

POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to new members and regular readers. I hope you enjoy this bumper issue of *Network News*.

At the Network's Twentieth Annual General Meeting held on 22 November 2008 the following members were elected to the Management Committee:

Gillian Thomas	<i>President</i>	Ron Goodwin
Merle Thompson	<i>Vice-President</i>	Bill McKee
Neil von Schill	<i>Secretary</i>	Rebecca Phillips
Alan Cameron	<i>Treasurer</i>	Alice Smart
Rachelle Andgel		Len Smith
Diane Bull		Mandy Stubbs

We were delighted with the support shown by members which enabled all 12 positions to be filled. After giving sterling service on the Committee since 2001 we were very sorry to lose the services of our experienced Seminar Co-ordinator, Bing Mak, who regretfully decided it was time to retire. As well as those members who re-stood for a further term, we were pleased to welcome Bill and Alice back to the Committee after a year away. They were joined by first timers Alan, Rachelle, Diane and Mandy. The Committee now has an invigorating mixture of experience and fresh ideas and is well positioned to actively pursue the Network's goals. In the next issue of *Network News*, we will start a regular **Committee Report** feature to bring you up to date with projects the Committee is managing and the contributions of individual Committee members.

On **pages 2 to 6** you will find full details of our upcoming **One-Day Seminar on 18 May** at the **Northcott Building** in **Parramatta** featuring **three presentations**. Please show your support for both the Seminar organisers and the speakers by coming along if you can. Note that an **RSVP by 8 May** is required.

As this will be the last issue of *Network News* this Financial Year, **Membership Renewal** forms for subscriptions due from 1 July 2009 are being sent out a little earlier than usual. You will find enclosed one of two forms, depending on your financial status. If you are currently paid up to 30 June 2009 (your address sheet reads **Renewal Due On: 1/07/09**) you will find a **Membership Renewal Form** enclosed for the period **1 July 2009 to 30 June 2010**. **Could you please confirm, complete, or amend your details as given on the Form, and return it with your subscription to the Network's Parramatta postal address.** A growing number of members are choosing pay their membership subscription via **internet banking**. If you take up this option, **please ensure that your name is recorded on the internet payment and email us at <ppntreas@post-polionetwork.org.au> to confirm the payment transaction and membership details.** Without this information it may be impossible for us to credit the payment to your membership. Also, if you post in your payment, please be sure to **return the entire Renewal Form** with your subscription.

There are still a few people whose annual subscriptions are overdue, and so their address sheet reads **Renewal Due On: 1/07/08** (or earlier). **In this case, the Membership Renewal Form covers more than one year's membership.** We would appreciate prompt payment of the outstanding dues, together with next year's dues, to ensure that you continue to receive *Network News* and other important information.

The Network is self-funded and needs your continued support to enable us to keep providing services to polio survivors and their families.

If you are already financial beyond 30 June 2009 (as shown on your address sheet), you will receive a **Membership Update Form** which gives your current details but does not request payment of a membership subscription. **Please check your details and be sure to return the Form if your details need amending.**

We look forward to catching up with as many members as possible at our Seminar on 18 May.

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One-Day Seminar - Something for Everyone

Date: Monday, 18 May 2009

Time: 9:30 am – 2:30 pm

Venue: The Northcott Building
1 Fennell Street, North Parramatta
See page 3 for location and parking arrangements

Refreshments: Morning tea and a light lunch will be provided
The cost will be subsidised by the Network

Cost: \$10 per person – ***please RSVP by Friday 8 May 2009***

Program:

- 9.30 Registration
- 10.00 Darren Pereira – *Stance Control: Ron Bell's Orthotic Journey*
- 11.00 Morning Tea
- 11.30 Diane Bull – *Stress: the Good, the Bad, and the Not So Cute*
- 12.30 Lunch
- 1.30 Nicola Clayton – *Dysphagia: Practical Management Strategies*
- 2.30 Close

Further details of the speakers and topics they will cover are given on pages 4 to 6. Each hour-long session will be interactive and include ample time for questions.



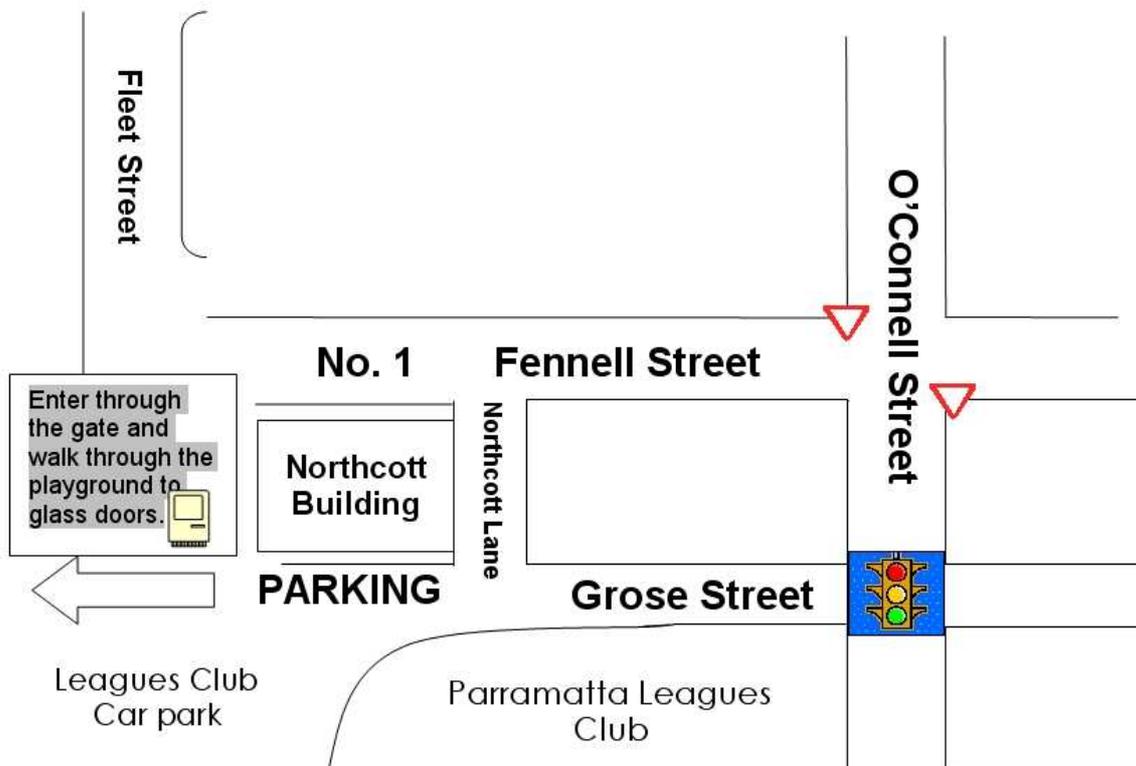
As advised in the previous *Network News*, over the last couple of years the Management Committee has become increasingly concerned about dwindling numbers attending Seminars. This, coupled with the growing costs to the Network of putting on the Seminars (due to venue costs) and the effort involved in actually staging the events, has necessitated a re-think of how we present information to members. In 2009 we are trialling a new Seminar format which will see two metropolitan events staged each year (one in May and one in November), rather than four (each generally covering a single topic) as has been the case in the past.

As shown above, for the first Seminar this year we have arranged an exciting line-up of speakers presenting different topics over the course of a day. Lunch is included at a nominal charge (the balance being subsidised by the Network). This format is similar to the very successful events that we hold in country NSW every second year. We hope that the revamped Seminar Program will enable a broader range of topics to be covered each year which will in turn encourage more members to attend. We will be interested to receive your feedback on the change (whether or not you are able to attend).

To secure your place at this Seminar, please complete the enclosed Registration Form and return it with your payment to the Network's Office by Friday 8 May 2009.

We look forward to seeing everyone there. If this will be the first Seminar you have attended, please be sure to introduce yourself to a Committee member.

Location of Northcott Building (1 Fennell Street) and Seminar Parking Arrangements



A special arrangement has been made to enable members 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 Post-Polio Network 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 playground, rather than the front entrance.



The front entrance of the Northcott Building at 1 Fennell Street, Parramatta

10:00 am Darren Pereira – *Stance Control: Ron Bell's Orthotic Journey*



Darren Pereira is the current Chief of Prosthetics and Orthotics at St Vincent's Hospital, Melbourne. He has been a member of the Polio Services Victoria team since 1998 and has provided consultancy to over 1,300 polio clients. He is a specialist in complex lower limb orthotics and has a wealth of experience in the provision of Ground Reaction Ankle Foot Orthoses (GRAFO), Knee Ankle Foot Orthoses (KAFO) and Stance Control Knee Ankle Foot Orthoses (SCKAFO).

Darren commenced in private practice with NeuroMuscular Orthotics in 2007. His Melbourne practice is based in Mt Waverley and he also consults in Sydney on a monthly basis.

Darren's one hour presentation will be delivered in two sections. First, Darren will speak on stance control components and the effect that they have on polio clients who are falling as a result of knee flexion instability.

The second half hour will be presented by Ron Bell. Ron is the first Australian to wear a weight-activated Stance Control Knee Ankle Foot Orthosis (SCKAFO).

Ron Bell contracted polio at the age of 9 in Victoria. During the acute episode, Ron wore two KAFOs (long leg calipers) to walk. By the age of 16, he had discarded his calipers and did not use any aid until the age of 60.

In 1998, Ron first started to experience the late effects of polio. He had to return to a below-knee orthosis due to progressive weakness of the left calf muscles.

In 2005, his left quadriceps started to also weaken and he was falling daily. Later that year, Ron Bell was fitted with the weight-activated SCKAFO. Ron will demonstrate his orthosis locked, free and in stance control mode. Darren will also show footage of Ron's orthotic journey.



Ron Bell demonstrating his weight-activated stance control KAFO to polio survivors in Wangaratta
Photos courtesy of Mary-ann Liethof, Polio Network Victoria

11:30 am Diane Bull – *Stress: the Good, the Bad, and the Not So Cute*



Diane Bull holds a Bachelor of Science (Honours – First Class) and a Doctorate of Philosophy, Faculty of Medicine. She is a registered Psychologist and a Director of the forethought consultancy group which deals with all aspects of psychology.

For the past thirty years Diane has held positions at the University of Newcastle, including Deputy Dean and Senior Lecturer and Postgraduate Supervisor in Psychology in the areas of Health, Psychoneuro-immunology, Clinical and Experimental Methodology. Her research over the last thirty years has progressed from laboratory-based research to an applied field of investigating the parameters of immune responses and other factors of wellbeing under conditions of both physiological and psychological stress.

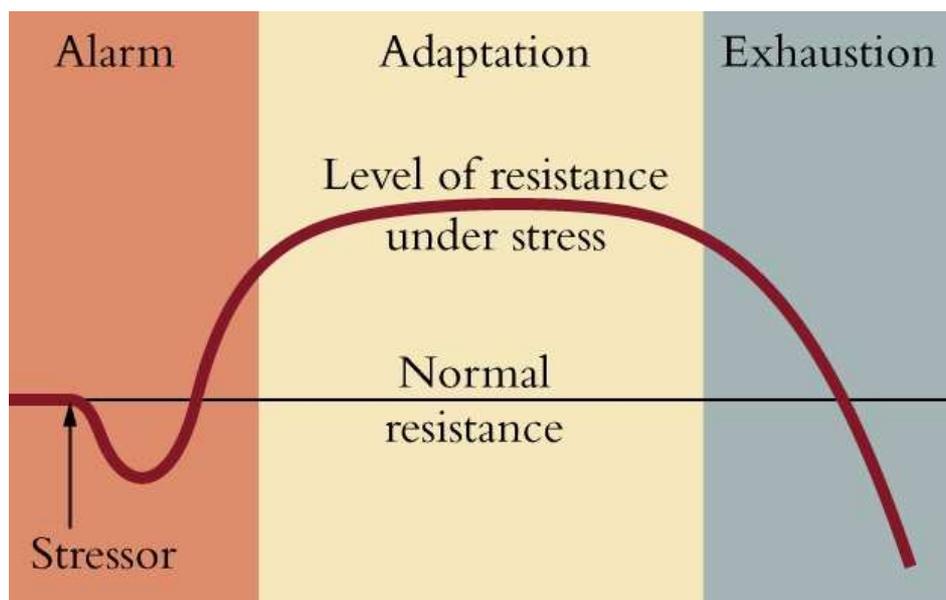
Does stress interrupt immune function?

Numerous studies have documented the adverse effects of stress on various aspects of immune function, both in humans and in laboratory animals. But when people such as polio survivors are under prolonged physiological stress, they are constantly in a state of heightened autonomic activation and may have a reduced immune response for an extended period.

Among other things, repeated stress can result in general wear and tear on an organism, or combine with pre-existing weakness, or new exposure to a virus etc, to produce specific illness which in itself is stressful and maintains the cycle.

This can lead to:

- ◆ direct physiological overload (eg increase in blood pressure)
- ◆ interactions with pre-existing ill health (eg polio)
- ◆ interactions with stress-prone personality (eg negative affectivity, pessimism)
- ◆ indirect effects on health behaviours (eg diet, exercise, relaxation)



As well as explaining the good and bad effects of stress on our health, Diane will introduce some strategies for coping with stress.

1:30 pm Nicola Clayton – *Dysphagia: Practical Management Strategies*



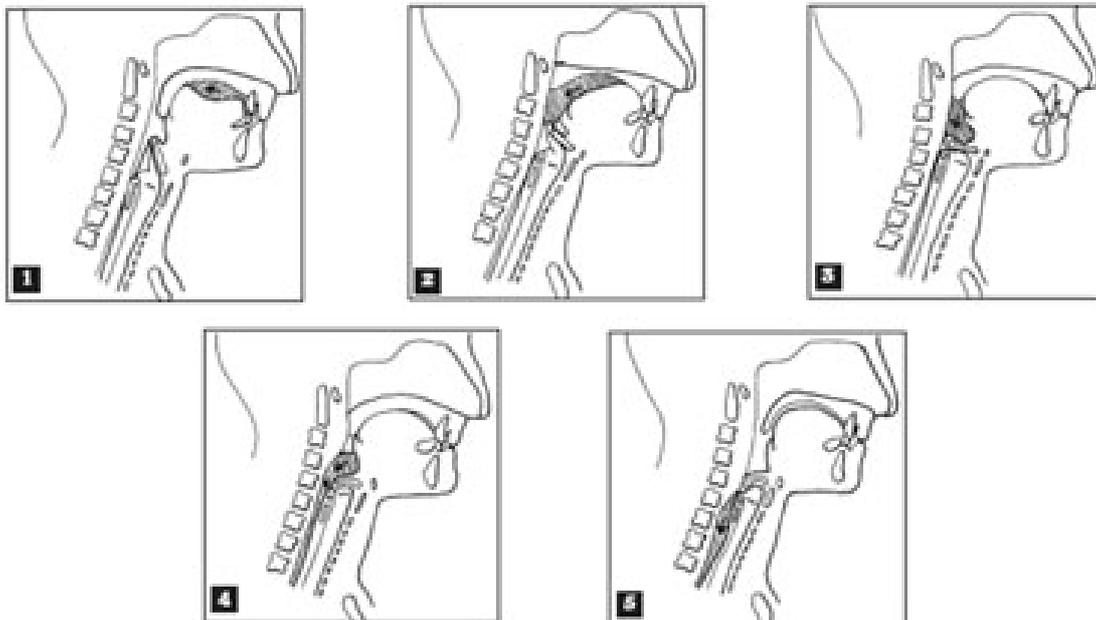
Nicola is the Senior Speech Pathologist at Concord Repatriation General Hospital, specialising in dysphagia management for over 10 years.

Nicola is also the NSW Dysphagia Interest Group Coordinator, has her Master of Science in Medicine (research based Masters examining dysphagia in respiratory disease), has coordinated the Modified Barium Swallow Clinic at Concord Hospital for many years (in which she has seen several post-polio clients) and now supervises the clinician who runs this Clinic. She is also a guest lecturer at Macquarie University, teaching Speech Pathology students about the assessment and treatment of dysphagia in a number of populations including respiratory disease.

Swallowing is an essential component of our activities everyday. Swallowing allows us to sustain ourselves nutritionally, is an important part of socialising and brings enjoyment through taste. Dysphagia can be defined as difficulty with swallowing during any stage of the swallow process. Dysphagia can present in a number of ways including difficulty chewing, and food or drink getting “stuck” or “going down the wrong way” (aspiration). Polio survivors may have difficulties with swallowing mainly as a result of postural problems, or due to difficulty coordinating their breathing and swallowing. Possible complications of dysphagia if left untreated may include recurrent chest infections or pneumonia, poor nutrition, weight loss, and even social withdrawal due to embarrassment eating around others.

Nicola will give us an overview of swallowing, dysphagia, and the relationship to polio. She will discuss the physiology of the swallow mechanism, its integration with the respiratory system, the effect of postural change, as well as the options for management of dysphagia. She will also include a practical component for attendees involving the practise of safe swallowing strategies, particularly relevant to polio survivors.

Stages of Swallow



2008 National Disability Awards

Mr Bill Bradley - Community Contribution Award



Recipients of the 2008 National Disability Awards were announced at an Awards ceremony at Parliament House in Canberra on 3 December 2008.

Minister for Families, Housing, Community Services and Indigenous Affairs the Hon Jenny Macklin MP; Parliamentary Secretary for Disabilities and Children's Services the Hon Bill Shorten MP; Minister for Ageing the Hon Justine Elliot MP; and Minister for Employment Participation Brendan O'Connor MP congratulated finalists and recipients of the Awards, who were selected from more than 240 outstanding nominations.

Network Member Bill Bradley receives his Award from Brendan O'Connor

At the age of 14, Bill, an avid sportsman, contracted polio and his dreams of competing in the Olympic Games were shattered. No longer able to compete in sports himself, he turned his attention to sports administration with the goal of helping others. In 1955 Bill established the famous Belrose Rugby League Club where he has fostered the talents of many young people, helping them focus on what they can achieve, rather than on what they can't.

Bill's passion and determination in supporting the involvement of young people in sport, particularly those from disadvantaged or marginalised backgrounds, has led him to contribute to sport at local, state and national levels. In particular, Bill has volunteered countless hours of his time and services to support wheelchair sports in Australia and across the world.

Bill is a keen lawn bowler and among his many achievements he has won the International Paralympic Committee's *World Bowls Championship* in 1998.

At the age of 70, Bill took up sailing and was placed 7th at the *World Single Person's Liberty Boat Championship* in 2005.

Bill is an outstanding role model and has made substantial contributions to his community through his inspirational sports leadership and mentoring roles. His inspirational leadership has helped to turn around the lives of hundreds of people, over many decades.

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>, and some will be posted out to you.

What's New in PPS ? Presented by Mary-ann Liethof

Seminar Report by Wendy Chaff



We were delighted to have Mary-ann Liethof, Polio Community Officer, Polio Network Victoria, present our AGM Seminar in November 2008. Earlier in 2008 Mary-ann had undertaken a six-week, ten-city *Churchill Fellowship Study Tour* of the USA and Canada. The purpose of the Study Tour was to identify the latest research into the cause and management of late effects symptoms; observe a variety of “best practice” services for polio survivors; learn about the range of resources and equipment available; and enhance understanding of the wider implication of emotional and psychological issues that impact on polio survivors and family members.

Mary-ann explained that her Study Tour in the USA and Canada aimed to identify techniques to better manage the late effects of polio. She also hoped that her visits would open communication lines with North American based post-polio clinicians, and create networks and links for Australian health professionals to pursue. Mary-ann told us that *“The inspiration for this project was born out of witnessing the courage and determination revealed to me on a daily basis by the ‘community’ of polio survivors I work with, who are now experiencing post-polio syndrome”*.

There are 32 Post-Polio Clinics operating in the USA and only 1 in Canada. All the clinics visited by Mary-ann indicated that they were consistently busy with local, national and international patients (international patients can pay from \$US1,500 to \$US3,000 for a clinical assessment).

While visiting the major clinics and various support services, Mary-ann was glad to be enlightened by the many interesting polio survivors she was able to meet along the way.

In the USA it is conservatively estimated that there are 1 million polio survivors, with 433,000 reporting as paralytic polio survivors. In the USA they have had far more assistive services throughout the years since the epidemics than we have in Australia – but there are still not enough. Surprisingly, polio support groups there have reduced from over 300 in the 1980-90s to approximately 150 today.

Many survivors are only in their 40s or 50s, as North Americans and Australians were still contracting polio into the 1960s. Younger survivors may not be aware of the late effects of polio and post-polio syndrome (PPS), or admit that they have a problem.

Although polio services have excellent websites and information available, they are not actively ‘outreaching’. Older polio veterans will tire and withdraw from the ‘active’ polio community. It is vital that new or younger survivors be identified, informed and encouraged to continue the campaign for better services for their own future needs, for another 20 to 30 years. Post-Polio Health International’s slogan “POLIO MAY BE GONE, BUT WE’RE STILL HERE!” is a reminder that we really need to keep up the fight.

There is still no definitive diagnosis for PPS – just tests to check if symptoms could relate to something other than polio. No bio-markers have yet been identified.

Post-Polio Health International funded a small study at the University of Arkansas on “*Regulatory T Cells as a Biomarker of PPS*” (2007/8), suggesting a problem with the immune response in polio survivors, which could contribute to PPS – however, further work needs to be done.

At the *John P Murtha Neuroscience and Pain Institute* in Johnstown, Pennsylvania, complementary and alternative treatments are encouraged. A Physiatrist (Physical Rehabilitation Specialist) discusses mind, body and spiritual wellbeing. Aromatherapy, meditation, yoga, massage and acupuncture are discussed by a nurse.

In 2004 the Institute’s research project on “*Hatha Yoga and Meditation in Patients with PPS*” found that 23 participants significantly improved in areas of fatigue, weakness and pain, and continued to practice their skills over 12 weeks.

The Institute is currently researching “*Cognitive Fatigue: Cognitive Function Status in Polio Survivors With and Without Post-Polio Syndrome*”. Not every polio survivor will develop PPS (generally considered to be 50%). For research purposes, healthy or ‘stable polio’ survivors are sought for controlled comparison studies with those diagnosed with PPS.

The Medical Director of the Institute’s Post-Polio Centre is Dr William DeMayo, who hosts a monthly Teleconference of the *Post-Polio Clinics Directors Network* – anyone interested in the treatment of PPS can join in.

When: Third Wednesday of each month

Time: 8:00 am (Australian EST) (remember to make allowance for daylight saving time)

Dial-In Number: International from Australia – 0011 1 404 835 7069

Participant Code: 545076#

Further Details: Barbara Hull – *Email:* BHull2@conemaugh.org

Polio survivors travel long distances from all over USA, Canada and Mexico to attend the *Roosevelt Warm Springs Institute for Rehabilitation* in Georgia. Many of them want ‘tried and true’ treatment and their old orthopaedic aids fixed – like old-style iron and leather braces from the orthotist – not ‘new fangled stuff’.

As there is only one PPS clinic in Canada – which has a 6-month waiting list – many Canadians travel to USA for clinical services. Canada, like Australia, has no clear statistics on the number of people living with PPS.

In Ottawa, Ontario, Marcia Falconer (PhD, Virologist, researcher and polio survivor) has conducted research into inflammation and PPS. She suggests some ways to minimise inflammation in the body and with that, there may be a reduction of PPS symptoms.

Meditation helps if consistent. Drinking *green tea* encourages weight loss and has neuroprotective qualities. *Undenatured whey protein* may be beneficial but high quality Omega 3 (fish oil) has proven anti-inflammatory properties. Dr Falconer recommends two books by Dr Barry Sears – “*The Anti Inflammation Zone*” and “*The Omega Rx Zone*”.

At Ottawa Hospital, Dr Douglas McKim (Medical Director, Respiratory Rehabilitation Services) works with polio survivors experiencing respiratory problems. As with other muscles, it is important to keep the airway supple. Lung Volume Recruitment (LVR) is proving to be a simple and successful management technique for polio survivors. It improves chest movement, prevents small areas of the lung from collapsing, improves cough, and increases speaking volume. Two ways to achieve this for a person with PPS is by the tried and true ‘frog breathing’ that many will recall from their childhood, or with a ‘volume augmentation bag’. A full step-by-step explanation of LVR can be found online: <www.irrd.ca/education/presentation.asp?refname=e2r4>.

In Montreal, Quebec, Dr Daria Trojan (Director of Post Polio Clinic, Montreal Neurological Institute and Hospital) has completed clinical research projects, including:

- ❖ Osteoporosis in a Postpolio Clinic Population (2007)
 - ❖ Sleep-Disordered Breathing in Fatigued Postpoliomyelitis Clinic Patients (2006)
-

As knowledge of polio's late effects and PPS may be difficult to find within the health sector, polio survivors need to ensure that they are well informed about their own condition. Information can readily be obtained from Polio Networks, and extensive library material is available on-line.

So, what IS new in PPS?

- ❖ Increasing indications that PPS symptoms are not exclusively associated with general 'wear and tear' of fragile motor neurons over the years.
- ❖ Inflammation may play a much greater role in exacerbating symptoms.
- ❖ Studies in inflammation may offer a broader range of treatment and management options to polio survivors.

What did this study tour reveal?

- ❖ The most effective way of managing PPS symptoms and ensuring polio survivors remain as active and independent as possible is through self-management techniques coupled with regular specialist clinic assessments and intervention strategies.
- ❖ Services for polio survivors will be required for at least another 20-30 years.
- ❖ Services are merging PPS with other neurological disorders in order to attract funding to continue service provision.
- ❖ There are very few clinics/institutes/individuals doing PPS research.
- ❖ The apparent lack of active community outreach to younger polio survivors, who may be unaware of PPS, is reflected in the decline of support groups in the USA/Canada.

Are there techniques to better manage the late effects of polio?

- ❖ Pacing activities of daily living is still one of the most effective means of self-management
- ❖ Meditation / yoga / tai chi
- ❖ Appropriate exercise
- ❖ Omega 3 supplements
- ❖ Anti-inflammatory diet
- ❖ Lose weight (if overweight)
- ❖ Glossopharyngeal or 'Frog' Breathing to keep airways supple
- ❖ Aromatherapy / Complementary / Alternative Medical Therapies

How does this apply to Australia?

With potential funding for Polio Australia, lessons learned could inform some of its operations, for example:

- ❖ discussing modes of clinical and information-based service provision with funding bodies/service providers;
- ❖ arranging for further discussions with organisations representing other neurological conditions;

- ❖ promoting participation in monthly *Post-Polio Clinics Directors Network* teleconferences among Australian health service providers;
- ❖ compiling a kit of self-management strategies and techniques provided by the various clinics to give to polio survivors; and
- ❖ continuing to provide outreach to polio survivors currently unaware of PPS via community education programs, media opportunities, support group activities, and electronic and hard copy information resources.

This is only a brief summary of Mary-ann's extensive presentation, as so much information was conveyed within a limited time. The audience of over 50 members and friends appreciated her willingness to answer questions and mingle during break periods.

In conclusion, Gillian expressed our thanks to Mary-ann Liethof for her enthusiastic fact-filled presentation, then as a memento gave her a hand-crafted wooden platter made from jarrah timber. After farewells, it was time for Mary-ann to fly back to Melbourne.

Mary-ann's 40-page report of her Churchill Fellowship Study Tour can be downloaded from the Polio Network Victoria website <www.polionetworkvic.asn.au>. Click on the *Travelogue* link to access the report, to read Mary-ann's daily blog written while on the Study Tour and see the many photos she took during her trip. For copies of Mary-ann's presentation slides; papers on aromatherapy, inflammation and Omega 3; and a list of suggested reading and recommended websites, please ring or email our Office.

Post-Polio Post



My mail bag has been a little lean recently, so it was good to hear from Joy Hay, one of our more remote members, after she received the last issue of Network News. She has a great suggestion for spreading the word about the late effects of polio and the work of the Network. If you would like to help us to get the message out, please contact our Office for brochures and other literature. Also, if anyone would like to catch up with Joy in Cairns, just let us know.

Hello, this is Joy Hay from Cairns, Far North Queensland, a member of your NSW Post-Polio Network. Hey, you should be up here today, last night the temperature fell to 20 degrees. And today it is going to be 30. Great for the pain.

You had a plea for people to help promote the Network. I'll tell you what I did to help promote ours. My husband and myself and our two friends from Newcastle went for a holiday together, driving. Whilst planning this I got some of the posters about "polio is gone but the effects are still here". I attached three of my Spinal Association business cards to these posters and as we travelled from Cairns over to Kurumba, which is on the west coast of Queensland, on the edge of the Gulf of Carpentaria, at all of the little towns we left a poster. We left them in doctors' rooms, bush clinics, the small hospitals, recreation rooms at caravan parks, and visitor information offices. All up we travelled just over 2,350 kilometres. We were blown away by the number of "grey nomads" that were out in this part of Queensland. And when you think about it, the people who have survived polio are generally in this age bracket, "grey nomads".

I love your news magazine and I am impressed with the items you have in them, I especially liked your item in this last one about "to replace ... or not to replace". I have had numerous operations on my joints and my latest 2 operations were in July 07 and April 08 where I have had the mid-foot on both feet fused. I am now the proud owner of 4 plates and 16 screws in each foot, but all the pain of the operations was well worth it as now I walk without the pain.

I am the convener of the Post Polio Support Group here in Cairns and if I can be of assistance to any of your members travelling up here, just let me know. You can give them my contact details.

It's Raining Today and I Can't Go A Scootering !

Peter Willcocks

Peter Willcocks was four years old when he contracted paralytic polio in 1954. He started to experience the late effects of polio about 9 years ago. Peter is a member of the Polio Network Victoria Advisory Committee and Co-Convener of the Bayside Polio Support Group. His article was first published in Polio Network Victoria's "Polio Perspectives", Vol 20, No 4, Summer 2008, and is reprinted here with the kind permission of the author and Polio Network Victoria.

It took two years to agree to a scooter. I wasn't old enough. I wasn't crook enough. I'm only 58. Where would I use it anyway? Lots of emotions had to be put in place, not only mine but just as importantly those of my family.

How would my partner feel about an obvious recognition that my physical "wheels" had started to fall off? She would accept the idea; but love it? I doubted it. I broached a scooter with my 14 year old son, he squirmed; he was not ready. My 9 year old, fashion-conscious social-queen daughter said "Yeah cool". She understood my loss. We used to walk to school, then half way, then even a street became too much. I tried hard to disguise pain and exhaustion. On good days I drove to the park walked across the oval, waved good bye and then struggled back with dog in tow.

I knew that conserving energy would help not only with pain and energy levels, but more importantly to my outlook on life. I had been searching for an outlet for my inexhaustible desire to do things, to build things, to clean things, to make things, to keep moving in case I stopped and couldn't start again.

Polios must be hell for occupational therapists. Recovery from polio involves extremely painful physio. Polios are hardened, toughened against signs of weakness. Most have disguised their polio callipered gait. Feeling failure, I asked my Occupational Therapist (OT) for a referral to *Yooralla Independent living Centre*. In a cold sweat I drove to my appointment, I felt I was going for a car license, and in a way I was.

Some places make you feel good. *Yooralla's Independent Living Centre* is one of them. "Hello you must be Peter". "Sorry I'm a bit early". What a great way to begin a new journey. Jane the OT and I had a cuppa; she asked me about my arm, my hand and about my hip. Her notes told no lies. I learnt that 3-wheel scooters often are more suitable; turning is easier and passing through doorways is not as stressful. Four-wheel scooters tip just as easily if you're not paying attention.

I drove a green three-wheeler followed by a red four, but Jane had sized me up for my dream machine. Gold and bold it didn't look like an old fogy's chariot. "Would you like to ride it outside?". "Sure would". I was crushing weeds on the demo track, bumping over small bridges and cobble stones, across tram tracks, around tight corners and down rough slopes. I had taken control. OT's don't take chances.

The dream machine would cost \$4,000. I sat on a cheaper four on the floor. My crook leg was cramped; no suspension, limited seat adjustment, and the wheels were hard. "How long do you think you would be able to sit on that scooter", I was asked. We spoke of scooters that did not fit; of scooters that lacked easy hand control; we spoke of scooters without suspension offering little hip support; we mourned scooters that ended up dusty in the shed. I had to find a second-hand three-wheeler that would fit my mix. I couldn't justify spending \$4,000; I have two children to rear and that sort of money belongs to them.



Mobile again – Peter takes his dog Gus for a walk

I Googled, I eBayed, I phoned, I rode, I deceived my needs. I did all I could to justify not spending big bucks. I rode a four-wheeler that felt almost okay and nearly bought it after a 10-minute ride because it was only \$1,300! I was offered a demo model at half-price \$1,800; I later discovered it was dud and no longer being manufactured. I nearly bought a fold-up that would fit in a car boot, justifying the squeeze into the seat as it cost only \$800.

I was saved by Yooralla's notes and by Jane's kind caution. I knew the fool I'd be, if after all the pain and all the emotional justification, I ignored expert advice. *Scooters Australia* (a supplier on Yooralla's list) rang they had traded a dream machine, 2 years old, used for 3 months and left in the shed; the owner had joined the mob in the marble orchard.

After a quick look at the 2006 model, I spent the afternoon "demo-ing" other dealers' wares and nearly bought a four-wheeler to save \$700. The Merits Challenger II 3-wheeler was pre-loved but still cost over \$2,000.

The next day the sun shone the right light. I did a deal. *Scooters Australia* takes great pride in what they do. Tests assessed a two-year battery life and a travel range of 35 – 40 kilometres. Delivery the next day was confirmed and an hour set aside an affirmation of my learning. A place has been set aside for tethering and charging. There's a challenging path to exit its stable. If I can't get it out of the backyard, I should go back to bed.

My pioneering journey took me down the garden path, to the drive way, to the front gate, to the street, to the biggest hill. I turned the throttle up to boiling point. I was alive. I was out and about and I was having fun. I soon accepted a statelier pace and enjoyed gardens, strangers' smiles, and waving cars on at intersections (wise move as rushing can result in a crushing). I hauled and let the older walkers pass. I had a chat with neighbours. My first outing was a hoot but the best was yet to come.

Next morning I woke my daughter with "*if you want me to ride to school with you, you'll need to pick up the pace if we're to leave at half past eight*". She was showered and breakfasted, manicured, hair tied and lunch packed by eight and a bit. We chatted about this and that. She insisted that I ride right up to her classroom. I could see her glance at friends. "*This is my Dad and ain't he beaut!*" Turning me loose she gave me a special hug at the gate. I had begun my next life journey.

I scooted through busy shopping centres, stopping where I may, and even going back for a second look, something I had ceased doing long ago. I eventually arrived home with the catch of the day, to a rather concerned better-half. "*I knew you'd be okay but you were gone for such a long time*". It was high noon; I had been out and about for over 3 hours. I handed over my new prepaid phone card to reactivate an old phone that had been put aside and said "*I must away to get some bread, I could be gone for some time*".

That afternoon, my daughter and I did a Pied Piper to the school gate and half-way down the street. One of my daughter's friends asked whether she had had a ride. When at home I turned the power down, gave her a quick lesson and a go in the safety of the backyard. My 14 year old son had a ride and, bother it, he was really good at it. I even did something naughtier, I rigged an elastic strap to a dog lead and took Gus for a run around the block. I am now Peter with the scooter.

Country Conference

As indicated in Neil von Schill's *Support Group Report* on page 26, the Country Conference this year is being held in **Wagga Wagga**, hosted by the local Support Group. The Conference will be held on **Saturday, 26 September 2009** and the venue is the **Country Comfort Motel** on the corner of Tarcutta and Morgan Streets in central Wagga Wagga.

Proposed speakers include Physiotherapist **Simon Mathieson**, Service Co-ordinator of the Polio Services Victoria Clinic located at St Vincent's Hospital in Melbourne. **Mary-ann Liethof**, Polio Community Officer from Polio Network Victoria will have returned from the USA following her attendance at Post-Polio Health International's polio conference in Warm Springs, Georgia, titled "*Living with Polio in the 21st Century*" and will address us on aspects of interest. From **IDEAS** at Tumut, a disability service provider, we should have **Sue Gorman** who will speak on a range of available services. Full information about the Conference will appear in the next issue of *Network News*.

We have many members throughout the state who regularly support our biennial Country Conferences. Members who live in the ACT, Riverina and southern NSW are particularly urged to put the date for this year's Conference on their calendar. I know that we will also have strong support from our friends in Wodonga and the north east of Victoria. Of course, everyone is welcome, no matter where in Australia you live.

Support for Post-Polio Second Round Battlers

Len Smith, Publicity Officer on the Network's Management Committee, recently wrote to the national *Australian Senior* newspaper group to let them and their readers know about the late effects of polio and the work of the Network. Len's efforts resulted in this story, an interview with Network President Gillian Thomas, appearing in the March 2009 NSW issue of *The Senior*. Several new members were welcomed to the Network as a result of this welcome publicity.

Pictured: Gillian Thomas receives an Australia Day Community Service Award from Randwick Mayor Bruce Notley-Smith for her work with the Post-Polio Network



The determination of her mother helped Gillian Thomas overcome the effects of polio after she contracted the debilitating disease at 10 months old in 1950.

"I was in Wollongong and I spent the next three years in hospital recovering", Gillian said. "I was told I would never walk, but my mother decided that wasn't going to be the case. She found me a Physio who worked with me for 12 years and he got me up walking with 2 calipers, so I had a mainstream education."

Gillian went on to a career in the Commonwealth Public Service, but remained in contact with the Northcott Society – which supports people with a wide range of disabilities – because of her mobility problems. In 1988, the Society invited a US speaker to be guest at a seminar in Sydney on post-polio syndrome, and Gillian attended. The meeting resulted in the Post-Polio Network, now celebrating its 20th year with about 1,000 members.

A founding member and now the Network's President, Gillian said she was fortunate the group had been formed before she began to experience the late effects of polio herself. *"Survivors of polio went back into the community, and didn't really associate with other survivors",* she said. *"I was lucky in that by the time I started experiencing symptoms I did know what was happening."*

Australia is now officially polio-free, however 20,000 to 40,000 people developed the paralytic form of the disease from the 1930s to 1950s. It could destroy the nerves which controlled the body's major muscles.

While secondary nerves can create new pathways and recover movement, these connections deteriorate with age and there is a gradual decline in physical health.

Only about 2 per cent of polio cases progressed to paralysis, but even people who had the virus without being paralysed at the time have experienced late effects.

Symptoms generally develop 25-40 years after the first illness. The most common are fatigue, muscle pain and weakness.

Gillian said post-polio syndrome was diagnosed by elimination and other causes for symptoms should be ruled out first.

"But trying to get doctors to understand you have had polio and consequently you have health problems is hard, because most of our doctors weren't born when the epidemics occurred", she said.

The Post-Polio Network provides support as well as lobbying for health reform including educational support for health professionals. Phone (02) 9890 0946, email <office@post-polionetwork.org.au>.

Our Polio Legacy

This issue we present two more stories in the “Our Polio Legacy” series. Both contributors write of contracting polio when past their childhood. 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.

Barbera Moret



Thank you for inviting members to share their stories. Mine follows below.

I understand that many people who had polio were too small at the time to remember the actual experience of the acute stage of the disease. I was a fifteen-year-old teenager in 1951 when I contracted polio and would like to share that particular part of my experience.

Pictured: Barbera at age 16, after recovery from acute polio

I lived next to a wide river in Holland and my siblings and I spent all summer in the water. I read about people referred to as “icebergs” who continued swimming in icy waters throughout winter. I decided to give it a try and when by October no one swam any more I continued. In hindsight I probably hit a stretch of contaminated water and contracted polio there.

We were a very religious family and knelt at our beds at night to say our prayers. One evening in mid October I had problems crawling into bed. I felt feverish and stiff and had a terrible pain at the base of my skull. I hoped that once warm, the pain would go away and I would fall asleep. This did not happen. Instead the pain began to travel down my spine as the night wore on. Everyone was fast asleep and I did not want to wake anyone. By about three or four in the morning the pain had reached just below my waist and it was unbearable.

None of us were to help ourselves from the medicine cabinet but at fifteen I was no longer a child and I reasoned that such a bad pain allowed for self-medication. I took three or four aspirins, an unheard of number, but in my youthful ignorance I figured that such excruciating pain warranted a double adult dose, the pain eased and I went to sleep. Only recently did I learn that the best thing to do for suspected polio is to administer a large dose of aspirin to stop the fever. I believe that purely accidentally I saved myself from severe paralysis.

In the morning I found that my upper arms were stuck to my torso and I could only move from the elbows down. In hindsight my right leg and hip were affected too, but I could still walk and the situation with my arms was the most obvious and worrying so I paid little attention to my lower limbs. My family simply did not believe that anyone could wake up one morning unable to move her upper arms. They suspected that I was acting, although I hasten to say that I had no such history. I myself believed at the time that it was the effect of my “illegal” dose of aspirins and did not dare mention it.

After two days nothing had changed and it dawned on the family that my problems might be genuine. Our house doctor was called who informed my parents that I probably had polio. They were horrified and made an appointment with a specialist. What puzzled both the doctor and the specialist was that only my arms were obviously affected, while practically all polio patients exhibit paralysis of the legs as well. (Once again I never mentioned the self-administering of the aspirins.) So I was never properly diagnosed as a polio sufferer. After some questioning the specialist learned that I belonged to an athletics club and believing that exercise would be good for me advised me to keep up my membership and attendance.

After a couple of weeks at home my arms had “loosened” enough to go back to school again. Eventually I also went back to the athletics club and the coach was very helpful. I had always been a top athlete in our club, but now I came way behind in running, my high jumps were poor and I struggled with the gym equipment. Nor was I ever able to return to ice-skating. I still swam, but no longer the distances along the banks of the river I had so enjoyed before.

I believe that whatever damage was done to tissues at the base of my skull affected my ability to learn new things at the time. Back at school I had not forgotten previous knowledge but I never quite mastered a new subject that was introduced later that year. This was unusual for me as I had always been one of the first to understand new concepts. Off and on throughout my life I have also suffered severe migraines which always start at the base of the skull.

After a year I could lift my arms above my head again and eventually my learning of new concepts improved as well (I gained a degree from UNSW in my forties). I have no visible impairments. I married in 1957 and came to Australia with my new husband that year. I had two children and worked as a teacher during my adult life. Like most people who had polio I actually do not know what it is like to be an adult with even average normal muscle strength. I now look back over my life and know that I have always made a very conscious effort to walk up straight. One leg seems to move automatically when I walk but I seem to need to lift up the other more consciously and place it forward (polio people know what I mean). My left ribcage has been affected and while my right lung fills automatically I regularly seem to be pushing air down the left one in a more conscious way (again polio people know what I mean).

In my late thirties (twenty years after contracting polio) I felt as if I had slipped out of the groove of my demanding lifestyle of childrearing and full time employment and could not get back into it. After a break I got going again. By my mid fifties my body started to refuse and I began the journey that so many polio people undertook and which so many of us have now in common.

September 2008

Jean Grayson



Jean's story was recounted to her niece, Wendy Davies (herself a polio survivor and Network member). Wendy writes:

This is the story of Jean Gillespie, born on 6 October 1923 and married to Noel Grayson, my mother's oldest brother.

Killarney, where she grew up, is a small rural town near Warwick in Queensland. It's about two miles from the New South Wales border. The epidemic of 1951 hit the people of the town severely in late January around the time of the local agricultural show.

This is an unaltered transcript of a tape which was made at my request after a flying visit in May 2003. All the italics entries in brackets have been made by me to provide additional information.

Pictured: Jean at around age 20, before she contracted polio. In April 2009 Jean is 85 and a Nursing Home resident.

I was twenty-seven years old. My son Victor was five years old and my son Derek was three months old. At the time we moved from Killarney (*from the Grayson family farm which was supporting three families*) to The Falls (*near Queen Mary's Falls National Park*) to share-farm a dairy property. I hadn't really recovered from the birth very well due to the baby having reflux and didn't sleep very much. By the time we packed and moved, I was in a very run-down condition.

The home we moved into was only half finished, no steps, just a big block of wood to climb up on. No water laid on. We had to carry it all from the backyard. The farm was very neglected. Noel had his hands full trying to get it in order. No time to help me in the house. I laid lino, moved furniture, set up each room. It rained all the time, there was no sun and to dry the baby's nappies etc or any other things, I had to dry them in the space around the wood stove in a big stove recess. It was terrible conditions and I got more and more tired as the days went by. Noel wanted me to have a rest each day but I said I would when I got the house in order.

Then, the first part of polio started on one weekend. I had something strange happen. I went to bed and I was so cold that I put extra blankets on the boys and the eiderdown on our bed. When Noel came in, he said it wasn't cold so he removed the blankets that I'd put on the boys. He pushed the eiderdown off his side of the bed, over on top of me but when he got in beside me, he realised how cold I was. His body helped to warm me, plus the eiderdown doubled on top of me and finally I got warm enough to go to sleep. About 2 am I awoke. I was very hot and had a headache. Next morning I was freezing cold again.

Over the weekend, Noel helped with the baby and I stayed in bed, still cold. I seemed to recover slowly during the week but the boys were both not well. Victor complained about pains in the muscles in his legs and we had no car at the time so someone gave Noel a lift to town on Thursday. He took Victor to the doctor who said it was rheumatism. Derek cried every time I lifted his legs to change nappies.

Someone took me down on the Saturday and the doctor tested Derek and said he wasn't getting enough to drink whereas I had previously had an oversupply. Dr and Mrs Hall said that the fever I'd had over the weekend had probably caused the breast milk problem. The chemist, Miss Laurenson, asked about the feverish weekend and I told her I was alright again but she disagreed. She said I still looked sick in the eyes. She was a very clever lady. She was right about me not being well.

Then we got two sunny days after all the rain. I washed all the baby's clothes on Saturday and all our clothes on Sunday. Monday morning, Don Lyons who worked for us, was sick so I got up early and helped Noel with the milking. I was so sick when I finished that I left the baby in the pram for Noel to bring home from the cow yard. I just couldn't do it. And that was when he realised how sick I was. When I walked into the kitchen, Don said, "*You look terrible, worse than I am*". So I just went to bed and there I stayed.

During this time, my mother and father were up to help. Then my father got sick and wanted to go home so my sister Phyllis had to try to get up and down to help him. Mum had to stay and it was very hard on her. Her bad knee was worse because of no step, and water in the back yard and looking after baby, household and raining all the time.

The only break from pain and sickness was to listen to the radio near the bed. Then it stopped. When Noel investigated, he found that the pigs had got out and the only dry patch on the farm was under the house so they dug and scratched around under there and they dug out the ground wire. That's why the radio wouldn't go.

The doctor gave instructions to stay in bed for ten days and then I could get up if it was okay. Mum and Noel helped me to the dinner table one day. They sort of part-carried me, then to the phone where I had to ring the doctor to see what period of time Victor had to be kept at home because he was due to start school. The doctor's wife answered the phone and asked a lot of things about what I could and couldn't do and she said, "*No, you've got paralysed muscles*" and then the doctor came and said that I'd have to go to the Warwick Hospital.

Dr Hall asked how Noel got the cream down to the road to be picked up by the cream carter and he said Noel would have to take me that way. Well, that was on a slide pulled by a draught horse. Then the ambulance would come up there and meet me. But Arthur Dagg (*the telephone exchange operator and cream truck driver*) rang up and said he'd put the chains on the big cream truck and try and get up the hill on the grass. This worked and Noel and Arthur carried me to the truck, with port of clothes etc and Derek and his clothes because Pa and Ma (*paternal grandparents*) were going to take him. They came up, took Derek and I and we met the ambulance down the town along there towards where Phyl Bloomfield lives. They loaded me into the ambulance and then told Pa to take the port away because I wasn't allowed to take clothes or anything but just to get me a comb and a toothbrush from the port.

So, as it happened then, I had no money to even buy a paper to look at. I didn't have a book to read. I just had nothing. The ambulance driver said they had all the clothes in there but when I got there, they were short of clothes. So I finished up just in my pants and a man's pyjama coat.

In the Warwick Hospital no-one was allowed to move on the bed, you had to lie flat and not move around. In the five days there, I got much worse. All were waiting to go to Brisbane for treatment and no-one was allowed in except one day, while the Warwick Show was on, Big Chief Little Wolf (*the wrestler*) in all his Indian gear and his big feathered head dress came all through the hospital. Noel had no car so he couldn't get in to see me. Pa and Ma brought Derek in and held him up at the window down at the end of the ward so I could see him but none of our husbands were allowed in. Then one day, Dr Fitzhardinge talked to me and told me Mrs Hall would be able to treat me. That she had been in charge of the Sister Kenny Clinic in Brisbane for five years before she married Dr Hall so I thought that that was wonderful. I always thought that Sister Kenny treatment sounded good.

So they brought me by ambulance to Killarney Hospital and she really worked hard to get me mobile. There was lots of nastiness among some of the Killarney folk. They didn't know of her ability to treat and they wrote nasty, anonymous letters to her and said all sorts of things about how she had no right to be doing this, that I should have been sent to Brisbane.

But she started the treatment that night. The first thing she did was get a small, soft pillow and put it down at the foot of the bed between the sheets to keep my feet sitting upright. Very comfortable. I had slight curvature of the spine from where I used to, if I wanted to sit up, lean

over to the right, get both my hands under the mattress and drag myself up and around that way. She said that was what was causing the curvature of the spine so I had to stop that. Then I had to be left flat, on the bed, and to sit up someone got at the end of the bed and pulled me up straight by both my hands, straight forward and because I couldn't sit with my legs flat along the bed (*I could sit on the edge of the bed with my feet hanging down*), I couldn't reach over to the locker and I couldn't sit any other way, only for my legs hanging over the bed and the hospital kitten used to come in and play with my feet and I couldn't get away.

The first treatment she did was wring big towels out of hot water and put them on the sore muscles and then massage. Later, Mrs Hall and Matron would get me to the bath, one each side of me. My leg wouldn't hold me up but I could move it along while they held me up. Then I had a long soak in a very hot bath, deep water, and after a long time in that, I was very weak and they got me back into bed. All that did the muscles good. Exercise. The bad leg used to get the foot bent back under me and the knee up and then back down straight flat. During the exercise you had to think as a leg came up, you had to think "up" and as it went down, you had to think "down". So it was "up", "down", "up", "down" and she said that this was so the brain got the message to the muscles to teach them to work. This was carried out three times a day and before long, she and Matron had me walking. Well, I'd call it staggering.



This photograph was taken in Killarney in 1951. Jean Grayson is the fair-haired woman in the centre of the photo. Physiotherapist Mrs Leila Hall is on the far right, with her husband, Dr Noel Hall, behind her and to the right. A young Wendy Davies stands close to Mrs Hall.

Of the 10 adults and 7 children in this photo, at least 4 of the adults and 5 of the children were polio survivors.

She worked real hard on me to show people that she was qualified and as a result I got extra treatment in the following weeks. Within weeks I was very slowly walking alone but I had trouble turning corners as I lost balance. My sister, Isobel, came every afternoon after work at the chemist shop and Mrs Hall then gradually let her take me for a walk down the footpath. I had to go down the steps on my bottom because I couldn't walk down but I could drag myself up with the rails and then Isobel and I walked along the footpath to the corner and then down to those flats which are opposite the sawmill (*approximately 50 metres return*). I had a rest on the

first lot of steps and then back to the hospital. Because the private hospital was expensive, I then moved in with my aunt and Miss Laurenson. She used to drop me off at Mrs Hall's as she went to the chemist shop each morning and then pick me up at lunch time. During the morning Mrs Hall treated me and in spare time I did some sewing for her on her electric machine.

After a number of weeks, I can't remember how long, I went home and then I had to come down every second day for treatment which took a whole day in between milking. Noel didn't get anything done on those days, only the milking, and it was so terrible at that time because I had Derek back. I was still doing exercises twice a day and had to keep resting every now and then and on the days that we went to town, Derek often missed out on having a bath and I didn't get nappy washing done. It was terrible to miss his bath but it was just impossible to do it all. Other days, I did the two days washing and I was so tired that I used to sit down and cry.

Noel then had to learn to wash up, cook and do things around the house that he had never ever had to do but we battled our way through it. Then he got very sick. We found out later that he'd had Q fever but the farmer/owner came and I had to go to the cow yard and he helped me and we had to do the milking. Mrs Hall said I wasn't to do it because I wasn't fit but Dr Hall, by this time, was able to drive up to the house and he said that he knew that the milking had to be done but it was a big relief when Noel got better.

All the time I suffered terribly with cramps from my toes to the groin, the front and back of my legs so I had to get Noel to massage and rush for a drink of water if all things went black. All I wanted to do was lie down but as soon as I moved, the cramps all came back again. That went on for years.

After three and a half years, we went to the Daintree (*Far North Queensland*). Still had to go to a physio but gradually improved. When I went to my aunt and Miss Laurenson and the people saw how well I got along, they started to bring back their polio patients, back from Brisbane to Mrs Hall for treatment. She had a large number of patients who didn't do quite as well as me because they had been too long lying without treatment and some in plaster casts on limbs etc. Mrs Hall said what helped me was that home during the first of the illness, I moved about on the bed as I could and kept the muscles moving. The best results obtained, she said, are straight after the first of the illness is over and then to get the muscles moving. The others were too long in Brisbane to recover so well.

At this time, Mrs Hall told me that Dr Salk was working on the polio vaccine, too late for us but wonderful for the future. The Halls then moved from Killarney and we used to visit them when we came down from North Queensland. She always checked my walking while I was there and everything else and she was very pleased with my progress. I finally came to Caboolture for Victor's wedding in 1967, told your mother we were going to see the Halls the next day but she told me that Mrs Hall had just died. I was very upset at the news. I'd lost a wonderful friend and the world had lost a great lady remembered for her polio treatment. Before she was married, she was Sister Leila Cooper from the Sister Kenny Clinic in Brisbane.

Over the years I've got by without too much trouble but in later years I have had the post-polio problems such as muscles disappearing. At nearly 80 years of age, I feel I've survived very well.

[Postscript: Wendy Davies] What has not been detailed here was Auntie Jean's life at work after her first husband, my uncle Noel, died in Tasmania in 1969. She worked on her feet in cafés and as a hospital cook. In her spare time she made wedding dresses for many brides wherever she lived in eastern Australia. Auntie Jean also played the piano accordion in a band for many years. Until her recent illness, she thought nothing of driving her car alone from Warwick in southern Queensland to visit her sons near Gladstone. "It was easier", she said, "to go by yourself. If you took a passenger, you might be so busy talking that you were caught for speeding !"

Polio Australia - A National Voice For Polio Survivors

Neil von Schill

On 12 September 2008 Polio Australia held a teleconference to elect the inaugural office bearers for the association. All states were represented and the result of the election was as follows:

President	Gillian Thomas	NSW
Vice President	Arthur Dobson	Tasmania
Secretary	Tessa Jupp	WA
Treasurer	Trevor Jessop	SA

Congratulations to Gillian, Arthur, Tessa and Trevor. The remaining state representatives complete the Management Committee. Committee members are elected for a two-year period. After the first year of operation of Polio Australia, one Committee member from each state must stand down, but is eligible for re-election. This provision ensures that at each future annual election, only half of the Committee members stand down, thereby facilitating the smooth continuation of projects in progress at year end.

Originally Victoria was represented by observers while the governing body of Polio Network Victoria, Independence Australia (formally Paraquad Victoria), finalised issues of governance and representation. Those matters have now been resolved and Polio Network Victoria is represented by Mary-ann Liethof and Michael Judson.

In late September 2008 we had another sojourn to Canberra to meet with Federal politicians. On this occasion the delegation comprised Gillian Thomas, Peter Garde, Rebecca Phillips and Neil von Schill, very capably led by John Tierney. Many thanks go to Rebecca and Gillian for their endeavours in preparing a new funding submission for presentation to key ministers from both major parties. We are indebted to ACT Senator Gary Humphries who joined us for lunch on both this trip and the earlier visit twelve months earlier. Senator Humphries provided invaluable feedback about our submissions. Whilst we have not yet obtained that elusive bucket of money, the tenor of the discussion and level of understanding that we had with Ministers and staff has increased significantly from our original visit to Canberra. Our special thanks are extended to John Tierney who has given so freely of his time and expertise in arranging and making possible our visits to the Federal Parliament.

Last month the opportunity arose to seek substantial federal funding through the Department of Health and Ageing. The submission addressed the "*Education of consumers in chronic disease self-management and lifestyle risk factor modification*". Gillian and Mary-ann devoted untold hours, at very short notice, to preparing a funding submission which complied with the guidelines and fitted within a defined budget.

The funding sought (\$200,000) is to conduct three-day Wellness Retreats for polio survivors in each state. The retreats would use the services of a wide range of state-based health professionals to assist polio survivors to better manage their condition and the participants would then disseminate this information to members in their state. To give the submission the best chance of success, a joint proposal with the NSW Post-Polio Network was developed. This partnership brings together the Network's 20-year history of good governance, fiscal responsibility and "runs on the board" and Polio Australia's established links with all states to deliver the proposed program effectively throughout Australia.

We are hoping to learn the outcome of our submission by the end of May. Our sincere thanks are extended to Gillian and Mary-ann for their devotion to achieving the objectives of Polio Australia by seeking this funding.

Vale - Tony Marturano

Gillian Thomas

It was with great sadness that we learned on 22 January of the sudden and untimely passing of Tony Marturano at the age of 57.

In 1995 Tony served a term on our Management Committee as well as taking on the role of the Network's Librarian for several years. He also wrote an occasional article for *Network News*, and featured on our 1998 *Post-Polio Awareness Week* poster which he helped design.

Tony's major contribution to the Network was the establishment in 1996 of our first internet pages on his home internet service. The Network's website grew rapidly from this humble beginning and two years later Tony registered our own domain name. As the website outgrew the space Tony had available, he moved it to professional hosting and over the next five years Tony and the Management Committee developed and expanded the site into Australia's premier resource for polio survivors. Our Members' Forum established by Tony during this time was again a ground-breaking achievement for the Network.

In 2003 Tony moved on to pursue other interests. He did a magnificent job as our Webmaster over eight years and we are very grateful for the dedication, time and effort he put into it.

Those familiar with Tony know that his first and enduring love was archery in which he had been involved in many capacities since a young man.



We were thrilled when Tony competed in archery at the 2000 Paralympics and I am very glad that as part of a fan club of Network members I was able to be present to see him shoot. At our Annual General Meeting in November 2000, I moved a round of applause to Tony for his performance in the Paralympics in which he competed not only as a member of the Australian archery team but also as the sole representative for Australia in the individual competition.

I represented the Network at Tony's funeral on 6 February and the esteem in which he was held was evident in the large gathering of those who came together to farewell him.

I thought that these two postings from a Vale thread on the *Archery Forum* summed up Tony as I knew him:

Tony was a great archer, coach, mentor and friend and will be sorely missed. Tony was someone who spoke what he felt and went out of his way if he saw someone in trouble.

Tony was a great archer and a friend. He will be remembered for his sense of humour, his opinions, his coaching and his archery ability.

Post-Polio Network Office Co-ordinator's Report

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**George Laszuk
Office Co-ordinator**

Greetings once again from the staff and volunteers at the Parramatta Office.

Carlie, our Administrative Assistant who has been on maternity leave since December, gave birth on 6 March to a healthy baby boy, Hamish Aden. We wish them both well.

While Carlie is on leave this year we have employed a young lady named Fatma Alameddine. Fatma is 23 years old and this is her first opportunity to obtain employment in the workforce. We recruited her through an employment service called Jobmatch, a division of Northcott, which specialises in finding work for people who have a disability. We are sure this job will give Fatma valuable experience for the future.

Unfortunately we have lost the services of Michael Lee who is one of our volunteers. Michael is also a member of the Network and I am very grateful for his assistance over six months. Michael is going back to Tech for 3 days a week and has indicated he would help out if required and his timetable permits.

I have recruited another volunteer who commenced on 2 February 2009. His name is Peter Gooley, he is in his mid 50's, and was unfortunately retrenched just before Christmas, he comes from an IT background and lives in Glossodia. I'm sure I will be able to utilise his skills. Peter has had an interest in post polio for some years as he has a relative with PPS and he feels his involvement with the Network will give him a better understanding of the condition.

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

	PPN OFFICE ROSTER
GEORGE	Monday, Wednesday and one "floating day"
PETER	Monday
FATMA	Monday and Wednesday
NOLA	Tuesday
SHYLIE	Wednesday and Thursday
RAY	Friday

Helpful Resources

This regular series is aimed at bringing you information about services and products, that you might not otherwise be aware of, for people who are ageing and/or have a disability. The Helpful Resource in this issue is brought to you with thanks to the RSPCA NSW.

Pets of Older People - POOPS



What is POOPs?

Pets can be immensely therapeutic for elderly people as they provide loyal companionship and help to keep their owners active. However, age and disability can prevent elderly pet owners from adequately caring for their pet. Both pet and owner welfare can be compromised when elderly people and their animals live at home without any assistance.

POOPs was established by the Aged Care Assessment Team (ACAT) at St Joseph's Hospital Auburn in 2003 to temporarily care for the pets of elderly people who were admitted to hospital. The RSPCA became involved to provide assistance with veterinary care and emergency boarding when it was required.

POOPs now assists clients throughout the entire Sydney metropolitan area. Pilot programs are also being developed in other areas in association with various RSPCA NSW branches.

What Services does POOPs provide?

- ❖ Temporary foster accommodation and/or emergency boarding of the pet should the owner require hospitalisation.
- ❖ Assistance with veterinary treatment at the RSPCA Sydney Hospital when required.
- ❖ Assistance with dog grooming if required.
- ❖ Home visits when required to assist the elderly with basic pet care.

Who is eligible for POOPs?

POOPs is specifically designed to help elderly people over 65 years of age who do not have any relatives or friends that are able to help care for the pet in time of need.

Palliative care patients of any age who are socially isolated may also access POOPs services.

What does it cost?

Where possible, clients pay the veterinary, grooming and boarding fees at the time of service. Pensioners receive a discount on all services and payment plans can be arranged if required. All cases will be assessed on an individual basis.

Further information

Phone: (02) 9770 7555

Website: www.rspcansw.org.au/what_we_do/veterinary_hospitals/veterinary_programs/poops

We hope that the items in this series are of interest and some use to you. If you know of any resources that might be helpful for members please pass the details on to the Office.

Support Group News

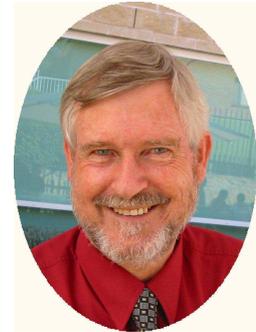
Neil von Schill

Support Group Co-ordinator

Phone: (02) 6025 6169

Fax: (02) 6025 5194

Email: support@post-polionetwork.org.au



During 2008 many Support Groups and individual members completed a survey conducted by the Physical Disability Council of NSW on *Ageing with a Disability*. The response was excellent and the data collected from that survey has been collated and analysed and published in a **Report on the Impact of Ageing on the Needs of People with Disability**. The findings were presented by myself and Ann-Mason Furmage at the Annual General Meeting of the Physical Disability Council last November. I would be very happy to present the findings of the report to Support Groups during the year. Please contact me if you are interested.

Our Network also conducted a survey, prepared by Rebecca Phillips, in the latter half of last year. The **survey reviewed our Support Group structure** and sought ideas on how we can provide a service which better meets the changing needs of members who are experiencing decreased mobility and increased disability. My sincere thanks are extended to over 80 members and Support Group Convenors who made a contribution. The responses have been collated and will be considered by the Management Committee over the coming months. My special thanks go to office volunteers Nola Buck and Michael Lee for recording and compiling the responses.

In December 2008 I was very pleased to be able to attend the Christmas function organised by the **Wagga Wagga Support Group**. We enjoyed very tasty Chinese fare in pleasant surroundings with good company. Convenor, **Isabel Thompson**, led us in a discussion on proposed arrangements for the Country Conference which the Wagga Wagga group is hosting. Further information is detailed on page 14.

It was great to hear from **Sutherland Support Group** convenor, **Ruth Hatton**, who recently reported that they had a very well attended meeting for their first gathering in 2009. There were fifteen people in attendance which is an excellent response. The group meets on the first Wednesday of the month at the Tradies Club at Gynea. If you are interested in attending, please contact Ruth on 02 9525 3987.

Later this year we hope to hold an inaugural meeting to establish a Support Group in the **Hills District** of northern Sydney. Member, **Leona Bruce**, has very generously offered to guide this group. The proposed venue is the **West Pennant Hills Sports Club** in New Line Road, West Pennant Hills, with which I have had preliminary discussions. Members living in this area will be contacted mid year with details of the date and time of the inaugural meeting. In the meantime, if you are interested in talking to Leona, she can be contacted on 02 9980 2345. Members living in the vicinity are urged to consider attending.

At the Management Committee's annual planning meeting in January it was decided that we would attempt to better service Support Groups by offering groups a visit by a member of the Management Committee or by our Office Co-ordinator. Convenors are asked to canvass the thoughts of their members on whether they would like to have a member of the Management Committee or George, the Network Office Co-ordinator, attend one of your meetings. If you would like a visit please contact me and I will make arrangements for a representative to attend a mutually convenient meeting.

Polio Particles

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.



Positive results in trial of Xepol for PPS

In February 2007 *Polio Particles* reported the results on a randomised, placebo controlled, double blind trial of intravenous immunoglobulin for PPS. In this type of trial participants are randomly assigned to either the group that receives the drug being investigated or the group that receives a placebo. Neither the participants nor the researcher that administers the drug/placebo know what the participant is receiving. The polio survivors who received the immunoglobulin showed some increase in muscle strength, activity levels and vitality six months after treatment while those who were given the placebo did not.

Now the Swedish pharmaceutical firm Pharmalink has released the results of a similar follow-up study of 142 patients 12 months after they received the drug, which is being registered with the name Xepol. Pharmalink reports that the results *strengthen the position of this novel treatment modality for PPS by demonstrating a reduction of inflammatory cytokines in the cerebrospinal fluid and a significant reduction of symptoms of PPS while also showing that Xepol is safe and well tolerated with few or no side effects.* [Cytokines are chemical substances that enable the body to communicate. They are involved in the regulation of inflammation and immunity.]

The polio survivors who received Xepol showed a reduction in pain and muscle weakness and improvements in walking ability and on some measures of physical and psychological wellbeing. Xepol is described as *the first medical PPS treatment, [it] is an injectable biologic product, administered once every 9-12 months, which down-regulates the inflammatory process in the nervous system of PPS patients ... Pharmalink is actively seeking a partner to bring Xepol to the market. More than 1,000 patients have been treated with the drug and many return on an annual basis for new treatment courses.* It is not yet available in Australia.

Orphan diseases and orphan treatments

Orphan diseases are defined as diseases that are so rare that there are fewer than 5 cases per 10,000 of the population. The majority of orphan diseases are inherited and caused by defects or mutations (changes) in genes. Post-Polio Syndrome which is listed on orphan disease website lists is of course not genetically caused. A GP in a busy practice would not expect to encounter more than one case of an orphan disease a year and may well not have learnt about the disorder during his or her training.

The American FDA (Food and Drug Administration) *Consumer Magazine* says that as *disparate as rare diseases are, patients share many common frustrations. For example, for one-third of people with a rare disease an accurate diagnosis can take one to five years. And people are often so isolated that they may never know anyone else with the same disease. Patients often have to travel long distances to visit the few doctors knowledgeable about their illnesses, and the costs involved with diagnosis, treatment and other related expenses can be exorbitant.*

In 1983 the USA passed the *Orphan Drug Act* to encourage the development of drugs which are needed to treat orphan diseases but would be prohibitively expensive and unprofitable to develop. Under the Act companies that develop such drugs are given tax reductions and a marketing monopoly for an extended period of time. Xepol, described above, has already received Orphan Drug Designation by the USA. In the USA medical devices are not eligible for orphan designation but in 1996 the Humanitarian Device Exemption was made to the Safe Medical Devices Act. This allows a medical device to be approved without expensive clinical trials if the manufacture can demonstrate that is safe and will probably benefit people with an extremely rare condition (affecting fewer than 4,000 cases per year in the USA). Collaboration by researchers investigating a range of orphan diseases is also occurring. For example, the ENMC (European Neuromuscular Center) is concerned with the investigation of rare neuromuscular diseases which includes PPS. Treatment of a group of different rare diseases may have some similarities, for example, ventilatory support for respiratory insufficiency. The role of support groups, many of which operate via the Internet, is extremely important for people with orphan diseases both in providing information and social and psychological support.

Polio Paralympians

Polio athletes participating at the 2008 Paralympic Games included Xiao Cuijuan from China who won a gold medal for power lifting. She contracted polio at the age of one. Heba Said Ahmed from Egypt who had polio as a child won a gold medal in power lifting having previously won gold at the Athens Paralympics. Heba broke a world record in her 181 pound class by lifting 341 pounds. She is 5 foot, 1 inch tall, walks with crutches, swinging her legs forward from the waist. Heba was written up in several US newspapers because despite her sporting successes there was little recognition of them in Egypt where on her return she continues to be treated as a second class citizen. Ironically, wrote the *New York Times*, *during the Olympic Games, which preceded the Paralympics, Egypt did poorly, earning only one bronze medal. But in the Paralympics, Egypt won 12 medals, including four golds. 'Face savers', read the headline on Al Ahram Weekly, an English-language Weekly newspaper. It is an extraordinary achievement coming from a country where physical disabilities are largely seen as props for street begging.*

Dilemma for Pakistanis opposed to polio vaccination

Polio Particles reported two years ago that Saudi Arabia had made it mandatory for Haj pilgrims who were less than 15 years of age to provide proof of polio vaccination. Children arriving from countries where polio is endemic were given vaccination at Saudi border points. The increase in the number of cases of polio in Pakistan this year led the Saudi Arabian government to issue a directive to the Pakistani Ministry of Religious Affairs that *all* Pakistani pilgrims going to Saudi Arabia to perform the Haj must have had at least two doses of polio vaccine, verified by a polio vaccination certificate. This occurred against a background of strong resentment and resistance by some Pakistani religious leaders to their country's national anti-polio campaign. Some have declared that polio vaccination is 'haraam' (forbidden), an un-Islamic act. They have threatened parents and forcibly driven them away from health teams administering the free vaccine. The irony is that *now the same people, many of whom are intending to perform the Haj this year, will be up against their own 'fatwas' (edicts) and would find it difficult to wriggle out of the situation because they would be required to take the same antipolio drops that they themselves have declared 'haraam'* according to Pakistan's *The International News* (26/9/2008). Many religious leaders opposed to vaccination also have relatives who plan to attend the Haj. Authorities are said to be making a database of religious leaders who have challenged the vaccination campaign that will be released to the media *when these 'elements' would kiss the holy ground, that is, attend the Haj.* Some of those who *had given fatwas in the past*

against the anti-polio campaign [are] now using different tactics such as issuing positive fatwas and [saying] the vaccine is now 'halal' as it is being imported from Muslim countries. On 3/11/08 The International News reported that the first 'polio-free' Haj flight from Pakistan reached Jedda on Sunday. Two drops of oral polio vaccine were administered to every passenger at Jedda airport. Interestingly, no less than 27 persons who spread rumours by issuing religious edicts against polio vaccine have embarked on the holy pilgrimage.

Photos of polio epidemics

Google has placed online the over ten million photos from the archives of the now defunct magazine LIFE. Many of these were never actually published. They can be found at <<http://images.google.com/hosted/life>>. If you type 'polio' into the search option you will find several hundred photos related to the epidemics. The captions underneath the photos relate to the associated story though these photos relating to the same story are not always placed together. There are a number for the story 'Soprano (Australia's Marjorie Lawrence) stricken with polio'. Another story 'Polio mother' shows her husband having to iron his own shirts!

Wife divorced over polio vaccination

Alhaji Bulama Ali, the chief of a village in the northern Nigerian district of Maisandari, ordered his wife from their home and divorced her because she had their children vaccinated against polio. The head of the district suspended Ali from office and ordered him to reunite with his wife or face dethronement, stating that a traditional ruler was supposed to educate his subjects on the importance of immunisation. In 2003 some Islamic leaders in Nigeria condemned immunisation as a plot to make Muslims infertile. This resulted in a year's halt to immunisation in the north of the country leading to an explosion of new cases of polio. According to the BBC news (12/9/08) Ali still believes polio vaccine makes children infertile. Like many interesting stories in the press the final outcome does not appear to have been reported but in searching for it I found other stories of Indian and Nigerian wives being divorced or threatened with divorce for having their children vaccinated or wanting to do so.

International post-polio awareness campaigns

Post-Polio Health International ran a *We're still here* campaign in October 2008. Two buttons were available free from PHI, with a request that a donation be made to the organization. A red, white and blue round badge, which was intended for use in the USA, proclaimed *We're still here! One million US polio survivors, Ask me about it.* A square green button could be used in all countries and stated *We're still here! www.post-polio.org.* PHI encouraged its members to contact their local Rotary clubs with an offer to speak during *We're still here* week.

In October the *British Polio Fellowship* which celebrated its 75th anniversary in 2008 issued a number of press releases to increase awareness of post-polio. In *Nursing in practice*, a journal for primary care nurses, Graham Ball, the Fellowship's CEO cited results of a recent survey revealing that 55% of British GPs are unable to diagnose the debilitating effects of PPS. *We know from members that many people who have had polio may not be aware that PPS might affect them and therefore [do] not understand their symptoms. If their GP also doesn't understand the symptoms then what chance do they have? It is clearly an urgent requirement that GPs be trained in the diagnosis of PPS.* Ball called for all cases of polio to be registered by GP practices to facilitate faster recognition of PPS symptoms. A survey of Fellowship members found that the average number of years from first going to a doctor with symptoms to receiving a diagnosis of PPS was six years.

Dental procedures for polio survivors

Dr Richard Bruno has written a useful leaflet titled *Preventing complications in polio survivors undergoing dental procedures*. The leaflet can be downloaded at <http://gbppa.org/dental.htm>. It is particularly important to read and discuss with your dentist if you are undergoing dental surgery. Survivors with lung involvement are recommended to have pulmonary function tests before undergoing such surgery. Bruno notes that *breathing and swallowing can be compromised in those who had bulbar polio or chest wall paralysis, not only by anesthetics, but also merely by reclining in a dental chair. Polio survivors often have difficulty breathing or swallowing saliva when reclining. A comfortable reclined position must be identified before the procedure begins. And the procedure may need to be interrupted frequently to allow the patient to breathe fully and to swallow. Also a number of polio survivors have experienced severe neck or back pain following lengthy procedures, since their muscles spasm easily when placed in unusual or awkward positions, including hypertension (extreme bending backward) of the neck.* Getting onto and off the dental chair can be difficult and survivors may need to request help in transferring particularly if they are still partly anesthetized. Survivors typically don't ask for help. Bruno suggests avoiding long explanations. A simple explanation such as, *'My legs (arms) are paralyzed and I can't get into/out of the chair. I will need help'* should suffice. If professionals make comments such as *'I bet you can do it if you tried'* you may need to repeat your comment that you need assistance. Bruno reiterates the rules about anaesthetics for polios. They typically need more local anaesthetics but less for general anaesthetics than do their able-bodied counterparts.



A Generous Offer

The following items are available free of charge to any member or members who could make use of them:

- ❖ Jazzy heavy-duty powered wheelchair
- ❖ small Regal scooter with front basket and swing seat

For further information, please contact the donor, Ms Abbe Whitteron, on 02 6658 4950.

The items are in the Coffs Harbour area (Toormina) and interested parties will need to arrange to pick them up. However, if pick up is a problem, please ring the Network office on 02 9890 0946 as George and his team may be able to assist.



2009 Australia Day Honours

I did my usual search through the Honours List announced on 26 January to see if I could spot any members or friends of the Network.

I did not recognise any members (please let me know if I inadvertently missed your name) but did see that polio survivor Kim Beazley was awarded a Companion of the Order of Australia (AC). The citation read: *"For service to the Parliament of Australia through contributions to the development of government policies in relation to defence and international relations, as an advocate for Indigenous people, and to the community."* Having retired from politics in 2007 after 17 years service, Kim Beazley is currently a professorial fellow at the University of Western Australia, focusing on politics, public policy and international relations.



2009 Post-Polio Network Seminar Program

Monday 18 May 2008	The Northcott Building 1 Fennell Street Parramatta	One-Day Seminar – Something for Everyone Darren Pereira – <i>Stance Control: Ron Bell's Orthotic Journey</i> Diane Bull – <i>Stress: the Good, the Bad, and the Not So Cute</i> Nicola Clayton – <i>Dysphagia: Practical Management Strategies</i> See full details on pages 2-6 RSVP required
Saturday 26 September 2009	Country Comfort Motel Tarcutta & Morgan Streets Wagga Wagga	One-Day Country Conference Simon Mathieson , Polio Services Victoria Mary-ann Liethof , Polio Network Victoria Sue Gorman , IDEAS <i>Full details will appear in the next Network News</i>
Saturday 28 November 2009	Burwood RSL Club 96 Shaftesbury Road Burwood	Annual General Meeting and Seminar The Network is 20 years old in 2009 Looking Back, Looking Forward A review of past achievements and future vision <i>Further details will appear in the next Network News</i>

Management Committee - Executive Members Contact Details

Gillian Thomas	President	president@post-polionetwork.org.au	02 9663 2402
Gillian Thomas	Network News	editor@post-polionetwork.org.au	02 9663 2402
Gillian Thomas	Membership and general enquiries	gillian@post-polionetwork.org.au	02 9663 2402
Merle Thompson	Vice-President	vicepres@post-polionetwork.org.au	02 4758 6637
Merle Thompson	Polio stories	stories@post-polionetwork.org.au	02 4758 6637
Neil von Schill	Secretary	support@post-polionetwork.org.au	02 6025 6169
Neil von Schill	Support Group Co-ord	support@post-polionetwork.org.au	02 6025 6169
Neil von Schill	Public Officer	support@post-polionetwork.org.au	02 6025 6169
Alan Cameron	Treasurer	ppntreas@post-polionetwork.org.au	02 4478 6046 0407 404 641

PPN Office and Other Contact Details

Office staff and volunteers		office@post-polionetwork.org.au	02 9890 0946
Bill McKee	Website Webmaster	webmaster@post-polionetwork.org.au	---
Mary Westbrook	Q's about polio & pps	askmary@post-polionetwork.org.au	---

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.

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.

Books etc (* indicates Post-Polio Network publication)	Size	Cost
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome</i> Second Edition Edited by Lauro S Halstead MD (<i>see description below</i> ☞)	288 pages	\$40.00 <i>incl 10% GST</i>
<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 <i>1st copy free</i>
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 <i>plus \$1 postage</i>

☞ ***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.

Another important objective of the earlier edition was to reach as wide an audience as possible – an objective that far exceeded our expectations with more than 15,000 copies in circulation. As news about PPS spread, the demand for more information continued to grow. This new edition is in response to that continued demand for information. Also, we have added a new theme to this edition – aging with disability, as once again polio survivors are “pioneers” – the first large group with a chronic physical disability to undergo aging. Since the initial edition, we are all nearly 10 years older, and, hopefully wiser. Quite possibly, we are also more disabled and, therefore, more challenged. It is my hope that this book will help guide us as we journey along this new path together.

Audio tapes of many of the Network Seminars and Conferences held since 1989 are also available at reasonable prices. For further details please contact the Network.