



NEWSLETTER

Editor: Gillian Thomas

P.O.Box 888, KENSINGTON 2033

GENERAL INFORMATION

This Newsletter is a little briefer than usual. There aren't enough hours in the day at the moment, and this issue has to get out in time to give details of the **Annual General Meeting and Seminar "Yoga for People With Disabilities"** which will be held on **Saturday 8th May** in the Paraquad auditorium. Full details appear on page 3. Also included with this issue of the Newsletter is the Annual Report detailing the Network's activities during 1992/1993.

We look forward to seeing you at the AGM and hope that we'll be inundated with people wanting to join the Committee and make a contribution to the Network's direction over the coming year. You might remember that in the last issue it was foreshadowed that some Committee members would not be re-standing for election. In particular, Gwen Tubb would like you to know that she is not re-standing as Treasurer. Gwen has done a sterling job in this role since the inception of the Network. Unfortunately, the pressure of other commitments means she won't have the time available to devote to the Network's finances in the coming year. If there are any financially-minded Members who would like to nominate for this most important position on the Committee, please be sure to come to the AGM.

The Committee is delighted to report that the out-patient clinic at Prince Henry Hospital which began in March, specifically to meet the needs of people experiencing the late effects of polio, has received good support from Network members. So much so in fact, that the clinic is now held every week instead of every second week. Remember that 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 local doctor is also necessary. It is planned to include a report on activities at the clinic and people's impressions about it in the next issue of the Newsletter. If you'd like your experience included in this report please drop a line to the Editor.

Committee Member Alicia Lee reports a fair response to her plea in the last Newsletter for members' experiences/difficulties with obtaining orthoses. She would like still more letters from members, so if you have a story it's not too late to send it to Alicia, care of the Post-Polio Network (PO Box 888, Kensington 2033). It is hoped that a questionnaire will be circulated at the AGM (and also forwarded to regional support group conveners) to help identify and quantify the sorts of problems people are having.

The last issue of the Newsletter included a very detailed account by Nola Buck (the Network's President) of the talk given by Dr Mary Westbrook about the First Australian National Conference on Post Polio, successfully held in Adelaide last November. A few people have since enquired about contact details for the Australian Odd Feet Association. As you may recall, Lillian Mattner established this organisation (affectionately known as "Sole Mates") in 1982 to link up people who have different sized feet. You can write to Lill at 34 Acacia Avenue, Loxton, South Australia 5333.

Because of time constraints, a report prepared by Nola on the talk given by Faunia Smith, Naturopath from Blackmores, to an enthusiastic audience at the March Seminar has been held over until the next issue.

Similarly, the report compiled by Shirley Roach (the Network's Support Group Co-ordinator) on the activities of regional support groups will now appear in the next issue. This means that if any conveners have not yet sent in their quarterly report (due 31 March), it's not too late to have the details for your group included in Shirley's report. In possible, venue and meeting date details should be given so that they can be publicised for the benefit of members.

What did make it into this issue is a copyrighted article reprinted from Polio Network News. The Network subscribes to this quarterly newsletter which is published by the International Polio Network. Polio Network News contains much of interest to Network members, but since the majority of the material is copyrighted, we have to seek permission on an individual basis before we can reprint articles. As well as the article reprinted in this issue, we have also sought permission to reprint some articles about scoliosis; all being well these should appear in upcoming issues.

You'll find the first article in what we hope will become a periodic series in this Newsletter reproduced on page 4. This is entitled "The Three Types of Three Types of Polio" and is reprinted with permission of International Polio Network, Polio Network News, 5100 Oakland Avenue., #206, St. Louis, MO 63110 USA 314/534-0475.

In upcoming issues it is also planned to repeat some articles from older issues of the Newsletter for the benefit of new members. Remember that back issues are available from the Network for the cost of copying and postage.

So you can plan ahead, the dates for our remaining Seminars this year have been confirmed. They will be held on Saturday 7th August and Saturday 20th November in the Paraquad Auditorium. Details of speakers are still being finalised; further information should be available in the next issue of the Newsletter. This is scheduled for June and should be a bumper issue.

The Network has identified a speech pathologist who is very familiar with swallowing difficulties (dysphagia) and whose advice has already helped Network members. Monika Kaatzke-McDonald works at the Department of Speech Pathology at Concord Hospital. She can be contacted on (02) 736 6949. You will need a referral from your doctor before you can be assessed.

The Committee would like to remind all our members that membership fees (\$10 employed, \$5 not employed) are due from 1 April 1993 and should be sent to PO Box 888, Kensington 2033. A renewal form is enclosed for your convenience. To try and reduce the workload of the Treasurer, receipts will no longer be issued for other than cash payments unless specifically requested. Such requests should be accompanied by a stamped self-addressed envelope. Thank you to all those who have already renewed their membership and for the many kind comments received about the work the Network is doing.

A copy of the Network's poster has been included on the bottom of the renewal form. If you are able, please cut this off and put it up in a public place in your local area, such as a chemist's window, community notice board, public library or your doctor's surgery. In this way, the Network will be able to reach many more people and inform them about the existence of the Network. You can make additional copies of the poster if you wish or write to the Network to have some sent out to you.

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

TO BE FOLLOWED BY A SEMINAR: "YOGA FOR PEOPLE WITH DISABILITIES"

- Date : Saturday, 8th May 1993
- Time : 11.30 a.m.
- Place : Paraplegic and Quadriplegic Association of NSW
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.
- Business : Confirmation of previous Annual General Meeting Minutes
Presentation and adoption of Annual Report, Financial Statement and Auditor's Report
Election of Management Committee
Election of Auditor
General Business
- Lunch : Please bring along your own packed lunch to have at the conclusion of the AGM. Tea and coffee will be provided.
- RSVP : Phone Rae Newhouse on (02) 337 6315 or write to the Secretary, P O Box 888, KENSINGTON NSW 2033
By Thursday, 6th May 1993.

The Seminar will commence at 1.00 p.m.: it will be conducted by Sophia Brandjes, I.Y.T.A., Y.H.R.T. (Certificated). Sophia is President of the Yoga for Health Foundation (an international organisation) in Australia. She has been practising yoga for thirty-three years and teaching for twenty-three. As well as in Australia, Sophia has conducted seminars in Denmark, Holland, Wales, Scotland, and many other places. On her next overseas visit she will be conducting two seminars in Moscow. Sophia is the author of a book, "You Gain A Living Skill", and is currently writing a second book. Apart from helping multiple sclerosis sufferers for twelve years at the MS Rehabilitation Centre at Chatswood, Sophia also gives lectures for the International Yoga Teachers' Association as part of their teacher training scheme. She also works a lot on a one-to-one basis with people who have cancer, Parkinson's Disease, polio, and those who have suffered a stroke. At the Seminar, Sophia will talk about yoga and will give some practical exercises, particularly in breathing for people in a sitting position.

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 Three Types of Three Types of Polio—

Polio has occurred for thousands of years in all parts of the world. The bone formation of an Egyptian skeleton of the period of 3700 B.C. indicates the effects of polio, as does an Egyptian plaque from 1300 B.C.

Polio has had many labels: poliomyelitis, infantile paralysis, Heine-Medin disease, and poliomyelopathy. Poliomyelitis is a combination of two Greek words: Polios or gray, denoting the gray matter of the nervous system, and myelos or marrow, denoting the myelin sheath around certain nerve fibers.

The recording of polio as a disease dates from the late 18th century. By the early 19th century it was reported as being widespread in Europe and India. It was regarded as ubiquitous and caused by teething, foul bowels, or fever.

Presently, it is known that the infection is primarily an inapparent one involving the alimentary tract, that paralytic polio is a relatively uncommon complication, and that silent infection in childhood provides long-lasting protection. The disease is spread by asymptomatic persons through the shedding of the virus from the throat and intestinal tract. Dissemination of the disease is enhanced by poor sanitation, crowding, and low standards of personal hygiene such as those that are common in many tropical and subtropical areas. It is still a widespread problem of endemic proportions in parts of the Eastern Hemisphere.

—1 Immunological Types of Virus—

The poliomyelitis virus is an obligate intracellular parasite which has been classified into three main types: *Brunhilde* — named after the Rhesus monkey in which the virus was first identified, *Lansing* — isolated from a fatal case of bulbar polio in Lansing, Michigan, and *Leon* — identified in a child named Leon during the Los Angeles epidemic. Because of these three separate immunological types, in theory, you can get polio three times.

2 Types Based on Severity of Infection

Probably the most common type of poliomyelitis is the form least identified by the general public. It is known as *abortive polio* and is difficult to diagnose, since the symptoms are often overlooked. These symptoms may consist merely of headache, fever, vomiting, sore throat, or an upset stomach. There are no evidences of paralysis. It is this form that helps to bring about lifelong immunity for a vast number of persons. It is not known how many mild

With special thanks to ... Ernest W. Johnson, M.D.

Dr. Johnson, the former chairman of the Department of Physical Medicine and Rehabilitation at The Ohio State University Hospitals was awarded the 1991 Henry B. Betts Award recognizing his work with people with disabilities. He continues in his medical practice and much of his work involves assisting polio survivors.

cases of this disease occur, nor the ratio of these mild abortive cases to paralytic cases.

If, on the other hand, the virus on reaching the central nervous system carries on pronounced activity, it will bring on identifying symptoms of recognized poliomyelitis. First, it may cause merely a stiffness of the neck and back, but no clinically evident paralysis. This type is known as *non-paralytic poliomyelitis*. The nerve cells involved are not sufficient in number to result in clinically evident weakness. It is known that those with recognized and definite poliomyelitis, at least one-half get entirely well without any significant paralysis.

The most familiar and more dramatic, but fortunately the least common, form of the disease is *paralytic poliomyelitis*. Here large numbers of the nerve cells are rendered useless and the muscles which they innervate are unable to cause motion. A person may become paralyzed in the arms, the legs, or in other parts of the body. The disease may affect the muscles of respiration that cause the breathing action of the lungs.

3 Types by Location in the Central Nervous System

At times the virus may settle in the region of the medulla, or "bulb," the thickened collection of nervous tissue at the upper end of the spinal cord. It is in this bulb that many of the vital nerve centers of the body are lodged. When the infection localizes in this region, it is known as *bulbar polio*. The virus, lodging here, may affect the nerves controlling the muscles of the throat, thus making it impossible to swallow or to speak plainly. Lodging in the medulla, the virus could affect the breathing "centers." Bulbar poliomyelitis is very serious. However, this form of polio is fortunately relatively rarer than the spinal polio, where the infection localizes lower down in the spinal cord. Spinal polio is divided into two types: *high spinal polio* because the nerves controlling the muscles of breathing — diaphragm and intercostals — are located in the high spinal area; *low spinal polio* which involves the lower limbs.

All these forms — spinal and bulbar — are the same illness, the only difference being in the location and the extent of damage done to the nerve cells which control the various muscle activities.

SOURCES: *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* edited by Gini Laurie, Frederick M. Maynard, M.D., D. Armin Fischer, M.D., and Judy Raymond. *Poliomyelitis, a Source Book for High School Students*, published by The National Foundation for Infantile Paralysis, Inc. *Treatment of Acute Poliomyelitis*, edited by William A. Spencer, M.D.

EDITOR'S NOTE: A few sources list six types: inapparent infection, abortive poliomyelitis, non-paralytic poliomyelitis, spinal paralytic poliomyelitis, bulbar paralytic poliomyelitis, and encephalitic manifestations.

ANNUAL REPORT OF POST-POLIO NETWORK (NSW) INC.

FOR THE PERIOD 1 APRIL 1992 TO 31 MARCH 1993

As I search through the files to refresh my memory for this Report, I realise that while there are some areas where there is still much work to be done, much has been achieved since the Network was officially established in 1989. This Report will concentrate on the many achievements of the last twelve months.

First, I would like to thank all the Committee members for their hard work. During this year the Network has reached almost 500 financial members and this has involved all members of the Management Committee in a greater effort. The Committee can be congratulated on the manner in which each member has substituted for the other when requested. In many ways the Committee members would not function as well without their partners and I'd particularly like to extend the Network's appreciation to the partners of Committee members who helped get us from A to B, prepared meeting venues, helped with the refreshments and in setting-up the sound system for seminars, and assisted in collation and the distribution of the Newsletter.

To the NSW SOCIETY FOR CHILDREN & YOUNG ADULTS WITH PHYSICAL DISABILITIES, especially to Mrs Judith Mitchell, the Network's grateful appreciation. Without The Society's assistance in printing and mailing the Newsletter, the Network would have limited communication with its members and considerably less funds.

THE PARAPLEGIC & QUADRIPLEGIC ASSOCIATION OF NSW has also been extremely helpful in assisting the Network in photocopying articles for distribution and also in providing its Homebush auditorium and facilities for seminars. The Network's special thanks to the Directors and staff at Paraquad.

PUBLICITY:

Unwittingly the Post-Polio Network (NSW) Inc. was instrumental in giving the post-polio syndrome national promotion via the television programs, the ABC's "G.P." and Channel 7's "COUNTRY PRACTICE". By these channels featuring the post-polio syndrome in program segments (as suggested by the Network) people all over Australia who have had polio were made aware of the late effects of polio. All state networks were flooded with enquiries, not only from people who have had polio but also from health professionals. The NSW Network received approximately 350 enquiries. In satisfaction of all these requests, as well as enquiries from other sources, the Network's Information Kit was forwarded. This Kit includes the two books dealing with the late effects of polio which is distributed by the Post-Polio Support Group of S.A. (Inc.). Overall during this current year the Network sent out over 500 Information Kits.

CONFERENCES:

The NSW Network participated in two conferences this year. In September 1992, the Network combined with the Australian Polio Network (Victoria's state body) to present a one-day conference, "A COMBINED EFFORT FOR POLIO". New South Wales appreciated being invited to join Victoria to present this conference which was well supported by NSW Network members. Both Victorian and NSW post-polio experts addressed an interested audience and a closer relationship now exists between the two state networks. Following the Conference, members of the NSW Network had the pleasure of dining with some of the Victorian Network members.

In November 1992, the First Australian Polio Conference, organised by the Polio Support Group of S.A. (Inc.), entitled "POLIO PARTNERSHIP" was held in Adelaide. This was also well attended by NSW members, including three Committee members. A world-renowned Neurologist, Dr Neil Cashman, was the keynote speaker. Two of the Network's members were honoured to be invited to present papers at this Conference: Barbara Merrington, a Support Group Convener and past President of the Network, spoke on "THE PATIENT AS TEAM LEADER", and Mary Westbrook, Ph.D., Department of Behavioural Sciences, Faculty of Health Sciences, University of Sydney, spoke on "POST-POLIO: ASSOCIATED STRESS AND ITS PSYCHOSOCIAL MANAGEMENT".

SEMINARS:

As has been the practice over past years, the Network continued to hold seminars during the year (in May, August, December, and March) selecting speakers to assist members to cope with post-polio problems. Areas covered have included: COPING WITH THE POST-POLIO EXPERIENCE, the role of TECHNICAL AID TO THE DISABLED, the experience of a SUPPORT GROUP FACILITATOR, report on THE FIRST AUSTRALIAN NATIONAL CONFERENCE ON POST-POLIO, MOBILITY 2000 and its 4-wheel drive buggy, and advice from a NATUROPATH.

JOURNALS / MEMBERSHIP OF ORGANISATIONS:

In line with the Network's philosophy to aim to keep its members abreast of the latest findings on post-polio, the Network subscribes to several journals including: "POLIO NETWORK NEWS" (published by the International Polio Network, U.S.A.), the "LINK" (a South Australian journal which informs members of national disability events), and "INDEPENDENT LIVING" (the quarterly journal of Independent Living Centre (NSW) Inc. The Network also appreciates the assistance given by Mary Westbrook in providing information concerning relevant articles from local and overseas scientific journals.

To support the disability movement, the Network is a member of PEOPLE WITH DISABILITIES (NSW) INC. and ACROD, bodies which lobby the Government on behalf of people with disabilities.

NEWSLETTER:

The Newsletter remains the chief organ by which communication with members is maintained. Our dedicated editor, Gillian Thomas, burns many litres of midnight oil to produce this Newsletter. All members of the Network appreciate that effort. There were five issues published in the past year and Gillian also produces and up-dates the mailing labels. Our mail-out working bees are now quite time-consuming efforts with each issue now being forwarded to over 600 people.

POLIO AUSTRALASIA:

Since this national organisation was formed in 1991, growth has been slow. Most recently, a meeting was held following the Adelaide conference; the next step will be to formulate a constitution for the national body, to be approved by all states and New Zealand.

SUPPORT GROUPS:

During this year the Committee compiled the Support Group Booklet which gave guidelines for the formation of local or regional Support Groups. Groups are now springing up state-wide. The Committee looks to the Support Groups to take the Network to those people in outlying or isolated areas, and to give peer support and practical help to members. The Network has been blessed by the calibre of those members who offered to be conveners as they have put so much of themselves into the initial work of the Support Groups for the benefit of other members.

POST-POLIO CLINIC:

This year has seen a further growth in co-operation between health professionals and the Network. During the Year members of the Management Committee met with Simon Gandevia, Principal Research Fellow, Prince of Wales Medical Research Institute, and learned what his research involved in seeking answers to the post-polio syndrome.

The first official post-polio clinic in New South Wales opened at The Prince Henry Hospital on 3 March 1993. The Network appreciates the effort Associate Professor Richard Jones, Director, Rehabilitation Medicine, The Prince Henry Hospital, has expended in getting this clinic started. It comprises two Rehabilitation Specialists and operates one day a week. It is up to members to support it, as with a greater demand on the clinic, the Network has a greater chance to argue for the need for additional clinics throughout the state when talking to health authorities.

FINANCES:

Since incorporation, the Network has been pursuing with the Taxation Department the granting of tax deductability of gifts made to the Network. Committee members had a meeting with a representative from the Public Interest Law Clearing House who have confirmed that the Network is eligible for ongoing legal assistance. At present a law firm has undertaken to study the Network's constitution regarding eligibility to gain tax deductability status.

The Committee wishes to sincerely thank all who generously gave donations to the Network's funds over the past year.

The Management Committee would also like to express its appreciation to Mr Peter Roebuck for acting as Honorary Auditor. Mr Roebuck's confidence in the Network's accounts is evidenced by the fact that he has now acted as the Network's auditor for several years.

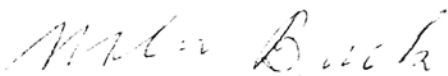
ORTHOTICS:

At the last Annual General Meeting it was agreed that the issue of problems involved in the making and cost of orthotics for people with disabilities would be pursued. Progress has been rather slow and more input from members is required. Committee member, Alicia Lee, who has been involved in this action has also sought the help of her local state member, to see if the Network can get the relevant Government ministers to take action.

THE FUTURE:

With the new year and possibly some new Committee members, the Network will continue to build on the labour of past Management Committees. Awareness of the necessity to immunise infants against the polio virus is an area which needs greater work, as does the development of a viable national body.

The 1992/1993 Management Committee wishes to thank Network members for their confidence in them and wish the new Management Committee every support during 1993/1994.



Nola Buck
President

13 April 1993