Editor’s Corner

Welcome to our regular readers, as well as to new members. There’s a mixed bag again in this issue, which I hope you’ll enjoy. My post bag has been a bit thin recently. I would love to publish your stories and thoughts, brickbats and bouquets. Please write soon!

Our next Seminar will be held on Saturday 14 June. We have obtained permission to republish a timely paper on Myofascial Release, the topic of the Seminar. You will find this paper, which explains what myofascial release is, on pages 2 and 3. If you are intrigued by the treatment described, come along and hear a qualified practitioner, physiotherapist Elspeth Ferguson, give a presentation on the topic. Elspeth will be introduced by member Terry Fletcher, who first heard of myofascial release from Dr Stanley Yarnell at our recent Conference and subsequently sought out someone who could provide such treatment to her. Full details of the Seminar are given on page 3.

I have at last finished editing the Proceedings of our November 1996 Conference Living with the Late Effects of Polio. If you attended the Conference, the final papers will soon be sent to you at no cost. (If you could collect your copy at the Seminar on 14 June it will save us postage.) If you were unable to attend the Conference, you don’t need to miss out on the valuable information imparted by polio survivors and health professionals alike. The Proceedings contains over 140 pages packed with facts, advice, tips, personal stories and much more. Please complete the enclosed Order Form to get your copy. 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.

Included with this Newsletter is your Membership Renewal Form for the period 1 July 1997 to 30 June 1998. If you do not receive a renewal form, this means that you are already financial for the coming year. Your address label will confirm this. Please make life easy for our Treasurer by only paying if you need to, and by returning the Renewal Form with your subscription. Help your Network to continue its vital work by renewing promptly. Thank you for your continued support.

In the Australia Day Honours List, long-term member and supporter Hazel Atkinson was awarded the Order of Australia Medal for “service to people with disabilities and special needs in relation to access to independent living”. On 2 May Hazel was thrilled to receive her medal from Sir Gordon Samuels, the Governor of NSW, at Government House. Even her recently broken arm couldn’t dampen her excitement. Hazel tells me it was a glorious day and a great honour to receive such recognition. The Management Committee congratulates Hazel on her achievement which was so richly deserved.

The article "Myofascial Release: Perspective of an Informed Consumer" is copyrighted and may not be reproduced without permission from Gazette International Networking Institute. 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.
As the recipient of over 50 myofascial release treatments for my polio-related symptoms administered by Steven Moreau, MS, PT, I want to discuss the topic from the perspective of an informed consumer. I have paraphrased and quoted from materials prepared by Moreau.

Overview of Structure and Function of Fascia

Someone has said that if all tissues except fascia were removed from the body, our external appearance would remain relatively unchanged. This is because fascia, a three-dimensional network of connective tissue, extends without interruption from head to toe. It encircles, separates, connects, supports, communicates, and remembers. In general, fascia fibers are arranged longitudinally, although there are four major extensions of transverse fibers. Fascia plays a role in many areas of interest to polio survivors, including postural symmetry and balance (static and dynamic), support and shock absorption, cellular respiration, and metabolism. It is intricately involved with the maintenance of health at the system and cellular levels and influences immune function (Travell, 1983).

There are three layers of fascia: superficial, deep, and subserous. Superficial fascia, located just below the skin, surrounds structures found near to the surface in our bodies, including capillaries and nerves (including pain receptors). Deep fascia surrounds and separates all muscles and internal organs. Subserous fascia covers internal organs including the brain and spinal cord.

Fascia can be injured in a number of ways, including by physical and emotional trauma and long-term overuse. When fascia is injured, it becomes restricted; the restriction then spreads like a pull in loosely woven fabric, forcing the body out of alignment and into postures and ways of moving that are inefficient, energy consuming, and fatiguing (Becker and Seldon, 1985). Further possibilities of increasing imbalance include muscle spasm, pain, and increased potential for degenerative changes.

Changes in Fascia Related to Polio and Post-Polio Syndrome

Moreau provides us with a hypothetical example of how fascial changes could affect a person who has had polio. A polio survivor is fatigued. In response to this fatigue, movement creates asymmetry. The fascia provide support by tightening, causing more asymmetry. Muscle spasms occur as a protective reaction, compressing pain receptors in muscle and fascia in the process. The muscle spasms increase the pain and asymmetry. Fascial restrictions begin to spread affecting other areas of the body, increasing the stress on joints. If the fascia is not treated, chronic pain and degenerative changes may begin.

Myofascial Release Treatments

Myofascial release is a treatment for restrictions in fascia. To restore the body’s natural equilibrium, the therapist gently applies a tractioning or compressive force with his/her hands to any part of the body that is out of balance. The changes in fascia resulting from such treatment include lengthening elastic components, increasing mobility of tissue layers, increasing fascial tissue glide, and decreasing abnormal proprioceptor (movement and body position) activity. Sensations reported by people receiving myofascial release include warmth, tingling, increased or decreased
pain, emotional changes, and profound relaxation. My treatments have been restful and pleasant, with symptom relief either immediately or within an hour of treatment. Apparent long-term changes include increased range of motion, decreased frequency and duration of muscle spasms, and increased endurance.

References


If you would like to hear more about myofascial release from an Australian practitioner, come along to our next ...

Seminar: Myofascial Release

Date: Saturday, 14 June 1997
Time: 1:00 pm - 2:30 pm (followed by afternoon tea)
Bring a packed lunch to eat from 12:00 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: The Northcott Society
2 Grose Street, Parramatta
Ample parking is available in a 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.

Our guest speaker will be physiotherapist Elspeth Ferguson. Elspeth studied for her Diploma in Physiotherapy in Sydney from 1973 to 1975, and completed her registration year at Royal Newcastle Hospital. The next three years were spent working in Hong Kong as sole Physiotherapist setting up a department in a TB hospital which was changing to a rehabilitation hospital. She returned to Sydney in 1980 to convert her Diploma to a Bachelor of Applied Science (Physio) while working at Croydon Rehab. From there she went to take the Charge position at Blacktown Hospital, where she worked in all areas. During her 10 years there, Elspeth did extra courses in backs, necks, peripheral joints, women’s health, neonatal and paediatric physio, arthritis, burns, and also conducted prenatal classes.

November 1992 saw a move to Texas, USA, for further work experience over three years. Here she had her first introduction to Myofascial Release (MFR) Therapy and Craniosacral Therapy which she has found to be the most effective and holistic treatment approach she has encountered, even though it is “different”. In the USA Elspeth attended five courses in MFR run by physiotherapist John Barnes, and can use these techniques alone or in conjunction with other physio techniques. Elspeth is currently in her own practice at home in Toongabbie, and with two young children to look after we are most grateful to her for giving up a Saturday afternoon to be with us. We hope to see you there.
AN APPROACH TO THE PATIENT WITH SUSPECTED POST POLIO SYNDROME

This article was originally written by Dr Warren Anderson and the Medical Advisory Board of the Post Polio Program, Easter Seal Society of Oregon in the USA. Although aimed at health practitioners and with an American slant, this article, obtained from the Internet, has a lot of useful information for we Australian polio survivors as well. You may like to give a copy to your doctor, especially if s/he has only recently started investigating your post-polio difficulties.

Polio survivors are at risk for the occurrence of certain physiologic changes in the nervous system which result in a characteristic set of symptoms now known as Post Polio Syndrome. In addition to these unexpected physiological changes there are anticipated complications such as arthritis, scoliosis, and entrapment syndromes that frequently accompany paralytic conditions. These anticipated complications are not the problems that distinguish PPS from other diseases of the nervous system. Post Polio Syndrome (PPS) is a major chronic illness and one which poses unique problems to its survivors and their physicians.

No Diagnostic test exists for PPS, so clinical criteria must be used to establish the diagnosis. Many Physicians lack training in the diagnosis and management of a syndrome only recently acknowledged as existing. Patients are often uncomfortable with physicians they feel do not understand their problems. They also fear increased disability, often at the same time they are coping with limitations of aging. Patients are often trapped in a "conquer the disease" mentality derived from the experience of recovering from the acute episode an average of 25 years earlier. This is incompatible with the lifestyle adjustments necessary for optimal results in PPS rehabilitation.

INTRODUCTION

Definition of Post Polio Syndrome

An otherwise unexplained constellation of symptoms which may include weakness, fatigue, pain, heat or cold intolerance, and swallowing, breathing, or sleep disturbance developing in a patient who had paralytic polio. Post Polio Muscle Atrophy (PPMA) has been used as the label for the above symptoms when they include progressive muscle atrophy.

Scope of the Problem

1987 National Health Interview Survey estimated 1.63 million American polio survivors (=0.625% of population), 50% with some Post Polio Syndrome symptoms.

Diagnostic Criteria

1. PPS is a diagnosis of exclusion and should be based on a thorough history and physical exam.

2. Evidence of prior paralytic polio: via EMG, an appropriate history, or characteristic residual atrophy.

3. Period of apparent stability before any new symptoms. New symptoms may often be seen after an illness or injury.
4. Exclusion of other conditions (especially motor neuron diseases and overuse syndromes).

PATHOLOGY: PHYSIOLOGIC AND CLINICAL CONSEQUENCES

Extensive Neuronal Involvement in the Acute Polio Infection

1. The extent of central nervous system infection by polio virus is not well appreciated. Infection is far more widespread than anterior horn cells alone. Often anterior horn cell infection is largely subclinical due to residual capacity of uninfected and surviving neurons. Infection outside the anterior horns is likely to be largely subclinical also, but may help to explain the disabling symptoms of fatigue and pain which are subjective and controversial (because the physiologic basis is uncertain).

2. Ninety-five percent (95%) of motor neurons are infected in an average acute infection, with a 50% neuronal fatality rate.

3. There is frequent segmental involvement, accounting for the lack of symmetry of weakness.

4. In addition to the anterior horns in the spinal cord, infection involves intermediolateral horns and dorsal root ganglia.

5. Infection also involves motor cortex, hypothalamus, and globus pallidus, brainstem nuclei, reticular formation, cerebellar roof nuclei, and vermis.

Motor Unit Remodeling in the Post Recovery Phase

1. A normal quadriceps has, on average, 200 muscle fibers/anterior horn cell and a normal anterior horn cell can adopt as many as 1,000 orphaned muscle fibers.

2. Over 50% of motor units may be lost without symptoms. (Normal walking uses only 15-20% of maximum muscle strength.)

3. Clinical improvement occurs acutely through recovery of mildly affected neurons, collateral sprouting, and strengthening (hypertrophy) of intact musculature.

4. Increased demand on surviving motor units results in increased firing frequency which in turn produces a change in fiber type to predominantly aerobic “slow twitch” fibers with increased vascularity.

Decompensation Then Produces Post Polio Syndrome

While a single underlying etiology for PPS has not been proven, several theories exist:

1. There is an increased metabolic burden on surviving anterior horn cells (even in asymptomatic muscles) as they direct more muscle fibers to contract, more often, to achieve the same force of contraction. This leads to anterior horn cell fatigue and can lead to premature metabolic injury, perhaps even cell loss. Fatigued neurons may be unable to continue to trophically support as many muscle fibers. The collateral sprouts to some muscle fibers will degenerate. The strength of these muscle fibers will be lost to the motor unit, and a spiral of decline may set in. This mode of decompensation augured by fatigue, may be anterior horn cell based. This appears not to be a static process and there may be dynamic denervation and reinervation.

2. Another mode of decompensation is muscle fiber based: Rapidly firing muscle fibers produce more lactic acid which may not be adequately dissipated. This is especially
true with any degree of isometric contraction. Muscle fiber fatigue may, lead to muscle fiber injury, lost function, and a spiral of decline.

3. Any increase in mechanical load (such as would result from increased weight or increased physical activity) or decrease in force generating capacity (such as would result from inactivity following illness or injury) may trigger metabolic failure in motor units or in muscle fibers functioning close to their capacity.

4. The resulting relative weakness may lead to joint and muscle misuse and overuse. This may lead in turn to both arthritis and overuse syndromes.

5. In addition to anterior horn cell and muscle fiber modes of fatigue, central fatigue may also be a factor. Polio virus infection of the motor strip and the reticular activating system is well described. A working definition for central fatigue is: “Increased mental effort necessary to perform a fixed amount of muscle contraction”. This is very much how Post Polio Syndrome patients describe their feelings of fatigue, many report hitting a “post polio wall”.

PATIENT PRESENTATION

Prime Symptoms

A common presentation is a polio survivor who previously had lower extremity involvement in a well defined polio episode. The patient may have restricted ambulation from hiking or jogging, lived a sedentary life, and did not feel disabled. After a period of relatively stability he or she may begin to notice unusual fatigue and discomfort and may further restrict activity. Denial of decreased functional capacity may lead to a crisis as the patient can no longer can meet occupational, social, and family commitments. Persistence and attempts to continue at a previous activity level may lead to a downward spiral of decreasing functional capacity with resulting depression and despair. On examination, relative obesity may be present and weakness is easily demonstrated, often in the “good” leg; limbs considered unaffected are often subclinically affected with polio and may present with “new” polio.

A statistical summary of the clinical characteristics of several series of PPS patients is as follows:

1. Fatigue, Pain, and Weakness are almost always present. Fatigue (89%); Pain in Muscle or Joint (86%); New weakness (83%) in previously symptomatic (69%) or asymptomatic (50%) muscles.

2. New Atrophy (28%); This equates to Post Polio Muscular Atrophy (PPMA).

3. Activities of daily living difficulties (78%) = functional loss. Walking (64%); Climbing Stairs (61%); Dressing (17%).

Additional Presenting Problems

1. Pulmonary dysfunction

Patients with Post Polio Syndrome may suffer from weakness of the breathing muscles, namely the diaphragm and ribcage. Occasionally, this can be severe enough to cause symptoms of dyspnea on exertion and even at rest, poor clearance of respiratory secretions increasing the risk of pneumonia, and elevations in the resting arterial CO2 level. Measurement of pulmonary function tests in these patients usually shows a significant restrictive pattern (small lung volumes) on the basis on neuromuscular
weakness.

If respiratory muscle weakness is severe enough mechanical ventilation may be required. Small mechanical ventilators have been developed which deliver breaths through a comfortable plastic nose mask. This is often performed while the patient is asleep at night and results in improved daytime function.

2. Sleep Disorders

Patients with Post Polio Syndrome have a high incidence of sleep disturbances with poor sleep quality and frequent awakenings which may be due to several factors. However, the most important etiology to rule out is central, obstructive and mixed sleep apneas. Nocturnal hypoxemia and hypercarbia can lead to worsening of daytime function of the breathing muscles. Nocturnal non invasive ventilation can be used in these patients to improve sleep quality and reduce symptoms of daytime sleepiness, and perhaps improve daytime respiratory muscle function.

3. Dysphagia

Many PPS patients reported some new difficulty with eating or swallowing more commonly in those with bulbar polio. Video fluoroscopy has been used for evaluation and has frequently revealed pharyngeal constrictor weakness. Laryngeal penetration and loss of the cough reflex may occur without symptoms, suggesting an underestimation of the presence and severity of dysphagia in this population. Many patients have already employed compensation such as altering diet, cutting solids into small pieces, chewing it thoroughly, taking small sips of liquids, eating slowly, and using postural maneuvers. Most patients with dysphagia also experienced some progressive speech difficulty such as increased hoarseness, weakness, or slurring.

4. Cold intolerance (29%)

Limbs may be cold and cold exposure produces weakness. This is thought to be due to intermediolateral column involvement resulting is vasoparesis, venous pooling, and excessive heat loss.

5. Degenerative arthritis

A joint that is biomechanically disadvantaged may develop degenerative arthritis.

6. Social and psychological problems

Long term disability and denial may result in social and psychological problems.

Past History

1. Average age of polio onset is 7 years. Median time to maximum recovery is 8 years. Median period of stable neurologic and functional status is 25 years. Median post polio symptom duration before patient presents for evaluation is 5 years.

2. Variables associated with shorter interval to PPS: greater severity and greater age.

3. Initial symptoms are most frequent in the lower limb most affected in the acute illness. (Upper extremity weakness is easier to compensate for without overuse resulting.)

4. The onset is usually insidious but is frequently precipitated by injury, illness, bed rest, or weight gain.
EVALUATION PROCESS

Identify Areas of Dysfunction

1. The history is especially useful in identifying fatigue, dysphagia, sleep disorders, and alteration in activities of daily living.

2. The Neurologic exam will identify atrophy or weakness and verify that reflexes are not increased. Pay special attention to the “good” limb as significant weakness may be present in which the patient has never been aware. With leg muscles, functional tests must be used because manual testing may not detect quadriceps weakened to 30% of normal even though this is sufficient strength for routine daily activities. Seek a mechanical advantage in manual muscle testing: Test the triceps or quadriceps with the elbow or knee flexed more than 90 degrees. Test the psoas in the supine position.

3. The general physical exam and biomechanical exam note obesity, joint deformity, overuse syndromes, and scoliosis.

4. Electromyography may be requested when needed to document previous anterior horn cell disease (especially when the previous history of polio is in doubt). EMG can also be used to rule out other neuromuscular pathologies or to identify subclinically involved muscles.

5. CK elevation may be seen in patients but may not correlate with progressive weakness.

Formalize Treatment Goals

After the diagnosis of PPS is established, a patient conference is a convenient way to formalize treatment goals and begin patient education. These areas should be addressed:

1. Lifestyle Modifications

This item is the “sine qua non” of all attempts at successful management of PPS. At the time of formal diagnosis, patients are often desperate, yet imbued with a belief in their own ability to overcome their disability through the “no pain, no gain” approach. This approach may have served them very well after their acute attack of polio many years ago but is now actually self-destructive. Persistence in this approach of “overcoming” illness has led to a spiral of deteriorating function and frequently a parallel decline in self worth. Patients must understand the concept of “living with” PPS in order to lead the fullest life possible. An understanding of the need for lifestyle modification is rarely achieved at the first visit and is often best reintroduced by a knowledgeable Occupational or Physical Therapist and reinforced and monitored at subsequent physician office visits.

2. Increase Muscle Capacity

(a) Muscular capacity can be increased by achieving increased strength or endurance. Strength can be increased through isometric exercise. However, muscles must be carefully selected for isometric exercises. Some muscles will already be functioning at their maximum. Exercise may actually have a deleterious effect by forcing these muscles beyond their metabolic capacity and producing injury.

(b) Endurance may be increased, susceptibility to fatigue decreased, and long term deterioration minimized through appropriate exercise supervised by a physical therapist experienced with post polio patients. Almost all patients have initial difficulties with exercise programs resulting from overdoing. They may also equate fatiguing daily activities (which challenge the weakest musculature and do not provide an effective aerobic training level) to
exercise. This can be an instructive opportunity for the patient in understanding the "Lifestyle modification" and to experience its benefits.

Goals in aerobic exercise are:

- Educate the patient to avoid potentially harmful exercise-induced fatigue. A reasonable approach would be to establish the level of peak performance by patient history. Then start at 50% of peak performance and slowly increase performance as tolerated.

- Select exercises which can create a training effect in the patient with weakened, atrophic musculature and overuse syndromes. Exercise intervals with intervening rests are necessary, just as is pacing of daily activities. A knowledgeable Physical Therapist can be crucial to this aspect of management.

- Muscle capacity can also be increased by bracing, orthotics, or other aids which extend, amplify or substitute for muscles.

- Pharmacologic treatment of fatigue: Some medications seem to raise the threshold for fatigue. These observations are, as yet, anecdotal and await confirmation from clinical trials.
  
  1. Amantadine: up to 100 mg BID as tolerated.
  2. Deprenyl: up to 5 mg BID as tolerated.
  3. Meston: up to 60 mg TID when careful monitoring is available.

Medications for the amelioration of fatigue must be understood as aids which can give a running start to the rehabilitation process. However, if they are perceived by the patient as a form of curative treatment, they will only forestall the day of reckoning.

3. Decrease Muscle Load To Less Than Muscle Capacity

(a) PACING of activity is the logical consequence of a successful LIFESTYLE MODIFICATION. Implementing of PACING requires that patients identify for each of the activities of daily living the length of time they may participate before experiencing fatigue. They must then break up their activities into smaller modules of time, each of which is of less duration than the time required to produce fatigue. A corollary concept to PACING is ENERGY BUDGETING which imagines that one has a fixed expenditure of energy for each day and that this sum should be "spent" on activities of the highest personal priority. (Exceeding this daily limit may be conceptualized as spending principle or acquiring debt but probably correlates to metabolic injury of the motor unit through overuse.)

(b) Other means of decreasing muscle load are diet when overweight, use of orthotics to improve mechanical efficiency, use of wheelchairs or scooters to save energy expenditure, and treatment of chronic overuse syndromes.

4. Treat Specific Complications

(a) Attention to specific complications such as dysphagia, pulmonary dysfunction and sleep disturbances may require specific referrals. The goals of these referrals can be addressed with the patient at this first conference.

(b) Functional consequences also result from overuse syndromes which can lead to joint deformity. Physiatry consultation can be helpful here and orthopedic intervention is occasionally required. Evaluate need for orthotic prescriptions (i.e., splints, braces, AFO's).
(c) Somatization, depression, anxiety, and self worth problems may occur as capacity decreases. Referral for counseling should be considered (MSW, psychologist) or polio support group (see reference section).

(d) Evaluate and/or modify work duties through referral to occupational therapist or vocational counselor.

Prognosis

Patients often present during a period of decompensation. Decompensation may be caused by even slight embarrassment in strength due to inactivity or injury superimposed upon aging. It may also result from slight increase in muscular work resulting from weight gain or increase in activities. In either case, a spiral of deterioration may result from potential overuse injury to the motor unit and subsequent decrease in functional capacity can result. Patients may easily become fearful and depressed at this ominous decline in their previously stable, if compromised, neuromuscular status.

It is important to clarify for the patient the difference between deterioration in function and deterioration from disease progression. In fact, there is little evidence that any loss of function experienced by PPS patients is due to progression or recurrence of polio virus infection. If patients can understand that opposing forces of muscle strength versus muscle load are acting near a capacity threshold, they will be quicker to accept PACING concepts, to employ an appropriate exercise program, and to utilize other elements of rehabilitation. In most cases, this will allow the patient to return to or approach the previous functional baseline. It is not difficult for patients to then minimize deterioration in function over the years by:

1. Achieving an optimal balance between muscle strength and endurance (achieved and maintained by exercise) versus muscle burden (resulting from body weight, mechanical inefficiencies, and activity level).

2. Utilizing PACING and restriction of activities after the point of fatigue so that muscle work is kept within the limits of muscle capacity and decompensation does not occur.

3. Gradually decreasing total daily energy expenditure over the years much as a non PPS individual might do. This rarely results in much loss of individual activities or functions, only in the amount of each that is performed each day.

RESOURCES IN PATIENT MANAGEMENT

The patient with PPS is best served by having a physician who has experience evaluating post polio symptoms, formalizing treatment goals, and making the appropriate referrals such as those listed below:

Neurology Consultation

When the Diagnosis is in question.

Physiatry (Physical Medicine and Rehabilitation)

A Physiatrist is a physician with expertise in the orchestration of the rehabilitation process. Especially when disability is severe, complex, or when biomechanical problems are prominent, physiatry consultation can help with the initial planning and selection of specific exercise programs, physical therapy, orthotics, and adaptive equipment.
Physical Therapy

A Physical Therapist who is experienced regarding PPS will be of tremendous value in introducing and customizing the lifestyle modifications and in introducing the useful concepts of pacing and energy budgeting. Physical Therapists can also screen for inefficiency in movement resulting from deformity or weakness, assist in establishing your patient on a safe exercise program, and monitor for the almost inevitable initial over indulgence in that program.

Occupational Therapy

Occupational Therapists are trained to assess the home environment and the patient's daily activities in order to restructure tasks, introduce mechanical aids like grab bars, and provide devices such as sock lifters which make possible physical activities otherwise compromised by disability. Instruction in PACING of routine daily activities and associated lifestyle modification can also be provided by an Occupational Therapist.

Speech Pathology

A speech pathologist can help in the evaluation and treatment of swallowing and speech problems.

Pulmonology

A Pulmonologist can evaluate and manage respiratory dysfunction and sleep dysfunction.

Psychology

A psychologist or MSW can evaluate and counsel regarding reactive depression, coping strategies, pain management and life style adjustment. This is especially important to help the post-polio survivor deal with the "re-emergence" of a neuromuscular disorder they thought had been previously conquered.

Support Groups

Local education/support groups meet on a monthly basis in various locales, offering education, support, and social opportunities for polio survivors and their families.

Other

Orthopedics, nutrition, and social work referrals for evaluation will occasionally be useful in specific circumstances.

BIBLIOGRAPHY

SUPPORT GROUP CO-ORDINATOR’S REPORT

This regular feature has been missing from a few issues due to the pressures of space associated with our recent Conference. Thanks to Nancye Bonham, Support Group Co-ordinator, for compiling the following report.

February 1997

This is my first report for the New Year. Hope you all had a great Christmas. Thank you to those who sent me Christmas cards, your kind thoughts are appreciated. Support Groups were in recess during the holiday period, so there isn’t a lot to report.

Hunter Area

Sent a review of their meetings in 1996. With Barbara McCormack as Convener (phone: 049) 51 1647, they had a very busy and productive year. Their plans for this year include a visit to the Coffs Harbour Group.

ACT

Had their first meeting for 1997 on 1 February. Maureen Kelleher gave an overview of the Conference in November and was duly thanked for an excellent presentation. Brian Wilson has expressed the wish for members of other Groups to visit them. Contact Brian on (06) 293 2747 if you would like to take up his kind offer.
I would like to see other Groups involved in exchange visits. If you would like me to arrange them, let me know (phone: 043) 96 1580.

Central Coast

Had a great response from Polio Awareness Week, with several new members attending their meeting. Convener Shari Brewster has moved to Berkeley Vale (phone: 043) 88 3304 and has found a better venue for meetings in the Neighbourhood Centre; they’ll be held on the last Thursday each month at 10:30 am. Speakers are being approached and the response is very good. A Medical and Health Register (along with other resources to help members in every aspect of daily living) is being compiled and should be ready in the near future.

Other News

I would like to welcome two new Convener: Dorothy Robinson, 167 Mt Keira Road, Mt Keira 2500, telephone: (042) 26 6221 (Wollongong Support Group), and Jeanne Parke, 66 Leawarra Avenue, Barrack Heights 2528, telephone: (042) 95 1341 (Illawarra/Warilla Support Group). Anyone wishing to join either Group, please contact Dorothy or Jeanne. Finally, I hope that more Convener will join my “regulars” and let me know how they are going.

March 1997

Central Coast

With a new venue, this group is doing very well. Membership in this area has grown to 22, with 12 attending the first meeting at the Berkeley Vale Neighbourhood Centre. Convened by Shari Brewster, it was an informal meeting with members - new and old getting to know each other. Shari is planning to have speakers at some future meetings. Recently Shari and I were invited by the Central Coast Division of GPs to attend a meeting of the health reference group at Gosford. We were also asked to write a small piece for the their newsletter to explain what the Polio Network does, who we are, and to ask any doctor in the area who would be interested in learning about and treating the late effects of polio to contact us. So far we are still waiting for the letter to be printed; the newsletter is bi-monthly so its too early to expect any results. Also, thanks to this active group of GPs, Shari has been asked to present a 10-minute paper on the late effects of polio for a public meeting at Mingara Sports Centre, Tumbi Umbi, 30 April 1997. The main topic of the evening is vaccine preventable diseases.

Hunter Area

I visited this group again and heard speaker Kerry Thorley, Toronto Community Health Centre, who demonstrated a new concept in “transferring”. Kerry is a very capable young lady and a pleasure to listen to. Kerry told the meeting she has learnt so much from the “polios” and is very grateful to them. I will find out details of the transfer aids, and the company that makes them, and pass the information onto the Editor.

Other News

I have been in touch with all the conveners again, unfortunately some of them are experiencing ill health - hope they are on the mend now. Congratulations to Maureen Kelleher of the ACT who is getting married soon and will move from the area. I am sure she will be sadly missed by the ACT Support Group. Moving home is in the air - Beverley Baker is also relocating - hope all goes well for her. Bye for now.
SUPPORT GROUP DEVELOPMENT PROGRAM

In May 1996 the Management Committee submitted a comprehensive funding proposal to the NSW Ageing and Disability Department. The following extracts from the proposal should give you an idea of what we were aiming to achieve should the funding be granted.

Regional Support Groups were first established by the Network during 1992. In doing so, the Network sought to provide rural and remote members with opportunities for information sharing and mutual support which were otherwise unavailable. Support Groups were originally set up to be small intimate groups of people who have had polio, convened by one of their number who has group leadership and possibly counselling skills. The members meet as frequently as they feel the need. The Group develops in whatever way satisfies its members, but the emphasis always remains on mutual support and the pooling and sharing of information and experiences. Where distances are too great for members to physically travel to meet in person, telephone support groups have proven to be a viable option. As well as the advantages derived from being members of the Network, it has been shown that participating in local Support Groups enhances the quality of life of polio survivors.

Over the last four years, the Committee has done what it can to nurture the groups and encourage the development of new ones. Despite the Committee’s best efforts to strongly underpin the Support Group structure, it has become increasingly apparent as the groups mature that the conveners require more support than it is possible to give from the remoteness of Sydney and with the Network’s limited financial resources.

[Some] groups have someone willing to convene them, but the convener lacks the knowledge or training to get the group up and running. It is hard for such conveners to maintain their enthusiasm when they are not making contact with polio survivors. On the other hand, the Network receives many requests from members to join a Support Group, but since no-one has expressed willingness to convene a group in their area, there is little that can be done in the short term. Identifying suitable people to act as conveners, who have the time and energy to do so, and then training and supporting them as the Groups get established is extremely difficult for a voluntary organisation with limited resources.

As regular readers will be aware, we were later advised that funding was not available for our proposal; all surplus funds had been directed towards the “transition” (or quality improvement) of existing (already funded) services. We have now re-submitted our proposal, but are still not hopeful that this worthwhile project will receive funding. In the meantime, we feel we cannot wait forever to provide better support to our rural members.

Over the last twelve months your great support of our raffle and other fund-raising ventures means that the Network is in the best financial position it has enjoyed since its foundation. The Management Committee believes that we are now able to put some financial resources into stage one of a Support Group Development Program. A feasibility study will be held to determine what can realistically be achieved and what it will cost. A Sub-Committee has been formed to undertake this study. The Terms of Reference require, in part, that the feasibility of the Network conducting a training and support program for Support Group Conveners be determined. The Sub-Committee will consult with Support Group Conveners, identify the aims and expected outcomes of such a program, and outline the general content of the training envisaged to be conducted. A costing for conducting training over a twelve-month period is to be provided, and training locations are to be identified. The Sub-Committee is to report the results of its study to the Management Committee within three months. The Committee will consider the recommendations made and decide what we can achieve with available resources.
I recently received the following letter from Monika Kaatzke-McDonald, Senior Speech Pathologist, Concord Repatriation General Hospital, where she co-ordinates the Swallowing Clinic. Monika has experience in the assessment of polio people at this Clinic. She gave a presentation at our Conference Living with the Late Effects of Polio, held in November 1996, on the subject of Dysphagia and Post-Polio Syndrome (dysphagia is difficulty in swallowing; in severe cases it can cause choking and aspiration pneumonia). Her workshop session was well attended and generated a lot of interest amongst Conference delegates.

"During your last Conference I became aware of the absence of a co-ordinated service for the assessment of voice and swallowing for people with post-polio syndrome. Following a request from one of your members, I was able to co-ordinate the involvement of various health professionals for assessment. Following the success of this approach, I would like to let you know that we can now offer a voice, swallowing and respiratory assessment. This involves speech pathologists, physiotherapists, ENT and respiratory personnel. The program would therefore involve:

- respiratory function test (Respiratory personnel)
- review of vocal cord function (ENT)
- voice analysis including respiratory support (Speech Pathology and Physiotherapy)
- swallowing review / modified barium swallow (Speech Pathology)

I would appreciate it if you could pass this information on and hope that this may provide a valuable service."

To utilise this service, first get a referral from your doctor and then contact the Speech Pathology Department at Concord Hospital on (02) 9736 7449 and say that you wish to have a post-polio assessment carried out. It is great to see health professionals take the initiative like this, so if you feel that this new service would assist you please take advantage of it.

**BITS ‘N’ PIECES**

- Member Ivy Smartt rang to let me know that if you are looking to purchase a second-hand electric scooter or wheelchair, try browsing through *The Trading Post* in the rather strange (to us) category of *Beauty, Fitness and Medical*. Ivy says the brands are listed within this category in alphabetical order. Apparently member Alicia Lee has since asked *The Trading Post* to reclassify these items under a more appropriate *Disability Aids and Appliances* category, but in case they can’t see our point at least you now know where to start looking. Thanks Ivy!

- Author, Carol Mara, who is writing a book which takes in the polio epidemics of the early 50’s wishes to contact former patients of The Royal Far West Children’s Hospital at Manly (late 40’s to early 50’s) and who have memory of their experience.

She can be contacted at:

Carol Mara  
RMB 5331 Wattle Tree Road  
HOLGATE NSW 2250

or by telephoning (043) 67 6178 and she will ring you back.
Reunion - Nepean District School for Crippled Children. The Nepean District School for Crippled Children started operating in May 1962. In 1988-89, students were slowly integrated into local public schools and by 1993 the School had closed its doors. Now, a group of former students have come together and formed a Reunion Committee and are seeking out students, teachers, support staff and parents involved with the school over its 31 year history. The date for the reunion has been set for Saturday 18 October 1997 (starting at 10:00 am and finishing at approximately 4:00 pm) at The Northcott Society's Headquarters, 2 Grose Street, North Parramatta - the former Northcott School. With over 100 people already indicating their interest (some will be travelling from Perth and Queensland), the reunion is set to be a major social event. It will be a great opportunity to meet old friends, teachers and acquaintances. The cost is $15 per head to cover catering costs. If you are interested in attending, please call Lynne on (02) 9318 2813 for more details.

This may sound like obvious advice but ... *don’t forget or neglect to tell all the health care professionals that you come into contact with (your GP, specialists, physiotherapists, nurses etc) that you have had polio. This is especially important if you go into hospital.* You cannot assume that because you know you have had polio and are aware of the limitations it causes, that everyone else will understand as well. The problem is, we and our families are so used to living with polio that we sometimes forget that the extent of our disability may not be obvious to others. We have to keep in mind always the need to inform and educate people about the late effects of polio on us.

L-CARNITINE UPDATE

*Thanks to Joan Mobey, Convener of the Sydney Inner West Support Group, for providing the following information.*

The Inner West Support Group meets at Five Dock and at the April meeting we were visited by Carmel and Greg Jarmain. Greg’s father John is a Network member. Carmel is a naturopath and Greg is the proprietor of the local health food store. They gave us the following information.

The therapeutic dose of L-Carnitine is much higher than can be obtained through food. It is heat susceptible and well-cooked meat contains little. World-wide, especially in Europe, many tests have been done as Carnitine is widely used in athletics. In continental Europe (not the UK) it is in common medical use, particularly for heart conditions. It has been found to be very useful for treating angina. People who have had polio may show observable muscle improvement when taking the therapeutic dose of L-Carnitine. When L-Carnitine is ineffective for polios, it may be because they are lacking in certain co-factors, such as vitamin C. Carmel and Greg believe that we need to persevere beyond the first container to feel the benefits of this treatment. We should persist with the recommended dose of two grams (1 level metric teaspoon) taken in water before breakfast. The dose should not be varied - neither decreased or increased.

Mushasi manufactures L-Carnitine in Australia, and they have a free call enquire line (1800 646 300) available to doctors, health practitioners, and consumers. The address of their technical department is 32 Miles Street, Mulgrave, VIC 3170. Greg is making a very generous offer to polio people. He is prepared to make a mail order service available through his health food store Go-Vita at a 20% discount, which will allow little profit for him. The reduced price for Mushasi L-Carnitine is $41.00 for 50 grams, and $74.25 for 100 grams. Greg’s phone/fax number is (02) 9713 6423, and his postal address is 93a Great North Road, Five Dock 2046.
Member Neville White recently wrote a thoughtful letter expressing thanks to the Network for its work, and making some suggestions for improving Network operations which the Management Committee will certainly consider. Neville would especially like to see more input from country towns and rural areas, and to have Support Groups more involved in Network activities. As the special report on page 13 shows, the Committee hopes that it will be able to establish stage one of a Support Group Development Program to help achieve these aims.

Neville also sent me his personal story to share with you, and he encourages other members to do likewise. To quote from his covering letter: “In relation to Support Groups I was wondering if it was possible to gain more information and sharing of what groups are doing and how they are helping members. Could some of these be sought and printed? [Ed: See Nancye Bonham’s Support Group Co-Ordinator’s Report on page 12.] Other areas I and others have found helpful is when the stories of survivors are shared - how they cope, what are the symptoms being faced, how are some surviving on pensions and financially, family issues and other responsibilities being faced, while themselves being limited and disabled. Also how they face increasing weaknesses and symptoms as well as adjusting personally to having to use orthotics, and so on. I have sensed a reluctance of many to talk about themselves and their symptoms, maybe as a way of coping, but unless we have the opportunity to share, how are we able to help each other?” Well, Neville has given you the challenge - I hope my mail bag will soon be full of stories to share. And now to Neville’s own story.

That infectious disease called Polio became a reality for me at age 21 in early 1951 when, after a week or so of not feeling well and off work, paralysis began to show up in the left leg, foot, arm, and face. The Doctor immediately began treatment and provided splints and massage as no beds in hospital seemed available, and the paralysis was mainly partial. Treatment and isolation was provided by Mum and for eight years I was receiving her help, even financially.

Some use returned to very sore muscles and, after eleven months, half a day’s work was possible, and continued for eight years; then it became necessary to seek other than physical work in a trade. Some weaknesses persisted and ankle support, and care in eating, were necessary. My energy levels were often low and I tired easily, but study and counselling work in Christian ministry were able to be maintained for 34 years, with spells of not being able to cope, which re-occurred every four to five years. No diagnosis was ever made except stress.

Finally, symptoms developed which made it impossible to continue working. The GP, on hearing of the Prince Henry Hospital Clinic, sent me there - it was a possibility. He had no other answer, over a period of nearly four years. After many tests the Clinic diagnosed possible symptoms of Post-Polio.

Since that time, in late 1993, further symptoms have developed, and the inability to cope came up most often. Mental ability has also decreased, together with increasing fatigue and weakness. Most of my working life had been managed by having a spell during the day or before attempting night sessions. More and more rest was needed, and night driving, and driving while fatigued, was not safe or possible. Muscles were maintained over twenty years by light prescribed exercises, including deep breathing, and chiropractic.

Of late the most difficult areas are the shoulder and back and chest pain, continuing in spite of pain killers, the weakness and heavy legs syndrome, cramps, body twitches and jumps, inability to wake up after falling asleep, throat with swallowing and voice going off, prickly and sore skin spasmodically, and even driving ability lessening as well as emotional and nerve instability, which leads to stumbling.

Retirement is a help as more time is needed to manage life. Support Groups have opened my eyes to what others are facing, and how to present ourselves to the medical world for help. Increasing limitations means adapting. A good book on chronic pain is helpful. Maybe some orthotics are now needed apart from neck brace and walking stick. Mood swings and anger and resentment have taken some dealing with, and for others, the irritability. Life is able to be maintained with help from hydrotherapy, pain killers from my GP, and any other help I can get. I am still learning to listen to what the body is saying and act accordingly.

All the very best of everything to all who battle through, and keep positive in this way of life; able to be disabled yet living with it and maintaining our interests and support and not afraid to ask for help or to educate those who fail to understand. Each of our lives is still very special - to one another, ourselves, and to God.