

# **POST-POLIO NETWORK (NSW)**

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## **NEWSLETTER**

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### **PRESIDENT'S CORNER**

During discussions with members of the Network at our meetings and with individuals, it has become obvious that one of the major difficulties facing many of us is obtaining suitable orthopaedic equipment.

Members have told us of paying large sums for shoes/calipers that are unwearable, of the difficulty of finding good boot-makers (and doctors who understand their needs), and of the lack of available information. Many of you have talked about spending hours going between doctors, orthotists and boot-makers in order to gain a wearable appliance. Some members have even travelled overseas regularly to find suitable equipment.

As a result, the Post-Polio Network is holding a seminar on "Orthopaedic Equipment - Current Technology", following the Annual General Meeting on Saturday 21st April 1990. (ED: Further details later in the Newsletter.) We hope this will be a useful and informative day, and that you will come and share the issues that concern you. We also hope it will be a starting point from which we can begin to have these issues brought to the attention of those working in the field and that together we can achieve more effective services.

### **THE MANAGEMENT COMMITTEE**

This issue we continue our series of profiles of members of the Management Committee.

#### ***Gwenyth Tubb: Treasurer***

I contracted polio in the mid-1946 epidemic and spent three months in Prince Henry Hospital where two large ward blocks were really packed with polio cases. As there was insufficient treatment being given in the public hospitals, I returned home and received private treatment from Mr L.M. Featherstone which helped me considerably.

I elected to use a wheelchair from an employment point of view, being unable to cope effectively with spinal brace and crutches and be independent. After doing a secretarial course, I worked in the Welfare Department at the Poliomyelitis Society at Milson's Point from 1957 to 1959 and then at Royal Prince Alfred Hospital in the Medical Record department for 26 years.

I joined the Polio Society's first Fellowship in 1953 then the St George District Fellowship when it was formed in May 1954, and I am still actively involved in it, being Treasurer and Newsletter Editor, under its new name since 1977 of St George Association for Disabled Inc. I am also Treasurer of D.P.I. (NSW) Inc. Central Metropolitan Region.

I enjoy gardening, swimming, wheelchair square dancing, craftwork, and joining in the activities of my local church. It is my hope that our Post-Polio Network in New South Wales will grow and consolidate, and be able to provide support, fellowship and information to post-polios in need of it.

### ***Terry Fletcher: Publicity Officer***

I work in TAFE in the Disabilities Unit. My job is to develop policies and services for people with physical disabilities in TAFE. I am an active member of the Disabled Peoples Movement and have a special interest in access issues and integration. I swim (to help tone my muscles and because I really like it); enjoy music especially Opera; am interested in current affairs; reading; and I love dining out with friends.

### ***Shirley Roach***

Hi! I'm Shirley Roach (nee Dopper). After contracting polio in 1950 and spending 17 months in Wollongong Hospital, I then had 18 months at Kooyong Rehabilitation Centre and while there learnt shorthand and typing enabling me to become a taxpayer again! Much of my working life has been in legal offices and I spent 3 enjoyable years working as a lay missionary in Papua New Guinea.

I was a member of the first Fellowship of the Poliomyelitis Society of NSW and have been a member of the St George Association for Disabled Inc. since its formation as a Fellowship of the Society in 1954.

My interests include: involvement in church activities, reading, visiting sick friends, KYB Bible Study and wheelchair squaredancing. I'm also a member of D.P.I. (NSW) Inc. Central Metropolitan Region.

Achieving the objectives of The Network, I believe, will have long-term benefits for many people affected by the post-polio syndrome.

### ***Anne O'Halloran***

I contracted polio in 1945 and was at the Children's Hospital for about a year with many others.

I work full time as an Occupational Therapist for the NSW Society for Crippled Children at Parramatta. Now living, where I grew up, at Concord West so I haven't ventured far in all those years except for brief journeys during holiday time.

My interests are reading, music (most types), and I love travelling once the planning is over. Meals and fun with family and friends are high on my leisure list and gardening and the results of renovating come next.

ED: Since writing this, Anne has made a move to the North Coast and no longer works at Crippled Children's and regretfully cannot continue to serve on the Management Committee. The Committee would like to thank her for her efforts on our behalf and wish her well in the future.

### ***Joan Mobey***

I contracted polio in 1929, when I was three years old. I spent a year in bed at home, supervised by Dr Hurtz, who was not approved of by the medical community. This was because my father refused to allow my spine "to be split open", which is what he believed the mainstream doctor proposed. Dr Hurtz operated when I was eight and again when I was eleven. I have had three orthopaedic operations during my adult life. My health has been very poor, but is improving.

I am the mother of three children, and my eighth grandchild was born last November. I graduated from the Nursery School Training College in 1947 and subsequently worked in pre-schools for many years, finally retiring in 1979. I am currently writing my autobiography - 50,000 words to date. I am an active member of The Society of Friends (Quakers). Since 1980 I have been involved with facilitating groups. My first experience was with S.A.G.E. (Senior Australians for Growth and Exploration), then for some months I was employed by the women's Health Centre at Leichhardt, to facilitate groups for women over forty. I now teach Re-evaluation Counselling (co-counselling) and in 1988 was funded by the Re-evaluation Community to attend a Disabilities Workshop in California.



## COMMITTEE NEWS

The General Meeting and social afternoon held on 9th December was a great success, despite the fact our guest speaker had to cancel at the last minute. Dr Mary Westbrook did a great job at short notice to fill us in on some of the early results of the Polio Survivors and Their Health Survey. All of the data hasn't been analysed yet so a full report won't be available for a while. Watch this space! The proceedings of the Meeting were taped and typed transcripts are available to members for a small production charge (please contact the Editor for further details). The afternoon was full of gastronomic delights and no-one left hungry. Thanks to all those who attended and provided food for thought as well as for the stomach.

The Committee wishes to remind all members of the Network that membership fees are due on 1st April. Please note that everyone on the mailing list is not necessarily a member. Due to the Network's limited funds, we regret we will be unable to send future issues of the Newsletter to people who are not financial members or who have not made a donation to cover production and mailing costs. Your co-operation in promptly completing and returning the enclosed Renewal/Membership/Donation Form will be greatly appreciated. Please note that only financial members will receive a copy of the Annual Report and Financial Statement prior to the Annual General Meeting.

The "Great Logo Search" is over; the winning entry was submitted by Meg Molloy and will feature in the next Newsletter (unfortunately the art-work did not make the deadline for this issue). The Committee would like to thank everyone who participated.

## ANNUAL GENERAL MEETING

Formal Notice is hereby given that the Annual General Meeting will be held on Saturday, 21st April, in the Auditorium of the Paraplegic & Quadraplegic Association of NSW, 33-35 Burlington Street, Homebush (between Rochester and Meredith Streets), commencing at 11.00 a.m. This is where the December General Meeting was held; the venue is wheelchair accessible with off-street parking for approximately 40 cars. Please come and support your Network. In order to ensure we have sufficient seating, could you please phone Gwen Tubb on (02) 797 0575 (or write to her at 24 Hampton Street, Croydon Park NSW 2133) to confirm your attendance by 17.4.90.

Attendees are requested to bring along their own packed lunch to have at the conclusion of the AGM. Tea and coffee will be supplied.

Starting at 2.00 p.m., a Seminar entitled "Orthopaedic Equipment - Current Technology" will be held, with two guest speakers. Mr Kevin Laybutt, orthotist at the NSW Society for Crippled Children, will speak on orthopaedic equipment; he has recently returned from an overseas trip where he studied the current technology. Dr Stephen Wilson, Lady Davidson Hospital, Turrumurra, will speak on Rehabilitation Medicine and how it relates to polio. Discussion and question time will follow, with the Meeting to conclude at 4.00 p.m. Invitations to attend the Seminar are being extended to The Orthotists' Association, The Physiotherapists' Association, The Australian College of Rehabilitation Medicine, and each of the Sydney Hospitals (Rehabilitation/Orthotic Sections).

## OFFERS OF HELP

*Joan Mobey* (one of the Management Committee whose profile appears earlier) has written to me concerning setting up local support groups for members of the Post-Polio Network. She writes:

"At meetings of the Post-Polio Network it has become obvious that members have a need to talk with each other, to share experiences and information. As this is difficult to do in large infrequent meetings, I think that it would be useful to set up a number of local support groups to meet on a monthly basis.

I would encourage members to take the initiative of volunteering to facilitate such a group in their own area. I would like to start a support group for members in the Inner West (of Sydney). If you would like to participate, please contact me by phone or letter (I will get back to you)."

Joan Mobey, 14 Mt Vernon Street, GLEBE NSW 2037, Phone: 660 8769

Please follow Joan's lead: if any members would like to facilitate groups in other areas, please drop a line to the Editor so the details can be publicised in the Newsletter.

Also in my mailbag was a letter from a physiotherapist (whose name is withheld for ethical reasons) concerning the benefits of massage. The letter reads:

"Apparently at the last meeting of the Network, discussion about the benefits of physiotherapy for people who have had polio took place. I believe concern was expressed that not enough 'old fashioned physios' were still around who offer massage instead of using electrical equipment. The possible benefits of some alternative types of 'hands on' therapy I believe were also mentioned.

I trained as a physiotherapist in the 60's in Sydney and during the last polio epidemic. I have had some, though not a lot of experience with the problems that people who have had polio experience. A feature of my training was a sound course of massage and I have always favoured using massage as an integral part of my work. In recent years I have become interested in Shiatsu and the use of natural oils in the ancient art of aromatherapy and I would be very interested to work with any of your members who would also be interested.

Home visits would be a preference because I feel that a great deal of the benefit of massage comes from rest afterwards and then gradual activity."

If people would like to make contact with the author (if only to chat about their difficulties, to ask questions, or to offer suggestions) please write to the Editor.

## ANESTHETICS AND TRANQUILLISERS

Laurie recently wrote to several doctors about the use of certain drugs by people suffering from the Post-Polio Syndrome. Two replies are reproduced below.

*Dr Neil R. Cashman, Neurologist, Montreal Neurological Institute and Hospital:*

"Your question about the use of tranquilizers and anesthetics in post-polio syndrome is not completely resolved at present. Some tranquilizers, such as the benzodiazepine derivatives (e.g. Valium, Atavan) can actually worsen weakness by blocking communication between the nerve and the muscle. In this capacity, they can also increase the sense of generalized fatigue and muscle fatigability that many patients experience. Thus, I tend to encourage patients to avoid these agents, except for certain limited specific indications. However, there are other tranquilizers which do not appear to inhibit neuromuscular transmission, and still others that are of overriding importance to continue (e.g. Phenothiazines). Thus it is difficult to give across the board advice about the use of tranquilizers.

The use of anesthetics in patients with post-polio syndrome is also a disputed area. Some agents for general anesthesia will depress communication between the nerve and the muscle as their major action. Thus, recovery from general anesthesia may be prolonged in patients with post-polio syndrome, and mechanical ventilation may have to be maintained for longer than thought necessary in normal patients. There is no theoretical reason for thinking that general anesthesia results in a permanent decline in muscle strength in patients who need surgery. However, several of the patients under my care have stated that they date the onset of their symptoms or an exacerbation of their syndrome to surgery, major trauma, or severe medical illness. I am not sure if this is a statistically significant result, however."

*Dr H. Newton-John, Specialist Physician, Fairfield Hospital:*

"Yes, there may be problems with administering drugs which affect the brain to polio sufferers. However, this is not because the brains of old polios are especially susceptible to the drugs, it is because some polio survivors have breathing difficulties which can be exacerbated by certain centrally-acting drugs.

The three main breathing difficulties are 1) obstructive sleep apnoea, 2) central sleep apnoea, and 3) chronic respiratory insufficiency.

1. Obstructive sleep apnoea is cessation of breathing in sleep due to the structures in the throat collapsing together and causing an airways blockage. This is well known as snoring when asleep. In some patients, however, more than just snoring occurs - there is total occlusion of the airway above the glottis (the voice-box) by the tongue and other muscles, and the oxygen level in the blood falls. It becomes dangerous when severe, so that very low oxygen levels are reached.

Tranquillisers, sedatives and narcotics (morphine etc.) can affect the control of the airway muscles and make the obstruction more severe at night. Alcohol does the same. If a polio survivor has obstructive sleep apnoea then these drugs are best avoided.



2. Central sleep apnoea is cessation, or severe slowing, of breathing caused by partial failure of the breathing centre in the brain. This can't be recognised except by a 'sleep study'. It is probably not as common as the obstructive type, but can occur in old polios, and is also worsened by the same types of drugs.
3. Chronic respiratory insufficiency is the most important type of breathing involvement for most old polios. The affected breathing muscles (taken as a whole) are too weak to cope with the usual demands of breathing and the person usually has symptoms such as fatigue, shortness of breath and lack of stamina.

Anaesthetic agents are not risky in themselves for old polios, but having a surgical procedure under a general anaesthetic may be very hazardous for an old polio with unrecognised chronic respiratory insufficiency. In such a case, the anaesthetist may not be alerted to take special post-operative precautions, and respiratory failure (i.e. a medical emergency) may occur in the post-operative period. The correct precautions to be taken should be: local anaesthetic where feasible, or, post-operative ventilatory support in ICU for a short period to ensure adequate return of breathing capacity. To avoid trouble, all old polios who have any symptoms should get checked to make sure their breathing muscles are okay.

P.S. I've had a couple of patients who were given anti-depressants whose respiratory problems became very much worse as a result. These should also be used with care."

## LETTERS

Quite a few people read my plea for letters in the last issue and some are reproduced below. Unfortunately, I can't print all that I receive due to space limitations, but rest assured your contributions are appreciated and ideas you put forth are discussed at Committee Meetings, even if your letter doesn't make the Newsletter. This issue I am focusing on those letters concerning orthopaedic appliances, as the subject is very topical considering the forthcoming Seminar.

*Glennis Sewell of Albany, WA, writes:*

"One problem that I have always found a continual headache is that of procuring shoes that are wearable. (I would hate to add up the total amount of dollars that I have spent on what turn out to be unwearable shoes over the last 20 years.) My disability is in my left leg and I do not wear a caliper. Occasionally one does find a style with a strap or T-strap of some sort but if they are not in fashion - and they usually are not - then it is very difficult to find any.

I did have some surgical shoes made but found them so heavy that I couldn't lift them with my weaker foot. I find that I need shoes as light as possible to help overcome the problem - not something that is more suitable for an elephant. They also do not look aesthetically attractive. As I work as a secretary and like to dress with some style (as I'm sure the rest of us do) it is important to my well-being and morale to be able to look good, even down to my feet. They can't be hidden under the desk all the time!

I am sure that there is a good percentage of polio people who do not find it necessary to have a lot of orthotic work on their shoes and that a well made, suitably designed, shoe will suffice. Is it possible, therefore, for some discussion with shoemakers in this regard. I have found, for example, that the Footrest people often have suitable shoes in their catalogue which I have been able to purchase successfully in the past. Perhaps it is worth pointing out to these manufacturers that a large percentage of people (not only those affected by polio) would like to be able to buy an attractive shoe - and that perhaps they could make more effort to think of those who cannot buy 3-inch heels.

The experience I had with the Orthotic people was that they had little - or no - thought for the aesthetic look - as if it doesn't matter to us what our feet look like. I think this seems a very insensitive point of view and that they could be made aware that because we need help with our shoes doesn't necessarily mean we want to look like clumsy elephants."

Offering a different viewpoint is *Howard Ross of 72 Southampton Street, Christchurch 2, New Zealand*, who is interested in corresponding with others who have similar problems to those he describes below. He also says he has a few funny stories about wearing calipers! He writes:

"The lack of trained staff in orthotics is a problem. The trainees nowadays can only work in plastic, velcro, etc. 'Comfort and Support' seem to be forgotten and although a lot of these 'plastic fantastic' calipers might have a cosmetic appeal, from bitter experience they are not very comfortable to wear and not all that supportive either. The older Technician who could work in leather etc is dying out.

I myself had a light-weight plastic caliper; for me it was totally useless, but I was not listened to for quite some time. Only after one of the older technicians saw how I walked and stood did I get the right caliper which gave excellent support and was comfortable to wear - although it's the older type with a padded hip ring and steel side bands, fitting into my shoe.

Cosmetic appeal to me is of no concern. Some women and girls prefer this type of caliper (plastic fantastic), but I have seen them walking in them, as I did; the plastic buckles and breaks away from the hinge areas, and sweats badly."

## POST-POLIO UPDATE

*Dr Westbrook* has very kindly compiled and forwarded the enclosed bibliography of Post-Polio References with the comments:

"One group of articles provide good discussions of the medical issues and could be of value for people to pass on to their health practitioners. Another set look at more psychological issues; matters which are of considerable interest to many members."

Copies of these articles are available from the Network at a copying charge of 20 cents per page. A late entry for the book list is "How to Cope: Practical Tips for Polio Survivors". It is written by LaVonne Schoneman of the Washington Polio Survivors Group. It is available from LaVonne Schoneman, 16734 - 8th NE, Seattle, WA 98155, USA, and costs \$US7.

### BOOKS

Halstead, L.S. & Wiechers, D.O. (1985) (Eds.). Late effects of poliomyelitis. Miami: Symposia Foundation.

Halstead, L.S. & Wiechers, D.O. (1987) Research and clinical aspects of the late effects of poliomyelitis. Proceedings of the second research symposium on the late effects of poliomyelitis. New York: March of Dimes Birth Defects Foundation.

Laurie, G., Maynard, F.M., Fischer, D.M. & Raymond, J. (1984) Handbook of late effects of poliomyelitis for physicians and survivors. St. Louis: G.I.N.I.

### MEDICAL ARTICLES (which may be of use to show your health practitioner).

Agre, J.C., Rodriguez A.A. & Spering K.B. (1989) Symptoms and clinical impressions of patients seen in a post polio clinic. Archives of Physical Medicine and Rehabilitation 70, 367-370.

Codd, M.B. & Kurland, L.T. (1985) Polio's late effects. In 1986 Medical and Health Annual, New York: Encyclopaedia Britannica.

Dalakas, M.C., Elder, G., Hallett, M., Ravits, J., Baker, M., Papadopoulos, N., Albrecht, P., & Sever, J. (1986) A long-term follow-up study of patients with post-poliomyelitis neuromuscular symptoms. New England Journal of Medicine, 314, 959-963.

Eulberg, M.K., Halstead L.S. & Perry (1988) Post-polio syndrome. How you can help. Patient Care, June, 131-165.

Halstead, L.S., (1988) The residual of polio in the aged. Topics in Geriatric Rehabilitation, 3(4), 9-26.

Holman, K. (1986) Post-polio Syndrome: The battle with an old foe resumes. Postgraduate Medicine, 79 (8), 44-53.

Perry, J., Barnes G. & Gronley, J.K. (1988). The postpolio syndrome: An overuse phenomenon. Clinical Orthopedics and Related Research 233, 145-162.

### ADJUSTMENT AND PSYCHOLOGICAL ISSUES

Backman, M.E. (1987) The post-polio patient: Psychological issues. Journal of Rehabilitation, 53, 23-26.

Bozarth, C.H. (1987) Unfinished business: some feelings surrounding the late effects of polio. Unpublished document. Polio survivors' support group of Lansing, 4815 Arapaho Trail, Okemos, Michigan, 48864, USA.

Frick, N.M., (1985) Post-polio sequelae and the psychology of second disability. Orthopedics, 8, 851-853.

Frick, N.M. & Bruno, R.L., (1986) Post-polio sequelae: Physiological and psychological overview. Rehabilitation Literature, 47, 106-111.