be improved.
- Melissa was very knowledgeable and helpful as was Darren.
- Overall the day has been very helpful – very packed too! Was almost brain-dead by the end. The presenters/facilitators of all three sessions were experts in their fields and were very forthcoming and helpful to participants.
- Organisation excellent, venue superb, facilitators excellent but perhaps [could] speak louder
- Thanks to all the experts in their fields for excellent presentations. I was particularly impressed with Dr Steve de Graaff – his depth of knowledge, accompanied by great communication skills was great to experience.
- Dr Steve gave a most informative lecture on pain relief and alternative measures
- I'm sure I can truthfully say I don't think I've ever received so much helpful information in one day. I find it almost too good to be real! Many thanks to everyone! One very happy-tired-resident on campus.
- A most useful and enjoyable day.
- What a great day. So informative. Wonderful to hear of other's experiences and recommendations. Comforting to have some clarification of some issues – very helpful. Wish there was more than 1 session on nutrition – missed out due to other session booked at the time. Thank you.
- A well organised day
- Enjoyable day with appropriate speakers relevant to my PPS issues – thanks.
- This is the first polio thing I have ever been to and have found it very helpful. Thank you.
- And excellent day! Very informative and getting to know everyone is priceless.
- Overall a really good day. The night session was a bit late for me! The interchange with others was interesting, enjoyable and valuable.
- The day was helpful, informative and well worthwhile and not to be missed
- I thought the Q & A session gave a good start to the day. I enjoyed the singing practice and relaxation CD.
- Long day but enjoyed every minute
- Was very impressed with the acupuncture
- Melissa was very good with her professional knowledge
- Lily was an excellent presenter
- [Lily's food session] was very well presented – a very nice person, knows what she's talking about
- Pleased I came. Met so many people with similar problems who were easy to talk to.
- I had an excellent day. I received a wealth of information on managing my work load on a daily basis. Provided me with a better understanding of how to monitor my energy output. Physiotherapist, Melissa, gave a very good talk on what to expect, etc. Thank you.
- This information is fascinating, riveting and vital for my future self-management. I know I would benefit by having a lot of this information re-presented. I am aware that often (with the same presentation) I will perceive different aspects and facts at each time.

- As one of the symptoms of post-polio is exhaustion, I would have like to have had more time to rest. I have felt very tired.
- Very intense day – some sessions seemed too long, though several of us went off for a nap to be better refreshed
- The best length of a session for me would be 1.15 mins. Found 1.45 too long. Felt pain session ‘ran out’ (which was fine as so had I) before the bell.

4.2 Day 1 Spouse/Carers

Which sessions did you attend today?

10.30am to 12.00pm

Session	Most useful Aspects	What other information would have liked
Scoters	<ul style="list-style-type: none"> • Only attended for a little while as I had heard most of the info when spouse bought a scooter • Demonstration rides 	<ul style="list-style-type: none"> • Presenters lacked the enthusiasm which should have been part of such a good product
Exercise	<ul style="list-style-type: none"> • Only attended part of it. Thought the information very helpful. • Suggestions on how to gain most from, aids to help with problems and best types of exercises to use • Exercise hints and precautions • So much help is available in Sydney – an excellent session. 	<ul style="list-style-type: none"> • Would love to have had some print out • More individuals given chances for brief assessment. A few outspoken people dominated session • Melissa spoke so quickly that it was difficult for me at times to keep up and grasp all that she said. She is very knowledgeable and understands polio problems. One person said he could walk 1km while most were much more limited but didn't get a look in.
Foot Care	<ul style="list-style-type: none"> • Making a mould for my foot • A very practical, down to earth approach communicated to survivors. Very useful. • Extremely helpful with respect to foot care and potential problems. A much greater understanding of podiatry. 	<ul style="list-style-type: none"> • Care of the feet if you are a diabetic.
Breathing Problems	<ul style="list-style-type: none"> • General Interest • Was good to see the new machines • Useful information on what is available • Comprehensive sleep apnoea machines 	<ul style="list-style-type: none"> • Found information was limited. Other brands would have been helpful. • Other breathing problems

2.00pm – 3.45pm

Session	Most useful Aspects	What other information would have liked
Pain	<ul style="list-style-type: none"> • Very interesting person, helpful information 	<ul style="list-style-type: none"> • Each person being allowed in turn at least 1 question to give quiet ones an opportunity.

	<ul style="list-style-type: none"> • Comments by doctor re missing medications and uses of various medicines • Understanding of the drugs for pain • Medications a focus • Presenting doctor treated us as individual clients but with quality of communication which was breathtakingly interesting to all. Many thanks. • Dr de Graaff's candour and down to earth responses to questions, especially about medication and other doctors. • The explanation of the different painkillers • Steve de Graaff had so much knowledge to impart, hard to take it all in. Another excellent presenter. 	<ul style="list-style-type: none"> • Burning foot pain – what medication appropriate?
Allied Health Professionals	<ul style="list-style-type: none"> • The interaction and sharing of resources available • Useful information about what my wife should be doing • Awareness of where to turn to for informed professional services for post polio sufferers 	
Carers Cuppa	<ul style="list-style-type: none"> • Openness with which session conducted • Very useful talk – just informal sharing of issues and perspectives • Well facilitated, personal aspects aired 	<ul style="list-style-type: none"> • Session not long enough

4.00pm – 5.45pm

Session	Most useful Aspects	What other information would have liked
Pain	<ul style="list-style-type: none"> • Very interesting to find out about the different medications for pain relief • Holistic management approach • Very good information for me to help my wife and myself • Use of drugs and side effects 	
Food	<ul style="list-style-type: none"> • Reminder of general dietary principles • The presentation was excellent. Well explained and handouts mean you can remind yourself of info. • A lot of eye opening information, may change cooking practice • Good information on sizes of meals and proportions of food types • Ways to cut back on wrong food and choose better and how to cook low fat way. Pleased with excellent hand outs supplied. 	<ul style="list-style-type: none"> • More demonstrated sensitivity re dietary issues for people with limited exercise capability • Taste test?

	<ul style="list-style-type: none"> • The portions of a meal when you eat healthily • Lily knew her subject but hard to teach old dogs new tricks 	
Bracing	<ul style="list-style-type: none"> • How the braces have changed 	

Follow-up action from today's information:

- More equipped to prepare balanced meal plans
- Better mix of food types (protein, carb, etc)
- Low fat eating
- Make better use of allied health system
- Will be working on some lifestyle changes
- Do more exercise
- Will be making appointment with a podiatrist and orthotist
- Will take follow up action for both my wife and myself
- Send my wife to St Leonards clinic for check ups
- Take more medication for pain
- Pressure our doctor to find out more about PPS
- Further reflection of issues raised at Partner's Cuppa
- Acupuncture – it has helped with pain relief

Other Comments:

- Generally very engaging sessions with useful information at times
- Sessions very informative but possibly too much activity in one day. Suggest morning session, longer rest break then afternoon session. Those who are more active can socialise or do other things in rest period if desired.
- Acupuncture was very good
- As a carer, the carers discussion was very worthwhile
- The Warm Springs movie was an inspiration to us all
- Podiatrist was most helpful
- Very interesting day, very informative and enjoyable
- Very enjoyable day
- Groups seem to find sessions useful. Worth continuing with similar format. Maybe limit to 1½ hrs.
- I am now better informed to help my wife let alone myself
- Lovely and comfortable accommodation. Friendly people. Good meals.
- Notice board for program preference was very awkward and very hard to access, even for more able bodied people. A table or chairs nearby to lean on would have helped for writing. Layout of our activities hard to comprehend. I realise this was a major challenge, handled very well from an organising viewpoint. A simplified individual list for each person through a computer program would be a helpful achievement if possible.
- I love the way you are keeping the sessions moving and on time. The organisation is superb. Thank you.
- An excellent day at my first PPS meeting. I hope I can come again. Attended all the extra activities and enjoyed them immensely. Great fun night at Trivia event, even if our table came sixth.
- The whole day was well thought out with various aspects of post polio services. Well organised and on time.

4.3 Day 2 Polio Survivors

Which sessions did you attend today?

10.30am to 12.00pm

Session	Most useful Aspects	What other information would have liked
Yoga	<ul style="list-style-type: none"> • Time to stretch and relax • Losing fear of yoga and moving from physical to meditation • Being able to modify yoga for an individual ability. Used to do yoga but given up years ago but can do it again. • My first time and I thoroughly enjoyed it. I will continue with yoga sessions. • The explanation of yoga and how to do it sitting in a chair • Breathing exercises very helpful • Stretching exercises, relaxation techniques, soothing atmosphere • Relaxation and breathing techniques • Wonderful • Fantastic realistic yoga practitioner! Excellent relaxation session. • Relaxation techniques and ability to exercise even in unusual ways. • Relaxing and very therapeutic • Joined group late but learned a little about relaxing and stretching 	<ul style="list-style-type: none"> • More relevance to polio survivors • Yoga website • Would have liked a DVD
Strategies for an active mind	<ul style="list-style-type: none"> • How to deal with or avoid stress by being organised and flexible. • Stop sign technique and more structuring of day/week • Planning • Strategies for dealing with stress, importance of pacing oneself according to fatigue levels • Interesting information which can be used • I didn't find session of much use but other participants seemed to get something of use 	<ul style="list-style-type: none"> • The title was a bit misleading as we didn't get anything except for 10 mins at the end for keeping our minds active. It was mostly OT stuff, similar to Dianne Bull's talk. • A little more on link with post polio and stress and strategies to overcome • Session didn't meet my content expectation except for last 5 mins
Early Memories	<ul style="list-style-type: none"> • Sharing others memories brought out tears and laughter – we have survived. • Shared experiences sorted out some of my own • Very painful • Reliving early days of polio – the good and the bad times • Very interesting to hear other people's experiences and talking through the past • Other survivor's stories • Great venue to let survivors vent – but with fun, many tears and distress 	<ul style="list-style-type: none"> • Maybe a professional attend to deal with distressed? Other people became distressed and could escalate.

	<ul style="list-style-type: none"> • Although distressing for some, discussion was very open. • I could relate to everyone, so everything. Coming from different areas, particularly the treatment. • Share experiences, also the research document Merle read on attitudes of the time. • The new research and findings in neuro-anatomy • Hearing other's experiences-realising the effects that separation at a young age (2) had on myself during my life. • Interaction with other people and their stories was very interesting • Finding out polio survivors early memories • How different the stories but also how similar 	
--	---	--

2.00pm – 3.45pm

Session	Most useful Aspects	What other information would have liked
Finding your story	<ul style="list-style-type: none"> • The informative instruction toward the writing of one's own story and the open sharing of Margaret and Neil's experiences • Very helpful in learning how to set out writing your story. Wonderful. • The facilitator/moderator • I actually wish to forget those days • Contact number to access history of my hospitalisation when I got polio • Learning how to start and how to plan to write your story • It was all good • Helpful mind map for a way to structure your story. Also having other people's skills. 	<ul style="list-style-type: none"> • Perhaps more input from the group in what attempts they had made with stories
Internet	<ul style="list-style-type: none"> • Computers for Seniors took away the fear of using the internet • General tips • It was OK • Learning different ways to navigate the internet 	
Origami	<ul style="list-style-type: none"> • Very entertaining and the guest presenter very nice • Great fun and harder than you'd think. He gave us handouts and sheets to practice with. • Lots of fun and a skill you can use to entertain big and little kids. • Techniques and handouts - a nice thing to do • An intriguing craft but I think not for me • Well presented and very professional • The opportunity to learn something entirely different • Very fun and helpful instructions, good to concentrate on a different skill. 	
Bridge	<ul style="list-style-type: none"> • Just learning a new thinking game • Fun and entertaining – a new interest for me 	<ul style="list-style-type: none"> • Playing my own hand and not being the 'dummy' each hand

	<ul style="list-style-type: none"> • Small group size helped with teaching – a fun activity 	<ul style="list-style-type: none"> • Limited time meant only introductory material – this will be followed up by presenter emailing links to online self teaching resources
Sudoku	<ul style="list-style-type: none"> • Encouragement of the instructor. A warm and enthusiastic teacher. • Different ways to solving the puzzles. 	

4.00pm – 5.45pm

Session	Most useful Aspects	What other information would have liked
Finding your story	<ul style="list-style-type: none"> • Hearing other's stories, sewn the seed for writing my story • Ways to start your story • Learning from people that have completed a story – tricks of writing 	
Inner Artist	<ul style="list-style-type: none"> • Fun and freeing. I liked the immediate removal of expectations by use of non-dominant hand. • Everyone's enjoyment and laughter • Lovely, very enjoyable. Fran is lovely. • Doing things using my non-dominant hand. The ability to be free to interpret. • Very enjoyable and relaxing with lots of laughter and fun • Observing the individual art expressions. Mine was not so good. • A good laugh • It was fun – relaxing • It was a great time for enjoyment - using charcoal in a supportive, fun environment • The free drawing and having fun with others 	
Bonsai	<ul style="list-style-type: none"> • The man that made the presentation was most informative and gave us a plant to start us off • Another fun thing to do – I can enjoy gardening on a small scale • The hands on experience – really good and great fun • Ray was easy going – now I can start a new garden while sitting • Fun • Very informative and a practice learnt – new horizon gardens for survivors! Very gentle and likeable presenter. • Hands on after all the other activities was very relaxing. • Clear, personalised replies and very generous with his knowledge. • Presenter very friendly and knowledgeable. Wonderful being able to make our own bonsai to take home. 	
Singing	<ul style="list-style-type: none"> • Listening to everyone's stories about their singing. • Warming up techniques 	<ul style="list-style-type: none"> • Sing-a-long 'to raise the roof by' songs

	<ul style="list-style-type: none"> • Learning to find my voice again • The enjoyment of joining others in expressing our feelings in song and harmony • The different techniques of learning to sing in a choir - fun! 	<ul style="list-style-type: none"> • What it would be – general consensus expecting more a sing-a-long
--	---	---

Follow-up action from today's information

Yoga

- Do more yoga
- Explore yoga further
- Will take up a seated yoga
- Do yoga
- I may investigate yoga
- Talk to my masseuse about stretching exercises on a chair

Bonsai

- Start a bonsai garden
- Improve my bonsai skills
- Start a new garden
- Continue manageable gardening.
- Get involved in bonsai
- I'll probably do some research on bonsai care and visit Ray's website

Story

- Think more about developing my story preparatory to writing it
- Start to write my story
- Get back to writing my story
- With Margaret's input, hopefully write my polio story
- Continue to write life story in a different format that currently using
- Research my history of polio especially when I was hospitalised at Far West Children's Home 1954

Mixed

- I feel I now know how to fold origami and have a few things in mind
- Do more origami
- Play on the internet
- Do more Sudoku
- Learn bridge
- Do more drawing

General

- Being organised and assertive when appropriate
- More attention to planning activities and stopping
- Accessing medical help
- Podiatry – not getting what I need and will be more assertive
- Pay more attention to fatigue levels so as not to exceed reasonable levels. Ask for help when necessary.
- Mind activity games
- Physio for assessment of my current exercise program
- My calliper needs replacing – will visit Darren P for advice on new technology
- My need to get holistic rehab assessment was confirmed

Other Comments

- I'll be telling others back home what they missed out by not attending.
- It was a great idea to have more recreational activities on the second day.
- A good day and a nice balance with some practical activity sessions to balance others. All were good and activities fun.
- A nicely paced day with lots of variety and some sessions a lot of fun. A good idea to have this as the second day (rather than first) because participants also now know each other better and interact well in fun activities.
- None of the 4.00-5.45 sessions were of interest so I took a nanna nap. Would have liked a wider range of activities. Too much fun today – need to swap last session to Friday and serious teaching activity from Friday to the first Sat spot.
- Sessions could have been a bit shorter to give more rest time and interaction time with others. A great day.
- Had a very good day but feel a bit of extra rest time useful.
- By this time the intensity of the program was beginning to take a negative turn (physically)
- I had a wonderful day full of laughter and tears. Met some beautiful people whom I hope to see again one day at the next post polio retreat hopefully? The stories I have heard are priceless and will stay in my memory for a good while to come. Hope to hear more. Thank you.
- The introductory talk by Dianne Bull was an ideal set up for the rest of the day's activities.
- The 9.15 session with Dianne Bull was the best part of the day – full of good ideas. I think my other choices for the day, apart from yoga, could have been better for me – Merle Thompson (Early Memories) or Zeina Merhi (Strategies for an active mind) perhaps.
- Again, very impressed with the knowledge and dedication of presenters.
- A very busy and interesting day!
- Although I didn't do much I enjoyed the interaction with other people here.
- Another successful and excellent day!!
- Very interesting day finished with a great evening of singing.
- Very helpful experience. Thank you.
- Another good day. Thank you.
- Enjoyable day.
- This retreat has been very calming for me. I feel a lot more at ease now.
- A very enlightening day.
- An absolutely great day. Had an appointment with Dr Steve, a truly generous man! Many thanks. A massage with Carole – perfectly wonderful and helpful, topped with an appointment with Darren, another generous person who will contact my local orthotist with a report! What can I say? Words can't express my gratitude. Thank you.
- Dr de Graaff helped clarify issues. Really refreshing to have doctor 1) not query polio 2) understands polio issues 3) answer questions based on having managed many polio patients.
- Spoke to Steve de Graaff who confirmed I was taking the right decisions physically.

4.4 Day 2 Spouse/Carers

Which sessions did you attend today?

10.30am to 12.00pm

Session	Most useful Aspects	What other information would have liked
Yoga	<ul style="list-style-type: none"> All of it Finding it is not difficult and very relaxing My introduction to yoga and its broad range of practices 	
Strategies for an active mind	<ul style="list-style-type: none"> Wide subject and not enough time to cover Information on benefits Helpful STOP sign technique – energy conservation 	<ul style="list-style-type: none"> More information on brain exercise activities Coping with stress within families (big one)
Early Memories	<ul style="list-style-type: none"> The other survivors talking about their treatment Interesting to hear other people's experiences 	

2.00pm – 3.45pm

Session	Most useful Aspects	What other information would have liked
Finding your story	<ul style="list-style-type: none"> Mind map – don't be a victim 	
Internet		
Origami		
Bridge	<ul style="list-style-type: none"> I'll be looking to play bridge in the future 	
Sudoku	<ul style="list-style-type: none"> Looking at the puzzle from a different perspective A different way of solving to what I have been doing I'm not as dumb as I thought with these things 	
Carers Cuppa	<ul style="list-style-type: none"> Sharing fears and doubts Carers tea was very good 	

4.00pm – 5.45pm

Session	Most useful Aspects	What other information would have liked
Finding your story	<ul style="list-style-type: none"> The whiteboard thing 	
Inner Artist	<ul style="list-style-type: none"> Fun and laughter. Discovered I don't like using charcoal. Using non-dominant hand. Freeing the creative spirit within. Great ideas and practice on how to get started 	
Bonsai	<ul style="list-style-type: none"> Interesting concept, was great The explanation was in easy to understand language and I have a very nice plant 	
Singing	<ul style="list-style-type: none"> It was fun Seeing what serious singers do to limber up 	<ul style="list-style-type: none"> Would have enjoyed a couple of simple sing-a-long songs

Follow-up action from today's information

- Seek counselling on how to cope with polio partner's downward deterioration
- To find a yoga practitioner in our area and good massage therapist – the ones we had today were fantastic
- Helping wife to investigate St Leonards Centre
- I will be doing a little more bonsai
- I'm going to check on yoga classes at home
- Mind games
- Checking Freedom of Information about hospital records

Other Comments

- The accommodation is generally wonderful but could do with some rails in the bathroom, i.e. beside the toilet, and non-slip mat for the shower. The heaviness of the doors is also awkward for those with walkers and wheelchairs.
- Notice board not used enough for advising program change of rooms. Partner 'worn out' by not knowing room was changed and going that extra mile.
- The whole day has been very informative. I have learnt a lot. Thank you – great.
- Glad to have accompanied wife in getting to know other post-polio people better. Also glad to offer some small services to others from our experiences. Best regards for future events.
- Session times were too close. Fantastic.
- Great day – thoroughly enjoyed it
- I have had a very enjoyable retreat. I will come back.
- A most enjoyable day, learnt a lot and appreciate all of the hard work that has gone into every aspect. Hats off to all concerned.
- Great day with variety of talks, activities and fun.

4.5 Day 3 Polio Survivors

Which sessions did you attend today?

10.30am to 12.00pm

Session	Most useful Aspects	What other information would have liked
Awakening the Spirit	<ul style="list-style-type: none">• Very creative – labyrinth was very relaxing• Uplifting - the informative Sister Annie conveyed was truly wonderful• The different ways Annie helped me look at my spirit within• The haiku, labyrinth and mandala as methods of stilling a racing mind. A very different approach but interesting.• Travelling the labyrinth• Lovely session. Sister Annie's presentation was excellent – very considerate of other beliefs.• Professional advice and the reminder of enhancing my spirit• I did enjoy Sister Annie's talk – she is a joy to start the day. I was so pleased to hear the message about God's handing things over.	<ul style="list-style-type: none">• Time constraints a pity• Perhaps a little discussion on the nature of spirit and creativity?

	<ul style="list-style-type: none"> • Enjoyable 	
Meditation	<ul style="list-style-type: none"> • The emphasis that each of us can contribute to life • Knew nothing about it beforehand • Indications of the benefits to be achieved by meditation • Practical. Fran is a fantastic presenter. • Learning the skills to relax by meditation 	
Herbal and Nutritional Options	<ul style="list-style-type: none"> • Alison knew what she was talking about – made me aware you don't always need medication • Alison was excellent • Vast knowledge base and very generous with how to do. We were given full range of Q & A and then interrelated with other factors already in the presentation notes. • It gave me a greater appreciation of the benefits of herbal and nutrients. A very explicit lecture and most helpful. • Explanation of various herbal options • Very informative – lovely girl. Very good at explaining information 	
Balancing your life	<ul style="list-style-type: none"> • Some tools to reflect upon the next transition point • Identifying where my energy is used and balancing it • The sharing and the ideas presented re finding the balance in our 'new' lives • Considering transitions and how energy is used • Its interactive nature and the practical exercise we undertook. Liz was excellent. • Talking to people with the same problems as me • Very enlightening • Transition process 	

Follow-up action from today's information

Spirit

- To complete the mandala and labyrinth were just great – I shall continue these
- I have homework Annie gave us
- Discussion with old friend keen on philosophy (about spirit)
- Nurture my spirit

Meditation

- Value meditation
- Will follow up with reading (about meditation)
- Restart meditation
- Practice further meditation as means of quieting the mind
- Practice what I have learnt (meditation)

Herbal and Nutrition

- I will follow up on advice – visit a local health shop
- Find someone who is trained as a naturopath

- To try some of the recommendations in today's (herbal and nutritional options) session
- Buying supplements
- See Alison (Naturopath) for advice

Life Balance

- Reflect more on transition and actively work on a personal strategy plan
- Make more time for ME
- Reassessing the distribution of energy in my life
- Reconsider my priorities and maybe consider my own needs more
- Confirms need to visit Independent Living Centre and Rehab Centre
- Consider further new activities in community

Other Comments

- An excellent day and enjoyable time with all you beautiful people. A magnificent retreat – sad to end. I can't wait till the next one. I will be there with bells on. Thank you to all you beautiful people who put so much work into planning such a beneficial retreat for all us polio survivors.
- The sky is the limit
- An inspiring end to a wonderful three days.
- A great Retreat!
- Really enjoyed the company and listening to everyone's story.
- Many thanks. These sessions were so enjoyed.
- Thank you for a wonderful weekend.
- Thank you! Thank you!
- Some feedback to all participants of the retreat would be helpful, particularly to help promote another retreat through word of mouth. I would like to find out the evaluation details for my own interest.

4.6 Day 3 Spouse/Carers

Which sessions did you attend today?

10.30am to 12.00pm

Session	Most useful Aspects	What other information would have liked
Awakening the Spirit	<ul style="list-style-type: none"> • Very relaxing. Sister Annie is a beautiful speaker • Practical examples. I thought Sister did a great job when it was such a difficult topic to speak about to a mixed audience. 	
Meditation	<ul style="list-style-type: none"> • Peace, learning how to meditate 	
Herbal and Nutritional Options	<ul style="list-style-type: none"> • Being told what the supplements were for and how they worked more efficiently • The use of different herbs, etc • The information was very good and the presenter was most impressive • Info on dosage of herbal nutrition 	
Balancing your life	<ul style="list-style-type: none"> • Very helpful basis for reassessing life priorities • I am hopelessly conflicted since my partner facilitated the session. However that notwithstanding, I found the session very good. 	

Follow-up action from today's information

Spirit

- Doing some of the activities learnt in Awakening the spirit session

Meditation

- To learn more about meditation

Herbal and Nutrition

- Over last couple of days, information to set up a better nutrition and vitamin plan.
- Ask for more information (from naturopath) at home
- Will buy some of the products discussed (by naturopath)
- Follow up with my own naturopath

Life Balance

- Carrying on a good thing
- Use the analysis we were given to carefully reassess life balance
- Balancing my life

Other Comments

- Excellent!
- Very good – informative and well organised.
- An excellent conclusion to a very helpful and inspiring weekend.
- Great

4.7 General Activities

Did you attend any of the following activities?	What aspect of the activity did you find the most useful?	Do you think you will take further follow-up action after attending any of these activities?
Carer's Cuppa	<ul style="list-style-type: none"> • Sharing fears and doubts in small group • A great insight into potential future situations • Personal contacts supporting others in the group • Terrific • Good to hear other carer/spouse comments regarding help required by partners. I feel very fortunate in comparison to some others. 	<ul style="list-style-type: none"> • Various behaviour practices, plus exploring various additional aids • Next time I could run a laughter session (phone number supplied)
Acupuncture	<ul style="list-style-type: none"> • I'm glad I took advantage of this being available • Pain management • Good session • Fair • Finding an acupuncturist I felt I could trust • Very appreciated 	<ul style="list-style-type: none"> • Will follow up • Will follow up • Restart acupuncture treatment • Will follow up
Podiatrist	<ul style="list-style-type: none"> • The advice and treatments that are available to improve my quality of life • Most successful • Very appreciated • Podiatrist helped greatly • Orthotic assessment 	<ul style="list-style-type: none"> • A complete assessment of my condition and regular follow-ups • See another podiatrist, as advised • Regular visits to podiatrist

	<ul style="list-style-type: none"> • Personal time out of normal environment with practitioner 	<ul style="list-style-type: none"> • Seeing Darren for further assessment and provision of, perhaps, an orthotic • Follow up podiatry • See a podiatrist regularly
Massage	<ul style="list-style-type: none"> • Less stressed muscles • Very appreciated • Very soothing • Massage was fantastic 	
Orthotics Assessment	<ul style="list-style-type: none"> • The advice and treatments that are available to improve my quality of life • I found out a lot about brace management • All useful – excellent service • I'm glad I took advantage of this being available • Orthotics assessment • Dispelled some doubts mum was having about getting a new calliper • It was very useful to have arranged for orthotic work to be done • Explanation of how to improve my gait with a few changes in my calliper 	<ul style="list-style-type: none"> • A complete assessment of my condition and regular follow-ups • Will be making an appointment with Advance Rehab Centre • Will follow up • Visit orthotics specialist in Brisbane • Try orthotics again • Get an orthotic assessment • Mum to get new calliper. • Arrange appointment to see orthotist Darren Pereira • New calliper
Occupational Therapist Appointment	<ul style="list-style-type: none"> • Mind game to improve memory 	<ul style="list-style-type: none"> • Purchase mind game
Self-Management Discussion with Dr Steve de Graaff	<ul style="list-style-type: none"> • The advice and treatments that are available to improve my quality of life • Individual attention • Meeting with Steve extremely helpful. His capacity to ask questions and give realistic advice was excellent. • Self management of pain I'm glad I took advantage of this being available • Dr Steve was brilliant • He strongly enforced other information and advice I have received • Honesty of discussion re pain management • Pain management, level of drugs discussed and suggestions for management. 	<ul style="list-style-type: none"> • A complete assessment of my condition and regular follow-ups • Partner's pain management • A rehab assessment! • To strongly and vigorously follow his advice • Contact local professionals to discuss further pain programs • Change pain medication

Carer's Comment

I attended both Carers' Cuppa's, one as participant and the other as facilitator. I found both sessions very important in helping me think about partner/carer issues. Participants came from all parts of the carer/partner spectrum and it was important to hear about how they all deal with their various situations. People were very honest in sharing their feelings.

Both sessions ran for their allotted 1 3/4 hours which is a good indicator of how useful people found them. The feedback seems to support this.

I would like the title of the sessions in the future to include the term "partner" as well as carer. I think the informality of the "cuppa" concept is good as it helps people feel more relaxed about participating.

I found the whole experience of attending the Retreat very meaningful. By the time it finished, I was feeling that I was part of the Polio Community and also found that I was not conscious of who is a survivor and who is a partner or carer in my interactions with them.

Participating in sessions for partners reinforced this sense of belonging and I think these sessions should be part of all future Retreats.

Your Comments

- Great to find people who have experience with polio survivors to get the correct advice.
- Very good of professionals to give up time for these appointments
- More slots of the above (and other) one on one therapies
- More appointment times for 1 to 1 with professionals
- The desire to participate in other activities as well as those attended
- Would have liked opportunity for massage
- Specialist follow-ups
- Attend speech therapist
- Very helpful to see physio
- Will get more informed on health and nutrition
- We will definitely be following up with orthotist at home and if necessary with Darren in Melbourne
- Will follow up physio at rehab clinic
- Will get assessment at St Leonards Clinic
- Will attend hydrotherapy – this was the most recommended and talked about exercise for us polio's
- I found out things that could be useful that I didn't know about
- My main object was methods of pain control. Unfortunately this did not eventuate.
- I'm sorry I didn't book in to the Carer's Cuppa

4.8 Miscellaneous Feedback

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
41	0	37	4

Please rate your overall experience of the following

1 = Below standard to 5 = Excellent	1	2	3	4	5
Standard of Venue				4 (9.09%)	40 (90.90%)
Standard of Room Accommodation			2 (4.44%)	7 (15.55%)	36 (80%)
Standard of Meals			9 (20%)	18 (40%)	18 (40%)
Organisational Standard				8 (17.77%)	37 (82.22%)

1 = Below standard to 5 = Excellent	1	2	3	4	5
Met any special requirements			1 (3.44%)	6 (20.68%)	22 (75.86%)
Standard of Retreat activities				14 (31.81%)	30 (68.18%)
Standard of Retreat entertainment			4 (10%)	17 (42.5%)	19 (47.5%)

Grouped Themes

Venue

- An excellent Retreat. Excellent service. Beautiful venue. Hope to visit again.
- Accommodation great – rooms a little hot. All in all a very successful retreat – well done to those who made it all possible. Thank you.
- Had a great time and all the staff were very helpful
- Beautiful venue outside.
- What a wonderful venue.
- An informative retreat in pleasant surroundings. Splendid organisation, good presenters with inspirational participants.
- Great place for this to occur. Staff should be appreciated. Sister Annie beautiful lady.
- Excellent venue. Could not find fault with anything.
- Venue superb. Organisation and administration excellent. Presenters very knowledgeable. Spirit of community great. Congratulations, a fine effort.
- Congratulations on a magnificent venue and flow of info.
- A marvellous venue. Everything was excellent.
- Wonderful venue with excellent facilities. Very generous provision of drinks, morning teas, etc and friendly staff. Lovely grounds. Hope we can find something half as good in Victoria.
- Bathrooms could do with handrails and non-slip surface in shower. Also doors quite heavy. All other aspects of facility and activities excellent.
- More rails needed in bathroom
- No grab bar at toilet.
- Difficult access to car and baggage – reliant on others. Departure awkward for us after excellent assistance on arrival.

Meals

- Only reservation on meals – which were plentiful and thoroughly enjoyable – was their neglect of nutritional advice in main meals. But great supplies of fruit, etc, and teas all very good.
- The venue was outstanding for our purposes and limitations. Food was not exactly the best diet for people like us, but you can't have everything.

Notice Board

- Notice board needs improvement for convenient access and notation space. Keep it up to date about changes.
- Being the first Retreat, organisation was very good. I found looking for preference acceptance very confusing and tiring to stand at notice board. Also activity room location map not clearly marked.

Rest Breaks

- A packed program made day 1 especially exhausting, but the after lunch rest break was helpful.
- The pace was a little brisk – needed more rest time.

- The days were long and a little exhausting for post polio survivors. The diversity of sessions was very good. Small numbers in group sessions worked well. Everything ran to time and was well organised. Thank you all very much.
- The 3 days were great. Some sessions could be longer and some shorter. A little more time for relaxation. Overall, excellent. Well done to all who organised it and many thanks.
- Perhaps you need to look at a longer time period as so many people needed more rest times. Thanks to the organisers. We had a great time and learnt so much from others.
- The whole retreat good – maybe another rest period slotted in would help.

Entertainment

- The evening events were fun – thank you Lions Club.
- Just sorry I was too tired to participate in evening entertainment. Any chance of an extra day so we could participate in more?
- Trivia night could have been a little shorter as most people were pretty stretched by the end of the first full day.
- Music too loud for our age.

Sharing Experience

- Basically a wonderful, helpful and enjoyable retreat for both myself and my wife.
- I had a great time meeting other polios and their carers. Thank you NSW.
- A very enjoyable and informative 3 days and we met a lot of very nice people. Thank you Polio Australia.
- I met a lot of very nice people and had a great three days.
- Being with and sharing with other people like me – I wasn't the odd one out.
- A very worthwhile exercise and I found it most enjoyable, mixing with fellow survivors. A great big thank you to all concerned.
- Quality of all sessions was excellent. Thoroughly enjoyable, especially liked having spouse/carer to share in our activities. Thanks to all for the event – well done.
- Well done team – diverse program with plenty of time to mingle and talk to other survivors. Many contacts made and always lots of practical info learnt from other survivors.
- An excellent few days, unlike anything I have ever done. The interaction with other survivors, as well as all the sessions.

General

- I'll be taking more time to look after myself in all areas – mind, body and spirit!
- A very well organised and run retreat – thank you, thank you – far better than expected! There are many follow up actions to be taken on my part (and will be!).
- This has been the most productive, helpful, excitingly happy experience of my life! I'm so grateful to all those who helped organise this Retreat and especially those who help fund it and make possible this incredible shared time.
- The best weekend we have had for a long time. Fabulous people, great organisers. Mary-ann a real live wire. Looking forward to next one.
- Overall excellent. Well organised. Congratulations to the organisers. Achieved so many things out of this. Would attend additional activities next time. Well done!
- Having people who volunteer their time and talents such as those who organised this Retreat. Greatly enhances our ability as polio survivors to endure life's little hardships. Thanks.
- The summary with all attendees making their comments was the perfect commentary on the retreat.
- I appreciate the great, real thought and effort put into organising this retreat. Congratulations to all concerned.
- A wonderful concept and a fantastic first up. Fine tuning can only make a good thing better.
- Congratulations Mary-ann and the NSW team.
- Couldn't be better. Met all expectations.
- Overall wonderful weekend.
- Wonderful experience all round – congratulations.

5. Polio Network Newsletter Reports

5.1 Tasmania

From Ron and Jan Storay

Firstly let us thank the Tasmanian Committee for asking us to attend the Conference and then paying the Registration Fees. It truly was an enlightening experience and a great privilege to attend. The Convent of St. Joseph Centre was an excellent venue for the Retreat. Staff were very helpful, they fed us too well and accommodation was first class. The meeting rooms were sometimes hard to find but by the end of the Retreat we had learnt to find the correct room.

We threw them into a panic as we arrived late in the morning (not 2pm, the time suggested to arrive) but more people started arriving shortly after and our rooms were ready.

Dr. John Tierney spoke at the welcome on his experience in the U.S.A. at Warm Springs. This was followed by the screening of the movie "Warm Springs", the story of Franklin D. Roosevelt and the challenges of getting Polio before he learnt to walk again and became President. Many of the viewers had damp eyes when the movie finished. (This movie is available to borrow from our Network Library.)

Breakfast began the day at 7:30 am followed by the guest speaker. Melissa McConaghy was the Friday speaker, a trained Physiotherapist, who spoke on "The Polio Body" and exercises to help all. Dr. Diane Bull, Psychologist, spoke on "The Healthy Mind". What a great lady she was, herself a Polio victim. Sunday, Sr. Annie Bond, the Centre Director at St. Josephs, spoke on "The Healthy Spirit". She was a very modern Nun in high heels, great outfit and jewellery, a keen photographer, who would escape daily to talk to the cows grazing on the hillside.

Every day after another delicious morning tea, Friday we joined with Melissa again and learnt practical exercises for Polio, differing to people recovering from accidents and heart attacks. As our muscles are dead or wasted, we don't respond to some forms of physio. Saturday, we attended "Early memories of having Polio" with Merle Thompson, Vice President of the PPN (NSW). We shared past experiences; many were overcome with sadness and found it too difficult to speak. Some remembered the noise of the iron lungs operating. A very moving experience. Sunday I attended a session with Alison Mitchell, a naturopath, who spoke on herbal and nutritional options for managing pain and fatigue. This was a very interactive question and answer session. I informed Alison about placing any normal cork in your bed to relieve cramp. Alison found this hard to believe but another lady supported my story saying she never goes anywhere without her cork mat (used for casseroles) under her pillow. Alison learnt something.

After lunch each day, Mary-ann conducted a deep relaxation class and called for volunteers to form a choir to perform at the closing session. This was in the time set aside for rest and relaxation sessions. Two men were very relaxed, one on the floor and another in a reclining chair. They amused us with their loud snoring. I attended choir practice although my voice was affected by the air conditioning. We sang two songs in parts. I think one was called "Let it Go" and the other was "Bella Mama" with hand movements. Mary-ann led with us following. When we gave our performance, I started to follow the other groups hand movements, so a few followed me (in the front row) and we started laughing.

Friday afternoon we joined Dr. Steve de Graaff, a rehabilitation specialist and Director of Pain Services, Epworth Rehabilitation in Camberwell, Victoria, who specialises in Post Polio Syndrome and pain management. This session was very informative about taking various drugs to a Polio victim and reactions to the drugs. One particular drug was for cholesterol and the possible side effects. Following afternoon tea, Ron went to a session with Darren Pereira, Orthotist, who showed various types of orthotics, joints and fittings. Ron spoke to him about the problems he is experiencing with his orthotic and Darren will follow it up with John at the Launceston General Hospital to try and alleviate the problem.

Whilst Ron was with Darren, I attended "Food for wellbeing and practical weight management strategies" with Lily Noviana, a dietician. I did not particularly enjoy this session, although her talk was well prepared, I felt it was a bit late to teach old dogs new tricks, Only to have meat a few times a week the size of your palm and as thick as your little finger with lots of vegetables and pasta was not on my menu. In contrast, Alison, the naturopath advised Polios needed lots of red meat, I agree.

After dinner on Friday night our four from Launceston sat together for Trivial Pursuit. We didn't do so well as the brainy ones sat at other tables but we had lots of fun and had funny answers to some questions. Saturday we had musical entertainment from Roe and David, who played music of our era. We won a bottle of wine during the raffle draws.

I went to a Sudoku challenge and Ray Nesci came and created a mini Bonsai with us. My son who lives out of Gosford, really enjoyed the plants (Billie had given me hers also) and will take care of them. Ron was tired and needed to rest whilst this was happening.

Congrats to Mary-ann and all the helpers who made the weekend so enjoyable. Thanks again for the opportunity to attend. Jan and Ron Storay.

From Carol and Barry Squires

Only one word comes to mind to describe the retreat - EXCELLENT. On arrival at St. Josephs we were welcomed by volunteers from a local service club, we think Rotary, who carried bags and escorted us to our first class accommodation and to the car park. After dinner on Thursday the members were welcomed by Polio Australia/Post Polio Network (NSW) President Gillian Thomas and Treasurer Neil von Schill. This was followed by a talk by Dr. John Tierney about his experiences as a polio person and his visit to Warm Springs in America comparing the superior all in one building venue at St. Josephs with bunkhouse style accommodation and distances between living and working areas at Warm Springs. After a series of announcements and introductions by Mary-ann Liethof the evening concluded with a showing of the film Warm Springs.

The theme for the retreat was Body-Mind-Spirit with the first morning session each day devoted to one topic. Friday's presentation by physiotherapist Melissa McConaghy was entitled The Polio Body, Saturday morning Dr. Dianne Bull, psychologist, The Healthy Mind and Sunday Sister Annie Bond, Director of St. Josephs, dealt with the Healthy Spirit.

Following these three excellent sessions attendees broke into smaller groups to discuss with and be guided by experts in almost every imaginable profession. Where else could you talk to such a range of qualified professionals in one venue, e.g., Pain Management, Psychologist, Orthotist, Massage Therapist, Occupational Therapist, Dietician, Physiotherapist, Podiatrist, Acupuncture, Alternative Medicine, Healthy Spirit and Meditation, and Mobility Scooter Demonstrations.

PPN (NSW) Vice President Merle Thompson held discussion groups on the early memories of Polio-very interesting but also quite emotional for most participants with not a few tears flowing. Surprising how many participants said how their parents never discussed their early days with polio.

On the lighter side instruction was available on Origami, Bridge, Sudoku, Drawing and Bonsai to name a few. Evening entertainment was provided on Friday night with a lot of laughs with Trivial Pursuit and on Saturday night by live entertainers RoeZone sponsored by the Mt. Druiitt Lions Club.

Meals were first class with morning and afternoon tea each day including scones, muffins, cake etc. Tea and coffee making facilities and biscuits at every corner of the premises available all day and night.

Congratulations must go to organisers Gillian Thomas, Neil von Schill, George Laszuk and Maryann Liethof for such a professional retreat from which we gained so much information. Maryann with her little bell kept everything flowing and still managed to find time to organise and train a choir of attendees to perform at the closing session.

Finally the camaraderie between presenters, organisers and participants is something we have never experienced - everybody appeared to be equal which is something we believe is almost unknown to polio survivors.

If as indicated another retreat is held in the future we will be among the first to register and would advise all polios the benefits to be gained are really worthwhile.

From Billie Thow, Chairperson

After an early start and a smooth flight to Sydney, Georgie (Black, Vice Chairperson) and I caught a train then a bus and were finally met at the gate by Jan and Ron Storay to be made feel very welcome to the St. Joseph's Centre, what a wonderful facility.

That evening we watched the Warm Springs Movie and if you have not seen it, make the effort to do so.

At breakfast the next morning we found it was the norm to limp or use some sort of aid to get around and no one asked what happened to you, plenty of chatter about family and where you were from, etc.

The Retreat program was based on "Body, Mind and Spirit", so each day started with a guest speaker till morning tea. They were Dr. John Tierney and Dr. Diane Bull, both polio survivors, and Sr. Annie Bond, Director of St. Joseph's Centre.

In sharing their stories they allowed me to reflect on different perspectives and the questions asked at the end of each session showed the special and interesting lives polio survivors have led regardless of what effect polio had on their bodies.

Each day had three sessions in the morning then lunch followed by relaxation then six in the afternoon of which you could select your preferred one for the morning and two after lunch.

These covered many areas—Physiotherapy, Rehabilitation Support, Mobility Scooters, Exercises for people with limited mobility, Foot care for polio feet, Pain management, To brace or not to brace, Food and weight management, Yoga whilst sitting, Keeping the mind active, Hands on internet, Origami, Bridge (Card Game), Crosswords, Finding your story, Art, Sudoku, Bonsai and Singing.

Then you could also have an appointment with a massage therapist, orthotist and acupuncturist for 30 minutes at a fee.

You can see how interesting the four days became and I did find that I needed to pace myself better by the Saturday. The meals were wonderful, great company and conversations with lots of laughter and sharing stories.

Friday evening was trivial pursuit and on Saturday evening the entertainment was Roe and David with songs from the 60s and 70s. These evenings were sponsored by Mt Druitt Lions Club and they did a great job looking after us.

By Sunday afternoon we all felt we had experienced an insightful and joyful four days. I hope we can get support for an ongoing retreat program and congratulations to the team that worked so hard to bring it all together.

From Georgie Black, Vice Chairperson

Hello everyone, I have been asked to say a few words about what I experienced on my trip to Sydney at the Retreat for polio people. As it was my first time ever going such a trip, I was amazed at the friendliness of other people polio people from all states. When Billie and I arrived at St. Josephs Convent Centre we were met by Jan and Ron Storay who escorted us up to the main entrance. We collected the keys to our room and what a lovely surprise, everything was beautifully laid out.

Then downstairs, all you could wish for in food. Firstly breakfast, then morning tea, lunch afternoon tea and lastly dinner. The meals and service could not be faulted.

There was something on each day. We had a singing session in which I participated, I don't have a very good voice but no one complained so that was a bonus. Then there was the meditation with Mary-ann. That was great until two of the men started snoring.

Everything was going fine for me until I went to my next session. All was well until each person had to express what their emotions had been for the last couple of years, what traumas you had experienced. I'm afraid I had to leave because I couldn't tell strangers how I was feeling about the loss of my beloved Rex and my darling son, Wayne. It was too close to home.

That same day I didn't have any more sessions so I went and strolled around the gardens and the peace and quiet there got me back on track.

Asked if I would go to another one the answer would be yes. Billie was the perfect person to go with, she was well organised and great fun.

Sister Annie of St. Josephs farewelled us on Sunday morning in the Chapel and the choir that Mary-ann put together from some of the polio people was very good for having only a couple of rehearsals.

Then it was time to say goodbye to everyone. A nicer lot of people you could not find and finally no one looked like the odd one out because we all had a disability.

I hope this has given you all a little insight into my first retreat.



The Tasmanians: Billie Thow, Georgie Black, Ron and Jan Storay

5.2 Victoria

From Jill Burn, Chair of the Polio Advisory Committee

The setting for the Retreat was perfect, the grounds lovely to walk in, and the rooms perfectly suited to those with disabilities. Many of the participants were in wheelchairs and had no difficulty in getting around the rather complicated layout of the buildings. The bedrooms were spacious, including the en-suites which could easily cope with wheelchairs. The meals were basic but everyone seemed to be happy with them. Tea and coffee stations were set at various locations around the building.

Each day started with a presentation in the beautiful Chapel. Everyone was seated at tables, making note taking easy. Friday morning Melissa McConaghy, from a multi-disciplinary centre that specialises in physiotherapy and mobile rehabilitation spoke about working smarter, not harder to conserve energy, take rests, use whatever devices we need to help us through the day, and avoid physical and psychological stress. Melissa is a neurological physiotherapist. The issue of stress came up a lot during the weekend.

As the theme for the Retreat was Mind, Body and Spirit, it was good to get such a comprehensive overview of what was to come. Exercise was a common thread, Melissa called it "Exercise Prescription" – we get prescriptions for medications, so we should get good advice and a prescription for our exercise. In the past many polios' have been given incorrect information, and many of us have overworked our bodies. The benefits have to be balanced with side effects, our respiratory needs and other considerations such as access to suitable types of exercise.

The right exercise programme can produce very positive neural effects, improved mechanical outcomes and should include some resistance and cardio vascular work. But Melissa warned us to not work muscles to fatigue, and avoid overdoing the repetitions.

Saturday's very full programme started with Dr Diane Bull, a polio survivor and Psychologist and Neurologist, and a member of Post-Polio Network NSW. Diane encouraged us to be aware of our emotions and psychology when we are dealing with the Late Effects of Polio and Post Polio Syndrome. Most things aren't physical; they are governed by our brains. Fatigue, tension, headaches, upset stomachs, difficulty sleeping, tense muscles and shortness of breath can cause a change in appetite. Polios try to do everything 100%, and low self-esteem and withdrawing can result if we don't achieve what we set out to do. Getting the support of family is important as well as keeping them informed as to how we are feeling. Don't suffer in silence, or fret about the future as 95% of the things we worry about won't happen, and the 5% that do happen, we will cope with. We are a generation of 'fixers,' but we can't fix everything, we have to let others fix themselves.

After the morning sessions each day specialists from a wide range of services were set up in 'break-out' rooms throughout the complex. On Friday we could find out about scooters, experience acupuncture and seated massage. People with breathing problems could discuss what options are open to them. Podiatrist Paul Musarra said having the right shoes and orthotics is so important for our continued mobility.

After lunch each day, Mary-ann ran a deep relaxation session, and people could book personal sessions with specialists including Steve de Graaff and Darren Pereira. A dietician talked about 'energy in – energy out' always a problem for polios with low mobility.

Saturday was fun day, focusing on keeping our minds active - learning to write our own stories, computers, origami and understanding the mysteries of bridge. Fran Henke asked people to explore their inner artist, a nurseryman created bonsai and John Sattler, a PPN volunteer challenged us with Sudoku and Mary-ann introduced us to community singing.

Our final day on Sunday started with a wonderful and inspirational presentation by Sister Annie Bond, the Director of St Joseph's Centre for Reflective Living. Sister Annie later led a session on 'what is spirit'. She talked about what it means to have a healthy spirit, not in the religious sense, although that is relevant, but as a human person. Western ways of thinking used to divide body/mind/spirit but now we think differently, but it's still intangible. Often these things come to us through the lives of other people, people who are 'alive', who give off a sense of harmony. It's an ideal but something to strive for. And keep self-talk positive. Our own Liz Telford, from the Polio Advisory Committee, encouraged us to balance our lives. Looking at our priorities and how much energy we use in our daily lives.

On Friday evening the local Lions Club entertained us with a Trivia night (sorry, the Victoria table came second) and on Saturday night RoeZone took us back in time with some terrific music.

If you're reading this and thinking you missed a great event, don't despair. Planning is already underway for the next one, possibly in Victoria. Watch this space.



The Victorians: Jill Burn, Liz Telford, Ron Exiner, Fran Henke

6. Conclusion

The Evaluation Section of this Report overwhelmingly proves the Polio Health and Wellness Retreat format to be positive and effective on a number of different levels – not least of which is the shared experience of the participants. The ‘open circle’ Question and Answer forums fully engaged all participants in free-flowing discussion and information exchange, resulting in a clearer understanding and better retention of the management strategies being presented.

Numerous comments regarding participant’s intention to follow up on a range of self-management strategies presented over the three days justifies Polio Australia’s claim that education of polio survivors and their family/carers in self-management techniques aimed at stabilising and/or reducing symptoms of the late effects of polio (LEOP) will enable people to achieve general wellbeing and ensure that they remain as mobile and independent as possible in their own homes.

The knowledge gained during this Retreat will not only assist people to better manage their condition but can also be shared with their respective health service providers, facilitating improved care for patients presenting with LEOP.

The wonderful venue and staff of St Joseph’s Centre for Reflective Living in Baulkham Hills, NSW was also a major contributing factor to the overall success of this Retreat.

Main lessons learned and to be considered for future Retreats include:

- Improving logistics around the Notice Board
- Incorporating more rest breaks, which can be achieved through scheduling shorter sessions
- Factoring more ‘social’ time into the program
- Providing clear descriptions about what each session aims to cover – for both facilitators and participants

Overall, the organisers believe that the ‘Mind, Body, Spirit’ theme is an effective framework for Polio Health and Wellness Retreats, taking a holistic approach towards Chronic Condition Self Management for polio survivors, their families and carers.

It is intended that funding be sought so that Polio Health and Wellness Retreats can be facilitated across Australia as a key program component towards achieving Polio Australia’s 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.