



Editor's Corner

Page 4 of this issue gives details of our upcoming Seminar, "The Post-Polio Clinic", to be held on Saturday 20 November. This Seminar will be presented by Dr Jill Middleton who runs the Clinic and is not to be missed. This will be the last Seminar for 1993 and so it is the venue for the usual pre-Christmas get-together of members. The Summer Issue of the Information Bulletin will be available at the Seminar for members attending. We hope to see you there.

While I'm on the subject of the Clinic, bookings for the clinic are made through the Prince Henry Hospital Out-Patients Booking Service, telephone (02) 694 5799. Please have your Medicare Number available when booking. A referral from your doctor is also necessary.

The first Seminar for 1994 will be held on **Saturday 5 March 1994**. Please note this date in your diary now. Further details will be in the next Newsletter, to be issued in February 1994.

President Nola Buck has written a report on what the Management Committee is doing to keep members informed. Her report which begins on page 2 will become a regular feature in the Newsletter.

Change of Address

The address of the Disability Information Service Inc. of Lismore (as advertised in the recently issued Information Bulletin) has changed. The service is now located at the Goonellabah Community Centre, 27 Oliver Avenue, Goonellabah NSW 2480; phone: (066) 24 4977, fax: (066) 24 4989.

Are you financial?

It's that time of year again when I go through the membership files to determine who has not yet renewed their membership. If you have a large **RED DOT** on your address label, you are unfinancial for the year 1 April 1993 to 31 March 1994. In order for you to continue to receive the Network's Newsletters and Information Bulletins (eight issues in total per year), your early remittance of \$10 (employed) or \$5 (not employed) would be appreciated. Please forward your payment to the Secretary, Post-Polio Network (NSW) Inc., PO Box 888, Kensington NSW 2033.

International Day of Disabled Persons: December 1993

The Network has recently become aware of the proclamation of this annual event by the United Nations. Publicity Officer Jeff Baldwin is currently gathering further information about the day. He hopes to make an information sheet available soon to NSW Support Group Convenors. Convenors who would like to take advantage of the event to promote the Network and its objects through the media in their local area are requested to contact Jeff on (02) 958 8078.

From the President's Desk

The Management Committee has felt for some time that it needs to make a concerted effort to have a line of communication open between itself and the Network membership. To help achieve this, it has been decided to include a report in each Newsletter which broadly details the work the Management Committee has undertaken on behalf of the Network's members in the previous three months. It is important to realise, however, that although the Committee meets monthly, many ideas and projects take several months to evolve to a final outcome.

Committee member Jeff Baldwin, Publicity Officer, has been concentrating on the need for immunisation. He has written to leading immunologists, informed anti-immunisation bodies of the devastating effects of polio, and followed up on radio and television interviews where the "for" and "against" arguments have been debated. The work on immunisation has been a long-term project of the Management Committee, with correspondence as detailed above being written by Committee members over the last three to four years. The NSW Department of Health has now moved to exclude children who are not immunised from attending school when an epidemic occurs. In this way it is hoped that parents will be encouraged to have their children immunised. With this positive approach being taken, the Management Committee now feels it can let this issue rest for a while.

Jeff's other major role is to promote the Network to Health Professionals, people who have had polio, and the community at large. He is also available to advise Support Group Convenors about local publicity which has proven very beneficial in bringing the Network's existence to the notice of people who have had polio. It is important, however, that the Network's Support Groups ensure that correct and up-to-date information is published about the late effects of polio, so if you are a Convenor and thinking of organising some publicity, Jeff would like to hear from you. You can reach him on (02) 958 8078 (or write to him care of the Network).

Achievement of the status of a "public benevolent institution", which brings with it the benefit of gifts to the Network being tax deductible, is something that the Committee has put a lot of energy into over the last few years. Unfortunately the first application to the Australian Taxation Office (ATO) was rejected. Once the Network became an incorporated body, renewed efforts were made to achieve tax deductibility status. Committee member Gillian Thomas, Secretary, approached the Public Interest Law Clearing House (PILC) who, after meeting with several Committee members, and studying the Network's constitution and other documentation, advised that they considered another approach to the ATO was warranted. PILC placed our application in the hands of a leading firm of Sydney solicitors who wrote to the ATO on our behalf. We were pleased to report in the first issue of the Information Bulletin that our second attempt was successful. The Committee feels that being classified as a public benevolent institution will enhance the Network's chances of receiving funding, should applications be made in pursuit of the Network's objectives.

Although established prior to this financial year, support for the Support Groups is another area in which the Management Committee puts considerable effort. As the Groups are energetic, viable bodies, growing pains are inevitable and it requires the knowledge and experience of all members of the Management Committee to reach, it hopes, a satisfactory direction. The Support Groups have spread the word of the Network throughout NSW as it is on that local level where publicity has its greatest effect.

Committee Member Shirley Roach, Support Group Co-ordinator, gives a brief report at each Management Committee meeting on how the Support Groups are progressing. She also compiles the Support Group quarterly report which appears in this Newsletter for the benefit of all members. The report includes contact details and information about activities undertaken or planned. If you are a Support Group Convenor, it is important to get your information to Shirley by the end of November, March, June and September to ensure its inclusion in her report.

Another long-standing item on the agenda is the development of a Professional Resource Register database. Those of you who have been Network members for a while may remember seeing the yellow Professional Resource Register forms which were sent out with Newsletter Issue 10 in February 1992. That was the Committee's first attempt to get the register off the ground, but it was not as successful at that time as we'd hoped. Now we are trying again.

The Committee often hears from members who tell us that they have had a good diagnosis/treatment by a doctor (or other health care professional) who looked at their condition with the knowledge of them having had polio. Unfortunately, we mostly get such information as "off the cuff" remarks. The Network is also not able to publicise the doctor's details for the benefit of other members without the doctor's written permission. Nonetheless, the Committee is interested in hearing from members who have had help and would like to recommend the person who gave it. If you fit this bill, could you please write to the Secretary with details of the symptoms/problem experienced which caused you to seek help. A copy of the Professional Resource Register form will then be sent to you. We are asking that you approach the person who treated you and ask him/her to complete the form and return it to the Network. By doing so, the Network is given written permission to pass contact details to other members, on request, who are experiencing similar problems.

Naturally, the Committee is making no recommendation that the person who helped you will necessarily be able to help others with apparently similar problems. We also acknowledge that someone you think is terrific might not be to someone else's liking. Nevertheless, being able to put other member in touch with a health care professional who may be able to help is a starting point. Sometimes all it needs is to get a foot in the door; and members can always seek a referral to someone more appropriate if necessary. The Committee hopes that members throughout the state will be prepared to help us in developing the database - your good experience could be of benefit to other Network members.

All members will have received the first issue of the Information Bulletin and from members' comments, it has been well received. The Bulletin is compiled by Committee Members Janet Malone, Vice President, and Gwenyth Tubb. Besides being members of Australian disability organisations, the Network subscribes to several journals both in Australia and overseas. These journals include "Independent Living", "Link - Australia's Disability Magazine" and the USA publication "Polio Network News". We also exchange newsletters with each state's polio network, as well as with New Zealand and several groups in the USA and Canada. In addition, Assoc. Professor Mary Westbrook keeps the Committee informed of any new published information on the late effects of polio. It is from the foregoing sources, as well as appropriate information passed on by members, that the Information Bulletin is compiled.

Newsletter Issue 19 will convey more details of the Management Committee's activities. The Committee hopes that these tangible results are very encouraging to all members.

Nola Buck

Seminar : The Post-Polio Clinic

- Date** : Saturday, 20 November 1993
Time : 1.00 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** : 12.00 p.m. - 1.00 p.m. Please bring your own lunch and a plate for a festive afternoon tea. Tea and coffee will be provided.
- Afternoon Tea** : 3.30 p.m.
- RSVP** : Phone Rae on (02) 337 6315 or write to the Secretary.

Dr Jill Middleton is a Rehabilitation Medicine Specialist at the Prince Henry/Prince of Wales Hospital group. She runs the Post-Polio Clinic at the Prince Henry Hospital. She participated in the post-polio syndrome study undertaken through the Prince Henry Hospital Neurosciences Research Unit during 1991/92. Dr Middleton also works in other areas of rehabilitation at Prince Henry and Prince of Wales Hospitals, including the Spinal Injuries Unit and General Rehabilitation, as well as Geriatric Rehabilitation at the War Memorial Hospital in Waverley.

Dr Middleton received her medical training at Sydney University and Royal North Shore Hospital, then undertook specialty training through the Australasian College of Rehabilitation Medicine while working in several hospitals' specialised Rehabilitation Medicine Departments. She worked for six years at the Mount Wilga Rehabilitation Centre until its closure.

Dr Middleton will begin the Seminar with a brief talk about polio, and late problems being experienced by people who had polio in the past, including the post-polio syndrome. She will go on to speak about the first nine months' operation of the Post-Polio Clinic and what rehabilitation may have to offer people experiencing the late effects of polio. Dr Middleton will then open up the Seminar to questions and discussions, so put your thinking caps on before the Seminar to ensure you get the most out of your attendance.

Our pre-Christmas meeting is always a festive occasion. We hope you'll stay after the Seminar and chat to friends while you enjoy afternoon tea. If this will be the first Seminar you have attended, please introduce yourself to a Committee member. And remember, suggestions about Seminar topics or speakers are always welcome, as are suggestions or comments on Network activities and publications.

Report on Seminar : Travelling with a Disability

Pat Rich, past Vice-President of the Network, and Kevin Byrne, Executive Officer of ADEPT, spoke at the August Seminar about their recent study tour to the USA where they visited San Francisco, St Louis, Phoenix, Washington DC and Los Angeles. They did a lot of travelling throughout the trip, mostly by public transport. The description of how they caught and rode on buses was especially interesting since it is well-nigh impossible for people in wheelchairs to do the same in Australia. Apparently the Bay Area Rapid Transport (BART) system in San Francisco was a great thrill. In their spare time Pat and Kevin went sightseeing. At the Seminar they took it in turns to talk about their travels and the sights they saw, as well as describing some amusing moments in "accessible" hotels, in particular the flood-prone bathrooms. They also showed a video of their adventures which was very interesting despite a technical hitch which prevented the sound coming through. All in all it was a most enjoyable afternoon and Pat and Kevin certainly gave an entertaining account of their travels.

Sophia Brandjes' New Book About Yoga

Those of you who attended the May Seminar will remember that Sophia Brandjes, President of the Yoga for Health Foundation in Australia, gave a very interesting talk on yoga for people with disabilities. Sophia has recently advised the Network that her new book, "On the Gentle Path of Yoga in Sickness and in Health" is now available. She is offering it to Network members for the special price of \$15 including postage and handling. You can order the book by writing to Sophia at 23 Morgan Street, Thornleigh NSW 2120.

Support Group News

Greetings to you all! Thank you to all the Convenors who have forwarded reports on your support group meetings.

Positive feed-back from members is being received by a number of convenors, either through phone contact or at meetings, and the message is often, very simply, "thank you for caring". Many little things serve to indicate that support groups are meeting a very real need for people of all ages who are experiencing post-polio difficulties and who have in some instances not been able to obtain advice or help in working through or adjusting to coping with these difficulties. Several people have mentioned that it has been a "relief" to be able to talk about their polio experiences and this has helped them to re-evaluate their present situation.

The primary function of a support group is for members to be able to "meet together" (in person or by letter/phone) to share things of concern to them, and to ENCOURAGE EACH OTHER. Each group of course plans around the particular needs and levels of ability of its members.

BLACKTOWN-BLUE MOUNTAINS: Close friendships have been formed as the members of this group have grown together over recent months. At their next meeting they are having a demonstration of the "Bobby Limb Posture Care Chair". These chairs are made to measure and may help in the relief of a number of painful ailments. We look forward to hearing more about it.

CANBERRA: Membership has certainly increased here. While 12 - 20 people attend the bi-monthly meetings (held at the Pearce Women's Health Centre), a much larger number has heard about and joined the Network and the support group, thanks to the advertising efforts and encouragement of the two convenors. Discussions focus on a variety of relevant issues, including the Prince Henry Hospital Post-Polio Clinic, the Australian Institute of Sport Stress Flotation Tank, Building Codes/Standards for the disabled, and the free "Carers Kit" available from the Commonwealth Department of Health, Housing, Local Government and Community Services (NSW: phone 008 817 023). A hydrotherapist was invited to be guest speaker for their October meeting while plans are still being finalised for the Christmas meeting on 4 December. Everyone welcome!

COFFS HARBOUR: The group meets monthly on the third Saturday with an average attendance of ten people, many of whom travel quite a distance for the meetings. Seventeen people attended the first meeting and again the convenor's local advertising has brought much interest. It is generally agreed that the opportunity to have local contact, and to meet with others facing similar difficulties in a caring, friendly atmosphere, is greatly appreciated. Members also benefit from information and advice given by guest speakers on various topics.

The Coffs Harbour group was involved in a Disability Expo at Coffs Harbour on 9 September 1993. Thanks to the energetic efforts of group members, and the posters and photos etc supplied by the Network's Management Committee, there appears to be more awareness in the community of polio and its related problems.

ERMINGTON: Members of this group have been getting to know each other over several meetings. They find their time together relaxing and enjoyable and have recently welcomed two new members.

HUNTER AREA: Meeting are usually held on the first Wednesday of each month at Toronto Worker's Club. They often have guest speakers addressing various needs and interests. The most recent speaker brought a display of "Simply Clothing" which included garments with concealed panelled openings front and back, making it easier for people who experience difficulty getting in and out of clothing.

A "Disability Awareness" (Hunter Region) display at the University of Newcastle, a Disability Expo on 29/30 September, a radio interview and a newspaper article have brought a number of enquires regarding the Network and the Hunter Area Support Group.

An informal Christmas get-together will be held on 1 December 1993 - everyone is welcome.

INNER WEST: The average attendance at monthly meetings is eight. Members talk about personal issues and support each other in difficult times. They have discussions on matters such as shoes, chairs, calipers, and diet supplements. An interesting discovery at one recent meeting was that two people who needed different shoe sizes for each foot found that they had opposite feet the same size. They can now share two pairs of shoes between them!!! I think this would be a special blessing of the support group as the persons concerned may not otherwise have met or found this help for their particular need. The Inner West group appreciates the hospitality and the generosity of those members who act as hosts or provide transport for the meetings.

NORTHERN INLAND: This group was previously known as the "067 Group". Of necessity, this is a "meeting by phone or mail" group with its membership scattered over a very large area. Telephone contact is proving a real blessing for these people who often live in isolated situations.

The distances between, say, Collarenebri, Currabubula and Tenterfield, and many other country places where the members live, is perhaps considerably greater than you or I would like to drive for a two-hour visit or a picnic lunch! Hearing about the Network, the Support Group, perhaps about where assistance may be obtained, or just the chance for a friendly hello when one needs a boost, can be a great encouragement. This serves to show the special benefit of contact between the group members and the convenor, as well as the invaluable work of ALL OUR CONVENORS, both in the city and the country areas.

ROSELANDERS: Group membership has grown to twenty and various needs and queries are covered in the bi-monthly meetings usually held in a member's home or in a park. Not everyone can get to meetings but phone contact is maintained. They've also enjoyed several social activities together. The group is encouraged to attend Network seminars and the Committee was pleased to meet a number of them at our August seminar.

Details of all current Convenors are:

Albury	Neil Von Schill	358 Jacinta Court, Lavington NSW 2641	060 25 6169
Bellingen	Barbara Moret	"Koompartoo Retreat", Dudley Street, Bellingen NSW 2454	066 55 2323
Blacktown- Blue Mountains	Jeanne Parkes	2 Chelsea Place, St Marys NSW 2760	02 623 4989
	Irene Alexander	5/28 Bringelly Road, Kingswood NSW 2747	047 36 6154
	Shari Brewster	24 Gilmore Road, Lalor Park NSW 2147	02 674 2469
Canberra	Maureen Kelleher	30 Erldunda Circuit, Hawker ACT 2614	06 254 9288
	Brian Wilson	5 Hussey Cove, Bonython ACT 2905	06 293 2747
Central Coast	Barbara Merrington	41a York Street, East Gosford NSW 2250	043 25 2532
Coffs Harbour	Anne O'Halloran	20 Crescent Street, Urunga NSW 2455	066 55 5204
Eastern Suburbs	Terry Fletcher	32 Milford Street, Randwick NSW 2031	02 398 7820
Ermington	June Brown	4 Woodward Street, Ermington NSW 2115	02 638 1392
Grafton	Susan Stewart	11 Aquarius Drive, Junction Hill NSW 2460	066 44 7789
Griffith	Meryl Blanchard	136 Kookora Street, Griffith NSW 2680	069 62 5402
Hunter Area	Barbara McCormack	4 Englund Street, Birmingham Gardens NSW 2287	049 51 1647
Kandos	Joyce Cole	19 Dabee Road, Kandos NSW 2848	063 79 4114
Kellyville	Carole Turner	4 Jerilderie Avenue, Kellyville NSW 2153	02 629 1501

Liverpool-Sutherland	Robyn Robinson	168 St George Crescent, Sandy Point NSW 2171	02 771 4176
Northern Inland	Barbara Chapman-Woods	31 Kanangra Road, Manilla NSW 2346	067 85 1787
Northern Territory	Patricia Hull	76 Carew Road, Mataranka NT 0852	089 75 4734
Nyngan	Marion Wardman	PO Box 107, Nyngan NSW 2825	068 32 1350
Roselanders	Suzanne Rangi	12a Tooronga Terrace, Beverly Hills NSW 2209	02 554 4204
Shoalhaven	Judith Orford	70 Sheaffe Street, Callala Bay NSW 2540	044 46 5346
Wellington-Dubbo	Hugo Orro	"Tabletop", Wellington NSW 2320	063 46 7272
Wollongong	Raymond Davie	5 Koloona Avenue, Figtree NSW 2525	042 26 6196
Young	Jean Robinson	32 Nasmyth Street, Young NSW 2594	063 82 4337

I'd like to receive from convenors, as time permits and if it hasn't already been given, an up-to-date of your group's membership please.

I still have the names of quite a few members in both country and city areas wishing to join a group, but unfortunately no-one has indicated a willingness to convene. As the numbers of several groups are growing, some convenors might also perhaps be glad to have another person sharing this (rather rewarding) task.

If you would like to join a group, or you already belong to a group and think you may be interested in being a co-convenor, please contact the relevant convenor detailed above. Alternatively you can ring me or write to me c/- of the Network.

Christmas blessings to you all and thanks again. The Committee will be interested to hear about your Christmas get-together (for some the first birthday of their group) in your next reports.

Shirley Roach **Support Group Co-ordinator** **02 759 1578**

More Odd Feet

Suzanne Rangi from the Roselanders Support Group has asked me to advertise that a member of her support group has some odd-sized shoes to sell. These shoes are the other halves of the two pairs she always has to buy in order to get one pair to fit her. Although the shoes are useless to her, she is hoping that someone might have the opposite of her feet and be able to benefit. The shoes are both casual and lace-up and are in the following sizes: Right 6 - 6½ and Left 9 - 9½. These shoes have obviously never been worn and the member is willing to sell them for half their purchase price. For further details, please contact Suzanne on (02) 554 4204.