

POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

Editor: Gillian Thomas
Email: editor@post-polionetwork.org.au
Website: www.post-polionetwork.org.au

PO Box 888 Kensington
NSW AUSTRALIA 1465
Phone No: (02) 9663 2402

Patron: Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS

President's Corner

Gillian Thomas

Welcome to regular readers and new members alike to another bumper *Network News*. The articles on sleep apnoea in the last issue generated a lot of interest, and in this issue we follow them up with two related articles submitted by prominent and well-qualified members. You'll also find advance notification of our August Seminar with Dr Marcia Falconer, and of our upcoming 15th birthday celebrations. Of course, all your favourite features are here as well: *Seminar Report*, *Polio Particles*, *Support Group News*, *Post-Polio Post* and much more.

Full details about our Seminar to be held on Saturday 19 June are on page 2. Polio survivor **Allan Grundy** from **Sailors with disABILITIES** will recount the crew's adventures as they circumnavigated Australia in 2003, non-stop and unassisted, and broke a world record in the process. You won't want to miss his presentation.

Our office in the Northcott Society's brand new building in Parramatta is now open for business! We are extremely grateful to Northcott, with whom we have had a very long and happy relationship, for making this facility available to us. We already have three volunteers who are running the office on a part-time basis, but we still need more help. Turn to page 3 to read all about the office, the volunteers, and the opening hours so far. We look forward to seeing you out there.

It is Membership Renewal time. With this *Network News* you will find one of two forms, depending on your financial status. If you are currently paid up to 30 June 2004 (your address label reads **Renewal Due On: 1/07/04**) you will find a **Membership Renewal Form** enclosed, for the period 1 July 2004 to 30 June 2005. **Could you please confirm, complete, or amend your details as given on the form, and return it with your subscription to the Treasurer at the Network's postal address.**

There are still a few people who have not yet paid their subs for 2003/2004, and so their address label still reads **Renewal Due On: 1/07/03**. In this case, the Membership Renewal Form covers two years membership, from 1 July 2003 to 30 June 2005. We would appreciate prompt payment to ensure that this *Network News* is not the last one you'll receive.

If you are already financial beyond 30 June 2004 (as shown on your address label), you will receive a **Membership Update Form** which gives your current details but does not request payment of a membership subscription. Please check your details and be sure to return the form if any amendments are required.

The Constitution Sub-Committee has been working hard to finalise the discussion paper which will seek input from all members about possible changes to the Constitution. The paper will be sent out to members shortly.

Finally, thank you to those people who have ordered a copy of Danish film-maker Niels Frandsen's autobiographical documentary *The Epidemic – I don't remember anything, but I'll never forget*. An order has now been placed and we will be in touch with you as soon as the copies arrive from overseas.

Unless otherwise stated, the articles in this Newsletter may be reprinted provided that they are reproduced in full (including any references) and the author, the source and the Post-Polio Network (NSW) Inc are acknowledged in full. Articles may not be edited or summarised without the prior written approval of the Network. The views expressed in this publication are not necessarily those of the Network, and any products, services or treatments described are not necessarily endorsed or recommended by the Network.

Non-Stop, Unassisted, Around Australia

Date: Saturday, 19 June 2004

Time: 1:30 pm - 4:00 pm (we suggest you have lunch before you arrive)

Note the slightly later start time as the Hall is not free until after 1:00 pm

Venue: St Paul's Anglican Church Hall, 57 Princes Highway, Kogarah

The Hall is on the left-hand side of the Princes Highway as you drive towards Sydney, between Gladstone and Regent Streets. If you are driving from Sydney down the Highway, you need to turn right into Regent Street, left into Gladstone Street, and finally left back onto the Princes Highway. St Paul's is then a short distance along the Highway, on your left. Parking is available on the premises. It would be appreciated if those who are more mobile would leave the closer parking for members who are only able to walk or wheel short distances.

We are thrilled to have **Allan Grundy** join us to relate his experiences circumnavigating Australia as a crew member of the **Sailors with disABILITIES** yacht KAZ. His presentation will include a discussion of how their feat affirms the abilities of disabled people, and ways to change the wider community's perceptions of people with disabilities.

Allan writes "To prepare and take part in a world record attempt is a frustrating and exhilarating experience, at once. The logistics can be mind boggling (how much toilet paper, how much water?) and then we will throw 7 disabled sailors into the mix: 2 left arm amputees, 1 double leg amputee, 1 spina bifida, 1 deaf, 1 polio, and all in the hands of a dyslexic skipper. All with a will to be the first disabled crew to circumnavigate Australia, non-stop and unassisted, and if we can travel fast enough we may even break the World Record."

"We had to work together as a team, to look at our strengths and Abilities. We will leave in a storm to slingshot us up the NSW coast to the tropics and into the trade winds across the top down the West coast and into the Southern Ocean, where you can always depend on the weather to throw a storm or two our way as well as it being freezing cold in mid winter."

A Press Release issued after the crew's triumphal return to Sydney notes:

Sailors with disABILITIES yacht KAZ sailed through Sydney heads on 1 July 2003 and into the record books having achieved a non-stop circumnavigation of Australia in 37 days 1 hour 23 minutes and 57 seconds.

This amazing achievement is not only the fastest time recorded for a monohull yacht to circumnavigate Australia, but the first disabled crew to successfully complete the journey, breaking a record previously held by an able bodied crew.

This new world record time shaves over six and a half days off the previous record set by Kanga Birtles with Magna Data in 1999.

The entire crew, overcoming their disabilities to achieve their dreams, endured extremes of weather during their journey – enjoying balmy seas off the north-east coast through to freezing conditions in the Southern Ocean. Crew member Phil 'Bear' Thompson commenting, "It was so cold in the Southern Ocean, it was the first time I have ever seen people washing up with gloves on!"

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 and enjoy a cup of tea, coffee or fruit juice and a chat with fellow members at the conclusion of the Seminar around 3:30 pm.

The Network's Office is Open !

Ground Floor
Northcott Building
1 Fennell Street
Parramatta NSW 2151

Phone: (02) 9890 0946
Email: office@post-polionetwork.org.au

Volunteers and Office Hours

Nola Monday 10:00 am to 3:00 pm
Carmelita Alt Wednesday 10:00 am to 3:00 pm
Helen Thursday 10:30 am to 3:30 pm

Our postal address
PO Box 888
Kensington NSW 1465
is unchanged



On Tuesday 4 May 2004, the Network officially moved into our office at the Northcott Society's new building in Parramatta. We had a most friendly welcome from Northcott, including a fire drill complete with training in evacuation procedures, and a delicious morning tea where we met all the building occupants and introduced ourselves.

The office will be staffed by Network volunteers on a part-time basis. At the moment, we have three volunteers, but we need more if we are to open the Office every day of the week. Please contact Gillian if you are able to give some time to the Network each month.

At this stage we aren't planning an "Open Day" as such because we are still getting ourselves organised. Also, we are sharing our office with the Amputee Association of Sydney so we wouldn't like to disrupt them by inviting everyone to come on the one day.

Having said that, every day that we are staffing the office can be considered to be an "Open Day". If any members or prospective members would like to visit us, you will be welcomed most warmly. You'll also be able to check out Northcott's services for people with disabilities. Just ring our office (9890 0946) a day or so before you want to come out to make sure that one of the office volunteers will be there. When you arrive, sign in at the Northcott Reception Desk and Steve, Susie or Debbie will let us know that you're there.

Now, we'd like to introduce two of our office volunteers to you.

Nola Buck



I have volunteered to work in the new office at Northcott on Mondays, supposedly from 10:00 am to 3:00 pm, but being a notoriously unreliable time-keeper, it is more like 10.30 am (just as well I am not being paid)! I'm looking forward to the 'phone ringing madly with calls from members wishing to make contact.

Many of you probably remember me from my time as President of the Network, but for those new members here's a bit of biographical information.

I contracted Polio in 1937, in a small town in Victoria called Broadford, famous in my eyes for a paper mill owned by the former Australian Paper Manufacturers. Like most Australian companies, it now has a new name, Amcor Limited. At age 2, I left my parents to enter Fairfield Infectious Diseases Hospital and came home 4 years and several convalescent homes later, still unable to walk. My mother, like all of our mothers, never gave up and continued the exercises I had been receiving, until I was finally mobile.

Until about 1988, I had rarely met a person who had had polio, although my parents were clients of The Crippled Children's Society (now the Northcott Society) and in my mid-twenties Northcott became my shoe and orthotic supplier. In 1988 Northcott sent their clients a circular informing them of a seminar on a condition known as post-polio. This was a new word to most of us, but as I had been having a few difficulties, which I attributed to marriage and four children, I decided to go along to this seminar and it was here that the foundations were laid for the Post-Polio Network (NSW) Inc.

As can be seen Northcott has been involved in the Network since its inception, so it is fitting that we now have our office here in this wonderful building which is so accessible. On the ground floor, there are three accessible toilets, a fact which quite astounds me. Our office is in a very pleasant area, opposite the Independent Living Centre, and shared with the Amputee Association of Sydney. We look out over a sunny courtyard and also a very busy lane, and are able to avail ourselves of Northcott's facilities, such as computer, email, telephone, copier and the library. We will be incorporating our library with Northcott's to make our titles more accessible to members. So remember, if you are visiting the Northcott Equipment Services, the Independent Living Centre, or Dynamic Living Designs, please come and see your Network's office as well.

Carmelita Bongco



I am happy to insert my latest photo so that you can at least see Carmelita Bongco who came from the Philippines last May 1986.

After fulfilling the basic requirements of a migrant, I started scanning over the pages of the phone book where I found important information about disabled organisations assisting people with different types of disabilities. During that time, there was then Disabled Peoples International (NSW) where I became a member and through their "Link-Up" newsletter I read about the beginnings of Post-Polio Network in 1989. Having had polio, I got interested and attended some of their informative seminars. I had a feeling of belongingness with other polio survivors and their experiences on how to deal with the late effects of polio in our lives.

Our third volunteer, Helen Billingsley, was a little camera shy so her introduction will appear in the next issue, together with an update on our office facilities.

We look forward to hearing from you, and seeing you, soon! If you can spend a few hours a month in the office to keep it open five days a week, please contact Gillian.

Living and Breathing with Weak Respiratory Muscles

Hal John Hester Colebatch AM MD FRACP

Network member Dr John Colebatch was born in 1928 at Northam, Western Australia. He entered first year medicine at the University of WA, completing the course and graduating in medicine from Adelaide University in 1951.

In April 1953 while working at the Infectious Diseases Branch of the Royal Perth Hospital, he contracted poliomyelitis, becoming totally paralysed and requiring treatment in an iron lung. After a year recovering in hospital he rejoined the medical staff of the Royal Perth Hospital with responsibility for infectious diseases and rehabilitation.

In 1958 he commenced research on lung disorders in the Department of Medicine, University of Sydney. He continued his research at the University of California, San Francisco and then at the University of Oxford. In 1964, he was appointed to the academic staff of the University of New South Wales as Senior Lecturer in Medicine and joined the Department of Respiratory Medicine, becoming Associate Professor in 1970 and Chairman of the Department in 1985. In 1970-71 he was a Senior Fulbright-Hayes Research Scholar and a Visiting Associate Professor of Physiology at the Harvard University School of Public Health. From 1968 to 1992, he was a Senior Specialist in Respiration to the Royal Australian Navy. In 1989, he received the inaugural award of the Fisons medal of the Thoracic Society of Australia and New Zealand. In 1992, in recognition of his research on the lungs, he was made a Member of the Order of Australia.

Because of increasing muscular weakness – the post-polio syndrome – Dr Colebatch retired at the end of 1992 and was appointed a Visiting Professor of Medicine, continuing part time work until 1996. Muscular weakness led to the use of a ventilator at night and an electric wheel chair to maintain mobility.

We are grateful to John for writing this article especially for Network News. He will be pleased to respond to any questions on this subject – just send them to the Editor.

The return of muscle weakness 20 or more years after the initial paralysis and its relentless progression is well known to all who have experienced the post-polio syndrome. In this account, which is based on my own experience, I will be primarily concerned with the recurrence of respiratory muscle weakness in those patients who during the acute stage of their illness suffered respiratory muscle paralysis. I will assume that the lungs are normal and that chronic respiratory failure is the result of respiratory muscle weakness alone.

Breathing, when it fails, is a whole of life issue; it affects all activities during the day, as well as the quality of sleep. The aim of management is to maintain the best possible activity during waking hours. To understand how this can be achieved it is necessary to consider two important issues – first, how breathing is regulated and second, how muscles produce movement and enlarge the chest.

Background

In April 1953, while working in an Infectious Diseases Hospital, I became completely paralysed as a result of poliomyelitis and was placed in an “Iron Lung”. It was 74 days before I was freed from this coffin-like machine. About three months after my initial paralysis when I stood up for the first time I was unable to breathe at all, owing to the effect of gravity increasing lung volume. Since then I have always worn an abdominal support and/or a tight belt around the lower abdomen before standing up. It was one year before I was able to leave hospital, walking with the aid of crutches. I maintained a reasonably active life, including working overseas, but after 25 years it became clear that muscle

weakness was returning and gradually its severity increased until once again I was unable to walk and required assistance for showering and dressing. The relentless progress to dependence has been a deeply distressing experience.

In 1991, after a "Sleep Study" I was advised to use a machine to produce continuous positive airway pressure (CPAP) during the night. I persevered with this treatment, but was able to sleep using it on one night only. Subsequently I realized that CPAP was not the appropriate treatment for anyone with weak inspiratory muscles and discontinued my use of this machine.

In September 1992, after another "Sleep Study", I started using a fixed volume ventilator at night. Initially, there was some improvement in sleep quality, but this did not persist. Because it prevented spontaneous breathing, I found this ventilator intolerably uncomfortable to use. As a result of its use with an excessive level of ventilation, breathlessness during the day became severe and interfered with activity. After three weeks of nocturnal ventilation, I became troubled with irregular heart beats. By decreasing the amount of ventilation during the night, the irregular heart beats were abolished and breathlessness decreased.

In November 1992, I started using a BiPAP Ventilator which was intended to allow me to initiate breathing and be comfortable to use. However, this early model was unduly sensitive and was triggered into inspiration because the heart beat caused a small flow of air (about 10 ml) into the lungs. As a result, my breathing was not normally regulated, but was abnormally increased because it was initiated by the heart beat rather than by my own inspiratory efforts. I was soon troubled again with severe daytime breathlessness and irregular heart beats and, in addition, a feeling of impending death. These problems were overcome by the use of a modified BiPAP which was not triggered by the heart beat.

Recognition of Failing Breathing Muscles

Difficulty with breathing is likely to develop in post-polio subjects who suffered respiratory muscle paralysis during the acute stage of their illness. Initially there is increased breathlessness and fatigue and, later, difficulty sleeping. To assess this problem it is essential to measure:

- breathing capacity, and
- arterial blood gases.

Breathing capacity is usually assessed by measurements of vital capacity (VC) and the maximum volume expelled in 1 second (FEV1). Before there is a serious problem with respiratory failure, both VC and FEV1 decrease to less than 50% of the expected value. But a more significant measurement is inspiratory capacity (IC) or the volume which can be inspired from the resting position. It is this volume which represents how much the subject can breathe. As lung volume increases, inspiratory muscles are shortened and IC decreases, that is, the ability to inspire decreases. That is why it is more difficult to breathe when sitting or standing compared with lying down. A tight belt around the lower abdomen will decrease lung volume when standing and increase IC and therefore the ability to inspire.

Arterial blood gases require collection of arterial blood which is normally done in a hospital in close relation to the laboratory where the measurements are made. An increased arterial CO₂ level defines the presence of chronic respiratory failure. By the time this becomes a problem, arterial CO₂ will usually have risen from a normal level of 40-45 mm Hg to around 55 mm Hg. If arterial CO₂ remains in the normal range, assisted ventilation is unlikely to be required. In the presence of normal lungs, oxygen saturation is well maintained, so that oximetry is unreliable and of little value in assessing the presence of chronic respiratory failure.

The respiratory muscles and chest wall together make a pump which moves air into and out of the lungs and is referred to as “ventilation”. The pump is driven by the nervous system. When the pump cannot provide adequate ventilation there is a feeling of breathlessness and the arterial CO₂ increases until the quantity produced is expired in the smaller volume of ventilation. This situation is referred to as “chronic respiratory failure”.

When weakness of breathing muscles has caused chronic respiratory failure nocturnal ventilation is required. This ensures adequate ventilation during the night and allows recovery of fatigued muscles. The aim of this regimen is to maintain activity and independent breathing during the day. To minimise the increase in lung volume with gravity, when sitting or standing, it is essential to provide abdominal support. This will help to maintain the ability to inspire.

Managing Nocturnal Ventilation

When breathing is failing, one of the symptoms is difficulty sleeping. Sleep studies may be undertaken to help define the breathing problem. However, these studies are complex and in my view may lead to errors in management. Notwithstanding evidence of obstructive sleep apnoea, which is commonly observed, treatment with CPAP is not appropriate for anyone with weak respiratory muscles. This is because an increase in airway pressure increases lung volume and shortens respiratory muscles making it more difficult to further increase lung volume and maintain breathing. It is as if the subject were sitting up all night instead of lying down and instead of resting the inspiratory muscles it makes their work more difficult.

Breathing is driven by the acidity of fluids around the brain which in turn reflect metabolic activity. The best type of breathing assistance is one which allows this regulation to continue in its natural state. That is, the subject’s brain should drive the ventilator as part of the chest pump, the ventilator should not determine the amount of ventilation independently of the subject’s metabolism. It follows that the subject initiates inspiration to which the machine responds and supports – a demand-driven machine. A pressure support ventilator fits this criterion and such machines are in common use. My preference is for the BiPAP Ventilator operated in demand mode. I have used this ventilator every night for more than eleven years.

Fixed-volume ventilators are uncomfortable to use at night for anyone who retains some ability to breathe independently. They also do not permit the subject to regulate his breathing. A similar disadvantage applies to a pressure-assist ventilator set to a fixed time, which excludes the subject from initiating inspiration. If there is concern about the occurrence of apnoea during sleep, this possibility can be overcome by setting the ventilator to a slow back-up rate, say 8 per minute, which will maintain sufficient ventilation if needed, but not interfere with the subject’s own breathing.

Improving Daytime Activity

One of the objects of nocturnal ventilation is to improve daytime activity. For this to be achieved the level of ventilation during the night must not exceed what the subject can maintain when breathing independently during the day. This is best achieved by using a ventilator in demand mode with the subject retaining regulation of breathing.

There should be no attempt to decrease to “normal” an increased arterial CO₂. The level of CO₂ is set by the ability of the chest pump to respond to the demands for breathing during daytime activity. To lower CO₂ during the night, in these circumstances by excessive ventilation, will increase daytime breathlessness. It may also be dangerous by causing irregularity of the heart beat. Normally CO₂ is a little higher during the night than during the day and this situation should be allowed to continue. If excessive nocturnal ventilation is

suspected it may be worthwhile to measure the electrolytes. The risk is an abnormal loss of potassium resulting in irregularity of the heart beat. This disorder may be fatal. Potassium supplements will correct this problem.

Weakness of post-polio muscles is an ongoing problem which cannot be overcome by exercise. It is sufficient to try to maintain the activities of daily living. To do this it is essential to have adequate periods set aside for rest during the day. (Exercise programs are for an earlier stage of life.) Post-polio paralysis is not a disease of muscle, rather it reflects a loss of those motor nerve cells and fibres on which initial recovery depended. The surviving muscles with their remaining nerve supply are normal. It follows that nutritional supplements or anabolic steroids aimed at improving muscle function are unlikely to have any lasting effect. On the other hand an adequate intake of the vitamin B group may be helpful for their essential role in the nervous system.

Besides exercise, metabolism and with it the demand for breathing is increased by intake of food. Breathlessness during the day, while at rest, is distracting and can be decreased by limiting intake of food to the smallest amount that can be tolerated. This regimen has the additional benefit of discouraging an increase in body weight when any increase is a serious disadvantage for continuing activity.

In situations where exertion cannot be avoided such as toileting it is an advantage to have the use of a ventilator. This can make the difference between dependence and independence.

The slowly progressive nature of the post polio syndrome means that new challenges to activity and independence arise year by year and even each few months. To meet the particularly difficult challenge of respiratory failure and yet maintain some independent activity it is essential to consider carefully all possible adjustments. Simple things such as limiting daytime intake of food and ensuring rest periods can help to reduce discomfort and make the days a little more enjoyable.



An iron lung on display in the Prince Henry Hospital Museum. John Colebatch and Ian Neering who share their experiences of respiratory failure in this *Network News* both spent considerable time in a similar “coffin-like” box when they contracted polio in the 1950s.

Sleep Apnoea Revisited

Ian Neering PhD MSc

Long-time Network member Ian Neering was Associate Professor of Physiology and Pharmacology at the University of NSW and now, as is appropriate with his degree of decrepitude (Ed. his description, not mine!), runs a drug consultancy from his home office.

Ian's article below provides further insights into the subject of sleep apnoea, and reinforces the message of Dr Colebatch's article – it is imperative for polio survivors to have their particular causes of sleep apnoea correctly diagnosed and appropriately treated.

Your articles in the last PPN *Network News* have prompted me to put down my experiences with sleep apnoea as they might be of interest to some of your readers. Let me stress that these are my personal experiences and people should not necessarily extrapolate from them to form any sort of generalisation.

By way of background, I should say that I contracted polio in 1950 when I was around 4 years of age. I was completely paralysed and spent a good deal of time in an iron lung. Over the years, with the sort of therapies most of your readers will know only too well, I made a pretty good recovery and was able to lead quite an active life without any prostheses of any kind. I have quite a marked kyphoscoliosis with significant deformity and associated low functional lung volumes. At around the age of 40, I started to notice the signs of PPS and my general condition started to deteriorate. I took to using a walking stick and was forced to modify my life style significantly. When I had respiratory infections, they lasted longer and were increasingly troublesome. I now need crutches to get around.

In 1993, a dose of flu saw me admitted to hospital with life-threatening respiratory failure which basically means that my lungs could not function sufficiently well to provide me with an adequate supply of oxygen. I was on a ventilator for a few days but was fortunate enough to make a good recovery. In the aftermath of my period in intensive care, sleep studies were performed and sleep apnoea was diagnosed. The respiratory specialist theorised that cumulative fatigue of my respiratory muscles, partially as a consequence of the sleep apnoea, was responsible for the respiratory failure and a CPAP device was prescribed.

Let me tell you, I struggled with that machine! Let alone the fact that no mask seemed to fit around my nose properly and jets of air burbled and squeaked from the poor seal around my face unless I lay "just so" in bed and didn't move a muscle. Not conducive to a good night as you can imagine. I felt no improvement in my overall well being after weeks of persevering and follow up visits to the doctors.

I'm afraid I have a general antipathy to the medical profession not uncommon amongst old polios and a general mistrust of "blanket treatments". I, like many polios, have become rebellious towards doctors' prescriptions and prefer to find my own bumbling way to the solutions that best suit me. At my wit's end, I decided to take matters into my own hands and here I have an advantage over most in that I am a physiologist by training.

I need to digress for a moment here. Your excellent articles on sleep apnoea didn't say very much about the sleep study used to definitively diagnose the condition. When you go in for an overnight study, you are fitted up with a number of sensors. Cables are attached to your scalp for an EEG which records your brain waves and allows the investigators to assess your level of sleep. A finger probe records oxygen saturation of the blood which is the critical measure telling us we are not receiving sufficient oxygen as a result of the sleep apnoea. A more sensitive measure of ventilation is that of carbon dioxide but not all sleep studies include this. Wires are also attached to our chest so that the activity of the respiratory muscles can be recorded. This is known as an EMG. It's important to understand that EMG records muscle activity only. A reduced EMG activity recording could be caused by a reduced drive from the motor nerves controlling the muscle or from a weakened muscle, unresponsive to nerve stimulation. There may be other sensors attached to measure airflow, leg movements and so

on. A good sleep study will look at all of these parameters; an inadequate one will not, and may lead to a misdiagnosis.

Now, your article referred quite correctly, to two main types of sleep apnoea: obstructive sleep apnoea and central sleep apnoea. In the former, the problem is mechanical in that respiratory muscles may be working well but actual airflow into the lungs is restricted for any of a variety of reasons. In the latter, there is reduced respiratory drive from the brain to the muscles of respiration resulting in a reduced or absent inspiratory effort. Weakness of respiratory muscles will exacerbate both forms of apnoea. Dr Joyner, in her classification, quite reasonably, has delineated a category just for polios which contains aspects of both forms of apnoea though, strictly speaking, does not add a third category to the two groups already defined.

A sleep study, by looking at the temporal relationship between the activity in the respiratory muscles, air flow and oxygen saturation of the blood, can determine what form of sleep apnoea you suffer from. The problem however is that getting to sleep with all those wires attached to you, in what for many of us is an unpleasant environment with unfortunate associations is not all that easy! The consequence is that we may not actually reach the deepest form of sleep during which REM or dream sleep occurs. The investigating physician therefore will not have a complete picture of what your breathing does during sleep.

Enough digression. I was lucky enough to be able to borrow (with appropriate bribing and inducements) some bits of equipment and set up to monitor my sleeping at home. I got hold of an oximeter to measure blood oxygen saturation. Diaphragm EMG was measured using a little battery operated portable device used by sports people. I measured airflow by taping a thermistor (which measures temperature of the air) under my nose. Measuring EEG was beyond the range of my ability to equip. It wasn't really necessary. The hardest part was logging all the data. After all, I needed to be able to record oxygen saturation, EMG and airflow over a period of at least 6 hours. After fiddling with chart recorders and ending up almost buried in paper upon waking, I ended up recording all the data continuously on my computer. My partner was not particularly impressed that I had turned our bedroom into a laboratory but I soothed her with a vision of a well-rested husband who would not be snappy and grumpy if he had a decent night's sleep. I can't adequately describe my satisfaction to you when I finally saw the definitive result. Obstructive apnoea is characterised by an **increased** inspiratory effort coincident with the decrease in airflow. In other words, when the airway is obstructed, we try a whole lot harder to breath in, at least initially, and you can see this in an increased response in the tracing of the EMG from the muscles that help us inspire. In my tracing, respiratory effort just faded away coincident with airflow, breathing stopped because the muscles were no longer being asked to contract, a sign of a centrally mediated sleep apnoea. My problem I now knew was that during sleep, the drive to my inspiratory muscles, the messages from my brain telling my muscles to breath (respiratory drive), was reduced. In fact it would cease all together, causing blood oxygen content to fall until all those alarm mechanisms that the body has to detect such a dangerous malfunction caused me to wake up.

It is known that respiratory drive decreases during sleep even in normal individuals. Many polios have weakened respiratory muscles. It seems not unreasonable to suppose that for some polios the combined reduction in respiratory drive from the brain and the weaker muscles could result in the sleep apnoea. EMG recordings would be unable to dissect out this scenario. Remember, the EMG cannot distinguish between a reduction in nerve impulses from the brain to the muscle, or a weakly contracting muscle.

How did this new knowledge make a difference? Well, it meant that the CPAP machine was quite inappropriate for my needs. CPAP is great for the obstructive types of apnoeas where the positive air pressure from the machine "splints" the airways in an open position and prevents their collapse during the respiratory cycle. It's a bit like breathing in a gale. CPAP won't help you if you simply stop breathing because its flow of air is continuous. There's no cycling. Armed with my new data, I was able to show my respiratory physician that a different form of therapy was required. He promptly prescribed a BIPAP machine which is a bit like a ventilator in that it cycles through an inspiratory and an expiratory phase. There is an obstructive component to

my sleep apnoea and the BIPAP machine will help against this also. That machine is now more than 10 years old and has become an essential chattel of my life.

Since using sleep support, I have had fewer respiratory infections and those I have had, have had a more benign outcome.

Why have I felt the need to put all of this down on paper? My main motivation is a fear that some of you may go through the same misdiagnosis that I did. My message is: **for those of us who had respiratory paralysis during the acute phase of polio infection (and possibly for others), CPAP may NOT be the treatment of choice** either because of muscle weakness, reduction of central drive or a combination of both.

I still have trouble with masks. Having spent much time and effort making plaster casts of my face and attempting to mould masks, cast masks, and experiment with various materials, I've found that the "disposable" resuscitation masks sold by the St John's Ambulance people work as well as any. Use of these with a fabric "gasket" and my partner's design of head harness has enabled me to sleep relatively comfortably even allowing me to toss and turn as the dictates of comfort demand.

One other fascinating aspect of these machines that I've not seen mentioned anywhere else is the tendency, for me at least, to cause psychological dependence. This manifests as an inability to sleep at all without the machine. On occasion when I've been camping and my car battery fails, in a power outage, or when I have had to travel in an emergency without my machine, I simply can not sleep without it. On one occasion I had no sleep for two consecutive nights. On the third night, I was so exhausted I did manage to sleep fitfully. I wonder if others have noticed this effect?



Vale – Alicia Lee and Joan Clarke

It saddens us to report the passing in recent weeks of two long-time Network members.

Dr Alicia Lee contracted polio as a child in 1937. Alicia served on the Network's Management Committee for several years in the 1990s and her input was much valued. If she saw injustice of any kind, she was not one of the silent majority but did something about it. For example, as Convenor of the *Callan Park Action Group*, Alicia was a vocal opponent of the State Government's several attempts to sell off the site. Alicia was also an inveterate letter writer, to politicians and newspapers alike, on a wide range of subjects. She insisted that language describing people with disabilities be positive and enabling. As a staunch advocate of access for people with disabilities, Alicia saw the need to not focus solely on the requirements of those using wheelchairs but urged others to recognise the different needs of those with walking difficulties. Alicia's willingness "to get out there and do it" will be missed.

Joan Clarke passed away peacefully on 1 June. Joan contracted polio at the age of three in 1923, while she was in a train travelling between Sydney and Goulburn. She went on to become an author, editor and researcher. Two of her books are of interest to polio survivors: *Dr Max Herz, Surgeon Extraordinary : The human price of civil and medical bigotry*, published in 1976, and Joan's autobiography *All on One Good Dancing Leg* which was published in 1994. Joan contributed to the Network over many years by convening a Telephone Support Group covering the Manly Peninsula area, and by writing articles, letters and poems for *Network News*. Readers might remember her humorous piece *In Memory of Oscar*, written about her faithful scooter.

Her son Jon is holding a Wake in celebration of "*Joan's Glorious Life*" on Friday 9 July from 12 noon at North Sydney Leagues Club, 12 Abbott Street, Cammeray 2062. Everyone who knew Joan is welcome to come along. Enquiries to Jon Clarke on (02) 6684 1710 or by email to <jonc@nrhs.nsw.gov.au> or mail to 15 Hottentot Crescent, Mullumbimby 2482.

Seminar Report – *Exploring the Feldenkrais Method* Presented by Elaine Altman on 6 March 2004 Reported by Wendy Davies

This issue we are grateful to roving reporter Wendy Davies for writing up our March Seminar presentation for the benefit of members unable to be there. It was a most interesting and informative talk and, as Wendy reports, very interactive.

There wasn't an overhead in sight when Elaine Altman presented the Network's first Seminar for the year in the brand new Northcott Society building at Parramatta. This was a very "hands on" session, giving members an opportunity to experience some Feldenkrais Method lessons while sitting comfortably.

So what is the Feldenkrais Method? A brochure from the Australian Feldenkrais Guild states that the Feldenkrais Method facilitates learning about movement, posture and breathing to ultimately increase the ease and range of movement, improve flexibility and coordination. It is suitable for all ages and abilities.

In a brief introduction, Elaine spoke of her involvement in Feldenkrais, both as a student and as a practitioner. While she has had no professional experience with polio survivors, she uses her Feldenkrais training in her role as an occupational health nurse in returning cardiac surgery patients quickly to the workforce. Elaine explained that Feldenkrais broke down everyday movements into tiny components. By observing closely, changes in movement could be detected. When the whole body system is involved, there is less strain.

Before guiding the large group of members in some Awareness Through Movement lessons, Elaine emphasised two very important points. The lessons needed to be done gently and comfortably. Soft pillows were handed out to those requiring support.

The first lesson could be loosely described as walking while sitting. Elaine led members through the components of walking one by one feet, hips, pelvis, back, arms, shoulders, head. She assisted members to pay attention as we moved by asking focus questions. Attention was drawn to breathing. There were frequent rests to allow the nervous system to process the information too.

The next lesson, circling with the pelvis while sitting, explored the pelvic clock. One foot was used to tilt the hip gently in hoola hoop fashion. Elaine asked, What is your head doing? Notice your ribs and waist. Can you feel flexibility in your ribs? How are you breathing? Elaine responded to questions from members throughout the presentation. We were advised to stop if in pain and to pay close attention so that an alternative method of moving could be found. We were reminded that movements should be small, safe and smooth.

The third lesson focused on turning the head. First, members sat with their feet on the floor before moving the head gently to the right with eyes closed. This was repeated several times before the exercise was completed with the eyes open. We were asked to note how far our head had turned by registering a mark on the wall. Elaine continued, This time, notice the spine. How far down the spine can you feel movement? Once members had made that observation, she asked, Can you feel any movement in your shoulder? Now deliberately move your shoulders as you turn your head. Members were then instructed to deliberately let their eyes move their head and shoulders to the right. The focus question was, How far did your head move this time? Then it was time for the left side to have a

turn! However, Elaine's teaching was different members were asked to imagine moving through the various instructions. Only then were we asked, How far can your head go to the left? For many participants, the results were a surprise as there was now less restriction in turning the head on both sides.

The last lesson concentrated on breathing, with the emphasis on exhaling. Elaine stated that while inhaling is automatic, breathing out well is vital. She asked members to inhale, then exhale, waiting for approximately four seconds before breathing the rest of the air out through the mouth. After a short pause, the new breath was taken in. Some alternative methods of breathing were given. One, based on the above, suggested swallowing before inhaling again. Another one involved leaning forward so that the belly was squashed. Members were asked to note if the ribs in the back expanded with the intake of air.

Elaine's presentation gave members just a very small taste of the potential of the Feldenkrais Method to assist them in improving movement, flexibility and breathing.

Gillian warmly thanked Elaine for giving up a Saturday afternoon to introduce members to the Feldenkrais Method. She then presented Elaine with a hand-crafted pen carved from Australian timber.

Finally, a note of clarification from Wendy. There are two forms of Feldenkrais lessons. Awareness Through Movement is usually conducted in small groups (as we experienced at the Seminar), while Functional Integration – which is practised one-to-one – is focused on an individual's needs. I attend Functional Integration lessons, for one hour every six weeks but choose to practice what I have learned almost every day.



PADP and Unmet Need for Aids and Equipment - An Update

The disability sector led by the Physical Disability Council of NSW (PDCN) is still working hard to achieve adequate resourcing by the NSW Government of the Program of Appliances for Disabled People (PADP). To this end, NSW Ministers and Parliamentarians have been forwarded daily stories of genuine need across the state that is not being met. PDCN recently received a reply from the Treasurer of NSW, The Hon Michael Egan. The Treasurer's response contained no new information and so the PDCN President, David Brice, immediately wrote back to reiterate the sector's position. Here is his letter.

Dear Mr Egan

Thank you for your letter of 20th May. I have a few points that I wish to make in reply.

We note the current expenditure of \$18.5 million. As is known to both the Minister for Health and senior officials at NSW Health the disability sector groups involved with PADP have welcomed in writing and verbally the budget enhancements made over the last four years. Most recently, we expressed our appreciation of budget increases in our letter to the Minister for Health dated 5th April.

The increases you cite are necessary but insufficient. Unmet need, the existence of which is disputed by no one, has not yet been eradicated by the action your Government has taken. For us, therefore, the key question is not, *what happened in the past?* In our view it essential to ask now, *what happens next?*

As you may be aware the PADP Budget has been under-financed for several years. In the NSW Equipment Study (sponsored by ADD and NSW Health Department) and published by the NSW Government during your term of office as NSW Treasurer, the Executive Summary states (on page vii):

“The projected cost of raw demand for PADP [IN 1997/98] is \$18.1 million based on the cost profile in the Survey. When this is [adjusted] ... the result is \$16.65 million including an estimate of \$3.6 million for oxygen.

This is \$4.85 million more than the 1997/98 budget allocation for PADP”.

The Government's own report makes it clear, therefore, that at the time the report was written the State's allocation for PADP met no more than 71% of perceived need. In short, there was not enough money in the Budget at that time.

Since then, however, the eligibility criteria for PADP have been substantially altered. An estimate made by the DADHC representative to the PADP Advisory Committee prior to the introduction of the new arrangements (on 1st January 2001) was that the number of people eligible for support would increase by “about 40%”.

Your observation about current expenditure levels takes no account of the changed eligibility criteria. On page xii of the Executive Summary of the NSW Equipment Study the authors note “*The projected costs [of PADP] rise to \$19 million in 2001...*” That figure is based on the old eligibility criteria not the new arrangements. Nevertheless, even that figure exceeds the current budget allocation described in your letter.

It is clear to us that the PADP Budget has not kept pace with rising demand or unmet need nor has it been adequately enhanced to accommodate the changes made to the eligibility criteria more than three years ago.

We further believe that it is helpful to recall that, since the introduction of the new arrangements, all PADP clients have been required to make a co-payment of \$100. That change alone has significantly enhanced expenditure on PADP from sources other than the State's Treasury.

We understand that governments must make difficult decisions about public finances. We realise also that there are balances that Government needs to strike between competing demands. But we are not simply asking you for “more” like the Oliver character in a novel by Charles Dickens.

By investing more in aids and equipment funded through PADP the Government would save money elsewhere across the whole of Government.

People with disability would spend less time, less often, in some form of more costly care (whether it be a hospital ward because of illness attributable in part to the absence of equipment or some form of respite or other facility). Other Government Departments and government-funded services would be required to intervene less often, less directly, in the lives of people with disability with unmet need for equipment. Family members could be freed from inappropriate support roles and enabled to take up more complete participation in the social and economic life of NSW. People with disability themselves would be enabled to be net contributors to NSW (including participating in the work force and paying taxes) if the equipment they need was provided and provided within a reasonable time.

We feel that, in the difficult and complex task of weighing competing demands for resources, investment in PADP is part of the solution rather than part of the problem. We look forward, therefore, with keen anticipation to the Budget Statement of 22nd June. We hope you will recognise that NSW has much to gain by making the small (in global terms) but significant investment that PADP needs to eradicate unmet need during the remaining period of this Government's current term of office.

David Brice
PDCN President

We are repeating the call made in the last issue of *Network News* for members to tell us your experiences with PADP over the last couple of years. We want to hear your personal stories. Please write to Gillian by email or mail 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 the disability sector will be able to work towards making PADP the effective program we all want and need.

Advance Notification of 31 August 2004 Seminar

We are thrilled to welcome Dr Marcia Falconer back to Australia to bring us up-to-date with her latest research findings. Marcia will be joining us in Parramatta at the Northcott Society's new auditorium to present what promise to be two very interesting talks. Marcia's biography and brief details of her presentations are given below – final details will appear in the next issue of Network News.

Dr Falconer got her Bachelor's degree in biology in 1964. Twenty years and two children later, she went back to university to get a Master's Degree in biology and then a PhD in cell biology where her thesis was on the development of neurons. This was followed by two years doing post-doctoral studies in molecular biology at the Massachusetts Institute of Technology and then returning to Ottawa where she ran her own lab doing research in virology. With a background in nerve cells and viruses, studying the polio virus and its effects on people is a natural outcome of her interests. She will use this information to provide us with a talk entitled *So You've Got Nerves of Steel – Not!*

Marcia had mild polio in 1949 at the age of 7 and recovered completely. When she was doing her Master's thesis, PPS first started making itself known. By the time she had completed her degrees and was doing research in virology, the fatigue levels had become so high that she was forced to retire. Since then Marcia has been doing "book" research in the area of PPS, concentrating on relevant findings as they are published in scientific journals and making them understandable to the layperson. She is also a member of the Medical and Professional Committee of the Ontario March of Dimes.

Since retiring, Dr Falconer and Eddie Bollenbach, a retired professor who also has PPS, have written several scientific papers together. In 2000 they compiled and distributed a large survey about PPS – some of you may have taken part in this survey or its follow-up questionnaire. The results of this survey provided the data for an article currently submitted to a scientific journal and also are the basis for her second talk, *Stress – Your Immune System – and PPS*.

With a son, daughter-in-law and 7 year old grandson living here in Sydney, Marcia and her husband Dave are frequent visitors to Australia and find themselves as much at home in the Eastern suburbs as they do in Ottawa – well – almost. She still claims to have trouble grasping the idea that July is wintertime and that the sunny side of houses is on the north!

So You've Got Nerves of Steel – Not !

New muscle weakness in PPS is thought to occur when fragile neuronal sprouts die. Although many of us have heard this theory, Dr Falconer will give us some useful background information about nerves and 'sprouts' (the neuronal kind, not the 'bean' variety). Keeping the topic light-hearted but informative, she'll tell us why our 'nerves of steel' aren't holding up as well as we would like. She'll also help you to understand why exercise is both good and bad for you but she promises not to turn it into an exercise class.

Stress – Your Immune System – and PPS

For a long time, many people in PPS support groups have been saying that stress makes their post-polio symptoms worse. It's common knowledge that physically overdoing things causes increased weakness and pain, but for some people this also makes them feel like they're coming down with the 'flu. They feel like they have a low fever, may have swollen glands, chills and whole body aches and pains. Mostly they don't report this to their doctor because they know that the symptoms will go away in a few days – if they rest. In fact, what is happening is that their immune system is being activated by stress. Marcia Falconer will tell how she and Eddie Bollenbach discovered this part of PPS, what probably causes it, and what might be done to alleviate it.

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.



New slant on Salk

The world premiere of *Undoing Salk*, a play by Robert Benedetti, took place in Pittsburgh in February on the 50th anniversary of the Salk vaccine's trials on 2 million American children. In an interview in *Art and Entertainment* (4/2/04) Benedetti explains that not everyone loved Salk. The play *examines both sides of Salk's controversial personality and the behind-the-scenes conspiracy within the medical community to squash the vaccine before it was released*. Salk was the son of Russian-Jewish migrants, the first person in his family to attend college. As a medical researcher he, with his staff at Pittsburgh Medical School, devoted 8 years to developing a polio vaccine. Unlike other scientists, who were experimenting with vaccines using live virus, Salk used killed viruses. Many who worked with Salk *came to resent what they perceived as his arrogance, professional distance, quickness to place blame, reluctance to share credit and tendency to disregard established medical practices*. Salk refused to patent the vaccine. *'On one level this is like the Galileo story', says Benedetti. 'The science which Salk based his research on was viewed as heretical and he was viewed as a heretic by the American Medical Association and the Eisenhower administration, which saw [the lack of patenting] as socialized medicine'*. The playwright says his play uncovers the undoing of Salk by a conspiracy between the profit seeking drug companies, the AMA, the government, jealous fellow scientists and Salk's own hubris. Salk never received a Nobel Prize. After several years of interviewing people who knew Salk, Benedetti describes him as *a flawed man with big dreams who continues to be hated by some and adored by others*. The Salk vaccine was used for 6 years before being largely replaced by Sabin's live vaccine. Western countries are now returning to the Salk vaccine as the safer option.

'Polio spreads like wildfire in West Africa'

We had hoped that as the WHO campaign to eradicate polio nears its end we would never again see such headlines. It appeared in the Johannesburg *Mail and Guardian* on 6 March 2004. On 16 April a headline in the British newspaper *The Guardian* announced, *'Polio strikes in Botswana as virus races across Africa'*. Since late 2003 newspapers have carried numerous stories about this deepening polio crisis. Since 1988 the number of countries in which polio is endemic had been reduced from 125 to 6 (Nigeria and Niger in West Africa, Egypt, Afghanistan, India and Pakistan). WHO hoped its campaign to vaccinate 63 million children in West Africa this year would be the final push to eliminate polio in West Africa. However Muslim clerics in some Nigerian states banned the vaccine on the grounds that it was a US plot to spread AIDS and make African girls infertile. By March all Nigerian states except Kano, where the outbreak originated, had agreed to permit the resumption of vaccination programs. (*Ed. As of 19 May the state of Kano, which was the last Nigerian state resisting polio vaccination, has reversed its boycott.*) However by then polio has spread to parts of Nigeria that were previously polio-free and to nine neighbouring, formerly polio-free countries. The Botswana case was the first case in Southern Africa since 1997. Laboratory tests showed that the virus in the Botswana case matched the Nigerian virus although no one in the area where the child lived had had recent contact with Nigerians.

The Boston Globe (14/4/04) quoted Jean-Marie Okwo-Bele, senior advisor on immunisation activities at UNICEF as saying: *This shows unless the virus is eradicated everywhere, no one is protected anywhere. As long as we have a couple of pockets of transmission, we are not safe at all.* The *Globe* reported that in contrast to Nigeria the 2004 immunisation programs in the five other countries where polio is endemic are going better than expected.

Polio slang

The word *polio* originated as a slang term for poliomyelitis. In an article in the Sydney Morning Herald (9/1/04) Bruce Elder regretted that *our dinkum Aussie vernacular is dying out.* He blames historical factors for the loss of expressions such as *'Wouldn't work in an iron lung'*, which means extremely lazy. He says it disappeared when *more modern medical equipment replaced the cure-all for polio.* If only it had been a cure-all! I've read the description, *'Empty as a swimming pool during a polio scare'* in an American novel. The phrase *'scotch polio'* is American slang for a hangover due to drinking too much whisky. Anyone know of other polio related slang?

Need for polio eradication exit plan

The prestigious scientific journal *Nature* in its *Science Update* 27/12/03 reported research by Vadim Agol and his team at Moscow State University. They tested samples (kept from the years 1963-66 when polio vaccination was halted in a region of Russia) to examine the genetic composition of polio virus circulating in the community at that time. They found nine new, rapidly mutating, strains of polio that had descended from the live virus in the Sabin oral vaccine (OPV) which had been used in the region prior to the halt. Agol says that the 37% of unvaccinated children in the region had probably been exposed to these strains. *The findings suggest that, if countries stop using OPV, mutant virus might spread into the unprotected population from neighbouring regions, warns Agol. Deploying stockpiles of OPV to combat these infections might unleash even more potentially harmful virus. 'It's like using petrol to fight a fire.'* WHO is devising guidelines for countries on how to best wind up use of oral vaccine once global eradication is complete. WHO sees Agol's paper as another warning that countries *can't just go cold turkey.* Helen Pearson, author of the *Nature* report, says that *Public-health officials woke up to the danger posed by the live vaccine in 2000. An outbreak in the Dominican Republic and Haiti was traced back to the vaccine, followed by similar incidents in the Philippines, Egypt and Madagascar. Other studies suggest that, if a population's immunity is boosted regularly, the risk from stopping the vaccine is low. In Cuba, for example, where doctors do mass vaccinations twice a year, the live virus dies out within three months because so few children are susceptible. Continuing such 'pulse' vaccinations is one option for countries after worldwide eradication. But researchers fear diligence will dwindle once countries see the risk as small. A second option, already taken up by many countries, is to give children a jab containing dead poliovirus [Salk vaccine]. But this inactive vaccine is expensive and may not be 100% effective at stopping transition of virus in faecal matter — both problems for developing countries.* Working out the most appropriate plan is a top priority at WHO.

Polio, every mother's fear

From February to September 2004 the Provincial Museum of Alberta, Canada, is staging an exhibition *Every Mother's Fear: Alberta's Polio Experience.* You can visit it at www.pma.edmonton.ca. Fifty years ago 37,000 of Alberta's children participated in the field trials of the Salk vaccine, one of the largest medical experiments ever. The news release on the exhibition says: *Few diseases have inspired the same sort of fear as polio ... Our cultural understanding of polio is largely defined by that fear, remembered so well by people who can recall the panic aroused by a stiff neck or a slight flu during polio season.* The curator of the exhibition, Matthew Wangler, hopes the exhibition will inform

young people many of whom have no idea what polio is. Wangler says: *For me polio reveals the paradoxical essence of human beings; their bodily frailty and their spiritual and psychological strength. This research has made me aware of the great gifts that crisis and tragedy can bear — how human suffering can call forth the most remarkable resourcefulness, courage, intellect and compassion. The exhibition focuses on polio survivors and those who care for them, but it can also illuminate our own lives in profound ways ... the perceived chasm that lies between the able-bodied and disabled is rooted in the fear that we all share the same bodily fragility. Once you recognise that fear — and the psychological distance it fosters — you can see polio survivors as the complex, wonderful people they are. And in so doing, we can come to a much deeper understanding of our lives and ourselves.*

Putting officials in wheelchairs

Disability simulations are not in favour these days as they often result in more fear of disability than enlightenment among those taking part. However a simulation for City Council members and top administrators in Fresno, USA, had *astounding* results according to a report in the online disability journal, *Ragged Edge* (12/03). Each of the 15 officials was provided with a wheelchair, paired with a real wheelchair user and a non-wheelchair using volunteer, and instructed to spend 90 minutes in downtown Fresno. Among the results were: *A City Council member almost fell out of his chair while going down an improperly constructed red sidewalk ramp. After going through mud-lined streets he needed lots of Handi Wipes to get himself clean! The head of the Fresno transportation system was never picked up at the bus stop where he waited for more than 40 minutes. Rolling down one curb, he almost got immobilized when caught between the down curb and uplifted asphalt in the street. He is now arranging for all of his top administrative personnel to go through a similar exercise.* Another astounded official was asked by an irate attorney to leave an office building as her wheelchair was interfering with a postman's ability to deliver the mail. At the debriefing luncheon, this incident opened the way for discussion of attitudinal as well as physical barriers. The organisers think that the officials' new awareness of the importance of curb cuts will speed up their provision.

Wheeling comfortably in the Third World

American Ralf Hotchkiss was paralysed in a motorcycle crash in 1966. He left hospital in a wheelchair and half a block later hit a crack in the footpath. This destroyed the front wheel beyond repair. This incident led to a hobby in wheelchair design and ultimately a career developing and supplying wheelchairs for the Third World. In an interview in *New Scientist* (20/2/04) Hotchkiss said that many westerners are still distributing wheelchairs like his first one *to the unpaved developing world and expecting them to stand up. They are unstable, unsafe and heavy when used there ... they cannot be repaired with local materials.* Hotchkiss could find few innovative wheelchair designers in the west as small manufacturers were squashed by the monopoly then in place. He was inspired by the innovations of Nicaraguan teenagers who had built a wheelchair. Hotchkiss now produces a wheelchair from the cheapest steel tubing that is used for restaurant chairs and can be easily repaired by the local blacksmith. His chairs always fold, essential if you are taking a bus in Africa or South-east Asia. Chairs have a larger wheelbase so they can go down a much steeper slope without tipping over (this is the main cause of injury among wheelchair users). He has produced a special model for Russia. Most lifts in Russia are 59 cm wide while their wheelchairs are 66 cm wide. Hotchkiss designed a chair that can be temporarily squeezed by pulling the lever on a horizontal folding parallelogram frame under the seat. Many people in Africa wash with a bucket and cup (which wets the wheelchair cushion) and use pit latrines. *One of the women in Kenya came up with the idea of a 'jump seat' – a second, lower seat between the footrests and the main seat. A user can hop down to wash, play with the kids or cook breakfast on the little floor stove and then pop right back*

*up again without much of a struggle. The jump seat has a trapdoor fitted which can be opened when you park over the latrine. One of the Nicaraguan teenagers became Hotchkiss' best mechanic and now works on capsule design at NASA. When asked about the rights of disabled people in developing countries, Hotchkiss said: *The attitude is different ... There is less reticence in asking for help and more willingness to offer it without being embarrassed. Also people don't pretend not to see you. The disability rights movement has erupted spontaneously all over the world. In Uganda, for example, the constitution now recognises people with disabilities as a sector of the population that deserves representation in government, along with women, racial and religious groups. ... some 40,000 disabled Ugandans are in elected positions ranging from the smallest village council to cabinet level.**

Post-Polio Network – 15th Anniversary Picnic

This year the Network celebrates 15 years of providing information and support to polio survivors, their families and friends, and the health professionals who care for them.

After considering various options to mark this milestone, it has been decided to hold a picnic at a central metropolitan location. The picnic will be held on **Saturday 30 October** at

**Kokoda Track Memorial Walkway
Rhodes Rotary Park
Killoola Street
Concord**

The Kokoda Track Memorial walkway is a community project involving Council of Canada Bay, Concord Rotary, the Returned and Services League of Australia, Department of Urban Affairs and Planning, and Concord Hospital.

The Walkway, an 800 metre rainforest walk, links Concord Hospital with Rhodes Station. The Walkway aims to provide a lasting memorial to all veterans who served in World War II, with a particular focus on the South West Pacific area.

Access to the Walkway is via Hospital Road, Concord or Brays Bay Reserve, Rhodes. Once there, you'll have a fairly easy walk (or roll, for those in chairs). The accessibility and parking are both good and the picnic area has a kiosk nearby for those unable to bring their own lunch. The Network will provide hot and cold drinks.

The Rose Garden Entry Area is peaceful and beautiful, featuring two semi-circular Memorial Walls amongst beds of roses. On the walls are plaques dedicated to the memory of individuals who served in the war. The Rose Garden is linked to the Walkway by the Bruce Kingsbury VC Path. The Walkway's Memorial Centrepiece features a striking series of granite walls on which images from the New Guinea Campaign have been sandblasted. Water also forms an integral part of the Centrepiece, cascading alongside the granite walls. The Rainforest Area includes a watercourse leading into a pond overlooking the Parramatta River. There are twenty-two Stations along the Walkway, each providing historical accounts and images of places of significance in the New Guinea Campaign where important battles were fought or events occurred. For those not so interested in history, there are water views to enjoy and many different birds among the trees.

Member Anne Buchanan, a frequent visitor to this picnic spot, writes "*I would like to congratulate the Network on their choice of venue for the anniversary picnic in October. My friends and family all find this area an interesting and pleasant way to spend some time together, and I think most people would enjoy a visit here.*"

Please put the date and venue in your diary now. Final organisation details will be in the next issue of *Network News*. We hope many members will join the celebration.

Support Group News

Neil von Schill

Support Group Co-ordinator

Phone: (02) 6025 6169

Fax: (02) 6025 5194

Email: support@post-polionetwork.org.au



I am pleased to advise that the **Northern Beaches Support Group** is up and running again. They have held two successful get-togethers over a cup of coffee. The group is now meeting on the **last Thursday of every month** in the Coffee Shop of **Dee Why RSL Club** in Pittwater Rd at **10:30 am**. All members are welcome and encouraged to attend. If you have any queries please phone **Pat Featherstone** on **9905 5065**.

Following a successful inaugural meeting in the Sutherland Shire I am delighted to announce that the **Sutherland Support Group** has been launched. My special thanks go to **Ruth Hatton** who has undertaken to convene the group and to **Carolyn Summers** who is going to assist. The group is meeting on the **first Wednesday of every month** at the **Sutherland District Trade Union Club** ("The Tradies" – main entrance off the Kingsway, GyMEA) at **2:00 pm** in the Dugout – enquire at Reception. Ruth can be contacted on **9525 3987**. All members living in the Sutherland Shire are invited to attend.

The **Marrickville Support Group** is now meeting on the **first Thursday of every second month** and their next meeting is **Thursday 5 August 2004**. They are meeting at 2:00 pm at **Petersham RSL Club**. Convenor, **Maura Outterside**, would be very pleased to see you along at the next meeting. Maura can be contacted on **9718 5803**.

In the southern part of the state we are working on establishing a support group in the **Wagga Wagga** area. I have been discussing plans with our convenor, **Isabelle Thompson**, and we are hopeful of holding an inaugural meeting in the next couple of months. If you live in the area and would like to register your interest with Isabelle please phone her on **6926 2459**.

I am in the process of putting together another country trip where I hope to catch up with some convenors in both the southern part of the state as well as up north. We are having a stand at the **IDEAS EXPO** in **Dubbo** in **September** so hope to see **Gregg Kirkwood** who is managing the venue. If possible I am also hopeful of seeing **Terry Bell** in **Moree**, **Bruce Buls** in **Muswellbrook**, **Ken Dodd** at **Coffs Harbour**, **Pat Adamson** in **Port Macquarie** and **Laurie Seymour** at **Kootingal**. These arrangements are subject to the availability of people when I am in their vicinity.

Brendan Egan, Community Officer with **Polio Victoria**, has informed us that he is moving on to a new position. Brendan has been of great assistance to my **Albury/Wodonga** Support Group over the past four years and also a great supporter of our Network. We have collaborated on a number of projects and he has attended one of our Network Annual General Meetings. Brendan's contribution to both the Victorian and NSW Networks will be sadly missed. We wish him well in his future endeavours and have invited him to join us at any future Seminars if he happens to be north of the border.

That's it for this time. If anyone wants to know more about the Network's Support Groups or would like to talk about helping fellow members by becoming a Convenor or a Regional Representative in an area not yet serviced, please get in touch with me.

Post-Polio Post



Member David Edgerley is seeking input from other members who might be wearing a brace similar to his. If you have some advice to offer, please drop a line to the Editor by mail or email so we can publish your tips.

A year ago, I began wearing an XCL knee brace to straighten a right leg that has been affected by childhood polio. The brace is attached to the leg by straps and pads that are tightened and held in place by Velcro.

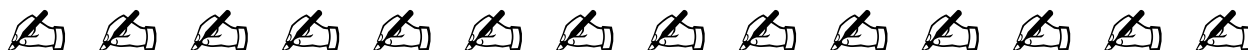
I have discovered that the constant strain placed on the same parts of the straps and pads by the Velcro eventually makes these areas impossible to use. The pad, for instance, a rubberised material covered by black cloth and the most essential part of the apparatus required to keep the brace in place, wears quickly to the rubber. The Velcro then has no place to which it can stick.

The brace cost in excess of \$800, part of the cost being born by Medibank Private. The life of the attachments is approximately 9 months. It seems that the user will thereafter have to constantly maintain the equipment at his or her cost. Absurd, isn't it?

I wrote to the manufacturer in the USA - without success. The orthopaedic centre that sold me the brace has been helpful but clearly cannot replace worn parts every nine months.

My conclusion to this little saga is that these braces are meant for short-term users. Those who wear the brace day in and day out must face the prospect of paying for the wear and tear.

I wonder if your readers have had similar experiences and what their solutions have been?



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 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 or give him a call on (02) 9628 0000 or 0412 082 983.



Post-Polio Network Seminar Program 2004

Saturday 19 June	St Paul's Anglican Church Hall <i>Princes Highway Kogarah</i>	Seminar presented by Sailors with Disabilities <i>Full details are on Page 2</i>
Tuesday 31 August	Northcott Society <i>1 Fennell Street Parramatta</i>	Seminar presented by Dr Marcia Falconer <i>Advance notification is given on Page 15</i>
Saturday 27 November	Charles Blunt Conference Room Royal Rehabilitation Centre <i>59 Charles Street Ryde</i>	Sixteenth Annual General Meeting followed by a Seminar presented by Andrew Buchanan Chairperson of the Disability Council of NSW <i>Further details 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 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
Bob Tonazzi	Treasurer / Public Officer	treasurer@post-polionetwork.org.au	02 9311 2555
Anne Buchanan	Publicity Officer	publicity@post-polionetwork.org.au	02 9771 2748
Anne Buchanan	<i>Information Bulletin</i>	bulletin@post-polionetwork.org.au	02 9771 2748
George Laszuk	Advocacy & Support	advocacy@post-polionetwork.org.au	0412 082 983
George Laszuk	Donation boxes	advocacy@post-polionetwork.org.au	0412 082 983
Bing Kwong Mak	Seminar Co-ordinator	seminar@post-polionetwork.org.au	02 9579 1460
Alice Smart	Executive Assistant	alices@hotkey.net.au	02 9747 4694
Neil von Schill	Support Group Co-ord	support@post-polionetwork.org.au	02 6025 6169
John Ward	Committee Member	coralyn@dodo.com.au	02 9451 5995
Terry Warwar	Website Webmaster	webmaster@post-polionetwork.org.au	—
Mary Westbrook	Q's about polio & pps	askmary@post-polionetwork.org.au	—

Network Office Volunteers and Hours

Nola Buck	Monday 10 am – 3 pm	office@post-polionetwork.org.au	02 9890 0946
Carmelita Bongco	alt Wednesdays 10 am – 3 pm	office@post-polionetwork.org.au	02 9890 0946
Helen Billingsley	Thursday 10:30 am – 3:30 pm	office@post-polionetwork.org.au	02 9890 0946