



# POST - POLIO NETWORK (NSW) INC.

## NETWORK NEWS

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### President's Corner

Gillian Thomas

Welcome to new members and regular readers alike to another issue of *Network News*.

Just as I was finalising this issue to send to the printer, a controversial paper about Post-Polio Syndrome, reporting on research undertaken by the Mayo Clinic, was published in America. The **Mayo Clinic News Release** issued on 21 August about the research findings has created considerable interest in the polio community and not a little heated debate. With the world media regrettably sensationalising the findings, this *Network News* was delayed a little and expanded not only to include information for members about the research, but to allow time for **Marcia Falconer, Edward Bollenbach and Mary Westbrook** to analyse and report on the research findings and help us put the media reports into perspective. This important information can be found on **pages 4 to 11 inclusive**.

As a consequence of this necessary delay, our publication date is a little closer to the upcoming Seminar than I would have liked. On page 2 you will find details of the **Seminar** which will be held on **Saturday 16 September** at the **Hornsby RSL Club**. The presenter is Network member and sportsman **Bill Bradley – A Man With A Mission**. He is currently in hard training as he attempts to qualify to compete in sailing events at the 2008 Paralympic Games in Beijing. Bill has had an amazing life and is not yet ready to slow down despite his 70 years. He deserves our support so please come along and hear his lively talk. **Afternoon Tea is being provided by the Network at no charge. To ensure adequate catering, an RSVP as soon as you receive this issue is essential. All the details are on page 2.**

The dates and topics for the remainder of our **2006 Seminar Program** have now been finalised and are given on **page 30 - please note these dates in your diaries**. Planning for the **2007 Seminars** is well underway.

**Post-Polio Awareness Week** is just around the corner and again we are seeking your support to publicise the Week. Posters and brochures will be sent out in early October, together with the official notification of our **Annual General Meeting** to be held on **Saturday 25 November** at the **Northcott Centre**, commencing at **11 am**. The 2005/2006 Annual Report, Financial Report and Proxy Voting Forms will be distributed in November.

At the **Seminar** to follow the AGM **Merle Thompson** will present the findings of our **2006 Research Project**. This research follows on from, and expands, our 1998 research and has again been well supported by members. **Advance notification** of Merle's presentation is on **page 14. We urge you to attend from 11 am.**

There are still some members whose annual subscriptions are due (or overdue). **If your address label on the back of this *Network News* has a Renewal Due date on it of 1 July 2006 or earlier, your subs are now due.** We would appreciate prompt payment of any outstanding dues (\$20 employed, \$10 retired or not employed, *per year*) to ensure that you continue to receive *Network News* and other important information.

**The Network is self-funded and needs your continued support to enable us to keep providing services to polio survivors and their families.**

In October 2005 representatives of **Polio Australasia** (the informal association of the Post-Polio Networks in Australia and New Zealand) met in Melbourne and discussed the possibility of holding a "**Think Tank**" to **plan future services for polio survivors**. At the request of the other Networks, we are moving this idea forward. A **PPN Organising Committee** has now met several times and undertaken preliminary planning to organise a **meeting in 2007** which aims to bring together **Polio Australasia representatives, health professionals and government policy makers** to map out a future plan. A report on progress will appear in the next issue.

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# Bill Bradley - A Man With A Mission

- Date:** Saturday, 16 September 2006
- Time:** 1:00 pm – 4:00 pm
- Lunch:** Bringing your own lunch is not an option at this venue  
Bistro lunches start at around \$7.00 for non-members (members \$6.50)  
The Palms Cafe has sandwiches at around \$4.50 for non members
- Afternoon Tea:** Courtesy of the Network – **RSVP before 12 September essential**
- Venue:** Boronia Room  
Hornsby RSL Club  
4 High Street, Hornsby

Bill Bradley is indeed a man with a mission. At the age of 70 when most men have been comfortably retired for some years, Bill is not only still working at Hornsby Hospital but has now taken on the next in a long line of challenges. He is in training to qualify to represent Australia in sailing at the 2008 Paralympic Games in Beijing. What is more remarkable is that Bill only took up the sport a couple of years ago and yet already has competition victories under his belt.

At school in the 1940s Bill excelled at all sport. His class was a team of dreamers who learned that you have to make your own dreams come true. Two of them were dreaming of the Olympics – Bill and his mate Betty Cuthbert. Her dream came true in 1956 when she won three gold medals at the Melbourne Olympics. Bill's dream was shattered at the age of fourteen when he contracted polio which left him an incomplete quadriplegic.

Not to be daunted by the prospect of never playing elite sport, Bill made the decision to organise sport for youth. Over many years he has held numerous positions in a variety of sporting and community organisations thus helping to keep thousands of children off the street through organised sport. He has been involved with junior rugby league, cricket, basketball and little athletics, to name but a few. In 1983 Bill started mini harness racing in the metropolitan area. This is a sport for children between the ages of 5 and 16 driving Shetlands or ponies. Bill believed that encouraging children into the sport of mini trotting meant that they had to look after their horse and stable, train the horse and then attend trotting meetings. His theory was that in learning to care for an animal they did not have much spare time to get into mischief!

The beginning of 1995 saw Bill's life change once more. Appearing in the local paper was a pictorial story about a wheelchair athlete who was going to a National Lawn Bowls Championship. After the tournament a team was to be picked to play in South Africa. Bill said to his wife Clover "*That would be a great trip, I'm taking up bowls*". After a few roll-ups on the grass, and hurriedly organising his entry into the event, Bill's sporting career was rekindled. Against all odds, Bill won that event and the rest, as they say, is history.

To learn more about Bill's life and varied sporting career, and his current quest to represent Australia again, come along and hear him speak – it promises to be a enthralling afternoon.

*In order to ensure that Afternoon Tea is sufficiently catered, you are requested to telephone Alice on 9747 4694 to confirm your attendance, or email her at <ea@post-polionetwork.org.au>.*

***Final numbers for Afternoon Tea must be advised to the Club on 12 September, so please get in touch with Alice as soon as you receive this Network News.***

*We look forward to seeing everyone there and hope that the move to Hornsby for this event will make it easier for some of you to get to a Seminar. If this will be the first Seminar you have attended, please be sure to introduce yourself to a Committee member.*

# From Iron Lung to Paralympic Legend

Bill Bradley contracted polio in 1950 at the age of 14 and spent three weeks in an iron lung, followed by fifteen months on his back in hospital.

He is pictured here with Nurse Paddy Knight (now Marshall) shortly after leaving the iron lung.

Bill and Paddy never forgot each other, and on 27 June 2000 they met up again for the first time in fifty years at the *Prince Henry Hospital Reunion of Polio Patients and Staff* organised by PPN member Doug Sutherland in conjunction with the Network.



Bill wins the International Paralympic Committee's World Championship Quadriplegic Division in South Africa in 1998. As the finals day went on the point score for countries was even between Australia and South Africa. The Aussie manager was pacing up and down as Bill played the last South African on the green. In front from the start, Bill kept the pressure on until he gained the gold medal. Bill's win was also a win for Australia as the team won the point score trophy.



Bill (at the rear) in the Skud 18 he hopes to qualify to sail in the 2008 Beijing Paralympics.

# Post-Polio Controversy

*Stories based on the following Mayo Clinic News Release have been quick to appear in the media around the world. Many of the stories have regrettably sensationalised and/or misreported the research findings. Such journalism may be distressing to Australian polio survivors who are experiencing polio's late effects and already having difficulty getting their problems acknowledged, assessed and treated. In order to make more sense for the non-technical reader of the research being reported, the original Mayo Clinic News Release is reproduced here, together with informative analyses by Dr Marcia Falconer PhD and Professor Edward Bollenbach, and by Dr Mary Westbrook PhD AM.*

## **Survivors of Childhood Polio Do Well Decades Later As They Age**

**News Release Issued by the Mayo Clinic, Rochester, Minnesota, USA**

**Monday, August 21, 2006**

Mayo Clinic researchers have found that years after experiencing childhood polio, most survivors do not experience declines greater than expected in their elderly counterparts, but rather experience only modest increased weakness which may be commensurate with normal aging.

*"Other researchers have suggested that polio is a more aggressive condition later in life, but we've actually found it to be relatively benign", says Eric Sorenson, MD, Mayo Clinic neurologist and lead study researcher. "Our results suggest that polio survivors may not age any differently than those in the normal population – they're not doing too badly compared to their peers. This tells us that the cause for the decline in muscle strength in polio survivors may be aging alone."*

Polio is a contagious, viral illness that peaked in the United States in 1952, when 3,000 people died of the disease. Mass immunizations in the mid-1950s began to slow the spread of the disease, and the last case of polio not caused by a vaccine occurred in the United States in 1979. The three major types of polio include spinal polio, a paralytic polio that attacks nerve cells in the spinal cord; bulbar polio, in which the virus attacks motor neurons in the brainstem; and bulbospinal polio, a combination of spinal and bulbar polios. The effects of polio run the gamut from a complete return to normal function to paralysis of limbs to acute death. Following the illness, most patients are worried about their long-term prognoses, according to Dr. Sorenson.

To conduct this study, the researchers randomly selected a group of 50 polio survivors from the general population of Olmsted County, home of Mayo Clinic, and followed them for 15 years. The average age of participants at the study's start was 53, and the patients were an average of 40 years past their childhood experience with polio. The researchers measured strength and loss of neurons at the beginning of this period, and then again five and 15 years later with electrophysiological testing, strength testing and timed tests of performing basic functions. They found modest declines. Each patient also completed questionnaires about symptoms of progressive weakness at the beginning and end of the study period. Though the majority complained of progressive weakness during the time they were studied, these symptoms did not correspond with their actual magnitudes of decline over time. Rather, the researchers found patients' symptoms experienced were associated with the degree of residual weakness immediately following their polio infections.

*“Overall, we found that strength changed very little in these polio survivors as they grew older, and we discovered the neurons dropped off at a rate comparable to other non-polio survivors as they aged”, says Dr Sorenson. “We concluded this was normal aging on top of their old deficits. Very few had to change their homes or add adaptive equipment. Those who had weakness problems during our study had a larger deficit at the end of their childhood disease, making them more likely to develop symptoms. So, as deficits at the end of the disease increase, the probability of experiencing post-polio symptoms increases.”*

The discrepancy between what some of the patients experienced with growing weakness and their actual measurements of strength and neuronal loss likely is due to increased sensitivity due to their disease experiences, according to Dr Sorenson.

*“Patients feel their weakness progressing, but when you measure it, it’s very modest”, he says. “Likely, they lost so much strength at the time of their illness that any change is very noticeable to them. Though the likelihood is high that patients who have had childhood polio will complain of weakness later in life, they can expect years of stability without the need for major lifestyle modifications.”*

Other Mayo Clinic researchers involved in this study include Anthony Windebank, MD, and Jasper Daube, MD.



## **Examining a Controversial PPS Publication**

Dr Marcia Falconer, PhD  
Professor Edward Bollenbach

*Marcia Falconer has a PhD in neuronal cell biology from University of Ottawa, Ottawa, Canada, and undertook post-doctoral study in molecular biology at Massachusetts Institute of Technology, Cambridge, Massachusetts, USA. Marcia led a virology laboratory with biotechnology applications at the Centre for Food and Animal Research, Agriculture Canada, Ottawa. She also holds an MSc in cell biology from Carleton University, Ottawa, Canada and a BSc from Simmons College, Boston, Massachusetts. Marcia is a speaker at many PPS conferences and meetings in Canada, Australia and Britain. Now retired, she researches and writes about Post-Polio Syndrome. She has numerous publications in peer-reviewed journals and on the Web, and is currently writing a book about inflammation and PPS.*

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*Edward Bollenbach is an Emeritus Professor of Biology. He has been a full Professor of Biology since the age of 39; he won the first Educational Excellence and Distinguished Service Award in the Connecticut Community College System, and has specialized in the Teaching of Microbiology and Chemistry at Northwestern Connecticut Community College for 32 years. Edward holds a Master of Arts in Biology from the State University of New York and New Paltz, New York, and graduate certificates in Cryptogamic Botany, Origins of Life, and Holistic Health. He currently writes about and researches Post-Polio Syndrome and has several articles in print and on the Web.*

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Recently a controversial article, “*Electrophysiological findings in a cohort of old polio survivors*” by Sorenson, Daube and Windebank was published in the Journal of the Peripheral Nervous System, volume 11, pages 241-246, September 2006. The findings in this article are the subject of heated discussion in the PPS world. Below we examine this article.

A scientific article usually is divided into parts: an abstract, which gives a brief overview of the article; the introduction, where related findings are discussed; the methods, which tell how the work was done; the results, which tell what was found in the study; and the discussion in which the results are put into context with previous findings. In this final section the authors can speculate on wider implications of their findings.

The discussion section is often the source of intellectual debate. On occasion this debate can be vigorous, particularly when data from different studies point toward very different conclusions. Science would not be science if it was not exciting and controversial. We can expect scientists to have honest disagreements about methods, results and especially the discussion section of a paper. Unfortunately the debate is sometimes removed from the scientific arena to the public one when the popular press, or the internet, seizes upon an idea or a statement in the article.

This appears to be the case in the article by Sorenson et al. In particular, one statement in the discussion section has been sensationalized. The statement is: *“This suggests that the most likely cause for the decline in our polio survivors is aging alone.”* It is easy to understand why this sentence was highlighted. Taken out of context, this statement can infer that Post-Polio Syndrome (PPS) does not exist. It can even be interpreted, incorrectly, to mean that people with PPS are no worse off than their similarly aged peers with all this implies. Taken within the context of the reported data, the statement does not mean any of this.

This study is based upon two electrophysiological studies with the results explained using statistical methods and models. It is complex for the layperson to read and understand but it was not designed for the general reader. It is designed to pass specific data to people working in the field who are conversant with the methods and the interpretations of this data. We present here a less technical, but still scientifically accurate, summary of the main points in this paper.

In this study, the muscle strength and symptoms of 38 people with a history of prior paralytic polio were studied at 5 year intervals for 15 years. Innervation to two muscle groups, the thenar muscle at the base of the thumb and the digitorum brevis muscle on the sole of the foot, was examined using two electrophysiological measurements. One technique, CMAP (compound muscle action potential), examines the maximum amount of muscle contraction that can be achieved. The second technique, MUNE (motor unit number estimate), provides information about the number of motor units in that muscle. A motor unit is a group of muscle fibers for which the message to contract is carried by a single neuron coming from the anterior horn of the spinal column. Both techniques indicate the functionality of the nerve that is tested.

The underlying cause of Post-Polio Syndrome remains unknown. Current theories include chronic inflammation of the spinal cord and die-back of recovered neurons from overuse. The “die-back hypothesis” suggests that fragile neuronal sprouts (which reinnervate muscles after the loss of neurons during acute polio) die because of metabolic stress caused by overuse. These two suggested origins for PPS are not necessarily contradictory but rather examples of different levels of observation; one at the tissue level, the other at the cellular level.

Thirty-one of the 38 people in the Sorenson study indicated they have PPS and experienced progressive muscle weakness during the 15 year period. Seven did not have PPS symptoms and did not experience this. It was found that the amount a muscle could contract (CMAP measurements) declined equally in people with PPS symptoms and people without symptoms. The number of motor units that could be activated (MUNE

measurements) declined in both groups, but, oddly, there was a greater decline in people who did *not* report new muscle weakness! Since increasing weakness is associated with increasing loss of nerve connections to motor units, clarification or discussion of this unexpected result would be good.

A significant flaw in this article is the use of results derived from another study with different methods. It is acceptable to discuss and compare results from different studies. It is not acceptable to *use the results* of others to replace missing elements of your own study. This is particularly true when different methods were used to obtain the results. The authors did exactly this in the most provocative part of the publication. Because this study does not have a 'normal control group', the authors took the results from another, undefined, study with different methodology, to get data about people who did not have polio. They then compared the results from their electrophysiology study on polio survivors with the results from this undocumented study. By doing this, their comparison of the effects of aging in polio survivors and normal people is meaningless.

It is clear that the statements causing most concern to people with PPS are the ones least supported by the evidence. Unfortunately, these statements also are the ones most likely to be picked up and sensationalized. They are, in the authors' own words, "... *the similarity of our results suggests that our polio cohort did not age any differently than a normal population. This suggests that the most likely cause for the decline in our polio survivors is aging alone.*" To make a statement with such import, the data that supports it must be impeccable. It is not. Without appropriate data the conclusion is unfounded and inflammatory.

Saying that "*the most likely cause for the decline in our polio survivors is aging alone*" invites many questions. For example, all polio survivors age, but not all polio survivors report an accelerated decline. What about them? What about young people, from the less developed world where polio is still endemic? They are reporting symptoms of PPS and they are not at the point where age causes loss of neurons. To ascribe aging as the main cause of PPS new muscle weakness ignores the other severe problem of PPS – central fatigue – which has no obvious connection to aging.

Indeed, to say that the decline is due to aging alone also suggests that the aging process is the root cause of PPS. This is a gigantic leap and ignores documented differences between similar aged polio survivors who have PPS and those who do not. Specifically, the profile of proinflammatory cytokines is significantly different in the two groups (Gonzalez et al *J. Neurol. Sci.* [2002] 205: 9-13), as is the presence or absence of poliovirus fragments in cerebrospinal fluid (Leparc-Goffart et al *J. Clin. Microbiol.* [1996] 34: 2023-2026). Neither of these is typical of an aging population.

In addition, the Sorenson et al citation of work by McComas et al is perplexing. McComas disagrees about aging being the most likely cause of new weakness. Indeed, he actually says the opposite. To quote from McComas et al "... *denervation progresses in patients with prior poliomyelitis ... and ... this progression is more rapid than that occurring in normal aging.*" (McComas et. al. *Brain* [1977] 120, 1415-1421).

The data in the current study shows that people with prior polio lost motor units at 3% per year. In the McComas article people with prior polio lost motor units at the rate of 6.7% per year and people without prior polio lost motor units at half this rate. Sorenson et al then say that "*The rate of decline in our polio cohort was approximately the same as the normal population in the McComas study but about half that in their polio patients.*" It is not clear why this statement is included. It appears the authors are saying that the decline in the polio group in their study is the same as the decline in the normal population of the

McComas study and this supports their contention that PPS weakness is due to normal aging. However they are comparing apples and oranges – results from two different studies. Moreover, the two studies came to diametrically opposed conclusions about PPS weakness and aging.

Another controversial part of the article is the suggestion by Sorenson et al that there are two models to explain new muscle weakness in PPS. One is “linear loss” where the loss of neurons (and hence of strength) is a constant rate of decline for everyone as happens in normal aging. The other model is “proportional decline” where the loss is related to the amount of damage from acute polio. In the discussion, the authors say that the proportional model best explains their findings. However the authors also say that neither model closely fits their data! This strongly suggests that neither model is correct. Therefore, the pattern for new muscle weakness is not related to a slow general loss (as is found in everybody with aging) and it is not (solely) related to the amount of original paralysis. There are other rate laws which could describe the way new muscle weakness is appearing. It might have been illustrative if these had been explored. It appears that the model preferred by the authors does not support their hypothesis that muscle weakness (loss) is related to normal aging (the first model).

Sorenson et al tell us that *“The large degree of variation seen in both models may be a reflection of the underlying variation known to occur with most MUNE techniques available currently.”* This means that the method used to obtain this data may not be adequate for the job asked of it. In other words, be a bit skeptical about the results.

On a different topic, the authors say that *“There was no association between the magnitude of decline in either the summated CMAP amplitude or the summated MUNE and the presence of symptomatic progression.”* One interpretation of this data is that a decline in the function of the two muscles they tested does not correlate with symptoms of new muscle weakness elsewhere in the body. If there is a significant relationship between the muscles tested and those generally reported as becoming weaker, this should be demonstrated or referenced.

This article is controversial not because of its actual findings, but because of the interpretation of its findings. The authors were poorly served by reviewers whose job was to point out all of the inconsistencies described above. This article has many statements that are not supported by the evidence. Unfortunately the popular press found a critical one and sensationalized it.



## **Inaccurate Mayo Clinic News Release Threatens Polio Survivors’ Wellbeing and Healthcare**

Dr Mary Westbrook PhD AM

*Mary Westbrook was Associate Professor in Psychology in the Faculty of Health Sciences at the University of Sydney before her retirement from fulltime work. She is now Conjoint Associate Professor in the Centre for Clinical Governance Research in Health in the Faculty of Medicine, University of NSW. Mary has published over a hundred research articles in peer reviewed scientific journals. She has published much about the late effects of polio and is currently part of a team evaluating the state-wide patient safety programs put in place by NSW Health over the last few years.*

The Mayo Clinic has issued a News Release on Sorenson et al's research which does not accurately reflect the research findings and limitations. The research failed to distinguish which, and how many, of the 38 polio survivors in the research sample had, or did not have, post-polio syndrome (PPS). The research also failed to include measures of major aspects of PPS, namely fatigue and pain. Although his research team found a significant decline over 15 years in around half of the measures of muscle strength made on their subjects, Sorenson said in the News Release that the late effects of polio are "*relatively benign*" and due to ageing. This oversimplification of what the results mean has been picked up by other media and further simplified so that by the time it was reported by the BBC news there were said to be "*no polio effects in later life*". There is a very large body of rigorous research showing the significant negative impact on functioning and quality of life that PPS causes for those polio survivors who develop it. It is disturbing to consider the impact of this News Release on the families and health professionals of polio survivors with PPS. They may well dismiss the reality of PPS thereby discrediting the reality of the symptoms that polio survivors with PPS experience. The reality of the problems polio support groups and post-polio clinics have struggled to bring to community attention may now also be dismissed.

I have read a copy of the Sorenson et al article "*Electrophysiological findings in a cohort of old polio survivors*", published in the *Journal of Peripheral Nervous System* [Volume 11, pages 241-246, 2006], on which the Mayo Clinic News Release is based. These authors have also published a recent article in the journal *Neurology* titled, "*A 15 year follow-up of neuromuscular function in patients with prior poliomyelitis*" [Volume 64, pages 1070-1072, 2005]. The same sample of polio survivors was the focus of the two papers. In the Mayo Clinic News Release Sorenson refers to findings from both these articles.

The aim of the article in the *Neurology* article was to examine "*1) the stability of strength in this cohort, 2) whether symptoms of progressive weakness are associated with the magnitude of the decline, and 3) whether symptoms of progressive weakness are associated with the magnitude of baseline residual deficits*". The article briefly describes 27 measures taken on each participant. These include the 2 electrophysiological assessments described in the 2006 paper. The aim of the most recent (2006) paper (discussed by Falconer and Bollenbach) was to describe in more detail the results obtained from the 2 electrophysiological measures.

The article published in 2005 *Neurology* gives a clearer overview of the whole research project undertaken and is easier for a non-neurologist to follow than the 2006 article. As the *Neurology* article is presented in the journal as a "*brief communication*" there is not great detail concerning the tests used and how they were scored so I may possibly have misinterpreted some of the authors' research procedure. The 27 measures taken on each subject included pulmonary vital capacity, tests of strength of 18 muscle groups, and a set of timed functional tasks such as time to walk 100 yards, and screw manipulation and pegboard tests requiring placement and displacement of objects. Depending on the statistical method you use to decide whether a real change in function had occurred over the 15 years (as opposed to a change so small it could only be attributed to chance), there was a significant change over time on 16 (59%), or 13 (48%), of the 27 measurements collected for survivors. For all of these measures a significant decline in function had occurred over the 15 years with the exception of one measure that showed an improvement in function over time. Ten of the measures that did not change over time were tests of muscle groups' strength. Decreased endurance often presents a greater problem for polio survivors than does decreased strength [1, 2]. In some instances survivors can perform an action once, or a few times, but their lower endurance prevents them from continuing to repeat the task the number of times their able-bodied counterparts can achieve. When examining survivors, health professionals may ask the person to

perform a movement and assume they can perform it all the time whereas they may only be able to do so again after a long rest period. Sorenson et al also calculated what they called a *Neurological Disability Score* by combining each subject's strength scores (from manual muscle testing) for some 27 muscles. Manual muscle testing is often unreliable and it frequently overestimates polio muscle strength [3] which may help explain why on this measure the subjects scored as having significantly less disability at the 15 year follow-up than they had when the research commenced. To help make more sense of the research findings we need to consider the actual sample used and its composition.

A major problem of the research is the sample of survivors used. The size of sample was small (making statistical inferences drawn from it, and particularly comparisons of the small sub-samples, questionable). Sorenson et al admit in their 2006 article that: *the fact that only seven subjects remained asymptomatic does limit our power to correlate progression with time to the development of symptoms*. The sample consisted of both polio survivors who did and did not report experiencing increasing weakness. The original study sample had consisted of 50 polio survivors tested 15 years previously. They had been randomly selected from the documented records of polio cases in Olmsted County, Minnesota. At the 15 year follow-up the number of subjects had decreased. Three had died and 9 refused to participate. Thus the sample size had dropped to 38 (though media reports keep talking about a sample of 50). In the *Neurology* paper the authors say that 25 (66%) of these 38 subjects had reported progressive weakness at the beginning of the study in 1987 and only 7 (18%) remained asymptomatic (reporting no increase in muscle weakness) at the 15 year follow-up. Clearly there seems to have been a mixture of survivors who did not have PPS with some (how many is impossible to say) who would be diagnosed with PPS at a post-polio clinic.

The major finding reported in the *Neurology* paper was: *"The greatest risk factor for the presence of progressive symptoms was the magnitude of neurologic deficit at baseline. In nearly all our measures, there was an association between symptomatic progression and magnitude of deficit at baseline."* In other words, survivors who had more polio related problems at the beginning of the study were more likely to experience progression of symptoms over the 15 year period. However, rate of progression of weakness was not related to the person's baseline symptoms.

Falconer and Bollenbach have described various other inadequacies in the research. However by far the most disturbing aspect of this research is not the research methods used but the chirpy media-catching spin put on them in the Mayo Clinic News Release. The release is being reported in many newspapers around the world. The BBC News (26/8/2006) had as a headline *"No polio effects in later life"*, followed by *"People who survive polio in childhood will not suffer further effects later in life, say US researchers"*. As a result of such inaccurate publicity many health professionals and family members and colleagues of polio survivors with PPS may dismiss their problems as 'all in the mind'. The hard work that polio survivors have done, and are doing, to try and obtain healthcare resources may be in some jeopardy. How do we convince governments of our requirements if research findings 'proving' there are no effects from polio in later life, are in circulation?

What the News Release from Mayo failed to explain was that:

- 1) There is a difference between the problems experienced by polio survivors with post-polio syndrome and other polio survivors. The latter may well experience late effects from living with a body compromised by polio (for example, carpal tunnel syndrome from using crutches) but do not report the combined symptoms of profound fatigue, increasing muscle weakness and pain reported by those diagnosed with PPS. Of course survivors with PPS may also have such other late effects such as degenerative arthritis in overused joints.

2) Sorenson et al's sample contained both types of polio survivor, that is, those with PPS whom we would predict would be more likely to decline in muscle strength and those who did not have PPS who would be relatively stable. (We can't assume that people who said they had experienced new weakness in the initial study would have been diagnosed as having PPS in a post-polio clinic.)

3) The results of a relatively small loss of muscle strength in a polio survivor can result in loss of ability to perform important, even major, functions. So a relatively slight loss on some of the type of measures used in Sorenson et al's research can have a dramatic impact ... in my case losing the ability to walk and needing to use a wheelchair. Sorenson's comments in the News Release that "*the discrepancy between what some of the patients experienced with growing weakness and their actual measurements of strength and neuronal loss likely is due to increased sensitivity to their disease experiences*". This reads to me like another 'all in your mind' judgment. It implies that survivors' early experiences as polio patients have turned them into fussy, over-reactive hypochondriacs.

4) Some experts on PPS see fatigue as both the most frequent and the defining characteristic of PPS. Polio survivors with PPS frequently say that the fatigue and pain of the syndrome interfere with their quality of life far more than does the loss of muscle strength. Dr Lauro Halstead, post-polio researcher and polio survivor with PPS, wrote: "*Of all the symptoms of PPS, new weakness is the easiest to study, and, thus has stimulated the most research. The results from this research have provided a better understanding of this symptom than any other aspect of PPS. Ironically, the symptom of fatigue is more common than new weakness in most studies, but, because it is more difficult to investigate, much less is known about the cause ... In addition to peripheral fatigue, another type is known as central fatigue. For many individuals, this type is the most disabling symptom of PPS*" [4, page 17]. Sorenson et al failed to include measures of PPS symptoms other than increased muscle weakness in their research.

Thus it is clear that this recent research suffers from several significant limitations. The sample was small in size and did not identify those with PPS and those without PPS. The measures failed to include important symptoms of PPS and these often have the most negative influence on survivors' quality of life. The spin placed on the results by the Mayo Clinic News Release is inconsistent with the study's results. The release ignores, and is contrary to, findings from a very large body of rigorous research into the late effects of polio; many examples of such research can be found in Silver and Gawne's recent book [5]. The greatest concern for polio survivors is the potential damage that this media release may cause by undermining their family and social support and increasing the risk that health professionals may dismiss their symptoms or prescribe inappropriate treatments. Post-polio support groups frequently witness how such happenings can have very detrimental effects on polio survivors' wellbeing.

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# Post-Polio Network Office Co-ordinator's Report

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**George Laszuk  
Office Co-ordinator**

Greetings once again. Our office in Parramatta is now an integral part of the Network's ability to service our members and its work relieves various tasks from overworked Committee Members, for example processing of information kits to the general public. The office provides a more accessible location for members to visit and provides our Network with a sense of identity in the eyes of the public. We all must remember that the members of our Committee are nearly all polio survivors and are getting on in years, therefore their ability to continue the huge work load in running our Network is diminishing. I would like to thank, and dedicate this report to, all the people and organisations that make it possible for the Network to run this office, for without them we would not be able to exist here in Parramatta.

Firstly, special thanks must go to **The Northcott Society** who not only supply us with an office but also give us administration and IT support in the everyday operation of this office. In addition to this Northcott make available seminar rooms for functions and conferences at very reasonable rates. The cooperation and friendliness of the staff at Northcott is extraordinary, where nothing is too much trouble when assistance is required.

**Sanofi-aventis Group**, which is the largest company in the world devoted entirely to human vaccines, supplied us with funding of \$10 000 per year for three years commencing in 2005. Again we are very grateful for their very generous contribution.

Another generous organisation who has assisted us financially is the **Lions Clubs of NSW**, especially **The Lions Club of Mount Druitt** who have taken this on as a club project for the past two years, have raised in excess of \$10 000.

A big "thank you" must go to our **dedicated volunteers** who work in our office. These valuable people come in on rostered days to answer your questions and help in the administration of the Network and I would like to introduce you to them again.

**Lesley Campion:** attends on Mondays and Wednesdays

**Nola Buck:** attends on Tuesdays

**Josephine Schoemaker:** attends on Tuesdays

**Noelene Teys:** attends on Thursdays

**Peter Boronowskis:** who is our newest recruit and attends on Fridays

Peter has taken over from Madeline Coelho who provided invaluable assistance helping us to set up our library. She has put in place procedures so we can appropriately maintain and expand the collection as new publications are received. Madeline is now enjoying her retirement and we wish her all the best for the future.

Without these dedicated volunteers, my job here in the office would be impossible given the hours that I am able to work.

Last, but by no means least, the **Network's Management Committee** should be congratulated for their foresight and support in opening this office two years ago.

Our biggest obstacle in keeping our office viable on a long-term basis is funding. As you are probably aware we receive no government assistance and rely solely on donations and subscriptions to fund our services not only to members but to the community. If any members can offer any assistance or give us any ideas in raising much needed funds please contact me or any member of the Committee.

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## Building Evacuation Procedures

Our lunch time chatter at the 9 June Seminar at the Northcott Centre was interrupted by the clamour of a fire alarm. We all had to rouse ourselves and make our way by foot and wheels across the road to the designated muster point, where we watched two firetrucks and quite a few firemen rush to our aid. Fortunately, it turned out to be a false alarm. The fresh air certainly helped to blow away the cobwebs, and invigorated us for the afternoon session!

*Photograph: courtesy of Lesley Bromley*



As part of our Occupation Health and Safety Policy we have procedures in place should a building evacuation be necessary at a Seminar or Conference. These procedures have been adopted to comply with regulations and to ensure the safety of members at functions. All evacuations must be treated seriously and you should follow instructions explicitly.

A member of the Management Committee will announce that an emergency situation exists and will ask you to leave the room NOW. You must comply with this direction immediately. He or she will specify which door you are to leave by and where the designated assembly area is located. You must only take with you what possessions you have with you at the time, for example, bag or stick. If possessions are elsewhere in the room you must leave without them. If you are eating or drinking you must stop and leave immediately. Please assist those who are less able.

At the designated assembly area a roll call will be conducted using the attendance roll to ensure that all members are accounted for. For this reason you must always sign the attendance roll on arrival at any Seminar or Conference. Only when the "all clear" is given should members return to the Seminar room.

# AGM and Seminar – Northcott Society, Parramatta

**Saturday, 25 November 2006 commencing at 11:00 am**

**Polio – The Impact of Late Effects – The Next Decade**

**Presented by Merle Thompson**



At 1:00 pm, following our Annual General Meeting, the Network's Vice President and Research Coordinator, Merle Thompson, will discuss the findings of our recent research questionnaire.

By way of background, in 1998 the Post-Polio Network published a report which analysed data gathered from a survey of its members which had been conducted over the previous 1 to 2 years. The response from members to that survey was very good with around 50% of the then membership completing the questionnaire. However, the previous findings were now nearly 10 years old. It was important to obtain up-to-date information.

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Our 2006 research project was designed to enable the Network to have:

- updated information on matters covered in our 1998 report;
- updated information on two issues which were of particular concern in the last report – the number of survivors who have had to retire early due to their polio-related difficulties and the reliance of survivors on family and carers for assistance with daily living;
- insight into matters such as other medical problems; and
- information on other factors which have become apparent from other research.

It is apparent from the response to our several research efforts that polio survivors want to understand their own situation and the on-going, and increasing, late effects of polio. Around 56% of our members responded to the request to complete the questionnaire which was sent to them earlier this year. Many researchers get response rates of only 10 to 30% so that is a very encouraging result. Just under 500 completed questionnaires have been received.

The information we gain from this research will provide us with facts to prove to others the effect that polio is still having on our lives. The major areas of interest are: the symptoms of the late effects of polio, when these were first experienced, the aids and appliances we need to use in our daily lives, whether we can be mobile within our communities, whether we can handle our own personal care and household tasks and be involved in employment or voluntary work. How many of us have problems in these areas? What has changed since the last report was published in 1998?

How many are relying on your spouse and family in order to live with your post-polio problems? Is this causing a strain in your family relationships?

A new area we looked at this year is what other health problems do polio survivors have, especially those conditions which are thought to be more common for us than in the general community.

The other issue we have addressed is your experience with falls and your concern about falling.

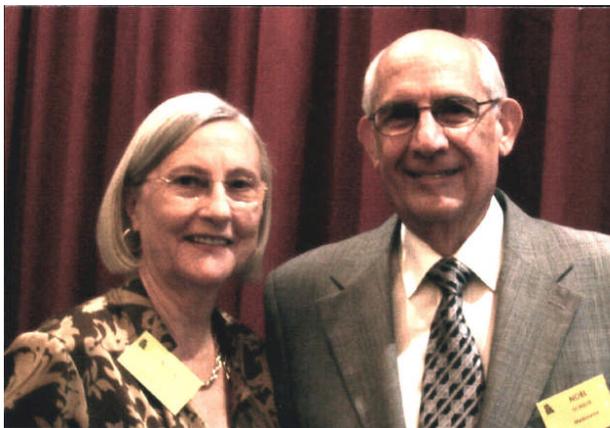
All of these issues are compounded by ageing and we hoped to compare polio survivors with other people of a similar age. This was the purpose for the "parallel" questionnaire which you were also sent. Not as many of these have been received but we have over 200.

**You are encouraged to come along not only to the Annual General Meeting, but to stay after the lunch break to hear Merle give what promises to be a most informative Seminar.**

# Seminar Report – 9 June 2006

## A Journey Through Loss

Report by Mary Westbrook



Cynthia was ably assisted on the day by her husband, Noel  
Photograph: courtesy of Lesley Bromley

On Friday 9 June the Network's third Seminar for 2006 was held at the Northcott Centre. Around 40 members attended a day-long workshop presented by Dr Cynthia Schultz, a Melbourne based psychologist.

Cynthia's research, publications, and community involvement have focused in particular on psychoeducational support-group programs for family caregivers and in loss and grief across the lifespan.

Now a free-lance academic, enjoying creative retirement, Cynthia maintains close links with current extensions of her earlier work, the most recent examples of which are co-authorship with Dr Elizabeth Bruce of the book, *Through Loss*, and of a group-leader training manual in psychological techniques for working with non-finite loss and trauma.

Dr Schultz spoke about life as a journey through loss, how loss shapes our lives and affects our reactions to later losses. Our first exercise was to fill in on a page the main losses of our lives, decade by decade. I was surprised at the pattern of clusters and periods of 'smooth sailing' in my life. The notion of non-finite loss was explored. This type of loss has "*a continuing presence*". Its "*presence can be blatantly obvious or shadowy, but always there – above or below the surface*". Examples may include chronic illness or disability, infertility, migration, sexual abuse, adoption or stillbirth, bereavement and so on. Non-finite grief may be also disenfranchised grief as talked about by Kenneth Doka in his book of this name. He said that disenfranchised grief is "*grief that persons experience when they incur a loss that is not or can not be openly acknowledged, publicly mourned, or socially supported.*" Traditional versus modern day ways of expressing and silencing grief were discussed.

Dr Schultz described the process of grieving as "*an adaptive process involving learning and taking on board a reality that was not expected and is surrounded by a certain dread. Over time, an individual:*

- *searches for the meaning of this loss, gradually recognising that things must change because of this loss;*
- *may begin to see self, spouse, world, child and significant others differently;*
- *discovers discrepancies, and experiences painful tension between what was and what is emerging as a new life;*
- *makes a series of compromises between the wish for 'what was' and 'what might have been' and reality;*
- *draws on and slowly recognises own essence of being: humour, imagination, touch, expressive arts, music, mutuality, self-disclosure, bonds formed in grief – enters a fellowship of shared suffering'.*

After lunch we broke into groups to discuss a list of "*Some questions on life's journey*", for example: Do I look back with satisfaction or regret? What difference has my life made? How might the remaining years be meaningful and of value to others? The final session included open discussion. We touched on creating bridges and building shelters that enable us to cope with grief.

The book "*Through Grief*" by Elizabeth Bruce and Cynthia Schultz (published in Melbourne by ACER Press in 2004) was available for sale at the Seminar for \$25. This provides a way of exploring more deeply some of the issues raised in the workshop. If you missed the workshop you might like to ask your bookseller to order a copy for you.

The quotes in this article come from Cynthia's overheads or from her book.

# David Bodian MD (1910 – 1992) and His Research

Henry Holland MD

*Originally published in POLIO DEJA VIEW, the newsletter of the Central Virginia Post Polio Support Group, and subsequently reprinted in Rancho Los Amigos Post-Polio Support Group Newsletter, January 2003, with permission of the author. Reprinted here with permission.*

For those of you who have read Dr Richard Bruno's recent book, *The Polio Paradox*, you may have noticed that Dr Bruno often cites Dr David Bodian's research on the pathogenesis of polio. Some years ago I went to the Medical College of Virginia medical library and obtained copies of three of Dr Bodian's medical research articles published during the time period of 1949 to 1952. Dr Bodian was a native of St Louis, earned a PhD in anatomy in 1934 and a MD in 1937 from the University of Chicago. He was on the faculty of the School of Medicine of the Johns Hopkins University from 1942 to 1992 at the time of his death. His research in the neuropathology of polio helped lay the groundwork to make possible the development of the Salk and Sabin vaccines. Dr Bodian's team of researchers demonstrated that the poliovirus was transmitted through the mouth and digestive tract and that there were actually three distinct types of polio virus and that antibodies to all three types were carried through the blood stream; thus meaning that a successful vaccine had to protect against all three types of the virus.

One of Dr Bodian's articles that was of particular interest to me was one entitled "*Histopathologic Basis of Clinical Findings in Poliomyelitis*". In this article Dr Bodian's findings are based on the detailed study of the central nervous systems (CNS) of twenty-four human autopsy cases of polio and from studies of experimental polio in monkeys. In the article Dr Bodian made the following statement, "*It is a remarkable fact that even in those non-nervous tissues from which the virus of poliomyelitis may be isolated at autopsy, its effect is so subtle that as yet it cannot be demonstrated by histologic means.*" Those of us who have been experiencing Post-Polio Syndrome often have many "subtle" symptoms, which cannot be demonstrated by histologic means.

Some of Dr Bodian's more interesting findings involve his description of the distribution of the virus in the CNS (brain and spinal cord). He wrote: "*Virus activity, nerve cell changes and inflammatory reaction are localized only in certain susceptible regions of the CNS. Lesions in the cerebral cortex are usually confined to the motor area of the precentral gyrus and the lesions are rarely severe enough to produce clinical symptoms. Encephalitic symptoms such as restlessness, stupor, disorientation, and coma are associated with severe inflammatory reaction in the brain stem. Brain stem centers principally involved in most instances are the reticular formation of the hind brain, the vestibular nuclei, and the roof nuclei of the cerebellum.*" Dr Bodian also made the statement, "*As far as the pathologist is concerned, all cases of poliomyelitis are encephalitic.*" The article also discusses the process of the damage done to motor cells of the spinal cord.

However, I am more interested in what Dr Bodian reported about the brain lesions and cranial nerve lesions. "*In the twenty-four human autopsies there was hardly an individual who did not have lesions, sometimes of a fairly severe degree, in most of the motor nuclei of the cranial nerves as well as in the surrounding reticular formation. Yet clinical signs of paralysis in the corresponding muscles were rarely recorded, except in the face, pharynx, and larynx in bulbar cases.*" Motor weakness in some of the other cranial nerves was often overlooked. This might involve eye muscles, facial muscles, and tongue movement. Dr Bodian also added that the three centers in the brain most often severely affected were the reticular formation, the vestibular nuclei, and the roof nuclei of the cerebellum. Severe

damage of the reticular formation could be fatal. This part of the brain maintains wakefulness. Dr Bodian was surprised that more cases were not fatal because of the reticular formation involvement. He also found that polio deaths due to respiratory failure with no bulbar involvement still demonstrated severe lesions in the reticular formation. The reticular formation can have an affect on respiratory, vasomotor, and swallowing function. There is also the possibility of lesions in the reticular formation causing autonomic dysfunction. Damage in the vestibular nuclei and roof nuclei of the cerebellum rarely produced clinical symptoms, but symptoms of ataxia, vertigo, nausea and vomiting could have been caused by involvement of these areas of the brain. The summation of all of this information is that Dr Bodian concluded that polio involvement of the mid brain, hind brain, and the reticular formation were very common and often severe.

Bodian's research is over fifty years old, but very little research on the pathogenesis of polio has occurred since the development of the vaccines. Many people with PPS are reporting a variety of symptoms in addition to new motor weakness, muscle fatigue, and pain. Some of these symptoms include brain or central fatigue, eye muscle weakness, cardiovascular and pulmonary problems, bladder problems, headache, dizziness, light-headedness, tinnitus, gastrointestinal difficulties and others. Of course, most PPSers are aging and can have numerous medical problems as anyone else in the same age group, but if other causes are ruled out by medical evaluation, then there is the possibility that a variety of symptoms could be explained by PPS. Because of the obvious concentration on motor paralysis and bulbar symptoms of respiratory and swallowing dysfunction, the other areas of polio brain involvement were not identified at the time of the acute polio infection, except at autopsy as described by Dr Bodian. Thus, some of our current symptoms of PPS may be better understood and possibly explained by trying to understand what this virus did in our brains. I believe that the brain fatigue that many PPSers complain about is possibly explained by Dr Bodian's research.

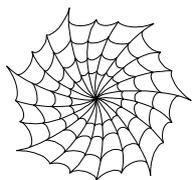
In another article, Dr Bodian concluded that the poliovirus was spread person to person and that the virus initially invaded the alimentary mucosa (gastrointestinal tract) and in some cases invaded the circulatory system resulting in a viremia. Once in the blood stream the virus was able to invade the CNS. Like many researchers, Dr Bodian wondered why some people experienced viremia with the poliovirus and most others did not. What conditions allowed the poliovirus to enter the blood stream? Dr Bodian wrote: *"If it is postulated that virus may penetrate the CNS from the blood stream, it is clear that this penetration is only a rare occurrence among the much greater number of sub clinical infections, so that the reason for this "accident" may be sought perhaps in unusual physiological or pathological circumstances. The possible effects of seasonal factors, of physical activity, of pregnancy, of trauma, or of concurrent infections with other agents on vascular permeability become logical objects of suspicion and curiosity."* How many of you contracted polio after a time of physical activity or exertion, following even minimal trauma, or when already harboring a minor infection?

Many of the mysteries of the damage inflicted by the poliovirus remain unexplained. As a result, some of the mysteries regarding the additional damage inflicted by PPS also remain unexplained.

### **References:**

Bodian, David, *"Histopathologic Basis of Clinical Findings in Poliomyelitis"*, Johns Hopkins University, Baltimore, Maryland; aided by a grant from The National Foundation of Infantile Paralysis, Inc. *American Journal of Medicine*, May 1949.

Bodian, David, *"Reconsideration of Pathogenesis of Polio"*, Johns Hopkins University, Baltimore, Maryland, *American Journal of Hygiene*, November 1952.



*Through Cobwebs each issue, Bill McKee 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.*

Hello again. Work on the new website is proceeding. The design is complete and the content is now being revised, updated and/or added. This is a meticulous and often frustratingly slow process, but we are getting there. We hope to launch the new site by the end of the year.

Regarding other website news, Committee members currently receive a large number of spam emails (akin to junk mail) as a result of having Network email addresses easily accessible via our website (Gillian is implementing processes on the new website to eliminate this problem). One consequence of our need to manage spam by filtering our emails is that messages occasionally don't reach us, especially if they do not have appropriately worded subjects. In this regard, Mary Westbrook usually replies to email enquiries sent to *AskMary* within 48 hours of receipt. If you do not receive a reply within a reasonable time, please send your message again. Alternatively, you can always write to her care of our Office (see page 12 for details).

Until next time, best wishes to you all.



## Voting Process for Network General Meetings

### Neil von Schill

We are very aware that because of health, mobility and the constraints of distance many members cannot participate as fully in Network activities as they may wish. At the Special General Meeting held in June 2005, and separately via a questionnaire posted to everyone, members were given the opportunity to make their views known about how the Network might better involve the membership at large in the election of, and voting for, the Management Committee.

At their April meeting the Management Committee considered a range of options to provide members with greater involvement in the democratic process and election of office bearers. The options considered included full postal voting by the membership, optional postal voting and voting by proxy. Following an informed and frank debate the following resolution was carried *“that Voting by Proxy, with provision for members to instruct their appointed proxy, be made available to members should any position on the Executive or Management Committee be contested at an Annual General Meeting.”*

Accordingly Proxy Voting Forms will be distributed to members early in November with other material relating to the Annual General Meeting to be held at the Northcott Centre on Saturday 25 November 2006. In order for Proxy Voting instructions to be taken into account at the Annual General Meeting they will need to be received at the Network Office at Parramatta, at a date to be advised, prior to the meeting.

If you are unable to be at the Annual General Meeting and you wish to be involved in the electoral process, please keep an eye out for this material.

# Support Group News

**Neil von Schill**

**Support Group Co-ordinator**

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I have curtailed my travelling in recent months following a bout of shingles in April which was obviously sending me a message. I have continued to attend Management Committee meetings in Sydney each month.

There have, however, been things happening which I am pleased to report. The Rotary Districts in Southern NSW have invited our participation in giving the post-polio perspective to their Polio Plus program in the eradication of polio world wide. **David Luck** from the **ACT Support Group** attended a Rotary meeting in Goulburn on 21 August to give Rotarians an insight into the late effects of polio. We thank David very much for his contribution and representation of the Network. We will continue to liaise with this Rotary District and may be involved in a convention later in the year.

Our Convenor in **Port Macquarie**, **Pat Adamson**, has reported that they held a very successful luncheon at the local Golf Club in August. There were 14 members of the Support Group in attendance and they enjoyed lunch and fellowship.

At the end of August the Albury/Wodonga Support Group hosted an information session in Wodonga conducted by **Mary-Ann Liethof**, Polio Officer of the **Victorian Polio Network**. There were over 30 participants in attendance and we hope to recruit some new polio survivors to the local Support Group. There was excellent coverage in the local print media.

The newly formed **Metropolitan Evening Support Group** continues to attract members and is obviously serving a need. The group meets at the **Sydney Rowing Club, Abbotsford** at 6:00 pm on the **first Tuesday of each month**. For enquiries members may contact Convenor, **Maura Outterside**, on (02) 9718 5803.

If you become aware of the death of a member, Convenors, Regional Representatives and members are asked to inform the office so that a card can be sent to the family and adjustments made to the membership register. This allows us to convey condolences and discontinue unwanted correspondence. Your help in this matter will be much appreciated.

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## 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 any member 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 by phone (02) 9747 4694 or email <[ea@post-polionetwork.org.au](mailto:ea@post-polionetwork.org.au)>, and some will be posted out to you.

As mentioned in the last issue of Network News, the links page on our website has been thoroughly overhauled and expanded. The links have also been separated into various categories to make finding appropriate information much easier. One section gives details of Government Allowances, Concessions and Services. While many of the entries there will be familiar to you (for example: Mobility Allowance, Carer Allowance, Mobility Parking Scheme) there may be some services that you weren't previously aware of.

In this issue, I have provided information on some resources for carers. For full details on these and other services and resources for carers (government and non-government), visit our links at <[www.post-polionetwork.org.au/linkmachine/resources/resources\\_sites\\_for\\_carers.html](http://www.post-polionetwork.org.au/linkmachine/resources/resources_sites_for_carers.html)>.

## Commonwealth Carer Resource Centres

Under the National Respite for Carers Program, the Australian Government has funded a Carer Resource Centre in the capital city of each State or Territory. These centres provide information and advice to carers. Commonwealth Carer Resource Centres can assist carers with referrals, counselling, support and resources on a wide range of topics including:

- carer support groups
- home help
- financial entitlements
- support services
- arranging respite

Most of the services provided are free.

### **For further information:**

- Telephone the Carer Resource Centre on Freecall™ 1800 242 636
- View State and Territory carer resource information on the Carers Australia website: <[www.carersaustralia.com.au](http://www.carersaustralia.com.au)>



## Commonwealth Carer Respite Centres

Commonwealth Carer Respite Centres support carers to access respite or “take a break”.

### **The Centres can:**

- provide information and advice about respite options
- help organise emergency or planned respite
- purchase or subsidise short term or emergency respite when needed

### **For further information:**

- Telephone the Carer Respite Centres on Freecall™ 1800 059 059
- <[www.centrelink.gov.au/internet/internet.nsf/services/carers\\_respite\\_centres.htm](http://www.centrelink.gov.au/internet/internet.nsf/services/carers_respite_centres.htm)>

# 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.*



### Polio survivor solves fridge frustrations

US polio survivor John Imre experiences the frustration many wheelchair users encounter from refrigerators. He has invented and patented the *Freedom Fridge*. According to Imre, *dodging the [fridge] door is only the first athletic feat. 'You still cannot reach up the back of the freezer or to the back of the crispers' ... the Freedom Fridge sits horizontally, it's centred on a pedestal and can be raised or lowered to meet a person's height. A motor rotates the shelves until what you want is up front. Jerry Johnson, director of the Center for Innovation and Development at UW-Stout, and some graduate students took the plans and formed it into the real thing. It's clear and partitioned reminding me of rotating vending machine. ... Feasibility studies put the price at \$US1,500 to \$US2,000 for a snazzier model to around \$US900 for a more basic one, Imre said. This is the first phase of the Freedom Fridge's lifespan. They're all waiting to see if their funding request to the Christopher Reeve Foundation will be approved.* (Information and quotes from an article by Mike Moore in *Journal Times*, 4/5/06).

### Hip protectors may not help polio survivors

Hip protectors are specially constructed underpants with pockets on the side for soft energy-absorbing padding or semi-rigid material that diverts forces to the surrounding tissue. Their aim is to prevent hip fractures of the femur if the wearer falls. Polio survivors are at high risk of falls and when they fall they are more likely than others to suffer a fracture particularly as they age. Dr Julie Silver and Dr Anne Gawne's book *Postpolio Syndrome* (2004) says that: *In polio survivors, fall pattern is often related to falling forward because of tripping or knee buckling or falling backward because of lack of balance. Thus the indication for hip protector use in polio survivors may be limited.* They note that people often cease wearing them. Reasons given are: *discomfort, too much effort, skin irritation, incontinence, too difficult to don and doff, and expenses caused by multiple pairs needed for hygiene.* An additional problem for many polio survivors, not mentioned, is that polio survivors often have hips that differ in size and a scoliosis that may make it extremely difficult and uncomfortable to wear these symmetrical close fitting pants. The book suggests that if polio survivors have a tendency to fall sideways protectors might be an option to decrease fracture risk. The *British Medical Journal* (11/03/2006) has recently published a systematic review (by Darker, Gillespie and Gillespie) of all well-designed research studies (14 in all) comparing hip and pelvic fracture rates in elderly people given hip protectors with control groups not given protectors. The BMJ concluded, in its editorial, that: *Accumulating evidence indicates that hip protectors are an ineffective intervention for those living at home and that their effectiveness in an institutional setting is uncertain. It asks: Are we back where we were before hip protectors were invented? Yes, probably – although the accumulated evidence suggests that hip protectors may be effective in specific subgroups of elderly people. Such groups might include highly motivated elderly people living in the community ... Until clinical trials among such groups confirm the effectiveness of hip protectors, the continued use of these devices should not be widely*

*advocated*. So if discussing with your doctor whether hip protectors might help you, you need to consider your falling pattern and whether you can get a pair of protectors that fit properly and comfortably so that you are prepared to wear them regularly. The lack of evidence of their effectiveness and the costs and possible discomfort involved indicate that you need to think carefully about whether hip protectors are for you.

### **A 'good read' with a polio background**

Novelist Elizabeth Berg has recently published a novel, *We are all welcome here*, loosely based on the life of Pat Raming an American who contracted polio when she was 21 and pregnant. She gave birth in an iron lung. Her husband deserted her. After three years in the iron lung she went home as a quadriplegic in a wheelchair using a portable respirator. After raising her daughter Pat returned to college and became an addictions counsellor and disability activist. The novel is set in Mississippi in 1964 at the time of the civil rights movement. The story is told from the viewpoint of Diana, Paige's (the polio survivor) 13 year old daughter. Diana is trying to break free from the authority of her mother and her Black daytime carer, Peacie. Paige battles to survive on welfare and prevent the social worker finding out how much help Diana is providing. Even inadequate carers are hard to find and Paige feels guilt about keeping her child with her. As an adult Diana says, *Despite her many obstacles, what my mother succeeded best in doing was appreciating the many forms of beauty in life — as well as its possibilities. And she relished perhaps more than any other mother could the growth of her daughter, seeing in me a part of herself set free.* Many local libraries have Berg's books.

### **Practical advice about coping with PPS**

*The post-polio experience: psychological insights and coping strategies for polio survivors and their families*, is a recently published book by Margaret Backman, an American clinical psychologist who specialises in helping people cope with chronic illness and disability. It covers the personal and social issues that PPS involves, in short pithy chapters with the main advice in point form. Sections include personal relationships (children, parents, spouses friends, developing new relationships), social encounters (help, the need for boundaries, changing roles), medical care (patient-doctor relationships, being part of the team), mental health (tacking stress, taking charge of your life, surviving in unsettling times) and psychological issues from the polio past such as fear of abandonment, distrust of authority, shame etc. Backman says: *The fact that someone has gone through something before is no reason to assume that it will be easier the second time around, or that the person will have a better understanding of the situation. On the contrary, having to relive the experience — an experience that the individual thought had been put to rest — reawakens anxieties and conflicts that he or she had been able to ignore for years.* The book is for sale on Amazon.com for \$US18.95.

### **Pulitzer Prize for history of polio**

David Oshinsky's book *Polio: An American story*, reviewed in Issue 67 of the Newsletter, has won the 2006 Pulitzer Prize for history for the 61 year old historian at the University of Texas. The Houston Chronicle (19/4/06) quoted Oshinsky as saying the prize is important *because it opens doors in terms of allowing you to write for a larger audience and speak in many more places.* [Ed. It might be of interest that President Bush recently took this book with him as part of his holiday reading (his other two books were about Abraham Lincoln).]

### **Plastic wheelchair for airports**

The French Atomic Energy Commission has developed a non-magnetic wheelchair, the PASS'PORT, made entirely of plastic polymers. It will not set off metal detectors in airports (From Mobility Magazine, 10/05).

## Mothers of unimmunised babies

An article, *Differences in risk factors for partial and no immunisation in the first year of life*, published in the British Journal of Medicine (3/6/06) reported UK research findings on factors associated with poor immunisation status in babies. These included: having a teenage or lone parent, large family size, and residence in disadvantaged areas. The researchers also found that mothers of non-immunised babies tended to be older and more highly qualified. The article concluded that the strategies used to encourage vaccination in socially disadvantaged families such as accessible or home vaccinations, are not likely to promote immunisation among older, more highly educated mothers who reject vaccination. A new approach is needed. These findings are similar to the NSW immunisation rates reported in Particles in December 2003 which were lowest in affluent Sydney suburbs such as Mosman and the eastern suburbs.

## Polio, Autism or Neither?

This was the headline of an article by Ronald Bailey, scientific correspondent of the American journal *Reason* (24 July 2006). Bailey says that the percentage of US children receiving childhood vaccination is dropping and that that *vaccine resisters are more likely to be highly educated and well off financially ... their chief fear is that vaccinations may trigger autism ... Many parents of autistic children fervently believe that the measles-mumps-rubella (MMR) triple vaccine causes autism ... However most research suggests parents are confusing correlation with causation – the symptoms of autism just happen to emerge at about the same time as recommended vaccines are given.* Anti-vaccine activists have also argued that it was the mercury in the vaccine preservative that led to autism.

The relationship between autism and vaccination was first suggested in 1998. Since then numerous research studies have failed to find supporting evidence. In 2005, a comprehensive Cochrane (a non-profit authoritative medical group) review of 31 such studies found *no credible evidence behind claims of harm from MMR vaccination.* Furthermore in 1993 Japan dropped MMR vaccination and began vaccinating for each disease separately but autism rates have risen significantly in Japan since then. Research in Quebec, after the vaccine preservative containing mercury was removed from vaccines, found that the rate of autism rose. Some researchers believe that the rise in autism is *largely the result of physicians applying boarder diagnostic criteria for the condition in recent years.* Others disagree. *The best medical advice is that whatever the cause of autism turns out to be, parents should not let their fears prevent them from immunizing their children.* Unfortunately *many parents are wrongly discounting the dangers that infectious diseases pose for their children because many have never seen a child afflicted with polio or whooping cough.*

## Adults at risk of polio

Increasing numbers of people world-wide are vulnerable to polio because they have never been exposed to the disease according to health experts quoted on the BBC news (27/7/06). *Adults who missed being vaccinated as children and who have not been exposed to the wild virus are most at risk.* In the current epidemic of polio in Namibia, which had been free of polio since 1995, most of those who contracted the disease have been between the ages of 15-45. *In contrast, most polio outbreaks affect children under five. The disease is more likely to cause paralysis in adults. Last month a campaign was launched to immunise the whole population of Namibia against polio. People can develop immunity to the disease by being infected naturally, through vaccination or by catching the live, but weakened, version of the virus which is in the oral vaccine from newly immunised children.* However with the switch from the oral to the safer Salk vaccine in industrialised countries this indirect source of protection for unvaccinated people has ceased.

## Knitting and sand sculpture encourage polio vaccination

Cilla Webster, editor of *The African Connection* (newsletter of the Post-Polio Network RSA, January 2006) has initiated the KNIT / CROCHET FOR POLIO campaign to encourage unemployed and poor families to bring their children to polio vaccination clinics. According to Cilla: *Although the vaccination is free, the transport to the clinics isn't. A knitted garment or blanket encourages those who live in poverty to give up a meal to bring their children to the clinic because they know when the child has been vaccinated they will receive something warm to wear, something they would otherwise not be able to afford. In December 2005 I received a thank you letter to say polio immunisation had gone up 5% in our area which means this campaign is really working.* Cilla's email address is <cilla.webster@scottburgh.co.za>.

Indian artist Sudarsan Patnaik built a large sand sculpture of a mother and child to spread the message of polio eradication. The sculpture which took 36 hours to build was erected on tsunami damaged Pondicherry beach. Watched by thousands the Tourism Secretary unveiled the sculpture using two polio drops.

## 'Warm Springs' available on DVD

In the December 2005 I wrote about this film, which covers the early years of President Roosevelt's life with polio. It was then showing in the US and is now available on DVD in Australia. Having seen it I recommend it highly.

## Guerrilla disabled parking campaigns

Coolz0r, a website blog where people can post their thoughts about marketing and advertising, recently reported an *interesting guerrilla campaign that targets reluctant, good-functioning and abled drivers who keep parking on the wrong place, making it difficult for disabled people to use what's rightfully theirs. The strong language is actually strengthening the message.* Three of the signs which feature the disabled wheelchair symbol can be seen on <<http://blog.coolz0r.com/2006/07/10/your-spine-or-mine>>. One caption reads: *'This parking space is for disabled only. Everyone else: THANK GOD yours is still over there, a bit further'*. Another advises: *'If it's hard to grasp why disabled people need this space, WE SUGGEST: Go and break your f---ing spine'*. One warns: *'MANY OF THOSE [who] used to park here illegally now do so legally. Is fate trying to tell you something?'*

One of the comments posted on the site says that police in several US states have run checks on people parking in disabled spaces illegally. *They found many had criminal charges and arrest warrants following them like tin cans tied behind a 'Just Married' jalopy ... Why such a high percentage? A psychologist speculated that law breakers are law breakers in small things as well as big. The police also found that many of the nasty parkers had only just committed a crime and were in 'I'm bullet proof' mode! Why aren't we brave enough to walk up to these people and ask them about their disability? Because they're probably carrying a gun ... Instead, push a potato up the exhaust pipe ... and run!*

From the blog on the Disability Studies website at Temple University, Philadelphia, I learnt that the signs are translations from a 2004 award winning Latvian campaign by the Riga agency ZOOM. This blog also describes a campaign by the organisation for Equal Rights in Brussels. They place a ticket under the windshields of illegally parked cars which reads: *'YES: I would like to park here again, SO I CHOOSE: amputation left leg, amputation right leg, paraplegia, multiple sclerosis, spina bifida'*. There are boxes to tick.

# One Step – and Then Another

## A Self-Published Memoir

**Joan Mobey**

*Miss Lank and her youngest sister, Patsy, used to take me for walks. They would admonish me, “one step and then another and the longest road is ended”, or encourage me, “walk to the gate-post – the next tuft of grass – the next crack in the pavement – the next ...”, and so I would get on bit by bit.*



Joan Mobey is a long-time Network member who has actively helped pursue our aims. Joan was a driving force behind the establishment of the Network's Support Groups, and led one herself for many years.

Joan celebrated her eightieth birthday earlier this year. In her memoir she recounts her life growing up in Sydney during the 1930s, having contracted polio at the age of three.

The story continues through the decades as the author faces the challenge of establishing a career and family, against the difficulties of the long lasting effects of this disease.

A preview of Joan's book, which includes the first few chapters, is available for download in PDF format from her website at <[www.onestepbook.com](http://www.onestepbook.com)>.

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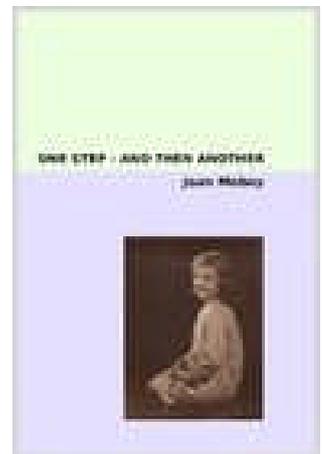
**One Step – and Then Another** is available for \$22 post paid to any address within Australia.

To order, please send a cheque or postal order payable to Joan Mobey, together with the required delivery name and address, to:

Joan Mobey  
PO Box 261  
Glebe NSW 2037

**Enquiries:** Please contact Joan as above, or by email to:  
<[joan@onestepbook.com](mailto:joan@onestepbook.com)>

The book is listed in Books in Print (ISBN number: 978-1-4116-0965-5) so it may also be possible to order it through your local bookshop.



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## Post-Polio Awareness Week : 1 - 7 November

The theme for this year's Post-Polio Awareness Week is *A World Without Polio – We Wish!* This is designed to draw attention to two ideas – the continued existence of polio in some countries and the continued effect of polio on those of us who were 'hit' by it some time ago. The Week is the vehicle for our major publicity drive each year and once again we are seeking your support to make it a success. A poster and brochures in support of the theme will be sent out to all members early in October and we encourage you to distribute them widely throughout your local community. A Press Release will also be available to those willing to speak to the media about their polio story. Watch out for more details in October.



*New member Pat Jensen, Gold Coast, Queensland has accepted our invitation to share her polio story and gives some practical advice along the way. Thank you, Pat!*

I am 67 years old and of slim build. I was born in the UK and when I was 6 years old (1943), I lost the use of my left arm. We were told I had Infantile Paralysis (as it was known then). I was not in an Iron Lung or hospitalized, and initially, my left arm was put into a firm metal brace (similar position to a Traffic Cop stopping traffic!!). I was eventually released from the brace and I received constant physio on my arm. I do remember having a lengthy stay in bed, and my legs being very feeble after that inactive period. As far as I, and family members, can remember, I recovered fully within 1 - 2 years.

Since that time, the only reference I have ever made to the polio problem was that my left arm was very slightly weaker and thinner than my right. I have always lead an active and busy lifestyle – my husband and I renovated houses for a number of years.

Approximately 4 to 5 years ago, I found I was tired after my weekly Tai Chi class and instead of coming home and practicing the moves I had learned that day, I found I was tired and had to sit down and recover. I also started a Yoga class 4 years ago, but found I was absolutely drained of all energy after a session. At first, I just put it down to age and perhaps I was not as active as before, so had become a little unfit. Approximately 3 years ago, I visited my doctor for my usual 2 yearly check and she noticed my leg and arm muscles had deteriorated, so suggested I do weight bearing exercises to build up my muscles. She showed me a “press up” and I told her I would have difficulty doing that exercise, as I had had polio as a child and that arm would not take my weight comfortably. She immediately told me I had Post Polio Syndrome and told me to contact our local Clinic. I had no idea what she was talking about, having not even given my previous polio problem a thought in 58 years or so. She did extensive tests to eliminate any other cause of the dreadful fatigue.

My doctor sent me to a Respiratory Specialist to have my breathing muscles checked out – they were slightly weaker than they should be but would not cause a problem. She sent me to a Sleep Disorder Clinic and we found that if I sleep on my back (as I always have done in the past), I have extreme obstructive sleep apnoea. At this Clinic I was not tested sleeping on my side and my doctor was not satisfied so she sent me to another Clinic for that test and we found that my breathing and oxygen levels were normal. I now sleep 100% on my side at night, with a timber (foam wrapped) wedge at my back to prevent me from turning onto my back. I also have a bodymate pillow to keep my bony knees and ankles apart!! I now have reasonably comfortable nights. The first Clinic had me back in for another night to trial a CPAP Machine, so my doctor's insistence on a further test saved me having to use a machine to sleep with. I do strongly suggest that should a member have to undergo a test for sleep apnoea that they ensure they are also tested sleeping on their side as well as their back. The Sleep Clinic said I did not fit the usual pattern of sleep apnoea sufferers, as I do not snore and I am of very slight build.

My doctor also sent me to a Neurologist at that time for further tests. My left arm is thinner than my right and about half strength. We also found that my leg muscles were originally affected by the polio (although I was unaware of that fact all my life). I had a follow-up test with him last year (2 year interval) and apparently whilst my left arm has deteriorated slightly, my right arm and legs show no deterioration at all.

I have a programme of exercise: walk 10 to 12 minutes each day – 1 hour of Tai Chi once per week – 40 minutes mediation and 30 minutes stretching exercises once per week. I did have 30 minutes of hydrotherapy exercise per week, but have recently stopped that class,

as although the exercise was great for my muscles and joints, I found the hot water exceptionally tiring and the physiotherapist taking the class felt it was doing me more harm than good, as I was completely drained after a session.

It has probably taken me at least 2 years to accept that my lifestyle has had to change and I do not have the energy that friends of my age have. I have always led a very active life and the tiredness has curtailed that a lot, but I am extremely lucky to have a very understanding and supportive husband, and a doctor who, although she was ignorant of post-polio facts initially, has absorbed every bit of information I have been able to pass on to her. I also have a physiotherapist who checks my exercise routine and my progress each 6 months.

*South Australian member Lyn Lillecrapp got in touch recently to respond to Nick Costin's long-held desire for he and his wife to "join the 'Grey Nomads' for a year or so and wander around our beautiful country" and his concern that post-polio limitations might mean they were unable to complete this treasured ambition.*

I've just received the recent "Network News" - as usual, excellent reading!

I was particularly interested in the "Post-Polio Post" page (24) and paragraph 3. I don't remember Nick Costin's original letter in Issue 67, it was probably not applicable to me at the time, but since then has become so. Last year I decided that "the time had come, the Walrus said, to think of other things", resigned from work, packed my tent and camping gear and became a "Wheelie Grey Nomad", and from July to September spent my days driving, camping, etc, from Adelaide to Daintree Rain Forest (only "the wettest dry season for many years" stopped me getting further north), then back inland to Carnarvon Gorge, back to and down the east coast to Brisbane and then home inland, and ... had one absolute ball!! Further trips – up to Uluru and the Flinders later this year, then next year across The Nullarbor and up the west coast are already in the planning stage. (All this by myself, not one moment's trouble in the 12,000 kms travelled and met some really nice folks).

So, just to encourage Nick, and other Wheelies, it can be done - many caravan parks and even State Forests now have wheelchair facilities. Roll on the Wheelies!!

I'll be happy for you to pass on my contact details to Nick if he wants them – I might be able to give him some tips and trips.

*Queensland member Amy Zelmer has written about the importance of having an Advanced Care Directive (also known as an Advanced Health Directive or Living Will) in place. You can learn more about Advanced Care Directives around Australia at the Australian Divisions of General Practice Website, here <[www.adgp.com.au/site/index.cfm?display=4207](http://www.adgp.com.au/site/index.cfm?display=4207)>.*

I'm writing in response to the item "Polio survivors pressured to sign do-not-resuscitate orders" which appeared on page 20 of *Network News* – Issue 70 – April 2006.

The item, based on experience in the USA (but perhaps not very different here in Australia), indicated that many polio survivors felt that they were being pressured into signing "do not resuscitate" orders when they went into hospital.

While this might be true in some situations, I think that there may also be another explanation – and one to which everyone (including polio survivors) might want to give attention.

Most countries and states now have legal provisions such that a competent adult can sign a legal document which indicates to carers (both in hospital and in the community) the

patient's wishes with regards to various kinds of treatment – everything from the use of antibiotics to artificial feeding, intravenous and oxygen. Since the rules and regulations vary from state to state I won't attempt to go into them here, but I would encourage everyone to find out what is required for an "advance health directive" (sometimes called a "living will") in the state in which they are resident, and to make sure that they have put a directive in place – and discussed the issues with their family. In Queensland copies of a blank advance health directive are available at the Post Office.

The "advance health directive" might easily be confused (particularly under conditions of stress) as a "do not resuscitate" but the advance health directive has a much wider range of directions to carers – and provides many more safeguards for the individual.

In many places it is also possible for an individual to appoint someone with an "enduring power of attorney for personal/health matters", so that someone in whom you have confidence can make decisions for you if you are not able to. Again, requirements vary from state to state.

We have all read of the appalling situations which arise when family members and carers are NOT aware of what the individual would like in the way of care – putting it in writing well ahead of any need for the document can remove stress from families, carers and the individual concerned.

I hope this information will not only relieve some anxiety, but also help polio survivors and others take steps so that their wishes with regard to care are known and respected.



## Convention on the Rights of People with Disabilities

### Australian Human Rights and Equal Opportunity Commission

#### Media Release – 26 August 2006

A United Nations committee today completed drafting on a convention on the rights of people with disabilities. If adopted by the General Assembly next year, it will be the first Human Rights Convention this century and join seven other core human rights conventions.

Human Rights and Disability Discrimination Commissioner Graeme Innes, in New York as part of the Australian delegation, said: "*This is a landmark event for the 600 million people with disabilities around the world. It will establish a benchmark for non-discrimination and inclusion of people with disabilities into society.*"

The Convention recognises equality for people with disabilities in areas such as employment, education, and access to community facilities and the built environment.

The Australian government has participated in all negotiating sessions of the working group.

*"I have been very proud of the positive contribution which Australia has made to this process",* Mr Innes said. *"Government input has been positive and constructive, and our community organisations have played an outstanding role",* he said.

*"I encourage the Government to quickly ratify the Convention when it is passed by the UN and continue its commitment to equality for people with disabilities."*

# 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 requiring 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 2799, North Parramatta NSW 1750) or email us ([office@post-polionetwork.org.au](mailto:office@post-polionetwork.org.au)) – what ever you feel comfortable with.



# Post-Polio Network Seminar Program 2006 / 2007

<b>Saturday 16 September</b>	Hornsby RSL Club 4 High Street Hornsby	<b>A Man With a Mission</b> presented by <b>Bill Bradley</b> <i>Full details on page 2</i>
<b>Saturday 25 November</b>	Northcott Society 1 Fennell Street Parramatta	<b>Annual General Meeting and Seminar PPN Research Project – What We Learned</b> presented by <b>Merle Thompson</b> <i>Further details on page 14</i>
<b>Saturday 3 March 2007</b>	Northcott Society 1 Fennell Street Parramatta	<b>Seminar</b> the Presenter and Topic to be advised <i>Further details in upcoming issues of Network News</i>
<b>June 2007</b>	“The Tradies” 57 Manchester Road Gymea	<b>Seminar</b> the Presenter and Topic to be advised <i>Further details in upcoming issues of Network News</i>
<b>September 2007</b>	Ballina Northern NSW	<b>Biennial Country Conference</b> the Presenters and Topics to be advised <i>Further details in upcoming issues of Network News</i>

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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.

<b>Books etc (* indicates Post-Polio Network publication)</b>	<b>Size</b>	<b>Cost</b>
<i>Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome</i> edited by Lauro S Halstead MD ( <i>see description below</i> 📄)	240 pages	\$25.00 <i>plus 10% GST</i>
<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 <i>1st copy free</i>
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 <i>plus \$1 postage</i>

### 📄 ***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:

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