

**POST - POLIO NETWORK (NSW) INC.**

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**NETWORK NEWS**

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## President's Corner

Gillian Thomas

Welcome to regular readers and new members to the first *Network News* for 2004.

Thank you to those members who contributed to our annual planning session in January. All suggestions were brought to the meeting. The Committee's major goals for this year are to refine and streamline our internal processes, including the development of volunteer protocols; to establish our office at the Northcott Society; to finalise the Constitution amendments; and to initiate a range of outreach activities. We aim to reach polio survivors from non-English speaking backgrounds; establish links with Nursing Homes; undertake speaking and training engagements; update our website; and establish four new Support Groups (Sutherland, Hurstville, Batemans Bay and Wagga Wagga). Progress against these goals will be reported on in *Network News* during the year.

The Constitution Sub-Committee will shortly reconvene to further consider comments from members and to finalise the discussion paper which will seek input from all members about possible changes to the Constitution. The process has been taking a little longer than we might like, however, Committee members are also polio survivors and our health and personal issues must sometimes take precedence. Remember that the Network has no paid staff to take on some of the workload. Notwithstanding this, you may rest assured that work is continuing and the task remains a priority.

Many people who have seen Danish film-maker Niels Frandsen's *The Epidemic – I don't remember anything, but I'll never forget* have asked about the possibility of buying a copy. We have been in contact with Niels about this, and he has advised that it will cost \$60 per video tape to purchase from Denmark. The tapes could then be collected at a Seminar, or posted at an additional cost of \$5. Due to the cost involved, we will not be purchasing the tapes without firm orders. If you would like to purchase a copy of the film, please forward to the Network by 31 March a cheque/money order for \$60, plus postage of \$5 within Australia if required. We will then purchase tapes to fill the orders received.

The Prince Henry Trained Nurses Association's *Nursing and Medical Museum* has now opened its doors to the public. Tracing right back to the Hospital's opening in 1881, the museum preserves 122 years of its history, not the least of which being the polio years. The Museum will be open every Sunday and Monday from 1 pm to 5 pm. Admission is \$3 for adults, children are free. It is worth a trip out to Little Bay just to see the working iron lung.

It is the Network's 15<sup>th</sup> anniversary this year – any thoughts on how this should be celebrated?

Finally, we are sad to advise that Vice-President Merle Thompson's mother, Mollie, passed away on 14 February at the age of 97. While Merle and her sister Lyn are naturally distressed at their loss they also know that Mollie is now at peace and are grateful that she had 97 years – 92 of them as an independent person. She was still caring for others until the last few weeks, and was feisty to the end. The funeral was held in a peaceful bushland setting in the mountains loved by the whole family. Committee members who attended the service at Leura report that the service was very moving and a fitting tribute to a fine lady.

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# Exploring the Feldenkrais Method

**Date:** Saturday, 6 March 2004  
**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

***Please note that this is the Northcott Society's new building which is in the same block as before, but the entrance is now in Fennell Street instead of Grose Street***

**Parking:** At this *Network News* goes to press, it is uncertain whether the Northcott Society's new underground car park will be completed in time for this Seminar. Limited parking is currently available in front of the new building in Fennell Street - it would be appreciated if those who are more mobile would leave this closer parking for members who are only able to walk or wheel short distances. As the area is quiet on weekends, there is usually street parking around Fennell Street. Parking will also be available as usual in the Parramatta Leagues Club car park at the end of Grose Street.

**Transport:** Bus 600 will take you from Parramatta Station to the Leagues Club.

At our first Seminar of 2004, our speaker will be **Elaine Altman**. Elaine is a Certified Feldenkrais Practitioner who graduated from the Professional Feldenkrais Training Program in Sydney. She is a Registered Nurse, qualified in occupational health and rehabilitation, and has been teaching the Feldenkrais Method since 1998. We are grateful to Elaine for accepting our invitation to present this Seminar when our advertised speaker, Zoran Kovich, was regrettably unable to be with us.

The Feldenkrais Method is named after its originator, Dr Moshe Feldenkrais, DSc (1904-1984), a Russian born physicist, judo expert, mechanical engineer and educator.

The Australian Feldenkrais Guild Inc, of which Elaine is a member, explains that the Feldenkrais Method facilitates learning about movement, posture and breathing to ultimately increase the ease and range of our movement, improve flexibility and coordination.

Through gentle movement lessons, you become more aware of how your habits may restrict your moving through life easily and pleurably. You will learn new, easier options for movement. As a result you can enjoy greater freedom of movement, an increased sense of vitality, and feelings of peaceful relaxation. After a session you often feel taller and lighter, breathe more freely and find that your discomforts have eased. You experience relaxation, and feel more centred and balanced.

The *Feldenkrais Educational Foundation of North America* says that anyone – young or old, physically challenged or physically fit – can benefit from the Method. Feldenkrais is beneficial for those experiencing chronic or acute pain of the back, neck, shoulder, hip, legs or knee, as well as for healthy individuals who wish to enhance their self-image. The Method has been very helpful in dealing with central nervous system conditions such as multiple sclerosis, cerebral palsy, and stroke. Many Seniors enjoy using it to retain or regain their ability to move without strain or discomfort.

*If this is the first Seminar you have attended, please introduce yourself to a Committee member. We look forward to seeing everyone there and hope you will stay for afternoon tea and a chat with fellow members at the conclusion of the Seminar around 3:30 pm.*

# Sleep-Disordered Breathing

Dr Elizabeth Joyner

*In this article, Network and past Committee Member Dr Elizabeth Joyner gives us a detailed understanding of sleep-disordered breathing. Starting with definitions, Elizabeth goes on to describe the causes of this problem, the physiology of sleep, the estimated scope of the problem, whom to suspect, investigations and treatment.*

## Definitions

Breathing disorders during sleep include the following:

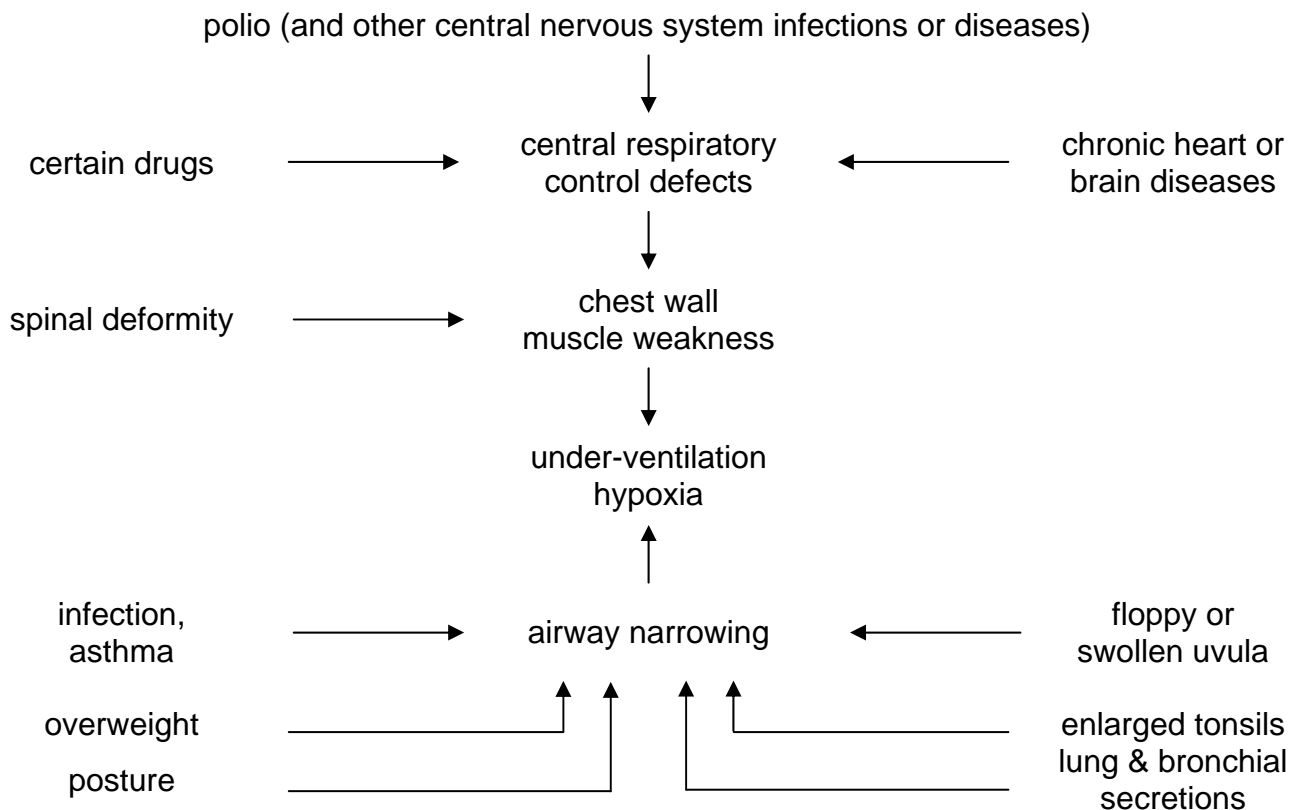
- 1) Sleep **apnoea** - periods of actual cessation of breathing during sleep.
- 2) Episodic **hypoventilation** during sleep resulting in significant lowering of blood oxygen levels or **hypoxia** which will damage vital organs, including the heart and brain. This damage can be manifested as an acute episode (for example, culminating in a stroke or heart attack) or as a subtle cumulative injury (for example, accelerated brain neuronal loss).

## Causes of Sleep Disordered Breathing in General

- A. **Airway obstruction**, upper or lower, may be acute or chronic, and is often associated with respiratory tract infections, asthma, obesity, sleep posture, floppy uvula, airway narrowing due to enlarged tonsils, tumour etc.
- B. **Central respiratory control defects**, with depression by sedative drugs or certain heart or brain problems, for example, heart failure and stroke.
- C. **Restricted expansion of chest wall or lung tissue**, eg. due to polio effects such as:
  - Weakness or paralysis of chest wall muscles of respiration dating from the original polio infection in the thoracic polio group.
  - Weak central respiratory drive reflexes (brainstem respiratory control centre damage in bulbar polio).
  - Diaphragmatic muscle weakness (the diaphragm is an important accessory muscle of respiration).
  - Spinal deformity restricting chest wall expansion.

A, B and C can all add to the increased work of breathing in certain post-polio patients and become significant during sleep or periods of unconsciousness.

*The flow chart on the following page may help to show these inter-relationships more clearly.*



## Physiology of sleep

The normal phases of sleep are characterised by initial drowsiness, with slowing brain waves on an electroencephalogram, followed by further phases with changes in voltage and frequency patterns until the larger slower waves of deep sleep appear; then lower voltage, random fast wave REM patterns appear periodically.

REM is rapid eye movement sleep associated with dreaming, profound muscle relaxation and loss of muscle tone, presumably to avoid us acting out our dreams. This is the period in normal subjects of lessened respiratory drive, when we are most susceptible to under-ventilation with resultant lower blood oxygen and higher carbon dioxide levels. As the heart rate speeds up and arteries constrict during REM sleep, it is also a time when we are more susceptible to heart attack, angina and stroke.

Respiratory rate, ventilation and responses to hypoxia and raised blood carbon dioxide levels, all decrease in earlier sleep stages. Breathing in REM sleep then becomes erratic, rapid and more shallow. Clearance of mucus and coughing are also reduced during sleep, hence the significantly increased risk of retention of lung secretions and resultant infections in people with already compromised lung function.

As we age, we tend to sleep less at night and the quality of that sleep deteriorates.

## Scope of the problem of sleep-disordered breathing

Polio has been notifiable since 1916.

Three major epidemics occurred in Australia in 1937 - 1938, 1945 - 1948, 1949 - 1956. The last minor epidemic was in 1960 (but cases in 1967 among migrants to Australia).

The number of cases officially reported was grossly underestimated in official figures because of under-diagnosis and under-reporting for many secondary reasons.

It is of interest that Tasmania had the second largest polio epidemic per capita in the world behind Iceland in 1937/38.

### ***Spectrum of polio infection effects in population (M Falconer)***

| Subclinical | Abortive | Non-paralytic | Paralytic | Bulbar     |
|-------------|----------|---------------|-----------|------------|
| 50%         | 30%      | 15%           | 1 – 5%    | up to 0.4% |

#### ***From the 1930s to 1960s***

- A. The estimated number of cases of **polio virus infection** in Australia was conservatively 1 – 2 million.
- B. The estimated number of **paralytic polio cases** was approximately 1 – 5% of A above: 20,000 – 100,000.
- C. The estimated number of **paralytic polio cases with respiratory muscles affected** was 10% of B above – approximately 2,000 – 10,000 resulting in a high mortality rate.
- D. The number of cases of **subclinical, unrecognised and recognised polio** is estimated at 4 - 8 million.

It is estimated about 40% of people who had **non-paralytic polio** will get post-polio effects (Falconer) but are no more likely to develop sleep-disordered breathing than the general population.

- E. Percentage of **expected cases of PPS in people with a polio history** 50% of 1 – 2 million, but need to allow for mortality rate.
- F. Number of **expected cases of PPS in those with a bulbar polio history** 2,000 – 10,000, but need to correct for a high mortality rate. Thoracic and bulbar polio survivors are likely to have a much higher risk of sleep-disordered breathing problems as part of their post-polio syndrome.

Thus it can be reasoned that there may well be a few thousand polio survivors in Australia today with some degree of current respiratory weakness at higher risk of sleep disordered breathing problems.

#### **Whom to suspect**

- People with a past history of polio, particularly if paralytic polio, and with thoracic, respiratory or pharyngeal muscle weakness or need for ventilation during the acute phase of the illness, for example, iron lung or other breathing aids. Note that there may well be a history of “full recovery” from the original symptoms.
- People with unusual levels of daytime sleepiness, broken sleep patterns, lack of refreshment following sleep each night, sudden arousal from deep sleep with a pulsating headache, choking episodes, tachycardia, drooling, twitching and convulsive movements, morning headaches (suggesting significant hypoxaemia).
- Greater index of suspicion required in snorers, obese/overweight people (suggesting respiratory tract obstruction during sleep), and those with swallowing difficulties, episodic inhalation of food and liquids.
- Polio survivors with asthma, wheezy bronchitis (periods of increased secretions and narrowing of the airway further compromising barely adequate ventilation, that is, tipping the balance).
- Polio survivors with kypho-scoliosis.

## Investigations

- Discuss possibility of sleep-disordered breathing with the GP.
- Full blood count, thyroid function tests, ECG etc, depending on symptoms, to exclude other causes.
- Referral to a respiratory physician.
- Referral to a sleep disorder clinic at a major hospital if sleep-disordered breathing is suspected.
- Blood oximetry (measures blood oxygen saturation overnight).
- Sleep study with ECG, EEG, oximetry, etc.

## Treatment

- Weight control, small evening meals to minimise pressure on the diaphragm when horizontal at night.
- Adjustment of posture during sleep – recovery position, avoid sleeping on the back, individualised posture recommendations depending on relevant disabilities.
- Treatment of excessive respiratory tract secretions.
- Treatment of wheeze, asthma and any other factors which might further obstruct or narrow the airway.
- Breathing / ventilation aids – for example, c-PAP (continuous positive airway pressure) and bi-PAP (bi-phasic positive airway pressure) machines.
- Directions / protocol for managing acute respiratory infections and asthma.
- Oxygen when required.
- Avoid hypnotics, sedatives or drugs which can weaken the respiratory drive, including narcotic analgesics and codeine.
- Alert anaesthetist / surgeon prior to planned surgical procedures.
- Periodic review of night-time blood oxygen saturation levels.

## Take-Home Message

- There may well be a significant number of polio survivors in the sleep-disturbed group who have unrecognised hypoventilation or apnoea problems during sleep, which may then be contributing to other important issues such as heart disease, hypertension and stroke risk.
- Alert sleeping partners and close family members to the increased risk of sleep-disordered breathing in relevant cases.
- Investigate promptly on suspicion of sleep-disordered breathing to minimise silent hypoxic damage to vital organs during sleep.
- Simple treatment can be life-saving and life-enhancing.

## References

Falconer, M Dr – PhD Virologist, Canada.

de Graaff, S Dr – Consultant Physician in Rehabilitation Medicine, Caulfield, Victoria.

# **Seminar Report –**

## ***Obstructive Sleep Apnoea and Sleep-Disordered Breathing***

**Presented by Dr David Barnes on 29 November 2003**  
**Reported by Wendy Chaff, Hunter Area Support Group Convenor**

*Once again we are grateful to Wendy for writing up a Seminar presentation for the benefit of members unable to be there. It was a most interesting and informative talk. Wendy summed up its message with “There is no substitute for sleep. Sleep nourishes our brains and helps us to function better. So value the gift of sleep as a blessing to be treasured.”*

Our Guest Speaker was introduced by Network Committee Member Ann-Mason Furmage, one of many patients who have benefited from his expertise. Dr David Barnes is Clinical Associate Professor in Medicine at the University of Sydney, and Respiratory Physician at Royal Prince Alfred Hospital, where he is also a member of the Sleep Disorders Unit.

The need for sleep is a drive similar to hunger or thirst. Dr Barnes suggested viewing our need for sleep by how it affects our lives if we don't get enough. Sleep loss or fragmentation results in sleepiness, impaired thinking and memory, moodiness, and increased risk taking. There are possible immune and hormonal effects, as well as other long term health risks (such as ulcers).

### **Sleep-Disordered Breathing (SDB)**

- Obstructive sleep apnoea (OSA) is the most common type by far.
- Central sleep apnoea (CSA) is less common – due to a problem with central brain regulation – the person forgets to breathe, for example, after a stroke or with bad heart disease.
- Hypoventilation – not breathing hard enough because the airway is being obstructed during sleep.

### **Symptoms of Obstructive Sleep Apnoea**

- Loud snoring – which can cause obstruction of airways.
- Witnessed apnoeas – up to 5 episodes per hour of stopping breathing are allowed – but more are considered abnormal and testing is required. In the USA, 23% of adult men have more stoppages than this. It is less common in women, until after menopause, when the numbers become almost equivalent.
- Nocturnal choking – some wake up with a choking sensation (no need to panic).
- Fragmented (broken) sleep - just as bad as not having a total amount of deep sleep.
- Waking unrefreshed, perhaps with a headache – this may impact on daily functioning as concentration and performance deteriorate.
- Excessive daytime sleepiness causes accidents - particularly in the early afternoon.

Driving is a potential risk if you have severe sleep apnoea, as sufferers have a higher rate of vehicular accidents, especially when alone. There is a lot of evidence that accidents can be caused by excessive fatigue during sleep deprivation (for example, the notorious oil spill from the tanker *Exxon Valdez*).

If you are unlucky enough to be born with a narrow throat (uvula), you will have a narrow upper airway aperture. Just lying down makes the aperture smaller; then, on falling asleep, it almost inevitably means that you will snore, and have obstructive sleep apnoea.

Reassuringly, Dr Barnes said: “*You won't die from sleep apnoea. You have protection from your brain waking you up. Go to sleep without any qualms.*”

**Overnight sleep study tests**, held at a sleep unit, can check out sleeping problems – how you breathe, when and why, and how low does your oxygen level go. It is rare to have an inconclusive sleep study test; almost always they can get enough information for a diagnosis – even from, say, 2 hours sleep time.

## **Health Consequences of Obstructive Sleep Apnoea (OSA)**

Hypertension (high blood pressure) is the most common and earliest risk factor for snorers. Other health consequences are stroke, heart strain, mental effects (depression, irritability), and related accidents.

## **Therapy for Sleep Apnoea**

This includes general measures such as:

- Weight control - sometimes abolishes apnoea, and can improve the efficacy of other treatments.
- Avoid alcohol - makes the upper throat muscles relaxed and floppy.
- Avoid sedatives.
- Treating nasal obstruction medically can occasionally help, but not often.

Surgery to the palate or tonsils has been a relatively dismal failure (with a low success rate of 30%) for people who just snore, and is ineffective for Sleep Apnoea.

## **Post-Polio and Impaired Sleep Quality**

Dr Barnes advised that there is limited information available about this relationship, but the following post-polio problems can lead to impaired sleep:

- Physical discomfort.
- Depression – if the patient exhibits excessive sleepiness but has no history of apnoea, depression may be the cause, for which there are many effective medications.
- Periodic limb movement disorder – brief jerks or twitches of legs or arms during sleep – bed partner may complain of being “kicked”.
- Restless Leg Syndrome can be related, and worse by night – a sensation that feels like a flea, or ants crawling. Discomfort is relieved by moving legs, standing or walking. If you have both twitching and restless legs at night, medication may help.
- Leg Cramps (from an unknown cause) – require completely different treatment – for example, quinine or tonic water.

Polio is a motor neurone condition. To differentiate between muscle cramps and spasms and jerky movements, diagnosis can be made from a sleep test.

## **Sleep-Disordered Breathing in Post-Polio**

- If Central Sleep Apnoea - bulbar dysfunction - severe impairment to breathing.
- Hypoventilation – under breathing, particularly if kyphoscoliosis is present.
- Diaphragm weakness leads to hypoventilation.
- Some people with bad sleep apnoea and weak diaphragms sleep better when propped up on pillows.

## **Obstructive Sleep Apnoea in Post-Polio**

Can be due to:

- Dysfunction of the upper airway.
- Weight gain – affected by less physical activity plus an increased risk of diabetes.
- Causes unrelated to polio.



## Treatment of Sleep-Disordered Breathing in Post-Polio

To treat obstructive sleep apnoea, similar principles to non-polio sufferers are applied:

- Sedative avoidance.
- Attention to sleeping position – clearly worse on your back.
- Weight loss – can be effective.
- CPAP machine if sleep study results are severe enough.
- Central Sleep Apnoea / Hypoventilation – oxygen or non-invasive ventilation (NIV) – looks like CPAP, keeps the airway open or closed - if required.

Dr Barnes indicated that it seems polio survivors need not be treated much differently to others.

### CPAP - Continuous Positive Airway Pressure

This machine is an Australian invention, originating from the Royal Prince Alfred Hospital in 1980. The lightweight mask revolutionised the treatment of bad sleep apnoea. Air which is blown at pressure through the nose keeps the throat from blocking. It abolishes excessive sleepiness and prevents snoring if fitted correctly.

The CPAP machine gives 100% control of the condition, but is NOT A CURE. If its use is stopped, there is a honeymoon period for a while, then the problem returns. Long term commitment is required to use it – until a cure is found, which is unlikely in the foreseeable future.

An alternative is a dental splint (like a fitted mouthguard) – which can be adjustable. It may have long term effects on the facial bones. Some people can't wear it because the muscles of the jaw can be under stress.

In Dr Barnes' view, people need to have enough willingness and expertise to tolerate CPAP and stick with it. The adjustment period can vary from two nights to two months.

Ann-Mason Furmage said that for the first week or two on a CPAP machine it is difficult to keep on using it. *"Having something strapped to your face is tough, when every fibre of your being is resisting"* – but after two weeks she became accustomed to it. She told us it can be *"worth the struggle to get used to that thing on your face – to wake up in the morning and feel refreshed, like a normal human"*. For her it is *"like a light being turned on"*.

Another member, George Laszuk, said he had tried the machine for some time, but could not stand it with the pressure being so high. Dr Barnes suggested having a sleep test on the machine to judge what pressure is really needed, for example, 10 to 15 degrees. The pressure level varies according to weight, so if you have lost weight the pressure needs to be reduced, or vice versa.

The ability and expertise of technicians at sleep centres to administer CPAP varies enormously. It was suggested that members should consider the quality of back up service from a provider, which is important for people who have difficulty going out. It may be possible to arrange for a trained person to come to your home with a CPAP.

The comfortable fitting of the face mask seems to be a particular issue for post-polio people, who can have some wastage of facial muscles. There is now an improved range of face masks (some are lined), with a greater choice of different sizes, as more children are being diagnosed with sleep apnoea.

## Question Time

Most members who come to our Seminars raise issues that seem common to a lot of us.

**Q: *Why do I sometimes wake up with a dry mouth?***

**A:** This occurs when you have a blocked nose during the night. You may be under-breathing, which could require a sleep study.

**Q: *Dr Barnes was asked to comment about the old saying: “Early to bed and early to rise makes a man healthy, wealthy and wise.”***

**A:** Whether early to bed or late to bed – it is better not to sleep in, but rather still get up at the same time. Try to keep sleeping hours as regular as possible, going to bed at the same time and getting up at the same time every morning, without breaking it up. As we get older we may not need as much sleep and the quality of sleep can change. It can become lighter, with more awakenings.

There are those who have claimed to function well on little sleep – but when tested, it was found that they actually performed better after proper (6 – 8 hours) sleep.

**Q: *What if you are a busy person who does not get enough sleep and needs reviving?***

**A:** Try having a siesta or nap of 20 to 30 minutes soon after lunch (about 1 – 2 pm). The best length of time for a nap is either about half an hour, or else 3 hours – not much in between is beneficial. For an insomniac it will not help to have naps during the day. (Here, Dr Barnes reminded us that he does not treat insomnia.)

**Q: *How do you recognise a sleep disorder?***

**A:** The degree of daytime sleepiness varies. In what situations would you fall asleep? When you fall asleep after a busy day it is not surprising. Failing to sleep enough can feel okay for a while, when mentally or physically active, and then you “crash”. A lot of people accept a degree of sleepiness as normal. What you and your family think about the situation can be quite different. If there seems to be a problem – what is the degree of inconvenience being experienced, and by whom?

**Q: *What if waking during the night bothers you and you never seem to wake up refreshed?***

**A:** Does it happen often enough to worry you? For weeks? Ask yourself “*Is sleepiness impacting on my daytime functioning and how I manage my life?*” How far do you want to take it, if it is bothering you during the day?

Dr Barnes suggested that any of the concerns raised should be discussed with your family doctor, and a referral requested to one of the many Sleep Physicians in Sydney, or else locally.

At the conclusion of this presentation, Vice President Merle Thompson told us she couldn't help wondering what the course of world history might have been, if some of those people who said they lived on about 4 hours sleep a night had slept much longer. Three examples mentioned were Margaret Thatcher (who boasted about not having more than 5 hours a night while she was British Prime Minister), Winston Churchill, and Napoleon Bonaparte.

In thanking Dr Barnes for his most interesting and well-received presentation, Merle warned him that as a result he could find the number of referrals to him increasing, and end up with many more post-polio patients! She then presented Dr Barnes with a pen specially carved from Australian red cedar, as well as a Network polio virus badge, and expressed our appreciation to him for giving up a Saturday afternoon to help us gain a better understanding of sleep-disordered breathing and obstructive sleep apnoea.

## The New Osteoporosis Clinic

*Member Anne O'Halloran wrote to tell us that she recently visited what is called The New Osteoporosis Clinic on the sixth floor of the Specialist Medical Centre at Concord Hospital (for those who are familiar with Concord it is in what was once the Nurses' Home). Here, she passes on her experiences for the benefit of fellow members.*

I had been taking medication for the past two years to help prevent further bone loss and had been disappointed with my last Bone Mineral Density (BMD) test so my GP referred me to the Osteoporosis Clinic.

Two appointments were made (I was offered a third for a BMD but had recently had one). The first visit was for history taking and a series of tests (urine, blood and x-rays etc), and the second for follow up where the results were interpreted and recommendations offered. All the tests were carried out at the hospital and all were offered on Medicare. A staff member had assured me that the professors at the clinic were highly respected in the study of osteoporosis. Answers to important questions that I raised at the second visit would be followed up with one of the professors and relayed to me via a phone call to my home.

My experience of the visits was positive. Waiting time for and at appointments was short. The staff that I met were courteous, open, good listeners, and able to answer my general questions. Written material with reference to osteoporosis, medications, exercise, pain and so on was freely available. I had taken with me some information on polio and its late effects and pointed out that probably many, if not all, polio survivors would benefit from information on osteoporosis and what treatment was available.

There are two things that I felt would have made my visit better. Firstly, I would have preferred to have had some direct consultation with a Specialist.

Secondly, the age-old problem of close PARKING!!!! I rang Concord before my first visit about parking for people with disabilities and was assured that there were a couple of designated spaces at the front and within the hospital grounds. This was right, however two spaces were inadequate for a hospital of this size and I felt that they were probably used by staff with disabilities; each time I drove past they were occupied. Street parking was impossible. Again I think hospital visitors and locals would get first pick (the hospital is in a suburban street surrounded by homes). However there is a large parking lot with many designated spaces for disabled parking. The lot is opposite the hospital. If possible, it would be easier for people with walking problems, or for whom self propelling is difficult, to be dropped off close to the Medical Centre. There is a road to cross from the parking lot to the hospital however it is not wildly busy. There is a pedestrian crossing and I imagine an awareness by people in the vicinity who are used to seeing people using all types of ambulation/mobility devices. The parking fee is \$5.00 and payable at a machine as you enter – the machine gives change.

My visits were beneficial. Test results showed that my system was low on Vitamin D. Understandable as I drive everywhere, don't even go for leisure walks in the sunshine, I shop in large shopping centres (parking underneath) and don't sit for long any more in the sun. As well my diet obviously doesn't provide enough Vitamin D. Since Vitamin D is important for the absorption of calcium I have now been offered a Vitamin D supplement, which is very easy to take. Here's hoping my next BMD shows a better result than the last one. I'll let you know!

To find out more about osteoporosis there is an Osteoporosis Australia Helpline 1800 242 141 and a web site <[www.osteoporosis.org.au](http://www.osteoporosis.org.au)>.

## PADP and Unmet Need for Aids and Equipment

*The Physical Disability Council of NSW recently gave an update in their email Bulletin on the state of PADP in NSW. The update is reprinted here with permission.*

As the New Year starts we're hearing, once again, more and more stories about unmet need for equipment. It is plain to us that the Programme of Appliances for Disabled People (PADP) is not yet functioning as it must.

- People are being denied equipment they have an assessed need for because of insufficient funds in the PADP Budget.
- Equipment needs often have to be re-assessed because of waiting lists and unacceptable delays in processing applications.
- Despite agreement at the State-wide Advisory Committee, 18 months ago, a new PADP 'equipment list' (based on equipment categories rather than specific items) has still not been 'signed off' by NSW Health. As a consequence, the PADP budget is paying for medical items it is no longer intended to pay for while people with equipment needs wait for approval of equipment or are told their needs can only be met when the new list is enforced.
- The budget enhancement of \$1.1 Million last year did not match levels of unmet need nor does it meet the expansion in demand resulting from agreement of new eligibility criteria three years ago.
- Consistent, high-quality data about need across the state has still not been made available to the PADP Advisory Committee. Although a new data collection system was launched recently we fear it will be months before we receive the information needed to make informed judgements about current levels of unmet need (which we believe are increasing).
- NSW Health has not yet proposed its preferred Priority Assessment Tool that could be used to assist local committees make reasonable decisions about applications for equipment.

PDCN is working with our colleagues in disability sector, non-government organisations in NSW to better understand the current situation with regard to PADP. We feel that the progress made over the last few years is in danger of stalling (at best). We need your help.

We are trying to gather information from people with disability about their experiences of PADP over the last two years. Please help us if you can.

- Have you (or a family member) applied for equipment through PADP?
- Did you get the equipment you needed or was your application rejected?
- How long did you wait for equipment to be supplied?
- What equipment did you receive?
- Will PADP maintain the equipment?
- Who paid for the equipment?
- If you paid some, how much did you pay out of the total cost?

These are just some of the questions we want to learn more about. If you have had ANY contact with PADP over the last couple of years, please tell us about it.

**We want to hear from Network members. Please write to Gillian by email or mail to tell us of your experiences so we can add to the information that PDCN is gathering. The more stories, good and bad, that we can pass onto PDCN, the better we will be able to work towards making PADP the effective program we all want and need.**

# Polio Particles

## Mary Westbrook

*Polio Particles is compiled by Mary Westbrook as items in the press or professional journals catch her eye. Included in this series are brief reviews of books on polio or post-polio, updates on post-polio research, information about immunisation and the status of global polio eradication, and other items of interest.*



### Polio eradication cheap at the price

An article, 'Costs and benefits of polio eradication: a long-run global perspective' by M Khan and J Ehreth was published in the journal, *Vaccine*, in January 2003. The authors used pre-vaccination polio incidence rates to predict the number of cases of polio that would have occurred in the world for the years 1970-2050 if the polio vaccines had not been developed and immunisation had not happened. They calculate that immunisation will have prevented 855,000 deaths, 4 million cases of paralytic polio and 40 million years that polio survivors would have lived with disability over the years 1970-2050. The medical cost savings from this would be more than \$US128 billion. The global polio eradication program will cost about \$US67 billion if vaccination is discontinued after 2010. Thus the polio eradication program will pay for itself in the longer term.

### Polio and Parkinson's disease

The Network has received enquiries asking whether polio survivors are at greater risk of developing Parkinson's disease. The polio virus does attack the neurons in the brain that make dopamine. It is the failure of these same neurons that is thought to be responsible for Parkinson symptoms (tremors and rigidity associated with severe fatigue and decreased ability to concentrate). So since the 1940s researchers such as David Bodian have wondered why they did not find an increased rate of Parkinson's disease among polio survivors. They hypothesised that if the damage caused to these neurons by the polio virus was very severe, then injury to other vital brain centres would also be severe, causing patients to die from bulbar polio. If damage to the dopamine neurons was less severe it was considered that it would be below the threshold necessary for the tremor and rigidity of Parkinson's disease to appear. Recently the *Journal of the American Medical Association* (*JAMA*; 3/4/03) reported a study by Nielson and others of a cohort of Danish polio survivors who contracted polio between 1919 and 1954. They were found to be about twice as likely to develop Parkinson's disease as people who had not had polio. The researchers speculate that the normal loss of neurons that occurs when we age, plus the loss that occurred when we contracted polio, may account for polio survivors being more vulnerable to Parkinson's disease. However this is the only research that has found an association between the two diseases. In his book, *The Polio Paradox*, Bruno wrote that he has not found a higher rate of Parkinson's disease among the polio survivors he has been treating for two decades. He says that some survivors worry about muscle tremors but these are often caused by doing too much and tiring polio-damaged, overworked neurons, particularly when survivors are emotionally or physically exhausted, and sometimes when they forget to eat.

### Polio and cancer

Neilson and his colleagues used the same cohort of Danish polio survivors mentioned above to investigate whether there is a link between polio and cancer, particularly between polio and cancer of the central nervous system. Their findings were published in the *International Journal of Cancer*, May 2001. The only association they found was that

women who had paralytic polio may have an increased rate of breast cancer. My hypothesis would be that the difficulty of having a mammogram might be a factor in such an association. The radiology practice I attend can theoretically do a mammogram while you are sitting down. The only problem is that when they do this they find the results are unsatisfactory. So I need to get out of my wheelchair, use crutches that I have to bring with me and hang onto the top of the X-ray machine like a panic-struck orang-outang as I attempt to pivot around into the various positions required. A little more disability and I'd have to make do with poor X-rays and maybe I'd begin to wonder if it was worth the effort. In the October 2003 issue of *Link* magazine, which examines disability issues in Australia, there is report on women with disabilities in the ACT not regularly accessing breast and cervical cancer screening. The ACT's Screening Program has set up a Disability Task Group to deal with this problem. To date it has developed three new resources: A brochure: *Women with disabilities: Your rights when accessing health services*, a *Pap Test Fact Sheet* for women with disability and a *Tip Sheet* for health practitioners which provides advice on how they can provide care that is inclusive of people with disabilities and in doing so help to avoid potential discrimination against people with disabilities.

### **Polio survivors' memories encourage vaccination**

An article by Elaine Ellis-Pegler in the November 2003 issue of *Polio News*, the Newsletter of the Polio Support Society NZ, describes how many survivors of vaccine preventable diseases have contributed to the project *Piercing Memories; remembering the past to protect the future*. The project was initiated by the Immunisation Advisory Centre at the University of Auckland. When the Centre was established in 1994 it became apparent from the numerous phone calls received that *many parents and a surprising number of doctors and nurses had limited experience of vaccine preventable diseases such as polio, diphtheria and even measles and even less understanding of their cruel complications and long term effects. As our old people died, their memories of the devastating epidemics of the early 20<sup>th</sup> century were fast disappearing from the national memory.* To date Ellis-Pegler has videoed the stories of over 180 people who contracted such diseases, and the memories of their family members. These are used in education programs for health practitioners and community groups. The Prime Minister has supported the program by recording her childhood memories of measles and chickenpox. Ellis-Pegler says that her overwhelming impression of people's stories *is of a sense of loss that pervades these experiences and the ongoing effects on families, such grief and so many tears. ... So many accounts of polio describe devastating loss: the death of a beloved five year old sister, loss of childhood, lost mobility, lost expectation of a normal life. The young father with polio who always regrets he could never kick a ball around with his sons. The 17 year old student nurse with TB who lost her youth and watched six of her nursing friends die during two years on a freezing TB sanatorium verandah. ... But also wider social losses; huge disruptions to social networks and travel arrangements, businesses closed and families separated during epidemics. Financial loss – the costs of visiting children in hospital for months or years ... Educationally the losses were and continue to be significant. ... A Maori woman, a high academic achiever and badly affected by polio, had such a poor self image of her crippled body and was so afraid of how she would cope with the wide world ... that she refused to pass any of her school certificate exams, a decision that led to a lifetime of social and economic deprivation. The loneliness remembered vividly 60 years later, of children isolated in hospitals for weeks, months, sometimes years away from their families. Widespread prejudices have been recalled ... Fear, too, still pervades people's lives. Ongoing fear of Post Polio Syndrome ... Another sentiment, widely expressed, is a sense of disbelief that people choose not to immunise. One polio survivor said: The difference polio has made for me is everything I do is such an effort and a lot of pain with it. Another said: You would not want your family to go through what we've gone through, so I think people can learn by what we have experienced. One survivor who was videoed was an*

unimmunised woman who developed polio in 1999 at the time her baby received the oral vaccine. The master tapes from the project have been placed in New Zealand's Oral History Archive.

### **Polio kick-started William books**

In your childhood you probably read some of the 38 William books or saw a William film. The series was written by Richmal Crompton, classics mistress at a school in Kent who wrote a story about William for the women's magazine *Home* in 1917. In 1924 at the age of 33 she contracted polio which left her with a paralysed leg. Crompton returned to teaching but found it too difficult and gave it up to write full time. She then wrote the first William book which she intended for adults but it was very popular with younger readers so she concentrated on writing for them. At the time of her death in 1969 over 8 million William books had been sold.

### **Early Australian polio treatments and preventatives**

The book, *Paradise of Quacks: An alternative history of medicine in Australia* by Phillipa Martyr (published by Macleay Press, 2002), describes what was probably the first recorded after-care treatment for polio prescribed by an Australian doctor. Dr Philip Muskett, surgeon superintendent to the NSW government in the 1880s, advocated mustard poultices, heat treatment, purges, faradisation (electrical stimulation) and rubbing. Martyr found some non-orthodox preventatives against polio in letters sent to the Public Health Department in the mid 20<sup>th</sup> century. *Vera Grey of Karrgonning believed it was due to constipation, while Mrs A Beck of Margaret River came up with an explanation of polio guaranteed to please the children at risk of the disease — 'a collapse of the nervous system through lack of blood sugar'. Her preventative diet included: 'a good pudding every day made with milk and sugar, and either boiled, steamed or baked. Like custard, rice, tapioca, sago, date and jam roly poly (with sweet sauce), castle pudding, suet dumplings, apple dumpling, syrup dumplings, and always ½ an ounce of boiled lollies daily'. Camphor bags worn round the neck were used as a preventative by some Tasmanians during the terrible epidemic of 1937-38. These had been used against smallpox in the 19<sup>th</sup> century.*

### **Orthopaedic surgeons fail to investigate osteoporotic fractures**

The Bone and Joint Decade was launched in 2000 to advance understanding of musculoskeletal disorders through research and to improve quality of life for people with these disorders. The organisation is headquartered in Sweden and is supported by medical societies, patient advocacy groups worldwide and WHO. For information visit <[www.boneandjointdecade.org](http://www.boneandjointdecade.org)>. It has helped fund Dr Karsten Dreinhofer's 2003 multinational (UK, Italy, Spain, Germany, New Zealand and France) study of 3,500 orthopaedic surgeons. *Since Orthopaedic surgeons are often the first and only physicians to see fracture patients, they are in a unique position to identify untreated cases of osteoporosis, and as such reduce the risk of subsequent fracture* according to Professor Olof Johnell of the International Osteoporosis Foundation, co-funder of the study. Dreinhofer found that 50% of practicing orthopaedic surgeons had received little or no training about osteoporosis. Only in Germany were the majority of patients referred for a bone density test; in the UK only 16% were. Only half of the orthopaedists in Southern Europe knew about the importance of external risk factors for hip fractures, for example, cataracts, poor lighting, pathway obstacles, poor balance. Only 25% of orthopaedists in the UK and France felt knowledgeable about managing osteoporosis in their patients. How many are aware of the localised osteoporosis that polio survivors tend to have in their affected limbs, which may or may not be accompanied by generalised osteoporosis? (Report on the study at <[www.boneandjointdecade.org/news/default.html](http://www.boneandjointdecade.org/news/default.html)>).

## The Revelation – The Story of Elsa

*Here is a rather unusual polio story from a new member – thank you for sharing, Elsa.*

It was not until approximately mid-September last year, because of my breathing problems and after a series of x-rays and scans, that I was advised that at some-time in my life, I had had Polio or Infantile Paralysis as it was then known.

The breathing problems, I was told, were caused by the left side of the diaphragm and left phrenic nerve being paralysed. When I enquired how could this be determined, I was told, in reasonable detail, that research had provided the information.

In my car and on my way home everything suddenly fell into place and I remembered the events from when I had been ill. It was an illness I had never forgotten but had never been able to find out what had been the matter with me. For years afterwards, whenever I asked my mother what had been wrong with me, she always replied that she could not remember.

On reflection, I realise that my mother would never have told me because, even though it was years later, she would still have thought she would be in trouble for not having sent me to hospital. Infantile Paralysis (Polio), was a notifiable disease. It and Diphtheria were rampant at the time of my illness.

That night I rang my sister to tell her I had finally found out that my illness had been Infantile Paralysis. She was as astounded as I was. I commented to her that I had waited 66 years to get an answer to my question. I hope you will not mind my relating the circumstances to you.

The year was 1937 and it was approximately one month before my eighth birthday. I had become ill the evening before and I remember my mother saying I had measles. As I lay ill, perhaps it was the following day, I heard my parents having a conversation with our doctor, whose name was Abernethy. I have never forgotten the words I heard.

*“I must report it, she has to go to hospital.”* the doctor said emphatically

*“Please doctor, leave her here with us. We’ll take care of her.”* my mother pleaded.

*“She has to go. I have no choice. I’ll be in serious trouble if I leave her here.”* the Doctor added.

*“Please Doctor.”*

He then said, *“She wont last, you know.”*

*“Yes, I know.”* my mother replied.

*“We would rather have her here with us. We won’t tell anyone you have let her stay. We will take full responsibility.”*. This time it was my father begging the doctor to leave me with them.

The Doctor said *“You must make sure you tell no one what is the matter with her or that I have left her here in your care. We will all be in a lot of trouble if you do.”*. I heard my parents give the doctor their assurance and being the type of people they were, they kept their word.

I remember the doctor coming back many times to see me. As well, I had an aunt who was a nurse and she too, was frequently there. I also remember the Minister from our local church coming to the house often.



As I lay ill, there were two other conversations I remembered. One was a discussion between members of my family about buying my birthday presents early. I heard one of my brothers say he knew I wanted a tennis racquet and he would get that. I remember the presents being given to me but I was too ill to do more than acknowledge them.

On a later occasion I heard my mother and father discussing who would stay at home from my brother's wedding to look after me. My father said to my mother that she should go and he would stay with me. I remember him being with me and the others leaving for the wedding.

I know I was ill for a very long time, but I do not know how long. My initial schooling had begun at the school run by the church. I remember my mother telling me that the school had closed and I had to start at what I later learned to be the local Public School. I always disliked that school and was never happy there.

One day in class, our teacher talked to us about Diphtheria and Infantile Paralysis. The brother of one girl had died of Diphtheria. Another girl had a caliper on one of her legs. She'd had Paralysis.

I was about 20 the last time I asked my mother what had been the matter with me. I got her usual reply that she could not remember.

Looking back now, I had always had a fascination about Infantile Paralysis. Any time I saw a person with a paralysed arm or leg, I wanted to know if they'd had Infantile Paralysis. I wonder, during my illness, if I had heard my sickness referred to as that, and whether the term had remained buried in the depths of my memory. Even recently, I saw a woman, who looked a generation younger than myself, wearing a caliper on one leg. I had to use a lot of restraint to stop myself asking whether she'd had Polio. She had been the first person I had seen with a caliper for many years.

The first month or so of my learning that I'd had Polio, I felt as though I was in a state of total shock. I do not know why, it just had that effect on me. It was only recently I thought to access the internet to find if any information was available.

I must admit that since learning the details associated with Post-Polio, it does give me a possible explanation for some of things that have happened over the years. I have Scoliosis, Osteoarthritis and Osteoporosis. I have to use a walking aid. As well I have Angina. With only half of my diaphragm working, my heart has to work harder to pump the oxygen through. I have severe Oesophagus Reflux. This I am told may also be associated with the Polio. Plus, during the last ten years, the usage of my left arm has gradually diminished.

The most debilitating part is the almost constant, exhaustive tiredness. The times when I feel every ounce of energy drain from my body and leave me with not even enough strength to raise my arm. I now wonder how many of these problems relate to the Polio. In the new year I will see a Neurologist, hopefully, to discover what other damage may have been incurred. Not that there is any cure, but at least I will know.

Unfortunately, there is no one to tell me what paralysis I'd suffered during the period of illness. I can only assume that when the time of my recovery arrived, the fact that I was not showing outwardly any signs of paralysis, it would have been presumed that I had fully recovered without any after-effects.

**Merle has gratefully added Elsa's polio story to our growing collection. Merle has also asked me to thank everyone who has contributed a story so far, and encourages all members to write down or tape record their own unique experience and send it to us. We want to preserve our shared history so it is not lost to future generations.**

# Support Group News

**Neil von Schill**

**Support Group Co-ordinator**

**Phone: (02) 6025 6169**

**Fax: (02) 6025 5194**

**Email: [support@post-polionetwork.org.au](mailto:support@post-polionetwork.org.au)**



On pages 19 and 20 of this *Network News* you'll find a list of **Support Groups** and **Regional Representatives** with contact details and information regarding meeting days, dates and times where applicable. If you live near a Support Group location and would like to attend a meeting please ring the local Convenor. Support Groups are great places to meet, to share information and to gain mutual support.

**Maura Outterside**, Convenor of our **Marrickville/Canterbury Support Group**, has received some excellent publicity in her local media, both newspapers and radio. They held a successful second meeting at Petersham RSL Club; the next meeting is scheduled for Thursday 8 April. If you live in the area you would be most welcome to attend.

I travelled to **Port Macquarie** in early February to be present at this newly formed Support Group. There was another excellent response to the meeting with 19 of us in attendance. This is due to the interest of local members and the tremendous effort that Convenor **Pat Adamson** is putting in. It was wonderful to see members travelling from Kempsey and Forster to attend the meeting. Their next meeting is scheduled for Sunday 16 May 2004.

To cater for members living in the **Sutherland Shire** we are holding an **inaugural meeting** to establish a Support Group. The venue is the **Sutherland District Trade Union Club** at 57 Manchester Road, Gympie. We are meeting in the Bass and Flinders Room at **2:00 pm** on **Wednesday 24 March 2004**. All members living in the area are invited to attend. The meeting will be followed by afternoon tea. If you are interested in convening the group please contact me on (02) 6025 6169.

Members living in the **Condobolin** area are reminded that **Bill Worthington** is the Convenor. At present he is conducting a Telephone Support Group and can be contacted on (02) 6895 2870. In the north west of the state **Terry Bell** has undertaken the responsibility to be Regional Representative for the **North West Slopes and Plains**. Terry can be contacted by phoning the National Relay Service on 13 36 77 and asking to be connected to him on (02) 6751 1554. Bill and Terry would be delighted to hear from you.

To assist members of the **Northern Beaches Support Group** to stay in contact with one another I am proposing that we meet at an accessible venue for morning or afternoon tea. I was made very welcome at the **Dee Why RSL Club** where there are excellent facilities and suitable meeting areas. **I am going to be in Sydney in late March and suggest that we meet at Dee Why RSL Club for morning tea on Thursday 25 March 2004. I will be in the foyer of the club from 10:00 am to 11:00 am to meet members.** Anyone interested in attending are urged to ring me on (02) 6025 6169. I would very much like to continue the wonderful work begun by Elizabeth Woods who is leaving the area.

Finally, **Dorothy Robinson**, Convenor of the **Wollongong Support Group**, has advised me that the group's next meeting will be a week later than usual so as not to clash with Easter; it will now be held on **16 April**, instead of 9 April, at their usual venue, the West Wing Conference Room, Port Kembla Hospital. Contact Dorothy on (02) 4229 6221.

That's all for now. I hope to catch up with some of you during my travels around the state during the year.

# Network Support Groups and Regional Representatives – Annual Update

*This update is published in the first Network News issued each year. It provides contact and meeting information for the Network's Support Groups throughout NSW and the ACT. You will also find contact details for the Network's Regional Representatives who provide a contact point for their local community in areas not yet served by a Support Group. If there isn't a Support Group operating in your local area and you would be interested in helping to start one up, or if you are willing to act as a Regional Representative, please contact our Support Group Co-ordinator, Neil von Schill, on (02) 6025 6169 or email him at <support@post-polionetwork.org.au>.*

## **Support Group Meetings**

**ACT:** Meets at Pearce Community Centre, Collett Street, PEARCE, 1<sup>st</sup> Saturday of every second month (commencing February) at 2:00 pm. Contact Convenor Brian Wilson on (02) 6255 0875.

**ALBURY:** Meets informally three or four times per year for lunch, usually on a Sunday. Contact Convenor Neil von Schill on (02) 6025 6169 for details.

**BANKSTOWN:** Meets at Revesby Workers' Club, 2b Brett Street, REVESBY, 1<sup>st</sup> Wednesday every second month (commencing February) at 2:00 p.m. Contact Convenor Pam Solomon on (02) 9773 7679.

**BLACKTOWN / LOWER BLUE MOUNTAINS:** Meets at Kingswood Community Centre, Corner Bringelly Road and Baden Powell Avenue, KINGSWOOD, 3<sup>rd</sup> Monday of the month (except January and December) at 11:00 am. Contact Convenor Bernie O'Grady on (02) 9688 3135.

**CAMPBELLTOWN:** Contact Convenor Brian Toby on (02) 9618 2279 for information.

**CENTRAL COAST:** Meets at Kincumber Neighbourhood Centre, Corner Avoca Drive and Kincumber Street, KINCUMBER, 1<sup>st</sup> Saturday of the month at 10:00 am. Contact Convenor Bara Tunnington on (02) 4369 2397.

**COFFS HARBOUR:** Meets informally several times per year. Contact Convenor Ken Dodd on (02) 6655 1112 for details.

**CONDOBOLIN:** Contact Convenor Bill Worthington on (02) 6895 2870 for information.

**DUBBO:** Contact Convenor Gregg Kirkwood on (02) 6884 9108 for information.

**EASTERN SUBURBS:** Meets at the Labor Club, Alison Road, RANDWICK, 3<sup>rd</sup> Saturday every second month (commencing February) at 1:00 pm. Contact Convenor Eric Sobel on (02) 9389 7967.

**GRAFTON:** Contact Convenor Susan Stewart on (02) 6644 7789 for information.

**GRIFFITH:** Contact Convenor Dawn Beaumont-Stevens on (02) 6962 4249 for information.

**HORNSBY:** Will meet casually when there is sufficient interest. Contact Convenor Kerry Jenkin on (02) 9476 1468 for further details.

**HUNTER AREA:** Meets at Toronto District Workers Club, James Street, TORONTO, 1st Wednesday of the month (except January) at 10:30 am followed by lunch. Contact Convenor Wendy Chaff on (02) 4957 5254.

**INNER WEST:** Meets at the home of Convenor, Claire Dawson, at 29 Halley Street, FIVE DOCK, 2<sup>nd</sup> Saturday of every month at 11:00 am. Contact Claire on (02) 9713 6565 for further details.

**MARRICKVILLE / CANTERBURY:** Meets at Petersham RSL Club, Regent Street, PETERSHAM, 1<sup>st</sup> Thursday every second month (commencing February) at 2:00 pm. Contact Convenor Maura Outterside, on (02) 9718 5803.

**NORTHERN INLAND:** Contact facilitator and editor of *THE LINK*, Laurie Seymour, on (02) 6760 3085 for further information and a copy of the newsletter.

**NORTHERN RIVERS:** Meets in both LISMORE and BALLINA on last Saturday of the month, every second month. Ballina meetings are at Ballina Hospital in February and April. When in Lismore the meetings are at the Lismore Workers Club in June, August and October. The Christmas get together is on the 1<sup>st</sup> Saturday in December. Contact Convenor Rosalie Kennedy on (02) 6622 0307 for further information.

**NORTHSIDE:** Meets at the home of Convenor, Ruth Wyatt, at 106 Shirley Road, ROSEVILLE, on 1<sup>st</sup> Saturday of every second month (commencing February) at 2:00 pm. Contact Ruth on (02) 9416 4287 for further details.

**NYNGAN:** Contact Convenor Marion Wardman on (02) 6832 1350 for information.

**ORANGE:** Contact Convenor Susie Simmons on (02) 6361 0630 for information.

**PORT MACQUARIE:** Meets at the Recreation Hall, Retreat Village, 3 Lincoln Road, PORT MACQUARIE, on a Sunday every third month (commencing February) at 2:30 pm. Contact Convenor (Mrs) Pat Adamson on (02) 6581 3704 to confirm meeting dates.

**SHOALHAVEN:** Meets at the Nowra Library meeting room, Berry Street, NOWRA, on 3<sup>rd</sup> Friday of each month at 2:00 pm. Contact Convenor Dorothy Schünmann on (02) 4448 7541.

**UPPER HUNTER:** Contact Convenor Bruce Buls on (02) 6545 1993 for information.

**WOLLONGONG:** Meets at the West Wing Conference Room at Port Kembla Hospital on 2<sup>nd</sup> Friday of every second month (commencing February) at 2:00 pm. Contact Convenor Dorothy Robinson on (02) 4229 6221.

### ***Regional Representatives***

**ARMIDALE:** Contact Doug Crocker on (02) 6772 8335 for enquires in the Armidale area.

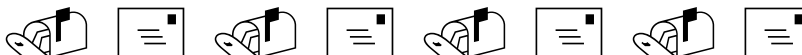
**BLAYNEY/COWRA:** Contact Peter Drady on (02) 6367 5095 for enquiries in the Blayney/Cowra area.

**NORTH WEST SLOPES AND PLAINS:** Terry Bell can be contacted by phoning the National Relay Service on 13 36 77 and asking to be connected to him on (02) 6751 1554.

**URALLA:** Contact Daphne Field on (02) 6778 4455 for enquires in the Uralla area.

**WINMALEE:** Contact Morrie Foster on (02) 4754 3008 for enquires in the Winmalee and Blue Mountains area.

## Post-Polio Post



*Members of the Mail-Out Mob were saddened to learn of the death in January of Norma Hinde. Norma was born in 1924 and contracted polio in 1929. She joined the Network in 1997 and with her husband Len was a regular and enthusiastic attendee at Network Seminars and Conferences. Despite her failing health, Norma and Len were frequently to be found helping out at mail-outs. I was personally enriched by Norma's friendship and will miss her. Len selflessly donated \$250 in Norma's memory to help the Network's work.*

Dear Gillian

I am sorry to have to let you know that my dear Norma passed away a couple of weeks ago. The polio finally caught up with her, but she died very peacefully and all the family were by her side.

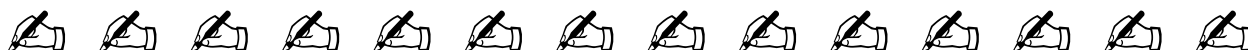
Discovering the Post-Polio Network had a great effect on her life. We learnt so much about the disease and its after-effects, but just as importantly it gave her the opportunity to meet others with the same or similar problems. It also gave us some new friendships, particularly with yourself. She enjoyed those mail out days, even though they were getting more difficult for her.

We were both very grateful to you and all the others who worked for the Network and it is important that it continues to give the help and comfort to post-polios which it has been doing so successfully up till now.

I would like to donate a little towards that end and in memory of Norma. Please feel free to apply the money however you think appropriate.

Yours sincerely

Len Hinde



## Can You Help to Promote the Network?

We are getting a very good response to our new pamphlets. We are most grateful to everyone who has been able to distribute the pamphlets widely throughout their local communities. If anyone 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 Alice on (02) 9747 4694 or by email at [alices@hotkey.net.au](mailto:alices@hotkey.net.au) and she will post some out to you.

## Donation Money Boxes Project – An Update

This is a fund-raising venture being managed by Committee Member George Laszuk which is slowly gaining momentum. With members' help, the boxes are placed in commercial areas where cash is exchanged. We need more sites for the boxes and so we are again asking: *Are there any members out there, who own or work in a small shop or service station, who are prepared to place one of these money boxes on their counter?* Once the box has been placed you won't have to do a thing. All boxes are key locked and we will make arrangements with you to ensure they are cleared at regular intervals.

If you can help, please email George on [advocacy@post-polionetwork.org.au](mailto:advocacy@post-polionetwork.org.au) or give him a call on (02) 9628 0000 or 0412 082 983.



# Post-Polio Network Seminar Program 2004

|                                 |   |  |
|---------------------------------|---|--|
| <b>Saturday<br/>6 March</b>     | Northcott Society<br>1 Fennell Street<br>Parramatta             | <b><i>Exploring the Feldenkrais Method</i></b><br>presented by <b>Elaine Altman</b><br><i>Full details are given on page 2</i>   |
| <b>Saturday<br/>19 June</b>     | St Paul's Anglican<br>Church Hall<br>Princes Highway<br>Kogarah | Seminar presented by<br><b>Sailors with Disabilities</b><br><i>Full details will be in the next issue of Network News</i>  |
| <b>Tuesday<br/>31 August</b>    | Northcott Society<br>1 Fennell Street<br>Parramatta             | Seminar presented by<br><b>Dr Marcia Falconer</b><br><i>Further details will be in upcoming issues of Network News</i>   |
| <b>Saturday<br/>27 November</b> | <i>Ryde</i><br>(venue to be<br>advised)                         | <b>Sixteenth Annual General Meeting</b><br>followed by a Seminar presented by<br><b>Andrew Buchanan</b><br>Chairperson of the Disability Council of NSW<br><i>Further details will be in upcoming issues of Network News</i> |

## Management Committee and Webmaster Contact Details

|                   |  |                                    |              |
|-------------------|--|------------------------------------|--------------|
| Gillian Thomas    | President                              | president@post-polionetwork.org.au | 02 9663 2402 |
| Gillian Thomas    | <i>Network News</i>                    | editor@post-polionetwork.org.au    | 02 9663 2402 |
| Gillian Thomas    | Membership and<br>general enquiries    | gillian@post-polionetwork.org.au   | 02 9663 2402 |
| Merle Thompson    | Vice-President                         | mkthom@bigpond.com                 | 02 4758 6637 |
| Merle Thompson    | Polio stories                          | stories@post-polionetwork.org.au   | 02 4758 6637 |
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