

POST-POLIO NETWORK NEWSLETTER

Issue 1, November 1988

Editor: Laurie Alsop

On the 2nd July 1988, a Seminar/Workshop on the late effects of Polio was held in Sydney. Several years ago, in the United States, people who had contracted polio 30 and 40 years ago began to notice symptoms such as undue fatigue, muscle and joint pain, respiratory problems and muscle weakness occurring. These symptoms became known as the post polio syndrome. Although research to date has produced no conclusive data as to the cause of this syndrome, it appears that the problems are likely to be linked to polio. Thousands of polio survivors in the United States were reporting similar symptoms, and all were experiencing problems in having their symptoms taken seriously.

Polio survivors in Australia were also experiencing similar symptoms and the same lack of understanding of their problems.

In 1987 a number of Australians attended the Fourth International Polio & Independent Living Conference in St Louis USA. Some eight hundred people from around the world were present, all of them having symptoms of the syndrome. It seemed that too many people were experiencing difficulties for it all to be in their "imagination".

Those returning to Australia felt that attention must be drawn to the possible late effects of polio and that information should be provided to the many people who had contracted polio during the epidemics of the 30's, 40's and 50's.

It was decided to hold a Seminar on the subject, and to invite Professor Irving Zola, a member of the International Polio Network, and himself a polio survivor. The Seminar provided the first opportunity in many years for people with polio to get together. It was discovered during the course of the day, that most of those present were experiencing symptoms identified with the syndrome.

The major recommendation from the Seminar was that a Post Polio Network be established with the following aims:-

1. Provision of up-to-date information on the late effects of polio.
2. Establishment of a support group for post polio survivors.
3. Establishment of an information base.
4. Encouragement of research into the Post Polio Syndrome.
5. Organisation of Seminars on the Post Polio Syndrome.

A Working Committee was elected to pursue these and other recommendations from the Seminar.

The Workshop inspired a great deal of media interest, including articles in the Sydney Morning Herald and coverage on the national radio show, Health Report. As a result enquiries were received from across Australia. There are now plans to establish similar post-polio support groups in Victoria and South Australia.

Following the Seminar/Workshop, the Working Committee has met twice and has prepared the enclosed questionnaire. We would appreciate your co-operation in completing it and returning it to the Convenor, c/- of The New South Wales Society for Crippled Children, PO Box 4055, Parramatta NSW 2150.

The questionnaire will help assist the Working Party to establish a Network that will meet your needs.

Also enclosed is a Survey "*Polio Survivors & Their Health*", prepared by Dr Mary Westbrook. Again, we would appreciate your co-operation in completing it and returning it to Dr Westbrook at the address shown at the bottom of the survey form.

The possibility of producing a regular newsletter has been discussed. This would contain articles on the syndrome, methods which may assist in relieving its symptoms and information on useful contacts. We would also like to hear of your experiences and solutions you may have found that have helped you to deal with the Syndrome. We would very much like the group to be a self-help network. After all, as one participant said during the Seminar, "*we have outlived most of our doctors and carers*". In many cases, we have had to find our own solutions to the difficulties we are experiencing, and we should continue to help ourselves and others by sharing this information.

So to start the information sharing here are several items:

- ❖ The Fifth International Polio Conference will be held in St Louis, USA from May 31 to June 4, 1989. Apart from providing up-to-date information on the management of post polio, there will also be an exhibition of the latest aids and equipment for people with disabilities. We will bring you more information about the Conference as it becomes available.
- ❖ A useful journal, which often contains articles on Post Polio is the *Rehabilitation Gazette*, published by Gazette International Networking Institute (GINI), 4502 Maryland Avenue, St Louis, MO 63108 USA. Subscription is \$25.00 (US) per year to individuals.
- ❖ The August/September Supplement to *Breakthrough* contains information on the Post Polio Syndrome in a convenient pull-out form. Free copies of *Breakthrough* are available from GPO Box 9848, Canberra ACT 2606.

The Network has begun to compile a list of articles on the late effects of polio. We would be interested to hear about any articles you may have. We would then publish these references in the Newsletter.

Please share this information with other people you may know who have had polio.

One of the most important things that came out of the Post-Polio Seminar/Workshop was the feeling for so many of us that at last we are no longer isolated from each other in our experiences. What a relief to know that "*I'm not the only one who has this after all*".

We look forward to your comments and ideas, and to working together to build a strong self-help network.