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## NEWSLETTER

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Editor: Gillian Thomas

P.O.Box 888, KENSINGTON 2033

### EDITOR'S CORNER

The first Newsletter for 1993 contains much exciting news. A lot has happened since the last issue went out in October. Most important is that our first Seminar for the year will be held on **Saturday 6th March**. Full details are given on page 2. We hope to see you there.

The Network is delighted to announce that an out-patient clinic at Prince Henry Hospital will start in March, specifically to meet the needs of people experiencing the late effects of polio. Full details on the clinic and how to make a booking are given on page 3. Members need to support the clinic if we are to be successful in establishing similar ones in other areas of the state.

At last December's Seminar, members and friends heard a first-rate talk from Dr Mary Westbrook about the First Australian National Conference on Post Polio, held very successfully in Adelaide in last November. A report on her talk is given on pages 3 to 7. Also at this Seminar (before a very cheery Christmas afternoon tea), Dr Bernie Silberstein gave a guided tour of the four-wheel drive wheelchair he is developing. He hopes it will be on the market later this year, and a few of us are saving up our pennies already.

A report on the establishment of local support groups throughout the state is also included in this issue, including contact details for the conveners of many new groups. Because of the importance the Committee puts on helping these groups to set up, a Support Group Co-ordinator has been appointed to assist the groups as they establish. Full details appear on pages 7 and 8.

So you can plan ahead, we would like to give advance notification of the date for this year's Annual General Meeting (which will be held in conjunction with a Seminar as usual). **The AGM will be held on Saturday 8th May 1993.** This year some Committee members who have worked hard since the Network was first established are retiring. This is a good opportunity for you to show your support for the Network in a tangible way and nominate to be on the Committee. We can always use new ideas, they keep the Network vibrant and responsive to the needs of its members.

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. Please note that new membership application fees received after 1 January 1993 also cover the ensuing year (1 April 1993 to 31 March 1994). 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.

Finally, we have been updating our records and want to make sure that all members have received their copies of the books: "A Practical Approach to the Late Effects of Polio" and "The Late Effects of Polio (Information for Health Care Providers)". These books are a must for people who have had polio, so if you missed out please drop me a line or ring Nola Buck on (02) 636 6515.

## SEMINAR: NATURAL THERAPIES SUPPORTING PEOPLE WITH POST-POLIO

Date : Saturday, 6 March 1993

Time : 2.00 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 : 1.00 - 2.00 p.m. Please bring your own lunch.  
Tea and coffee will be provided.

Afternoon Tea : 3.30 p.m.

RSVP : Phone Rae on (02) 337 6315

At our last Seminar, some members suggested that the Network have a speaker on nutrition and natural medicine. Faunia Smith, from Blackmores, who is a Naturopath (with a post-graduate degree in herbalism) and a qualified remedial therapist, has kindly accepted our invitation to address members and friends. Her talk will focus on the use of natural therapies to manage the late effects of polio. She will also demonstrate some light exercises.

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.

### PROBLEMS WITH ORTHOSES

Committee member Alicia Lee is concerned with problems experienced in getting orthoses, both because of their availability (or lack of) and their cost. Alicia has had great difficulties in this regard herself, and being a woman of action not merely words, Alicia has been in touch with her local MP, the State member for Port Jackson, Sandra Nori. Ms Nori has taken a great interest in the problems identified by Alicia, and has already been in contact with the Orthotists' Association.

Sandra Nori has a background in health matters and is extremely active and resourceful. She will do all she can to bring the difficulties being experienced to the relevant Government Ministers and try to get something done. To help her in this, and to try to gauge the extent and type of problems, she would like as many individual stories as she can get of individual persons' difficulties in obtaining orthoses.

If you have a story, please send it to Alicia care of the Post-Polio Network (PO Box 888, Kensington 2033) and she will send it on. Alicia would herself be very interested to read these stories, and she will of course treat them confidentially. If you would rather keep your story private, just put it in a second sealed envelope marked ORTHOSES and she will forward it unopened.



## POST-POLIO CLINIC

The big news this issue is that Professor Richard Jones has advised the Network that an out-patient clinic for people experiencing the late effects of polio is being established at Prince Henry Hospital, Little Bay.

Dr Jill Middleton, Rehabilitation Medicine Specialist, will be running the clinic. The first clinic will be held on 2 March 1993. Because of the complexities of investigating the post-polio syndrome and financial constraints associated with the needs of persons with the syndrome, the initial clinics will be limited to three new patients and two review patients. Professor Jones will assist as necessary in the establishment of the clinic and there will ultimately be a research fellow attached to the service who will be associated with the research aspects in conjunction with the Department of Neurophysiology.

Bookings for the clinic are to be 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.

Professor Jones has always been very supportive to our Network and very understanding of our members' need for a post-polio clinic with a multi-disciplinary approach. The Committee would like to express thanks to him on behalf of all members for his work in getting the clinic established. We know we can rely on members to make full use of the clinic. The way to get further clinics established in New South Wales is to make this initial one a success.

## MARY WESTBROOK : REPORT ON CONFERENCE "POLIO PARTNERSHIP"

The following is a summary of a talk given at the December Seminar by Network member, Mary Westbrook, PhD, Department of Behavioural Sciences, University of Sydney. Mary presented her impressions of the First Australian National Conference on Post Polio, held in Adelaide on 15-16 November 1992, in an amusing and informative way. To get the maximum benefit from her speech it is recommended that the Conference Papers be obtained from the Post Polio Support Group of South Australia Inc., c/- The Neurological Resource Centre of South Australia Inc., 37 Woodville Road, Woodville, South Australia 5011. The cost is \$15 (\$10 for the papers and \$5 for postage).

Included in the papers presented at the Conference was one by Mary entitled "Associated Stress and Its Psychosocial Management", and one by Barbara Merrington (the former President of the NSW Network and Convener of the Central Coast Support Group) entitled "The Patient as Team Leader".

In Mary's words:

"The first impression was of an exciting Conference because we were hearing for the first time about possible medications which may be available within the next year or so to lessen fatigue and possibly to slow down the deterioration. The second impression was how rewarding it was meeting so many people from all over Australia and New Zealand who had had polio. As I listened to people talking of their experiences and present feelings, I began to realise what a resilient group we polios are. It is important to remember that polios were the first group of people with disabilities in this modern western world to be integrated back into society. We were really the forerunners in the thirties, forties and fifties of what the aims of our

disability movement now are. In fact, we were so successful at integrating that we lost touch with each other until fairly recently, and we must remember that we managed to integrate in a world far less physically accessible than it is today, and in a world where attitudes to people with physical disabilities were far more negative than they are today."

Mary went on to describe what was contained in the papers of some of the speakers. The Keynote Speaker was Professor Neil Cashman, an American neurologist currently working at the University of Montreal. Mary said this was the first time most of the audience had heard of any possible treatments (beyond the aids, rest and so on that are usually trotted out) and Professor Cashman was the man who brought that message. He made some very interesting points, including the fact that the most common motor neurone disease in the United States is polio. He believes this is probably also true in Australia. In Australia, the number of people who have had multiple sclerosis is about a quarter of the number who have had polio. The most common cause of paralysis in the USA is stroke, followed by polio.

Professor Cashman went through the general history of post-polio. He pointed out that from recent figures it would appear that post-polio affects about one half to two thirds of people who have had polio - typical symptoms occur about thirty-five years after the initial attack. The best predictor of whether you may experience it or not is the severity of the original attack. He emphasised that when EMG (that is, electro-myography) tests are done where a needle is inserted and nerve impulses tested, they typically find that the disease has been much more wide-spread than people suspected that it was, so that most of us have much more muscle involvement than we realised. He also emphasised that deterioration is very slow, so that is one good thing.

Cashman talked about the three main problems we face (weakness, fatigue, and pain) and what can be done in terms of treatment.

Weakness: The polio virus attacks the motor nerve cells in the spinal cord and it might destroy the root completely, in which case you have a totally paralysed part of your body, or it may partially kill it - this is where we have weak muscles. What happens when you get over the attack of polio is that the "good" nerves send out all these extra sprouts to neighbouring muscle cells that have lost the nerve. This is what happened when we regained strength after the initial attack. One of the things they think is happening with the post-polio syndrome is that a lot of these little extra sprouts are dying off - often a nerve fibre which has sprouted is supplying about seven times the usual number of muscle fibres, so they work very hard. They seem now to be dying off and not regenerating like they used to.

Cashman cited some research studies. He and other people have found that polio survivors who appear to be getting post-polio symptoms have low levels of a substance called "insulin-like growth factor one" in their blood and his current research is in this area. He is working on what is the effect on nerve cells if you can get this growth factor back. In this way, you would slow down (hopefully) the degeneration of the sprouts and also enable the nerve to keep re-sprouting as it used to. This is one of the big areas he is working on. He is getting good results with animal studies and he is hoping within the next year or so to be able to work with humans, and within a couple of years provide some medication that will slow down the increasing weakness.

Fatigue: Professor Cashman looked at the two types of fatigue: systemic, where you are tired all over, and muscle fatigue, where you have exerted yourself too much. Cashman seems to think that a lot of the systemic fatigue is due to problems of transmission at the juncture of nerves. If you



are getting this systemic fatigue you do need to be properly evaluated. A lot of the speakers emphasised the need for proper evaluation when problems occur - don't assume that everything that goes wrong with you is due to polio. Lots of diseases can cause systemic fatigue; for example, diabetes, thyroid disease, depression etc.

Cashman has been treating people with polio who experience systemic fatigue with a drug called Mestinon. This drug is used to treat a neurological disorder called myasthenia gravis which is characterised by muscle fatigue and weakness; the drug is used to try and cut down people's fatigue. Cashman has been treating people with polio with one tenth of the dose which people have for myasthenia gravis and they have been taking it three times a day; in many of them there has been a significant improvement. Every six months he stops them taking the drug for a day or so, and asks if any difference has been noticed when not taking it. Sometimes people do not notice any difference, so he keeps them off it for a while and he may then put them back on it and it seems to work again. He suspects that this "on again, off again" effectiveness may be due to where you are at with respect to your nerves sprouting. This suggests quite promising results in the reduction of fatigue. He emphasised that the trouble with this drug is that people do not feel so tired so often, and frequently overdo it. Side effects which can exhibit from Mestinon are: increased salivation, more nasal mucous, diarrhoea, intestinal cramping, some people get more mucus in their lungs and some get more muscle twitching and cramping. Hence it should never be used without supervision. It has been used for a couple of years clinically in the United States. Doctors have been giving it to people but Cashman has carried out proper drug trials using it on people who have had polio, and that is going to be published in the Journal of Neurological Sciences early in 1993.

(When requested to give an opinion on Mestinon, Professor Richard Jones, Director, Department of Rehabilitation Medicine, Prince Henry Hospital, and Professor Simon Gandevia, Medical Research Institute, Prince of Wales Hospital, stated they would like to see the results of the trials before committing themselves.)

Pain: Professor Cashman feels that many of the people he sees with post-polio have fibromyalgia. Fibromyalgia is where you have diffuse muscle pain and it can be experienced in conjunction with sleep disorders. There are trigger pain points which are very tender. Cashman is treating that with a very low dosage of a drug called amitriptyline. This is a drug which is typically used for people with depression - he is using about one tenth of the normal dosage and he warns you that if you take it you will feel worse initially and better later. Cashman advised that a rheumatologist is the best person to evaluate fibromyalgia and to prescribe appropriate medication.

(Professor Jones, when requested for an opinion, felt that if people were not sleeping well they should first have a look at the bed to see if it is comfortable, or that they do not have sleep apnea etc. He had some concern with the drug amitriptyline as it could sometimes increase bladder problems and can, in males, exacerbate prostate problems.)

To summarise, Cashman made the following main points:

Weakness: Cashman is hoping that within a few years drugs may be available to slow down axonal deterioration and stimulate axonal sprouting.

Fatigue: He feels fatigue can be helped by small doses of Mestinon - he should have more information early in 1993.

Pain: Fibromyalgia may be helped by a rheumatologist by prescribing a very low dose of amitriptyline.

Finally, Cashman mentioned that a recent study had found that when people who have had polio have anaesthetics they take some hours longer to recover. It is important to let doctors know this so that they are prepared.

Another speaker was Dr Liz Falkner, a GP from New Zealand who had had polio. She was sympathetic with the problems we are having with doctors, general practitioners etc because they tend to dismiss complaints and tend to make moral and psychological attributions such as "lazy", "menopausal", "all in your head" etc. Liz Falkner cannot understand why doctors cannot admit that they do not know. If doctors admit they don't know, they leave themselves in a position where further investigations can be made.

Liz again emphasised the importance of not thinking every symptom you have is due to polio and she pointed out that some of the drugs used for asthma and arthritis may in fact exacerbate symptoms. She also emphasised not overdoing it but regulating physical activity so that you do not have this shattering fatigue which needs a day in bed to get over. There has been research recently in America which indicates that if you are doing physical activity and have a couple of short breaks muscles revive quite quickly.

Liz advised to be open to alternative help. Mineral supplementation, vitamin supplementation, investigation for food allergies, have been quite helpful. Liz Falkner concluded that people with post-polio need a mixture of commonsense, acceptance, and sheer bloody mindedness.

In America, Vitamin B6 has been prescribed by a lot of doctors. In a report from the Centre for Diseases Control - which is one of the big research centres in America - it was suggested that it would be useful to have a supplementation of vitamins A, B6 and C. Taking a multiple vitamin capsule is another suggestion.

Another speaker, Ann Buchan, physiotherapist, works with people with post-polio and has a water aerobics group which meets weekly in Adelaide. Ann went through stretching exercises - if you have a strong muscle in one direction, such as you can push your foot down really well, but cannot get it up very much, the muscle at the back of the foot starts to get really tight. There are ways of stretching that. She stressed the importance of keeping general fitness, aerobic fitness, and not over-exercising.

Mary had a personal consultation to have her own exercise program evaluated. One aspect Ann helped Mary with was oedema - swelling in her "bad" leg which didn't go down. Ann suggested the use of a Pelican footrest, cost \$50. Mary says this works well. There are two Sydney outlets: Nursing Home Bedding Specialists, 13/15 Seven Hills Road, Seven Hills 2147, phone: (02) 838 7338; and Stanimed, 142 Sailors Bay Road, Northbridge 2063, phone: (02) 958 3617.

Ann also suggested that if you are lying on the floor, just put your legs straight up against the wall for a few minutes and also massage your legs. Massaging the "good" leg as well is important, as the muscles get very hard due to waste materials from over-work. What struck Mary from her visit to Ann is that we have to have our own personal tailored approach, and she made the comment that every person who has had polio is so different from another that a personal muscle chart is necessary.

Lill Mattner is a leader from the Riverland Self-Help Group. She doesn't look disabled, she limps only when tired and conceals her thinner leg under long dresses. Lill suffers, however, from pain, weakness and fatigue. Lill is a very vibrant person who has odd-sized feet and established in 1982 the "Australian Odd Feet Organisation", affectionately known as "Sole Mates". With 400 members you are linked up with someone whose feet are the reverse of yours - a practical solution to something that affects a lot of us.



Mary found the Conference very emotionally draining while at the same time very exciting. Following from her paper, which included a segment "Time Bombs From The Past", she has had correspondence from people who have said it has given them licence to think about their feelings and thoughts which they have suppressed for years.

## SUPPORT GROUPS

The Committee had a very encouraging response to the Support Group Information Kits which were sent out last October to people who had indicated an interest in convening a group. As a result a number of groups are now forming, and some have already started to hold meetings with people in their local areas. A list of the names and contact details for Support Group Conveners is given below. Where more than one person was willing to start a group in a particular area, they will initially work together; if there is enough demand and the group becomes too large then further groups would probably be formed. If you live in one of the areas given below and previously advised the Network that you wished to join a group, your name has already been forwarded to the relevant convener(s). So far almost a hundred names have been passed on to the twenty conveners. If the convener has not been in touch with you yet (or if you've just decided that you'd like to join a support group), please contact the convener direct.

To try and make the establishment of support groups easier, and to assist the conveners and members where possible, the Committee has appointed Shirley Roach as Support Group Co-ordinator. Shirley has been an active member of the Network's Committee since its first meeting; those of you who have spoken to Shirley know how easy she is to talk to. If you have any problems or concerns or ideas about the groups please feel free to ring Shirley on (02) 759 1578 or write to her care of the Network (PO Box 888, Kensington 2033). Shirley has asked me to remind all conveners that reports on activities are due, and could these please be forwarded by the end of March. This will allow Shirley time to compile an overall report for the next Newsletter because it is important that all members get the opportunity to hear what the groups are doing.

Terry Fletcher	32 Milford Street, RANDWICK 2031	(02) 398 7820
Joan Mobey	14 Mt Vernon Street, GLEBE 2037	(02) 660 8769
June Brown	4 Woodward Street, ERMINGTON 2115	(02) 638 3045
Carole Turner	4 Jerilderie Avenue, KELLYVILLE 2153	(02) 629 1501
Suzanne Rangi	12a Tooronga Terrace, BEVERLEY HILLS 2209	(02) 554 4204
Jeanne Parkes	2 Chelsea Place, ST MARYS 2760	(02) 623 4989
Irene Alexander	5/28 Bringelly Road, KINGSWOOD 2747	(047) 36 6154
Raymond Davie	5 Koloona Avenue, FIGTREE 2525	(042) 26 6196
Barbara Merrington	41a York Street, EAST GOSFORD 2250	(043) 25 2532
Judith Orford	70 Shaffe Street, CALLALA BAY 2540	(044) 46 5346
Barbara McCormack	4 Englund Street, BIRMINGHAM GARDENS 2287	(049) 51 1647
Neil Von Schill	358 Jacinta Court, LAVINGTON 2641	(060) 25 6169
Joyce Cole	19 Dabee Road, KANDOS 2848	(063) 79 4114
Anne O'Halloran	20 Crescent Street, URUNGA 2455	(066) 55 5204
Susan Stewart	11 Aquarius Drive, JUNCTION HILL 2460	(066) 44 7789
Barbara Chapman-Woods	31 Kanangra Road, MANILLA 2346	(067) 85 1787
Hugo Orro	"Tabletop", WELLINGTON 2820	(068) 46 7272
Maureen Kelleher	30 Erlelunda Circuit, HAWKER ACT 2614	
Angela Hanbury-Sparrow	2 Climpson Place, GOWRIE ACT 2904	(06) 292 1237
Brian Wilson	5 Hussey Cove, BONYTHON ACT 2905	(06) 293 2747

Shirley has advised me that there are still about thirty members in the Sydney metropolitan areas around North Shore, Frenchs Forest, Guildford and Blacktown who would like to join a group but no-one has yet felt able to be the convener. If you might like to give it a go, why not ring Shirley and have a chat about what's involved. As Shirley keeps saying, it's not a hard task to take on, it can be simply a matter of organising some regular get-togethers and letting people know where and when. A couple of people could perhaps split the job between them. In cases where some people can no longer get out and about, the conveners can also set up telephone support networks. If you are interested in being involved, Shirley will send you out an Information Kit and you can take it from there.

#### NETWORKS IN OTHER STATES

In case you aren't aware of it, there are post-polio support networks in most other States of Australia. If you happen to be travelling interstate you might like to make contact with the relevant group. Most other States also have smaller regional support groups such as we are establishing in New South Wales.

##### Victoria

Beth Brodribb  
Australian Polio Network  
PO Box 493  
HAWTHORN VIC 3122

##### Queensland

Christine Tilley  
Post Polio Support (Qld)  
PO Box 5651  
WEST END QLD 4101

##### South Australia

Post Polio Support Group of SA  
Neurological Resource Centre  
37 Woodville Road  
WOODVILLE SA 5011

##### Western Australia

Post Polio Network of WA  
PO Box 257  
SUBIACO WA 6008  
  
WA Post Polio Support Group  
Unit 29 Wattle Hill Lodge  
BUNBURY WA 6230

##### Tasmania

Bill Sullivan  
TasPolio Support  
51 Tottenham Road  
GAGEBROOK TAS 7030

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Well, that's it for another Newsletter. There were a few technical problems with the production this time, so it got out a bit later than I hoped it would. The next Newsletter is scheduled for early April.