



POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to regular readers and new members to the second issue of *Network News* for this year.

On **pages 13 and 14** you will find full details of our regional Conference to be held in the **Hunter Area** at the **Beresfield Bowling Club** on **Saturday 17 September**. Neil von Schill and Conference Co-ordinator Barry Chaff (Hunter Support Group) have worked very hard to assemble an interesting program with speakers presenting a range of topics that should appeal to all. **The Registration Form for the Conference is included with this Network News**. At only **\$10 person** for the whole day including morning tea, lunch and afternoon tea it is great value. You won't want to miss this one so **be sure to return your Registration Form by Friday, 2 September**.

At the **Northcott Society** in **North Parramatta** on **Monday 8 August** the **Independent Living Centre** is holding a **FREE Scooter Safe Training Day especially for our members**. The day is being **sponsored by Scooters Australia**. Safety, maintenance, and legal and liability issues will all be covered so if you already use, or are thinking about purchasing, a scooter you are encouraged to come along. **If you wish to attend, please be sure to RSVP as soon as you receive this newsletter**. Numbers are limited, but if there is sufficient interest the Independent Living Centre will look at holding a repeat event.

The remaining dates and topics for our **2005 Seminar Program** and the first two dates and topics for the **2006 Seminar Program** are given on **page 26**. **Please note these dates in your diaries**.

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

At the Network's **Special General Meeting** held on **15 June**, twenty Special Resolutions were passed to amend the Network's Constitution – see page 3 for more details. On page 4 you can see a photographic record of the awarding of the Network's first Life Memberships.

I hope you find much of interest within the pages of this *Network News*. Starting on page 6 is a report by Dr Elizabeth Joyner on the March Seminar presented by Dr Stephen Buckley. From page 9 you can read Mary Westbrook's reviews of six new books about polio. As well as these, all your favourite features can be found, including the return of our website column *Cobwebs*. Letters from members round out the issue – happy reading!

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Post-Polio Network Office Co-ordinator's Report

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**George Laszuk
Office Co-ordinator**

I have just completed nine months as Office Co-ordinator in Parramatta and gosh hasn't it gone by quickly, it only seems like yesterday that I took up the position. It has been both a very busy and a frustrating nine months, which I will expand on in my following report.

When the site of the Royal South Sydney Community Health Complex was sold and we had to give up our office there, most of our filing cabinets and various bits of office furniture were moved to a storage facility. Once the Amputee Association relocated upstairs in the Northcott Building we were able to bring all this equipment into our Parramatta office. The next task was to go through all the files, record all the contents and file them in an efficient manner. This was achieved with the fantastic efforts of our office volunteers, Nola Buck, Carmelita Bongco, Helen Billingsley and Madeline Coelho. I come into the office every Monday or when it is required, Nola comes in on Tuesdays, Carmelita comes in every second Wednesday, Helen looks after Thursdays and Madeline comes in on Fridays.

We also now have a Post Office Box at Parramatta (see above) which is for the receipt of general correspondence. Until further notice our existing Post Office Box at Kensington is still to be used for membership renewals and other financial matters.

Remember if you have any questions, need advice or just want a chat – give us a call, drop us a line or even better come in and see us if you are in the Parramatta area.

As I mentioned in my first paragraph there is also a frustrating part to my job – fundraising. We have sent out many requests and applied to many clubs and service organisations for financial assistance, unfortunately with very little success to date. Putting it bluntly, if we are to be able to continue providing this expanded and valued service to our members and to the community we need to secure ongoing funds not only to staff and run the office, but also to more effectively reach out to polio survivors across the state.

This is where you as a member of this Network may be able to help. We are not asking you to dig into your own pockets, because so many of you already do this very generously. We are instead hoping that you might know, or be a board member of, a club or an organisation and may be able to put in a good word for us. If so please contact me and I will do the rest.

We are also looking for members who have had some experience in fundraising in the past and need a bit of a challenge – again, please contact me anytime, day or night. After business hours you can reach me on 02 9628 0000 or 0412 082 983.

Just before I go I thought I'd repeat the information published in an earlier *Network News* about the car parking which is available at the Northcott Society for visitors with disabilities. The photo and description below tells you how to access the main car park beneath the Northcott building. It is still a good idea to let us know if you are going to come and visit.



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 Office and the gate will be opened to let you through. Once you park, take the lift to the Ground Floor and sign in at the Reception Desk. The Receptionist will let our Office know that you have arrived.

Remember also what I wrote in my last report, *"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."*



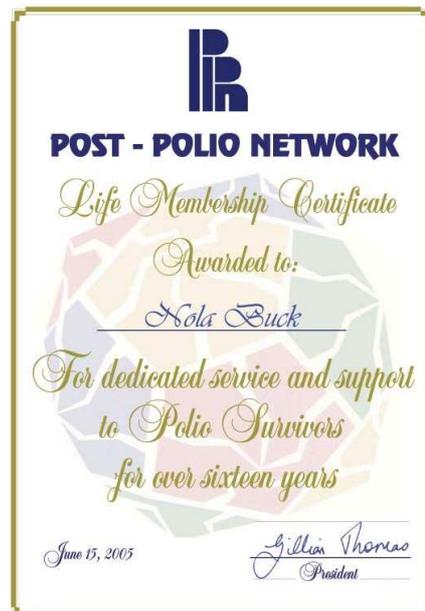
Special General Meeting – 15 June 2005

At the Special General Meeting held in June, twenty Special Resolutions to amend the Network's Constitution were presented to members. As stipulated in the Constitution, such Resolutions must be passed by at least 75% of the members who attend and vote (in person or by proxy) at a Special General Meeting of the Network. All twenty Special Resolutions were passed, with at least 95% of members in attendance voting "For" each Resolution. You may obtain a copy of the revised Constitution adopted on 15 June 2005 by contacting the Network's office. It is also available for download from our website.

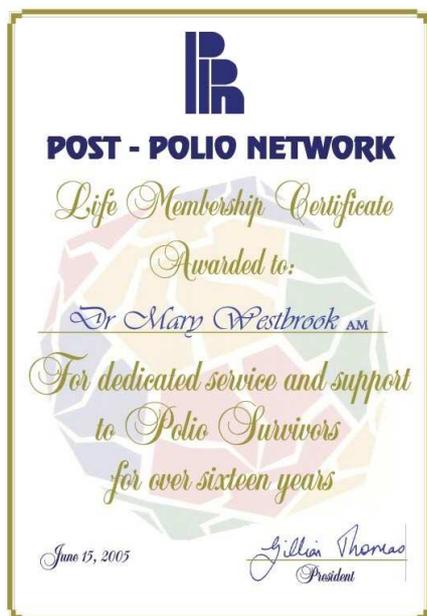
Members present at the Meeting were also given the opportunity to discuss the issues raised in the *Discussion Paper on Committee Membership: Length of a Single Term in Office, Maximum Time in Office, Postal Nominations and Postal Voting* which had been circulated to members in May. In addition, fifty-nine Discussion Paper Questionnaires were completed by members (just over 6% of those posted out). We would like to thank the members who took the time and trouble to give us their views on the issues canvassed. The Constitution Sub-Committee will re-convene shortly to discuss the responses and recommend the way ahead. Members will be kept informed through *Network News*.

Finally, the Special General Meeting awarded Life Membership to long-serving members Nola Buck and Dr Mary Westbrook by resoundingly passing two Special Resolutions to this effect – see page 4 for photos of the presentations to the Network's first Life Members.

Network Life Memberships Awarded 15 June 2005



Nola Buck joined the Network at its inception in April 1989. She stood for the Committee in 1990 and took on the position of Publicity Officer with a great deal of enthusiasm and initiative. In this role she advertised and promoted the Network and its Seminars far and wide and assisted potential members to learn about the late effects of polio and the services provided by the Network. In 1992, Nola was elected as the Network's third President and remained in this position until she stood down in 1997 to pursue other interests. As President, Nola led the Network through its early growth and was a tower of strength as we took on the daunting task of hosting an International Conference in 1996. For the past twelve months Nola has been volunteering at our office at least one day a week and her knowledge and experience with Network operations have been invaluable as we strive to establish an effective resource for members.



Dr Mary Westbrook AM was also a foundation member who joined in April 1989. Mary's involvement goes back even further than that, though, as she was a member of the Working Party set up in 1988 to look at the feasibility of establishing an information and support Network for polio survivors. Mary, a psychologist, published the first Australian research investigating the late effects of polio and how polio survivors were coping with these new problems; she has presented these findings at Australian and International Conferences. Mary has served on the Committee for many of the past 16 years and the Network has grown strong under her guidance. As Seminar Co-ordinator for several years Mary arranged a wide range of interesting and informative Seminars. Her *Polio Particles* series in *Network News* is the regular feature many turn to first. Early in 2001 the *Ask Mary* service was started whereby Mary responds to email enquiries from around the world about polio and post-polio. Mary is an outstanding resource for the polio community.

Summary of Anaesthesia Issues for Post-Polio Patients

Selma Harrison Calms MD

Clinical Professor of Anaesthesiology, UCLA

Dr Calmes has kindly given us permission to reprint this Summary which she wrote for anaesthesiologists. Although its intended audience means the Summary has some technical language, it still contains much of interest to a lay audience. It would be very helpful to give a copy of the Summary to your doctors before you have any surgery.

Polio results in wide-spread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes can get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience with these patients. They may need to be adjusted for a particular patient.

- Post-polio patients are nearly always very sensitive to sedative medications, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
- Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the poliovirus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intra-op helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.
- Succinylcholine often causes severe, generalized muscle pain post-op. It's useful if this can be avoided, if possible.
- Post-op pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multimodal post-op pain control (local anesthesia at the incision plus PCA, etc) helps.
- The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining blood pressure when anesthetics are given.
- Patients who use ventilators often have worsening of ventilatory function post-op, and some patients who did not need assisted ventilation have had to go onto a ventilator (including long-term use) post-op. It's useful to get at least a VC pre-op, and full pulmonary function studies may be helpful. One group that should all have pre-op PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC < 1.0 liter. Such a patient needs good pulmonary preparation pre-op and a plan for post-op ventilatory support. Another ventilation risk is obstructive sleep apnea in the post-op period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.
- Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred post-op, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be useful.
- Positioning can be difficult due to body asymmetry. Affected limbs are osteogenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

Seminar Report – Post-Polio and Pain – 5 March 2005

Dr Elizabeth Joyner

Committee Member Dr Elizabeth Joyner has kindly written this account of Dr Stephen Buckley's presentation at our Seminar on 5 March.

Dr Buckley (pictured right), a long-time supporter of the Network, has been a Rehabilitation Specialist for twenty years and is a consultant at the Royal North Shore Hospital and at the Royal Ryde Rehabilitation Centre (Coorabel), specialising in neurological impairment. Dr Buckley's private practice is 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 spoke to members about how polio survivors can better manage their symptoms, with particular emphasis on pain problems.



Dr Stephen Buckley, Rehabilitation Specialist

In his opening remarks, Dr Buckley reminded us that there is no cure for polio and its later consequences. This truth has unfortunately generated a defeatist attitude in many medical consultations. However, there is really much practical help which can be offered by the well-informed Rehabilitation Specialist in order to help post-polio people function more efficiently and enjoy life to a greater degree.

When we consider the nature of pain and its biological purpose, it can be seen to provide:

- 1) an indication of an acute or chronic medical or physical disorder,
- 2) a "burnt-in" memory of physical injury / illness, or
- 3) an emotional response to these problems.

There is no real yardstick to compare one person's pain level or experience to that of another. There are also difficulties in describing pain characteristics, varying pain thresholds between individuals, and responses to similar pain. However the personal experience of pain is very real and generally requires prompt action.

As acute injury requires diagnosis and then specific action, so pain requires diagnostic analysis before the appropriate treatment can be given.

It can be of great assistance to your doctor if you have taken the time and effort to analyse the characteristics of your pain before consultation. The following lists can provide a framework to help you in this task:

Current pain diagnosis

site of the pain – the exact location is very important

time pattern – e.g. constant, intermittent, sudden onset, spasms, duration of the pain

severity – comparison with past pain experiences e.g. bone fracture, burn

nature of the pain – e.g. aching, burning, stabbing, pressure, tension, stinging etc.

radiation elsewhere – e.g. to lower limb

causative / exacerbating factors

response to past treatments – e.g. Panadol

It is vital to avoid minimising or exaggerating your pain or using overly emotive language. The doctor may well decide to try a milder treatment if the pain is treated as minimal by the patient.

Polio may well be the *underlying* cause of a particular pain but is by no means the usual cause of many common pain problems. For example, although osteoarthritis may be exacerbated by abnormal stresses and forces on joints due to weak or paralysed muscles, it is very common in all people over 50 years of age and the treatment is largely the same whether or not the person has had polio. Indeed there are many treatments readily available to all.

Where pain is *specifically* due to polio, it needs careful diagnosis by a process of exclusion of other common causes. To do this the doctor needs to take a careful history of the pain and then proceed to an hypothesis as to the cause. This is followed by physical examination which confirms, or changes, his hypothesis. Observation of gait or joint function is a vital part of the examination. Sometimes too much emphasis can be put on the past history of polio and another cause missed.

Important medical aphorisms in diagnosis include

“Common things occur commonly”

“Never say never”

“Never say always”

“Avoid hasty conclusions”

Osteoarthritis is an example of a very common pain problem. It affects weight-bearing joints, in particular the hip and knee, highly mobile joints (e.g. shoulder), and stressed joints (e.g. neck and lumbar spine). Osteoarthritis in small joints in the spine can cause neuralgic pain like sciatica. There is a range of treatments available but the most important involves strengthening muscles around the affected joint.

Fear of too much exercise may need to be addressed. Providing that the planned exercise program is individualised to the abilities of each patient and gradually implemented, avoiding discomfort and exhaustion, harm is unlikely.

Certainly, excessive joint movement can increase damage due to osteoarthritis. One way to avoid this is to do isometric exercises, that is, increasing the tension or tone of muscles against resistance without actual movement of the joint. Gentle stretching of tight muscles can give good relief of pain.

Decreasing inflammatory changes within the joint can alleviate pain, for example, by using cold packs (in preference to hot packs which increase inflammation). Beware, as sometimes cold packs can cause initial discomfort.

NSAIDs and the COX-2 Inhibitors can make enormous differences to day to day living for some individuals, providing the contraindications and risks of side-effects are appreciated (e.g. gastric irritation, bleeding and cardiovascular disease / stroke risks). As with all drugs, there is the need to discuss and weigh the risk of side-effects and adjust the dosage.

Joint injection can be offered in certain cases (e.g. steroids with local effects only).

Surgical treatments can be used as a last resort in some cases (e.g. fusion or replacement), being mindful of the risks associated with all surgery, such as anaesthetic and infection risks.

Decompression of nerves by surgery can also be offered in some cases where bony osteoarthritic outgrowths are causing pain.

Measures to stabilise a painful joint include strengthening the surrounding musculature, judicious splinting to decrease the load on the joint (good fit and perseverance required) and again surgery such as fusion of the joint.

In rehabilitation medicine, there is usually no 'quick fix'.

Don't resort to replacement surgery too early as there are significant risks associated with this procedure. Very weak muscles around the joint, osteoporosis and poor lung function are contraindications to replacement surgery. Sometimes a good muscle strengthening program can make surgery unnecessary or defer it indefinitely.

Pain specifically secondary to post-polio effects can theoretically be due to further degeneration of a motor nerve to muscle, with the nerve losing its impulse-transmitting ability, particularly giant nerve units which have taken over the function of previously damaged ones. Further degenerative damage can then lead to increased weakness and thus vulnerability to exercise stress and pain.

PPS is characterised by increasing muscle weakness, muscle pain and muscle fatigue. It is a diagnosis by exclusion of other possible causes.

PPS Treatment

Exercise - judicious, tailored	→	for muscle weakness
Massage Cold Packs Analgesic medicine	→	for muscle pain
Appropriate rest Exercise – as appropriate Medication – as appropriate	→	for muscle fatigue

Serious deterioration in function is not easy to manage. There is a need to approach specific difficulties with the aim of keeping people going and finding new ways of doing things.

Unremitting pain can sometimes require anti-epileptic or anti-depressant medication for relief.

Cost and availability issues with some new drugs are an area of fierce debate.

Points arising from audience questions

- We were reminded that aspirin (e.g. dispirin) is an effective NSAID (the first used) but there is a high risk of gastric irritation / bleeding, and hearing loss (can cause liver damage in children).
- There is value in gentle stretching exercises for tight muscles which are causing pain. Slow paced exercise is best.
- Dietary supplements? There is no good data – results tend to be assessed subjectively, anecdotally. A normal healthy diet plus or minus multivitamins is recommended.
- In certain conditions, like diabetes, coronary artery disease, hyperlipidaemia etc, specific dietary measures required.
- Hydrotherapy in a heated pool can give very good pain relief and a worthwhile exercise program.

Six New Books about Polio

Mary Westbrook

Here are brief reviews of six recently published books about the polio epidemics, the development of the vaccine, and the aftermath of the epidemics. Most have been published by university publishing presses and this is reflected in the quality of the writing.

With the exception of Marc Shell and Patrick Cockburn the authors are Americans and their focus is almost exclusively on the American polio experience. Shell, who is a Canadian by birth, knows there is a wider world out there where people lived and still live with polio. It's nice to see references in his book to many other countries including Australia, for example, the Tasmanian polio epidemic and its survivors and Carol Mara's book *Iron Cradles*. Anglo-Irishman Cockburn contracted polio as a six year old child in Cork. Wilson, Shell, Cockburn and Irvin are identified as polio survivors. Probably for the polio survivor Wilson's book is the most tempting to buy as it is entirely devoted to what concerns us most, polio survivors' life experiences.

Encourage your local library to order books that appeal to you. I have given the Amazon.com prices. Amazon also sells second hand books via their website so you may pick up a cheaper copy. My experiences of this facility have worked out satisfactorily to date although some second-hand booksellers on the Amazon lists do not send books to Australia.

Polio: An American Story by David Oshinsky

The author, a professional historian, gives a detailed, very interesting, accurate 'warts and all' description of the American polio epidemics and the protagonists in the race for a polio vaccine. The focus is unrelentingly American. The author writes: *Americans were primed to see polio as an indigenous plague ... Why did it [polio] thrive in the United States?* (No mention that there were worse epidemics elsewhere, for example, Iceland and Tasmania had higher per capita rates). It was the *good old Yankee virtues of know-how and can-do* that resulted in the conquest of polio and even though the main players, Salk, Sabin, Koprowski and Basil O'Connor were not *genetically* American, as they were all the children of migrants, that is *all the more reason to view the conquest of polio as truly an American story*. (How does one become genetically American I wonder?). The heroes have feet of clay. Oshinsky says that Sabin's *best friends described him as arrogant, egotistical ... 'Smart. But a brainsucker' who took too much credit for a collective discovery*. Salk was accused of similar behaviour. *Not everyone applauded Salk's announcement about the development of the vaccine. His co-workers were angry as no mention was made of their contribution. Some saw Salk as a man who cultivated the press with the same care he cultivated viruses. This damaged Salk's standing among scientific researchers*. Oshinsky says: *It is revealing that while Salk was awarded his country's two highest honours — the Congressional Gold Medal in 1955 and the Presidential Medal of Freedom in 1977 — he was denied admission to the elite National Academy of Sciences for the reason, it was said, that he had made no 'basic scientific discovery'*. As Albert Sabin, a long-time Academy member sneered: *'You could go into the kitchen and do what he did'*. *The feud between Salk and Sabin would outlive them both. There is still ongoing debate about which man produced the better vaccine*. Oshinsky concludes that there is much about polio that remains a mystery. *One of the ironies of the great polio crusade is ... that the successful vaccines helped close the door to future research*.

Published by Oxford University Press, 2005, Amazon price \$US19.80

Living with Polio: The Epidemic and its Survivors by Daniel Wilson

The chapters in Wilson's book cover the various stages of life with polio from the diagnosis (titled *I'm afraid it's polio*), through life in hospital, going home, living with polio to *An old foe returns: Post-polio syndrome*. The story is developed from quotations from biographies written by over 150 polio survivors and these are of considerable interest. The experiences of these survivors resemble those of their Australian counterparts: long periods in hospital with limited visiting hours, staff coldness and at times cruelty. Wilson has used a somewhat biased sample of polios as he acknowledges. Survivors who write biographies are usually coping well with their disabilities. Wilson refers to a study of polio patients discharged from the Seattle Respiratory Center during the epidemics. About 10% died within two years. These patients *didn't necessarily have different physical problems ... from those who 'succeeded', but rather seemed 'to lack the initiative, drive, imagination and support systems to achieve what the more successful patients had'*. In the conclusion Wilson writes: *One didn't so much overcome polio as learn to live with its legacies and compensate for its losses. Polio survivors have endured and have succeeded in many things ... but no one who had paralytic polio truly overcame the disease*. Wilson speaks of how polio survivors helped break down social barriers for people with disability and were among leaders in the disability rights movement. Reading this book will bring back many memories and give you new perspectives on some aspects of your polio past.

Published by Chicago University Press, 2005, Amazon price \$US 19.14

Splendid Solution: Jonas Salk and the Conquest of Polio by Jeffrey Kluger

This book concentrates on Salk's role in the conquest of polio. Kluger, a writer for *Time* magazine, has the journalist's knack of telling a good story and he gives a lively account of the research and politics behind the development of the Salk vaccine. The book begins in early April 1954 when a rumour spread through the US that its government had stashed tens of thousands of little white coffins *in depots around the country*. *The location of these coffins was never specified, and that was just as well. If you knew where the coffins were kept, you'd know where the government expected the people to start dying ... Jonas Salk would be the person responsible for the deaths*. Journalist Walter Winchell, whose popularity was failing, was responsible for broadcasting and writing this story that the Salk vaccine could be a killer. In the storm of anxiety that followed, 150,000 individual children and some areas of the US that had been going to participate in the vaccine trials were withdrawn from the trials. Despite this setback the Salk vaccine trials commenced on April 26th, 1954 and were successful. The book presents a more generous and heroic portrait of Salk than does Oshinsky's book.

Published by Putnam, 2005, Amazon price \$US17.13

Polio and its Aftermath: The Paralysis of Culture by Marc Shell

This was this book I found most stimulating of the six because Shell goes beyond the medical history and the biographies of polio survivors and talks about some of the broader cultural and political implications of the epidemics and the drive to eliminate polio. Shell writes that: *No study yet written attempts in any way to take in the whole world of the polio pandemics or allows us to see the universal in the particular*. The effects of race, social class, religion, time have been ignored, for example, the different experiences of black and white Americans. He notes the placing of black and white children in the same polio wards in a few hospitals was an early landmark in racial integration. The polio epidemics coincided with the development of movies and the cold war and influenced attitudes toward these events. Shell's own story is woven through the book, often in the form of imagined

conversations with his parents. When he was a child they denied he had been left with any after effects of polio, never spoke of his polio, insisted he take part in activities that were dangerous because of his polio weaknesses and punished him by strapping his polio affected leg. The book is a fascinating meditative ramble about numerous ways in which polio left its mark. Shell discusses a relationship between polio and stuttering. He compares the approach of orthopaedic specialists who put polios on *the rack of perfection* with their surgeries (which seem to have been much commoner in the US than here) and physiatrists (rehabilitation specialists). The former *seem to convey to polios the message, 'This is not the way to be'* while the counterstatement from physiatrists is *'Learn to be the way you are'*. Ultimately Shell says, *most people with long-term disabilities learn none too soon that there is a limit to what medical science can do to understand and treat us ... so we are often, in the last analysis, probably less dependent on doctors for the way we 'get along' than we are on ... architects, urban planners, and legislators — those who build the city and interpret its books of justice — and engineers, who make devices like telephones, stair-climbing wheelchairs, hearing aids, talking crosswalks, portable respirators, and voice recognition machines.* There are many ideas to ponder in this book. This is not everyone's book and some readers may agree with the reviewer in *The Economist* (16/6/05) that, *Alas, his [Shell's] own interesting story and that of other famous 'polios' are lost in a mess of literary analysis. The result is as wet and woolly as one of Sister Kenny's treatments.*

Published by Harvard University Press, 2005, Amazon price \$US35.00

Home bound: Growing up with a disability in America by Cass Irvin

The author contracted polio, aged 9, in 1954. After six months in hospital Cass returned home to spend most of the rest of her childhood in bed. As a member of a dysfunctional family, *it was just easier on my mom if I didn't get in my wheelchair.* Cass's only times of liberation were periods spent receiving treatment at Warm Springs. As an adult Cass gradually took control of her life, moved out of home with attendant care and in the process came to see disability as a social and political issue. *The only difference between Roosevelt and most disabled people was power and money. Our degree of living a 'normal' life has more to do with resources than with disability ... Roosevelt's message —that you cannot let them see how disabled you are, not if you want to succeed — is the message today's 'successful' disabled person has internalized. This belief has kept most of us from joining activist groups to change society.* The book is full of vivid, oh so true, examples of life with disability, for example, asking whether you can get into a venue. *People usually do not know whether their buildings are accessible or not. And, even when they think they know [you] cannot rely on them. This time the school was ramped and he insisted I would have no trouble getting into the building. He forgot about the four inch curb before I ever got to the ramp.* Or when Cass was looking for a job; *finally a few encouraging words: 'You know dear, I know if God wants you to have this job, He will provide you with a driver'. I wanted so badly to reply, 'He told me to call you' but I didn't have the guts.* Ironically most of what Cass learned about disability issues and the connections she made enabled her to organise good care for her father when he became disabled in old age.

Published by Temple University Press, 2004. Amazon price \$US19.95.

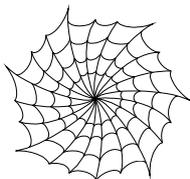
The Broken Boy by Patrick Coburn

Patrick Cockburn contracted polio during the Cork epidemic in 1956. Peter Preston who reviewed the book in the *Guardian* (12/6/05) wrote: *Patrick is six, a cheerful cosseted lad ... Suddenly he has a fever. Suddenly his whole life turns on its head. He is alone, utterly alone ... He'll be a cripple forever ... He remembers the thin grey, hospital slop of minced*

meat and potato; the fear of tyrant nurses snapping his head off ..., the ward tours by lordly consultants brooking no questions nor arguments. It sounds like Children's Hospital. I remember that when I was at the Collaroy annexe and finally got callipers, one of my first walking activities was to wrap up my bed-bound friends' and my mince and slop, walk to the end of the grounds and throw it over the fence where fortuitously there was a public litter bin. Very few polio memoirs express the anger that Cockburn does. I suspect many of us buried our anger deep because to show it was so dangerous. Cockburn is angry with his parents for moving the family back to Ireland when there was an epidemic and at the way the authorities handled the epidemic. The book also recounts the goings on of his Anglo Irish ancestors and his research into the epidemic but we are told almost nothing of his own life as a polio survivor once he returned to school. Cockburn says he carries *a lot of emotional scar tissue from polio. But I also thought — probably rightly — there was not much I could do about it.* He mentions having a severe limp and worrying about post-polio syndrome. From the cover and book's acknowledgements I learnt he is a foreign correspondent in the UK and is married. Cockburn's final words are: *Polio inflicted and continues to inflict great suffering among its surviving victims. Very occasionally well-meaning people suggested to me as a child that sufferings built character and endurance. Even at the age of seven or eight I suspected I had acquired those supposed benefits at an excessive price.*

Published by Jonathon Cape, 2005, £11.19 at Amazon.co.uk

Cobwebs



Bill McKee

PPN Webmaster

www.post-polionetwork.org.au

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Cobwebs returns! Committee Member Bill McKee has taken on the challenging position of PPN Webmaster. Bill contracted polio in 1952 at the age of seven but escaped relatively lightly, scoliosis and a propensity to tire very easily being the main effects of the disease. He once spent five months aboard a scientific research vessel in the South Pacific and somehow managed to complete a PhD at Cambridge in 1970. He has produced 27 scientific research papers and retired in 2003 after almost thirty years attempting to teach Mathematics at the University of New South Wales.

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

My first task as Webmaster was to review the entire website and decide what work was needed. The site is very comprehensive but over the last couple of years there has not been anyone available to maintain it on a day-to-day basis. As a result, many pages needed to be updated and this has been my first priority. So far – all Australian and overseas links have now been validated; the Committee, Support Groups and Seminar pages brought up to date; past issues of *Network News* progressively added; the Constitution page updated; and a new Life Members page added. Keep watching the site as it further develops.

We lost our popular Member's Forum last year when it was "hacked" but after a long search and much testing over the past 12 months we have now decided on new, more secure, Forum software with more features – its implementation is almost complete. In the next issue of *Network News* I will tell you more about the Forum and how to participate in it. Until next time!

Support Group News

Neil von Schill

Support Group Co-ordinator

Phone: (02) 6025 6169

Fax: (02) 6025 5194

Email: support@post-polionetwork.org.au



Late in March I undertook a tour of the Central West to catch up with some people. I was made very welcome at Lyndhurst by **Heather Drady** who has undertaken to continue the work of her late husband **Peter** as Regional Representative for the **Blayney/Cowra** area. I am very grateful to Heather for accepting this task following the sad loss of Peter. I know that she is working towards making the stay of a polio survivor in hospital a more understood experience.

In **Orange** I was very pleased to meet up with **Michael and Lyn Hutchinson** again. We were discussing the possibility of establishing a Support Group in the **Orange** area. If you live in this locality and are keen to be involved with a local support group, please give me a ring. I would be delighted to hear from you. At **Dubbo** I was very pleased to catch up with great Network supporter and convenor, **Gregg Kirkwood**. Whilst Gregg is still working full time he takes every opportunity to promote the Network.

I travelled back through the Riverina and stopped off to view the Rotary exhibition "A World Without Polio" which was then on display at the Museum of Riverina in Wagga Wagga. Our **Wagga Wagga Support Group** held their latest meeting at the Museum to take advantage of this very worthwhile display. For Sydneysiders this exhibition will be available for viewing next year at the Mary McKillop Museum (old Mater Hospital) at North Sydney from 26 May to 31 August 2006.

In the **Hunter** area, Conference Co-ordinator, **Barry Chaff**, has been very busy securing speakers for our **Country Conference** which is being held at the **Beresfield Bowling Club on Saturday, 17 September 2005**. This should be an excellent program and you are encouraged to set this date aside and endeavour to be in attendance. Full details are given on this and the following page, and the Conference Registration Form is enclosed with this issue of *Network News*. **Registration Forms should be returned by Friday, 2 September.**

Hunter Post-Polio Conference – Saturday, 17 September 2005

TIME Registration 9:30 am
 Commence 10:00 am
 Conclude 4:00 pm

VENUE Beresfield Bowling Club
 Rainbow Room (Ground Level) off Entry Foyer
 Anderson Drive
 BERESFIELD NSW 2322
 (see the next page for how to get to Beresfield)
 Phone: 02 4966 3361

COST \$10 per person (includes morning tea, lunch and afternoon tea)
 the Network is subsidising the cost of catering

Hunter Post-Polio Conference Program – 17 September 2005

9:30 am	REGISTRATION
10:00 am	Dr Michael Pollack – Rehabilitation Specialist, John Hunter Hospital
11:00 am	MORNING TEA
11:30 am	Peter Wilson – <i>Walk on Wheels</i> Mobility Aids – “ <i>Get On With Life</i> ”
12:30 pm	LUNCH
1:30 pm	Darren Thorpe – <i>Total Podiatry Solution</i> – “ <i>Keeping On Your Feet</i> ”
2:30 pm	AFTERNOON TEA
2:45 pm	Neil von Schill – IPTAAS (<i>Isolated Patients’ Travel and Accommodation Assistance Scheme</i>)
3:00 pm	Anneke Redman – Service Manager, Hunter Area PADP (<i>Program of Appliances for People with Disabilities</i>)
4:00 pm	CLOSE

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 coming 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. Here are some more details.

HOW FAR IS BERESFIELD ?

Beresfield is in the Newcastle City Council area on the north western boundary approximately 30 km (about 30 min) from Newcastle.

It is at the northern end of the F3 Freeway approximately 170 km (about 2 hours) from the northern side of Sydney.

It is approximately 33 km (30 min) west of Williamstown Airport.

Beresfield is approximately 15 km (10 min) east of Maitland.

Cessnock and the Pokolbin Wineries are approximately 30 km (30 min) west of Beresfield.

Beresfield is approximately 18 km (20 min) west of Raymond Terrace.

It is approximately 70 km (60 min) west of Nelson Bay (Port Stephens).

Beresfield is on the Northern Railway line. The station is wheelchair friendly (eg lifts and ramps) and is approximately 1 km from the Bowling Club (slightly uphill).

Details of the Conference venue, accommodation in the area and maps are available for those intending to attend. For those people who will require accommodation Barry and Neil have visited many motels in the area and have compiled a recommended list. **Please contact either Barry on 02 4957 5254 or Neil on 02 6025 6169 for further information.**



INVITES YOU TO ATTEND A

Scooter Safe Training Day

This day is designed for new and seasoned scooter users
and those contemplating using a Scooter

Date: Monday 8 August 2005

Time: 10:00 am – 4:00 pm

**Place: No 1 Fennell Street
Parramatta**

Cost: No Charge

Morning Tea and Lunch will provided

On the day we will cover:

- Safety principles of using a scooter
- Up to date information about legal and liability issues
- Practicing scooter driving skills in a safe environment
- Your rights and responsibilities
- Australian Road Rules
- Maintenance of your scooter

To secure your place or obtain further information contact:

Joan Pack - 02 9890 0967 or email - joan@ilcnsw.asn.au

RSVP: Monday 1 August 2005 and obtain parking instructions

The day is proudly sponsored by

SCOOTERS[®]
AUSTRALIA
www.scootersaus.com.au



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.



Ageing with polio

'Aging with a disability', a book edited by Bryan Kemp and Laura Mosqueda, has been published by Johns Hopkins University Press, 2004. Although aimed at health practitioners (it is subtitled *'What every clinician needs to know'*), people who live with disabilities acquired earlier in life will find it interesting and informative. Of the 16 chapters, four are concerned with specific disabilities. Dr Jacquelin Perry wrote the chapter on polio. I found the facts about the early course of paralytic polio and its typical recovery pattern interesting, for example, 10% of patients regained normal function within 2-4 weeks, patients attained 93% of their eventual recovery within one year and, on average, affected arm muscles recovered more than did leg muscles. There are chapters on ageing with spinal cord injury, cerebral palsy and developmental disabilities. The rest of the book covers issues common to all disabilities and polio survivors' experiences are frequently referred to. Chapters include: *'A consumer's perspective on living with a disability: How change in function affects daily life'*, *'Family members' perspective on aging with a disability'*, *'Quality of life, coping and depression'*, *'Family and caregiver issues'*, *'Maintaining health and function'*, *'Secondary conditions'*, and *'Barriers to care: the provider's and the consumer's viewpoints'*. The introduction points out that we are among *the first generation of people with early-onset disabilities to live into middle and late life. Consequently we [the authors] know very little about how they might age. However information ... has been accumulating for the past twenty years [and] what has emerged is a picture of atypical aging; these people frequently undergo substantial and even profound changes in health and functioning in midlife. These changes were neither anticipated or planned for in earlier generations. The usual practice in rehabilitation was to urge people to do all they could and to push a little (or a lot) past normal limits to maximize their abilities. Professionals in rehabilitation paid little attention to the long-term consequences of disability or the issue of aging ... The first group to notice that aging was not going well was the population with polio. While PPS is unique to polio survivors we share some late effects with other disability groups. People with cerebral palsy develop inordinate rates of orthopedic problems and falls. Those with spinal cord injury develop osteoporosis. The authors remind us that: Aging is not the same as being aged. People begin to age long before they begin to notice the changes normally associated with being aged. This means that the best time to influence how you age is when you are young. Small changes early in life have a major impact on later life ... What are the long term consequences for joints of continuing to walk despite pain? ... How long should a person with a disability plan on working?* Dr Mosqueda comments that, *Olympic athletes are among the small proportion of people who push their bodies to their highest possible level of functioning. Perhaps people with disabilities share this characteristic with elite athletes; but instead of pushing their bodies during training in the quest for a gold medal, they must do so every day just to accomplish their daily activities and fulfil their social roles.* She says that able-bodied people have physiological reserves that enable them to accommodate much of the decrease in capacity which occurs with ageing but people with disabilities have a much reduced buffer zone. Dr Kemp discusses depression and quality of life of people with disabilities. He says that while depression is more

common among the disabled population there is little association between depression and severity of disability. For example, one research study found no difference in the occurrence of depression rates among paraplegics and quadriplegics. Kemp, who has researched polio survivors, found that having social and community activities was strongly linked with feeling happier. The moral is that if fatigue limits the number of activities you can do, choose social activities with friends and have the groceries delivered. If you are on the Internet you can order them online. The book can be purchased from Amazon.com for \$US24.95.

Some positive aspects of PPS

Norwegian polio researcher Anne-Kristine Schanke has published a study titled '*Never second best? A narrative perspective on shaping and reconstruction of identity in twenty polio survivors*', in the *Scandinavian Journal of Disability Research* (2004). These survivors, all of whom were experiencing late effects of polio, told Schanke their life stories. She says that in childhood and youth survivors inhabited a *dual world; the internal one, feeling different, and the external world, behaving as non-disabled. As adults, before the onset of the late effects of polio, they were all somehow in the 'normal mainstream' by confirming important aspects of their normal identity on par with other non-disabled people by means of marriage, parenthood and paid work.* Schanke found that for many the onset of PPS led ultimately to a changed and more favourable view of themselves. One woman began her story '*I've gone through such a big change. You know, before I was affected by the late effects, I was polio-Beth. Now I am the woman Beth.* Beth's story is similar to the experiences of many Network members. She contracted polio aged five and was in hospital for two years. *My mother was over-concerned about appearances, she only wanted to talk about 'nice things' ... I was not satisfied with myself. I always had to show endurance and prove myself.* Beth worked, married and had a child. Like a number of people in the research she was helped by counselling when she developed PPS. Survivors also found that becoming friendly with other survivors, often for the first time, contributed to this personal growth. Beth describes beginning to empathise with her five year old self. *It was like the woman-Beth started taking care of polio-Beth ... I do not regard myself as disabled as before, my self-image has changed [although] I use a wheelchair permanently now ... some women get more mature and secure as they get older. So did I ... I think [PPS] has made me grow as a human being. I think my curiosity and interest in others has developed. In spite of the fact that that my disability complicates my daily life and also makes me feel tired and sometimes depressed, I feel richer and more complete as a human being than before. Without polio I think my life would have been a more ordinary and boring one.*

Work lives of women with disabilities

Mary Grimley Mason, a polio survivor, has written '*Working against the odds: Stories of disabled women's work lives*' (Published in 2004 by Northeastern University Press). Mason tells the stories of the working lives of 18 disabled women, two of whom had polio, that she interviewed. In America *73.9% of women with work disability status are unemployed, compared with 24.7% of women without work disability status.* The employment figures for polio survivors are much higher than for other disability groups. Mason says that she, and many of those she interviewed, had for many years denied the discrimination they experienced in the workplace due to having disabilities. Like most of us they felt alone in their struggles and devised strategies to overcome workplace obstacles of gaining and maintaining employment in the days before disability rights were heard of. Sally, a food technologist and polio survivor, used a walking stick until she had unsuccessful back surgery for her scoliosis at the age of 46. '*The operation didn't stop my work*', Sally says. '*I worked from my hospital bed. I never lost pace. I never lost any pay*'. She now needed to

use a wheelchair which led to greater discrimination at work. *'They would think you could not make a presentation because you were in a wheelchair ... I knew I absolutely had to change my image. When I used to go to work I wasn't required to look like I was highly successful — you know to wear expensive suits and dresses. But when I was in a wheelchair I made a decision. I was going to dress for success because I realised that people thought that if you were in a wheelchair, you were really not as professionally competent as someone who wasn't ... So I totally changed my image'*. The book is \$US20 on Amazon.com.

Famous polio cases

Jack Nicklaus contracted polio when he was 13 at the same time as his sister. Jack recovered within a few weeks but his sister was not so lucky. Network member, Ian McKenzie, sent me information about Manon Gropius who contracted polio aged 17 in 1934. Manon's mother Alma was married to the composer Mahler. While writing his Symphony No. 10 Mahler discovered that Alma was having an affair with the architect, Walter Gropius. He died before the symphony was complete and Alma and Walter married. Their beautiful daughter Manon was described as *an angelic gazelle from Heaven*. She had wanted to be an actress but after she got polio she used a wheelchair. She died unexpectedly in 1935. Alban Berg wrote his violin concerto *'To the memory of an angel'* in her memory.

Preserving polio shoulders

A 31 page booklet titled *'S.O.S. Save our shoulders; a guide for polio survivors'* is available as a free download from the web at <www.einstein.edu/polioandmobility>. It was produced by staff at the Moss Rehabilitation Research Institute in Philadelphia. Most polio survivors experience some shoulder problems. Even if the polio virus did little damage to our shoulder muscles most of us with weak leg muscles have overused our shoulders to compensate, for example, to push ourselves up from chairs, to pull ourselves up stairs. The shoulders of most people with PPS have started to show symptoms such as loss of strength and pain at a time when they are now more dependent on their shoulders than ever. This booklet tells you what you can do about shoulder problems and how to avoid further problems. There are lots of useful illustrations. You can see what the rotator cuff (the muscles that support the shoulder joint) looks like and positions to assume when exercising shoulder muscles. The booklet points out that most polio survivors do not realise the stress and strain they are placing on their shoulders. It gives many tips on how to avoid making your shoulder problems worse, for example, put your shirt or jacket on your painful arm first, do not sleep on your painful shoulder, keep items used most frequently in cabinets below shoulder level.

Here are several suggestions not included in the booklet. Purchase a higher toilet seat. They fit over the existing seat and you can try them out in the display bathroom at the Independent Living Centre, now located in the new Northcott building at North Parramatta. I found that nursing baby grandchildren exacerbates shoulder pain so I now place a pillow on my knees and rest the baby on that, laying an arm across the baby to provide security. I have a small chair that two-year-olds use to climb onto my lap.

Dr Julie Silver in her book *'Post-Polio Syndrome'* reminds us that our *arms are the key to independence ... if you cannot use your legs at all, you can still remain totally independent — living alone, bathing yourself, feeding yourself, driving a car. But if you cannot use your arms at all you immediately cease to be independent.*

New polio cases in 2005

From time to time during the year there have been brief reports in various newspapers about an increase in the number of polio cases in various parts of the world. From a wide range of sources I have put together this picture of the state of play in early July.

In 2003 a year-long boycott of the immunisation program occurred in northern Nigeria due to fears of the vaccine. The numbers of cases of polio in Nigeria increased sharply but are now decreasing since vaccination recommenced. In the two months from early April to early June 2005 there were 144 cases in Nigeria compared to 217 cases in the same period last year.

At the time northern Nigeria stopped vaccination polio was endemic in six countries but polio has now spread to at least sixteen other countries that had previously been declared polio free. Many of these countries were in Africa, for example, Burkina Faso, Chad, the Central African Republic, Mali, Sudan and the Ivory Coast. The Nigerian polio virus has spread to Yemen and Indonesia, both of which had been polio free for some years, possibly via pilgrims to the Haj. As of 22/6/05 Yemen had had 243 cases of polio this year. This is almost half the 533 new cases of polio so far in 2005 worldwide according to WHO on June 22. New cases of polio in Indonesia are being reported regularly; as of July 16 there had been 125. Massive increases in vaccination are occurring in these two countries to stamp out the epidemics.

There are signs of improvement in India, one of the countries where polio is still endemic, with only 18 cases overall this year, although there has been a recent set-back. Until May 2005 India used a polio vaccine that attacked the three strains of the virus. In mid-May it switched to a vaccine that only targeted strain 1 (as there had been no cases of strain 2 since 1999 and strain 3 was also thought to be on the way out). The single strain vaccine was considered to be more effective against strain 1. In July two cases of strain 3 were diagnosed. *Polio has displayed its stubborn staying power* wrote the *Times of India*.

In early July Angola reported its first case of polio for four years; the genetic composition of the virus indicated that it came from India.

There have been only seven cases of polio in Uttar Pradesh to June 25 this year compared to 1200 in the same period three years ago. Cases are down in Pakistan; 10 cases this year, 40% less than in that period last year.

Even though the number of cases worldwide is up this year remember that in 1988 there were 350,000 cases.



New low-cost internet access service

Technical Aid to the Disabled Australia now offers a low-cost dial-up internet access service to people who have a Disability Service Pension, Aged Pension or DVA Entitlement Card.

Fees for the service are \$5.50 per month. The service includes unlimited downloads, no setup fees, no annual fees, local call anywhere in Australia and flexible contract period.

To register, visit <<http://tadaustconnect.org.au/Register.php>>.

For further information, contact TAD ACT: Phone 02 6287 4290

Fax 02 6287 4288

Email tadact@tpg.com.au

Postpolio syndrome — “We aren’t dead yet”

Ruth Bridgens, PhD candidate, Medical Sociology

(School of Social Sciences, Cardiff University, Cardiff CF10 3WT)

This article from England struck a chord for its similarity with the Australian experience and the invaluable support provided by the Network. Reprinted from the British Medical Journal, Volume 330: 1318-1319 with permission of the author and the BMJ Publishing Group who retain copyright.

Alice is 58 years old and is married with two sons, both in their 20s. She works for several charities, is a magistrate, and is out most days and evenings. She fits in a gentle game of tennis every week, but cannot walk more than a mile, even on the level. This was not always the case. A few years ago, she was jogging at least three miles every day and playing squash several times a week. Gradually, she began to notice that jogging uphill became difficult. She tried to find more level routes. Climbing stairs became difficult, and her legs and back began to ache after exercise. This carried on for a couple of years. She realised that the aching was in three areas — her left arm, right leg, and back, the three places that had been most affected by polio when she was 12 years old. At that time, she had spent a month in hospital and then, after several years of taxing physiotherapy and exercises, she recovered completely, except for slight atrophy in one leg.

As she continued becoming weaker, she would suddenly find herself overwhelmed by exhaustion, which was relieved if she lay down for 15 minutes. She remembered an article about something called postpolio syndrome, which she had made a mental note of at the time but had thought nothing more about. Her general practitioner referred her to a neurologist, who said, “Nothing wrong with you”. She mentioned postpolio syndrome, and he replied, “There’s no such thing as postpolio syndrome”.

Next, she saw a rheumatologist, who said, “Yes, well, you’ve obviously got a problem, but I don’t know what it is”.

She provided her general practitioner with some information about postpolio syndrome, but nothing came of it, and she has not been to see him since. “I was effectively dismissed”, she said.

By this time she was having trouble getting up from a chair and was at her “lowest ebb”. Her next attempt at finding help was to telephone the British Polio Fellowship, which she had belonged to as a child. She described her problems to a welfare officer and asked if she had heard any similar stories. The officer replied that she listened to the same story all day every day, and told Alice to pace her activities and learn to rest before the pain and fatigue set in.

The relief Alice felt from this one telephone call was tremendous. Having thought she needed to continue exercise to strengthen her muscles, she now stopped doing so much and found her muscles becoming stronger. She no longer had episodes of fatigue, as long as she rested a couple of times in the day. This acknowledgement of her symptoms and advice was all she had wanted from her doctor.

I interviewed Alice as part of my research for a PhD in medical sociology. She spoke in a gentle voice, softly laughing with surprise once or twice at the story she was telling. After the interview, I asked Alice if she had ever told anyone her story before, and she answered quietly, “No, never”. She felt it had always been too difficult to explain, and she hadn’t really wanted to. Even in 1958, when she had had polio, she felt it was something of a curiosity and a disease doctors knew little about. Because of the vaccine, the research into the complexities of polio that had accumulated in the 1940s and ’50s had never been disseminated. Doctors expect weakness and visible atrophy in someone who has had polio, but not the muscle fatigue, pain, and fatigue that are also common. The knowledge that all cases of polio, including mild ones, involved wide-spread damage to the nervous system had been lost [1].

In parting, Alice said to me, “If one doctor changes his mind about postpolio syndrome from your research, I will be happy. We aren’t dead yet”. Although Alice has sorted her life out now, I felt everything could have been made a little bit easier for her.

Reference

[1] Howard RS. *Poliomyelitis and the postpolio syndrome*. BMJ 2005; 300: 1314-8.



Back in 2003, member Norm McCarthy sent me the above photo. He wrote:

Was sorting through some old bits and pieces recently and found an old 'photo, taken at Jervis Bay in 1952. In those days the Government "took over" the Naval College and utilised it as a rehabilitation centre where males who were recovering from disabilities were taught occupational skills whilst continuing with their individual medical/physio treatment etc. I spent six months down there and remember it as a most enjoyable period before re-joining the workforce. I have indicated on the 'photo those who were "polios" – three of whom you would know!

I published the photo in *Network News* Issue 59, August 2003. One of the "polio gang" at Jervis Bay was member Roger Smith, now living in Canberra. Roger wrote in some time ago to fill in some missing names.

The photo forwarded and included in the Network News from Norm McCarthy was of great interest and brought back memories of the "Rehab" at Jervis Bay.

The guy standing at the foot of the stairs with the guy on his back is Dave McIlain, Gym Instructor (not sure of spelling). Concerning the fellow Dave is carrying I do not recall his name but remember an incident when he arrived at the Centre. In his wheelchair he failed to negotiate the ramp which led from the billiard room up to the dining room area and subsequently fell out of the chair. Now people seemed to be keen to know what was wrong with patients that arrived. After he was helped back in his chair he was asked "Are you a Polio?" He replied "No, I'm a Greek".

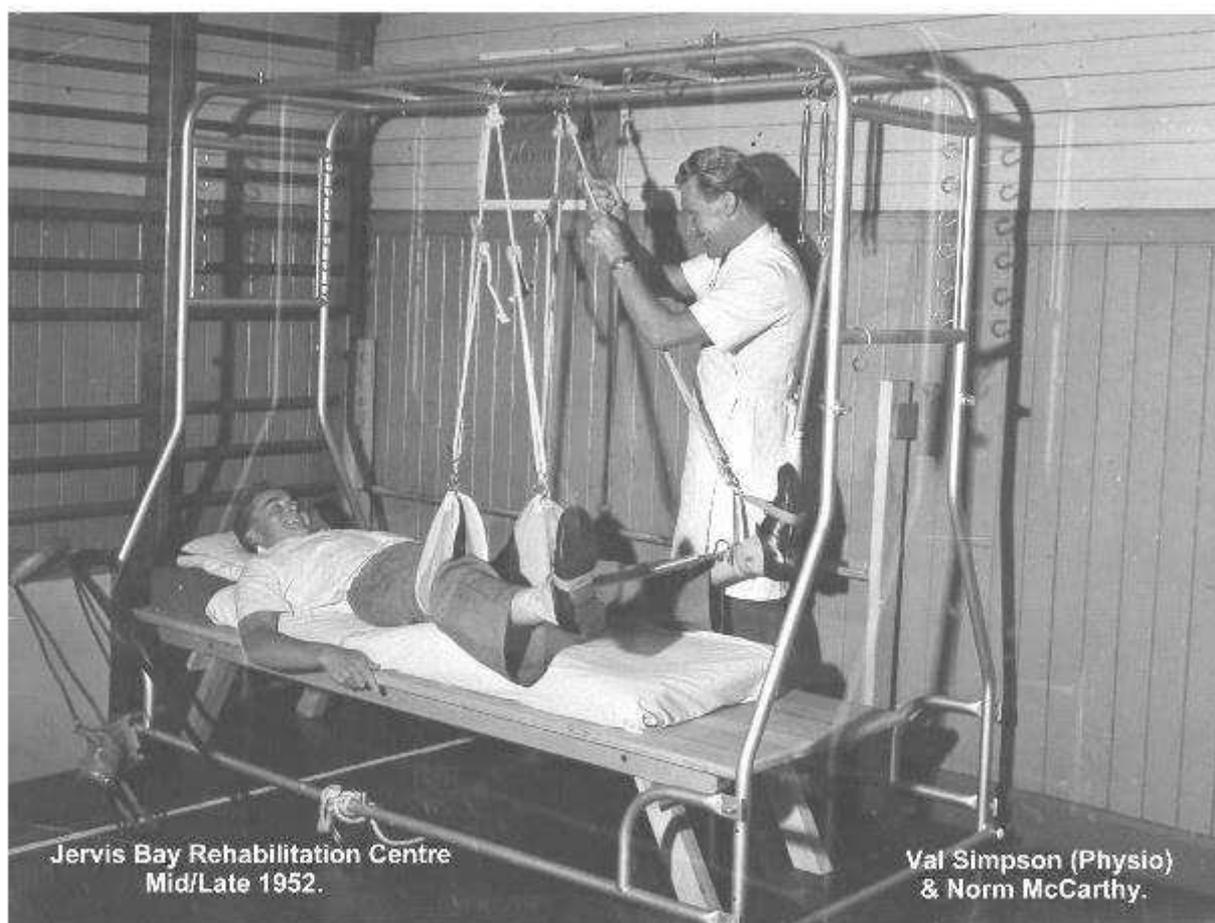
Standing on the steps with Bill Bradley in his arms is Val Simpson, a physio at the Centre.

The bloke on Peter Allenby's left (our right, facing the picture) I think was called John (somebody) who had a broken leg and was strong in the upper body and he did workouts on the rings suspended above the gym floor.

Next to John on his left could be Doug Dransfeld.

Hoping this may be of interest and some help.

It is interesting that Roger recognised Val Simpson. Norm had sent me another photo which I haven't published before which also features Val, this time putting Norm through what looks like a rigorous exercise routine. Norm comments that *Val looks like a mix of Errol Flynn and Clarke Gable!*



Regular correspondent Ruth Crowder has been following our advocacy about inactivated polio vaccine with interest. She recently wrote:

It was with delight and relief that I heard on the ABC News last night that you had won the long hard battle to have the IPV (the safer non-active polio vaccine) funded by the Government.

Thank you for clarifying the difference between the OVP and the IVP vaccines in the last *Network News*. The confusion has caused concern.

Those of us who live with the after-effects of polio know all too well how important it is for all children to receive the injection so that the poliovirus will finally be eliminated.

Thank you for all you have done to make this possible. My sincere thanks and appreciation.

Member Brian Yates had some memories triggered after reading about Sister Kenny.

After reading Mary Westbrook's article on Sister Kenny, I thought I would share a couple of thoughts with you.

The 24th December 2004 was the 70th anniversary for me of contracting polio at the age of 4 whilst living at Concord West. Dr Stergiad came to our home and treated me – including a three-stitch scar in my left elbow – and fitted a paper splint to my left affected leg. I was unable to walk for several weeks. However, between 1936 and 1938 my parents took me to see Sister Elizabeth Kenny at her clinic at the Royal North Shore Hospital. She accepted me for treatment – which involved (as far as I can remember) two visits a week which included warm baths with exercise and later more exercise on a physio table. The point of all this recalling is that Sister Kenny told my parents to never allow any surgeon to operate on me. Later, when I was 12 years of age, this nearly happened (again at North Shore) when the surgeon wished to operate on tendons behind the knee, on top of the big toe, and ankle areas – what a disaster that would have been! Now aged 74, I have “survived” very well, having a right knee replacement for all its years of coping with the affected left leg.

Member Nick Costin is seeking some input from fellow members about their PPS experiences. You can contact the Editor to be put in touch with Nick, or reply to him through these pages.

HELP!

I have been a member of the Society for some years now and I am wondering if there is anyone out there with a similar experience to my own.

I got my polio in 1950 at the age of 8 years ... was hospitalised and in the Iron Lung for a period of three weeks through the acute period. I was fortunate enough to have a doctor who followed Sister Kenny's principles and after a lengthy period of recuperation I was released and suffered (apparent) minimal damage ... some withering of the left leg and a shortening of that limb.

I returned to normal life and played various sports throughout my teen years and was very active swimming, fishing and walking ... various other activities right up until I turned 58. My first experience with PPS was on an occasion crossing the Tweed River Bar – we usually stand at the centre console and hold onto the grab rails placed there for that purpose. I just found that my legs could not support me against the pounding of the boat as it crossed the waves.

I was at this time totally unaware of the cause of this problem and my GP was similarly mystified as I could still walk etc without problems. The next thing was experiencing difficulty in raising myself from a seated position or kneeling; by now I was avoiding situations where I had to get down onto the floor and selecting chairs which were easy to get out of.

By some chance my wife read an article on PPS and we started adding the symptoms together and came to the conclusion that this was probably what I was experiencing. I eventually was referred to a specialist in the field in Brisbane, Dr Wilbur Chan, and I must say that he has been magnificent.

This is where I am needing some help in the form of experience from others if possible. What is likely to happen from here? I am now sixty-two and although the symptoms persist, I am having gentle physiotherapy at three-week intervals and am continuing to walk on a regular basis ... these treatments seem to hold my PPS symptoms in a state of limbo. Is this a common experience? Is there likely to be a further sudden deterioration with increasing age? I have been following the exercise/don't exercise debate – can't quite make up my mind ... but have continued with the physio and gentle exercise as it seems to help me.

Anyone who has had the syndrome a lot longer than myself give me some info?

Much appreciate the articles in the Post Polio Network Newsletters ... I now realise a lot of us are having trouble sleeping etc. When I read of others having "odd" sleeping hours, I can relate to that.

The final letter this issue comes from Marilyn in Tasmania. Marilyn and I have exchanged a few emails over recent years and Mary and I have previously given her some advice about the late effects of polio. Like Nick above, Marilyn is seeking input from members, especially those who spent some time in an iron lung, to help her manage her symptoms. If you can help, please contact the Editor to be put in touch with Marilyn.

Hi Gillian, My name is Marilyn and I wrote to you some months ago regarding being able to make contact with another polio survivor who had spent some time in an iron lung during the early stages of polio. Unfortunately I have not been able to find anyone here in Tasmania that had this experience and from whom I can maybe get some helpful advice as to how to manage different pain relieving methods etc. I don't know if you can help me or not, I hope you don't mind me asking. I contracted polio at the age of 19 months in 1952 and as the years have gone by, my muscles have deteriorated and I am now in a wheel chair and suffer mainly pains in my pectoral muscles at night and sometimes during the day. I use analgesic cream and mainly Panamax for the pains and any discomfort. Many thanks for taking the time to read this email. Kind regards from Marilyn

Queen's Birthday Honours – 13 June 2005

Network and Hunter Support Group Member Keith Messenger was awarded a Medal of the Order of Australia (OAM) in the recent Queen's Birthday Honours. The medal was awarded "*For service to the community through a range of church, youth and sporting organisations.*" Well done, Keith!

Scooter For Loan, Hire Or Sale

We have been advised of the availability of a well-used, but still faithful, "RASCAL" scooter for loan, hire, or purchase (\$500). The present owner has had so much pleasure from it that she would like to make it available to any member who is contemplating making life easier and more manageable in the future. RASCAL NO. 1 has been succeeded by a slightly younger RASCAL NO. 2 and over the years they have travelled to Tasmania, Perth, Brisbane and all over Sydney. Pat or Frank will tell you more – 02 9905 5065.

Network Office Hours

The Network Office at the Northcott Society is 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 2799, North Parramatta NSW 1750 (*not for payments*)

Can You Help to Promote the Network?

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

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 / 2006

Saturday 17 September	Beresfield Bowling Club <i>Beresfield</i>	One Day Hunter Post-Polio Conference <i>See full details on pages 13 and 14</i>
Saturday 3 December <i>(note new date)</i>	Northcott Society 1 Fennell Street Parramatta	Annual General Meeting <i>the Network's annual business meeting</i> Seminar – Keeping Mobile <i>Presented by Sue Slattery, Occupational Therapist, Independent Living Centre, in conjunction with Scooters Australia</i> Selecting and using scooters, manual and power wheelchairs, mobile ramps and more <i>Further details in the next issue of Network News</i>
Saturday 4 March 2006	Northcott Society 1 Fennell Street Parramatta	Seminar – Maximising Cardiac Fitness for Polio Survivors presented by Cardiologist Dr David Rees <i>Further details in upcoming issues of Network News</i>
Friday 9 June 2006	Northcott Society 1 Fennell Street Parramatta	One Day Workshop – A Journey Through Loss conducted by Dr Cynthia Schultz <i>Further details in upcoming issues of Network News</i>

Management Committee Contact Details

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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	---

About the Network

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

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

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

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

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

Resources for Members

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

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

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

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

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

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

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

If undeliverable return to:

Post-Polio Network (NSW) Inc

PO Box 888, Kensington NSW 1465

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PP 250595/00006

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