

POLIO NSW INC

formerly *Post-Polio Network (NSW) Inc*

NETWORK NEWS

Incorporating – Polio Oz News

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President's Corner

Gillian Thomas

Welcome to the first edition of *Network News* for 2016. This issue is the first that will be going out by email to those members who have elected to receive it electronically. To date, just under 40 members have chosen this option. If you are currently receiving a paper copy of the newsletter and would prefer to instead receive it by email in future, please just let the Office know.

On pages 2 and 3 you will find full details of our upcoming mid-year Seminar, to be held at the Northcott Society in Parramatta on Wednesday, 18th May. The topic for the day is "*Pain Management*". With three excellent speakers presenting on various aspects of the subject, this is a Seminar you won't want to miss. Note that this year the mid-year Seminar is being held two months earlier than usual, in order to avoid the colder weather – we hope this will encourage more members to attend. It takes many hours of work to organise a Seminar and we encourage you to make an effort to support not only the Seminar but the presenters who freely give of their time to speak to us. Of course, Seminars are also a great opportunity to meet up with other members and socialise in the breaks and over lunch. Please be sure to return the enclosed Registration Form by Friday, 13th May so sufficient catering can be arranged.

In less than six months, 20th to 22nd September this year will see the *Australasia-Pacific Post-Polio Conference "Polio – Life Stage Matters"* staged in Sydney. In organising this Conference, Polio Australia has done its utmost to keep costs for polio survivors, their families, carers and friends to an absolute minimum. With time ticking down to this watershed event, and many already registered, it is time to book your place. Full Conference details can be found on the dedicated website <www.postpolioconference.org.au>, and online registration is quick and easy. If you can't register online, just ring the Conference planner, Interpoint Events, on 02 8586 6103 or 1300 789 845.

As Mary-ann Liethof, Polio Australia's National Program Manager, writes: "*This unique Conference aims to provide a broad range of health professionals with gold standard diagnosis, treatment, and management strategies to provide the best care possible for post-polio patients. Polio survivors, and their family/carers/friends, will also gain unprecedented access to information to assist them with self-management techniques. In short, there is something for everyone! DON'T MISS OUT on this not-likely-to-be-repeated education opportunity. Register now!*"

To whet your appetite as to what the Conference has to offer, here are a few quick facts. There are 26 invited speakers (14 Australian, 12 international), and more than 60 abstracts have been received for oral presentations across the three days. There will also be poster presentations. The full program and abstract summaries can be downloaded from the Conference website, or you can contact the Polio NSW Office for assistance if you don't have internet access. In the *Polio Oz News* accompanying this edition of *Network News*, you can also have a sneak preview of just four of the Conference presentations. We look forward to seeing many Polio NSW members in September.

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One-Day Seminar - Managing Pain

Date: Wednesday, 18th May 2016

Time: 9:30 am – 3:00 pm

Venue: The Northcott Building, Ground Floor, 1 Fennell Street, Parramatta

A special arrangement has been made to enable members and friends attending the Seminar to park in the Parramatta Leagues Club car park, thanks to the generosity of the Club management. Simply tell the security person at the car park entrance in Grose Street that you are attending the Polio NSW Seminar in the Northcott Building, and please park in the right-hand back corner of the car park. You can then enter the Northcott Building via the gate into its adjacent playground.

Refreshments: Morning tea and a light lunch will be provided

Cost: \$10 per person **RSVP by Friday 13th May 2016**

Please return the **enclosed Registration Form** with your payment to the Polio NSW Office by 13th May. You can pay when you arrive at the Seminar, however, if you elect to do this, you **MUST** still contact the Office [*email* office@polionsw.org.au or *Phone* 02 9890 0946] by Friday 13th May to confirm your attendance so sufficient catering can be arranged.

Program:	9:30	<i>Registration</i>
	10:00	<i>Morning Tea</i>
	10:20	Welcome by Polio NSW President, Gillian Thomas
	10:30	Dr Toby Newton-John , Senior Clinical Psychologist, North Shore Private Hospital Pain Centre <i>Self-management of Persistent Pain: 5 Useful Strategies</i>
	11:30	<i>Break</i>
	11:45	Amal Helou , Nurse Practitioner, Royal Prince Alfred Hospital Pain Management Centre <i>Pain Management</i>
	12:45	<i>Lunch</i>
	1:45	Melissa McConaghy , Neurological Physiotherapist, Managing Director of Advance Rehab Centre, Artarmon <i>Care of the Shoulder</i>
	3:00	<i>Close</i>

All are welcome – we look forward to catching up with everyone on 18th May 2016

Dr Toby Newton-John: Dr Newton-John is a Clinical Psychologist and Senior Lecturer in the Graduate School of Health at UTS (University of Technology Sydney). He completed undergraduate psychology and postgraduate clinical psychology training at the University of Sydney before moving to the UK to undertake a PhD in pain psychology at the University of London. Toby has worked in a range of clinical health settings in Australia and the UK. He established a large multidisciplinary pain management program in Newcastle NSW and moved into an academic position in 2013. He continues to practice as a clinical psychologist on a part-time basis at Northern Private Pain Centre, North Shore Private Hospital. Toby's clinical as well as research interest has been in the social aspects of chronic illness, particularly the reciprocal influences of the primary relationship on illness adjustment. He has ongoing research collaborations with Relationships Australia and overseas universities.

Dr Newton-John has expressed an interest in collecting information from our members for his research.

Amal Helou: Amal has over 30 years' experience in pain management, and is employed as a nurse practitioner in the Pain Management Centre at Royal Prince Alfred Hospital. Amal has particular interest in patient and family education and has actively worked and advocated for pain management in the older person in hospital and community settings. She is also interested in exploring patient narrative as a therapeutic intervention and the impact persistent pain has on the whole individual. Amal is on the ACI (Agency of Clinical Innovation) pain network steering committee which helps to support new pain services and develop pain research in NSW.

Melissa McConaghy: Melissa McConaghy has extensive experience in neurological rehabilitation and holds a Master of Health Science (Neurological Physiotherapy) and Graduate Certificate in Public Health. Melissa is also an APA Titled Neurological Physiotherapist and Chair of the APA NSW Neurology Group Chapter. Melissa established Advance Rehab Centre in 2005 after recognising the need for a rehabilitation service providing expert and professional neurological therapy in Sydney. During her career, Melissa has worked in a variety of rehabilitation settings both here and overseas including Wales, India, Thailand and England. She is a senior clinician and has been supervising and teaching junior staff for over eight years. Advance Rehab Centre now comprises a growing team of over 15 allied health members offering both a home-based service and purpose-built rehabilitation centre in St Leonards, Sydney. As the lead educator for Polio Australia's pilot *LEoP Clinical Practice Workshops* series (see page 15) Melissa is currently delivering training on management of the late effects of polio to a wide range of health professionals.



Interviews - ABC Radio National

On Saturday 13th February 2016 at 1 pm, Gillian Thomas (*President of Polio NSW and Vice-President of Polio Australia*), John Tierney (*President of Polio Australia*) and Billie Thow (*polio survivor from Tasmania and Board Member of Polio Australia*), were interviewed on ABC Radio National – *The Body Sphere* Program – about post-polio.

Also featured was Medical Historian, Kerry Highley, talking about her book "*Dancing in My Dreams: Confronting the Spectre of Polio*". Kerry will be giving the Closing Plenary at the Australasia-Pacific Post-Polio Conference being held in Sydney on 20-22 September 2016.

To listen to the interviews, go to this page and click on **Listen Now**:

www.abc.net.au/radionational/programs/bodysphere/polio-then-and-now/7143534

REMINDER: LEOp Assessment Clinic - Mt Wilga

The *Late Effects of Polio Assessment Clinic* is a one-day clinic, held fortnightly, and includes medical, physiotherapy and occupational therapy assessments under the direction of Mt Wilga's Rehabilitation Physician, Dr Helen Mackie.

How do I make an appointment to attend the Clinic?

Obtain a referral from your GP or other specialist who can fax it to Dr Helen Mackie on **02 9847 5013**. Once it has been received, Dr Mackie's secretary will telephone you to make an appointment for assessment. **Dr Mackie has recently advised that Clinic appointments are booked up to August 2016 and new appointments will not now be made until after the Australasia-Pacific Post-Polio Conference in September, 2016. In the meantime, you can still make contact, as names will be put on a waiting list.** If you would like any more information, please contact Dr Mackie's office on **02 9847 5085**.

You will also be sent a medical questionnaire to be completed and forwarded to Dr Mackie **two weeks** prior to your appointment.

Return the questionnaire by email to <helenmackie@bigpond.com.au> or by mail to: LEOp Clinic, Mt Wilga Private Hospital, 66 Rosamond Street, Hornsby NSW 2077.

Where does the Assessment Clinic take place?

The Assessment Clinic is at Mt Wilga Private Hospital, a specialist dedicated rehabilitation hospital and day-therapy centre. The address is:

66 Rosamond Street
Hornsby NSW 2077

www.mtwilgaprivate.com.au

**** Read the AGM Seminar Report on Dr Mackie's Clinic presentation (pages 6-9) ****

ORTHOTIC AND MEDICAL GRADE FOOTWEAR

by Susan Ellis

Many of our members will be accustomed to wearing a calliper (or brace) that perhaps inserts into ferrules in their shoe or boot heel. Callipers are now more commonly known as orthoses, AFOs (ankle/foot orthoses) or KAFOs (knee/ankle/foot orthoses). These usually have a moulded section under the foot that goes into the shoe. These orthoses require footwear that can accommodate this extended foot section, that is, a shoe that is deeper and wider than we would normally wear.

I have spoken to a number of members recently who have had difficulty finding suitable footwear, some of whom have their shoes custom-made as I once did. I have found a solution for my shoe/orthosis issues at Barefoot Freedom who provide medical-grade shoes that are double depth and double width to accommodate my orthosis. The brand of shoe I order is Drew. They also provide shoes for very narrow feet and sizing from 5 -13.

Some of our members may remember Barefoot Freedom attending our 2014 Retreat to display their footwear. They are registered as a provider with all major medical funds as well as being an approved provider for the Department of Veterans' Affairs (DVA).

Barefoot Freedom also provide a service where you can purchase split sizes, for example, left foot size 4 and right foot size 7, eliminating having to purchase two pairs of shoes (a small additional fee applies, however). Alterations can also be made, for example, a build-up to one shoe, elongating a strap. They look after many different foot problems.

**Barefoot Freedom are at: St Leonards, Pymble, Enfield and Newcastle. Ph: 02 9438 5554
Email: <enquiries@barefootfreedom.com.au> Web: <www.barefootfreedom.com.au>**

AGM Seminar Report

by Susan Ellis

Saturday, 5th December 2015

Gillian Thomas, Polio NSW President, introduced the Seminar and offered some insight into how the Clinic came to fruition as well as other interesting developments to take place in 2016.

Today we are very pleased to welcome Dr Helen Mackie, Rehabilitation Physician, and Nadege van Drempt, Occupational Therapist, both from Mt Wilga Private Hospital in Hornsby, to tell us all about the multi-disciplinary *Late Effects of Polio Assessment Clinic* which has been established at Mt Wilga.

Before I hand over to Merle to introduce our first speaker, Dr Mackie, I thought a little background might be in order.

Those of you who have been members for a long time will remember that we had a Polio Clinic at Prince Henry in the 1990s which was established by Professor Richard Jones and staffed by rehabilitation specialist Dr Jill Middleton and, later, her colleague Dr Pesi Katrak. After Jill retired, and Prince Henry closed, with its services relocating to the Prince of Wales Hospital, Dr Katrak still saw some polio patients but the concept of a Clinic was really lost. Although this Clinic was not exactly multi-disciplinary (for example, it did not include a physio, occupational therapist, orthotist etc as part of the rehab specialists' team) at least it was somewhere we could go for an assessment of our polio-related difficulties and get relevant referrals, and so its loss was felt keenly. The Management Committee has been lobbying hard for a similar service ever since.

A number of years ago, Advance Rehab Centre (ARC) at St Leonards started a Polio Mobility Clinic and I know many of our members have taken advantage of it. This Clinic includes consultation by a physiotherapist, neuromuscular orthotist, occupational therapist and speech pathologist. ARC also do home visits. This Clinic has gone some way to filling the gap, but we needed more for members.

In 2014, Committee members Nola Buck and Merle Thompson started working with Dr Mackie with a view to having a multi-disciplinary *Late Effects of Polio Assessment Clinic* established. With Dr Mackie's support and Nola's and Merle's dedicated efforts we have now seen the Clinic come to fruition.

Just before Merle introduces Dr Mackie to you, I wanted to quickly bring you up to date with some related work that Polio Australia is doing, in conjunction with Rotary District 9685. This district stretches from the Blue Mountains to the sea, north of Sydney Harbour, across the Hawkesbury River and north to Toukley on the Central Coast.

Over the next few months, a series of ten clinical practice workshops are being delivered to allied health professionals wishing to learn more about management of the late effects of polio. The experienced therapists at ARC are providing the training, and we are hopeful that across the series we will improve knowledge about management of the late effects for more than 150 allied and other health practitioners such as physiotherapists, occupational therapists, orthotists, exercise physiologists, nurses, podiatrists, speech pathologists, dietitians, social workers, case managers, and anyone else who is interested in knowing more about the post-polio body.

This is a very exciting development and a successful pilot will give us runs on the board to get Rotary's ongoing support to replicate the workshop series across NSW, and the rest of Australia, over time.

So with the Mt Wilga Clinic, the Clinical Practice Workshops, and the Australasia-Pacific Conference next September, these are exciting times.

The New Assessment Clinic for Polio Survivors at Mt Wilga

Dr Helen Mackie is a Consultant in Rehabilitation Medicine at Mt Wilga Private Hospital. She is the Director of the Late Effects of Polio (LEoP) Assessment Clinic, newly established in 2015, as well as Director of the Lymphoedema Service at Mt Wilga Private Hospital which was established in 1991. She is the current President of the Australasian Lymphology Association and is a member of the International Society of Lymphology.

One of the reasons Dr Mackie wanted to give her talk was to thank everyone for their support. It has been the wonderful advertising of the Clinic by Polio NSW that has really made it a success. Dr Mackie explained the Clinic's current status, some of the issues that have been found and subsequent changes made, and then looked forward to the future.

Dr Mackie met some of us at Polio NSW's 2014 Retreat and from there suggestions were made for a Clinic and she was keen to get involved. It was from various conversations, often with people who came as patients to see Dr Mackie at Mt Wilga for other problems, legs swelling and so on, that led to a discussion with Polio NSW about a Clinic. With Merle Thompson's recommendations, Mt Wilga contacted Victorian rehabilitation specialist Dr Stephen de Graaff and Polio Services Victoria to see what they were doing, as well as NSW rehabilitation specialist Dr Jill Middleton, and neurophysiotherapist Anne Buchan from South Australia.

Talks ensued with Mt Wilga and costs were discussed and it was eventually decided that a monthly Clinic would be set up with three people being assessed at each Clinic with the out-of-pocket expenses being \$330 for the actual assessment. This was made up of Dr Mackie's assessment (covered by Medicare), and physiotherapy and occupational therapy assessments, with some rebate available from a private health fund or a Chronic Care Plan.

Response came after the Clinic was advertised by Polio NSW and also by Mt Wilga's connections as well through local medical services etc. **All arrangements are made through Dr Mackie's office – the direct line to her office staff is 02 9847 5085.**

The Clinic started in April 2015 but was really getting going by June where it was found that all appointments were filled up for 2015 (a total of 15 people). It was realised that some fortnightly clinics had to be opened up which meant that by year's end they will have seen 26 people in total. The Clinic is now booked through to May 2016, with 6 people on the waiting list. By end of June 2016, 50 people will have been assessed. [Ed: The Clinic is now booked up until August 2016 – see page 4 for more information.]

Clients are required to obtain a referral from their GP or specialist (ask them if you are eligible for a Chronic Care Plan) and a patient questionnaire is sent out to the client to be completed and returned to the Clinic at least two weeks prior to the appointment. This questionnaire will also ask what your issues are, what your goals are, and what you expect from the Clinic.

The three-hour Clinic starts at 9:30 am with a one-hour per session rotational basis, seeing Dr Helen Mackie, Rehabilitation Specialist; Catriona Morehouse, Physiotherapist; and Nadege van Drempt, Occupational Therapist. Dr Mackie noted that the client at the beginning of the three hours can be a very different person by the end of the three hours, for example, their voice may start to wane.

Immediately after these sessions all three clinicians attend an LEOp Case Conference to discuss their thoughts and recommendations – this is really important in the assessment process. This process has been very constructive in getting an understanding of what polio survivors are going through. Some plans are made and each clinician makes individual

reports which are then compiled along with an executive summary. These reports are posted to the person attending, and to their doctor and other medical professionals that the person attending nominates, for example, their local physiotherapist.

The executive summary will include any recommendations as well as a full medical summary, history, examination details etc. The physiotherapy report will include muscle charting, balance and physical assessments, and recommendations. The occupational therapy report will include a functional assessment and recommendations. All up, it is a 7- to 8-page report. Follow up can be made with Mt Wilga after discussions with your GP or specialist.

Demographics

- 21 clients to date (26 booked to end of 2015)
- 7 males, 14 females – between 53 and 88 years of age
- year at polio onset – 1935 to 1964
- years with polio – 50 to 80
- age at polio onset – 18 months to 11 years
- severity – minimal to moderate (nil wheelchair)
- education – nil attended special schooling
- highest level of schooling – Year 10 = 5, Year 12 = 4, Tertiary = 11 (3 teachers, 2 accountants etc)

Ratings

- quality of life (out of 5) – mean result was 4 (good)
- quality of health (out of 5) – mean result was 3.2 (neither satisfied nor dissatisfied)
- level of fatigue (out of 10) – mean result was 7

Age Changes and LEOp

With ageing changes, skeletal muscle atrophy (thinning) appears to be inevitable. There is a gradual loss of the number of muscle fibres after the age of 50 and this continues so that by age 80 approximately 50% of the fibres are lost from the limb muscles.

The timing and magnitude of the loss of motor units is similar to that for muscle fibres and suggests that the mechanism responsible for this loss of fibres and the loss of whole motor units is the same.

The degree of muscle atrophy (thinning of the muscle) of the remaining fibres is largely dependent on the physical activity of the individual. The problem for people with polio is that there is a triple whammy – they have had polio, they have the natural ageing changes, and the activity level is difficult to maintain. Three issues that need to be addressed.

Fatigue

Fatigue is a very common problem; it is a sensation of weariness not relieved by rest. One in five GP consultations involves a component of fatigue as a symptom. Fatigue is more common in people over 60 and more common in women. Blood tests to investigate causes for fatigue, for example, anaemia, Vitamin D deficiency etc, will be abnormal in only 3% of tests. When looking at fatigue we need to look at a whole range of things – not only physical but psychological issues, as well as lifestyle and social causes of fatigue, and NOT just polio issues.

Also after speaking with polio clients, Dr Mackie's impression is that there are two different types of fatigue, generalised fatigue (tiredness) and muscle fatigue.

Pain

Dr Mackie found that pain hasn't been a major polio symptom as such. Sometimes people talked about pain in weak muscles, very rarely in muscles that are very weak or severely wasted, but rather in the muscles that are under strain – those that are weakened but are trying to do the job of a lot more muscles. This is really similar to the concept of fatigue in muscles, which can be quite painful.

Mostly people talk about pain in relationship to their joints and to areas where muscles are quite normal on the muscle chart but are doing a bigger job resulting in problems with tendons, muscles (rotator cuff tears) – all those sort of things are really a feature of pain.

Respiratory

A number of clients have had sleep studies and even if it was recommended, they very rarely use a CPAP machine.

Cold intolerance

This proved to be universal, and some also experienced humidity intolerance.

Swallowing

Swallowing issues haven't been a feature. However, there were issues with voice fatigue, some could no longer sing, and some by end of their interviews had difficulty 'getting a word out'. Some were recommended to have speech assessments by Mt Wilga's speech therapist.

Sleep

In the general community there is a lot of problem with sleep. Dr Mackie doesn't think it is any worse in the polio community. Restlessness and pain can cause poor sleep patterns.

Psychology

Psychology hasn't been assessed to any extent in the LEO P Clinic. There isn't enough time left for a psychology assessment and fatigue has been an issue after completing all the questionnaires for three assessments. Maybe the Clinic could do better in this area in the future. From Dr Mackie's point of view, there have been a variety of psychological issues being raised. There is certainly an issue about the anger of non-recognition of polio; a "pat on the back" and saying "*there, there, polio is gone, don't worry about it*". Also feelings of concern, worry, frustration or depression when having to deal with new changes after having coped all their lives and now finding it more difficult which is quite distressing.

What have they learnt?

In the first week of Clinic assessments they were doing a 6-minute walk test but after about a minute they realised it wasn't going to work for polio clients so they threw that one out of the assessment process!

What has been quite extraordinary to learn about has been the clients' childhood experiences – incredibly long hospitalisations, the isolation, and the stigma that was often felt. Although even more extraordinary seems to be that polio survivors were left behind in a sense through schooling, but everyone went back into the school system and got on with life and, although not leaving their experiences behind, they moved forward with resilience.

Clients have presented with a variety of symptoms, some quite minor problems, as well as as muscle wasting which can be put down to polio. It is here that muscle charting is essential for all muscles to detect the prevalence of muscle weakness. It is beneficial to bring along any previous muscle charts to the assessment to see if there has been any significant change over time.

What Issues Concern Clients?

The main issues that people have asked us to address are ‘future- proofing’ – the issues of balance and falls, concerns about their future post-retirement, planning for the future as we age and live longer. There has been a bit of resistance to aids and equipment, most thinking that they don’t need to see an occupational therapist (OT), but after their OT assessment they had found it to be really helpful. It is quite a normal response to resist equipment and aids as they are an indication of change, but in many cases it is the one thing that we *can* do to alter our environment. There is an extraordinary range of things that can make life easier – why not take advantage of them?!

Outcomes

Of the 21 clients (some rural clients), 5 attended Mt Wilga following their assessment, 2 as inpatients and 3 as day patients. Information is made available as to what services are available in the client’s local area and we try to link them with their current therapists.

Plans for the Future

A survey will be sent out to LEOP Clinic attendees to get feedback, to ask for ideas and suggestions, and to try and quantify the experience people have had and how useful the Clinic has been.

In April 2016, Mt Wilga will be one of the venues for the Polio Australia/Rotary Late Effects of Polio Clinical Practice Workshops. Mt Wilga has been in contact with the therapists who are presenting the workshops, Advanced Rehab Centre at Artarmon, and are very keen to network with them as they offer some services as well. They have had wonderful experience with polio clients.

Finally, Dr Mackie will give a more extensive presentation of the data from the LEOP Clinic at the Polio Australia International Conference in September 2016.



***Nadege van Drempt** is an Occupational Therapist (OT) who has a special interest in neurological rehabilitation. She has worked in a number of inpatient and outpatient settings in the Newcastle area, including a rural stroke team and with amputee clients. She has worked at Mt Wilga since 2004 working with patients with both neurological and orthopaedic conditions. She has completed her Masters in research. She is currently one of the OTs undertaking assessments at the LEOP Assessment Clinic.*

REDUCING FALLS RISKS AND SIMPLIFYING DAILY ACTIVITIES

Occupational Therapy is about day to day activities and how to make them easier with some hints and tips to make life easier. An occupational therapist can come out to your home to assess your needs and offer ideas about equipment and solutions.

INTRODUCTION TO FALLS

Polio can cause muscle weakness, joint pain and fatigue which all can increase your falls risk. We know that people with polio fall more often than other adults over 55. Polio survivors report falling more, often in and around the home, and more often in the afternoon (about 60% of falls).

Predictors of falling identified for polio survivors:

- problems maintaining balance,
- “knee buckling” in the weaker leg,
- fear of falling.

Falls definition and causes

According to the World Health Organisation, a fall is “*an event which results in a person coming to rest inadvertently on the ground or other lower level*”. A fall is an accident, it can be a slip or a trip, and causes may be environmental (for example, around the home, or in the garden, or when out and about) or personal (for example, due to weak or fatigued muscles, arthritis, changes in vision, fear of falling or dizziness).

Presentation Overview

- How can we reduce environmental hazards associated with falls?
- What personal factors can lead to falls occurring?
- How can we simplify daily tasks and conserve energy for daily activities?
- What to do if a fall occurs?

Environmental Hazards – the top 10 falls hazards

1. Slippery surfaces
2. Obstacles in corridors
3. Poor lighting
4. Floor mats
5. Footwear
6. Climbing ladder / step ladder / chair
7. Bath
8. Uneven, broken or loose pathways
9. Trailing cords
10. Steps / stairs

Studies have found that just making small changes to your environment can significantly reduce your falls risk.

Floor Hazards

- Wipe up spills – be mindful to look out for spills, eg around the pet’s water bowl.
- Floor surfaces – don’t polish floorboards, watch out for talcum powder on floors, make sure carpets are not frayed or a possible trip hazard. Mats and rugs can have corners turned up and if you are experiencing some difficulty lifting your toes, or if you are carrying something and suddenly change direction, then that mat becomes something that trips you up.
- Keep walkways clear.
- Electrical appliances eg small heaters – hide electrical cords under furniture or around skirting boards.
- Changes in floor level eg from bathroom to hall, or from carpet to kitchen, there is often a lip – there are wedge strips that can be used to prevent trips.

Lighting

- Ensure adequate lighting (75W globe recommended), there are vision changes with age ie difficulty judging depth and contrast.
- Leave lights on at night eg when visiting bathroom during the night, use lamps.
- Light switches should be easy to reach.

- Reduce glare.
- Make obstacles or hazards stand out eg glass coffee tables can be a hazard, use a contrasting colour to your floor.

Bathroom

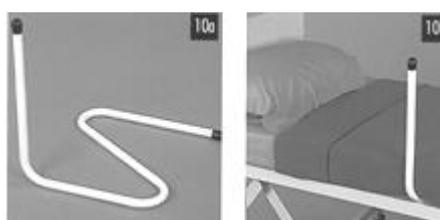
- Ensure toilet is easy to get up from – install weight-bearing grab rails (not towel rails) or over-the-toilet aid.
- Safety of getting out of shower – use shower chair/stool, grab rails, shower bench for transfers.
- Non-slip mats to reduce slipping
- Proximity of bedroom to toilet – an option is to use a bedside commode, bottle or urinal
- Bathroom modifications
- Equipment



Around the house

Furniture

- Bed and chair – make sure these are firm enough and high enough to get up from easily, raisers (called elephant feet) can be purchased to increase bed or chair height, this can reduce strain on your shoulders and wrists.
- Position and safety of furniture – keep any walking aid close to where you are lying or sitting for when needed, look out for electric blanket cords or bed sheets getting caught up. Bed sticks/poles are useful to hold on to when standing up until you are steady (and hold when turning over in bed)



Steps / Stairs

- Rail – or stair lifts, or ramps. Edges easily identified.
- Consider fatigue.



Pets

- Reduce falls risks.

Outside

- Don't leave things lying around the garden like hoses – retractable hoses available.
- Keep outside paths in good condition.
- Eliminate shadows across paths if possible.

- Access into the home – install easy to open doors, beware of screen doors closing on you, catching shopping bags etc.
- Adequate lighting.

Outings

- Go out when you have most energy / fewer crowds.
- Transport considerations – disability parking permits, trains – sit in the side section ie no stairs – buses, ask driver to wait until you are seated, use an electric scooter or a wheelchair for distances when shopping.
- Take any walking aids, glasses or hearing aids.
- Pay attention to your surroundings – it is recommended that you scan four paces ahead for changes in surfaces etc.
- Plan the outing and rest breaks.
- Consider how to manage shopping – use of carts, shopping delivery services.

Footwear and Clothing

Shoes

- Supportive, well-fitting shoes with low heels and non-slip soles.
- Fastening to hold the foot.
- Thin, firm midsole for your feet to feel the ground.
- Not worn, and support the foot in a good position.

Clothes

- Non-restrictive.
- Not too long or loose fitting.
- No loose cords.

Personal Factors

- General medical issues – dizziness, light-headedness, some medications can be an issue (a combination of 4 or more medications can increase your falls risk), bone health – how to reduce your risk of a fracture.
- Fear of falls.
- Vision – have eye tests regularly; make sure your glasses are clean!!
- Sickness or injury.
- Cold intolerance – muscles are weaker when cold; wear layers.
- Personality – do you rush, are you a multi-tasker?
- Fatigue.
- Physical ability and activity.



MAKING THINGS EASIER

This is when we talk about fatigue and conserving energy. It is the same information that is given to people with heart problems or respiratory problems or anyone dealing with energy conservation.

Four Principles of Energy Conservation

Pacing

- Work out a baseline of activity that is comfortable for you ie not overusing those weaker muscles that are at risk of harm or damage. Signs of overuse are twitching, pain, weakness, a feeling of heaviness, spasm – all signs that muscles need to rest, and for some it may be for either a few minutes, or others they may need to lie down

for an hour, it is very individual. You may just have to change your activity to something using different muscles. Using a diary is useful, you can note how long you performed say gardening (eg 30 minutes) before you experienced some symptoms which meant it was too long a period, and so the next time you could reduce the time to say 20 minutes; particularly if you are getting even more than normal fatigue, this a sign that you need to cut back.

- Break activities into smaller steps, with rest periods eg vacuum one room per day.
- Listen to your body – don't rush!

Planning

- Schedule your daily activities to use your energy wisely.
- Stick to time limits eg 20 minutes gardening.

Prioritising

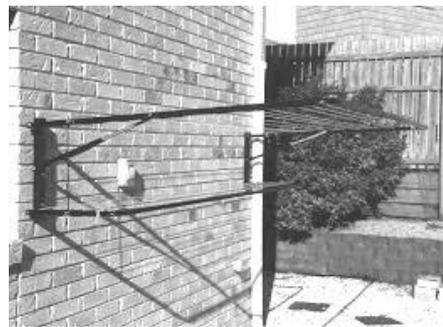
- Eliminate non-essential tasks where possible eg shop on the internet, have shopping delivered, hire a cleaner, and a gardener to do the lawns.

Positioning

- Sitting uses less energy than standing – it gives your leg muscles a rest eg sit to chop vegetables.
- Keep items in easy reach – reaching and bending reduces your balance.
- Consider modifying the way you do things.
- Use equipment eg transfer bench – little changes can make a big difference.

Some practical ideas

- Have items handy eg chair outside shower, put on terry towelling robe to dry yourself and have clothes there ready to get dressed OR if cooking, having everything ready in one area and then sit down to chop and peel and cook; a breakfast station or ironing station where everything is in one place.
- Sit where possible eg when gardening, use a kneeler which doubles as a seat, or when grooming pets.
- Avoid awkward postures – bending and reaching, take that extra step to be closer and turn your feet to be right where you need to be. To reduce bending you can get a pick-up stick or use a toe wiper when sitting down, long-handled pan and broom, long-handled everything for the garden, long-handled stocking aids, folding/wall mounted clothes lines. Back up to sit down into a car, then lift legs in from a sitting position rather than trying to balance on one leg.
- Stay at ground level ie the higher you go, the harder you fall – so getting up high is NOT a good idea.
- Pace yourself – rushing is a real problem eg when the phone rings, let it go to voice message or carry a cordless or mobile phone (this is also useful if you do have a fall because you can phone somebody for help). Changing directions suddenly causes greater falls risk, think about your feet!
- Simplify where you can, use short cuts eg frozen vegetables, clothes that don't need ironing, have shopping delivered.
- Consider aids eg tray mobiles or laundry trolley to carry things from the kitchen to the lounge room. The Independent Living Centre is a great source of information about products; if you find some task difficult, you can phone them and speak to an occupational therapist for advice on what product might be helpful for you.
- Avoid dual tasks (and lifting).



If a fall happens

- Lying on the floor can cause problems – without help you can get cold, pneumonia, miss medication etc.
- It is important to make a plan of what to do in the event of a fall: *Raise the alarm* – carry a mobile phone, wear a personal alarm pendant or wrist band which can be pressed to alert the monitoring company who will call your nominated person to come or they can call an ambulance. *Providing access* – a box outside with a combination lock can store your house key to allow access for ambulance paramedics.



Getting up from the floor if you have fallen

- Calm down
- Check your body
- Roll onto your side
- Crawl over to the chair
- Put your arms up onto the chair
- Bring stronger knee forward and put that foot on the floor
- Push up, pivot your bottom around
- Sit down



If you cannot get up

- Do not panic.
- Think through all possibilities for raising the alarm and getting up.
- Try to stay warm.
- Gently move around to reduce pressure.

Questions

It was asked if others experienced muscle cramps, many in the audience did and the advice was to take magnesium and potassium and keep hydrated. It is a sign of muscle fatigue and overuse.

Alice told us of a small torchlight that she has attached to her walking stick which is very handy when walking in the dark etc. The small torches are available from most \$2 shops.

Anne O'Halloran explained how Technical Aids for the Disabled (TAD) helped her solve a problem she had with her garbage bin, they designed a special gadget that had four wheels to make it easy for Anne to push it. They are mostly retired engineers who design and make products to solve problems for disabled people. You only have to pay for the components of the 'gadget'.

Anne Buchanan told us of a water bottle holder that is made for push bikes and can be attached to your walker, it is available from Kmart.

Finally, when the topic arose of walking-stick rubber tips being slippery when going from outside to inside, Anne and Nola showed members the type of tips used on their sticks for stability. They are called Flexyfoot ferrules – they come in various sizes and are available for purchase from:

Advance Rehab Centre, St Leonards. Phone: 02 9906 7777



Polio Post



Member Shirley Roach wrote recently wishing to share some information with fellow members.

I've learnt about (and am using) a product which I thought some members may be interested in trying so wanted to let you know. It's called "Pea Protein Isolate" – all green vegies, especially peas, by "Nature's Goodness" and another by "Vital" – both very good.

In September I had a very bad fall and the dietician in hospital said I needed building up (at 40 kg, I'd agree). She wanted me to take some milky drink but I'm allergic to dairy.

The chemist sourced this for me on the 'net – I've used both brands (Health Food stores stock it as well) for about 4 weeks now and already feel better than I have in 5 years at least! I use 2 tablespoons in a glass cup of water once or twice a day. Using just a 450 gm container is worth a try. I do eat a lot more greens, especially peas, as well.

My left hip (already skin and bone for 65 years) has filled out a little! I've only got 27% sight but it looks better to me! I've a lot less general pain except for the right shoulder with the torn tendon, and it isn't so painful pushing my wheelchair. My fatigue seems less – I still have a rest each arvo but don't fade by the wayside so much. It helps with weight management, has no chemicals, dairy/lactose, soy, gluten etc.

I really hope some who feel the need of a bit of help may want to try it and gain the benefit I have (it's yum to drink too).

Update on Clinical Practice Workshops - Final 2 Sessions

Polio Australia is very pleased to be partnering with Rotary District 9685 to bring this series of FREE clinical practice workshops to allied health professionals wishing to learn more about management of the late effects of polio (LEoP). The workshops are driven by best-practice research from Europe and the USA and are open to all health and allied-health professionals.

Gosford
Conference Centre, Gosford Hospital, Holden Street

Thursday, **28 April 2016** : 1:00 pm – 4:00 pm

Narrabeen
The Tramshed Hall, 1395a Pittwater Road

Thursday, **5 May 2016** : 1:00 pm – 4:00 pm

Who Should Attend?

Allied and other health practitioners such as: physiotherapists, occupational therapists, orthotists, exercise physiologists, nurses, podiatrists, speech pathologists, dietitians, social workers, case managers, and anyone else who is interested in knowing more about the post-polio body.

How Can You Help?

If you live in the above regions and are consulting any health professionals in your local area, please be sure to let them know about the workshops and encourage them to register to attend.

For more information, visit: www.poliohealth.org.au/workshops

Remembering Polio NSW through a Bequest

Would you like to support Polio NSW by remembering the organisation in your Will?

Over the past 26 years, thousands of polio survivors have benefited from Polio NSW either through their membership or through assistance that the organisation has provided. Polio NSW owes an enormous debt of gratitude to the generosity of people who have made donations or bequests to assist with the continued development of its services.

Why leave a Bequest to Polio NSW?

Polio NSW does not receive any money from government departments or other entities. The organisation depends almost entirely on donations and bequests from members. Polio NSW has grown into the organisation that it is today because of the support of the many people who believe in its purpose and objectives and who have been committed to ensuring its future through the giving of their time and/or by their financial support.

To sustain and develop Polio NSW into the future, we need your assistance. Through a bequest in your Will you will be able to ensure that the work of Polio NSW will continue for the benefit of polio survivors.

In particular, your bequest can help to:

- maintain an effective and viable organisation;
- provide for the employment of office personnel to relieve the workload of ageing polio volunteers;
- assist in developing an effective communication network;
- ensure the continuation of support at the local level;
- develop further services for polio survivors and the health professionals who care for them.

What to do

In consultation with a solicitor or adviser, consider making a bequest to Polio NSW in your Will and determine the type of bequest which best suits your circumstances and wishes.

For your information, Polio NSW is incorporated under the Associations Incorporation Act, is registered with the Australian Charities and Not-for-profits Commission, and is an authority holder under the Charitable Fundraising Act. The Network is recognised by the Australian Taxation Office as a Public Benevolent Institution and endorsed by them as a Deductible Gift Recipient (Number 90 039 932 667).

If you decide to include a bequest to Polio NSW and are willing to let us know, we can thank you personally for your generosity and forethought. If you would like any further information, just get in touch to see how we can help. Phone us (02 9890 0946), write to us (PO Box 2799, North Parramatta NSW 1750) or email us (office@polionsw.org.au).



Support Group Change

The Sutherland Support Group Convenor, Ruth Hatton, reminds us that they now meet at **CLUB MENAI**, 44 Allison Crescent, Menai, on the 1st Wednesday of each month at 2 pm.

Book Review - "The Polio Paradox" by Dr Richard L. Bruno

by Susan Ellis

This book has only recently come to my attention when searching the 'net for useful polio information, and I was surprised to find that it had been written in 2002. Many of our members may already be familiar with Dr Bruno's book or may know Dr Bruno from his well known article "The Ten Commandments for PPS" (this can be viewed on <www.poliohealth.org.au/pps-the-australian-experience/>) or for his advice – "Conserve to Preserve" and "If anything causes fatigue, weakness or pain, don't do it (or do less of it)".

For more than 30 years Dr Bruno studied and treated nearly 6,000 polio survivors. Some of his research was in collaboration with his late wife, Dr Nancy Frick, herself a polio survivor. Dr Bruno is a psychophysiologicalist, he himself has multiple sclerosis and uses a wheelchair.

On further searching I found that Dr Mary Westbrook reviewed the book in our *Network News*, Issue 56, December 2002:

Book about the puzzles and paradoxes of polio

In June 2002 Dr Richard Bruno's book, "The Polio Paradox", uncovering the hidden history of polio to understand and treat 'post-polio syndrome' and chronic fatigue, was published. It is full of fascinating little-known details about the history of polio, much useful information about relieving post-polio symptoms and hunches e.g. as to how polio and chronic fatigue syndrome may be related and why polio survivors seem less likely to be diagnosed with Alzheimer's disease. The many paradoxes or seeming contradictions of the polio experience are highlighted through the book e.g. the extreme exercises and therapies that helped polio survivors to appear 'normal' set the stage for PPS and are the opposite of what you need to do to manage PPS today. In the 1980s, doctors were ignoring and rejecting the same polio survivors whose plight had riveted the attention of the world's medical community and spurred it to action just thirty years before. Bruno says that to take the leap of faith to cope with PPS you should read the words POLIO SURVIVOR again and again taking in the breadth and depth of their meaning. If you can remember all you have survived and appreciate how you have thrived in spite of polio, there can be no question that you have the ability to make the physical and emotional changes necessary to survive and thrive with PPS.

Dr Mary Westbrook

I found Dr Bruno's book very informative, it explains the whys and hows of contracting polio and of its effects on our brains and bodies. It has lots of practical advice based on research, experience and sometimes just common sense. At times I found some of his recommendations difficult to take 'on board' but overall it has the most relevant information that I have found to date. As with most information that we as polio survivors come across, you take from it what is relevant to you – try some new ideas or suggestions and then make up your own mind what works for you.

I myself have made some changes as suggested in Dr Bruno's book which are relevant for me and found them useful and constructive. I think it will be a go-to book for when new issues crop up in the future.

Available from Fishpond.com.au \$34.48 (free shipping) or www.amazon.com.au to download to your Kindle for \$19.99.

No Interest Loan Scheme (NILS)



The No Interest Loan Scheme (NILS) provides individuals and families on low incomes with access to safe, fair and affordable credit. Loan amounts are between \$300 and \$1,200 for essential goods and services such as fridges, washing machines and medical procedures. Loans cannot be used for cash, bond, rent arrears, debt consolidation, holidays or bills. Repayments are set up at an affordable amount over 12 to 18 months.

NILS is offered by more than 250 local community organisations in over 650 locations across Australia.

What are the loans for?

Loans are available for the purchase of essential goods and services. These may include:

- Household items like fridges, washing machines, stoves, dryers, freezers and furniture.
- Some medical and dental services.
- Education essentials such as computers and text books.
- Some other items as requested.

Do you qualify for NILS?

To qualify you must:

- Have a health care card/pension card.
- Reside in your current premises for more than 3 months.
- Show a willingness and capacity to repay.

How does it work?

1. Enquire about a loan now or call **13 NILS (13 64 57)**.
2. Bring your documentation to a meeting with the local loan provider.
3. Your loan application is assessed.
4. You are informed of the outcome of your loan application and agree repayment terms.

For more information: Website: <www.nils.com.au> **Phone:** 13 64 57

Information sourced from NILS website

AIDER Program - Assistance for Infirm, Disabled and Elderly Residents

What is AIDER?

AIDER is a one-off FREE service, supporting residents to live safely and confidently in areas where bush fires may start. The AIDER program offers a one-off FREE service to reduce bush-fire hazards around your home. The property must be bush-fire prone, meaning an area of land that can support a bush fire or is likely to be subject to bush-fire attack.

Who is eligible?

Aged residents and residents with disabilities who have limited domestic support from family, relatives, friends or other services.

AIDER service may include:

- Thinning vegetation.
- Removing leaves, sticks and fallen branches.
- Trimming branches from around and overhanging the home.
- Mowing or slashing long grass.
- Cleaning gutters.

To request an assessment of your property call: 02 8741 4955

Website: <www.rfs.nsw.gov.au/plan-and-prepare/aider>

Phone: 1800 679 737

Information sourced from NSW Rural Fire Service website and flyer

Smoke Alarm Subsidy Scheme

It can take less than three minutes for a fire to completely engulf a room and the risk of fatality increases as much as 60% without an effective smoke alarm. Additionally, Fire and Rescue NSW research shows that between 2000 and 2014, 56% of fire fatality incidents had no smoke alarm present, with the vast majority of these fatalities occurring between midnight and 6:00 am. For deaf and hard-of-hearing people who cannot hear a smoke alarm, specialist alarms that include a strobe light and pillow shaker are available at the cost of \$20.

If you live in NSW and experience severe to profound hearing loss, or know someone who does, apply to receive a subsidised alarm by contacting the Deaf Society at:

Website: <www.deafsocietynsw.org.au>

Phone: 02 8833 3600 or 02 8833 3691

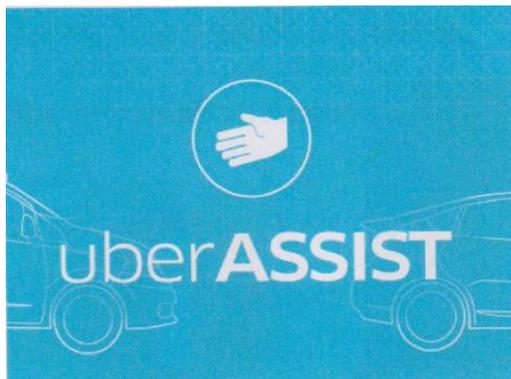
Life Tec



In partnership with Independent Living Centres Australia, Life Tec has designed a free online National Equipment Database (NED). NED provides free information on over 10,000 assistive technology products and equipment options across Australia. Users can browse by product topics, search for suppliers, create shortlists, and compare products to find a practical solution to everyday life activities.

Website: ilcaustralia.org.au/search_category_paths

UberASSIST

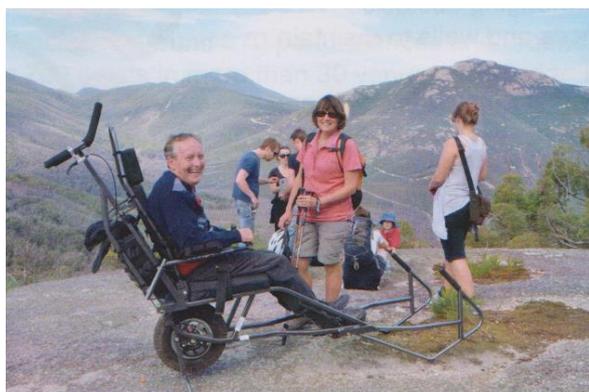


Uber Australia has launched a new service called UberASSIST. UberASSIST is designed to provide additional assistance for users. Top driver-partners receive training and knowledge of safety requirements and can accommodate folding wheelchairs, walkers, and collapsible scooters. The UberASSIST driver training has been developed by the Open Doors Organisation (USA), along with consultation from the Australian Network on Disability (AND).

Uber doesn't yet cater for passengers requiring lifts or accessibility ramps, but is looking for people owning wheelchair-accessible vehicles to partner with Uber, so this service can be offered in the near future. To access UberASSIST, download the Uber app and enter the code 'ASSISTAU' in the promotions tab.

Website: <www.uber.com>

Trailbike Rider



New all-terrain wheelchair gives everyone access to Dandenong Ranges National Park

To celebrate *International Day of People with a Disability*, all visitors to Dandenong Ranges National Park will now be able to enjoy trails in the park thanks to a motorised all-terrain wheelchair – called a TrailRider. A modified version of a Canadian invention, the motorised TrailRider was created by Parks Victoria and is the first of its kind in the world.

TrailRider all-terrain wheelchairs are a cross between a rickshaw and a wheelchair and can handle more rugged bush trails where conventional wheelchairs cannot go.

The motor on the chair makes it easier to manoeuvre the chair over rough trail surfaces and makes it easier for visitors with mobility limitations to access steeper and longer trails than ever before.

"Everyone has the right to enjoy the benefits of being in nature and we want to help everyone to be active in our parks. This is just one way we are making this possible", said John Kenwright, Community inclusion Coordinator, Parks Victoria.

"The TrailRider really opens up park areas that people with limited mobility may never have been able to see or experience."

The TrailRider has recently been trialled by a YMCA Recreation camp in the Dandenong Ranges for children with disabilities. Having a TrailRider based in the Dandenong Ranges will make it much easier for the YMCA, other organisations and individuals to regularly access a TrailRider chair to explore parks.

The TrailRider is located at *Grant's on Sherbrooke* café at Grant's Picnic Area in Mount Dandenong National Park. It can be booked by calling **03 9755 2888**.

Key Facts

- For work on improving access to parks, including making TrailRiders available, Parks Victoria won a 2015 National Disability Award.
- TrailRider all-terrain wheelchairs are just one of the facilities and programs supported by Parks Victoria to ensure parks are accessible to everyone.
- There are now 11 TrailRider all-terrain wheelchairs available in the Grampians National Park to assist visitors with disabilities to explore the many spectacular park trails using the TrailRider chairs.
- There are now ten child and adult beach wheelchairs available to explore Victoria's coastal parks.
- Trained volunteers from the Sherpa Volunteer program are available to explore Victoria's coastal parks.
- Thirty-eight of Victoria's most visited parks now have more comprehensive park access information provided to help visitors plan their park visit and park activities.

Website: <www.parks.vic.gov.au/visit/improving-park-access-for-all>

Phone: 0448 572 342

Information sourced from Park Victoria Media Release



SCIA Independence Expo

When: Friday 15 April and Saturday 16 April 2016, 10 am – 4 pm

Venue: Australian Technology Park, Sydney

Cost: Free to attend, register at www.scia.org.au/expo or **1800 819 775**

Spinal Cord Injuries Australia (SCIA) is holding the 3rd biennial SCIA Independence Expo to tackle the #1 issue for people with physical disabilities – enhancing their independence. The event showcases how people with physical disabilities can live as they wish in their own homes, workplaces and communities.

The SCIA Independence Expo will give people with physical disabilities the opportunity to find new ways to enhance their lives with amazing products, equipment and technology on display. Information-packed demonstrations and workshops on issues that matter to them. People can also explore lifestyle options like travel, sport, art and music. There will be opportunities for people to socialise and enjoy fun activities over the Expo's two days.

Thanks to the support of sponsors like PME Auto Conversions, the SCIA Independence Expo is free for anyone to attend – people with disabilities, family, friends, carers, professionals working in the disability, healthcare or community service sector or students embarking on their career in the sector. People registering to attend at <www.scia.org.au/expo> or **1800 819 775** will go into the draw to win a \$500 gift card.

Funding will also be available for people with physical disabilities to assist with the travel, accommodation and care costs required to attend the SCIA Independence Expo.

Contact: Claire Beaver, Marketing Manager, Spinal Cord Injuries Australia – 02 9356 1121



2016 Polio NSW Seminar Program

Wednesday 18th May	Northcott Society 1 Fennell Street North Parramatta	Managing Pain <i>Full details on pages 2 and 3</i>
Annual General Meeting Date TBA	Burwood RSL Club 96 Shaftesbury Road Burwood	Annual General Meeting and Seminar <i>Details to be advised in upcoming issues</i>

Management Committee – Executive Members Contact Details

Gillian Thomas	President	president@polionsw.org.au	02 9663 2402
Susan Ellis	Vice-President	vicepres@polionsw.org.au	02 9487 3094
Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641
Committee Members (for contact details please ring or email the Network Office): Charles Anderson, Anne Buchanan, Nola Buck, Madeline Coelho, Ella Gaffney, Anne O'Halloran, Alice Smart, John Tierney			

PPN Office and Other Contact Details

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Office volunteers: Diana and Nola			02 9890 0953
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Ella Gaffney	Webmaster / Support Group Co-ordinator	webmaster@polionsw.org.au	0407 407 564
Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	02 9890 0946
Nola Buck/Susan Ellis	Co-editors <i>Network News</i>	editor@polionsw.org.au	02 9890 0946

Have You Included Your Polio Details on the Australian Polio Register?

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,000 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <www.polioaustralia.org.au>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.