



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

Editor: Gillian Thomas

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EDITOR'S CORNER

First, as promised in the last Newsletter, some important news on support groups in this issue. The success that our President, Barbara Merrington, and Committee Member, Joan Mobey, have had in each running a local support group has meant the matter of forming more such groups is at the top of the Network's busy agenda. Over the coming year, the Network will be striving to foster the formation of local support groups. However, we need your help to make it happen. The Committee is more than aware that with our far-flung membership, only a few can get to the Network's Seminars on a regular basis. We are therefore anxious to try and facilitate the setting up of local support groups, especially for those of you who are far away and feel isolated as a result. We also have to be careful not to wear ourselves out trying to set up too many groups all at the same time. Based on the information received in response to the questionnaire we will be able to work out what area or areas to concentrate on first. Detailed guidelines on running support groups will be given to all organisers and leaders; you won't be left on your own, unsure of what to do.

As a first step in this process, you are requested to complete the enclosed questionnaire and return it with your Network membership renewal fee. We need your help to work out the level of interest people have in starting up (or attending) a support group in their local area. Please answer the questionnaire even if you would just like to attend a group, but don't feel you are able to organise or run one. Also in this issue is a very good article on support groups.

If you have already sent in your renewal (and many thanks to those who have) please still return the support group questionnaire.

Thank you as well to all the people who have completed and returned the Polio Australasia Questionnaire. If you haven't yet gone around to filling it out, you are urged to do so, even if you are not having problems at present. From now on, all completed Questionnaires should be returned to this Network at the above address (and not to Western Australia as stated previously).

The Annual General Meeting and Seminar "Coping with the Post-Polio Experience" will be held on Saturday 9th May, in the Paraquad auditorium. Full details appear on page 2. Also included with this issue of the Newsletter is the Annual Report detailing the Network's activities during 1991.

The dates for our remaining Seminars this year have been finalised. They will be held on Saturday 15th August and Saturday 12th December. The topics have not been decided yet. If there is anything you would like to have discussed at these Seminars, please drop a line to the Editor at the above address.

ANNUAL GENERAL MEETING / SEMINAR

POST-POLIO NETWORK (NSW) INC. : ANNUAL GENERAL MEETING

Date : Saturday, 9th May 1992

Time : 11.30 a.m.

Place : Paraplegic and Quadriplegic Association of NSW
33-35 Burlington Road (between Rochester and Meredith Sts)
HOMEBUSH NSW

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 : Please bring along your own packed lunch to have at the conclusion of the AGM. Tea and coffee will be supplied.

RSVP : Phone Rae Newhouse on (02) 337 6315 or write to the Secretary, P O Box 888, KENSINGTON NSW 2033 By Thursday, 7th May 1991.

After lunch, the Annual General Meeting will be followed by an interesting Seminar, entitled "Coping With The Post-Polio Experience", details of which are given below. The Seminar will be held between 1.00 p.m. - 3.30 p.m., and will be followed by afternoon tea.

Coping with the late effects of polio can be difficult. People are finding that they require new ways of coping. One of the problems some of our members have discovered is getting their families and friends to understand their new difficulties.

The talk will be given by Caroline Bray who is a Counsellor at the University of Sydney. She has worked for many years assisting people who are experiencing loss and grief situations such as adoption, cot death, and post-polio syndrome.

A question and answer session will follow - and, of course, afternoon tea. Afternoon tea is a good time to mingle and get to know other members of the Network. If this will be the first seminar you have attended, please introduce yourself to one of the Committee members.

THE COMMITTEE NEEDS YOU!

We are still looking for willing people to join the Committee for 1992. The Network can always use more assistance. Why not nominate yourself at the AGM?

MARCH SEMINAR REPORT

Committee Member Janet Malone gave me the following report on our last Seminar, for the benefit of those members who were not able to attend.

"The Seminar entitled 'Life-Style Modification and Energy Conservation' was generally agreed to be a success. The official attendance was forty-seven, and a very happy crowd they were too. Members mingled freely and swapped experiences and information.

Sue Gibson of G.A.T. was the first speaker. She advised of facilities in the Lower North Shore area and gave us some general advice on energy conservation.

Ann Gibson of the Independent Living Centre showed slides and advised of equipment available to assist with energy conservation. I personally have visited the Centre and found them to be most helpful. The number of aids available to help with everyday living is remarkable. I recommend a visit by all members - just ring for an appointment to ensure someone is available to assist you. Should you have a particular need and be unable to visit the Centre, do not hesitate to ring - the staff are only too happy to assist you.

Following on from these talks, Network members Joan Mobey and Alicia Lee demonstrated devices that they find beneficial and gave a few hints regarding energy conservation which they have found to be of help.

We look forward to meeting again all those who attended the Seminar, and also all members who can attend the Annual General Meeting and Seminar in May."

REHABILITATION CENTRES

Further to the article in the last Newsletter on Rehabilitation Centres, I realised after the Newsletter has been posted that I had omitted the details for the Centre in Albury. The details are now given below. My apologies to Dr McLaren, and my thanks to Mrs Betty Wedgwood, who also drew my attention to the omission.

ALBURY BASE HOSPITAL
SMOLLETT STREET, ALBURY NSW 2640
PHONE: (060) 23 0116

Dr Gerry McLaren has been a member of the Network for some time, and I know he is interested in helping people experiencing the late effects of polio. He has also been to the U.S.A. to study the post-polio syndrome. To be assessed by Dr McLaren, first obtain a referral from your GP and ring the above number for your appointment.

SUPPORT GROUPS

As a guide to help you decide whether a support group is for you (and whether you may be interested in organising and/or facilitating such a group in your area), Joan Mobey has prepared the following article.

"All people are influenced by the experiences of their lives and polio people, profoundly so. Many of us have had extreme trauma at an early age and were separated from our loved ones when we needed them most. We were encouraged to play down the experience and get on with our lives as though nothing had happened. We were not allowed to tell how hard it was, or to grieve for what we had lost. Instead we buttoned up our lips and determined to prove that we were as good, if not better, than anyone else. Most of us achieved highly. Now, later in life, many can no longer get away with the pretence that everything is just fine, and the grins are a bit hard to force. New symptoms are getting the better of us. Well, we are down but not out!

A support group gives us not only a chance to pool and share information but also an opportunity to review our life to notice that it is not the same as the average able-bodied person's, and to appreciate how well we have done. Then perhaps we can let up on ourselves, and set our goals more realistically.

Support group leaders need to be interested in this process, but not so desperate to tell their own story that they are unable to make space for others to tell theirs. They need to appreciate the value of a listening ear and be free of the compulsion to give advice, although ready to hand on information. They must have a friendly respect for each member of the group, realising that each person has the ability to make the best decisions for themselves. In the group there must be a feeling of safety and each person must be sure of being heard.

Leaders need to be able to move towards accepting the expression of feelings, knowing that if they happen, tears, raging and laughter all have their own value. They can help the group to know that they don't have to force these feelings back, but also know that there is no responsibility to resolve these feelings. Acceptance of free expression will lead to a resolution by the person themselves, in either the short or long term.

Leaders need to be sufficiently assertive to see that the group members take turns, do not indulge in "put downs" or power plays, and that the Support Group Guidelines laid down by the Executive Committee of the Post-Polio Network (NSW) Inc. are adhered to. This ensures that no inappropriate agenda, such as political action or fund-raising, is introduced into the support group. Remember that support group leaders need support themselves."

COUNTRY PRACTICE / GP

Stories dealing with the late effects of polio are expected to screen in late June/early July. Watch your TV guides for the exact dates!