



POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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Editor's Corner

The Network has received some welcome, if unheralded, publicity recently. Every couple of years **Dr James Wright** generously promotes our Network in his column published in Sunday papers in all Australian capital cities. Whenever this happens, we get letters from people all over Australia who write that they are experiencing the late effects of polio but were previously unaware of the existence of our (and the other States') Networks and the information that is available. It's all hands on deck for a couple of weeks to get information kits in the mail to these people.

Our next **Seminar** will be held on **Saturday 6 September**. **Allan Gill** will be speaking about the **Treatment and Management of Oedema**. **Full details are given on page 2**.

Copies of the **Proceedings** of our November 1996 Conference ***Living with the Late Effects of Polio*** are still available at a cost of \$29. You can pay for and collect your copy at the Seminar on 6 September, or send us the Order Form enclosed with the last Newsletter. You can also use the Order Form to purchase Conference audio tapes and our Network T-Shirt which features a colourful graphic of a polio virus particle.

Thank you to all those members (75% of the membership) who have so promptly paid their **Membership Renewal** for the period **1 July 1997 to 30 June 1998**. If you are one of the 25% of members who is yet to renew, your address label will still read "Renewal Due: 01-07-97". Please don't delay - send in your Renewal Form and membership subscription today. Help us to keep helping you. Thank you for your continued support.

In Issue 31 of the Newsletter I made a plea for anyone who had **Conference photos** to consider donating copies to the Network. To my surprise, no-one came forward. Now member Edie Morris, who travelled from Japan to attend and present a workshop at the Conference, has asked whether anyone took photos of her workshop. If anyone out there has any photos taken at the Conference we'd love to hear from you. Could the other State Networks please pass this request on to their members who attended the Conference.

This year **(Post) Polio Awareness Week** will be held from **2 to 8 November**, and will be celebrated **nationally with all State Networks participating**. Planning is now underway and again we are seeking your involvement at a local level. Your participation will make this year's media coverage even more successful than that achieved last year. **If you can help, please complete and return the enclosed form no later than 30 September 1997. More information on the Awareness Week can be found on page 12.**

Finally, please take a moment to **read, complete and return the enclosed Member Questionnaire**. The item on page 5 explains why it is important for you to do so.

Unless otherwise stated, the articles in this Newsletter may be reproduced for the benefit of people who have had polio, provided that the articles are reproduced in full (including any references) and the source is acknowledged. Articles may not be summarised without the prior written approval of the Network. The views expressed in this publication are not necessarily those of the Post-Polio Network (NSW) Inc, and any products and services described are not necessarily endorsed or recommended by the Post-Polio Network (NSW) Inc.

Seminar : Oedema

Its Treatment and Management

- Date:** Saturday, 6 September 1997
- Time:** 2:00 pm - 3:30 pm (followed by afternoon tea)
Bring a packed lunch to eat from 1:00 pm and catch up with friends before the Seminar and afterwards at afternoon tea. As usual, fruit juice, tea and coffee will be provided.
- Venue:** St Paul's Anglican Church Hall
57 Princes Highway, Kogarah
Parking is available on the premises. It would be appreciated if those who are more mobile would leave the closer parking for members who are only able to walk or wheel short distances.

Many of our members suffer from oedema. This is swelling of the limbs (frequently legs) and can be caused by some or all of the following: poor circulation, lack of muscle bulk and movement, and lack of physical activity. Despite it being a common problem among polio survivors, there is very little written about it in the "polio press" and research on the subject appears to be minimal. All the more reason why your Committee thought a Seminar on the subject would be worthwhile.

Our guest speaker will be **Allan Gill**, an orthotist who specialises in the treatment and management of oedema. He runs the Lymphoedema Clinic at The Lymphoedema Therapy Centre, Avalon.

Allan's presentation on this topic promises to be very informative. His talk will be interactive with a question and answer session following. If you suffer from swollen legs, don't miss this Seminar.

After the Seminar, we hope you will stay and have afternoon tea with fellow members. This is always a good opportunity to catch up with old friends and make new ones.

This is the first time that a Seminar has been held in this area of Sydney. The Management Committee endeavours to make Seminars accessible to members throughout the metropolitan area, and hopes that the choice of Kogarah as a venue this time will enable more members from this region of Sydney to attend.

If this will be the first Seminar you have attended, please introduce yourself to a Committee Member. We hope to see you there!

JUNE 1997 SEMINAR REPORT:

MYOFASCIAL RELEASE - AN INTRODUCTION

What it is, how it works, and why it is so effective ...

The Seminar on Myofascial Release presented by Physiotherapist Elspeth Ferguson, B.App.Sc. M.A.P.A., on 14 June was well attended and very interesting. Following her talk, Elspeth handed out the following article (adapted from "Therapeutic Insight", Physical Therapy Forum, Week of October 3, 1988). If you are interested in consulting Elspeth, she can be contacted on (02) 9631 4617.

Myofascial Release is a relatively new treatment approach for physiotherapists and, although different from traditional therapy, it can be used in conjunction with these traditional techniques. What is it? Myofascial Release is generally an extremely mild form of stretching that has a profound and far reaching effect on the body tissues. Because of its gentleness, many individuals wonder how it could possibly work. This article should help you to understand.

The fascia is a tough connective tissue which spreads throughout the body in a three-dimensional web from head to toe without interruption. Fascia surrounds and invades every other tissue and organ of the body, including nerves, vessels, muscles and bone. Fascia is composed of two types of fibres (a) collagenous fibres which are very tough and have little stretchability, and (b) elastic fibres which are stretchable. Fascia is more dense in some areas than others. Dense fascia is easily recognisable, for example, the tough white membrane that we find surrounding butchered meat.

It is estimated that fascia has a tensile strength of as much as 14,000 Newtons per square centimetre (2,000 pounds per square inch). No wonder when it tightens it causes pain! Trauma, surgery, disease, posture, inflammation etc can cause binding down of fascia resulting in excessive pressure on nerves, blood vessels, bones and organs. Because fascia permeates all regions of the body and is all interconnected, when it scars and hardens in one area (following trauma, disease etc), it can put tension on adjacent pain-sensitive structures as well as on structures in far away areas. Some patients have bizarre pain symptoms that appear to be unrelated to the original or primary complaint. These bizarre symptoms can now often be understood in relationship to our understanding of the fascial system.

The majority of the fascia of the body is oriented vertically. There are, however, four major planes of fascia in the body that are oriented in more of a crosswise (or transverse) plane. These four transverse planes are extremely dense. They are called the pelvic diaphragm, respiratory diaphragm, thoracic inlet and cranial base. Frequently, all four of these transverse planes will become restricted when fascial adhesions occur in just about any part of the body. This is because the fascia of the body is all interconnected, and a restriction in one region can theoretically put a "drag" on the fascia in any other direction.

The point of the above information is to help you understand that during myofascial release treatments, you may be treated in areas that you may not think are related to your condition. It is necessary to release fascia in areas that the therapist knows have a strong "drag" on your area of injury. This is, therefore, a whole body approach to treatment. A good example is the chronic low back pain patient; although the low back is primarily involved, the patient may also have significant discomfort in the neck. This is due to the gradual tightening of the muscles and especially of the fascia, as this tightness has crept its way up the back, eventually creating neck and head pain. Also, just about all low back pain

sufferers have fascial and muscular restrictions in the abdominal region which drag forward and prevent normal movement in the low back as well as dragging up to the chest and neck. Fascial restrictions and tightness are common in the upper chest and front of the neck too. Experience shows that optimal resolution of the low back pain requires release of the fascia of the head, neck and anterior trunk; if this tightness is not released it will continue to apply a "drag" in a downward or forward direction until fascial restriction and pain has returned to the low back. Muscle provides the greatest bulk of our body's soft tissue. Because all muscle is enveloped by and ingrained with fascia, myofascial release is the term that has been given to the techniques that are used to relieve soft tissue from the abnormal grip of tight fascia ("myo" means "muscle").

The type of myofascial release technique used in treatment will depend on where in your body the fascia is restricted. If restriction is through the neck to the arm a very gentle traction may be applied to the arm, slowly moving it through its range as restrictions are released. If the thoracic inlet deep transverse fascia is suspected of being restricted, one hand will be placed on the upper back and one over the collar bone area in front and held with an extremely gentle pressure.

The viscoelastic quality of the fascial system causes it to resist a suddenly applied force. This treatment approach consists of the gentle application of sustained pressure into the fascial restrictions. The fascia will soften and begin to release when the pressure is sustained over time so this is the key to treatment. This essential "time element" has to do with the viscous flow and the piezoelectric phenomenon: a low load (gentle pressure) applied slowly will allow a viscoelastic medium (fascia) to elongate. It can be likened to pulling on a chewy toffee with a small sustained pressure.

Myofascial Release is gentle, but has profound effects upon the body tissues. Do not let the gentleness deceive you. You may leave after the first treatment feeling like nothing happened. Later (even a day later) you may begin to feel the effects of the treatment.

In general, acute cases will resolve with a few treatments. The longer the problem has been present, generally the longer it will take to resolve the problem. Many chronic conditions (that have developed over a period of years) may require several months of treatments two or three times a week to obtain optimal results. Experience indicates that fewer than two treatments per week will often result in fascial tightness creeping back to the level prior to the last treatment. Releasing techniques, range of motion and stretching exercises given to you, will, however, keep this regression between treatments minimal.

Frequently there is increased pain for several hours to a day after treatment, followed by a remarkable improvement. Often improvement is noted immediately during or after a treatment. Sometimes new pains in new areas will be experienced. There is sometimes a feeling of light-headedness or nausea. Sometimes a temporary emotional change is experienced. All of these are normal reactions of the body to the profound, but positive, changes that have occurred by releasing fascial restrictions.

It is felt that release of tight tissue is accompanied by release of trapped metabolic waste products in the surrounding tissue and blood stream. It is highly recommended that you "flush your system" by *drinking a lot of water* during the course of your treatments, so that reactions like nausea and light-headedness will remain minimal or nil.

Please feel free to discuss any concerns or questions about the treatments or your reactions with me.



Elspeth Ferguson has since written to me with details of other physiotherapists who can assist with Myofascial Release treatments. Her letter reads:

Some physiotherapists in Sydney who have attended Myofascial Release courses in Sydney (slightly different approach but along the same lines) are:

John Bragg	(Nicole Vass' rooms) Neutral Bay	(02) 9953 7991
Helen Goodman	Rose Bay	(02) 9371 0640
Peter Magna	Northmead	(02) 9623 2220
Louise O'Brien	Balmain	(02) 9810 2839
Mary Pentecost	Elanora Heights	(02) 9913 1023

My apologies to the person who wrote for this information and sent a stamped self-addressed envelope - I have misplaced them! Sorry. Please ring me if the above information is not helpful.

MEMBER QUESTIONNAIRE

We need your help to develop the Network to meet your needs. Last year we devised a Questionnaire to assist us do this. To test its usefulness, we piloted the Questionnaire with thirty members selected at random and obtained a good response. We have now fine-tuned the Questionnaire and include it with this Newsletter. We earnestly ask you to complete and return it to us by **30 September 1997** in the enclosed envelope (your stamp helps contain our costs). If you participated in the pilot survey, you don't need to complete the Questionnaire again unless you want to.

We need to collate this information because as the Network has become well-known in the community and amongst health professionals, and as we seek funding to help the Network to do more for you, we are frequently asked for a profile of our membership. Although we collect some details on our membership application form, this information is not detailed enough. To help us to help you, we need to know how severely you were affected when you contracted polio, how you functioned at maximum recovery, how you are functioning now, what aids you have and/or need, and so on. Without the data to prove the need for support, our attempts to have services established or expanded to benefit people who have had polio have little chance of success. You are not identified in any way on the Questionnaire and only aggregate data will be used in any submissions we make.

LIBRARY SERVICES FOR PEOPLE WITH DISABILITIES

The State Library of New South Wales, Macquarie Street, Sydney, has issued an open invitation to attend a Seminar on their library services for people with disabilities. The Seminar is made up of three sessions:

- *The Disability Information Service* - a short talk on the type of enquiries received and where they find the answers, plus a demonstration of the relevant databases.
- *The Alternative Formats Collections* - a session on talking books, captioned videos, and other resources collected by the State Library; what is available and how to borrow them.
- *Adaptive Technology and Building Access* - a walk around the library looking at building and information access, including demonstrations of equipment and software.

The Seminar runs from 9:30 am to 12:30 pm on the following Thursdays: 4 September, 9 October, 20 November, 4 December. There is no cost, but bookings are essential, phone (02) 9273 1583.

MEET THE MANAGEMENT COMMITTEE

Over the coming issues, I'll be including pictures of the members of the Management Committee. It's always nicer to know who you are talking to, and to be able to picture the volunteers working on your behalf. This issue, I'm featuring three of the office bearers. Thank you to Network Librarian Tony Marturano who gave freely of his technology and time to bring you these photos. More next issue.



This is Network President, **Nola Buck**. Nola is most often the voice on the end of the telephone when you ring with a query. Nola also sends out all the information kits to new enquirers, as well as organising Seminar speakers, chairing monthly Committee Meetings and quarterly Seminars, and representing the Network in many forums. Nola has raised the profile of the Network significantly during her Presidency.



Janet Malone is the Network's Vice-President. Janet has not only filled this role for a number of years, but until recently was also the Minute Secretary. At one stage, Janet took on the job of Treasurer as well when we were having trouble filling the position. Janet organised our fifth anniversary dinner in 1994 and now with Committee Member Alice Smart is in the throes of planning for (Post) Polio Awareness Week.



Gillian Thomas is the Network's Secretary. Gillian was a member of the original Working Party set up in 1988 to establish the Network, and was subsequently elected as Secretary. She has been the Newsletter Editor since May 1989, and recently produced the Proceedings of the Network's International Conference *Living with the Late Effects of Polio*. As well as these roles, Gillian maintains the membership database.

REHABILITATIVE PRINCIPLES AND THE ROLE OF THE PHYSICAL THERAPIST

This Internet article was written by Patricia L. Andres and is excerpted from the book entitled "Post-polio Syndrome", edited by Theodore L. Munsat, 1991 published by: Butterworth-Heinemann, 80 Montvale Avenue, Stoneham, MA 02180. In America, a physiotherapist is called a physical therapist.

Post-polio syndrome (PPS) is an extremely challenging problem for the physical therapist. The common clinical manifestations of PPS are weakness, pain, fatigue, and decreased functional mobility. Although the etiology of PPS is poorly understood, these symptoms can be explained, at least in part, by postural imbalances and faulty biomechanics.

Virtually all patients with paralytic polio are left with isolated muscle weakness. The human body has an extraordinary ability to efficiently compensate for weakness using muscle compensation and substitution. A secondary effect of compensatory techniques is that weak muscles tend to become overstretched and therefore weaker; and strong muscles become shortened and overworked. Over time, these muscle imbalances and faulty biomechanics lead to mechanical strain, ligamentous instability, abnormal stresses on joints, and increased energy expenditure, resulting in pain and further disability.

Since postural imbalances and faulty biomechanics are at least contributing factors to PPS, treatment should concentrate on correction of postural deficits. However, several factors make this goal difficult to achieve. First, the underlying disease mechanisms are unknown, making formulation of appropriate exercises difficult. Second, postural deficits have developed over several decades of compensation, therefore achievement of significant results in the short term is unlikely. Third, changing longstanding compensatory patterns by altering the biomechanics of one part of the body may cause adverse effects in remote parts. For example, the addition of a shoe lift will alter the forces exerted through the trunk and may actually cause new back pain.

Unfortunately, during the acute phase of polio the hallmark of successful rehabilitation was often seen as the ability to throw away orthotics and assistive devices. Thus, many patients relied on substitution and compensation techniques to achieve functional mobility rather than using their braces or canes. This has taken its toll over the years. Long-term ambulation with gait deviations has created tremendous mechanical strain and greatly increased energy costs, which contribute to pain and fatigue.

Physical therapy treatment of the PPS patient should focus on correction of faulty postural alignment in lying, sitting, standing, and ambulating. Postural abnormalities in any of these activities, if uncorrected, can result in greatly increased energy expenditure and mechanical strain [1]. Restoration of postural alignment will decrease the abnormal forces across adjacent joints and reduce the compensatory muscle activity throughout in the body [2].

Common postural abnormalities seen in sitting include forward head, protracted shoulders, insufficient lumbar curve, and/or asymmetrical ischial weight-bearing. This can usually be corrected using a properly fitting chair with lumbar support. Isolated lower extremity weakness may result in increased lateral sway, abnormal head and trunk postures, improper weight-bearing, genu recurvatum, and/or high-steppage gait, and so forth. Use of a cane may improve weight-bearing and decrease excessive lateral sway. An ankle-foot orthosis is often used to correct foot drag, prevent genu recurvatum, and eliminate the patient's need to lean forward to watch the floor. Many patients who reported back pain and fatigue from walking are aided by use of custom-made orthotics for the shoes. Patients who have cervical pain or report discomfort through the night may benefit from using cervical pillows and a padded mattress (water, gel, or foam).

The role of exercise in treating patients with PPS is the subject of great controversy. Several investigators report that intensive, nonspecific exercise of partially denervated muscle may actually cause increased weakness [3-6]. One hypothesis to explain exercise-induced weakness in PPS is that the surviving motor neurons sprout to reinnervate a great number of muscle fibers. This produces large motor units that may stress the cell body. After decades of chronic overwork, these motor neurons may not be able to maintain the metabolic demands of all their sprouts. Thus, increased work may actually cause motor units to deteriorate even faster [7].

There are also some reports in the literature of improvement of strength in PPS following standardized exercise programs [8-10]. Einarsson and Grimby reported significant and long-lasting improvement of strength using a standardized isokinetic training program [8]. Feldman reported significant strength improvement using nonfatiguing exercises in weak muscles, though he cautioned against overworking partially denervated muscles [9,10]. More comprehensive research is needed to properly understand the benefits and risks of different exercise strategies in PPS.

It is clear that exercise philosophy in PPS has to be different than it was during the acute phase. Initially, the treatment philosophy was that if you worked hard, despite the pain, you were rewarded by overcoming your disability. Today, this philosophy simply does not work. Because of the evidence suggesting that improper, intensive exercise can actually lead to worsening of the symptoms, exercises should be nonfatiguing and specific. Exercises designed to improve posture should consist of gently stretching tight, overworked muscles combined with exercises to reactivate weak, overstretched muscles by placing the muscle in an optimal position to contract.

Management of the PPS patient must be comprehensive and include consideration of life-style modifications. Rest is every bit as important as exercise. This means that habits must change to assure regular rest periods each day. Modifications of the home and work environments should be considered to reduce mechanical strain and conserve energy.

Brief symptomatic relief of pain may be achieved using physical measures such as transcutaneous electrical nerve stimulation, ultrasound, and/or analgesics. However, the underlying mechanical strain must be reduced to achieve long-term relief. Therefore, use of modalities to alleviate pain should be used in combination with efforts to improve posture and movement.

SUMMARY

Physical therapy management of the PPS patient should focus on restoring postural alignment by (1) use of orthotics and/or assistive devices and (2) exercises that stretch tight, overworked muscles combined with nonfatiguing exercises of weak, overstretched muscles in the shortened range. Part of the challenge of working with patients with PPS is that every patient has a unique presentation depending on muscles affected, body type, and compensatory strategies, which all lead to very unique faulty biomechanics.

Therefore, the key to successful treatment lies in careful evaluation of posture and movement followed by a comprehensive but cautious individually tailored treatment program.

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THE BATTLE WITH BRACING

Another article from the Internet, this one focuses on scoliosis and was written by John R. Fisk, MD, Southern Illinois University School of Medicine, Springfield, Illinois. Dr Fisk's introduction to polio came in the early 1970s when he was a U.S. Army orthopedic surgeon in Korea for two years and saw acute polio firsthand. He travels annually to Central and South America to work with children with polio. The article gives American examples, but the information provided is still relevant to us.

In post-polio survivors the incidence of scoliosis has been estimated at 30%, a rather large number. Factors contributing to scoliosis are the severity of the weakness at the time of the acute illness and the region of the spine affected (the curve location may be dependent on those muscles that are weak). However, there are individuals who have significant spinal deformities with very little demonstrable trunk weakness - only lower extremity problems. The factor important, in this instance, is the age at which the paralysis occurred. The younger the age, the longer the growing period of the individuals and, consequently, the greater the likelihood the progression of curvature.

In post-polio survivors, the iliotibial band, that thick bank of tissue that goes from the side of the pelvis down to the knee, frequently becomes tightened and contracted and can cause the pelvis to tilt. Once a spine is out of balance in a growing individual, scoliosis can progress and develop.

There are different curve types. The classic, paralytic curve not only typical of polio, but also of cerebral palsy, muscular dystrophy, and some of the other spinal cord lesions, is the long C curve. Other curve patterns may also be present in these cases.

A frequently problematic curve is the lumbar curve - the lower curve that causes obliquity (not level) of the pelvis. Pelvic obliquity can impact the level of function. Someone with a pelvis at a 45 degree angle who is a full-time sitter, in reality sits all day on one cheek. It is a significant problem, not only with sleepiness in the skin, but with pressure sores and actual discomfort.

School screening done now for most of our children is a major priority of the Scoliosis Research Society. It began in 1962 in Delaware and Minnesota looking for residual deformities of polio. They soon found that scoliosis was not only due to polio but due to other causes, primarily idiopathic (cause unknown) scoliosis.

In 1956, Jip James, MD, felt that the curve was due to a weak side. If muscles are imbalanced, the spine is going to become crooked. Considered an oversimplification, we now know one of the underlying causes of idiopathic scoliosis may be very subtle spinal cord abnormalities and abnormalities in the balancing mechanism.

How are these deformities treated today?

What about bracing? A modern Milwaukee brace is much different than the old one. Bracing by a new Milwaukee is only effective in individuals who are not yet through growing. Bracing of spinal deformities in a skeletally mature individual as an adult is of real questionable benefit. Certainly, one cannot straighten the spine or prevent it from progressing. However, one may be able to slow that process of progression. Frequently braces simply cover up what is underneath. To illustrate, consider an African lady who wore copper rings around her neck as a ritual of beauty. Women wore this adornment unless they were adulterous, in which case it was taken off. Frequently, the neck was so weak the head fell over and the individual died. *National Geographic* found a lady who had her rings taken off and compared her x-ray with a normal x-ray. They showed that the neck did not change at all. It was only a deformity of the ribs that occurred to give it the appearance of an elongated neck. The point being - this is what braces may do.

A modern Milwaukee brace

Braces have to push on something and when the curve is too severe, they will push on the ribs and deform the ribs much more than they will control the curve. For treatment in growing individuals, we observe curves from zero to 20 degrees, we brace curves between 20 and 40 degrees, and we operate on curves over 40 degrees. The effectiveness of the brace has been better defined within the last 10 to 15 years to be for a very small range of severity, such as curves with proven progression with the above defined limits in an individual with at least two years of remaining growth.

Treatment is quite different, however, in the adult. Traction has been proposed, but is fraught with complications such as osteoporosis and the loss of mineral content from immobilization. These, as well as phlebitis, may result from the prolonged bed rest necessary for the traction.

The development of the halo allows us to apply traction in a sitting position, or even in a walking position, and thus prevent osteoporosis, facilitate pulmonary function, and allow a period of time of convalescence for individuals with severe pulmonary problems.

In a series of patients from Minnesota, halo traction was offered to 20 patients with severe deformities between 90 and 200 degrees. Fifteen had severe pulmonary function with a lung capacity in the range of 25% of normal. Whereas 15 of the 20 opted to try the halo traction, only nine of them were able to go on for surgery. In the nine who were able to tolerate the process, the blood arterial oxygen went from 55 mmHg to 64 mmHg. After surgery, the CO₂ came down from 52 mmHg to 43 mmHg. Vital capacity almost doubled

by improving the chest wall deformity (mmHg millimeters of mercury; measurement of pressure of oxygen in blood).

Who should have surgery?

It is a question about which all of the experts would disagree. Here are some guidelines. Surgery may be indicated if one has curve progression, has pain, or pulmonary compromise. There are many factors that affect pulmonary function so it is a soft indication.

The last criteria is osteoporosis or the softness of the bones. Good bone structure is needed to anchor hooks and wires and hold the spine straight. (My oldest patient has been 55 years. Some will operate on age 60, but it becomes very individual based on bone stock.)

Surgery is much safer than it used to be and every year is getting more safe. A cell saver that will recapture blood after surgery, cleanse it, and return it to the patient is now used, significantly diminishing the need for blood transfusion. Spinal cord monitors are also used during the surgery to help insure that the spinal cord is not injured.

A representative patient

A 45-year-old post-polio gentleman had a curve measuring 90 degrees inside his corset. He knew he had a spinal curvature, but felt quite erect. Without the corset, he could not sit for more than 30 minutes without getting back pain. His pelvis was at 45 degrees. Not knowing whether he was stable, having minimal symptoms, or whether he was progressing and having difficulties, we followed him. A year later he had progressed 18 degrees. We proceeded with pulmonary function studies and other appropriate tests and operated giving him a level pelvis. He will be the first to tell you that it was not easy. He was advised he would be out of work for six months. And indeed he was. He is now a year following surgery and quite comfortable. His vital capacity went from 61% to 73% of normal. His ability to cough and create a good expiratory effort went from 57% to 79% of normal. He no longer wears a corset and, most importantly, his energy and stamina are greatly improved.

Accurate diagnosis is important

In the case of scoliosis, there are other things besides post-polio syndrome, and frequently it is simply degenerative changes in adulthood. The number one thing the medical profession can provide is education and understanding. Then patients can make the decisions for the proper approach to treatment.

Rest with judicious exercise, and in the case of extremity involvement, new orthotics are offering a great deal to post-polio survivors. However, in the spinal deformity area, I am cautious about recommending braces.

There is treatment available

The approach is one of appropriate evaluation, not simply rushing because something must be done.

FAREWELL TO A POLIO IDENTITY

Those of you who attended the Conference last November will certainly remember Esther Keesing-Styles, a delegate from New Zealand. We recently learned from the Post Polio Support Society NZ Newsletter that Esther died suddenly in early March. In *Polio News* Denis Hogan paid tribute to Esther's crusade for polio immunisation, her fund-raising skills, and her selfless donation of large collections of polio papers and videotapes to the NZ Society following her attendance at many international polio conferences. I'll personally remember Esther for her "thought of the day" and "joke of the day" delivered with much gusto at breakfast each morning of our Conference. Esther will be missed by those on the Conference circuit.

(POST) POLIO AWARENESS WEEK: 2 TO 8 NOVEMBER

This year we are supporting the Commonwealth Department of Health and Family Services' *Immunise Australia* program. Our poster will depict people who have disabilities resulting from polio. The message we want to give the community, particularly young parents, is that no matter what we have achieved in life, polio and the disabilities it causes have had a profound effect on us. Had immunisation been available when we were children, our lives would have been quite different.

We encourage all our members to support (Post) Polio Awareness Week. You can do this in a number of ways: by putting up posters and flyers in your local area, doing interviews on your personal story with local press/radio/TV, participating in regional Support Group activities, and so on. If you can help, please return the enclosed form by 30 September.

Remember that the emphasis is on immunisation during the Week. Any interviews you give should include this aspect. We now have an immunisation kit available which has been designed to help you speak knowledgeably on the subject (more details on the kit can be found on page 14). If you would like a copy, please contact us.

To culminate the week, the Network is hosting a gathering on Sunday 9 November at Pecky's Playground, Prospect Reservoir, Prospect (near Blacktown). Barbeques are available, so bring your lunch and turn the event into a giant picnic and social day.

If you have any ideas about activities to hold during (Post) Polio Awareness Week or how to make the picnic day a special celebration, please contact the Week's co-ordinator, Janet Malone, on (02) 9787 1042. Janet would also like to hear from you if you have any public relations experience and would like to lend your expertise to promote the Network.

MOBILE OUTREACH SERVICE

The Independent Living Centre's Mobile Outreach Service is on the road again! The itinerary for September to December is given below. It is advisable to phone the Service closer to the time of the visit to ensure there have been no last minute alterations to their plans. If you require further details, contact Gilleen Hilton and Jocelyn Sloane, Mobile Outreach Service Co-ordinators, on (02) 9808 2233, or on their mobile telephone 019 603 155 when they are travelling.

3 - 11 SEPTEMBER	NORTH COAST
3 - 4 September 5 September 8 - 10 September 11 September	Kempsey Coffs Harbour Port Macquarie Taree
7 - 10 OCTOBER	HUNTER
7 October 8 October 9 October 10 October	Singleton Maitland Charlestown Cessnock
11 OCTOBER	LANE COVE
27 - 31 OCTOBER	SOUTH COAST
10 - 21 NOVEMBER	NEW ENGLAND
12 November	Tamworth
1 - 12 DECEMBER	CENTRAL WEST

AREA HEALTH SERVICES

DIVISIONS OF GENERAL PRACTICE

PROMOTING IMMUNISATION

An Update by Merle Thompson

AREA HEALTH SERVICES

Last year I wrote an article in the Newsletter summarising the responses we have received from the letters we sent in late 1995 to each area and district health service in NSW asking them about the services available for our members. A number of services had promised to forward, for example, rehabilitation plans and to include the Network in consultation processes.

A follow-up letter was sent this year asking specific questions according to their earlier responses and seeking responses from those who had not responded. The amount of additional information gained was not great but there were positive responses from a number of areas, although a number have provided promises to include us in consultations and contact names if we wish to seek more detailed information. I can pass on this information to any member who contacts me.

Central Sydney Area Health Service have provided a copy of their Directory of Clinical Services - a booklet of about 90 pages with a page for each type of service. I also received brochures from Griffith and Goulburn.

In this second letter I indicated that we could assist them with immunisation campaigns in the same way as we have offered to Divisions of General Practice. A few areas have expressed interest.

DIVISIONS OF GENERAL PRACTICE

A letter was sent to every Division encouraging them to include the Network in their local consultative processes and offering our assistance in their immunisation programs. We now have a member on the consultative committee for the Central Sydney Division and have participated in the consultative processes in research projects to assess consumer needs and priorities for services with both Blue Mountains and Canterbury Divisions.

We regularly receive community newsletters from Hornsby/Ku-ring-gai which also includes their Ryde group and invitations to their meetings. We are still looking for someone to actively participate in their programs.

Unfortunately we have not had responses from all areas, including some where we have members very keen to be involved.

Some health services and Divisions are also having contact with the local support group.

All members are requested to keep the Management Committee informed about such contacts. If you write an article, for example, for a local GPs' newsletter please send a copy to the Committee.

Attendance fees

Some programs, particularly when they are part of a research consultancy, pay attendance fees to members of voluntary organisations. In other cases the member or the Network

has to pay the expenses incurred in attendance. In order to handle this inconsistency the Management Committee recently passed a motion as follows:

"When attendance fees are paid the person should be paid expenses with the remainder to be paid to the Network. A record of these amounts should be made and the funds used to pay expenses for other members attending sessions for which no fees are paid. Car travel will be reimbursed at the Taxation Department rates."

IMMUNISATION CAMPAIGNS

We have a number of health services and Divisions of General Practice who have indicated interest in our participating in their campaigns but to date little has progressed.

The following Divisions have welcomed our approach and indicated that they will contact us when they are conducting programs: Blue Mountains, Canterbury, Fairfield, Northern Rivers, St George and also Shoalhaven and New England area health services. Some of these have expressed concern at the falling immunisation rates.

The Deniliquin Division of GPs and the Goulburn Health Service have said that immunisation rates in their areas are high and no programs are needed:

The Macarthur Division of GPs and the Macquarie Health Service have passed the letter from the Network to their immunisation coordinators.

Northern Rivers and Illawarra have published short articles in their newsletters.

The immunisation coordinator in Newcastle has contacted the Network and has been put in touch with the local support group for on-going contact.

To assist members who become involved in campaigns a kit has been prepared providing sections of the *Australian Immunisation Handbook* and copies of articles from newspapers and magazines. A copy will be provided to members who are invited to represent the Network in such activities. You should contact me on 047 58 6637/ fax 047 58 7169. From August the number changes to 02 4758 6637 [but it is still STD from Sydney].

The Commonwealth Department of Health and Family Services recently contacted the Network as we endorse their publication *Understanding Childhood Immunisation*, which is a booklet to help parents make decisions on their child's immunisation, based on accurate information.

We were invited to participate in a meeting in Canberra to discuss a draft of *The Australian Childhood Immunisation Charter*, and were represented by Nola Buck. The draft Charter seeks to achieve:

- greater than 90% coverage of children at 2 years of age for all diseases specified in the standard vaccination schedule;
- near universal coverage of children of school-entry age for diphtheria, tetanus, pertussis (whooping cough), polio, measles, mumps, and rubella;
- near universal coverage of girls and boys by 17 years of age for measles, mumps, and rubella.

We have since approached NSW Health and they are keen for us to support them by promoting immunisation at a grass-roots level, for example, being involved with local immunisation programs and demonstrating to young parents the disabilities caused by polio. We will let you know of further developments in this area.



We would like to extend our condolences to our President Nola Buck and her family on the sudden death of Nola's mother on 16 July.

HOSPITAL ADMISSION FACT SHEET

A few members raised the idea of a "fact sheet" for members to take to hospital. Several members have experienced difficulties because of the lack of understanding of Post Polio among hospital staff. Some are not provided with the help they need to deal with their disability, there is a lack of understanding about problems with anaesthesia and drugs, and some are either given inappropriate physiotherapy or not given the therapy they need. The Committee thought that, as there is so much individual variability, it would not be possible to provide one detailed information sheet. Instead, a card which alerts staff to the possibility of special needs could be developed in consultation with members and rehabilitation specialists at the Post-Polio Clinic.

A smaller version which members could carry in their wallet was also suggested. We have ordered some of the Drug Alert Cards produced by the Victorian Network on behalf of Polio Australasia and will advise on their availability in the next Newsletter.

A draft was shown to members at the last seminar. It is reproduced below and we invite all members to send comments on:

- their ideas on the need for something to take to hospital
- suggested improvements to the wording
- the need for something to carry with you, and if it needs to have different wording

In the meantime all members are reminded **that they must advise all medical and para-medical people that they have had polio and that standard treatments may be disadvantageous.**

THE RESIDUAL AND LATE EFFECTS OF POLIOMYELITIS

The person who carries this card has had Poliomyelitis and now experiences the Residual and Late Effects of Poliomyelitis.

The symptoms can include paralysis, breathing difficulties, muscle weakness, muscle fatigue, joint and muscle pain and general fatigue.

These symptoms can cause difficulties with anaesthesia and drugs.

Some patients will require physiotherapy while hospitalised for unrelated conditions. For others, any physiotherapy, exercise and manipulation can be damaging.

Some may need assistance with personal care.

PLEASE DISCUSS ANY TREATMENT WITH THE PATIENT, RELATIVES AND REGULAR PRACTITIONERS.

Issued by Post-Polio Network (NSW) Inc

President: (02) 9636 6515

Postscript: Since preparing the above draft a member coincidentally wrote to ask us to prepare a card to carry in one's wallet. He was sent a prototype of the above card made into a double sided wallet size version. His suggestions on our draft were to:

- add ATTENTION [at the top]
- add "This person may be in a delicate physical condition and may need assistance" [particularly on the wallet card for use when someone could have been injured]
- include "muscle cramping / spasm" [in the list of effects of polio]
- add "including pain killers and muscle relaxants" after "anaesthesia and drugs".

POST-POLIO POST

Member Joan Clarke is one of those who suggested that the Network needs to develop a "fact sheet" on the late effects of polio for members to take with them to hospital. She recently wrote to us about her latest sojourn in hospital.

Heading for hospital again? Then no matter what your complaint is, if you're a polio survivor take some brochures and articles on post-polio syndrome, for few of today's nurses and doctors know anything about post-polio problems. I did this when recently I was admitted for one more operation on my polio leg. Fortunately my surgeon is well aware of post polio, but not so many of the hospital's staff. It took patience and persistence to ensure that my leg was properly nursed.

Bed pans became a worry. "The other side, please Sister", I'd request. "I can't lift that hip." "Of course you can. Now get up! Nothing's wrong with your hips. It was your knee that was operated on." "Sorry, but I can't move that leg or hip. Please bring it round to the other side." She obeyed, but gave me a look of disbelief.

Starting to walk on a frame was also greeted with scepticism when I walked well in the mornings but was too tired in the afternoon. But the stress syndrome was the difficult one; try convincing a young Sister that the bad news you had about a friend had left your legs useless.

Yet in the few weeks I was hospitalised, I shared a room with three other women who had had polio. They were all being treated for "foot trouble", but had not heard of post polio, and so had never discussed it with their doctors.

How can we help the hundreds, perhaps thousands, of other polio survivors likely to develop post-polio symptoms? Perhaps each post-polio support group could act on the following suggestion. Find two or three people - local doctors, physios, occupational therapists etc - to read, study and condense all new material on post polio, so we can do copies to circulate to our local hospitals, clinics, doctor's surgeries, libraries, newspapers - everywhere it can be displayed.

People should know that polio has not disappeared. It still exists in countries where poverty prevails, and can easily be brought into Australia by our travelling population and other tourists, particularly when so many children are not immunised.

Member Clem Johnstone heeded my request for people to share their stories with us and sent me the following which tells of his encounter with polio.

I always look forward to correspondence from you - thank you ever so much. I am now 78 years going onto 79. I contracted polio in 1945 whilst still serving in the RAAF.

After intensive care at the Infectious Diseases Hospital at Fairfield, Melbourne, I was admitted to Heidelberg Military Hospital in Melbourne where I had thirteen months of very good care. So over fifty years I have had several operations, and now suffer lots of arthritis and PPS, with the aid of my wheelchair and very good wife who has stood by me at all times. The Department of Veterans Affairs has also always been very good to me.

Thanking you once again. Wishing you all the best.

