



# POST - POLIO NETWORK (NSW) INC.

## NETWORK NEWS

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**Patron: Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS**

### President's Corner

Gillian Thomas

At the Network's eighteenth Annual General Meeting (AGM) held on 25 November 2006 the following members were elected to the Management Committee:

Gillian Thomas  
Merle Thompson  
Neil von Schill  
Bob Tonazzi  
Anne Buchanan  
Elaine Byrne

*President*  
*Vice-President*  
*Secretary*  
*Treasurer*

Ron Goodwin  
Bing Kwong Mak  
Bill McKee  
Maura Outterside  
Alice Smart  
Mary Westbrook

Dr Elizabeth Joyner decided not to stand for re-election at the AGM. We thank her for her work for fellow members over the four years that she served on the Committee since 2000. Elizabeth's medical knowledge was always of great assistance to the Committee. We were especially grateful for her Seminar Reports which made complex medical topics accessible to the membership. We hope that Elizabeth will still be able to fill the role of Seminar Reporter as time permits.

Following the AGM, Merle Thompson, the Network's Vice President and Research Coordinator, discussed the findings of our 2006 research questionnaires. The information gained from this research provides us with facts to prove to others the effect that polio is having on our lives. Merle is currently hard at work on the mammoth task of writing the resultant Research Report for distribution to funding organisations, government personnel, health and ageing authorities, research associates, and other polio organisations, as well as to the State and National Libraries to fulfil our obligations regarding statutory deposits. Copies will also be available for sale to members. More on this in the next issue.

On **page 2** you will find details of our **first Seminar for 2007** to be held on **Saturday 3 March** at the **Northcott Society, Parramatta**. The presenter is **Physiotherapist, Kristi Harvey-Walker**, and she will be speaking about the work of **Technical Aid to the Disabled**. Amongst other services, their volunteers make unique custom-designed aids to suit the individual requirements of people with disabilities to help them gain or maintain safety, dignity and/or independence. We look forward to seeing everyone there.

The dates and venues for our **2007 Seminar Program** have now been set and are given on **page 22**. **Please note these dates in your diaries**. All speakers and presentations are currently being finalised.

**Thank you to the many members who have already renewed your 2006/2007 membership. If your address label still reads "Renewal Due on 1 July 2006" (or an even earlier year), we have not yet received your membership renewal. In that case you will find another copy of your Renewal Form enclosed. Please send in the Renewal Form and membership subscription as soon as possible. If you don't wish to renew, please let us know. The Network is self-funded and needs your continued support to enable us to provide services to polio survivors and their families.**

Finally, the meeting of **Polio Australasia** to plan future services for polio survivors is now set down for **3 and 4 May 2007**. **All Networks have committed to send representatives. The NSW Network is organising and hosting the meeting. The outcomes of this milestone event will be reported in the next Network News.**

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# Seminar - Technical Aid to the Disabled

- Date:** Saturday, 3 March 2007
- Time:** 1:00 pm – 4:00 pm  
**Bring a packed lunch to eat from 12:00 noon**  
Fruit juice, tea and coffee will be provided
- Venue:** The Northcott Society  
1 Fennell Street, North Parramatta
- Parking:** Please contact the Network's Office with any queries about parking



Hi, my name is Kristi Harvey-Walker and I am a Physiotherapist working with Technical Aid to the Disabled NSW (TADNSW). Since recently returning to Australia, following 2½ years of working as a contract Physiotherapist in the UK and seeing the sights of Europe, I have been fortunate enough to find myself working for TADNSW.

My current role is as the Sydney Therapist where I am responsible for, but not limited to, ensuring that the therapeutic considerations for the aids custom designed by TAD are adhered to.

I am also the Physiotherapist for our Bike Clinic which modifies bicycles for people with disabilities throughout NSW.

Technical Aid to the Disabled (NSW) has been serving people with disabilities for over 30 years. Located in Sydney, our volunteers have developed over 25,000 devices that have assisted people with disabilities from all age groups.

I am looking forward to presenting at the Post-Polio Network Seminar where I plan to tell you about the following:

- **Who are TAD?** This will include a discussion about TAD as a not-for-profit organisation.
- **What services can TAD offer?** This will include a discussion about our Custom Designed Aids and Computer Loans Services, as well as our Regional services.
- **Examples of previous projects done by TAD for people with a diagnosis of Post-Polio.** Examples may include aids for the kitchen and aids to assist mobility but will not be limited to this.
- **How to make a referral to TAD?** Including a discussion about who can make a referral, where you get the referral forms from, and what will happen once a referral has been made.
- **How much do TAD projects cost?**

I look forward to seeing you there and will be happy to answer any questions you have about TAD.

*If this is the first Seminar you have attended, please be sure to introduce yourself to a Committee member. You are also invited to stay for afternoon tea and a chat with fellow members at the conclusion of the Seminar around 3:30 pm.*

# June's Iron Lung Guinness World Record

Following an application by the Polio Advisory Committee of Polio Network Victoria, on 2 February 2007 Mr Peter Turner, CEO of ParaQuad Victoria, joined with team members of AFL's Carlton Football Club to present a very proud June Middleton her *Guinness World Record Certificate*. The wording on the Certificate reads:

***June Middleton of Melbourne, Victoria, Australia, has relied on an iron lung to keep her alive since contracting polio in April 1949. Ms June Middleton (b. 4 May 1926) spends approximately 16 hours each day on the negative pressure respirator and has done so to date for over 57 years.***

Carlton Captain, Anthony Koutoufides, assisted in the presentation of Ms Middleton's World Record Certificate. "*June has been a wonderful supporter of the Carlton Football Club for a long time; she has built some very strong friendships*". In fact, June keeps a poster of the team on the inside lid of her iron lung stating that she "*sleeps with the whole Carlton Football team every night*".

June Middleton, 80, contracted polio in 1949 at the age of 23 and now spends 18 hours a day at Austin Hospital's Bowen Centre inside the machine which helps her breathe. "*I suppose it is amazing when you consider the doctors told my parents I wouldn't last 24 hours, and I'm still here 57 years later,*" June said. This Guinness World Record may seem a dubious honour, but June still sees her life as a major achievement. She hopes her record will spotlight polio and encourage parents to vaccinate their children.

Also present at the Award presentation were representatives from the Victorian Polio Network's Polio Advisory Committee, Members of the Austin Hospital team and some of June's family members and closest friends.



June Middleton being presented the Guinness World Record by AFL Carlton Football Club Captain, Anthony Koutoufides and ParaQuad Victoria's CEO, Peter Turner



June Middleton with (L-R) Barbara Watson (*Polio Advisory Committee member*), Mary-ann Liethof (*Polio Community Officer*) and Michael Judson (*Polio Advisory Committee member*), all from Polio Network Victoria



June in her iron lung at the Austin Hospital's Bowen Centre

# Ask Dr Perry - Revised

**With Jacquelin Perry, MD**

Reported by Mary Clarke Atwood

*Rancho Los Amigos Post-Polio Support Group Newsletter – May 2006*

Editorial assistance by V Duboucheron, J Perry, MD

*Updated March 2006*

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Our thanks to Dr Perry for so graciously taking the time to review and update these responses. Since retiring after 40 years of dedicated, full time county service, polio specialist Dr Jacquelin Perry continues her work at Rancho but in a new capacity – as a volunteer consultant. The Rancho Los Amigos Post-Polio clinic continues to be a source of excellent care each Friday afternoon due to the commitment of two other excellent physicians. Dr Sophia Chun is the current chief of the clinic; her medical training includes both internal medicine and rehabilitation. Dr Vance Eberly is an orthopaedic surgeon. Both attend the clinic regularly and Dr Perry is there frequently. Dr Perry also volunteers as a medical consultant to the Rancho Los Amigos Pathokinesiology Laboratory. She no longer gives lectures.

## **Question 1. What is the natural progression of post-polio syndrome? Will a person return to the same degree of paralysis that was experienced at onset?**

**Answer:** When focusing on the natural progression of PPS it is important to understand that muscle function depends on three systems:

1. Control from the brain
2. Sensation from the periphery
3. The lower motor system from the spinal nerve cell (anterior horn cell) down to the muscle

The third system is the most important for people with PPS because if you lose the nerve, you lose the muscle. We talk about muscle weakness, but polio is actually a nerve disease that damaged or killed anterior horn cells. This makes a lot of difference in terms of exercise, etc.

**Acute:** During the acute phase of polio some spinal nerve cells died while others were injured but later recovered. Some people had paralysis but others did not. The effects were like spatter paint. If you had a lot of “paint” you had a lot of damage, while others were just touched lightly. But all survivors were left with a damaged neuro-muscular system.

**Recovery:** Recovery from polio entailed all three methods of recovering function:

- Neuro recovery  
Between 12% - 91% of the nerve cells that were injured by the poliovirus recovered.
- Axon sprouting  
New branches of the remaining nerve cells were sent out to adopt the orphaned muscle fibers. The result was that each nerve was then doing 50% more work, or even up to four times as much as normal.

- Hypertrophy  
The muscles enlarged themselves up to about 40% so they could increase function.

It is not known how much a survivor's recovery was due to spontaneous nerve generation, nor how much could be credited to patching by the axon sprouting, nor what amount was due to hypertrophy. Upon recovery polio survivors had a random disability in regard to the amount of paralysis. The amount of muscle weakness a person had was pure chance; it depended upon the amount of poliovirus a person had and where it went. Some survivors remained paralyzed, while others looked or felt normal although they were not.

**Research:** During the 1940s Bodian traced the poliovirus in the motor nerve cells of monkeys. He found that polio, a systemic disease, affected 95% of these cells by either injuring or destroying them. Research confirms that there is some obvious weakness as a result of polio:

- Agre found that polio survivors with no current symptoms had only 80% of normal muscle strength. Symptomatic survivors had 60% or less muscle strength compared to the normal group.
- Following a four-year study Grimby reported a normal 2% - 5% loss of muscle strength in asymptomatic polio survivors, but for symptomatic survivors this loss may be as high as 13%.
- A study by Grimby confirms that weaker muscles work longer and twice as hard.
- An electromyographic study by Dr Perry also confirmed that weaker muscles work longer and twice as hard.

This research says that it is necessary to protect an overused muscle system. The muscles that are grades 3, 3+, and some 4s are getting all the exercise they can tolerate. In order to maintain this function these muscles must be protected from overuse. Dr Perry added, *"New damage is prevented or curtailed by being active, but avoid getting tired. When fatigue begins, STOP and rest. Two 20-minute rest periods a day preserves one's endurance."*

**Now:** For many, many years polio survivors have been working with a damaged neuro-muscular system that keeps working harder than ever to meet normal demands. We need to appreciate the fact that each anterior horn cell innervates several hundred muscle fibers and the surviving horn cells have been doing 50% more work than normal. Plus it appears they don't like being overworked!

Because of this overuse of the neuro-muscular system, new weakness is now developing. Survivors may develop new weakness not only in "polio" muscles but also in other muscles that did not seem to be involved during the acute phase.

Although the amount of weakness a polio survivor develops in later life depends upon the original involvement, age is also a factor. Anterior horn cells do not have infinite durability – they begin aging at about 60 years of age. So polio patients aged 70 and up have a natural weakness just from age that needs to be appreciated and put in perspective also.

**Question 2. Do you know of any research on treatments for PPS?**

**Answers:**

- **Mestinon:** There was a six-center study of the drug Mestinon (pyridostigmine) in 126 patients. Mestinon acts at the nerve-muscle junction by changing the chemistry and making the connection last longer. For many years this drug has been used for myasthenia gravis patients. Since Grimby's research has shown that polio survivors

can overuse the nerve-muscle junction, the use of Mestinon for some polio survivors makes sense to Dr Perry.

In this 1995 Mestinon study, Dr Daria Trojan reported that there was trouble getting statistical significance, but the best correlation between Mestinon and relief versus the placebo occurred in subjects who had 25% or less normal strength, that is, muscle grades 3+ and down. Dr Perry believes Mestinon has a role for those who are quite weak, but for people with grade 4 muscles and up she has observed no improvement with its use.

- **Anti-inflammatory Drugs:** These medications have been Dr Perry's mainstay because the first reaction to muscle overuse is inflammation. These drugs take away the added insult from having overdone but they are not pure pain medicines. Dr Perry does not use pain medications per se for PPS because they only mask a person's overuse and do not help that problem. She wants patients to control their lifestyle and not overdo and thus avoid the pain of overuse.
- **Growth Hormones:** These drugs have been found to relate more to muscle function than to nerve control. They seem to parallel function rather than control function. No significant changes have been found for polio survivors.

### **Question 3. Are you familiar with electro-stimulation for polio survivors?**

**Answer:** The answer is yes and the answer is no. The easiest way to stimulate a muscle is to use one that has a nerve. Therefore, this involves the nerve-muscle junction. Electro-stimulation has been tried on a few polio survivors at Rancho with no effect; Dr Halstead, a polio survivor affiliated with National Rehabilitation Hospital in Washington DC, tried it on himself with no effect; several of Dr Perry's patients tried it at Dr Pape's office in Canada with no effect. So electro-stimulation is not an answer. Post-polio patients' problems are with the nerves.

**Exercise:** Some researchers in other parts of the country favor exercise for certain polio survivors. I observed that their research has been done in parts of the country that have bad weather – so their subjects already have about 3 months disuse due to climate. Here in Southern California we do not have disuse because of bad weather. If disuse of muscles does exist, then exercise may be needed. But if there is no disuse, such as here in Southern California, exercise is not indicated.

### **Question 4. Can trauma be a trigger for PPS?**

**Answer:** The answer is yes. Following an acute injury there is a period of disuse during recovery. Up until the time of injury a person's strength has been built up very gradually. There is an old saying that says, "*If you can lift a calf every day, when you become an adult you can lift a cow. But don't ever stop.*" This phrase is saying that if you got a very small amount of increased exercise on a regular basis (as the calf got larger) you built up yourself gradually. But don't ever change the model. As soon as you stop, there is no way you can exercise that gently anymore. It is very difficult to recover on a therapeutic basis after that. Once there has been an injury the model has been changed.

### **Question 5. Does spinal stenosis occur earlier for polio survivors?**

**Answer:** Spinal stenosis is the thickening of bone around the spinal canal. It does occur in natural society but it is not very common. I have not seen any PPS patients with spinal stenosis.

## Question 6. Could you give us some tips for putting less stress on our upper extremities?

### Answers:

- **Problem 1:** Shoulder pain develops in crutch users  
What does a crutch do? It supports body weight. The more weight, the more it goes on your hand, elbows, and shoulders. When the normally powerful shoulder depressors (pectoralis major, etc) wear out, the shoulder takes the strain and the supraspinatus tendon gets impinged (pinched). This impingement cannot be prevented. Pain indicates it is time to ride – in a wheelchair or scooter if appropriate.
- **Problem 2:** Upper arm pain when reaching overhead  
Reaching overhead uses two muscle systems. A person can avoid overhead reaching by using a reacher when necessary and by not placing things above the shoulders. Find other activities that do not involve shoulder use.
- **Problem 3:** A person's arm dropping away from the socket (usually about 1/4 - 1/2 inch).  
Slings don't usually work well because they hang from your neck. I prefer to use a gunslinger apparatus to help support arm and shoulder. A gunslinger is a device that rests on the hips/pelvis area and has one or two attached pieces to support the forearm(s). Some patients use a fannypack under the arm for support.
- **Problem 4:** Shoulder and neck pain when working at a desk  
When working at a desk, do not lean forward to do your work. Instead, try to lean back ten degrees so gravity is helping your muscles. Bring your work to you.

There are three things a person can do to relieve the strain on the upper body muscles:

1. Eliminate reaching
2. Support the arms
3. Break up activities

**Advice:** Listen to your body. Feel the aches and pains. Then do something about it. **“Be an intelligent hypochondriac!”**

## Question 7. When should we use cold packs or hot packs?

**Answer:** Cold for 5 minutes or less is good. It breaks up the edema formed by overuse. Then follow with heat for 10 minutes and REST a while.

## Question 8. Are you sending any PPS patients for acupuncture?

**Answer:** I am not sending anyone for acupuncture although some patients are trying it and getting help. It is not going to do any harm. The reason I do not prescribe it is because I do not have any indication of whether it will help or not help. When I make a prescription I would like to know the outcome.

## Question 9. Can PPS be part of a weakening heart muscle?

**Answer:** No, PPS cannot be part of a weakening heart muscle. The muscles and nerves to the heart are a different system so there is no direct connection to PPS.

A person can be deconditioned by not being active, but if you are not strong enough to be active your heart does not have to be that conditioned. So don't worry about it. Just don't get fat and do avoid cholesterol!

### **Question 10. How can a polio survivor control muscle twitching and/or cramping?**

**Answer:** Muscle twitching is a sign of overuse. It can happen to anyone, not just people with PPS. Cramping is also a sign of overuse. A polio survivor needs to change his lifestyle to avoid overuse of muscles. [Conserve it to preserve it.]

### **Question 11. What are your thoughts on hip or knee replacement surgery?**

**Answer:** For an arthritic hip, total joint replacement is just fine if you have the muscles to control it. A polio survivor needs to have about grade 3+ hip muscles for this surgery to be successful. Otherwise the hip will dislocate.

The knee is simpler to handle because it can be put in a brace since it is a tubular structure. But there is no brace for a hip.

### **Question 12. How can sleep problems be helped?**

**Answer:** A study on sleep disorders compared people with PPS to average people. Both groups had the same problems -- restless legs, etc. I suggest that, before going to bed, people get themselves comfortable, warm, and perhaps take 2 Advil (or something like that) to get rid of the aches and pains. If a person awakens in the middle of the night, it may be helpful to get up and start again. Half the world has trouble sleeping all night. This is not unique to polio.

If a polio survivor has been diagnosed with sleep apnea it is probably related to breathing or swallowing problems from PPS.

### **Question 13. Is there any connection between polio and meningitis? When I was a baby my parents were told I had meningitis. Several years ago a doctor told me I never had meningitis but I had polio.**

**Answer:** Meningitis is an inflammation of the coverings of the spinal cord and brain. Polio is an infection of the anterior horns of the spinal cord. The inflammatory reaction also involves the meninges. At one time it was called polio-encephalo-meningitis. It was actually an involvement of the whole system. The main way of identifying polio was with a spinal tap. If it got into the anterior horn cells it was called polio. There are a lot of neurological problems that are not highly defined, but can be identified by lesions revealed during autopsy.



## **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 the Office during business hours, or Alice after hours by phone (02) 9747 4694 or email <ea@post-polionetwork.org.au>, and some will be posted out to you.

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

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**Correspondence** (and payments from 1 July 2007)  
PO Box 2799 North Parramatta NSW 1750

**Payments** (until 30 June 2007)  
PO Box 888 Kensington NSW 1465



**George Laszuk  
Office Co-ordinator**

Greetings from the staff and volunteers at the Parramatta office, we hope you had an enjoyable Festive Season.

Since I started with the Network in the Office Co-ordinator role in October 2004, I have been employed for 20 hours a week. Late last year the Management Committee accepted my recommendation that I reduce my hours to 10 per week and that the Network employ an Administrative Assistant for the other 10 hours a week, for a similar overall cost. As well as broadening our skills base and allowing flexibility, this gives us added security in the event of one employee being unavailable through sickness or leave.

We were fortunate to identify a suitable candidate for the second position very quickly and following an interview Carlie O'Reilly commenced with us in November 2006. Carlie is a very vibrant 25-year-old young lady who lives with her husband in the Penrith area. Carlie has excellent office skills and a very pleasant disposition. She has had over two years experience in clerical work with The Down Syndrome Association in Parramatta and is continuing to work there part-time as well. Carlie is fitting in well with the team and we are all happy to have her. Initially, Carlie is taking over the membership management functions and from 1 July will also be assisting the Treasurer.

On a sadder note we have recently lost the services of two of our Office volunteers who have given us years of invaluable support. Firstly, Josephine Schoemaker who started in July 2005 and worked in the office on Tuesdays assisting Nola with filing and data entry, left us in January for health reasons. Secondly, Lesley Champion who commenced in October 2005 and was rostered on Mondays and Wednesdays has decided to move up to Queensland at the end of March and so will leave us on 28 February. Both of these ladies have contributed greatly to our operations and will be dearly missed. On the subject of volunteers, if any members feel they could contribute to our team of Office volunteers we would love to hear from you – please contact me in the Office or on 0412 082 983.

Our current roster in the Office is as follows, from 10:30 am – 3:30 pm, Monday to Friday (if you ring outside these hours you will find yourself talking with our President, Gillian):

| Monday | Tuesday | Wednesday       | Thursday | Friday |
|--------|---------|-----------------|----------|--------|
| George | Nola    | Carlie & George | Noelene  | Carlie |

So that you can put faces to the names, here are recent photos of the Office Team (with glimpses of different parts of our office in the background).

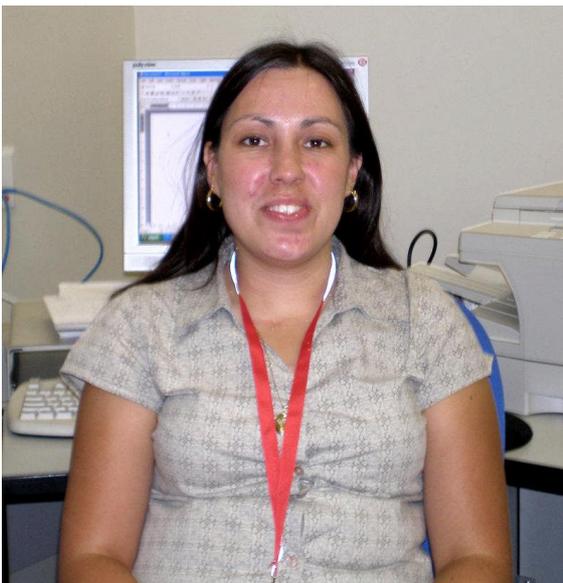
Carlie and I hope to catch up with some of you at our next Seminar on the 3<sup>rd</sup> of March.



Nola – manages our Office records and keeps the filing system under control



Josephine – at the entrance to our Office



Carlie – Administrative Assistant



Lesley – collects mail from the PO Box and helps out with many other Office tasks



Noelene – hard at work in front of the computer

# Northcott Disability Services

The Northcott Society currently provides over 45 distinct services for people with disabilities across NSW, with 15 services located in, or covering, regional and rural areas.

Throughout its 76-year history Northcott has been a prominent non-government organisation in NSW (previously The NSW Society for Crippled Children) providing services to adults and children with a broad range of physical disabilities (although it was originally founded to provide services for children with polio or cerebral palsy).

Amongst others, Northcott provides the following services:

**Transitional Accommodation** – Northcott currently has three transitional accommodation services which promote independence and opportunities for individuals with a physical disability to gain the skills and support necessary to make important life changes. This may include moving from a situation where they are supported by other people, to living more independently.

**JOBMATCH** – JOBMATCH is a specialist employment service which assists people with disabilities to gain employment in the open labour market. The service was established in 1992 to provide support for people with a physical disability. Today JOBMATCH supports people with a range of support needs and disabilities, including people with acquired disabilities such as a spinal cord injury or an acquired brain injury. JOBMATCH achieves positive outcomes by matching people to the right jobs.

**Computer Assistive Technology Services (CATS)** – CATS provides information, advice and support regarding assistive technology options (computer access, communication, environmental control) for people with disabilities. It is staffed by occupational therapists and speech pathologists with specialist skills in the area of assistive technology.

**Consultative Therapy Services** – Northcott provides a range of therapy services: occupational therapy, physiotherapy and speech therapy, through which clients are provided with information and support to access specialised equipment and home modifications. Therapists work closely with other team members as well as other Northcott programs to provide a coordinated and integrated response to clients' identified needs. Programs providing this service include the Early Childhood Support Service, the Computer Assistive Technology Services, Case Management, the NSW Paediatric Spinal Outreach Service, Metropolitan Family Support, the Adult Outreach Program and Northcott Equipment Solutions.

**Adult Outreach** – The Community Living Service outreach team provides services to adults with physical disabilities who live in the metropolitan Sydney area. Community workers and occupational therapists support clients to locate suitable accommodation and personal care services and offer information, learning opportunities and practical assistance to individuals and their families who are concerned with issues of everyday living.

## Northcott Equipment Solutions - An Overview

At Northcott Equipment Solutions (NES), sales, expert advice and service of products which allow people with disabilities to achieve greater mobility, independence and freedom, are all in one organisation. This provides an efficient and complete customer service – second to no other mobility equipment outlet. Profits from NES directly help to fund Northcott.

## **Service**

The service arm of NES boasts one of the most comprehensive mobility facilities in the country. NES assists more than 2,000 people with mobility and rehabilitation needs across NSW each year. The mobile van service means we can visit clients who are unable to make it to our workshops.

## **Wheelchair Maintenance**

Our trained technicians repair and maintain manual and powered wheelchairs as well as hoists and scooters. A mobile service for visits to private homes, hospitals and community centres operates throughout Sydney, the Central Coast, Illawarra and the Hunter areas.

## **Seating and Orthotics**

Experienced clinicians offer a wide range of customised seating solutions, beginning with a thorough assessment of the needs of an individual and using a variety of methods to manufacture the required seating.

These methods include a combination of off-the-shelf seating products, the Silhouette state of the art shape sensing technology with computer-assisted design and manufacturing and then for more complex seating requirements we use a simulator and moulding bags to measure the surface shapes and contact areas to produce a totally customised moulded seating system.

For more specialised support needs, the NES orthotist team prescribe and provide custom-made orthotics products or modified off-the-shelf products. The clinicians specialise in ankle and knee-bending orthosis, callipers, orthotics, specialised seating and custom made shoes. NES also has a long history of supporting specific groups of people including polio survivors, therefore has acquired specialist knowledge in the area. NES currently supports a range of clients post-polio, who began accessing the service in the 1930's.

The NES workshop at the Northcott Head Office, North Parramatta, provides an accessible facility for those people using the service. Accessible features include parking, bathrooms, hoists, and change tables to ensure the clinicians are able to meet the needs of the clients. Clients who access this facility have indicated their preference for using NES, because although there are a range of clinicians available in NSW to provide this type of service many operate from locations which are not accessible or convenient.

These two services regularly coordinate and attend clinics in regional NSW to provide an outreach service to those who are unable to access the Northcott workshops. These clinics are offered once each month in Coffs Harbour, Tamworth, Wagga Wagga and Dubbo. Approximately 7 clients attend each regional clinic.

## **Sales**

The sales arm of NES sells a range of quality products that form the basis for greater mobility, rehabilitation and independent living.

NES' extensive product range includes everyday and specialist wheelchairs, for example handcycles and specific recreation wheelchairs, as well as a host of everyday and leisure activity aids. The assistive technology products specialise in home automation, computer aids, eating aids and many more products to assist people with disabilities to be more independent.

NES represents a large number of national and international companies with a diverse range of products. We are Australia's sole distributors of Permobil and Colours wheelchairs, as well as distributors of many other reliable wheelchair brands. We also offer free service for the first 12 months on any wheelchair purchased from us.

# Parramatta Pieces

*This is the second in an occasional series by member Anne O'Halloran about Parramatta, the location of the Network's Office. Parramatta is easy to get to from anywhere in Sydney. By road it is approximately 24 km from central Sydney. You can drive from central Sydney via Parramatta Road and the M4 Western Motorway or Victoria Road; from the west, travel via the M4 Motorway or the Great Western Highway; from the south and south-west Sydney you can come via Woodville Road and the Cumberland Highway. You can also reach Parramatta by train, bus and river cat – visit the PPN Office while you are there.*

*In this series, Anne brings us interesting snippets about Parramatta's history (there is a great deal), its society, good eating places that are accessible, places of interest, and more.*

## **Some interesting facts about Parramatta**

*Information obtained from DISCOVER PARRAMATTA - Official Visitors Guide*

- Australia's oldest surviving exotic tree is the olive tree planted in 1805 at Elizabeth Farm in Rosehill. It still bears fruit.
- The Woolpack Hotel on the corner of George and Marsden Streets holds Sydney's oldest hotel license, dating from 1796.
- Parramatta has more than 140 restaurants and cafes and over 800 outdoor dining seats.
- The oldest public building in Australia (*Old Government House*) and oldest private building (*Elizabeth Farm*) are located in Parramatta.
- In 1910 HMAS Parramatta was the first vessel laid down for the Australian Commonwealth Naval Forces.

The Post-Polio Network is in historical company! Perhaps in time to come the Network may be included in the "*Interesting Facts about Parramatta*"!

## **Parramatta's First People**

*Compiled from information obtained from various booklets from Parramatta Visitor Information Centre Church Street, Parramatta phone (02) 8839 3311*

The head of the Parramatta River was home to the Burramattagal people, a clan of the Dharug (*sometimes spelt Darug*) people whose territories stretched from Botany Bay to Picton and Springwood. I have read of different interpretations to the word Burramatta – some say 'burra' meaning eel and 'matta' meaning creek, another is a bit more descriptive – 'the place where the eels lie down'.

The Dharug people's clans consisted of between five to sixty people and each clan had their own rights and responsibilities and each were custodians of their own territory.

The Burramatta clan's area was the Parramatta region, which was thought to have extended from what we now know as Homebush Bay in the East to what is called the Crescent in Parramatta Park in the West.

There is evidence within Parramatta Park of Aboriginal occupation. Several scarred trees and artefact scatters have been located around the area known as the Crescent.

Local Aboriginal people and groups are consulted in the management of Parramatta Park.

For more information about early Aboriginal history go to <[www.parracity.nsw.gov.au](http://www.parracity.nsw.gov.au)> and click on *Discover Parramatta*.

Once again Network members have been invited by the researcher to participate in an online  
**Fatigue Self-Management Program**

The Self-management Program is a **free** 7-week course. This is a project conducted as a research study. Face-to-face (for WA members) and online courses are available.

| <b>Start date</b>            | <b>Deadline for registration</b> |
|------------------------------|----------------------------------|
| 2 <sup>nd</sup> May 2007     | 11 <sup>th</sup> April           |
| 27 <sup>th</sup> June 2007   | 6 <sup>th</sup> June             |
| 3 <sup>rd</sup> October 2007 | 12 <sup>th</sup> September       |

### **About Fatigue Management Online**

Managing Fatigue online is an internet version of “*Managing Fatigue: A Six-Week Course for Energy Conservation*” (Packer et al 1995).

### **Who can benefit from Online Managing Fatigue?**

Managing Fatigue online is a self-management course designed for people with severe or extreme fatigue: the type of tiredness that affects the way they function in everyday life. The online course has been designed for people who for various reasons are not able to attend a face-to-face Fatigue Management Course. Participants are drawn from people with Post-Polio Syndrome, Multiple Sclerosis, Parkinson’s Disease, Cerebral Palsy, Chronic Fatigue Syndrome.

### **What does the Online Managing Fatigue Course offer?**

The course is facilitated by a health professional and lasts for seven weeks, including an orientation week. New materials are posted on the website each week. The course comprises an interactive approach to learning, offering a variety of views, skills and information as well as weekly tasks to support practical application used in the home and the community. There are lots of opportunities to discuss experiences and learn from others, without needing to step outside your own home.

The course offers enrolments of up to ten people and a facilitator for the seven week course. Group members are given the opportunity to interact with each other and a facilitator about practical management skills and information.

The course blends the knowledge, expertise and experience of health professionals and an expert panel of participants from previous Fatigue Management courses.

Welcome Week: Orientation to the course and the group members

Week 1: Fatigue and energy conservation

Week 2: Energy conservation: communication and posture

Week 3: Ergonomics: home and work

Week 4: Priorities and standards

Week 5: Living a balanced life

Week 6: Putting it all together

If you would like to participate in the project or would like more information regarding it, please contact the researcher:

**Ms Setareh Ghahari**, School of Occupational Therapy, Curtin University of Technology

**Phone:** (08) 9266 1790 or 0401 442109

**E-mail:** <ghahari.setareh@postgrad.curtin.edu.au>

**Further information is available at <<http://livingeffectively.net.au/>>**

# Support Group News

**Neil von Schill**

**Support Group Co-ordinator**

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



The **Marrickville Support Group** has a change of venue and will now be known as the **Canterbury / Marrickville Support Group**. They will meet at the **Canterbury Leagues Club**, 26 Bridge Road, Belmore NSW 2192, opposite Belmore Station. The group will meet in the Coffee Shop at 2:00 pm on the third Wednesday of each month (excluding December, January and February) for coffee and informal discussion. Club membership is \$4.00 for those interested. All members living in this area are encouraged to attend. For enquiries please contact Convenor **Maura Outterside** on (02) 9718 5803.

The **Northside Support Group** has changed their meeting schedule this year and will now get together quarterly in Roseville. The meeting dates for **2007** are **3 March, 2 June, 1 September** and **8 December**. For further details, please contact Convenor **Ruth Wyatt** on (02) 9416 4287.

The **Metropolitan Evening Support Group** continues to attract members and is obviously serving a need. The group meets at the **Sydney Rowing Club, Abbotsford** at 6:00 pm on the **first Tuesday of each month**. For enquiries members may contact Convenor **Maura Outterside** on (02) 9718 5803.

I was able to meet with members of our **Wagga Wagga Support Group** early in February as they had their first meeting for the new year and was able to update them on current Network activities. Convenor **Isabel Thompson** would love to hear from other members living in the greater Wagga Wagga area. You can contact Isabel on (02) 6926 2459.

In travelling to Sydney for our February Committee meeting I came via Dubbo and Orange. In **Dubbo** I caught up with **Gregg Kirkwood** who hosted our Dubbo Conference and in **Orange** had a very pleasant morning tea and chat with Regional Representative, **Michael Hutchinson**.

In the **north west of the state** our **long serving editor of THE LINK, Laurie Seymour**, has penned his last edition of this wonderful newsletter. Unfortunately Laurie is experiencing declining health and is reluctantly relinquishing his role as editor of THE LINK. We wish to thank Laurie and his wife, Beryl, for the fantastic job that they have done in publishing this quarterly journal which is eagerly read by members throughout the state. Many thanks, Laurie!

Our **Northern Rivers Support Group** is hosting this year's **Country Conference** which will be held at the **Ballina RSL Club** on **Saturday, 15 September 2007**. I am very grateful to our Convenor, **Rosalie Kennedy**, and her organising committee who have devoted great thought and enthusiasm into planning this year's conference. I hope to visit Ballina again early in March to finalise arrangements. **Please put this date in your diary and watch this space for further details.**

If you become aware of the death of a member, Convenors, Regional Representatives and members are asked to inform the office so that a card can be sent to the family and adjustments made to the membership register. This allows us to convey condolences and discontinue unwanted correspondence. Your help in this matter will be much appreciated.

# 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.



### No polio vaccination, no travel

As a result of the alarming rise in polio cases in India WHO is considering asking the Indian government to issue an order whereby Indians travelling abroad will have to ensure that their children travelling with them are vaccinated against polio. The order, if implemented, would mean that children below five years of age will have to get certificates from a doctor (Indian news website rediff.com, 25/9/06). Last year the spread of polio to Indonesia from Saudi Arabia was thought to have occurred via Haj pilgrims. Saudi Arabia has announced it is now mandatory for travellers who are under 15 years of age to have up-to-date proof of polio vaccination in order to obtain entry visas to Saudi Arabia. Additionally all children under 15 arriving from countries reporting wild polio will be given polio vaccinations at Saudi border points. In India polio free certification will be given to Hajjis by their district health official. The Indian Health Secretary said: *The sanctity of the pilgrimage is affected if the message goes out that polio is spreading through Haj. It gives the pilgrimage a bad name. We are telling Uttar Pradesh [the Indian state with the highest rate of polio] that they will be hemmed in for travelling if they continue to export polio.* (IBNlive.com)

### Call for development of drugs to treat polio

When we contracted polio there were no drugs with which to treat it. With the development of the Salk and Sabin vaccines, research into possible treatments for the polio infection virtually ceased. As discussed in previous *Particles* the fear remains that there may be future outbreaks of polio despite the eradication campaign. Now a committee of the US National Research Council has recommended that antiviral medications to treat people with polio be developed (Associated Press 10/03/06). The committee said that: *The development of one or more antiviral drugs against poliovirus, although expensive, serves as an insurance policy that provides an additional means of reacting to repeated outbreaks due to continued circulation of Vaccine-related strains, should they occur.*

### Goat with polio

*Our neighbour's goat was just diagnosed with polio. We thought this disease had been eradicated. Is polio in goats contagious to humans? How dangerous is this?* This query was sent to Pete Keesling, a Californian veterinarian, who writes a bi-weekly advice column in the *Gilroy Dispatch* (5/9/06). He replied: *First, let's make it clear that polio in people has not been totally eradicated. It's extremely important that most children be vaccinated for this terrible disease. Recent reports show that some people have not taken their children in for vaccinations, leaving them potentially susceptible to devastating consequences if they are exposed to this contagious virus. On the other hand you have no need to worry about the neighbour's pet. Polioencephalomalacia (polio) in goats is not caused by a contagious virus, but results from abnormal Vitamin B-1 metabolism. In many cases this polio can be successfully treated with injections of vitamins and the patient can make a full recovery. So even though the goat's neurologic symptoms seem similar to those suffered in humans infected with the polio virus, the disease is significantly different in goats. So the good news is that goats with the disease can recover and do very well with few long-lasting effects.*

## Feelings of déjà vu

*The talking point at the wedding was not about the bride's beauty. And she was impossibly or extremely beautiful. The dominant comment was about the bridegroom's 'stupidity'. He was tall and had an athlete's stature, not the one enhanced by steroids. But not even steroids could do anything for the bride's left leg. It was thin and shorter than the right one. Polio had made her almost a cripple. Many people commented that the man was foolish to have chosen such an obviously deformed woman as his bride. Someone claimed it was not love but a love potion that led the man to propose to the lady. And there was a time during the ceremony when the bride had almost fallen on her face ... dancing was apparently new to her. She may not have had many dates before her wedding. Not many young men care to take a polio victim dancing. This was the beginning of the editorial in the Nigerian Tribune (31/10/06). I'm sure this story will remind many polio survivors of feelings associated with not being considered socially or matrimonially acceptable particularly when they were young. The editorial went on to criticise the many Nigerians who think that polio is caused by *the cannibalism of a witch* rather than by a virus. Such beliefs and rumours about the dangers of the polio vaccine, the editorial said, have caused resistance to vaccination. As a result Nigeria accounts for more than half the world's polio cases and is transporting polio to other countries. The editorial ended with the following scenario: *It is 2028 and a wedding reception is being held. 'Look at the bride,' one woman says to her friend. 'What great legs she has'. The mother of the bride is within earshot. She smiles broadly though her own left leg is withered.* The scenario reminded me of the relief that I think most survivors felt when the advent of the Salk vaccine meant their children could never get polio. It reminded me also of the anguish and anger we sometimes feel at some Australian parents' refusal to have their children vaccinated.*

## Murder concealed by diagnosis of polio

If you enjoy a good detective yarn then a current US murder case will be of interest. Sally Mercer, the 31 year old wife of a Michigan physician Charles Mercer, died at her home in 1968. Her eight year old daughter found her body when she returned from school. Emergency medical workers on the scene said Sally's fists were clenched as if she had been in a struggle. A detective at the autopsy noticed multiple bruises (which can still be seen on photographs taken at the autopsy). As the detective had previously been an apprentice at a funeral home he realised during the autopsy that the body had already been embalmed. When questioned, the pathologist Dr Black said he had embalmed the body as he had not noticed any trauma. Dr Black ruled that Sally died from bulbar polio. This cause of death was accepted despite the fact that Sally had written to a friend saying she was afraid her husband might kill her. She knew Charles was having an affair and he married his lover soon after the death. In June this year Sally's husband, now aged 72, was brought before a preliminary hearing when the case was reopened. A second recent autopsy found lethal levels of a powerful pain reliever, propoxphene. Charles' defence lawyer argued that the polio verdict was reasonable given that two other local women had died from a viral infection around the time of Sally's death. Her daughter testified at the preliminary hearing that she had always believed that her mother died of polio. Dr Black, the pathologist, died in 1981. On January 25<sup>th</sup> a Michigan District Judge ruled that Charles be tried for murder. He remains free on a \$1 million bond. The trial will probably be set for later this year. The Lansing State Journal was my main source for reports of this case.

## Ups and downs of polio rates in 2006

There were 1874 cases of wild virus polio notified in 2006 compared to 1749 in 2005. However the distribution of cases was very different. In 2005 there were 778 (44.5%) cases in endemic countries and 971 (55.5%) in non-endemic countries. Last year there were 1756 (93.7%) cases in endemic countries and only 118 (6.3%) in non-endemic countries. Countries recording marked increases last year were India (624 in 2006, 62 in 2005), Nigeria (1062 in 2006, 675 in 2005), Namibia (19 in 2006, 0 in 2005) and Afghanistan (31 in 2006, 7 in 2005). A marked decrease occurred in Somalia (33 in 2006, 131 in 2005). On 12/10/06 WHO announced the first

case of polio in Kenya in 22 years. It was found in a 3 year old Somali in a refugee camp in north east Kenya but only one further case occurred. Other countries which had no polio cases in 2005 but reported cases in 2006 were Bangladesh (17 cases) and the Democratic Republic of the Congo (11 cases).

### **Alarm at rise of polio cases in India**

The BBC news (25/10/06) reported that there had been 119 new cases in the past month in India. India's final total of 624 cases in 2006 represented a third of the cases in the world last year. The state of Uttar Pradesh accounted for well over half the Indian cases. Polio has been reported in the cities of Delhi and Mumbai where it had become very rare of recent years. A Mumbai headline read: *Calls flood doctors for polio info*. Officials said all cases found in Delhi and Mumbai could be linked to children who had come from the states of Uttar Pradesh or Bihar in the past few months. Poor sanitation in these states means that children may need more than the usual three doses of vaccine because they often have diarrhoea at the time of vaccination.

### **Immunoglobulin used to treat PPS**

As Dr Marcia Falconer has explained in her recent seminar presentations to the Network, there is evidence that an inflammatory process may be the major cause of PPS. Thus anti-inflammatory medications should help relieve PPS symptoms and several recent research studies have shown this to be so. Dr H Gonzalez and others reported the results of a randomised controlled trial in the journal, *Lancet Neurology*, June 2006. In this research patients in four clinics were *randomly assigned infusion of either 90g in total of intravenous immunoglobulin or placebo during 3 consecutive days, repeated after 3 months*. There was some improvement in muscle strength in the treatment group as well as in activity levels and vitality. There was no significant change in pain experienced. The Summer 2006 issue of the *Post-Polio Health International Newsletter* (St. Louis) had an article by Drs Halstead and Silver evaluating and discussing the implications of this research (You can read it at <[www.post-polio.org/ipn/pnnback.html](http://www.post-polio.org/ipn/pnnback.html)>). A major disincentive is the cost of the treatment which they estimate would be at least \$US10,000 for the course of therapy. They say: *It is not entirely clear who would benefit ... Because the diagnosis of PPS is still imprecise, perhaps the only way to be certain if you would be a good candidate or not, is to have your cytokine [an indicator of inflammation] levels checked. This involves having a spinal tap [lumbar puncture] to obtain a sample of CSF [cerebrospinal fluid] and access to a lab that performs these tests on a regular basis*. The length of time that the positive effects are sustained is obviously of great importance. On the Post-Polio-Med online mailing list a spokesperson for Post-Polio Health International said it had received the following response to this question from the research group: *We have preliminary results from follow-up studies showing that the cytokine level in the cerebrospinal fluid is [still] significantly decreased one year after the treatment. There is a statistical improvement of quality of life 2 years after the treatment. For the individual, the effect may last from 6 weeks to several years*. It will certainly be of great interest to follow the development of this research. Hopefully a less costly treatment will be found.

### **Enticing nerve cells to paralysed muscles**

The Salk Institute for Biological Studies in California has issued a press news (15/6/06) in which Dr Samuel Pfaff, a leading researcher there, describes how his team has *identified a molecule that guides a specific subgroup of neurons to connect to the muscles that line our spine and neck ... piece by piece, we are uncovering general principles that ensure that the developing nervous system establishes proper neuronal connections. Understanding how axons find their destinations may help restore movement in people following spinal cord injury, or those with motor neuron diseases such as Lou Gehrig's disease [ALS or motor neurone disease], spinal muscle atrophy and post-polio syndrome*. There is a lot more research to be done before this research is applied to people but they are starting to treat mice.

# A Great Read about Coping with Post-Polio

**Review by Mary Westbrook**

*This review by Mary Westbrook of Dr Halstead's "Managing Post-Polio" book first appeared in Network News Issue 40, February 1999. Since that time, the Network has imported bulk copies of the book from the USA several times for the benefit of members wishing to purchase a copy. We currently have stocks available and so thought it timely to repeat the review as many members who have joined the Network since 1999 will not have read it before. Ordering details for "Managing Post-Polio" are at the end of the review.*

1998 saw the publication of *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, the most informative, readable and relatively cheaply priced book yet to appear on this topic. Dr Lauro Halstead, an American rehabilitation specialist who was responsible for early research and conferences on PPS, is the editor. Halstead has himself experienced polio and its late effects. One of his goals in writing the book was *"to distil and summarise in lay terms the wealth of information presented at conferences and published in the medical and allied health literature over the past 10 to 15 years"*. The 13 chapters and seven personal stories are written by 20 authorities in their fields, the majority of whom are polio survivors.

Halstead describes how people who developed PPS felt anger, bitterness, and despair. *"Fortunately, the feelings did not stop there. The knowledge and skills of not just how to endure but to prevail ... were still intact. Our shared history of knowing how to overcome adversity led us to take action that, once again, turned our lives around and made us feel proud to be called survivors. One step was to stimulate the medical community to take our new health problems seriously. Over the years this has led to a significant increase in the attention given to polio by researchers and clinicians leading to a more precise definition PPS, a better understanding of the possible causes, and the development of more rational and effective strategies for its management"*.

In the first two chapters of the book Halstead gives a detailed, easily understood account of the stages of acute polio, PPS and its causes and management. There are sections on the evaluation and treatment of muscle weakness, fatigue, pain, respiratory complications, swallowing problems, and cold intolerance. These and the section, *"Important considerations when getting ready for surgery"*, would be useful to copy and give to appropriate health practitioners. Halstead comments that new muscle weakness has been the easiest symptom of PPS to research and there is now a better understanding of this than of any other symptom. The most common symptom of PPS, fatigue, is more difficult to investigate and much less is known about its causes. Halstead distinguishes peripheral fatigue, which is felt in muscles after repetitive contractions, from central fatigue which is for many people the most disabling symptom of PPS. It is characterised by *"the rapid onset of mild to extreme tiredness, generalised headache, difficulty in concentrating and general malaise"*.

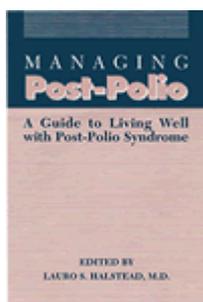
There is a long chapter on energy conservation by Grace Young, an occupational therapist. She gives advice on using your body efficiently and making your environment user friendly. Laura Smith, a physiotherapist, discusses the preservation and protection of muscle and joint capacity and how to manage injuries, pain and fatigue. She describes the abnormal forces that occur in polio bodies because of the substitution of other muscles or ligaments in compensation for muscle losses. *"Substitute muscles may have had to pull at an angle and apply a greater force in a different direction. In mechanical terms, this situation would be like running an automobile on three cylinders (instead of six) with the front end out of alignment."* She says that health practitioners frequently do not appreciate the complex

causes of post-polio pain so they provide only temporary relief by prescribing medication and heat. Another chapter discusses starting, running and being a member of a support group. In the introduction to the book Halstead tells of the hundreds of PPS support groups that emerged overnight in the USA. He says that such support groups are not only a way reaching out to others with similar new problems but also part of a journey of self-discovery. *"In my own case, it was only after I joined a local support group and began talking with other polio survivors that I started to grieve the body I had lost more than three decades earlier. Although I have still not made peace with my disability, and probably never will, I'm getting better at incorporating it into my life and the person I am."*

There are two excellent chapters by psychologist, Rhoda Olkin. In the first she discusses psychosocial aspects of PPS. Because we live in a non-disabled world we are bi-cultural and much of our experience is only fully understood and shared by other people with a disability. Many polio survivors describe discovering the disabled community as 'coming home'. *"This statement is not meant to minimise some of the emotional difficulties of identifying yourself with a group of people with disabilities. When I first walked into a room full of people in wheelchairs, little people, people using sign language ... I thought, 'I'm not one them. I had polio, but they're disabled'. It took a while to sense how comfortable this group was for me, how so much that went unsaid was understood"*. In her second chapter Olkin discusses how PPS effects our relationships with our families (parents, partners and children) and includes self-assessment items and suggestions for increasing well-being. Sexuality, parenting and ageing are covered. Although ageing presents additional problems for polio survivors, *"We also come with some strengths; we have been members of a disadvantaged group of lower status (persons with disabilities) and hence have learnt ways of coping prior to entering a second group of lower status (the elderly). We've developed ways to cope with functional losses. Further, we've developed wisdom through experience. We've learnt that we have to prioritize everything, give up on some items further down the list of priorities, and make compromises."*

Other chapters describe how to get the most out of visits to your doctor and strategies for coping at work as your health declines. Another is a guide to the Internet, giving information on using the Net as well as a list of PPS resources available there. The chapters on gaining social security benefits and navigating managed medical care will be of little value to Australian readers. However they will relate to polio survivors' stories of various aspects of the polio experience. For example, Hugh Gallagher describes the stress and final relief of moving from a manual to an electric wheelchair, two people write of the need to change their job or retire because of PPS, others of embracing their pasts. Carol Gill writes, *"To relinquish the strain of trying to be nondisabled and to let go of it deliberately, in celebration, not in disgrace, is a truly liberating idea. Far from giving in or giving up, self-acceptance is an empowering process"*. There are also eight pages listing additional resources: primarily books, articles and web sites.

This is an excellent book. It is the book I would recommend to any newcomer to the post-polio scene, whether they are a survivor or a health practitioner. It also has a great deal to offer 'old hands' being full of facts and ideas to which you'll often want to refer.



This 240-page book provides a comprehensive overview on dealing with the medical, psychological, vocational, and many other challenges of living with post-polio syndrome. Written by 20 authorities in their fields, the majority of whom are polio survivors themselves, *Managing Post-Polio* distils and summarises in lay terms a wealth of post-polio information.

*Managing Post-Polio* can be purchased from the Network for \$27.50, including GST, post free throughout Australia. Simply write to the Network including your cheque or money order, or pick up a copy at a Seminar.



# Post-Polio Network Seminar Program 2007

|   |   |  |
|---|---|--|
| <b>Saturday<br/>3 March 2007</b>          | Northcott Society<br>1 Fennell Street<br>Parramatta | <b>Seminar – Technical Aid to the Disabled</b><br><i>presented by Physiotherapist, Kristi Harvey-Walker</i><br><i>Full details on Page 2 of this issue</i> |
| <b>Saturday<br/>16 June 2007</b>          | “The Tradies”<br>57 Manchester Road<br>Gymea        | <b>Seminar – Technology Advances in Orthotics</b><br><i>Presented by Mark Raabe</i><br><i>Full details in the next issue of Network News</i>               |
| <b>Saturday<br/>15 September<br/>2007</b> | Ballina RSL Club<br>Ballina<br>Northern NSW         | <b>Biennial Country Conference</b><br>the Presenters and Topics to be advised<br><i>Further details in upcoming issues of Network News</i>                 |
| <b>Saturday<br/>24 November<br/>2007</b>  | Northcott Society<br>1 Fennell Street<br>Parramatta | <b>Annual General Meeting and Seminar</b><br>the Presenter and Topic to be advised<br><i>Further details in upcoming issues of Network News</i>            |

## Management Committee Contact Details

|                  |                                    |                                    |              |
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| Maura Outterside | Committee Member                   | ---                                | 02 9718 5803 |
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| Mary Westbrook   | Q's about polio & pps              | askmary@post-polionetwork.org.au   | ---          |

## PPN Office Contact Details

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|---|---------------------------------|--------------|

# 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 quarterly Seminars, publishes *Network News* and *Information Bulletin* quarterly, 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.

| <b>Books etc (* indicates Post-Polio Network publication)</b>   | <b>Size</b>      | <b>Cost</b>                           |
|---|------------------|---------------------------------------|
| <i>Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome</i><br>edited by Lauro S Halstead MD ( <i>see description below</i> 📄)  | 240 pages        | \$25.00<br><i>plus 10% GST</i>        |
| <i>A Practical Approach to the Late Effects of Polio</i><br>Charlotte Leboeuf   | 39 pages         | \$2.50                                |
| <i>The Late Effects of Polio: Information for Health Care Providers</i><br>Charlotte Leboeuf  | 56 pages         | \$2.50                                |
| * <i>Living with the Late Effects of Polio</i><br>Conference Proceedings, edited by Gillian Thomas  | 170 pages        | \$29.00                               |
| * <i>Polio – A Challenge for Life – The Impact of Late Effects</i><br>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<br><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<br>23 mm | \$5.00<br><i>plus \$1<br/>postage</i> |

### 📄 ***Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome***

This 240-page book provides a comprehensive overview on dealing with the medical, psychological, vocational, and many other challenges of living with post-polio syndrome. Written by 20 authorities in their fields, the majority of whom are polio survivors themselves, *Managing Post-Polio* distils and summarises in lay terms the wealth of information presented at conferences and published in the medical and allied health literature over the past 10 to 15 years. This information is supplemented with personal stories of seven individuals who provide eloquent testimony to the many ways people have prevailed in the face of ongoing disability.

Intended for persons who have had polio, their families, friends, and loved ones, *Managing Post-Polio* was also written for health professionals who are unfamiliar with the late effects of polio and those who would like to learn more. As Dr Halstead, a polio survivor himself, observes in the introduction, "this book was written and edited partly to help me deal better with my own unique disability and to help the many thousands of other polio survivors in this country and around the world deal more effectively with their unique version of polio disability."

**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.**

If undeliverable return to:

**Post-Polio Network (NSW) Inc**

PO Box 888, Kensington NSW 1465

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