



# POST - POLIO NETWORK (NSW) INC.

## NETWORK NEWS

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### President's Corner

Gillian Thomas

Welcome to regular readers and new members alike to the first *Network News* for 2003. We had some unexpected publicity in December when the Post Polio Support Society of South Australia arranged to have an item on post polio included in the Centrelink magazine *News for Seniors*. This has generated a lot of enquiries and resulted in quite a number of new members.

This issue of *Network News* gives an update on our polio stories collection and includes an article with tips to help members get started on their own stories. You will also find reports on Network activities, an article and member's letter on making the transition to a wheelchair, the ever popular *Polio Particles*, meeting details for Network Support Groups, and much more. Our next Seminar will be held at the Northcott Society, Parramatta, on Saturday 1 March. Full details are on page 2.

Members of the Management Committee recently met with the NSW Minister for Disability Services, The Hon Carmel Tebbutt MLC, and her Senior Policy Advisor, Michael Refshauge. We received a very good hearing from a sympathetic Minister – in fact, our originally-scheduled half-hour meeting was extended to nearly an hour. At the conclusion, we were confident that we had brought our message home to the Minister, and that she has a much better understanding of polio, its late effects, and the numbers of polio survivors in NSW experiencing, or potentially experiencing, post-polio problems. As expected, the Minister did not offer immediate resources to the Network to enable it to consolidate and expand its operations in support of polio survivors – work no other organisation or government body is undertaking. The meeting was only one step in our campaign to bring post-polio to the attention of the NSW Government, its policy-makers and funding bodies. It is going to take sustained proactive action to secure sufficient resourcing. We must all take every opportunity to tell our local members about the problems we face and the lack of support services. This is especially important with a State election almost upon us. If anyone wants some background information to help you in your approach, please contact me by phone, mail or email.

Finally, we would like to congratulate Heidi Forrest on her election as President of People with Disabilities (NSW) (PwD). Heidi's involvement with the disability movement and PwD began in the early 1980's, when she began working as a volunteer at the Disabled Persons Resource Centre for the then Handicapped Persons Alliance. Heidi was later employed by Disabled Peoples International (NSW), and worked in various areas including administration and policy and development. Whilst working for PwD, she studied welfare for three years. At the completion of her course she moved back to her home town in the Hunter Valley, travelled overseas, married and now has two school-aged children. Besides representing the interests of people with disabilities at various levels in her local area, Heidi has been involved in internal committees of PwD and was a Director on the Board. Heidi believes involvement in the disability rights movement is not only rewarding but empowering. She is committed to the enhancement of the disability rights movement. The Network has been associated with PwD for many years and we look forward to working with Heidi and her team.

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# Orthotics Seminar

- Date:** Saturday, 1 March 2003
- 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  
2 Grose Street, Parramatta
- Parking:** Ample parking is available in the Parramatta Leagues Club car park at the end of the street (the venue is then a 100 metre walk away)  
Limited parking is available on the Northcott Society premises - it would be appreciated if those who are more mobile would leave this closer parking for members who are only able to walk or wheel short distances
- Transport:** Bus 600 will take you from Parramatta Railway Station to the Leagues Club across the road from the Northcott Society

Our first Seminar this year focuses on orthotics. Have you been told that you need an orthotic? With weaker muscles, is your current orthotic no longer meeting your needs? Or have you worn it into the ground and now find it needs to be refurbished or replaced? Who prescribes orthotics? Who makes orthotics and what do they cost? Do you know what options are available with regard to design or materials?

We have assembled a panel of orthotists to answer these and related questions. Following individual presentations covering their particular areas of expertise, illustrated by examples of various orthotics, the panel members will participate in a *Question and Answer* session. Have your questions ready!

**Richard Dyson-Holland** is with the Technical Orthopaedics Department of Otto Bock (Australasia) Pty Ltd. Richard will discuss in brief the spectrum of physical impairments that may affect PPN members and the opportunities that innovations in orthotics offer over currently available solutions. New materials, manufacturing processes and mechanical designs offer weight savings, increased freedom of movement and improved cosmesis. The concepts of laminated orthoses, pre-impregnated carbon composite orthoses and KAFOs with stance control knee joints will be presented. Benefits, drawbacks and costs of these newer techniques will be discussed.

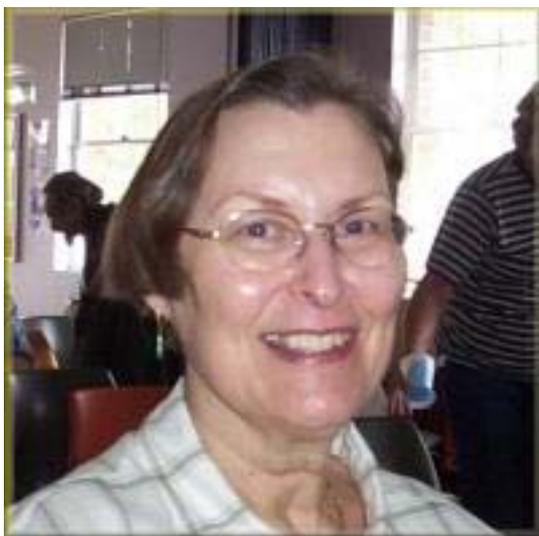
**Mark Raabe** was previously Sales Manager at Otto Bock. Over the last three years he has been building up his own company called Orthosynergy. He has recently taken on the role of orthotist at the St George Orthotic Clinic and reports he is seeing many polio clients. Mark's expertise includes a detailed knowledge of materials and fabrication techniques.

**Derek Lee** is the orthotist at Northcott Equipment Services and will be known to many members. Derek is at the "coal face" of orthotics manufacture and will tell us about the range of polio clients he sees, the unique challenges or problems they present with, and the types of orthotics he is making for them to address their specific needs.

*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.*

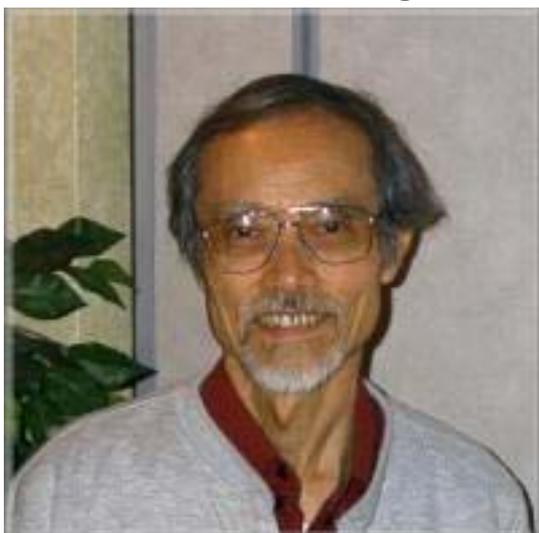
## New Faces on the Management Committee

*This occasional series introduces you to new faces on the Network's Management Committee. Ann-Mason joined the Committee at our 2002 Annual General Meeting. Bing and Bob joined the Committee at the 2001 AGM, but haven't previously been formally introduced to members.*



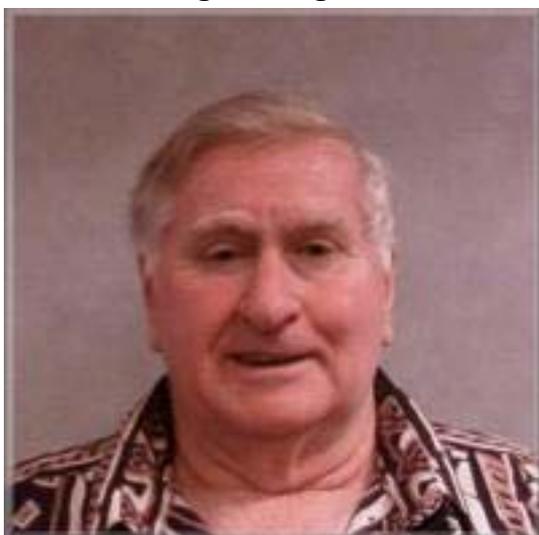
**Ann-Mason Furmage**

Ann-Mason contracted polio in the USA in 1950, at the age of 12. She now uses an electric wheelchair. Ann-Mason retired from full-time employment as an accountant and financial controller in 1996, when her post-polio symptoms became troublesome. Her interests and activities include the design and stitching of cross-stitch and tapestry, reading, attending concerts, serving on the local Disabled Access Committee for Burwood and, most importantly, the enjoyment and appreciation of her two adult daughters and her wonderful adolescent grand-daughter. Ann-Mason is particularly concerned with the effects of aging on post-polio affected persons.



**Bing Kwong Mak**

I came from China in the late 1950's as a student; after finishing my education, I stayed. My polio conditions were diagnosed in the mid-1990's by specialists in Sydney although my illness started in the late 1930's when some local (where I came from) and foreign physicians informed my parents that I was suffering from a different disease. Since 1995 I regularly attend the seminars of the PPN and am gaining more insight into the nature of the polio disease. I have led a fairly normal life although oftentime I am aware of my disability. My wife and I have a daughter and a son, and full time retirement is very much on my mind. My present activity is centred around my family.



**Bob Tonazzi**

I was diagnosed with Polio in early 1945, aged 5 years. I was first admitted to Prince Henry Hospital, and later transferred to the Children's Hospital Camperdown where I spent 4 months before returning home. I was born, raised, and still reside in the Eastern Suburbs of Sydney. I have been semi-retired since 1998 after 45 years in engineering with BHP. I first made contact with the Network 5 years ago, but put off joining while still working full time; I finally joined the Network in 1999. As the Network's Treasurer I am interested in helping to further the cause of the Network and its members.

# Falls, Fear of Falling and Activity in Older People with Polio: What can be done to help?

**Wendy Chaff**

*Roving Reporter Wendy Chaff, Convener of the Network's Hunter Area Support Group, has kindly written this account of Dr Keith Hill's presentation on falls prevention at our AGM/Seminar on 30 November 2002. We are very grateful to Wendy for the time she put into this report which gives members who were not able to attend an understanding of the material presented by Dr Hill. Copies of the slides used in Dr Hill's presentation are available on request from the Network, as is an audio tape recording. Contact us for more information.*

Guest speaker Dr Keith Hill, Physiotherapist & Senior Research Fellow, from the National Ageing Research Institute, Melbourne, told us there is encouraging evidence that fall prevention strategies can reduce the likelihood of falls, then proceeded with his interesting presentation illustrated with detailed slides.

While a lot of research has been done into falls prevention generally, there has been very little research here or elsewhere on falls connected with polio and how survivors can best be helped, but hopefully that will improve. As there have been no randomised-controlled trials conducted into falls prevention for older people with late effects of polio, it is necessary to extrapolate from other research and clinical best practice.

To show the magnitude of the problem in the community, one-third of **all** people over the age of 65 have a fall at least once a year, and some have many falls. Ten percent of all falls in the home result in serious injury or fracture. Falling is the greatest fear of 25% of older people generally. Balance dysfunction in older people is a major public health problem. Health care costs in Australia for falls-related injuries among those aged over 55 years were estimated at \$2,369 million annually (in 1994). Other than physical injuries there are the psychological and emotional results to consider. Surely prevention is better than cure.

There are common factors that go hand in hand with growing older and contribute to our potential to have falls. While a person's state of health is a major part, there are also environment and activity related risks. Medications are an extremely important factor – anyone on 4 medications or more has a moderate risk of falls. In particular, psychoactive medications (such as sleeping tablets) make balance reactions slower. If someone remains on a medication for years, it must be regularly reviewed in case adjustments need to be made. After any fall it is vital to have a check-up to find out what may have contributed, and how to avoid it happening again.

## **Risk Factors commonly associated with fallers**

- Previous falls.
- Lower extremity weakness.
- Arthritis in hips/knees.
- Gait/balance disorders.
- Bladder problems (incontinence, urgency, frequency, night calls).
- Visual disorders.
- Medications (psychotropics, sedatives, hypnotics, anti-hypertensives).

## **What preventatives work?**

Dr Hill said there is good research evidence that a number of single interventions can reduce falls for older people in the community - but not with instant results. For example:

- Exercise (home exercise; tai chi; group exercise) - at least once a week for 3-4 months.
- Vitamin D and Calcium supplementation can be most effective. Vitamin D affects bone structure and sunlight exposure is often not enough, as we cover up more; 15-20 minutes per day is recommended, and a lot of older people are not getting that.
- Psychotropic medication withdrawal – gradual slow weaning can be effective.
- Home visits by Occupational Therapists – to identify falls hazards.
- A Falls Risk Assessment, as a basis for multiple interventions, has also been shown to be effective.

Leading on from these general findings, Dr Hill then focused on aspects that concern polio survivors, who frequently report falls. He emphasised that all falls should be investigated as to cause, circumstance and consequence.

### **Falls risk and the person with polio**

Primary risk factors are muscle weakness, asymmetric limb length, plus ageing. Secondary risk factors are postural alignment change, pain, musculoskeletal adaptation, and surgical procedures.

### **What works in falls prevention for older people with polio?**

Dr Keith Hill and Amber Stinson carried out a detailed survey of falls over 12 months, on a sample of 28 (anonymous) respondents from the Eastern Polio Support Group in Victoria. This sample group consisted of 7 men and 21 women (mean age 66.2 years). Of these, 46% lived at home alone, while 46% lived at home with family or a carer; 61% reported being fearful of falling.

### **Falls**

Fourteen people (50%) reported having a total of 35 falls. Of these, 50% reported only 1 fall in the last 12 months, while 50% reported multiple falls, with 10 being the most. There was no significant difference in age or gender for fallers and non-fallers. The most recent 4 falls were analysed.

### **Circumstances of falls**

- Activities prior to falling: walking 63%, turning 9%, bending 6%, carrying/lifting 6%, reaching 3%, other 13%.
- Location: 52% occurred indoors; 23% were not able to get up after fall.
- Obstacles involved: uneven path 17%, indoor object 14%, slippery surface 10%, step 7%, slippery object 3%, nil obstacle 48%.
- Glasses worn during fall: don't wear 36%, bifocals 33%, use but not worn 21%, normal distance glasses 14%.

### **Interventions undertaken to reduce risk of falls**

Dr Hill described a wide range of interventions the polio survivors had undertaken which aimed to reduce falls.

- Had vision checked 43%.
- Review of medication by doctor 25%.
- Home exercise program 21%.
- Specialist regarding osteoporosis 18%.
- Changed walking aid 14%.
- Podiatrist for foot and footwear care 14%.
- Hydrotherapy 14%.
- Supervised exercise program by Physiotherapist 11%.
- Had a bone scan 11%.

- Home assessment by Occupational Therapist 11%.
- Modifications to home 7%.
- Dietician 7%.
- Had a review by a Falls Clinic 7%.
- Bought hip protector undergarments 4%.

### **Clinical implications**

- Need to explore causes of new falls in people with polio.
- Education regarding PPS and new problems.
- Introduce multiple risk factor reduction strategies.
- Encourage maintenance of activity levels (monitor fatigue).
- Closely monitor exercise and balance programs.
- Further research is needed.

### **Hydrotherapy appears a practical, acceptable form of exercise for older polio survivors**

Keith Hill gave details of a single case study design he conducted at Geelong, with Stephanie Millard and Toni Hogg, to evaluate the effectiveness of hydrotherapy on people with polio. Over a period of 8 months a woman aged 52 with PPS, who had averaged 8-10 falls per month to begin with, took part in a hydrotherapy program once a week. She was regularly measured for balance, gait, mobility and muscle strength. In the last 2 months of the study no falls were experienced and the woman reported a marked improvement in confidence with gait and ability to save herself from falls.

Explore your options. Temperatures in hydrotherapy pools can vary (from 29° to 35°). Indoor pools may be warmer. Check beforehand if the temperature will suit your needs.

From other recent research on strength and balance in polio survivors conducted by Dr Steven Lord in Sydney and Silver & Aiello in USA (2002): "Both muscle weakness and poor balance were independent predictors of falls risk". Over 12 months 64% had falls, 67% had multiple falls and 35% sustained fractures. [Ed. see *Mary Westbrook's Polio Particles in Network News Issue 56, December 2002, page 18, for more details of this research.*]

### **Discussion points**

There is a need to make polio survivors more aware of the most effective ways to avoid or cope with falling. One thing is clear – there is a poorer outcome the longer the wait to minimise possible risks. Activities seem more likely to be curtailed after experiencing a fall. Unfamiliar or changed surroundings can lessen confidence. The majority of environmental hazards within the home are more easily rectified than those outdoors. An Occupational Therapist can assess your home for potential falls hazards and recommend modifications.

To balance effectively needs good sensory information. Visually, using bifocals appears to be a high risk factor. Having two pairs of glasses may lessen the risk of a fracture. From your own viewpoint – how often do you make misjudgements, and will you be so lucky next time? Is there sufficient light, or too much glare? Vertigo sensation of "room spinning" is fairly likely to be something to do with the ears, and requires investigation. Crystals in the inner ear can degenerate with ageing or due to a knock to the head. These crystals sit in a fluid while staying still, but turning, or standing up from sitting or lying down could cause dizziness. A "black-out" or fainting spell definitely needs a prompt check-up. It was suggested that one's bio-rhythms may have an effect.

After a fall or near fall, monitor your activities and timing to compare to other falls – write down all relevant details. Consider all possible contributors to your falling, then discuss and review with your GP, for an opinion and referral if required.

Polio affected limbs often have weaker bones, as can be shown in the difference between a paralysed leg and “good” leg. Help is needed to strengthen, preserve, and hold off further decline. Supplementation with Vitamin D and calcium can be beneficial. Bone scans can check the possibility of osteoarthritis and osteoporosis.

How to manage getting up after a fall concerned many of our members, and various methods were discussed. Depending on flexibility, the most common way is to roll over onto the stronger side, crawl until able to reach something to use for leverage, or back into a corner. Some members keep a garden kneeler with handles on standby inside and outside. These can be useful for getting into low cupboards or the bottom of the refrigerator. A typist’s chair dropped down to its lowest level can prove useful. Find out how to fall in a safe way – as taught in karate, for example.

There are a number of specialist *Falls and Balance Clinics* in both Victoria and other states. In country areas there is a shortage of physiotherapists and occupational therapists in aged care, which is not as attractive as the more glamorous sports injury field.

Physiotherapists assess and advise individuals about ways to help particular problems. Keep an honest check on exercises and do them safely – if necessary, modify to suit yourself. To be effective, balance exercises cannot include hand support – you should be safely boxed in by a chair, bench, or a wall within reach. Gradual introduction to an exercise routine is best – do less more frequently, in small doses, rather than too much at once. Home exercise programs can be individually tailored and explained, and can be more appropriate than group exercises. If you have a problem or feel pain – don’t be stoic or ‘soldier on’. Stop and contact your physiotherapist. Communicate!

### **Feet and footwear**

Wide base of support is important for effective gait; so for more feet contact with floor, wider or larger-sized shoes/boots with orthoses (custom-made inserts to realign foot imbalances) could make a difference.

### **Walking aids**

While issues of independence, pride and appearance may be a concern, they are trade-offs outweighed by the safety aspects and other benefits. The more stable the walking aid the better. Maintenance is important, for example, rubber tips on walkers or sticks can get very worn and pose a risk. You need a walking frame most when turning around.

### **Injury minimisation**

Hip protectors are undergarments with pads or shields that slip into pockets. These really work like “crash helmets for hips” by absorbing the impact of a fall to protect the hip from damage, reducing the risk of fractures. [*The Safehip hip protector (endorsed by the Australian Physiotherapy Association) is available from Abena-Sanicare Australia, phone (02) 9437 9611.*]

Personal alarm systems can include cordless telephones, mobile phones, a buzzer alarm, and personal response systems – emergency call buttons or pendant alarms [e.g. Vital Call] – work out what suits you best, preferably something you can carry around with you.

In summary, Dr Hill indicated that from the limited data specific to older people with polio available, there appears to be a high rate of falls causing injury. However, from a positive point of view, there is increasing evidence that it is possible to reduce the risk of falls with a targeted falls prevention program. We each need to take personal responsibility for our own protection. Falls are never expected, but you can recognise danger zones and take precautions, just in case.

In thanking Dr Hill for his most informative presentation, Merle Thompson mentioned her own experience of going from 9 falls in 3 days, to 1 in 12 months after she started wearing callipers 7 years ago. She reminded us that when there is something that can help make you safer, even if it might be ugly (like callipers or bigger shoes), don't let vanity or self-consciousness keep you from using it.

Merle passed on our grateful thanks to Keith for generously giving up his Saturday to travel from Melbourne to help make us more aware of our falls potential and preventative strategies that work. As a memento Merle presented Dr Hill with a wooden platter together with one of our badges featuring the polio virus logo.

In view of time limitations, it was greatly appreciated that Dr Hill remained available during afternoon tea time for individual members to approach with personal questions.

**Verdict:** A rewarding seminar that was well worth attending.



## FDR Talks About His Paralysis

*The following letter written by Franklin Roosevelt in 1924 recently caught my eye. The letter is reprinted with kind permission from Polio Post News, North Central Florida Post-Polio Support Group, January 2003 (previously published in The Polio Heroes of Tennessee Newsletter, July 1996).*

Warm Springs, Georgia, October 11 1924

My Dear Dr Egleston  
Hartsville, SC

Please excuse my delay in replying to your letter which has been forwarded to me down here in your neighboring state where I am spending a few weeks swimming and getting sunlight for my legs. I am very glad to tell you what I can in regard to my case, and as I have talked it over with a great many doctors can, I think, give you a history of the case that would be equal to theirs.

First symptoms of the illness appeared in August 1921, when I was thoroughly tired from overwork ...

In February 1922 braces were fitted on both legs from the hips to the shoes, and I was able to stand up and learned gradually to walk with crutches. At the same time, gentle progressive exercises were begun ...

The recovery of muscle paralysis began at this time, though it seemed for many months I made very little progress. In the summer of 1922, I began swimming and it seemed that this exercise seemed better adapted than any other because all the weight was removed from my legs and I was able to move the legs in the water far better than I had expected. Since that time I have carried out practically the same treatment with the result that muscles have increased in power to a remarkable extent ...

One year ago, I was able to stand in fresh water without braces when the water was up to my chin. Six months ago, I could stand in water up to the top of my shoulders and today can stand in water just level with my armpits.

To sum up, I would give you the following "don'ts":

- Don't use heavy massage but use light massage ... toward the heart.
- Don't let the patient over exercise any muscles or get tired.
- Don't let the patient feel cold, especially the legs, feet or any other part affected.
- Progress stops entirely when the legs or feet are cold.
- Don't let the patient get too fat.

The following treatment is so far the best judging from my own experience and that of hundreds of other cases which I have studied:

- Gentle exercise especially for the muscles which seem to be the worst affected.
- Gentle skin rubbing – not muscle kneading – bearing in mind that good circulation is a prime requisite.
- Swimming in warm water – lots of it.
- Sunlight – all the patient can get.
- Belief on the patient's part that the muscles are coming back and will eventually regain recovery of the affected parts.

I hope that your patient has not got a very severe case. They all differ, of course, in the degree in which the parts are affected. If braces are necessary, remember that [they] are only for the convenience of the patient in getting around – a leg brace does not have a chance for muscle development. This muscle development must come through exercise when the brace is not on ...

I trust that your own daughter is wholly well again.

Very truly yours

Franklin Roosevelt



## Rotary to Celebrate Polio Eradication

*We have recently been alerted to an upcoming exhibition, to be staged by Rotary in Canberra, which will focus on the world-wide polio eradication program.*

An exhibition to be mounted at the National Museum of Australia from December 2004 to February 2005 will feature the world-wide polio eradication program, which Rotary International initiated in 1985. Joined by WHO, UNICEF and US Centres for Disease Control, the aim of a polio-free world is expected to be achieved by the Centenary of Rotary in February 2005.

The Rotary Australia Centenary Exhibition (RACE) will include award winning photographs, items used in National Immunisation Days, objects used in polio treatment (including iron lungs), Movietone News clips, film of Sister Kenny, video on the polio eradication work, and interactive electronic telecommunications. Thanks to the Network, RACE will also include information about the late effects of polio.

If you are interested in knowing more, or if you can contribute items or ideas to RACE, please contact:

Dr Kris Klugman, Chair, RACE  
 President, Rotary Club of Canberra Burley Griffin  
 Postal address: 51 Ardlethan Street, Fisher ACT 2611  
 Phone: (02) 6288 6137 Email: klugman@netspeed.com.au

# Polio Particles

Mary Westbrook

*Polio Particles is compiled by Mary Westbrook as items in the press or professional journals catch her eye. Included in this series are brief reviews of books on polio or post-polio, updates on post-polio research, information about immunisation and the status of global polio eradication, and other items of interest. Mary's series is now being syndicated around the world as other post-polio newsletter editors pick up on the interesting items Mary includes.*

## Nana needs a nap

One afternoon Canadian polio survivor, Beryl Baker, *was out with our seven year old granddaughter. When she asked me why both of her parents and her grandfather worked out at the local gym and I didn't, I explained as best I could about me having Polio as a child and now I had Post-Polio Syndrome. It was at that moment I decided that I needed a book to explain the symptoms of Post-Polio Syndrome.* The book is written from the perspective of a grandchild and has amusing, colourful illustrations. It tells how Nana contracted polio, gradually recovered, and got on with her life. When the grandchildren arrived Nana loved playing with them but things started to go wrong. *Nana's muscles had stopped working properly. She would get very tired. Nana had a problem called fatigue. That's even worse than being tired.* Nana developed many symptoms of PPS and has had to find ways of coping. *When I go to visit Nana and she's in bed, I just get a video and crawl in beside her, because she'll watch whatever video I put in the machine ... she'll let me use some of her blankets to make a fort.* Her granddaughter has learnt when to say 'Nana, you need a nap'. The book costs \$US9.95 (plus postage). You can order it by mail from Computer Elite, 3105 Hwy 11 East, RR2, Oro Station, Ontario, Canada, L0L 2E0 charging it to VISA or MasterCard (give name on card, card number and expiry date). It can also be ordered by phone (1 705 487 6595). Computer Elite is open Monday to Friday from 1 am to 2 pm (Australian eastern summer time).

## Synthetic polio virus manufactured

Dr Eckard Wimmer, head of a biomedical research team at the State University of New York made a polio virus in a project funded by the Pentagon to combat biological warfare. Reporting on US Tech Live TV, Jessica Rappaport said that what is disturbing is that the team re-created the virus by using the Internet to obtain the virus' genome sequence. It took three years to create the virus. Wimmer says he choose polio because *it's a relatively simple virus. Re-creating a virus like smallpox would be much more complicated.* Wimmer says the ability to manufacture polio means that even if polio becomes extinct people will still need to be vaccinated and vaccines will need to be stockpiled because of the threat of terrorism.

## Polio in Madagascar

In March-April 2002, four cases of paralytic polio were reported in Madagascar. None of the children affected had been fully vaccinated. The strain of the virus was a type-2 vaccine-derived virus which had mutated and recombined with non-polio enteroviruses. The danger of Sabin vaccine virus mutating and affecting non-vaccinated people was discussed in this column in *Network News* Issue 48.

## West Nile virus mimics the effects of polio

There were numerous recent news releases about the US outbreak of the mosquito-borne West Nile virus and the surprising symptoms it is causing in some of those infected. The Boston Globe (24/9/02) described *stunned neurologists* in Mississippi and Georgia reporting patients *suffering from the hobbled limbs, impaired breathing, and fevers that are the hallmark of polio*. Patients are also enduring *prolonged muscle weakness and respiratory ailments that will require months of treatment and probably will disable some of the patients permanently*. As with polio the symptoms tend to be asymmetrical, for example, one leg affected. The West Nile virus which is common in Africa and the Middle East was first detected in the US in 1999. Mosquitoes acquire the virus from birds and pass it on to other species. The description of the infection will sound familiar to polio survivors. Most people who are infected develop no symptoms, or flu-like symptoms. About one percent becomes severely ill with encephalitis or meningitis and about 10% of these people die. The West Nile virus comes from a different group of viruses than poliovirus. In the polio-like cases of West Nile the virus attacks the grey matter of the spinal cord which contains the neurones that cause muscle movement. Only a small number of polio-like cases have been reported but is now believed that many patients with West Nile virus may have been misdiagnosed, for example, as having Guillain-Barre Syndrome, and prescribed potentially life-threatening treatments. In the past severe West Nile was characterized by meningitis and encephalitis but the muscle weakness and other symptoms similar to polio were not evident. *Nature* (23/10/02) says that *the West Nile virus and its infection pattern may be changing over time — attacking other parts of the nervous system beside the brain ... The US population might be particularly susceptible to attack by the virus. Unlike populations in regions where West Nile is endemic, they may lack natural immunity. Alternatively, the virus itself could be different. 'There does seem to be an evolutionary change in the virus', says neurologist Richard Johnson of Johns Hopkins University. The US strain seems to attack the nervous system more*. There is no vaccine or any specific treatment for West Nile virus apart from supportive care. There is no effective treatment for West Nile's polio-like symptoms and doctors are unsure will happen to these patients in the long term.

## Did older people have polio more severely?

For many years it has been accepted wisdom that the severity of polio increased with age at infection; older patients being more likely to develop paralysis or die from the disease. To find out whether this is so, a group of Danish researchers, headed by Nete Nielson, examined the patient records of 5590 people who contracted polio between 1940 and 1953 and were admitted to the main infectious disease hospital in Copenhagen. They found that severity of polio (measured by rates of paralysis and death) did not show a steady increase with age, but rather a U-shaped graph with severity being greatest for youngest and oldest patients. Fifty-three percent of children under 2 had a discharge diagnosis of paralytic polio. The rate decreased to 20% among those aged 8-9 years and increased to 43% among those over 35 years. The steep increase in severity of polio among young adults was associated with a change in type of paralysis, with respiratory paralysis being much more frequent. The researchers speculate that this was caused by differences in the commonest mode of transmission of the polio virus for children and adults. *The faecal-oral route of transmission is usually considered the main mode of virus spread, but as the virus is present in the pharynx, droplet spread from person to person is possible*. As adults have better sanitary practices than children they may more often infected via droplet spread. *Furthermore it has been suggested that bulbar symptoms might result from infection with the virus through the tonsillo-pharyngeal route, whereas gastro-intestinal infection might initially result in paralysis of the legs*. (International Journal of Epidemiology, 2002, p. 181)

## Survivors of vaccine associated polio

VAPS (*The Vaccine Associated Polio Society*) is an American organization dedicated to solving the problems faced by people with VAPP (vaccine associated paralytic polio). Its website, which is still partly under construction, can be found at <[www.vaps.us](http://www.vaps.us)>. VAPS estimates that there are at least 8-10 cases of VAPP in the US each year. It believes that some cases are misdiagnosed and that in reality the figures are higher than this. As its mission statement proclaims while VAPS is *pro immunization* it is *pro safe polio vaccine*. The society has influenced current US polio vaccination policies which now favour the Salk over the Sabin, or live, vaccine.

*Ed. The 7<sup>th</sup> Edition of The Australian Immunisation Handbook (which is currently under revision) estimates that "1 case of VAPP occurs for every 2.5 million doses of OPV [Sabin oral vaccine] distributed. The risk is greater for the first dose than for subsequent doses and is slightly greater for adults than children." As reported in Network News Issue 53 (March 2002) the head of the Health Department's Communicable Diseases Branch, Greg Sam, says the planned replacement of oral Sabin with an inactive injectable vaccine will eliminate the rare adverse reactions. We are expecting this replacement to occur in 2003.*

## Mice may provide answers about cause of PPS

Neurologist Dr Burk Jubelt and his colleagues are using mice in research to test the truth of the three principal theories that attempt to explain post-polio syndrome. Jubelt and his colleagues infected a group of mice with polio and are comparing their muscle function and nerve damage with a group of non-infected mice. Later the mice were sacrificed and their tissue analysed. Findings of the research will be published soon. A group of mature mice, analogous to older polio survivors, is currently being studied. The theories being evaluated are: 1) The most popular, degenerative theory, which *postulates that the new sprouts which grew to substitute for the sprouts killed by the original infection are dying back due to exhaustion from increased metabolic demand over years of use.* 2) The viral theory that argues that the polio virus has either *lain dormant in the central nervous system or mutated into a form that is slowly destroying nerve tissue.* 3) The immune mediated theory that argues that *inflammation or an autoimmune mechanism has led to the symptoms.* Jubelt believes that once the cause of PPS is established mice can be used to test the efficacy of different treatments for symptoms. (This story is from *Polio Network News*, Fall, 2002).

*Ed. I contacted Dr Jubelt to see if more information is available yet. He replied "We will be finishing this first study and writing the paper in March for submission this Spring". We will bring you an update on the research findings as soon as they are available.*

## PPS costs minister his job

Tom Zingale, an American polio survivor, is a Lutheran minister. Last year PPS resulted in him being prescribed a wheelchair. His congregation and bishop found it more difficult to adjust than Tom did and against his wishes Zingale was forced to retire. *New Mobility* (December 2002) reports that in his farewell sermon Zingale said: *I am tired of those who play games with my faith by accusing me that because God's glory has not been manifested in some visible way, in total healing, that I am any less a Christian, or have a weak faith, or have a hidden sin, which an anonymous tape accused me since I remain in the brokenness of chronic illness.* Zingale says much of the suffering of people with disabilities is caused by Christians who subscribe to the view that *if you're right with God, everything's right in your life, that you have health, wealth and prosperity. I believe in the theology of the cross, because Jesus died on a cross and through the brokenness of the world we have strength from God to go on.* In his 'retirement' Zingale has become a locum

pastor for ministers on vacation and has established a website called [www.dodgenet.com/~tzingale/SermonIIIst.html](http://www.dodgenet.com/~tzingale/SermonIIIst.html) which averages 350 hits a week. He says: *When I was in the parish, the most people who would come to church on Sunday was about 150, so more people are reading my stuff now.*

To audit the barriers (attitudinal, architectural and communication) to people with disabilities being part of the congregation in your church go to the questionnaire on the website of the American National Organization on Disability at [www.nod.org/cont/dsp\\_cont\\_item\\_view.cfm?viewType=itemView&contentId=547](http://www.nod.org/cont/dsp_cont_item_view.cfm?viewType=itemView&contentId=547)

Some items query whether the church has: *Seating space with extra leg room for people using crutches, walkers, braces or casts; scattered spaces or 'pew cuts' for users of wheelchairs; large print hymnals; and marked accessible parking spaces close to accessible entrances.*



## Every man and his dog should know about Post-Polio Syndrome !



Remember this picture of Allan and his assistance dog, Jacko, from last year's Post-Polio Awareness Week poster? Allan and Jacko encouraged all polio survivors to find out about the late effects of polio by contacting the Network. The poster was very successful and we received a lot of enquiries. However, it seems from a recent item in *Post Polio News*, the Newsletter of the Post Polio Support Group of South Australia, that our poster's message may have had an unexpected interpretation. It was reported that while in Cleve on an annual field day talking to polio survivors "one gentleman asked me for some information on post polio for his 16 month old Alaskan Malamute ... he saw the dog poster (a man with post polio with a dog) and presumed that dogs got polio and post-polio syndrome" !

## Network Member Wins Access Award

*One of our "spies" sent a clipping from the "North Shore Times" of 8 January 2003 and so we learnt that long-time member Shirley Bevan has recently won an award. Well done Shirley! If you know of any members who have received recognition for their community work please drop us a line so we can congratulate them in their Newsletter. Here are some excerpts from the news item.*

North Sydney Council marked the International Day of Disability by announcing the winners of its Community Access Awards for 2002 at a recent presentation.

The awards were set up in 1998 to recognise the achievements of individuals and organisations that have made particular efforts to support the needs of disabled people in the council's area.

Operating under the motto "Access For All", awards are given for initiatives or programs that increase access for the disabled to services that others in the community take for granted. More than 20 nominations were received for this year's three awards.

Shirley Bevan's award was in the category "advocacy on behalf of people with disabilities" and recognised "her work on various committees supporting the disabled, particularly the North Sydney Access Committee".

# Transitioning To A Wheelchair - An Exploration of our Fundamental Fears

Linda Wheeler Donahue

*Linda Wheeler Donahue is a polio survivor, Professor Emeritus of Humanities, and the President of The Polio Outreach of Connecticut. She is a frequent speaker at conferences, focusing on the social/emotional complexities of disability. As a result of her grassroots advocacy work, President George Bush Sr invited Linda to the White House Rose Garden signing of the Americans with Disabilities Act on 26 July 1990. Professor Donahue has published numerous articles on subjects of positive living, disability dignity, and increasing happiness through conscious choices. She welcomes feedback and can be reached at <LinOnnLine@aol.com>.*

*Transitioning to a wheelchair has been a hot topic on the Network's web Forum recently. To encourage further debate, our eagle-eyed Web Site Liaison Officer, Peter Preneas, posted a link on the Forum to an earlier version of this article. In asking Linda for permission to reprint her thoughtful words for the benefit of all members, she very generously provided this updated version, together with some thoughts on "Positive Points of Using a Wheelchair".*

When actor Christopher Reeve sustained his spinal cord injury in a horse riding accident, his transition from *Superman* to *Man in Wheelchair* was instant. In contrast, we polio survivors usually go through a lengthy, angst-ridden decision making process before we plunk ourselves down in one.

We listen to the recommendation of our physicians and we sheepishly explore the idea with our loved ones. We recognize that using a wheelchair would keep us from tripping and falling. It would help us conserve our limited energy and sure would make daily life a lot easier. Why, then, is this decision so emotionally intricate and agonizing?

## ***You were paralyzed by polio; do not be paralyzed by society!***

Let's go all the way back to the beginning. Like many of you, I contracted polio as a baby and endured a long hospitalization. I was separated from my family at the tender age of 18 months, and still have psychological wounds from that trauma. I emerged using braces and crutches for mobility. However, doctors encouraged eliminating these aids so that I could walk like "normal" people. Does this sound like you?

Many polio survivors made an impressive recovery, walking unaided for decades, only to find that about 30 years later, they had excessive weakness, fatigue, and pain. At that point, many of us were diagnosed with post-polio syndrome. We were now told to go back to using a cane or braces and crutches to walk.

## ***Life is much more difficult with PPS***

Striving to walk as "normal" people at a very young age taught us that reaching that goal, that ideal, was success. Therefore, it is understandable that many of us equate our new muscle weakness, and need for physical aid, with failure. That could not be farther from the truth! One of the biggest obstacles to our self-acceptance is realizing that when we embrace our wheelchair or our braces, in essence we are embracing ourselves. When we conserve our strength, we succeed in the task of being whole, much more so than when we push through the pain and fatigue.

Are you declining activities that involve walking? Do you sit back and reluctantly stay home, unable to do some of the activities you once enjoyed due to increased weakness, pain, fatigue, fear of falling, and lack of endurance?

Did you once adore pop concerts in the park? But decline to go now because walking on uneven grass is far too difficult? ***Do you choose to stay home?***

Did you once savor the fun of cruising the mall with your daughter-in-law? But decline to go now because that much weight-bearing and walking is far too painful. ***Do you choose to stay home?***

Did you once thrill to walk the boardwalk at the beach absorbing the sights and sounds of the ocean, but decline now because the length of that long, winding boardwalk is too much to manage without pain and fatigue? ***Do you choose to stay home?***

Have your polio medical professionals recognized that the time has come for you to use adaptive equipment for most of your mobility needs? Does the thought of ***appearing in public*** in a brace, crutch, or wheelchair fill you with dread? The key phrase there is “appearing in public”. Alone in your home, you may love the way a wheelchair allows you to move smoothly, gracefully, and without pain and fatigue, but the image that most terrifies you is the thought of using a wheelchair out in public. Your emotions overflow with panic and anxiety. Why? You realize on a rational level that using a wheelchair or other assistive device would be very liberating. However, that rational base is overpowered, indeed almost buried, by the negative emotional overtones that shout: “No! No! No medical equipment for me!”

### ***Let's examine the underlying origin for this resistance***

- As a child, you received considerable praise for your attempts to walk unaided.
- Society places an inordinately high value on walking.
- The wheelchair makes it virtually impossible to be a “passer”, that is, to pretend you are able-bodied.
- Indeed, it is the image of a wheelchair that is the universal symbol of disability.
- Much of your *positive* self-esteem is wrapped up in the fact that you are still able to walk.

These are some of the contributing factors in your resistance to using a wheelchair. However, we have only examined the surface reasons.

The deeper, overriding reasons for your reluctance stem from a negative association of ideas. Think of it like an algebraic equation: YOU are on one side of the equation and DISABLED is on the other side. Especially if you have been walking unaided, or “passing”, you don't feel like you belong on the DISABLED side of that equation. Your association of that side is laden with shameful emotional overtones. Why?

One reason is that historically people with disabilities have been stigmatized. They occupy a low rung on society's ladder. I remember the various social cliques in high school. Back in the 50's, teenagers were ranked in hierarchical order as “Preppies”, “Jocks”, “Greasers”, and “Nerds”. The most popular kids were the Preppies and the least popular were the Nerds. The terms today may have changed, but the hierarchy remains very much intact.

Very few handicapped kids land in the popular crowd. In a time when adolescents are learning how they fit into society, the message to many disabled kids is “you don't belong”. We absorbed that message like water into a sponge. As we grew up, society's hierarchical classifications undergo various transformations. The discrimination is not as overt, but is still there. I have a sense that most of us still long to belong to the “popular crowd” and for many, the ticket in is pretending you do not have a disability.

Our resistance to using a wheelchair is intimately connected to our unwanted view of ourselves as disabled. We have integrated the societal message that it is better to be

ambulatory than to be in a chair. Often that message is reinforced in our everyday interaction with the world. For example, there could hardly be a greater medical triumph than getting someone “up out of a wheelchair”. Consider the hidden negatives in our language: “wheelchair bound”, “confined to a wheelchair”.

Almost universally, people who are not totally wheelchair dependent, make too little use of the wheelchair, if they are willing to use it at all. Likewise, people who are gait impaired but not crutch dependent, make far too little use of crutches, if they are willing to use them at all. “I’m not *THAT* disabled” or “I don’t *NEED* them” are rationalized as sufficient reasons to forgo the enhanced function, ease, safety, and health benefits they could have from using adaptive aids.

When a polio survivor chooses to transition to assistive equipment, he/she faces emotional, interpersonal, and social issues that can be deeply troubling and anxiety producing. I have always walked with a severely compromised gate, but as long as I was walking, I too saw myself on the opposite side of the disability equation. How my heart pounded with dread and self-consciousness the first semester I wheeled into a faculty meeting. That wheelchair gets the credit for “outing” me. I now had to admit to the world, and more importantly, to myself, that I was, indeed, a Person with a Disability. But ever since that day . . . oh, the liberation that has been mine!

### ***. . . oh, the liberation that has been mine!***

It is an important healing step to incorporate the belief that is OK to be YOU. Know that the consumer driven, stereotypical images of “attractive” and “popular” are oppressive falsehoods rather than the truth. It is stunningly attractive and appealing for a person with a disability to exhibit confidence and self-acceptance. We all admire people with confidence . . . *including* people with disabilities. We have the power to change some of the prejudices and false perceptions of our society. Most of society is not used to seeing confidence and self-assuredness in someone who is disabled. Do not accept that preconception. Be as vivacious in your chair or with your brace as you were when you walked unaided. That exhibition of confidence is our best weapon to break the old mould and change prejudices.

When you live with confidence and self-acceptance, it is amazing how easy it is to transition to adaptive equipment and make the changes that will add so much to the quality of your life. When you live your life “out” in the open, you will witness people around you change their preconceived notions of disability. When you see their positive responses and you realize that their response is to YOU, as you are, you will be freed. You will receive positive reaction to the real you, not despite your disability, nor because they are unaware of your disability, but to the whole YOU. You will shed a burden you may have carried for most of your life.

### ***The good news is that the stigma is diminishing***

Societal attitudes about people with disabilities are vastly more accepting today than they were in the doo-wop era of the Fifties. Are you still suffering from antiquated tapes playing incessantly on your mental tape recorder? If so, it is time to erase those old tapes. You can trade in your negative thought patterns for powerful new positive beliefs. You can liberate yourself and claim your rightful place in society.

If you love the comfort and ease of using assistive devices in private, but dread the thought of using these out in public, you can use the power of your human consciousness to restructure your perceptions and free yourself. You may not have control of your body but you certainly do of your thoughts. If we want society to change its idea about people using adaptive equipment such as wheelchairs, we have to start by changing our own thoughts.

All you have to do is change your mind ... That may sound simple, but it is very powerful. You will be amazed at how easy the rest falls into place.

### ***All you have to do is change your mind***

Think about sitting proudly, head held high, in your sleek manual chair or perhaps zipping around in your sporty, power-chair. Imagine your security in your new orthotic brace. Visualize yourself manoeuvring gracefully over the grass at the pops concert in the park. How lovely the grounds look when you are no longer fearful of tripping. How sweet the evening air, as the melodic musical sounds touch your heart.

Picture yourself on a swift mobility scooter at the shopping mall with your favorite friend, scooping up bargains. You don't have to shop till you drop, you will still have energy left over to go out to dinner at the end of your day.

Envision yourself traveling the length of the boardwalk at the ocean. Your senses overflow with the ambiance of the seashore. Since you have no pain or fatigue, you are much more free to hear the seagulls, smell the salty sea breeze, and celebrate the sheer joy of an outdoor experience.

### ***I know that this is still a difficult decision***

The key to solving your disability equation is confidence and self-acceptance. Dread of using durable medical equipment is based on old emotional baggage. If you choose, you can toss that baggage out like a sack of old trash and fill the void with acceptance as you wheel forward with pride. You will be an inspiration to all who encounter you.

Generally speaking, we are still in a climate where the mobility-impaired person has to swim upstream against self-imposed inner conflict. We have stress from well-intentioned family and friends, caught up in the "use it or lose it" mantra. If we are to take optimum advantage of adaptive equipment, we need a lot more people willing to swim upstream, proudly and confidently, to change that climate.

### ***Won't you join me in the swim?***



## **Positive Points of Using a Wheelchair**

- \* At picnics, you always have a chair
- \* You can move really fast
- \* You can hold grandbabies
- \* You won't fall down
- \* No problem waiting in long lines
- \* You will conserve (to preserve) your arms and hands
- \* You can linger longer on enjoyable errands
- \* Ladies, you can now wear stylish shoes
- \* You will save oodles of energy by walking less
- \* Socializing will be much easier when seated
- \* You will be able to concentrate on the natural world, butterflies, wildflowers, a friendly face
- \* You can express yourself with bright colors
- \* You will have less pain in hips, knees, and ankles
- \* You will be more authentic when you cover up less
- \* You will be fluid, flowing, and ***graceful !***

This is a great time to be wheelchair shopping. You are entering the market in time to benefit from modern technology. The new mid-wheel drive allows tight turns, small turning radius, easy pivoting. The new gearless brushless motors offer strength, speed, and manoeuvrability. On board chargers are standard. And the infinite seating options well suit our post-polio needs.

# How to Record an Oral History of Your Experiences and Your Thoughts about Polio

Mary Le Clair

*Member Mary Le Clair arrived in Australia from Canada in 1973 and formed a public relations business where she designed and presented segments of public platform speaking and other aspects of communication. Due to the late effects of polio Mary has now retired and uses a scooter to get around.*

*Mary presented this "fun and cathartic" workshop at our 1996 International Conference "Living with the Late Effects of Polio". Considering our call for members to tell their polio stories, I thought Mary's article might help those who "don't know how or where to start".*

Many people have urged me over the past few years to relate the story of my life. The idea wallowed in my mind until I met Janet Simpson, the perfect person to do the writing! She was an English teacher for many years before becoming a lawyer thus bringing the perfect skills to the job ... writing, attention to detail, and the ability to seek out details.

My main reason for beginning the project was to give my own children some details of their life in Canada and some background of their ancestry. I also think it is imperative for each of us to preserve some snapshots of life as it was when we lived it. Unless we contribute to history, our own contribution, however small it may seem, is lost forever.

For polios it is particularly important that our stories be told. It is inconceivable to most people that children could be snatched from all they know and love and be "abandoned" for not days but years! This experience colours our actions and reactions. It is also possible that our contributions will keep alive the debate about vaccinating children. Young parents today just have no idea of the devastation of polio. Young doctors aren't even studying the disease in Medical schools.

So for these reasons over the period of a year Janet and I worked on my memories.

The exercise has given my children some snapshots of their past and talking about the project has kept the vaccination issue up front. It has also been a cathartic experience. At the end of the book I liked myself better ... a most unexpected result.

But the most valuable and unexpected result was that the polio experience was put into perspective. Let me explain. We are often urged to write about our fears or demons. One problem about that for polios is that most of us had it as children and the memories are buried so far into our psyches they can never be retrieved. Even those of us who had it as adults have buried many of the terrible memories so deep that we must dig long and hard to get them up to our consciousness. Another problem with writing only about the polio experience in isolation is that we can too often lose sight of the fact that it is only a part - however traumatic part - of a WHOLE LIFE.

Everyone, when reaching middle age and beyond, feels the urge to look back on their lives and this is an excellent way to do it for everyone.

Consequently I strongly recommend that you stop worrying about what you can't remember and concentrate on what you CAN. It is amazing how those memories will trigger others ... unbidden.

This paper is written to encourage you to consider writing your stories and memories down, and to give you some tips and tools to help you do it.

There are a variety of ways to retrieve memories and some of them may help you.

## **1 TIME LINE**

Take a note pad preferably with lines and record every year from the year of your birth down the pages. Then enter significant dates from your own life.

For example, your birthday, family members' birthdays, weddings, graduations, deaths etc.

Then enter major events that you remember or can research, such as the opening of the Harbour Bridge, Kennedy's assassination, the Queen's first visit to Australia, the Stock Market crash, the Darwin cyclone.

Each of these entries may spur a tiny, tiny memory ... jot down key words about that memory onto the back of the paper to be expanded later.

## **2 FAMOUS PEOPLE**

Make a list of famous people. Sister Kenny, Menzies, Ghandi, Sinatra. What made you think of them ... a dress? another person? Remember, key words on the other side of the paper for later then forge ahead with ...

## **3 SONGS**

What were you doing when ...? Who did you know?

## **4 PHOTOGRAPHS**

Try to look at the clothes and the surrounds of the picture. Try to remember one characteristic of some of the people in the pictures.

## **5 OLD BOOKS AND MAGAZINES**

If you have none, spend some time in the local library. Sometimes the model of the car you see, the different artefacts or the price of something may twig a memory. Jot it down. Try not to fill in any in depth memories while you are doing any of these things.

## **6 DRAW A PICTURE OF THE HOME/HOMES YOU LIVED IN**

When you do this put into the rooms the furnishings you remember ... the colour of the walls, the carpet ... the paintings on the wall. Maybe you can remember the hospital ... draw the floor plan ... see the people in your mind's eye.

## **7 TAPE RECORDERS**

If possible keep a tape recorder handy. As you think of something as you go about your daily chores, mention them onto the tape for writing about later.

## **8 PETS AND TOYS**

## **9 SCHOOL DAYS**

## **10 SMELLS**

Interestingly, few people realise that smells are the most potent memory enhancers.

## **11 OTHER PEOPLE**

I put this near the end because sometimes others will remember something differently. This can influence your recording of your own memories.

## 12 HOLDING KNICK-KNACKS IN YOUR HANDS

## 13 HOLIDAYS

## 14 MODES OF TRANSPORT

As you begin to fill in the blanks you will find that you will have to move things around on the time line because it will be difficult at first to get things in the right order. Don't worry about that.

### RESULTS

You will remember more than you think! Some of the later memories will take on new meaning when they are seen in relation to all the things that have happened in your life. Even though you still may not be able to record the "polio experience" in detail many of the things you do remember will help you fill in missing pieces.

You will be amazed at how many happy memories will be intertwined with the sad ones giving you a balanced look at your life. Hopefully you too will like yourself better at the end of the exercise!

*Postscript. During the workshop at the Post-Polio Conference people who were convinced that they couldn't remember things surprised themselves! Almost at the beginning of the time we had together one man insisted he couldn't retrieve ANY memories. How surprised we both were when he was the first one who had a flash back when someone mentioned cod liver oil!*

*Another lady had visions of some tiny chicks she found at home when she was released. Others told of favourite toys beings whisked away when they fell on the floor in the hospital.*

*I was gratified when many people told me they were really enthused about giving the project a try. I hope they let me see, hear or read some of the results!*



## How Will They Know?

*Regular correspondent, member Ruth Crowder, has written to Merle and Peter to congratulate them on their initiative in collecting polio stories.*

What a brilliant idea. I think it is vital that aspects of our lives are passed on. Thankfully polio is very much on the way out and most young people know nothing about it. It is right that there is anecdotal information as well as scientific knowledge of the polio years.

This may interest you. About ten years after my husband's death I wrote the story of my life – really just for me. I typed it up and kept it in a folder. It is just the story of my life, all of it, so naturally the polio bit comes into it. It no way dominates the story perhaps because it did not dominate me. I did have a calliper and crutches so my life was different because of that but there are many aspects of my life that are more important to me.

In December my grandsons came to stay with me. They are 14 and 19. They found my booklet on my desk and asked if they could read it. They loved it and were amazed by it. On the long drive back to Katoomba they talked about it non stop to their father. The next day, slightly "gob smacked", he phoned me and told me it had been a revelation to him. He said he had always loved me and been proud of me but there was so much he did not know because I never spoke about it. He had always taken the way I was and lived for granted. He begged me to re-write my story and enlarge it. I will. I am, and it is good for me. I have always had a wonderful relationship with my sons but now we are even closer. This is why I know how important your project is.

# The EPIDEMIC – I don't remember anything, but I'll never forget



*Still on the theme of polio memories ...*

*Shortly before Christmas, members of the Management Committee were privileged to meet Danish film maker Niels Frandsen and his wife, Lone, who had just arrived in Australia. Niels is a polio survivor from the great Danish epidemic in 1952 in Copenhagen. He was affected in his legs and in his hip. Today he works as a film director and recently completed a documentary film called "The EPIDEMIC - I don't remember anything, but I'll never forget". The film earned the Grand Prix at the International Film Festival in Denmark in 2001, and was selected to be shown at the Berlin Grand Prix 2001 and the Mumbai (Bombay) International Film Festival in 2002.*

*Niels generously offered to give Network members a day out of his short stay in Australia to show us the film, and talk to us about it and the polio scene in Denmark today. With a limited time to organise a screening before Niels flew home at the end of January, it was not possible to do a full mail-out to members. Members with email addresses were invited to the screening on 29 January, with the request that if anyone knew another member without email access that the message be passed on.*

*Neil von Schill, our Support Group Co-ordinator, will be in touch with Conveners regarding getting the film to them for viewing at a Group meeting if desired. Also, if anyone would like to purchase a copy of the film, please drop us a line. If there is enough interest we might be able to arrange a bulk purchase.*

*Niels' film is a personal journey walking down memory lane - what happened in 1952? He was one year old when he got polio and the film documents his early polio years and the impact of his illness on his family. It will make you want to explore your own polio history. Following the screening, member Wendy Davies told of the impact the film had on her.*

What a privilege it was to gather with members of the Network to see the film *The EPIDEMIC - I don't remember anything, but I'll never forget* by Danish polio survivor and director, Niels Frandsen ! What a privilege too to speak with Niels and his wife, Lone !

The film itself, which was beautifully shot, resonated with colour, tone and texture. It could have been an art house film as it was so alive with the subtle and the evocative memories of Niels' elderly parents, his older sister, and of course, Niels himself, complemented by sensitive footage taken from black and white documentaries of the 1950s.

Like many in the audience, Niels was a young child when polio struck. His father told of the ostracism by friends, his mother of her fear at being told by the doctors, "He'll never walk again" and then of her absolute determination to prove the experts wrong. We know from seeing Niels in the flesh that she succeeded !

Tears welled in my eyes as I recalled my own father, 30 years on, crying uncontrollably as he recounted how, in sheer desperation, he had smacked me on my legs in an attempt to quieten my screaming before the doctor came. I remembered too my mother, with pain etched in her face, describing the sheer terror of overhearing the doctors saying, "The little Davies girl will never walk again". Like Niels' mother, she had been alone, with her husband at work, far away. How incredibly strong those parents were in the face of loss !

And how incredibly strong the youngsters in hospital, removed from the cuddles, hugs, kisses and physical presence of their family members, were asked to be ! Niels told of the first time he was allowed to go out of the ward to meet his parents and sister, with strict instructions not to touch. I know I laughed out loud as he told how Lisabet had gently held his little toe, just for a brief moment.

We saw a myriad of tiny beds, occupied by babies and young children with a range of contorted limbs. We saw exercise regimes and the hot packs used in treatment. (Some members told of their aversion to wool to this very day !) We saw the iron lungs and I for one stopped breathing at the sight of them. (Oh, yes, the body remembers !) We saw hundreds of discarded plaster casts and knew immediately what Niels thought of them ! How poetic to throw them slowly, slowly, slowly down into the basement ! What a pity the despised plaster cutters didn't follow a similar fate ! Oh, yes ... I don't remember anything but I'll never forget !

Of course, there are some things which are remembered with clarity and will stay with us to our dying day. The treatment of patients as objects was depicted subtly. The words may not have been there but the impact was made nevertheless. I identified immediately with the young girl who was forced to pose in many different positions for the photographer. She, however, didn't have her name tucked into her underpants, front and back for easy identification at medical conferences. Informed consent - now that's a modern concept !

Does it all sound bleak ? It wasn't. There were poetry, music, natural landscapes and laughter too. I especially loved the works of Rosa Abrahamsen, a young polio woman whose moving poems were set to music and broadcast on Danish radio. There were scenes from the holiday hotel by the sea in Copenhagen which was established to reunite families while treatment continued. There were European trees shown in all their magnificence and there were delightful scenes of children at play.

Whoops ! That reminds me. I nearly forgotten the dolphins. The film opens and closes with the hydrotherapy pool at the hospital where Niels was treated, where some carved dolphins adorned the walls. Fortunately, he commenced filming just before the building was demolished. In the closing scenes, we saw the dolphins being prepared for relocation.

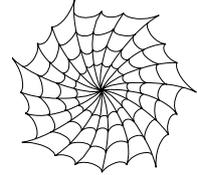
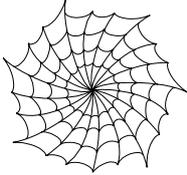
Dolphins have long been associated with healing. I see them as a symbol for us all, as a reminder that times have changed and that it is indeed time to move on. If we choose, we can use the film to understand the bewilderment, the isolation, the abandonment, the lack of control, the humiliation and the often unspoken pain we experienced as children and young adults.

*The EPIDEMIC - I don't remember anything, but I'll never forget* is a beautiful film. Yes, it jabbed at our minds as well as our bodies and it certainly evoked an emotional response but it also acted as a reminder that we, as polio survivors, are very strong, capable and able to stand in another's shoes. In our crazy world, empathy is a gift we can give to others. It's something we all need !

When we were watching the film, I noticed a woman with enormous tears in her eyes. I made a mental note to speak to her afterwards. You can imagine my surprise when Gillian did her thank-you to Niels and Lone to discover that the woman who'd been crying stood up and waved to acknowledge it ! Later, Lone told us she'd seen the film about 20 times and it still has that effect !

I have felt a wee bit fragile since the film but have been determined to cope with the feelings and the tears in a positive way. (How many others abided by the dictum, "Be a good girl/boy and don't cry" for years or even decades ?) So, I've been stretching and dancing for physical release, fiddling with my crayons and drumming on every surface in the kitchen to draw on my creativity and (gasp !) sewing a dress. (Now they're things my mother never thought I'd do ! If only she could see me now !)

Alternatively, you may like to write. Perhaps I should rephrase that. Try writing to express your thoughts and feelings. Just start with the first memory which comes to mind. Who cares about spelling, punctuation or legible handwriting ? It's that ease of movement, that flow of ideas, which will aid the healing. You never know - you too might feel like a dolphin as you experience freedom, that inner jump for joy !



*Cobwebs is a new feature in Network News which will be brought to you by Peter Preneas. Cobwebs will bring you up-to-date information on 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.*

Well it's February 2003 already, I hope every one got at least an email for Christmas, I certainly got a few! 2002 was a good year for [www.post-polionetwork.org.au](http://www.post-polionetwork.org.au) and we are looking forward to a great year in 2003. Our visitors per day have now exceeded the 200 barrier.

Thank you everyone for your fantastic response to our appeal for polio stories. So far we have received about 12 stories and are still going strong. Correct me if I'm wrong but I don't think anyone has yet compiled an Australian catalogue of stories about polio survivors, so keep those stories coming as Merle needs as many as possible.

Again don't forget that any photo's supplied will be returned so please if you have any photo's of your polio past send them in so we can copy and archive them.

Your stories can be emailed or posted to the addresses given above.



A story soon to appear on the website comes from member Lynne Ellis.

Lynne contracted polio as a young adult and spent quite some time in Prince Henry Hospital. After more than twelve months of orthodox treatment - immobilisation with physiotherapy but no weight-bearing - Lynne met Sister Kenny ... with an unexpected result!

To whet your appetites for Lynne's full story, here is an excerpt.

*[Sister Kenny] did most of her work in America but was on a visit back to Sydney and insisted (aided and abetted by the media) on going to the hospitals and looking at the polio cases there.*

*When the authorities at Prince Henry found they couldn't get out of letting her see some of their cases, they decided to move me to an unused operating theatre and let her examine me there. She was accompanied by lots of reporters, radio persons and photographers and her photo with me made it into the Sydney papers that day.*

*Unfortunately, to show how clever she was, she got me up to stand on my feet! When my specialist, who was an Honorary at the Hospital, heard about it he was furious and resigned from the Hospital.*

*I didn't like the photos of me that appeared in the paper, because my hair looked awful, it hadn't been washed for weeks!*

# AFFORD Celebrates Its Fiftieth Anniversary

Gillian Thomas

I was delighted to be invited to attend the AFFORD 50th Anniversary celebrations on 13 December 2002 at the Blacktown Workers Club. For those who may not know, AFFORD (Australian Foundation for Disability) started life as *The Poliomyelitis Society* in 1952. Once the polio vaccines came in, referral of new clients with polio virtually ceased by the mid 1960s and so they diversified their operations to provide services to people with other disabilities, leading along the way to a few name changes - most recently to AFFORD. However, they strongly acknowledge that their roots lie in providing services to polio survivors and their families.

It was a very friendly gathering of about 150 - not all polio survivors, many supporters of the organisation over the years were also there. There was a very detailed photographic spread around the room which graphically illustrated the 50-year history of the organisation. I caught up with some members, including Wendy and Jack Nolan, Margaret Greig and Brian Toby, and saw a number of photographs of them in earlier years. I also chatted to AFFORD's CEO, Tim Walton, and we agreed to talk in the New Year about how our two organisations might work together to further the interests of polio survivors.

Everyone attending was given a copy of *A Concise History* which was put together especially for the anniversary. Here we learnt that "*The Poliomyelitis Society* was established at the height of the most devastating Polio epidemic the State had ever experienced, when over 1,500 cases were recorded and 121 deaths occurred" and that the Society was "dedicated to providing for the after-care of persons suffering from Poliomyelitis and research into the health needs of people with Polio". As well as giving AFFORD's history in words and pictures, the 74-page booklet includes a number of stories written by polio survivors (most of whom are Network members I'm pleased to say). These stories are fascinating reading and provide an insight into the lives of polio survivors, particularly in the 1950s, 1960s and 1970s. The stories are good examples of those which Merle and Peter are hoping to receive from the wider membership. Peter's *Cobwebs* feature on page 23 gives an update on how our own story collection is growing.

Gough Whitlam (a patron of AFFORD, appointed in 1966 when he was the Leader of the Opposition) was the special guest at the celebrations and gave a very entertaining talk (in which he praised the work of volunteers many times).

After he unveiled a commemorative plaque I chased him around the Blacktown Workers Club so I could introduce myself and the Network – appreciating my persistence, he very graciously stopped for a photo and shook my hand! The man behind me is Dr Malcolm Borland, AFFORD's President.



## A Photographic History of the Network

Recognising the importance of recording the Network's history, Webmaster Tony has recently set up a new section on our web site called *Network Photos*. Photographs which have been taken of Network meetings and other activities over the last 14 years are currently being catalogued and scanned and will be added progressively to the site; some pictures (such as the one of Gough Whitlam above) are already there. Why not visit the site today?

## Support Group News

**Neil von Schill**  
**Support Group Co-ordinator**  
**Email: [support@post-polionetwork.org.au](mailto:support@post-polionetwork.org.au)**

**Phone: (02) 6025 6169**  
**Fax: (02) 6025 5194**

It was very heartening to hear from so many convenors in the latter part of last year as we prepared for the Annual Report. Following are snippets of what groups are doing.

**Brian Toby** who operates in the **Campbelltown** area gains great support from the Newsletters and Information Bulletins. Brian's group met at his home for a Christmas function with seven present and three new members. It was a very successful gathering and the first meeting for some years.

In **Wollongong**, **Dorothy Robinson** is very happy for members to phone her for a chat if they cannot get to meetings. She has a listening ear and would welcome a call.

Our convenor in **Orange** is **Susie Simmons** who has had a preliminary meeting and discussed a suitable venue with a view to holding an inaugural meeting in the New Year. Please let Susie know if you are interested in attending.

On the **Central Coast** we have **Bara Tunnington** who says that whilst numbers are down a little, members find benefits from attending meetings. This is a trend which is prevalent in many groups and will continue as our members age and become less mobile.

The **Northside** group continues to meet at the home of convenor, **Ruth Wyatt**, and whilst their topics of discussion are wide and varied they had a very interesting session on scooters and towards Christmas shared many Christmas craft ideas.

At **Dubbo** our convenor, **Gregg Kirkwood**, is gearing up for a big year as he prepares to host the **Dubbo Country Conference** on the weekend of 6 and 7 September. Preparations are well in hand. Our venue is the Dubbo Showground Expo Centre where Gregg is Manager. There are good motels only a couple of blocks away and we are having a Conference Breakfast at the Western Plains Zoo on the Sunday morning.

In the north of the state at **Coffs Harbour**, **Ken Dodd**, our convenor, keeps in regular phone contact with members and they have several social meetings each year. The **Northern Rivers** group meet in Lismore and Ballina and **Rosalie Kennedy** tells me that their meetings are well attended and enjoyed by all.

**Dorothy Schünmann**, our convenor for the **Shoalhaven** area has told us that the Northcott Society has opened an office at Bomaderry on the northern side of the river at Nowra. This may save some members having to travel to Sydney. Dorothy's group is very active - monthly meetings include a Christmas luncheon and beginning-of-year barbecue.

The **Hornsby** group has a variety of contacts – by phone, coffee meetings and a combined Christmas meeting with the Northside group. Convenor, **Kerry Jenkin**, also sends a Christmas greeting to all members in the group.

This year we have two groups celebrating their 10<sup>th</sup> Anniversary, both in April! They are the **ACT** and **Blacktown/Lower Blue Mountains** groups. In **Canberra**, convenor **Brian Wilson** tells me that they have had some excellent guest speakers during the year and Brian has compiled some very interesting statistics on meeting attendance over the past ten years. In **Blacktown**, under the guidance of **Bernie O'Grady**, the group has gone from strength to strength in recent times.

The **Inner West** group who meet at the home of convenor **Claire Dawson** is our longest-established group, having celebrating its 10<sup>th</sup> Anniversary in November 1990. The Support Group structure grew from meetings being held by this group.

In the northwest of the state the **Northern Inland** group keep in regular contact with each other through the efforts of **Laurie Seymour** at Kootingal who compiles, edits and publishes an excellent publication, *THE LINK*.

One of our newer groups, the **Eastern Suburbs** group, has increased its numbers quite substantially over the past twelve months. Convenor, **Eric Sobel**, encourages all members to try to get along to at least a couple of meetings each year.

Our newest group, the **Northern Beaches** group, has now had several very successful meetings. Convenor, **Elizabeth Woods**, would love to hear from people who live in the area and wish to come along to a meeting.

In **Albury** we hold regular luncheon meetings which are very well attended. We also held one meeting in Wodonga (some members belong to the Victorian Network) where our guest speaker was Polio Network Victoria Polio Officer, Brendan Egan.

In **Nyngan** is my old friend **Marion Wardman** who wrote me a letter which gave me the inspiration to initiate the concept of **Regional Representatives**. Thank you, Marion!

If you are interested in taking a more active role in the Network and your area does not have a Support Group I urge you to consider being a Regional Representative.

A Regional Representative does not have to convene a support group nor conduct meetings. The responsibility of a Regional Representative is simply to be the Network's reference person in your local community (country or city), to promote the benefits of being a member of the Network, advise people how to join the Network and refer people to other personnel who may be able to assist them, such as the President or Support Group Co-ordinator.

Please contact me if you would like further information or if you would like a copy of the guidelines. I would love to hear from you!

In closing, here is the list of meeting and contact details for Support Groups and contact details for Regional Representatives as promised in the last issue of *Network News*.

### ***Support Group Meetings***

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

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

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

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

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

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

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

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

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

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

**HORNSBY:** Meets informally four times a year as per notification. Contact Convenor Kerry Jenkin on (02) 9476 1468 for further details.

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

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

**NORTHERN BEACHES:** Meets at the Nelson Heather Centre, Jacksons Road, WARRIEWOOD, 4<sup>th</sup> Sunday of every second month (commencing February) at 2:00 pm. Contact Convenor Elizabeth Woods on (02) 9913 3131.

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

**NORTHERN RIVERS:** Meets in both Lismore and Ballina on last Saturday of the month, every second month. When in Lismore the meetings are at the Lismore Workers Club. Contact Convenor Rosalie Kennedy on (02) 6622 0307 for further information.

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

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

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

**SHOALHAVEN:** Meets at the Nowra Library meeting room, Berry Street, NOWRA, on 4<sup>th</sup> Friday of each month at 2:00 pm. Contact Convenor Dorothy Schünmann on (02) 4448 7541.

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

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

### ***Regional Representatives***

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

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

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

# Post-Polio Post



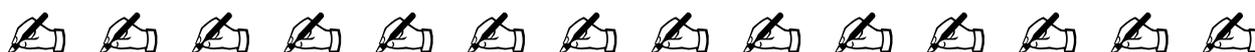
Member Ruth Crowder's recent letter complements the article "Transitioning to a Wheelchair" on page 14 of this Network News very nicely.

Possibly a few of your readers may find the following interesting. From 18 years old to nearly 80 of difficult walking with callipers and crutches and some recent falls I decided that enough was enough and it was time to make a change. I realised that I was using all my energy, will and strength just to keep walking so I decided to use a wheelchair full time.

This was something I thought I would never do because it was my determination not to use a wheelchair that got me onto my feet in the first place.

Psychologically it was not easy but now I have overcome the feeling that I was wimping out I am amazed at how much easier my life is. I have made a few modifications to my house and life style. I am less stressed and tired. I ache less and can now use my energy for other things that interest and delight me. I can move around my house and garden freely without watching every step. I can carry things on my lap and even take my dinner into the garden on a hot night.

If walking becomes too hard make the change without fear and do it when the decision is yours.



## Seminar Program 2003 – Dates To Remember

<b>Saturday 1 March</b>	Northcott Society <i>North Parramatta</i>	A panel of orthotists will discuss their particular areas of expertise with regard to the prescribing and fabrication of orthoses, and the different materials available <i>Full details are given on page 2</i>
<b>Saturday 21 June</b>	Maroubra Seals Sports Club <i>Maroubra Beach</i>	Special General Meeting to consider Constitution Following lunch (to be provided) there will be an Open Forum for members to discuss and debate future directions <i>Further details will appear in the next issue of Network News</i>
<b>Weekend 6 and 7 September</b>	Showground Expo Centre <i>Dubbo</i>	Planning has commenced for this exciting weekend which will include a full-day Mini-Conference and Support Group Convenors Workshop <i>Further details will appear in the next issue of Network News</i>
<b>Saturday 29 November</b>	The venue and topic for our 2003 AGM and Seminar will be advised <i>Further details will appear in the next issue of Network News</i>	

## Can You Help to Promote the Network?

We have been getting a good response to our new pamphlets which were sent out to members with their annual *Post-Polio Awareness Week* poster. We are very grateful to everyone who was able to distribute the pamphlets widely throughout their local communities. If you can help to get more on display in, for example, pharmacies, doctors' surgeries or waiting rooms, clinics, shopping centre notice boards, libraries and community health centres, please contact Alice on (02) 9747 4694 or by email at [alices@hotkey.net.au](mailto:alices@hotkey.net.au) and she will post some out to you.