

POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

At the Network's sixteenth Annual General Meeting held on 27 November the following members were elected to the Management Committee:

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

Following the Meeting, Andrew Buchanan, Chairperson of the Disability Council of NSW, gave a very entertaining talk the essence of which was capably captured by Wendy Chaff in her Seminar Report on page 5.

On **page 2** you will find details of our first **Seminar** of the year to be held on **Saturday 5 March** at the **Northcott Society, Parramatta**. **The presenter is Rehabilitation Specialist, Dr Stephen Buckley, and his topic is *Managing the Late Effects of Polio – with a particular emphasis on pain problems***. Dr Buckley has been consulted by Network members over many years and his presentation will draw on his considerable experience treating polio survivors as he explains how to better manage our post-polio problems. You won't want to miss this one!

All dates for our **2005 Seminar Program** are given on **page 30**. **Please note these dates in your diaries**. You will see that this year we are holding another **Mini-Conference** in a regional centre, this time in the **Hunter Area** at the **Beresfield Bowling Club** on **Saturday 17 September**. Neil von Schill has provided preliminary details on page 25 in his Support Group Report.

If your address label still reads "Renewal Due on 1 July 2004" we have not yet received your membership renewal for 2004/2005. In this case, you will find another copy of your Membership Renewal Form enclosed. Please send in the Renewal Form and membership subscription as soon as possible. The Network is self-funded and needs your continued support to enable us to keep providing services to polio survivors and their families. In order to reduce our Treasurer's work and also speed up his processing time, he has asked me to *beg* you to return the **entire** form with your subscription – please *don't* tear off and return only part of the form.

This *Network News* has been in the pipeline for a while, so it is a bumper issue. I hope you find much of interest within its pages. In particular, Marcia Falconer's article *Post-Polio Syndrome and Inflammation*, which is based on the talks she presented to our August Seminar, appears on pages 6 to 9. Following this is a report on the Rotary Exhibition currently on display in the National Museum in Canberra – *A World Without Polio : Truly Remarkable*. All your favourite features can be found in this issue, together with an immunisation update and articles submitted by members.

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Managing the Late Effects of Polio

with a particular emphasis on pain problems

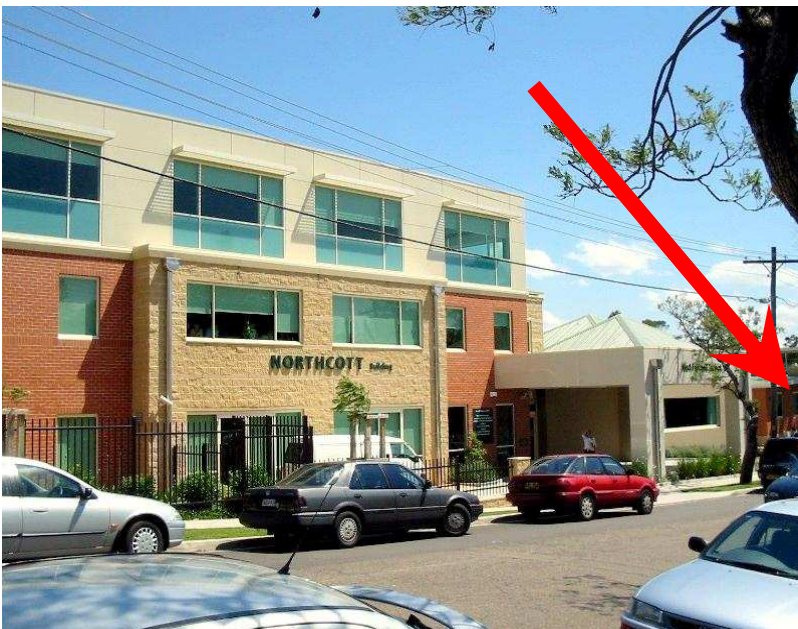
Date: Saturday, 5 March 2005

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

Venue: The Northcott Society
1 Fennell Street, North Parramatta

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

Parking:



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

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

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

Dr Stephen Buckley has been a Rehabilitation Specialist for twenty years and is a consultant physician in rehabilitation medicine at the Royal North Shore Hospital and at the Royal Ryde Rehabilitation Centre (Coorabel), specialising in neurological impairment.

Dr Buckley also runs a private practice at Chatswood, where he is regularly consulted by people experiencing the late effects of polio. Drawing on his considerable experience treating polio survivors, Dr Buckley will speak to us about how polio survivors can better manage their symptoms, with particular emphasis on pain problems.

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

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

Post-Polio Network Office Co-ordinator's Report

**Ground Floor
Northcott Building
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Parramatta NSW 2151**

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

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**

As you know from our last *Network News* I have been employed by the Network to assist manning our new office in Parramatta, hopefully raise funds and increase the profile of the Network generally.

I have been here four months now and everything is coming together quite nicely. We now are able to open the office five days a week between 10:30 am and 3:30 pm, with the assistance of our valuable volunteers Nola, Carmelita, Helen and Madeline. If anyone has some business with Northcott or is visiting the North Parramatta area we would love to see you. Come in and have a chat – who knows, you may even get a cup of coffee; Gillian always seems to get two cups out of me when she visits the office but she's a caffeine addict. I'm not surprised considering the amount of work she does for the Network and I would like to take this opportunity to thank her for all her support in making this happen. I would also like to thank the Management Committee for the support and encouragement they have given me in embarking on this new phase of the Network's activities. If you can't come in and see us, give us a ring on 02 9890 0946 and talk about any problems you may be having or about anything at all, we would love to hear from you.

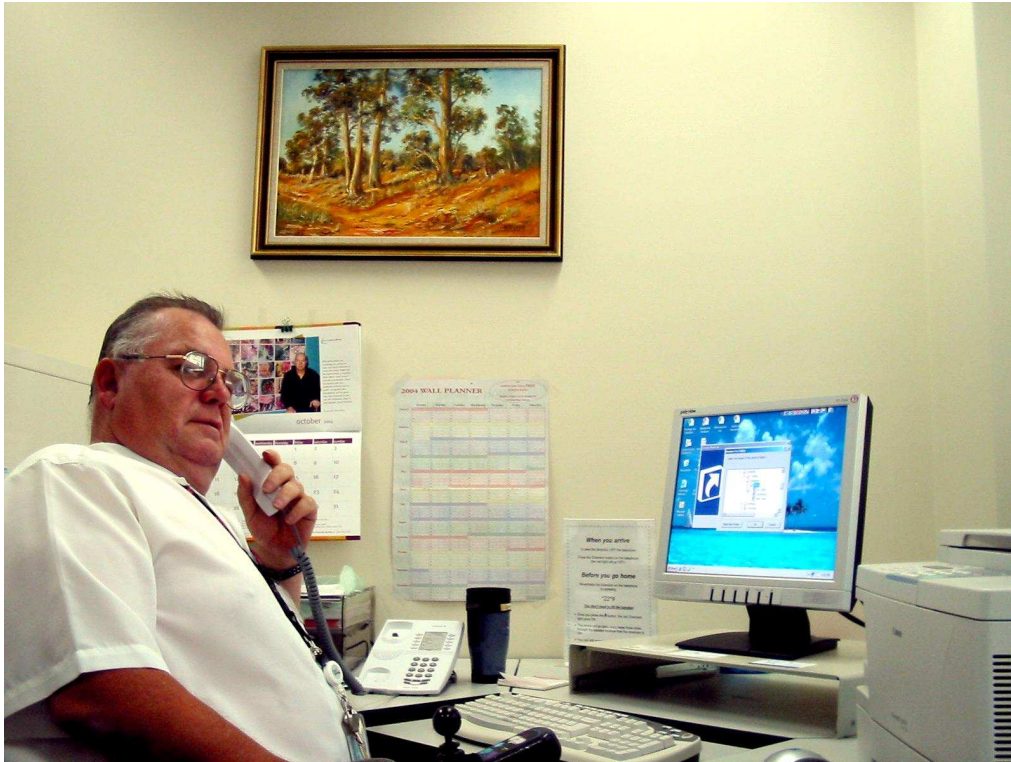
We have had a few calls from our members with concerns about the distance to walk from the car park when they have to visit the Northcott Equipment Services (NES). I have approached the Property Manager and he very well understands our predicament. He has advised me that anyone visiting NES who can't walk very far can park in the No Parking area, in the adjacent courtyard. As usual the Northcott management is very caring and very generous in attending to our needs.

When we moved into our new office we were sharing our accommodation with the Amputee Association of Sydney, but just before Christmas they relocated to the first floor of our building. This means that for the time being at least we have a lot more space, and both organisations are enjoying more privacy.

If anyone has any problems regarding equipment, services or any other issues please give me a ring anytime, even after hours on 0412 082 983. Don't forget that's what we are here for, to serve our members or anyone who has had polio.

I hope you all had a very Merry Christmas and a Happy New Year and I look forward to seeing or hearing from you in 2005.

At The Network's Office



George Laszuk hard at work in our office in the Northcott Building. The painting donated by Margaret Greig can be seen on the wall.

Parramatta Pieces

Anne O'Halloran

Now that the Network has its office at Parramatta, past Committee Member Anne O'Halloran thought it might be interesting for readers to learn some facts about Parramatta – its history (there is a great deal), its society, good eating places that are accessible and places of interest. To start off this occasional series, Anne tells us about St Patrick's Cathedral.

The rebuilt St. Patrick's Cathedral at Parramatta has won the Sir Zelman Cowan Award for Public Buildings in the 2004 Royal Australian Institute of Architects (RAIA) 24th National Architectural Awards. This is the first time this Award has gone to a place of worship. The rebuilt cathedral is the work of MGT Architects and Design Architect Romaldo Giurgola, the 84 year old Italian-born architect who designed the new Parliament House in Canberra.

As most people know, St Patrick's Cathedral was destroyed by fire on 19 February 1996. The Cathedral is on the corner of Victoria Road and Marist Place Parramatta, which is quite close to the Network's new office at the Northcott Society. It is well worth a visit when in Parramatta and what's more it offers disabled parking and level access into the Chapel and the new extension of the Cathedral.

The Cathedral is home to some beautiful and interesting expressions of art and sculpture. It is open on Monday to Friday from 6:00 am until 5:30 pm, with the hours on the weekend varying slightly. St Patrick's welcomes visitors either as individuals who want to make their own way or as groups. Group tours can be arranged (usually a minimum of twenty is required, however I would suggest those wishing to join a group might talk to the group organiser at the Cathedral). A donation for the tour is requested. Visitors are asked to respect that many people visit the Cathedral for worship and prayer as well as to enjoy its art and design.

Tours can be organised by phoning the Cathedral on 02 9630 1115 and asking for Annette Hartman. As well, interesting facts about the Cathedral can be viewed on the website <www.parra.catholic.org.au> by following the links to the Cathedral.

Seminar Report – 27 November 2004

Wendy Chaff

Roving Reporter Wendy Chaff, Convener of the Network's Hunter Area Support Group, has kindly written this account of Andrew Buchanan's presentation at our Seminar on 27 November. Andrew is the Chairperson of the Disability Council of NSW (the official adviser to the NSW Government, and State Disability Advisory Body to the Commonwealth Government). We are very grateful to Wendy for taking on the role of "roving reporter" to bring Seminar reports to members unable to attend.

Andrew Buchanan – a fellow polio survivor – was an entertaining speaker with much of interest to tell us. During his lifetime he has observed and experienced many aspects of what it means to be a person with a disability.

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

Andrew told us that as a baby he contracted polio, passed on from his mother. He shared personal insights of his younger years, and how he started his career with the ABC as a radio announcer in rural New South Wales. Andrew recalled some happy years spent in Newcastle, managing ABC Radio Station 2NC, before moving on to Queensland with his wife and their two children. Later they returned to New South Wales.

Having carried on regardless of his physical limitations, it came as a shock when he broke his leg. That was how he learned the hard way about loss of independence and how much one needs to rely on others. Having to depend on a wheelchair for a while made him truly aware of how many adjustments are needed, by all concerned.

We were told of some encounters Andrew has had with insensitive people showing their ignorance, back before it became "politically incorrect" to discriminate in respect of disability. He has watched with interest as attitudes have begun to change over time, influenced by changing laws which now enforce the rights of people with disabilities.

Andrew told us about his involvement and role with the Disability Council of NSW, and some of the Council's achievements. One major event was the Conference when the late Christopher Reeve visited Australia to express his support for stem cell research, which stimulated public debate and media interest. Andrew mentioned that sometimes there are contrasts and differing attitudes between older and younger people disabled by disease or accident.

My personal impression from what I heard discussed, was that some younger "victims" may hold on in expectation of possible miracle cures and breakthroughs in technology. Many older "survivors" of diseases (such as polio) can show more acceptance of their conditions, having managed to adapt and cope by making the best of what they had left, as there were limited prospects in the past.

In the quickly changing world of the 21st Century, we all hope that new medical research and discoveries will make improvements possible.

Merle Thompson, our Vice President, thanked Andrew Buchanan on our behalf for spending his Saturday afternoon with us, and presented him with a memento of the occasion, a finely-crafted pen hand-made from Australian timber.

Post-Polio Syndrome and Inflammation

A report of her presentation at the Network Seminar held 31 August 2004 by

Marcia Falconer, PhD



Marcia Falconer contracted polio as a child in 1949, recovered completely and forgot about the summer she spent in bed. The first symptoms of Post-Polio Syndrome (PPS) appeared 36 years later. With no connections to the polio community, she had never heard of PPS and had no idea what was happening to her body. Neither did her doctor. The journey between onset of symptoms and diagnosis of PPS is what spurred her to do research in the field of post-polio problems.

Marcia received a BSc in biology from Simmons College in Boston, Massachusetts and then worked as a technician at the Massachusetts Institute of Technology (MIT). She married Dave Falconer and had two children. With her children in junior high school, Marcia went back to university and got a Master's degree in plant cell biology. Learning was so much fun that she continued on and did a doctorate in the development of neurons, receiving her PhD in cell biology in 1990. She spent two years learning about molecular biology as a post-doctoral researcher at MIT while the first symptoms of post-polio syndrome (PPS) appeared. Having no idea what they were, Marcia did her best to ignore them. Two years later and home again with her family, Marcia developed a virology lab doing research in the area of biotechnology for Agriculture Canada. PPS symptoms became steadily worse until fatigue levels began to interfere with her research. Just at this time the Canadian government decided to close the research institute. She and over 100 other scientists were without jobs. After six months spent recovering her energy she realised that she truly missed research. Synchronicity appeared in the form of an internet meeting with Eddie Bollenbach, a kindred spirit – a biologist, a polio survivor and also struggling to continue working. They teamed up and have written several scientific papers together. In 2000 they compiled and distributed a large survey about PPS – some of you may have taken part in this survey or its follow-up questionnaire. The results of this survey provided the data for an article currently submitted to a scientific journal and also are the basis for her other presentation to Network members last August, "PPS 'Flu' and the Immune System".

With a son, daughter-in-law and 7 year old grandson living here in Sydney, Marcia and her husband Dave are frequent visitors to Australia and we have been privileged to twice have Marcia present her latest research findings to members. Marcia gives lively talks making complicated research easily understood by people with no scientific training, and you will similarly find her following article not only very informative but easy to follow.

Post-Polio Syndrome (PPS) has been a recognized condition for more than 25 years, with reports of similar symptoms going back to the 1800's. However we still do not have a grasp of the underlying cause, or causes, of PPS! We do not know how many polio survivors will develop PPS, estimates range from 20% to over 80%. We do not know why some polio survivors develop PPS and others do not. There is no diagnostic test and PPS remains a diagnosis arrived at after exclusion of other somewhat similar conditions. We do not understand why there is a lag time between recovery from the acute illness and development of symptoms severe enough to compromise the quality of life. It seems there is very little that we do understand about PPS. However, if we can discover the underlying cause(s) of PPS, if we can find out what is happening at the cellular and even sub-cellular level, there is promise of being able to answer all of these perplexing issues. There is also promise of being able to treat and possibly even prevent the onset of many, perhaps most, PPS symptoms.

Little research has been done on PPS, probably because polio survivors are a dying breed. After world wide eradication of polio, the 'lifespan' of PPS will be equal to that of the youngest living polio survivor. Or will it? Poliomyelitis continues to cause paralysis although now the virus causing the illness is not the polio virus but the West Nile Virus, or enterovirus 71, or one of several Cocksackie viruses. The nerve damage caused by these viruses is identical to that caused by the polio virus and therefore it is likely that PPS, perhaps by then called Post-Viral Syndrome, will continue to bring new limitations to survivors many years after they thought they had recovered.

So it remains important to examine the underlying cause of new muscle weakness, central fatigue, pain, memory and word finding problems and other symptoms that accompany PPS. Fortunately, current research in other areas holds great promise for explaining what is happening to so many polio survivors.

The cause of virtually all PPS symptoms can be explained by one word: ***inflammation!*** Front line research in the fields of neurology, immunology, physiology and virology is coming together and the many pieces of the puzzle are being laid upon the table. A good analogy is to think about a jig-saw puzzle. When you dump a 1,000-piece puzzle out of the box, some pieces land right side up, others upside down. There is little hope of assembling the puzzle until you turn all the pieces right side up. The next step is to put all the straight edged pieces in a pile and then assemble the outer edge of the puzzle to give you a general outline. After this it is helpful to group pieces with similar patterns or colours together. This is approximately where we are today in our understanding of how inflammation is related to almost all chronic diseases: PPS, MS, ALS, CFS, Parkinson's, irritable bowel syndrome, arteriosclerosis and many, many others. This also give you some idea of how far we have to go until we have a complete picture!

Let's look at the puzzle pieces that seem to belong to PPS. Inflammation has two major causes: injury – including viral and bacterial infection, cuts, strains, operations, etc and stress – including major events such as death of a relative, divorce, and job loss, but also including milder, repetitive stress that is encountered every day. In a person with PPS, when the body suffers an injury, such as physically overdoing by climbing too many stairs, walking on uneven ground, etc the first reaction is for the cells in the affected area to release a chemical messenger. This messenger, called a *proinflammatory cytokine*, tells specialized cells, whose job it is to protect you from invading organisms, to come to the site of the injury. At the same time the proinflammatory cytokines activate resident cells and cells that have migrated to the injury and all of them produce more proinflammatory cytokines setting up a cascade of events that will involve the entire body.

Two proinflammatory cytokines, Interleukin-1 and Tumour Necrosis Factor- α , are especially important in triggering an acute immune response, the body's first line of defense. The acute immune response involves developing a fever, fatigue, loss of appetite, sleepiness and other symptoms. It goes away within a few days. However if the injury is repeated often – say if a person with PPS persists in exercising a stressed out muscle – then a chronic immune response will set in. This response to chronic stress involves the entire body including the brain and it will produce **central fatigue, new muscle weakness, problems with short term memory and word finding, irritable bowel syndrome** and other symptoms.

Recognize them?

Indeed. These are the post-polio syndrome symptoms we are so familiar with. In an effort to keep this article shorter than a textbook on immunology, I have omitted the complex chain of events that takes place in the body between the original stress and the onset of PPS symptoms. There are many, many research papers that amply document what

happens in the body after activation of the immune system by proinflammatory cytokines and that eventually results in symptoms identical to those of PPS.

Let's take a brief look at how proinflammatory cytokines may be the underlying cause of new muscle weakness. We begin with acute polio and the death of a large number of nerves whose job was to innervate muscles by telling the muscles to contract or relax and thereby allowing you to move a leg or an arm. If all the nerves leading to a leg or arm died, the limb was paralyzed. However in many people, original paralysis or severe weakness eventually resolved, voluntary movement was restored and you could once again use your arm or leg. The body developed a neat trick to allow this to happen. The surviving nerves were able to send out 'neuronal sprouts' to attach to and innervate muscles that had been orphaned when the nerve originally attached to them died off. Thus the surviving nerves were able to activate not only the muscle that they always innervated, but also surrounding muscles creating something called a 'motor unit'. This repair was essentially stable for many years.

However 30 or more years after recovery from polio, many people begin experiencing new muscle weakness. Often the weakness is in the 'good' arm or leg. This may be due to the fact that the 'good' arm or leg was used more. Clearly something happened to the neuronal sprouts; either they no longer could maintain full time attachment to the motor unit or else they may have died off completely. This caused the appearance of new muscle weakness. Once again, I've simplified this a bit – although the general picture is correct. But this is a description of what is happening, not an explanation of why it is happening.

Enter proinflammatory cytokines. Remember them? Researchers have well established that proinflammatory cytokines cause cells to release neurotoxic proteins. These neurotoxic proteins can damage or even kill neurons by a number of mechanisms including changing the outer membrane of the nerve cell resulting in cell death or increasing reactive oxygen inside the nerve cell which also leads to cell death. It is probable that the neuronal sprouts, that have served so well for so long, are more fragile and may be the first target of proinflammatory cytokines in the central nervous system.

A very important fact is that nerve death only occurs in an activated immune system. The next question is "Do people with PPS have an activated immune system?" The answer is **YES!** There have been a number of research papers indicating that polio survivors with PPS symptoms have an activated immune system while polio survivors who do not report PPS symptoms do not have an activated immune system^[1].

A very recent research paper^[2] looked at cytokines in people with PPS, polio survivors without PPS, people with multiple sclerosis (MS), a well known inflammatory neurological disease, and people who had no neurological problems. They found that people with PPS and MS have proinflammatory cytokines in their central nervous system while polio survivors who do not have PPS and people without neurological problems do NOT have proinflammatory cytokines in their central nervous system.

What might cause the presence of these proinflammatory cytokines in people with PPS? One hypothesis is the presence of very low levels of polio virus RNA hiding in nerve cells. This polio virus RNA is not capable of infecting you or other people, but is capable of triggering the production of proinflammatory cytokines and with that, an underlying state of chronic immune system activation.

Other researchers have demonstrated a clear connection between the presence of proinflammatory cytokines and central fatigue^[3]. Psychological stress – the kind that doesn't involve overdoing physically – is perceived in the brain and the brain produces proinflammatory cytokines. This can cause profound fatigue, inability to concentrate and other symptoms^[4].

Remember that 1,000-piece jigsaw puzzle we have spread out on the table? We are now able to put together some of the same coloured pieces to make small pictures that are part of the larger picture. In the same way, we are piecing together what happens when a person with PPS experiences physical or psychological stress. We start to see small pictures and we can just begin to discern the larger picture coming together.

We are coming to the place where it may be possible to treat PPS symptoms using anti-inflammatory medications. A very exciting trial, using intravenous Iv immunoglobulin treatment, is currently underway in Sweden. Preliminary trials of this treatment in people with PPS have yielded dramatic improvements in fatigue and muscle strength!^{[5],[6]}

Other treatments to reduce PPS symptoms may be based upon traditional anti-inflammatory medicines such as aspirin, ibuprofen, indomethacin and others. All treatments would have to be done under the supervision of your doctor, but in the meantime, there are some things you can do that are known to minimize inflammation in the body – and with that you might have a reduction of PPS symptoms. You might try meditation. Yes it works ... if you do it consistently. Appropriate exercise, under the guidance of a knowledgeable physiotherapist, will definitely lower inflammatory cytokine levels. Pace yourself and don't overdo. This is easier said than done but if you understand that seriously overusing muscles will start the proinflammatory cascade of events and with that bring on or intensify PPS symptoms, perhaps you will be able to justify resting before you go too far.

Adipose tissue – commonly known as fat – is also a producer of inflammatory cytokines. If you needed a good reason to lose weight, here it is. Finally there are a few things you can try. Drinking green tea encourages weight loss and it has neuroprotective qualities. There are also reports that undenatured whey protein may be beneficial. These things are probably not as effective as direct medication to lower proinflammatory cytokine levels, but as we incorporate them into everyday life, they will bring positive benefits.

And let's keep working on that jigsaw puzzle!

References:

- [1] Dalakas, MC. *Pro-inflammatory cytokines and motor neuron dysfunction: is there a connection in post-polio syndrome?* J Neurolog Sci. 205:5-8, 2002.
- [2] Gonzalez et al. *Prior poliomyelitis-Ivlg treatment reduces proinflammatory cytokine production.* J Neuroimmunol. 150:139-144, 2004.
- [3] Patarca, R. *Cytokines and chronic fatigue syndrome.* Ann NY Acad Sci. 933:185-200, 2001.
- [4] Black, PH. *Stress and the inflammatory response: a review of neurogenic inflammation.* Brain, Behavior and Immunity 16:622-653, 2002.
- [5] Farbu et al. *Intravenous immunoglobulin in postpolio syndrome.* Tidsskr Nor Laegeforen. 124:2357-2358, 2004.
- [6] Gonzalez et al. Study in progress.

A World Without Polio : Truly Remarkable

This exhibition has been developed by the Rotary Club of Canberra Burley Griffin in conjunction with the National Museum of Australia, Canberra. The exhibition tells the story of polio and traces Rotary International's heavy involvement in helping authorities around the world eradicate the disease, hopefully by the end of 2005. Rotary's 100th anniversary will be celebrated during the exhibition, on Wednesday 23 February 2005.

A World without Polio explores the effect of the disease, the science behind the polio vaccine and the development of the Rotary inspired and funded global eradication program.

Visitors can view images of Rotary volunteers delivering the vaccine as well as see T-shirts and banners used to promote "vaccination days". A feature of the exhibition is an iron lung developed by a South Australian, ET Both, which was used Australia-wide to treat polio patients. A second iron lung is on display in the Hall. This iron lung is operational and is turned on for demonstrations at 11:00 am and 2:30 pm daily.

Entry is free to the exhibition which is on show daily in the Nation Focus Gallery until Sunday 27 February 2005, and will then travel around Australia.

Thanks to Dr Kris Klugman, President of the Burley Griffin Rotary Club, the Network was invited to contribute to the exhibition. This resulted in space being made available for information about the late effects of polio and for the Network's contact details to be included. We are very grateful for this exposure. In addition, some polio memorabilia was contributed by members of the ACT Support Group.

President Gillian Thomas and ACT Support Group Convenor Brian Wilson were delighted to be invited to the official opening of the exhibition by Kim Beazley on 9 December 2004.



In opening the Rotary Exhibition Kim Beazley shared with us his story of polio, contracted at age five. *"I remember first waking up in the morning, and it must have been a terribly frightening experience given that I can still remember it, but I couldn't move,"* Mr Beazley said. *"Most of all I remember the ambulance coming to our front gate and the crowds of kids around it, and I suddenly felt for the first time in my life important."* He went on *"My mother tells me, because this I didn't know, that I induced a special terror because at the time I was afflicted the Queen was visiting Australia and my mother had met the Queen. So the royal family went into total panic because my mother may have transmitted it to her, and indeed my mother did get a mild variant of polio from me. It was an early republican gesture on my part. I nearly drove the royalty out of the country!"*



Pictured at the launch with Kim Beazley are renowned Australians Sir Clem Renouf AM (left) and Professor Frank Fenner AC CMG MBE (right). [Photographs on pages 10 and 11 courtesy of Brian Wilson]

Australian Frank Fenner is recognised worldwide as a most distinguished microbiologist. As the undisputed world expert on poxviruses, he has been closely involved with the World Health Organisation (WHO) in various capacities since 1965. Most notable was his service to the WHO Intensified Smallpox Eradication Program, then as Chairman of the Global Commission for the Certification of Smallpox Eradication. The eradication of this dreadful disease in 1979 constitutes perhaps the greatest practical achievement in the history of microbiology.

As Frank was instrumental in the eradication of small pox, Sir Clem Renouf, an Australian Rotarian from Queensland, had the vision to seek a polio-free world. As Rotary International President 1978-79, Sir Clem saw the potential of a pilot project in The Philippines. Thoughtfully, he contrasted \$100 million being spent on building warships, and wondered what the worldwide Rotary organisation could do against disease with that amount of money and Rotary's ability to mobilise people. Even though the community service organisation had never before attempted such a global project, he asked the question – which disease could Rotary tackle? Polio was the expert answer. *“PolioPlus can be seen as a natural extension of the first Rotary-funded project to immunise more than six million children in the Philippines in the late 1970s,”* Sir Clem, who was knighted for his contributions to society, has written. Global partners Rotary, WHO, UNICEF, and the US Centres for Disease Control, as well as national governments and other major donors, subsequently co-ordinated their efforts in the 1980s. The outcome is that one Australian's vision has led to a world on the brink of eliminating the second disease ever.

Professor Frank Fenner and Sir Clem Renouf spoke at a sponsors' lunch after the opening of the Rotary exhibition, and gave those present an insight into their massive achievements.

The Post-Polio Network used the launch to call on the Federal Government to announce the funding of inactivated polio vaccine (IPV) on the National Immunisation Program. The Network's Press Release was part of our ongoing advocacy on this issue. Pages 12 to 14 bring you up-to-date with our continuing work in this regard.

Polio Immunisation Schedule

The Network has received several requests from members for information on the recommended polio immunisation schedule. The following information comes from the booklet, *Immunisation*, produced by the Australian Government, Department of Health and Ageing. It says that children should be immunised four times against polio at the following ages: 2 months, 4 months, 6 months and 4 years. Three doses are needed to provide good protection during childhood with a booster at 4 years. Two types of vaccination are available, OVP and IPV.

The Sabin live oral vaccine (OPV) contains small amounts of 3 types of polio virus which have been altered so they do not cause polio and a very small amount of an antibiotic (neomycin). OPV is available free of charge. As the virus from the vaccine is present in faeces for about six weeks after vaccination, strict personal hygiene is advised for people caring for the baby, particularly when washing their hands after changing nappies. Anyone in the family who has not been immunised against polio should consider being immunised as in rare cases adults have contracted polio in this way. A child should not be immunised with OPV if anyone in the family has a disease such as HIV/AIDS or is on medication which lowers immunity as the risk of illness caused by the vaccine virus is greater in people with compromised immune systems. Children living with such people should be vaccinated against polio with IPV. A few people have mild side effects from OPV such as headache, muscle pains and mild diarrhoea. Very rarely (about one in 2.5 million doses) OVP has caused paralysis in a person who is immunised with it.

The Salk vaccine (IPV) is made from inactivated or dead virus and is given by injection. At present it is only available in Australia as a single injection but in future it may be combined with other vaccines. It is recommended that it be given at the same time as other vaccines. IPV is not free. As IPV is not a live vaccine, there is no risk of contracting polio from it. Possible side effects are muscle aches, soreness, swelling or redness at the injection site. About one in 10 children may experience a low grade fever or loss of appetite.

If a child starts on OVP, IPV can be used to complete the schedule or vice versa. On its website the Government advises health practitioners that the National Health and Medical Research Council (NHMRC) recommends IPV be used in preference to OPV when IPV in combination vaccines becomes available.

Why Should We Switch to an Inactivated Polio Vaccine?

The Australian Technical Advisory Group on Immunisation (ATAGI) was established in 1997 by the Commonwealth Minister for Health to advise and make recommendations on the technical and scientific elements of the National Immunisation Program. One such recommendation, the change to an inactivated polio vaccine, has not been implemented. Over recent months, therefore, the Network has been advocating for Australia to join other developed countries in changing from OPV to IPV to deliver the safest vaccine to young Australians.

Last June we wrote to both Federal and State parliamentarians urging them to support our call for IPV to replace OPV. We received a number of supportive responses and were also advised that ATAGI had been asked to review its earlier recommendation to switch to IPV. We understand that this review has been long completed and ATAGI's previous recommendation confirmed. However, as this Network News goes to press, almost nine months have passed since our original letter and yet there has been no action – we are still waiting for an announcement that IPV will receive funding.

Some excerpts from our June letter follow.

A very effective “inactivated” vaccine is now available to replace the oral polio vaccine. The “inactivated” vaccine is considered to be safer than the currently funded “live” vaccine as there is no risk of causing paralytic polio in either the child who has been given the vaccine or in someone in close contact with the child.

ATAGI and the NHMRC have recommended that the dose of “live” polio vaccine be replaced by a dose of the “inactivated” polio vaccine.

In giving their advice, ATAGI and the NHMRC are doing no more than recommending practice which is already routine in countries with public health systems comparable to those of Australia such as New Zealand and the USA.

We are only asking for the best and safest immunisation program. As an organisation we have vowed to work to increase immunisation rates to safe and proper levels in Australian children. We are concerned that progress towards this goal may be impeded if a fully-funded vaccination schedule for children is not retained and access is restricted on the basis of cost.

In September we tried again, this time writing to all Federal politicians, urging them to consider the issue during the election campaign. The election is now well and truly over and, as noted before, we are still waiting for an announcement that IPV will receive funding.

Some excerpts from our September letter follow.

At this election the Post-Polio Network would like you to put in the front of your minds the response of the political parties to childhood immunisation.

Only recently did the advent of a polio vaccine celebrate its 50th anniversary. Yet ironically at this time we are again faced with the fact that the recommended polio vaccine has still not been guaranteed Coalition Government support.

It has been almost two years since the Federal Government's key expert committee advised it to fund a new, safer polio vaccine.

The Post-Polio Network knows only too well the impact this preventable disease can have on lives. Our organisation advocates and articulates all the issues that have impacted on our members and constituency.

The ALP pledged to fund the safer inactivated polio vaccine in May 2003. For that we congratulate the responsible announcement of putting the welfare of our children first.

The Coalition continues to prevaricate on the issue of the recommended polio vaccine. For a decision that has been recommended for 2 years – the delay is inexcusable.

I would implore all Members of Parliament, before the election is over, to ensure that all recommended vaccines for childhood immunisation are funded.

In December, we issued a Press Release in conjunction with the Rotary Exhibition “A World Without Polio : Truly Remarkable”. In part, it read:

Gillian Thomas believes the Exhibition is a celebration of the enormous work that has gone into eradicating polio in Australia and the world and urges Health Minister, The Hon Tony Abbott MP, to use this remarkable milestone to clarify the Government's position on funding the safest possible polio vaccine in Australia.

“The NHMRC’s recommendation to switch from OPV to IPV was based on the preference to eliminate the small risk of vaccine associated paralytic polio (VAPP) from OPV [but] ... the Government has so far failed to act on it,” Ms Thomas said.

“Given that the cost to the Government of changing from using OPV to IPV is only in the order of \$3 - 5 million each year – a rather insignificant amount when you consider the benefits of providing the safest possible vaccine for Australian children – it is difficult to imagine that ATAGI will alter its original recommendation. The Minister must now heed the expert advice which he has requested and make clear the Government’s position on this issue.”

“With 40 countries around the world now providing their children with universal access to IPV, most recently in the UK and Korea, Australia needs to stop dragging its feet. Tony Abbott must now take action to ensure we are providing our children with the safest protection against polio and its associated risks”, said Ms Thomas.

“While we no longer have polio epidemics in Australia, the disease is not forgotten by Australia’s many polio survivors. The majority of us are now experiencing what are known as the late effects of polio. We suffer debilitating symptoms including unaccustomed fatigue (either muscle fatigue or a feeling of total exhaustion); new muscle weakness (including muscles apparently unaffected at the time of the initial polio infection); joint and/or muscle pain; sleeping, breathing or swallowing difficulties; increased sensitivity to cold temperatures; and a decline in the ability to perform basic daily activities. We owe it to our children to ensure they don’t ever contract this disease with its life-long impact on everyone it touches.” Ms Thomas said.

Vale – Dr John Colebatch AM

Regular readers will remember the article “Living and Breathing with Weak Respiratory Muscles” by Dr John Colebatch which was published in Issue 64 of Network News, June 2004. Many will not know, however, that John was extremely ill when he wrote that article and later answered questions from polio survivors in Australia and overseas about his work. Despite his poor health, John was as keen as ever to impart his knowledge to help other polio survivors. The following obituary was written by John’s daughter Eve and published in the Sydney Morning Herald on 18 October 2004 under the title “Lifelong Study That Helped Thousands Breathe Easier”. It is reproduced here with Eve’s kind permission.

Associate Professor Hal John Hester Colebatch, who has died at 75, was world famous in the science of respiratory medicine, in which he carried out research for more than 40 years. He was a clinician investigator of the highest integrity.

He was also a lifelong devotee of literature, classical music, the opera and theatre, a keen traveller, and a gracious host to the many who shared his table and his red wine. Despite his post-polio difficulties, he retained a quirky sense of humour.

“Prof” Colebatch, as he was widely known, was born at Northam, Western Australia in 1928 and attended local schools. He entered first-year medicine at the University of WA, completing the course and graduating in medicine from Adelaide University in 1951. In 1952 he was made a captain in the CMF (Army Reserve).

In April 1953, while working at the Infectious Diseases Branch of the Royal Perth Hospital, he contracted poliomyelitis, becoming paralysed and requiring treatment in an iron lung for 74 days. After a year recovering in hospital, he rejoined the medical staff of the Royal Perth Hospital with responsibility for infectious diseases and rehabilitation.

Colebatch took up research on lung disorders in the Department of Medicine at Sydney University in 1958. He continued his research at the University of California, San Francisco and then at Oxford.

He was appointed senior lecturer in medicine at the University of NSW in 1964 and joined the Department of Respiratory Medicine, becoming associate professor in 1970 and department chairman in 1985.

In 1970-71 he was a senior Fulbright-Hayes research scholar and a visiting associate professor of physiology at the Harvard School of Public Health. The Thoracic Society of Australia and New Zealand awarded him its inaugural Fisons medal in 1989 and, in recognition of his research on the lungs, he was made a member of the Order of Australia in 1992. For many years – from 1968 to 1992 – he was a senior specialist in respiration to the Royal Australian Navy.

Because of increasing muscular weakness – the post-polio syndrome – he retired at the end of 1992 and was appointed a visiting professor of medicine to Prince of Wales Hospital in Randwick, continuing part-time work until 1996.

Colebatch was passionate about the role of science in medicine and how the scientific method had transformed it. He was an advocate against anything likely to affect research and its rigorous pursuit of knowledge, and was equally passionate about teaching and the importance of statistical data.

He believed the role of medicine was to outwit nature for as long as possible, but when Mother Nature called, it was not the doctor's role to try to continue the patient's life. Nature should be allowed to take its course.

In addition to his professional career, and despite his many medical complications and physical limitations, he loved reading, classical music and going to the theatre.

He was also a keen traveller and devoted correspondent with his colleagues and family.

He treated all who knew him as equals and gained a profound respect from his colleagues and the local community which supported and loved him. Throughout life, Colebatch maintained his humour and free-thinking philosophy on the vagaries of day-to-day survival. When asked about his achievements, he would say, "*Survival is my greatest achievement by far.*"

Colebatch and his wife, Dr Elvita Evelyn Clough, divorced in 1976; she died in 1996. He is survived by his son James and daughter Eve, and by his brother Reg and sister, Mary Maude.

For Colebatch, the family motto was most fitting: *Post multas difficultates*. After many difficulties.

Vale – Kevin Byrne AM

Kevin Byrne, disability advocate extraordinaire and husband of Network foundation member Patricia Rich, passed away suddenly on 11 September 2004 leaving behind a great sense of loss. Kevin joined the ranks of people with disabilities (his words) following a surfing accident in 1964. Throughout the next 40 years he fought many battles for the rights of people with disabilities and, despite inevitable frustrations, had many victories along the way. In 1995 Kevin was appointed Executive Officer of the Disability Council of NSW and filled this position until 13 August 2004. He took up his new role as Manager of Stakeholder Relations, Disability Action Plans and Across Government Agencies at the Department of Ageing, Disability & Home Care on 17 August. He was excited about the new challenge and was looking forward to achieving tangible outcomes in his new role.

The following excerpt from the Disability Council of NSW website encapsulates Kevin's worth to us all:

Kevin's involvement, dedication, participation and single-mindedness in fighting for the rights of people with disabilities will sorely be missed. His friendship, guidance and sense of humour will be missed even more.

Kevin strongly believed that people with disabilities were an integral part of any planning, within both the Government and non Government sectors. He fought to ensure that people with disabilities would be fully accepted and respected as citizens of this country and that they could contribute in a positive way as a real member of their community. He was passionate about the need for an inclusive attitude and society and believed that when we all work together much can be achieved.

Kevin might have left us but his legacy lives on, and many people with disabilities into the future who never knew him will continue to benefit from his work.

Poet's Corner

ACT Support Group Convenor Brian Wilson recently sent me this poem by member George French. Brian wrote "George's poem was presented in our limerick competition at our Christmas party on 4 December. We had 26 attend the party at the Ainslie Football Club and a great time was had by all. In a hotly contested competition, George again was a prize winner – a Santa mug for the second year in a row. Other prize winners were Andrea Osborne and Peter Seldon. Judy Fitch and Sylvia Sampson won door prizes."

The Lament of the Caliper George French



Caliper technology
Is dragging at the chain
And needs a fresh infusion
From a scientific brain

We can take a broken body
And make a million dollar man
But if a caliper is needed
It tends to spoil the plan

For if our hero is a cowboy
He can't get in the saddle
And if he is a sailor
He's up-creek without a paddle

And if she was a dancer
She'd have problems with her rumba
While if she were a model
She'd have troubles without number

A million dollar man of course
Must have lofty aspirations
But lesser mortals such as we
Live within our limitations

Our caliper relationship
Is one of love and hate
But we value our mobility
And accept it as our fate.

Invalidity Retirement

David Luck

A recent letter from member David Luck reads *“You may recall my contacting you, Mary, and speaking to you, Neil, when you were in Canberra, about retirement. I sought information about other PPS Network members who may have retired early and recall Neil mentioning that he had retired because of problems associated with polio. I thought I should advise you that I have recently been successful in my application for invalidity retirement from the Commonwealth Public Service. Your advice helped me in taking the plunge to make the application.*

I should note that the process was quite a long and complicated affair. All up it took eight months. In case other members might be interested in my story I have provided some background below which I would be happy for you to publish in Network News.”

Mary responded: *“Thanks for your interesting account of your retirement struggles. I will forward your email to Gillian who is Editor of Network News. I’m sure many members would find it interesting. It reminded me very vividly of my own experiences. Even in retirement I find it hard to remember my fatigue threshold and am continually overdoing and paying the consequences. I hope you enjoy your retirement.”*

I was a member of the Commonwealth Public Service for 37 years, starting with a cadetship in 1967. I studied economics during my cadetship in Brisbane and came to Canberra in 1972 with the Australian Bureau of Statistics. I had moved to other agencies over the years but finally started to experience problems coping with full time work about five years ago. At that time I was the head of an economics research unit in the Department of Communications, IT and the Arts. Then I was approaching fifty.

I had contracted polio in 1950 in Rockhampton. Like many others I was hospitalised for many months, in Brisbane. When I was four my parents decided to move to Brisbane permanently for easier and better access to medical treatment.

I did well at University and quickly worked my way up the totem pole in Canberra. Economics was quite a marketable qualification in the 70s and 80s. I was also at my peak physically, polio not being a major handicap apart from my noticeable limp. It is recorded on my medical record that I could walk up to a kilometre unaided. It is interesting to read subsequent records. Not till I was about forty did I need a walking stick. By then it is recorded that I could walk only about a hundred metres unaided. Within a few years I had become more dependent on the walking stick. By forty five I had to use two sticks. By then I had moved to sticks with moulded hand grips because of carpal tunnel pain. Fortunately, I have not had that pain since.

By fifty, I was struggling to keep up a full time job. I was spending almost all of the weekend recovering and then starting the new week not fully recovered. My doctor agreed with me that I should reduce my hours of work. I started taking Wednesdays off work. I was lucky that I could manage the job four days a week although I didn’t always get a day off and still had to work at home for some time each week. I was also grateful for the cooperation of the senior management of the Department who were very understanding. I was also thankful that I had not dipped into my sick leave credits and had plenty to utilise.

Eventually, at the end of 2003 I felt I could not continue at four days a week, but that the job could not be done with any fewer hours. As I was the head of the unit I couldn’t job share. So I applied for invalidity retirement. By then I was able to walk only very short distances without assistance and, even with my sticks, only about fifty metres before I needed to sit down. I had recently purchased a wheelchair for the shopping centre and other occasions when it is too far to walk.

Applying for invalidity retirement was a difficult exercise in itself because one has to be declared unfit for work and on long term sick leave before one can apply. My local doctor was not keen on agreeing to this. He was worried that I would vegetate once I had stopped full time employment. Also he was determined to find another reason for my tiredness, besides polio. He prescribed various drugs, and even suggested depression as a cause. His theory was that chronic pain can affect the chemistry of the brain leading to depression. While that might be true, I have resisted it as I have not been keen to start taking anti depression drugs.

Eventually he suggested that I be assessed for sleep apnoea. I went through all the tests, and I did indeed have mild sleep apnoea but not, in the opinion of the thoracic specialist, sufficient to cause the wave of tiredness that would often overcome me at work.

Ultimately, however, my doctor did agree to declare me unfit for work. My application for leave took eight months to come through and in September I was given a certificate for invalidity retirement. The process, while slow, was fairly straightforward. My claims relating to PPS, supported by my doctors, were basically accepted.

I have found over the last eight months being away from work that I am not any less tired. However, the most comforting thing is that I can rest when I want. I can pace myself and spread out my activities. That way, so far, I am coping much better. I can also do things that I was too tired to do when working full time. This includes gardening, studying languages and playing more contract bridge. I am comforted by Richard Daggett's article in the October 2004 *Network News* in favour of mental and social activities such as contract bridge. My stress levels are a lot lower and I can control pain a lot better by not pushing myself too far – as most polios do.

I am indeed grateful that ComSuper has become more reasonable in its decisions on invalidity retirement. It has recently relaxed its former rigid approach and now takes into account broader lifestyle considerations. They appear to take into account such factors as being tired to the extent that one has a significantly impacted lifestyle outside of work. I would like to think the Network's campaigns over the last few years to allow Post Polio Syndrome sufferers access to early retirement has borne fruit in my case. Thanks for your efforts.

Vale – Wendy Nolan OAM

Wendy Nolan contracted polio at the age of five and passed away in September 2004, aged 74. Wendy spent much of her life on crutches until a bad fall in the 1970s made her reliant on a wheelchair for mobility. In 1954 Wendy was a foundation member of the St George Polio Fellowship, later to become the St George Association for People with Physical Disabilities, and remained active in the association for the last 50 years. It was there that she met Jack Nolan, another polio survivor, and they married in 1973. Wendy and Jack were foundation members of the Drummoyne Advisory Group for the Disabled, later to become the City of Canada Bay Access Committee. Wendy was Secretary on this Committee for 23 years where she worked tirelessly to improve facilities and services for people with disabilities. Wendy was a member of the Post-Polio Network for over ten years and a keen supporter of its activities. Most recently she contributed to our Constitution Review Sub-Committee.

Her commitment and dedication over many years saw Wendy honoured with a Rotary of Australia Award, a Commonwealth Recognition Award for Senior Australians in 2000, a Centenary Medal in 2001, and an Order of Australia Medal in the 2004 Queen's Birthday Honours. The awards went some way towards acknowledging her contribution to her local community, particularly as an advocate for people with disabilities seeking access to community facilities.

Canada Bay Councillor, Michael Megna, in speaking at Wendy's funeral said "*I know I will miss, but never forget, her constant smile which lit up her face*". This is also how we will remember Wendy, and are glad that we will be able to continue to share our memories with Jack.

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.



Queensland research into polio survivors

An article, *The late effects of poliomyelitis in Queensland*, by physiotherapists Mary Lynch and Nancy Low Choy was published in the June 2004 issue of *Australasian Epidemiologist*. It reported a questionnaire survey of 126 survivors who were recruited from the waiting list of a Brisbane Post Polio Clinic (no longer operating). The most common new symptoms experienced by polio survivors were new muscle weakness (87%), unusual tiredness (79%), joint pain (79%), cramps (71%), walking changes (69%), muscle pain (61%), and increased falls (60%). The main activities of daily living which survivors needed increased assistance with were heavy household tasks (46%), climbing stairs (42%), and using public transport (37%). Changes to their employment (eg working fewer hours) had been made by 67% of respondents who were still working. Almost all survivors (83%) reported having made lifestyle changes as a result of their symptoms.

Expert patients and doctors

As very few health practitioners are well informed about the late effects of polio, most polio survivors have had experiences of having more knowledge about some aspects of their condition than do the practitioners they consult. Some practitioners value their patients' knowledge and are keen to learn more about PPS. Other practitioners ignore or angrily dismiss our knowledge. The editorial in a recent issue of the *British Medical Journal* (27/3/04) carried the headline, 'Expert patient — dream or nightmare?' It said that when doctors come across the term 'expert patient' they hear different things, ranging from doctors who regard expert patients as people who have the confidence, skills information and knowledge to play a central role in the management of life with chronic diseases to those whose expert patient of the imagination is one clutching a sheaf of printouts from the internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or possibly worst of all, a treatment the doctor has never heard of. The BMJ comments: *If one asks lawyers, architects, social workers, or management consultants whether they prefer clients who take an interest in the issues they face and are motivated to work in partnership to achieve successful results, the answer seems obvious. So why does the idea of expert patients provoke such antipathy within the medical profession?* The Chief Medical Officer for England is currently promoting the idea of the person with chronic illness becoming an expert or knowledgeable patient. Surveys show that most British doctors dislike this promotion; 63% saying expert patients will take up more of their time. In fact, says the BMJ editorial, research studies show that expert patients make fewer visits and better use of visits to doctors and manage their symptoms better. In any case, says the editorial, all patients with chronic conditions and their carers are experts regardless of how much medical knowledge they may have ... *As highly educated professionals in well paid employment, doctors are not necessarily best placed to understand the realities of life for many of their patients, particularly those living with debilitating medical conditions, who are disproportionately unemployed, old and poor.* The editorial concludes: *Long live expert patients — but in the interests of doctor-patient relations, let us find something else to call them. What we need is a simple,*

understandable phrase that is less prone to evoke hostility. For our money the best term is 'involved' ... involvement clearly requires at least two parties, rather than implying that the health professional role is somehow redundant ... Neither intimidating or patronising, involvement is a broad church in which many if not most of us would be happy to find a home.

'End of polio' exhibition

The Griffin Museum of Photography near Boston recently presented this exhibition by Brazilian photo journalist Sebastiao Salgado. One reviewer (Milford Daily News 29/8/04) wrote that Salgado *documents the suffering and hopes of humans ravaged by polio with unforgiving realism. An 11-year-old polio-stricken child, wearing sandals on his knees for protection, crawls into a soccer game in Somalia. A father pours a vial of vaccine into his son's mouth in a railroad car in India where they've been confined to prevent the disease's spread ... [the museum director says] Salgado's photos 'go far beyond promoting public awareness of a cause. They grab you and force you to face the pain of others with the hope that you will be motivated to fight for change'*. Many of the photographs can be viewed on <www.endofpolio.org/home.html>. Large posters of some of Salgado's photos were recently on display at Westmead Hospital. His photographs are also featured in a Rotary exhibition *World Without Polio : Truly Remarkable* at the Australian National Museum in Canberra until 27 February 2005. The Managing Director of Aventis Pasteur, a major sponsor of the Rotary exhibition, has presented the Network has a book of Salgado's photographs.

Rhonda Galbally and polio

Rhonda Galbally AO has recently written her autobiography, *Just Passions*, published this year by Pluto Press. Rhonda was CEO of VicHealth and has started a company, *Our Community*, to support and advocate for community groups. Rhonda contracted polio when she was 13 months old and spent much of her childhood in hospital having surgery. Her family *all hated my disability. We saw it as the worst thing that could happen to a family ... I would have given any thing, promised anything, for the miracle of complete recovery.* Her parents resisted health practitioners' pressure to place her in a school for crippled children. Some children, she writes, *were not so fortunate. Their parents would choose full-time medicine over full-time education ... By focusing on physical gains, these children would end up as adults with little education, often having to take jobs in sheltered workshops (some of which are sweatshops) or having no job at all.* As an adult Rhonda confesses to *an awful secret – I shared other people's loathing of disability. Until I joined the disability rights movement I didn't recognise my own hatred of disability — it had been repressed ... I was leading a split life. I demonstrated in front of the Miss Australia Quest, a beauty contest run by the Spastic Society on behalf of disabled inmates who were never going to win ... At the same time I would still have done anything to avoid being thought of as really disabled. So I refused to use a wheelchair at airports, even though I'd nearly pass out from pain and exhaustion as I struggled down the concourse.* The late effects of polio led to Rhonda in turn adopting walking stick(s), crutches, scooter and wheelchair. *Paradoxically, the more I use equipment the more disabled I look to others, but the more mobile I am. I tried to explain this to my mum, who took months to agree to go walking with me in my chair. It's not a failure, I told her ... it's a symbol of flexibility and success in finally coming to terms with my disability.* Rhonda says her first childhood experience of technology was as a *sadistic tool of mainstream medicine.* One evening with a friend, who has cerebral palsy, *The grog loosened up our memories and took the edge off them, making them bearable to recall and even tell one another. It also loosened our sense of humour. We shrieked with laughter (with a strong edge of hysteria), as we tried to imagine the mentality of the person who made up instruments of torture to stretch little babies; he must be called Thomas, because the main weapon was the double-Thomas splint, a rack*

where little children were spread-eagled on a crucifix with parted legs and tied in with bandages so they could move only their hands. Your feet were bandaged into plaster boots, and a strap drew out your knees ... Your hands were set into beautiful beaten stainless steel, to prevent them going out of shape. And you just lay on a bed and looked at a ceiling. After spending two years in one of those things all my muscles had atrophied. It was gross and excruciatingly painful. And in hospital I missed my mum and dad and big brother and lay in a state of terror and despair like a torture victim. As an adult the much travelled Rhonda still found leaving home extremely anxiety provoking, even for domestic flights (even for car trips). I had a dread of never returning, or of getting back and discovering that home had disappeared. I was still stuck in the feelings I had as a baby of thirteen months, when my home disappeared completely ... For years after I came home from hospital, if things weren't directly in my sight, I'd think they'd gone. I even hated playing hide and seek — I might never be found. There is much else of interest in this fascinating book. Look for it in your local library.

Post-polio and menopause

Post-Polio Health International (formerly GINI) has funded research at the University of Michigan, to investigate whether women with late effects of polio experience menopause differently — physically and emotionally — than do their non-disabled peers. A group of male polio survivors was also included in the study to examine whether their well-being differed from age-matched polio women both pre- and post-menopause. The complete report is online at <www.post-polio.org> (click on research). These are some of the findings: Polio women who had a natural menopause (eg not caused by hysterectomy) did so at the same age, on average, as did non-disabled women. Polio survivors were more likely to have had a hysterectomy (almost 35%) than the US average of 21%. More polio women (39%) used hormone replacement therapy than did their non-disabled peers (23%). It would be interesting to know why these differences occurred and whether they exist in Australia. Overall there were no differences in post-polio symptom severity, activities of daily living or emotional well-being between polio women who took, or did not take, HRT. Polio women using HRT did not report an improvement in post-polio symptoms. On average polio women approaching menopause were more satisfied with their lives and less unhappy than were post-polio men their age, but women who were at least five years into menopause were more stressed than their male counterparts. They also reported more severe post-polio symptoms. The authors say that the findings *suggest an acceleration of decline for women compared to men in later years; this will require further investigation*. In general, polio women in this study had an overall positive (45%) or neutral (35%) experience of menopause. Fewer had a negative experience (18%). Both female and male polio survivors reported somewhat more stress than the national US ratings for their age groups. The differences in stress levels was only substantial in the case of middle aged (45-55 years) polio women who reported much greater stress than their non-disabled peers.

Elimination of vaccine related polio in USA

The 13 October 2004 issue of JAMA (Journal of the American Medical Association) reported that the changes in US polio vaccination policy have resulted in the elimination of vaccine-associated paralytic poliomyelitis (VAPP) in the US. Prior to 1997 vaccination in the US was from the Sabin oral live vaccine (OPV). Then a policy of using IVP (Salk inactivated vaccine, IPV) for the initial vaccination followed by OVP for subsequent inoculations was introduced. In 2000 an exclusive IVP schedule was adopted. Between 1961 and 1989 an average of 9 cases of VAPP were confirmed each year in the US. Between 1990 and 1999 59 cases of VAPP occurred. No cases occurred among people who had the IPV-OVP schedule nor among those who had only IPV. The last case of VAPP in the US occurred in 1999.

In Australia IVP is recommended as the preferred form of vaccination but IVP is not as yet funded by the government, which does fund OVP. An article, titled *Polio cases slipping through the net*, appeared in the Sydney Morning Herald on 16 October. It said that *According to international guidelines, one case of VAPP can be expected from every 2.4 million doses of Sabin vaccine ... in Australia this equates to one case every three years but there have been only two probable cases since 1986*. Concern was expressed that some cases of VAPP are going unrecognised here.

Ed. An update on the Network's recent advocacy on this issue appears on pages 12 to 14. The lack of a positive response from the Federal Government means that this advocacy will continue in 2005.

Polio virus escapes twice

The polio eradication exercise is beginning to acquire shades of a science thriller, according to *The Times of India*, 6 October 2004. Polio virus has escaped twice from Indian laboratories and caused 10 cases of paralytic polio. Laboratory strains of the virus were identified in three polio cases in 2000 and in seven recent cases. A task force has been set up to investigate which laboratory(s) the viruses came from. Initially however it has to come up with a list of laboratories that store polio virus, a formidable task that may take two years as there are many private laboratories in India and there is no requirement that they be registered.

Vale – Hazel St Barbe Atkinson OAM

Hazel Atkinson passed away in June 2004 at the age of 82. Hazel was not only a stalwart member of the Post-Polio Network and its Northside Support Group, but also a well known and revered contributor to the Lane Cove community where she lived for many years.

In March 1950, at the age of twenty-nine and five months after the birth of her third child, Hazel contracted polio and was severely paralysed in both hands, right arm, lungs and stomach muscles. In a typically polio way, Hazel later stated that she counted herself lucky because the disease *"affected my legs only slightly"*. However, she was left with one paralysed hand, the use of only three fingers on the other and a body brace for the rest of her life. Polio wasn't Hazel's only brush with ill health – she also suffered from breast cancer, an inoperable benign brain tumour and her sight was reduced in later life by macular degeneration. Despite her disabilities, Hazel set out with determination to turn her difficulties to positive use for others, starting on a campaign to remove physical barriers which prevented others with a disability from participating in community life. One of her most important accomplishments was her role in the establishment in 1985 of the Lane Cove Access Committee, and her assistance to other municipalities in this regard.

Hazel served on the Network's Management Committee for a number of years in the early 1990s. She will be remembered for the tenacious way she tackled issues – Hazel was not content to leave problems for others to solve, she was always the first to volunteer.

In 1996 Hazel was one of only ten people to receive the Premier's Seniors Achievement Award on United Nations International Day for Older Persons – for her lifelong service to the community in the disability area. In 1997 she was awarded an Order of Australia Medal for *"service to people with disabilities and special needs in relation to access to independent living"*. She was further recognised with a Centenary Medal in 2001 *"for service to the community through voluntary work"*.

Hazel was a great supporter of the Network and a regular attendee at Seminars – we will miss her and her indomitable *"never say can't"* spirit.

Support Group News

Neil von Schill

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I am always inspired at the end of each year as I hear from Convenors and Regional Representatives from all over the state as part of our annual reporting process. Our groups are as diverse as the individuals that comprise them and I am constantly encouraged at the range of activities undertaken.

Our original Support Group, the **Inner West** group led by **Claire Dawson**, comprises a group of old friends who meet at Claire and Bill's home. They recently celebrated Christmas in July at a nearby Club and had a thoroughly enjoyable day.

On the **Northside**, convenor **Ruth Wyatt** who also hosts her group at home has written to tell me that she has a group of approximately 10 people who are able to get along to gatherings. The group very much regretted the passing of one of their members, Network stalwart, Hazel Atkinson.

Out in the far west of the state at my first teaching posting at **Nyngan**, a truly remarkable 80 year old, **Marion Wardman**, keeps in regular contact with polio members in the district and promotes the Network. In addition to her Network commitments Marion works at the Nyngan Museum as a volunteer, is involved with her local church and other charities, and travelled down to Dubbo to spend two days with us at the IDEAS Expo.

On the **Northern Beaches** we are indebted to the work of **Pat Featherstone** and **Jim Dewar** who help co-ordinate this group. A regular band meets at 10:30 am on the last Thursday of each month in the coffee shop at Dee Why RSL Club which is a very pleasant location. If you are in the vicinity they would welcome your presence.

We are represented in the far north of the state by the **Northern Rivers** group, convened by **Rosalie Kennedy** and assisted by **Faye Mortimer**. They meet at both Lismore and Ballina and Rosalie tells me that they have had a number of interesting speakers including talks from visiting doctors, a session on Tai Chi and gardening for the disabled.

The **Sutherland** group, our newest group which we established in March, is going well. Convenor, **Ruth Hatton**, reports that they have 8 to 10 members attending each meeting which is held at 2:00 pm on the first Wednesday of each month at the Tradies Club at Gympie. They would welcome hearing from new members.

I was pleased to hear from **Brian Toby** who convenes the **Campbelltown** group and coincidentally was able to practice our policy of networking within the organisation. Brian has been experiencing some medical problems and I was able to put him in contact with our regional representative in the north west at Moree, **Terry Bell**, who was able to provide both moral and practical assistance. **Terry** has been very pro-active in his part of the state, lobbying for better transport facilities for the disabled and speaking to community groups about the Network. Well Done, Terry!

Bara Tunnington from the **Central Coast** group had a long conversation with me and echoed the concerns of many Convenors regarding the fall in numbers attending some groups. The reality is that we are an ageing group with decreasing mobility. I believe that we should continue to meet no matter how small the number because we are serving a

need for those members. We still provide other forms of support through phone contact, our newsletter *Network News* and the website.

A prime example of this concept is the telephone support service offered by Convenors such as **Dawn Beaumont-Stevens** at **Griffith**, **Ken Dodd** at **Coffs Harbour**, **Gregg Kirkwood** at **Dubbo** and **Bill Worthington** at **Condobolin**. This service is just as valued as some meetings and, in country areas, more practical.

The group in **Port Macquarie**, very ably led by **Pat Adamson**, is a well supported group which is obviously filling a need on the mid north coast. There are generally 15 regulars in attendance at each meeting which is held at a wonderful venue in a retirement village.

The south coast is served by long established groups. At **Wollongong**, where **Dorothy Robinson** is Convenor, the group will continue to meet at Port Kembla Hospital where, in the new year, Dorothy is hopeful that numbers attending meetings will increase. She encourages members to get a referral to Dr Chris Poulos at Port Kembla Hospital. He has some familiarity with post-polio problems. In the **Shoalhaven**, **Dorothy Schünmann** leads an active group who regularly attend meetings. It was great to see Dorothy, Lorna and Roma make the journey up to Parramatta for Marcia Falconer's Seminar in August.

Eric Sobel, convenor of the **Eastern Suburbs** group, reports that a small band of regulars continues to meet at the Labor Club in Randwick for lunch of a Saturday. Members living in the area are very welcome to join the group.

It was pleasing to hear from the **ACT** where the trio of **Brian Wilson**, **Susan Wallis** and **Roger Smith** provide active leadership to this well-established group which regularly has guest speakers.

I am pleased to report that **Kerry Jenkin** from **Hornsby** has embarked on a recent initiative. Kerry has produced a very comprehensive newsletter which she has circulated to members living in her area in an endeavour to keep people in touch. Congratulations Kerry on this excellent publication.

The **Blacktown/Lower Blue Mountains** area is very capable serviced by **Bernie O'Grady** who devotes much time and effort to ensure that members in his group enjoy a friendly, supportive meeting environment.

In the **Albury/Wodonga** area I am indebted for the support that I receive from **Margaret Bennie** who is my very able assistant. Many of our members received invitations to attend an afternoon tea with the Victorian Governor, Sir John Landy, at Government House as part of the Victorian Network's Polio Day. I am told that it was a memorable experience.

The **Northern Inland** of the state continues to be served by that wonderful publication "THE LINK" which is edited by **Laurie Seymour**, capably assisted by his wife **Beryl**. Members who receive this newsletter are very grateful to Laurie for the time that he devotes to preparing this communication. Thank you, Laurie.

I am delighted that the **Hunter Group** have taken up the challenge of hosting the Country Conference which will be held in their area this year. They are well positioned to conduct the Conference and have a large pool of guest speakers that they have used over many years. The Conference will be held at Beresfield Bowling Club on Saturday, 17 September 2005. Many thanks to **Barry and Wendy Chaff** for their efforts in securing a suitable venue. Preliminary information is on page 25 and more details will be provided in the next *Network News*.

I am very grateful to regional representative, **Morrie Foster**, who has serviced the Springwood/Winmalee area of the Blue Mountains for the last couple of years. She has

ably promoted the Network and answered enquiries. It is with regret that we accepted Morrie's resignation from the position. Thank you, Morrie, for your endeavours.

It is my sad task to inform you of the recent death of **Peter Drady**, our regional representative for the **Blayney/Cowra** area. Peter died at the end of October after a period of illness with a number of complications. Peter was a great supporter of the Network and we are indebted to his wife Heather, who has offered to carry on his work as Regional Representative. Many thanks, Heather.

At the beginning of December we held a very successful inaugural meeting to launch the **Wagga Wagga** Support Group. There were eleven people present at the home of Isabel and Clarrie Thompson. Isabel prepared a beautiful lunch which was enjoyed by all. People living in the greater Wagga Wagga area are invited to join the group which meets at Isabel and Clarrie's home on the outskirts of Wagga Wagga at 57 Cummins Street commencing at 11:00 am every second month, starting in February. Special thanks are extended to Isabel for her initiative in making this meeting happen.

May I take this opportunity to remind members of some tasks that are not a Convenor's responsibility. It is not the role of Convenors to visit members unless both the Convenor and member is comfortable with it. Convenors are happy to receive phone calls and provide a listening ear but are not required to make regular phone contact with all members in their area. These comments do not apply to Telephone Support Groups or Regional Representatives.

On pages 26 and 27 of this issue of *Network News* you will find a full list of contact details and meeting information for each Support Group. Members are encouraged to attend a Support Group if there is one in their area.

Hunter Conference

This is an opportune time to remind everyone that we are again conducting a Country Conference for members – to be known as the Hunter Conference because of its location. The Conference will be held at the **Beresfield Bowling Club** on **Saturday, 17 September 2005**. Registration will be at 9:30 am with the Conference commencing at 10:00 am. The cost will be \$10.00 per person for morning tea, lunch and afternoon tea. The Network is subsidising the cost of catering. Registration Forms will be included with the next *Network News*.

The town of Beresfield is centrally located in the Hunter area for people travelling to the Conference. It is just off the northern end of the F3 Freeway for people travelling from Sydney and the Central Coast. Beresfield is on the New England Highway just east of Maitland for people travelling from the inland, and just over the Hexham Bridge for those travelling down from the north. Locals will know that it is just west of Newcastle.

With the help of Barry and Wendy Chaff and the Hunter Support Group we are putting together a program that we hope will be of interest to everyone. We are currently negotiating with a rehabilitation specialist, podiatrist and mobility aids specialist from the Hunter area.

For those people who will require accommodation Barry and I have visited many motels in the area and have suggested a list of recommended ones. Details of venue, location, accommodation and maps have been compiled and will be available for those intending to attend.

Please put the date of the Hunter Conference (Saturday, 17 September 2005) in your diary for future reference. You will be kept informed of arrangements for the Conference through regular updates in *Network News*.

Network Support Groups and Regional Representatives – Annual Update

This update is published in the first Network News issued each year. It provides contact and meeting information for the Network's Support Groups throughout NSW and the ACT. You will also find contact details for the Network's Regional Representatives who provide a contact point for their local community in areas not yet served by a Support Group.

If there isn't a Support Group operating in your local area and you would be interested in helping to start one up, or if you are willing to act as a Regional Representative, please contact our Support Group Co-ordinator, Neil von Schill, on (02) 6025 6169 or email him at <support@post-polionetwork.org.au>.

Support Group Meetings

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

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

BANKSTOWN: Meets at Revesby Workers Club, 2b Brett St, REVESBY, 1st Wednesday every second month (commencing February) at 2.00 p.m. Contact Convenor Pam Solomon on (02) 9773 7679.

BLACKTOWN / LOWER BLUE MOUNTAINS: Meets at Kingswood Community Centre, Corner Bringelly Road and Baden Powell Avenue, KINGSWOOD, 3rd Monday of the month (except Jan and Dec) 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, 1st Saturday of the month at 10:00 am. Contact Convenor Bara Tunnington on (02) 4369 2397.

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

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

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

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

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

HORNSBY: Will meet casually when there is sufficient interest. Keep an eye out for Kerry's newsletter. Contact Convenor Kerry Jenkin on (02) 9476 1468 for further details.

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

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

MARRICKVILLE: Meets at Petersham RSL Club, Regent St, PETERSHAM, 4th Thursday every second month (commencing January) at 2.00 pm. Contact Convenor Maura Outterside on (02) 9718 5803.

NORTHERN BEACHES: Meets at Dee Why RSL Club for coffee on the 4th Thursday every month commencing at 10.30 am. Contact Pat Featherstone on (02) 9905 5065.

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

NORTHERN RIVERS: Meets in both Lismore and Ballina on last Saturday of the month, every second month. Ballina meetings are at Ballina Hospital in February (Gentle Exercise – Tai Chi) and April (Easy Gardening). When in Lismore the meetings are at the Lismore Workers Club. June (The Polio Personality), August (Post-Polio Assessment) and October (Your Artistic Side). All meetings 1.30 – 3.00 pm. Xmas get together is Sat 3rd December, 12.30 pm. 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 1st 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.

PORT MACQUARIE: Meets at the Recreation Hall, Retreat Village, 3 Lincoln Rd, PORT MACQUARIE, on a Sunday every third month (commencing February) at 2.30 pm. Contact Convenor Patricia Adamson on (02) 6581 3704 to confirm meeting dates.

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

SUTHERLAND: Meets at the “Tradies” Club, Kingsway, Gympie (Disabled Parking off Manchester Rd) on 1st Wednesday every month (commencing February) at 2.00 pm. Contact Convenor Ruth Hatton on 02 9525 3987 for further information.

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

WAGGA WAGGA: Meets at the home of Convenor, Isabel Thompson, at 57 Cummins Rd Wagga Wagga on the first Wednesday of every second month (commencing February) at 11:00 am. Contact Convenor Isabel Thompson on 02 6926 2459.

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

Regional Representatives

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

BLANEY/COWRA: Contact Heather Drady on (02) 6367 5095 for enquiries in the Blayney/Cowra area.

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

ORANGE: Contact Nita Halsey on (02) 6363 1378 and leave a message.

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



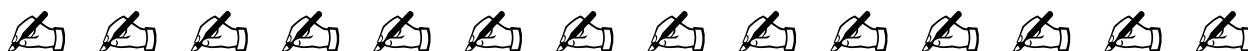
Regular correspondent Ian McKenzie put pen to paper after receiving the last issue of Network News. We are very grateful for your ongoing support, Ian.

Thank you once again for a Newsletter full of interest.

I hope that the Anniversary Picnic was a great success. I happened to hear just the day before that that the Kokoda Walkway had been subjected to another despicable attack by vandals.

I look forward to reading Dr Falconer's writings in the next issue.

My main reason for writing is to congratulate you and the Executive for tackling the problem of staffing the office. I know that the move to paid employment involves a lot of hard work and a great many difficulties but if they can be overcome the outcome should be improved services and, I sincerely hope, a lessening of the burden on the volunteer executive so that the Network can continue its work into the future. I wish George Laszuk well in his new role.



For Sale

Jazzy 1121 powered wheelchair in Viper Blue with mid-wheel drive and right-hand controls. This wheelchair is two years old but has had very little use.

The asking price is \$3,900 with 10% of the sale to be donated to the Network.

For further information, please contact George on 0412 082 983.



Management Committee Contact Details

Gillian Thomas	President	president@post-polionetwork.org.au	02 9663 2402
Gillian Thomas	Network News	editor@post-polionetwork.org.au	02 9663 2402
Gillian Thomas	Membership and general enquiries	gillian@post-polionetwork.org.au	02 9663 2402
Merle Thompson	Vice-President	mkthom@bigpond.com	02 4758 6637
Merle Thompson	Polio stories	stories@post-polionetwork.org.au	02 4758 6637
Neil von Schill	Secretary	secretary@post-polionetwork.org.au	02 6025 6169
Neil von Schill	Support Group Co-ord	support@post-polionetwork.org.au	02 6025 6169
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
Elizabeth Joyner	Committee Member	---	---
Bing Kwong Mak	Seminar Co-ordinator	seminar@post-polionetwork.org.au	02 9579 1460
Bill McKee	Website maintenance	billmc@maths.unsw.edu.au	02 9398 6886
Maura Outterside	Committee Member	---	---
Alice Smart	Executive Assistant	alices@hotkey.net.au	02 9747 4694
John Ward	Committee Member	coralyn@dodo.com.au	02 9451 5995
Mary Westbrook	Q's about polio & pps	askmary@post-polionetwork.org.au	---

Have You Made Your Will Yet ?

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

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

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

There are four simple steps in making a Will

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

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

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

As you are probably aware the Network is a self-funded organisation and we are always trying to improve services to our membership, while keeping our costs low. With more and more polio survivors 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 Seminar Program 2005

Saturday 5 March	Northcott Society 1 Fennell Street Parramatta	Managing the Late Effects of Polio – with a particular emphasis on pain problems presented by Dr Stephen Buckley <i>Full details are on page 2</i>
Wednesday 15 June	Burwood RSL Club 96 Shaftesbury Road Burwood	Special General Meeting <i>to consider Constitution changes</i> Seminar <i>Further details in the next issue of Network News</i>
Saturday 17 September	Beresfield Bowling Club <i>Beresfield</i>	Mini-Conference <i>Further details in upcoming issues of Network News</i>
Saturday 26 November	Venue to be advised	Annual General Meeting <i>the Network's annual business meeting</i> Seminar <i>Further details in upcoming issues of Network News</i>

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

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 give George a call on (02) 9890 0946 or 0412 082 983, or email him at office@post-polionetwork.org.au.

About the Network

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

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

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

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

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

Resources for Members

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

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

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

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

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

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

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

If undeliverable return to:

Post-Polio Network (NSW) Inc

PO Box 888, Kensington NSW 1465

NETWORK NEWS

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