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Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS Patron:

President's Corner

Welcome to regular readers and new members alike to this issue of Network News. The Committee has been extremely busy since the last issue was published. We have held two successful Seminars. On 19 June, Allan Grundy from Sailors with disABILITIES recounted the crew's adventures as they circumnavigated Australia in 2003, non-stop and unassisted. On 31 August, Canadian researcher Dr Marcia Falconer attracted more than 120 members and friends to a daylong Seminar. Her two presentations brought brand new information to the polio community. Again, as with Marcia's presentations to us in 2002, Network members were chosen to be the first to hear her new research findings. Both talks had to do with the relationship of the immune system to PPS. Marcia is currently writing up her presentations for inclusion in the December issue of Network News. The presentations were tape recorded, but unfortunately there were technical problems with the recording. Due to the importance of the information presented, one tape (PPS Flu and the *Immune System*) will still be made available on the understanding that it is not up to our usual high technical quality. The cost is \$16 (including postage).

All the details of our 15th Anniversary Picnic being held on Saturday 30 October at the Kokoda Track Memorial Walkway, Concord, are given on page 2. We encourage everyone to come along with their families and friends, even if you can only stay for a couple of hours - it will be a great opportunity to catch up with fellow members in a purely social gathering and help celebrate our first fifteen years.

There has been a significant development in the staffing of the Network's office - turn to page 3 for further details. We are thrilled that member Margaret Greig, an artist who paints by mouth, has donated a magnificent landscape for our office wall. Just one more reason to visit the office!

All the work over the last few months associated with Marcia Falconer's Seminar, development of our office and participating in the Dubbo Expo has meant we haven't had the resources to finalise the Constitution amendments as early as we had hoped. In order to give members an appropriate amount of time to receive and consider a discussion paper on possible changes preparatory to finalising and circulating proposed amendments, the Management Committee resolved at its last meeting to hold the required Special General Meeting to consider the amendments in conjunction with the June 2005 Seminar.

In recent weeks we have lost several dear friends who contributed much to our Network: those well known to members were Hazel Atkinson, Wendy Nolan, John Colebatch and Kevin Byrne. We have passed on our deepest condolences to Hazel's family, Wendy's husband Jack, John's daughter Eve, and Kevin's wife Patricia. In the next issue of Network News we will reflect on their lives and achievements.

Finally, on a happier note, we would like to congratulate member Ron Finneran who in the Queen's Birthday Honors List announced on 14 June was awarded a Medal of the Order of Australia (OAM) for service to sport for people with disabilities as an administrator and competitor.

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Gillian Thomas

Post-Polio Network – 15th Anniversary Picnic

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

After considering various options to mark this milestone, it has been decided to hold a picnic at a central metropolitan location. We hope that the venue and format will enable many members, their families and friends to join us in a great celebration.

The picnic will be held on Saturday 30 October at

Kokoda Track Memorial Walkway Rhodes Rotary Park Killoola Street Concord

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

The Walkway covers more than 800 metres from Rhodes Station to Concord Hospital in Sydney's inner-west, and runs along the mangrove-studded shores of Brays Bay on the Parramatta River. The Walkway has been planted with lush tropical vegetation simulating the conditions of The Kokoda Track.

The Walkway aims to provide a lasting memorial to all veterans who served in World War II, with a particular focus on the South West Pacific area.

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

The picnic arrangements

When: Saturday 30 October 2004 (we are undercover, so it will be on even if it rains)

Where: We have reserved the undercover picnic shelter near the Kokoda Café

Public Bus: Route 461 City – Ryde

Transport: *Rail*: To Rhodes station, then a short walk, or wheel, down hill towards Concord road and onto the Walkway at Brays Bay Reserve

Parking: Entry to Rhodes Park is via Fremont and Killoola Streets. There is free parking which is limited to 2 hours, so make sure to bring your *RTA Mobility Parking Scheme* Parking Authority. Once parked, you are close to the picnic area with easy access to and along the Walkway for those wanting to explore.

Time: You can come at any time during the day (between 9 am and 5 pm) and stay for as long as you like – bring a picnic lunch, have a barbecue, or buy some lunch at the Kokoda Café. The Network will provide hot and cold drinks so even if you don't have lunch, please join us for a cuppa.

We look forward to seeing many of the friends we have made over the last 15 years

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George Joins the Team in the Network's Office

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Office Hours

Monday to Friday 10:30 am – 3:30 pm

Our postal address PO Box 888 Kensington NSW 1465 is unchanged



George Laszuk Office Co-ordinator

Since the idea was first mooted of opening an office for the Network, the Management Committee has been wrestling with how to fully staff it, and how to provide support to the volunteers who have so generously given of themselves to provide information services to fellow polio survivors.

Regular readers will recall that on Tuesday 4 May 2004 we officially moved into our office at the Northcott Society's new building in Parramatta. Initially, Nola, Carmelita and Helen put their hands up to work in the office one day a week. After the report in the last *Network News*, Madeline offered to join their ranks. Their generosity has meant that over the next few months we were generally able to open the office on 5 days out of every 10. We have been acutely conscious, however, that we were not supporting our volunteers as well as we wanted to, simply because as Committee members we were already over-stretched and unable for many reasons to travel to the office regularly enough to co-ordinate and support the volunteer activities.

At our Committee meeting in June. Committee Member George Laszuk offered to resign his position and instead manage the office. In this role he could provide consistent and regular co-ordination of, and support to, our volunteer efforts. He would also be able to develop our services to members and expand our reach to polio survivors as yet unaware of the Network's existence. George proposed that the position be part-time paid employment, at 20 hours per week. George was requested to submit a written proposal to the Committee for its consideration at the following meeting. In July, after considering George's proposal carefully and thoroughly discussing the matter, the Management Committee resolved to endorse in principle his appointment for 12 months. It was agreed that one of his duties would be to seek funding for the continuation of the position beyond this time. It was further decided that the Committee would seek the assistance of The Northcott Society to determine the extent of our commitment with respect to the employment (not only the cost but also our industrial relations and other responsibilities) before we would give final approval. During August and September, President Gillian Thomas and Treasurer Bob Tonazzi met with the Society's Human Resources Manager to explore and assess our options. After developing a Duty Statement for the position and considering a comprehensive briefing paper prepared by the President, the Management Committee resolved on 28 September to approve the financial commitment, and appoint George to the position with employment to commence on 5 October. The Network and The Northcott Society are working in partnership to make this position possible, and we are very grateful for their involvement and assistance.

Pending a decision by the Committee, George volunteered his services several days each week during September and the value of his involvement became readily apparent. To reduce the load on the Committee, the time had come to make this move to ensure the Network can continue into the future. We are confident that in following this path we will provide more comprehensive services to members and potential members and more effectively utilise our volunteer resources.

Exercise Improves Brain Function

Richard Daggett

Reprinted with permission from Rancho Los Amigos Post-Polio Support Group Newsletter, June 2004.

Oh no, not another log on the "more exercise" or "no exercise" debate fire. I'm afraid so. I was going to call this article, "Uh-oh. I'm in Trouble Now" but decided on the more descriptive title.

First a little background on me. I had what could be fairly described as a severe case of polio. I was in a tank respirator for six months, and hospitalized for the better part of three years. Even so, like most polio survivors, I've led a pretty full and active life. When I left the hospital I was walking, and for about thirty years my level of function was stable. In the early 1980s the late effects of polio began to take their toll, leading to the point where I now use a power chair and ventilator.

As I've become less mobile and lost strength I've also become what is loosely described as, "out of shape". Let's face it, I couldn't fight my way out of a paper sack. I know from personal experience that inactivity leads to weakness, and too much activity leads to weakness. What to do?

Now another study indicates that inactivity, physical inactivity, is detrimental to your brain. Actually, what the study found was that physical exercise improves brain function. Researchers at the University of Illinois established that brisk walking or other aerobic exercise could make the brain work better and more efficiently.

The study, recently published in the Proceedings of the National Academy of Sciences, used neuro-imaging to observe the effect of exercise on the brain's structure, specifically that area of the brain that involves decision making.

A group of people, aged 60 to 79, were given tests before and after six months of brisk walking. The tests showed increased connections between neurons in parts of the brain that make a person better able to pay attention, compared with people who were physically inactive. Those in the exercise group were able to focus more clearly on goals while disregarding competing but irrelevant information.

William Thies, vice president for medical and scientific affairs for the Alzheimer's Association, said "It's a powerful demonstration of the fact that there's a direct relationship between fitness and brain health. People are often reluctant to engage in physical exercise because they think they have to run marathons and look like Arnold Schwarzenegger. But this shows that with a relatively modest aerobic plan you end up improving brain function."

The National Institute on Aging provided funds for the research. Molly Wagster, director of the neuropsychology of aging research program at the Institute stated, "Here's a demonstration where physical exercise in humans is something that produces not just a hedging against cognitive decline with age, but actually shows that one can have improvement of cognitive function. The findings are very interesting and very hopeful."

Interesting? Yes. But hopeful, I'm not sure. About all the exercise I can handle is bringing a fork to my mouth, brushing my teeth, and standing to transfer. Even eating and brushing my teeth are tiring. On the other hand, if I'm in bed for more than a day my remaining strength diminishes.

The only hopeful thing I can find is that similar studies have found the same kinds of brain neuron improvement can occur in purely mental exercise. Most research into this area suggests that doing crossword puzzles, playing cards with friends or board games with the grandchildren, can stimulate the brain. Even shopping helps keep the brain fit.

So, here I sit, staring at the computer screen, trying to make one sentence follow the other in logical order. I can't do the "brisk walk", so I'll have to content myself with some brain exercises. Uh-oh. I'm in real trouble now!

Actually, exercising your brain does not mean you have to "beef up" your brain, and the image of a muscular brain is not one that fits the physiological mold. As uncomfortable as we might be with the thought, our brains are primarily fat – apparently about 60 percent of the brain is fat.

An article in the Tufts University *Health & Nutrition Letter* suggests 10 ways to keep your brain in top shape. Using this as a guide, and adding information from several other sources, I'll share some of the things I've learned.

As we age we have a harder time absorbing vitamin B_{12} from the food we eat. This vitamin is necessary for proper neurologic function. Without enough B_{12} we could have trouble with memory. As odd as it may seem, even if we can't absorb B_{12} from food, we can still absorb it from supplements. A supplement should have at least 2.4 micrograms of the nutrient.

It is also important to eat a diet rich in vegetables, fruits, grain products, and legumes (peas and beans). Moderate amounts of beef, poultry, and fish are also recommended. These food groups have been linked to better memory and reasoning ability.

One in four adults has high blood pressure, a documented risk for heart disease. Evidence also points to high blood pressure having a negative impact on mental function. A study by the National Institute on Aging linked people 50 and older, with a history of high blood pressure, with lower scores on language and memory skills. Tests also indicated that high blood pressure often led to brain atrophy – not something very pleasant to contemplate.

So, what can you do to improve brain function beside eating the right food, exercising, and keeping your blood pressure under control? You can start by having some fun!

Yes, that's right. Studies have shown that having fun, or doing things that bring enjoyment, can improve brain function. Here are a few that were suggested in my research:

- Remain socially active. Socializing is one of the best mental workouts you can do for yourself. Connecting with others has the potential of a good brain "buzz" of mental stimulation, which improves the pathways between neurons.
- Play mind games. Studies indicate that the more active you are mentally with leisure activities such as hobbies, reading, crafts, etc., the stronger the connection between brain cells.
- Reduce stress. Chronic stress, anxiety, and negative distraction can actually do permanent damage to your brain.
- Get enough sleep. Losing an hour or two of needed sleep, on a regular basis, can impair brain function. If you are having problems with sleep you should check with your doctor. Sometimes the medications you take are the culprit. See if a change in dosage or dosage schedule might help.
- Get help for pain. Chronic pain can be one of the greatest obstacles to good brain function. Many of us with PPS have pain as an almost constant companion. But could a reassessment of your physical activity level help with pain? Research and common sense indicates that it might.

These are just a few of the suggestions that will allow us to make the most of our mental resources.

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Polio Word Search

Millie Malone

A light-hearted look at something we all experience – at least I know I do!

Reprinted with permission from the Florida East Coast Post-Polio Support Group Newsletter, Vol 12, #1, July/August 2004 (previously published: Post Polio Awareness & Support Society of British Columbia, PPASS News, May/June 2004; GLEANINGS, January/February 2003, Nebraska Polio Survivors Association).

If you are expecting a grid to appear and a list of words, I am truly sorry. The polio word search is a totally different game. A polio survivor can be rattling along (chatterboxitis is a well-known polio residual) when all of a sudden ... what was the word I was going to use? This leads to a fun game played by all polio survivors. Sometimes we play via e-mail, sometimes in person.

Polio survivor 1: "... and then I saw this really remarkable ... ummmmm, you know, that thing. I think it starts with an "R." Maybe not."

Polio survivor 2: "Is it bigger than a ... oh, shoot ... you know, you keep that sliced stuff in it so it won't get all dried out?"

Polio survivor 1: "Breadbox? Is what bigger than a breadbox?"

Polio survivor 2: The really remarkable thing you saw ... remember? Is it bigger than a breadbox?"

Polio survivor 1: I have no idea. I can't even remember what it was I saw now!"

This scenario is played out over and over. Polio Survivor 1 will, in all likelihood wake up at 3 am shouting "Rifle! It was a rifle!" At which point his/her spouse will jump out of bed and have 911 dialed before Polio Survivor 1 can explain that it was a lost word that just found its way home.

I talk to many polio survivors via the Internet every day. None of us can remember anything. I am thinking of inventing one of those, you know ... they suck stuff up ... no, not a straw ... a vacuum, yes that's the word.

What was I saying? Oh, yes, I am thinking of inventing a vacuum that will suck up all the words we lose in our everyday conversations and restore them to our heads where they belong.

I can see it now ... a group of polio survivors are sitting around a table, each holding some playing cards in his/her hands. No-one can remember if they were playing Hearts or Euchre, so they lapse into a conversation instead. One woman is telling her friend about a new place to shop, the men are swapping fishing stories. The conversations peppered with "oh, you know what I mean" and "I'll think of it in a minute, just hang on." Words are wandering off, some of them not just leaving but taking hostages as well.

TADA! In I come with my new invention, the thingie ... you know what I mean. I plug it in and start vacuuming up the words that have drifted into a pile in the corner of the kitchen. Then I get a large box and dump the bag. "Hey! Who was talking about fishing? I found "flycasting" in here. Did someone say something about hot flashes? This word is sort of bent and scuffed, but I think it's "menopause." Anybody need a perfectly good "repercussion"? Ooooops ... I think I have to adjust the settings here ... all that is left is a pile of odd vowels, four exclamation marks and several hundred commas. They could be

semi-colons ... maybe this one is an apostrophe. Anyone want any of these before I dump them in the wastebasket?"

I am thinking of perhaps opening a used-word store. I could vacuum up all those lost words, dust them off, polish them up a bit and sort them alphabetically. I could put up some shelves and line them all up. Then when a polio survivor calls me and asks for a word, I could help him/her find it. "You were talking about your mother-in-law, you say, and totally lost the word you were searching for. Does it start with a B? I have an entire shelf of B words. Bountiful? Good, I will sent it right over."

I might need to hire a ... hmmmmm ... they take letters ... no, not Vanna White. She turns letters, but she doesn't actually take any. No, I mean those people with the pads ... not bachelors ... damn it, I know the word. Secretary, yes, I might need to hire a secretary to help me keep track of the uh ... you know ... those things on the shelves in my new store. Words, that's what I was going to say. Words.



Sixteenth Annual General Meeting and Seminar Saturday 27 November 2004

The Network's Sixteenth Annual General Meeting will be held at the Charles Blunt Conference Centre, Royal Rehabilitation Centre, 59 Charles Street, Ryde, and will commence at 11:00 am. The official AGM Notice is enclosed with this *Network News*.

Please try and come to this important yearly meeting. This is your opportunity to not only have a say in the running of the Network, but to offer your time and talents to help achieve the Network's goals. In a particularly busy year, the Committee has been at less than full strength for some months – we encourage you to step forward and help to share the load.

After the AGM concludes at approximately 12 noon, we will break for lunch (bring your own – tea and coffee provided). At 1:00 pm our special guest presenter is Andrew Buchanan.



Andrew is the Chairperson of the Disability Council of NSW, which is the official adviser to the NSW Government and the State Disability Advisory Body to the Commonwealth Government. Andrew will tell us about his role and his work with people with disabilities.

Andrew contracted polio as a baby and he will also give us insights into his unique polio story.

Professionally, Andrew's career has been in radio and television broadcasting, as a presenter and in senior management with the Australian Broadcasting Corporation. He has particular expertise in communication, staff motivation and facilitating corporate change, and has his own company AB Communicates Pty Ltd.

He serves on a number of boards. Having lived and worked in rural NSW and Queensland, he is a strong advocate for those disadvantaged by distance.

We are delighted to once again welcome a fellow polio survivor to address us. Those who have heard Andrew speak before will know that we are in for a treat. He is a fascinating raconteur with a wealth of stories.

Sister Kenny: A view from her homeland

Mary Westbrook

You may have seen the recent story on Sister Kenny which screened on 29 August in the ABC television series Rewind. The ABC team travelled to Nobby in Queensland where Sister Kenny's adopted daughter lives and where the Kenny museum is housed. The team also interviewed a polio survivor treated by Sister Kenny and Mary Westbrook. Despite this research, the ABC treatment of the subject was disappointingly superficial. To give readers a more balanced view of this somewhat controversial figure and her legacy we thought you might be interested in the following article. In 2002 Mary was asked to write about Sister Kenny for the Florida East Coast Post-Polio Support Group Newsletter. The article appeared in volume 9, part 3 of their newsletter. Since then the Sister Kenny Professorship in Rural Health mentioned in the article has become a reality.

When I meet American polio survivors I am often greeted warmly because I'm an Australian *"like Sister Kenny". "Without her, I'd never have walked again,"* they say. Yet few Australian survivors express such indebtedness. Kenny developed her treatment for polio in Australia and established ten clinics during the 1930s. All closed during the Second World War when Kenny went to America. By then she had lost most of the considerable support she had once received from the Australian press and from some doctors. It is rare to find an Australian polio survivor who was treated by the Kenny method. Most recall that there was controversy about her treatment but are confused about how it differed from orthodox treatment. Kenny received numerous honours in America where the Kenny Institute is a memorial to her work, but today few Australians recall her name.

Kenny is most remembered in the northern state of Queensland where her family farmed on the Darling Downs. Here she saw her first case of polio as a bush nurse in 1911. When her father died the family moved to the township of Nobby, two hours drive south-west from Brisbane. In 1952 Kenny was buried in the old Nobby cemetery. A memorial website says, "The grave of Sister Kenny nestles against that of her mother. A gum tree casts shade in scattered patterns. Grass curls against the rusted cemetery gate. From here, the rich paddocks unfold as guilts as far as the eye can see. It is peaceful here. Nobby's daughter has come home." [1]. In 1999 her gravestone was modified to show her correct age as six years older than she had claimed. The Kenny museum and gravesite are advertised on Nobby travel brochures along with the Rala Ostrich farm and historic century-old Rudd's Pub where tourists can enjoy a "monstrous roast lunch". In 1998 the Queensland National Trust placed the Rockhampton building that housed a Kenny clinic on its "Endangered Places" list but despite this it was destroyed to make way for a car park. Kenny's adopted daughter Mary McCracken recently established a Memorial Fund in conjunction with the Nursing Faculty at the University of Southern Queensland. The fund hopes to raise \$A1.5 million to establish a Sister Elizabeth Kenny Professorship in Rural and Remote Nursing to commemorate her work as a pioneer bush nurse. The Fund website contains a loving daughter's recollections of her mother many of them in hyperbole that is uncharacteristic of Australians' somewhat laconic speech. Kenny is described as "Mother Theresa to the world's sufferers of poliomyelitis, Sister Saint and Mother Mercy" [1].

Kenny's departure from Australia is usually attributed solely to her conflict with doctors. However Dr Phillipa Martyr's research [2] reveals that the role of the Australasian Massage Association's (precursor of the Australian Physiotherapy Association) antagonism against Kenny has been overlooked. Kenny threatened therapists' livelihood, particularly the growth in the number and status of their workforce provided by the polio epidemics. Martyr cites numerous examples of how the Massage Association went "*out of its way to discredit* Kenny and to align themselves securely with the orthodox medical profession, keeping up a steady pressure on their respective medical connections which contributed to the eventual rejection of Kenny and her methods in Australia." [2]. In Queensland the Association attempted to prosecute Kenny because she practised "what she calls re-education ... As re-education is an essential part of physiotherapy and as Sister Kenny is untrained and unauthorised by the Board she should not be allowed to either practice or teach". When therapists found that legally nothing could be done, they commenced investigation of Kenny's nursing background and "a steady flow of communication with other branches warning them about Kenny's activities". One letter lamented, "It's hard indeed when our medical men support such rubbish" as the Kenny method. Worried at their inability to compete with Kenny's public profile the Association appointed two officers to publicize cases of recovery from polio after treatment by physiotherapists. Kenny visited England in 1937 and on her return said that many hospitals had offered her facilities. The Association had warned its British counterpart of Kenny's lack of credentials and used this connection to expose Kenny's claims of British support as false. Martyr argues that in its attack on Kenny the Association "gained state and public attention ... and thanks to its policy of association and alliance with the medical profession it had gained the advantage". Ironically much of Kenny's method was integrated into physiotherapy. "Kenny herself had not been legitimised but her methods of treatment had." [2]. Interestingly the website of the Kenny Memorial fund describes her method as "hydrotherapy in warm salt baths, extended manipulation of affected arms and legs, together with daily massages ... much like contemporary physiotherapy" [1]. Such a regimen was typical Australian physiotherapy for polio in 1949 when I contracted the disease. I possess mimeographed notes on treating polio that were issued to physiotherapy students at that time. They emphasise the new trend for "splinting selectively, rather than in an unnecessarily immobilizing form" and the need for regular liberty periods from splints. Starting ambulation earlier and using hydrotherapy to lessen stiffness and tenderness were now encouraged. However the hot packs that dominate American survivors' stories were not adopted and splinting remained, though to a lesser extent than previously.

In retrospect, how wise were the exclusion of hot packs and the continuation of splinting in the treatment of polio in Australia? Canadian post-polio researcher Elizabeth Dean has reviewed the Kenny method and discusses which of its aspects are appropriate for treatment of polio contracted in developing countries today [3]. She argues that there is no scientific evidence for prolonged heat treatments, though heat may have a role in alleviating muscle pain and spasm in the acute stage of polio. Dean considers that in the recovery period the two important aspects of treatment are firstly, prevention of deformity (by good body positioning and orthotic support if necessary) and secondly, judicious active exercise to "stimulate muscle hypertrophy of both unaffected and recovered muscle fibres, maximize the potential for muscle re-innervation, and maintain strength and endurance in non-affected muscle groups".

I suspect that Australian polio survivors' unrecognised debt to Kenny is for igniting the optimism of the community, and indirectly of health professionals, regarding outcomes for people who contracted polio. Because of the hope engendered by publicity about the Kenny method a greater number of Australians with polio probably received rehabilitation and rehabilitation led to more successful outcomes due to the application of treatment that focussed more on improvement of function than prevention of deformity.

- [1] Martyr, P (1994) *The Professional Development of Rehabilitation in Australia, 1870-1981.* PhD thesis, Department of History, University of Western Australia. (Martyr also tells the story of Kenny in her book *Paradise for Quacks: An alternative history of medicine in Australia.*)
- [2] Sister Kenny Memorial Fund website: www.sisterkenny.org.au
- [3] Dean, E, Agboatwalla, M, Dallimore, M, Habib, Z, Akram, D (1995) Poliomyelitis: Revised principles of management. *Physiotherapy*, 81, 22-28.

Polio Particles

Mary Westbrook

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



Second wave of post-polio in Australia?

Professor Elizabeth Dean, prominent post-polio researcher, who has presented several seminars to the Network, was quoted by Canada NewsWire (15/3/04) as predicting a second wave of people with post-polio syndrome in Canada. This is due to the large number of migrants from countries where polio is, or was until recently, endemic eg India, Pakistan the Middle East and Africa. Many of these people had polio when they were young and are unaware that *they may face the challenges of post-polio syndrome. Immigration support groups need to be alerted to post-polio clinics and their role,* says Dean. From emails to *Ask Mary* it is apparent that some Asian polio survivors who have migrated to Australia do not know that they had polio. As they try to make sense of the onset of post-polio symptoms they begin to recall vague stories of a childhood illness and to wonder what really caused mild polio symptoms they have lived with since childhood.

Polio vaccine caused AIDS theory is finally dead

In three previous issues (43, 45, 46) I have discussed increasing evidence against this theory but it still receives publicity as in a recent TV showing of *The River*. This was based on the book of the same name by Edward Hopper who maintains that an AIDS-like virus (SIV) from African chimpanzees contaminated polio vaccine grown on tissue cultures of chimps in the 1950s. An article in *Nature* (22/4/04), describes how Michael Worobey and his colleagues collected faecal samples from chimps in the Congo to obtain SIV viral genetic material. Analysis proved that that SIV was highly divergent from HIV, confirming that chimps were not the source of the crossover of SIV to humans. Worobey said that his final proof was necessary because previous evidence against the theory was indirect. Such evidence that HIV originated at least 30 years before polio vaccine was manufactured. *It would be nice*, Worobey said in an interview, *if these findings could eliminate some of the fears and suspicions that hang over polio vaccines currently in* [use in] *countries like Nigeria. Polio vaccines weren't infected with AIDS viruses in the 1950s, and they're not now either, and driving that message home can only be a good thing.*

Contaminated Soviet polio vaccine

Soon after the release of the above story the journal *New Scientist* (July 2004) published findings, which were reported in many newspapers, that as late as the 1981 some polio vaccine produced in the Soviet Union was contaminated with monkey virus SV40. This vaccine was used throughout the Soviet bloc and probably exported to China, Japan and parts of Africa. The consequences of exposure to the virus are unclear. There have been claims the SV40 virus may be linked to rare cancers but this has not been proved. In 1981 the Soviet switched to a polio vaccine 'seed' free of SV40 that was provided by the World Health Organisation.

Polio and a life of crime

I find references to polio in novels intriguing because of the attitudes they convey and the messages they may give readers. *'Doctored evidence'* is the most recent addition to a series of very enjoyable detective stories set in Venice, by Donna Leon. The murderer in this novel is thought to be a past member of the School Board and to have been blackmailed by the murder victim. A detective describes to Commissario Brunetti the various Board members but has left one out. Brunetti asks:

'And the other?'

'He's in a wheelchair'.

'What?'

'He's the guy who got polio when he went to India. You read about him, didn't you?' The story rang a faint bell, though Brunetti had forgotten the details. 'Yes, I remember

something. How long ago did it happen? About five years?'

'Six. He got sick while he was there, and by the time they managed to diagnose it, it was too late to evacuate him, so he was treated there, and now he's in a wheelchair....That might not be enough for you to exclude him, but I think a man might have other things to think about after landing in a wheelchair than continuing to pay blackmail'

...'I think I'd like to talk to the one who's not in a wheelchair. The rugby player'.

Will this exchange remind readers to have their polio shots before travelling to India? Should polio survivors who use wheelchairs feel safer from detection if they embark on a criminal career? Leon makes no further reference to the polio survivor and unlike other School Board members he is not even given a name. That's the problem: people consider that being in a wheelchair is all there is to say about such a person; they believe that being in a wheelchair is of itself a full time occupation.

Death of Hugh Gallagher

American polio survivor, Hugh Gallagher, died in July. He contracted polio aged 19 and spent three months in an iron lung. On one occasion it broke down and he had to instruct the agitated nurses on how to pump the lung by hand. Gallagher played a vital role in the development and drafting of the US legislation, The Architectural Barriers Act of 1968. This was the precursor of the Americans with Disabilities Act of 1990. Gallagher's autobiography, Blackbird Fly Away, was reviewed in Newsletter 41, 1999. His best known book is FDR's Splendid Deception which describes how President Roosevelt hid his disability. Among 35,000 photographs of Roosevelt in his presidential library Gallagher found only two showing him in his wheelchair. Gallagher said he understood Roosevelt's stoicism and near-disavowal of his disability because he himself had lived much of his life in the same way. For years I tried to work harder than any able-bodied person would. My drive to become a super hero exacted a terrible price. I paid no attention to my emotions. I became an automaton. Gallagher played a major role in having a statue of Roosevelt in his wheelchair added to the Roosevelt Memorial in Washington. 'Don't let them steal our hero!' he repeatedly told reporters during this campaign. In another book, By Trust Betrayed, Gallagher wrote about the rarely remembered thousands of people with disabilities who were exterminated by Germany in the Holocaust.

'Polio victim ousts Philippine political clan'

This headline in *The Straits Times* (31/5/04) recounts the victory of 40 year old accountant Grace Padaca who has just been elected governor of Isabela, one of the largest provinces in the Philippines. The paper described the win as a *Cinderella story...With just half a million pesos* (\$US15,000) in donations and a core volunteer group of 15 youths, Ms Padaca...hauled her crutches into a beat-up van to campaign among the largely agricultural province's 1.4 million voters. She defeated Faustino Dy, heir to a logging and construction magnate whose family had ruled the province for over 30 years. The article went on to say that, *In a political system dominated by all-powerful political clans, Ms Padaca is a symbol of democratic reform.*

Post-polio syndrome recognised by European Parliament

In the Lancet (1/1/04) Xavior Bosch reported: Representatives of patients with post-polio syndrome (PPS) gathered on Nov 12 [2003] at the European Parliament in Brussels to bring this poorly understood disorder to the attention of health professionals and policy makers. At the meeting—which was supported by 20 members of the European Parliament—PPS organisations agreed to create the European Polio Union with the aim of obtaining recognition and funding from the European Parliament and Commission. There are thought to be 250,000 patients with PPS in Europe and 20 million worldwide....Although WHO declared in June that Europe was free of poliomyelitis, 'the other side of the coin is that there are very few health professionals practising today who have seen acute poliomyelitis' says Bijttebier [chairman of the Belgian PPS organisation]. Jim Costello, the chairman of the Irish PPS groups—the only EU country where PPS associations receive public funds—says 'our mission is to create awareness and to provide information regarding PPS among both polio survivors and the wider medical profession'.

Melbourne iron lung user's 78th birthday

Melbourne polio survivor, June Middleton, celebrated her 78th birthday recently at the Austin Hospital, Melbourne. June contracted polio in 1949 when she was 23 years old and spends 16 hours a day in an iron lung. She also uses a portable respirator and goes for occasional outings in a specially fitted van. *The Age* (9/5/04) told her story under the headline, *'Iron grip of a forgotten disease'*. June moves the index finger of her left hand, rolls her eyes and pokes her tongue to show the only other movement possible to her. The [Australian Ventilator users] Network has been lobbying the State Government for funds for a long-promised 20-bed supported housing development on a site, already purchased, in Thornbury.

Nigeria reels from new cases of polio

By July 2nd there had been 62 new cases of polio in Nigeria in the preceding fortnight bringing the total number of Nigerian cases for the year to 259. Health officials were waiting for results of tests on an additional 85 paralysed children. The 259 Nigerian cases accounted for 77% of polio cases in the world so far this year. The Nigerian state of Kano suspended immunisation in September 2003 due to Muslim leaders' belief that Western vaccines spread AIDS and cause infertility. In May Kano agreed to resume vaccination using vaccine from Indonesia. However by July vaccination had still not recommenced as Muslim clerics considered more tests were necessary. WHO is fearful that the coming rainy season will provide ideal conditions for the spread of the virus and is attempting to create a firewall around Nigeria through vaccination of children in the surrounding countries.

Statues with disabilities

The winning entry in a recent British sculpture exhibition will be placed in Trafalgar Square for 18 months. The statue is of a naked, pregnant woman, Alison Lapper, who has no arms and short legs due to phocomelia, a congenital disorder. The Disability Rights Commission has congratulated the artist Marc Quinn for realising that disabled bodies have a power and beauty rarely recognised in an age when youth and 'perfection' are idolised. Quinn says: At first glance it would seem as if there are few if any sculptures of people with disabilities. However a closer look reveals that Trafalgar Square is one of the few public places where one exists. Nelson, on the top of his column has lost an arm. Alison says that Venus de Milo is admired as one of the great classical beauties, despite having lost her arms. (From the *Guardian* 16/3/04)

Support Group News

Neil von Schill Support Group Co-ordinator Phone: (02) 6025 6169 Fax: (02) 6025 5194 Email: support@post-polionetwork.org.au



I have recently returned from a long trip around the state where I was able to catch up with old friends and make new acquaintances. My first port of call was **Wagga Wagga** where I had a pleasant morning tea with **Isabel and Clarrie Thompson**. Isabel is our Convenor in Wagga Wagga and will soon host an inaugural meeting at her home. Members in the region will be notified of meeting details by letter. If you wish to contact Isabel please ring her on **02 6926 2459**.

In **Dubbo** I had a meeting with **Gregg Kirkwood** who, in his capacity as Manager of the Dubbo Showground Complex, hosted the **IDEAS EXPO** in September. As Dubbo Convenor, Gregg helped us to set up our stand. A number of convenors, regional representatives and committee members assisted me over the weekend of 18 to 20 September to promote the activities of the Network. The weekend was very successful – see a full report on page 14.

Unfortunately I was unable to coincide my visit to **Muswellbrook** with a time when our **Upper Hunter** Convenor, Bruce Buls, was available. Bruce is Senior Engineer for five Upper Hunter hospitals and as such has a busy round of commitments. Bruce can be contacted at home on **02 6545 1993**.

I then journeyed on to **Moree** where I caught up with Regional Representative **Terry Bell** and had the pleasure of meeting his wife **Adele**. Terry prepared a beautiful lunch for myself and Adele who had just returned from family commitments in Brisbane. Terry has been very active in the Moree community promoting the interests of people with disabilities. He has lobbied politicians and government departments in an attempt to ensure that services for regional residents are not further eroded. Well done, Terry - keep up the fight!!

Following a few days with family and friends in the Grafton/Maclean area I travelled down the coast to Fernmount where I finally had the pleasure of meeting **Coffs Harbour** Convenor, **Ken Dodd** and his wife **Claire**. Ken has been a willing and active advocate of the Network on the north coast for many years and we very much appreciate his endeavours. Claire, thank you for the most beautiful scones and cream that I have ever tasted!!

I concluded my calls in the north of the state with a visit to **Laurie and Beryl Seymour** at Kootingal. Laurie keeps members in the **Northern Inland** in touch with one another through his quarterly publication, THE LINK, which is a popular and informative journal. Laurie, keep up the good work. I then enjoyed a delicious soup lunch which Laurie had prepared. This helped sustain me as I completed my journey to the south.

It was very encouraging to meet up in June with members of the **Northern Beaches** group who now meet on the last Thursday of every month at **Dee Why RSL Club** at 10:30 am and enjoy a cup of coffee and informal chat. All members living in the area are welcome to attend. For further information contact **Pat Featherstone** on **9905 5065**.

Finally, following on from our successful presence in Dubbo, the Network will be represented at the **Nepean Disability Expo 2004** to be held on **Thursday 2 December 2004**, from **10 am to 6 pm**, at **St Marys Leagues Club, Corner Forrester and Boronia Roads, North St Marys**. Everyone is welcome and **admission is free**. Wheelchair accessible transport will be available from St Marys Railway Station to the Expo. More than 75 exhibitors will be displaying a range of disability-related equipment, specialised transport and mobility aids, and you can also learn more about Government services as well as community services available in the region.

Our **Blacktown/Blue Mountains Convenor Bernie O'Grady and his wife Irene** are generously manning the PPN stand. If you live in the area why not attend the Expo to catch up with the latest equipment and services, and drop over to see Bernie and Irene and perhaps give them a hand.

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Dubbo Expo – The Weekend That Was

Neil von Schill

The most significant factor relating to our presence at the IDEAS Expo in Dubbo on 18 to 20 September was the excellent response to it from Network members – not only people who assisted but members who attended. The contingent from Sydney included George Laszuk, the courier, whose organisational skills, PR capabilities and work ethic are excellent and whose contribution to the office team should be immeasurable. Bob Tonazzi, the treasurer, arrived Saturday afternoon and kept everybody on track. John Ward, the farmer, arrived by ambulance and made a memorable entrance as well as a valuable contribution. Maura Outterside, the convenor, who attended all day Saturday and Monday, was an excellent ambassador for the Network and a great asset to our team.

The central west contingent comprised Peter and Heather Drady from Lyndhurst near Cowra. They joined us on Saturday afternoon but unfortunately Peter was experiencing bad pain so they left Sunday morning so that Peter would be closer to Orange Base Hospital. Bill and Ruth Worthington travelled from Condobolin and spent time with us Sunday and Monday with Ruth dispensing Bowen treatment to Gregg Kirkwood and Neil. Marion Wardman at age 80 caught the bus down from Nyngan on Saturday and manned the stall Sunday and Monday. Gregg Kirkwood was a very regular visitor to our site over the three days and gained much from the interaction with other polio survivors.



Other Network members were also making a contribution at the Expo.

Margaret Greig, an artist who paints by mouth, spent the whole weekend demonstrating her talent and sold several of her works to stall holders.

Pat Davies was representing her funding group as well as making a social contribution.

It was wonderful having these members present at the event and also joining us for the group photo (thanks to Gregg for providing the photo which shows a typically happy group of polio survivors).

L to R (standing): Neil, Marion, Bob and Gregg L to R (seated): Margaret, George, John, Maura and Pat

A number of Network members from Wagga Wagga, Moss Vale and Dubbo called in to say "G'day". I made a number of contacts from Wagga Wagga which will assist us in launching a group there in the near future.

Whilst enquiries from new polio survivors were not many I believe that our attendance at such Expo's is vital if we are to continue being "out there" in promoting the existence of our Network. Many people picked up a range of our materials and I know that our contact details will filter through to potential members who will require our services.

Post-Polio Post 🐨 🖃 🐨 🖃 🐨

In the last Network News, member David Edgerley sought input from other members who might be wearing a brace similar to his. David's main issue was that the straps and pads used to secure the brace wear out with constant use and require replacement. Although Medibank Private assisted with part of the cost of the brace itself, David is responsible for maintaining the equipment at his own cost. David received some replies from to his letter and has written in with this update.

Matters concerning the brace have progressed since I first wrote to you.

The straps attached to the brace will show wear and tear – there is no avoiding that. But Insurance, having paid for half the cost of the brace (state of the art stuff and made of carbon fibre) will not contribute to their repairs. These will be on-going and repeating at intervals of nine months, I estimate.

Fortunately, the orthopaedic firm who supplied me with the original brace have acted in an exemplary manner and I have been given new attachments for a very modest sum indeed.

I would like to thank those who have written to me. We seem to share various forms of the same affliction but have been provided with different solutions to them. It is gratifying to have been the recipient of their kind suggestions.



I frequently have late night email exchanges with Else, a member who keeps the same ridiculous hours I do. Else recently purchased a copy of our 1996 Conference Proceedings. Amongst the papers at the Conference was one I presented on my experience with dysphagia (swallowing difficulties) and this hit a chord with Else.

Regular readers will remember Else's last contribution to Network News. In Issue 63 she shared her unique polio story with other members – Else only recently learnt that she had childhood polio.

I was extremely interested to read your article on dysphagia. I compliment you, that you were able to recognise that you had a definite problem. I tend to shrug things off. I first noticed my problem in 1995. On four separate occasions when I was having dinner, I had an instance of not being able to swallow my food. It was as if I had forgotten how to swallow. That was the worst, then at intervals becoming more frequent, it would happen in milder ways, sometimes just saliva. I mentioned it to our doctor at the time, got no response from him so decided it must be nothing unusual, so I learned to live with it.

Much the same with my sleep apnoea. For the previous couple of years I'd felt that something was wrong, but had no concept of what. Fortunately, over the months my doctor, a different doctor to above, listened to things I described until eventually, when he was convinced I had sleep apnoea, he sent me to a specialist. They were horrified with the result. While sleeping, my breathing was normal for 119 seconds, then I did not breath at all for the next 2 full minutes which meant I spent more time not breathing, than breathing.

Of course all of this was prior to my having been told that I'd had Polio as a child (which had left me with the left side of my diaphragm and left phrenic nerve being paralysed).

When I knew I was to be tested for a mask to help with my breathing, I read with interest the articles in Issues 63 and 64 of *Network News*.

My first hospital trip was unsuccessful in finding a suitable mask – within minutes of having each one fitted, I felt I was suffocating. Then I went to Concord Hospital for two days.

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There I trialled another seven masks, the first 5 with the same result as the previous two. The next two, apart from the sensation of claustrophobic suffocation, also emphasised my swallowing problem. The doctor detected the trouble immediately and sent me for a barium swallow, which proved my dysphagia. Needless to say, I am unable to tolerate a mask over my face so I live with the problem, knowing that the sleep apnoea will worsen.

For the last ten years, my only relief – if you could call it that – was sitting upright in bed to sleep. This started because, when I lay down flat, I could not breath properly – all of which was blamed on my heart condition. Where any illness of mine is concerned, I know I am too casual in my attitude – I do the same thing when I have a TIA¹. I work on a wait-and-see basis. So far, each TIA has passed over. The last one, although not the most frightening, was the worst – my left side was paralysed for $1\frac{1}{2}$ hours. I find I just cannot make myself press that button for an ambulance. One day, I'll wait-and-see too long – that's the way I am.

Gillian, if you feel that any of the above will be of interest for publication, you have my permission to use it. Hopefully, after the next three weeks or so, I'll get to the next part of my story. You may find that part of interest too. Strangely enough, prior to my learning about the polio, I'd commented to my doctor that the use of my left arm had deteriorated over the last 10 years. I'd said to him that everything that happened was always on my left side. Little did we know!

¹ Ed. From my reading, a transient ischemic attack (TIA) is a short-lived episode (less than 24 hours) of temporary impairment to the brain that is caused by a loss of blood supply. A TIA causes a loss of function in the area of the body that is controlled by the portion of the brain affected. Many people refer to a TIA as a "mini-stroke". TIAs occur when a blood clot temporarily clogs an artery, and part of the brain doesn't get the blood it needs. The symptoms occur rapidly and last a relatively short time. Most TIAs last less than five minutes. The average is about a minute. Unlike stroke, when a TIA is over, there's no injury to the brain. TIAs are extremely important predictors of stroke. Don't ignore them! If symptoms appear, seek medical help immediately. A doctor should determine if a TIA or stroke has occurred, or if it's another medical problem with similar symptoms.

Can You Help to Promote the Network?

We are most grateful to everyone who has been able to distribute our pamphlets widely throughout their local communities. If anyone can help to get the message out about the late effects of polio and the Network by putting more pamphlets on display in, for example, pharmacies, doctors' surgeries or waiting rooms, clinics, shopping centre notice boards, libraries and community health centres, please contact Alice on (02) 9747 4694 or by email at *alices*@*hotkey.net.au* and she will post some out to you.

Donation Money Boxes Project – An Update

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

If you can help, please email George on *office*@*post-polionetwork.org.au* or give him a call on (02) 9890 0946 or 0412 082 983.

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Have You Made Your Will Yet ?

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

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

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

There are four simple steps in making a Will

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

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

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

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

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

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

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

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

		Post-Polio Network Meetings 2004	
Saturday 30 October	Kokoda Track Memorial Walkway Rhodes Rotary Park <i>Killoola Street</i> <i>Concord</i>	PPN 15th Anniversary Picnic Full details are given on Page 2 Please come and join in the celebrations	
Saturday 27 November	Charles Blunt Conference Room Royal Rehabilitation Centre 59 Charles Street Ryde	Sixteenth Annual General Meeting followed by a Seminar presented by Andrew Buchanan Chairperson of the Disability Council of NSW See further details on page 7	

Management Committee and Webmaster Contact Details

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Merle Thompson	Polio stories	stories@post-polionetwork.org.au	02 4758 6637
Bob Tonazzi	Treasurer / Public Officer	treasurer@post-polionetwork.org.au	02 9311 2555
Anne Buchanan	Publicity Officer	publicity@post-polionetwork.org.au	02 9771 2748
Anne Buchanan	Information Bulletin	bulletin@post-polionetwork.org.au	02 9771 2748
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Alice Smart	Executive Assistant	alices@hotkey.net.au	02 9747 4694
Neil von Schill	Support Group Co-ord	support@post-polionetwork.org.au	02 6025 6169
John Ward	Committee Member	coralyn@dodo.com.au	02 9451 5995
Terry Warwar	Website Webmaster	webmaster@post-polionetwork.org.au	
Mary Westbrook	Q's about polio & pps	askmary@post-polionetwork.org.au	

Network Office Hours

The Network Office at the Northcott Society is now open 5 days a week, from 10:30 am to 3:30 pm. If you have any questions or require any information, please contact George, Nola, Carmelita, Helen or Madeline. It is a good idea, especially if you are coming from a distance, to ring first before dropping in. When you arrive, just sign in at the Northcott Reception Desk and ask the receptionist to let us know you are there.

Office: Ground Floor, The Northcott Society, 1 Fennell Street, North Parramatta Phone: (02) 9890 0946 Email: office@post-polionetwork.org.au

Mail: PO Box 888, Kensington NSW 1465

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