# POST - POLIO NETWORK (NSW) INC.

# NETWORK NEWS

Editor: Gillian Thomas
Email: polio@fastlink.com.au
Website: www.post-polionetwork.org.au

PO Box 888 Kensington
NSW AUSTRALIA 1465
Phone No: (02) 9663 2402


*Patron:* ***Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS***

## President's Corner

**Gillian Thomas**

This Newsletter has a been long time coming as our volunteer resources have been stretched to the limit this year. For your patience, you have been rewarded with a bumper issue which should keep you in reading material for some time to come!

Another result of our over-stretched resources is that the Annual General Meeting (AGM) which was to be held on 22 September has been deferred until December. A Seminar is still being held on 22 September though – full details appear on page 2.

The AGM will now be held on Saturday 15 December, from 3:00 to 4:00 pm, in conjunction with a *Support Group Conveners' Workshop*. Holding the AGM at this time will also mean that many country Conveners who are usually unable to attend will be able to participate. We have been very fortunate to secure funding of $2,727 (excluding GST) from the Department of Family and Community Services' *International Year of Volunteers* grants. The funding will contribute towards Conveners' transport and accommodation costs to attend the Workshop, and the Mini-Conference to follow on Sunday 16 December. Support Group Co-ordinator Neil von Schill will shortly be in touch with Conveners about arrangements for the Workshop.

Plans are progressing for the visit by Dr Halstead and his wife Dr Jessica Scheer in December. The Management Committee has set the registration fees for the Seminar series in Canberra, Sydney and Newcastle as follows: members $40, carers/family $20, non-members $80. The cost will include a Conference program and light refreshments. Bookings will be essential and Registration Forms including venue details, dates and times will be sent out at the end of September. Raffle tickets will also be sent out at that time to those members who have indicated their willingness to buy or sell tickets to help fund Dr Halstead's visit.

A successful funding submission was made to Randwick City Council under its Small Grants program. Funding of $475 (excluding GST) was granted to help establish a Post-Polio Support Group in Sydney's Eastern Suburbs. The funding will enable a public meeting to be held, and will go towards venue hire, advertising, printing and postage, and light refreshments. Members in the region will be invited, as well as polio survivors living in the area who have previously not been aware of the Network. Attendees at the meeting will learn about the Network's support group structure, and how participating in a local support group can help polio survivors and their families better understand and manage the late effects of polio. While the major outcome sought from the meeting is the establishment of a Network Support Group, it is hoped that a model for the development of support groups in other areas of NSW not yet serviced will be another outcome.

Happy reading, and the Committee hopes to catch up with existing and new members alike at the 22 September Seminar.

# Post-Polio Network Seminar

## What Northcott's Equipment and Technology Services have to offer Network members

**Date:** Saturday, 22 September 2001

**Time:** 1:00 pm - 4:00 pm

**Bring a packed lunch to eat from 12:00 noon**
Fruit juice, tea and coffee will be provided

**Venue:** The Independent Living Centre
600 Victoria Road, Rye

Ample parking is available on the premises. It would be appreciated if those who are more mobile would leave the closer parking for members who are only able to walk or wheel short distances.

Ian Shearman, General Manager of Equipment and Technology Services at the Northcott Society, will present this Seminar. Northcott services include the sale of a wide range of wheelchairs and disability equipment, including environmental control units, the installation of home technology such as automatic doors, the manufacture of Knix wheelchairs and Northcott FreeWheelers, wheelchair and mobility repairs, and the manufacture of orthotics, seating and footwear. Northcott has recently tripled the size of these services with its purchase of the *Dynamic Living Designs* store at Auburn.

As usual, Ian's presentation will be interactive and will be followed by a question and answer period. Whether you are in the market for an orthotic or calliper, a pair of shoes, a wheelchair or other disability equipment, then this is one Seminar you won't want to miss.

*If this is the first Seminar you have attended, please introduce yourself to a Committee member. We look forward to seeing everyone there.*

## 2002 Seminar Update

**Dr Elizabeth Ellis** has accepted our invitation to present the results of her research into sleep-disordered breathing in polio survivors. She will speak at a Seminar to be held on Saturday **2 March 2002**. She reports that over 50% of the questionnaires sent to members were completed and returned to the research team – a very pleasing response rate. The data is currently being analysed.

We are also pleased to announce that the Seminar to be given by Canadian virologist and non-paralytic polio survivor, **Dr Marcia Falconer**, which was deferred this year, has now been re-scheduled to Saturday **18 May 2002**. We are planning to hold a day-long Mini-Conference and expect that Marcia will present topics including *Non-Paralytic Polio and Post-Polio Syndrome*, and *The PolioVirus - Getting to Know Your Old Enemy*.

Further details of both these Seminars, including venues, will be advised in upcoming *Newsletters*, but please note the dates in your diaries now.

# The Late Effects of ME

## Can They Be Distinguished From The Post-Polio Syndrome?

**Dr EG Dowsett MBChB, Dip Bact**

*Dr Dowsett is Honorary Consultant Microbiologist to the Basildon and Thurrock Hospitals NHS Trust and a Member of the [UK Government] Chief Medical Officer's Working Party on ME/CFS. This article was originally a presentation to the All Party Group of MPs on ME/PPS on 31 January 2001. The article is © Lincolnshire Post-Polio Network, was published in their Library in February 2001 and is reprinted here with permission.*

### Introduction

Few people would dispute that ME (myalgic encephalomyelitis), an illness which blights the hopes and aspirations of all sufferers, especially the young, is denied equal treatment in respect of diagnostic facilities, medical coverage and welfare provision. Comparable chronic and unpredictably disabling neurological conditions, for example, Multiple Sclerosis, which was formerly ascribed to “hysteria” and similarly neglected, now receive government recognition, facilities within the NHS, and more generous research funding - though the potential cost of effective treatment can still arouse bitter debate.

### What is ME? [1,2,3]

#### *Onset*

It is a syndrome (a group of linked symptoms) initiated by one or more of a related group of enteroviruses which circulate annually in the community in summer and autumn in temperate climates, but all the year round in tropical areas.

#### *Minor Illness*

The majority of encounters with these viruses are asymptomatic but some subjects, more commonly teenagers and adults, suffer a seemingly trivial minor illness, usually described as a non specific summer ’flu accompanied by gastrointestinal upset, sore throat and occasionally by generalised glandular enlargement.

#### *Secondary Phase*

The minor illness is self limiting in 90% of adults. However, some 5-10% of all age groups exposed, may progress to a more significant episode with severe headaches and vertigo, a stiff neck and back and generalised muscle pain, signifying that the central nervous system has now become involved with a possible progression to viral meningitis and encephalitis [3]. Clinical recovery at this stage is normally possible, but does not preclude further effects of the illness in later years. It has to he remembered that ME is a life-long disability where relapse is **always** possible.

#### *Final Stage [1,2]*

After a variable interval, a multi-system syndrome may develop, involving permanent damage to skeletal or cardiac muscle and to other “end organs” such as the liver, pancreas, endocrine glands and lymphoid tissues, signifying the further development of a lengthy chronic, mainly neurological condition with evidence of metabolic dysfunction in the brain stem. Yet, stabilisation, albeit at a low level, can still be achieved by appropriate management and support. The death rate of 10% occurs almost entirely from end-organ

damage within this group (mainly from cardiac or pancreatic failure). It has to be said that suicide in younger patients and in earlier stages of the disability is related to the current climate of disbelief, rejection of welfare support and loss of educational and employment prospects. It is an additional and potentially avoidable factor.

## What are the Late Effects of ME?

Most doctors with substantial experience of examining these patients would agree that the outlook for any individual is unpredictable. Case records need to be kept up to date for prolonged periods because patients who have remained clinically stable over 40 years or more and have worked normally for most of their lives are still subject to significant late effects. These include: overwhelming fatigue both physical and mental; cognitive disturbances; muscular and joint pain; muscular weakness and wasting; difficulty with breathing; episodes of hypothermia and low blood pressure; problems with swallowing and voice production as well as sudden attacks of breathlessness while sleeping. The similarities of these symptoms to those complained of by sufferers from the post-polio syndrome, is striking and requires further explanation.

## Which Group of ME Sufferers are Chiefly at Risk of the Late Effects? [4]

The majority of ME patients contract their illness in the 3rd and 4th decade (50%) with secondary peak at puberty (18%). The incidence at the extremes of age (below 10 years and above 50 years) has, until recently, been low (about 10% in each group). Epidemiological surveys made between 1988 and 1998, in 2 Essex hospital clinics dedicated to ME, indicate that the percentage of patients over 50 years of age attending with new illness has risen from 6% in 1988 to 16% in 1995 and 18% in 1998. Some patients indeed, present with paralysis. Others have a vague past history of illness in childhood. Some years of “weakness” or “growing pains”; recovery, but always poor at sport; possibly a stable work record for 25 years or more, followed by a decline in walking ability; unusual fatigue after simple tasks; problems with climbing stairs, dressing and with short term memory. The current age range of these patients is from 40-92 years, so it is not easy to dismiss their symptoms as due solely to “ageing”. Their social and medical problems are especially severe, as they share all the difficulties of access to remedial and support services complained of by other disabled people in the same age group. However, in the UK, there is almost nowhere to refer patients with suspected post-polio symptoms as the medical profession has largely forgotten or never experienced the many manifestations of that disease. Successful immunisation against only 3 polio viruses among some 69 enteroviruses currently in circulation is deemed to have solved all problems!

## What Is The Post-Polio Syndrome? [5,6,7]

Poliomyelitis is an acute enteroviral infection with a wide range of clinical manifestations and multi-organ involvement (a fact which was frequently overlooked by physicians dealing with large numbers of dangerously paralysed patients, between 1940 and 1950). Ninety-five percent of people who contract the infection remain symptom free or suffer only a trivial non-specific respiratory or gastrointestinal illness as in ME.

Some 5% of those contracting the minor illness develop muscle weakness or paralysis before more serious or fatal complications supervene. The diagnostic distinction between “paralytic” and “non-paralytic polio” was entirely arbitrary in the days of the big epidemics. In fact, the category of “non-paralytic polio” contained many patients with mild or temporary paralysis and with encephalitis, which occurs in patients reaching the later stages of this illness. Modern studies indicate that overt paralysis in these patients depends entirely on the percentage of spinal nerve cells destroyed. For damage to be visible as weakness or

paralysis at least 50%-60% of the nerves controlling muscular action must be damaged or destroyed. Thus, patients with less damage who may only have had a minor illness, and some who were asymptomatic can still present many years later with a classic post-polio syndrome.

Recent publication [6,8] of this information (originally derived from studies made in 1955) has resulted in a re-definition of the post-polio syndrome and will certainly include many patients currently seen in ME clinics.

## Suggested New Criteria for the Diagnosis and Assessment of the Post-Polio Syndrome [7]

a. A history of remote paralytic or **non-paralytic** polio, or findings on history, physical examination or laboratory and other technical studies compatible with damage to the central nervous system in earlier life.

b. A period of recovery.

c. A period of stable functioning for 10-50 years.

d. New symptoms for which no other explanation can be found. Many patients and research workers point out that the assessment of sufferers will now have to become more holistic, that standard electrical tests of muscle function (EMG) will have to be more widespread (and repeated), and that manual muscle testing must refer to repetitive activity and daily tasks rather than a single examination on the couch [16].

## Is it Possible that Many Patients Diagnosed as Having ME are Sufferers from an Illness Clinically Identical to "Non-Paralytic" Polio? [6,8]

Yes, undoubtedly! This is an important question with fundamental implications for further research into the diagnosis, treatment and prevention of both disabilities. Modern research published currently in a dedicated supplement of the American Journal of Physical and Medical Rehabilitation by the Editor and 3 leading research teams [6,8], indicates that part of the current difficulty in obtaining a clear diagnosis of the post-polio syndrome lies in the error of dividing acute poliomyelitis into "paralytic", "non-paralytic", "abortive" and "sub clinical" categories. It has to be recognised that there is a **wide range** of nerve damage in every patient. The post-polio syndrome may therefore include:

a. Patients whose nervous system damage was not clinically obvious at the time of diagnosis.

b. Those who had minimal paralysis for a short period and were misdiagnosed as non-paralytic polio.

c. Those patients suffering from infection due to **non** polio enteroviruses with potential to cause nervous system damage and the "post polio" syndrome, equal to that of polio viruses e.g. Coxsackie viruses A9, A7; Coxsackie B viruses 1-6; ECHO virus 9; Enteroviruses 70, 71 - all of which have been implicated in outbreaks of ME or epidemics clinically identical to paralytic poliomyelitis.

d. Patients with symptoms clinically identical to the post-polio syndrome whose nerve damage arises from some other cause, for example, local muscle problems due to metabolic dysfunction, the effects of persistent virus infection, immune reaction to fragments of viral genetic material etc.

It is essential that patients with clinical symptoms suggestive of post-polio syndrome should be referred to a Physician to exclude other nervous diseases (eg, Motor Neurone Disease), and especially those which are treatable.

## Is it Necessary to Differentiate Between the Late Effects of ME and the Post-Polio Syndrome? [8,9,10]

Not really, even if it were useful or practicable to do so at present, as the two conditions are clinically identical and similar in respect of neuroanatomical, neuroendocrine, neuropsychological electroencephalographic and other techniques, including brain imaging and molecular biology, as indicated by a remarkable series of research papers published by Bruno and colleagues over the past 20 years.

## What is the Evidence that the Late Effects of ME and the Post-Polio Syndrome Can Be Caused by Enteroviruses Other Than Polio Viruses 1-3?

a. [11] In 1948, the year in which polio viruses were first cultured, specimens from 2 children with clinical poliomyelitis, yielded a non-polio enterovirus, (eponymously called Coxsackie after the neighbourhood in which they lived). This finding opened a Pandora's box of some 70 previously undiscovered enteroviruses of which 14 strains were later found to have neurogenic potential equal to that of polio viruses.

b. [12] From the late 1940s, studies in the USA indicated that outbreaks of major or minor enteroviral illness (e.g. paralytic or non-paralytic and non specific “summer ’flu”) could be caused by varying proportions of virulent and non virulent polio viruses combined with other neurogenic enteroviruses, for example in Akron and Cincinnati [Table 1], Ohio (1947) Delaware and Connecticut (1949).

c. [13] In the UK, an outbreak of poliomyelitis affecting an Edinburgh housing estate from August 1961 to February 1962 (a period when polio immunisation with the Salk (injectable) vaccine had recently been introduced) provided evidence that a “mosaic” of enteroviruses, including Polio type 3, Coxsackie viruses B2 and B4, Echo viruses 5 and 15 could act in combination to enhance virulence in individual patients, to block the spread of polio virus type 3 and to interfere with vaccine efficiency. Each virus type appeared sequentially until the arrival of Echo virus 5 in November which ended the outbreak by the following February (as indicated by serial sampling of the local school sewer). It has to be remembered that a sudden change in the virulence and spread of enteroviruses in the 20th century has been due to alterations in human hygienic behaviour rather than to viral mutations.

| TABLE 1. 1947 OUTBREAK OF SUMMER 'FLU, CINCINNATI, USA [12] | | | | | | | |
|---|---|---|---|---|---|---|---|
| **DIAGNOSIS** | **CASE No** | **CSF CELL COUNT** | **VIRULENCE OF POLIO VIRUS** | **3 LABORATORY TESTS FOR COXSACKIE VIRUS (NON-POLIO ENTEROVIRUS)** | | | **SUMMARY OF LABORATORY FINDINGS** |
| **Summer Flu** | 1 | 0 | Polio HV | - | - | - | High virulence polio virus only |
| | 2 | 40* | Non paralytic polio LV | - | - | - | Low virulence polio virus & infection of CSF |
| | 3 | 3 | " | + | + | + | Low virulence polio virus & coxsackie virus |
| | 4 | 150* | " | + | + | + | Infection of CSF & low virulence polio virus & Coxsackie virus |
| **Non Paralytic Polio** | 5 | 734* | Polio HV | - | - | - | Only high virulence polio virus & infection of CSF |
| | 6 | 27 | Polio HV | - | - | - | Only high virulence polo virus |
| | 7 | 70* | - | - | - | - | Only Coxsackie virus & infection of CSF |
| **Paralytic Polio** | 8 | 107* | Polio HV | - | - | - | Only high virulence polio virus and infection of CSF |

**KEY** * Raised cell count in cerebro-spinal fluid indicates infection in the central nervous system
Polio HV - Polio type one, virulent.
Polio LV - Possibly polio type two, low virulence (non paralytic)
Coxsackie is a neurovirulent, non polio enterovirus

## How May Symptoms of the Late Effects of ME and Polio Be Explained? [9,10]

It has to be accepted that some degree of encephalitis has occurred in all these cases and that the **areas chiefly affected include the upper spinal motor and sensory nerve roots** and **the spinal nerve networks traversing the adjacent brain stem** (**a nerve centre controlling all vital bodily functions which is always damaged**). The most troublesome symptoms of both conditions are **progressive muscle weakness, fatigue and pain,** and the commonest cause of relapse **over use of repaired nerve networks and an inappropriate response to physical or mental stress** in combination with the **increasing effect of normal ageing.**

### *Fatigue*

This is almost always central and due to damage affecting the reticular activating system (which keeps the brain awake and alert as well as maintaining some control over muscular activity). Fatigue is characteristically intermittent, but profound and incapacitating and related even to minor activity.

### *Muscle Weakness and Wasting [14]*

This may have a central cause (as above) or a local origin due to loss of motor units controlling individual muscles (including the breakdown of repair to these over time). Metabolic, immune or ongoing viral injury to muscle fibres, are other possibilities where infection persists.

### *Pain*

This is a severe symptom which is difficult to treat and is usually due to dysfunction of the thalamus, an important sensory relay station in the brain stem. Failure to produce natural painkillers (e.g. endorphins and encephalins), may be an additional factor.

### *Inappropriate Reaction to Physical or Mental Stress*

This also arises from injury to the brain stem which normally controls the production of cortisol (a steroid required for stress control) via the hypothalamus, pituitary and adrenal glands. In the absence of an efficient response, even minor stress can cause catastrophic collapse in these patients. *NB*. Because of the many and varied symptoms arising from encephalitic damage to the brain, all symptoms reported, however bizarre they may seem, must be taken as possible evidence of organic disease.

### *Management*

Despite promising reports from the USA of anti-enteroviral agents [18], and of Dopamine receptor agonists [9] (to correct some deficiencies in neurotransmission) no specific medical treatment is yet available in the UK and the main principles of management rely upon **conservation of energy, reduction of stress, and simplification of manual tasks at home or at work.** These objectives cannot possibly be achieved without financial and social support, aids to mobility, house conversions and suitable rehabilitation facilities. In the USA it is claimed that (with counselling, if necessary, for those who find such adjustments to life style difficult) 91% of patients will stabilise in view of the fact that, at this stage, the disability is only slowly progressive. Patients have to be cautious about drugs, especially those acting on the central nervous system including psycho-active preparations and alcohol. In general, these patients need less anaesthetic but higher doses of pain killers than usual and more time to convalesce from surgery. There are now many new options for muscle problems including modern orthoses and corrective surgery.

## Comment [15]

a. **There has been little government interest or support for patients suffering from the late effects of ME or from the post-polio syndrome.** It is generally expected that survivors of polio will gradually disappear because of successful immunisation of the UK population 40 years ago. However the fact that "post-polio", by any other name, can arise from **currently** circulating enteroviruses has not been taken into account. The Chief Medical Officer's Working Party on ME (set up in 1999 and funded privately by the Linbury Trust) has made it clear that its remit is **only** with management, and that all discussion about the cause, epidemiology and social benefit requirements of these patients is ruled out. It seems that it will be difficult to advise on rational management in the absence of such vital information.

b. **The potential size and cost of the problem.** This is impossible to assess in the UK because no **official** epidemiological surveys have been made. However, increasing numbers of patient support groups and individual research workers have been making their own calculations. In the case of ME, prevalence appears to range from 300 per 100,000 to 500 per 100,000 in occupations at high risk of infection [2], but no information is yet available about the number likely to suffer late effects (except that it may have trebled in the last 10 years) [4].

   The number likely to be affected by the post-polio syndrome has been calculated as between 200-270 per 100,000 currently [7], but no account has been taken of survivors from non-paralytic polio which could easily double that figure. Possible costing for ME support has been based on 3 times the cost of maintenance for multiple sclerosis on the supposition that ME is 3 times as common [4]. The only costs that we can be **sure** of are those derived from the **failure of appropriate management**, and of **inappropriate assessments** which waste vast sums of money and medical time while allowing patients to deteriorate unnecessarily [16].

c. **Some Immediate Steps that Could Be Taken** [7,17,18,19,20]. These patients could be referred to NHS rehabilitation clinics and welfare facilities as for any other chronic neurological disease but physiotherapy must include exercise suitable for patients with some damaged muscle fibres which have been overused while others are normal and liable to deconditioning [7]. Separate "ME" and "Post-Polio Clinics" are more expensive and often inaccessible. We should be educating doctors and paramedics **now** about the very common and seriously disabling effects of neglect [7]. Rapid diagnostic tests for enteroviruses, anti-enteroviral drugs and possible vaccines are already in preparation here, or in use (in the USA) to deal with the tremendous burden of circulating enteroviral infections, (for example, leading to febrile respiratory infections, viral meningitis and myocarditis, let alone unnecessary admissions to hospital and inappropriate prescription of antibiotics in children) [17,18]. These methods could well be employed for the benefit of young people in the UK and to prevent the rising tide of ME in schools - the commonest cause of long term absence and subsequent educational deficit! [19,20]

d. **Research workers must be encouraged and appropriately funded to work in this field.** However they should first be directed to papers published before 1988, the time at which all specialised experience about poliomyelitis and associated infections seem to have vanished mysteriously! [11,12,13]

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# I Didn't Have Polio - Did I ?

## Marcia Falconer, PhD

Dr Dowsett and other researchers suggest that fibromyalgia, also known as myalgic encephalomyelitis (ME), is virtually identical to post polio syndrome. The acute illness caused by a group of closely related viruses, including polio strain 1, polio strain 2, polio strain 3, Coxsackie and Echo viruses, can be quite similar. Survivors of all these viruses have the possibility of developing virtually identical symptoms years after the initial infection. People who were diagnosed with polio call this group of symptoms, post polio syndrome or PPS. People who had Coxsackie or Echo viruses, or who had undiagnosed polio, call it fibromyalgia or ME. Those of us who had diagnosed polio can be assured that the problems we are experiencing have a physical cause and that there are some things we can do to help alleviate the symptoms; things such as pacing, using aids, and perhaps investigating some medical and alternative medical procedures. However imagine the problems encountered by people who had undiagnosed polio, or a related enterovirus, and now have PPS-like symptoms. Here is the true story of one such person.

Three weeks after the end of first grade, Ellen felt sick. She had a moderately high temperature and an upset stomach. World War II had ended four years previously and the family didn't have a car so her mother took her to the doctor by streetcar. Years later Ellen recalled the trip, especially the piercing headache made worse when the conductor rang a bell as he approached each cross street.

The doctor told Ellen to put her chin on her chest. Ellen remembered this because she did it even though it hurt. After taking her temperature, testing her reflexes and looking at her throat, the doctor told them to go home by taxi. Almost 50 years later, Ellen could still remember how good it felt to finally lay down on the cool sheets of her bed. After this, she recalled only snatches of events; a horrible backache, being carried from her bed to the bathroom, being unable to stand any light from the window. After an unremembered amount of time, she began to feel better.

Boredom. Ellen, still in bed, remembered the boredom and trying to cut out paper dolls, but her right hand and arm were clumsy and she kept cutting off "important" parts of dresses or the feet of the dolls themselves. In fury, she threw the scissors and heard it clunk against a hated piece of furniture. Her father had brought her old baby potty chair up to her bedroom. By grasping the arms of potty chair, Ellen could move from the bed to the potty and use it but the humiliation of doing this at the grand age of six, remained for a long time.

The rest of the summer she spent in bed or on the sofa. Her friends weren't allowed to visit though she remembered them waving at the window as they went off to do something interesting. Finally Ellen returned to second grade. At first she wasn't allowed to run during recess, but eventually she had no restrictions except those imposed on her by her body, and these she thought of as quite normal. For the rest of her school years Ellen was terrible at sports and hated them. Quite often she was tired. Dead tired, when everyone else thought she should feel fine and be helping the family to unload the car or some such thing. But the summer illness of her childhood was forgotten.

Fast-forward to 37 years later. Ellen now works as a secretary and does much typing. She's a two-handed touch typist but her right hand, arm and shoulder are starting to give her problems. The muscles twitch oddly after she does any repetitive work. But she ignores this.

Skip another 5 years. Ellen is a medical secretary and notices that she often "trips" while walking down the smooth hallway floors. And sometimes she is so unbearably tired that she can't think straight, much less function as a secretary. While taking a report to another floor, she trips and falls upstairs, badly bruising herself.

Ellen knows something is wrong and fears the worst. Her right arm and leg muscles are obviously getting weaker. There is almost continuous pain in her arm, leg and lower back. At night the muscles seem to have a life of their own, twitching so it's hard to fall asleep. Driven by desperation and fear, Ellen finally sees her doctor. After a general examination, the doctor pronounces Ellen to be fine. There is no obvious physical cause for her pain and the weakness she is experiencing in her muscles just means she needs to exercise more! And lose some weight.

Ellen takes on a program of aerobic exercise and muscle strengthening. She loses weight, but the pain and fatigue she feels from the exercise classes soon outweigh any benefits. She tells her doctor that exercise makes things worse, but the doctor either isn't listening or doesn't believe her. In frustration, Ellen leaves the doctor's office. It is getting hard to go up and down stairs and to open heavy doors, but since outwardly she looks fine, nobody believes her. At some point Ellen also begins to believe that it may be "all in her head".

Then at a chance meeting in a shoe store, Ellen meets Susan. Brought together by the difficulties of buying shoes when one foot is almost a whole size different than the other foot, they feel like kindred souls. Three hours later the two women are still talking and are amazed at their similarities. Sue's more understanding doctor has diagnosed her virtually identical symptoms as fibromyalgia, also called myalgic encephalomyelitis (ME), and suggested Sue join a support group. Ellen accompanies Sue to the next support group meeting and is vastly relieved to find that not only is there another person with similar problems, but there is a whole *group* of people who can relate to her problems.

If we were able to go back and diagnose both Ellen and Sue during their childhood illness, we would find that Ellen had polio, strain 2 virus, while Sue had a related virus, Coxsackie A7. The symptoms during their acute illnesses were virtually identical and the problems they are encountering some 35 or more years later also are virtually identical. One had polio, the other had a very similar disease that is just not called "polio".

Ellen does not know that she had polio as a child. The doctor never diagnosed poliomyelitis and she was never hospitalised. She only remembers bits and pieces of being sick the summer she was six years old. Unless she undergoes a series of tests, she will *never* know that her increasing muscle weakness and pain are due to previous polio. Rather than being able to learn what is useful and helpful to polio survivors who are experiencing post polio syndrome, Ellen will be counselled to do what is in vogue to treat fibromyalgia. Right now the suggestion is to "exercise away" the pain, something which may very well worsen her muscle condition.

People who were diagnosed with paralytic polio and have obviously affected limbs still have trouble convincing some doctors that post polio syndrome (PPS) is "real" and not in their heads or simply the result of using crutches for too long. People with a history of non-paralytic polio have even greater difficulty convincing the medical establishment that their fatigue, muscle weakness and pain are related to childhood polio. These people have a history of polio, either documented by hospital stays or by family stories but there are many people who had polio and don't even know it.

The statistics of polio look something like this: in 100 cases of polio (both diagnosed and undiagnosed cases), only 1 person will have paralytic polio. Ten people will have non-paralytic polio and all will have some nervous system damage which means they may develop PPS later in life. The remaining 89 people do not even know they had polio. The majority will have had no symptoms at all. Some had a fleeting stomach upset and felt a bit ill but none of these will have had nerve damage. However somewhere between 10 and 20 people will have had undiagnosed polio, possibly even paralytic polio as was the case with Ellen. These people are all at risk of developing post polio syndrome but will not realize that they had polio and hence will never even think of this as a possible reason for their symptoms!

Finally, nobody knows the infection rate for the viruses closely related to polio. But the number of cases is likely to be high with many undiagnosed. The symptoms produced by these viral infections are numerous, but include muscle weakness and/or paralysis in some cases. Because they do not cause visible epidemics of childhood paralysis, as the 3 strains of polio virus did before immunisation began, doctors and researchers do not considered them to be a problem. Perhaps, for 90 percent of the people who contract these viruses, there is no problem. But the remaining 10 percent - still a large number of people - may go on to develop fibromyalgia or other symptoms similar to those of post polio syndrome.

It is unlikely that people will devote sufficient money to developing a test to differentiate between people who had polio virus strains 1, 2 or 3 and people who had a closely related virus. Therefore, perhaps the best thing to do would be for doctors and people experiencing fibromyalgia, to initiate contact with people who deal with PPS. Perhaps, indeed, it is one large group of people who suffer from the same basic group of symptoms and who, together, can help each other deal with these problems in their lives.

# Tax Concession for People with Disabilities Buying Cars

The Tax Commissioner, Michael Carmody, has used his discretion under the Tax Act to allow people with a disability who meet the eligibility rules, including veterans, to replace a car GST-free as soon as it reaches 40,000 km.

Previously, those people who met the criteria to purchase a car GST-free had to keep it for a minimum of two years to be eligible for the tax concession.

“These changes will help people with a disability, especially those living in rural and remote areas who travel long distances for work or to attend city-based medical treatment and register high mileage”, Carmody says.

Those eligible include people who hold a current disability certificate from Health Services Australia, provided they intend to use it to travel to or from paid work and are unable to use public transport.

Eligible disabled veterans may replace their car GST-free once it reaches 40,000 km if they intend to use it for their personal use.

For further information about eligibility of the purchase of a car GST-free, call the Australian Taxation Office’s infoline on 13 24 78.

# Living Through A Hip Replacement Operation

## David Carter

*Member David Carter passes on his experiences with having a hip replacement in the hopes they might be of help to other members considering this option.*

I am now aged 60, but my hip problem started when I was a little boy of 7. I went down with polio and was left with a right leg with no muscle strength at all and a left leg with just enough to use.

I needed a full length, weight bearing calliper on my right leg, but my left leg was able to take weight, although a lack of strength in the quadriceps meant that I straightened that leg by throwing in back using my hip and bottom muscles. I also used a walking stick.

As any older post polio would recognize, this lead to a degeneration of the hip, and, by my mid fifties, I had the pain of an arthritic left hip, and knew that the only answer to the pain was to have a total hip replacement.

I also knew that, at my age, this was going to be one of the most important events of the rest of my life, and that I needed to do some careful planning.

I started off with a referral by my GP to that great friend of the Post-Polio Network, Dr Pesi Katrak, a consultant in Rehabilitation Medicine, at Prince Henry Hospital. He examined me at length, testing muscle strength and taking a most detailed history. He then spelt out that I should prepare myself for the inevitable operation by losing weight and taking more exercise. He also indicated that I would need to find a rehabilitation centre to go to after my operation.

I soon found that the one nearest to my home was Mt Wilga Rehabilitation Centre at Hornsby, and a referral from my GP led me to one of its rehabilitation expert with experience of Post Polio, Dr David Prendergast. He and I looked at the times when I could conveniently fit in the operation with my business life, and he recommended that, before the operation, I start a period of physiotherapy and hydrotherapy, to build up the muscles in and around my hip. He also told me that, if I did this by way of day admission to the hospital once a week, he thought he could obtain the consent of my private hospital fund for this treatment.

This proved to be correct, and I started a period of exercise on land and in the pool, the like of which I had not experienced for many years.

At the same time I obtained a referral to a local orthopaedic surgeon, selected after much enquiry and recommendation, Dr David Hale. With all my X rays and much trepidation I went off for my first appointment. He examined me at length, and then gave me the good news that my post polio musculature would not prevent me from having a hip replacement. Because of the combination of problems I presented, he asked me to see another expert for a second opinion, and I duly visited one of the most delightful of men, Dr Stephen Ruff, who confirmed that I was a possible candidate for such a procedure. He also confirmed that my exercise regime at Mt Wilga was a great preparation for the road ahead.

After some months of exercise, and with the pain in my left hip worsening, I went back to my orthopaedic surgeon to plan an appropriate time for my operation. He explained that, after the procedure, I would need about six weeks before I could get around, and before I could drive again, and we decided on an operation just before Easter, so that my work would suffer the least.

Among other places, he operated at my local private hospital, Sydney Adventist Hospital, so he booked me in and I went off to its pre-admission clinic.

That was a most reassuring time because the hospital staff spent a great amount of time letting me know what would happen to me before, during and after the operation. I also saw the physiotherapist, who examined me and explained the post operative treatment, which would be to have me up walking from day one onwards.

I duly entered the hospital and had a titanium and porcelain joint installed. The next day, true to their word, the physios had me up in a walking frame. A few days later I was in the hydrotherapy pool giving my new hip a workout.

After about a week, I was transferred to Mt Wilga Rehabilitation Centre where I was to stay for the next three weeks. That time was spent in physiotherapy and in the hydrotherapy bath. The occupational therapy staff took me back home and suggested various small changes that could be made to make sure I could cope when I returned home. We also practiced various ways I could get in and out of my car without the risk of dislocating my new hip.

When I was finally ready to come home, I was walking slowly but surely, using a single elbow crutch instead of my usual walking stick, the better to take some of the weight off my left leg. The muscles in my left leg were weaker because of lack of use but I was able to return to my business and start the road back to pain free living.

I am told that I can expect my joint replacement to last for my lifetime, and that the mobility of the joint and the strength of the surrounding muscles will improve with time and exercise.

# Join Us For A Day Out – Saturday 17 November 2001

We have been invited by member Sister Diadema, Evangelical Sisterhood of Mary, to visit the home of the Sisterhood at 30 Taylor Place, Theresa Park (near Camden) for a picnic and social get-together.

Born in the aftermath of World War II in Germany, the Evangelical Sisterhood of Mary has grown to be an international and interdenominational community. With their roots in the German Evangelical (Protestant) Church, they now have Sisters from many denominations and nationalities, as well as a small brotherhood. There are branches of the Sisterhood in various countries around the world. A branch was established in Australia in 1979, which serves as a base for their ministry in the South Pacific, South East Asia, and the Indian Subcontinent. At present, there are twelve Sisters from seven different nations at Theresa Park. In addition to celebrations at Christmas, Easter and other church holidays, the Sisters hold Days of Fellowship about 5 times a year, and their centre is open daily to visitors and groups.

There is plenty of parking at Theresa Park, and there are gentle pathways all around making it very accessible for those with walking difficulties, and for wheelchair users. You should plan to arrive for morning tea (around 10:30 am), bring your own picnic lunch, and aim to leave about 2.30 or 3.30 pm, depending upon whether you want to include the Sisters' 15 minute prayer time which is at 3:00 pm each day. Sister Diadema asked me to especially welcome men to come along – it is in no way an "all girl" event.

After morning tea Sister Diadema will take us all on a tour of her home, and show us over the print shop, gardens, chapel, and other points of interest. Lunch time is usually leisurely, with free time attached for wandering around the grounds, or for further questions. Tea, coffee, boiling water, and cold drinks will be provided by the Sisters.

Please join us for this all too rare opportunity to meet with other members in a social setting. To help the Sisters prepare for our visit, please let Alice know [(02) 9747 4694] before 7 November if you will be coming along. A map showing how best to get to Theresa Park will be included with the next *Newsletter*.

# Cultural Diversity in the Post-Polio Network

## Merle Thompson

A significant feature of the community of New South Wales is its culturally and linguistically diverse nature. In its planning session for 2001 the Management Committee decided that one of its aims for this year would be to assess how the Network reflects this diversity and to consider how we can more effectively assist a broader group of polio survivors within our community. In particular the Committee hopes to ensure that both the message of the existence of the Network and the information and services it provides are reaching people of an Aboriginal and Torres Strait Islander descent and people who are from a non-English speaking background.

Our initial steps in this regard include:

- Including questions on the membership renewal form to ascertain how many of our members are of Aboriginal and Torres Strait descent or of non-English speaking background.
- Initiating contact with Aboriginal health and advocacy services and the Aboriginal Affairs Department.
- Identifying other such organisations and services such as websites which we can use to increase our knowledge or to reach out to communities.
- My attendance at a workshop conducted ACROD in association with the Multicultural Disability Advocacy Association of NSW (MDAA) on Cultural Diversity and Service Access for disability organisations.
- Joining the MDAA email information group.

There are a number of reasons for this type of action – legal under various anti-discrimination acts, economic and social justice. It was said at the workshop that if an organisation does not reach all groups in the community it is putting 100% of its resources to only 75% of the population.

The workshop explored issues which should be considered when setting up a model for the organisation to follow for improving the cultural diversity of its services. There are a few factors which are essential whatever model one uses:

- Identification of who are members are and who in the community accesses our services; is our information gathering adequate for us to know this without being too intrusive?
- What barriers are there which limit people from accessing our services?
- Have we identified what communities we need to contact?
- Is our information accessible and easy to read?

It is this type of assessment we need to make. There are obvious issues such as availability of material in other languages but it is not necessary to go to the expense of translation if the need is not there. There are other more subtle things which could make our services not culturally appropriate for all our actual or potential members. Language style; community attitudes and ways of handling disability; cultural approaches to talking about oneself and one's difficulties and attitudes to being dependent or reliant on others are all significant. Even the way we have refreshments can be inappropriate for some people. An obvious issue is that we always have our seminars on Saturdays which prohibits participation for people of certain religious groups.

The Committee would welcome comments from members, in confidence to Gillian or myself if you prefer, on any matters which you consider relevant.

We would also welcome the assistance of members who belong to community groups, or who speak other languages, in providing information on their communities and how we might best reach polio survivors in your community. Help with simple translations or contact with community newspapers, radio stations and so on would be of assistance. You might also like to share with us the different experience of polio in your homeland.

If you can help, please contact Gillian on (02) 9663 2402 (PO Box 888 Kensington 1465, Email: *polio@fastlink.com.au*) or me on (02) 4758 6637 (PO Box 38 Woodford 2778, Email: *mkthom@bigpond.com*).

# Keeping Post-Polio Syndrome on the Political Agenda

*Although we may not have achieved our goal of having further debate in Federal Parliament on post-polio syndrome, Network members nevertheless did much over the last several months to raise politicians' awareness of the late effects of polio, and of their impact on our lives. The Committee is very grateful to all members who took the time and trouble to ring, write to or visit their local members. On 1 May members of the Committee met with Jenny Macklin, Federal Shadow Minister for Health, and discussed a range of issues of interest to Network members. In May we also received the following letter from the Federal Minister for Health Care and Ageing, The Hon Dr Michael Wooldridge, in response to our representations.*

Dear Ms Thomas

Thank you for your letter of 31 December 2000 concerning the needs of people affected by Post Polio Syndrome and requesting support for the Post Polio Network. I sincerely apologise for the delay in responding.

I have noted your requests for support of the polio networks in each State, the need for assessment clinics, the need to educate health professionals on Post Polio Syndrome and the fact that many polio survivors have had to retire early due to their polio-related difficulties.

Some of your requests fall into the category of being disability issues rather than a vaccine preventable disease issue, even though the original cause was an infectious disease. I have referred the matter of support for people affected by Post Polio Syndrome to my colleague Senator the Hon A.E. Vanstone. Her Department of Family and Community Services includes a Branch which addresses the problems faced by people with disabilities, particularly in the area of support funding.

You express the concern that many general practitioners and other health professionals lack expertise in recognising and treating Post Polio Syndrome. As part of the implementation of its Enhanced Primary Care initiatives, the Commonwealth Government has supported activities aimed at increasing the awareness among general practitioners of the importance of community support organisations in the management of patients with specific chronic conditions. I anticipate that this will create a climate of improved acceptance by the medical profession of organisations such as the Post Polio Network. You also requested special assessment clinics to assess and assist people affected by Post Polio Syndrome. Under the Health Care Agreements, responsibility for the provision of specialist health services such as these lies with each State and Territory government.

You may also like to note that in 1997, the Government introduced the Immunise Australia Program - Seven Point Plan. The Immunise Australia Program is a joint Commonwealth and State/Territory initiative and includes, among other strategies, the provision of free vaccines to all providers. One of the major outcomes from the Immunise Australia Program has been to increase vaccination coverage rates from 53% in 1997 to greater than 90% in the year 2000. Recently you joined me for the announcement that immunisation rates for infants at 12 months of age had reached 91.3%. This is very reassuring for the hundreds of dedicated persons who have been working diligently at this task for the past five years.

This success underlines the importance of sustaining high childhood immunisation rates and dispelling any feelings of complacency. Another success attained in October 2000 was the declaration by the World Health Organisation (WHO) of Australia (as part of the Western Pacific Region) being "polio free", that is, free from the transmission of wild poliovirus. While this is great news in the world of communicable diseases, it is distressing to find that people who have suffered and survived the polio epidemics of the forties and fifties are now succumbing to the symptoms of polio again, under the name of "post polio syndrome".

Thank you for raising these issues with me and I will follow with interest the progress of support for Post Polio Syndrome groups.

*We were pleased that Dr Wooldridge appreciates the problems that polio survivors are now facing. I would like to be able to report that we subsequently received a positive response from Senator Vanstone but, alas, we have had no response at all! Similarly, our representations to the NSW Health Minister, the Hon Craig Knowles, resulted in a curt reply that he was unable to find any time to meet with us; he failed to address, or even acknowledge, any of the substantive issues we raised. In the International Year of Volunteers the Committee finds the lack of meaningful response from both levels of Government extremely disappointing, and will continue to press for positive outcomes.*

# Network Members in the News

## Maree Dent

Member Maree Dent, Bellingen, contracted polio at 6 months old and was left with weakness on her right side and in both legs. At the age of 11, Maree developed epilepsy and her disabilities forced her to stop conventional schooling in year six. Her life continued as a litany of denied opportunities and institutionalisation. But Maree's strong spirit is now winning through. She lives by her affirmation "I refuse to give up, no matter how hard the going gets!". Maree grew up in rural NSW, where she learned to love the Australian bush. Her passion for the environment lead her to enrol as a mature-aged student in Landcare and Environment Studies at *Open Training and Education Network – Distance Education*, to gain a fuller understanding of nature and environmental issues. In recognition of her progress in this course, despite her multiple disabilities, Maree recently had the thrill of travelling to Sydney to receive a NSW Disability Council *Achievement Award*. Despite now experiencing the late effects of polio, Maree continues to work hard to achieve her goals. She writes "I am a person who has to be kept occupied, always anxious of learning. Next year I'm going to continue doing my School Certificate." Well done, Maree!

## Maureen Donnelly

Following decades of voluntary work on committees in secretary and treasurer positions, Member Maureen Donnelly, Cessnock, was honoured with a *Premier's Seniors Achievement Award* in 2000. Along with 10 others from across the State, Maureen accepted the prestigious award from Premier Bob Carr at a ceremonial lunch in Sydney. Maureen contracted polio in 1948 and spent the next two years in various hospitals around Newcastle. Her community work covers a range of interests from the Cessnock Dog Club, where she is the chief instructor, to the Art Society to the Lower Hunter Temporary Care at Kurri, a respite service covering Cessnock, Maitland to Port Stephens. Five years ago Maureen pushed to set up an Access Committee within Cessnock Council to lobby and advise Council on issues of access in public spaces, which Maureen believes has been pretty successful. Out of interest and as an aid in her various committee roles, Maureen has completed two-and-a-half years of Information Technology courses at TAFE and built a web site for the Lower Hunter Temporary Care service. It is easy to see why Maureen thoroughly deserved a *Premier's Seniors Achievement Award* and we give her our congratulations.

# Countdown to a Polio-Free World

*The World Health Organisation, UNICEF and Rotary International are campaigning strongly to finally eradicate polio. A series of global briefing were held earlier this year to encourage world-leading corporations, foundations and philanthropists to contribute towards the eradication effort. However, the battle won't be over for polio survivors, young and old, until appropriate assessment and treatment facilities are available. Polio Networks around the world now have the unenviable task of convincing governments and health authorities not to rest on their laurels but to put as much energy into understanding and ameliorating the late effects of polio as they have put into eradication of the virus itself.*

*We are therefore grateful to members Shirley Whitcroft, Brian Wilson, David Luck and Roger Smith who spoke at Rotary meetings in Sydney and Canberra during February and March and raised the awareness of the impact of polio and its late effects on our lives. Les Whitcroft is a past District Governor of Rotary International and a special invitation was issued to his wife Shirley to tell her story at Rotary's "Polio Eradication Private Sector Campaign Briefing" held on 4 February (she was such a hit she was lined up by Rotary for a repeat performance on 7 August). Shirley has kindly given us permission to publish her presentation "Polio Up Close".*

Les and I had only been married just under four years when the Infantile Paralysis epidemic broke out in Melbourne during the spring of 1949. Having an 18 month old daughter I was terrified *she* would contract it. I never imagined that *I* would be the one.

I remember the day well. It was a Wednesday and I felt distinctly "off colour". I went straight to bed after dinner that night and stayed in bed the following day. By Friday I developed a bad backache and the local doctor said "Oh, don't worry, everyone thinks they've got polio these days if they have aches. You have probably just strained your back." If only that was the case. I was so ill on Saturday with a blinding headache and a high fever that a specialist came to see me. He took one look, rang for an ambulance and next thing I found myself being taken to the Fairfield Infectious Diseases Hospital.

The only medication available at the time was a few aspirin. It was not until Monday or Tuesday that the paralysis set in. My legs and feet got heavier and heavier until gradually I couldn't move them. My back and stomach muscles were also markedly affected. The doctors put my feet and legs in plaster with a board through the heel to keep my legs 18 - 20 inches apart. You can't imagine the obsession one gets to move and turn over. Occasionally they would turn me on my side but in a few minutes I ached so badly I had to return flat on my back. I wasn't even allowed a pillow. Our meals were plonked on our chest and we had to eat it as best as we could without even seeing what it was! For the first three weeks I was not allowed any visitors - that included my husband. As you could imagine, I was worrying as to what had happened to my daughter and who was looking after her while Les was at work.

As the only treatment was physiotherapy twice a week I felt I might as well be at home. So, after a month I was discharged from the hospital. The Health Department supplied a physio and a nurse came each morning to wash me and make the bed. My parents came down from Brisbane to look after our daughter, Diana, and after Christmas they took her back north live with them. They had her for 18 months and by the time she came back to us, we were complete strangers. This separation affected her tremendously. She was too young to understand what had happened. All Diana knew was that she was taken from all the people she loved and felt secure with, to go to her grandparents that she did not really know.

I cannot recall what I did in bed all day on my own. My mother in law, who lived next door, would bring me in some lunch each day and provide a meal for us at night. As my bed was located in a west bay window it would get very hot during the day. So I had a fan to keep me cool. Unfortunately, it did not oscillate and so I developed Bell's Palsy - or, in layman's terms - paralysis of the face. If I could have crawled to the gas oven I would have put my head in it. The facial paralysis took a month or so to disappear. In the meantime, I had a great pink gadget glued to my teeth to keep my lip and the right side of my face up. I could not close my right eye and, as such, it just ran all the time.

By now, business was going well for Les and he was being transferred to Sydney. The only problem was that the specialist said he really wanted to keep me in bed for a few months longer. Whatever for, I can't imagine! When I explained to him why I had to get up, he then agreed saying that I should cut my losses and get on with life.

My first attempt to walk after being practically flat on my back for 18 months involved two steps forward and two steps back to bed! For my husband, it was a miracle as the specialist had told him early on that they never expected me to walk again.

With time we came to Sydney and I had to wear a long straight iron on my right leg. The Lord was very good in providing me with a wonderful English woman who helped me five days a week in the house and prepared the evening meal. I can't imagine how anyone who couldn't afford help would have coped with a house and a family. Diana came back to us several months later. We had to get used to each other and she seemed like a brand new daughter.

Well, I got on with life and we had another daughter, Prue. By then I had started to drive our manual Mini Minor car (which had been fitted with a hand accelerator) with my right foot resting on top of a book on the brake. There were no indicators and what with hand signals, the hand accelerator, holding the wheel and changing gears, I did not have enough hands. I drove cars like that for 15 years until automatics were available. I have never had an accident in all the years I drove!

It may seem to you that since my recovery I was able to live a reasonably normal life. Yes, I was able to run my home, cook and entertain, shop, travel, attend our beloved football games, even help out at the school tuckshop and do some gardening (well, that is if you can call hanging upside down over a stick "gardening"!). However the hard reality was that I had to watch every step that I have ever taken, to ensure that I would not lose my balance and fall over; I have never been able to get down on my hands and knees and scrub a floor which has always meant that we have needed help in the house; every time I get off a toilet, bed or chair I have to push myself up with great effort as my legs could no longer do the work for me and if I ever did lose my balance I would fall and I would have no means of getting up unless someone came by to help me. You can't imagine the embarrassment and loss of dignity to fall over in public and not be able to get yourself up. I could no longer share a game of golf or tennis with Les or my friends, and I have not been able to "hurry along" or run since that fateful day in 1949.

I never thought that further deterioration (aside from just plain "getting older") would occur. No one knew back then that the polio virus remains dormant in a victim's body and its symptoms can reoccur further down the track. [*Ed. Shirley is referring here to the late effects of polio and post-polio syndrome*] I never thought that one day I would lose the independence that I had fought so hard to regain all those years ago.

Now I can no longer shop unaided, cook a meal or get out of a chair on my own. As for using public toilets or sleeping on a regular bed - they are impossible. This means that I can no longer travel, stay overnight with friends, or even take myself out onto the patio and sit and enjoy the sun. I think this is what has hit me the hardest. Having to rely on other

people to do so much for me. I get very impatient when something needs to be done and I cannot do it. I cannot even freely stand to butter a piece of toast or fold a serviette without needing to do it sitting down. As I come from a family of "long livers" I try not to think of my future. It is frightening. Losing all your independence is one of the worst things to bear and I hope that I can do something in the world to prevent anyone else having to suffer as I have all these long years - 51 to be exact.

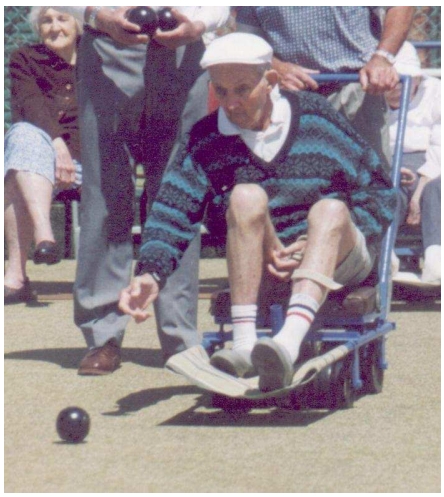
Although this was 51 years ago, only one infected person could come into Australia and there could then be hundreds of people ending up like me.

You see, not everyone who contracts this virus has had the support of a wonderfully loving and faithful husband like I have had. Not everyone who contracts polio has the financial means to have help in the home, physiotherapy each week, and afford one of the early few private pools in which I could exercise my legs. We have been able to modify our surroundings in accordance with my changing needs. I have been blessed in many ways. What if I had been a 27 year old Nigerian girl who lived in a poor village? My life could have been very different.

It is because of this that I believe the program to eradicate polio in the world is worth every dollar spent. When we have finally achieved our target all the work and planning done over the years by so many wonderful individuals and organisations will be worth it.

## Bowlers on the Central Coast – Brian Wants You !

For some time now, bowlers with disabilities have enjoyed a social outing and exercise at the Toukley RSL Bowling Club on the fourth Friday of each month (February to November). Member Brian Nash (pictured at right in full swing) is trying to build up numbers and encourages other members to join the group. Bowls uniforms are not necessary, but correct footwear must be worn. Lunch is provided at the Club for $3.00. Limited transport is available. Brian reports that the Toukley Club has gone to a lot of trouble to provide special wheelchairs (such as that pictured) for those who need them. For more information, please contact Brian on 0412 204 945.



## Bill and Jim – Winners Again !

While we are on the subject of lawn bowls, we were thrilled recently to learn that members Bill Bradley and Jim Newton were each winners in their respective singles divisions at the *Australian 2000 NSW Open State Wheelchair Lawn Bowls Championship* held in November 2000. They are pictured at left proudly showing off their magnificent trophies. Past Network Treasurer, Marianne Newton, also had a successful competition, coming third in the Ladies Pairs.

# A Tribute to My Mother

*Member Winsome Sutton from Port Macquarie recently sent her fascinating polio story. She writes: I am enclosing a short story about my very caring Mother which I thought might be of interest. Having two daughters who contracted polio must have been a great sorrow to her. I might add we were both isolated cases as there were no epidemics that my family was aware of, at either time.*

In 1909 when my sister was six months old, she was diagnosed with infantile paralysis. Mother took her to Newcastle from the country from time to time for adjustment for her calliper and any treatment available.

When I was 2½ years old and my sister was 15 by then, I too was diagnosed as having infantile paralysis so I was taken to the specialists in Newcastle who gained their knowledge of treatment (very sparse) from U.K. In 1925 our maternal grandfather told Mother of the remarkable improvement to one of his students who had undergone surgery for his paralysis by Dr Max Hertz, so off we went to see him in Sydney. Dr Hertz performed two operations on my sister's left leg which enabled her to discard her calliper and to wear shoes, one of which was designed and especially made for her smaller foot. She was able to lead a very active life and I remember walked a lot and it was hard to keep pace with her when she was in a hurry!

Dr Hertz advised Mother how to massage my ankle and suggested she take me take to him after a year of massage. I can still remember going to sleep every night while my wonderful Mother massaged my ankle. Alas, after a year my ankle was still very weak and Dr Hertz performed an operation transplanting the muscle from my big toe into my ankle. I was in plaster for some weeks. The operation proved very successful although over the years Mother continued to have orthotics made for me and later it was found that building up the outer side of my right shoe with a slither of leather was even more satisfactory.

During my younger years I played tennis vigorously and did a great deal of bush walking. Both my sister and I had interesting business lives in accountancy and many times were thankful for our Mother's loving care and Dr Hertz' brilliance.

My sister died when she was 64 after a successful of coronary occlusions. For about 8 years prior to her death I noticed her leg became very weak and some days gave her a great deal of pain and I can now recognise the onset of post-polio syndrome but it was not known then.

My own pps has been troubling me for the last 6 years and quite by accident the syndrome was acknowledged and I was helped thank goodness. Previously we were told it was old age.

I have become a Tai Chi enthusiast in the last 9 months and through these gentle exercises I am coping much better.

# For Sale

Second-hand electric wheelchair in excellent condition. The hand controls can be mounted for either left- or right-hand use. The wheelchair can be taken apart for transportation in a car. It comes with new batteries and a tyre pump. This wheelchair is being made available to Network members at a special price of only $1,500. Please ring Lyn on (02) 4368 2826 for further details.

# Polio Particles

## Mary Westbrook

*Polio Particles is compiled by Mary Westbrook as items 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, information about immunisation and the status of global polio eradication, and other items of interest. Mary's series is now being syndicated around the world as other post-polio newsletter editors pick up on the interesting items Mary includes.*

### Type 2 poliovirus eradicated

On March 29 Associated Press reported: *One of the three strains of polio has apparently been wiped out – a milestone in the global effort to eradicate the paralyzing disease. The World Health Organization said on Thursday that the global network of laboratories that tracks the disease reported no new cases of Type 2 polio in 2000. The last recorded cases were in India in 1999*. There are three main types of the polio virus. Originally they were named after the patients in whom they were first isolated — Brunhilde, Lansing and Leon. Then they became known as Types 1, 2 and 3. Type 1 is the virus most frequently isolated in cases of paralytic polio and Type 2 the least commonly found in such patients. Infection from one type does not confer protection against the other two types.

### Being a person with an eradicated disease

Polio survivors experience mixed emotions when they hear talk about the eradication of polio, particularly from justifiably satisfied public health officials. We have survived polio but we still have to cope with its effects on a daily basis. I recently read a book, "*Sorting Things Out"* (by Geoffrey Bowker and Susan Star) which discusses medical classifications of illnesses and consequences of their applications. When the authors talk about the issue of time and disease they give the example of polio. *In September 1994 the World Health Organisation sent out a world-wide press release about the eradication of polio from the planet. A year earlier sociologist Fred Davis, who suffered polio in his youth, and was one of the most eloquent analysts of uncertainty in illness died of a stroke at the age of 65. Was polio eradicated for him? Was this stroke in part the legacy of his earlier illness? Many of those who had polio in the 1940s and 1950s are now beginning to lose their ability to walk as their overburdened spinal cells, designed for backup purposes, are wearing out after years of tough therapy and rehabilitation. Is the disease thus eradicated or delayed? In the lives of these patients, the answer is not so clear*. I sometimes wonder if it would be more accurate to say "I have polio" rather than that "I had polio" so I was interested to read a comment by Professor Sharrad who began researching polio at the time of the epidemics. Sharrad was quoted in the February LincPin (Newsletter of the Lincolnshire Post-Polio Network) replying to a question about late effects of polio: *What you are describing is polio fullstop. It does not go away, you did not HAD it. You have it. Polio has the most remarkable recovery system and that is what you have lived with and without which you would have remained at your worst. You are just describing what we knew could happen to you in your later years. It's just polio.*

### "Passage through Crisis" – a polio classic

Among the books written by Fred Davis, mentioned above, was "*Passage through Crisis: Polio Victims and Their Families"*. It was published in 1963, was last reprinted in 1991 and is still around in libraries. Davis studied the impact of polio on 14 American children and their families in 1954-55, just prior to the introduction of the Salk vaccine. The families were interviewed at regular intervals beginning in the week of the child's admission to

hospital and continuing until 15 months after discharge from hospital. One of Davis' most striking findings was that although obvious and abrupt changes occurred in the families over the two years of the study (eg the changes in the sick children's interactions with their siblings, the negative reactions to the children's handicaps by their peers) each *time parents were asked whether anything seemed changed, whether anyone in the family felt or acted differently toward the handicapped child, whether the child acted or felt differently about himself almost invariably … the answer would come back that nothing had changed*. Maintaining a sense of sameness and stability in their lives helped families survive the crisis Davis believed. He found that there were two main ways in which families did this. One strategy was denying that their child's disability had any social significance. Parents would make light of the disability, explain it away, and insist that others regard their child as normal. An example was Laura's mother. Laura had callipers, a pelvic band, and used crutches. Immediately she left hospital her mother re-enrolled her at her old school and insisted that no special arrangements be made although help was essential. The pretence of normality required enormous effort on Laura's part and resulted in upsetting experiences, as she could not manage public transport. The other less common strategy was insulating themselves from contacts and situations that would force them to admit that they themselves, and others, regarded their child as disabled. An example was Marvin's mother who discouraged him from joining groups or making friends with disabled or able-bodied children. Marvin's shame led him remove his brace with her tacit approval resulting in a fracture. Although Davis acknowledged the *callous, depersonalized and deadeningly routine treatment meted out in hospital* he did not believe the changes that we have seen in the care of hospitalised children over recent decades were possible.

## Bradman hailed for polio cure

This headline appeared in the News section of *Cricketline.com* after Bradman's death. I knew that the Don walked on water but curing polio was news indeed! Chris Salter of the Lincolnshire Post-Polio Network who sent me the item commented that it was a *contender for the most overstated and inappropriate headline of the year*. According to the article Kim Beazley claimed Bradman helped cure him of polio by mailing Kim's father a set of exercises. Beazley said*, As I used to sit down scrunching up towels between my toes Mother would say to me: "Well, Don Bradman says you have got to do this so you better do it." I can't say I liked the exercises, but they were help*. The Sun-Herald reported that Bradman's son John contracted polio when he was 12 in 1951. *He spent the best part of a year in a steel frame and underwent daily therapy. During this dark and worrying period for the Bradmans, John's recovery was never certain. However after a courageous fight, he overcame the illness and became a champion athlete* (hurdler). *But for a knee injury he could well have represented Australia in the 1956 Olympic Games*. Perhaps the list of exercises that Bradman passed on were those given to John by his physiotherapist.

## Wheeling tortoise

The March issue of *Link*, the Australian magazine that examines disability issues, reported the story of Doris a 50-year-old paraplegic tortoise. She has weak rear legs due to a degenerative disease. Her vet glued a plastic base to the underside of Doris' shell and fixed wheels to this base. The vet said this helped *the tortoise achieve a better quality of life* but warned that *this treatment can only be carried out by specialists highly trained in tortoise diseases. I would strongly advise people not to try this at home.*

## Are you a sleepwheeler?

This story was recently told to me by a British GP: *I received the following request for a home visit yesterday: 'Request visit. Cannot get to surgery. She is in a wheelchair. Keeps sleepwalking'. Curious, I phoned the patient who confirmed that she couldn't walk. I asked how she then managed to walk in her sleep. She replied that she 'sleepwalks' in her wheelchair.* The doctor wants to know if I'd heard of any similar sleepwheeling experiences.

## Changing views of Salk and his vaccine

*Which one of these words best describes Jonas Salk: a) altruist, b) pure scientist, c) chump, or d) all of the above?* asked Ellen Goldman in the Boston Globe (1/3/01) in an article titled *"Scientists Now Go For Gold"*. She continued: *The man who discovered the polio vaccine never made a penny from it. When asked who owned the vaccine, Salk answered, "the people" …. What would have happened if he'd begun his research today? Would the funders and the institutions have preferred that he apply his genius to a cure for baldness or impotence rather than polio? Would the scientist himself have held out for a piece of the vaccine action?* In 1990 Jane Smith wrote a book on the discovery of the Salk vaccine. Its title, "*Patenting the Sun",* came from a comment by Salk on TV the night it was announced that his vaccine was safe. When the reporter asked who owned the patent, Salk replied, *Well the people I would say. There is no patent. Could you patent the sun?* In fact lawyers had advised the National Foundation for Infantile Paralysis who funded the development of the vaccine from donations, that no patent was possible since neither the processes nor the materials used in the vaccine were new. Of course they were put together in a novel way to create the vaccine. Salk never received the Nobel Prize largely because of the opposition of scientists such as Sabin who dismissed his work as unoriginal. Smith quotes Sabin as saying that *there was NO evidence to say that it* (polio) *was conquered* (by Salk vaccine)*, and it was NO breakthrough … There was no new science in that vaccine. There was a hell of a lot of new science in the oral* (Sabin) *vaccine.*

In 1990 when Smith wrote her book the Sabin vaccine was considered better than the Salk vaccine which had hardly been used in the USA or most countries for 25 years. However over these years some countries such as the Netherlands continued exclusive use of Salk vaccine and began manufacturing the vaccine themselves. The Dutch improved the Salk vaccine so that it provided full protection with two doses. They combined the Salk in a vaccine with diphtheria, whooping cough and tetanus. Then the US had a turnabout when its Advisory Committee for Immunization recommended that from January 2000 US children be immunised by the Salk vaccine. The tiny risk of contracting vaccine–induced polio from the Sabin vaccine was causing more concern as global eradication approached. As mentioned in earlier *Newsletters* there are also worries that the live mild virus in the Sabin vaccine can mutate and spread among unvaccinated groups. (My information is from an article in *Science* by Blume and Geesink 2/6/00.)

On March 2001 Reuters reported that the giant drug company GlaxoSmithKline had asked the US government to approve a combined vaccine for infants that would give protection against diphtheria, tetanus, whooping cough, hepatitis B and polio. Three shots would be needed. The company currently markets a vaccine targeting the first four illnesses. However the US Food and Drug Administration voted against the vaccine (six members were against, five for and one abstained). Their biggest worry concerned the higher rate of fever reactions in babies who received the 5 compared to the 4 disease combined immunisation currently in use (which does not include polio). More discussions and clinical trials of the vaccine will take place. Public health officials believe the less complicated vaccination schedule of the 5-in-one vaccine will result in fuller immunisation in the community and it looks only a matter of time till a combination immunisation is adopted in the US, and in due course probably in Australia.

### Cases of undiagnosed polio

Dr Marcia Falconer talks about undiagnosed cases of polio in her article in this *Newsletter*. An interesting example was Dame Ninette de Valois, ballerina, choreographer, ballet company director and teacher who died in March aged 102. The New York Times obituary caught my attention with its comment that: *Later in life a medical examination revealed that she had survived childhood polio without the disease being diagnosed at the time*. Searching for more information I found in the BBC obituary that de Valois was a *leading dancer in London before joining Diaghilev's Ballet Russe in 1923 … She gave up dancing while still young after discovering she had been suffering for years from polio.*

Marianne Weiss, a physiotherapist from Ohio, spoke at the GINI post-polio conference that I attended in St Louis in 1994. She said that she not infrequently encounters patients who do not have a history of polio but who have symptoms suggesting that in the past they had minimal cases of polio that went undetected. Examples of such symptoms included underdeveloped muscles, sometimes blatant asymmetry of muscle development, mild scoliosis, a history of being good at sport and suddenly without known reason declining in performance, and poor breathing capacity in the absence of known lung dysfunction. Weiss said that frequently these people had been given a diagnosis of fibromyalgia because of the significant tenderness of their muscles. She said, *I worry that no other diagnosis fits these people, and that indeed they may be suffering the late effects of polio as surely as known polio survivors do.*

## Update on PPN Professional Resource Register

Committee Member Dr Elizabeth Joyner is continuing with the task of compiling a 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. The register is being compiled as a service to members. All members are asked to recommend any health professionals they have found to be informed and caring by inviting them to list their name and practice details on the *Professional / Allied Health Resource Register* form available from the Network (call Alice on (02) 9747 4694 if you would like more copies) For the register to be of value to members you have to contribute towards it, so don't forget to take a form with you on your next appointment (be it to a GP, specialist, physiotherapist etc) and have it completed and sent in to us.

Several names of physiotherapists and orthotists from the previous Register and Sleep Disorder Clinics have already been transferred to the new listing.

For its part, the Committee is contacting professional bodies encouraging registration. Dr Joyner has sent letters to regional centres and head office of Divisions of General Practice, Colleges and Associations of relevant specialist groups, and two weekly medical newspapers for GPs.

Two Colleges have responded positively and one newspaper has printed the invitation to register and a separate article on PPS. The Newsletter of the *Australasian Faculty of Rehabilitation Medicine* has also published an article on PPS and our invitation to register. The Australian Medical Association (AMA) has also been keeping a watching brief on PPS. Dr Kerryn Phelps has advised that the AMA will inform its members through its magazine *Australian Medicine* of the existence of the Post-Polio Network.

We await further contact from health professionals who read the above publications.

# Support Group News

**Neil von Schill** **Phone: (02) 6025 6169**
**Support Group Co-ordinator** **Fax: (02) 6025 5194**

In early March I toured through the west and central west of the state and was very pleased to catch up with a number of our Support Group Conveners.

In Nyngan, where I taught in the late 1960s, I was made very welcome by Convener Marion Wardman, who took me for morning tea to the local museum which is housed in the old railway station building. Marion also organized a visit to the local newspaper, the *Nyngan Observer*, and this photo of us (with Marion wearing her colourful Network T-shirt) appeared in their 14 March edition. The editor included a short article encouraging polio survivors in the region to get in touch with Marion.

Following a reminiscing drive around Nyngan I continued on to Dubbo where I met with new Convener, Gregg Kirkwood, who is keen to hear from any polio survivors in the Dubbo area. Gregg may be contacted after 6:00 pm on 0419 283 417 and would welcome any enquiries.

In the very picturesque Bell River Valley out of Wellington I caught up with long term Convener, Hugo Orro, and his wife Anne. We enjoyed a very pleasant morning tea and had a long chat about current happenings.

I then journeyed on to Orange where I met and lunched with Convener, Susie Simmons and her personal trainer, Lindy, who was a former student of mine 30 years ago! Susie has made contact with a dozen members in the Orange area and is planning a meeting in the near future.

On my return trip I called in at Young and renewed acquaintances with Convener, Jean Robinson, who is a very vibrant senior citizen. Jean, who has a wonderful attitude to life despite her difficulties, inspires a small group of country members.

I extend my thanks to all Conveners who I visited for their welcome hospitality and commitment to the Network. I hope to continue my visits to Conveners in the latter half of the year.

Early this year Upper Blue Mountains Convener, Liz Lynes, moved to Sydney but is keen to maintain her involvement with the Network. We are exploring the possibility of establishing a Support Group in the Eastern Suburbs where Liz currently resides and have just received word that some funding has been received to help us achieve this goal. Watch this space for more details! We still, however, require a Convener to keep the Upper Blue Mountains Support Group functioning. If you live in this area would you please consider offering your services as a convener so that we can maintain the group. Please ring me on (02) 6025 6169 if you are interested in furthering your involvement with the Network.

We have a new Support Group operating in the Upper Hunter in the Scone/Muswellbrook area where Bruce Buls is the Convener. Bruce is anxious to hear from members in his area and can be contacted on (02) 6545 1993. To the north of the state Rae Say is establishing a new group at Glen Innes. If you live in this vicinity Rae would be very pleased if you gave her a call on (02) 6732 1879.

We would like to thank Cliff Cook for his involvement with the Network in the Lower South Coast region but are now looking for a member in this area to take over as convener. If you live on the Lower South Coast and would be prepared to undertake the role of Support Group Convener, please contact me.

# Post-Polio Post

*New Member Rachel Constable (nee Bawden) from Emu Park in Queensland has written hoping to catch up with girls she was in hospital with in the early 1060s. If you recognise any of the names below, you can write to Rachel care of the Network.*

I contracted polio in Queensland in 1950. Do you know of anyone that was in Townsville's *Cootharinga Home for Crippled Children* from 1959 to 1965 as I would like to get in touch with them. I can only remember a couple of girl's' names that were in the hospital and Cootharinga Home with me: they were Diane and Linda Cavhill, and Marjory Ridge (I think that is how you spell their names). They caught polio the same time as I did - Diane was about 2 years older than me, Linda was about 1 year older, and Marjory was about 7 or 8 years older. Diane and Linda were from Mt Speck and Marjory was from Giru. That is all I can remember about them.

*Vice-President Merle Thompson has dropped me this note under the category of "Better Late Than Never".*

If you attended the *Prince Henry Hospital 50 Year Reunion* at the Burwood RSL Club on 27 June 2000, and left behind a mauve checked cushion / seat cover could you please let me know [by phone: (02) 4758 6637, email: *mkthom@bigpond.com*, or post: PO Box 38 Woodford 2778]. Announcements at subsequent Seminars have been unsuccessful so I have been minding it all this time, but would like to return it to its rightful owner.

*Barbara Chapman-Woods, long-time member and past Convenor of the Northern Inland Support Group, has experienced deteriorating health over the last year or so and has now moved to Perth to be close to her daughter and her family. Barbara keeps in touch and nothing stops her promoting the Network and raising the awareness of the late effects of polio wherever she is. Barbara sent this "moving poem" to share with her friends in the east.*

Though the trip from East to West is long –
(Especially for an "Oldie")
Here half my family lives – and thrives –
It's been well worth the journey.

I think I'll be living near Armadale
– Much spadework has been done –
I've been greatly helped with the interviews
Thanks to my daughter, Jen.

I still have much to learn of Perth –
(I'm a "migrant" to the West),
And of course I'll want to keep in touch
With family and friends back East.

So remember me from time to time
Dear friends in New South Wales,
And I am sure our thoughts and prayers
Will meet – across the miles.

*© Barbara Chapman-Woods, June 2001*

Members in NSW's Northern Inland will remember Barbara's active Telephone Support Group and her innovative "Round Robin" letters. If any members in Western Australia would like to chat with Barbara from time to time, she would appreciate the contact and has a lot to offer. How about starting up a western version of the Round Robin? Until she gets settled in a hostel, you can contact Barbara on her mobile: 0419 967 883.