

POST - POLIO NETWORK (NSW) INC.

NETWORK NEWS

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President's Corner

Gillian Thomas

There is something for everyone in this issue of *Network News* – so much so that I have had to add an extra four pages to fit everything in. Our Mini-Conference on 18 May promises to be a most informative day with some the material being presented for the first time in the world – full details of the day appear on pages 2 and 3. A Registration Form to attend the Mini-Conference is included with this Newsletter. Once again we have kept the cost as low as possible by subsidising attendance costs and urge you to support the Mini-Conference by returning the Registration Form as soon as possible – you won't be disappointed.

If you have indicated that you are able to sell or buy a few raffle tickets to help us continue to hold Mini-Conferences you will find a book of raffle tickets enclosed. The majority of the prizes have been generously donated by Network members and friends and the raffle deserves your support. The ticket butts, together with any unsold tickets, must be returned with the money by Tuesday 30 April 2002 to Alice Smart, PO Box 327, Burwood, NSW 1805. If you have any queries please ring Alice on (02) 9747 4694 or Gillian on (02) 9663 2402. The raffle will be drawn at the Mini-Conference on 18 May.

The Australian Foundation For Disabled (Afford) began as The Poliomyelitis Society in 1952 offering care and support to polio survivors and their families. Since its formation, the Society has undergone many name changes and broadened its service delivery to assist other than polio survivors. This year marks the 50th Anniversary of the organisation and a number of activities will be held in celebration. Late last year Afford sought our help to contact former members of the Poliomyelitis Society, especially those who joined in the 50s, 60s and 70s, so they could be issued a special invitation to join the anniversary celebrations. We assisted by printing an item in Issue 50 of *Network News*, October 2001, and a number of Network members got in touch with the Organising Committee at Afford. We have now been advised that plans are progressing well and a celebration is expected to be held in May (they have promised not to hold it on the 18th). This is therefore another call to Network members who may previously have been members of the Poliomyelitis Society to contact Maureen Turner at Afford on (02) 4777 4250 as soon as possible. To reciprocate the help we are giving Afford through this Newsletter to reach out to past members of the Poliomyelitis Society, they will help us by promoting the Network to polio survivors on their guest list who may not yet be aware of the Network or the services it provides.

Finally, the back page of this *Network News* highlights upcoming activities. Please note the dates in your diaries now so you don't inadvertently double-book yourself. There is an exciting Seminar program arranged, not to mention a couple of social activities. Please note in particular that the date of this year's Annual General Meeting has been set for 30 November.

The Committee looks forward to meeting as many members as possible at the Mini-Conference, and to the hosting of another successful Support Group Conveners' Workshop, on 18 May.

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Mini-Conference

Dr Marcia Falconer from Canada will be our special guest presenter at the Mini-Conference. Biographical details for Marcia and a description of her four presentations are given on page 3. Registration for the Mini-Conference is essential for catering purposes. If you would like to attend, please complete and return the enclosed Registration Form by 30 April 2002.

Date: Saturday, 18 May 2002

Time: 9:30 am - 4:00 pm
Refreshments and a buffet lunch will be provided

Venue: Sea View Room
Mezzanine Level
Maroubra Seals Sports and Community Club
212 Marine Parade (enter from Fitzgerald Avenue)
Maroubra Beach NSW
The venue is readily accessible for those in wheelchairs or with mobility difficulties, with a lift to the Mezzanine Level.

Parking: There is a small parking area on the premises, and ample parking nearby. 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.

Public Transport: Bus 376 from Circular Quay via Randwick Junction, Bus 395 from Railway Square via Maroubra Junction, Bus 396 from Circular Quay via Maroubra Junction, or Bus 400 from Bondi Junction.

Registration: As the Network is subsidising the Mini-Conference, the registration cost is only \$15.

Program:

9:30	<i>Registration and tea/coffee</i>
10:00	Polio and the Heart
11:00	<i>Morning Tea</i>
11:30	Some Interesting Discoveries about PPS
12:30	<i>Lunch</i>
1:30	Non-Paralytic Polio and PPS
2:30	<i>Afternoon Tea</i>
2:45	The Polio Virus - Getting to Know Your Old Enemy
3:45	<i>Wrap up – exploring unanswered questions</i>
4:00	<i>Finish</i>

Dr Marcia Falconer



Marcia Falconer contracted polio as a child in 1949, recovered completely and forgot about the summer she spent in bed. The first symptoms of Post-Polio Syndrome (PPS) appeared 36 years later. With no connections to the polio community, she had never heard of PPS and had no idea what was happening to her body. Neither did her doctor. The journey between onset of symptoms and diagnosis of PPS is what spurred her to do research in the field of post-polio problems.

Dr Falconer received a PhD in cell and molecular biology from the University of Ottawa, Ottawa, Canada, in 1990 and considers herself a “late but happy bloomer”. For seven years she led a laboratory that did research on viruses and eventually she started a biotech company in partnership with three other scientists. Retired for the past three years because of PPS problems, she continues to do research in Post Polio Syndrome and will be presenting results of some of her research at the Mini-Conference. She gives lively and illustrated talks making complicated research easily understood by people with no scientific training. Questions and discussion with the audience are welcomed and appreciated.

Mini-Conference Program

Polio and the Heart

In the years when polio was epidemic, it was common knowledge that the heart was often affected during the acute illness. This aspect of polio has been almost completely forgotten but between 1930 and 1957 medical literature was full of papers documenting this aspect of polio. Heart problems were common during the first few weeks of the illness. Changes in heart rhythm and blood pressure occurred in most cases of polio and were a leading cause of death. Dr Falconer will tell us more about this topic and provide some insights into the implications this has for polio survivors today.

Some Interesting Discoveries about PPS

One way to learn more about the causes, symptoms and possible treatments of PPS, is to interview a wide range of polio survivors. Two years ago, Dr Falconer and Edward Bollenbach distributed a survey asking people about their polio history and their experiences with PPS. More than 400 people responded to the survey. This Mini-Conference is the first time that any results have been made public. Dr Falconer will tell us about the survey and present some interesting and unexpected findings.

Non-Paralytic Polio and PPS

Before immunization, polio was a common childhood disease. Most people did not realize they had polio and only 1 out of 100 cases suffered noticeable weakness or paralysis. It is widely believed that the other 99 people completely escaped any nerve damage and will never develop PPS. However the medical literature from the 1940's and 1950's presents a very different picture about these “mild” cases of polio but once again, this information was forgotten.

People with a history of paralytic polio and obvious paralysis noticed fatigue and new weakness occurring 30 years after the acute polio illness. Many doctors were reluctant to diagnose these problems as PPS. People who had been diagnosed with non-paralytic polio and now had similar problems with fatigue and muscle weakness were told that they could not possibly have PPS. Dr Falconer will tell us how this problem has been resolved and what the implication of this finding is for a relatively large percent of the population.

The Polio Virus - Getting to Know Your Old Enemy

Everyone who has PPS has been infected by the polio virus. But what do we know about this virus? Perhaps we know there are 3 strains of polio and that the Salk and Sabin vaccines can immunize us and prevent us from getting ill. But did you know that there are not 3, but 12 strains of polio virus and that there is no vaccine to the other 9 strains? Do you know why you need to be immunized even if you had polio? Dr Falconer will present a fascinating glimpse of this virus that altered so many of our lives.

Breathing

Augusta Alba, MD, and Alice Nolan, RN

**New York University Medical Center, Department of Rehabilitation Medicine
Goldwater Memorial Hospital, Franklin D Roosevelt Island, New York, NY**

This article is reprinted with permission from the March 2002 issue of Polio Post News, North Central Florida Post-Polio Support Group, 7180 SW 182nd Court, Dunnellon, Florida 34432, USA.

If you have had polio or suffer from other neuromuscular disorder and have weakness of the neck, upper trunk, or shoulders but are not on a respirator, you may want to evaluate your respiratory needs. Such a disorder may be polymyositis, muscular dystrophy, amyotrophic lateral sclerosis, spinal muscle atrophy or spinal cord injury. As you grow older, your respiratory reserves will diminish. A potentially serious problem may develop whereby carbon dioxide is retained and oxygen is decreased in your blood-stream. These changes may be obvious but in most cases they are subtle. You can easily recognize weakness: if you cannot pick your head up off the bed, raise your arms above your shoulders, turn over in bed by yourself, come to a sitting position or sit independently without back support. However, it is difficult to recognize when the muscles of respiration (the muscles and rib cage that expand and contract your lungs) are not working adequately. When these muscles are impaired, a restrictive respiratory problem results. This is different from obstructive pulmonary problems or disorders of the airways.

In the course of normal aging, our lungs and chest wall become less elastic. We do not breathe as deeply. Our vital capacity, the biggest breath we can take into our lungs and then push out, decreases by 30cc per year (1oz). Our cough is not as vigorous. Aging and neuromuscular disorder produce more serious changes. These changes are maximized by conditions such as kyphoscoliosis and airway obstruction or chronic bronchitis. Symptoms which may be associated with failing respiratory reserves are numerous and for the most part non-specific. This means that the other medical problems can cause them as well. However, they do serve to alert to a possible respiratory problem. These symptoms include feeling more tired or becoming exhausted from ordinary activities, and reducing usual activities because of fatigue. Anxiety, inability to fall asleep, restless sleep, awakening during the night with nightmares and awakening in the morning with a headache or slight confusion may occur. Brain functions are altered so depression, inability to concentrate, dizziness, sleepiness during the day and blurring vision may be present. Vascular symptoms such as peripheral cyanosis or an abnormal sensitivity of extremities to cold and the tendency to develop high blood pressure or a rapid heart-beat may be caused by respiratory insufficiency. Breathlessness during activity including such a simple task as speaking may occur. Your voice may be lower than it had been. The breaths you take when you are awake may be very shallow and even more shallow when you are asleep. This is the way early symptoms usually occur in sleep. Tranquilizers and sedatives will further depress your respiration and should not be taken especially at bedtime or during the night.

For many people, the first changes may be difficulty raising secretions and feeling congested with frequent colds. Difficulty raising secretions leads to sealing off of lung tissue from the airways (atelectasis), or to infections of the lung tissue (pneumonia). The work of breathing becomes even harder and respiratory failure occurs more rapidly. With respiratory failure, the right side of the heart fails causing generalized edema and protein in the urine.

If you have any of the signs and symptoms described above, you should make an appointment to see your doctor. Your breathing can be evaluated by simple tests. One of these is measuring your vital capacity (the maximum amount of air that can be moved into the lungs and then forcibly exhaled). If your vital capacity is reduced but is still above 50% of a predicted value for your age and sex, it is unlikely that your symptoms are related to your diminished breathing capacity except in three situations: marked obesity, partial obstruction of the throat during the night in deep, and the presence of an intrinsic lung disease such as an old tuberculosis or emphysema. If your doctor considers it necessary, he will refer you to a pulmonary specialist.

The pulmonary specialist will do screening pulmonary function tests, more comprehensive pulmonary function tests if he finds them necessary, and arterial blood gases. He may not find it necessary for you to have a ventilator but may wish to follow you on a regular semi-annual or annual basis, or to see you immediately if you develop an intercurrent respiratory infection. If he suggests mechanical respiratory support, you need not be alarmed. Such support is an insurance policy for your well being.

The respirator will help you sign your lungs (stretching or range of motion). It will help you to cough, speak and even regain energy that had to be funneled into increased work that you expended in breathing prior to the use of the respirator. For the most part, the respirators used today are small portable units that operate on either battery or wall current. They are silent, inconspicuous, and are used with a mouthpiece both day and night, unless the person has a weakening of the throat. In selected cases, respirators including the iron lung, rocking bed and chest piece, which provide a person with expiration are still in use. Some people prefer a special body respirator called the pneumobelt bladder held against the abdomen in a non-elastic corset and cycles with a portable ventilator that mimics the abdominal muscles. If the mouth and throat are weak, a tracheotomy can be considered and the ventilator is connected to a tracheotomy tube.

With the appropriate follow-up and mechanical ventilation you will increase your sense of well-being and longevity.



Oral polio vaccine to be dropped

The Sabin (oral) polio vaccine was in the news again earlier this year. If you missed the reports at the time, the following is reprinted thanks to ABC News Online, 24 January 2002.

A booster dose of oral polio vaccine, which is taken in the late teens, is soon to be dropped from Australia's immunisation schedule.

The active vaccine which is used against polio on 250,000 children each year, is also to be replaced for the first time in 46 years.

Australia is one of the only countries still administering the fifth oral polio vaccine of Sabin.

The head of the Health Department's communicable diseases branch, Greg Sam, says there is a one in five million risk with each dose that it will cause paralysis.

"The evidence now suggests that we no longer need the fifth dose, that four doses of oral polio vaccine will offer protection and the risk from exposure of wild type virus has decreased significantly and should continue to decrease", he said.

Mr Sam says the planned replacement of oral Sabin with an inactive injectable vaccine later this year, will eliminate the rare adverse reactions.

[Ed. Dr Mary Westbrook notes that re-introducing an inactive vaccine will also address the issue of the Sabin vaccine mutating and spreading in an unimmunised pool of people as happened in the Philippines and Haiti for example - reported in Network News Issue 48.]

Reports on 16 December 2001 Mini-Conference

We were very fortunate to have two "roving reporters" take the time and trouble to write-up their perspectives of the talks given by Dr Stephen de Graaff at our Mini-Conference in December. Dr de Graaff is a Consultant Physician in Rehabilitation Medicine and is currently Chief of Rehabilitation Medicine at Cedar Court Healthsouth in Camberwell, and Head of the Neurological Rehabilitation Unit at Caulfield General Medical Centre, Victoria.

Dr Elizabeth Joyner Committee Member

Our PPN Mini-Conference at the Burwood RSL Club on 16 December was well attended by about one hundred members, family and friends.

Dr Stephen de Graaff, interested and knowledgeable about Post-Polio Syndrome (PPS), flew up from Melbourne for the day, in order to deliver two talks entitled *The Late Effects of Polio: Are They For Real?* and *Is Pain Necessary in Polio Survivors?*

The first paper dealt with the definition and diagnostic criteria of PPS, the scope of the problem, pathology, symptom presentation, symptom evaluation process and resources for patient management.

Dr de Graaff emphasised the vital importance of a careful evaluation of symptoms and signs by an appropriately qualified medical practitioner with methodical exclusion of other disease processes which might be complicating the diagnostic process and which require different and often urgent treatment (for example, thyroid disease or different forms of malignancy).

Dr de Graaff estimates that 0.625% of the Australian population had polio symptoms and signs previously and there is evidence that approximately 50% of this group develop PPS at some point later in life.

The pathology involves:

- Extensive initial nerve cell involvement in acute polio infection.
- Spinal muscle unit remodelling in post-recovery phase.
- Decompensation then produces post-polio syndrome

The acute initial polio attack involves most of the body including the brain and spinal cord. The brain is also more widely involved than was originally realised .

It has been estimated that often more than 50% of motor nerves to muscles were affected to some degree and the patient left "running on 4 instead of 6 cylinders". Then a gradual decompensation process occurs over a lifetime.

The average age of onset of polio is 7 years with a median recovery time of approximately 8 years and a period of stability approximating 25 years (20 - 40 yrs) before any new symptoms appear.

The initial symptoms of PPS most often occur in a lower limb and are insidious in onset. PPS is a progressive chronic disease. These new symptoms may progress rapidly or gradually and may be triggered by certain factors such as infection, certain drugs, and trauma.

The prime symptoms when the patient presents to the doctor are physical and mental fatigue (89%), pain in muscles and joints (86%), weakness (83%), new muscle atrophy or wasting (28%), and decline in activities of daily living (78%). Additional presenting

problems may be breathing difficulties, sleep disorders, swallowing difficulty, cold/heat intolerance, degenerative osteoarthritis and musculoskeletal problems, social and psychological problems. Increasing muscle weakness and atrophy need to be documented by measurement with baseline and comparison tests.

Physical exercise tests need to be detailed and accurate with endurance muscle testing, not just a quick movement check (particularly in newly affected limbs). PPS is more likely in those patients most severely affected in the initial attack and the older the patient at the time of the attack, where often it is less than 20 years before PPS develops. (The adult is perhaps less able to compensate for the initial damage compared to a child who is still growing and developing.)

Breathing difficulties are a common problem due to restrictive lung disease with the chest wall stiffer secondary to spinal deformity, and thoracic muscle weakness. Together they result in poor expansion of lungs and increased work of breathing. Damage to the brainstem's respiratory control centre causes an increased likelihood of sleep apnoea leading to lack of refreshment after sleep, daytime napping and cognitive fatigue.

Dysphagia or swallowing difficulties are due to pharyngeal muscle weakness secondary to brainstem control deficits and primary weakness of the local musculature. This can result in significant dangers from food inhalation (choking on food), under-nutrition and increased risk of inhalational pneumonia.

We were reminded that musculoskeletal problems and a certain amount of osteoarthritis result from the altered biomechanics, increased joint pressure and work required to overcome the polio muscle weakness. Observation of gait and posture may be necessary to understand the immediate mechanical trigger(s) for particular problems such as a new backache.

Dr de Graaff then detailed the process required to evaluate the individual situation and identify areas of dysfunction. The basic tools are the medical history and the various aspects of the physical examination.

Treatment goals were itemised including:

- Lifestyle modification.
- Improvement in muscle strength/capacity with a tailored exercise program (but if this causes pain, then it is doing damage and should be avoided).
- Decreasing the level of fatigue, increasing functional strength, endurance and energy efficiency. This may involve weight control, and using orthotics and other physical aids where appropriate.
- Appropriate use of medications, for pain and depression for example.
- Cognitive treatment, for example, looking at solutions rather than problems, tackling pessimism directly, may be a vital management tool in many cases.

The principles of disability prevention and management including anticipation of certain problems, their early detection and intervention, the therapeutic partnership (involving mutual respect and dignity) and a goal-orientated rehabilitation plan were then discussed. The difference between decreasing function and deterioration in the disease process was clarified. It is rare for the polio disease pathology to progress but we can realistically expect 1% - 2% decreased overall efficiency per year.

The overall goal is the optimal management of the patient, with reduction in pain and return to their previous level of function or maximal functional improvement, while most efficiently managing limited resources, despite some degree of pain in many cases, to improve the quality of life.

The second talk on pain management initially dealt with essential definitions including:

- The subjective nature of pain and the difficulty in describing its nature and degree to aid the therapist in understanding its cause and target treatment.
- Principles of pain/disability prevention.
- Pain management/rehabilitation teams.
- The role of therapy and pain-relieving medications.

The basic conundrum for patient and therapist is the question of whether this particular patient's pain is due to PPS (otherwise unexplained new symptoms of fatigue, weakness and pain etc) or the expected late-effects of polio, such as:

- biomechanical dysfunction,
- orthopaedic discrepancies,
- overuse injuries,
- ergonomic inefficiencies,
- the demands of an over-achieving personality, and
- the inexorable functional deterioration with time and age.

There can be subtleties in this distinction which may be difficult to grasp and are the basis of much misunderstanding between patient and therapist.

In the polio survivor's case, a clear understanding of the expected long-term effects of polio is necessary to ensure all preventative and interventional treatments are appropriate.

Pain management uses the relevant physical, cognitive and psychological strategies by patient/family/carer and the therapy team of rehabilitation physician, nurse, physiotherapist, psychologist, occupational therapist, social worker etc, where appropriate and available.

Local measures to manage pain may include mobilisation, stretching (useful in overuse syndromes, restless legs etc), hot/cold packs, massage and swimming. There should be an emphasis on joint protection and stabilisation using appropriate orthotics and other aids to avoid later problems.

Therapy roles include:

- endurance activities,
- ergonomic and pacing education,
- psychological counselling and support,
- stress management,
- work hardening and retraining, and
- hobbies and other interests or activities.

With regard to pain medications, simple analgesics such as paracetamol in adequate dosage remain the mainstay of treatment with fewest side-effects. Other medications include NSAIDs, Cox2 inhibitors, antidepressants, anti-seizure drugs for certain types of neuralgic pain, steroids and injections (local and systemic). In certain situations, relaxants, sedatives, calcium channel blockers and narcotic analgesics may also be appropriate.

The overall goal is to optimise the quality of life for each person, with reduction in pain, and maximal functional improvement, using limited resources most efficiently.

Our distinguished speaker unwisely elected to stay for the late afternoon Annual General Meeting and Volunteer Awards ceremony. He soon found himself very busy indeed, running up and down the aisle, narrowly avoiding collisions with wheelchairs, presenting official *International Year of the Volunteer* certificates and badges to well over 30% of the audience, until he was able to make good his escape from his enthusiastic questioners and drop exhausted into his aircraft seat en route to Melbourne. We really know how to make VIPs work for their lunch!

Wendy Chaff

Convener, Hunter Area Support Group

I found Dr de Graaff's presentations to be very informative and delivered in an easy-to-understand way. I hope my personal impressions of the day will help those who weren't able to be there to get a flavour of what we heard and hopefully learn something more about themselves.

Late Onset Effects of Polio – Are They For Real?

Although polio has been a notifiable disease since 1916, there is a definite lack of knowledge of what happens after the initial episode of polio years ago. The medical fraternity is only now coming to grips with polio's late effects on survivors. While Dr de Graaff has worked in this field for 8 years, there has been a major increase in referrals of polio patients in the last 2 years.

Post-Polio Syndrome (PPS) is recognised as a major debilitating illness, with more and more cases being identified worldwide.

Dr de Graaff pointed out that the late onset effects of polio are not necessarily PPS. He warned that sometimes if a patient is labelled as having PPS, it can be considered "that is it – finished". It is important to understand that because someone had polio, every condition they have now does not have to be related to polio. Diagnosis is by exclusion. There is no diagnostic test for PPS, which is estimated to occur in at least 36% of polio survivors. Other diseases must be excluded (for example, motor neurone disease), or the effects of drugs (such as cholesterol lowering drugs, which can cause muscle weakness).

Although it is known that many cases were not originally diagnosed as polio, it seems some patients were told they had suffered polio when actually they had not. In the last year Dr de Graaff has had 4 cases where clients had been wrongly diagnosed. In the 1940s there were cases of encephalitis thought to be polio, during times of epidemics. Sometimes "foot drop" can be the result of a stroke (which can occur in young people). The younger you were when you contracted polio, the more chance your body could compensate. If polio was contracted in your late teens or after twenty (as the body starts to decline after 18 or 19), skills already learned were harder to emulate, and effects could be more severe.

Symptoms The locality attacked by polio initially is most usually affected in later life - often a lower limb (which, since it is weight bearing, needs more compensation). If an upper limb is affected, the dominant arm has to do twice the amount of work. Problems are often noticed after a fall, injury, bad cold or virus, but often some symptoms were appearing before that key time. Being overweight can aggravate problems.

Treatment Goals Lifestyle modification is not curative, but a compensatory process. It is guaranteed that if pain is caused, you are doing damage! Choose appropriate exercise, avoiding harmful strategies, to increase muscle capacity and treat fatigue. Plan to build up strength and endurance for just what you need to do in your general lifestyle.

Pacing is an important concept. Dr de Graaff suggests making a sign saying "PACING" to put on your toilet wall as a reminder for you to budget your energy. Take longer to do your chores – spread them out. Pride as an achiever is often ingrained, a result of fighting since young to keep high standards. At risk are "house proud" people. If it wrecks the rest of the week for you to vacuum floors or mow the lawn – you need to get someone else to do it! Dr de Graaff noted that lawn mowing is the most common cause of recurrent heart attack in males.

Medication Dr de Graaff said that on the whole drugs were disappointing (not all that effective) for post-polio problems. He cited Mestinon, Amantadine and Deprenyl as drugs

he no longer used. He said NSAIDs, for example Voltaren, can be useful for pain relief, but when some people have side effects such as stomach bleeding, Cox2 inhibitors, eg Celebrex, are an alternative.

Prognosis It is important to clarify the difference between deterioration in function, and deterioration from the actual disease process and its potential for affecting overall day to day performance. If the person is over 65, the therapist must consider whether problems are age related or due to polio's late effects. With respect to functional deterioration, 1% to 2% loss of use per year can be expected.

Coping Strategies Balance what you do and how you do it to minimise deterioration and mechanical deficiencies. Plot your day's activities. Create a balance between strength and endurance versus burden. When you need assistance to develop strategies to cope with day to day living, and assistance to cope with change, best results are achieved if you work for a common goal with a Multi-Disciplinary Team which might include a Neurology Consultant, Rehabilitation Physician, Physiotherapist, Occupational Therapist, Speech Therapist, Psychologist (not an analyst) and an Orthotist.

If you are wondering why an Orthopaedic Surgeon is not included in this list, it is because surgery should be considered as a last resort. When you cannot cope any more, before consenting to a joint replacement, make sure the Surgeon will take time to talk about what can be expected after surgery, as there are many complicated issues involved.

Dr de Graaff made the point that Networks like ours and local Support Groups are incredibly important to polio survivors as they cope with polio's late effects.

Other Resources While there is a wealth of information on Internet Websites, be sceptical. Don't take what is out there as "nothing but the truth". Sit back and view, evaluate, question. Check out information - ask someone who has knowledge in that area. As a doctor, Stephen de Graaff said he appreciates information dissemination and respects the opinions of his patients.

Is Pain Necessary in Polio Survivors?

Dr de Graaff frankly admitted he does not know what it feels like to have had polio and its after effects - nor can anybody who hasn't had that experience really understand just what a survivor goes through.

Definitions or perceptions of PAIN differ from person to person. There can be a problem with how you measure pain and how you talk about it or report it to a doctor. Your viewpoint can be positive or negative. A patient may get stuck in chronic pain – an extreme pain reaction which lasts beyond what would normally be expected. Such a person needs to develop strategies to handle the pain and how it affects his/her lifestyle and relationships.

It is important to define the cause of pain, to allow for appropriately targeted treatment. In PPS it is also really important that the physician understands the sequelae of polio.

Prevention of pain is the best form of management. You need to look ahead and avoid possible risks now rather than later, such as with stairs. If problems are likely to arise due to ankle weakness or foot drop which may cause a fall, manage it now in the simplest way, *before* an accident occurs. Don't be unwilling to use assistive devices like orthoses.

Common Complaints "My doctor doesn't understand what I am saying" or "My physio does not listen to what I tell her". You can only succeed if the doctor can "get off his high horse" and allow the patient to make a decision that will help. A patient can say to the doctor, "I am not comfortable with that decision". You have to develop a partnership!

There are always issues that could be discussed, if you remember during the doctor's visit. So beforehand, if you ever think of anything – WRITE IT DOWN! Then the question or information is there, ready for you to refer to - in case you are running late, feeling stressed, are distracted, or have a limited consultation. Dr de Graaff thinks this is a fantastic idea – as it is often just what the doctor needs to know! He may not always ask you the right questions, without your input. The doctor may not have all the answers – but he could find out for you. We are capable of providing the clues that the investigating physician needs to solve our individual case.

Be goal oriented. If you try a certain strategy, what can you expect to come out of it? What do you really need? Why are you doing that? Do you want a response within a certain time? Trying a new strategy must make a difference to be worthwhile. Don't let your trial go on forever without any noticeable improvements. Monitor changes – keep a DIARY of any new treatment, be it medication, orthotics or exercise, to show results.

Pain Management You are not going to get rid of pain. But you may be able to control it. If you sleep better, you have more control, better energy levels. Pain management involves the patient and his/her family/carer. A patient focussed on pain acts differently to the person you thought you knew. Any therapy needs to be tailored to the individual's needs. Therapy involves six elements: medical diagnosis, precautions, goals, type of therapy, frequency, and duration. I noted that Dr de Graaff does not recommend using TENS machines.

Polio Precautions Not trying to over achieve. Avoid doing too much. Prioritise the day's goals. If someone is an "emotional mess" they may need medication. If on pain medication they need to be doing self-help therapy, and take responsibility for management of pain at home, with guidance.

Frequency of exercise therapy varies according to the individual's needs – it's too much if you feel too tired afterwards. Take responsibility for decisions about exercise - start gradually over one or two days. Be sure the exercise is making an appreciable difference, to make it worth the effort. Joint and muscle pain can be helped by gentle stretching (like athletes do before events). Take adequate rest breaks. If cramps are a problem, sports drinks or Quinine may help.

Have a Positive Attitude Think "How am I going to cope with this?" rather than "I can't cope with this." We can COMPENSATE – not cure. It can all work out if you take the time to look at a problem and find solutions, make adjustments – before using up your limited energy reserves. Realise we can be our own worst task masters, setting ourselves up for a fall if we can't achieve. If a goal is too high, such as a 30 minute walk per day – try two 15 minute walks instead. Use the PACING strategy. During the day have half an hour with your feet up, perhaps reading the newspaper – increasing general knowledge. Reading is simply a different form of "doing".

Medications Dr de Graaff said there is nothing wrong with Panadol, a simple analgesic (never take more than 8 a day) – but this may not be the only answer. Sometimes we might need Panadeine (with codeine) or Panadol Forte. Anti-seizure medication can alter the perception of pain but may have side effects. He mentioned anti-depressants, for example amitriptyline, as useful not only in lifting mood etc, but if given in very low doses at night they affect pain transmission in the brain and can improve sleep. Effective medication mean fewer visits to doctors and hospitals. If it makes a worthwhile difference – take it. BUT... if medicine makes you feel worse than before, and not better, there's not much point taking it. Let your doctors know that.

Question and Answer Session

After lunch the indefatigable Dr Stephen de Graaff returned for yet another bout, ready to tackle our members' numerous questions. To mention just a few of the topics dealt with:-

Carpal Tunnel Syndrome This occurs in the wrist. It may be mild, like a shake in the hands. It can occur when a crutch or walking stick is used; in this case, the walking device needs review. Exercise by stretching the wrist back. Try sleeping with your hand on a higher pillow – it may be affected by fluid retention overnight. It is aggravated by over-use. If it is so severe that there is muscle wasting associated with pain – get it checked NOW!

Coronary Disease Not related to polio, but will compound its effects. If you have to use more energy to do things, that will cause greater stress on your cardiovascular system.

Osteoporosis / Polio Connection Generalised osteoporosis will occur through inactivity, and regional osteoporosis will occur in a limb which is not used sufficiently.

Unstable Bladder If there was some bladder problem in your early days of polio there could be more problems in that same area. Men's prostates may be affected, and women's hormones, as well as the pelvic floor muscles after childbirth. He advised that the only way to ascertain a bladder problem would be urodynamic studies.

Vitamins and Minerals It is not uncommon for Aussie males to resist taking these - it seems to be a "bloke thing". Some can be beneficial for treatment or prevention, for example Zinc which oxygenates the skin and may improve muscles, and Magnesium which is good for muscle twitching. Coenzyme Q10 (an antioxidant nutrient which can boost energy, the immune system and circulation) can help some. Dr de Graaff knows 4 or 5 patients who have had successful results (about 5 out of 20). It can be bought at health food outlets. While it is expensive, it may be worth a limited trial of two months (costing about \$60) to find if it works for you or not, by keeping a diary.

Orthopaedic Footwear As a general rule, good supporting boots are far more beneficial than shoes, for ankle strength.

Resistance to Callipers If your condition deteriorates, you are going backwards. Falls will increase in frequency, without extra support. Remember "PRIDE COMES BEFORE A FALL". A full calliper may need a built-up shoe so work with an Orthotist and Bootmaker to make sure your calliper and footwear complement each other. Don't worry about becoming dependent on orthotics. These are energy efficient and *increase* your independence

In conclusion, Dr de Graaff commented: "Don't let others dictate that they know better than you what is right for you." If you have doubts, get another opinion if necessary. You have the right to decide what is right or wrong for you.

It seems clear that Rehabilitation Consultant Dr Stephen de Graaff respects his patients and prefers to work in partnership with them in investigating and treating their problems. His genuine interest and concern impressed us. We felt encouraged by his willingness to listen and give honest opinions, showing consideration for the feelings and needs of polio survivors and their carers – for which we are most grateful.



To show our appreciation to Dr de Graaff for giving up half of his precious weekend to travel to Sydney to speak to us, the Network presented him with a camphor laurel platter, hand-made especially for him by Network member Rob Guilfoyle from Canberra, a craftsman woodturner and carver. Rob's work is unique and beautiful (see the item on him in Issue 51 of *Network News*, November 2001). We also gave Dr de Graaff one of our colourful virus badges as a memento of his day with us.

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.

Earliest known polio case was over 4,000 years ago

Many books about polio include a picture of the man considered to have had the earliest known case of polio. He appeared on an Egyptian carving dating from the period of the eighteenth Egyptian dynasty, around 1552-1306 BC, about three and a half thousand years ago. The young man had an atrophied and shortened left leg such as is found in many people who contracted paralytic polio in childhood. He is supporting himself with a staff held under his arm like a crutch. Some Egyptologists think that he was a priest.

However an earlier case of polio was identified in 1989 during archaeological excavations at Tell Abraq, on the coast of the Arabian Gulf in the northern Arab Emirates. Professor Dan Potts from the University of Sydney headed the Australian team of archaeologists working on the site. On UAEinteract (the website of the United Arab Emirates) Potts is quoted as saying that *Tell Abraq site is without doubt, one of the most important yet discovered in the United Arab Emirates, showing evidence of successive settlement from around 2,500BC for a period of at least two thousand years. There is extensive evidence of international trade with Mesopotamia and with the Indus Valley ... Tell Abraq may have been the site of a petty kingdom in the Third Millennium BC... At its peak Tell Abraq must have been a dominant feature of the coastal plain. A fortress 40 metres in diameter was excavated, the largest Bronze Age building yet discovered in the Arabian Peninsula. Ten metres west of the fortress a large stone circular tomb about six metres in diameter was found. It contained the remains of several hundred people. The skeletons showed no signs of malnutrition though a number had signs of chronic diseases. The grave was covered by sand some time between 2,000 and 1,000 BC. One of the skeletons excavated was that of a young woman, who was identified as having had polio, the earliest evidence yet discovered anywhere in the world of the disease.*

I contacted Professor Potts who put me in touch with Professor Debra Martin, a biological anthropologist from Hampshire College, Amherst, Massachusetts, who was the member of the archaeological team responsible for the diagnosis of Leslie's polio. This name was given to the skeleton before her gender was identified. Professor Martin was kind enough to send me a copy of some of her data on Leslie, which is yet to be published, including a photograph and medical assessment of her skeleton. Leslie was about 20 years of age and it is thought that she developed polio in her teens. Her legs were of similar lengths. Her right leg shows evidence of overuse in the early osteoarthritic changes in the knee and ankle. There is evidence of muscle weakness and wasting in the left leg with some deformity in the left foot. Some of the bones of the lower legs show early osteoporosis. Leslie's pelvis is asymmetric and she had scoliosis of the lower spine. The type of curvature of her lower spine suggests that she was fairly sedentary and sat much of the time. Leslie is now at Amherst. Her discovery moves the date of the earliest known case of polio back around 500 years.

Polio during pregnancy

A question sent to Dr Richard Bruno's column, *Post-Polio Forum*, in the April 2001 issue of *New Mobility* asked: *My mother had polio when she was pregnant with me. At age 35 I began suffering symptoms that match PPS very well. I am wondering if I caught polio in the womb from my mother?* Bruno replied that the chances of this occurring are infinitesimal. He described a study done in Los Angeles and Illinois during the polio epidemics that identified almost 1000 pregnant women who contracted polio. None of their babies were born with polio-like symptoms and it is assumed that their mothers' antibodies protected them. Catching polio while pregnant is particularly dangerous, however. In the Los Angeles-Illinois study, pregnant women who contracted polio were five times more likely to die from polio than were other polio cases. Miscarriage rates were not higher than normal among these women. Autopsies of their miscarried fetuses did not show signs of polio. However the doctors who treated these women considered that their polio had contributed to the loss of their babies. Bruno referred to another research study, which looked for records of cases of polio in babies less than six months of age born between 1897 and 1956. It identified 150 cases. Four of these babies showed signs of paralytic polio at birth. So it seems that in very rare cases the mother's antibodies do not protect the foetus. One such person recently asked on an Internet mailing list, to which I belong, whether anyone knew of another case. Only one of the thousand or so list members responded in the affirmative.

PPS in Recent Novels

Finding passing references to PPS in recent novels suggests that knowledge of the condition is becoming more widespread. In Barbara Kingsolver's widely acclaimed book *The Poisonwood Bible* an American missionary takes his family of four daughters to the Belgian Congo in 1959. Adah is the only daughter who returns to the US where she becomes a doctor. Middle-aged at the end of the book she describes her pastimes: *Sometimes I play chess with one of my colleagues, an anchorite (hermit) like myself, who suffers from post-polio syndrome ... Sometimes we go out to a restaurant in the Atlanta Underground, or see a film at a theatre that accommodates his wheelchair.*

Ellie and the Shadow Man is the latest book by prize winning New Zealand author Maurice Gee. It tells the life story of painter Ellie Crowther. Early in the novel 14-year-old Ellie meets Hollis Prime the brother of a wealthy school friend. He is a law student who contracted polio aged 11. Ellie recalls the 1954 epidemic: *the schools were closed. She remembered doing schoolwork at home, and a girl called Muriel in her class who had caught polio, although not badly. Back at school, no one wanted to share a desk with her. They pretended they could see germs hopping over, and ran to the taps and washed their hands if they had to touch Muriel in folk dancing. Ellie blushed slightly remembering her part in it.*

Ellie asks Hollis what happened when he contracted polio. *Nothing much. I got carted off. Then I was in a wheelchair. I wore calipers. I'm OK now,* he replies.

So you'll always limp?

Sure ... You want to know the worst thing? It's my parents.

Why? asks Ellie.

I don't mind being crippled. It's no big deal. But Mum thinks I'm spoiled. Like a bloody bike that's got a buckled wheel. She doesn't want me any more.

She doesn't say that?

She doesn't need to. She used to be all over me when I was a kid, but now she doesn't even like touching me. She's always telling me to wash my hands. She went along to school after it happened ... She accused them of letting me play with dirty kids ... Polio is working class, not for the Primes.

About 300 pages on, now middle aged, Ellie and Hollis meet again. He has given up law and is buying a vineyard. A relationship develops. A few years later Ellie wonders, *Why is Hollis so tired just as he is set to succeed?* Hollis tells her that he has *post-polio syndrome*. *She had never heard of it. He explains: after the illness some of the nerve cells partly recover. New fibres and filaments transmit the messages. So the victim carries on with his life (in Hollis's case limping with his slightly shortened leg). Then as you start ageing the new pathways wear out, become overgrown - 'choose your metaphor', Hollis says -- and your trouble starts all over again: a sort of flaccid weakness, then sudden deadly fatigues. Mysterious pains, and pain referred in the butt and thigh. Loss of mobility and loss of balance. 'Bitching and bad temper'. Hollis says, 'I'm sorry, love'. Ellie almost cries. But it's not fair. 'What can we do?' she asks instead. 'Live with it. Keep going. Pull my horizons in' ... 'If I can't do much work here, at least I can manage it.' He tries to grin. 'I'll still be boss'. 'Yes,' she says, 'of course you will. But treatment, I mean.'* He tells her *pain-killers, and massage and mudpools up at the hospital in Rotorua*. By midwinter Hollis is forced to change his stick for crutches. Later Ellie watches Hollis walk up the path to the vines. *He had mowed it ... instead of going straight up, he'd cut an easy dog-leg so he could manage on his crutches ... He pushed himself too hard and seemed to have a dark enjoyment of his pain. He reminded her more and more of the boy she had first seen forty years before, sitting in the rain by the tennis court. He had been a singularity — but no, she protested, he's not any more, not sucking everything into himself. Soon: There were daily changes in him — more pain, stronger pills and, since Christmas, a trip to Rotorua and another one planned. She had learned to massage his legs. And now there were the modified controls ...*

The book is published by Penguin and sells in Australia for \$26.

PPS in developing countries

In a recent article in *Disability World* (May-June 2001) Dr Christopher Howson, director of global programs for the March of Dimes, is quoted as saying: *In developing countries, where polio outbreaks still occur or have ended more recently (than in the west) medical systems will be facing PPS for decades into the future.* He says that in developing countries PPS is less recognised than in advanced countries and speculates as to the reasons for this. *Perhaps PPS is underreported because health care providers are not recognizing it. Or perhaps people who are more at risk of PPS in developing countries tend to die before they reach the age of recognized disease onset. Also, PPS seems to be more common and severe in people who successfully rehabilitated themselves from the initial polio attack. Perhaps a lower percentage of people in developing countries have had the opportunity for rehabilitation and thus, haven't put themselves at additional risk of PPS.*

Deborah Goebert, medical researcher at the University of Hawaii speculated (in articles in *World Health* and *The Rehab Journal* in 1990) on the influence of cultural practices on the development of PPS symptoms. She found in a small study that far fewer polio survivors in the Marshall Islands (8%) reported fatigue, reduced energy and exhaustion than did those in Hawaii (65%). The lifestyles of the groups differ. The Marshallese, both ablebodied and polio survivors, rest for an hour or more several times during the day. Goebert suggested that this habit of rest breaks might delay, or perhaps even prevent, the development of some PPS symptoms.

President Roosevelt and the onset of PPS

Roosevelt is arguably the world's most famous polio survivor. Without his fundraising efforts far fewer American polio cases would have received rehabilitation and the development of the polio vaccine would have been delayed for years. Roosevelt dealt with polio and PPS by total denial as Hugh Gallagher has discussed in his books *FDR's*

Splendid Deception and Black Bird Fly Away (see review in Newsletter 41). FDR never discussed his polio or PPS symptoms with ANYONE. Lorenzo Milam, a polio survivor, has speculated about FDR's reaction to PPS in his (Milam's) memoirs, *The Cripple Liberation Marching Band Blues: There was one crucial day in Roosevelt's life-as-president which has never been documented. ... It was the day Roosevelt decided not to try any more. It was the day that, for the first time since the fever crusted his nerves, he decided not to get up and walk. It was the day he decided that strapping on the braces, hoisting his weight on the crutches, feeling the squeeze of leather against thigh and calf, the burning weight of wooden handle against palms was just too damn much trouble. I am sure it didn't come about just that way. I am sure that Roosevelt said to himself: 'I don't have time to get up today. Tomorrow, I'll do it tomorrow'. And then tomorrow came, and then tomorrow, and then there was no petty pace at all. None of the grinding strain to get up and move about. More comfortable in the wheelchair -- the wheels have become my hand. I'll do it next week. Meanwhile, I will let the helping hands move me on these round rubber legs, with their spokes, and these comfortable leather arms. ... Roosevelt succumbed to the unmitigating, undeniable truth of his body. Accompanied by terminal despair, he found he was growing, again, to be as helpless as he was in the awful days at Campobello. He learnt that the disease is the master, the ultimate master; and our efforts to surmount it are ... tinsel, cut from the glaze of ultimate defeat. When my friend Gallagher, the historian, asks people who knew Roosevelt, asks how he reacted to the second crippling that must catch all 'old ' polios ... they always say 'O, No problem. Nothing at all. Didn't bother him at all. He was magnificent' ... Didn't bother him at all? Didn't bother the Master of Control at all? Fat. F---ing. Chance.*



Post-Polio Internet Resource for GPs

The Queensland Department of Health has written a manual entitled *The late effects of polio: Information for general practitioners*. The manual can be downloaded from the Department's website at www.health.qld.gov.au/polio/gp/home.htm. Members of the Network's Committee were consulted during the development of the manual. It is extremely comprehensive with sections on acute poliomyelitis, the late effects of polio, clinical features of the late effects of polio, assessment, management, the role of the GP in treating the late effects of polio and a list of resources.

The opening screen on the site reads, "*General practice is most often the first point of contact with health care for members of the community. As a result, the GP has a major role in managing the health of their patients. GPs act as gatekeepers for their patients to access the rest of the health care system. To provide quality of care to patients experiencing symptoms related to the late effects of polio it is essential that health professionals be aware of the diagnosis of this condition and have an understanding of the underlying aetiology and pathophysiology of the symptoms a multidisciplinary approach to the assessment and management of these patients is often necessary due to the complex range of symptoms that these patients may experience.*"

This could be a useful site to which to refer your health practitioners; one that is likely to have high credibility in their eyes.

Will 2002 be the Year of the Polio Survivor?

Dr Richard Bruno, Chairperson of the International Post-Polio Task Force (IPTF), has recently sent some interesting material to the Network.

The material notes "Polio survivors are no longer poster children. We are accomplished adults who are being disabled by the unexpected symptoms of Post-Polio Sequelae (PPS) -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain, and difficulty swallowing and breathing -- that occur about 35 years after the poliovirus attack."

Dr Bruno estimates that "There are 20 million polio survivors throughout the world, nearly 2 million in North America and over 3 million in Europe. About 70% who had paralytic polio and 40% who had 'non-paralytic' polio are experiencing PPS. Yet many polio survivors and most doctors do not know PPS exist, let alone know how to treat them and deal with polio survivors' special medical needs."

He continues "With your help 2002 will become *The Year of the Polio Survivor* and the IPTF motto will become a reality: "*Every child vaccinated. Every polio survivor -- and doctor -- educated.*" With your help every doctor will learn about PPS and be able to give polio survivors the care we so desperately need."

To achieve this goal, the IPTF is working on many fronts, including:

- In 2002, UNICEF will partner with the Task Force and provide information about PPS as part of its polio eradication education program.
- In March 2002, polio survivors Mia Farrow and her 13 year old son Thaddeus are co-chairing *The Post-Polio Letter Campaign*. *The Post-Polio Letter* is a one page summary about the cause and treatment of PPS that is appearing in magazines, newspapers and on websites throughout the world. [Ed. *The IPTF is fortunate to have a high-profile polio survivor like Mia Farrow who is prepared to use her position in the community to promote the needs of polio survivors. If only some of our high-profile Australian polio survivors would do the same.*]
- In April 2002, Scripps Howard will begin filming the first documentary on PPS which will air on US television later this year [Ed. *hopefully it will also screen in Australia.*]
- In September 2002, the IPTF will present the first *David Bodian Memorial Awards* to the "Unsung Heroes" of PPS throughout the world.
- Last November the IPTF requested that European Health Ministers discuss their governments providing information about PPS to health professionals and polio survivors, their national health services providing treatment for polio survivors to prevent them from becoming disabled, and providing disability benefits to polio survivors who can no longer work. The Ministers have agreed to place these items on their November 2002 meeting agenda. [Ed. *Over twelve months ago the Network attempted to achieve a similar outcome in Australia. While our efforts to date to have PPS discussed at a national level by Australia's Federal and State/Territory Health Ministers have not borne fruit, the success in Europe encourages us to try again.*]

Dr Bruno concludes "These events and others may finally allow awareness of PPS to reach critical mass. To insure that end, the International Post-Polio Task Force is asking the United Nations, Parliaments throughout the world, the US Congress and each state and provincial legislature to declare 2002 *The Year of the Polio Survivor*, and September 2002 *Polio Survivors Month*." The Network is lending its support to these initiatives, and will report on progress.

Vale – Rae Newhouse

Many long-term members will remember Rae Newhouse as the softly-spoken empathetic voice on the other end of the telephone when they first rang to enquire about the Network. We are sad to advise that Rae passed away recently. Rae and her husband of 55 years, Joe, have been good friends to the Network since it was formed and have always been great supporters of our work. The late effects of polio kept Rae mostly at home for the last few years but she still helped out wherever she could and was a recent recipient of one of our *International Year of Volunteers* awards. We are pleased that Joe wishes to maintain contact with the Network and know that all who remember Rae with affection will wish Joe well.

Post-Polio Syndrome Orthotic Care Presents Challenges

Comments by Paul Galy, David Windsor Shoemaker Pty Ltd, Bondi

Member Paul Galy presented a Seminar called "These Boots are Made for Walking ..." to Network members in March 1998. At that time, Paul already had many polio clients (some of whom had been seeing him for more than 30 years). Since his Seminar and subsequent article in the Newsletter (Issue 35) he now has many more.

I was interested to read the article in your November 2001 issue of *Network News, Post-Polio Syndrome Orthotic Care Presents Challenges*, by Miki Fairley. While agreeing with most of what was written, and recognising that the article was written on orthotic care, it fails to mention that orthotics, prosthetics, callipers and splints represent only part of the treatment, and can assist only partially in improving stability, posture, weight distribution, gait and mobility. Without the proper footwear which accommodates the above-mentioned appliances, the appliances are rendered only partially beneficial or, at times, useless.

I have seen callipers fitted to boots with no heel counters and without a shank (most manufactured footwear today do not have shanks or proper counters; they usually have only a moulded sole-heel unit which distorts very easily. The person wearing this equipment was continually falling, with the added risk of major injury as he was wearing full length callipers and was unable to put himself into a protective position.

On a recent visit to the United States I inspected a number of orthotic and pedorthic facilities. The trend in the US (as here in Australia) is to make these orthotic devices and then try and modify existing footwear. In most instances it becomes "make do with what we've got", the heels and tongues padded at times up to 2 cm of felt and incorrectly fitted inserts and t-straps and other unsightly external build ups (leg shortening up to 25 cm), flares usually out of heavy rubber materials or lightweight materials that collapse within a couple of hours and make the whole exercise to help polio sufferers ineffective. As an added tax on their life they have to go back to the person who made the build up weekly because the materials keep collapsing and they don't wear appropriately.

Quite often by wearing orthoses and ugly built up orthopaedic shoes or boots it makes the polio sufferers self-conscious and, by wearing inappropriate footwear, worse off. They are less likely to use these appliances which limits their mobility, lowers their self-esteem, they tend to gain weight which puts further strain on their already weakened limbs.

There is a large group of people who have had dealings with unprofessional orthotists who dictate what a patient should have without taking the patient's individual needs, frailty and dignity into account resulting in patients having a bad experience and giving other lower limb practitioners a bad reputation.

In my 40 years of experience as an orthotist, pedorthist, prosthetist and gait analyst, assessing weight distribution and designing (and actually making) orthoses and all other orthotic devices I have a great deal of experience with polio sufferers and I specialise in solving and enabling polio sufferers to continue their mobility with greater safety and maximise weight distribution.

I believe the footwear is as important as the appliances and in most instances it should be purposely built to the individual's requirements. Bulky appliances can be concealed. Footwear can be specially designed (with the patient's input) and these days the footwear can be as aesthetic as one requires. The materials that are used can be especially selected (polio sufferers usually with bad blood circulation can be high risk for whom special linings should be used) and reinforcements should be specifically designed.

As a large number of Network members and subscribers to the *Post-Polio Network News* are already my clients, I just wanted to reiterate and emphasise the importance and need for the orthotic appliance to work in conjunction with the appropriate footwear which was not mentioned in the article.

Support Group News

Neil von Schill
Support Group Co-ordinator

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Email: neilvon@optusnet.com.au

We were very saddened to hear of the death late last year of our Cowra Convenor, Vera White. Vera, with her husband Bill lived on a farm out of Cowra and was very involved with a range of community activities. She had been Convenor since 1994 and conducted an active Telephone Support Group which gave members in the Cowra district a focus and a concerned friend. She will be remembered by members for her interest in the welfare of others and her caring compassion. Vera will be sadly missed by her family and friends. We extend our sincere condolences to Bill and his family.

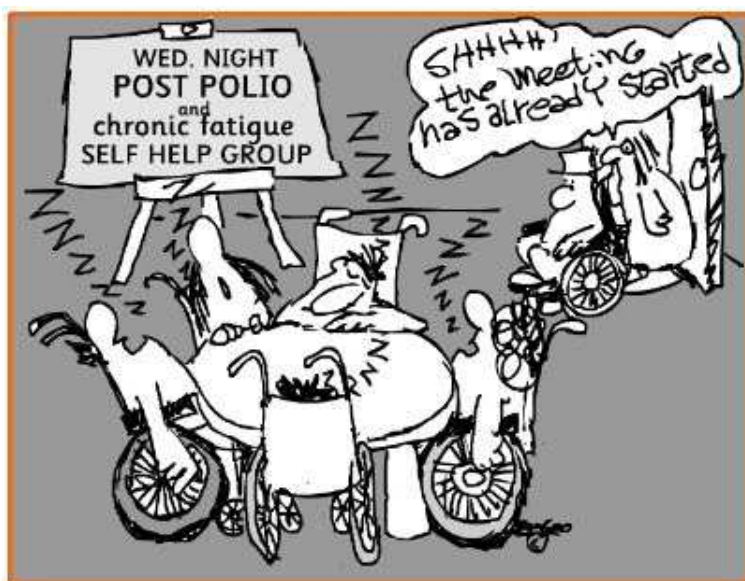
On a happier note, I recently had the pleasure of visiting a number of Convenors in the Riverina, Northern Tablelands, North Coast and Central West regions of the state and will bring you a full report of my trip in the next *Network News*. In the meantime, here is an update on Network Support Groups since my last Report.

The new Support Group in the Eastern Suburbs which had its inaugural meeting last October is off to a strong start. They have now had several meetings and we wish to thank Eric Sobel for taking on the important role of Convenor. The next meeting of the Group will be held on Saturday 15 June at the Labor Club, Alison Road, Randwick. Any members living in the Eastern Suburbs who would like to attend this or future planned two-monthly meetings are invited to contact Eric on 9389 2822 (work) or 9389 7967 (home). I know that he would be delighted to hear from you.

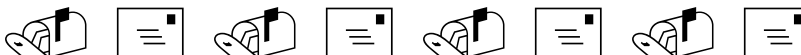
It has been very encouraging to receive positive feedback from a number of Convenors who were very appreciative of receiving their *International Year of Volunteers* Certificates and pins. All members who were presented with these awards were deserving of the recognition of their efforts from the Network.

In conjunction with our next Mini-Conference which is being held at Maroubra Beach in May, we are conducting another Convenors' Workshop which will be held at lunch time. All Convenors are encouraged to consider attending following the very successful Workshop that we held last December. You will not only get the opportunity to hear what promises to be a fascinating day of presentations by Dr Marcia Falconer, but will once again have the chance to network with and learn from other Convenors around the state.

And now for some comic relief - I thought Support Group Convenors and Support Group members alike might see something of themselves in this cartoon sent to us by Dr Falconer. Hope you enjoy it!



Post-Polio Post



Having read recent Letters to the Editor about accommodation options when we are no longer able, or willing, to live at home or by ourselves, the Australian Foundation for Disabled has provided the following information for members who may be contemplating a change in their living arrangements.

The Australian Foundation for Disabled (formerly known as the Poliomyelitis Society) operates a residential facility, known as Cherrywood Village, for thirty-two adults at Llandilo, near Penrith.

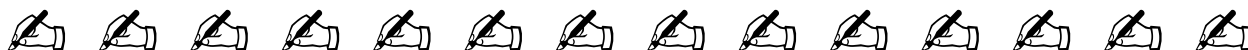
Accommodation is in motel-style units with meals served in a central Dining Room. There is a lounge room, recreation hall and swimming pool for the use of residents.

Support staff are available twenty-four hours per day. Transport including a wheelchair-accessible van is provided for residents attending medical appointments and so on. There are a limited number of organised recreational activities.

If you are able to tend to your own personal needs, although you require a little more than fully independent accommodation but are not yet ready for aged care, contact:

Norma Denicolay
 Acting Accommodation Manager
 Cherrywood Village
 844-876 The Northern Road
 Llandilo NSW 2747

Phone: (02) 4777 4250



Reminder – Coming Events – Dates To Remember

Saturday 18 May	Maroubra Seals Sports Club <i>Maroubra Beach</i>	Full-day Mini-Conference presented by Dr Marcia Falconer <i>(see presenter and program details on pages 2 and 3)</i>
Saturday 3 August	St Paul's Anglican Church Hall Princes Highway <i>Kogarah</i>	<i>Murder at the Sydney Opera House</i> a musical murder mystery in one act in the Agatha Christie short story tradition written and performed by Barbara Thompson
Saturday 31 August	Northcott Society <i>North Parramatta</i>	Adam McLean Counselling Co-ordinator, Carers NSW
Friday 25 October	Regency Function Centre Burwood RSL	<i>Social Event - Luncheon Reunion of Polio Survivors and Prince Henry Hospital Nurses</i> <i>(all are welcome – full details will appear in the next Newsletter)</i>
Saturday 30 November	Independent Living Centre Victoria Road <i>Ryde</i>	<i>Falls, fear of falling and activity in older people with polio: what can be done to help?</i> presented by Dr Keith Hill Senior Research Fellow, National Ageing Research Institute (NARI), and Co-Director, Falls and Balance Clinic, Melbourne Extended Care and Rehabilitation Service
AGM and Seminar		