

POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

Welcome to new members and regular readers. I hope you enjoy this bumper issue of *Network News*.

The Seminar on *Osteoporosis – General and Regional* at the Burwood RSL Club on 17 November 2007 was most informative. The speaker was Dr Rory Clifton-Bligh, a Research Fellow at the Kolling Institute of Medical Research, Royal North Shore Hospital, and a Senior Lecturer in the Faculty of Medicine, University of Sydney. Although numbers attending were down somewhat, those who came along were treated to an excellent presentation which contained much of relevance to polio survivors. Dr Clifton-Bligh has promised to provide an article on osteoporosis for the benefit of those members unable to travel to the Seminar, and it is hoped that his article will arrive in time for the next issue.

At the Network's nineteenth Annual General Meeting (AGM) held on 12 December 2007 the following members were elected to the Management Committee:

Gillian Thomas	President	Ron Goodwin
Merle Thompson	Vice-President	Bing Kwong Mak
Neil von Schill	Secretary	Rebecca Phillips
(position unfilled)	Treasurer	Len Smith

As you can see, we did not manage to fill all available positions but were pleased to welcome Rebecca and Len to our ranks. We ask you to consider if you can give some time to the Network this year by contributing your skills and experience to the Committee. For the Network to remain viable the Committee must be adequately skilled and we need to spread our considerable workload more widely than is presently possible.

Our Treasurer, Bob Tonazzi, resigned from the Committee effective 31 August 2007. Bob had given dedicated service to the Network in this role since 2002 and paid scrupulous attention to his duties. His expertise is sorely missed. Unfortunately, at the AGM the Treasurer's position remained unfilled and I am currently acting in the role until we can find a replacement. We urge a member with bookkeeping or accounting experience to step forward and help out. Please get in touch with me if you can fill any of the five Committee vacancies.

Also in August the Committee lost the services of Anne Buchanan, our long-standing Publicity Officer, due to a change in her work conditions. Anne has given stalwart service to the Network since elected to the Committee in 1997. Her commitment to widely advertising Seminars and to organising and promoting our annual *Post-Polio Awareness Week* has introduced many new members to the Network. We greatly miss Anne's good-humoured input to the Committee from her perspective as the carer of Gary, her husband and polio survivor.

Four Committee Members decided not to re-stand at the AGM due to ill health and declining stamina: Bill McKee, Maura Outterside, Alice Smart and Mary Westbrook. Bill has acted as the Network's Webmaster since he first joined the Committee at the 2004 AGM. Although Bill has decided to take some time out from Committee duties he is continuing as Webmaster at least until June so his talents are not totally lost to us. Maura had not been well throughout 2007 and we appreciate the time that she was able to give to the Committee since 2004. Alice is well known to all who attend Seminars and help at mail-outs. Alice had served on the Committee since 1995 and has been a invaluable assistant to me over recent years, despite her steadily declining health. Alice is still hoping to get to Seminars and to continue her involvement with mail-outs and *Post-Polio Awareness Week* as her health permits. Last, but by no means least, Mary Westbrook no longer has the stamina to be an active Committee member. Mary has served on the Committee for many of the last nineteen years and the Network would have been a much poorer organisation without her participation. We were very sorry to lose her extensive post-polio knowledge and wise counsel in Committee deliberations but we look forward to seeing Mary at Seminars and are delighted that she will continue to assist people with their post-polio queries via AskMary and to contribute her excellent *Polio Particles* series to *Network News*.

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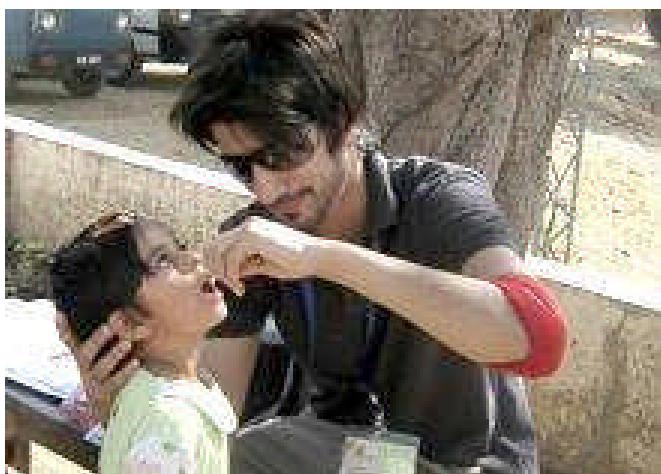
Australia's First Case of Wild Polio Since 1986 - An Update

Regular readers will recall from a recent issue of *Network News* that a national Public Health Alert was issued last July by Australia's Chief Medical Officer, Professor John Horvath, after Victorian health authorities reported the first case of wild polio in this country since 1986. Media around the country quickly picked up the story, reporting that "A 22-year-old Pakistani student is being treated in isolation at Melbourne's Box Hill Hospital, after he fell ill with polio earlier this month following a visit to Pakistan."

At the time, Victoria's chief health officer Dr John Carnie said test results on 13 July 2007 confirmed that the man, who was admitted on 7 July to Box Hill Hospital, in Melbourne's north-east, had the viral disease. "*Test results tonight from the National Polio virus Reference Laboratory in Melbourne confirmed the presence of the polio virus. ... [The man] will be kept in isolation as a precautionary measure until he returns successive negative test results for polio. ... The doctors at Box Hill Hospital have to be congratulated because this is a disease that has not been seen in Australia for many years and yet they were able to make a clinical diagnosis that has been backed up by laboratory tests,*" Dr Carnie said.

The student, Zaheer Ahmed, was released from hospital on 9 August 2007. On their website <www.rotary.org> Rotary reported: *Melbourne-area Rotarians reacted promptly to support Ahmed's recovery after learning about his case from fellow Australian Rotarian Jenny Horton, who works in Pakistan as a consultant for the World Health Organization on the Global Polio Eradication Initiative. Because the student's clothing had been confiscated when he went into quarantine, arrangements were made to provide him with new clothes. Jennifer Coburn, of the Rotary Club of Mont Albert & Surrey Hills, visited the patient in isolation after verifying her own polio immunisation. She brought Ahmed books, puzzles, and the daily newspaper. "This is a definite and very easy way to assist a person in need of support," said Coburn, noting how far the student was from his family and the intense media scrutiny he'd been under after the alert was issued. "He is really delighted that he is receiving support from Rotary. The need for human interaction is so important."*

In December, Rotary gave another update: "*When Zaheer 'Zak' Ahmed finally returned to Pakistan, after being diagnosed with polio and enduring weeks of isolation in Australia, one of the first things he did was sign up for a National Immunization Day. Ahmed's was the first case of polio diagnosed in Australia in 21 years, so he knows firsthand that until polio is eradicated worldwide, it has the potential to strike virtually anywhere. While a student in Australia, Ahmed contracted polio after a visit home to Pakistan – one of four remaining endemic countries, along with Afghanistan, India, and Nigeria. When he returned again to Pakistan after being treated, he contacted Rotarian Jenny Horton in Islamabad, who works as technical consultant for the World Health Organization. She helped him get involved with local immunization activities.*"



Ahmed participated in a five-day immunisation campaign, held in October, which reached 32.2 million children.

It included three National Immunization Days and two mop-up days, with health care workers and volunteers going door to door to administer the vaccine.

Pictured left: Ahmed immunizes a child in Pakistan

Polio - The Living Legacy - Executive Summary

Network Vice-President Merle Thompson's comprehensive research report "Polio – the living legacy", subtitled "Ten years on – A new assessment of the impact of the late effects of polio on the lives of polio survivors", has now been published. Merle had conducted the painstaking research over two years and has previously made presentations on the evolving results at the Network's Annual General Meeting in November 2006 and at the Polio Australasia "Designing a Future" Conference in May 2007 (where delegates from all Post-Polio Networks in Australia and New Zealand were in attendance). The research was supported by a grant from the Australian Seniors Foundation, but printing of the resultant report has largely been funded from the Network's own resources which means that initially only a limited print run has been possible. As well as making the required statutory deposits, copies have been distributed free of charge to the other state Networks and to the New Zealand Post Polio Support Society, the Australian Seniors Foundation, research associates, appropriate health professionals, and to relevant members of the Federal and State Governments and Oppositions. A number of copies have also been purchased by libraries throughout Australia.

The report's Executive Summary follows, which should whet your appetites to read the complete report (over 150 pages). At this time, a limited number of copies are available for sale to members on a cost-recovery basis. If there is sufficient interest from members a further print run will be organised. To order your copy, please write to the Network's Office enclosing a cheque/postal order for \$50 (which includes postage and GST).

In 1998 the Post-Polio Network conducted a survey of its members. The information obtained was extremely valuable in providing a greater understanding of the level of restrictions and difficulties experienced by members in their daily lives. It enabled officers to speak with authority on these issues and provided resources for use when conducting training programs for people such as health professionals and home care workers.

The data contained in that Report was gathered during the previous 2 years and is, therefore, 8 to 10 years old. The desire for up-to-date and additional information on the post-polio experience of Network members and the continuing membership of so many people made it possible to have a study which built on and added to the information obtained in the earlier study.

This research provides an unusual and valuable opportunity for comparison between two studies which had many of the participants in common and in which many of the issues addressed were the same.

The current research aimed:

- to obtain up-to-date information on a range of issues which were assessed in the earlier report;
- to see if respondents consider that their difficulties have increased over the past ten years;
- to re-consider those factors which were of particular concern in the previous study, namely having to retire early due to polio-related difficulties and the reliance of survivors on family and carers for assistance with daily living;
- to assess matters which had been raised by other researchers as well as other factors which had not been assessed in the 1998 research.

Methodology

A 12-page questionnaire was developed to cover these areas. This was mailed to all full members of the Post-Polio Network (NSW) Inc as at March 2006, that is, those members who have had polio. This totalled 863 members. The response rate was 56.7%.

Some of the issues which the research aimed to assess are also relevant to other older members of the community, such as reliance on family and carers, who are also ageing, and experience of falls. This was a factor in obtaining funding from the Seniors' Foundation.

A parallel questionnaire was developed in order to be able to compare polio survivors with other 'senior' people. This was to be completed by a friend or relative who is of the same sex and similar age to the polio survivor.

Changes Over 10 Years

The survey asked participants in the polio survey to respond to questions which covered similar topics to those covered in the Network's 1998 research. This provided both up-to-date information in each of these areas, often of a more detailed nature, and also the opportunity to compare response profiles with the earlier research.

The fact that many of the respondents also participated in the 1998 research, and that many of the factors assessed are similar, means that comparisons of ratings on similar items are more likely to be valid than comparisons with other research projects.

For many items respondents were also asked to indicate whether the specific activity had become more difficult for them over the last ten years.

Statistical data

The data obtained from the questionnaires is shown in a series of tables and graphs with associated written analysis and comments on the implications of the findings. In some areas the responses of the polio group are differentiated for age and/or gender. For some items data was also assessed in relation to other factors such as the interval from initial polio illness to the onset of the late effects, the age at the time of the initial illness and the year of polio illness.

In addition, the responses of the polio and parallel groups are compared. In some aspects of the sections on the problem of falls, comparison is also made with a study conducted by the University of New South Wales (UNSW). Reference was also made to other research about the late effects of polio, both in Australia and overseas.

A study of the response patterns indicated that, despite the complexity of the questionnaire, Network members had put considerable thought into their responses.

Biographical information

The proportion of females to males was 60.5% to 38.1%, a similar ratio to that of the Post-Polio Network membership. The average age of those who stated their age was 66.3, with a range of 38 to 95 years.

The year in which they contracted polio ranged from 1916 to 1980, with the highest numbers being in the years of major epidemics, that is 1937–38, 1945–46 and 1950–55. The community perception is that polio is a disease of young children but, while 70% were under the age of 10 at the time of the initial illness, 35 (7%) were between 21 and 30, and 8 respondents (2%) were over 30.

The average age of the parallel group was 65.1 years, with a gender ratio similar to the polio group.

The Late Effects of Polio

Respondents were asked to indicate whether they experience those symptoms which are generally regarded as being involved in the late effects of polio or Post Polio Syndrome and to specify whether the problem has been on-going for over 10 years without increased severity, has been on-going for over 10 years with increased severity in that time, or is new during that period.

The responses confirmed that the nominated 15 symptoms are all relevant in the late effects of polio and that those experienced by the greatest number of respondents are also those which have been identified previously as of major significance by a wide range of researchers. They show that almost all polio survivors experience the debilitating problems of muscle weakness (92%) and fatigue (89%).

It was also seen that at least 64% report, in order of frequency, muscle pain, joint pain, sensitivity to cold, muscle atrophy, tendency to fall, sleep problems and muscle cramps. More than half experience muscle twitching and problems with finding words. The other listed symptoms – breathing difficulties, headaches, change in voice and swallowing difficulties – were reported by between 37% and 43%.

The number of symptoms which individual survivors experience was assessed and 10% of respondents reported having all 15 symptoms. The average number was 9.2 symptoms. There was little variation between males and females or between the responses within age groups.

The interval between the initial polio illness and the onset of the new problems of the late effects of polio was also studied. For around 14% the onset was less than 30 years after the initial illness. This development was between 30 and 39 years for about 30% and over 40 years for more than 40%.

While these conditions may be exacerbated by ageing, they are not directly age related as most difficulties are experienced across the full age range of participants, with younger respondents experiencing many problems equally, or even at a greater rate, than older participants, and sooner than would be considered to be the result of ageing in the general population. It is also apparent that many of these difficulties have increased over the past ten years.

Difficulties with Personal Living

Participants provided information on a number of aspects of personal life including personal care, undertaking household tasks, mobility and transport, exercise and, for the polio group, their use of aids and appliances.

Since the average age is over 60, it could be anticipated that participants' natural ageing would mean that they would experience the same problems in living as others of their age. The parallel survey enabled comparisons to be made between the polio group and a non-polio group. It cannot be assumed that the parallel group is a fully representative sample of the general population of a similar age range to the polio group but it is large enough to enable inferences to be made.

It is apparent throughout the survey that the majority of polio survivors have significant problems in handling many aspects of daily life, although there is a great deal of variance in the level of their difficulties. It was seen that many in the parallel group also have difficulties in daily living, especially with transport, household tasks, personal care and falls. In general these are not experienced by as large a proportion of this group as of the polio group.

In the Home: The number of respondents who live in assisted accommodation is very small, particularly when the age range is taken into account. Over 90% of both groups live in independent houses or units/villas or in retirement villages without assistance.

In the course of daily life, the ability to attend to personal care, to undertake household tasks, prepare meals and to shop influences one's independence and the possible need to rely on others.

For 24% of the polio group even walking around the home is difficult.

Only a very small number of this group find specific personal care activities impossible but at least a quarter of participants, who can manage to care for themselves, find it difficult to do so. This particularly applies to having a bath/shower. Overall at least a quarter reported an increased level of difficulty in personal care.

Similarly, only a few people find the most essential daily activities of preparing meals and basic housekeeping impossible but many have varying levels of difficulty in doing so. Apart from light household tasks, such as washing up, and cooking snack meals, which could be managed by two-thirds of respondents, all tasks in the home and garden present problems.

Again, at least a quarter of respondents reported increased difficulty over the past ten years for each item and some more demanding activities, such as heavy housework, major shopping and gardening, have become more difficult for larger proportions of respondents.

The parallel group were only asked whether they need assistance with these activities. Only 3% reported having difficulty. Getting dressed and showering were the most difficult.

In view of the above difficulties it would be expected that many participants would use professional or community services. However, only 28% of polio respondents use such services. Predominantly the services used are for housework, gardening and home maintenance. Only a small number use services such as personal care and bed changing. With the exception of housework, where a greater number have Homecare, most assistance is fully or partially self-funded. Some do not access services because they do not wish to do so but many are unable to do so. They may not be eligible for Government funded services or they find the cost of self-funded services prohibitive or suitable providers are not available. For those who do have assistance many report that the level has increased in recent years.

In the parallel group 17% reported that they access services.

Reliance on Family: In the Network's 1998 report it was noted that respondents' comments showed that many polio survivors were reliant on their family and, in particular, their spouse, in order to manage many aspects of daily living. This raised concern that, as many of their spouses are also ageing, they, as a family unit, might not be able to manage in future, particularly if the spouse became ill.

This concern is substantially endorsed as 62% receive assistance from family members and, of these, two thirds do not receive any other assistance. For 21% of all participants their carer has become less able to provide care, with ageing and their own medical problems being the main reasons. Over a quarter of participants live alone, including some who have difficulty managing personal care.

While only 14% consider that the need for the provision of care has caused a strain in their relationship, the written comments describe some very difficult situations. This was also the case for some of the polio survivors (15%) who provide care for others.

About a third of participants think they will need more assistance within a few years but only 14% think they will need to change their living arrangements.

In the parallel group 65% do not need assistance. For those who do, assistance is mainly provided by the spouse then a son/daughter. The percentage of respondents who say that the provision of care has caused a strain in their relationship is marginally higher than in the polio group but a smaller proportion stated that they will need to change their living arrangements or have more assistance.

Mobility and Exercise: The fact that many respondents have considerable difficulty in personal mobility is evident from their reports of inability to handle a number of specific aspects of walking. Activities which do not generally present difficulty to most people are demanding for polio survivors with 14% reporting that they cannot walk or are very restricted in the ability to do so. As the aspects of walking become more demanding fewer can manage without difficulty with, at best, 40% reporting no difficulty with the task.

Many respondents have found these activities to have become more difficult in the last 10 years, even for those who said that the activity does not cause them any problems. Up to two thirds indicated that individual activities have become more difficult.

For some participants the limitations in mobility have developed more recently with the onset of the late effects of polio. Of those who now report that they cannot walk, 20 indicated in the Exercise section that they had previously undertaken strenuous activity or demanding sport during their years of maximum recovery. At least 89 whose past activity was at that high level now have some degree of difficulty climbing stairs.

Others have had restrictions since their initial illness. Fifty-one percent indicated that they could undertake a lot less physical activity than other people of their age during their period of maximum recovery.

Despite their difficulties more than half stated that they undertake some form of regular exercise. Many have innovative approaches to exercise and at least 40% include at least some non-walking exercise. Professional opinion varies on the advisability of exercise for polio survivors but consensus is that exercise should not lead to excessive pain and fatigue but only 24% have a prescribed program.

Tiring is a significant factor. For both walking and exercise, over 60% of polio respondents report being restricted by tiring.

Transport: The ability to drive oneself and to use public and private transport is necessary to participate in community life. In the polio group a number commented that they had never been able to use public transport or could no longer do so. Fewer than 30% indicated that they can use buses, trains and ferries without difficulty or the need for assistance and over a third have found using public transport has become more difficult in recent years. In the later section *Worry about Falls*, nervousness regarding crossing roads and using public transport emphasises how transport issues can restrict one's life.

While 80% say that they still drive a car, only 35% can get into or out of a vehicle without difficulty or assistance and only 42% can be a passenger in a car without difficulty. Ten percent have special modifications or wheelchair/scooter lifts but others have found the cost prohibitive.

Respondents to the parallel questionnaire are generally more able to walk and use public transport than the polio group but a significantly high number of 23% indicated that they are restricted in the ability to walk and 20% cannot use public transport without difficulty or assistance.

Health and Medical: The majority of participants have check-ups with their general practitioner. Of the other health professionals listed, podiatrists and physiotherapists were the services most often used by polio survivors but very few of the parallel group accessed

such services. Medical screening programs were accessed by significant proportions of both the polio and parallel groups, particularly for breast, prostate and cervical cancer and for diabetes.

Over 80% of participants in the polio group rely on at least one appliance and 12% use at least 6 appliances. Many have found their need to use aids has increased, particularly with mobility aids. The lack of availability of appropriate and/or affordable appliances is a source of difficulty for members as is the distance to, and accessibility of, suppliers.

Polio respondents nominated the non-prescription medications which they use and the major usage was of proprietary pain and arthritis medications and dietary supplements. Very few used what might be termed alternative medications.

It has been conjectured that a number of medical conditions, in addition to those regarded as being late effects of polio, are more prevalent among polio survivors than in the general community. The problems which were experienced by the most respondents were difficulty with memory for words and names (62%), depression (47%), being overweight (46%), and a range of sleep problems (total 74%). A number of other conditions were also reported frequently – oesophageal reflux problems, swallowing difficulty, urinary problems, carpal tunnel syndrome, osteoporosis, osteoarthritis and scoliosis.

Only 4% of participants said that they are current smokers and 30% are former smokers, while 55% have never smoked.

Employment and Financial Matters: Only 24% of respondents indicated that they are in paid employment or are self-employed. The need to retire early because of polio-related problems was noted in the Network's 1998 survey and this factor is confirmed in the current survey. Overall 122 people indicated that their retirement was at least partly resulting from polio-related problems, more than half of whom are in their 50s or less. Others had reduced their hours of work because of their polio-related problems, including some who were only in their 40s and 50s.

The age pension and self-funded superannuation are the major other sources of income. Only 13% have a disability pension. The number of respondents who receive a Mobility Allowance or whose carer receives the Carer's Allowance is less than might be expected. While all aspects of income were not studied, it seems likely that many members have financial limitations.

The Problem of Falls: A tendency to fall is an important symptom of the late effects of polio and falls are regarded as a major issue for older people generally. Two sections of the questionnaires asked respondents to indicate aspects of their experiences with falling and their nervousness about falls.

There was very little difference between males and females but a study in age groups revealed some interesting patterns with younger participants having had as many or more falls than in the older groups.

In the polio group 66%, and in the parallel group 44%, indicated that they had fallen during the past five years. Among those who had fallen, 81% of the polio group and 58% of the parallel group reported having fallen in the past year, with some reporting large numbers of falls. The UNSW figure was 37%.

Participants' nervousness about falling was assessed. Only 11% of the polio group and 47% of the parallel group did not have any fear of falling. On the other end of the 5-level scale 15% of the polio group and 3% of the parallel group were 'extremely' nervous. In the UNSW study 42% said that they were 'not at all' nervous and only 2% 'extremely' nervous.

Respondents were also asked to rate their concern about falling in a number of specific circumstances. Confidence in undertaking activities without falling varied according to the nature of the activity, with those within the home generally being regarded as safer. Both groups considered using public transport and crossing roads as of most concern.

General impressions from respondents' written comments on the issues studied

Comments throughout the survey revealed some recurring and contradictory themes among the polio group. These included:

- The need to be 'normal' has been a significant factor in the lives of many respondents.
- An approach to life which embraces learning to live with one's physical limitations and make the most of life.
- Lack of willingness to accept help or even to acknowledge the need for it.
- A view of life which puts responsibility on oneself.
- Optimism to deal with future problems.
- Love, commitment and mutual caring within many families which has enabled them to face problems.
- Difficulties which appear insurmountable for a small number of respondents.
- Isolation and/or separation from families for some.
- Lack of care and understanding in a minority of families.

FAMILY AND CARER PARTICIPATION

An innovation in this survey was the provision of an opportunity for family members and carers to write comments on the polio survivors' experiences and their effect on their relationship and their lives in general. These provide a revealing insight and elucidate both the high and low points of the life of polio survivors and their families.

CONCLUSION

The legacy of polio for those who contracted it, and for those who are significant in their lives, can be clearly seen in the responses of the survivors to the survey questions and in their and their families' comments. The overall picture is of a group of people who have many personal physical limitations and many difficulties in handling daily live.

The experiences of survey participants endorse the relevance of those symptoms which have been identified in previous research and in clinical practice as being indicative of Post Polio Syndrome and the late effects of polio.

From a social perspective of the lives of polio survivors, especially when considering their current and future needs, theoretical distinction between Post Polio Syndrome and the late effects of polio and the application of different clinical diagnoses seem artificial and even irrelevant.

It is important to highlight the diverse patterns of symptoms and difficulties experienced by individuals and to focus on the problems with which survivors have to contend and the impact of these difficulties on their lives. It is essential that there be understanding of the totality of the person's needs and to ensure that rigid diagnoses do not impair access to services.

It is apparent from the parallel survey that many non-polio people have difficulties in daily living, especially with transport, household tasks, personal care and falls but these are not experienced by as large a proportion of this group as of the polio group.

PPS Forum

by Richard Louis Bruno, December 2007 (excerpted from *New Mobility Magazine*)

Dr Richard Bruno is director of The Post-Polio Institute at Englewood Hospital and Medical Center. You can email him at <postpolioinfo@aol.com>.



Fatigue decreased 27 percent with Provigil, but by 43 percent with the inactive placebo

After a wait of more than a dozen years, the US government study of modafinil (Provigil) for treatment of post-polio fatigue has been published. But wait! There's more. The University of Alberta beat the Americans and published their own study of modafinil and post-polio fatigue. Does Provigil reduce post-polio fatigue, you eagerly ask? Well, that depends on whether you read the actual study or listen to the author's interview about the study. Let's start in Canada, where cooler heads prevail.

Researchers at the University of Alberta gave 14 polio survivors reporting moderate to severe fatigue 200 mg of Provigil or placebo twice a day for five weeks. Half took Provigil first and then the inactive placebo; the other half took placebo first. Anxiety and dry mouth were reported by 60 percent of the subjects on Provigil during the first days of treatment, so they likely knew they were on the drug. Subjects completed fatigue and sleepiness scales, plus memory and reaction time tests, before the study and at weekly intervals.

Fatigue decreased 27 percent with Provigil but by 43 percent with the inactive placebo, not exactly a ringing endorsement. However, neither this difference, nor smaller differences on the other test scores, were statistically significantly different between Provigil and placebo. The authors note that Provigil is thought to affect neurons that are responsible for wakefulness, not those in the brain stem's reticular activating system that "bore the brunt" of the damage done by the poliovirus. The authors conclude that the damaged brain activating neurons responsible for post-polio fatigue are not affected by the drug, which is why "*Provigil was not effective in alleviating the symptoms of fatigue*" in polio survivors.

In the US study, 33 polio survivors who had had paralytic polio and reported at least moderate fatigue received 200 mg of Provigil or placebo twice a day for six weeks, with a two-week "wash out" between drug and placebo. Subjects completed three fatigue severity scales and the *Short-Form Health Survey* before and after the study. There were no statistically significant differences between Provigil or placebo on any of these measures, with the American authors concluding that "*Provigil was not superior to placebo in reducing self-reported fatigue or improving quality of life*" in polio survivors, stating "*our results validate*" the Canadian study.

But, then, the US authors strangely wrote that Provigil "*appears ineffective in most polio survivors with PPS. We say most because, despite the overall negative results of our study, a considerable fraction (22) of the 33 subjects reported benefit*". Provigil had no effect on 11 standardized tests of fatigue, health and well-being, yet 22 subjects "*reported benefit*"? That's like saying subjects taking a new blood pressure-lowering drug "*reported benefit*" even though their actual measured blood pressure didn't decrease.

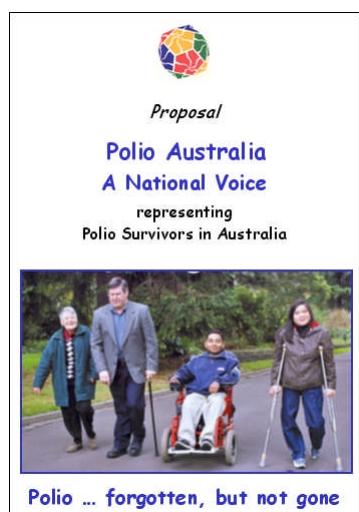
One reason 22 of the subjects “reported benefit” may have been that 13 of them reportedly guessed correctly that they were taking Provigil. What’s more, 41 percent reported benefit when taking placebo, an unusually large placebo effect. The authors grudgingly admit, “*The magnitude of a placebo effect on the outcome measures used in our study was not considered during the design, representing a possible shortcoming*”. That “possible shortcoming” invalidates 60 percent of the so-called “reported benefit”.

However, in a wire-service article headlined, “*Provigil may have limited effect on some patients with post-polio fatigue*”, the study’s lead author states that “despite the overall negative results of our study” an “*after-study analysis (revealed) that nearly half of the patients in our trial improved substantially*”. If that were true, why wasn’t the substantial improvement published in the journal article, instead of the “*overall negative results*”? The author also stated that a “*significant proportion of polio survivors in the community may actually benefit from a low daily dose (100 mg) of Provigil*”. If the study data show that 400 mg had *no significant effect* on fatigue, why put people on only 100 mg? The author concluded, “*the negative results of our study should be considered with caution. Several factors could be involved, including a high placebo effect or the faulty selection of patients*”.

Indeed, consider with caution any study that has a “high placebo effect” and “overall negative results” where the author presents the results of a positive “*after-study analysis*” in the media, instead of publishing them in a medical journal.

Polio Australia - A National Voice For Polio Survivors

While the establishment of Polio Australia has not been moving at lightning speed, nevertheless considerable effort has been put into the work required and progress is being made.



During August/September a comprehensive submission was prepared detailing the aims and goals of Polio Australia and seeking funding to achieve them. Letters of Support from all state Networks were included, together with a short history of each Network and their achievements, background information about polio and its late effects, and a discussion on the best-practice approaches to the management of the late effects. Federal funding of \$1 million over four years was sought to establish Polio Australia and help achieve its goals. On 12 September, Gillian Thomas, Neil von Schill and Peter Garde in company with retired Senator Dr John Tierney spent an exhausting day in Canberra presenting the submission to various government and opposition Members of Parliament in meetings expertly arranged by John. Naturally, the purse strings were not magically opened on the day, but we received some valuable feedback about how to fine-tune and further focus our funding submission; work on this is proceeding,

Pictured above: The submission cover. Thanks to Polio Network Victoria for permitting use of their eloquent poster.

A pre-requisite to obtaining funding is that Polio Australia be an incorporated body, which requires that a Constitution first be developed and agreed to by all the Networks. We were fortunate to have access to the *Alzheimer's Australia* Constitution as a starting point, as their national organisation has a similar structure to that of Polio Australia as decided upon by the states. Following a number of email discussions to hone the drafts, a phone link-up in late January involving all state Networks aimed to iron out the few remaining wrinkles and the Constitution is now close to being finalised.

Polio Australia is also working on raising its profile as opportunities arise. For example, we took advantage of the Treasurer’s call for community input into the new Federal Government’s first budget by providing our perspective on the ongoing unmet needs of polio survivors. Similarly, a submission is currently in preparation for the *Australia 2020 Summit* to be held in April. Updates about Polio Australia will continue to be provided in *Network News*.

Mia Vacanza in Italia !

This is part one of a fascinating report by member Anne O'Halloran on her long-dreamed-of holiday to Italy – proving once again that “where there's a will there's a way”!

A dream come true? A dicey adventure? A personal challenge? My last big travel experience? With the exception of the last question, I have decided that all these describe my recent journeys and stays in the cities of Perugia and Florence in Italy.

Why Perugia?

Over 40 years ago a school friend and I had decided to learn to converse in the Italian language. We attended classes in the city once a week for two years and learned the basics however there was little opportunity for the regular practice and use of the language so after two years other interests took over. But I have always remembered one evening at our Italian class, when one of our fellow students arrived back after many months absence. She waltzed into the class and immediately was conversing fluently (my perception) with our teacher ... she had arrived back from a place called Perugia in Italy where she attended the Universita per Stranieri (University for Foreigners) and had been studying the Italian language there. At once I wanted to do that!

The years went by (about 44 to be exact!) with other life decisions and responsibilities taking priority. Then in May 2006 an insignificant advertisement appeared in the Travel section of the *Sydney Morning Herald* ... to travel to, and to learn the Italian language in, the Italian city of Perugia, well known for its special University for Foreigners and giving a contact email address.

So started my journey with the plan to live and enrol at the University in Perugia for four weeks. I made contact with the advertiser and did much research via the internet about Perugia, accommodation, best times to be there, and transport. I read of Perugia's description as a hill-top town and discovered that the classes were four hours per day, five days per week, with a three hour siesta break in the middle. Knowing I would probably be in an introductory class which was held on the outskirts of the old town centre and which would mean much walking up and down steep slopes four times a day, or remain seven hours in a building when I could be discovering other aspects of the city, made me change my plans. I decided to spend two weeks in Perugia, two weeks in Florence, and two nights in Rome, and to use the Italian I had learned all those years ago, practising via tape in the car on a regular basis. Then I could spend my days in Italy mixing, communicating and enjoying being “one of them” as well as sitting at alfresco restaurants or bars (bars have a different connotation than in Australia) and soaking in all that Perugia and now Florence has to offer.

Flights in economy were booked with Emirates Airlines. I wanted to keep my baggage to a minimum so invested in a large bag on 4 wheels which allowed me to carry, on the level top, my spare calliper and second crutch as well as providing a good support while walking. Assistance at all airports had been booked. (I was flying both ways via Dubai where I had two stopovers). As well I had an aisle seat close to Business Class and so was a short distance from the cabin door and the toilets.

This was really my first trip so far away when I had needed this degree of assistance (twenty-eight years ago I had visited Italy and needed nothing special in the way of assistance), so while readers may already have experienced what I am writing it was a new encounter for me. I cannot speak highly enough of the service at all the airports and on board the planes. However my only objection (in my head/heart?) was a feeling of loss of independence in that the efficiency of the service was such that I felt a bit phoney having

people hand over my passport and talk for me and so on. I was able to reconcile the feeling though when I realised how this efficiency was helping me conserve energy to use in more creative experiences.

My stay in Dubai was brief, however I found the heat – 45° – unbearable and getting on and off the tourist buses difficult ... that first step is soooo high now. What I saw of Dubai impressed me ... the multi storey buildings built on what was once desert. There were green gardens throughout the city (they rely on desalination for their water). It was a very modern place and the residents mainly depend on cars for transport – oil is cheap but according to our guide this will run out in approximately ten to fifteen years; that is why they are building Dubai as a tourist ‘Mecca’. Already Dubai attracts many tourists from Europe and Emirates (the national airline) is adding more cities to its destinations.

For accommodation in Dubai I had requested a room with shower that was not over a bath (I always carry a non-slip mat with me when I travel). After much searching for this request, I found Novotel catered for those who use wheelchairs and provided straight access to the shower. This was to be my room, however as Terry Fletcher well knows from her research and work with Standards Australia, the use of the shower needed much juggling for those who are ambulant with aids, because the drainage for the shower was well away from the rose outlet and consequently water covered the floor. A nightmare for people on crutches or walking sticks, or even senior people who might not be as firm on their feet as those younger. Thank heavens for the six white towels that were provided which became ‘sponges’ to absorb the water and allowed me to walk with crutches, if very carefully, on them.

I found the assistance for people with disabilities very efficient at Dubai airport which is huge, though I really didn’t take to the special room they provided for people with special needs and to where I was taken while awaiting my flight. I usually informed the personnel at the desk and then took myself off to have a browse.

Next stop Rome – Fiumicino Airport – after a six hour flight from Dubai. Then a four hour trip in the coach to Perugia which left outside the airport. The coach ran once a day. The coach was soon filled with locals as well as students from the USA who were planning to study Italian at the University in Perugia.

(I won’t go into travelogues of the places I visited; rather I’ll concentrate on access issues and experiences that meant something for me and I hope will be of interest to the reader).

Perugia at last after 44 years!!! Or, to be exact – Ponte San Giovanni (coach stop), twenty-five minutes from Perugia city. I had booked via the internet to stay in a B&B in a semi-rural area called *Casa di Anna* (after its owner). I was picked up by Gigi (Gigi had come to Italy from the Philippines and had learned English at school so was a great help to Anna). *Casa di Anna* was a 17th century home that Anna had been renovating for 25 years. It was a three-storey residence with a staircase without any handrails! I had requested a private bathroom and level access and I was being accommodated in a newer smaller building which housed a museum of collectibles and extra accommodation. It was built in keeping with the old home, brick floor and a large wooden door with a giant key and huge wooden ceiling beams. My part in what Anna called “the Dependence” (funny, I was quite independent there) was self-contained and when I saw the little bathroom I was “over the moon”, non-slip material on the floor of the recess, easy reach from recess to hand basin where I could leave my towel, I could use the window ledge next to the toilet to assist manoeuvring on/off the bowl. I found hooks which were easily reachable to attach my clothes line. To use the bidet though I would have needed to be a gymnast. The bathroom would not have been good for someone who used a wheelchair full-time.

Anna, the lady of the Casa, spoke minimal English which meant I was able to converse, ever hesitatingly, in Italian. I had wanted to try this so my dreams seemed to be falling into place. Anna, through Gigi, had told me by email that there was a pulmino (a small bus like our community buses) which stopped at her front gates and went to Perugia Centro (CBD) several times a day and made the return journey as well. It was easy for me to access the pulmino and we had the same driver every day – Paula – who knew the best place for everyone to get on or off, especially in wet weather. She even took different routes when people rang her from home and wanted her service for just that morning. I got to know Paula and I took opportunities to use the basic Italian that I had been memorising for months. I have to tell you the trip into town was just beautiful, along narrow lanes the width of one mini-bus where one or other of the drivers had to pull up onto the verge to let the other past. Many of the laneways had become avenues of summer-leaved trees and their foliage met in the middle forming a covered way. I was told they flowered later in the month and perfumed the area. I felt overawed by the beauty of the drive. Every here and there were small roadside devotional shrines of a religious nature. These looked as if they were tended to regularly with fresh flowers and cleaning.

Perugia city (not as I know cities) would be like one of our large NSW country towns. Cars with permits were the only vehicles allowed into some city streets. The buses were all in special bus areas. The streets (*via* or *corso*) were wide and cobbled but in Perugia the cobbles were not the small type as in Rome, rather they were large, what I would describe as 'pavers' but still very old so I found them easier to walk on than I was anticipating. Not having to watch traffic was a plus (especially as it comes the opposite way to traffic in Australia) and one could walk down the centre of, say, Corso Vanucci (the main street) taking time to stop, look around, take photos and then make for the nearest *alfresco* coffee bar and order a cappuccino with a delicious 'weight watchers' (of course) Italian pastry while I enjoyed a bit of sun and watched the 'passing parade'.



Piazza dell'Repubblica off Corso Vanucci, Perugia, Italia

While in Perugia I made visits as well to towns nearby such as Assisi, Gubbio and Spelo. Anna from the B&B introduced me to good friends who offered to drive me to a couple of places and I travelled by local bus to the others.

I became very familiar with using their local buses. I was educated in their use by Gigi and Anna, that is, tickets for use on the buses in Italy are not sold on the bus. There are no conductors either. I bought bus tickets at a tobacconist in the street or at a magazine/newspaper stand. Each ticket is valid for 70 minutes and can be used on as many rides/buses as you like within the 70 minutes. The tickets are validated with date and time in a machine on the bus. Inspectors can check tickets at any time and if not valid or not validated a fine is imposed. In Perugia one ticket cost €1, the equivalent to about \$A1.62 when I was there. The pulmino operated in the same way.

I was able to find toilets with disabled access off the main street of Perugia and at one of the bus stations. I am sure there were others as well.

I saw people using wheelchairs; some looked as if they were visitors and I noticed the senior people used a single forearm crutch in preference to a walking stick. I thought the crutch may give better stability on the cobbles or 'pavers'. I used a single crutch in Perugia. The time came for me to travel on to Florence (*Firenze*) and I had been advised by Anna that the coach would probably be easier than the train. One oversight on my part (I really think I had over-estimated my physical capabilities) was that, while I had organised my stays in Italy, I thought travel between towns/cities would be easy to organise from there. I was to leave Perugia on Wednesday 13 June. When I went to book a seat on the coach, I found out the coach from Perugia to Firenze didn't run on Wednesdays! So the train it was, and thank goodness for that!

Gigi accompanied me to book a train seat, she allowed me to try communicating my needs in Italian however she came to my aid when I asked was there any assistance to help me lift my large bag onto the train (I found it wasn't so much trying to speak in Italian, my difficulty was understanding when the person replied fairly swiftly and probably using colloquialisms that had not been included in my tape!). *Assistenza! Si!*

The woman in ticket sales directed us to a gentleman in an office who was so very helpful. He organised for a special attendant with a wheelchair (*una sedia rotella*) to be available on the Wednesday morning at Perugia station, he booked my seat, then faxed details to *SMN Stazione Firenze* (Florence main station) and advised me there would be someone to meet me there to help with my bag and a wheelchair to take me to a taxi!!!

At the station in Perugia the platform was not level with the train door however that was overcome by a strong but careful push on my "backside" and an extra arm under mine, while I was pulling myself up the ladder type steps to the door!

Brava Assistenzaclientidisabili!

By the way the email address for disabled assistance on trains in Italy is <assistenzaclientidisabili.fi@trenitalia.it>.

In the next episode I will continue my adventures in Italy ... in Firenze.

To be continued ...

Post-Polio Network Office Co-ordinator's Report

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**George Laszuk
Office Co-ordinator**

Greetings from the staff and volunteers at the Parramatta Office, we hope you are all keeping well.

The Office has been very busy lately because of the added responsibilities such as banking, keeping financial records up to date, and entering data into our accounting software *Mind Your Own Business* (MYOB). This change is due to the resignation of our Treasurer last August with the position remaining unfilled at the Annual General Meeting in December. Most of us in the Office needed training in these areas and fortunately for us Gillian has the necessary financial skills and experience which she has been able to pass on to us, and to deal with queries as they arise.

If any members have ever thought about joining the Management Committee this would be a great time as there are a few vacancies available. The Committee meets on the third Wednesday of each non-Seminar month at the centrally-located Burwood RSL Club, between 11 am and 2 pm. As you know, the Committee has a vital role in governing the Network and it is important that we fill the Committee vacancies so the existing members are not overloaded especially as they also work towards the establishment of Polio Australia.

For your information the roster in the office has changed slightly. Apart from my regular spot on Mondays you will find me in the Office on various other days of the week as I train and keep in regular contact with all our volunteers as well as ensure the Office is staffed whenever someone can't come in or is on leave.

Monday	Tuesday	Wednesday	Thursday	Friday
Ray & George	Nola	Carlie & Shylie	Noelene	Carlie & Shylie

I hope to catch up with you in person at a Seminar later this year – the Committee has arranged a very interesting program to look forward to in 2008.

Please Check Your Address Sheet - Are You Financial ?

Thank you to the many members who have renewed your 2007/2008 membership. However, if your address sheet still reads "Renewal Due on 1 July 2007" (or an even earlier year), we have not yet received your membership renewal. In that case you will find another copy of your Renewal Form enclosed. Please send in the Renewal Form and your outstanding membership subscription as soon as possible. If you don't wish to renew, please let us know. The Network is self-funded and needs your continued support to enable us, in turn, to support polio survivors and their families.



Speak up – Be heard

IDEAS NSW is proud to present their latest expo to be held in Queanbeyan in May this year. The Expo titled IDEAS Expo 2008 *Speak Up – Be Heard* is to raise awareness and promote the development of advocacy in the Southern Highlands region.

It will be the perfect opportunity to explore and learn more about the range of organisations, services and equipment available to you. With over 40 companies and organisations represented and on display this is an opportunity for you to find out who and what is available to support and assist you when needed.

The Expo will be held at the Queanbeyan Conference Centre in Crawford Street, Queanbeyan, which is a very centrally located venue with plenty of parking nearby.

Opening times will be :

Thursday 22 May 2008 – from 12 noon to 5 pm

Friday 23 May 2008 – from 9 am to 4 pm

Saturday 24 May 2008 – from 9 am – 12 noon

A range of education workshops will be held in conjunction with the Expo at a venue across the road – the Queanbeyan Community Centre. Initial interest to run workshops has come from Public Guardian; NSW Ombudsman - Community Services Division; Intellectual Disability Rights Service and Family Planning NSW.

Visit the IDEAS website <www.ideas.org.au> for further details on exhibitors and the range of workshops as they come to hand or call them on 1800 029904 to be added to their mailing list and kept up to date with details of the event.

For further details please contact Diana Palmer at IDEAS on 1800 029 904.

FALLING

by Margaret Bennie (*Network member from Albury*)

It was a bright sunny October day when I left the library, pulling a trolley of books behind me with one hand and my walking stick in my other. Children were frolicking all over the lawn near the library. Loud music was playing, there were clowns on stilts, balloons, and face painters. It must be a children's picnic I thought.



After having my right arm operated on for a rotator cuff injury eight weeks before, I had just got it out of the sling and it felt good using both of my arms again. Next thing I know is that my nose is buried deep into some lush green grass. My right foot had gone into a small hole.

The pain from my toes to my knee was excruciating, and I could feel my ankle immediately starting to swell. A man came and turned me over and all I saw was a sea of faces young and old staring down at me. '*Oh my god*', I thought. '*Please earth, swallow me up.*'

Two men stood me up, as I screamed, '*be careful of my shoulder, I've just had it operated on, and I've got a gammy left leg.*' They took me a few paces to a chair. You wouldn't believe it; I had fallen right next to the St John Ambulance Van. On top of this they noticed the wound on my right arm. I had burnt it badly on the oven door that morning, when I was baking bread. The bandage I put on had come off in the fall.

The St John Ambulance people had gathered around me now and were all very eager to help. By this time the pain in my foot was starting to make me swoon. I began to tell them all about my polio, the operation on my arm, and how walking was going to be hard with a sprained ankle. Then on top of this I started to tell them how to bake bread! I could hear myself talking sixty to the dozen. '*Stop babbling*' I thought to myself.

All had quizzical looks on their faces. With a gammy leg, swollen foot, sore shoulder and bad burn on my arm, plus a trolley full of books, what did they think of me? The mind boggles doesn't it? They expertly bandaged my ankle and covered the wound on my arm for me. They were very kind and made sure a family member picked me up.

It took a while for my ankle to heal as I had torn a tendon. My shoulder is now okay. One thing I have noticed is that whenever I am in one of these situations I tend to laugh. We can either laugh or cry and I wasn't going to cry in front of all those people.

Support Group News

Neil von Schill

Support Group Co-ordinator

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This year promises to be another busy year for many of our Support Group members. Through my further involvement with the *Physical Disability Council of NSW* we are designing a questionnaire which will survey the needs of people who are ageing with a disability. The data collected from this survey will be taken directly to the *Department of Ageing and Disability* for inclusion in future planning. We are hopeful that this may bring results which are beneficial to our members.

Already members of the **Albury/Wodonga Support Group** have participated in a trial of the survey and their involvement will help us fine tune the final version. I am very grateful to members for their valuable feedback.

On Saturday 12 April members of the **Northern Rivers Support Group** will have the opportunity to contribute to the survey. We are meeting at **Lismore Workers Club** at 1:30 pm where members will receive an update on Network activities and complete the survey. There will also be a breakfast meeting at **Ballina RSL Club** on Sunday 13 April for those who cannot be in Lismore.

The **ACT Support Group** has agreed to change their meeting date to **Saturday 24 May** so that I can address the meeting on upcoming events and present the survey. Members are asked to keep an eye out for notification of these arrangements.

Early in February I travelled to **Wagga Wagga** to be involved in their first meeting for the new year. At this meeting members agreed to host the **Country Conference** which will be held in Wagga Wagga during **September 2009**. The Wagga Wagga group will also be involved in completing the survey a little later in the year.

I had the great delight of catching up with an old friend and Network member, **Val Pierce**, when I was in **Hay** in early March. Val keeps track of happenings through *Network News* which she enjoys reading and has also been to Melbourne to see Dr Stephen de Graaff.

During the Network's **June Seminar** which will be held at the **Ryde-Eastwood Leagues Club** I will also present the survey for metropolitan members who may wish to participate. There will be other meetings which I have not yet planned and other opportunities for members to contribute to the survey. I am hoping to complete the gathering of data by the end of June.

In the second half of the year we plan to hold an **Inaugural Meeting** to form a Support Group in the **Greater Tamworth Area**. I am pleased to advise that **Ron and Jeanette Smith** have very kindly undertaken to convene the group. Watch this space for further advice.

Finally, please read on for a wrap up of the very successful **Country Conference** which was held in **Ballina** last September. Until next time!

Country Conference - Ballina - September 2007

Neil von Schill

The Country Conference in 2007 was hosted by the *Northern Rivers Support Group* and held in Ballina on Saturday 15 September 2007. We enjoyed glorious North Coast weather at the Ballina RSL Club on the banks of the Richmond River. The venue was superb and the response from members was excellent.

There were over 70 participants in attendance with a very encouraging response from the local area by people who had read the advertising and came along to see what the day had to offer. We also had intrepid travellers from all over the state who heeded the call to come to Ballina. People travelled from the Victorian border, the Southern Highlands and the Sydney metropolitan area. From the north we had representatives from Brisbane and southern Queensland as well as the northern border region. It was gratifying to see people cross the divide and travel from the west of the state including friends from Tamworth.

The *Northern Rivers Support Group* organised a quality program of speakers and supporting activities. Despite our keynote speaker having to withdraw at the eleventh hour because of a family crisis, the program presented was a credit to the organising committee. With the help and co-operation of Ballina RSL staff the support group mounted an excellent display of polio memorabilia which was clearly visible in a window in the entry foyer. Across the road, a large banner promoting the Conference adorned the Club's car park. Special mention must be made of the assistance and quality service that was provided by the management and staff of Ballina RSL Club and a letter of thanks has been forwarded to the General Manager.

Proceedings began with a welcome address from Northern Rivers member, John Heaton, and his comments set the tone for the remainder of the day. Opening remarks were provided by Mrs Ann Aboud, a psychologist now living in Brisbane and the mother of a local doctor. When Ann contracted polio as a child she learned how fortuitous it was that her father was a doctor and her mother a nursing sister! Of further interest in her polio story was that a decade earlier her father had been asked to review Sister Elizabeth Kenny's treatment. He reported favourably. Later, he wrote the anatomy chapter of Sister Kenny's book and she paid tribute to his balanced and scientific review of her work in the introduction. It was therefore not surprising that Ann received the Kenny treatment regime.

Our first Conference presenter was Craig Knox, a physiotherapist from Lismore Base Hospital, who spoke on *Orthopaedic Surgery Recovery and the Polio Patient*. Craig prepared an excellent presentation based on his first-hand experience in assisting polio patients in their recovery phase following orthopaedic surgery. So impressed were members of the Management Committee present in Ballina that we have invited Craig back to speak at the June Seminar in Sydney at the Ryde/Eastwood Leagues Club.

Following Craig we heard pharmacist, Karen Kennedy, who spoke on medications commonly used by polio survivors. Karen brought a wealth of pharmacological experience to her talk having a very varied history in the pharmacy field. Her previous involvements included teaching pharmacy at the Victorian College of Pharmacy, twelve years serving with the Army Reserve, as well as stints in retail pharmacy and her current position in the dispensary at Lismore Base Hospital. Karen's talk focused on the medications commonly used by polio survivors including pain medication and anti-inflammatory drugs. She discussed their main uses and the limitations of various drugs.

At lunch time we were treated to a live singing performance by a local group *The Messengers* led by member Elizabeth Brand. The group's extensive repertoire of folk songs held the audience enthralled.

After a wonderful lunch our next speaker was fittingly a nutritionist! Richard Grzegrzulka is a clinical dietitian who works with *Ballina Community Health* specialising in community nutrition, school education programs and aboriginal health. He spoke on *Nutrition for Polio Survivors* emphasising the basics of good nutrition practice for healthy living. He provided a very valuable handout on diet which will be published in full in the next *Network News*.

Our final speaker for the day was Mrs Val Kwong, a well known and respected natural remedies expert from Lismore. Val spoke on *Natural Remedies and Herbs for Physical Well Being*. She focused on many herbs which are readily available in the local environment and how they can be used to enhance our physical condition. She had samples of some of her suggestions which participants were able to try. Her presentation was again very well received.

In the morning session Gillian and I updated participants on the Network's history and directions and the establishment of Polio Australia. Members of the *Northern Rivers Support Group* had a very professional day-long display of some of their artistic wares including paintings, art, craft and photography.

The Management Committee also took the opportunity during the day's proceedings to present a *Certificate of Appreciation* to Fae Mortimer for her dedicated service and contribution to the Post-Polio Network. Fae has played a stalwart role in the *Northern Rivers Support Group* for many years.

In the evening a number of participants attended a production of the local theatre group *Ballina Players* who presented the play *Cosi* which was thoroughly enjoyed by those present. Some other members gathered for dinner at the RSL Club. On Sunday morning a farewell breakfast was held at Ballina RSL Club overlooking the beautiful Richmond River and more good fare was enjoyed by all.

Special thanks must go to Rosalie Kennedy, Convenor of the *Northern Rivers Support Group*, and her organising committee. They devoted twelve months and many meetings to arranging a memorable and very informative Conference. Thanks also to Helen Moore for her great photographic record of the day.



Rosalie Kennedy (front, left of centre) leads a round of applause from an appreciative audience



Neil von Schill presenting the *Certificate of Appreciation* to an over-whelmed Fae Mortimer

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.



Osteoporosis rates among polio survivors

'Osteoporosis in a postpolio clinic population', a report of Canadian research by Dr Muriel Haziza and colleagues, appeared in the journal, *Archives of Physical Medicine and Rehabilitation* in August 2007. The authors reviewed charts of 379 current patients at a Montreal clinic and studied the 164 patients who had had bone density tests of the lumbar spine and a hip. Muscle strength testing of patients' legs had also been carried out. The researchers found that osteoporosis of the spine was less common than osteoporosis of the hip; 32% of men tested had osteoporosis of the hip but only 10% were affected in the spine. Among post-menopausal women osteoporosis of the hip was present in 27% of cases and of the spine in 11%. (Among the small sample of pre-menopausal women the rates of osteoporosis were 9% for the hip and 6% for the spine). Thus osteoporosis was regional rather than generalised among the majority of these polio survivors. A significant relationship was found between bone density of the hip and muscle strength of the associated leg. Participants with osteoporosis of the hip had weaker leg muscles than other patients in the study. The weaker that patients' leg muscles were, the more likely they were to have osteoporosis of that hip. When the rates of osteoporosis of these polio survivors were compared with the Canadian population rates (which are 4.8% for men and 7.9% for post-menopausal women), the rate was higher among survivors. How representative are these findings of the post-polio population? The authors point out that the patients who had been sent for bone density testing were weaker than those who had not been referred so were probably somewhat more likely to have osteoporosis. However, about 19% of survivors who had bone density scans, had had them performed only on their stronger hip. So if they only had osteoporosis in their weaker hip this would not have been apparent in their bone scans and they would have been assessed as not having osteoporosis. The authors recommend that when having bone density tests *all post-polio patients be evaluated for osteoporosis at both hips (or less preferably at the hip of the weaker lower extremity) and at the lumbar spine.*

Exotic crutches

LemonAid Crutches of Colorado is the place to visit at <www.lemonaidcrutches.com> if you want to make your crutches a fashion item. The company was founded by Laurie Johnson after a plane crash which killed her husband and son and left her using crutches. To cheer herself up she had her crutches professionally painted and used gorgeous designer fabrics to make padded covers for the tops and hand grips. As Laurie says, *No one wants to be on crutches. They hurt your hands, they hurt your arms and they certainly hurt your sense of style. Many have tried to tackle the challenge of adding comfort to an uncomfortable item, but duct tape and washcloths look ... well ... tacky. That's why we created designer crutchware that's not only comfortable, but fun and fabulous looking.* The hundreds of possible combinations of colour and fabrics available are organised around six themes, Safari Adventure (various animal print fabrics), Asian Inspiration (exotic silks), Arctic Warmth, American Energy, British Tradition and Island Inspiration. You can purchase short or longer matching bags that attach to the hand grip of the crutch and several sets of

covers to mix and match with your wardrobe.

Purchases can be made online. However Canadian (forearm) crutches are not available at LemonAid. Try <www.fetterman-crutches.com> for these and some interesting crutch design innovations. LemonAid.com is worth a visit even if you don't need or plan to buy and it may give you ideas for smartening up your appliances.

Disability in popular songs

A unique listing of songs performed or written by or about people with disabilities has been developed by Anthony Tusler on his website <www.aboutdisability.com>. In the *Tuscaloosa News* (7/10/07) Susan Swartz wrote about some of his collection. *Remember the song 'Save the last dance for me', and how the man tells the woman to go ahead and dance as long as they leave together at the end of the night? ... It's a romantic snapshot. She dances. He watches. And when the music's over, they put their arms around each other and go home. The songwriter was Doc Pomus, a blues singer who had polio and used crutches and a wheelchair. His wife was a Broadway actress who liked going out on the town. Tulser, who's been in a wheelchair since he was injured as a kid, considers the song real poetry. 'He [Pomus] talks about something universal that men don't usually voice. He discloses that he feels vulnerable. But the part that really gets me is how he says with complete certainty that he knows she'll go home with him. I love his confidence'.* Mention is also made of DuBose Heyward who had polio as a child and wrote *Porgy*, a novel about a disabled man which George Gershwin used as the basis for the opera *Porgy and Bess*.

Buying petrol in Delaware

Many of us face the hassles of having to drive miles to a service station which provides driveway service (and where petrol costs are higher than at most service stations) or waiting until we have a friend with us in the car who can fill up. In Delaware it is law that all fuel retailers provide petrol for people with disabilities at the self-service rate. Service stations with only one worker who operates the pumps from a remote location are exempt from providing driveway service. A new law has been approved by the government which requires self-service stations to install at least one calling device that will allow disabled drivers to call for assistance. Some people say disabled drivers should just honk their horn but visits to a number of Delaware service stations showed that no one paid any attention to honks (from an article by JL Miller in *The News Journal*, 13/6/07).

Governor with polio has access problem

The new lieutenant-governor of Ontario, David Onley, is a polio survivor who uses leg braces and a scooter. According to *The Star* (12/7/07): *Under the Ontarian Human Rights Act, people with disabilities have the legal right to access premises with dignity and without impediment. But in order to access his own suite of offices at Queen's Park, David Onley ... will have to use a side door and go through the administrative cafeteria. It is a perfect symbol of the issues still facing the 1.5 million disabled Ontarians.*

Polio murder case update

Last issue we reported on the murder charge laid against American Dr Charles Mercer for murdering his wife in 1968. The death was blamed on polio despite the disease almost having been eliminated at that time and much evidence suggesting murder. However the judge trying the case has thrown it out of court, ruling that *the passage of almost four decades and the loss of files and evidence make it impossible to proceed. The County Prosecutor plans to challenge the ruling.* (*Free Press, Michigan*, 6/8/07)

Israeli polio survivors block Jerusalem

There has been much recent publicity given by polio support group newsletters to the decision of the Israeli government to compensate polio survivors for the fact that the Israeli government in the early years of the state failed to provide adequate vaccination. Many Israeli polio survivors were also harmed by experimental surgery. The new law, passed in March 2007, provided a lump sum and life-time monthly payments depending of survivors' degree of disability. However in July the *Jerusalem Post* (18/7/07) reported that the Finance Ministry intended to cancel the law. On August 5th the *Post* told how *hundreds of polio victims demonstrated on Jerusalem's Rehov Shazar in front of the Central Bus Station Sunday morning, blocking the roads into the city.*



Blogger Franne Golan (<http://gimpsopinionsfromthenorth.blogspot.com/>) who took part in the demonstration was irate: *our criminal government is trying to get out of it [payment]. For that alone I think they should be sent to prison, or given polio themselves ... Our fearless Prime Minister is so scared of a bunch of cripples in wheelies that he brought in police and anti terror back up to protect himself from us. On second thought maybe he was right. We can be a dangerous bunch when we get going. ... In the end it was decided to make a partial payment to the polio people, but we might well be back to make them hand over the rest.*

Ed. Subsequent to this report, Mary-ann Liethof (Polio Network Victoria) received an update from Jacob Surany of the Association of Polio Patients in Israel who advised: "I would like to update you that on August 12th 2007, an agreement was reached between the government and the Association of the polio victims in Israel whereby the Polio Law will not change except that the lump sum payment will be paid in two yearly instalments linked to the cost of living index. The first instalment will follow the approval of the claim, and the second one a year after. The government committed to the full implementation of the Polio Law. At the beginning of September 2007, the claims file will be ready for submitting to the Social Security and hopefully most of the polio victims will start to get the benefits."

If you are interested in finding out more about *The Polio Victims Compensation Law 2007* and details of the compensation available to Israel's polio survivors, you can visit the website of the *National Insurance Institute of Israel* <www.btl.gov.il> (click on "Benefits" then on "Compensation for polio victims"). It is a great result for Israel's polio survivors!

Polio vaccine team beaten up

On August 9th 2007 the Pakistani paper *Dawn* reported that a team of health workers administering Sabin vaccine to children in the village of Charmang near the Afghan border were attacked. *The assailants manhandled the health workers and damaged vaccine kits. The health workers later said they were kept hostage for more than four hours. After the attack, the administration suspended the vaccination program for an indefinite period.*

Muslim clerics roped in to increase vaccination rate

In Uttar Pradesh, the state of India most affected by polio, *the health authorities have roped in Muslim clerics to administer polio drops to counteract the resistance of parents due to rumours that vaccination is a western conspiracy to make their children sterile. Daily India* (5/8/07) quoted a cleric and parents as saying these misconceptions had been reduced and larger numbers were turning up for vaccination.

A house at last for iron lung users

Recently we reported on June Middleton's Guinness World Record as living longer than anyone else in an iron lung. June who is 81 contracted polio in 1949 aged 23 and has lived in hospitals ever since. She has now moved into Australia's first home (house) for people with chronic ventilator dependency in Melbourne which has been funded by the state government. The other residents are Jill who is on a ventilator and Julian who has muscular dystrophy and uses an iron lung. June says *her contribution to the design was asking the architects to provide large wardrobes. 'At last, I've got a large wardrobe'*. Jill's greatest pleasure is being able to wash her dishes after a meal. ... She showed off her new room – her cherished mystery novels, the chardonnay in the fridge, and the spot where she'll put the budgie. Julian says *his new environment has completely changed his attitude – he has transformed from sullen and withdrawn to exuberant and optimistic ... his new home has given him an independence he could never have imagined.* (Story from the Herald Sun 2/8/07)

Pregnancy outcomes after polio

When I was having my first child I asked the doctor if having polio could affect the pregnancy. *Of course not*, he replied but it seems that some of the problems I had are more frequent among mothers who had polio. *'Pregnancy, delivery and perinatal outcomes in female survivors of polio'* has been published in the July issue of the *Journal of the Neurological Sciences*. Dr Gyri Veiby and colleagues examined the 2,495 births by Norwegian polio survivors between 1967 and 1998 and compared them to the 1.9 million deliveries to non-polio mothers in the country. All Norwegian births since 1967 have been recorded in detail in the Medical Birth Registry. The researchers found that polio survivors had higher rates of pre-eclampsia, urinary tract infections and vaginal bleeding during pregnancy. Their deliveries were more likely to be complicated by obstruction during the birth process. Caesarean sections (both emergency and elective) were more common among polio mothers. The higher Caesarean rate is thought to be due to *mechanical obstruction during labor. Bony deformities in the pelvis and spine and paralysed muscles responsible for expulsive efforts during the 2nd stage of labor, can lead to operative delivery in polio patients*. ... *The increased rate also of emergency sections shows that the need for operative intervention was underestimated in these patients.* Deliveries were also more likely to be induced in the polio group. Polio survivors' babies were of lower birth weight and the risk of death of the baby was greater. There were more presentation problems for polio mothers older than 34; mainly a higher proportion of breech deliveries. There was no difference in the length of pregnancy of the two groups of mothers. The authors argue that the research findings are relevant to the considerable number of female polio survivors of childbearing age in developing countries where information on the risks of complications in pregnancy when the mother has had polio is difficult to collect.



I have recently been chatting with Susan Murphy of Tuncurry. Susan is on a mission to help her husband who is having health problems which his specialists think may be due to exposure to chemicals while in utero. Susan sent along this letter seeking advice from any Network member who may be aware of chemical spraying in the homes of those who contracted polio. If you or your family remember this occurring, Susan would like to hear from you – please write to her at 8 Guy Place, Tuncurry NSW 2428.

“Do any readers remember, or have heard about, homes being sprayed in the 1950s for the polio virus?

My husband’s sister had polio as a young child and was taken to hospital. While she was being treated, the family home was sprayed and the rest of the family were asked to leave the home.

The house was sprayed in 1953 in the Sutherland Shire area, however, not all of the homes that had a polio victim living in the house were sprayed as it appeared it depended on how severe the case of polio may have been.

I am trying to find out exactly who sprayed the homes and what chemicals may have been used.”

Polio spray in the shire

I am wondering if any of your readers can recall the polio outbreak of the early 1950s?

During that time some homes in the shire were sprayed for the polio virus.

I need to find out who sprayed the homes.

Some of your readers may remember whether it was carried out by the health department, or the local council or whether people paid one or several private chemical companies to spray their family home.

Hopefully, this letter may jog the memory of some of your readers and help us understand some of my husband’s medical problems.

Reply post to: 8 Guy Place, Tuncurry, NSW, 2428.

Susan Murphy
Tuncurry

Member and ACT Support Group Convenor, Brian Wilson, also directed my attention to Susan’s quest. He wrote: *A family member spotted this article in the St George & Sutherland Leader newspaper dated 22 January 2008. Brian asked his Support Group members whether they were aware of any spraying programs in the 1950s. None were, however, George French, a retired Vet, wrote in response: It seems logical that decontamination (spraying or fumigation) of known or suspected contaminated premises would be attempted. The virus is relatively stable and it is generally accepted that the incidence is significantly higher in unsanitary situations. I have no first-hand knowledge of it nor can I find any reference to it in the few relevant documents on my shelf. It is interesting to note that decontamination of floats, harness, grooming instruments etc has been mandatory in the control measures recently used against equine influenza.*

Since this small item appeared in the paper, Susan tells me that she has received a lot of telephone calls (a few of which referred her to the Network!). It seems some people remember the spraying taking place but, so far, who did the spraying and what chemicals may have been used remain a mystery.

It is always good to hear from member Ian McKenzie from Kingscliff in Northern NSW, who wrote in after receiving his last issue of Network News. Like Ian, I have had innumerable items of clothing “chewed up” by the knee joints of my callipers, but the move from my “straight leg” callipers which gave me the ability to not only stand and walk but to bend my legs when I sat down somehow made it all worthwhile.

Thanks for yet another very interesting News.

The splendid article on *Walking and Bracing Support Systems* made me realise how far science and technology in orthotics and prosthetics have advanced in the last half century, and had me thinking about those “early days” when just getting sort of upright was considered progress enough. Those first callipers, ill-fitting, heavy and rigid, without knee joints, so awkward and bad for the body! The suggestion, thankfully not carried out, that bones should be fused to remove the need for callipers! And then the introduction of knees that would bend – bliss! No matter that the locks were primitive and extremely hard on trousers which time and again were caught in the lock and torn. Oh that this advanced technology had been there fifty years ago!

We are still a long way from having this sort of expertise widely available, with more improvements to come, for the article says “*orthotic design and technology has not kept pace with the benefits realized in prosthetics*”. Another reason why the Post-Polio Network and, now, Polio Australia organisations are very necessary.



2008 Post-Polio Network Seminar Program

Saturday 14 June 2008	Ryde-Eastwood Leagues Club <i>117 Ryedale Road West Ryde</i>	Orthopaedic Surgery Recovery and the Polio Patient <i>presented by Craig Knox</i> Physiotherapist, Lismore Base Hospital
Saturday 20 September 2008	The "Tradies" Club <i>57 Manchester Road Gymea</i>	The Baribunma Wheelchair See this revolutionary electric wheelchair (which can potentially return the freedom of the road to you) demonstrated by its designer Wally Bancroft
Saturday 22 November 2008	Burwood RSL Club <i>96 Shaftesbury Road Burwood</i>	Annual General Meeting and Seminar Mary-ann Liethof from <i>Polio Network Victoria</i> will report on her <i>Churchill Fellowship</i> study tour to the USA and Canada where she aims to " <i>identify techniques to better manage the late effects of polio</i> "

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About the Network

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

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

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

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

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

Resources for Members

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

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

Books etc (* indicates Post-Polio Network publication)	Size	Cost
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome Second Edition</i> Edited by Lauro S Halstead MD (see description below ☞)	288 pages	\$40.00 incl 10% GST
<i>A Practical Approach to the Late Effects of Polio</i> Charlotte Leboeuf	39 pages	\$2.50
<i>The Late Effects of Polio: Information for Health Care Providers</i> Charlotte Leboeuf	56 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 1st copy free

The Network has its own four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about the Network. Not only is the badge a great fashion statement, it is an innovative way to promote the Network.	23 mm x 23 mm	\$5.00 plus \$1 postage
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☞ ***Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition)***

The second edition was published in 2006. Editor Lauro Halstead writes about the rationale for this edition:

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

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

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