



# POST - POLIO NETWORK (NSW) INC.

## NETWORK NEWS

Editor: Gillian Thomas  
Email: [gillian@post-polionetwork.org.au](mailto:gillian@post-polionetwork.org.au)  
Website: [www.post-polionetwork.org.au](http://www.post-polionetwork.org.au)

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

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

### President's Corner

Gillian Thomas

Welcome to regular readers and new members alike to another issue of *Network News*. There is a mixed bag in this edition, including useful tips on how to communicate better with your doctors for your mutual benefit. The outcomes of the Special General Meeting and Members' Forum held on 21 June are given on pages 4 and 5. Of course this issue also includes your favourite features *Polio Particles* and *Support Group News* and many other items of interest. Note that Committee Member George Laszuk is still seeking your support for a new fund-raising venture – full details are given on page 16. Please contact George if you are able to help out.

We have now received from America our latest order of Dr Halstead's book *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*. This 240-page book provides a comprehensive overview on dealing with the medical, psychological, vocational and many other challenges of living with post-polio syndrome. As Dr Mary Westbrook said in her February 1999 review "This is an excellent book. It is the book I would recommend to any newcomer to the post-polio scene, whether they are a survivor or a health practitioner. It also has a great deal to offer 'old hands' being full of facts and ideas to which you'll often want to refer." The book is great value at \$27.50 including GST and postage to anywhere in Australia. To purchase a copy, drop a line to the Network or download an Order Form from our website.

Readers should watch out for a documentary about the life of Annette Kellerman, *The Original Mermaid*, which is due to screen on SBS TV soon. Annette Kellerman overcame childhood polio to become a champion swimmer, a vaudeville star, film star and pioneering health expert. As we go to press the screening date is not yet available, so keep an eye on your TV guides.

Prince Henry Hospital will celebrate its 122nd anniversary on Saturday 27 September. The Network will be there - come and share in the celebrations!

Finally, we would like to record our thanks to Microsoft Pty Ltd who, under their *Community Assistance Initiative*, have donated some software to the Network. The donation will mean that more of the Management Committee can now operate with compatible, interfacing, quality software and this will greatly enhance our capability to deliver information to our members, health professionals and to the general public. Thank you Microsoft!

**Now please turn to page 2 for the details of our upcoming Mini-Conference to be held in Dubbo on 6 September 2003. This is the first time in several years that we have been able to venture out to a regional centre and we particularly hope that members and their families living in the central west will take advantage of the opportunity offered. The Network is subsidising the day and so cost has been kept to a minimum. A Registration Form is enclosed – please complete and return it by 31 August. See you there!**

*Unless otherwise stated, the articles in this Newsletter may be reprinted provided that they are reproduced in full (including any references) and the author, the source and the Post-Polio Network (NSW) Inc are acknowledged in full. Articles may not be edited or summarised without the prior written approval of the Network. The views expressed in this publication are not necessarily those of the Network, and any products, services or treatments described are not necessarily endorsed or recommended by the Network.*

# Dubbo Mini-Conference

Members and family/carers are invited to attend this exciting Mini-Conference on the weekend of **6 and 7 September 2003**. People living in the central west of the state and within driving distance of Dubbo are particularly encouraged to attend. Members from Sydney and other areas are also most welcome. The Conference is being held in Dubbo to give country members the opportunity of hearing and learning from a variety of well-informed speakers on post-polio issues and is particularly designed for people who may not have attended a similar Network event. Many Support Group Convenors and Committee Members will be in attendance.

**The main day of the Conference is Saturday 6 September, with registration from 9:30 am. The Conference will take place in the Expo Centre of the Dubbo Showground Complex, off Wingewarra Street.**

The day commences at 10:00 am with a *Know Your Network* session to be presented by Committee Members and Convenors, and includes an introduction to the Network, services offered and the role of Support Groups. Following morning tea we will view a film by Danish film-maker Niels Frandsen which is an emotional journey back to our polio days and is titled *THE EPIDEMIC - I don't remember anything but I'll never forget*. After a time for reflection and looking to the future we will break for lunch. The afternoon session will include a presentation from a Canberra-based physiotherapist, Jac Cousin, on *Physiotherapy, Pain Management and the Polio Survivor*. A country-based information service IDEAS (Information on Disability – Equipment Access Services) will advise on the services that it offers, particularly for those experiencing the late effects of polio. Finally we will hear from Sydney orthopaedic shoemaker, Paul Galy, on *The Importance of Mobility*.

**The Conference cost (which is subsidised by the Network) is only \$10.00 and includes lunch and morning and afternoon tea. Please register early to assist our organisation.**

For those who intend staying in Dubbo for a day or two we have organised a special Zoo package on the Sunday morning which includes a very informative and unique early morning walk behind the scenes. This is suitable for people in wheelchairs with or without carers, for those with scooters and also for people who can walk 3.8 km with a stop approximately every 100 mt (one walk is 200-300 mt without a stop). The walk commences at 6:45 am and lasts approximately 2½ hours, followed by a full cooked breakfast. The cost is \$22.30 (carers pay only \$14.00) which entitles you to spend the rest of the day at the Zoo if you so desire. The normal cost of this package is approximately \$44.00. Following the walk and breakfast, Support Group Convenors and Committee Members will meet at the Expo Centre for a workshop session.

There are over 30 motels in Dubbo to choose from if members need to stay a night or two. Neil has visited a number of motels closer to the venue and checked their facilities.

**Please fill in the Registration Form and return it by 31 August.** This is our first venture out to a country venue for a few years and we hope to see many new faces. Country members from nearby towns are particularly urged to consider attending to help make the Mini-Conference a success.

**If you need any further information about the Mini-Conference, including advice on motels or transport, please do not hesitate to contact Support Group Coordinator, Neil von Schill, on (02) 6025 6169 or by email at [support@post-polionetwork.org.au](mailto:support@post-polionetwork.org.au).**

# Advocacy and Support Liaison Officer

**George Laszuk**

**Phone:** (02) 9628 0000

**Mobile:** 0412 082 983

**Email:** [advocacy@post-polionetwork.org.au](mailto:advocacy@post-polionetwork.org.au)



In the last issue of *Network News*, I wrote to tell you about the expansion of my advocacy role on behalf of members.

Have you or your partner had difficulty in dealing with Government red tape or finding the right services for your needs? I have, and I remember how frustrated and angry I got. Well, now you are not alone - we are here to support you and your family in your hour of need, that is what we at the Network are here for.

With the help of the Committee and all the resources of the Network I hopefully will be able to assist any members of our Network through potential hardship or anguish. We all imagine our problems are unique but since my involvement with PPN I have found we share many of the same challenges and experiences.

I can't promise we will be able to solve all your problems but at least you won't be alone in your struggle. Even if you just need someone to talk to in times of sorrow or isolation please write to or phone me. Without question your privacy and confidentiality will always be observed.

Finally this time, we have been approached by the Mount Druitt Lions Club who are looking for a second-hand electric wheelchair for a lady in the community with a severe mobility impairment. If anyone out there has an electric wheelchair they no longer have a need for, I'd love to hear from you.



## Changes to Mobility Allowance

The Office of Disability has advised the Physical Disability Council of Australia that recent legislative changes regarding the Mobility Allowance now allow a person to qualify if undertaking any combination of employment, vocational training or voluntary work. The 8-hour rule has been changed and the new requirements are 32 hours every four weeks, that is, an average of 8 hours a week. For more information, contact Dominique Lynch at the Office of Disability, phone (02) 6244 5207.



## PPN Website Members' Forum ... A Comment

It is interesting to me that the Members' Forum on the Network's website now has 102 registered members, and yet so few people take the opportunity to post questions, answers or thoughts in it. I realise some people feel there is insufficient "polio content", but surely that is the result of those same people not posting such items. The Forum is there to find answers to queries, have a joke and brighten your day, learn more about any topic you care to mention, or anything else that may be of interest to anyone. What a shame so many are not taking advantage of the opportunity offered them.

Ronnie (*Ed. one of the Forum's valued contributors*)

# Report on Special General Meeting – 21 June 2003

**Gillian Thomas**

In the 2001/2002 Annual Report, at the Annual General Meeting held on 30 November 2002, and in subsequent issues of *Network News*, members were advised that a review of the Network's Constitution was underway, with changes to be considered and voted on at a Special General Meeting to be held on Saturday 21 June 2003.

As a result of new taxation legislation, certain additional clauses were required to be included in the Constitution. In addition, the Network's Constitution had last undergone a review and revision in 1996, so in 2002 the Management Committee set up a Constitution Sub-Committee, chaired by Janet Malone, to review the Constitution and recommend any amendments to members. As well as members of the Management Committee, the Sub-Committee included members Wendy and Jack Nolan, Doug Sutherland and David Buda. David's legal expertise and plain English drafting of clauses was particularly valued. A few members asked to participate in the review and, if not directly involved on the Sub-Committee, they were invited to comment on the final draft prior to circulation to members.

A copy of the revised Constitution, together with a summary of the proposed amendments, was sent to all members in May 2003. The Sub-Committee had comprehensively reviewed and revised the existing Constitution, focusing on streamlining and more logically ordering the document and with the use of plain English an aim throughout. In general, the content or intention of most clauses was unchanged from the existing version.

Thirty-four voting members attended the Special General Meeting, and sixty-eight proxy forms had been received from members unable to attend. The following Special Resolutions were put to the vote:

*Special Resolution 1:* That the additional sub-clauses 4(c) and 4(d), which propose a new membership category of Life Member and better define the existing membership category of Honorary Member, and all consequential amendments, be adopted.

*Special Resolution 2:* That the additional sub-clause 28.3, which allows for periodic review of the Constitution, be adopted.

*Special Resolution 3:* That the additional sub-clauses 33.2 and 33.3 and the revision to sub-clause 34.2, all of which are required in order to comply with Australian Taxation Office requirements, be adopted.

*Special Resolution 4:* That all other amendments be adopted.

The Constitution requires that amendments to it be passed by 75% of members voting at a General Meeting, being present in person or by proxy. The resolutions were all adopted, being passed by 98%, 100%, 99% and 94%, respectively, of members voting.

During its deliberations, the Sub-Committee had discussed at length whether terms of office for Office Bearers and/or Committee Members should be incorporated in the Constitution but, after weighing up the arguments for and against, decided not to recommend such a change at this time. As the matter was raised at the Special General Meeting, the Sub-Committee reconvened on 19 July to reconsider the issue. Other written comments which had been received were also reviewed, and in this regard it was resolved to recommend some further minor amendments to members. However, the Committee particularly feels that the issue of terms of office requires consideration by the entire membership. So that you can have informed input, a discussion paper detailing the pros and cons of implementing such a change, including the possibility of introducing postal nominations and postal voting, is being developed and will be presented in the next *Network News*.

After considering the views of members, the Committee will develop and circulate amendments to members. The amendments will be voted on at a Special General Meeting to be held in conjunction with the March 2004 Seminar.

# Report on Members' Forum – 21 June 2003

## Merle Thompson

The Seminar on 21 June was devoted to a Forum in which members could raise issues relating to the Network, its administration and its services to members. Members had been encouraged to send in written questions in advance or to place them in a box or ask them from the floor at the Forum. The number of issues raised was relatively small. Does this mean you are all happy with what we do and how we do it?

Support Group Convenor, Neil von Schill, chaired the session with President, Gillian Thomas, and Vice-President, Merle Thompson, making up the panel.

The principal issues discussed were:

### **Network office**

An office will be available when the new building being erected by the Northcott Society at Parramatta is finished. The ability to staff the office will still depend on volunteers. Network records will be kept at the office, but a decision on whether volunteer tasks such as mailouts will be done there will take into account the needs of the volunteers engaged in these activities. It is hoped that the Network's library will be integrated with Northcott's and that of the Independent Living Centre to make our resources more accessible to members. It is expected that one of our quarterly Seminars will continue to be held at the Northcott site.

### **Personal notices in the Newsletter**

The general consensus was that the role of *Network News* is to provide information on the late effects of polio and managing this condition. In addition, the wide circulation and quarterly publication of *Network News* makes it inappropriate to publish information on illnesses of members, even assuming details are known. Local Support Groups more appropriately provide this kind of information and support to their members. Obituaries of those who have made a significant contribution to the Network are published. Committee Member George Laszuk reminded attendees that the Committee has created a position to specifically provide individual advocacy and support to members as they negotiate red tape and deal with agencies. George reported that there have been successes directly resulting from our intervention.

### **Seminar venues**

The Committee welcomes information on accessible venues in different areas, preferably those which do not charge a hiring fee. Parking availability is important in organising a venue. If members are able to provide transport to Seminars, please let the Editor know so contact information can be published in *Network News*. Support Groups can also provide this assistance. The idea of holding a Seminar or Mini-Conference in a country venue, say every second year, was endorsed.

### **Social functions**

It was considered that organising such activities is not the role of the Network but that Support Groups provide such activities. It was noted that the Network's occasional anniversary dinners and activities at country Seminars provide social opportunities.

### **Financial costs of Support Group Convenor's travel**

Neil's attendance at Management Committee meetings (every 2-3 months) and his visits to Support Groups around the state are important and should be supported. It was noted that Neil only claims fuel for trips; his accommodation is provided by his extensive network of relatives and friends. Rotary North Albury have made donations over the last three years which have been used towards the cost of Neil's travel. The meeting passed a motion that a *Certificate of Appreciation* be sent to Rotary to say how much their assistance is appreciated.

### **Publicity**

Procedures for assisting Support Groups to deal with local enquiries were discussed.

All members were encouraged to provide their stories for publication on the Network's website and inclusion in a package to be placed in the Mitchell Library.

# Avoiding Going to the Doctor

Margaret E Backman, PhD

*Margaret E Backman PhD is a Clinical Psychologist specialising in Health Psychology. She is on the Faculty of the New York University Medical Center and has a private practice in psychotherapy in New York City. Dr Backman is the author of the book "The Psychology Of The Physically Ill Patient", published by Plenum Press.*

*This article was first published in the Newsletter of the Florida East Coast Post-Polio Support Group, Vol 10, No 5, March/April 2003, and is reprinted here with the kind permission of its editor Barbara Goldstein.*

Polio survivors have had a lot of experience dealing with the medical establishment. However, with age comes new medical conditions that need to be attended to as well. Having had your fill of going to doctors, you may avoid following up on these other health-related problems. The anxieties associated with your past experiences with polio may resurface when you are confronted with new medical problems.

Physicians often wonder why patients wait so long before coming to see them. There are many reasons, which are tied to how people perceive their conditions, as well as their characteristic ways of handling anxiety, and their past experiences with illness and disability. These reasons or rationalizations are outlined in the *Reasons for Delaying Going to the Doctor* you'll find at the end of this article.

## The Fear of Knowing

The fear of a "bad" diagnosis and treatment can strongly influence the decision not to go to the doctor. Yet with some medical conditions, the loss of time may give the disease time to progress. The delay may in effect cause the feared extensive treatment, the feared pain, and the feared disfigurement. Although most people know this intellectually, putting off going to the doctor is a common occurrence. Some people wonder if the doctor will consider them a hypochondriac, vain, or someone who is wasting their precious time.

"Maybe it's in my mind."

"Maybe it will go away."

"I'll go to the doctor later when I have more time."

## Learning to Communicate

As a patient you may be worried about things that your doctor has not even considered.

"Will I suffer? Will I be in pain?"

"Can I afford it? Will my health insurance cover this?"

"Will I be incapacitated?"

"Will I be able to work during treatment and after treatment?"

"How will I be able to take care of my family?"

"Will I be disfigured?"

"Am I going to die?"

Prepare your questions before-hand and write them down. Then you will be able to ask your questions when you see the doctor and not get distracted by your anxiety.

When appropriate, don't hesitate to get others involved, such as family and friends. Let them come to appointments with you, so you will have four ears instead of two. As many of you have already done with your PPS, educate the supportive others about the medical condition and what to expect.

But bear in mind that family and friends have their own personalities and coping strategies. They also have their own limits regarding how much they can take on, both practically and emotionally. Since these people are not acting as professionals, in trying to be supportive they may inadvertently add to the problem.

In trying to alleviate anxiety – yours and their own – significant others may say, “Don't overreact”, and thus add to the denial and delay in seeking treatment. Or the contrary, their persistent urging that you see a physician may set up more resistance on your part.

Bearing all this in mind, working as a team – with physicians, mental health providers, and significant others – is a good way to increase communication and avoid unnecessary delays in getting treatment.

### **Reasons for Delaying Going to the Doctor**

- Lack of accurate information about one's condition.
- Procrastination – feeling that treatment is not urgent.
- Wish to avoid the expense of medical treatment.
- Responsibilities related to self, family, and work.
- Other medical conditions given priority.
- Memories of your own or others' illnesses.
- Distrust of the physician's competence or skill.
- Personal dislike of the physician.
- Fear of pain and disfigurement.
- Fear of finding out that one has a serious, perhaps fatal illness.
- Normal coping mechanisms, such as denial, avoidance, and anger.
- Underlying psychiatric disorder which interferes with perception and judgment.

*Having now got over your fear of going to the doctor, how best do you communicate with, and sensitively educate if necessary, him or her? The next two articles explore these questions. The first article also comes from Dr Backman and was first published by the North Central Florida Post-Polio Support Group in “Polio Post News”, August 2003; it is reprinted here with their kind permission.*

## **The Doctor Dilemma**

**Margaret E Backman, PhD**

Polio newsletters often have editorials urging those with the late effects of polio to educate their physicians about Post-Polio Syndrome (PPS). Some polio survivors have expressed concern about doing this, wondering:

- Will doctors really listen to me?
- Will they get angry with me for trying to tell them what to do?
- Will I transmit the information correctly?

## Fears and Resentments

Patients can have underlying fears about “educating” the doctor:

- A fear of making the doctor defensive, of having him or her withdraw from you, yell at you, criticize you.
- A fear of having something that is not understood, that the doctor doesn't know enough to help you or doesn't care enough.
- A fear of being different, rejected. Some patients harbor resentments, resenting the idea of having to ‘educate’ the doctor – feeling that the doctor ‘should know’. “I’m paying him – why should I be the one to tell him anything?” Resentments may come from wanting to be taken care of (and here you are trying to help someone else, in this case a caretaker/doctor).

## Changing Roles and Communication

This is a many faceted problem. We are talking about roles in society today and how communication is affected by the changing roles and the information explosion. We are talking about your taking a more active role in your health care, something that one needs to do more and more at this period of history.

There is a flood of information on all kinds of medical problems and new information coming out every day. Physicians are very busy, they have many pressures on them and there is only so much that they can keep up with in their fields. If they don't have many (or any) patients with PPS, they may not have had a reason to keep up with the syndrome or the latest developments. They may care, but not have the time to investigate an area, as they might need to or want to. You can help them and in turn help yourself. For what we are talking about is your getting the best care that you can.

Pointing the physician in the direction of your interest or giving them some condensed information on the subject is helpful to the doctor and in the long run to you. But ... how to do this without offending the professional?

## Techniques for Improving Communication

- Begin with a positive attitude.
- Be concise and to the point. Don't overload the doctor with stacks of articles or articles that are overly long or that all say the same thing. Find something to the point and something that illustrates what you feel is important in your case. He may not have time to read lengthy articles but might appreciate something that he can refer to or that will lead him to places that he can research on his own. Sometimes including an Internet web site address is helpful, if he is the kind who likes to use the computer.
- Think of yourself as being a part of a team. Not that you are all equal on all levels, but you all have something to gain by the cooperation. How you deal with your physician depends upon your personality and the physician's personality. That always needs to be taken into account. Try to find someone with whom you feel comfortable.
- Come to the appointment prepared. Have your list of questions written down so that you can clearly go over each one. You could even give a copy of the list to your physician. Review the list before you go; revise it so that it only includes the most important questions and concerns.

## What About Specialists?

Perhaps you are saying to yourself “I'd prefer to go to a specialist; then I wouldn't have to do any educating”. There are at present no official specialties in PPS, but there are physicians who have an interest in and experience working with people with PPS.

*[Ed. In Australia, It is recommended that polio survivors be assessed by a doctor who is a specialist in Rehabilitation Medicine and who is experienced in treating polio survivors.]*

*The third article comes from Dr Henry Holland, an American polio survivor and board-certified psychiatrist. The article is reprinted from Polio Network News, now Post-Polio Health, Spring 2003 Vol 19, No 2, with permission of Post-Polio Health International (www.post-polio.org). Any further reproduction must have permission from the copyright holder.*

## **Improving Communication with Our Doctors**

**Henry D Holland MD, Richmond, Virginia ([Henry4FDR@aol.com](mailto:Henry4FDR@aol.com))**

*Why am I qualified to offer these suggestions? I have had the experience of being a patient many times in my life.*

*I have used a ventilator since I had a permanent tracheostomy in 1970. This treatment resulted from the damage initially caused by polio in 1950. I have an intensified interest in post-polio syndrome because I have experienced its effects since about 1990.*

*I have been a physician since 1966, and my specialty is psychiatry. I am currently a clinical professor at the School of Medicine of Virginia Commonwealth University (formerly the Medical College of Virginia), and each year I instruct second year medical students in the technique of interviewing patients.*

Most physicians follow the medical model, which is generally based on the scientific method. The thorough physician would get a complete history from you and possibly members of your family, perform a physical examination, try to obtain copies of previous medical records from other medical sources, and would get laboratory and other objective tests. Routine tests usually include a complete blood count, blood chemistries including electrolytes, liver enzymes, kidney screening tests, cholesterol, and others. A chest x-ray and thyroid function studies might also be included.

I think it is essential and extremely important to have a doctor who will listen to you. As a patient I think it is equally important for you to present your history of polio and post-polio syndrome symptoms in a concise manner and as objectively as possible. I recommend that you answer the physician's questions in a similar manner. If your doctor seems hurried, that is a distinct disadvantage for both you and him/her. It is a good idea to write some notes so you remember to tell the doctor about the onset of symptoms, when the symptoms seemed to progress, and what you have done that seemed to increase the symptoms or decrease the symptoms.

Most physicians will formulate a possible or differential diagnosis based on the history and physical exam even before the objective test results are known. In some cases, treatment may be started at that time. After the results of the objective tests are known, often the diagnosis can be made.

The diagnosis of post-polio syndrome is one of exclusion. The usual symptoms – weakness, fatigue, and pain – are very similar to other conditions. Therefore, your physician must exclude these other possible disorders as an explanation for your symptoms. The most important initial factor is to make sure that your physician knows of the history of polio in your life.

My initial diagnosis in 1991 was a self-diagnosis. A neurologist and a pulmonary doctor did not think that I had post-polio syndrome, but I am not sure that they knew much about it. Fortunately my primary care (internal medicine) doctor was willing to listen to what I had to say. He was also willing to read the articles that I brought him. Admittedly, I had an advantage because, as a physician, my opinions and observations were not immediately dismissed.

As a patient, you can become frustrated early on in the diagnostic process. Hopefully your physician will be honest and not defensive and will admit if he/she knows little about the

disorder. This is likely a good sign that the physician is willing to learn. If you can afford it, give your doctor either *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome* (1998) by Lauro Halstead, MD [*Ed. reviewed by Dr Mary Westbrook in Newsletter Issue 40, February 1999, and available from the Network at \$27.50 including postage and GST*] or *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families* (2000) by Julie Silver, MD, now in paperback (*Ed. reviewed by Mary in Network News, Issue 51, November 2001*). A gesture of this type can be mutually beneficial, but I would not recommend presenting any literature with a know-it-all attitude or to a doctor with a similar attitude. A little humility is good for both the doctor and the patient.

I often hear that polio is not taught any more in medical schools. I think this is an inaccurate perception. Infectious diseases, including polio, are taught in accredited medical schools despite the possibility that an American physician may never see an actual case. I have never seen a case of leprosy, bubonic plague, elephantiasis, or yellow fever. However, I studied and was quizzed on all of these diseases.

Post-Polio Syndrome is probably taught less because this disorder is a “syndrome”. A syndrome is a group of symptoms that collectively indicate or characterize a disease, a psychological disorder, or another abnormal condition. The causes of some syndromes are known and others are not known. When the cause of a syndrome is not clearly known, the teaching emphasis would be on recognition. As treatment may vary or change, a precise treatment plan may be suggested but with reservation. This is the case with post-polio syndrome. For example, how much exercise is enough or how much exercise is too much? The treatment of post-polio syndrome is more individualized and less empirical than known disease processes.

The average physician may never have a case of post-polio syndrome cross his/her office threshold. If a case does, that physician may focus on other causes before considering the diagnosis, assuming that he/she knows about post-polio syndrome and assuming you told him/her your polio history.

Communicate honestly about the severity of your symptoms. Many polio survivors minimize the severity and dysfunction of their symptoms. Don't hesitate to tell your story with complete disclosure of how bad you are feeling or hurting. It is important for you to communicate with clarity and emphasis about what has changed and what you are experiencing. You could simply complain of fatigue, pain, and weakness, but if you explain how the fatigue etc is limiting, then your doctor will begin to understand. For example, if you report that walking up a flight of steps is no longer possible without resting or extreme effort, you are more objective in your description than simply reporting fatigue. You, as a polio survivor, understand what you are experiencing. If the doctor has a genuine ability to empathize, he/she may also be able to understand. However, the doctor may worry about missing something that is more treatable than post-polio syndrome, such as a malignancy, multiple sclerosis and other CNS diseases, HIV, or any other disease that might present with a complaint of fatigue, pain, or weakness.

The successful doctor/patient relationship depends in part on a feeling of comfort between the two personalities involved. The patient wants help with a problem and trusts the doctor to use his/her expertise in solving the problem. The doctor's goal is to diagnose correctly the patient's problem and initiate the appropriate treatment promptly.

This process will be more rewarding if the doctor and the patient have mutual respect, are not competitive, and both are capable of listening with attention and interest. If a doctor does not seem interested, finding another doctor would be wise. If the doctor admits unfamiliarity with post-polio syndrome and is not interested in learning more, then that doctor should refer you to a colleague who is both more knowledgeable and more interested.

The best outcome is to find a doctor who knows about post-polio syndrome or is willing to learn, is a good listener, is not obviously hurried, respects all of his/her patients, and takes a genuine interest in you as a patient with a problem and as a person. You will know when you have found a doctor with whom you can relate.

# 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.*



---

### Bone density tests for polio survivors

The May 2003 issue of the Rancho Los Amigos Post-Polio Support Group Newsletter reported a question and answer session that followed a talk by Dr Carol Vandenakker, director of the Post-Polio Clinic, Department of Physical Medicine and Rehabilitation, University of California, Davis. She was asked: *'When you do a bone density test for osteoporosis, do you do a specific limb?'* She replied: *'We have started a study comparing a polio limb with a non-polio limb. There is a huge difference. What you want to be aware of is if your doctor just wants to know your over-all bone density they should not test a polio affected limb by itself. It will come out severely osteoporotic, and the rest of your limbs might be just fine. If you test a polio limb then it is important that they test your more normal limb as well.'* My experience was that I was asked which was my worst hip and the radiographer then proceeded to do a scan of my left hip and an area of the spine. I insisted that she also do the right hip and after some fuss she did. The left hip was very osteoporotic but on the other sites the bone density was good.

### Iraqi stores of polio virus stolen

The *New York Times* (20/4/03) reported on what they described as *bad Friday in Baghdad*. *On the Islamic holyday, thousands of Iraqis marched through downtown, shouting for America to 'leave our country'. Looters, continuing their rampage, stole vials of polio virus from a public health laboratory and set the Information Ministry on fire.* Nothing more was said in the article about the polio virus, and I can find no other reference to it on the web, so one can only speculate. Why was the virus being stored and what did the looters do with it?

### Polio kick

Canadian, Dianne Hicks Morrow, has published a book of poetry titled *Long Reach Home* (Acorn Press, 2002). One section of the book, *Polio Kick*, contains ten poems about Dianne's life with polio. In the first poem she describes her mother asking:

*'You're not going to write another poem  
about polio are you? One was all right,  
but you don't want people to think you're fixated.'*

*Breathe stops. Heart pounds.*

*We keep swimming. At last I say,*

*'I don't care what anyone thinks.'*

*After forty-seven years of holding my breath, it's  
Time.*

*I am on a polio kick.*

One poem describes the photo of Dianne taken when she was seven months old, the day she developed polio. In the poem her mother says:

*I sent the door-to-door photographer away,*

*Then called him back in case you were so sick you died.*

In *Mirror* Dianne asks

*'You mean if I have surgery my skinny leg will look like my big one, Mommy?'*

*'Well no dear. You'll be able to walk better.'*

As her mother shows her, in front of a mirror, how to lift her foot when walking Dianne realises she is different

*I've seen people who walked like that.*

*I didn't know I was one of them.*

Difference is a theme of many of the poems. The boy she has a crush on

*He confessed he always thought*

*I was great but he couldn't ask me out*

*because of my (uh) limp, I know it isn't right,*

*but I just can't handle (uh), you know deformity'.*

In the era of miniskirts she dreamt of wearing long skirts. She was born *too early for the blue jean craze / that would make her look like everyone else*. The author writes of envying *other legs / - fat ones, skinny ones, bowed ones - / they match*. Alas her *traitor ankle can turn, / drop me without warning, / force me to admit / I am unbalanced*. I wished some poems had spoken of post-polio issues. In the acknowledgements Dianne refers to an editor whose advice to *'write about what haunts you' allowed me to look at the unspoken theme of disability in my family*. Some of the poems are about her mother's visual impairment. Of added interest to me was that the author lives on Prince Edward Island and though *Anne of Green Gables* is not mentioned there are references to places and landscapes I first read about in the Anne books.

## **Polio Eradication strategy revised**

In its *Science Update* (16/5/03) the journal *Nature* reported that WHO has just launched a revised polio eradication program because of lack of financial resources. This could be the undoing of the campaign warned its coordinator, Bruce Aylward, who says an extra \$US275 million is needed. In the revised program *51 intensive immunization campaigns will target 13 polio hotspots ... the new tactic re-routes dwindling funds, which previously ploughed into another 80 countries to areas where polio is rife or where people are deemed 'at risk' from re-infection from neighbouring countries*. According to *Nature*, *some experts warn that the total eradication of polio is an unrealistic goal. ... One problem is that even in areas now free of polio, long-term vaccination is needed to protect against the occasional immunized individuals who carry and spread the disease. One man in Britain has excreted high levels of poliovirus for 20 years (see Network News Issue 56); indeed 14 carriers have been found by chance since 1988. What's more, the live, weakened form of poliovirus used for vaccination can mutate into a more aggressive, disease-causing form. This can be a problem in areas where vaccination levels are low and the virus can gain a foothold. In 2000, more than ten vaccine derived polio cases were reported in the Dominican Republic and Haiti. This is further evidence, says Henderson, that 'we need to plan to provide the vaccine indefinitely.'* (Dr Henderson led WHO's successful eradication of smallpox).

## **Being a parent with polio**

Many of us who had children after we contracted polio met with some social disapproval. *How can you manage to look after a baby properly?* We worried ourselves at times whether our children were disadvantaged by our disability. So it was heartening to read in the *Australian's* column *The Making of Me* (17/5/03) that Caro Llewellyn, director of the Sydney Writers' Festival, puts her father at the top of the list of important influences in her life. She said: *A disabled father. My father is in a wheelchair and I think his attitude has*

*had a profound effect on me. He's led such a full life — he's 65 and still working, which has inspired me to make the most of life. I had never heard him complain that he couldn't play with us or be a dad in the traditional sense until one day as an adult, we were watching my little brother and sister playing cricket on the beach and Dad said to me, 'It's times like this I wish I wasn't sitting in this chair'. As a child Dad had woken up one morning and couldn't move. He had polio. Growing up knowing this I don't take anything for granted. JoAnn le Maistre who has MS wrote that she has come to realise that parents with a disability may give our children something that is uniquely the result of our physical disabilities. If we are self-accepting our children will learn not to be afraid of disabled people, will admire and wish to emulate the strength of our daily struggle, and will accept for an entire lifetime the simple, but too often hidden fact, that there are no perfect people, no perfect lives.*

Some years ago Dr Darien Chinnery and I carried out research comparing the pregnancies and early childrearing experiences of able-bodied mothers with those of mothers who had a mobility disability (*Australian Disability Review*, 1995, no. 3). We found that women with disabilities were much more likely to encounter negative reactions to their pregnancies (including pressure to have an abortion) and were less likely to receive help from their relatives after the birth of their babies. The satisfactions and problems of childrearing encountered by the two groups of mothers were very similar. We concluded that negative social attitudes toward physically disabled women having children create an additional handicap for them.

### **National influences on polio outcomes**

Differences in social attitudes, social conditions and healthcare make some countries a better place to contract polio. A research study by T Rekand and others (published in the *Journal of Epidemiology and Community Health*, May 2003) examined the long term outcomes for polio survivors in an eastern and in a western European country. They compared patients who were hospitalised with polio in the 1950s in Norway and Estonia. The medical records of the 148 Norwegians and 128 Estonians were examined and survivors were interviewed. Despite the fact that the Norwegians had more severe disabilities in the acute stage of polio they were significantly more likely than the Estonians to be working (both full or part time) in 1998, the year of the study. The Norwegians were also more likely to have worked in the preceding 40 years. This finding was unexpected as disability pensions are more readily available in Norway. In both countries 30% of the survivors had done manual work and 18% had changed their type of work during their careers. Survivors' incomes were evaluated in terms of their national average. Having a low income (less than 50% of the national average) was reported by 73% of Estonians and 35% of Norwegian survivors. The late effects of polio reported by the two national groups were similar except that Norwegians reported more muscle pain. Norwegians were more likely to exercise regularly. Use of assistive devices was similar for the two groups. However Norwegians were more independent and less likely to need assistance with housekeeping. The authors concluded that there are advantages of living in a country with more social, economics and medical resources such as availability of ongoing rehabilitation e.g. physiotherapy. They point out that today the largest and youngest populations of polio survivors are living in countries with few such resources. I recently read of a rehabilitation program for amputees and polio survivors in Afghanistan which gives them mobility by training them to ride a bike. I couldn't help thinking of all the polio survivors who would not have the muscle strength necessary to succeed in such a program and who remain isolated at home.



## More Recognition for Network Members

*In December 2001, the Prime Minister announced the creation of a Centenary medal to honour living persons who have made a contribution to Australian society or government, including those who have lived during the last hundred years.*

*Designed by Balarinji, the medal features a seven-pointed federation star to symbolise federation with the six states becoming one.*

Following the notification in the last *Network News* that three Network members were in the list of Centenary Medal awardees announced on 23 April 2003, we have learned of another.

Michael Hutchinson      For service to the community through the Orange Rescue Unit

Congratulations Michael!



*Three members of the one family living in Western Australia are all polio survivors and members of the Network. Doreen Westerduin contracted polio in 1946 at the age of 23, together with her son Len, aged 20 months and her daughter Margaret, aged 8 months. Doreen keeps in regular contact and recently sent me this note about Len's volunteer work.*

Thank you all for a terrific informative Newsletter. You had asked if any members have received recognition. Len is with the Fremantle Sea Search and Rescue Service and has been doing this voluntary work for 11½ years now. He has studied First Aid, Radio Operator and Navigator. He was awarded a Badge for 10 years as a volunteer for his excellence, trustworthiness and reliability to come whenever called for emergency call-out. We are very proud of Len's success as he had very little schooling due to years of constant treatment to enable him to walk and work. He has a rod and screw in his arm as well.



## Queen's Birthday Honours – 9 June 2003

Member Wendy Nolan is in the news again! Following receipt of a Centenary Medal in April, she is now the proud recipient of a Medal of the Order of Australia (OAM), as is also her husband Jack. The medals were awarded "For service to people with disabilities, particularly as an advocate for access to community facilities." Well done, Wendy and Jack!



Also spotted in the Honours List was Professor Margaret Burgess who was made an Officer of the Order of Australia (AO). Professor Burgess received her recognition "For service to public health in Australia and overseas, particularly through the provision of policy advice to government and through undertaking research into vaccine preventable diseases and the control of infectious diseases, and to paediatrics." Our heartiest congratulations to Professor Burgess, a long-time supporter of the Network's promotion of immunisation.



## Healthcare Trial in Victoria is looking for 3,600 participants 65 years old and over

Between 1997 and 1999 nine Coordinated Care Trials were undertaken throughout Australia, focussing on the needs of older Australians, people with chronic illness and people who require a range of different services to support them in the community. Two of the trials operated in New South Wales, one in the Hornsby area and the other in the Illawarra. The Network was not approached to publicise these trials, but perhaps some members participated nonetheless.

Following an evaluation of the trials, the Federal Government is now supporting a further round of trials. This round will target the frail aged; those with chronic conditions such as asthma, diabetes, and heart conditions; and Aboriginal communities experiencing problems associated with chronic disease. The trials aim to offer better care to those with chronic and complex illnesses through improved tailoring of care to meet their needs, particularly through enhanced coordination in service delivery (especially where there may be benefits associated with a more organised approach to prevention, early intervention and treatment) and by making better use of existing resources.

The second round of nation-wide trials includes mainstream trials in Victoria and Queensland, and three others based in indigenous communities. Although we do not yet have any details on the Queensland trial, the following information has been provided about the one in Victoria.

*Coordinated Healthcare is a Research Trial involving a partnership between individuals over 65 with chronic and complex health conditions (such as a heart condition or diabetes), their GP and a Service Coordinator (usually a nurse). The study aims to find out what impact Coordinated Healthcare staff and GPs have on assisting you to navigate and benefit from the Health system as a whole.*

*As this is a research study, each person who consents to participate will have a two out of three chance of being in the intervention group which receives Care Coordination. For both the Control and Intervention groups, Coordinated Healthcare will collect data about their health service utilisation. **Both Commonwealth and State Privacy Acts will ensure that your privacy and confidentiality will be maintained.***

*Coordinated Healthcare provides peace of mind for actual group participants. The burden of organising care will be undertaken by the Service Coordinator in consultation with the GP. The Coordinated Healthcare Trial, as one of a number of trials nationally, is a Council of Australian Governments initiative. The trial is supported by both Commonwealth and State Governments, and the Victorian trial is sponsored by Northern Health.*

**Coordinated Healthcare are now seeking 3,600 people over 65 years of age from the North Eastern Melbourne Municipalities of Banyule, Nillumbik, Darebin, Whittlesea, Yarra, Hume, Boroondara and Moreland.**

In seeking our assistance to publicise the trial, Megan O'Donnell from Coordinated Healthcare wrote "I have visited your website and we believe that the people who use your site could benefit from being part of the Coordinated Healthcare trial. By providing a partnership between the client, the GP and a Service Coordinator, intervention clients can be guided through the existing healthcare system and have one point of contact for all their care needs. This project stands to benefit people with complex care needs, including the after affects of polio. We are trying to recruit 3,600 participants to the trial by 30 June 2004, and the trial is due to end on 30 June 2005. This project could impact on the type of care people with complex and chronic needs receive in the future. We would appreciate your support in contributing to its success."

Megan has promised to keep in touch with us as the trial progresses, and advises that the results will be widely published.

For further information on participation, contact Coordinated Healthcare on **(03) 9495 3197**.

# Message From Your Committee - We Need Your Help

**George Laszuk**

*I am repeating this article from the last Network News because we are still looking for people who can help raise money for the Network through our Donation Box venture.*

Just in case you were not aware, our association does not receive any regular income except from annual subscriptions, which we keep as low as we possibly can, and donations. As you can appreciate, with the ever-increasing costs of running our organisation, we are always looking at ways of offsetting these costs.

One solution we have come up with is placing Donation Money Boxes in commercial areas where cash is exchanged.

This is where you can help. Are there any members out there, who own or work in a small shop or service station, who are prepared to place one of these money boxes on their counter?

Once the box has been placed you won't have to do a thing. All boxes are key locked and we will arrange to clear them at regular intervals. (This clearing procedure applies to the Sydney metropolitan area only. If country members are able to assist, we will work out an alternate clearing method.)

Can I also remind members that all work for our association is carried out by dedicated volunteers and if this venture is successful we may be able to employ someone on a part-time basis to help with our ever increasing work load.

Remember the more we can do, the more you the members will benefit.

A famous President once said, "Ask not what your association can do for you, but what you can do for your association".

If you can help please email me on [advocacy@post-polionetwork.org.au](mailto:advocacy@post-polionetwork.org.au) or give me a call on (02) 9628 0000 or 0412 082 983.



## Free to a Good Home – a Pre-Loved Car

Member Elizabeth Joyner has made an extremely generous offer to a fellow polio survivor. Elizabeth recently had to upgrade to a car with power steering, and regretfully had to say goodbye to her much-loved Volvo.

Elizabeth is willing to give her old car to a member who could make good use of it. She reports that this one-owner car is in very good physical and mechanical condition and has always been reliable. Here are some vital statistics:

Volvo, 1981 model, automatic

Low kms - approx 186,000

Good tyres, interior perfect, good sound system

The car's registration is due on 12 September so you will need to move fast if you are interested.

Please contact Elizabeth on (02) 9144 7318  
(evenings are best)



## What a Day for a Picnic – Saturday 1 November 2003

Members and their families have once again been invited by fellow member Sister Diadema, Evangelical Sisterhood of Mary, to visit the home of the Sisterhood at 30 Taylor Place, Theresa Park (near Camden) for a picnic. Those who attended the last picnic had a wonderfully relaxed and peaceful afternoon and thoroughly recommend a return visit.

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

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

It is very generous of the Sisters to open their home to us and it is a great way to help celebrate *Post-Polio Awareness Week*. A final reminder will be included in the next *Network News* – a map is available to help you get there. Please ring Alice on (02) 9747 4694 with any enquiries.



## Does This Picture Bring Back Memories?



Long-time member Norm McCarthy recently sent me this photo from his time at the Jervis Bay Rehabilitation Centre in 1952. Does anyone recognise any of those not named?

## Volunteering – A Way of Life

*Kerry Jenkin, Convenor of the Network's Hornsby Support Group, wrote to tell of her experiences volunteering in many different environments, and described how each has brought her fulfilment and happy memories.*

What generally sparks me into action is the conscious action or word of another. In my case it was the presentation in 2001, on behalf of the Committee and the *International Year of Volunteers*, of the Volunteer Certificates and Badges by Dr Stephen de Graaff at the Seminar he gave at Burwood. I felt absolutely overwhelmed as it was the first time that what I had always felt was a privilege was being acknowledged by my peers.

Volunteering has always been an integral part of my life as it has for many other of our polio pals, but I hadn't thought of it as something for which recognition needs to be acknowledged – but time has proven me wrong as the latest *Network News* attests.

My volunteering life began in the late 50s, early 60s at the Mission to Seafarers in Kent Street, City – a Catholic-run ecumenical organisation welcoming all. We would dance with the seamen from the ships in the docks that were, but now are part of Darling Harbour. Rock and Roll and the Twist were in, the Beatles, Beach Boys, Chubby Checker and more. We would try to make the evenings for these men a bit brighter with some female company although at times it was hard going. It was very early in our young lives and we knew little of the ways of different nationalities. In retrospect, I wouldn't recommend it to the faint-hearted, however, we did have fun and made friends.

Next came a five year stint with Professor Piper from Sydney University and his team at Royal North Shore Hospital trialling medications for stomach ulcer eradication. It was a wonderful experience and ran from the late 80s into the 90s. Then, after arriving at my now home base of Hornsby, I enrolled in the wonderful work of Easy Care Gardening which was right up my alley as I love the garden. Spending quality time with older lonely members of the community over a coffee and scone while they still try to cope with living in their own homes was a bi-weekly treat, pruning and cutting down unruly trees and shrubs. We don't realise the necessity for these wonderful folk to be able to enjoy their surroundings in safety, both within their garden and from intruders if the property is unkempt. Anyway, who could say this is work!

Then came the Hornsby Information Centre where my knowledge of the wider community really began – listening to those facing that insurmountable search for resources and departments to reorganise their lives and to just listen. The Parish Pastoral Council, the Parish Pastoral Care Support Group and the Diocesan Ecumenical Commission followed – my term on each now complete. Now, of course, comes the Network, the Hornsby Shire Council Access Committee, the Division of General Practice for Hornsby Kur-ing-gai Ryde and Hunters Hill, and last, but never least, our Hornsby Post-Polio Support Group. All wonderful and challenging and “had I the strength to do it all again, would I, could I?”. You bet I would! Ah, memories.

Can you believe this, though, I was simply knocked out to find during some research of my early life during polio, a reference in the memoirs of the McLeod history of the Spastic Centre, *Nothing Is Impossible*, a paragraph “*Kerry is a popular child. She can walk and talk, and mothers the others with a comical seriousness. She is writing what Julie dictates, because she must have someone to turn the pages.*” The lovely Julie was badly affected with Cerebral Palsy and passed away many years ago. What an angel!

## Support Group News

Neil von Schill

Support Group Co-ordinator

Phone: (02) 6025 6169

Fax: (02) 6025 5194

Email: [support@post-polionetwork.org.au](mailto:support@post-polionetwork.org.au)



A very successful inaugural meeting was held on Wednesday 25 June to form the **Bankstown Support Group**. There were 15 members in attendance and we are very grateful to **Pam Solomon** for volunteering her services to be Convenor for the group. I am confident that the group under Pam's guidance will be a strong and viable entity. The group will meet at the Revesby Workers Club at 2:00 pm on the first Wednesday of the month. Pam would welcome any enquiries and can be contacted on **(02) 9773 7679**. May I pay special tribute to Committee Member **Anne Buchanan** for the great effort she put into organising and advertising the meeting.

Recently I travelled north to visit Convenors in the northern part of the state. I stopped off in **Dubbo** to see **Gregg Kirkwood** who is assisting with the organisation of the Dubbo Conference in September. While in Muswellbrook I made contact with **Bruce Bulls** who is Convenor of the **Upper Hunter** group. On the North Coast I met up with **Pat Adamson** who lives in **Port Macquarie** and has undertaken to convene a group based around Port Macquarie. An inaugural meeting will be held in the coming months. If you live in the Port Macquarie area Pat would love to hear from you. Pat may be contacted on **(02) 6581 3704**. On my return trip I called on **Laurie and Beryl Seymour** at Kootingal near Tamworth. Laurie and Beryl publish a very popular newsletter *The Link* which keeps members in the northwest of the state in contact with one another. We hope to catch up with Laurie and Beryl again at the Dubbo Conference.

In the metropolitan area we have received assistance to promote the formation of a Support Group in the **Marrickville** area. If you live in this vicinity of the city and are able to assist with the organisation of an inaugural meeting or you are prepared to convene the group I would be delighted to hear from you. Members living in the **Sutherland Shire** can be assured that plans are in hand to establish a support group in your area in 2004. An inaugural meeting will be held in the first half of the year to form a group. Finally for this Report, I will be visiting Peter Whelan at Batemans Bay later in the year to discuss the possibility of forming a group on the **Lower South Coast**.

## ACT Support Group 10 Year Anniversary

In the last *Network News* I reported that Neil had travelled up from Albury on 5 April to attend the 10<sup>th</sup> Anniversary celebrations of the **ACT Support Group**, convened since its beginning by Brian Wilson with assistance from Roger Smith and Sue Wallis. Brian has now sent me some pictures for our archives. The photo at right shows Brian, Sue, Roger and Neil standing in front of displays of memorabilia from the Group's first ten years.



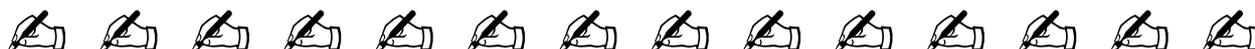


*We were pleased to receive this note from member Shirley Roach with her renewal. Shirley was a valued member of the Network's Management Committee from 1989 until 1994 when she moved to Queensland's warmer climes. As well as taking on the Treasurer's demanding role for a couple of years, Shirley was also the Network's first Support Group Co-ordinator. This position was established by the Management Committee in 1992 to give practical assistance to the Network's Support Groups as they were established, and provide a conduit to the Management Committee. Shirley set up many of the procedures which are still assisting Neil today.*

Dear Gillian and all

Belated congratulations to all of you who've received the various awards, and thanks to the hard-working Committee and others for the continued good work. Special congratulations for the 10-year milestones for the Support Groups. Remember when we were just beginning them? All the best.

Shirley



## Post-Polio Network Seminar Program 2003

<p><b>Weekend 6 and 7 September</b></p>	<p>Showground Expo Centre <i>Dubbo</i></p>	<p>All are welcome to join us on this exciting weekend which includes a full-day Mini-Conference and Support Group Convenors' Workshop <b>See Program information on page 2 and complete the Registration Form included with this Network News</b></p>
<p><b>Saturday 29 November</b></p>	<p><i>Ryde</i> (venue to be advised)</p>	<p>Fifteenth Annual General Meeting followed by a Seminar on <i>Obstructive Sleep Apnoea</i> presented by Professor David Barnes Royal Prince Alfred Hospital <i>Full details will appear in the next issue of Network News</i></p>

## Can You Help to Promote the Network?

We have been getting a good response to our Network pamphlets and are very grateful to everyone who has been able to distribute them widely throughout their local communities. If you can help to get more on display in, for example, pharmacies, doctors' surgeries or waiting rooms, clinics, shopping centre notice boards, libraries and community health centres, please contact Alice on (02) 9747 4694 or by email at [alices@hotkey.net.au](mailto:alices@hotkey.net.au) and she will post some out to you.