



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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President's Corner

Gillian Thomas

Dr James Wright has given us unprecedented publicity, in Sunday papers and on his radio programs, over the last four months and we are extremely grateful. Since Christmas, we have sent out over 320 information kits to people making their first contact with the Network. Memberships from these enquiries are trickling in; many people do not join for some months after receiving information. Sadly, others appear to feel they now "know it all" and don't see a need for ongoing contact. Any feedback from new members on this subject will be most welcome. We will be taking steps to further boost Network membership over the coming months. One strategy is the development of a publicity plan for the Network, and we are looking for input from members.

The Network is currently supporting the Commonwealth Department of Health and Family Services' *Immunise Australia* program, and has proudly endorsed its *Understanding Childhood Immunisation* booklet. On 25 March, I will be travelling to Canberra at the invitation of the Hon Dr Michael Wooldridge, Minister for Health and Family Services, to attend a launch to mark the signing of the *Australian Childhood Immunisation Charter*. The Network is a signatory to this most important document.

The **Seminar Program** for the remainder of 1998 is given on page 3. I urge you to put the dates in your diaries now. Further details about each Seminar will be given closer to the date. As usual, there will be a Seminar in June, and a Seminar will be held in conjunction with our Annual General Meeting in October. In August, we are planning to take our regular Seminar out of the Sydney metropolitan area for the first time. In conjunction with the ACT Support Group, we are developing the program for a **Mini-Conference** to be held in Canberra. The day after the mini-Conference, we will be holding some Workshops to identify issues for Support Group Conveners and develop some strategies for better serving our country members. We hope that by holding the Conference/Workshops in Canberra, members from the surrounding areas who may be unable to travel to Sydney will be able to attend. However, everyone who can get there will of course be welcome. Holding such an event will be a first for us, and as we do not want to overstretch ourselves, we made the difficult decision to not hold a fourth Seminar in Sydney this year. Our aim is that each year we will hold a Seminar in a rural area of New South Wales. After evaluating our first attempt, we hope next year to return to holding four Seminars in Sydney.

Polio Awareness Week this year will be held from **1 to 7 November**. We are also planning a social event in conjunction with the Week. If you would like to become involved in the Week's activities, please call Alice on (02) 9747 4694. We must start early to make the Week a success.

Copies of the 170-page **Proceedings** of the November 1996 Conference *Living with the Late Effects of Polio* are still available at a cost of \$29, as are Network T-shirts at \$15 (plus postage). Finally, if you would like a copy of the Network's Constitution incorporating the changes adopted in September 1996, please give Alice a ring.

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March Seminar Report

These Boots Are Made For Walking ...

Our guest speaker on 7 March was orthotist, prosthetist and pedorthist Paul Galy. Paul's topic proved very popular and around fifty people were present, some having travelled from far afield. Paul commenced his presentation by recounting his qualifications and his considerable experience in working with polio survivors.

Ladies and Gentlemen, thank you for inviting me to speak.

I would like to provide you with some background of my professional expertise.

I am firstly an orthotist trained in the tradition of making orthotics, calipers, splints, and other prosthetic devices.

I am secondly a qualified prosthetist. I make prostheses for lower-limb amputees, for example. In this instance I would usually make a "false forefoot". Some people in the audience have two different sized feet and it is very important for aesthetic reasons to make a false front to the shoe so that both limbs will look identical.

My third qualification is that of pedorthist. Pedorthists make foot appliances and medical grade footwear (orthopaedic shoes and boots).

I am a third-generation pedorthist. My father started his practice in Australia in 1956, when my family arrived in this country. I was nine years old at the time. Within a short period of time I learnt to speak English. My father was in his late fifties and had great difficulty learning a new language. As a result, I would attend work with him at 6:00 am every morning, to act as interpreter for his clients, who he would see between 7:00 and 9:00 am. And then after school, between 3:30 and 7:00 pm, I would also be there to interpret.

I completed my apprenticeship with my father in 1965. I then attended the McMaster's College in Hamilton, Canada, where I completed two courses in prosthetics and graduated as an orthotist. On my return to Australia I resumed working with father.

My father had a special interest in making shoes and appliances for polio survivors. I am sure you are aware that the effects of polio is the result of nerve injury by the polio virus which results in the loss of muscle function. He explored how the lower limbs react in terms of weight-bearing and altered function.

The complications of polio were also very important considerations. For example, the heel bearing most of the weight may develop hard, thick and sensitive skin. Painful cracks may also develop, which may weep, making the client prone to infections. Painful ulcers commonly result. There are simple effective ways of preventing this scenario.

My father passed his knowledge about the foot-care management of polio on to me. In the last 30 years I have been asked many times to speak at venues, but have declined because of my busy practice. I treat a large number of diverse clients. They suffer from vascular disorders, diabetes, arthritic deformities, trauma (or accident) cases, stroke, MS (multiple sclerosis), as well as polio survivors. I have some clientele who travel from South Africa, New Zealand, Noumea, Japan and the far reaches of Australia. I have some clientele who have been attending for over thirty years.

I have a particular way of running my practice: dress is always casual, t-shirt and jeans the norm. Once a client is accepted, we become friends - for example, a first-name basis is

used - the aim is for clients to feel free to express their concerns, specific needs, expectations and sensitive problems. In this environment we usually achieve optimal results.

Footwear needs to be functional, comfortable and aesthetic. The client shouldn't walk with a limp if possible. Aesthetics is important - the footwear should not look bulky or heavy and I have become skilled at this over many years. Mobility is particularly important. If it is restricted, all other bodily functions become adversely affected. If the client sits all day because they can't mobilise, they gain weight, retain water, become constipated, their muscle bulk wastes - all this causes further immobility - a vicious cycle. Everyone who can should break out of this cycle, with the cornerstone being to improve mobility. This will ultimately improve their quality of life.

There are a large number of polio survivors who have managed with ready-made shoes, stuffed with stockings, built up by unqualified untrained shoe repairers. Lots of you have recently seen specialists who have referred you to podiatrists. Many of them have never seen a polio survivor, but they have attempted to make an orthotic devised to be put into ready-made shoes. Most of them have not worked, mainly because they simply do not fit into ready-made shoes. So they might try to put them into oversized joggers, which go out of shape quickly and do not provide support. Coping becomes more difficult.

This was the end of Paul's formal introduction. He then threw the session open to those present. He spent the next hour answering questions on a whole range of issues to do with footwear. From the start of his presentation it was apparent that Paul has a real understanding of polio and the unique problems it causes. In particular, he understands how critical our balance can be. Paul insists that you should have a fitting of, and practice walking in, your new footwear before it is fully built, as adjustments can then easily be made to ensure the footwear fits correctly. Following on from this, he has promised to develop a Checklist of questions that you can ask of a bootmaker to ensure your footwear will be made by someone who understands your special needs. I hope to publish this Checklist in the next Newsletter. With his emphasis on customer service it is not hard to see why some clients have been seeing Paul for over thirty years. His busy practice, Starbright Orthopaedic Shoes, is located at 80A Blair Street, Bondi NSW 2026, and he can be contacted on (02) 9130 3117.

Post-Polio Seminar Program : 1998

Saturday, 20 June 1998	Seminar : Tai Chi and Qigong for Post Polios Presenter : Dr Paul Lam Venue : St Paul's Anglican Church Hall, Kogarah
Saturday, 29 August 1998 Sunday, 30 August 1998	Mini-Conference (program being developed) Support Group Workshops Venue : Canberra, ACT (actual venue to be advised)
Sunday, 31 October 1998	Annual General Meeting Seminar : Strategies for Feeling Less Tired Presenter : Leonie McMahon Venue : Independent Living Centre, Ryde

EMG: What, Why and Why Not

Paul E. Peach, MD

Dr Peach has written numerous articles relating to post-polio issues including a chapter entitled "Late Effects of Poliomyelitis in Clinical Aspects of Rehabilitation Medicine", has published original research, and has presented at many post-polio conferences. Dr Peach has recently established the Palmyra Post-Polio Clinic in Albany, Georgia, which provides comprehensive services to polio survivors, and previously served as medical director at Warm Springs.

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What Is An EMG Study?

An electromyogram (EMG) is a diagnostic instrument that detects the presence of motor units. (A motor unit consists of the nerve and all the muscle fibers it stimulates.) In the diagnostic EMG, a very small diameter needle is inserted into a muscle.

In an EMG study, a number of observations are made. First, any spontaneous resting activity is noted while the individual is completely relaxed. Normally, no resting activity should be present. If abnormal activity is observed with the muscle at rest, a neuropathy (a disease of the nerves) or myopathy (a disease of the muscles) may be the cause of the problem.

Next, the polio survivor is asked to contract the muscle up to full effort. During this phase of the examination, the readings of the individual being tested are compared to the readings of normal motor units, which fall within a given size range and with a maximum number of phases. Motor units which have too many phases (polyphasic) and are larger than normal could indicate a neuropathy. On the other hand, if smaller than normal motor units are observed which are also polyphasic, a myopathy may be indicated.

Additionally, the EMG can document the rate of recruitment (the rate at which the number of motor units are activated) and degree of interference at full effort. Incomplete interference at full effort can indicate the severity of the neuropathic or myopathic process.

The second part of what is commonly referred to as an EMG study is the nerve conduction study (NCS) in which surface electrodes are used. In the NCS, a controlled electrical shock at a certain threshold stimulates the nerve. At the end of the arms and legs, the time delay from onset of stimulus to the response is termed the distal latency. In some neuropathies, for example, carpal tunnel syndrome, this time delay is extended.

Also, the nerve conduction speed can be calculated by stimulating a nerve at two points. A lower speed may be found in a systemic disease, such as diabetes mellitus. A slower nerve speed in one section may be found when a nerve is compressed, for example, across the elbow.

Data from the EMG and NCS is combined and the determination can be made whether a neuropathy or myopathy is present and whether it is acute (is presently active) or chronic (occurred in the past but is no longer active). Further, it can be determined whether the problem is localized or generalized throughout the body. Finally, the severity of the problem can be estimated. The EMG of polio survivors will typically show evidence of chronic neuropathy which reflects the paralysis of many years ago.

What is the Value of an EMG Study?

For those who have had paralytic polio, an EMG study will detect evidence of the prior effects of polio. This will also be true of those who had initial paralysis or weakness and experienced complete clinical recovery. The apparently complete recovery that occurs in those instances, and partial recovery that

occurred in those with greater involvement, resulted primarily from a process that has been termed collateral reinnervation or "sprouting". After the acute episode of poliomyelitis, various areas of muscles are "orphaned" of nerve supply as a result of the motor nerve cells that did not survive the viral attack.

Depending on the relative number of motor nerves surviving, these surviving motor units (in the areas of their terminal sprouts) send out sprouts to the orphaned muscle tissue. As a result, much larger than normal motor units are formed.

This process which occurs months after recovery from acute polio results in functional improvement for the polio survivor. Therefore, an EMG study of an individual who has paralytic polio will show much larger than normal motor units. Characteristically, these motor units also will be polyphasic. This finding in polio survivors is termed chronic polyneuropathy. These findings reflect only a past pathology and do not indicate that anything is currently active.

A question that has been asked by many polio survivors is whether an EMG can detect the presence of post-polio syndrome. A straightforward answer to this question simply is that an EMG is of no value whatsoever in detecting post-polio syndrome. Well-founded research studies have established that EMG findings of polio survivors who have been appropriately diagnosed with post-polio syndrome, and those of survivors who are not experiencing symptoms, are not significantly different. It is well established among medical practitioners experienced in managing post-polio patients that the diagnosis of post-polio syndrome is a clinical diagnosis. No objective test is available that can reliably and specifically denote the presence of post-polio syndrome. The diagnosis is made only after well-established clinical criteria have been met, and other possible medical conditions that could also cause symptoms of progressive fatigue, weakness, and pain have been excluded.

If an EMG is of no value in diagnosing post-polio syndrome, then under what circumstances would performing an EMG be justified on an individual who is being evaluated for post-polio syndrome? In the post-polio clinics I have developed, I have never used EMG studies as a screening test, but rather, utilize them with a specific purpose in mind, and only to the specific limbs which may yield maximum diagnostic benefit. The reasons for this are twofold: the EMG-NCS is not an inexpensive test, and the majority of polio survivors will endure some degree of discomfort from these procedures.

I will recommend an EMG in two situations. Generally, it is preferable to have medical records available to confirm a history of paralytic poliomyelitis. However, this frequently is not feasible. If a person gives a history compatible with acute poliomyelitis, and he or she presents with obvious atrophic paralysis with complete sensory preservation, a history of poliomyelitis is supported, and an EMG is unnecessary. If no residual paralysis is clinically apparent, however, then an EMG is useful to confirm the presence of chronic polyneuropathy (or earlier acute poliomyelitis as evidenced by large motor units).

Occasionally, someone is seen who had been misdiagnosed with poliomyelitis. If, for example, someone has spastic paralysis rather than flaccid paralysis (as seen in polio), or if sensory impairment is present, this is not consistent with a history of poliomyelitis and an EMG is helpful in determining the existence of another disorder.

Another situation where an EMG is appropriate is when, during the clinical evaluation, there is reason to suspect the coexistence of another disorder other than post-polio syndrome or chronic poliomyelitis. For example, carpal tunnel syndrome is much more common among crutch walkers than the general population. In persons with diabetes mellitus, for example, fatigue, and often sensory impairment, may also be present. An EMG-NCS is very useful in confirming the presence of these as well as other non-polio related disorders. Sometimes follow-up EMGs at a reasonable interval can be useful in monitoring response to clinical interventions, or, in some cases, confirming the progress of a disease process such as neuropathy of diabetes, carpal tunnel syndrome, or radiculopathy (a "pinched" nerve).

In summary, the EMG-NCS is a diagnostic study that can be very useful during the evaluation and clinical management of post-polio survivors. It does, however, as with any other diagnostic test, have its limitations. When utilized appropriately, it can be of very material assistance to the clinician in the evaluation and management of polio survivors.

The Use of Pyridostigmine (Mestinon) in Post-Polio Syndrome

Preliminary results of the multi-center, placebo-controlled NAPPS (North American Post-Poliomyelitis Pyridostigmine Study) trial of pyridostigmine (Mestinon) in post-poliomyelitis syndrome (PPS) were presented on November 15 [1997] at the annual meeting of the American Academy of Physical Medicine and Rehabilitation (AAPM&R) in Atlanta by Daria A Trojan, MD, Assistant Professor at the Montreal Neurological Institute and Hospital of McGill University in Quebec. Pyridostigmine was not found to provide significant benefits with respect to quality of life, fatigue, or isometric muscle strength compared with placebo, although a trend was noted towards increased strength in very weak muscles.

The NAPPS study was initiated by the participating investigators and received support from ICN Pharmaceuticals, the company that markets and distributes the medication (Mestinon is currently approved for the treatment of myasthenia gravis). One hundred and twenty-six (126) patients participated in the trial: 64 received pyridostigmine and 62 received a placebo. All patients completed the double-blinded study, a study where both the patients and the study personnel (investigators and evaluators) are unaware of which patient received the pyridostigmine or the placebo. During the six-month course of the study, 70.3 percent of patients on pyridostigmine and 72.6 percent of patients on placebo had at least 80 percent compliance with the medication.

In the main data analysis, which included all patients in the trial, the study did not show a difference between pyridostigmine and placebo patients in terms of their health-related quality of life, fatigue (as measured by two fatigue scales), and most measures of isometric muscle strength. Similar results were noted for the subgroup of patients who were assessed as being compliant with the use of the medication. However, Dr Trojan noted, there was a non-significant increase in strength in very weak muscles (1% to 25% of predicted normal strength) in pyridostigmine-treated patients of six (6) months of treatment. In general, the study medication was well tolerated: four (4) severe adverse events were observed during the trial, (three (3) of which occurred in pyridostigmine-treated patients.

These results, which showed no statistically significant effect of pyridostigmine on the outcomes assessed, were unexpected by the investigators. Dr Trojan commented that the results did not reflect the investigators' clinical impression that there appeared to be a clear benefit with the medication in at least some patients. It is possible that another study that utilizes different or more-sensitive outcome measures (such as measures of muscular endurance, physical activity, or disease-specific quality of life) might yield different results, she noted. The open-trial phase of the NAPPS study is on-going, and further data analyses are in progress.

Member Questionnaire

It is not too late to return the Questionnaire which was distributed with the August 1997 Newsletter (Issue 33). If you have joined the Network since 1 September 1997, a Questionnaire is included with this Newsletter. Merle Thompson is keen to have as many completed and returned as possible. This gives greater validity to the results which we will be seeking sponsorship to have published and presented to Government Health Ministers.

Australia is seeking to be certified "polio free" by the World Health Organisation. This is not as simple as you might think. It doesn't only depend on no wild poliovirus cases being confirmed. Australia has to jump through some hoops with respect to carrying out Acute Flaccid Paralysis surveillance so that every possible case of poliomyelitis is detected, investigated and classified. Unfortunately, it appears the level of surveillance in Australia is not it all should be. Dr Rennie D'Souza, who sits on the National Certification Committee for Poliomyelitis Eradication, recently forwarded the following flyer which exhorts medical personnel to improve their surveillance so that Australia has a real chance of being certified polio free by the year 2000.

Polio Eradication and Acute Flaccid Paralysis Surveillance

Although there has been no confirmed wild poliomyelitis case in Australia for many years, Australia, along with most countries of the World Health Organisation's (WHO's) Western Pacific Region, has agreed to carry out Acute Flaccid Paralysis (AFP) surveillance as part of the initiative to declare the world polio free by the year 2000.

A highly sensitive surveillance system for AFP will ensure that every possible case of poliomyelitis is detected, investigated and classified. This is critical for the successful eradication of polio.

A number of indicators have been established to monitor the performance of AFP surveillance systems. Most importantly, even in the absence of wild poliovirus circulation, surveillance systems should be capable of detecting at least one case of AFP per 100,000 population aged less than 15 years.

Several countries in the Western Pacific Region have moved from a clinical to a virological case definition for AFP cases. Before this can occur in Australia, adequate stool samples must be collected from at least 80% of all cases and cultured for poliovirus. "Adequate stool samples" have been defined by WHO as two samples of stool taken at least 24 hours apart, within 14 days of onset of paralysis and transported appropriately to the laboratory, with adequate documentation.

When we use a clinical case definition, many cases are mis-classified as "poliovirus compatible" because "residual paralysis" is found at the 60 day follow-up examination. If adequate stool samples had been found negative for wild poliovirus, these could have been discarded as "not polio".

The expected rate of notifications was achieved in the first year of the active AFP surveillance through the Australian Paediatric Surveillance Unit (APSU). However, the level of reporting declined to 0.7 cases per 100,000 in 1996. In addition, the proportion of adequate stool samples being taken within 14 days was only 26%.

If recommended reporting is not adhered to, WHO standards will not be met for certification. All cases with incomplete information (i.e. no clinical information received via questionnaires, or stool samples not tested adequately) will have to be considered "polio compatible" by the expert committee that reviews each notification.

Australia has a key role to play in the Western Pacific Region in contributing to protection from polio in the region, and in maintaining high public health standards. Therefore, for Australia to be certified polio free, it is requested that all medical personnel phone in notifications of all cases of AFP and not only those where polio could be a possibility. Secondly, they are requested to ensure that stool specimens are collected and forwarded to the National Polio Reference Laboratory, and that all cases of AFP are reported to the APSU and that completed questionnaires are returned.

Post-Polio Clinic and the Redevelopment of Prince Henry

If you have rung to make an appointment at the Post-Polio Clinic at Prince Henry Hospital recently, you would have learned that the Clinic is currently in recess because the Rehabilitation Specialist in charge, Dr Jill Middleton, is taking a well-earned break. Jill is expected back in July. In the meantime, Dr Pesi Katrak, Rehabilitation Specialist, has been regularly seeing polio patients at Prince Henry Hospital for some years, and is still doing so. You can make an appointment to see Dr Katrak by ringing (02) 9382 5931. He has asked me to remind you that you need a referral from your GP.

While on the subject of the Clinic, the Management Committee has been keeping a close watch on the redevelopment of Prince Henry Hospital. The Network has written a number of times to the NSW Minister for Health, Andrew Refshauge, raising our concerns about the future of the Hospital, and with it, the Post-Polio Clinic. On each occasion, the Minister has responded that Prince Henry is to become a "centre of excellence" for rehabilitation and that our concerns are unfounded.

To date, little redevelopment has taken place. Indeed, many of Prince Henry's services have been transferred to the Prince of Wales Hospital. The last meeting of the *Coalition of Concerned Residents - Friends of Prince Henry Hospital* held on 12 February, which was attended by Network representatives Marianne Newton and Margaret Dicalfas, resolved that the meeting "urge the Premier to proceed with the redevelopment of Prince Henry Hospital at the Little Bay site, as a Centre of Excellence for spinal rehabilitation and aged care services with a minimum of 120 beds." The meeting further resolved that "details of the time frame proposed for the redevelopment" be provided by the South Eastern Sydney Area Health Service. These resolutions were forwarded to the Premier, in a letter dated 2 March, by Randwick Councillor Margaret Martin on behalf of the Coalition.

It seems that some progress is now being made. On 17 March, a local paper reported the future of Prince Henry Hospital "... will include a new centre of excellence for aged care and rehabilitation, possibly of up to 120 beds." The paper further reported "The Department of Urban Affairs and Planning would also invite interested parties to become involved in the design of a master plan for the entire Prince Henry site. The master plan will be completed by September and, according to Mr Carr, would decide the best position for new facilities and integrate all services already on site."

The next meeting of the Coalition will be held on 26 March, while this Newsletter is at the printers. The Premier has been invited to attend, but we do not know if he has accepted. We hope there will be opportunity at this meeting for the Network to be recognised as an "interested party". If not, we will write directly to the Premier and to the Minister for Urban Affairs and Planning. Further developments will be reported in the Newsletter.

Post-Polio Network Office Accommodation

Some ten months have passed since the Management Committee first looked at possibly leasing office accommodation within the *Royal South Sydney Community Health Complex*, Joynton Avenue, Zetland. We needed a ground-floor office that was big enough to accommodate us and give the Network a higher profile, but not so big that we could not afford to lease it. We found an office that suited our needs, but we could not move in until a refurbishment of another area, and a lot of related moves, took place. The wheels have been grinding ever so slowly, but we are hopeful that by the end of March we will be close to our goal. Management Committee member **Ruth Wyatt** (02) 9416 4287 would like to hear from anyone who could volunteer their services for a roster to operate the office. At this stage, we are looking for a "show of hands" - no firm commitments are required yet.

Poet's Corner

Prolific poet Mark O'Brien is an American polio survivor whose poems can be controversial and provocative. Mark has kindly given us permission to reproduce Breathing from his first collection of poems. Mark spends the majority of his life in an iron lung. Permission to reproduce the article must be sought from Mark. You can Email him at <marko@well.com>.

Breathing

Grasping for straws is easier;
You can see the straws.
"This most excellent canopy, the air, look you,"
Presses down upon me
At fifteen pounds per square inch,
A dense, heavy, blue-glowing ocean,
Supporting the weight of condors
That swim its churning currents.
All I get is a thin stream of it,
A finger's width of the rope that ties me to life
As I labor like a stevedore to keep the connection.
Water wouldn't be so circumspect;
Water would crash in like a drunken sailor,
But air is prissy and genteel,
Teasing me with its nearness and pervading immensity.
The vast, circumambient atmosphere
Allows me but ninety cubic centimeters
Of its billions of gallons and miles of sky.
I inhale it anyway,
Knowing that it will hurt
In the weary ends of my crumpled paper bag lungs.

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Nepean School Reunion

The following letter from the Nepean Reunion Committee reports on the success of their Reunion which we had promoted in Newsletter Issue 32, June 1997.

Dear Gillian

Further to our recent telephone conversation, it is with great pleasure that I can inform you of the wonderful success of the Nepean School Reunion that was held on Saturday, 18 October 1997, at the Northcott Society in North Parramatta.

With your help we were successful in contacting many former pupils and teachers we could not otherwise have advised of the Reunion. Several of these people travelled great distances, including interstate, to attend and share the day with folk they had not seen for years.

All enjoyed a day of wonderful shared memories of our Nepean days, with much laughter and a few tears, but an enjoyable day for all involved. The day's activities included speeches from all former Principals, also memorabilia displays of Nepean history, the school flag, etc, and the releasing of balloons in memory of former students and staff who have passed away, many of whose families were present. A very special day for all associated with Nepean School.

Our grateful thanks for your wonderful support.

Yours sincerely

Lynne Mulryan

Support Group Report

Since his appointment as Support Group Co-ordinator, Bernie O'Grady has been making regular contact with all Conveners. He has been working hard to match new members up with the Support Group nearest to them, and to encourage new Groups to get underway. This is a very time consuming task, but Bernie expects to start a regular feature in the next Newsletter which will give current contact/meeting details for all Groups, as well as an update on Group activities. This information will also appear on our Internet site.

The Network Support Groups provide peer support to their members through an exchange of experiences and ideas. Support Groups meet in a variety of ways, including telephone contact, by corresponding with each other, and by holding meetings. Listed below are the details for some Groups which regularly meet in person.

Support Group	Convener	Meeting Dates and Times	Meeting Venue
ACT	Brian Wilson (02) 6293 2747	1st Saturday of every second month, starting February 2:00 pm - 5:00 pm	Pearce Community Centre Collett Street PEARCE
Blacktown / Blue Mountains	Bernie O'Grady (02) 9688 3135	3rd Monday of the month (except January and December) 11:00 am - 1:00 pm	Kingswood Community Centre Cnr Bringelly Road and Baden Powell Avenue KINGSWOOD
Central Coast	Lynne Ellis (02) 4368 2826 Barbara Tunnington (02) 4369 2397	1st Saturday of the month 10:00 am - 12 noon	Kincumber Neighbourhood Centre Cnr Avoca Drive and Kincumber Street KINCUMBER
Coffs Harbour	Joan Ward-Harvey (02) 6651 3104	3rd Sunday of the month Starts at 11:00 am	Alternates between the URUNGA Golf Club and the COFFS HARBOUR Catholic Club
Hunter Area	Wendy Chaff (02) 4957 5254	1st Wednesday of the month (except January) Starts at 10:30 am	Toronto Workers Club James Street TORONTO
Northern Inland	Barbara Chapman-Woods (02) 6766 5093	1st Monday in February, May, August, November	Unit 19 St Andrews Village Tribe Street TAMWORTH

If you are unable to get to meetings, you might be interested in joining a letter-writing "round robin" where an exercise book is regularly sent around a list of members, starting and ending with the Convener. Participants read other members' contributions and add their own. Inner West Convener, Joan Mobey, developed this idea and suggested that it is

a way for more isolated members to interchange ideas with other polio survivors. Joan prepared a booklet which gives Conveners ideas on how to get such a "round robin" underway. This booklet was sent to all Conveners last June. Barbara Chapman-Woods has taken up the challenge with her Northern Inland Support Group members who cover a large area of New South Wales. As Barbara points out, she cannot rely on a "one size fits all" approach with such a far-flung membership. She writes:

It seemed best to limit each Round Robin list of names to a small number - making two short groups rather than a long list where there could be added risk of the Round Robin exercise book getting lost or perhaps not being posted on in a reasonable time.

The first Round Robin book has just completed its first round to members in Moree, Collarenebri, Gilgandra, Griffith and Coonabarabran, and I have just sent it on its second round. I was very happy with the enthusiastic participation of all these Western Round Robin members. I've just started a Northern Round Robin with another short list of members in Dundee, Inverell, Armidale, Walcha and Gunnedah.

Other members in the Northern Inland region are welcome to join in - just give Barbara a ring on (02) 6766 5093. If you are a member of another Support Group and would like to participate in such a Round Robin, have a chat to your Convenir. If you are not yet in a Support Group, give Bernie a call if you want to give a Round Robin a try.

Bernie is also in the process of getting several new Support Groups up and running.

Ruth Wyatt is the Convenir of the new **Northside Support Group**. Ruth will draw her members from Sydney's North Shore. Her first meeting will be held on 4 April. Please contact Ruth on (02) 9416 4287 if you would like to join this new Group.

Dorothy Schunmann is the Convenir of the new **Shoalhaven Support Group**. Bernie has just sent Dorothy a list of members who appeared in our records as wishing to join a Group, and Dorothy will be touch with them soon. If you would like to participate in this Group, please give Dorothy a ring on (02) 4448 7541.

Cliff Cook from Tathra will soon be starting up a **Lower South Coast Support Group**. We know there are at least half a dozen members wishing to join a Group in the area. If you are interested in participating, please give Cliff a call on (02) 6494 4113.

Bernie is also hopeful that before too long we will have **Support Groups** operating in the **Lismore, Orange, Liverpool, Sylvania, and Sutherland** areas. Watch this space for Convenir and meeting details as they come to hand.

Finally, **Barbara McCormack** recently resigned as Convenir of the **Hunter Area Support Group** to pursue other interests. Barbara has ably convened this Group since it commenced in 1992. She has put in a lot of hard work to make it the highly successful Group it is, and she will be sorely missed. In fact, four people have now taken over the jobs that Barbara used to do! **Wendy Chaff** is the new Convenir and we wish her well.

One reason Barbara McCormack reluctantly had to give up her work for the Support Group is that she is off to England in May to attend the *International Conference on Family Care*. She is being sponsored by Carers NSW Inc to travel to London and will represent that association and Australian carers at the Conference. Carers NSW reports that a strong field of applications for sponsorship was received from people satisfying the advertised selection criteria. Barbara was one of three people chosen to receive sponsorship, with the selection panel being particularly impressed with the commitment the three had displayed in their application to using information they gained at the Conference to lobby to further the interests of carers, and to inform government and the general public about carer issues. Well done, Barbara! Perhaps you might write a report for us on your return.

This article is reprinted with permission from an excellent publication that the Network subscribes to: Abilities (Canada's lifestyle magazine for people with disabilities), Issue 33, Winter 1997. The article was written by Linda Ironside, a freelance writer living in Vancouver, British Columbia. While Linda does not state the cause of her disability, her experiences with adaptive equipment seemed to me to parallel our own.

Permission to reproduce the article must be sought from Canadian Abilities Foundation, 489 College Street, Suite 501, Toronto, Ontario M6G1A5.

Cane Quandaries

Not exactly putting on a top hat!

Linda Ironside

Having a disability is not much of a problem on my scooter. In fact, it can be fun passing able-bodied "walkers" on the sidewalk with a friendly little beep ... although sometimes, I must admit, I am tempted to invest in the kind of air horn used so effectively by 16-wheelers when they want a little attention. But in general, on my scooter, I get quite a lot of joy from showing off for young children, who are always enthralled with what must look to them like a super toy.

My cane, though ... now, that's another story.

I used to associate a cane with Fred Astaire, so nimbly drifting across my screen. He was using a walking stick, of course, but from my child's perspective it was a cane.

I also watched the elderly gentleman down the street going for afternoon walks, always with his cane. He walked purposely - strode, actually, back straight, eyes fixed just ahead. He didn't use his cane so much as *flourish* it. It was an accessory, part of the image he created on the street. I couldn't imagine him without it.

What a disappointment it was, therefore, when I started to use a cane myself. And still now, years later, I have failed to copy the Fred Astaire look: the grace, the artistry, the flair.

They both made it look so easy, Fred and the dignified-looking neighbour. But it turns out it's not that simple. I don't walk tall. I lean. I wobble. And I still occasionally plant the cane tip firmly on someone else's foot, or whack a person on the shins (crowds are a challenge!).

All in all, the world's a much safer place with me on my scooter rather than prowling around with a big stick.

The problem is not the cane itself. It's my hands - namely, the fact that I have only two. The cane takes one, leaving only one other for the many, many things I cannot do with my teeth, knees or other parts of my body that occasionally hold things.

Like when I get in the car in the morning. With a purse, keys, cane and briefcase, I am completely overwhelmed with baggage, feeling more like a world traveller than a woman off to tutor a student. What does one do with a cane while unlocking a car door? At that point, it's just an impediment. No one needs a cane to open a car door - what one needs is hands, of which I find myself in short supply!

I've tried leaning the cane against the car. I have even placed the cane on the ground or car roof temporarily, but that seems to lack a certain *je ne sais quoi*.

I invariably end up using a tactic I call the BPM, or "body pressure manoeuvre". It's simple enough, if a bit lacking in the style department. I sandwich the cane between my body and the car, with one hand hanging on to the baggage and the other free to do the key work. This is only successful, mind you, if I have remembered to make the "sandwich" against the back door, leaving the front door accessible.

I wonder how the man down the street did it?

Another place I always run out of hands is a cafeteria. I've seen kids deftly carry their tray in one hand and fish for money with the other. How do they know where their centre of gravity is? (Physics students, all?) Maybe I just eat the wrong kinds of foods - a little on the heavy side? Sadly, I cannot carry my tray with one hand and, again, I find I have just too much baggage for only two hands.

The scooter is definitely more appealing. It has places to *put* things. And it's classier. A scooter has wheels and a motor - a big attraction with anyone over the age of two. A cane tends to make people think of ski accidents and hospitals.

For me, though, a cane will always evoke the image I have failed so miserably to recreate: Fred Astaire, complete with top hat.

But I take some solace in remembering Ginger Rogers. She didn't need a cane. But, as I've heard it, Ginger could do everything Fred Astaire could do - except she did it backwards and while wearing high heels.

There may be hope for me yet.

Delayed Fatigue

Grace Young

Mary Westbrook sent me this reply by recently-retired Occupational Therapist Grace Young to much "mail" on the Internet about overdoing things and paying for it with total exhaustion for several days after. Grace, who has post-polio, has spoken at several post-polio conferences, particularly about energy conservation.

I think most of us can relate to delayed fatigue. We overdo on good days and then are sidelined for several. It helps if you can identify right when the fatigue starts and stop for a rest before you reach the "point of no return" (easier said than done). Here are a few ideas:

- Stop when you feel a little tired. This sounds simplistic, but most of us were taught to ignore pain and fatigue, so we don't notice until the fatigue overwhelms us.
- Decreased quality of movement. Stop if motions that are usually done smoothly develop a tremor or become shaky.
- Decreased quantity of movement. Stop if your range of motion declines while you are working.
- Stop if you start using compensatory motions. For instance, you start having to "hunch" your shoulder in order to raise your arm, or your leg starts swinging out to the side instead of flexing at the hip when you walk.

If you stop in time, you can usually resume the activity after you rest for a while (you may need more than one rest period). This is much more productive than being out of commission for several days afterward.



I asked Mary Westbrook to help me identify some brief, yet informative, articles that we can send to people making initial contact with the Network. It has always been a bit of juggling act to find articles that are easy to read without being simplistic, and detailed enough to answer people's immediate questions without overwhelming them. Mary has now found a couple of such articles from the Internet which will go out to new enquirers. One is "Post-Polio Sequelae: True Answers For Friends and Family", written by the Kessler Institute in the USA. I thought the last section of this article is equally relevant to people who have been members of the Network for a while, so I am reproducing it below.

What can Friends and Family do to Help?

Polio survivors have spent their lives trying to look and act "normal". Using a brace they discarded 30 years ago and reducing their typically super-active daily schedule is both frightening and difficult to do. So, friends and family need to be supportive of life-style changes, accept survivors' physical limitations and their new devices. Most importantly, friends and family need to be willing, when asked, to do the physical tasks polio survivors probably could do, but should not do any longer. Friends and family need to know everything about PPS and say nothing. Neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of their own bodies and ask for help when it's needed.

Australia Day Awards

We extend our congratulations to the following members and friends of the Network who have received awards in recognition of their work in the community.

Appointed Members in the General Division of the Order of Australia (AM)

Professor William Cumming

For service to medicine, particularly through the teaching and practice of orthopaedic surgery in Australia, and through the Orthopaedic Training Scheme in Indonesia and Pacific countries.

Associate Professor Mary Westbrook

For service to people with disabilities, in particular those suffering from post-polio syndrome, and to education in the field of health sciences research.

Awarded the Medal in the General Division of the Order of Australia (OAM)

Mrs Elaine Lenaghan

For service to the community, particularly the Stroke and Disability Information (Hunter) Incorporated and other community care organisations in the Newcastle area.

Tennis Champion Volleys Against Polio

I spotted this item about Martina Hingis, who recently won back-to-back Australian Open tennis championships, in the Bunbury (Western Australia) Post Polio Support Group's Newsletter (February-March 1998). I reproduce it here with Bunbury's kind permission.

Martina Hingis, the world's top-ranked women's tennis player, added star power to the global polio eradication effort with her gift of US \$75,000 to the World Health Organisation (WHO) to help protect children against vaccine-preventable diseases. WHO has earmarked the money for national immunisation days against poliomyelitis in Ethiopia. Health officials estimate that there are currently more than 500 cases of polio a year in Ethiopia, making it a crucial reservoir of the wild polio virus in East Africa.

Martina presented a cheque to WHO during a press conference in Zurich, Switzerland. Past Rotary International President Robert Barth was highly impressed by Martina's decision to join the ranks of individuals who have volunteered to assist eradicate polio in Africa. He added: "When a young and successful sports star such as Martina Hingis offers her help to achieve an outstanding gift to the youth of the next century, she sets a unique and outstanding example." Earlier, Robert Barth had presented a Paul Harris Fellow recognition to Martina Hingis, who serves as a goodwill ambassador for WHO's Expanded Program on Immunisation.

Caravan For Sale

This 11 foot aluminium caravan has been specially modified for a person with a disability. It features a high bed and a high stand for a "porta potti". It has a fridge, stove, sink and lots of cupboards, as well as a tank, spare wheel and gas bottle. It comes complete with a two-piece easy-to-erect ramp with handrail. The caravan is in good condition and can be towed with a 2-litre car. For more information, telephone Lynne on (02) 4368 2826.

Medical Alert Card

Member **Maurice Tarragano** gave us the following feedback on the Network's Medical Alert Card which was developed by Merle Thompson. The Management Committee is seeking sponsorship to enable us to issue the card free of charge to all members. We hope to have some good news to report on this in the next Newsletter.

Dear Nola

Just a brief note to let you know what a success the Medical Alert card is. I recently had to go to hospital for a burn. Not only did the card save me from tedious explanations about PPS, but the treatment and consideration I received were terrific. I was consulted about every step of the treatment, and every drug and procedure was explained to me before any decisions on usage were made. There was such a noticeable difference once I had presented the card, I feel it is worth its weight in gold. Judging by the reaction to the card it obviously sets out the information in a way that is thorough and easy to digest. Congratulations and many thanks to you and Merle and all who contributed.

Mobile Outreach Service

The Independent Living Centre's Mobile Outreach Service is based in a specially designed, wheelchair accessible, seven tonne truck. Information is available for people of all ages who have difficulty communicating, have poor vision or hearing, have difficulty with mobility, balance, coordination or grasp, or who need advice on redesigning their home to suit their specific needs. The service also displays equipment such as lightweight cutlery for people with arthritis, pick-up sticks for people who find bending difficult, long-handled gardening tools, wheelchairs and scooters, as well as numerous kitchen, bathroom and bedroom items, chairs, cushions and backrests. The itinerary for May and June is given below. It is advisable to phone the Service closer to the time of the visit to ensure there have been no last minute alterations to their plans. If you require further details, contact Gillean Hilton, Mobile Outreach Service Co-ordinator, on (02) 9808 2233. Country callers should ring 1 800 800 523.

	DAY VISIT
16 May	Merrylands
18 - 22 MAY	LOWER HUNTER
18 May	Raymond Terrace or Nelson Bay
19 May	Cessnock
20 May	Maitland
21 May	Singleton
22 May	Dungog
25 - 29 MAY	RIVERINA / MURRAY
26 May	Wagga
27 May	Charles Sturt University
28 May	Tumut
8 - 12 JUNE	CENTRAL WEST
9 June	Lithgow
11 June	Orange
22 - 26 JUNE	NEWCASTLE / CENTRAL COAST
22 June	Toronto
23 June	Newcastle
24 June	Charlestown / Lake Macquarie



*Member **Alice Foo Wong** wrote with some good news about shoe purchases.*

Please inform members that "Speeds" shoe stores are willing to sell one pair of different size shoes for the price of one pair if feet are more than two sizes different. Speeds, Hornsby, has obliged me with three pairs so far.

I then take mine to "Pete the Pom" in Hornsby Mall to have my left shoe raised and my right shoe heel strengthened.

This is great news. I have not found anyone to go shoe shopping with so that we could buy two pairs (different size) and wear them. Post-polio survivors can only look and drool over those lovely court shoes for normal feet!.

*Member **Janet Malone** has recently discovered the thrill of scooter travel. I couldn't resist including this picture - courtesy of Scooters Australia - because it epitomises the freedom that Janet now has, and doesn't look unlike her either as she scoots around her neighbourhood!*



Dear Gillian

I send this letter in the hope it may be of interest to other members of the Network.

I recently bought an electric scooter and was advised by a relative that I would need a NSW Roads and Traffic Authority (RTA) permit.

I visited my local RTA office and was given the following information.

A permit is not compulsory but, should I have one, I would be covered by third-party insurance whilst driving on a public footpath or crossing a public roadway. The decision to have one or not is up to each individual.

The annual cost of the permit is \$62, or free for aged pensioners.

This information from Janet is very timely, in view of our article Selecting a Scooter which appears in the current Information Bulletin (Issue 15, Summer 1997/98). As the RTA says, whether or not an electric wheelchair or scooter user decides to hold an RTA permit is his/her own choice. I suspect it is a matter not many of us have previously considered. However, since the permit is free for aged pensioners, it seems sensible for this group of people to make sure they avail themselves of the insurance cover provided. Just ask at your local RTA office. I have sought more information from the RTA about the permit, and will publish it in the next Newsletter.

