



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

Editor: Gillian Thomas

P.O. Box 888, KENSINGTON 2033
Phone No: (02) 636 6515

Editor's Corner

When I told you in April that the next issue would be out in June, it seems I was a little ambitious! Everything has been in rather a turmoil lately as the Network has been busy getting everyone's name and address details onto a database. Our records will be more accurate and able to be updated more readily as a result. It will also assist me in producing mailing labels for the Newsletter. It has been a pretty big task though, and we still haven't quite finished. My thanks go to Barbara Merrington for her work on the database.

Page 3 of this issue gives details of our upcoming Seminar, "Travelling with a Disability", to be held on Saturday 7 August. This Seminar is a must for anyone thinking of travelling overseas. We hope to see you there. If this will be the first Seminar you have attended, please introduce yourself to a Committee member. Lunch and afternoon tea are also great times to mingle and get to know other members and share experiences and helpful hints. The last Seminar for the year will be on Saturday 20 November. Please note this date in your diary now. Dr Jill Middleton from the Post-Polio Clinic at Prince Henry Hospital will be speaking about the clinic's first nine months.

The AGM was held on Saturday 8 May 1993 and a new Committee was elected (see details below). Those members who were unable to attend the AGM will find the 1992/93 Financial Statement included with this Newsletter. The AGM was followed by a Seminar presented by Sophia Brandjes, President of the Yoga for Health Foundation in Australia. Sophia spoke about yoga for people with disabilities and led us through some practical relaxation exercises.

The 1993/94 Management Committee members are:

Nola Buck	President
Janet Malone	Vice-President
Gillian Thomas	Secretary & Newsletter Editor
Shirley Roach	Treasurer, Public Officer & Support Group Coordinator
Jeff Baldwin	Publicity Officer
Henriette Foster	
Barbara Merrington	
Joan Mobey	
Virginia Morgan	
Suzanne Rangi	
Robyn Robinson	
Gwen Tubb	

Following the AGM the Committee has decided upon the objectives the Network is to pursue over the coming year. These are:

- Four Newsletters are to be issued to all members during the year, and four Information Bulletins are to be issued between the Newsletters. (See further details below.)

- The feasibility of the Post-Polio Network (NSW) Inc. holding a conference during 1994 is to be explored.
- Support Groups are to be consolidated and strengthened. This will include developing the role of the Management Committee's Support Group Co-ordinator to ensure good liaison and information-sharing between the Committee and the Group Convenors.
- A Professional Resource Register covering New South Wales is to be established.
- The extension of the immunisation programme is to be encouraged.

We need your continued support if we are to achieve these goals over the following months.

With respect to the decision to issue regular Information Bulletins as well as the Newsletter, it was felt that Network members want to receive a broad range of information but there is little space for additional material in the Newsletters. Newsletters give details of upcoming Seminars and reports on Seminars already held, along with regular reports from Support Groups, Committee news, updates on the Post-polio Clinic at Prince Henry, Letters to the Editor, and so on. Newsletters will now be issued in January, April, July and October each year. Support Group Convenors are requested to send their quarterly reports to Shirley Roach, Support Group Co-ordinator, by the end of November, March, June and September to ensure their inclusion in the following Newsletter.

The Information Bulletins will focus on providing more general information, including reprints from Polio Network News (USA) and other publications, as well as information on issues of interest to people with disabilities. Information Bulletins will be issued to coincide with our Seminars. If you can attend the Seminars, you will be able to collect the Bulletin there. If you cannot attend, the Bulletin will be posted to you. Because of the time necessary to get this system set up, the first Bulletin will not be ready by the August seminar; instead it will be mailed to you in September. We expect, however, that the Information Bulletins will be available for collection at the November, March, May and August Seminars over the coming year.

The Committee would welcome any feedback on this new approach to keeping you informed as well as any ideas you have on what you would like to see included in either the Newsletters or Information Bulletins.

Problems with Orthoses

Alicia Lee is continuing to gather information from people about problems they may be experiencing with the availability, fit and cost of orthoses. Alicia distributed a questionnaire at the AGM to help her collect this information. A copy of the questionnaire is included on page 9 of this Newsletter. Alicia would appreciate it if you could complete and return the questionnaire to her, care of the Post-Polio Network (NSW) Inc. (PO Box 888, Kensington 2033).

Seminar : Travelling with a Disability

- Date** : Saturday, 7 August 1993
- Time** : 2.00 p.m. – 3.30 p.m.
- Place** : Paraquad, 33–35 Burlington Road, Homebush
This venue is wheelchair accessible, with off-street parking for approximately 40 cars. Entry to the Paraquad auditorium is only from the car park. The parking area is flat, and the auditorium is then only a short walk away.
- Lunch** : 1.00 p.m. – 2.00 p.m. Please bring your own lunch. Tea and coffee will be provided.
- Afternoon Tea** : 3.30 p.m.
- RSVP** : Phone Rae on (02) 337 6315

Pat Rich, past Vice-President of the Network, recently accompanied Kevin Byrne, Executive Officer of ADEPT, and others on a study tour to the USA. The tour was organised by ACROD/COMPRO and took in five cities: San Francisco, St Louis, Phoenix, Washington DC and Los Angeles. The focus of the trip was to look at employment facilities for people with disabilities and was designed to link in to conferences being held in Phoenix and St Louis. Pat and Kevin did a lot of travelling throughout the trip, mostly by public transport. In their spare time they went sightseeing. Pat says using the Bay Area Rapid Transport (BART) system in San Francisco was a great thrill. Pat and Kevin will speak about their travels and how they found the various forms of public transport, as well as commenting on some of the employment facilities they visited.

Report on March 1993 Seminar : Natural Therapies Supporting People with Post-Polio

For the benefit of members unable to attend the Seminar held on Saturday 6 March 1993, President Nola Buck prepared the following summary:

The address by Ms Faunia Smith, Naturopath from Blackmores, centred on the four main systems associated with post-polio problems and on the various herbs, vitamins and minerals which might assist. Ms Smith stressed that her address was a guide only, and a client would need to be assessed by a qualified naturopath before undertaking a vitamin course.

Immune System

- Herbs**
- Garlic** – a good antiseptic. If taken daily acts as a preventative measure and assists immunity to flu.
 - Echinacea** – used for post-viral syndromes. Stimulates white blood cells.
 - Onions** – very close to garlic and very therapeutic for immune system.

Vitamins **Vitamin A** – in the form of beta carotene which is turned into vitamin A as needed by the body. Increases immune responses – lowers risk of heart disease. Sources: cod liver oil, green and yellow vegetables and fruits, egg yolk, dairy products.
Vitamin C – anti-bacterial and anti-viral. Holds cells together, vital for bones. Sources: alfalfa and mung beans (sprouting seeds – also very good for stomach upsets and indigestion), tomatoes, capsicums, rosehips, citrus fruits, most vegetables.
Vitamin E – anticoagulant – very good preventative of heart disease. Sources: wheat germ oils, whole grains, nuts, vegetables and fish-liver oils.
Vitamin B6 – very important for red blood cells. Helps muscle spasms. Acts as a diuretic. Helps absorb magnesium. Sources: liver (highest), black-strap molasses, beef, unprocessed bran, cabbage.

Mineral **Zinc** – very important because if it is deficient you cannot absorb other foods. Helps in insulin and lowers cholesterol. Sources: red meats, eggs, wheatgerm, brewers yeast, pumpkin seeds.

Nervous System

Nervous system damage cannot be repaired. One of the best tonics first thing in the morning is oats – used where there is degeneration or wasting.

Herbs **Hypericum** – (St John's Wart) – very good restorative – good for stomach upset. Good for sleeping.
Ginseng – adrenal function – secretes stress hormones.
Rosemary – specifically for liver function and as a general booster.

Vitamins **Vitamins B1 to 17** – most important for the nervous system. Essential for converting carbohydrates to glucose – essential for muscle build-up. Sources: brewers yeast, liver, milk, cheese, eggs, pumpkin and sesame seeds, prunes, dates, figs and fish.

Minerals **Magnesium Phosphate** – converts sugar into energy. Helps where nerve cells are damaged. Helps muscle function. Sources: sesame seeds, apples and figs, dark green vegetables, lemons, grapefruit, seeds in general.
Potassium – functions to send oxygen to the brain. Lowers blood pressure and helps where muscles wasted. Sources: lettuce, bananas, brown rice, avocados, fish, nuts, pumpkin and sesame seeds.
Phosphorous – nervous system tonic, aids in absorbing fats, helps in heart irregularities (as does calcium). Sources: brown rice, fish, nuts, eggs, whole grains, lentils, figs, raisins, molasses, dried beans, sunflower seeds.

Muscular Skeletal System

Co-enzyme Q10 – good for chronic fatigue.
Magnesium / Calcium – good for muscle twitching, leg cramps.
Sources: natural anti-inflammatories (arthritic symptoms) – fish oil, halibut liver oil.
Evening Primrose oil – broad spectrum.
Linseed Oil.
New Zealand Green-lipped Mussel – in capsule form.
Devil's Claw – obtained from herbalist.

Respiratory System

Mucous build-up leads to pain. Not advisable to suppress a cold.

Herbs

Horseradish.
Fenugreek.
Garlic.

Vitamins

Vitamins A, C and E as in immune system.

Minerals

Potassium Chloride.
Iron Phosphate – used for inflammation problems.
Magnesium – coughing spasms.

Support Group News

Greetings to you all! It is my pleasure to share with you some of the encouraging reports received from Convenors of the Network Support Groups which have already met or have had telephone contact. It would appear that an important objective of the Network is being achieved as people are enabled to share together their hospital experiences and the various triumphs or difficulties encountered since then. Each group of course plans around the particular needs of those involved. It is important for people who have had polio to allow themselves to slow down; an effective support group can also be a relaxed group.

Thanks to the tremendous efforts of many Convenors through their advertising with the Network's posters and interviews, as well as their letter, telephone, and personal contact, quite a number of hospitals, medical and paramedical professionals are more aware of the post-polio difficulties being experienced by many who have already attended or have appointments to attend the post-polio clinic at Prince Henry Hospital.

Committee members have been encouraged to hear, both from Convenors and group members, encouraging comments on the benefits enjoyed even after one or two meetings. Members agree that being able to share with others with similar difficulties and to gain information from those who have received help has been a tremendous blessing, particularly to those who haven't known where else to turn for assistance.

Appreciation has also been expressed for the articles and information given via the Network's Newsletter, the Information Kit, and the Seminars. It helps to know that others care, and understand that their problems are real, not "just in the mind" as many had previously been told.

Some groups have been so successful and generated so much interest that they are already looking to divide up the group in order to keep membership of each group to around ten people. Once a group gets well established, someone is usually willing to become the Convenor of a second group. Experience has shown that support groups are able to function best when they remain intimate.

The Inner West, Central Coast and Hunter Support Groups have been active for some time and a number of close friendships have been formed as members have grown together in the small groups.

The Blacktown-Blue Mountains, Canberra, Ermington, Grafton and Roselanders groups have commenced over the past nine months, generally meeting monthly or bi-monthly. An exciting venture for the Grafton group members in June was their involvement in the Disability Expo in that city. Using posters and other forms of advertising supplied by the Network Committee, this provided a great opportunity for more people to learn something about the Post-Polio Network (NSW) Inc. and also let them know there is a support group in their area.

The primary function of a support group is for members to meet and share together things of concern to them, and to encourage each other. Some groups have decided to have brunch followed by a meeting, a picnic, luncheon, or go swimming or to a movie as a means of getting to know each other. The Canberra group has invited a chiropractor as guest speaker for their August meeting. Often members have found in their area doctors, physiotherapists, chiropractors and other professionals, as well as shoe suppliers (including some who make odd-sized shoes) who have been quite helpful. The sharing of this information is much appreciated by the group. It is also important that such information is passed onto the Network Committee for the benefit of the whole membership.

Two groups which recently enjoyed their first meeting are Bellingen and Coffs Harbour. As a result of some good publicity in local papers, many enquiries were received from interested people who had either not heard of the Network or had hesitated to join a group. Those who attended the meetings were glad of the opportunity to have local contact.

The 067 Telephone Support Group (covering the Northern Inland NSW Region) is perhaps unique in that it includes such a large area. Enquiries have come from Currabubula, Inverell, Moree, Quirindi, Tamworth and Uralla, as well as from places outside the 067 region such as Coonabarabran and Griffith. An article is now being prepared for submission to newspapers circulating within the Armidale-Glen Innes area, enabling wider coverage of this region.

Others which may work more as telephone support rather than meeting groups are Griffith, Kandos, Nyngan, Shoalhaven and Wellington-Dubbo; I'm sure the Convenors would welcome any enquiries. A few groups not yet underway due to health or other problems are Albury, Eastern Suburbs, Kellyville, Wollongong and Young. We look forward to hearing from Convenors when they've been able to do some advertising and arrange a meeting. We also have a member in the Northern Territory willing to be a Convenor; we send best wishes to Patricia in her endeavours to start a support group there.

As Support Groups are under the auspices of the Post-Polio Network (NSW) Inc. group members must become Network members and Convenors are urged to encourage their new people to join. It is important also that the Network's address and telephone number be included in your advertised. The strength and viability of the Network depends upon its ability to grow and thereby have a real voice in the community.

The Support Groups have been named mainly for identification purposes though in many cases they cover a much wider area than their names imply. We still have many people (in both the city and the country) expressing interest in joining a group but, unfortunately, some groups cannot commence due to the lack of a convenor. Should there not be a Support Group in your area and you would like to join one, perhaps you may be interested in helping to facilitate such a group? Please contact me or write to the Network for further information. We'd love to hear from you.

June Brown, Convenor of the Ermington Support Group, has a new telephone number: 02 638 1392.

Details of new Convenors since the February 1993 Newsletter are:

Barbara Moret	"Koompartoo Retreat", Dudley Street, BELLINGEN 2454	066 55 2323
Jean Robinson	32 Nasmyth Street, YOUNG 2594	063 82 4337
Meryl Blanchard	136 Kookora Street, GRIFFITH 2680	069 62 5402
Marion Wardman	PO Box 107, NYNGAN 2825	068 32 1350
Patricia Hull	76 Carew Road, MATARANKA NT 0852	089 75 4734

Finally, don't forget the deadline for your quarterly reports on activities as given in the Editor's Corner. This deadline has been set so that I can compile an overall report for each Newsletter. A complete list of Convenors will also be published in the next Newsletter. All the best till next time.

Shirley Roach Support Group Co-ordinator 02 759 1578

Did You Know?

The No Interest Loans Scheme (NILS) – The following information is reprinted with permission from "Paraquad News", Summer 1992:

The Department of Industrial Relations, Employment, Training and Further Education, ParaQuad, A.Q.A., G.I.O. and the State Government's Office on Disability have developed a scheme that hopefully will assist people with a disability, who are in the workforce. People can apply for a loan to purchase equipment and aids and not have to pay any interest on the loan. The interest is paid by the Government.

NILS aims to assist people to purchase prescribed aids such as motorised wheelchairs, electric beds and environmental control systems etc. People with a disability can access from \$1,000 to \$15,000 interest free for a period of up to four (4) years. To be eligible for the scheme people will need to:

- Produce a prescription for a prescribed mobility, communication and/or daily living aid which has been authorised by an approved subscriber.
- Show they were or would have been able to get P.A.D.P. assistance before commencing work.
- Show they are not eligible to receive assistance for the purchase of items under any other government scheme.
- Show they have not received a related insurance settlement in the last five (5) years.
- Have been in continuous employment for the past twelve (12) months at least.
- Be able to make the loan repayments.
- Purchase only those appliances which are on the list of eligible items for the P.A.D.P. (with a few additional items such as car phones, portable ventilators, hoists, hand controls and air conditioners).

People should be aware that they are taking out a loan and hence are liable to meet repayments. The benefit is that they are only paying the principle whilst the Department of Industrial Relations, Employment, Training and Further Education will pay the interest out of a pool of \$30,000 made available for the scheme. The NILS seeks to remove a disincentive for people with disabilities in the workforce and to help them to retain their jobs. If you wish to apply, call Lyle Briggs from G.I.O. on (02) 228 1818 for an application form.

Mobility Allowance – this has been extended to include people with disabilities who are working in a voluntary capacity for at least eight (8) hours per week for certain types of organisations. If you believe you may qualify for this allowance, contact your local Department of Social Security.

Letter to the Editor

Network member Tony has written to tell about Bulletin Board Services he accesses with his personal computer at home via his telephone line (using a modem). Tony says he has lately been accessing information from America on the subject of post-polio syndrome. If any member with a computer and modem would like some help connecting to a BBS to try it out, drop me a line and I'll pass your details onto Tony.

Comfort & Fit – Orthopaedic Footwear

We recently received a letter from Mr Casper Ozinga, Managing Director of Comfort & Fit Australia Pty Ltd, specialists in comfort and orthopaedic footwear. Comfort & Fit are located at 130 Hampden Road, Artarmon 2064 (telephone: 411 1198, fax: 412 3241) and also at 18-20 Ross Street, North Parramatta 2151 (telephone: 630 0044 or 630 0066, fax: 630 2235). While the Network does not recommend any particular specialist in any field to members, the information given by Mr Ozinga is detailed below for the benefit of members who may be interested in seeing what Comfort & Fit can offer them.

"We are specialists in providing and fitting orthopaedic and comfort footwear. We have retail outlets in Artarmon and Parramatta, plus an extensive dealer network in Australia.

Our main function is to fit shoes to people who have problem feet, plus we have a comfort range for people who have difficulty in finding shoes that fit.

We have from time to time fitted shoes to people who have had polio. These clients may have a shortening in one limb, who buy a pair of our shoes, and we then carry out external shoe modifications. More significantly however, is our ability to provide a split size service, provided their feet fit into our normal off the shelf orthopaedic footwear. Our basic message is that is possible that through our system, stylish orthopaedic shoes can be supplied, at a substantial saving to the traditional way. We are not saying of course that it is for everybody as every case is different. Furthermore, an important part of our business is to provide a home visit service."

Orthotics Questionnaire (Confidential)

Name _____

Address _____

Phone _____

- | | | |
|--------|--|----------------|
| 1 | Do you use an orthosis or orthoses? | Yes/No |
| If yes | | |
| 2 | Was the organisation that provided it/them | Private/Public |
| 3 | Are you satisfied with its/their | |
| | (a) quality or fit? | Yes/No |
| | (b) availability? | Yes/No |
| | (c) cost or payment arrangements? | Yes/No |

Please attach any other comments you would like to make.
Thank you for your assistance in completing this questionnaire.