



POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

At the Network's seventeenth Annual General Meeting held on 3 December 2005 the following members were elected to the Management Committee:

Gillian Thomas	<i>President</i>	Elizabeth Joyner
Merle Thompson	<i>Vice-President</i>	Bing Kwong Mak
Neil von Schill	<i>Secretary</i>	Bill McKee
Bob Tonazzi	<i>Treasurer</i>	Maura Outterside
Anne Buchanan		Alice Smart
Ron Goodwin		Mary Westbrook

John Ward also stood for election at the AGM. As there were nine nominations for the eight Committee positions a secret ballot determined those elected. We thank John for his work for fellow members over the six years he served on the Committee. John's understanding of rural and remote issues was valuable and he was a staunch advocate for country members, particularly with regard to hospital and medical treatment. John has been in poor health for several years but was still willing to stand for election each year. We hope the break from Committee duties will now give him more time to take care of himself and to look after his health.

Following the meeting, Sue Slattery, Occupational Therapist with the Independent Living Centre, spoke to us about keeping mobile. See Elizabeth Joyner's Seminar Report on page 5.

On **page 2** you will find details of our **first Seminar for 2006** to be held on **Saturday 4 March** at the **Northcott Society, Parramatta**. The presenter is **Cardiologist, Dr David Rees**, and his topic is **Maximising Cardiac Fitness for Polio Survivors**. You won't want to miss this one.

The dates so far determined for our **2006 Seminar Program** are given on **page 30**. **Please note these dates in your diaries**. The remaining Seminar dates will be advised in the next newsletter.

Thank you to the many members who have already renewed your 2005/2006 membership. If your address label still reads "Renewal Due on 1 July 2005" we have not yet received your membership renewal. In that case you will find another copy of your Renewal Form enclosed. Please send in the Renewal Form and membership subscription as soon as possible. The Network is self-funded and needs your continued support to enable us to keep providing services to polio survivors and their families. Our Treasurer, Bob Tonazzi, has noted that quite a few members have taken up the option of paying their membership subscription via **internet banking**. Bob has asked that members **ensure that your name is recorded on the payment transaction and send an email to him at <treasurer@post-polionetwork.org.au> to confirm the payment details**. He says that without this information it may be impossible for us to credit the payment to your membership. Also, if you post in your payment, please be sure to **return the entire Renewal Form** with your subscription – please *don't* tear off and return only part of it.

This is a bumper issue of *Network News* and I hope you find much of interest within its pages.

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Maximising Cardiac Fitness for Polio Survivors

Date: Saturday, 4 March 2005

Time: 1:00 pm – 4:00 pm
Bring a packed lunch to eat from 12:00 noon
Fruit juice, tea and coffee will be provided

Venue: The Northcott Society
1 Fennell Street, North Parramatta

Parking:



The Northcott Society building is on your left (just past Northcott Lane) after you turn into Fennell Street from O'Connell Street. To access the car park, continue past the main building and the courtyard gates to the car park entrance at the top of a ramp down into the underground car park.

Push the button on the right-hand side of the car park driveway just before the sliding gate. Tell the Northcott staff member who answers that you are attending the PPN Seminar and the gate will be opened to let you through. Once you park, take the lift to the Ground Floor where the Seminar is held.

Parking will also be available as usual in the Parramatta Leagues Club car park in Grose Street.

Dr David Rees is a cardiology specialist who practices at St George Hospital, Kogarah. He is also Senior Lecturer (Conjoint), Department of Medicine, St George Clinical School, University of NSW. Dr Rees has experience treating polio survivors and we have asked him to draw on this experience in his presentation to answer some questions of particular interest to us. Our questions include: What is the hard evidence of increased risk for cardiovascular disease from a sedentary life-style? What is the best form of aerobic exercise for sedentary people? Is the daily struggle to move from A to B of *any* value as aerobic exercise, if it causes a significantly increased pulse rate and is performed frequently? What are the indications for stress tests for cardiovascular disease and modifications for patients with disabilities. Are staff likely to be aware of the modifications needed? Are stress tests worth the effort? What are the special considerations with respect to cardiac surgery and aftercare in post-polio patients?

This promises to be a very informative Seminar and as usual there will be plenty of time for questions and answers.

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.

Post-Polio Network Office Co-ordinator's Report

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**George Laszuk
Office Co-ordinator**

At the beginning of October 2005 I completed my 12 month contract with the Network and was very pleased that after a review the Management Committee decided to extend my contract for another year. Even though we achieved many goals during the year as outlined in previous issues of *Network News* and the recent Annual Report, I still have some unfinished challenges to complete, especially in the fundraising area.

With the valuable assistance of our volunteers we have been able to keep the office open between 10:30 am and 3:30 pm, five days per week, throughout the year.

I have recently recruited two new volunteers, Josephine Schoemaker and Lesley Campion, who we welcome to our team.

If anyone has occasion to ring the office here is the current roster:

Lesley	every Monday
Nola and Josephine	every Tuesday
Lesley	every Wednesday
Helen	every Thursday
Madeline	every Friday

You will also find me in the office about three days a week, usually on Monday, Tuesday and Wednesday, but I fill in on other days as well when needed. As you can see Madeline has decided to return to the team and we welcome her back after a short break. Unfortunately we have lost the services of Carmelita who for health reasons is unable to continue her valuable work in the office; she will be missed.

We had some funding successes during the year. As noted in the Annual Report we secured a donation of \$10,000 per year for three years from Aventis Pasteur. I have also made some very promising advances with The Lions Clubs, beginning with a \$1,000 donation from the Mount Druitt Lions Club. Having subsequently secured permission to contact every Lions Club in NSW (450), as of December 2005 we have now received a further \$4,000 from other Clubs. On this subject, if any members out there are a member of a Lions Club please put in a good word for us.

In the next 12 months I will continue to raise the profile of the Network, explore funding opportunities, and coordinate and develop Network activities in support of polio survivors.

Upcoming Seminars – Northcott Society, Parramatta

**Monday, 15 May 2006 at 1:00 pm – Anti-inflammatory Strategies for PPS
Presented by Dr Marcia Falconer**

Dr Marcia Falconer is a molecular biologist and virologist who led a government research laboratory in Ottawa, Ontario, Canada. Marcia is also a polio survivor – she retired from active research in 2000 because of post-polio syndrome (PPS), but continues to follow new developments in areas such as neuroinflammatory processes and virology. From this information, Dr Falconer develops talks for the PPS community. Her talks are both lively and interesting and prove that seemingly difficult scientific research can be made accessible and useful to the public and to PPS support groups in particular. With a son, daughter-in-law and young grandson living here in Sydney, Marcia and her husband Dave are frequent visitors to Australia and we have been privileged twice already to have Marcia present her latest research findings to members.

Increasingly, researchers are linking the symptoms of PPS to persistent inflammation in the bodies of polio survivors. The cause(s) of this inflammation remain to be discovered although there are a number of good candidates. Stress of all sorts, both physical and emotional, causes an inflammatory reaction in the body and certainly plays a role in PPS. This is why “*pacing*” works! However there probably is a deeper underlying cause of inflammation – the presence of polio virus particles, or part of these particles, remaining hidden in the nervous system of polio survivors. These virus particles are not infective, but their presence is sufficient to trigger a permanent state of inflammation which in turn has consequences that produce the PPS symptoms we are all familiar with.

It is also becoming increasingly clear that PPS needs to be addressed using anti-inflammatories of various kinds. What inflammatories work best, how to administer them and how to minimise side effects are cutting-edge research in neurology and many other medical fields. People with MS and heart disease, to name two common problems, are currently being treated successfully with inflammatory agents. Trials are going on in people with PPS and they too have proven amazingly successful.

In her presentation Marcia will cover the background of how inflammation arises and then talk about current treatments that may address this problem.



**Friday, 9 June 2006 at 10:30 am – A Journey Through Loss
Presented by Dr Cynthia Schultz BA (Hons) PhD**

*Dr Schultz earned her doctorate in psychology from the University of Queensland, with special interest in counselling, community, and health psychology. As Senior Lecturer in the Faculty of Health Services, La Trobe University, she authored, taught, and coordinated undergraduate and postgraduate courses in interpersonal skills, family dynamics, group processes, and loss and grief in health care settings. Her research, publications, and community involvement have focused in particular on psychoeducational support-group programs for family caregivers and in loss and grief across the lifespan. To her credit also are research and program development grants and the foundation editorship of the Journal of Family Studies. Now a free-lance academic, enjoying creative retirement, she maintains close links with current extensions of her earlier work, the most recent examples of which are coauthorship with Dr Elizabeth Bruce of the book, *Through Loss*, and of a group-leader training manual in psychological techniques for working with nonfinite loss and trauma.*

Losses and subsequent grief are part of life's journey. Declining health, unrealised hopes, crushing disappointments, the death of a loved one, personal or family tragedy, as well as the losses we sometimes dread, can devastate us emotionally, physically, and spiritually. We may even begin to have doubts about adapting to our losses. This Seminar, based on the recent publication by Dr Cynthia Schultz and Dr Elizabeth Bruce *Through Loss* (ACER, 2004), is designed to support participants as they explore their experiences of personal loss and gain insight, strength, and direction to look ahead with renewed hope.

Cynthia's one-day workshop will conclude around 3:00 pm after afternoon tea. There will be a break for lunch, which will be catered, between 12:00 and 1:00 pm. A registration form will be included with the next issue of Network News.

Seminar Report – Keeping Mobile – 3 December 2005

Dr Elizabeth Joyner

Our guest speaker following the AGM on 3 December at The Northcott Society, Parramatta, was Sue Slattery, an Occupational Therapist from the Independent Living Centre (ILC).

Sue Slattery (*pictured right*) has had more than 20 years experience as an Occupational Therapist (OT). Sue has been employed with the ILC for the past 4 years. At present she is involved in several different areas of the ILC. As the senior OT clinician she provides support to the OT staff. As part of the Access Consultancy team she works with designers and builders to achieve access into public buildings for people with disability. She also delivers training to therapists, care workers and nurses in the areas of Manual Handling and equipment prescription.

Prior to joining the ILC, Sue has worked for the Department of Education and Training as a consultant and educator and for a supplier of rehabilitation equipment in both sales and training.



Sue's subject was the range of mobility aids that the ILC has on display to demonstrate to all in need, including the elderly population and those of any age with significant disabilities affecting mobility.

ILC has an information line (1300 885 886) with an Occupational Therapist available to answer queries. There is a display room opposite our Network's office at The Northcott Society premises. You can also visit the ILC website at <www.ngo.net.au/ilcnsw>.

Sue reminded us to embrace all that modern technology has to offer, in order to maintain our chosen lifestyle and save on energy expenditure. To do so we must often overcome certain psychological hurdles including self-image and stubborn, illogical attitudes, as well as practical problems such as transport, maintenance and storage of often cumbersome equipment. Surely discreet use of a walking stick, wheelchair or scooter is preferable to slow, awkward, uncertain gait and the risk of frequent falls. Perhaps the greatest fear is that we will become utterly dependent on the full-time use of a wheelchair but there are many ways to address that particular anxiety.

Basically there are four types of mobility aid to consider:

- walking sticks or walkers
- manual wheelchair
- power wheelchair
- motorised scooter

Walkers

- Stick plus or minus additions such as suction pad, pivot base, stand-alone model, Canadian crutch, etc. All are cheap and easily stored but offer poor stability unless there is good balance.
- Four wheel walkers plus seat or basket.
- Two wheel walkers.

- Shopping trolley type.
- Three wheel trolley but more likely to tip for example on a gutter.
- Traymobiles offering carriage of articles and stability.

Considerations with walkers include cost, weight, storage and personal energy consumption.

Manual wheelchairs

- Standard models – clumsy, heavy, but suitable for occasional use.
- Lightweight – some weigh only 6 kg due to the use of titanium metal, are customised to the purchaser's needs, can be stowed in a regular car, but cost about \$7,000.
- Sports model featuring specialised wheels with a certain splay and camber designed for speed and manoeuvrability.
- Recreational – designed for ease of travel on uneven terrain such as beach, golf course.
- Standing chair which can offer a vertical posture to perform certain tasks such as reaching into tall cupboards.
- Tilt-in-space model which has heavy padding, head rest, and can tilt back to a more horizontal position.

All chairs are designed to last about five years depending of course on regularity of use. Recreational type wheelchairs can be hired at surf clubs and a few councils.

Additions for the manual chair include

- Samson battery pack with separate wheels which clips on and turns it into a power chair.
- Roll-aid tiller attached to the front to propel the occupant.
- Power-assist motorised wheels – about \$6,000.
- Rollee type with a battery pack under the chair making it easier for a carer to push with minimal force required.

Considerations and equipment for transporting a manual chair

- Folding frame chair less bulky for transport but has a certain inevitable instability when in use.
- Rigid frame - easier to push but heavier for transport.
- Lifters of various types, for example, some can be attached to a tow bar, some lift the occupant as well, using a car battery and boot storage.
- There is also a Wymo wheelchair hoist which flips the chair onto the roof of the car but this needs plenty of clearance space above the vehicle.

Power wheelchairs

Here, the fingers do the walking!

- Rear wheel drive with motor on rear wheels, stability and tight turning circle.
- Mid-wheel drive – better for indoor use and good turning circle. Some reasonably priced at around \$2,500 to \$5,000.
- Front-wheel drive – best for dealing with uneven surfaces, bumps, obstacles and so on.

There is a power wheelchair called an iBOT which can even climb stairs but it is very expensive and not available here. [Ed. The iBOT is certainly a fascinating machine – to see what it can do, visit the American website <www.independencenow.com/ibot>].

Considerations

- Weight, storage, bulky, parking space for re-charging, cost, travel distance (about 30 km maximum).
- Energy conservation, circulation space, room and door size, additions available for extra comfort, chair transport, and so on.

Scoters

- Three wheel version – some instability.
- Four wheel – stable.
- Folding – small, less stable, solid wheels, no arm rests, suitable for short distance transport.
- Two-person type.

Considerations

- Battery charging, cost (range \$2,500 to \$3,000), large second-hand market, need to extend arms for long periods while driving, bulky, less manoeuvrable than a power chair.
- Hoists for scooters are available.
- Shopping centre hire of scooters.
- Scooter trailer system for transport (about \$2,500).

New arrivals from the USA include the trendy Segway, costing about \$8,000, where the owner stands on a wheeled platform and leans forward to advance. Driver needs good balance. Could be a hazard for pedestrians. It can be locked when parking.



Network members trying out the ILC's scooter range.

Photo: courtesy of Bing Mak

At the conclusion of the Seminar Sue was presented with a hand-made pen finely crafted from Australian timber in thanks for giving up her Saturday to pass her knowledge on to us.

Report on Scooter Safe Training Day

presented by Independent Living Centre on Friday, 4 November 2005

*Network life member and volunteer **Nola Buck** attended the recent Scooter Safe Training Day and provided this report for the benefit of members unable to attend.*

This was a very worthwhile and informative day.

There were 19 people present, some already owners of scooters and others who were thinking of acquiring a scooter.

The first item on the agenda was **welcome and introduction**. Sue Slattery, an Occupational Therapist from ILC, was the main presenter with assistance from representatives from Parramatta Police and Scooters Australia.

The presentation from the policeman, Alex, was quite informative. He covered **Australian Road Rules**. A scooter is classified as a motorised wheelchair which in turn is classified as a pedestrian; scooter drivers should obey the road rules as if they were a pedestrian. That is, they should drive on the footpath. If there is no footpath and it is uncomfortable to drive on the grass they may use the road, and proceed facing the traffic and remain close to the kerb. If only one side of the street has a footpath, that footpath side should be used.

When crossing the road, it is illegal to cross in the middle from driveway to driveway. The correct way for pedestrians to cross the road is from corner to corner and this is what is expected of scooters. The difficulty of scooter drivers being able to turn and see if a car behind them was turning into the street they proposed to cross was raised. This difficulty was acknowledged, and the suggestion made that scooter drivers should be extra careful when negotiating the crossing of a street. If they cross in the middle, which makes it easier for them to see approaching cars, and are hit by a car, they will be at fault.

Although classified as a pedestrian, it was emphasised that a scooter is a machine and should be handled with care. Discussion ensued on the fact that many people think that having lost their licence, regardless of the reason, they can turn to a scooter – even those with vision impairment.

There were lots of questions asked of Alex, many of them raising other issues regarding scooter ownership. From Alex's input I'm sure those present realised that having a scooter was not merely sitting on it, turning a key, and away they go!

Insurance was another area covered. Discussion centred on property cover, liability cover and the Nominal Defendant Scheme. Many questions were asked on insurance cover for loss or damage of the scooter, and if it is covered when away from the house, particularly if insured under the Home Contents Insurance Policy. A list of questions to ask a scooter owner's insurer was given.

Safe Scooter Practice was discussed, such as planning and preparation – colours to make one visible, wearing a hat and using sunscreen, and planning your journey (in case areas are inaccessible). Again, the importance of being aware one is driving a powered machine, which if not handled correctly could be dangerous, was stressed. If feeling ill or tired, do not drive your scooter. Be aware of effects of new medication and do not drive if alcohol has been consumed.

Scooters Australia discussed general safety principles. Although ILC had mentioned that 4-wheel scooters were considered safer and more stable than 3-wheel ones, Scooters Australia questioned this and said as long as one approached the ramp or kerb ramp straight on and did not go up or down a ramp at an angle, 3-wheel scooters were equally as safe as 4-wheel ones and much more manoeuvrable.

However, **State Transit will not allow 3-wheel scooters to be used on buses as they consider them unstable**.

The day concluded with people driving scooters and getting a feel for them.

Three-Wheel versus Four-Wheel Scooters

The Network is now aware of several members who are being disadvantaged, they believe inappropriately, by the State Transit Authority's decision to refuse access to buses for those using 3 rather 4 wheels. Member Mary Le Clair has decided that she is going to put up a fight about this policy (she is a polio survivor after all!) and sent us a copy of the letter she has written to policy and decision makers, the media, and advocacy organisations.

In researching the question while preparing this *Network News* I came across a recent document on a Canadian website <www.assistive-technology.ca> which discusses the pros and cons of 3 wheels versus 4 wheels at some length. Here are some salient quotations from the document's Summary:

An unbiased reader will probably determine that while there are no absolutes four wheeled scooters certainly tend to be more stable than their three wheeled brethren. If stability is the only issue considered, then they might also conclude it is reasonable to limit a consumer's choice to four wheeled scooters. The same reasoning can be applied to motor vehicles. If stability were the only factor considered when selecting a vehicle we would all be driving a wide sedan with a modest engine. No trucks, no SUVs, no mini vans, no motorcycles, and no buses. Clearly the number and variety of vehicles seen on the road indicates characteristics beyond stability were considered when determining the most appropriate vehicle for an individual; these vehicles were selected to meet needs beyond stability, so it is with scooters.

A scooter which is stable may be lacking in manoeuvrability; if that same manoeuvrability is what someone needs perhaps a three wheeled scooter is the best choice – and policy makers should not be making particular choices unavailable through well intentioned, albeit misdirected, concern about client welfare or their institution's liability.

Client awareness, or driver skill, has an enormous impact on the successful use of a three-wheeled scooter. ... It is better, in my view, to perform a thorough assessment of the consumer's abilities and needs, and match those same abilities and needs to the appropriate mobility device – whether it be a three-wheeled scooter, a four-wheeled scooter, a power chair, a manual chair, or a walker.

A copy of the complete document (which I have already passed on to Mary) can be downloaded from <http://www.assistive-technology.ca/Scooter_Stability.pdf> and is well worth reading. Your feedback about this issue is welcomed – have you been adversely affected by the State Transit Authority's decision, or do you support their policy? Here are Mary's views:

Giant strides have been made to accommodate the disabled in the community and I am a very grateful recipient. In fact without many of the modifications I wouldn't have been able to run my business for years.

When buses appeared with the disabled sign on the side I thought all my Christmases had come at once! Then, after years of a wheelchair the scooter transformed things further. I could finally go out alone (with a chair it was either with a friend or very sore arms!).

Recently I give up my car but I knew I could go across the road, catch a bus and continue to do all the things I would ever want to do, shop, pay bills, visit the library, or visit friends for coffee. Right? Wrong! It is the policy of the transport authority to ban 3 wheel scooters from the buses.

It is reasonable to have a look at the scooters and their drivers. The space and manoeuvring involved in organising oneself in the bus would be overwhelming if not impossible for some. Having said that if someone cannot handle a 3 wheeler how on earth could they manage a 4 wheeler? Having used both 3 and 4 wheel scooters for quite a few years let me assure you each can be as unstable as the other. In fact I have been tipped into the aisle on a 4 wheeler when I used one during the Olympics because there was nothing to hold onto (stability being the reason given for banning the former).

It is the inflexibility of this policy that is so frustrating. People have to take tests to have licenses, or get them renewed. Then they are graded, L or P or whatever. It would seem to me that the same type of system could be implemented for those of us very adept and comfortable with the scooters.

So here I sat twiddling my thumbs or taking a taxi every where, watching these big bright expensive buses drive by. Twiddling my thumbs is rather pointless so today I am composing this letter and sending a copy to each and every person who is prepared to help get this policy reviewed: RTA, Sydney Buses, the Minister of Transport, newspapers, my local Council, my local state and federal members, TV channels and pertinent organisations.

A Rebel's Story

Allan Grundy

Network member and self-confessed rebel Allan Grundy gave a presentation to members in June 2004 about his experiences as a crew member of the Sailors with disAbilities yacht KAZ. They 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. And that achievement is just one of many for Allan who tells us here more about his life and sailing experiences.

My name is Allan Grundy and I contracted polio in 1954 at the tender age of one year and I wear a full calliper on my right leg and a gold hoop earring in my left ear.

In 1993 I had been noticing some new muscular problems and contacted the Post-Polio Network to get some information. They sent me their Newsletter, along with some information, and inside was an article seeking sailors with disabilities to join a crew and enter the 50th anniversary Sydney to Hobart yacht race. I used to watch the start of the race from my backyard in Watson's Bay and dreamed of one day being a part and here was an opportunity knocking on my door. I called the phone number and arranged to meet them on that fateful day. There were hobblers, wheelies, shakers, white sticks and deaf people saying "What!", all moving towards a gleaming 54' cruiser/racer yacht. It looked like a pilgrimage to Lourdes. The yacht was named "Carpe Diem" (Seize the Day ... how apt).

I had ridden over on my motorbike, splendiferous in my battered old leather jacket and worn down cowboy boots and promptly the skipper took one look at me then said I could come aboard, but the boots were not welcome. I removed them and literally hopped on board. We went for a short trip around Port Hacking that day and my life changed. I knew nothing about sailing but knew I wanted to learn and be a part of this grand adventure. That first year was a hard and near-vertical learning curve as I reluctantly took orders and they began turning a "loner" into part of a crew; the best life lesson I have ever been part of.

The crew consisted of two paraplegics, three amputees, a triple heart by-pass, a woman navigator with myasthenia gravis, a blind cook, a deaf mastman, a chap with Parkinson's disease, myself with polio and we all placed our lives in the hands of a dyslexic skipper. They made me bowman with Albert, a double leg-above-knee amputee, with an obviously very low centre of gravity and without doubt the fastest man on a foredeck. I think David Pescud, the skipper, did it to dissuade me and I took it on to distance myself from him but I liked getting wet so much he left me there for years.

In 1994, we were the first fully disabled crew in the world to enter an ocean race and we did every race there was to do that year: Sydney to Southport, Mooloolaba to Airlie Beach, Hamilton Island Race Week, Hogs Breath Regatta, Gosford to Lord Howe Island, and every other race in between – and then came the Hobart. Oh, what a thrill, the biggest fleet ever assembled, 370 starters, this is what all our preparations had been leading up to. We met a SW front in Bass Straight and battled it for 12 hours, then afterward the sun came out and all was rosy as we sailed under spinnaker down the Tasmanian east coast. The weather went south again and, as the ABC helicopter hovered above us, David made Albert and I slide onto the foredeck, a metre deep in water and "*Look like you're doing something, for the camera*" as we turned the corner at Tasman light, in this 25 knot SSW with its 4 to 5 metre swell coming direct from Antarctica. We banged across Storm Bay, cold and wet, with two reefs in the main and a flapping, half-furled number 2 and I thought, "*I am never, ever going to do this again*". But when we crossed the line, 130th, and met

cheering friends, family and half of Tasmania at the dock, the discomfort disappeared and was replaced by an overwhelming warmth of emotion, pride and achievement. God, I felt like a star that day on the biggest stage of all.

At the Customs House Hotel later that day, David asked me if I would do it again and, suffering short-term memory loss as to all of the previous year and the day before, I answered, "Yes!" This was definitely to be the beginning of a whole new way of life. Since then I have been an active member of SWD (Sailors with disAbilities).

I have been in more regattas and done more sea miles than I can remember including seven Sydney to Hobart races as well as many other off-shore ocean races. My claim to fame is that in 2003 I was part of a crew of seven disabled sailors who set off on a non-stop, unassisted circumnavigation of Australia in an attempt to break the record of 43 days set by an able-bodied crew. We did, by 7 days, to complete the odyssey in 37 days and 1 hour. So now I am a part of history and of a wonderful crew who hold a world record, but that's another story. Who'd have thunk it all those years ago?

In 1994 it was going to be a once only adventure but I found a real passion in sailing and especially with SWD, as it made me realise what I **can** do and how incredibly fortunate I am. I continue sailing to this day with paraplegics, amputees, deaf, blind and others, living with the gamut of diseases and misfortunes that befall human beings and I am continually amazed at the attitude and optimism of all of them as they say, "*the glass is half full*", even though outside observers look and think the glass is broken.

Nowadays I work as an office manager at BioScientific in Kirrawee, NSW, a distributor of mostly biological reagents and diagnostic kits for research labs in universities and hospitals. I hadn't had a real job forever, I was a gypsy, and believed there was an opportunity to settle down a bit and maybe become a legal citizen, vote, pay tax, wear a watch etc. I met my partner Karen the week before I started here in 1987 and the job and relationship have been going ever since.

We bought a 100 year old house in Bulli 4 years ago before I got too old to pay it off. Before that I still tried to hold on to the rebel in me by saying, "*No mortgage, no credit card, no mobile, no watch etc*" but a trip overseas opened my eyes and the rebel surrendered to the real world, although his sense of humour remains.

Life goes on dictated by the SWD sailing calendar. I still ride my bike, a '47 HD knucklehead, but not as often as I would like, with so many weekends taken up either competition racing, taking kids out on the yacht, renovating a wooden house and now SWD's latest project, an on-loan Compass 29 to manage. Ah, so much to do, so little time. Truly, a most fortunate life thanks to PPN and SWD.

PS (I still won't wear a watch).



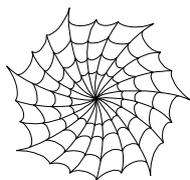
Powered Wheelchair



Through the generosity of one of our members the Network has been donated a Pride Mobility Jazzy 1120 wheelchair. This is a mid wheel drive chair, similar to the one pictured, which is only 3 years old and has had very little use. The current retail value of a similar new chair would be about \$8,000.

It was our member's express wish that this chair be provided to someone who could not afford a new chair but if any payment was offered it would be donated to the Network.

For more details please ring our Office Co-ordinator, George Laszuk, on 02 9890 0946 or 0412 082 983.



Through Cobwebs each issue, Bill McKee will bring you up-to-date information on changes and additions to our web site, tell you what you can find on the site, and show you how to get the most out of your visit to its pages. Bill welcomes feedback about the website and can be contacted on the email address above.

Hello again. Since you received my first Cobwebs report in Issue 67 of *Network News*, work on the website has continued. In particular, I have added a *What's New* page and an *Upcoming Events* page. The former contains some information about me, an account of what has been done so far this year and a list of things planned but yet to be done. The *Upcoming Events* page has links to our Seminars page and to events such as the Beresfield Conference (which are removed once the event has occurred). Unfortunately, our new Forum is not quite ready to roll out yet but we are working very hard on it.

You may have noticed that the general appearance of our website is somewhat old-fashioned by the standards of 2005. Well, we have plans to deal with that too. These days, various software packages exist which enable one to create modern-looking websites and, most importantly, make it easier to update their content. Indeed, I recently went to a presentation by a company in Sydney which was offering to do exactly this for us for the price of \$11,000. Fortunately some of these packages are available free and we have been able to enlist the assistance of a recent computer science graduate to help us modernise the appearance and functionality of our website. This young man is a member of a group of volunteers who assist organisations like ours in this sort of thing and we are fortunate to have him to help us. We do not yet know how long this project will take to complete but I should have more information in the next edition of Cobwebs.



Odd Shoe Project

We have been advised of the establishment of a single and odd shoe database established by e-bility on their website <www.e-bility.com/shoeswap.php>.

This initiative is for people requiring single shoes, or shoes for different sized feet. The project came about following a request from a person with polio who was tired of buying two pairs of shoes to get one pair that fitted. The aim of e-bility is to make it easier for amputees and people with disabilities (such as polio, oedema, arthritis) to exchange shoes with other people in a similar situation in Australia. They hope their project will save people who are amputees and those with different sized feet some money and frustration!

Stage one of the project has just been launched and includes a database listing of shoes available. As more entries are added to the database a search function will also be provided. Stage two is a member's directory (if there is interest) where individuals can register their details and look for someone who is their mirror image.

The site owners are looking for feedback and ideas for a name for the project are welcome.

Support Group News

Neil von Schill

Support Group Co-ordinator

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I was very pleased to receive my Spring edition of THE LINK which is a newsletter published by **Laurie Seymour** and his wife, **Beryl**, of the **Northern Inland** group. THE LINK is received by members all over NSW and is the means by which Laurie keeps these people in touch with one another as they are scattered too widely to meet regularly. I urge recipients of THE LINK to make a regular contribution to this publication and I commend Laurie and Beryl for their endeavours.

The **Sutherland Group** convened by **Ruth Hatton** took the initiative of inviting Carolyn Rice from the *Quality Use of Medicines* program to their November meeting. By all accounts it was a most informative meeting. Another speaker that you may wish to access will be addressing the Sutherland Group at the "Tradies" Club, Kingsway, Gymea in the Matthew Flinders Room on Wednesday 1 March 2006 commencing at 2:00 pm. She is Occupational Therapist, Janice Williams, who has expertise in community rehabilitation. Please put this date in your diary.

For those members who are still working or unable to attend daytime support group meetings we have an exciting initiative happening in the New Year. We are going to launch a **Metropolitan Evening Support Group** which will meet at the **Sydney Rowing Club, Abbotsford** on the first Tuesday of each month from March to November commencing at 6:00 pm. You can travel to the Sydney Rowing Club by ferry, bus or car. If you are working or it suits your circumstances to attend an evening support group please contact Convenor, **Maura Outterside**, on **9718 5803**.

Maura, who also convenes the **Marrickville Support Group**, has advised that in 2006 this group will meet on the second Thursday each month from March to November at the Petersham RSL Club, Regent St, PETERSHAM, commencing at 2.00 pm.

It was very encouraging to see many members and convenors of Support Groups, particularly Hunter and the Central Coast, in attendance at the **Hunter Conference** in September. There is a full report of the Conference on page 15. We also had enquiries from a number of new members who were interested in joining a support group in their locality.

As a change of format the **Wollongong Support Group** will meet for lunch at the **Illawarra Yacht Club** on **Friday 10 February at 12 noon**. All members in the Illawarra area are invited to join us. It is with regret that I must inform you that I have accepted Dorothy Robinson's resignation as Convenor of the Wollongong group. Dorothy has done a marvellous job over the past nine years and I thank her and Lloyd sincerely for their contribution and commitment to the group. I intend to be at the meeting on 10 February as we plan the way ahead for the Wollongong group and look forward to seeing many faces at the gathering.

Early in the New Year I am planning to visit a number of people south of Wollongong. I am hoping to catch up with **Brian Wilson** in **Canberra**, talk with **Peter Whelan** in **Batemans Bay**, and attend a meeting of the **Shoalhaven Group** at **Nowra**.

Report on the Hunter Conference – 17 September 2005

Neil von Schill

What a wonderful gathering we had at the Beresfield Bowling Club for the Hunter Conference. We had participants in attendance from Newcastle in the east, as far as Mudgee to the west, from Coffs Harbour in the north and Albury in the south. There were in excess of 70 members and speakers present for what was an excellent day.

The scene was set during our first session with Dr Michael Pollack, specialist rehabilitation physician from John Hunter Hospital who covers the Hunter and New England Health Service. Regular seminar and conference participants agreed that Dr Pollack's presentation was the best of its type that they had attended. His address was both informative and easily understood and comprehended. Dr Pollack defined Post-Polio Syndrome and its criteria for diagnosis before outlining its history and epidemiology. He discussed the nature of the polio virus, the effects of polio and the symptoms of PPS and what happens to our bodies and the risk factors involved, stating that all polio survivors are potentially at risk. Dr Pollack then went on to address specific symptoms including new weakness, pain, bulbar dysfunction and the psychological consequences of having survived polio.

He concluded that PPS is a potentially frightening prospect for a group of people who have already survived a major impairment and that not all symptoms can be effectively treated. Dr Pollack contended that our lifestyle may need to change but that quality of life does not need to change dramatically.

Following morning tea the auditorium was filled with mobility aids as Peter Wilson and his team from *Walk on Wheels* explored the theme of *Life – Get on with It*. Peter was the founder and first Managing Director of the *Walk on Wheels* franchise so was well qualified to speak on the technology available to assist us with mobility. He discussed and displayed a wide range of walking sticks, manual wheel chairs, electric wheel chairs and scooters. In each category there was a range of prices and applications. Price had to do with quality, durability and sophistication. The application depended on the needs of the user. Affordability had to do with the requirements of each individual. Many members present took the opportunity throughout the day of trying out various products. Peter's presentation was a practical and hands-on approach on how we can improve our quality of life through utilising available aids.

After the lunch break we had an inspirational address from a young podiatrist, Darren Thorpe, who had a wonderful command of his field of expertise. In a very articulate presentation, Darren spoke on *Keeping on your Feet*. He explored many of the foot problems confronting polio survivors and suggested practical ways in which we might deal with our difficulties. Many local members were keen to tap into his obvious expertise.

Our final session included a short presentation from Neil von Schill who alerted people to the existence of the *Isolated Patients Travel and Accommodation Scheme*. Members who have to travel more than 200 km to access specialist medical and dental services may be able to receive some financial assistance to help cover travel and accommodation expenses incurred.

This was followed by an address from Anneke Redman, Manager of the Hunter Area PADP and Equipment Services. Anneke gave a very informative talk on *PADP (Program of Appliances for People with Disabilities)*. She outlined the types of items and equipment that are available through PADP and how members could access the services. Anneke discussed the scope of the service and how to apply for assistance.

At the conclusion of the Conference participants agreed that it was an excellent and very informative day. Special tribute must be paid to Barry and Wendy Chaff for the enormous amount of work that they put in to ensuring that the day was a success. Many thanks Barry and Wendy!

The proceedings of the whole day were videoed and are available on a double DVD set for the cost of production which is \$20.00 (including postage). If you are interested in ordering a DVD set please ring Barry Chaff on 02 4957 5254.

Polio Particles

Mary Westbrook

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



Unsung women heroes of the polio vaccine breakthrough

An article by David Oshinsky in the Los Angeles Times (12/4/05) argues that amid all the honours heaped on Salk in the 50 years since he made one of the greatest medical breakthroughs of all time, the role played by other scientists, particularly two women, is forgotten. One was Dorothy Horstmann who at Yale University in 1942 set out to discover the route of polio through the body. In what was described as *medical history ... she succeeded in showing that poliovirus circulated briefly in the blood before entering the central nervous system. This meant that a vaccine designed to raise antibody levels in the bloodstream might be able to neutralise the poliovirus before serious harm was done.* Isabel Morgan at Johns Hopkins University took the next step. *Morgan's experiments to immunise monkeys against polio brought very promising results. In the late 1940s, her primates, vaccinated with a killed-virus solution, were able to withstand high concentrations of live poliovirus without succumbing to the disease. None showed the telltale symptoms of paralysis. But in 1949, in the prime of her career, the 38 year old Morgan left Johns Hopkins to marry and become a homemaker. Had she remained, it's quite possible she would have beaten Jonas Salk to the killed-virus vaccine. The next step involved the testing of children, one she never got to take.* Horstmann became the first woman professor of medicine at Yale in 1961. Morgan returned to work in cancer research in the 1960s. Her bust is in the Polio Hall of Fame at Warm Springs.

Kano polio survivors unite

The refusal, for some months in 2004, by officials in Kano, Nigeria, to allow polio vaccinations has been the major cause of the recent spread of polio to 16 countries that had been previously declared polio free. However Kano also has an active post-polio support group. Twenty years ago they formed the *Kano Polio Victims' Association* to help survivors learn a trade so that they did not have to beg for a living. It has 5,000 registered members. Post-Gazette.com (29/4/05) writes: *Underneath their long silk caftans are shrivelled limbs. Some hobble on crutches. Some crawl, lifting themselves slightly off the ground with two wooden blocks. Others walk spiderlike through the dirt on their knees, their hands tucked into sandals. On this spot of borrowed ground men and women gather each day under canopies of guinea corn leaves and in a tin shack to build the tricycles, knit infant sweater sets and make petroleum jelly to sell.* The group have now begun to focus on advocacy. They accompany the immunisation teams into areas of resistance to *show doubters what can happen if their children don't get the vaccine.* The cooperative's land is under treat as the owner plans to build on it. It receives little help from the government or foreign agencies which makes many survivors bitter. One said, *The United Nations' effort to eradicate polio is like a parable of two houses. One house is on fire, the other is safe. The UN is putting all its efforts into making sure the fire from the burning house doesn't reach the safe one, while allowing the burning house to burn down. We, the polio victims, represent that house on fire ... We have already been ravaged. The UN and other agencies ought to give attention to us to assuage our pain;* sentiments most polio survivors have felt at times.

Polio and Warm Springs made the man

A television film, *Warm Springs*, recently shown on US TV stars British actor Kenneth Branagh as FDR. The Chicago Sun-Times review (29/4/05) wrote: *Branagh embodies the president-to-be at the critical turning point of his life [when he contracted polio] ... In a wheelchair, believing his political career is over ... FDR retreats to Warm Springs. At first, it's clear he wants to hide from the world. Then he begins to believe in a cure. But as he takes in the poverty of the region and adapts to his physical limitations, he finds renewed purpose ... 'Warm Springs' portrays an enlightening episode that doesn't figure in many history books. Not only did Roosevelt clean out his trust account to buy Warm Springs, but he died there, in the tiny cottage known as 'the little White House', in the 13th year of his presidency. It's still a rehabilitation center today. We haven't forgotten Roosevelt or his impact. But it's one thing to know that he guided the nation through the Depression and a world war; it's quite another to watch him make people forget he's a paraplegic. 'Warm Springs' suggests that FDR's physical weakness wasn't just a political setback — it was the source of his strength.* Let's hope it shows on Australian TV.

Shaggy dog cure for polio

Miracle dog licks polio: Pet 'heals' crippled Wendy was a headline in the *Daily Record*, a Glasgow newspaper, on 29/3/05. Wendy Francis, a polio survivor, had had no movement in her feet for 50 years but on Easter Sunday her dog licked her feet and Wendy felt tingling and found she could wiggle her toes. Experts are baffled reports the paper which quotes a microbiologist as saying, 'We are still learning about how polio develops in people over the years. All I can say is good luck to her; I can't see it doing much harm'. Wendy says she is going to let her dog lick her toes as much as he wants.

How long does the Sabin vaccine related poliovirus survive?

The editorial of the British medical journal, *The Lancet*, (3/5/05) says that *one of the outstanding 'endgame' questions for polio eradication is how long vaccine related polioviruses will circulate after the cessation of the use of the Sabin vaccine.* It reports a recent study by Sue Huang and colleagues in New Zealand where there was a change from the Sabin back to the Salk vaccine in 2002. For 18 months after the switchover they monitored cases of acute flaccid paralysis, poliovirus excretion in children in hospital, people with suspected enterovirus infection and sewage plants. The first three methods revealed no poliovirus after two months except in one child who had conjunctivitis. Virus in sewage fell during the first three months and after that was only detected once every three months. (This was probably caused by people who had recently received Sabin vaccine in other countries). These findings suggest that there has been little if any persistence of Sabin related virus in New Zealand. However the editorial asks, *what happens if vaccination with OPV [Sabin] is stopped without switching to IPV [Salk] as will happen in many tropical developing countries?* The recent cessation of vaccination in some parts of Nigeria because of the boycott in the province of Kano resulted in the spread of wild poliovirus to eleven [now a higher number] countries previously free from poliomyelitis. *Compared with New Zealand, the risk of importation of vaccine-derived or wild poliovirus from neighbouring countries is much greater in land-locked central Africa. Nevertheless the isolation from sewage of probable imported strains in New Zealand indicates that even this island nation is not immune from poliomyelitis importation. While the lack of long-term persistence of vaccine-related poliovirus in New Zealand is encouraging, it does not allow for the cessation of poliovirus vaccination in any country. There is no room for complacency in the poliovirus eradication endgame.* The question remains as to what will occur in developing countries in the long term after the WHO initiative ends.

Polio survivors receive state compensation

The Israeli newspaper *Haaretz* reported on 7/7/05 that new legislation will provide around 2,000 polio survivors with a one time payment of state compensation for not being vaccinated against polio and for treatments that worsened their condition. Polio was prevalent in Israel in the 1950s. The vaccine was introduced in 1959 and by 1988 the country was polio-free. The prime minister of the time, David Ben-Gurion, promised survivors free medical treatment and equipment but this never happened. A spokesperson for polio survivors is quoted as saying that the new law *corrects an injustice of many years when the government refused to admit its guilt for the spread of the epidemic and damages suffered by victims because of inept treatment, medical experiments and unnecessary operations.* One survivor said: *They put most of us insolation in a church in Jerusalem and got our parents to sign an agreement to experimental treatments and operations. They grafted bones and muscles, tried to straighten legs and operated on backs and thighs. Some people underwent 20 operations.* Survivors' payments will be based on the number of years they have had polio and their monthly disability grant will be increased.

Hope of future treatment for PPS

Post-Polio Health International (it used to be known as GINI) held its Ninth International Conference on Post-Polio Health in St Louis in May 2005. I have been reading the synopses of the papers and one of the most interesting is *Immunopathogenesis of the post-polio syndrome* by Kristian Borg, Henrik Gonzalez and other researchers from Sweden. They refer back to their previous research findings of *a chronic inflammatory process in the [cerebrospinal fluid of the] CNS of PPS patients* and their finding that this can be reduced by intravenous immunoglobulin. This was associated with an improvement in muscle strength and quality of life in patients treated. The researchers have now conducted a multi-centre, double-blinded and placebo-controlled study to examine whether their previous findings stand up to this rigorous test. The results supported them. Berg and his colleagues found that patients with PPS given immunoglobulin showed a significant improvement in muscle strength, an increase in physical activity, a decrease in pain and an increase in their rated quality of life. They conclude *there is an inflammatory process in the CNS of patients with PPS. The origin of the inflammatory process is unknown but it may play a part in the pathophysiology of PPS. The inflammation is down-modulated by means of treatment with intravenous immunoglobulin leading to a clinical improvement. This might lead to new therapeutic strategies for the treatment of patients with PPS.* Such possible treatments are not going to be available in the near future. At the time of presentation Berg and his colleagues had submitted their papers to scientific journals for publication but they were yet to be accepted and published and the information disseminated among doctors. While the improvements cited were statistically significant I did not get the impression this treatment would allow recipients to take part in the Sydney City-to-Surf race. These findings link in with the research Dr Marcia Falconer talked to us about at her Seminar last year so we will look forward to what more she has to tell us at her next talk in May 2006.

Polio cases in the USA

In September 2005 a baby in Minnesota, who was admitted to hospital with an immune condition, was found during tests to have polio. The child, who did not have any symptoms of paralytic polio, was found to have a strain of virus found in oral polio vaccines that had not been used in the USA for five years. The child had not been vaccinated against polio because of its (the gender of the baby and other identifying information has not been released) medical problems. Investigators began testing relatives and people who had close contact with the child to find if anyone else had been infected. This is the first case of polio infection reported in the US since 2000 when the country stopped using the oral vaccine and reverted to the Salk vaccine. In October *Associated Press* reported that

the baby came from an Amish community and three other children there had been found to be infected with the same polio virus though again they showed no symptoms. These children were siblings and had not been vaccinated. They were not related to the baby but had been in contact with it. Officials are investigating how an infection from a vaccine given in another country reached Minnesota. Some families in the Amish community are allowing their children to be vaccinated while others are not. Officials fear that without the community's cooperation there is a chance of an outbreak similar to one that occurred in 1979 in Amish communities in Iowa, Wisconsin, Missouri and Pennsylvania which left ten people paralysed. At that time wild (as opposed to vaccine related) polio virus was introduced into the communities by a visitor from Europe.

Rally by Nigerian polio survivors

Reuters (9/11/05) reported that around 1,000 Nigerian polio survivors staged a rally in Kano to encourage parents to have their children vaccinated against polio. The state of Kano has been the epicentre of resistance to vaccination following the pronouncement by Muslim clerics that vaccines were being used by the West to spread HIV or make Muslims infertile. The ban lasted 10 months but that was long enough to allow the spread of polio to 18 other countries and set back the global campaign to eliminate polio. Although vaccination has recommenced the response of parents has been slow according to Aminu Mohammed Tudon Wada, chairman of the Polio Victims Association of Kano and '*That is why we decided to stage this public demonstration*'. The demonstrators included adults and children. Many rode hand-pedalled tricycles or boards with wheels. During the demonstration they visited the state governor and the emir to gain their support for the round of intensive vaccination due to commence the following week.

A comeback for iron lungs?

The bulky iron lung respirator, invented in 1927, is *essentially a metal box with two vacuum cleaners which applies negative pressure to pull a patient's chest cavity upwards, allowing the lungs to fill with air.* Since the end of the polio epidemics only a few survive in Australian hospitals. They are still used in the Austin hospital in Victoria *keeping alive polio survivors and patients with progressive conditions such as muscular dystrophy.* *The Australian* (21/11/05) reported that the iron lung *could return to intensive care units as researchers claim it can be more effective than the equipment that replaced it.* Dr Mark Howard, Director of Respiratory Support Services in Victoria, says that one advantage is *that iron lungs used negative pressure while mouth ventilators use positive pressure to help the patient breathe. 'Trying to expand the lungs through negative pressure may be more effective in preventing collapse.'* *Using an iron lung also removed the need for 'invasive' ventilation such as a tracheostomy.*

Cartoon novelette history of polio

Polio: a virus' struggle, a cartoon story by James Weldon, has the polio virus telling its story at a group therapy session of the *Diseases Nearing Eradication Support Group*. The hexagonal virus sits on a chair and has its turn after smallpox ends its tale in tears. 'Okay, ummm ... hi, my name is poliomyelitis, and I'm nearing eradication ... I'm a contagious epidemic enterovirus or at least I was until the vaccine...' The 14 page story can be found at <www.bioteach.ubc.ca/quarterly/?p=45>. It's a great vehicle for telling children about polio and vaccination. It's very informative with lots of amusing bits. '*Everything was going well says polio until I infected someone famous. In 1921 I was contracted by Franklin Delano Roosevelt. I was such a fool! I should have known he'd run for office!*' Leprosy responds '*Polio, you can't blame yourself.*' Polo continued '*I panicked LA in 1935, and all the time they were trying to contain me the wrong way, isolating the clinical cases and ignoring the asymptomatic carriers. They were treating me like TB!*'. The emails to Ask Mary indicate that polio is a very popular topic for school projects and this is a good reference.

Home Modifications for Accessibility and Safety

Barrie Stevenson

Member Barrie Stevenson and his wife Billie are very regular and supportive attendees at Network Seminars and other events. Earlier in the year Barrie mentioned that he was getting his bathroom modified to make life easier and safer. I asked him to write up the process and his experiences for the benefit of other members who are (or should be) contemplating something similar.

Barrie has forwarded the detailed report below, but first here is some background on the government program he accessed to make it all happen.

The Department of Ageing, Disability and Home Care is responsible for the Home and Community Care (HACC) Program which is jointly funded by the NSW and Australian Governments. This program funds home modifications and maintenance services to assist frail older people, people with disabilities, and their carers to remain safely and independently in their own homes. The service is subsidised for eligible HACC clients who pay a contribution towards the costs of the work, with the remaining costs being paid by the HACC Program.

It is worthwhile checking if you qualify for assistance with modifications and maintenance to your home. As in Barrie's case, this may involve changes to the bathroom, toilet or kitchen or the installation of ramps and rails.

For more information about home modification and maintenance services in your area, get in touch with your local Council or Hospital. You can also ring the Commonwealth Carelink Centres on 1800 052 222 or visit their website <www.commcarelink.health.gov.au>.

Here is the further information I promised you when I spoke about our bathroom modifications earlier in the year.

The home modification scheme is funded by state and federal governments and administered by local government so it should be available in all areas. Note that there is no requirement to be on a Centrelink pension so it is available equally to self-funded retirees.

In my own case my first enquiry was made to my local hospital (Ryde) where I asked to be put through to the *Aged Care Assessment Team*. I was asked for the names of my doctors (in my case, the GP and cardiac physician) who I suppose would have formed part of the assessment team.

Next, I was phoned and visited by an occupational therapist from the Hospital who looked at safety and mobility problems.

It was indicated that I could certainly have a handrail installed at the front steps and probably have extensive modifications (that is, rebuilding of the bathroom).

A deteriorating timber deck was not eligible for subsidised help but ended by being largely rebuilt as a private job by one of their tradesmen. The labour charge was comparatively modest. This included a step on the edge of the deck and a grab-rail. If it had been necessary, the step could have been substituted by a ramp but I am fortunate in not needing that.

I was quoted a firm price for the handrail at the front steps, which I accepted. The rail was pre-formed and installed in a matter of an hour or two but I did have to wait about three months before it actually happened. It has been very welcome to have the assistance of the rail.

The bathroom took a lot longer to happen. It had to wait for budgetary approval – in fact, rather more than a year. Eventually I had word that approval had been granted.

Then I was visited by a building inspector from the scheme who discussed the alterations proposed, measured up and drew up plans on which quotes would be obtained. The quoting process did not involve me at all. The scheme had its own preferred builder(s) based on previous work done and one of these submitted a price which was accepted. At no time did I discover what that price was – I was only told what my contribution would be. It did seem quite a deal less than I would have expected so I was happy to agree. At that stage I was asked to pay 10% deposit.

Work started one month after that and took exactly seven weeks to finish. It started with total demolition of the old bathroom back to raw brick on walls and bare concrete on floor. It was noisy and dusty because of three days of jackhammering. Noise was unavoidable, but the dust was minimised by having temporary plastic curtains put over doorways and plenty of drop-sheets everywhere. The rubble was carefully carried out of the house in boxes rather than being wheeled out in barrows.

The room ended up being completely re-rendered, walls and floor waterproofed, re-tiled and re-painted; toilet pan and hand-basin re-positioned to more convenient locations and of such conformation as to be wheelchair compatible if needed in the future; ceiling exhaust fan and heat-lamps fitted; power-point provided next to the hand-basin; whole new floor drainage fitted; doorway widened (again to suit possible future need for wheelchair access); and the old hinged door removed and replaced by a sliding door as precaution against inability to open the door if someone (me?) collapsed against the inside of the door.

On completion of the work and after inspection, Ryde Council forwarded an invoice to me for the balance of my payment and invited comment on my degree of satisfaction with the job. Very satisfied!

Subsequently, I arranged with the occupational therapist for the kitchen and laundry taps to be changed to the new quarter-turn taps with lever operation making them easily responsive to finger pressure and avoiding any future need to change washers. These taps are designed to work by setting holes into alignment or out of line anywhere in-between, instead of the old style washers which choke off the supply and which wear out and need to be replaced from time to time.

So that's it! We had the good fortune to have had a toilet and water supply put in the garage years before and were able to use that while the bathroom was out of action. If we had not had that available we would have had to hire a "Portalo".

The full extent of the "disabled" facilities are not strictly needed at this juncture but, on the other hand, I would not have found it easy to cope with all the disruption if I had waited until they were.

Incidentally, I am glad it all took place in the warmer months of the year. It would not have been pleasurable to have had to go out to the garage in the cold, winter months.

I forgot to mention that I now have a hand-held shower with plenty of grab-rails – two in the shower and one alongside the toilet – no shower-hob to trip over; new shower curtain and curtain rail provided. The floor is cleverly sloped (but only slightly) to direct water to the new drain which goes right across the floor (but flush with the floor).

The whole exercise was very worthwhile and a very good way of achieving it. Recommended!

Welfare to Work Legislation

Merle Thompson

Members will be aware that the Federal Government has introduced legislation reforming various welfare payments, including those which relate to people with disabilities.

It is not the Network's role to be involved in political discussion or direct political lobbying. However, as a mutual self-help organisation, it is important for us to understand if individual members are adversely affected by changes, including ones which impact on their financial security and their employment.

Please let the Committee know if the changes are causing difficulties for you. We may be able to provide information on the nature of such effects on members to those peak disability organisations which are able to undertake lobbying or perhaps support you in your own representations.

Quality Use of Medicines

Maura Outterside

On Thursday 11 August 2005 I attended a planning session representing the Post-Polio Network in Canberra under the auspices of the Consumers Health Forum (CHF). This was a "brain-storming" for Stage III of the Community Quality Use of Medicines (QUM) ongoing health promotion approach to raising awareness, knowledge and skills to familiarise consumers with their medicines.

Stage I was the production of "*AAAACHOOO! Harvey catches a cold*". A free handout to childcare centres, this clear, simple booklet encourages parents to question whether a prescription is required for every complaint or visit to the doctor.

Stage II is the current program of "*Quality Use of Medicines For Seniors*". The informative locally-run, locally-resourced community discussions detail ideas seniors could use to reduce or simplify their medicines and get a much clearer picture of how to manage their current health issues more confidently. This is coordinated by David Goodbody at COTA National Seniors: telephone (02) 9251 6088 or email <d.goodbody@nationalseniors.com.au>.

Stage III is looking at defining a Community QUM for People with a Chronic Illness. We examined three main areas of planning: Chronic Pain, Diabetes and Cardiovascular Diseases. The groups who had provided representatives were: Diabetes Australia, Carers Australia, Chronic Illness Alliance Victoria, Chronic Illness Alliance NSW, Heart Support Australia, National Heart Foundation of Australia, Arthritis Australia, Prostate Support Group, Brain Foundation, Post-Polio Network, PiP (People in Pain) Support Groups, The Chronic Pain Group, Consumers Representatives on the National Health Priority Action Council (NHPAC), Chair of the National Prescribing Service (NPS) Community QUM Manager, National Prescribing Services Program Officer, CHF Director of Policy and Projects and CHF Community QUM Project Officer. An impressive collection of community groups and government instrumentality officers.

Well we hit the ground running and kept up the pressure all day. Meal and tea/coffee breaks were taken as we worked on!

The main thrust was that with the individuals' response to their illnesses and the variety of treatment modalities, the patient and/or their primary carer have to gain a clearer concept of their own priorities and confidence in managing their health regimes. The concept of "evidence-based prescribing" is being aware of the pathology before "trying" this or whatever treatment. The maxim, as far as I could gather, was GET TO KNOW YOUR MEDICINES. This concept seemed to fit with the activities I see used by many polio survivors.

I look forward to the program being devised for Stage III. If it is as clear and as streamlined as Stage II, and gives good guidelines in the three categories of Chronic Pain, Diabetes management and Cardiovascular Disease it will be well worth the wait. Further information about the Quality Use of Medicines program can be found on these websites: <www.chf.org.au> and <www.nps.org.au>.

Polio and Post-Polio not understood by most Doctors

As Neil von Schill has previously reported, the Network's Regional Representative in the Blayney/Cowra area, Peter Drady, sadly passed away earlier this year. Peter's wife Heather stepped forward to take on the role of Regional Representative for this area and we are very grateful for her ongoing commitment to, and involvement in, the Network.

In a moving account Heather writes below of Peter's difficulties in hospital resulting from a lack of understanding not only of the limitations imposed on him by polio, but of the impact of its late effects. Over several years the Network has presented training sessions to inform medical and service personnel about polio and its late effects. Merle Thompson has prepared a training program which can be used as the basis for future sessions, particularly with medical groups. The difficulty we have faced is having our program included in already overcrowded curriculum. Heather's letter reminds us again how important it is that we keep pushing to have information about the late effects of polio readily available to doctors, nurses and other health professionals.

I am writing this on behalf of Peter my husband, now deceased. Peter had polio in 1952, but he managed to work, with difficulty, till about 10 years ago.

As time went on, he got more disabled, and started to use a walking stick, then a walker. He put several handrails in the bathroom, toilet, and also ramps and rails outside to help him.

He never complained and took it in his stride. We found he had blocked arteries so doctors operated and did five bypasses including a carotid artery. This kept him going for about twelve years or so.

As it was very hard for him to get around, he started to use a scooter. We even had a car equipped with a lifter so we could travel.

He has been unwell on and off for the last couple of years and ended up in Hospital last August. From then on he went down hill.

Personally I felt it was the lack of understanding of polio and post-polio. I talked to the doctors, did everything in my power to help the staff understand, by handing them out brochures (with the help of Gillian who sent the brochures, thank you so much for that) and talking to them. They just did not understand.

I am still so hurt and frustrated that they would not listen to me. Peter fractured his leg. It was no one's fault, but that meant he just could not bear weight on his legs at all, especially after being in bed for about a week. Since then he just could not get up. The nursing staff were very determined to get him up, with the result they let him fall five times that I know of, at different times.

I was afraid to leave him in case he fell again. Is there anything that we as a Post-Polio Network could do to help the Doctors and Nursing Staff to understand this problem, maybe have it included in their studies, at least make them more aware of polio?

It is worth it if it can help others (or some one) and not to have to go through what Peter and myself went through.

I will always be wondering if Peter would still be with us, if he did not have so many falls.



Can You Help to Promote the Network?

We are most grateful to everyone who has been able to distribute our pamphlets widely throughout their local communities. If 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 the office during business hours, or Alice after hours by phone (02) 9747 4694 or email <ea@post-polionetwork.org.au>, and some will be posted out to you.

Poet's Corner

Regular readers may remember reading a poem *The Lament of the Caliper* by member George French in *Network News* Issue 66 (February 2005). George's poem had won first prize in the ACT Support Group's 2004 Christmas party limerick competition. Convenor Brian Wilson has now sent me a copy of George's effort this year – again a prize winner. Brian wrote with this and other news:

Our group again had an excellent Christmas party at the Ainslie Football Club in early December and we again had a poem/limerick/joke competition and the entries were again excellent and very entertaining making the judging very very difficult (so this year we had 3 prizes). The winner for the third year in a row was George French's entry.

George has a real talent capturing the plight of polios into verse and I feel he deserves due recognition. I would appreciate if you could again publish his poem in the Newsletter. I recall a Support Group in England publishing (with permission) last year's entry in their Newsletter.

Roger Smith has had his story published in the National Museum of Australia's magazine and he has been presented with a lovely certificate acknowledging his contribution of the "Roger Smith Collection" to the Museum. The collection includes his old caliper and shoe so dominant in last year's Rotary Polio Exhibition at the NMA and now touring Australia.

The End of an Era

G T French

We are the PP Network,
And our ranks are fading fast,
Because of Salk and Sabin,
We are doomed to be the last.

Of course we're deeply thankful,
That no one else will share our fate,
But now and then we wonder why,
For us, science came too late.

We were a happy band of misfits,
We did not whinge nor yet complain,
And we'll pass with little notice,
Like a summer shower of rain.

We've jumped full many hurdles,
And crossed bridges by the score,
We fought our battles, some we won,
But always looked for more.

Alas for our potential,
We were on the scene too soon,
And a nasty little virus,
Was allowed to play its tune.

Without hindrance from the vaccines,
That had not yet been made,
By Jonas Salk and Sabin,
And others in that trade.

Such talent as we may have had,
Was thus nipped in early bud,
And on the world's great sporting scenes,
We have never spilt our blood.

Sport was not our forté,
For our muscles lost the plot,
But it hurts that our replacements,
Will be a super lot.

Of supermen and women,
Trained by the public purse,
To run and jump dive and swim,
For better or for worse.

But we won't descend to envy,
For the athlete's happy lot,
But go happy in the knowledge,
That we gave it our best shot.

Perhaps we were more suited,
To study science and art,
And literature and music,
And the function of the heart.

And now we are a dwindling race,
Our numbers fading fast,
And soon we will be history,
Mere memories of the past.

They'll read of us in books, perhaps,
And give us passing thought,
But how will they appreciate,
The battles that we fought.



The photograph of polio survivors at the Jervis Bay Rehabilitation Centre in 1952 published in Network News Issue 67 triggered this memory for member Russell King, Thirroul.

Just a short note. After reading the July *Network News* the photograph of Peter Allenby brought back memories. It was the winter of 1951, I was 5 years old. Peter and another lad, Keith Hill, were in their teens – we were in the same ward in Wollongong Hospital.

Peter and Keith were unable to walk. As time went on and I was able to walk in a fashion sometimes I would go and get a trolley from down the hall and push it back to our room. The three of us would then go visiting the other wards until the Sister would catch us. It was then a quick trip back to our ward!



Member Sandra Lawrence's letter confirms the importance of having a supportive GP, a knowledgeable and helpful Rehabilitation Specialist, and the Post-Polio Network all working for you as you learn to live with and manage the late effects of polio.

As I have been a bad girl over the last year or so and have not paid my membership, I thought I would give you an update.

In May 2003, I was forced to give up my job as a Director and a Financial Adviser of our family business. This was due to one of the worst and longest bouts of post-polio that I had experienced. My husband continued running the business and looking after me. When the bout started to get better we decided that my husband should retire and sell the business. My GP didn't seem to think that post-polio existed so we looked through the copies of *Network News* and were able to track down Dr Steve De Graaff in Camberwell. He agreed to see me in November 2003 and at the end of just an hour, he told me that it most certainly did exist and that I was a classic case. This was the first time that a medical person had confirmed, and this was a Specialist. We went through the period from when I first showed the symptoms and found that Steve was telling me what I had been experiencing at the times the symptoms showed. He then prescribed Cipramil to supplement the other medication I was taking and I have found this has helped me a lot. He also dictated a letter to my GP and gave me a copy. This was basically a blow-by-blow report of all that had been discussed at the meeting. He gave me lots of useful advice that has helped. We told him that we were looking to sell the business and move to South East Queensland and he looked a little concerned until we said it was the dry heat part between the coast and Toowoomba. Then he said the climate was ideal for my situation and could think of no better place to be.

We had a second appointment in January 2004 and his astonishment was because I was looking so much better than the first appointment. He checked me over and I told him that we had just come back from a holiday to Queensland and we had purchased a block of land in Laidley and had signed a contract for a new home to be built. He made another appointment for April 2004 and said at that appointment that I was doing so well that he would not want to see me again – unless I needed to see him again.

My husband retired upon selling the business in June 2004 and we bought a caravan for touring and living in until our new house was ready and we drove away from Melbourne on August 1st 2004. Our Mooroolbark home was still up for sale when we left but we wanted to get away from the colder weather in Victoria. It sold a month later.

We lived in a caravan park in South East Queensland and were able to check on the construction, colour planning etc until we moved in in February 2005. Our old house was a 2 storey but this is a large one-level house on a one and a half acre block with 360 degree views. During this time, a re-direction notice for mail was making sure we got, inter-alia, *Network News*.

As you can see, we have been extremely busy in the last two years but it has been well worth it.

We are both very glad that I joined the Network and I thank you for continuing to send the *News*. We are particularly thankful for the contact with Steve, who has been truly marvellous. Without that mention of the meeting he attended in Sydney, we would never have found him. We also are thankful to Marcia Falconer's tapes as she covered the heart problem that I have.

I am now more conscious of the need to pace myself and having my husband around to tell me I'm not resting enough, has improved my situation which has also been substantially helped by the constant dry heat up here.

I recently applied for Disability Support Pension and enclosed a copy of Steve's letter plus the form completed by my "converted" GP and thought that it would be difficult to get it because of the way the Government was cracking down on it. I saw the Centrelink Consultant and he said all he needed was the letter from Steve. A few days later I was accepted for the DSP.

I attach the Membership Renewal Form for the two years. I couldn't do without my *Network News* and the helpful articles, tapes etc. Keep up the good work!



Judith Plummer last wrote in about her mother, Marjorie Corby, in 2002 and her letter was published in June of that year in Issue 54 of Network News. Judith wrote again in August but we have not had the opportunity to publish her letter before this. We are thrilled that Marjorie is still doing pretty well and are glad that Judith plans to keep in touch.

My apologies for the late subs cheque. Each day I would put posting off so I could write and update you on my mum's Health (Marjorie Corby). Mum is now 94 and 95 in October this year. She is as well as can be expected but the PPS has advanced significantly from my last letter in June 2002 and she now needs assistance from wheelchair to toilet (and return) also getting into bed at night.

I have so much I would like to say about PPS and the lack of understanding the medical and nursing staff have on this affliction. Mum had three weeks in hospital in May for adjustment to medications, and staff could not comprehend how Mum and I managed on our own when it took two or three nurses to manage her; also the lack of empathy for Mum's sensitivity to cold and inability to generate body heat, so each day I would place warm wheat-packs, long woollen socks and a cape around her shoulders.

This has become one of my projects in life. When Mum is no longer here, I want to help educate people on PPS. I have been Mum's carer since 1992, and 14 years is a long time to observe this insidious ailment.



On a cheerier note, I have enclosed a photo of Mum taken on Christmas Day in 2004 – isn't she beautiful?

The best Mum in the world!

Member Nick Costin's letter published in Issue 67 of Network News (July 2005) sought some input from fellow members about their PPS experiences. Nick's request struck a chord with members and generated the most number of responses received to such a request that we can recall. Member Graham Duncan, Cooranbong, sent the following letter in September and requested its publication in Network News which we are more than happy to do.

I would like to reply to Nick Costin's article in Issue 67, to share my polio story with some thought on how I am looking ahead as I become less mobile and alert.

I was born in 1941 on a farm in Tasmania and four years later our family moved to a seaside town where I spent my childhood roaming the beaches, reserves and climbing trees – in spite of having wasting in my left arm and shortened left leg (by 2.5 cm), with no flexibility of ankle or toes on that leg. There was a hospital close by and I became aware that I was different from other kids when I spent some time there during my first year at primary school.

During my primary school years I became aware of another problem. I had very poor hand-eye coordination. After being laid out cold with missing front teeth during a game of cricket at school sport I had no further interest in sport. In later years backyard games of cricket with my own children were not easy as I could not bat, catch or run, but the children were understanding.

My work life has been spent as a repair maintenance technician with small appliances and then on larger factory machinery, which I enjoyed, but after many years standing on concrete floors it was necessary for me to have surgery on my left foot to correct a deformity. I realised that at 51 years of age my spine was not as supple any more, and that I needed a shoe build-up. I had tried this as a child but discarded it due to the heavy leather build-ups in those days, and the embarrassment of clomping about in front of school mates. I chose the option of having an insert fitted to off-the-shelf sneakers (wide fitting) which offered some correction, but I still walked with a limp. About that time I was diagnosed with sleep apnoea and now use a CPAP machine at night. I am not sure whether this is entirely polio related as I was 16 kgs overweight at the time.

I am now 64 with approximately 6 months of working life to go before retirement. Because of back strain I work reduced hours with lighter duties, but still manual factory work, though I am learning that I need to pace myself and aim for a half to one hour sleep mid-afternoon each day as I tire very easily. My polio leg aches, my word-finding ability suffers, I stumble over words, and find even pronouncing simple words difficult at times. Sometimes I have trouble swallowing and can lose my voice altogether. I experience similar problems to many PP sufferers in that I never feel warm, even now living in the Lake Macquarie area of NSW with summer temperatures in the 30s it feels like a mild day. Winter time is one big ache.

After consultation with my GP I aim for a 30 minute walk each day – any more and my left foot drags and I trip easily. An occasional tuneup by a physiotherapist does wonders, but my number one priority is to keep my weight down, which is not easy. With high blood pressure also giving me incentive I have undertaken a weight loss program with satisfactory results. When I retire next year I intend to keep fit and supple as much as I can, for I believe that light exercise is very important to keep the spine flexible. After 64 years of walking with a shortened leg I have very little curvature of the spine, no doubt due to being an outdoor active person. To help keep fit I use the Heartmoves exercise DVD from the Heart Foundation, and also I am looking at doing simple Pilates type exercises from a DVD in the comfort of my lounge room. I would also like to extend my knowledge of playing the guitar to continue to keep my fingers nimble. Being a mechanical technician I found it very frustrating to lose the flexibility of fine motor skills needed for that type of

work, so took up the guitar to try to retain some flexibility and to try to keep my mind active in learning – I enjoy music but do not have natural musical ability. If I am still reasonably mobile I would like to take up some volunteer work helping others who have a need.

I do not drive much now, only around my local area – small country town – in familiar surroundings, as my reaction times are too slow to cope with fast moving traffic, and I cannot cope with the glare of night-time or wet-weather driving. My wife is always willing to take the wheel, and my grown children are only too happy to lend a hand with repairs around the house. I feel it is important to keep the family in touch with one's deteriorating physical and mental condition, so that they understand and can give the required support.

As for the future with PPS, who knows? New problems, new challenges, but we are a great bunch of survivors.

Nick Costin received so much feedback to his letter that I have asked him to write again to share what he had learned. Nick's letter will be included in the next issue.



Member Terry Fletcher has a wealth of knowledge and experience in the area of access for people with disabilities gained through many years working in the field. For some time Terry has represented people with ambulant disabilities on Standards Australia Committee ME 64 which reviews and revises the Australian disability access Standards AS1428. Terry has long advocated the need for AS1428 to include shower facilities that suit people with walking difficulties. Earlier this year she reported that her advocacy had been successful. Terry is now seeking your input regarding back support in wheelchair-accessible toilets.

At the recent Standards meetings I was very pleased to get two types of shower facilities included in part 2 of AS1428. The two types of showers are for people with ambulant disabilities. One is to be installed in swimming pools, recreation centres, gyms and the like. Its features include a fold down seat in a dry area for undressing/dressing and storing equipment. One will be able to slide from a seat in a dry area to a seat in the wet area to shower and then return to the dry area without having to stand. It is a safer facility than the wheelchair accessible facility where one had to walk unsupported across a slippery floor with no dry area for dressing or storing mobility equipment.

The other shower will be installed in hotels/motels in new buildings. It will consist of a regular sized shower cubicle with no hob and a grabrail to provide safe entry to a fold-down seat and the adjustable shower head. The bathroom area outside the cubicle will be the place to undress, dry oneself, dress, and remove/replace equipment. Again, this is a safer option than using the wheelchair accessible facility. A chair would need to be placed outside the cubicle within the bathroom to serve as a dry area for dressing.

The other issue is back support in wheelchair accessible toilets. This is to be included in AS1428 part 1 which will be published in 2006 and will be mandatory. It is based on the UK back support model. Our design is similar to theirs except the back support will not be at the vertical. Ours will have an angle of 100 to 105 degrees which spinal injured people say will not provide support and believe that people with poor trunk control would fall off the toilet.

I would be interested in hearing from people who believe that back support should be at the vertical. I can then lobby Standards for the change. As there will not be public consultation of the draft it is vital that Standards make changes before publication. Your responses would help me in lobbying for the changes. You can contact me by phone (02) 9398 7820, fax (02) 9314 5791 or email <disaware@optusnet.com.au>.

Have You Made Your Will Yet ?

Our Office Co-ordinator, George Laszuk, gives readers some information about the importance of making a Will and how you might continue to support the Network and fellow polio survivors into the future. If you would like more information, please don't hesitate to get in contact with George.

This is probably a subject that we all like to avoid but our passing is inevitable and it is very important that we make sure our affairs are in order.

Did you know in Australia more than 30% of people die without leaving a valid Will? As a result, their assets are distributed according to law and not necessarily according to their wishes. Not having a Will can cause a great deal of worry and often a great deal of legal expense to your family. Peace of mind is important to us all, especially as we grow older.

There are four simple steps in making a Will

- 1. Choose an expert to help you.** Family solicitor or The Public Trustee.
- 2. Choose Your Beneficiaries.** Who you wish to benefit and to what extent. In addition to providing for your family you might consider charities etc.
- 3. Appoint an Executor and a Guardian if needed.** The person who will be responsible for seeing that your wishes are carried out.
- 4. Keep your Will safe and secure.** Many people leave their Will with their solicitor or trustee company. If you keep it yourself, make sure your Executor knows where it is and how to retrieve it.

This brings me to my other motive for writing this article, have you or would you consider including a bequest to a charitable organisation in your Will? Many such organisations derive a considerable proportion of their income from bequests; without this help they would cease to exist.

If so, why not make a bequest to the Network?

As you are probably aware the Network is a self-funded organisation and we are always trying to improve services to our membership, while keeping our costs low. With more and more polio survivors requiring our services, we need to expand and improve our facilities in order to continue to provide quality resources.

One area that we feel has potential to augment our resources without being a burden is accepting bequests from members of the community. Many wish to join us in our quest for better care and support for polio survivors but don't know how best to help.

All it requires is amending a Will to include the Network as a beneficiary of some part of the donor's estate. Bequests can be made for general or specific purposes.

If you would like to make a bequest, you should contact your solicitor or trustee for advice. For your information, the Network is incorporated under the Associations Incorporation Act and is an authority holder under the Charitable Fundraising Act. The Network is recognised by the Australian Taxation Office as a Public Benevolent Institution and endorsed by them as a Deductible Gift Recipient (Number 90 039 932 667).

Naturally your Will is confidential. However, if you decide to include a bequest to the Network and are willing to let us know, we can thank you personally for your generosity and forethought. If you would like any further information, just get in touch to see how we can help. Phone us (02 9890 0946), write to us (PO Box 888, Kensington NSW 1465) or email us (office@post-polionetwork.org.au) – what ever you feel comfortable with.



Post-Polio Network Seminar Program 2006

Saturday 4 March 2006	Northcott Society 1 Fennell Street Parramatta	Seminar – Maximising Cardiac Fitness for Polio Survivors presented by Cardiologist Dr David Rees <i>See full details on page 2</i>
Monday 15 May 2006	Northcott Society 1 Fennell Street Parramatta	Seminar – Anti-Inflammatory Strategies for PPS presented by Canadian molecular biologist and virologist Dr Marcia Falconer <i>See advance notification on page 4</i>
Friday 9 June 2006	Northcott Society 1 Fennell Street Parramatta	One Day Workshop – A Journey Through Loss conducted by Dr Cynthia Schultz <i>See advance notification on page 4</i>
To be advised	To be advised	Remaining Seminar dates and other details will be advised in the next issue of <i>Network News</i>

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Office Contact Details

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About the Network

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

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

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

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

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

Resources for Members

On joining the Network, members are issued with free resources including a brochure *Hospital, Medical And Dental Care For The Post-Polio Patient – A Handy Reference*, and a Medical Alert Card which can be carried in the wallet.

The Network also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for Network members and postage is included. To order, just write to the Network – please make cheques / money orders payable to Post-Polio Network (NSW) Inc.

Books etc (* indicates Post-Polio Network publication)	Size	Cost
<i>Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome</i> edited by Lauro S Halstead MD (see description below 📄)	240 pages	\$25.00 plus 10% GST
<i>A Practical Approach to the Late Effects of Polio</i> Charlotte Leboeuf	39 pages	\$2.50
<i>The Late Effects of Polio: Information for Health Care Providers</i> Charlotte Leboeuf	56 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 1st copy free
The Network has its own four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about the Network. Not only is the badge a great fashion statement, it is an innovative way to promote the Network.	23 mm x 23 mm	\$5.00 plus \$1 postage

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

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

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

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

If undeliverable return to:

Post-Polio Network (NSW) Inc

PO Box 888, Kensington NSW 1465

NETWORK NEWS

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