



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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President's Corner

Gillian Thomas

Welcome to regular readers and new members alike. We hope you all had a restful Christmas and New Year. We look forward to seeing everyone at our first Seminar on Saturday 3 March - see page 2 for details.

A sincere thank you to all members who contacted their local members over the holidays to advocate for funding of the Network. An update is given on page 8. We still have a few weeks before the Parliamentary motion will lapse so it is not too late for you to take action. The more individual members that speak up about the vital services the Network provides, the better our chances obtaining funding.

At the Committee's meeting in January we reviewed our achievement of goals for last year and decided on this year's priorities. We considered 2000 had been a good year with the appointment of Sir Gustav Nossal as Patron, the development of an improved publicity strategy, release of our *Handy Reference* brochure, and making a start towards the establishment of a *Professional / Allied Health Resource Register*. Our major goal this year is to hold a series of successful Seminars with Dr Halstead. Other priorities decided by the Committee are continuing to advocate to both federal and state politicians about the needs of polio survivors and resourcing of the Network, finalising and releasing a *Medical Alert Card* for members, marketing the Network and its services to people of Aboriginal and non-English speaking background, and continuing to pursue funding opportunities.

In the last issue's wrap-up of Post-Polio Awareness Week, I inadvertently omitted to acknowledge the publicity that Support Group Co-ordinator, Neil von Schill, gained. A full-page article appeared in the *Albury/Wodonga Twin Cities Post* which is a free community newspaper with a circulation of 30,000. Following an interview with the editor the article complete with photo was published a week or so after Post-Polio Awareness Week. It immediately generated half a dozen phone calls.

Committee Member Dr Elizabeth Joyner is continuing with the task of compiling a register of medical and allied health professionals who have expertise in, and/or an interest in, evaluating and managing the late effects of polio and post-polio syndrome. The register is being compiled as a service to members. All members are asked to recommend any health professionals they have found to be informed and caring by inviting them to list their name and practice details on the *Professional / Allied Health Resource Register* form included with the last *Newsletter*. For the register to be of value to members you have to contribute towards it, so don't forget to take the form with you on your next appointment and have it completed and sent in to us.

With the December *Newsletter* we gave members advance notice of an international survey to research the extent of sleep-disordered breathing in polio survivors. This is the first ever cross-cultural study of the sleep profiles of polio survivors in Australia, Canada and New Zealand. To keep the project within manageable proportions, and because of cost considerations, the researchers had to limit to 500 the number of Australian polio survivors invited to participate, and the Network assisted by randomly selecting 500 members. By the time you receive this *Newsletter* the survey forms will have been distributed. If you receive a questionnaire, we encourage you to participate in the study. Although you will not directly benefit from your involvement, completion of the questionnaire will aid health professionals in understanding the effects of polio on the sleep patterns of polio survivors and subsequently on their general health and well-being. In due course the researcher, Helen Papadopoulos, and Senior Investigator, Dr Elizabeth Ellis, will present the results of the Australian research in the Network's *Newsletter* and at a Network Seminar for the benefit of all members.

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Post-Polio Network Seminar

Dietary issues for polio survivors

Date: Saturday, 3 March 2001

Time: 1:00 pm - 4:00 pm

Bring a packed lunch to eat from 12:00 noon

Fruit juice, tea and coffee will be provided

Venue: The Northcott Society
2 Grose Street, Parramatta

Ample parking is available in the Parramatta Leagues Club car park at the end of the street (the venue is then a 100 metre walk away).

Limited parking is available on the premises. It would be appreciated if those who are more mobile would leave this closer parking for members who are only able to walk or wheel short distances.

If you are travelling by public transport, you can catch Bus 600 from Parramatta Railway Station to the Leagues Club.

For many months we have been endeavouring to identify a dietician to speak to members on this important topic. We are therefore very pleased that **Susan Thompson** has agreed to present a Seminar to members.

Susan has a Bachelor of Science degree in nutrition and is an accredited practising dietician. She was dietician in charge at the Children's Hospital but now works there part time (at the Western Sydney Genetics Service) and also does consulting work. Susan has written two books, *Healthy Bones* and *Healthy Start for Kids*.

Susan is aware of the dietary issues of concern to polio survivors. The topics she will cover include the glycaemic index, eating for maximum energy, diets that don't make you feel very hungry, weight control and dietary supplements.

As usual, Susan's presentation will be interactive and will be followed by a question and answer period. Whether you want to know how to safely shed those extra Christmas kilos, or want to learn how to control your weight in the context of post-polio restrictions and an often sedentary lifestyle, then this is one Seminar you won't want to miss.

If this is the first Seminar you have attended, please introduce yourself to a Committee member. We look forward to seeing everyone there.

2001 Seminar Program Update

The best laid plans of mice and men, and Seminar Co-ordinators, sometimes come unstuck. We have been advised by Marcia Falconer that she will not be visiting Australia during May, after all. This means our planned Seminar with her will have to be deferred until her next visit. Accordingly, we have revised the date and program for our second Seminar which will now be held on Saturday 16 June 2001 at the Northcott Society, Parramatta. Seminar details are still being finalised, but we are hoping to have speakers from the NRMA and the Council of the Ageing to present topics of interest. Full details will be given in the next *Newsletter*.

Aspects of Muscle Compensatory Processes and Physical Activity in the Survivors of Polio

Gunnar Grimby MD PhD

Professor of Rehabilitation Medicine, Göteborg University, Göteborg, Sweden

Gunnar Grimby is Professor of Rehabilitation Medicine at Göteborg University and head physician at the Department of Rehabilitation Medicine at Sahlgrenska University Hospital, Göteborg. Since 1983, he has conducted numerous studies on muscle function in polio survivors.

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With the increasing understanding of the factors causing new symptoms in polio survivors comes an increasing awareness of the benefits and risks of physical exercise and training. Some training studies have been reported lately in the literature that can be of help in recommending appropriate training regimes. An important aspect is that different muscles in different persons can be very differently affected by polio: some may be atrophied to the point where no exercise or training is possible; some may be moderately weak but in an unstable state showing progressive weakness and a risk for overuse; others may be moderately weak but stable to where some training might be of value; and in some muscles, compensation by reinnervation has resulted in “nearly normal” or “normal” muscle function, but there might be risk for disuse. It is, thus, important to individualize the training advice, not only among individuals but also for different muscle groups of a particular individual.

In practice, this is a great challenge to the physiotherapist, and other professionals who design the training programs, and requires a detailed analysis of the muscle function both with clinical testing and laboratory investigation using dynamometer measurements and electromyography. Our experience is that by having detailed information, the polio survivor has a better opportunity to adopt a daily physical activity pattern that provides the appropriate amount and type of exercise but without overuse and fatigue.

Does too much daily physical activity and exercise training cause acute and/or persistent damage of polio-affected muscles?

To answer this question, detailed knowledge about the compensatory processes in the polio-affected muscles is necessary. Compensation occurs through reinnervation by adjacent nerve fibers to muscle fibers (muscle cells), which have lost their innervation by the death of nerve cells in the acute polio phase as well as later on. The polio-affected muscles otherwise would have atrophied. This compensatory mechanism seems to be very powerful: a nerve cell can reinnervate 4-5 times the normal number of muscle fibers and, in extreme cases, even more than 10 times. The other compensatory mechanism is hypertrophy of the muscle fibers, most likely caused by extreme use of the weak muscle that is still strong enough to be used in daily activities. Even to rise from a chair or walk on a flat surface may give a near maximal load and by that be a stimulus for increase in size of muscle fibers, but not in number, just as in very heavy resistance training. Muscle fibers may then reach a size double or three times the normal size. Thus, whereas physical activity does not seem to be a prerequisite for reinnervation, it is for the increase of muscle fiber size.

Is there a danger in having large motor units (that is, too many muscle fibers innervated from the same nerve cell) and too large muscle fibers?

Our recent follow-up studies over eight years (Grimby et al, 1998) indicate that very large motor units more than 20 times normal, with around 10 times the normal number of muscle fibers, may have problems. Either they may lose some of their muscle fibers and thin out due to defective neuromuscular connections, or they may just die easier. We have no systematic information available whether physical activity and overuse could bring about such a loss of muscle fibers or nerve cells. A defective neuromuscular transmission can be identified in some motor units, but we have not found in our studies an indication that this is a major factor for muscle weakness. Whether it can contribute to muscle fatigue is still under debate. The other compensatory mechanism - hypertrophy (increase in size) of muscle fibers - has a positive effect on the maintenance of strength, but it could be a negative for endurance, as capillarization and the aerobic metabolic system of the muscle cell (mitochondria) do not increase in response to the increase in size. Indeed, such large muscle fibers may be less resistant to overuse.

We know, in fact, very little about the risk of overuse causing persistent muscle damage. What we know now is the risk for long-lasting fatigue after too strenuous exercise in polio-affected muscles. They need a longer recovery period than "normal" muscles, which must be taken into account when designing training programs and adjusting daily activities. In training studies, we have the experience that with long enough rest periods, which could be days or weeks after a too strenuous bout of exercise (Agre et al, 1998), full recovery will occur. Thus, there is a risk for overuse but, with proper attention to the fatiguing symptoms, the function will recover after the exertion. The risk occurs when the polio survivor does not rest enough, and his/her muscles remain in a constant condition of overload with its negative effects on function. Although this is not easy to prove scientifically and experimental studies would be unethical, we must rely on a successive collection of data to understand the balance between the pros and cons of physical activity. My personal view is that an approach of trial and error under professional monitoring will yield in practical terms what is a beneficial level of physical activity and what could be deleterious for a specific individual.

The literature now documents a number of training studies. Of prime importance is separating resistance from endurance training programs. A person with weak muscles may use them close to their maximum only for a short period of time, for example, climbing stairs. Thus, there will be no time for adaptation to endurance. By reducing the intensity, such as walking slower and taking short breaks for other types of activity, both resistance and endurance training at an appropriate level may be achieved. Another way is to choose a medium where the load can be more individualized between muscle groups as in pool training. In a study with a control group at our polio clinic, increased general endurance and less pain in daily life was demonstrated in the group with pool training compared to the group that received advice about their physical activity. There was no deterioration of function after the pool training (Willen et al, 1999).

Other training studies indicate the possibility of improving the general endurance of polio persons by using individual training programs, as on a bicycle ergometer, or group training on the floor with combined endurance and submaximal resistance training with music (Ernstoff et al, 1996). In general, it would be of value to encourage endurance types of programs with proper intensity and the possibility of individualizing the load as in pool training, giving proper time for rest between the exercises.

The role of resistance training for polio muscles is more controversial. However, short-term resistance training at high or maximal intensity has been demonstrated to give an increase of muscle strength in moderately affected muscles, measuring more than 3 on the manual muscle testing scale (Einarsson, 1991). Such an increase in strength seems to be maintained, probably by adaptation of the physical activity level in daily life, and could be beneficial and allow a broader type of exercises with relatively less effort. Such a program did not result in any negative effects or evidence of muscle damage when properly supervised. Also low intensity strength training can improve muscle performance and reduce the experience of fatigue. There was no change in serum creatine kinase after a 12-week muscle-strengthening program, which would have indicated muscle damage (Agre et al, 1997).

To learn the appropriate level of physical activity to avoid unnecessary overload on the one hand and disuse on the other is important for maintaining optimal physical function in polio-affected muscles. As important is to avoid pain, it being both a limiting factor for physical performance and an indication of overload that could be on muscles as well as joints and other tissue structures. The experience of pain is evidently closely related to physical activity. Individuals who spontaneously chose a walking speed close to their maximum speed were more prone to experience pain in their daily life (Willèn et al, 1998). The results of that study indicated also that those who were less affected by muscle weakness experienced more pain than individuals with weaker muscles, and they might, thus, have a pattern of daily activity that was too strenuous. Advice and adaptation of the daily physical activity to avoid pain is an important feature in the post-polio management.

REFERENCES

Agre JC, Rodriguez AA, and Franke TM (1998). *Subjective recovery time after exhausting muscular activity in postpolio and control subjects*. American Journal of Physical Medicine & Rehabilitation, 77, 140-144.

Agre JC, Rodriguez AA, and Todd FM (1997). *Strength, endurance and work capacity after muscle strengthening exercise in postpolio subjects*. Archives of Physical Medicine & Rehabilitation, 78, 681-686.

Einarsson G (1991). *Muscle conditioning in late poliomyelitis*. Archives of Physical Medicine & Rehabilitation, 72, 11-14.

Ernstoff B, Wetterqvist H, Kvist H, and Grimby G (1996). *The effects of endurance training on individuals with post-poliomyelitis*. Archives of Physical Medicine & Rehabilitation, 77, 843-848.

Grimby G, St Ålberg E, Sandberg A, & Stibrant Sunnerhagen K (1998). *An 8-year longitudinal study of muscle strength, muscle fiber size, and dynamic electromyogram in individuals with late polio*. Muscle Nerve, 21, 1428-1437.

Willèn C, and Grimby G (1998). *Pain, physical activity, and disability in individuals with late effects of polio*. Archives of Physical Medicine & Rehabilitation, 79, 915-919.

Willèn C, Stibrant Sunnerhagen K, and Grimby, G (1999). *Dynamic exercise in water in individuals with late polio*. Manuscript submitted for publication.



Australia Celebrates High Immunisation Rates – But There's No Room For Complacency

On 2 February 2001 the Federal Health Minister, Dr Michael Wooldridge, released figures which showed that as at 31 December 2000, 91.3% of children aged 12-15 months were fully immunised and 85.09% of children aged 24-27 months were fully immunised for their age. These figures contrast with a rate of only 53% of Australian children who were fully immunised five years ago.

"This is a wonderful turnaround with childhood diseases throughout Australia at their lowest level as a direct result of widespread immunisation coverage", Dr Wooldridge said. "Immunising Australian children was one of my highest priorities as Federal Health Minister and parents, doctors, nurses, teachers, health authorities and the media can all celebrate their part in this excellent result", he said.

Dr Wooldridge said complacency and the virtual disappearance of childhood diseases in the community contributed to the slide in immunisation coverage in the past. "Our research showed that 95 per cent of parents agreed with immunisation but for a range of reasons they didn't get around to having all the vaccinations done."

Dr Wooldridge said new immunisation initiatives are being pursued in an effort to ensure that Australia continues to successfully reduce the incidence of preventable childhood diseases. These initiatives may result in fewer injections needed by babies and young children to be fully protected.

The Network was pleased to be especially invited to attend and speak at Dr Wooldridge's Press Conference. With only a couple of days notice our President, Gillian Thomas, flew to Melbourne to represent the Network. Part of her speech follows:

Polio was previously considered to be a self-limiting disease, once the acute stage was over. The amount of residual damage determined the degree of recovery, which was thought to be stable once optimum function had been achieved. However, it is now well established that polio has a second, slowly progressive degenerative phase, unrelated to normal ageing. ... Our lives have been thrown into turmoil again, as we lose function and mobility. Over 25% of survivors are increasingly unable to manage the normal activities of daily living. One of the aims of the Post-Polio Network is to inform polio survivors so they can modify their life style and thus reduce the impact of polio's late effects.

There is no register of polio survivors in Australia and for the last ten years the volunteer Post-Polio Networks have taken on the enormous task of identifying, informing and supporting those experiencing polio's late effects, and educating those who care for them.

There have been quite a few famous Australians who contracted polio, and many tens of thousands who aren't famous. We all have one thing in common, though. We fought against the disease and those that survived, thought we had conquered it. We went on with our lives. The same fighting spirit that helped us overcome polio contributed to many of us becoming high achievers. We often rose to the top of our professions, and all of us have contributed greatly to Australian society. Now we have a new battle on our hands.

Polio survivors all know the importance of immunisation. We all wish that immunisation had been available when we were young. We are reminded of this every day. No matter what we achieved in our lives every single one of us would have preferred to have never had polio. Now that polio immunisation is available, we know the importance of high immunisation levels and this is why we gave our full support to the Australian Childhood Immunisation Charter and became a signatory to it. I would like to congratulate the Minister on the achievement of the high immunisation levels we are here to celebrate. Parents and children today don't have to live under the threat of another polio epidemic. Simple, safe and reliable vaccination is readily available, and it is fantastic to see that vaccination rates are now so high.

Q and A

Eddie Bollenbach

Eddie Bollenbach is a polio survivor and teaches microbiology, biology, and chemistry at Northwestern Connecticut Community-Technical College. He is a long time and valued contributor to several post-polio mailing lists on the Internet, and is especially noted for his knowledge and skill at communicating the current scientific understanding of the biology and biochemistry of viruses and other scientific topics relating to polio and post-polio conditions. His recent answer to a question about the effects of overusing muscles was an easy-to-understand explanation of a complex topic.

I know that people with post-polio syndrome (PPS) are losing end fiber attachments to muscle fibers. Everybody knows that. I believe we can say, at this point, that this is in the realm of fact and not theory. The end fibers of a neuron may be as long as a meter (yard) away from where its nerve cell body is in the anterior horn of the spinal cord. If end fiber attachments to motor nerves are lost, or lose functionality, the power and endurance of muscles will decrease. As this occurs the abilities that one possesses diminish. Late polio loss is a unique way to lose motor function, bit by bit. It is insidious. Some people begin falling, some get exhausted and don't know why, and some experience muscle pain because the remaining functional fibers must do much more work to support daily activities which the individual expects to do without trouble.

So, we have a loss of motor nerve end fibers and overuse will lead to pain or other symptoms. I have no doubt that overuse will damage muscles whether they were affected by polio or not. Will overuse damage the nerves that innervate these muscles? I don't know. If you are sore and fatigued should you rest? Absolutely! Does overuse cause PPS? I have absolutely no idea. No one else does either. But constant overuse of damaged muscles will cause more damage. Increased damage could cause more loss of motor nerve synapses. No PPS sufferer needs that.

There is more emphasis now on exercise for people with PPS for muscles that work normally and which were not affected by the acute infection. Earlier, such exercise was advised against more often than it is now. I have experienced the benefits of it. But everyone with polio has a different degree of damage and has damage distributed in different areas. So you must be evaluated by a competent physiatrist to be advised properly about your unique situation.

One of the problems that can decrease quality of life is deconditioning. It may be possible to avoid this by using tailored exercise. Did I say exercise sore muscles? No! Did I say exercise muscles that are undergoing a progressive weakening? No! In my own situation I lost a lot of function, suddenly, in 1984. This transformed me from a walking person with no visible deficit to a motorized scooter. If I stand now I hurt like hell for a week. So I don't. My legs have become much more skinny than they were.

But I have found that in the pool I can kick my legs. I am not using antigravity muscles which were damaged severely during acute polio but I am moving and exercising my legs. I also swim long distances rapidly (at a competitive pace). I've been doing this for more than 10 years and it has only helped me. With manual muscle testing (a blunt instrument) my physiatrist told me this past September that the only clinical weakness was in my right calf. [Ed. See Eddie's article on manual muscle testing in Newsletter Issue 47.] Funny, I have no endurance in other leg muscles and can't stand or walk without getting wiped out. Nevertheless, for me, exercise obviously should not be ruled out as a means of improving function and conditioning. The caveat here is that one MUST be evaluated by a competent physiatrist. I am able to be up all day without significant fatigue. When PPS first reared its ugly mug I had to lie down every couple of hours.

In summary, overuse produces strained or damaged muscle fibers. You need all the healthy fibers you can preserve. PPS is primarily a disease resulting from nerve end fiber degeneration secondary to earlier damage. There may be many causes and I don't know if overuse hurts nerves, or if so how much it does. Nobody knows this as far as I know.

Keep Post-Polio Syndrome on the Political Agenda

Members of the Network have rallied around our call for assistance to have debate on The Hon Dick Adams' motion about post-polio syndrome resumed in Parliament. Many members have advised us that they have written to or spoken with their local members and we are very grateful for their support. If you have had contact with your local member and have not yet told us, please let us know the details as this will help us in any meetings.

If you haven't yet contacted your local member, it is not too late to do so. The more individual voices that speak out in support of the Network and its work, the more our profile is raised and the more chance we have of receiving funding to continue to provide our services.

We only have three more opportunities to have resumption of the debate begun on 28 August 2000 re-accorded priority. If the resumption of debate is not listed on the Parliamentary Notice Paper on 26 February, 5 March or 26 March then the motion will lapse. While we cannot expect that further debate in the House of Representatives will necessarily gain for Australia's hundreds of thousands of polio survivors all that the motion sought, it is nevertheless important that this further debate occurs. The more that the late effects of polio are brought to the attention of Australia's policy makers, the greater chance we have of achieving real benefits for polio survivors. So again we urge you, before what has been gained so far is lost, to spend the next few weeks putting pen to paper and making your local politicians aware of the difficulties you are facing and of the work the Network is doing to assist you. It is vital that the Network be resourced to enable it to not only continue its services but expand them to reach the many, many thousands of people as yet unaware of what is happening to them.

The Committee has not yet received any replies to the nine letters we wrote to Federal and State politicians. We will be pursuing responses and seeking meetings with relevant Members and Ministers over the coming weeks. Anything you as individuals can do to help us keep post-polio on the political agenda will benefit all members.

Remember that if our combined efforts are successful in having the motion re-listed for debate, the Management Committee is considering hiring a wheelchair-accessible bus to take interested members to Canberra. We will not only hear the debate first-hand, but our presence will help to raise the awareness of politicians to the on-going effects of polio on people's lives. We may have little warning of when the motion will be debated, so if you would like to participate in supporting the Network in person, please register your interest NOW by phoning Gillian on (02) 9663 2402 or Alice on (02) 9747 4694.

Dr Lauro Halstead to Present Seminars in NSW

Arrangements are progressing to bring Dr Halstead to Australia this year to speak to Network members. Plans so far see him arriving in mid December and presenting three Seminars: one in Sydney on 16 December, one in Canberra and one in the Hunter Region. Dates for the latter two Seminars have not yet been decided and their planning will be done in conjunction with the Network's Support Groups in these areas. The content of all Seminars is still being discussed. It is expected that many aspects of the visit will be finalised in time for the May *Newsletter*. If you haven't yet read Dr Halstead's book *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, copies are still available from the Network for \$27.50 including postage and GST.

While we are pursuing funding from several quarters towards Dr Halstead's visit, we cannot rely on this coming through. We are therefore going to hold a raffle and are seeking donations of goods and/or services to make it a success. If you can help in any way, please call Alice on (02) 9747 4694 as soon as possible.

Orthotics Update

Anne O'Halloran

You may recall that early in 2000 the Network took the initiative to follow up the recommendations in the report called *Setting it Straight*, a survey of consumers' views of the quality and availability of orthoses in NSW. Three Network members were part of the original taskforce which oversaw the research and the *Setting it Straight* report which was released in 1996.

The provision of well-made, affordable orthotics is vital to many of our members and it is this that prompted us to ensure that the recommendations which were relevant to our members, were put into practice.

To follow up the recommendations, a sub-committee was formed to contact various bodies involved with the report and then make recommendations to the Management Committee on the Network's future role.

There are some positive happenings to report. TAFE is now offering a Technicians Certificate Course in orthotics/prosthetics which will be evaluated one year after commencement. This course is scheduled to commence in July 2001 at the Ultimo Campus. Network member Terry Fletcher is helping the course designers develop a disability module for the curriculum. TAFE has agreed to promote the course to people with disabilities who may be interested in pursuing a career in this field, and advertisements will appear in disability organisations' newsletters in the near future.

Work has also begun on a degree course in orthotics to be offered by the University of New South Wales (*recommendation 1.2.2.*). It will be a Distance Education Course using components from La Trobe University, Victoria. There is a committee comprising industry and consumers working on accreditation of this course. The starting date for the degree course is not yet known but it is not expected to be available before 2003.

In speaking with some members of the Australian Orthotists and Prosthetists Association, we learned that their pay scale has improved (*part recommendation 1.2.4.*). This is relevant to Network members as the improved pay scale should make this career more attractive, together with the new status of training in keeping with responsibilities appropriate to an orthotist as a health care professional.

Changes to the PADP (*Program of Appliances for Disabled People*) Scheme are to be implemented early in 2001 (*recommendation 1.2.9.*). See the report on page 10 of this *Newsletter* for further details.

The progress in the orthotics area is promising. However there is still an important recommendation to be followed up by the Network's sub-committee, namely the specialist course in orthopaedic footwear to be offered by DTEC and TAFE. This recommendation was made "to ensure the acquisition of certain minimum levels of competency and overcome the severe shortage of qualified shoemakers". The sub-committee will endeavour to pursue a satisfactory outcome to this recommendation this year and report in a future *Newsletter*.

If any member has any questions about the progress of the recommendations of the *Setting It Straight* report, or wishes to raise any issues about orthotics in general, please contact me care of the Network.

Program of Appliances for Disabled People (PADP)

The Program of Appliances for Disabled People (PADP) is a NSW Government program for people with disabilities. The role of PADP is to assist eligible residents of NSW who have a permanent or long-term disability to live and participate within their community by providing appropriate equipment, aids and appliances. Adults and children are eligible to apply. PADP is administered locally from Lodgement Centres within the Area Health Services.

Our President, Gillian Thomas, represents the Network and its members on the NSW PADP Advisory Committee. The Committee was established to oversee the implementation of the recommendations of the Carla Cranny Report which arose from her review of the PADP Scheme. The Committee has been meeting since early 1999 and has developed a new policy for the Scheme.

Late last year the Director-General, NSW Health Department, wrote to the Network to advise that he had approved the new policy, to come into effect on 1 January 2001. One of the most significant changes is new financial eligibility criteria, including universal access to the scheme for children. Although the broadening of the eligibility criteria will no doubt place more pressure on the scheme, it is hoped that the Physical Disability Council and other disability organisations (including the Network) will be successful in lobbying for increased funding to the scheme. PADP Co-ordinators at the Lodgement Centres should now be recording all requests for equipment, regardless of the availability of funding, to provide the Health Department with reliable statistics about the level of demand for equipment. If you find this is not happening, please advise the Network.

Another policy change is in the area of co-payments which in the past have been imposed by some Area Health Services and not by others. With the new policy, \$100 of the cost of the first item supplied by PADP in any year will be payable by the recipient, while other co-payments will be abolished, except in the case of above-average income earners. A full copy of the policy is available at your PADP Lodgement Centre or on the NSW HealthWeb at www.health.nsw.gov.au.

The new policy is seen as just the first step in improving the supply of equipment to people with disabilities throughout NSW. The Advisory Committee will continue to meet this year to review the equipment covered by PADP and to finalise an information brochure for users of the scheme. Further advice on these aspects will be provided to Network members as it becomes available. The PADP Advisory Committee will also have a role in monitoring consumer feedback on the ongoing operation of the scheme, and reviewing data on demand and waiting time.

More Than Getting Through The Gate - Parents' experiences of participating in their children's school education

The Disability Council of NSW is conducting a research project on the experiences of parents who have a disability with their children's school education. They are keen to talk with parents across NSW about their participation in their children's education, including:

- experiences with teachers, principals, school administration, P&C groups or any other school-related groups or individuals;
- any positive experiences you have had, and what made them work;
- any barriers that have restricted your access to your children's education; and
- what you think could be put in place to address some of the difficulties

To hear your views, the Council will be running a phone-in from 9 to 11 April 2001 –

Monday, 9 April from 10 am to 4 pm

Tuesday, 10 April from 10 am to 8 pm

Wednesday, 11 April from 10 am to 4 pm

Please call them on Freecall 1800 032 212, or by telephone typewriter (TTY) 1800 044 848 (for the hearing impaired). You can also participate over the Internet. A bulletin board discussion will be held throughout the course of the project. You can access the bulletin board through the Disability Council's web site www.discoun.nsw.gov.au.

My Story

We are always pleased to publish our members' polio stories, and this is a beauty from Dorothy Schünmann (nee Minson). Dorothy is the popular Convener of the rapidly growing Shoalhaven Support Group. Dorothy established the group three years ago and now provides local support for twenty-three Network members between Shoalhaven Heads and Ulladulla. Last November Dorothy got some much needed Post-Polio Awareness Week publicity for the Network by being interviewed by a journalist from the South Coast Register.

At the age of seven my life changed drastically. We had just moved to a new home in the western suburbs from the east. I was the middle child of six children.

At the ripe age of three or four a spinster aunt had taken me for a birthday treat to the ballet *The Red Shoes*. From that day on I danced everywhere awaiting the day I turned seven, the age I had to be to start dancing lessons.

That was 1953. I was in second grade, Infants School, and remember all too well the day my life changed and became a nightmare.

I used to walk roughly 2 km to school each day with my brothers and sisters. However on this day in November I found it difficult to make it home. I lay on the bed on arriving home and later on found I couldn't walk to the toilet which was out the back of the house. My mother thought I was play-acting and even Dad became quite cross with me. By next day I was unable to swallow and my temperature was so high that the doctor was called. Dr Rumone came and gave my parents tablets to give me, which was hopeless – I couldn't swallow jelly.

The days became hazy after this, I remember Mum moving me from bed to bed while she changed the bed, and sleeping beside me to stop me falling out of bed when I would convulse. On the fifth day the doctor called an ambulance – it took me away to Prince Henry Hospital. I was just conscious enough to remember the trip. Several doctors came to look at me on my arrival and prod at me; then the light went out. When next I awoke I was in a big plastic tent with tubes up my nose. How long I was like that I don't know.

Later on I was moved to a ward with many beds. At one end were several iron lung machines with patients in them; the hiss the machines made frightened me. I think I cried a lot. Mum and Dad couldn't visit very often, having five other children and children weren't allowed to visit. Dad also had a business to run.

I stayed in hospital for six months – with physio I learnt to walk again. My arms were pretty useless. Before I came home I was fitted with a metal harness which was buckled around my chest and had two arm supports to carry my arms at right angles to my body. It was so cumbersome and meant someone was always bumping into me. My mother took me for physio three times a week to Canterbury Hospital. I hated it.

Eventually my right arm was out of the frame – however my left arm never did recover. At nine years of age an operation was performed to try and tie off muscles to give me some use of it. The trauma left me depressed and shy. I left hospital this time with a positive remark from the doctor, to be and do all the things normal children do. So I started ballet lessons at last, and physical culture too. It wasn't easy, but again I was driven by something inside me wanting to dance.

It wasn't acceptable to dance on stage with a disability, however I did dance in some musicals and by 17 years of age I had my own dancing school and many happy hours teaching children to dance.

This year 2001 finds me the mother of four and grandmother of four, and still teaching dancing. Up until now I always accepted my challenged life with a positive attitude. My family and especially my husband and children have always thought of me as normal and not as a disabled person. Now I am having to change that and remind them I am disabled, and say "can you help me". Can I avoid post-polio syndrome? This will probably be my greatest challenge.

Polio Particles

Mary Westbrook

Polio Particles is compiled by Mary Westbrook as items in the press or professional journals catch her eye. Included in this series are brief reviews of books on polio or post-polio, updates on post-polio research, information about immunisation and the status of global polio eradication, and other items of interest. Mary's series is now being syndicated around the world as other post-polio newsletter editors pick up on the interesting items Mary includes.

Parking violators sentenced to wheelchairs

Since November last year able-bodied people in San Angelo, Texas, who park in disabled parking spaces could end up doing time in a wheelchair (Associated Press). A first offence of parking without a permit results in a fine of \$265. A second offence leads to a higher fine or serving 21 hours in a wheelchair. The 21 hours must be completed within three working days with a minimum of seven consecutive hours being spent in the wheelchair each day. The West Texas Rehabilitation Centre provides the wheelchairs. Each chair has a sign on the back stating that the user has broken the law. A toll-free number is listed to call if the chair is found empty. As violators do not have a valid disabled parking permit they cannot use disabled parking spaces while doing time.

Polio reappears in a polio free zone

In the last *Newsletter* I reported the concern that if vaccination ceases after the eradication of polio then the mild virus associated with the Sabin vaccine might mutate and infect non-vaccinated people. Such a mutation or change of the Sabin virus recently occurred in the Caribbean. In 1991 the Western Hemisphere was declared polio free after the last case of polio caused by wild-type polio virus was recorded (in Peru). However the Washington Post (1/1/01) reports that in the second half of last year there were 45 cases of polio or suspected polio in the Caribbean; 35 in the Dominican Republic and 10 across the border in Haiti. After the cases were diagnosed as polio, health officials there were swamped by people wanting to be vaccinated. A report by Associated Press focuses on the individual cases asking, *Will 3-year old Erika Pimental, who now drags herself across the floor on her hands, ever be able to run around the neighbourhood? How will 6-year old Alejandrina Arismendy, now unable to stand on her own, make it down the steep hill outside her home to school? Sandy Torres, who is described as now using a wheelchair because his body is forever damaged, told the reporter, I ask God when I will be able to walk again, and if I can continue playing baseball?* All the cases in the Caribbean were either unvaccinated or incompletely vaccinated. CDC (Centers for Disease Control) in the USA conducted a genetic analysis of the viruses obtained from patients. This revealed that the viruses were related and all were derived from the weakened virus used in the Sabin vaccine. Apparently the virus had mutated and spread from person to person among the 50% of people in the two areas who have not been vaccinated against polio. CDC estimates that it took about two years for the Caribbean Sabin virus to mutate as it spread. In a fully immunised population the vaccine virus dies off quickly. This is known from research in Cuba where the Sabin vaccine is only given twice a year on nationwide immunisation days and at no other times. Samples of sewage in Cuba contain no polio virus three months after immunisation days. As relatively few cases occurred in the Caribbean epidemiologists believe that this mutated virus strain is not as transmissible or dangerous as wild-type polio virus. Echoing the point made in the last *Newsletter*, Walter Orenstein, director of CDC's immunisation program said that the outbreak *highlights the importance of maintaining a high level of suspicion for polio, and for ensuring that our vaccination coverage is maintained.* Or as the Washington Post put it, *Even if the tiger you're holding by the tail is mortally wounded, is it ever truly safe to let it go?*

Legacies of the WHO Polio Eradication Program

The *Bulletin of the World Health Organisation* (Volume 79(3), 2000) had polio eradication as its special theme. These are some tidbits I extracted from its many articles.

- The greatest challenge to the eradication program has been war in countries such as Angola, Congo and Afghanistan where polio is endemic. However sometimes immunisation days had a peace-building impact. In part of Sri Lanka the process of arranging ceasefire days for immunisation enabled negotiations leading to the restoration of electricity to the region. In Somalia the demand from the local population for immunisation led local leaders to de-mine roads.
- In the 11 years since WHO resolved to eradicate polio, the estimated number of paralytic cases has fallen from over 400,000 a year to fewer than 20,000. The number of known or suspected polio-endemic countries has fallen from over 120 to fewer than 50. India now accounts for over 50% of reported cases of polio.
- In many developing countries the polio immunisation programs have helped develop better public health systems. Many countries have now established measles and malaria surveillance and eradication programs based on the polio programs. Polio immunisation days are being used to provide vitamin A supplements. Vitamin A is essential for the functioning of the immune system and healthy growth and development. Vitamin A deficiency is a major factor in causing 1-3 million child deaths and blindness in a quarter to half a million children per year.
- Many experts believe there are too many gaps in our knowledge to stop polio vaccination yet. Vincent Racaniello, Professor of Microbiology at Columbia University asks, *Are we willing to take the chance that infants and children will once again be paralysed and sent to iron lungs by a disease that can be prevented by vaccination? Even if some people are, who is willing to take responsibility for taking that chance by deciding to stop vaccinating?*

How many Australians have disabilities?

The Australian Bureau of Statistics (ABS) recently released the findings of its 1998 survey titled *Disability and Long Term Health Conditions*. A nation-wide sample of 42,667 (selected to be representative of Australians) were interviewed by trained personnel. The survey concluded that 3.6 million (19%) Australians have a disability (long term health condition or impairment that interferes with their daily living activities) and another 3.1 million (17%) have a long-term health condition or impairment that is not disabling. The ABS used the World Health Organisation's definition of disability: any restriction or lack of ability to perform an action in the manner or within the range considered normal for a human being. To be counted as disabled in the survey a person had to have had the condition for at least six months or be likely to have it for at least six months and be restricted in their ability to perform at least one everyday activity such as self care, mobility or communication.

Mobility restriction is the disability most frequently found among polio survivors. For the purpose of the ABS survey, mobility was considered to comprise the following tasks: getting into or out of a bed or chair, moving about your usual place of residence, getting to or from places away from your home, walking 200 metres, walking up and down stairs without a handrail, bending and picking up an object from the floor, and using public transport. Disabilities were classified from mild to profound depending on how difficult/ impossible tasks were for the person and how much help from others was needed to carry out tasks. The most common type of disabilities were caused by physical impairments (2.6 million or 14% of Australians) followed by sensory impairments/speech loss (1.2 million or 6% of Australians). Intellectual impairments, psychological impairments and head injuries/stroke/brain damage were much less common but were more likely to result in severe or profound disability than were mobility or sensory impairments. The survey collected information on disabled people's living arrangements, type of assistance they needed and received, and their formal and informal care providers. The disabilities of men and women and people of different ages were compared. Examples of ABS findings were that industrial deafness and intellectual disorders are commoner among males.

How many people with disabilities worldwide?

A billion people with disabilities by 2000 is the title of an article by Art Blaser in the US journal *Electric Edge* (July 1998). (The American definition of a billion is a thousand million). The author admits that his estimate is a guess but argues that the 'one in ten people are disabled' figure usually cited in calculating the number of disabled people in a population is too low. As the above *Particle* revealed, the Australian figures are almost double this. Blaser says that some factors are reducing the population of people with disabilities: *some may not be born because they have been aborted; some will join the non-disabled as a result of medical science; the death of some may be hastened when they are chosen not to receive scarce food supplies; some may become the subjects of euthanasia, whether voluntary or involuntary.* However the total disabled population is increasing. *People are not dying like they used to. Although many of the causes of death - automobiles, workplace hazards, and unclean water - are still with us, they now more often disable people than kill them. Many disabilities are easily preventable, but that does not mean that they are being prevented.* Examples are blindness, famine and land mines. *A high rate of disability may be the result of a society's success.* Examples are Alzheimer's and people with AIDS who are surviving longer but have disabilities. Often so-called cures for disabilities lessen their effects rather than eliminating them. Blaser concludes: *We are left with the question of whether the certain increase in people with disabilities is good news or bad news. I say it's good news. The challenge for society is to raise the quality of life for all of us, many of whom will be people with disabilities.*

Polio survivor invented teddy bears

Margarete Steiff was born in Germany in 1847. She contracted polio when she was two and used a wheelchair for the rest of her life. After attending school, where the janitor carried her up stairs, she took sewing lessons and opened a dress shop in her parents' home. This grew to several shops. Margarete began using scraps left over from sewing to make toys. These were so successful that she abandoned dressmaking and with her brother opened the Steiff Toy Company. The building was wheelchair accessible with long sloping ramps and wide spaces. By the 20th century according to an article in *Mainstream Magazine* (12/95) *the name 'Steiff' on a stuffed animal or doll was comparable to the word 'sterling' on silver.* Margarete wanted to create a stuffed toy animal that would compete with dolls in popularity. The animal had to one appeal to both sexes and be able to dressed liked a doll. After a visit to the zoo her brother suggested a bear. Their factory manufactured a toy bear made of *wool plush and cotton fabric called mohair to give the bear a furry, cuddly appearance. Wooden discs were placed at the neck, shoulders, and hips to allow the bear to be posed in different positions. Shoe buttons were used for eyes and silk thread for nose, mouth and claws.* The first bear was exhibited at the Leipzig Toy Fair but there was only one order. This was from a New York department store that placed a large order for 3000 bears. When the bears arrived in the US Theodore (Teddy) Roosevelt was the popular president who loved hunting. On a recent hunting trip he had shot nothing so his aides put a bear cub in his path. Roosevelt refused to shoot the bear. The picture of him with the cub captured Americans' imagination. The name 'Teddy' was attached to the Steiff bears and the world's love affair with teddy bears began. When Margarete died in 1909 her company was exporting hundreds of thousands of bears and it still produces them.

More Recognition for Network Members

Shirley Roach, Network foundation member, and Committee Member until she moved north to milder climes, has recently been recognised by the Boonah Rotary Club in Queensland for her work in the community by receiving an *Unsung Heroes Award*. Well done, Shirley!

Member Jan Wright, who is also the Chairperson of Post Polio Network – Tasmania Inc, won the West Tamar Council Australia Day Award for *Citizen of the Year*. The Tasmanian Network also won the *Community Organisation of the Year Award* for the West Tamar Municipality, Tasmania. These are well-deserved honours. Jan has earned our respect for her dedication to Tasmanian polio survivors and for her work for the Tasmanian Network which she established three years ago.

Support Group News

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Sadly this issue I have to report that two long-time members of the **Hunter Area Support Group** passed away in January. I am grateful to Arnold Davies and Wendy Chaff for providing the following details of their lives. The Hunter Area Support Group was well represented at both Bob's and Roy's funerals.

Robert (Bob) Thorburn (aged 81) of Rankin Park, and his wife of 53 years, Beth, had been regular participants at the Hunter meetings for many years. Bob survived polio affecting both legs when 16 months old in 1921, and managed to have a life full of achievements, in spite of the restrictions of two walking sticks and then a wheelchair. A perfectionist, he worked as an instrument maker at Smith Sons & Rees (now Repco). His life-time hobby was motor sports (cars, bikes and boats). Our sympathies go to Beth, their two daughters and their families on their loss.

Roy Wholohan (aged 77) of Mayfield, was married to Clare for 52 years. He contracted polio in 1924 at 15 months, which paralysed his right leg, but never let it hold him back for long. Over the years cheerful Roy was always busily involved with clubs and community service, not allowing his asthma and a walking frame prevent him from travelling and participating in various activities. An accountant, he worked for 38 years for Young & Green. While still working, Roy became an enthusiastic member of the Hunter Support Group. Our condolences are offered to Clare, their four sons and their families on their sudden bereavement.

On a happier note, I was fortunate just recently to be able to visit members in the southern part of the state. An invitation to visit the **ACT Support Group** had been extended last year and I was delighted to be able to attend one of their meetings in early February. The Canberra people gave me a very warm welcome and I was able to bring them up to date with events that are happening this year. May I express my sincere thanks to co-Convenors **Brian Wilson, Sue Wallis** and **Roger Smith** for their hospitality.

During the same trip I called at Shoalhaven Heads and met with Convenor **Dorothy Schünmann** and Lorna Symes of the **Shoalhaven Support Group**. We shared a very enjoyable morning tea and discussed current issues. It was pleasing to hear that members are discussing ways of attending the Halstead Conference in December. My thanks to Dorothy and Lorna for a very worthwhile morning.

I would urge all country members to follow the lead being set by the Shoalhaven group and consider making a pilgrimage to Sydney in December for this once in a lifetime opportunity to hear and learn at first hand from Dr Lauro Halstead.

It is pleasing to report that two more members have taken up the challenge of establishing a new Support Group in their local area. **Rachel Say** at **Glen Innes** (phone (02) 6732 1879) hopes to provide contact for members in the north of the state. At Scone, **Bruce Buls** (phone (02) 6545 1993) is keen to start a group which will cater for members in the **Upper Hunter** area. If you live in either of these locations Rachel or Bruce would be very pleased to hear from you. Many thanks to Rachel and Bruce for their commitment to the Network.

We now have Support Groups in the following country areas: Northern Rivers (Lismore and Ballina), Grafton, Coffs Harbour, the Hunter region, Central Coast, Wollongong, Shoalhaven area, Lower South Coast (Narooma/Bega), Glen Innes, Northern Inland, Upper Hunter area, Nyngan, Wellington, Orange, Upper Blue Mountains/Lithgow, Cowra, Young, Griffith, the ACT, and Albury. In the Sydney metropolitan area, there are Support Groups in Hornsby, the Hawkesbury, Northside, Blacktown and the Lower Blue Mountains, Inner West and Campbelltown. If you live in a part of the state nor currently served by a Support Group please contact me and I will provide you with material and personal assistance to get you started.

Post-Polio Post



Not long ago we received a phone call from Graeme O'Reilly of High Range who had only recently heard of the Network through some Post-Polio Awareness Week publicity. He was surprised to learn that the Network has been in existence since 1989. After receiving our information kit, Graeme sent in his membership application under cover of the following very interesting letter. If anyone remembers Graeme from the 1950s or later he would love to hear from you. If you contact the Editor I'll put you in touch with him. We would also be interested to know if anyone else has the badge that Graeme mentions.

I have your letter and contents to hand. A little bit of history first. I contracted polio in January 1953. I was in Tumut at the time and was told "No, definitely not" – a week later back in Sydney I ended up in Prince Henry Hospital at Little Bay. A huge ward with three iron lungs running.

I was getting physio twice a day and Saturday morning until some pencil pusher or desk jockey decided I should be transferred to St George Hospital at Kogarah – that was a culture shock. I was in St George for six weeks and received hydrotherapy only once in a concrete tank which wasn't up to the par of a horse trough, and it was just under a lean-to, no physio or anything else – needless to say what had been gained was very quickly lost. Also some other patients were in a closed-in verandah on an old house in the Hospital grounds. The food was to put it bluntly disgraceful to the point that the nurses on duty would take the hat around and one would go to the corner shop (another victim of progress) and buy eggs and make us scrambled eggs. Different patients' families would bring in different food – my grandparents carried a baking dish full of rice pudding from Penshurst to the ward several times a week.

Sydney's first Polio Club got off the ground at a Rotary Meeting at the Parisian Café at Campsie and our gatherings were at the Canterbury Hotel owned at the time by the O'Brien Family. The Saloon Bars used as pubs in those days closed at six o'clock. The building to be used was opposite but some bureaucrat decided that all disabled people be admitted including those unfortunately to be mentally handicapped. This led to some of the girls especially those in wheelchairs to feel insecure and eventually the whole business fell in a heap, although some of us kept a small group going for some years for weekend outings etc – eventually we drifted apart as some got jobs, others got married and so on.

Myself I have no working muscles in my left foot and ankle to speak of, wasted lower leg and a small amount of waste in my left knee, but the last couple of years, steps without a stair rail leave me on one step at a time as the knee is getting weaker.

Some of us were attendees at Mt Wilga Rehabilitation Centre, north of Hornsby, which was originally the home of Marcus Clark, the department store founder. I still have photos taken at the time. Some of the girls lived in a hostel which was a large house and estate at Warrawee in the northern suburbs.

A badge was struck for us, a small round disc, blue, with what could be described as a cross between Mercury and a winged angel holding the medical staff, coiled snake and rod, and the word "Fellowship" around the edge. I still have mine. I could go on about different things and different people all those years ago but I have most probably taken up too much of your time. I hope I have not bored you too much but it's strange how things come back to you as you put pen to paper.

