



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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President's Corner

Gillian Thomas

At the Network's twelfth Annual General Meeting held on 4 November 2000, the following members were elected to the Management Committee:

Gillian Thomas	<i>President / Newsletter Editor</i>
Merle Thompson	<i>Vice-President</i>
Alice Smart	<i>Secretary</i>
Peter Preneas	<i>Treasurer</i>
Anne Buchanan	<i>Publicity Officer / Information Bulletin Co-Compiler</i>
Elizabeth Joyner	<i>Committee Member</i>
George Laszuk	<i>Committee Member</i>
Janet Malone	<i>Public Officer</i>
Anne O'Halloran	<i>Funding Co-ordinator</i>
Allan Quirk	<i>Committee Member</i>
John Ward	<i>Committee Member</i>
Mary Westbrook	<i>Seminar Program Co-ordinator</i>

Ruth Wyatt did not re-stand for the Committee and our sincere thanks go to her for the contribution she has made to the Network over the last three years. It was Ruth and her husband Dick's initiative which saw the Network's four-colour enamelled badge based on our polio virus logo made available to members. The badge is proving very popular; it is a great way to promote the Network and raise a little money to help its important work. It costs only \$6 to have a badge posted out to you. Please order yours today.

Gillian and Merle launched the Network's latest publication ***Hospital, Medical and Dental Care for the Post-Polio Patient – A Handy Reference*** following the Annual General Meeting and it has been very well received. If you have not yet received your free copy, it is included with this Newsletter.

Members were again magnificent in their support for **Post-Polio Awareness Week** which is held annually from 1-7 November. Our poster was distributed far and wide and attracted a great deal of attention. We would like to particularly thank Wendy Davies, Ken Dodd and Dorothy Schunmann who sent information about the Network to their local and regional papers, and participated in media interviews. We also wish to thank People with Disabilities (NSW) who distributed our Press Release through their media and other networks.

On pages 5 to 7 there is an important update on the motion about post-polio debated in the House of Representatives on 28 August. We have provided helpful pointers to assist members take up the issues with their local members – we urge you all to take any action you can on this important matter.

At the Committee's meeting in January we will be discussing and deciding on our goals for the upcoming year. If anyone would like to make suggestions for Network services or activities over the coming year for the consideration of the Committee, please get in touch with me before 17 January.

If your address label still reads "Renewal Due on 1 July 2000" we have not yet received your membership renewal. In this case, you will find a Membership Renewal Form enclosed. Please send in your membership subscription as soon as possible. The Network is self-funded and needs your continued support. If you decide not to renew, please tell us why. We need to know if we are not meeting your needs.

This is a bumper Christmas issue to keep you entertained and informed over the holidays – happy reading!

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Post-Polio Network 2001 Seminar Program

The dates have been set for next year's Post-Polio Seminars and an exciting Seminar Program, including international speakers, is under development by Mary Westbrook. Please note the dates below in your diaries NOW so you don't miss out on some wonderful speakers. Final confirmation of speakers and topics will be given in the *Newsletter* before each Seminar.

Date: Saturday, 3 March 2001
Venue: The Northcott Society, Parramatta
Seminar: Dietary issues for polio survivors
Presenter: Susan Thompson
Description: After enquiries over several months we have identified a dietician to speak to members on this important topic. Susan's talk will cover weight control, dietary supplements, special diets, and much more.

Date: A Saturday during May 2001 (*actual date to be advised*)
Venue: To be advised
Seminar: The polio virus and its late effects: getting to know your old enemy
Presenter: Marcia Falconer, PhD
Description: Marcia contracted non-paralytic polio as a child in 1949. Although she lives in Ontario, Canada, she regularly visits family members in Sydney. On her next trip to Australia, planned for May 2001, she has generously agreed to present a Seminar to members. Marcia has a doctorate in neuronal cell biology and has a particular interest in the polio virus. She is currently researching Post-Polio Syndrome with Eddie Bollenbach with whom she co-authored *Non-Paralytic Polio and Post-Polio Syndrome*. This article was published in Issue 40 of the *Newsletter* (February 1999).

Date: Saturday 22 September 2001
Venue: Independent Living Centre, Ryde
Seminar: To be advised
Presenter: To be advised
Description: This is the Network's **Annual General Meeting** – please note the earlier date than usual. The Seminar topic and presenter will be finalised early next year and details given in the *Newsletter*.

Date: Sunday 16 December 2001
Venue: Burwood RSL Club, Burwood
Seminar: One-day Conference – *Program to be advised*
Presenter: Lauro S Halstead, MD
Description: Dr Halstead is an American rehabilitation specialist and himself a polio survivor. He was responsible for early research and conferences on post-polio syndrome, and in 1998 published *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*. This most informative and readable book provides a comprehensive overview on dealing with the medical, psychological, vocational, and many other challenges of living with post-polio syndrome (*copies of the book are still available from the Network for \$27.50 including postage and GST*). The Network is currently finalising negotiations with Dr Halstead to come to Sydney to speak to members. Further details will be given in the February *Newsletter*, but you won't want to miss this once-in-a-lifetime opportunity to meet and learn from Dr Halstead - make sure you keep this date free.

Why Are “Old Polios” Who Were Stable For Years Now Losing Function? What Should They Do About It?

Jacquelin Perry, MD, DSc (Hon)

Rancho Los Amigos National Rehabilitation Centre, Downey, California

Jacquelin Perry was certified by the American Board of Orthopedic Surgery - one of the first women to be certified - in 1958. Immediately after her residency in orthopedic surgery, she was invited by Dr Vernon Nichol (Chief of Surgical Services) to join his staff at Rancho Los Amigos in the Los Angeles area. She has been involved in the management of the problems of polio survivors since that time. She is Professor Emeritus Orthopaedics, University of Southern California.

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The basic problem is that polio destroyed some of the nerve cells that activate the muscles. To the extent possible, the neurological system responded by having the remaining nerves adopt the muscle fibers that had lost their original nerve supply. This meant that nerve cells now had a demand much greater than normal. While this was an effective solution initially, the passage of time (30+ years, usually) has taught us that overuse can be destructive. As a result, these secondary nerves are wearing out with resulting muscle loss, that is, post-polio syndrome.

Post-polio muscle strength is commonly over estimated as the usual test depends on manual resistance by the examiner. [Ed: See a further discussion of this point in the article on page 15.] In addition, polio survivors mask their disability by clever use of their normal control and normal position sense to substitute for missing musculature. The post polio muscle graded “normal” (5) averages 25% less than “true” normal (only 50% normal for the quadriceps). Similarly, the muscle graded “good” (4) is only 40% of normal strength. These strengths are adequate for a person to carry on customary activities in a typical manner, but at a demand that is 2-2½ times the usual intensity; hence, the muscle nerves have been experiencing strain for years.

The apparent abrupt loss in function relates to two functions. One is the buffer zone present in all of our physiological systems which enables them to accept strain for a considerable time, but once the buffer limits are exceeded, the loss is very prominent. Secondly, activities such as walking or lifting objects present fixed mechanical demands. As long as the person's muscle strength exceeds that demand, he/she can continue to perform as usual but with earlier fatigue. When the strength goes below the essential limit, suddenly that function is lost.

The answer is redesigning your lifestyle to avoid those activities that cause muscle strain, cramping, persistent fatigue, and, consequently, weakening. This means to very carefully look at how you are using your arms, legs, and back, and to avoid those tasks that cause the symptoms of persistent fatigue, muscle soreness, and/or a sense of weakness after use. At times, this requires the employment of special devices to take the load off of the arms. If the changes are made early, strength can be recovered. It will not be sufficient to prepare the muscles for excessive strain again, but it does bring the muscles up to a more useful level. Other ways of reducing strain is by using self care devices, walking aids, braces, and corrective surgery to lessen the stress.

Once the strain has been reduced, then cautious exercise may be of value. We have been using short duration (5 repetitions) or moderate intensity (50-70% of one's maximum capability). Let me caution you not to take on the exercises, however, until you have worked out a lifestyle that avoids the strain. Also, if the exercises cause any pain, persistent fatigue, or increased weakness, STOP! This means just the mechanics/activities of daily living (ADL) are sufficient exercise for your muscles.

Recent research on the course of muscle strength over time in persons over age 50 years showed a normal average decline of 1% per year, but for post-polio survivors the rate was 2% per year. The rate of change is so subtle that a four-year study was needed for a measurable change. Also, the weaker "polios" experienced greater functional loss. This latter fact *appeared* to indicate strength training by exercise would deter the process. However, retesting this group of polio survivors at eight years and adding muscle analysis told a different story. The muscle fibers were hypertrophied, twice normal size, not atrophic. The person with the greatest strength loss also had the greatest hypertrophy.¹ MRI recordings showed areas of muscle loss and fatty replacement. The source of the visible muscle atrophy is muscle fiber loss secondary to nerve fiber overuse failure. These findings confirm the need for a saving program rather than challenging exercise.

The advantage of having had polio rather than another disability is that it allowed one to resume a very active and profitable life for many years. Now it is necessary to recognize that excessive strain was being experienced and that lifestyles must be changed to accommodate this situation.

Be an "Intelligent Hypochondriac" - listen to your body and adopt a program that avoids the strain.

¹ "Several histologic studies have shown that the myofibers of polio survivors can be twice the size of those found in other persons. A few studies have provided indirect evidence for a possible transformation of some of the surviving type II (fast-twitch fibers) to type I (slow-twitch fibers). The few studies performed have shown a preponderance of type I muscle fibers in very weak muscles that were constantly being used in daily activities. It has been postulated that a person would have to utilize all motor units in these very weak muscles to perform all daily activities and that, over time, the type II fibers are transformed to type I fibers."

Source: Agre, JC, Sliwa, JA (2000). *Neuromuscular rehabilitation and electrodiagnosis*. Archives of Physical Medicine & Rehabilitation 81(3), Suppl S27-31.

A PostScript from Joan L Headley, MS, Executive Director, GINI

Dr Perry's article covers the basics and defines post-polio syndrome right up front. Definition continues to be a problem. The medical literature more narrowly defines post-polio syndrome; some lay literature equates post-polio syndrome and the late effects of polio. International Polio Network does not. When reading any information [Ed: including articles published in our own *Newsletter*], it is always wise to first establish how the author defines post-polio syndrome.

Definition was briefly discussed at the recent March of Dimes Warm Springs meeting (May 2000). The experts still need to reach a consensus. The information that was presented by the health professionals is now being edited. The Executive Steering Committee hopes to have the final product available by early 2001.

*Ed: The Warm Springs symposium was an exchange of information on the best practices for diagnosis and treatment of PPS to help improve the lives of polio survivors. We do not yet know how the resultant report **Practice Guidelines for the Management of Post-Polio Syndrome** will be disseminated, but hope to have more information in time for the February Newsletter.*

Keep Post-Polio Syndrome on the Political Agenda

In the last Newsletter we reported that a motion to recognise post-polio syndrome and the needs of polio survivors had been debated in the House of Representatives in Canberra on 28 August 2000. The Newsletter included a complete transcript, from Hansard, of the speeches made in support of the motion. We were pleased to note that the motion was debated on non-partisan lines.

Also in the last Newsletter we implored members to assist the Management Committee in its efforts to have debate on the motion resumed (if it is not resumed by March next year, the motion will lapse). Discussion on this matter at our Annual General Meeting centred on how the Committee might assist members in approaching their local members. Vice-President Merle Thompson has therefore put together the following pointers to help you in arguing the case for funding to resource the Network and to establish assessment clinics. If you need any further assistance, please don't hesitate to contact Gillian on (02) 9663 2402 or Merle on (02) 4758 6637.

First, the motion is repeated in full below to refresh your memory.

The Hon Dick Adams MP (ALP, Member for Lyons - Tas)

I move that this House:

- (1) recognises Post Polio Syndrome, as thousands of Australians are now experiencing the late effects of contracting polio some 30 to 40 years after the initial infection;
- (2) notes that it is estimated that a minimum of 20 000 to 40 000 people had paralytic polio in Australia between the 1930's and the 1960's and it has only been recently that this syndrome has been diagnosed;
- (3) gives support to the Post Polio Network set up around Australia;
- (4) helps the establishment of assessment clinics for those that suffer from this disorder;
- (5) helps educate medical professionals to recognise this syndrome and encourage further research; and
- (6) legislates to recognise the need for post polio sufferers to retire early because of chronic ill health due to past polio infection.

The first clause of the motion seeks recognition of Post Polio Syndrome and the second notes the large numbers of people who contracted polio. The other four components of the motion raise important issues for our members and you may like to take one or more of these and relate them to your own experience. A personal letter to your own MP discussing your own experiences, and using these to show the importance of supporting for the motion will have much more weight than any standard letter the Management Committee could put together, particularly as this style of campaign receives little acceptance by politicians and public service departments.

The need for support for the Polio Networks

What does it mean to you to have the support and the information provided by the Network? How much would you miss it if we all experience the late effects of polio problems to the extent that we cannot keep the Network going? Stress the importance of funding for paid help for clerical, financial and practical tasks currently undertaken by the Management Committee, other members and their families.

The establishment of assessment clinics

Have you obtained help from Prince Henry? Did you wish that such services were available in your own area? Perhaps you could even go further and suggest the need for clinics which provide coordinated treatment and assistance rather than just assessment – eg having a doctor, orthotist, physiotherapist and occupational therapist talking to each other and working together to maximise your survival, independence and well-being.

The need to educate medical professionals to recognise post polio syndrome and the need for research into the condition

What have been your own experiences in lack of acceptance of the late effects of polio as something which exists? Have you been told there is no such thing as post polio syndrome – it is only ageing and you are too fat? Have you had problems due to lack of understanding of your needs in hospital? Been discharged with no assistance to cope with the combined effects of your disability and the current treatment? Been given inappropriate drugs? Had problems with anaesthesia? Had inappropriate physiotherapy?

Recognises the need for post polio sufferers to retire early

Outline your own experiences regarding giving up work.

You might also like to mention some of your own problems in coping with your daily life. To assist you, the following is extracted from the Executive Summary of the research report *Polio - A Challenge for Life - The Impact of Late Effects* we released two years ago. You could relate your own life to some of these ideas.

The survey asked respondents questions regarding their physical condition, both at the time of their maximum recovery, and now when so many have new difficulties. It then asked them to show the effect of their physical limitations in a number of areas of daily life.

Some of the key findings are as follows:

Physical condition

- Nearly 80% have lower limbs affected by polio, and over 50% indicated effects relating to each other area of the body.
- Over 80% experience unusual tiredness, and around 70% each of muscle pain, joint pain and sensitivity to cold.

Mobility

- Around 50% cannot even walk easily on level surfaces, and over 80% experience difficulties with uneven surfaces and stairs.
- Only 21.5% do not need to use some sort of mobility or breathing aid.

Home life

- A third of respondents experience difficulty with having a bath or shower, for a quarter getting dressed is difficult, and a similar number find getting in and out of bed is not easy.
- Over 50% have difficulty with shopping, and over 80% cannot readily handle heavy household tasks or heavy gardening.

Recreation

- Over 80% have been restricted from active and physical activities, and for a quarter social activities are restricted.

Employment

- Polio related difficulties prevented a small number of respondents from ever working and are given as the reason for retiring for nearly 50% of those who have retired. Nearly three quarters of those considering leaving work cite post-polio problems as the reason.

Transport

- Only just over one third are able to travel by bus, train or ferry without problems, and for 20% buses are impossible, with trains and ferries only marginally more accessible.
- For a small number even travel in an ordinary car is not possible, and for another group this can only be managed with help.

A particular concern that became apparent from this research, both from the comments and the data, was that our members are very reliant and even totally dependent on their family, especially spouses, in coping with their lives. This puts physical and emotional stress on family relationships, and there must be an underlying fear for many people of how they would cope if they were left alone, or if the carer is no longer able to provide the necessary assistance.

Members are encouraged to select ideas from the above and send your own letter to your local MP and enlist his or her support for the motion. Whenever you approach your local member, please let us know to whom you wrote or spoke, and what reaction you received. The Management Committee would like to know who to follow up, and what issues might need to be addressed.

Assuming our combined efforts are successful in having the motion re-listed for debate early next year, the Management Committee is considering hiring a wheelchair-accessible bus to take interested members to Canberra. We will not only hear the debate first-hand, but our presence will help to raise the awareness of politicians to the on-going effects of polio on people's lives. We may have little warning of when the motion will be debated, so if you would like to participate in supporting the Network in person, please register your interest NOW by phoning Gillian on (02) 9663 2402 or Alice on (02) 9747 4694.

What has the Management Committee Done So Far?

Since the last Newsletter, we have written to the four members who spoke to the motion: Dick Adams, Barry Wakelin, Michelle O'Byrne and Tony Lawler. To Mr Adams we wrote in part, *Our members are extremely grateful to you for bringing to parliamentarians an awareness of the difficulties that those who have had Poliomyelitis encounter both in their daily lives and in obtaining understanding and appropriate medical treatment. It was particularly gratifying that your speech showed that you had researched the topic and could speak with both understanding and caring about the impacts of the late effects of polio on polio survivors. ... The members of the Network encourage you to strive for your motion to be again listed for debate.* We wrote to the other members that *It was also gratifying to see that there was bipartisan support for the motion. ... we thank you for your support and look forward to a positive outcome.*

We have also written to the Minister for Health, Michael Wooldridge; the Shadow Minister, Jenny Macklin; the Leader of the Opposition, Kim Beasley (himself a polio survivor); the NSW Minister for Health, Craig Knowles; and the NSW Shadow Minister, Jillian Skinner, seeking in part to have the health needs of polio survivors included on the agenda of the next meeting of Health Ministers.

The Paralympics ... or How I Cheered Myself Hoarse

Anne Buchanan

It was suggested that I write down my experience at the Paralympics to share with those who couldn't, or didn't, attend. "No worries" was my confident (and as I see it now, naive) reply. I have since realised that the big problem is ... how do you explain "atmosphere" to someone who wasn't present. I then figured out that when all else fails, the best thing to do is start at the beginning, so ...

I attended the Opening Ceremony with some friends, and it was nothing short of spectacular. Most of you probably saw it on TV, so I won't go on about it here, but will try to tell you about some things you didn't see on television.

I went to the Paralympic Games on Sunday 22nd October, and all went well. A fast, efficient transport system got me there easily. I was happy with that, and felt great on arrival.

I wandered around for a while just soaking up the sights and sounds. People from all over the world could be heard talking in many languages, but naturally, the main language I heard was the cheerful Aussie. Many of the people attending the games were dressed for the occasion, with clothes, hats and face paint ranging from quite trendy to over-the-top outrageous, but all supporting the wearer's chosen team. I felt even happier now - I was in amongst the fun.

The first event I went to was men's wheelchair basketball - Mexico vs South Africa. While this was not one of the main matches of the games, it was still great to see. I know we can all watch these things on TV at home, but truly it is just not the same. They move fast on TV; they move even faster in reality. They appear to turn on a spot on the court on TV; they appear to turn on an even smaller spot on the court when you are there to watch. And of course there were the spectators. Most cheered wildly when either team scored a goal and signed loudly when any penalty was awarded. No-one seemed to care much who won. We were all just there to have a good time, and we certainly did that. When I left the basketball, the only thing spoiling my day so far was the fact that the game had ended.

Next stop was that athletics stadium. Here I watched wheelchair races, visually impaired runners, shot put, discus, javelin, and part of the men's pentathlon. This venue proved a little disappointing in just one way - so much to see and only one pair of eyes to see it with! Even though it can be hard work enjoying yourself, I soldiered bravely on and cheered loudly with the rest of crowd - and there were thousands of them. I must say it was a fantastic experience. The day seemed to be getting just better and better, but none of this prepared me for the next event - archery.

I particularly wanted to see the individual and team events in the archery as Tony Marturano was competing in these events. I knew nothing about archery then, and not much more now, but thought it would be good to see someone you know competing. Ruth Wyatt and I went together to cheer Tony on. It seemed no big deal at that point in time. We got there early so had good seats near the firing line. By the time the competition started, all the stands were almost full, and still more spectators were arriving. As each group of competitors entered the arena they were cheered, and then it happened. The crowd went wild. The Australian had entered the arena. The expected cheers of Aussie, Aussie, Aussie could not be heard though, only Tony, Tony, Tony. There was chanting, there was foot stamping, there was screaming, as well as the usual signs (GO TONY of course), streamers, and goodness knows what else. Every shot was accompanied by another wave of noise.

When Tony finished competing there was even more acclaim. Tony was not the last competitor for the afternoon, but very soon after he left the arena, the stands were half empty again and others were leaving, almost as if the competition had finished, and I guess for Tony's fans it had.

I hope Tony enjoyed himself on that Sunday afternoon as much as his fans did. For me it was an experience I shall never forget. I arrived at Olympic Park happy because I had had good transport to get there. I left Archery Park after a mind-blowing experience that I could not even have imagined.

I returned to Archery Park the following week to see the teams event. There were three men in each team and while there is no doubt the Australian team was cheered on as a team, again the name most heard was Tony. The crowd was a little more sedate in their antics at this event, but nonetheless the spectators and atmosphere again provided a unique and overwhelming experience as did the athletes.

The Paralympics provided the experience of a lifetime and I for one am just so glad I did not miss it.

Ed: The Network was very well represented at the archery events, and Tony has asked me to pass on his thanks to everyone who encouraged and supported him over the last few years and to those who were able to go to the Paralympics and cheer him on. He says it was a real buzz to shoot in front of so many avid supporters. Next stop, Athens?



Tony "William Tell" Marturano zeros in on the bullseye at the Paralympics.

Polio Particles

Mary Westbrook

Polio Particles is compiled by Mary Westbrook as items on polio or post-polio in the press or professional journals catch her eye. Included in this series are brief reviews of books on polio or post-polio, updates on post-polio research, and other items of interest.

Polio survivor steals the show at Paralympic ceremonies

Atajan Begniyazov became the star of the athletes' parade at the opening of the Paralympic games when he threw away his crutches and walked on his hands with his feet pointing at the sky. As a result the organisers included him as a last minute addition to the closing ceremony. He walked on his hands to an armchair on centre-stage, the best seat in the house. The *Sydney Morning Herald* reported that Atajan does this to entertain family and friends back home in Turkmenistan, formerly part of the Soviet Union. He had not planned to do so at the Games opening until he became so excited by the enthusiastic crowd of nearly 100,000 at the Olympic stadium. Atajan, a 20-year-old medical student, contracted polio when he was one year old. His leg muscles are atrophied and one leg is shorter than the other. He is a weight lifter whose qualifying lift for the Games was 132.5 kg, nearly three times his own weight. He finished third in the last world championships for disabled lifters. Asked if he would win a medal in Sydney he replied that it depended on God's will. The *Herald* reporter questioned whether his legs were God's will? Atajan simply smiled.

Mia Farrow helps in polio eradication program

Mia Farrow contracted polio when she was nine years old. She spent three days in an iron lung. She was the only one of the seven children in her family to contract polio. While she was in hospital her parents drained their swimming pool, replanted the lawn, repainted the house throughout, reupholstered the furniture, had the carpets cleaned and got rid of the dog. Such was the fear of polio. Mia had a complete recovery from polio and in a recent interview in *USA Today* (10 June 2000) acknowledges that she may develop post-polio syndrome but as yet has experienced no symptoms. She describes contracting polio as, *a lastingly traumatic episode. But it was the beginning of my awareness of other people, that there were people suffering.* Her 13 children include Thaddeus, whom she adopted from India. He is a paraplegic as a result of polio. In June Mia, who is a UNICEF special representative, and Thaddeus took part in a United Nations conference on polio eradication and she hopes to visit Africa to publicise the program.

Polio is down but is it out?

The World Health Organisation (WHO) would like to stop universal polio vaccination once it has declared polio eradicated, hopefully by 2005. *New Scientist's* editorial (5 May 2000) talks of the possible dangers of stopping. The fact that polio is nearly extinct, it says, *is a fine example of vaccines at work. But we now face a tricky endgame. Ironically the very weapon that defeated polio has a sting in its tail. The main vaccine (Sabin) is made of live virus that's been weakened. Unfortunately this virus spreads in unvaccinated populations and can revert to its original nasty form. So, in a world free from polio and polio vaccination, the weakened virus could come back to haunt us. There are vaccines made from killed virus (Salk) that don't revert but they don't work as well as live vaccines. So we need a new vaccine but the drug companies are not going to develop a vaccine that would soon be redundant.* Debora MacKenzie in an article in the same issue of *New Scientist* gives more details. In theory polio eradication should be possible as *only humans carry the virus, so if enough people are immunised, the virus will no longer be able to find new victims and will die out as smallpox did. Then we can stop immunising.* However the weak form of virus in the Sabin vaccine can cause polio (in about one in a million vaccinations) and occasionally infects unimmunised people. Expert, Paul Fine, says that we don't know how long the viruses from vaccination will survive. They do not seem to survive long in the environment or in most people. *But the longer the viruses persist and, and the more people they infect, the more chance they have*

to change (to a deadly form). It is known that the Sabin virus can persist for years in people with impaired immune systems eg people with HIV, and here they mutate, or change, faster than normal. Fine estimates that the Sabin virus *might have to survive only for three to ten years before a large enough population of non-immunised people accumulated to start spreading the virus*. Reverting to the Salk vaccine worldwide for the last few years of the eradication program would give the Sabin virus more time to die out but the cost would be prohibitive. Already some developing countries are objecting to paying for the eradication program. *Another nagging concern is emerging that could make some afraid to stop vaccinating: bioterrorism. Laboratories all round the world have samples of polio virus. They are supposed to destroy them one year after the disease is eradicated. But prospective terrorists need only hide some now and wait for a generation of unvaccinated children to emerge before they strike. 'The horror of polio would make it a good weapon' says Roy Widdus of WHO. 'I would not want to be the one to stop vaccination, given that risk'. WHO is being criticised for an extraordinary act of ignorance, scrapping promising developments for an improved polio vaccine in the 60s. This might have eliminated the present concerns.*

How did wild polio virus get into French sewers?

In May this year an outbreak of 60 cases of gastroenteritis led officials in the French city of Strasbourg to investigate water pipes which they found to be contaminated by sewage. The officials were surprised to also find polio virus there. Initially they thought it was the weak strain produced by Sabin vaccine, which is not infrequently found in sewage. However analysis at the World Health Organisation's enterovirus laboratory showed that it was a Mahoney-type strain of polio virus. This strain of wild polio virus, which once killed thousands of people every year before vaccination began in the 50s, had been thought to be extinct in France though it is used in some research laboratories. The journal, *New Scientist* (18 November 2000), reports that laboratories in the area are being investigated to see if they have used the strain in the last 10 years. *New Scientist* says that, *Some of Strasbourg's citizens must have swallowed the virus. The four-month incubation period for poliomyelitis has now elapsed, and no cases of paralysis have been reported since the incident. But the incident happened during an outbreak of viral meningitis. No samples were analysed from these cases so some may have been nonparalytic polio. It is estimated that 5% of a population would need to be infected before the virus would be found in sewage. Such a large number of carriers of a lethal polio virus in Strasbourg would be unlikely without cases of paralysis. So it seems more likely that a concentrated dose escaped from a laboratory. However the head of the enterovirus laboratory is quoted as saying that, the Strasbourg incident highlights the continuing risks posed by the virus, whether or not it was an escapee (from a laboratory). ... it would be stupid to stop polio vaccination any time soon.*

Ed: The above two items highlight the importance of Australia's *Polio Containment Project* recently announced by the Commonwealth Department of Health and Aged Care – see the full story on page 14.

Itzhak Perlman on access at the Sydney Opera House

World famous violinist and polio survivor, Itzhak Perlman, gave a talk titled *To Help the Handicapped, Talk to Them* which was reported in *Polio Deja View*, the newsletter of the Central Virginia Post-Polio Support Group (June 2000). In it he says, *I've been in public buildings throughout the world and it's clear that people who design them have no idea what it feels like to use crutches or use a wheel chair. One of the great architectural catastrophes of all time, from the point of view of any concertgoer, much less one who is disabled, is the Sydney Opera House. A design contest was held and the winner was an architect who had conceived a truly fantastic-looking place with about a hundred steps leading to the entrance. There is no elevator - not for the general public, not for the poor musicians who have to lug instruments up all those stairs, and certainly not for the disabled. Why couldn't the prize have been given to the best design that was also barrier free? Why, when it's possible to make EVERYONE comfortable, is so little attention paid to accessibility? It's mind-boggling.*

Late effects of other disabilities

An article, *Post-Everything Syndrome*, appeared in the American magazine, *New Mobility* (September 2000). Author, Bonnie Moulton, discusses how polio survivors have raised medical and community consciousness about the late effects of all disabilities. She writes, *We should give credit where credit is due. Polio survivors - inarguably the largest, most vocal and most politically active disability group in history - have fought to get health care providers, insurance companies and policy makers to recognise that for millions, the experience of polio didn't end with recovery from the initial illness. The model of self advocacy they created has extended far beyond any single disability.* She goes on to describe how survivors of spinal-cord injury, cerebral palsy, spina-bifida, Guillain-Barre syndrome, long term amputation and other physical disabilities considered to be static are experiencing late effects that seem like early ageing. As you will recall from the Network's booklet *Helping polio Survivors Live Successfully with the Late Effects of Polio*, some polios develop post-polio syndrome which would seem to be unique to polio survivors. Most polios develop late effects due to the wear and tear of living with a compromised body. It is this that causes problems for people with other physical disabilities. Whatever the causes of their symptoms the different groups' experiences are often remarkably similar. *Pain tops the list, followed by increased fatigue, decreased endurance, increased spasticity and new muscle weakness ... protocols that have helped polio survivors, including a transition to a 'conserve to preserve' lifestyle may be equally valuable to someone with spinal cord injury or spina bifida. It means that people with Guillain-Barre syndrome have every reason to print out an article from a post-polio Web site and tell their family care physician, 'This sounds like me! Let's try some of these things'.* The stories in the article will sound familiar to polio survivors. Ken, aged 51, with cerebral palsy, says, *You slowly, or sometimes quite suddenly, realize that you can't do things you used to do easily. Then you realize that you're not really THAT old. That's the frightening part.* Steve, aged 59, who has spinal injury was told by his physiotherapist *'You have two speeds now, slow and stop' ... I can't do six things in one day anymore ... As I've grown older I've learnt to make sure that I don't make too many demands on myself. As I get better at doing that, I've begun to be at peace.* The author argues that people with long-term disabilities are more alike than different so they should be a community rather than a collection of enclaves. *To have access to services and supports we'll need as we age, we need to build coalitions.* Moulton has much to say about the failure of medicine in handling chronic conditions. She quotes one doctor who recommends that people with late effects of disability consult a specialist in rehabilitation medicine or in sports medicine, *Why sports medicine? Once you've had a disability for 30 or 40 years, the analogy that you're doing a marathon (every day!) doesn't seem that far off. For this we pay a price. 'There is no doubt that the presence of a disability causes a person to expend more physical, emotional and mental energy every day than a person who does not have a disability', confirms Renee Kirkby, an amputee for 30 years.*

Polio in novels

Lately I have been tracking down novels in which polio plays a significant role. Many such as *Lightning in July* by Ann McLaughlin are out of print. I bought a second-hand copy. The book, published in 1989, tells of Holly, a gifted flautist, and Dan, a history scholar at Harvard, who, to quote the cover of the book, *fall in love in a hospital, having both been struck by polio on the same night... Their story explores unsentimentally the issues of disability, love and courage.* The author and her husband, Charles, both contracted severe polio in 1955 from their baby son. The novel is based on the diary Ann kept while in hospital. The novel ends as the lovers are about to leave hospital. Ann has written her own story, *One Couple's Journey from Paralysis to Post-Polio* in the book *Polio* (Edited by TM Daniel and FC Robbins, 1997). After polio they went on to have successful careers and a second child. Now as a result of PPS Charles can no longer walk and Ann has a leg brace once more and swallowing problems. She says, *We sometimes speculate about how much easier it would have been if only one of us had developed polio, for there have been times when our combined disabilities have limited us severely. But they have bound us together as well and increased our understanding for each other.*

Crossing to Safety by Wallace Stegner, a winner of many American literary awards, was published in 1987 and is available locally (Try your library. Dymocks list it for \$18.61 but all stores do not

stock it). It tells of the lifelong friendship of two couples who meet in the 1930s. Shortly after their meeting Sally contracts polio and as a result needs to use calipers and crutches. Years later her health declines further. In the novel Sally's husband, Larry, says: *One of the peculiarities of polio is that its victims, once they have recovered from the virus and settled down to whatever muscular control is left to them, live a sort of charmed life. Crippled as they are, they are rarely ill, they are surprisingly tough and durable, they astonish their sound companions with their capacity to endure. But that is not forever. There comes a time in the life of every such patient when the whole system—muscles, organs, bones, joints—begins to fall apart all at once, like the wonderful one hoss shay.* That sounds like a description of PPS! Larry goes on to say, *Every polio patient is warned to expect that time, every polio family lives with the foretold doom waiting for it at some unknown time in the future. One learns to live with it by turning away from it, by not looking. And yet on occasion one is aware of an intense, furtive watchfulness, and the victim, the doomed one, must surely have just as often the vulnerable sense of being watched.* There may be some truth in this today when we wonder how much PPS will ultimately affect us but it was not the case when we contracted polio. Then neither medical textbooks nor doctors thought there were late effects. I do not know what Stegner's connection with polio was but he knows it well. In one scene Sally's voice is described as wearier *than I had ever heard it. Even in her worst spells she doesn't sound like this, and she takes care that there are very few bad spells, and that when she has them they do not show.* Larry vividly describes the impact of polio on their lives. *You can plan all you want to. You can lie in your bed and fill whole notebooks with schemes and intentions. But within a single afternoon, within hours or minutes, everything you plan and everything you have fought to make yourself can be undone as a slug is undone when salt is poured on him.* As he reflects on Sally's dependence on him he observes that contrary to what other people think, *my chains are not chains ... over the years Sally's crippling has been a rueful blessing. It has made her more than she was; it has let her give me more than she ever would have been able to give me healthy: it has taught me at least the alphabet of gratitude.* The book's title comes from the words of poet Robert Frost: *I could give all to Time except—except/ What I myself have held. But why declare/ The things forbidden that while the Customs slept/ I have crossed to Safety with? For I am There/ And what I would not part with I have kept.*

Sister Kenny Television Show Seeks Interviewees

My name is Clare Bonham. I'm a television producer working on a film about Sister Elizabeth Kenny. While she is little remembered these days Sister Kenny was held in high esteem in the early part of last Century thanks to her remarkable work with polio sufferers. I am planning a one-hour documentary about the life of this fascinating woman. It's clear that she was larger than life in many ways. She was over six feet tall and very imposing. She stood her ground too and fought for what she passionately believed to be right. As a result, tens of thousands of children around the world received a more humane and possibly more effective treatment for the debilitating effects of polio.

Kenny was a champion of what we now call a holistic approach to treating illness. She included radical ideas into her treatment, and though she was not a formally trained doctor her work was intuitively ahead of its time. She used concrete visualisation techniques and firmly believed in mind over matter. Kenny too is credited by some people with creating, or at least legitimising, what has become the highly respectable field of Physiotherapy.

On the other side however, the Kenny method has been called humane, though ineffective, by some people. She is remembered by some as being difficult, demanding and a monumental self-promoter. There's no doubt there are two sides to the woman that came from a struggling country town in outback Queensland and rose to considerable international fame. I'd like to hear all sides of the story – positive or negative.

My film will attempt to create an intimate portrait of this remarkable woman by interviewing people who knew her and remember their encounters with her. I would like to talk to people that were colleagues, nurses, children, or just friends of Sister Kenny. If you or anyone you know remembers an encounter with her and you would be happy to talk to me about it, you can contact me via email at clarebonham@hotmail.com, or by mail at 342 Belmont Street, Alexandria, NSW 2015.

I will be travelling around Australia and to the United States next year to film this documentary and would love to hear from anyone with a story to tell as soon as possible.

Polio Containment Project

As many of you will be aware, the Network is one of 23 signatories to the Australian Childhood Immunisation Charter and actively promotes immunisation. Edition 8, November 2000, of the Charter Members' Newsletter has just received and includes an update on polio eradication. The item is reprinted here with permission.

In September 1988 the thirty-ninth session of the World Health Organisation's (WHO) Regional Committee for the Western Pacific adopted a resolution calling for the eradication of polio in the Region by the year 2000.

On 29 October 2000 the WHO Regional Certification Commission on Poliomyelitis Eradication announced that the poliomyelitis eradication efforts in the Western Pacific Region, including Australia, had stopped the circulation of the indigenous wild poliovirus. As a result, the Region was certified as polio-free.

The Region is now focusing its efforts towards the goal of global eradication. As part of this effort the Commonwealth Department of Health and Aged Care is taking a lead role by implementing a laboratory containment campaign that aims to identify and develop an inventory of all wild poliovirus stock and potentially infectious materials that is stored in Australian laboratories.

The Victorian Infectious Diseases Reference Laboratory (VIDRL) was contracted to coordinate the laboratory containment of wild poliovirus in Australia. The project is funded by the Department and monitored by the National Advisory Committee on Poliovirus Containment.

The national laboratory survey targets all Australian diagnostic, biological, environmental reference, research, teaching, manufacturing and regulatory laboratories.

To assist VIDRL with the survey, the Department set up the Polio Containment Infoline, which was operational from 21 August until 22 September 2000.

The task of the Infoline was to contact over 1000 laboratories Australia-wide to ascertain whether they held stocks of wild poliovirus.

Once identified, these laboratories were asked to destroy unwanted materials appropriately. They were also asked to complete a Laboratory Screening Survey Form providing details of any remaining materials.

This information will assist with the development of a national inventory of poliovirus infectious or potentially infectious materials.

Polio May Be Gone, But We Aren't!

As a footnote to this item, there is a growing feeling amongst polio survivors that the enormous effort WHO has put into the polio problem cannot be allowed to wind down – we all know that eradicating polio, laudable though the achievement is, does not address the on-going issues faced by polio survivors throughout the world. Somehow, the world-wide community of polio survivors has to alert not only our own individual governments, but WHO as well, to our ongoing needs, and lobbying about this must start in earnest.

John Foyster from South Australia (polio 1956) recently drew our attention to a website devoted to "big" fundraising (foundations etc) for polio eradication (www.poliofreeworld.org). They invite comments to a forum. John made the following contribution and hopes others will also write.

All old "polios" - I am one - support the effort to eliminate new cases of polio. But the effects of having had polio will last for, probably, over fifty years after the last new case. The language of "eradication" implies that "polio" will no longer exist as a problem after there are no new cases. But there will be continued and mounting economic costs for so long as polio survivors are alive. It is time to start thinking more seriously about practical ways of minimising those long-term economic costs by relatively lost-cost support of young polio survivors.

In Post-Polio Syndrome, Manual Muscle Testing Problems Arise From Judgement and Biology

Eddie Bollenbach

Eddie Bollenbach is a polio survivor and teaches microbiology, biology, and chemistry at Northwestern Connecticut Community-Technical College. He is a long time and valued contributor to several post-polio mailing lists on the Internet, and is especially noted for his knowledge and skill at communicating the current scientific understanding of the biology and biochemistry of viruses and other scientific topics relating to polio and post-polio conditions.

This is a Lincolnshire Post-Polio Library Publication, 18 March 2000. The Lincolnshire website is an excellent source of information for polio survivors around the world. The core of this site is a library of well over eighty full text articles on Post-Polio conditions, many from peer reviewed medical journals. The library is catalogued to assist reading order and new articles are added typically every few weeks. A categorised directory of polio resources is also provided with every entry having a description. Polio news items from around the world are regularly included in the NewsBites section and all the bi-monthly LincPIN newsletters are available online. Members with internet access are encouraged to visit the library at <www.zynet.co.uk/ott/polio/lincolnshire/>.

When acute polio struck it was essential to measure the extent of paralysis quickly. One of the techniques used was manual muscle testing. There isn't too much to it really. The physician holds a hand against a patient's limb and coaches the patient to push as hard as possible. Depending on the judgement of the tester the patient's muscle strength is graded from 1, (Trace Strength), to 5, (Normal Strength). This assessment was very valuable because it provided a clinician with enough resolution in measurement to quickly evaluate the extent of neuromuscular paralysis from acute polio in one session.

From the standpoint of muscle biology these tests made sense too. During acute polio, motor nerves, and all their branches to muscle fibers, die. The muscle fibers are then unable to receive motor stimuli from the brain and spinal cord to induce voluntary movement. A manual muscle test would quickly show that many or all muscle fibers were orphaned and had no ability to do work. Appropriate therapy could then be initiated.

The biology of Post-Polio Syndrome (PPS) is distinct from that of acute polio. In PPS end fibers of motor nerves begin to lose function. This is a slow process which involves fatigue more often than muscle incompetence. Let me explain. If a normal person is standing it is possible that 30% of the muscle fibers in his leg are contracted to maintain his upright position and posture. When those 30% get tired they automatically rest (switch off) -- isn't the human body an ingenious creation? -- and another different 30% of fibers contract to allow the first group to recoup. This can go on for hours. Someone with PPS may have only 40% of his original muscle fibers. When he or she stands they have only 10% in reserve, so in a short while there are no substitutes to take the load off. The result is fatigue of contracting muscles.

In the case described above what would show on manual muscle testing? On contraction against a clinician's hand, strength may show normal (5). But this is instant strength, which is what manual muscle testing measures. Many people with PPS are not down in the (1) trace range, especially if they recovered well from their acute polio. They are in the 5,4,3, and 2 ranges.

Dr Sharrad in 1953 [1] found that in order to identify any weakness, by this kind of testing, more than half the anterior horn cells had to have been destroyed during the original polio infection. Other clinicians have also demonstrated the problems with manual muscle testing in grading PPS involvement. [2,3]

The biology of PPS explains the problem. What we should be looking for is fatigue in previously involved muscles, or less frequently in uninvolved muscles. Manual muscle testing just doesn't do that. The PPS health professional should be clear about what is being measured by manual muscle testing. It may be, for many, that what is being measured is the original weakness and not the new loss.

References

1. Sharrad, WJW: *Correlations between the changes in the spinal cord and muscular paralysis in poliomyelitis*. Proc. R. Soc. Lond. 40:346, 1953
2. Perry, J; Barnes, G; and Gronley, JK: *The postpolio syndrome. An overuse phenomenon*. Clin. Orthop., 233: 145-162, 1988
3. *Grading For Manual Muscle Testing* (attributed to Dr Jacquelin Perry - Rancho Polio Clinic) <www.eskimo.com/~dempt/grading.htm>

Seminar at the Independent Living Centre

The Independent Living Centre (ILC) was both the location and the topic for the Network's final seminar of the year. Occupational therapist, Bronwen Conn, who is Client Services Manager at the ILC, presented the seminar. Bronwen began by collecting a list of all the aids, products and issues members would like her to discuss. The whiteboard was soon covered with a double list ranging from electric scooters and scooter lifts to equipment for gardening and helping you to get up if you fall over. We were shown the numerous products including the latest devices for picking things up that are out of reach and "elephant's feet" (they are used to raise the height of your bed). The presentation continued informally over afternoon tea as members consulted Bronwen about their problems.

Of particular value was the advice Bronwen gave us on how to access information about the aids that are available and where to find them. The ILC is a major source of answers. It is now open five days a week and it is hoped that times will be extended to make it easier for people to visit in out of work hours. You no longer have to make an appointment to visit the ILC but if you want to make sure a staff member will be available to talk over your needs you can make an appointment by phoning (02) 9808 2233 (people in country areas can phone 1800 800 523). If you want advice you can also phone the ILC, or fax them ((02) 9809 7132) or e-mail them (ilcnswh@bigpond.com). You can also visit the ILC on the Internet (www.ilcnswh.asn.au). This is a great site where you can view more equipment than is available on ILC premises. I gave it a try looking up wheelchairs. There were dozens of products with pictures, detailed information about features, costs and suppliers. In the library section of their web site was a list of all the things you need to bear in mind when selecting a wheel chair along with many articles of interest. Bronwen also emphasised other sources of information on equipment. IDEAS is a freecall service (1800 029 904) that gives information on equipment, access and services for people with disabilities. The Yellow Pages list many suppliers of disability aids. Pharmacies usually carry some disability aids. It is a good idea to discuss equipment with other people who have similar disabilities to yours; their experiences may save you much time, money and frustration.

The Network is very grateful to the ILC for its ongoing support in providing us with a venue in which to hold our Annual General Meeting and associated seminar each year. We also thank Bronwen for giving us a stimulating and helpful seminar/workshop.

Commonwealth Recognition Awards for Senior Australians 2000

It is always gratifying when one's voluntary efforts on behalf of others is formally recognised. I am therefore thrilled to be able to tell you that *Commonwealth Recognition Awards* have recently been awarded to Network members Jean Magennis (Wagga Wagga) and Wendy Nolan (Five Dock) acknowledging their contribution to their local communities. Jean and Wendy each received a medal and a certificate signed by the Prime Minister. The sentiments expressed in Federal Parliament by Jean's local member, Mrs Hull, in announcing her Award apply equally to Wendy and the Network can be proud to have them as members: *It is with great pleasure that I stand here to applaud the work of volunteers, to applaud the work of senior citizens, to applaud the work of all those unpaid Australians who give so much to their communities in order to make Australia far richer and give a better quality of life for all people.*

Ed: If any other member has received one of these Awards and I've missed the announcement, please drop me a line so I can publish the details in an upcoming Newsletter.

Post-Polio Network Medical Register

Committee Member Dr Elizabeth Joyner has taken on the responsibility of compiling an up-to-date Register of medical and allied health professionals who have expertise in, and/or an interest in, evaluating and managing the late effects of polio and post-polio syndrome.

Elizabeth is taking a two-pronged approach. First, all members are being asked to recommend any health professionals they have found to be informed and caring. Second, a notice is being distributed to a range of professional journals and newsletters, inviting interested, knowledgeable and supportive health professionals to list their name and practice details on the Register.

Names on the Register will be provided to members on request. It must be understood, however, that the listing of a health professional in the Register does not imply an endorsement or recommendation by the Network. The Register is being compiled as a service to members, and individual members are responsible for making their own decisions about who they do or do not consult, based on their own individual circumstances. It is also important to remember that not every patient / health professional relationship is successful – for example, personalities in this area (as in all facets of our lives) do sometimes clash.

With the foregoing disclaimers in mind, you are encouraged to contribute to, and make use of, the Register. Our aim is for the Register to include relevant medical practitioners (including General Practitioners, neurologists, rehabilitation and chest physicians etc) and other health personnel (such as physiotherapists, occupational therapists, podiatrists, orthotists, speech pathologists etc) who are:

- * interested in and / or knowledgeable concerning the late effects of polio,
- * empathetic to those affected by the clinical sequelae of polio,
- * easily accessible for post-polio patients with walking difficulties, prostheses and wheelchairs, and
- * welcoming of additional post-polio patients.

Please contact Elizabeth Joyner at joyner@cia.com.au or c/o the Post-Polio Network, PO Box 888, Kensington NSW 1465 if you have a positive recommendation based on personal experience and after checking with the doctor / other professional concerned as to whether

- * he/she is willing to have their name appear on such a Register, and
- * he/she is willing to complete and forward the enclosed form which will clarify their facilities, and the services they offer for evaluating and managing the late effects of polio.



Following graduation in Medicine at Sydney University, Elizabeth Joyner embarked on a career in General Practice for over twenty years with emphasis on Family Planning / Women's Health. After a three year stint in rheumatology research, she opted for a calmer lifestyle pursuing interests in the arts. A growing concern and awareness of disability issues, with an increased sensitivity due to her own childhood experience of polio, led to membership of the Network and its Management Committee, where she hopes to be a useful team member.

Journey of a Nation – The Federation Parade and Centennial Ceremony

On 1 January 2001, Sydney will host two exciting events to start a year-long National Celebration marking 100 years since the inauguration of the Commonwealth of Australia in 1901.

Commencing at 4 pm, *Journey of a Nation – The Federation Parade* will present a showcase of Australia's achievements and challenges in the past 100 years through a spectacular parade from Macquarie Street to Centennial Park. Following the parade at 8 pm, *The Centennial Ceremony* will commemorate the momentous events of the past century from 1901 in a spectacular presentation in the Parade Ground of Centennial Park.

The New South Wales Centenary of Federation would like to invite you to participate in the Federation Day events by attending the parade or ceremony. You will also be able to watch both by tuning into the national television broadcast. Due to the large crowd numbers and distances between the events, you are encouraged to attend either the parade OR the ceremony. Both events are free.

The Centenary of Federation Committee is working to ensure that the Federation Day events are accessible to all Australians. A range of accessible facilities and services will be provided, and marshals will also be happy to assist anyone with particular requirements or needs.

The Federation Parade

- * **Registered Area with Accessible Facilities** – There will be an area in Queens Square which will have accessible facilities and services to assist people with a disability. Those wishing to attend the area must register by calling 1300 654 124. Please register by 22 December 2000.
- * **General Public Viewing** – Along the Parade route there will be accessible toilets and marshals to assist people with disabilities.
- * **Hot Spots** – For the best vantage points along the Parade, Hot Spots have been set up in Hyde Park, Taylor Square and Moore Park. Hot Spots facilities include screens showing the Parade, catering, live entertainment and accessible toilets. There will be no registration for the Hot Spots.

The Centennial Ceremony

- * **Registered Area with Accessible Facilities** – There will be an area which will have accessible facilities and services to assist the needs of people with a disability. Those wishing to attend the area must register by calling 1300 654 124. Please register by 22 December 2000.
- * **General Public Viewing** – The Centennial Ceremony will be a picnic style event. The Parade Ground at Centennial Park will have accessible toilets and marshals will be on hand to assist people with disabilities to access areas of the Park. The Ceremony will have screens and will show the coverage of the Parade from 4 pm onwards. There will be no registration for the general public areas.

A *Federation Day Access Guide* has been developed which includes information on the events, facilities and transport on 1 January. If you would like a Guide sent to you, please ring 1300 654 124 as soon as possible. Further information about Federation Day events is available on the Centenary of Federation website www.centenary2001.com.au.

Support Group News

Neil von Schill
Support Group Co-ordinator

Phone: (02) 6025 6169
Fax: (02) 6025 5194

The Network's Support Groups are now winding down at the end of another busy year and some are looking forward to their Christmas get-togethers. I pass on to all Convenors, their families, and Group members the Committee's best wishes for the festive season.

There is good news this issue about Network Support Groups in Orange and Dubbo.

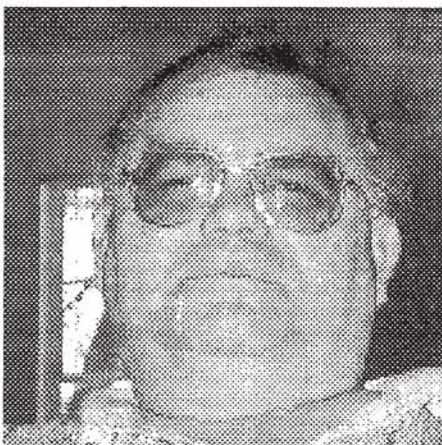
Susie Simmons in **Orange** has expanded her Support Group activities. *Post-Polio Awareness Week* gave her local publicity a boost and members in the Orange area are now getting together face-to-face for the first time. If you would like to join Susie's friendly group, why not give her a call on (02) 6361 0630.

Gregg Kirkwood in **Dubbo** has recently expressed an interest in starting a Support Group. I have sent him a Convenor's *Information Kit*, and will be catching up with him in person during the holidays as I visit my mother over the Christmas period. If you are interested in getting involved in Gregg's new Group, please contact him on (02) 6884 9108.

We still have many members who are not serviced by a Support Group in their area. As such they are missing out on local friendship and support from other polio survivors. If you are interested in getting a Group started, please give me a ring and I will provide you with guidelines and practical assistance. Our existing Convenors know it is not difficult or onerous to run one of the Network's informal Support Groups.

Towards the end of October, I sent all Convenors a copy of the Network's Media Release *Could Polio Be Affecting Someone You Know?* which described our new publication *Hospital, Medical and Dental Care for the Post-Polio Patient – A Handy Reference* to be launched during *Post-Polio Awareness Week*. We appreciate the support given by Convenors in getting the Media Release out to their local papers. In the last few years it has proven difficult for the Management Committee to devote what it considers enough resources to promoting *Post-Polio Awareness Week* in a timely manner. This has largely arisen because of the almost simultaneous timing of our Annual General Meeting (AGM), the preparation for which puts a huge drain on our volunteer Committee. Holding the Week in conjunction with the AGM affords some benefits in that the AGM provides a vehicle for launching new publications released to coincide with the Week. However, we believe the time has come to move the AGM. You will see from the Seminar Program for 2001 announced on page 2 of this Newsletter that the AGM will now be held in September, thereby freeing up resources to better promote *Post-Polio Awareness Week* next year.

Our Newest Committee Member - George Laszuk



I am 50 years young, and married with 4 children. I live in Western Sydney. Most of my working experience was in the transport industry, as a Despatcher and Operations Manager. I am presently employed by Optus Communications, as a Workforce Management co-ordinator, and have been there for 5 years. My youngest son was born with Down Syndrome. I then became actively involved with The Down Syndrome Association, and spent 15 years on their Committee. I was mainly involved in fundraising, and hope I can bring some of my skills to the Network's Committee.

Some of this Year's Memorable Events ...



Gillian Thomas, Peter Garde and Lynne Ellis ready to enjoy a sumptuous lunch at the Prince Henry Hospital 50 Year Anniversary held on 27 June 2000.

The Reunion was organised by Doug Sutherland with the support of the Network. Member Lynne Ellis lives on the Central Coast and generously reads each issue of the Newsletter onto an audio tape for the benefit of members who have vision impairment.



Gillian had the honour of carrying the Olympic Torch in Randwick on 14 September 2000. All dolled up in her official Torch Relay gear, she anxiously waits on her scooter for the Torch to reach her starting position.

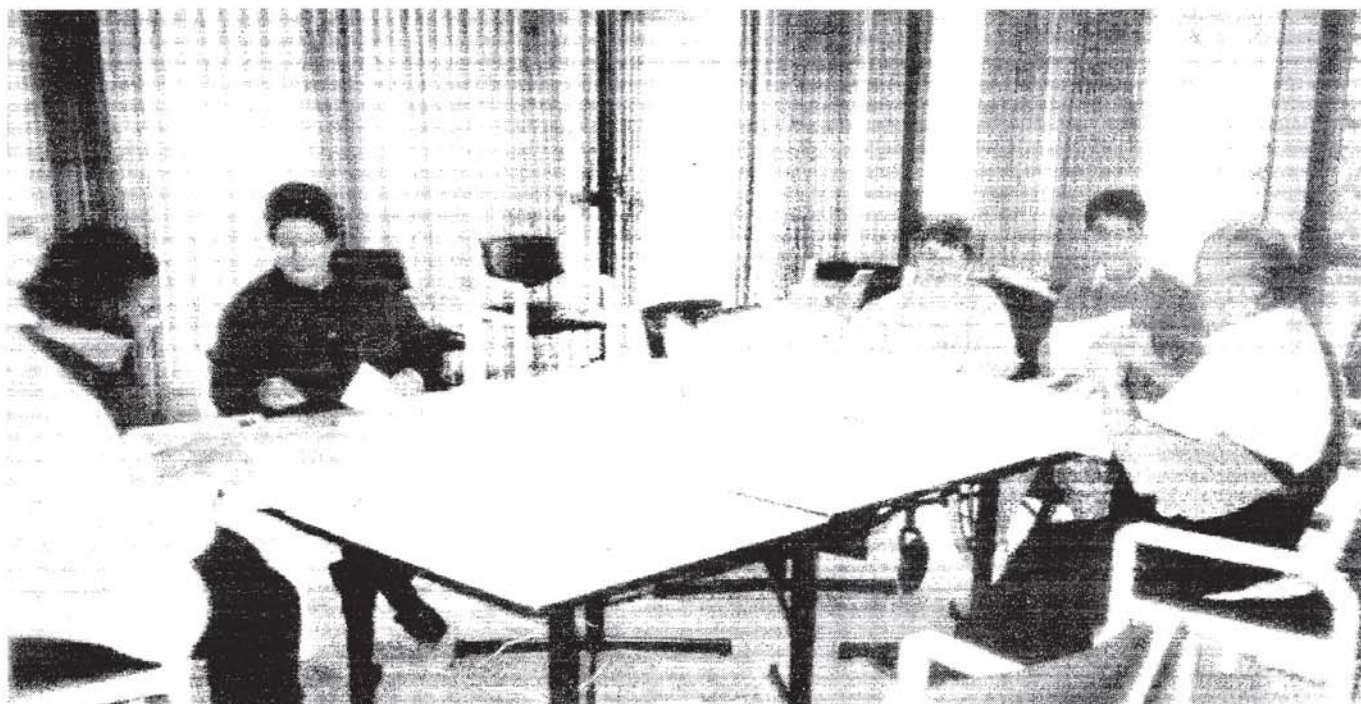


At the Randwick Town Hall after her leg of the Relay,
Gillian hands on the Olympic Flame to the next runner - Jim Kelly.
To transfer the flame they hold their torches together in an "Olympic Kiss".



After the run, Gillian meets up with her friends.
(L to R) Peter Garde, Anna McGee, Gillian Thomas, Alice Smart, Merle Thompson.
The Network's colourful T-shirts were out in force that day.

Some of the Network's Volunteers ...



An industrious band of merry Networkers in the middle of a *Newsletter* mail-out. With 900 *Newsletters* to be labelled, grouped and posted it's definitely all hands on deck, with some of the regular workers pictured above:

(L to R) Anne O'Halloran, Lesley Bromley, Gillian Thomas, Anne Buchanan, Gary Buchanan.
(Anne and Gary co-compile our quarterly *Information Bulletin*.)

Missing from this picture (because she took it) is Alice Smart who not only provides the venue and keeps the kettle boiling, but is kept on the hop making photocopies of things that simply have to get included in the mail-out.

Without these volunteers, Network members wouldn't receive eight mailings a year.



Allan Quirk's faithful assistance dog, Zuga, who recently had to be euthanised (see the tribute to him in the last *Newsletter*). Zuga was always willing to give advice, and to vacuum the crumbs from the floor after a Committee Meeting. We all miss him greatly.

Some Pictures from our Annual General Meeting ...



There was a tremendous roll-up at our Annual General Meeting held at the Independent Living Centre on 4 November 2000 with more than 50 members and friends in attendance. The seminar following the AGM was also very popular.



Gillian Thomas, Neil von Schill (Support Group Co-ordinator) and Mary Westbrook (Seminar Co-ordinator) relax at the conclusion of the formal AGM business.



After our Seminar in March, member Wendy Davies expressed her sentiments about what she had seen and heard. Our apologies to Wendy for not publishing her thought-provoking comments earlier.

What a great job you all do in organising the Network Seminars! I'm glad I made the effort to travel to Parramatta, despite getting lost on the way, being breathalysed by a charming policeman and being late into the bargain. My paralysing fear that "11 am sharp" would mean just that was groundless - the equipment failed to perform at the flick of a switch!

I'd missed the documentary, *A Paralysing Fear*, shown on ABC TV in October 1999 but I was spellbound at the depth of insight the program provided. There was so much for Australian polios to relate to that, for once in my life, I took notes. The dichotomies in issues were clear: shame/blame, isolation/ostracism, sense of letting parents down/anger at the body's failure to perform, disintegration of family relationships/integration into the community, different treatment of white/black, fear/acceptance, pity/cruelty, dependence/ independence, inclusion/exclusion from life's activities, self pity/sense of purpose, humour/ creativity.

The experience of polios can put them in a special place to relate to the experience of others. Migrants and their differences were blamed for the spread of the disease. They were subjected to ostracism and isolation, largely as a result of fear. Does this still happen in Australia? Black children were denied the treatments available to many whites. It's a familiar story, shocking but unfortunately true. The most beautiful part of the film for me was seeing the children from the school orchestra gather outside a home so that their iron lung clad former classmate could take part in the music! If only that sense of inclusion had prevailed in all our lives!

While polio has been eradicated from China and the Western World, it is still prevalent in South East Asia, the Indian sub-continent and Sub-Saharan Africa. India is hardest hit. Unfortunately, 70% of all polio sufferers now are under 3 years old. (And we all know what this means for families as well as the child afflicted.)

We all have the pain of our own experiences. However, who will forget the shudder which ran through the audience as the camera panned onto a boy, whose mobility was so affected, that he moved on all fours like a monkey? He lived in a country where begging in the street is commonplace. Yes, there were tears as I remembered my own experiences and thought, "There but for the grace of God go I". I'm sure I was not alone.

The service club, Rotary, has taken on the world wide responsibility of supporting a massive immunisation program. The biggest obstacle is raising funds to fight the disease if it is to be totally eradicated from even the most remote and inaccessible locations on earth. I wonder what can we as a group do to help Rotary achieve their goal?

There were two questions unanswered at the end of the documentary. Why was the virus referred to throughout as "he"? And what would have happened if President Roosevelt had insisted on showing his wheelchair, rather than proving his independence?

Following the screening of *A Paralysing Fear*, Carol Mara spoke movingly about her steps in writing *Iron Cradles*. It's hard to put the book down. Others have noticed it, including a receptionist who is doing her Masters in Psychology - her subject is "Fear". The book is a must read as it highlights the issues in the film, issues which will probably still dog those of us who were touched by polio.



The Management Committee
wishes you a
Happy and Holy Christmas
and a
Healthy and Peaceful New Year