



Issue 79  
March 2011

# NETWORK NEWS

## POST - POLIO NETWORK (NSW) INC

PO Box 888 Kensington NSW 1465 AUSTRALIA

Phone: 02 9663 2402

Email: editor@post-polionetwork.org.au

Website: www.post-polionetwork.org.au

Editor: Gillian Thomas

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### President's Corner

**Welcome** to the first *Network News* for 2011. Thank you again for your patience as the Management Committee came to grips over the past year with too many things to do and not enough hours in the day. We are painfully aware that this has adversely impacted on the timely publication of *Network News*. However, recognising the problem is one thing - resolving it has proven to be quite a challenge.

As a first step, Mary-ann Liethof, Polio Australia's National Program Manager, has put this issue together as Guest Editor, in her spare time. I am sure you will agree that she has done a wonderful job, and given *Network News* a fresh new look while maintaining all your favourite features.

The next *Network News* is scheduled for June, and with it we hope to bring some exciting news about future

editions.

In the meantime, please read on to catch up on Network activities in recent times, as well as coming events.



*Gillian Thomas  
Editor and President*

**Of particular interest in this issue is information about Australia's second Polio Health and Wellness Retreat to be held at Mt Eliza, Victoria, from Thursday 28 April to Sunday 1 May - see page 6 for more details. (The first Retreat held in NSW in 2010 was highly successful, as reported on pages 3 and 4.) There are still places available for this second Retreat, so please consider attending, particularly if you are one of our Victorian members.**

### Queen's Birthday Honours

**Belated congratulations go to Patricia Byrne** who was awarded the Medal of the Order of Australia (OAM) on 14 June 2010 for service to people with disabilities, and to the community. Patricia was a Founding Member of Post-Polio Network (NSW) Inc in 1989 and served as Secretary for a few terms. Patricia remains an active Member.

Patricia's other achievements include a long association (since 1959) with the

St George Association for People with Physical Disabilities Inc, previously known as the St George District Fellowship of the Poliomyelitis and Physically Handicapped Society. She has also been a Member of People with Disabilities (NSW) since it began and a Member of the Physical Disability Council of NSW, including being a Member of PDCN's Management Committee.

**Patron — Professor Emeritus Sir Gustav Nossal, AC CBE FAA FRS**

## Report on One Day Seminar – 20 July 2010



Associate Professor  
Brendon Yee

### Sleep Disordered Breathing Associate Professor Brendon Yee

Associate Professor Yee has been a staff specialist in the Department of Respiratory and Sleep Medicine at Royal Prince Alfred Hospital since 2003. He is also medical director of the Ventilatory Support Service and the Sleep Investigation Unit as well as a consultant at the Woolcock Institute of Medical Research clinic at Glebe which specialises in the diagnosis and treatment of sleep and breathing disorders (a GP can refer patients to this clinic) and in Outreach Services in Sleep and Respiratory Medicine in Central Western NSW. Professor Yee described the symptoms and causes of sleep apnoea and discussed its symptoms and treatments. A common treatment is ventilatory support with a CPAP machine and mask which provides positive continuous airway pressure. Other treatments include non-invasive ventilation devices which fit in the mouth and also surgery, however, this is only effective in about 10% of cases. Professor Yee also spoke about the effects of polio which can affect breathing particularly at night e.g. scoliosis, restrictive lung function and weak muscles. He suggested that bi-level ventilatory support may be more appropriate for some polio survivors than CPAP. These machines look similar to CPAP devices but deliver two levels of air pressure that are set to coincide with the patient's inspiratory and expiratory breathing efforts. It is important to choose health professionals who are familiar with the effects of polio when seeking assistance with sleeping and breathing problems.



Ozar Amir

### Foot Care for Polio Survivors Ozan Amir

Ozan Amir has Bachelor and Masters degrees in Podiatry and is a member of the Australasian College of Podiatric Surgeons where he is completing his final year of surgical training. The second session was presented by Ozan, who is the principal podiatrist at the Manly Foot Clinic and a director of the Centre for Podiatric Surgery and Medicine in conjunction with Royal Prince Alfred Hospital at Newtown. Using Neil von Schill to help demonstrate many of the techniques and ailments that were discussed, Ozan showed that the field of podiatry has a much greater scope and diversity than the services provided by chiropractors in the past. In addition to learning clinical practices associated with podiatry, practitioners complement their practical skills with a knowledge of anatomy, physiology, biomechanics,

diagnostic imaging, pharmacology and preventative health.

Ozan suggested that an initial visit to a podiatrist should include a full assessment of foot care needs as well as a medical history. Podiatrists should be seen as one of the allied health professionals in your personal health care team.

Questions from the audience resulted in discussion of a wide range of concerns. These included the use and prescription of orthotics and orthopaedic devices, essential elements of good footwear, the treatment of pain and preventative measures in foot care, the role of surgery in foot care management and many specific case management queries.

The number of questions from the audience indicated great interest in the topic and a need for specialist information in the area of podiatry.



Melissa McConaghy  
Practice Principal and  
Physiotherapist  
Advance Rehab Centre

### The Polio Body Melissa McConaghy

Melissa is a Neurological Physiotherapist, she holds a Masters in Neurological Physiotherapy, a Postgraduate Certificate of Public Health and is Chairperson of APA NSW Neurology. She has extensive experience in neurological rehabilitation and specializes in stroke and other movement disorders. Melissa, has been a senior physiotherapist supervising and teaching for over eight years, she has worked in a variety of rehabilitation settings in Australia and overseas. Melissa established Mobile Rehab Innovations in 2006 and the Advance Rehab Centre in 2009.

Melissa gave an interesting and informative presentation entitled "The Polio Body" which focused on the Late Effects of Polio and in particular, strategies and resources which can be used to ameliorate LEOP.

Initially Melissa spoke of the pathology of the polio virus and theories surrounding post polio syndrome. One theory attributes post-polio syndrome to overuse, causing degeneration of muscles. Another theory is that people most likely to suffer post-polio syndrome are those who suffered moderately severe initial polio paralysis but who have experienced a moderately good recovery. Various studies indicate a proportion of between 20-70% of people who have had polio could experience the symptoms of PPS.

The diagnostic criteria for PPS include a prior experience of polio, demonstrated changes in the body, certain patterns of recovery and the gradual or sudden onset of new weakness in previously affected muscles.

## Report on One Day Seminar – 20 July 2010 (cont'd from page 2)

### The Polio Body (cont'd from page 2)

Common issues affecting people who experience PPS include biomechanical and body system deficits arising from polio in addition to functional changes, and the need for equipment to assist with mobility and fatigue. With regard to changes in the body arising from PPS, new weakness can occur in 60-87% of previously affected muscles and in 37-77% of previously unaffected muscles. A smaller proportion (17-28%) of polio survivors can experience new muscle atrophy (39-41%), muscle twitching (39-41%) or muscle cramps (43-48%).

General fatigue is a common difficulty experienced by people with PPS, this can arise from chronic pain, respiratory difficulties, depression, sleep disorders, dysfunction of joints and what Melissa termed "Type A" behaviour. Muscular fatigue is also a common issue for people with PPS.

The pain, so often associated with PPS, can take the form of myalgia (muscle pain) or can arise from overuse or biomechanical changes in the body.

There are various ways to manage PPS involving changes to lifestyle, the use of resources, diet, gentle exercise and the use of assistive devices.

Lifestyle modification such as avoiding stress and undue effort in undertaking tasks can be beneficial. Thus avoiding heavy lifting and carrying, resting often and the use of aids should help. Additionally the use of specialized therapy can also be beneficial.

Physiotherapists can assess individual needs and manage symptoms as well as prescribe useful exercise programs. Hydrotherapy, involving gentle exercise can

**There are various ways to manage PPS involving changes to lifestyle, the use of resources, diet, gentle exercise and the use of assistive devices.**

soothe pain and improve cardio-vascular fitness as well as easing the tightness in muscles and stiffness in joints.

Yoga and meditation can also increase muscle relaxation and flexibility, This in turn reduces pain, improves the heart rate, blood pressure and also blood circulation.

Occupational therapists can assess for assistance at home, work or with mobility, identify equipment needs as well as provide relevant training.

Orthotic specialists can assess, prescribe and fit footwear, trunk support and customised assistive devices as well as help with stance control.

Speech pathologists can help with the assessment, treatment and education surrounding respiratory difficulties.

Acupuncture can improve sensory-motor response, reduce pain and anxiety and assist with rehabilitation.

A nutritional specialist can assess and prescribe a regime to improve health and

maintain healthy body weight.

Exercise is also important in managing PPS. The exercise recommended for people who experience PPS is based on a diagnosis of symptoms and history of muscles as well as that of respiratory and other difficulties. The types of exercise that are beneficial for people who experience PPS involve low resistance and gradual increase of movement. Exercise can be undertaken in a variety of ways and can improve endurance, resistance, bodily function and general wellbeing.

Adaptive aids can be used to assist with walking, transfer and transport. Adaptive furniture can also be helpful.

Melissa's presentation was warmly acknowledged by the audience.

## Report on NSW Health and Wellness Retreat – April 2010

In April 2010 Polio Australia together with Post-Polio Network (NSW) conducted the first three day "Polio Health and Wellness Retreat" in Baulkham Hills, NSW. The retreat, supported by GlaxoSmithKline and the Flack Trust, was held at St Joseph's Centre for Reflective Living.

The aim of the retreat was to develop and evaluate a model for strategies that can assist with the management of post-polio syndrome. If successful this model could be used as the basis of other such retreats. This model aims to develop a holistic approach to the management of PPS. To reflect this focus each day of the retreat presented a different aspect of health and wellness – being body, mind and spirit respectively.

Fifty seven people attended and they comprised polio survivors and their partners/carers. Among the therapists and professionals who offered their expertise at the retreat were: Melissa McConaghy, Neurological

Physiotherapist; Dr Diane Bull, GP, Psychologist and polio survivor; Paul Musarra, Podiatrist; David White, Acupuncturist; Dr Steve de Graaff, Rehabilitation Specialist; Darren Pereira, Orthotist; Lily Noviana, Dietitian; Heena Raikar, Yoga Instructor; Zeina Merhi, Occupational Therapist; Mary-ann Liethof, National Program Manager, Polio Australia; Carole Gridley, Massage Therapist; Sr Annie Bond, Centre Director, St Joseph's Centre; and Alison Mitchell, Naturopath.

The information and resources offered by the professional and therapeutic experts took the form of lectures on the key areas – body, mind and spirit. Interactive session with experts also enabled participants to ask specific questions about their needs. The therapy and resource sessions were also tailored to fit individual needs as well as group needs. Diverse resources such as exercise, foot care, acupuncture,

## Report on NSW Health and Wellness Retreat (cont'd from page 3)

yoga, therapeutic massage, orthotics, pain management, deep relaxation, and occupational therapy were offered to participants. In addition, the stories of participants were shared and training was offered in a variety of skills including origami, bonsai, art and bridge. On the Saturday night, dinner and entertainment were provided to all participants and on Sunday Sr Annie Bond of St Joseph's Centre spoke about spiritual resources.

The evaluation of participants' experiences at the retreat indicated that they benefited from the lectures, interactive sessions and private sessions. 65% of those attending indicated that they would attend another retreat in the future and 72% of attendees would recommend this type of retreat to others. As one participant commented: "I'll be taking more time to look after myself in all areas – mind, body and spirit!"

The success of the format was reflected on a number of levels, including the positive feedback on the sharing of individual experiences. The question and answer sessions resulted in a better understanding and retention of the self-management strategies offered.

Finally, the organisers intend to seek funding for future retreats across Australia as a holistic approach is regarded as an effective model for future retreats.



*Darren Pereira presenting "To Brace or Not to Brace"*



*Lily Noviana discussing dietary options*



*Fran Henke guiding meditation session*



*Sister Annie Bond on "The Spirit Within"*



*Paul Musarra presenting "Polio Feet"*



*Zeina Merhi facilitating "Seated Yoga"*



*Creating paper masterpieces in "Origami"*

## Polio Australia: A National Voice for Polio Survivors

Polio Australia was incorporated in 2008 and is governed by a Committee of Management made up of representatives from the state Polio Networks who have signed a Memorandum of Understanding. The two NSW members of the Committee of Management are Gillian Thomas (President) and Neil von Schill (Treasurer).

2009-2010 saw a major improvement in Polio Australia's finances which has provided a great impetus to Polio Australia's activities. 2010 was the first full year that Polio Australia operated and a number of significant developments have taken place.

In September 2009 Polio Australia was fortunate in gaining \$30,000 in philanthropic funding through a successful submission to the Trust Company. This was used to secure the services of the first paid employee of Polio Australia, Mary-ann Liethof, who took up the position of National Program Manager in January 2010 for two days per week on an initial one-year contract. At that time, Polio Australia set up a permanent office and headquarters in High Street, Kew, in Melbourne.

Then, in October 2010, polio survivor Neil Balnaves of The Balnaves Foundation, announced that he would provide \$180,000 over a three year period to fund staff and operational costs. With this generous contribution, Mary-ann was able to commence full time work for Polio Australia in January 2011. Having previously coordinated the Polio Network in Victoria, she has brought a wealth of experience and expertise to the position. The Balnaves Foundation has also agreed to separately fund a study by Access Economics into the incidence and prevalence of polio in Australia and the economic, social and public health burden of post-polio in this country.

Administratively, Mary-ann has been supported by Shylie Little, a volunteer working out of the NSW Post-Polio Network office in Sydney. In her two days a week Shylie helps with banking, scheduling payments, bookkeeping, and a myriad of clerical tasks which free up time for both Mary-ann and the Management Committee. Polio Australia is grateful for Shylie's dedication to polio survivors.

Since July 2009, Polio Australia delegates have made a further three visits to Parliament House, Canberra, to both raise awareness amongst the politicians about the late effects of polio and the current lack of services for Australia's polio survivors, and to lobby for funding to implement Polio Australia's programs. Visits took place on 26 November 2009, 10 March 2010 and 16 June 2010.

On all these occasions, Polio Australia was ably guided (pro bono) by Dr John Tierney, Partner, Government Relations Australia Advisory, Former Federal Senator for NSW and current PPN Committee Member. John has also accepted the role of National Patron for Polio Australia.



Friends of Polio Survivors Launch: L to R Neil von Schill, Mary-ann Liethof, Gillian Thomas (seated) and John Tierney

From these and earlier visits, a number of key outcomes eventuated:

- Four bi-partisan parliamentarians became "Parliamentary Patrons" of Polio Australia.
- A Motion (Private Members' Business) calling for the recognition of the plight of polio survivors and their needs was debated in the House of Representatives.
- The "Parliamentary Friends of Polio Survivors" group was established and launched.

The Parliamentary Patrons are:

- **Jill Hall**, MP (*Australian Labor Party*)  
Federal Member for Shortland (New South Wales) and Government Whip in the House of Representatives
- The Hon **Greg Hunt**, MP (*Liberal Party*)  
Federal Member for Flinders (Victoria) and Shadow Minister for Climate Action, Environment and Heritage
- **Catherine King**, MP (*Australian Labor Party*)  
Federal Member for Ballarat (Victoria) and Parliamentary Secretary for Health; Parliamentary Secretary for Infrastructure and Transport; and Parliamentary Secretary for Regional Development (Victoria)
- **Mark Coulton**, MP (*The Nationals*)  
Federal Member for Parkes (New South Wales) and The Nationals Chief Whip in the House of Representatives

Following the launch of the *Parliamentary Friends of Polio Survivors* on 10 March, Polio Australia delegates were invited to meet with officers from the Department of Health and Ageing. Whilst sympathetic to the cause the delegates were informed that the funding request did not fit into any program from which monetary support could be provided. Polio Australia subsequently received a written response which claimed that polio-specific needs could be met from existing generic Department of Health programs. As the Networks' more than twenty years experience shows this definitely not to be the case, Polio Australia arranged another sortie to Canberra in June 2010 to specifically engage with the Parliamentary Patrons prior to the impending Federal election.

## Polio Australia: A National Voice for Polio Survivors (cont'd from page 5)

The delegation met with government patrons Jill Hall and Catherine King followed by a meeting with coalition patrons Greg Hunt and Mark Coulton and sought their assistance in furthering Polio Australia's cause with the Health Minister and with the Health Department. Further visits are planned in 2011.

The concerted effort to raise the profile of Polio Australia throughout the nation will continue, building on activities undertaken in 2010 including:

- conducting the first ever national *Polio Awareness Month* campaign in October;
- setting up a comprehensive and interactive website;

- preparing and widely distributing (both nationally and internationally) monthly e-Bulletins;
- establishing a multi-disciplinary *Clinical Advisory Group* to provide direction to Polio Australia in the creation of standardised information and education programs for both polio survivors and health professionals; and
- conducting a second *Polio Health and Wellness Retreat* in Mt Eliza, Victoria, in April/May 2011

Polio Australia is hopeful that with this and other fundraising initiatives it will be able to obtain sufficient funding to ensure that the full suite of nationally-consistent information and education programs can start to be rolled out across Australia.

Have you signed up with the **National Polio Register** yet? As our strength lies in numbers, every polio survivor is encouraged to complete a form which can either be downloaded from Polio Australia's website – [www.polioaustralia.org.au](http://www.polioaustralia.org.au) or contact the PPN office on Ph: 02 9890 0946 and ask for a copy to be sent to you.

## Polio Health and Wellness Retreat – Thursday 28 April to Sunday 1 May 2011

Following its highly successful NSW Retreat in April 2010, Polio Australia is once again facilitating a three day "Body, Mind, Spirit" Polio Health and Wellness Retreat, this year in Mt Eliza, Victoria. The venue is the Melbourne Business School, a stunning seaside heritage retreat located an easy 60 km/1 hour drive from Melbourne.

Participants will feel themselves relaxing as soon as they enter the grounds of this gorgeous property which looks out across Port Phillip Bay. This Retreat offers participants the opportunity of doing as much or as little as they like. Although there are plenty of activities to do each day, people are also welcome to take time out to stroll around the grounds, enjoy the view, or simply rest.

The stylish accommodation has one double bed per room and is suitable for double or single person occupancy. Each room has an ensuite with a walk-in shower. There are also a limited number of wheelchair accessible rooms and a small lift is available to transport people between floors.

All gourmet quality meals are included and served in a lovely dining room overlooking the grounds.

Special dietary requirements can also be catered for. For those who

enjoy a glass of wine with their meals, this can be purchased from the full bar service.

Watch the video of the NSW Retreat on Polio Australia's website: [www.polioaustralia.org.au/?page\\_id=39](http://www.polioaustralia.org.au/?page_id=39) to see what previous participants have said.

The 2011 Health and Wellness Retreat will be an experience to remember, and polio survivors are encouraged to bring along a loved one to share it with.

To ensure that the Retreat environment is conducive to friendly networking, numbers have been restricted to 70 people.

Bookings are only confirmed when payment is received and places allocated. Once capacity is reached, people will be contacted and asked if they wish to be placed on a waiting list. If the quota is exceeded and places have been allocated, there will be an immediate refund of payment.

The cost for this Retreat is:

\$350 per person double occupancy

\$450 per person single occupancy

Registration Forms can be found online: [www.polioaustralia.org.au/?page\\_id=2496](http://www.polioaustralia.org.au/?page_id=2496) or contact Polio Australia by phone on 03 9016 7678 or on Mobile 0466 718 222 or email at [office@polioaustralia.org.au](mailto:office@polioaustralia.org.au).



## Our Polio Legacy

*In this issue we bring a correction to Wendy Davies' story published in the last Network News, together with the story of one of our more distant members, Maizie Valentine from the Northern Territory. We hope that by publishing members' stories in Network News as well as collecting them for posterity we will encourage other members to contribute to the archive. Our stories are a valuable reminder of the effects of polio in an unvaccinated population and deserve to be told and preserved. Stories of any length are fine and can simply be about a memorable polio-related incident or an account of your whole polio experience. Please send your contributions by email to Merle at <stories@post-polionetwork.org.au> or by mail to the Network.*

### Wendy Davies

In the last issue of *Network News* we published the polio story of Wendy Davies.

Unfortunately, the gremlins struck and the first photo (that of Wendy as an adult) was not the one which Wendy had provided to illustrate the beginning of her story. With apologies to Wendy for the oversight, here is the correct photo together with a reprint of the first few paragraphs of Wendy's story.



About a week after I turned two on New Year's Day of 1951, I became an adventurer. Milking was over and Dad had mentioned at morning tea that he was going to inspect some new poddy calves. Mum was preoccupied with morning sickness as she completed the housework and Dad hurried to saddle the horse so I didn't announce my intentions to anyone. Of course I had to

see the poddies. As an only child then, calves were my friends.

Dad was completely unaware that I was following him as he rode his horse up the steep, stony track which meandered through bush behind the house to a paddock about a third of a mile away. He whistled and sang heartily as he went. He was really easy to follow, even though my legs were finding the going tough.

Dad was gone when I finally arrived at the poddies. I clearly remember them putting their heads through the barbed wire fence and sucking my fingers. Playing with the Hereford, the broken bally (Hereford cross) and the little Devon calf was certainly worth the effort of the daunting climb up the hills.

A fortnight later, I was paralysed with polio.

### Maizie Valentine

Hi, I'm Marylee Valentine, called Maizie. I was born in Adelaide 1944 and wore a calliper from age 2 until end of high school, with a Sister Kenny influenced interruption aged 11-12 (hot oil baths, pyramid tents, stretching weights). I was brought up with brothers and a 'get on with it' ethic. I wore sand-boots before they were the in-thing, was good at sport but paid the price with pain and cramps. I taught in Darwin, lived for a time in Mt Isa, then limped through marriage and four kids on a South Australian mid north pig farm, teaching, being a librarian, member of Country and City Women Writers and Story Telling Guild of SA; then Post Polio. Relief when I read a newspaper article with a photo of three women, one in a wheelchair, outlining symptoms I'd been having - I sat and howled. My doctor had declared at 43 I was ageing, should accept as normal my work output going from excellent to very good - a back handed compliment, I guess.

In callipers again at 44, moved to Hervey Bay, Qld, Women's Health Centre librarian and writing for therapy tutor, wrote publicity for local theatre until our boy finished school, then husband Keith and I became highway wanderers, travelling Australia (for 12 years now), spending much of the last six years at Daly River, Northern Territory, minding properties between trips south, visiting kids, grandkids and great-grandkids. I love the peace and quiet riverside for reading, photography and writing a book set in suburban Adelaide of 1950s (never ending story but an amazing journey, surprises along the way and new learning experiences every day). Keith enjoys being on the river, keeping gardens up to scratch, reading and making lures. Out of mobile, TV and internet range at the end of a dirt road, so watch a DVD each night and file computer messages to send when we drive somewhere in range.

My deformed ankle made walking unsafe and painful about 5 years ago. No support I tried worked, so I used crutches until referred to a specialist and ankle fusing was recommended - no guarantees.

## Our Polio Legacy (cont'd from page 7)

I went on a list and last December had operation, hip bone and pins replacing deformity but – drop foot prevented the planned 90 degree fuse, foot now set at 45 degree angle to floor, but I can walk with heel build up and rocker, although unworkable toes slipping forward is a nuisance being addressed. Pluses, the strain, pain and roll of ankle is no more and I'm learning to walk safely, and last week I achieved a long time goal – purple footwear, a 66th birthday gift. I'm now the proud owner of lilac patent-leather Doc Martins. Perfect to wear with my purple outfits when I join my Red Hat friends for lunch, fun-loving ladies over 50 who are growing old disgracefully; they brighten my trips into Darwin.

In March they helped me through the doldrums, as did my best mate's urging to enter a poem in a project Dael Allison was running through the NT Writers Centre as part of her University studies on Ian Fairweather. A painter living in the Top End 1952, aged 60 Fairweather launched a flimsy raft from a Darwin beach into monsoon seas; pronounced missing at sea, memorial service held then he turned up again on a beach in Roti, most western island of Timor. Working words into haiku verses pulled me out of myself, the theme 'Adrift' relevant to how I was feeling – and in April Red Hatters were at the book launch on the beach where Fairweather set off, my name in the contents page alongside nine NT poets. Wow. Always look on the bright side, eh!

Below are those Adrift verses published ("Deviation"), plus a another relating to polio I wrote in Hervey Bay 1990s.

Cheers, delight in each day, Maizie.

### Maizie's Poetry

#### DEVIATION

callipers since youth stress aged limbs fused ankle  
pending

no guarantees crab step onto chosen path

Anaesthetic all at sea facing unknowns

mind numbing hospital routines outcome vague

Awash drifting through doubt on crutches

moods stormy wave after wave batters hope

slowly time heals feet on dry land I celebrate safe  
return

© Maizie Valentine 2010

#### DELAYED FLIGHT – living with polio

A lively toddler, she attacks the first step eagerly,  
climbers hands, knees and tottering feet onto the  
second,

then crumples, sliding to ground level, framed by viral  
forces.

Inaction counter-weighted, she hauls up,  
leans on the balustrade beginning another steep  
ascent.

Mounts one, slips, mounts two, then three, progress  
slow but deliberate.

Eventually she sets off alone, supports herself, skips  
stairs, leaping higher.

Occasionally she whizzes down polished banisters,  
bops, waltzes, jives,

hitting bottom in an agony of cramps but climbs again,  
reaching greater heights.

At times, like Christopher she just sits, perched between  
floors, ready to step up to challenges whenever they  
arise.

Finally accepting limits she heads for a comfortable  
stoop, enjoys the day, looks back, making short forays  
up and down as energy and excitement dictates.

© Marylee Valentine





**Wheelies with Wings**

Brian Wilson from Canberra is now a Director of the charitable organisation "Wheelies with Wings" (WwW) which provides Suzi Duncan Scholarships for mobility impaired to have the opportunity to fly a small plane at no cost to the person. Brian completed the course and said it was fantastic, in fact he continued flying and recently flew **solo** for the first time - how's that?!

Suzi started the WwW organisation and she is a polio survivor. Suzi continued on a career of flying ending up a Senior Flight Instructor.

The goal is really to provide an experience of completing an activity that a mobility impaired person may not normally achieve. This concept uses flying as the medium to gain independence and self-confidence.

The course is completely free and includes accommodation, meals, use of the plane and an instructor. It is held over 2 weeks as a live-in student at Temora NSW.

The main criteria are that you have a driver's licence and are capable of entering and leaving the aircraft. The aircraft is a low wing so the wheelchair user can transfer to the wing then bum-it up into the plane.

The program is not *just* for polios – any person with a mobility impairment is welcome to apply.

So if anyone would like to, or knows someone who may be interested, please call Brian Wilson on Ph: 02 6255 0875 or refer to the web site

[www.wheelieswithwings.com.au](http://www.wheelieswithwings.com.au)



Brian Wilson, Director, Wheelies with Wings

**Assistance Dogs Australia**



Author, Lynn Ellis and Toto

This is a picture of my recently acquired assistance dog called Toto. I have had her for three months now. Her trainer comes next month to check on her and then she is officially mine!

She is a delightful Golden Retriever, and has been

well trained in obedience. I am now training her to do lots of things for me.

I am always on a walking frame or wheelchair in the house and scooter when I am out. I have her on a short lead and for the first part of the walk I let her have a sniff around the grass on our Village Green, then we go for a fast run around the Village streets here. I am determined she will not get fat !!!

She does lots of things for me like picking up or carrying things, or going and getting things for me. I train her by repetition and treats when she does the command for me.

At the moment I am training her to put her toys back in her toybox (a thing I could never get my children to do !!!).

She is also trained to take things to Stan, my husband, and get him for me if I need him. This takes a lot of pressure off him.

I would recommend an assistance dog to anyone who has mobility problems. You may have to wait a few years and of course they come and interview you and you have to have doctors' certificates and so forth. I just adore my new "Assistant" (long-term PPN members might remember Allan Quirk who was one of the first people to get an assistance dog (Zuga) a number of years ago).

You can get in touch with Assistance Dogs Australia by visiting their website [www.assistedogs.org.au](http://www.assistedogs.org.au) or by writing to them at Assistance Dogs Australia, PO Box 455, Engadine NSW 2233, or by ringing them on 1800 688 364.

Believe me it's well worth doing. If you want to ring me and ask me any questions, please feel free to do so on Ph: 02 4364 0016.

Lynne Ellis

## Polio Particles by Mary Westbrook



*Polio Particles, written by Mary Westbrook, reports information and stories about polio, post-polio and disability issues of interest to polio survivors. These include press reports, research findings, book reviews and updates on polio eradication and immunisation. Polio Particles is syndicated in post-polio newsletters internationally.*

### **Sceptical expert now believes polio can be eradicated**

Over recent years several 'particles' have discussed some experts' doubts that polio can ever be completely eradicated. Dr Donald Henderson, often referred to as 'the man who wiped out smallpox', has often expressed doubts. However the *New York Times* (14/2/11) reported that he has changed his mind. Henderson has been 'impressed with the new nine-member monitoring board being set up to advise the World Health Organization... Polio has been driven down by 99 percent since 1985, but the last decade has been frustrating, with repeated outbreaks in countries where the disease had been eliminated. There's been too little dissent in the past 10 years by WHO and its partners, much of which depended on endless new rounds of fundraising. Now the thinking and muscle have changed'. Henderson has been impressed also by the commitment of Bill Gates who has stated that 'polio is his number 1 priority'.....Gates Foundation money will allow more experimentation with the oral vaccine used in poor countries. In theory the live virus in it can be weakened enough to prevent the one-in-a-million chance that it will mutate into a form that can paralyse, a problem known as vaccine-derived polio. While one in two million sounds infinitesimal, it is not when 134 million children are vaccinated in one day, as happened in India in 1998. And it may also be possible to make a vaccine that needs no refrigeration. Vaccine going bad in the tropical sun is a major problem for rural vaccination teams. Henderson has also been influenced by discussions with Dr de Quadros, currently executive vice-president of the Sabin Vaccine Institute. Henderson who once recruited de Quadros in the smallpox campaign described him at work in Ethiopia. The obstacles were unbelievable—the emperor assassinated, two revolutionary groups fighting, nine of his own (vaccination) teams kidnapped, even a helicopter captured and held for ransom. He kept the teams in the field—and the helicopter pilot went out and vaccinated all the rebels.

### **Polio band from Congo a hit world-wide**

The Congolese band *Staff Benda Bilili* (roughly translates as 'Look beyond appearances') received rave reviews during its triumphal initial UK tour (BBC News 21/11/09). The band played to a packed house in London's Barbican Hall and received a lengthy standing ovation. Its debut album, *Tres Tres Fort* (Very, very strong), was described in the BBC review as *Explosive... an example of African street music at its finest. The sound is a curious mixture of Afro-Rumba, Latin Rhythms and rich vocal harmonies. Each track is diverse, vibrant and wholly unique yet the album retains a uniformity of sound and style that is both interesting and infectious...While the sound is unlike anything else, there is a familiar rough authenticity in the rhythm and lyrics, comparable in style at times to the Buena Vista Social Club and at others to Fela Kuti...The craftsmanship of this album is remarkable.*

The eight piece band was founded by Ricky Lickabu and Coco Ngambali, both polio survivors living in Kinshasa, the capital of the Democratic Republic of Congo. Ricky and one of his two wives, also a polio survivor, made their money selling cigarettes in a market. Ricky and Coco met on a ferry that crosses the Congo; a good place to do business as disabled people get free ferry travel. Both were musicians but other bands in Kinshasa refused to work with them. Three other recruited band members also had polio. Roger Landu, a teenager, designed and made his own instrument from an empty fish can, a piece of wood and one guitar string. The band rehearsed and also recorded their first album in Kinshasa Zoo. *There are leopards and monkeys in the cramped cages, and on a patch of grass in the middle of the zoo there are a group of polio-victims sitting playing electric guitars in their wheelchairs.*

The band started playing in the streets hoping to be heard by foreigners who have more money to give buskers. *Amazingly it paid off. They came to the attention of Belgian record producer Vincent Kenis, a specialist in Congolese music...the band's debut album...was recorded by Kenis using microphones connected to his large laptop computer, with power provided by a mains cable connected to a deserted refreshment bar nearby.* The band was not popular in DR Congo; few people listened to it rehearse at the zoo or play in a small club near the airport. *But in Britain it has been a very different story. Their first British tour has been a triumph, with five-star reviews from national newspapers.... now, hopefully, Staff Benda Bilili will be able to give up their day jobs and become full-time musicians.* One of their songs urges: *I was born a strong man,/ But polio crippled me./ Look at me today, I'm screwed onto my tricycle/...Parents, please go to the vaccination centre / Get your babies vaccinated against polio.*

There has been delay in the publication of the newsletter so I wondered what had happened to the band since I wrote this 'particle' over a year ago. A Google search revealed that a film about the band was a hit at the Cannes Film Festival and is now showing across Europe. The band has tours scheduled in France, the UK, the Netherlands and Belgium in the early months of 2011.

### An issue of *The Lancet* about disability

The British journal, *The Lancet*, one of the world's leading medical journals, devoted its November 28<sup>th</sup> 2009 issue to disability. The title of the editorial was *Disability: beyond the medical model*. Among other things it said: *There has always been tension between the medical model of disability, which emphasis an individual's physical or mental deficit, and the social model of disability, which highlights the barriers and prejudice that exclude people with disabilities from fully engaging in society and accessing appropriate health care.... Unfortunately, one of the biggest barriers to accessing appropriate health care is the attitude of health professionals, which might further isolate and stigmatise people with disabilities. Despite what many health professionals might assume, people with disabilities can be healthy, do not necessarily need to be 'fixed', are often independent, and might well be consulting for a reason unrelated to their disability. Conversely, people with chronic conditions, such as chronic obstructive pulmonary disease, are often debilitated by their condition yet are often not perceived by health professionals as having a disability. Such perceptions matter: people with disabilities still have the same health needs as other people and are also entitled to specific rights, including the right to make choices about their health care. More exposure to people with disabilities, including colleagues, might help health professionals improve their attitude and change their assumptions... The medical profession has little to be proud about regarding its treatment of individuals with disabilities. Health professionals can sometimes behave appallingly towards people with disabilities. Disability is not a homogeneous entity... although there are some common experiences, every story is different depending on personal circumstances, environmental factors, type of disability, and the care received. There are 650 million people with disabilities in the world who all have their unique story to share. People with disabilities are individuals who do not all think or act according to the 'disabled' label that society has assigned them. Health professionals and policy makers please take note.*



### Ugandan polio survivor's story

The issue of *The Lancet* described above included eight personal accounts of living with disability; one, titled *The Long Road to Success* was about Ugandan polio survivor Milliam Namuddu. She contracted polio aged seven months and was paralysed in both legs. Her legs were operated on when she was 5. Her father refused to pay hospital fees for a useless child *but her mother struggled and paid*. Milliam now walks with crutches. At primary school in Uganda the teachers were friendly but the children would not sit near her for fear of catching polio. The walk to school was long and the steps at school difficult to negotiate. After school she attended a domestic science school. *The teachers did not treat me well. They would complain that I could not do manual work, such as digging, like other students ...they said I was a burden to the school*. After graduating as an instructor in fashion design and business management potential employers would not even consider Milliam's applications. When she tried to work on her own would-be customers refused to believe she could make good garments. *I lacked self-confidence and self esteem....in 2006, I was made aware of the potential and rights of people with disabilities by the Uganda National Action on Physical Disability (UNAPD). This organisation inspired me and built up my self confidence so much that I later secured a good job with the African Medical and Research Foundation...Having lost a son with a heart problem because she could not pay for an operation, Milliam now has a daughter. She said that, *The only problem I face at the moment is that I can't carry my baby without a helper*. Milliam was currently working as an instructor at a business school and was also treasurer for the women with Physical Disabilities wing of UNAPD.*

### 'The Giant-Slayer', a story for children about polio

A recent book for 10 to 14 year olds, *The Giant-Slayer* by Iain Lawrence, is set in a hospital polio ward in 1955. The book received many favourable reviews including one in *The Wall Street Journal*. Lonely 11 year old Laurie visits her only friend Dickie who is in an iron lung in a polio ward. *To comfort Dickie, the girl begins to tell a story of a cruel giant and the tiny boy who vows to slay him. Laurie's ever-more-dramatic narrative becomes so entwined with the emotional life of the 'polios' that, when she suddenly cannot finish the tale, they take turns carrying on the adventure. 'Life's a story, and you can tell it any way you want,' says a character in the tale -within-a-tale but of course that's only partly true. Young readers who know polio solely as something they're immunized against will not quickly forget this moving, imaginative glimpse of the not-so-long-ago past. Sounds like a good present for a grandchild. The book published by Delacourt Books sells for \$US12.74 plus packaging on Amazon.com.*

### New polio vaccine will assist eradication

Scientists at the University of Leeds have been awarded half a million dollars by the Gates Foundation to assist in the development of a new type of polio vaccine. The vaccine will use a *replica virus particle that looks and behaves like the real virus, but is actually an empty protein shell. The researchers believe the hoax virus will trigger the body's immune system but because it does not contain the genetic blueprint that replicates the virus inside the body, has no chance of causing or helping to spread the disease. ...it will be entirely safe to use as it can't ever cause the disease, and unlike the current vaccines, can be produced without needing to grow large amounts of the infectious virus.* It will not require refrigeration. A similar approach was used successfully to create the vaccine against cervical cancer but the polio virus is more complex than the virus that causes cervical cancer. If successful the vaccine will be an important tool in eradicating polio. (This information from [www.leeds.ac.uk/news](http://www.leeds.ac.uk/news))

### Popular music and polio

An article, *Crippled with nerves: popular music and polio, with particular reference to Ian Dury*, by George McKay, was published in the journal *Popular Music* in 2009. (It can be viewed at [http://journals.cambridge.org/repo\\_A637p9R8](http://journals.cambridge.org/repo_A637p9R8)). The article looks at a remarkable cluster of popular musicians who contracted and survived poliomyelitis epidemics through the twentieth century, and ways in which they managed and...explored their polio-related impairments and experiences in their music. Twenty-one musicians and groups are discussed including Neil Young, Steve Harley, Joni Mitchell and Israel Vibration. Symptoms of polio often led to musical individuality. Blues guitarist CeDell Davis explained: *'I was right-handed, but I couldn't use my right hand, so I had to turn the guitar around; I play left-handed now. But I needed something to slide with, and my mother had these knives, a set of silverware and I kind of swiped em'. This was the beginning of a guitar style that was utterly unique, in and out of blues.* US jazz pianist Carl Perkins had residual paralysis in his left arm so played with his arm parallel to the keyboard. He was known as *the crab* for this sideways technique which the cover of one of his LPs described as giving him *the most unique technique of them all...using his elbow to play additional bass notes [he has] a dynamic and exciting new sound.* Jazz pianist Horace Parlan took up piano playing as part of his physiotherapy for his polio affected arm and saxophonist David Seaborn learnt his wind instrument to help with his breathing.



McKay suggests that the large number of polio affected musicians may also be explained by *the solitariness and introspection of much of the treatment of the disease – separated from peers and family, polio children would draw on the artistic compensation of the isolated.* Pop singer Steve Harley who spent three and a half years in hospital said *polio changed my life...for a long time my life was in a bedside cabinet and it was a notebook and pen, all words, words, words...I am solitary as a result.* In his 2005 slow, heavy rock song *The Last Feast* he sang about his childhood experience with polio. He described it as a *primal scream...remember[ing] pain beyond description after the surgery.* Some of Ian Dury's songs draw from his five years of institutionalisation after he contracted polio aged seven. *'Dance of the Screamer'* draws on his memories of physiotherapy. He said, *It was called the screaming ward and you could hear people screaming on the way there, and it was you when you were there, and you could hear others on the way back.* Other songs of his about disability include *Crippled with Nerves, I Want to be Straight, The Body Song, Spasticus Autisticus and Manic Depression.* This last song queries:

*Is it fair we ask ourselves as we get our headaches, bad backs and complaints?*

*Is it fair my little ones? Is this fair?*

*Oh no, it f--ing ain't.*

*Well it's the way the cripple crumbles,*

*It's the flaw of the jungle*

*Be reliable and humble*

*You'll be beggared if you bumble.*

### Ramp Up—ABC Disability Gateway

**Ramp Up is a website where you will find ABC stories, interviews and videos on the subject of disability.** As you browse through the site, the links you follow will take you to stories as they appeared in their original context, whether from ABC News, a TV program or a radio interview.

*Ramp Up* will feature disability related news from across the ABC, as well as regular columnists and contributions from people with disabilities. In the near future the website will be home to active forums, dynamic video content and many other features that will allow you to take part in this online community. As they add features and improve accessibility you, the user of the site, can ramp up discussion about disability in Australia.

**Ramp Up**

<http://www.abc.net.au/rampup/>

## Member Services

### Support Group News



**Neil von Schill**  
**Support Group Co-ordinator**  
**Phone: 02 6025 6169**  
**Fax: 02 6025 5194**  
**Email: [support@post-polionetwork.org.au](mailto:support@post-polionetwork.org.au)**

Since George Laszuk and I travelled up the North Coast in 2009 the **Coffs Coast Support Group** has been very active, involving guest speakers at some of their meetings. It was great to catch up with **Tina and Eddie Demetri** at the Wellness Retreat in April 2010.

The **Port Macquarie Support Group** farewelled inaugural convenor **Pat Adamson and Gerry** who have moved into the Hunter area. We sincerely thank Pat and Gerry for their contribution over eight years. I am delighted to welcome **Gail Hassall** who was previously a member of our very active **ACT Group** as the new convenor of **Port Macquarie Support Group**. Many thanks **Gail** for your endeavours.

I am pleased to report that the **Hills District Support Group**, which was formed in July 2009, has become a very happy and active group ably led by convenor, **Elizabeth Woods**. They meet at the West Pennant Hills Sports Club at 10.30 am on the second Monday of each month. If you are interested in attending please contact Elizabeth on 02 9896 7818.

Late in 2009 the **Blacktown/Lower Blue Mountains Support Group** decided to close their operations. I would like to pay special tribute to inaugural convenor, **Bernie O'Grady**, who served the group tirelessly for 15 years and who was recognised for his contribution to the Network with the award of **Life Membership** at the AGM in November 2009. Sincere thanks **Bernie and Irene** for your commitment and friendship.

In March I was very pleased to catch up with old friends from the **Shoalhaven Support Group** attending a Community Consultation conducted by the Physical Disability Council of NSW in Nowra. Special thanks are extended to all members for their support and particularly to convenor, **Dorothy Schunmann**, for her help in organising the gathering. I am also pleased to announce that the Shoalhaven group have agreed to host our **Country Conference** which will be held at **Bomaderry Bowling Club** in September 2011 (see page 14 for details).

#### Vale – Cheryl O'Neill

From our conversations I knew Cheryl O'Neill always had a "fighting" spirit. She said that she had contracted polio as a young child following an admission to a children's hospital for another childhood illness. The effects of polio did not stop her taking an active part in life, however as the years went on she noticed an increased weakness in her limbs and new pain and until she contacted the PPN, around 2005, was unaware of the late effects of polio.

George from the PPN office rang one day and asked whether I could pop in to see Cheryl, a new member, as she lived in my street (unbeknownst to me). She was relieved to hear that other polio survivors could understand the changes happening to her. I know she felt validated.

Cheryl had led a life full of different experiences. She had a "wicked" sense of humour which helped her battle the down sides in the best way she knew how and often with little support.

As well as the late effects of polio Cheryl's general health too was deteriorating and those problems finally caught up with her last year.

Cheryl died in September last year in hospital following an operation unrelated to polio. She was still young (I think one of the "younger set" of PPN (NSW)). Cheryl is survived by her two daughters, Sarah and Danielle, her extended family and many friends who spoke of their memories of her at her funeral. Appropriately, I think, the last piece of music played at Cheryl's funeral was Frank Sinatra singing "I Did it My Way". *By Anne O'Halloran*

#### Vale – Laurie Fitch

It is with great sadness that we learned of the passing of Laurie Fitch on the 14th June 2010. He was a foundation member of the ACT Support Group and at the last Xmas Party he won the prize for the Highest Attendance at our meetings. Laurie was born in July 1925 in Victoria. After service in the RAAF he was engaged to be married in 1946 and planned to be married in 1947, however he contracted polio and spent 6 months in a iron lung and 3 years in hospital. He was given leave from the hospital for a couple of weeks to be married in 1948. He will be missed at our meetings. *By Brian Wilson*

## 2011 Post-Polio Network Seminar Program

### July Seminar

The July Seminar will be held in the **Auditorium at Northcott, Parramatta on Tuesday, 19<sup>th</sup> July 2011** with registration commencing at 9.30 am. The first topic will be on Speech and Breathing. This will be followed by a session conducted by Dr Ashley Craig from Westmead Hospital on Pain Management. After lunch we are going to examine "The Story Within – Your Polio Story". This theme will be explored by Management Committee members Merle Thompson and Neil von Schill. The cost for the day will be \$10.00 per person which will include morning tea and lunch. A Registration Form will be included in the next newsletter.



### Country Conference

Our next Country Conference will be held in the Nowra area and will be **hosted by our Schoalhaven Support Group**. It will be held on **Saturday, 17<sup>th</sup> September 2011 at Bomaderry Bowling Club** commencing with registration at 9.30 am. Participants can travel from the Sydney and Wollongong areas by train and we will arrange for a bus to pick you up and transport you to the club.

An excellent day has been arranged with the first speaker to be Dr Diane Bull who has prepared a very informative talk on "The Polio Mind" which she presented at the Wellness Retreat last year and it was very well received. We will then be joined by Diana Aspinall Director of Arthritis NSW who spoke at our AGM in November. With the assistance of local personnel she will examine the safe use of medication. After lunch we have arranged a very interesting presentation by Mr Bill Pigott of the World Health Organisation which conducted the Polio Eradication Programs in Nepal and Cambodia. In addition to discussing his experiences in these countries he will also examine aspects of living with the legacy of polio. The cost for the conference will be \$15.00 per person. Further details will be published in future newsletters.

### AGM and Seminar

Our AGM and Seminar will be held on **Saturday 26 November 2011** at Burwood RSL Club. Further details in the next Network News.

## Post-Polio Network Office Co-ordinator's Report



George Laszuk  
Office Co-ordinator

**Greetings from the staff and volunteers** at the Parramatta Office. The number of staff and volunteers working at the office has increased.

Carlie has now returned from maternity leave. She has decided to work only 2 days per week so she can manage her additional family commitments.

Fatma is our other paid staff member, and she works one day

a week.

Nola works one day and is continuing to archive our financial records and also laminate newspaper clippings.

Ray is currently in full time employment with Bunnings, but is still available, particularly for mail-outs, depending on his work roster and schedule.

Shylie volunteers two days a week for both PPN and Polio Australia working on MYOB and preparing information for Committee meetings.

John is now working one day to perform duties as required by the coordinator.

Barring unforeseen circumstances, the Office is generally open on Monday to Friday between 10:00 am and 3:30 pm.

### PPN OFFICE ROSTER

- |                        |  |
|------------------------|--|
| • <b>George</b>        | Monday, Wednesday and one "floating day" |
| • <b>Carlie</b>        | Monday and Friday                        |
| • <b>Fatma</b>         | Wednesday                                |
| • <b>Nola and John</b> | Tuesday                                  |
| • <b>Shylie</b>        | Wednesday and Thursday                   |

**Phone:** 02 9890 0946

**Email:** office@post-polionetwork.org.au

## Can You Help to Promote the Network?

**We are most grateful to everyone** who has been able to distribute our pamphlets widely throughout their local communities. If any member can help to get the message out about the late effects of polio and the Network by putting more pamphlets on display in, for

example, pharmacies, doctors' surgeries or waiting rooms, clinics, shopping centre notice boards, libraries and community health centres, please contact our Office on (02) 9890 0946 or by email at: [office@post-polionetwork.org.au](mailto:office@post-polionetwork.org.au), and some will be posted out to you.

## Proposed Network Name Change

At the 2009 Annual General Meeting we discussed a possible name change for the Network. Our existing title Post-Polio Network (NSW) Inc was adopted 20 years ago and was inherited from researchers in the United States who first identified the new and unexplained symptoms experienced by polio survivors.

As the majority of people do not understand the term “post-polio” we have been using the term the “Late Effects of Polio” to describe the condition experienced by most of us as polio survivors.

When we met to form a national polio organisation in 2007 it was unanimously agreed that the new entity be known as Polio Australia. As most organisations currently use a simple descriptive name such as Alzheimer’s Australia, Cricket NSW or AusPower we thought that we may be better served by the title Polio NSW.

An Agenda item in the form of a Notice of Motion is to be included at a Special General Meeting during 2011

(actual date to be advised). This will allow for debate by members and a decision made on the proposed name change for the organisation. In the SGM business papers there will be “For” and “Against” cases included for your consideration. Voting on the motion will either be in person at the SGM or by proxy vote prior to the meeting.



## Resources for Members

On joining the Network, members are issued with free resources including a brochure *Hospital, Medical And Dental Care For The Post-Polio Patient – A Handy Reference*, and a *Medical Alert Card* which can be carried in the wallet. The Network also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for Network members and postage is included. To order, just write to the Network – please make cheques / money orders payable to Post-Polio Network (NSW) Inc.

<b>Books etc (* indicates Post-Polio Network publication)</b>	<b>Size</b>	<b>Cost</b>
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome</i> <b>Second Edition</b> - Edited by Lauro S Halstead MD (see description below)	288 pages	\$40.00 incl 10% GST
<i>A Practical Approach to the Late Effects of Polio</i> , Charlotte Leboeuf	39 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 1st copy free
The Network has its own four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about the Network. Not only is the badge a great fashion statement, it is an innovative way to promote the Network.	23 mm x 23 mm	\$5.00 plus \$1 postage

### ***Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition)***

The second edition was published in 2006. Editor Lauro Halstead writes about the rationale for this edition:

As with the first edition of *Managing Post-Polio*, the major goal of this volume is to summarize the best advice available to diagnose and manage PPS in an easy-to-read, authoritative format for polio survivors, their families, and friends, as well as for health care professionals. The majority of contributors to this book are either polio survivors or experts who have worked closely with polios in clinical settings.

## About The Network

**The Post-Polio Network (NSW) Inc was formed in 1989** by polio survivors for polio survivors.

It is a self-help, self-funded organisation run entirely by volunteers. The Network provides information about polio's late effects and supports those who may be affected now or in the future. The Network conducts regular Seminars and Conferences, publishes *Network News*, fosters the establishment of regional Support Groups throughout NSW and the ACT, and maintains a comprehensive website.

Polio survivors, their family members and friends are all welcome to join the Network, as are health professionals and anyone else who supports the Network's aims. Membership provides information and support that can maximise the physical and psychological quality of life of polio survivors.

If you live in Australia, we can post you a free Information Kit and Membership Application Form. The Kit includes a copy of our booklet *Helping Polio Survivors Live Successfully with the Late Effects of Polio* which explains the late effects of polio and details the many benefits of Network membership. This booklet can be emailed to those enquiring from overseas.

The annual membership subscription (payable in Australian dollars only) is \$10 not employed or \$20 employed. On first joining, new members also pay a \$5 once-off joining fee. Those initially joining between 1 April and 30 June in any year are deemed to be financial until 30 June the following year. Membership renewal is due on 1 July each year and members are alerted to their financial status with each Network mailing. Over 80% of the Network's income which is used to provide its services comes from membership subscriptions and donations.

## Management Committee—Executive Members Contact Details

Gillian Thomas	President	<a href="mailto:president@post-polionetwork.org.au">president@post-polionetwork.org.au</a>	02 9663 2402
Gillian Thomas	<i>Network News</i>	<a href="mailto:editor@post-polionetwork.org.au">editor@post-polionetwork.org.au</a>	02 9663 2402
Gillian Thomas	Membership and general enquiries	<a href="mailto:gillian@post-polionetwork.org.au">gillian@post-polionetwork.org.au</a>	02 9663 2402
Merle Thompson	Vice-President	<a href="mailto:vicepres@post-polionetwork.org.au">vicepres@post-polionetwork.org.au</a>	02 4758 6637
Merle Thompson	Polio stories	<a href="mailto:stories@post-polionetwork.org.au">stories@post-polionetwork.org.au</a>	02 4758 6637
Neil von Schill	Secretary	<a href="mailto:support@post-polionetwork.org.au">support@post-polionetwork.org.au</a>	02 6025 6169
Neil von Schill	Support Group Co-ordinator	<a href="mailto:support@post-polionetwork.org.au">support@post-polionetwork.org.au</a>	02 6025 6169
Neil von Schill	Public Officer	<a href="mailto:support@post-polionetwork.org.au">support@post-polionetwork.org.au</a>	02 6025 6169
Alan Cameron	Treasurer	<a href="mailto:ppntreas@post-polionetwork.org.au">ppntreas@post-polionetwork.org.au</a>	02 4478 6046 / 0407 404 641
<b>Committee Members:</b> (for contact details please ring or email the Network Office)			
Diane Bull, Ron Goodwin, Bill McKee, Rebecca Rodwell, Alice Smart, Len Smith, John Tierney			

## PPN Office and Other Contact Details

Ground Floor  
Northcott Building  
1 Fennell Street  
Parramatta NSW 2151  
Phone: 02 9890 0946

**General Correspondence / Payments**  
PO Box 2799 North Parramatta NSW 1750

**Management Committee Matters**  
PO Box 888 Kensington NSW 1465

**Office Staff and Volunteers**  
02 9890 0946

[office@post-polionetwork.org.au](mailto:office@post-polionetwork.org.au)

Bill McKee  
Website Webmaster

[webmaster@post-polionetwork.org.au](mailto:webmaster@post-polionetwork.org.au)

Mary Westbrook  
Questions about Polio and the Late Effects of Polio  
[askmary@post-polionetwork.org.au](mailto:askmary@post-polionetwork.org.au)