# POLIO NSW INC *(formerly Post-Polio Network (NSW) Inc)*

# NETWORK NEWS

## *Incorporating* – Polio Oz News



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## President's Corner

**Gillian Thomas**

Welcome to the first *Network News* for 2013. We had hoped to bring you the report on Dr Nolan's AGM Seminar presentations in this issue but his talks were so extensive that they are still being written up. However, be sure to look out for the report in the next issue of *Network News* which is due for release in June. In the meantime, we hope you enjoy the variety of articles contained in this issue.

The beginning of the year has been a very busy time for your Committee. As foreshadowed in the last *Network News* we held our annual planning day in February. All Committee Members contributed enthusiastically but, sadly, there was little input from the membership at large about what *you* would like us to work on over the coming twelve months. However, it is not too late to have a say – for example, suggestions for Seminar topics and speakers are always welcome. The year's Seminar Program, currently under development, appears on page 20. Please make note of the dates in your diary.

Another task we do each year at our planning meeting is to allocate duties to non-Executive Committee Members. In particular, we are pleased to announce that Gary Fuller has taken on the role of Support Group Co-ordinator, the position that Neil von Schill held for many years. Gary is committed to continuing Neil's fine work providing practical support to our Support Group Conveners and Regional Representatives. Gary will be keeping in regular contact with you and if there is anything he can assist you with please don't hesitate to get in touch with him. Gary's contact details appear on page 20.

On 14 March 2013 the House of Representatives passed legislation to set up the Government's National Disability Insurance Scheme (NDIS). The NDIS Bill passed with the support of all MPs. Minister Jenny Macklin also moved amendments to the first reading version of the Bill; some of these amendments were made in response to matters raised in submissions to the Senate Community Affairs Committee Inquiry into the legislation. Polio Australia made a submission to the Committee's Inquiry on behalf of all Australian polio survivors and John Tierney and I gave verbal evidence (recorded in Hansard) in Canberra on 4 March. Significantly, Polio Australia's evidence was widely broadcast in the media, including an article in The Australian. Polio Australia's position, elaborated on in both its submission and verbal evidence is that "*those with polio-derived disability (being long-standing and permanent) which pre-dates the introduction of the NDIS should not be excluded from participation in the NDIS on the grounds of age because aged care programs demonstrably cannot meet their special needs*".

It was indeed disappointing that despite our best efforts the NDIS legislation was passed with the discriminatory age 65 cut-off still in place. Clearly we need to continue lobbying about the inequity of this age limit for polio survivors, many of whom are already over 65. As one avenue of making our voices heard, we are likely to make another visit to Canberra en masse in June to reiterate that "We're Still Here!" – this will be the last chance before the election to get the ear of Government and Opposition MPs and Senators. If you are interested in participating, please contact the Polio NSW Office to get your name on the list so we can be sure to keep you informed of developments as they occur.

# What Having Had Polio Causes, Might Cause and Does not Cause

Author: Marny K. Eulberg, MD Issue: Spring 2012, Vol 28, No. 2 "Post-Polio Health"



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**Introduction**: As time has elapsed since the major poliomyelitis epidemics ended, following the widespread introduction of the polio vaccines, persons affected by polio, their families and their healthcare providers seem to have less and less clear understanding about what symptoms are caused by polio, which are associated with polio, and which are not. Many healthcare providers in practice today have had little experience or training in the care of polio survivors, and they studied the basic pathology that the poliovirus causes years ago.

Organizations, such as Post-Polio Health International, which exist to provide information to polio survivors, are frequently asked questions about various symptoms and the relationship to the acute polio. Post-polio groups and expert professionals have indicated that many individuals have been given incorrect or confusing information.

Attributing symptoms or changes in functioning to one's previous polio when the symptom is, in fact, due to a disease or condition that should be treated by an entirely different medical regime than polio/post-polio is not only not helpful but may be dangerous. Polio clinics can help with symptoms that are polio related and can help a person sort out what is and is not related to polio. The primary care physician can treat the non-polio related symptoms, and can also manage polio-related symptoms with guidance from knowledgeable post-polio professionals.

The intent of this article is to provide basic information about what the poliovirus does to the human body to provide a general framework to guide patients, families and healthcare providers as they encounter new symptoms and try to understand them. Often a symptom can be caused by many different mechanisms and sometimes even by a combination of factors.

This article is not meant to be all-inclusive and list every possible cause/disease but to discuss the most common and most frequent conditions. As polio survivors age, especially as they approach the second half of their lives, other medical issues can emerge that may make it difficult to determine exactly what is causing what. Polio survivors should inform their healthcare providers about their prior history of polio because it can directly or indirectly affect their current medical condition.

**What does the poliovirus do (pathology)?**

The diseases that were called "infantile paralysis", acute poliomyelitis or acute polio encephalomyelitis, or simple "polio" were all caused by one of the three polioviruses (type 1, type 2 and type 3). The exact virus causing a person's disease can now be identified in the laboratory but each of the viruses can cause a similar pattern of disease when they infect an individual. As used here, poliovirus or virus refers to one or more of the three polioviruses.

The virus causes a "flu-like" illness with nausea/vomiting/diarrhea, a fever and perhaps a headache and muscle aches, and, in a small percentage of individuals, varying degrees of paralysis. The majority of persons infected with the virus had only the flu-like illness, did not develop any paralysis and were thereafter immune to that virus.

Less than 5 percent of all individuals that were infected with the virus developed paralysis of muscles ranging from a few muscles to nearly all the muscles of their body – some people died as a result of the infection. The virus circulates in the cerebrospinal fluid all around the brain and up and down the spinal cord. In the spinal cord, the virus attacked the anterior horn cells (the nerve cells that go out to the muscle and tell the muscle what to do) but did not affect the nerves that go back to the spinal cord with messages about touch, pain, temperature sensation or position sense (where the body part is in space, i.e., "*is my foot on the floor or in midair? Or is my foot on a flat surface or a slanted surface?*".

The poliovirus primarily affected nerves leading to voluntary muscles. Those are muscles that you can control with thought, such as, "*I think I'll point with my right index finger*". This may include the muscles involved in taking a deep breath, in swallowing, of the face, of the trunk and abdomen and the limbs. There is lack of consensus among medical professionals about how much the poliovirus affected non-voluntary muscles such as those in the bladder or gastro-intestinal tract. The poliovirus did not seem to cause permanent damage to the heart (cardiac) muscle.

## WHAT SYMPTOMS/SIGNS ARE LIKELY RELATED TO POLIO (PRIMARY EFFECTS)?

**Atrophy (muscle wasting).** The "skinny arm" or "skinny leg" is a result of the muscle or part of the muscle not getting the message from the nerve that it should contract or move. Related to this is the possible shortening of the limb. In a growing child, bone grows as a result of the muscle pull on it and/or weight bearing. Therefore, many who contracted polio as a growing child may have one arm or leg or foot that is shorter and smaller than the non-affected/less affected limb.

**New weakness**. In the more than 40 percent of polio survivors who develop post-polio syndrome, increasing muscle weakness in muscles previously affected or new weakness in muscles that were thought not to have been affected is one of the defining features of the condition.

**Loss/absence of reflexes at a joint.** For example, when the healthcare provider hits your knee with the reflex hammer and it does not "kick" out. But rarely, a polio survivor may have an exaggerated response to hyperactive reflex.

**Muscle fatigue/decreased endurance.** When a muscle does not have a full supply of "motor units" it may still be able to function for a limited number of repetitions but it "wears out" sooner. The person may be able to "sprint" but could not run a mile and certainly not a marathon.

**Muscular pain.** Polio survivors generally describe this as an "achy, burning or sore feeling". It is thought to be due to overuse of the muscle(s) in the area. Individuals who had acute polio when they were old enough to remember the event say it feels similar to the muscle pain that occurred with the acute polio. Others describe it differently, but polio-related muscle pain is rarely sharp or stabbing.

**Biomechanical problems.** These are problems related to abnormal positions of a limb around a joint, e.g., one leg being shorter than the other or abnormal curvature(s) of the spine. This can cause mechanical low back pain, increase the likelihood of "wear and tear"

arthritis in a joint or a chronic tendonitis/bursitis or even nerve compression problems.

**"Polio cold" leg or arm.** There are several theories about what causes it, but it is real! Generally the person doesn't perceive the limb as feeling as cold as it feels when it is touched. It occurs when the environment is cold – such as in winter or in an air-conditioned room. Unless the person has other reasons such as poor arterial circulation from diabetic vascular disease or severe hardening of the arteries that causes poor blood flow in the arteries, "polio cold" leg or arm will not cause delayed healing of fractures or injuries. It is mostly an inconvenience to the individual and his/her bed partner.

**Some problems with breathing.** These include decreased ability to move enough air in and out to get ample oxygen into the lungs or to exhale enough carbon dioxide due to new respiratory muscle weakness or from residual muscle weakness from the initial polio. Medically this is called "restrictive lung disease". Problems include "remembering" to take a breath or to take enough breaths per minute. This is broadly called sleep apnea (central apnea). Paralysis of some muscles of the throat can also cause intermittent blockage of the air passages in the throat, which may also be termed sleep apnea (obstructive).

**Certain problems with swallowing.** These can cause choking while swallowing, especially thin liquids such as water, and sometimes some of the swallowed material will go into the lungs instead of down into the stomach causing a pneumonia known as aspiration pneumonia. Some people lose weight and have difficulty maintaining adequate nutrition because eating is so time consuming or difficult.

Note: Many people over age 50 have other problems unrelated to polio that can cause problems swallowing. Various tests can determine the exact cause of the dysphagia.

**Osteoporosis/osteopenia.** Weight bearing exercise is necessary for bone to become and remain strong. In persons who had paralytic polio the affected limb(s) may have bone that has less than the normal mineral (calcium) content. The terms osteoporosis and osteopenia refer to decreased amount of normal bone tissue; osteoporosis is more severe than osteopenia. These conditions can mean the bone is more "brittle" and may break more easily than normal bone. (Generalized osteoporosis/osteopenia can also occur in certain medical conditions and with increasing age and is usually not related to polio.)

## WHAT SYMPTOMS/SIGNS MAY BE RELATED TO POLIO (SECONDARY EFFECTS)?

**Increased wear and tear on joints including osteoarthritis, tendonitis, tendon tears, bursitis.** When a person has a weak limb, the unaffected or lesser affected leg or arm does more work to compensate, and weakness from polio can lead to arthritis problems in the good limb as well. People who use their arms in place of their legs (crutch walkers, users of canes, manual wheelchair users) put more stress on the joints of the upper extremities than someone who has normal use of their legs, and this can result in damage to cartilage, tendons and ligaments in the wrist elbows and shoulders.

**Nerve compression.** Carpal tunnel syndrome can be caused/aggravated by pressure on the heel of the hand and palm from crutches and canes or from propelling a manual wheelchair. Other nerves may also be compressed by abnormal positions of joints and of the vertebrae in the spine. Symptoms of nerve compression are usually a numbness or tingling, an "electric shock" sensation and sometimes progressive weakness in the area of the body supplied by the particular nerve that is being pinched.

**Increased respiratory problems** from increasing curvature of the spine resulting in less room for the lungs and internal organs.

**Fatigue from increased energy expenditure.** Walking with an abnormal gait, use of crutches and propelling a manual wheelchair all require more energy than unimpeded walking. For example, walking with a locked knee can use up 20 per cent more energy than walking with an unlocked knee, and walking with two crutches can burn up to twice as much energy as a non-disabled person would use walking the same distance.

**Headaches.** These can be "muscle contraction" headaches that may be caused by chronic overuse of neck muscles, unusual use of neck muscles when doing daily tasks or related to abnormal positions of the neck from muscle imbalance or scoliosis. Headaches, especially upon awakening, can be from inadequate ventilation (breathing) overnight that may be due to respiratory muscle weakness and/or sleep apnea that may or may not be connected to prior polio.

**Emotional issues.** These can include post-traumatic stress disorder associated with hospitalizations and medical procedures and/or teasing by childhood peers or dysfunctional family interactions with the person who contracted polio.

## WHAT SYMPTOMS MAY BE COMPOUNDED BY HAVING HAD POLIO (TERTIARY EFFECTS)?

**High blood** pressures **and/or coronary heart disease** aggravated by weight gain and decreased exercise that were related to limitations imposed by polio.

**Weight gain** (including overweight and obesity) linked to decreased exercise/activity. Significant obesity, can, of itself, lead to obstructive sleep apnea and restrictive lung disease plus other problems including diabetes, osteoarthritis of hips and knees, etc.

**Diabetes**, in susceptible individuals, related to decreased activity and/or weight gain.

**Skin breakdown, or pressure sores**, from prolonged sitting without shifting position, from sleeping in one position due to difficulty turning in bed or from poorly fitting supportive devices (corsets, braces).

Situational depression associated with decreased functioning and independence.

More important than establishing the relationship between a condition and prior polio is finding a treatment or solution for the medical problem. Post-polio experts agree that in most instances the management or treatment plan for the secondary and/or tertiary problems are the same as for people who did not have polio.

## WHAT SYMPTOMS/SIGNS ARE *NOT* RELATED TO POLIO?

- **Tremor of arm, leg or head** especially when that body part is at rest.
- **Problems with "sense organs"** – vision, hearing, taste, smell.
- **Seizures.**
- **Allergies** to medicines or to things in the environment.
- **Dizziness or vertigo** ("the room spinning").
- **Sharp, shooting pains or severe burning pain with numbness.** Generally, polio does not cause numbness, but nerve compression can result from abnormal positions around a joint or from crutch-cane walking or propelling a manual wheelchair and cause these symptoms.
- **Inability to know the position of a part of the body** or where it is in space (decreased proprioception).

- **Food getting stuck in the lower oesophagus** (in the midchest or lower).
- **Abdominal pain or diarrhea.**
- **Cancer of any kind.**
- **Liver disease.**
- **Kidney disease.**
- **Most infectious diseases,** except perhaps pneumonia in a person with a weak cough or who has swallowing problems and is "aspirating" food into their lungs.
- **Skin rashes,** but unrelieved pressure on areas of the skin can cause skin breakdown and redness.
- **Diabetes,** but weight gain and decreased activity often worsen blood sugar control in persons with other risk factors for diabetes.
- **Hardening of the arteries** (atherosclerosis) in the heart, legs, neck, brain, although lifestyle changes induced by polio may increase the likelihood of developing this when added to other risk factors.

# How and Why Did the Post-Polio Network Start in NSW - An Early History

**By Anne O'Halloran**

The Post-Polio Network in NSW has come a long way since the idea was born in 1988. According to an article featured in *Contact* – The NSW Society for Crippled Children "60 Years of Caring" edition (actual date not supplied but I estimate it would be sometime in 1989), the impetus to start a network for polio survivors in NSW followed a visit to *The Fourth International Polio and Independent Living Conference* in St Louis, USA by several Australians in 1988. Some of those attending had contracted polio and were experiencing its late effects. On their return it was felt that the information they had gleaned from the Conference should be available to polio survivors in Australia.

In 1988 Professor Irving Zola, was invited to come to Australia and address a public meeting. Professor Zola had had polio and was experiencing its late effects. He had found adaptive ways to manage these effects and was happy to pass them on. I think the Northcott Society (then the NSW Society for Crippled Children) may have assisted to sponsor him as the very first meeting with Professor Zola was held at the Society's Headquarters (as it was called then) in Cleveland Street, Strawberry Hills. It was a small meeting attended by Client Services staff including Anne O'Halloran (a polio survivor) as well as some polio survivors, including Laurie Alsop who became the Network's first President.

A Public Seminar was held in mid-1988 at Ashbury, an inner Sydney suburb. This provided an opportunity for people with polio to meet together, many for the first time in decades. Professor Zola was a speaker at the Seminar. At the conclusion of the Seminar, Laurie Alsop called for a show of hands for those interested in forming a network where people could hear about and share information about the late effects of polio. And that was the beginning!

To quote from the article in "Contact":

*"During the course of that day and from hundreds of letters subsequently received, it has been discovered that the majority of people are experiencing symptoms identified with the syndrome (i.e. Post-Polio Syndrome). As a result of the Seminar the Post-Polio Network was established in New South Wales with the following objectives:-*

- *To establish a support group for people who have contracted polio.*
- *To provide information on polio and its effects.*
- *To encourage research into the effects of polio."*

I have heard that for some of those attending the Seminar that they were somewhat overwhelmed and in some cases shocked by seeing others with polio who had survived and somehow triumphed over very severe disabilities caused by the virus. Many, or dare I say most, of those who had survived the original effects of polio went on to live 'normal' lives and while the day-to-day living was not always easy they managed their disability and pursued their chosen way of life.

The major recommendation from those present at the Seminar was to form a Post-Polio Network to provide information and support to polio survivors. Attendees were invited to put their names down to join a Working Party to progress that recommendation. The Working Party was tasked with investigating setting up an organisation of and for polio survivors who may be experiencing the late effects of polio.

Members of the Working Party were Laurie Alsop, Hazel Atkinson, Terry Fletcher, Anne O'Halloran, Angelo Psomadelis, Patricia Rich, Shirley Roach, Gillian Thomas and Gwenyth Tubb. They met monthly after work in an unused, cold, 'decaying' room somewhere in Lewisham Hospital. Hazel travelled by public transport from the North Shore to Lewisham even in the winter months. Gwen Tubb was accompanied by her sister, Beryl, who came to help and was kept busy serving sandwiches and tea. The interim Management Committee Office Bearers were Laurie Alsop (President), Patricia Rich (Vice President), Terry Fletcher (Secretary) and Gwen Tubb (Treasurer). Gillian Thomas is the only member of the original Working Party to have served continuously on the Management Committee to the present day.

Following development of a Constitution by the Working Party, in 1989 another public meeting was held this time to incorporate the Post-Polio Network (NSW) Inc. That was successful and elections were held for office bearers and membership details were organised.

**The rest, as they say, is history …**

My thanks to Judi Lipp, Librarian, Archivist and Records Management, Northcott Disability Services, Parramatta, who searched out the information for the above article.

## Just a bit of fun.....

Reprinted from Polio SA, No 108, Dec, 2012

**No English Dictionary** has been able to adequately explain the difference between COMPLETE and FINISHED. However, in a recent linguistic conference held in London, England, and attended by some of the best linguists in the world: **Samsundar Balgobin,** a Guyanese, was the clear winner.

His final challenge was this: Some say there is no difference between COMPLETE and FINISHED. Please explain the difference between COMPLETE and FINISHED in a way that is easy to understand. Here is his astute answer: "When you marry the right woman, you are COMPLETE. But, when you marry the wrong woman, you are FINISHED. And when the right one catches you with the wrong one, you are COMPLETELY FINISHED!

# OurHealth is here!

*From Consumers Shopping Health, Vol 6, Issue 5 Oct, 2012*

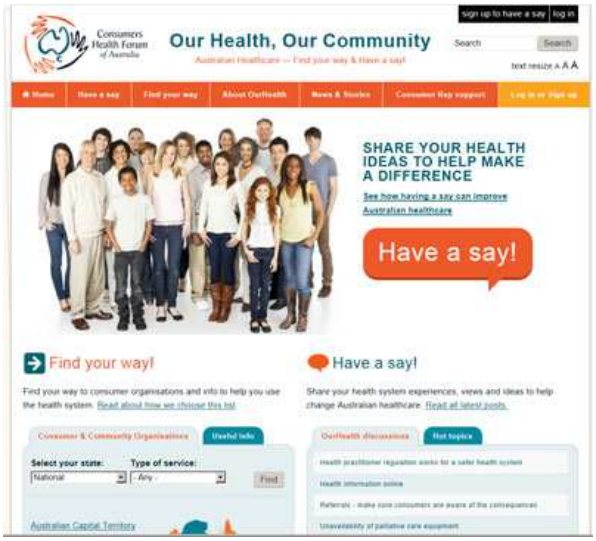
## OurHealth is here!

Australian consumers have the opportunity to have a say and contribute to better healthcare at a time that suits them – whether that's on a lunch break, after the children have gone to bed, or over a morning coffee.

The OurHealth website www.ourhealth.org.au, an initiative of the Consumers Health Forum made possible by the Australian Government funded "CHF Our Health, Our Community Project", supports a constructive and strengthened consumer voice in health reform.

The site is now live, with an official launch by Health Minister Tanya Plibersek held in mid-October.

"*This is all about giving consumers a say, listening to their healthcare experiences and taking that vital information into healthcare planning through informed and supported consumer advocacy*," said CHF Acting Chair, Ainslie Cahill.




*The OurHealth website is now live, and gives consumers an opportunity to make a contribution to health policy and discussion.*

CHF moderates the site which encourages Australian patients, their families and carers to join a consumer conversation on healthcare. OurHealth also recognises that more and more consumers are going online to find health information.

"*The trend is undeniable*," Ms Cahill said. "*The OurHealth website offers consumers a helping hand to better navigate the health system, pointing them towards reliable websites that can provide useful information.*"

Patient-centred care and a strengthened consumer voice were articulated as essential ingredients when the Government embarked on health reform. The Our Health, Our Community project gives consumers a place to share their experiences, ideas and thoughts on healthcare that works for them.

## Introduction to OurHealth *(reprinted from the website)*

What consumers – patients, their carers and their families – think about healthcare matters. The views and experiences of consumers can tell a lot about what works and what doesn't, and how healthcare could be improved. We hope this website will help you *find your way* to useful information and health services and that you will *have a say* on how healthcare could be improved. Your voice is important – **it can help make a difference.**

### What is the purpose of OurHealth?

Australia has one of the best health systems in the world, but it is complex and not everyone gets the care that they need.

One of the best ways to improve healthcare is to listen and learn from the experiences of consumers – the everyday Australians who use and pay for our healthcare system. That's why the Australian Government asked the Consumers Health Forum (CHF) to help give consumers a stronger voice in health policy decisions, and that's why we established this website, OurHealth.

OurHealth is here to help you find health information that will help you with your healthcare, and to invite you to 'have a say' about your healthcare experience and the way you would like it to change.

OurHealth also provides information and support for consumer advocates and consumer representatives – those people that participate on committees, advisory groups and reference groups to contribute a consumer perspective. To visit the Consumer Representative section of the website go to http://ourhealth.org.au/consumer-representatives-support.

### How can I help improve healthcare by contributing to this website?

Your experience with the Australian healthcare system and your ideas on how things could be improved are important. Healthcare, after all, has to be about the health and experience of the patient. By sharing your ideas, issues and feedback on this website created especially for consumers, you can help consumer advocates and consumer organisations work for change that improves things for patients, their carers and their families.

### What happens with the comments I make?

Your comments will help build a picture of what is important to patients, carers and families.

This will be shared with other consumers, consumer advocates and consumer organisations to help make things better in healthcare. Your comments:

- might help another consumer understand the health system, or find information that is helpful
- might tell consumer advocates about an idea or a service that is working very well in your local community that could make a difference for another community
- will contribute to an important knowledge base of consumer issues and experiences that can be used to improve healthcare for all Australians

### All just by having a say

It is important that you only make comments that you are prepared to share widely and without restrictions. Should you wish to remain anonymous, please register an appropriate username when agreeing to contribute to this website.

The conversation on this site is moderated by the Consumers Health Forum of Australia. This means that we reserve the right to remove, edit or not publish commentary that does not contribute to a constructive conversation on healthcare. Advertising and promotion of products or services is not permitted, nor is any commentary that may be libelous or offensive. Read our full Terms and Conditions and our Privacy Policy.

## Memorials

*Since our last newsletter we have become aware of the passing of three of our members and extend our condolences to their families:*

Paul Dixon
Merle Dawson
Mary Le Clair

## Thank You

*We would especially like to acknowledge the ongoing support and recent significant financial donation given to Polio NSW by:*

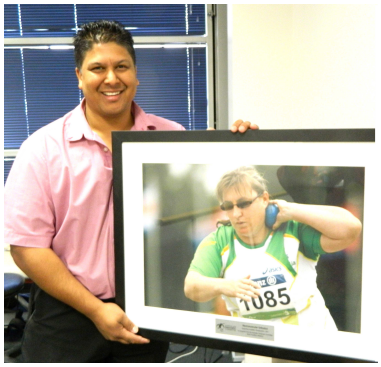
The Lions Club of Mt Druitt
$5,000

Darren Pereira was a speaker at one of our Seminars and also at a number of Polio Australia State Retreats and we thought you might like to know what he's been up to of late.

# How the Paralympics gave Darren even more ideas

By Fran Henke

*Reprinted with permission of Independence Australia, from the Inform Newsletter, Summer Edition.*




**Orthotist Darren Pereira wasn't around much from August to September last year.**

Darren, Principal Orthotist of NeuroMuscular Orthotics at Mount Waverley, was busy in London as consultant to the Australian Paralympic Committee.

Backing up a little …. at the time of this discussion, Darren was wearing one of his own creations, thanks to a broken foot.

"*I've worn orthotics most of my life*", he explained. "*I have a genetic disposition to excessive pronation*" (flattening of the foot).

Despite that, Darren was inspired to study orthotics by his cousin, who lost both legs in a work place accident at Jolimont Railyards at the age of 21. "*The only day he walked again was up the aisle at his wedding*", said Darren.

Consequently, Darren graduated with a Bachelor of Prosthetics and Orthotics from Latrobe University Melbourne in 1994. He became involved with the polio community as chief prosthetist at St. Vincent's Hospital and Polio Services Victoria.

**So how did he become involved with the Paralympics?**

"*At the Beijing Paralympics, athletes found themselves with a two kilometre walk from the Athletes Village to the dining halls*", Darren said. "*Many couldn't get there and those who did needed wheelchairs to get back*".

So the Australian Paralympic Committee (APC) decided for the first time ever to look at engaging an orthotist to improve walking efficiency. Enter Darren Pereira.

"*My first client was speech therapist Kath Proudfoot, a 'spastic quadriplegic', in that both legs and arms were affected, a silver medallist in discus*", he said.

Kath, 35, was one of the ones who struggled with the distances at Beijing. She had needed orthoses all her life, but discarded them because of fatigue and skin breakdown, much as polios do, Darren said.

So his challenging introduction to Paralympians, was to get Kath back into orthotics.

He also worked with athletes involved with rowing, equestrian, wheelchair tennis and table tennis. The aim was to prepare those with potential to medals in London, to compete in Rio and to help them walk as fluently as possible without fatigue.

**What about orthotics for the events?**

Darren said according to the rules, cyclists, rowers, table tennis players can wear orthotics as long as they don't provide an unfair advantage. Amputees however, might be wearing a $60,000 knee joint!

Darren found that many of the athletes were unsafe when running and had the potential for falls. If the athletes were allowed to wear an orthosis, falls would have been minimised.

The rules also state that technology has to be accessible world-wide for amputees. He found equipment was rudimentary for most of the athletes from Third World countries. Furthermore, many had received little or no treatment resulting in seriously distorted limbs.

Darren found 500 polio survivors competing in London, none from Australia, yet.

"*The results from the polio power lifters were amazing. Coming from Egypt, Nigeria and Ethiopia, they were the strongest women in the world in genetic makeup*", he said.

Other polios came from Kuwait, Asia, China, African nations, Egypt and India.

"*It was said at the athlete's village, many were provided orthotics for competition but not to walk"*, Darren said. "*We provide orthoses for some of our Australian athletes to compete in but there are many polio clients who did not even have an orthosis to walk in*".

So the Technology Centre for equipment repairs was extremely busy. "*They did 2000 repairs in two weeks. Prosthetist Cameron Ward from APC in Sydney worked there*", Darren said.

Orthotics worn by a couple of the African polios were in such bad repair they needed a complete rebuild. These were made at the centre, even though it was not tasked to provide new equipment.

Darren was not involved in London with repairs, his was a strategic role.

"*I wasn't exactly a spy*", he said, "*but a 'consultant' to see if any First World nations were using equipment that gave advantage*."

"*I saw phenomenal stuff. In orthotics we're on a par, if slightly behind the US, but ahead of Europe*".

What he saw to help Australian clients and athletes in the future principally was in custom-made wheelchair seating.

The Dutch wheelchair tennis player, Esther Vergeer, had a seat based on a scan of her body, built in carbon fibre and foam, which supported the torso for maximum generation of power for her strokes, Darren said.

"*Australia had advantage in cycling with cerebral palsy girls, who wore orthotics designed for maximum performance. It wasn't allowed to provide more in return of energy but for levels of stability*", he said.

The cyclists won two bronze, two silver and one gold medal.

Darren said tickets for the London Paralympics were sold out. One of the top rating spin

offs, was the Channel Four television program hosted by amputee Adam Hills. Called 'Last Leg', the show raised the level of understanding of disability, discussing classifications of ability for each sport. There was a section of the show called 'Is it OK to Ask'. Guest athletes were asked all kinds of questions ranging from sex to being able to sit at the dining table, he said.

His focus for Rio and now will be on developing athletes for wheelchair sports, as well as developing custom-made wheelchair seating to benefit clients.

In London there were eight sports for which Australia had no competitors including seated archery, bocce, wheelchair table tennis, and seated javelin.

Darren said he had 100 young polio clients formerly from Africa, Asia and Arab countries, who don't attend PSV (Polio Services Victoria) or want to join support groups. They were referred from general practice.

He aims to encourage the involvement of these young migrants in sports. Several 17-18 year olds had potential to be archers.

"*Sport helps general health and will bring them together*", he said.

The APC will also help young people to acquire suitable orthotics and offer introduction to sport.

Events like the 2012 Disability Sport and Recreation Festival, at Federation Square, Melbourne, on Monday December 3, is a prime opportunity, Darren said.

"*I always wanted to dance*", the journalist said wistfully.

"*Oh, dancing. That's something else I could suggest*", Darren thought. Then his door chime announced time was up, another client, more opportunity for someone else to move more fluently, dance even. ...

# Union stops work over pool sell-off

*Reported in the Southern Courier, 22.1.2013*

Health Services Union members at Prince of Wales Hospital stopped work for an hour yesterday to protest the possible sell-off of the hospital's hydrotherapy pool.

POWH management is considering privatising the pool to meet the state government's health cuts.

The rally at High Cross Park was the official launch of the HSU's *O'Farrell Cuts, We Bleed* campaign, which will travel across the state for the next six months.

HSU NSW secretary Gerard Hayes said the hydrotherapy pool was crucial for Prince of Wales patients with conditions as diverse as cerebral palsy, post-polio syndrome, musculoskeletal conditions and breast cancer. "*How can patients at the Prince of Wales have confidence that their recovery will be the priority, when a new private operator has commercial objectives to meet?*" he said.

# Health Consumers in NSW



**About HCNSW**

Established in late 2010, and funded by the NSW Health Ministry through a Ministerial grant, Health Consumers NSW is the state wide voice for health consumers in NSW, which helps to shape the health system by representing and involving consumers in health policy and program development.

We are an independent member-based organisation with members coming from all areas of the community and health sector. Our voting members are health consumer organisations and are representative of a wide range of disease groups and consumer health issues. Associate members include individuals, organisations and other stakeholders with an interest in health consumer issues.

Through its diverse membership HCNSW can ensure the consumer perspective is heard and included by government, policy makers and other health stakeholders - balancing the view of health care professionals, service providers and industry.

The arrival of HCNSW is timely. HCNSW as an independent and generic health consumer organisation established to provide and support the informed voice of NSW health consumers, is able to effectively assist government to develop and implement its patient-centred policies. We can do this by linking and networking organisations and consumers together to share information, ideas and experience.

**Who We Are**

HCNSW operates through a management committee and is involved, in policy and planning at state level, providing the views and perspectives of our consumer members.

HCNSW as a communication channel between health consumers and government on generic health issues is vital. This provides government, policy makers and other health stakeholders with the consumer perspective which balances the view of health care professionals, service providers and industry.

# From the Services Desk

*Newsletter of IDEAS Sept/Oct 2012*

**Smoke Alarm Subsidy Scheme**

NSW Minister for Disability Services, Andrew Constance, recently announced the Smoke Alarm Subsidy Scheme (SASS) to protect the lives of people who are deaf, deafblind or hard of hearing.

Usually smoke alarms with flashing lights and vibrating under-pillow pads to supplement the sound of the alarms can cost as much as $500, but under the Subsidy Scheme people who are eligible will only pay $50.

Further information and applications for the subsidy can be made to the Deaf Society.
You can visit www.deafsocietynsw.org.au/smokealarms or call
TTY: (02) 8833 3691 or Ph: (02) 8833 3600 or email: smokealarms@deafsociety.com

### Mobility Scooters on Buses

Thanks to one of our readers Danny who has been busy writing to politicians and Government departments to find out some information about using mobility scooters on State Transit Authority buses.

There are some types of scooters which are allowed on public buses. However there are some restrictions that apply such as having 4 wheels and being less than 300kg including the occupant. Three wheeled scooters and larger 4 wheeled mobility scooters are not allowed on public buses.

### Scooters and Bike Paths

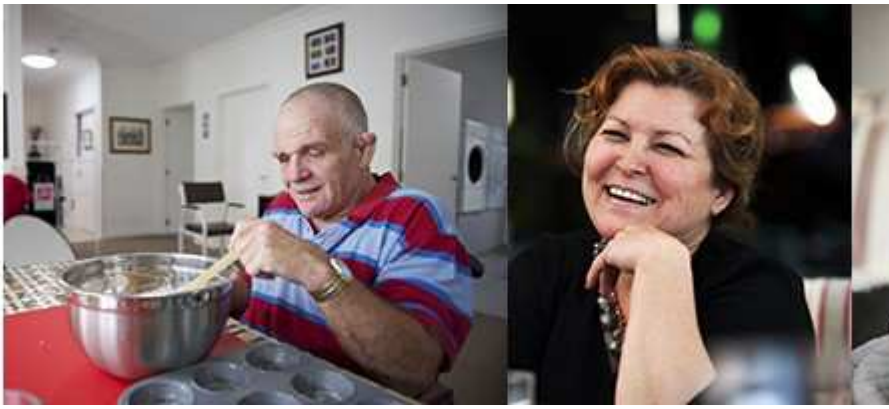
Danny also received a letter from the Minister for Roads and Ports providing some information about using mobility scooters and motorised wheelchairs on bicycle paths and shared paths.

The letter states based on the road rules that mobility scooters are able to be used on bicycle paths and shared paths as long as they are separated from the road by a physical barrier like a curb etc.

It is against the law to use a mobility scooter or wheelchair in a 'bike lane'. These bike lanes are the ones which are just painted on the road and not physically separated from the road. If you would like more information on these guidelines and road rules about mobility scooters you can give one of our Information Officers a call on 1800 029 904.



2013 PossABLE IDEAS EXPO
MAY 3RD & 4TH
NEWCASTLE ENTERTAINMENT CENTRE



### A Daring Enterprise

The 2013 **PossABLE** IDEAS Expo is a two day event to be held at the Newcastle Entertainment Centre on 3 and 4 May. **PossABLE** embraces the ideals of person centred systems, ability and believing anything is possible in enabling people to achieve an independent and fulfilled life.

### What's in it for me?

This expo is the single expo which answers "*what's in it for me?*", *ME* being a connection to anyone with a lived experience of disability. **PossABLE** will have the credible, trusted accurate suppliers and providers under one roof in the Hunter for the very first time.

# Some thoughts about Polio

*Reprinted from Polio Happenings, Auckland Post-Polio Support Group (Inc) Newsletter, Issue 59, August, 2012. Source: Polio Outreach of Washington, DC, Spring 2010. Reprinted from Polio Deja View, VA, Aug/Sept, 2010.*

*Author: Walter C. Stolov, MD, Professor and Chair Emeritus Stepping down Director of the UWMC Post Polio Clinic, University of Washington, Dept. of Rehabilitation Medicine, Seattle, WA*

The majority of patients seen in the Post Polio Clinics throughout the nation are those who contracted polio during 1950-56, the time of the last major epidemic before the vaccines were developed. The current age of the group, assuming polio was contracted before age 25, is 54 to 85 years of age. There are now 6-7,000 people from this group in the state of Washington.

The concerns expressed by these patients in almost all of the cases center around a decrease in function compared to function skills they achieved two to five years after the attack, sometimes up to 10 years later. The function decreases experienced for some began to occur about 20 or more after initial attack.

The areas of function that are diminished might include walking, stair climbing, posture maintenance, transfer skills (e.g. getting out of bed, on and off chairs), personal hygiene skills (e.g. bathing, toileting), dressing skills, eating skills, swallowing, breathing, avoidance of falls, and performance of responsibilities at home, work, school and the community. The symptoms associated with these function losses, can include fatigue, reduced endurance, pain, and a perception of weakness.

The cause of the function losses is multi-factorial in most patients. These factors include: (1) the severity and location of muscles completely or partially paralyzed; (2) the degree of joint destruction and deformity secondary to the lost muscle strength at the joints, particularly at the knee, ankle, foot, hip, shoulders, hand and spine.

Additional factors include diseases acquired over time that are not directly related to the original polio but which can magnify the functional losses. These factors include; (3) thyroid disease, (4) heart disease, (5) pulmonary disease, (6) cancer, (7) diabetes, (8) other neurological and muscle diseases, (9) osteoarthritis, (10) significant weight gain, (11) stroke, (12) the effect of injuries and (13) depression. For some patients, the polio residual is not the primary factor in causing function losses and associated symptoms.

A major additional factor contributing to the development of function losses is: (14) the normal aging process that begins at about age 25 to 30, and affects all of us whether we had polio or not.

The effect of this aging process for those with significant polio muscle weakness can lead to a profound effect on these muscles causing added function loss. The explanation for this is as follows.

The nerve fibers that cause muscle contraction originate in the spinal cord. Each muscle is served by many of these nerve fibers. Within a muscle, many individual muscle fibers attach to each individual muscle fiber. The number of nerve fibers per muscle and number of muscle fibers that are attached to each nerve fiber varies with the size and location of the muscle.

In acute polio, the virus attacks the cell bodies of the nerve fibers. Some escape the attack, some cease to function but then recover and some die. Therefore the muscle involved can end up totally paralyzed, partially paralyzed or fully recover. The partially paralyzed muscle ends up with less than the normal number of nerve fibers and hence less working muscle fibers. It is this group that is affected by the normal aging process.

The normal aging process causes all of us to lose about 1% of the nerve fibers to a muscle per year. In partially paralyzed muscle that already has a reduced number of nerve fibers, such additional losses can lead to a reduced ability to perform ordinary daily functional activities, and the appearance of fatigue and pain when performing activities that were not fatiguing or painful before.

The therapeutics used in post-polio clinics vary from patient to patient, but all are directed at re-establishing or delaying the losses in the functions enumerated above. The therapeutics may include:

- Bracing as needed to substitute for weakened muscles or correct deformity with appropriate design, fitting and training
- Appropriate prescription of walking and ambulation aids
- Suggestions to modify the environment to reduce energy costs
- Surgery recommendations for some deformities
- Referrals to other specialists to decrease the influence of non-polio related diseases
- Education about what polio is and what it is not
- Teaching a maintenance home-performed active range of motion, a stretching program, and aerobic condition
- Exercise to strengthen muscles that were not involved initially may be prescribed

Strengthening polio involved muscle should usually not be done as they are likely to be already at maximum strength. Such exercises may enhance fatigue. Any exercise that produces fatigue should be avoided or performed at a lower intensity. Any activity that one enjoys except for the fatigue that occurs can usually be managed by interspersing short rest periods and then resuming.

The polio group from the 1950's is a proud bunch. They have been highly productive. They have great pride in the fact that they "beat polio". They understandably are disappointed to find out that the polio is still with them. As long as they maintain their focus on function and come in time to worry less how they now need to do some things differently, they will be able to say, "I beat it a second time".

You may have noticed that I have not used the term "post-polio syndrome". I dislike it because it suggests a whole new disease, which it is not, and also implies that everybody with it are alike, which they are not. I prefer to say "post-polio, late effects as modified by the normal aging process and health status".

## Post-Polio Post

*Member Karen Begley has made a kind offer for fellow members.*

Karen has donated four pairs of shoes; right shoe is size 7 and left size 9. If anyone is interested in these shoes please contact the Polio NSW office.

*One of our foundation members, Terry Fletcher, recently lost her husband, Bill Capon. In 1988, following the Seminar at which the existence of post-polio syndrome was confirmed by a guest speaker, Professor Irving Zola, attendees at the Seminar agreed to form the Network. A Working Party was formed to publicise the imminent Network and to develop the constitution. Terry was a member of that Working Party and also a member of the inaugural Management Committee following the birth of the Network on 18th March, 1989.*

*Terry also served on the Network Management Committee in subsequent years. During most of those years when Terry has been involved with the Network she has been whole-heartedly supported by Bill. Apart from his devotion to Terry, Bill also pursued his love of bushwalking as illustrated by the following article which appeared under The Sydney Morning Herald's "Time Lines" on 14th December 2012.*

# Wonders of the bush taken in stride

**BILL CAPON, 1939-2012**

***Unconventional … the bushwalker often forgot various elements of his gear, but his resourcefulness made up for any absent-mindedness*.**

Bill Capon was a leading member of Sydney Bushwalkers Club for more than 40 years and was renowned not just for the many challenging walks that he led, but also for the charming eccentricity with which he led them.

In 1976, during a break on a Kanangra to Katoomba walk at one of the tops approaching Narrowneck, Capon was spotted rummaging around in his pack. He pulled out a hunk of cheese that was speckled with dirt and bits of dead leaf. He eyed it suspiciously for a moment, then popped it into his mouth and continued rummaging. In some ways, this set the tone for the next 35 years.

Capon was a master navigator, absolutely reliable, and always at home in the bush. He saw the country in a map. He led challenging trips through unfamiliar territory. Things sometimes went wrong, and in such situations he recovered well and always with good humour. Bushwalkers had confidence in his ability to cope with an emergency, it's not just the dramatic things that count on a walk. Capon was at the front when the scrub was thickest, and did more than his share at camp.

***Bushman's knack ... Bill Capon trekking in New Zealand.***

However, for all of Capon's bush skills, he was a little unconventional. There were few trips on which he had a full kit. Omissions ranged from a missing mug to forgetting his sleeping bag or bringing the wrong map. He lost and misplaced things regularly. There must be a compass or pair of his glasses lying in the bush on just about every walk he took, and he could rarely find his car keys at the end of a walk. Because he so often forgot his gear, he was innovative - using shoelaces for tent guys and sticks for tent pegs. To him,

this was small stuff, he had the bushman's knack of making himself comfortable.

For more than two decades, Capon led marvellous walks for Sydney Bushwalkers Club. He worked hard to get a balanced program, with a range of interesting trips in a variety of areas.

He not only made countless calls to leaders, encouraging them to put walks on the program, but thought up routes and found someone to lead them. His planning was done by spreading his maps over the floor and studying them with the aid of a glass, or two, of port, considering why no one had ever walked from A to B – and how it could be done.

He led wonderful long-distance and challenging walks – the Blue Mountains, Wollemi National Park, Ettrema and the Budawangs. He also walked in Nepal and the Southern Alps of New Zealand. Typical of his trips was the walk from Hilltop to Kanangra in 1995 when the party was out in the rain for seven days and dry for 24 hours. On another legendary effort, he led a group across the Wollemi, from Deep Pass near Lithgow to the Putty Road, carrying a considerable amount of water most of the way across the notoriously dry ridges.

Later, Capon embarked on an ambitious project to produce a database of all the overnight walks listed on the bushwalkers club since its start in 1927. He was justifiably proud of the result, which is now available to club members on its website. Days before his death, Capon was planning to improve and update the database.

William Capon was born on September 21, 1939, to Bert Capon, a journalist, and his wife Cal (nee Stumpt), a primary schoolteacher. After his schooling, he trained and worked as a teacher and married Terry Fletcher in 1993. He had an astute business sense and, after retiring from teaching, successfully managed real estate projects and invested well.

His interests included a deep appreciation and extensive knowledge of wine and classical and jazz music.

In recent years, health issues curtailed Capon's strenuous walking. However, as always, he was active and busy and his ill health had little effect on his full life in other areas.

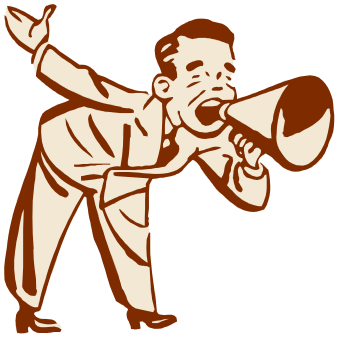
Bill Capon is survived by Terry and her family, Susie and cousins Julie Welsman and Rob Godhard.

## Have You Included Your Polio Details on the Australian Polio Register?

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,200 polio survivors on the Register and this number increases daily.

To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <www.polioaustralia.org.au>.

The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.



# 2013 Polio NSW Seminar Program

| | | |
|---|---|---|
| **9 July** | Northcott Building<br>*1 Fennell Street*<br>*Parramatta* | **Diane Bull – "It's not always about age"**<br>***Other speakers to be confirmed*** |
| **21 & 22 September** | Country Seminar<br>*Venue and Program details to be confirmed* | ***Speakers to be confirmed*** |
| **Saturday 30 November** | Burwood RSL Club<br>*96 Shaftesbury Road*<br>*Burwood* | **Annual General Meeting and Seminar** |

## Management Committee - Executive Members Contact Details

| | | | |
|---|---|---|---|
| Gillian Thomas | President | president@polionsw.org.au | 02 9663 2402 |
| Susan Ellis | Vice-President | vicepres@polionsw.org.au | 02 9487 3094 |
| Merle Thompson | Secretary | secretary@polionsw.org.au | 02 4758 6637 |
| Alan Cameron | Treasurer | treasurer@polionsw.org.au | 0407 404 641 |
| **Committee Members** (*for contact details please ring or email the Network Office*):<br>Charles Anderson, Anne Buchanan, Nola Buck, Wendy Davies, Barbara Fuller, Gary Fuller, Alice Smart and John Tierney | | | |

## PPN Office and Other Contact Details

| | | | |
|---|---|---|---|
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| Gary Fuller | Support Group Co-ordinator | support@polionsw.org.au | 02 9523 2428 |
| Susan Ellis | Seminar Co-ordinator | seminar@polionsw.org.au | 02 9487 3094 |
| Alan Cameron | Website Webmaster | webmaster@polionsw.org.au | 0407 404 641 |
| Anne Buchanan | Publicity Officer | publicity@polionsw.org.au | 02 9771 2748 |
| Mary Westbrook | Q's about polio & pps | askmary@polionsw.org.au | --- |

# About Polio NSW

The Post-Polio Network (NSW) Inc was formed in 1989 by polio survivors for polio survivors. In 2011 the Network changed its name to Polio NSW Inc but our services for polio survivors remain unchanged.

Polio NSW is a self-help, self-funded organisation governed entirely by volunteers. Polio NSW provides information about polio's late effects and supports those who may be affected now or in the future. We conduct regular Seminars and Conferences, publish *Network News*, foster the establishment of regional Support Groups throughout NSW and the ACT, and maintain a comprehensive website.

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

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 Polio NSW's income, which is used to provide its services, comes from membership subscriptions and donations.

# Resources for Members

On joining Polio NSW, 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.

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

| ***Books etc (❊ indicates Post-Polio Network publication)*** | ***Size*** | ***Cost*** |
|---|---|---|
| *Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome*<br>**Second Edition** Edited by Lauro S Halstead MD (***see description below*** ✍) | 288 pages | $40.00<br>*incl 10% GST* |
| *A Practical Approach to the Late Effects of Polio*<br>*Charlotte Leboeuf* | 39 pages | $2.50 |
| ❊ *Living with the Late Effects of Polio*<br>Conference Proceedings, edited by Gillian Thomas | 170 pages | $29.00 |
| ❊ *Polio – A Challenge for Life – The Impact of Late Effects*<br>Report: Survey of Members, Merle Thompson | 54 pages | $12.00 |
| ❊ *Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio*, Dr Mary Westbrook | 12 pages | $3.00<br>*1st copy free* |

| | | |
|---|---|---|
| Polio NSW has for sale a 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 Polio NSW. Not only is the badge a great fashion statement, it is an innovative way to promote Polio NSW. | 23 mm x 23 mm | $5.00<br>*plus $1 postage* |

✍ ***Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition)***

*The second edition was published in 2006. Editor Lauro Halstead writes about the rationale for this edition:*
As with the first edition of *Managing Post-Polio*, the major goal of this volume is to summarize the best advice available to diagnose and manage PPS in an easy-to-read, authoritative format for polio survivors, their families, and friends, as well as for health care professionals. The majority of contributors to this book are either polio survivors or experts who have worked closely with polios in clinical settings.

Another important objective of the earlier edition was to reach as wide an audience as possible – an objective that far exceeded our expectations with more than 15,000 copies in circulation. As news about PPS spread, the demand for more information continued to grow. This new edition is in response to that continued demand for information. Also, we have added a new theme to this edition – aging with disability, as once again polio survivors are "pioneers" – the first large group with a chronic physical disability to undergo aging. Since the initial edition, we are all nearly 10 years older, and, hopefully wiser. Quite possibly, we are also more disabled and, therefore, more challenged. It is my hope that this book will help guide us as we journey along this new path together.

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 Office.