POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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Editor's Corner

Only a few words from me this issue. First, an **URGENT** reminder to make sure you attend the **Annual General Meeting** on **Saturday, 24 June 1995**. Full details of the time and venue are given on page two, together with information about our exciting Seminar which will follow the formal proceedings. Support the Network by attending the AGM. We need new members on the Management Committee. We also need members who will make the commitment to be involved at whatever level they can in the planning for the first Post-Polio Conference to be held in New South Wales in November 1996.

Stay Involved and Keep Your Network Alive and Vital!

If you haven't yet renewed your membership for 1995/96, please show your support for the Post-Polio Network (NSW) Inc. and take the opportunity to pay at the AGM or forward your payment to : PO Box 888, Kensington NSW 2033.

And finally .... a note for your diary. Keep **Saturday, 23 September 1995** free as this is the date of our next Seminar. The venue will be the Dougherty Centre at Chatswood. The seminar topic and speaker will be advised soon. Watch this space!

Polio Consumers' Forum

In late March this year the XII World Congress of the International Federation of Physical Medicine and Rehabilitation was held in Sydney. In conjunction with this Congress and the Australasian Faculty of Rehabilitation Medicine, Dr Katrak (Deputy Director, Department of Rehabilitation Medicine, Prince Henry Hospital) organised a Polio Consumers Forum, designed for an audience of people who have had polio, their families, carers and health professionals. Speakers were: Dr Mary Westbrook ("The Hassles of Living with Post-Polio: Some Survival Strategies"), Dr Roy Lee ("Pain in the Post-Polio Syndrome"), Dr Robert Adler ("What Should I Avoid? A Look at Drugs, Surgery and Exercise"), and three Network members (Ken Mason, Hazel Atkinson and Gillian Thomas) who told their personal stories. Ken Mason's story is reproduced on page 4 (the other stories will follow in an upcoming Newsletter). Mary Westbrook's paper will appear next issue. Unfortunately neither Dr Lee nor Dr Adler had a paper of their presentation available. The Committee is endeavouring to obtain articles (or at least some notes) from the doctors that we can publish.

Equipment for Sale

Member Elizabeth Lynes has contacted us offering a *Niagra thermo cyclopad with both heat and massage functions* which she purchased in October 1994. Unfortunately, the item proved not to be what Elizabeth needed. She paid $1,440 for it and is willing to sell it for $985. Although Elizabeth lives outside Sydney, she advises she could get the unit to Kingsford (in Sydney's eastern suburbs) for viewing if this would help. If you interested in getting more information about this equipment please contact Elizabeth on (047) 88 1170.

Annual General Meeting

Date: Saturday, 24 June 1995

Time: 11:00 am

Venue: The NSW Society for Children & Young Adults with Physical Disabilities, 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.

The Annual General Meeting is your opportunity to have a say in the next year of Network activities, or to stand for a position on the Committee. The Network needs a strong hard-working Committee if it is to continue its important work. We look forward to seeing new and also long-standing members at the AGM.

Following the formal part of proceedings, there will be time to eat your packed lunch and catch up with friends. As usual, fruit juice, tea and coffee will be provided. Our usual jam-packed afternoon of information will start at 1:00 pm.

Seminar - Disability Council of NSW

The Disability Council of New South Wales is the official adviser on disability issues to the New South Wales Government. It reports to the Minister for Ageing and Disability, the Hon. Ron Dyer MLC. John Ahearn, Executive Officer of the Council, will talk about how it fulfils its advisory role. He will tell us how the Council is constituted, how its members are appointed, what specific work it does, the community consultations it undertakes, how it relates to peak organisations such as ours, and more. The Council has a number of Task Forces which look at specific disability issues. Two areas the Task Forces are currently addressing will be of special interest to Network members, namely parking and orthotics. This is a good opportunity to make our Network and the needs of its members known to Council and the Government. John will be happy to answer questions after his presentation.

Planning for the 1996 Post-Polio Conference

Following afternoon tea, Jean Skuse, who will be organising the 1996 International Post-Polio Conference in collaboration with a Network Committee of dedicated and enthusiastic people, will talk about what will need to be done over the coming months to ensure a successful Conference. Jean will be seeking your support and help in the planning. She will talk about the venue, costs, funding and time-lines. Her first task will be to arrange a brain-storming workshop to get ideas from members about what form the Conference should take, what topics or themes should be covered and who should be invited to speak. This is your Conference! Help to make it a success by being involved as much as you can.

Impressions of the Sixth International Post-Polio and Independent Living Conference

Mary Westbrook

In June 1994 I was invited to participate in three sessions at the sixth international post-polio conference which was held in St. Louis. In the first session "Living with disability: different perspectives" I was one of five speakers. I talked about how people's early experiences coping with their initial attack of polio can influence (and often interfere with) coping with the late effects of polio. The second session was entitled "Post-polio research. What's being done and what needs to be done." I presented a brief account of some of the findings from the five year follow-up survey of Australian polio survivors that I had conducted. I was also asked to participate in a session called "Health Care Reform: Its impact on people with disabilities". I was invited to describe the Australian health care system and people with disabilities in a section called "What can we learn from other countries?" In researching this topic, I concluded that our health services compare very favourably with the American in terms of cost and equity.

St. Louis is situated in Missouri, on the banks of the Mississippi. The city which was the gateway to western expansion is typical middle America. June was mid-summer and very humid. The conference was held in a large downtown hotel. I spent several days exploring St. Louis after the conference. This was a delight due to the wheelchair accessible metro stations and trains. A bus service called the shuttle-bug links up with the metro to service other parts of the city. These red buses painted like beetles have a ramp which lowers to make them wheelchair accessible. The city sights include an excellent art gallery, science museum, and shopping malls.

About 500 people attended the conference. They came from 13 countries and most of the US. Many people brought their electric scooters and when I'd looked out the hotel window I could see fleets of scooters going across the nearby park. Scooters and wheelchairs led to many traffic jams when exiting conference rooms or accessing lifts.

The conference lasted three days. On the morning of the first day sessions were aimed at first time attenders. I think this could be a useful strategy to adopt in future Australian conferences so that newcomers could learn the basic facts about post-polio and the role of support groups. For much of the conference only one session was offered but on one afternoon there were four and on one morning eleven concurrent offerings. This was extremely frustrating as very popular sessions such as "Living with disability: different perspectives" and "Energy conservation and lifestyle enhancement" ran side by side and it was rarely possible to obtain handouts from sessions not attended. The eleven sessions held on the Saturday morning ran for one or two hours. The former were presented twice. These sessions were not available on tape so it was quite difficult deciding between topics such as alternative therapies; dealing with chronic pain; disability legislation and rights issues; using ventilators; dealing with incontinence; face masks for ventilators and frog breathing; understanding EMG; aging with post-polio; post-polio clinics, goals and approaches and how to use them; oral history, polio histories must be told, and social security. Being a non-American made my choice a little easier as several sessions were specifically concerned with the American scene. I attended the sessions on alternative therapies and oral history. It seemed to me that some of the main sessions (that were the only offering available) were not of great interest to everyone e.g. the battle with bracing, facing surgery when breathing is a problem and the progress of the program to eliminate polio. The small sessions on the Saturday morning allowed people to participate which was very rewarding. The conference session I enjoyed the most was the one on oral history. The twenty or so participants all spoke (often for the first time) of the effect of polio and post-polio on their lives.

The display room at the conference proved very interesting particularly because of the copies of newsletters from various US support groups. I was surprised that most of the equipment on display was ventilator equipment and there were no aids such as wheelchairs, crutches or electric scooters. In fact I was surprised at the aids being used by conference attenders. I had expected American walking sticks and crutches to be more attractive than those available in Australia. Nothing I saw could be described as a fashion accessory or a work of art. The smartest pair of crutches I saw came from New Zealand.

My most enjoyable memories of the conference were my interactions with other participants. Toward the end of the conference I realised I was acting in a more extroverted and relaxed manner than usual. It struck me that it was like not being disabled. I'd never realised the extent to which having a visible disability affects you when meeting another person for the first time. Although not conscious of doing so, your mind is wondering what assumptions are being made about you, whether the other person is uncomfortable with disability and so on. At the conference almost everyone has had polio. It was constant. I realised, this is how ablebodied people must approach making new acquaintances. It was a wonderful experience. Our common polio experiences made it easy to find topics of conversation and since I returned I have enjoyed corresponding with several people I met in the US.

Many interesting papers were presented at the conference. On some issues there is no consensus. The controversy regarding exercise continues. Halstead presented an important paper in which he presented a classification for polio limbs. This takes account of how each limb was affected initially, its recent history, the results of a physical examination and EMG findings. Thus exercise may be appropriate for some limbs but not others. The classification will assist physiotherapists tailor programs which take account of the specific needs of each client. The network has purchased tapes of many of the conference sessions and these may be borrowed by members who want an update on issues such as recent research, post-polio theories, drugs for post-polio symptoms, surgery and living with disability.

Overall the conference was an exciting, stimulating and heart warming experience that I can recommend to anyone able to attend the Seventh International Conference (the date for which is yet to be announced).

My Experience with Polio

Ken Mason

I contracted polio in 1953 when I was nineteen years old. I was affected in both legs, however, I made a very good recovery, and after approximately five months in hospital was discharged. I continued to have physiotherapy at home and shortly afterwards I was able to return to full-time work.

To maintain my fitness, I became actively involved in playing sport, and later on joined an athletic club and took part in competitive running. In all of these activities I didn't have any after effects of the polio.

Then fourteen years ago, I did begin to notice my left leg giving way at the knee when I walked. I saw a physiotherapist who gave me an exercise program and suggested I take up bike riding to strengthen my leg muscles, and the symptoms eventually cleared up. So apart from that one incident, I could say I had thirty-six years of good health before any problems began to appear.

About five years ago, I began to have difficulties with my left leg again; also I was experiencing back pain and fatigue. As these symptoms got worse I found it harder to cope with my work. These symptoms continued periodically over the next couple of years, while I was also experiencing periods of physical weakness and frequent headaches. Whenever I went to the doctor I was told that I most likely had a virus, however a range of tests were conducted and they ruled out any serious disease. Therefore, apart from these symptoms, I was quite healthy!

In 1993 I saw Dr. Robert Adler in Melbourne who confirmed a diagnosis of post-polio syndrome. He indicated some management strategies, including taking rest periods during the day to manage my fatigue, and also suggested a polypropylene splint for my left leg which has helped with my walking.

All of the symptoms I have referred to continued through 1993, and because of the difficulties in coping with my work-load, I decided to reduce my hours; but unfortunately this made little difference so I decided to retire at the end of October.

<u>Well, what's happened since, and how is all this affecting me now?</u>
I think the main difference is that I have learned to manage my problems better, and to pace myself through the day, taking rest-periods when necessary; while I am also going to a heated indoor pool regularly for swimming, which I believe is helping my overall health. Recently I purchased an electric scooter which has made a significant difference, giving me independence again, because I had stopped going anywhere which involved a lot of walking.

My main problem is still fatigue and weakness in my legs. The fatigue isn't always related to activity; it can come out of the blue, as sometimes I can wake up in the morning feeling quite well after a good night's sleep, and within a short period be fatigued. At other times it will hit me in the afternoon and, while taking a rest helps, it doesn't always relieve the problem.

To conclude this summary of my experience with polio, I believe learning ways of managing my problem has been a major factor as it is for us all, then learning to accept limitations and getting on with my life.

Surfing the Internet!

Dr Westbrook has recently been reading interesting items on the "Internet". This is like a giant international library which you can connect into using your home computer. Mary sent me a copy of some of her browsing: "PPS Questions and Answers" written by Drs Richard Bruno and Nancy Frick. These doctors have undertaken post-polio research and presented papers at a number of conferences. They work at the Kessler Rehabilitation Centre.

First you must read the doctors' general disclaimer

These general answers represent what is written in the medical literature on PPS, our newest research and how we treat patients at the Kessler Post-Polio Service. They are NOT intended as therapeutic recommendations for you personally nor as a substitute for your being evaluated by your own personal doctor and a doctor who knows about PPS.

Every polio survivor (PS) is different and prescribed treatments must take those differences into account.

Post-Polio Sequelae (PPS) is a diagnosis of exclusion, meaning a physician must evaluate you and determine that no other condition is causing your symptoms. You may have PPS alone, PPS and another problem or a condition not related to polio at all. There are no medical tests that can prove you have PPS.

Read these answers, read the journal articles listed with each, and understand them fully. Take them to your doctor or therapist and ask them to read and understand them fully. Do not apply therapeutic techniques described here (especially exercise) on your own.

We very much hope these answers serve an educational purpose and that you integrate them with your own experience, personal wisdom and doctors' recommendations so that you can thrive, not just survive, with PPS!

About PPS Progression and Prevention

There are no long-term studies of whether PS who have no symptoms will develop PPS. Every time a study of PS is done, the percentage with new problems increases. The percentage was 22.4% in the first Mayo clinic study in 1982 and increased to 78% in a British polio hospital follow-up in 1987. At the NY Academy of Sciences Symposium on PPS April, 1994, the Mayo group and others thought that more than 90% of PS would develop some problems related to their polio.

Every PS is different. But, the rules that apply to every mortal apply to PS. Anyone who has too few overworked, damaged nerves compensating for muscle weakness for over 40 years is bound to have some problems. And, when you add PS super Type A lifestyles and the fact that they work more hours of overtime than non-disabled people, something's got to give.

But, the good news is that the study cited below and our new follow-up study of all the patients we have treated show that if you listen to your body and stop doing the things that cause weakness, fatigue and pain, PPS often plateau and can even decrease (see below: Exercise and Activity). One example: 18 months after their evaluation with us, PS who completed therapy reported 22% LESS fatigue; however, PS who refused treatment or dropped out of therapy early had 21% MORE fatigue at 18 months.

Peach PE, Olejnik S, "Effect of treatment and non-compliance on Post-Polio Sequelae", ORTHOPEDICS, 1991, 14(11):1199.

About Exercise and Activity

Exercise has been the most hotly debated area in PPS. The studies cited below say three things:

1) Listen to your body! If you are doing things that cause fatigue, weakness or pain STOP DOING THEM!!! PS need to pace their activities, that is work and then rest about two times the amount they worked. Jim

Agre showed that PS can do 240% more work if they PACE. You don't drive your car until it's out of gas; you shouldn't drive yourself to exhaustion, weakness or pain.

2) We only prescribe the non-fatiguing exercises by Rubin Feldman that have been shown not to hurt PS. But, these exercises are not given to all patients and are only prescribed after PS learn to pace and conserve energy! Patients are usually given gentle exercise after they get a new brace to keep muscle tone. The key word is NON-FATIGUING.

3) We have seen a small handful of PS who became deconditioned after surgery or illness. Pacing and resting doesn't mean sitting or sleeping all day and not moving. You should be doing what you need to do for yourself, and at your job, but in a paced, energy conserving, Type B fashion.

In our follow-up of all the patients we have treated, the three factors that were related to a significant decrease in fatigue were 1) completing the PPS therapy program; 2) doing absolutely nothing for 15 minutes twice a day; 3) using a wheelchair or scooter for distances.

Young GR, "Energy conservation, occupational therapy and the treatment of Post-Polio Sequelae", ORTHOPEDICS, 1991, 14(11):1233.

Feldman RM and Soskolne CL, "The use of non-fatiguing strengthening exercises in Post-Polio Syndrome", in Halstead LS and Wiechers DO (Eds) "Research and Clinical Aspects of the Late Effects of Poliomyelitis", White Plains: March of Dimes Research Foundation, 1987.

Fillyaw MJ et al, "The effects of long-term non-fatiguing resistance exercise in subjects with Post-Polio Syndrome", ORTHOPEDICS, 1991, 14(11):1253.

Agre JC and Rodriguez AA, "Neuromuscular function in polio survivors", ORTHOPEDICS, 1991, 14(12):1343.

About Feet and Legs

PS are notorious for having cold and purple "polio feet", caused in part by the smooth muscle around the veins being partially paralysed by the original polio. Without muscle to control their size, veins fill with blood and cause your feet to appear purple. Your feet become cold because the heat in this pooled blood escapes into the air. Back in 1983, we found that PS's nerves and veins act as if it's 20 degrees colder than the air, making it hard for the nerves, muscles and connective tissues to work. PS lost 75% of their muscle strength when the room temperature dropped from 85 to 65 degrees Fahrenheit.

Cold is the #2 cause of muscle weakness in PS but is the easiest to treat. We suggest that our patients take a bath in the morning, dry off and put on polypropylene socks or long johns while they are still warm. Polypropylene is a silk-like plastic that holds heat in but allows sweating.

Also, engorged veins can cause swelling, especially when feet get hot in summer or after a long bath. Jobst compression stockings sometimes help, as well as keeping your feet up a lot during the day. But, leg swelling must be evaluated by your doctor.

Bruno RL, Johnson JC, Berman WS, "Vasomotor abnormalities as Post-Polio Sequelae", ORTHOPEDICS, 1985, 8(7):865-869.

About Getting Other Diseases

PS can get all the diseases everyone else gets. That's why your doctor has to exclude all other causes for your new symptoms before you settle on PPS. In our 1985 National Post-Polio Survey we discovered that PS were on average more Type A - pressured, time-conscious, overachieving, perfectionistic - than any other group of Americans, including those who already had had heart attacks. However, PS were no more likely to have heart attacks or high blood pressure than anyone else.

We found that PS also had 3 to 6 times more trouble with gut problems - diarrhoea, constipation ulcer and colitis - as compared to the general population. PS also have more headaches (but not migraines) and muscle pain (often called Fibromyalgia). And, there is also one study that suggests that more PS have hypothyroidism.

Also, 66% of PS report frequent anxiety and 31% of those who see us for evaluation have a Major Depressive Episode - that's 6 times the rate for the general population. Both old and new types of antidepressants are effective if prescribed for PS. Again, your doctor needs to evaluate any and all new symptoms!

Bruno RL and Frick NM, "Stress and 'Type A' behaviour as precipitants of Post-Polio Sequelae: The Felician/Columbia Survey", in Halstead LS and Wiechers DO (Eds) "Research and Clinical Aspects of the Late Effects of Poliomyelitis", White Plains: March of Dimes Research Foundation, 1987.

Bruno RL and Frick NM, "The psychology of polio as prelude to Post-Polio Sequelae: Behaviour modification and pyschotherapy", ORTHOPEDICS, 1991, 14(11):1185-1193.

Halstead LS, "Assessment and differential diagnosis for Post-Polio Syndrome", ORTHOPEDICS, 1991, 14(11):1209.

About Drugs for PPS

A number of drug studies were presented at the NY Academy of Sciences Symposium on PPS in April 1994. Prednisone (a steroid) and Amantidine were tried without success to treat PPS weakness and fatigue. Growth hormone was not found to be helpful to treat new muscle weakness in one paper, but a multi-center study is beginning.

Neal Cashman again reported on the use of Mestinon to treat muscle fatigue. He found that a portion of PS whose motor nerves don't communicate well with muscles report a decrease in muscle fatigue while using Mestinon. However, the effect of Mestinon seems to wear off over time.

We presented our pilot study of a drug to treat PPS brain fatigue. In the 10% of our patients whose fatigue did not improve following the standard treatment for PPS (see above: Exercise and Activity), 60% reported less morning fatigue and less trouble staying awake on drug versus placebo. However, even if drugs are found that help, PS must still listen to their bodies and live their lives in a paced, energy conserving, Type B fashion. There is no magic pill.

Bruno RL, Frick NM, Lewis T, Creange SJ, "The physiology of post-polio fatigue: A model for post-viral fatigue syndromes and a brain fatigue generator", CFIDS Chronicle, 1994, 7(4):36-42.

About Muscle Twitching

In the 1985 National PPS Survey, we found that 63% of all PS report that their muscles twitch and jump as they fall asleep; 33% reported that their sleep was disturbed by twitching. This sleep disorder, called Generalised Random Myoclonus, is often only noticed by the PS's bed partner. In doing sleep studies, we found that a small dose of Ativa before bed usually stops the movements and restores sleep.

Other sleep disorders, such as sleep apnea, are not uncommon in PS. If you snore, wake not rested, with a headache or are depressed, you should talk to your doctor about a sleep study.

Many PS report another kind of muscle movement during the day: fasiculations. These are muscle twitches you can see or feel. Fasiculations are found in many non-disabled people. Usually they are a sign, as is muscle pain, of muscle overuse. Again, talk to your doctor about any twitching.

Bruno RL and Frick NM, "Stress and 'Type A' behaviour as precipitants of Post-Polio Sequelae: The Felician/Columbia Survey", in Halstead LS and Wiechers DO (Eds) "Research and Clinical Aspects of the Late Effects of Poliomyelitis", White Plains: March of Dimes Research Foundation, 1987.

Bruno RL, Frick NM, Creange SJ, "Nocturnal generalised myoclonus as a post-polio sequelae", Archives of Physical Medicine and Rehabilitation, 1995, (in press).

Bach JR and Alba AA, "Pulmonary dysfunction and sleep disordered breathing as Post-Polio Sequelae: Evaluation and management", ORTHOPEDICS, 1991, 14(12):1329.

The Cause and Treatment of Post-Polio Fatigue

Richard L. Bruno (PhD), Nancy M. Frick (PhD), Susan J. Creange (MA), Todd Lewis (PhD), and Terry Molzen (MS).

The following paper (pages 8-13) was placed on the Internet in April this year and comes from the "Proceedings of the March of Dimes Conference on Post-Polio Sequelae (1995)". The article details some current American research and is very easy to read.

Fatigue is the most commonly reported, most debilitating and least studied Post-Polio Sequelae (PPS) affecting the nearly two million North American polio survivors. Among polio survivors, 91% reported new or increased fatigue, 41% reported fatigue significantly interfering with performing or completing work and 25% reported fatigue interfering with self-care activities (1,2). Fatigue was reported to be triggered or increased by physical over-exertion in 92% and by emotional stress in 61%. Importantly, polio survivors distinguish between the physical tiredness and decreased endurance they associate with new muscle weakness, and a "brain fatigue" that is characterised by problems with attention and thinking. Between 70% and 96% of polio survivors reporting fatigue complained of problems with concentration, memory, attention, word-finding, maintaining wakefulness and thinking clearly, with 77% reporting moderate to severe difficulty with these functions (3).

Problems with attention, memory and thinking suggest that the symptoms of post-polio fatigue cannot be explained merely by the poliovirus damaging anterior horn motor neurons (4). Autopsies performed fifty years ago on people who died after having had polio, whether they had paralysis or not, showed that the poliovirus almost always damaged specific areas in the brain. These damaged areas include the brain's activating system that keeps you awake and allows you to focus your attention. The poliovirus also damaged neurons that produce neurotransmitters, including the enkephalins and endorphins (called the "body's own morphine") as well as dopamine and ACTH which activate the brain.

With poliovirus damaging the brain's activating system, you would expect that the original polio infection should cause brain activating problems. And, reports written during the polio epidemics did describe "drowsiness", lethargy, prolonged sleeping and even coma during the acute polio infection (7,12,21,22). One-third of patients with acute spinal, spinal and bulbar and even non-paralytic polio showed "disorientation, apathy, pronounced sleep disorder (and) irritability" (4). These mental changes were associated with the abnormal slowing of brain wave activity on the electroencephalogram (EEG). Further, a high percentage of children clinically recovered from poliomyelitis insofar as motor disability is concerned, had qualitative difficulties in mental functioning such as "fatiguability and fleeting attention" for months after the acute polio (5).

These reports of persistent drowsiness, fatigue and fleeting attention following the acute poliovirus infection are similar to polio survivors' recent complaints of late-onset fatigue and impaired attention (25). And, both acute and late-onset post-polio fatigue are reminiscent of nearly two dozen outbreaks during this century of post-viral fatigue syndromes (PFS) that are related clinically, historically or anatomically to poliovirus infections (26-28). These relationships and recent studies comparing post-polio fatigue and chronic fatigue syndrome will be described in an attempt to understand the cause and treatment of post-polio fatigue.

Can The Poliovirus Cause Fatigue?

Type II Poliovirus and Decreased Brain Activation

During the polio epidemics of the 1950's, there were several small outbreaks of patients having drowsiness, prolonged sleeping, slowing of brain waves, as well as some of the symptoms of both bulbar polio and Parkinson's disease (e.g. tremor and rigidity) (29,30). In 1952, Type II poliovirus was isolated from one group of patients having these symptoms and it was found that the neurons in their brain activating system had been damaged.

The association of decreased brain activation and Parkinson's disease symptoms remind Dr Oliver Sachs of the "sleeping sickness" patients with Parkinson's disease that he described in *Awakenings*. The relationship between "sleeping sickness", Parkinson's disease and polio may be important for understanding post-polio fatigue, since all of these conditions are associated with damage to a part of the brain activating system called the basal ganglia. For example, Parkinson's disease (PD) patients have severe damage to one of the basal ganglia, the substantia nigra (sub-STAN-sha NYE-gra), which produces the neurotransmitter dopamine (doe-PAH-mean). PD patients often describe fatigue. "Excessive fatigue" was reported by 48% of PD patients in one study (40) while nearly one-third of PD patients reported that fatigue was their "most disabling symptom" (39). As a matter of fact, one of the first descriptions of Parkinson's disease (41) could serve as a definition of post-polio fatigue, that is, a syndrome "characterised by a diminution of voluntary attention, spontaneous interest, initiative and the capacity for effort and work, with significant and objective fatiguability, and a diminution of memory" (38).

"Atypical Poliomyelitis" and Chronic Fatigue

Beginning in Los Angeles in 1934 and continuing for more than twenty years, there were over a dozen outbreaks of a disease that was as first thought to be poliomyelitis, was then called "abortive" or "atypical" poliomyelitis and finally named "Myalgic Encephalomyelitis" (ME) (6). Like poliomyelitis, initial symptoms of ME included headache, neck pain, low-grade fever and muscle pain that were often followed by muscle weakness. Patients were excessively sleepy and had "conspicuous changes in their levels of concentration"

that lasted for months after the initial illness. Slowing of the EEG similar to that seen in acute polio was also noted.

Unlike poliomyelitis, there were frequent complaints of numbness or tingling, usually no breathing problems, paralysis or muscle wasting and almost invariably no deaths. Also unlike poliomyelitis, recovery from the initial symptoms of ME sometimes required months with most patients being left with a marked "exhaustion and fatiguability" that were "always made worse by exercise (and) emotional stress". Patients continued to have fatigue, excessive sleepiness, trouble concentrating, difficulty with word finding, memory and thinking for years after the acute episode.

Despite the differences between poliomyelitis and ME, an association with the poliovirus was suggested by the fact that, of the more than one dozen ME outbreaks before the introduction of the Salk vaccine, nine occurred during or immediately after outbreaks of polio and several involved hospital staff who cared for polio patients (7).

Type III Poliovirus and Chronic Fatigue in Iceland

A more direct association between the poliovirus and ME was seen in 1948 in Akureyri, Iceland. Patients there presented with fever, muscle pain and weakness and were at first diagnosed as having poliomyelitis. After about a month, this diagnosis was discarded as patients reported additional symptoms not typical of polio, including tingling, numbness, "nervousness" and "general tiredness". Also unlike poliomyelitis, no deaths were reported and poliovirus was never isolated from any of these patients. When patients were reexamined six years after their original illness, 72% still had chronic "nervousness and general tiredness" and 21% reported a "loss of memory".

It was suggested that either an "unusual" and mild poliovirus or some unknown virus caused these symptoms that were called "Akureyri Disease" but are more commonly referred to as "Iceland Disease" (ID). Support for an "unusual" poliovirus as the cause came in 1955 (10). There was an extensive epidemic of poliovirus in Iceland caused by Type I poliovirus that coincided with and was followed by outbreaks of ID. Remarkably, two cities in which ID outbreaks were reported in 1955, as well as the area affected by the 1948 "Akureyri Disease" epidemic, were untouched by poliomyelitis. None of the children tested in the two ID-affected cities and only 13% of the children in Akureyri had antibodies to Type I poliovirus as opposed to 86% of the children tested in the polio epidemic areas. Further, following poliovirus immunisation, children in one of the ID-affected cities demonstrated antibody titres to Type II and Type III poliovirus that were four and twenty-five times higher than titres in a city where ID had not been reported. It was concluded that Type I poliovirus was not the cause of ID, but the citizens of the ID-affected areas had previously been exposed to something that was immunologically similar to Type III poliovirus.

An interesting coda to these findings is the report that when an American airman who had contracted polio in the 1955 Iceland epidemic returned to Massachusetts, a small outbreak of ID and polio occurred (11). More recent support for a relationship between poliovirus and ME came in 1989 when a "dangerously rising titre" to Type III poliovirus was documented in a patient who did not have polio but had been diagnosed with ME (12).

Post-Polio Fatigue and Chronic Fatigue Syndrome

A group of symptoms resembling ME was termed "Chronic Fatigue Syndrome" (CFS) following a Nevada outbreak in 1984 (13). Like ME and post-polio fatigue, CFS is characterised by complaints of chronic fatigue and trouble with concentration, memory and word finding that are triggered or exacerbated by physical exertion and emotional stress. And, although polio survivors are on average at least ten years older than patients with CFS, the years of education, sex distribution, frequency of difficulty with concentration and psychological symptoms are nearly identical in the two groups (17,18,19). However, unlike ME and PPS, CFS patients report recurring sore throat, swollen glands and fever, suggesting to some that CFS is caused by a recurring or chronic viral infection. It is important to keep in mind that there is no evidence that PPS is caused by a persistent infection by any virus, including poliovirus (14,15).

The recent occurrence of CFS has allowed it to be studied using techniques that were not available during the polio, ME and ID epidemics and now allow neuropsychologic, neuroanatomic and neuroendocrine comparisons between this newest CFS and post-polio fatigue.

Comparisons of Post-Polio Fatigue and CFS

Neuropsychologic Studies

Some of the subjective difficulties with attention and cognition in CFS patients and polio survivors have been confirmed with neuropsychologic testing. CFS patients and polio survivors with severe fatigue have been shown to have clinical impairments of attention and information processing speed (16,19). Polio survivors reporting severe fatigue required 23% to 67% more time to complete tasks requiring sustained attention and

vigilance than did polio survivors with no or mild fatigue. In spite of these marked impairments of attention, CFS patients and polio survivors have been shown to have I.Q.s within the high normal or superior range and have higher than average levels of educational and professional achievement (17). Further, despite the high frequency of subjective complaints of memory impairment in CFS patients and in 87% of polio survivors reporting fatigue, verbal memory has been shown to be intact on testing in both groups (16,19,20). However, polio survivors have twice been shown to have trouble recalling visual information whether or not they report fatigue (7,16).

These findings indicate that fatigue in CFS patients and polio survivors is associated with impairment of attention and information processing speed but not of memory or thinking ability. Given the findings of frequent and severe poliovirus lesions in the brain's activating system, it was hypothesised that damage to the brain's activating system is responsible for both fatigue and impaired attention in polio survivors.

Brain Scan Studies

To test this hypothesis, magnetic resonance imaging (MRI) of the brain was performed to look for evidence of poliovirus lesions in the brain's activating system. In a first study, small areas of hyperintense signal (which look like white spots) on MRI were seen in the brain's activating system and in the myelinated (insulated) neurons that connect the brain stem (at the bottom of the brain) to the cortex (the "supercomputer at the very top of the brain) in eleven of twelve polio survivors (1). In a second study, white spots were seen in 55% of polio survivors with fatigue but were not seen in any of the subjects without fatigue (21). The presence of the white spots were not only related to increased fatigue severity, but also to problems with memory, thinking clearly, mind wandering, attention and concentration.

Finding white spots on MRI supports the theory that fatigue and problems with attention in polio survivors may be related to damage the poliovirus did to the brain activating system. This conclusion is supported by a number of other studies that have shown a relationship between white spots on MRI, fatigue and problems with attention. Notably, white spots have been seen in between 40% and 100% of CFS patients (13) and even in healthy elderly patients who have problems with attention similar to those seen in CFS patients and polio survivors (22).

Hormonal Studies

The association of white spots in the brain activating system with the symptoms of post-polio fatigue suggested that the effects of poliovirus on other brain areas might also be evident in polio survivors. For example, poliovirus lesions were often seen on autopsy in the hypothalamus (hypo-THAL-ah-mus), the brain area that automatically controls the body's internal environment and its response to stress.

To test the functioning of the hypothalamus, we measured polio survivors' blood concentrations of ACTH (a-DRE-no cor-ti-co-TRO-pick hormone), one of the body's stress hormones whose release is triggered by the hypothalamus. ACTH was measured following an overnight fast, which is a mild stress known to cause the release of ACTH (7). ACTH was increased outside of the normal range (as it should be following stress) in polio survivors who reported mild fatigue. However, there was no ACTH increase in subjects reporting severe daily fatigue. Further, the higher the ACTH level, the lower the subjects' reported fatigue and the less the difficulty with memory, word finding, muscle weakness and staying awake during the day.

These findings indicate that the hypothalamus had not been activated in the subjects with post-polio fatigue and that ACTH production is reduced in these individuals. This conclusion is interesting for two reasons. First, ACTH has been found in humans to promote alertness, increase attention and decrease fatigue by directly stimulating the brain activating system. Thus, a decrease in ACTH production may prevent brain activation and contribute to the symptoms of post-polio fatigue. Decreased activation of the hypothalamus has already been found in patients with CFS and a decrease in ACTH stimulation of the brain has been suggested as a cause of CFS (23).

Second, a decrease in ACTH production may be caused by a decrease in production of its parent molecule, POMC. POMC also produces beta-endorphin (BAY-ta en-DOOR-fin) which, along with the enkephalins (en-KEF-ah-lins), are "the body's own morphine". Since poliovirus also damaged the brain area that produces enkephalins, both beta-endorphin and enkephalin production may be reduced in polio survivors. A reduction in the body's own morphine would help to explain why polio survivors have a nearly doubled sensitivity to pain (1).

A Model For Post-Polio Fatigue

Taken together, these findings suggest a model for the cause of post-polio fatigue:

- Poliovirus damaged the brain activating system;

- MRI and hormonal findings suggest that damage to the brain activating system is present today in polio survivors;
- Neuropsychological testing shows impaired attention in patients with post-polio fatigue;
- Therefore, poliovirus damage to the brain's activating system may cause decreased brain activation, impair attention and generate the symptoms of post-polio fatigue.

While poliovirus damage to the brain activating system would be expected to cause the sleepiness, inattention and fatigue reported during the original polio infection, it is the recurrence of these symptoms, or their appearance decades after the acute infection, that are more difficult to explain. The emergence of fatigue decades after the acute polio may result from normal age-related changes in and loss of brain activating system neurons that had survived the acute polio infection, combined with an already decreased number of neurons as a result of the original poliovirus infection. Eventually, the loss of brain activating system neurons would decrease cortical activation, reduce attention and produce the symptoms of fatigue as polio survivors reach mid-life (1).

The occurrence of these symptoms during physical or emotional stress in polio survivors may reflect the ability of stressors to uncover otherwise unseen damage in the brain activating system.

Is Fatigue "Hard Wired" into the Brain?

The findings presented above describe an intimate relationship between impaired attention and fatigue. However, difficulty with attention is not fatigue's only symptom. Even more disabling is the physical experience of fatigue: feelings of exhaustion, "passivity and an aversion to continued effort" that generate an aversion to both mental and physical activity. However unpleasant these feelings are in man, passivity and aversion to activity have clear survival value, especially in organisms without conscious awareness that their attention and thinking speed are impaired. For example, an animal that continues to explore its environment even though its attention is impaired would be less able to direct attention on the goal of its exploration (e.g. searching for food) and would thereby waste already diminishing energy stores. More importantly, impaired attention could also render the animal unaware of dangers in its environment (e.g. a predator stalking the animal in search of its food). Thus, there would be survival value in a brain mechanism that monitors cortical activation, biases an animal toward stopping motor behaviour and promotes rest when attention and thinking speed are impaired.

The Brain "Listens" to Itself

Groups of neurons near the bottom of the brain called the basal ganglia are in an ideal location to monitor the level of brain activation and stop an animal when it has too little attention to allow efficient and safe activity in its environment. All parts of the cortex connect to one of the basal ganglia, called the putamen (pew-TAY-men), which "listens" to the activity level of the brain (24). If the brain is awake enough, the putamen allows us to focus attention, to move and to act. When the brain activating system turns down, the putamen stops the cortex from allowing us to move. Damage to the putamen in animals has been shown to slow movement, while damage to another of the basal ganglia, the substantia nigra, decreases or even stops movement and prevents us from focusing attention (7).

The importance of the basal ganglia - and especially the neurotransmitter dopamine - in focusing attention and allowing us to move is most evident in patients with Parkinson's disease (PD). PD patients, whose damaged substantia nigra neurons produce too little dopamine, show not only slowed movement and an inability to focus attention but also excessive and disabling fatigue (7,38-41). And, remember Oliver Sachs' *Awakenings* patients whose damaged basal ganglia caused both Parkinson's disease and "sleeping sickness".

The Brain Fatigue Generator

It appears that the basal ganglia could produce the mental and physical symptoms of both normal and pathological fatigue. In normal fatigue, a long and hard day of work would slow the firing of brain activating system neurons. This decreased activity would impair attention and information processing ability (recognised by humans as symptoms of fatigue) and produce a decrease in cortical activation that would slow the firing of putamen neurons, prevent the release learned motor behaviours and slow or stop activity. Humans would notice problems with focusing attention, feel an aversion to activity and would be able to move only with significant conscious effort.

Animals would slow or even stop their activity. In both man and animals, rest or sleep would increase the firing of brain activating system neurons, restore cortical activation, increase the firing of putamen neurons and once again allow the release of motor behaviour.

Pathological states such as chronic fatigue syndromes could be produced by viral damage to the brain activating system, putamen and/or dopamine-producing neurons. This damage would chronically reduce the firing of brain activating system and putamen neurons, decrease cortical activation and produce the symptoms of fatigue. Poliovirus would be expected to cause fatigue, impaired cortical activation and decreased attention since it damages all of these brain areas.

Clinical Implications

This description of the basal ganglia as the brain fatigue generator suggests that increasing brain levels of dopamine (the neurotransmitter that stimulates the basal ganglia) might "turn on" the brain activating system, increase cortical activation and attention, release motor behaviours and reduce the symptoms of chronic fatigue. We are currently studying the use of a drug that stimulates dopamine receptors on brain neurons to treat post-polio patients whose fatigue has not responded to the current treatments of choice, that is, adequate rest, energy conservation, the pacing of activities and reducing physical and emotional stress (2,17,27,28). Preliminary results show that fatigue, impaired attention and difficulty staying awake during the day increase as the dose of the drug increases.

However, there is the very real danger that taking a drug that reduces fatigue will allow polio survivors to resume their hyperactive, Type A lifestyles (as they do now when they feel better following physical, occupational and psychological therapy for PPS) and further stress poliovirus-damaged, "metabolically vulnerable" neurons in the brain and spinal cord. Decreasing "overuse abuse" will always be necessary to treat PPS, regardless of whether a drug is found that decreases the symptoms of fatigue.

It is also possible that damage to the basal ganglia and a lack of damage may be related to other PPS symptoms. Word finding difficulties, reported by 82% of polio survivors with fatigue, appear similar both to word finding problems reported by CFS patients and the "tip-of-the-tongue" phenomena seen in PD patients (1,7). And, in a study we have just completed, polio survivors with severe fatigue had low scores on a test of wind finding ability - scores that were identical to those in PD patients.

In addition, 63% of polio survivors report Generalised Random Myoclonus (GRM), the slow contraction or rapid twitching of hand, arm, trunk and leg muscles at night that disturb sleep in 33% of polio survivors (2). GRM may provide more evidence that polio survivors have a brain dopamine shortage, since GRM are similar to periodic movements in sleep seen in PD patients.

We continue to examine the possible role of the basal ganglia and dopamine in PPS to help identify the cause and treatment of not only post-polio fatigue, but also to understand the neuro-physiology of fatigue itself.

Acknowledgments

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Editor's note: Unfortunately, the paper as placed on the Internet did not include the details for References higher than 22, and Reference 22 was incomplete.

Recent Publicity and Immunisation

A couple of weeks ago the Network received a telephone call from a researcher on Channel 9's *Today* show, asking for someone to go on national television the following morning to talk live on the Dr Kerryn Phelps segment about the post-polio syndrome and post-polio support networks. With barely half a day's notice, your Editor took up the challenge. It is very important to accept such chances at publicity, even though we usually receive no warning and little time to prepare or inform members. On the segment I talked about the late effects of polio, the Post-Polio Clinic at Prince Henry Hospital, Australian Post-Polio Networks, and the need to be constantly vigilant about immunisation. Afterwards, Dr Phelps said she was writing an article about post polio for her newspaper column which would appear in Sydney, Melbourne, Adelaide and Brisbane. As always when the NSW Network takes part in national publicity, we took pains to ensure that the contact details for the other state Networks were given in both the television segment and newspaper article. We usually also endeavour to let Network support group conveners and other members know of the upcoming publicity. Unfortunately, with the short notice this time it simply wasn't possible.

Shortly after the newspaper article appeared in Sydney, I received the following letter from Network member and long-time supporter Doug Sutherland.

Dear Gillian
Congratulations for inspiring the article in the Daily Telegraph Mirror of Monday, May 8, 1995.

I have recently taken the matter up with Sydney Rotary to see what that organisation can do to promote the immunisation within Australia, in the same way that Rotary International is promoting "polio plus" throughout the world, in conjunction with the United Nations.

Warm regards,
Yours sincerely,
Councillor Doug Sutherland, A.M.

We have received a large number of enquiries from this publicity and look forward to welcoming new members to the Network.

Post-Polio Post

My mailbag has been quite full recently. A number of members were inspired to write following the publication in the last issue of "The Crux of the Issue" by Elizabeth Cawley.

SO STOP AND THINK

I contracted polio in 1953, spent almost 2-1/2 years in hospital, and now wear a calliper (luckier than some).

In past issues of the PPN Newsletter and in the March 1995 issue I've read a lot of talk about "polio'ers" with our stubborn independent spirit, our sense of high expectation, achievement and denial, that we are just as good or even better than our able-bodied peers, always having to prove these points not only to ourselves, but to the rest of society.

Yes, I too was inculcated with this motivational psychology as a child. (My parents nicknamed me "Mr Independence".) "Thank your lucky stars", "by the grace of God", "there's nothing wrong with you, you're just as good as everybody else" (I know that!).

I can still remember some of my carers.

Dr Watts - strict, stern, Dr Watts. I can still hear Dr Watts scolding my father when he asked "Should we send Garry to a special school?". "What!" came the reply, "he'll go to a public school just like any normal child, there's absolutely nothing wrong with the boy!" Hmm! I thought - guess all the other kids will be wearing a calliper on their right leg too.

Miss Firth, head physiotherapist at the NSW Society, who only ever had words of wisdom, especially when it came to doctors who wanted to perform guinea-pig surgical procedures. "Now Mrs Barnett, just you wait, you never know what medical science will come up with in the future."

And Miss Hills, my very own physiotherapist, when I was in Strathallan Hospital. Well, a few of us shared her around.

These memories I shall keep safe. (I can hear all the Freudians working on that one now.)

The question I posed to myself: why did our carers take so much time and effort instilling the independent spirit into us? In their own stern, but I suspect caring way, they knew life was not going to be a bed of roses, no one was going to give us anything, and that we would have to fight manyfold to attain those things that able-bodied people take for granted.

I believe by saying there's absolutely nothing wrong with you, stop that self-sympathising, they were making sure that we were not going to become "victims" in our own minds, and in some unusual way building not only our self respect and
esteem, but also building in our self image a strong resilient person who is capable of achieving many things, not a group of self-sympathising "woe is me'ers", which I believe would have led to self destructive ways.

So what did our carers give us, or instil in us? Super independence, stubbornness (never give up), a sense of direction, not to be belittled or humiliated, a sense to achieve, self reliance, the spirit to fight for what we believe in (a sense of justice), the courage to take on the world.

So if our carers had not instilled these positive traits in us as children and young adults, then maybe, just maybe, Elizabeth Cawley would never have attained her masters in social science, Elizabeth Hastings to become Disability Discrimination Commissioner, Joan Clarke to write her books, F. Lionel Watts to build the "House with no Steps", FDR to become the President of the USA, Dr Mary Westbrook ... do I need to continue?

So I would like to take this opportunity to simply say "thank you" to all those who did care and understand because they knew that there would come a time when they would be gone, and we would be left to fend for ourselves, for you see they would have seen it all before.

Garry Barnett

Vera White [phone: (063) 42 2647] is bringing the Network a little closer to those in her area by agreeing to be the convener of the Cowra Telephone Support Group. She wrote shortly after Easter:

In the recent newsheet I felt the article "The Crux of the Issue" was written for me! It came in Thursday's mail and next morning I sat in church when everyone was standing for the Gospel which was the very long account of the Passion. I would not have done that, my ankles and feet pain when I stand in one position, but that article allowed me to sit and the best part, I felt comfortable in myself, doing it. Many thanks to Elizabeth Cawley.

Vera went on to say:

I have great trouble with footwear, painful feet and one "rotten" leg but I try not to let it restrict me too much. It has become easier for me to say in public "'I've had polio", since joining the Network."

The final letter comes from member Helen Tracy:

Dear Gillian
Every time I receive a journal or newsletter from you I think "I must write and say how much I enjoy them" - this time I'm actually doing it. The only problem is that I drop everything to have a quick browse and then of course read through to the end and then I'm waiting for the next one!

I also wanted to say that I found Dr Ian Neering's article extremely interesting and sent a copy to my acupuncturist/naturopath who remarked that it enlightened him as to the complexity of the problem.

Finally, Elizabeth Cawley's article was so typical of Pps - or of me anyway. I also recently started to think about getting crutches (because normal people use them) instead of the dreaded cane which resides in the depths of my boot never to see the light of day.

Sailors with disAbilities

We are the Sydney based group, SAILORS with disABILITIES. Our success in 1994 has meant we are able to continue in '95 with the support of our sponsor, Aspect Computing.

You see, we are a small group consisting of disabled sailors, and volunteers. Our program, "Sailors with disAbilities", was launched early in 1994. That year our primary goal was to get a group of sailors safely to Hobart. With the aid of sponsorship from Aspect Computing and ComTech, we were able to pursue our goals successfully. In 1994 we developed a training program, competed in various ocean yacht races, culminating in the ultimate Australian classic, Sydney-Hobart. But what of 1995?

We are looking forward to 1995 and its challenges with great enthusiasm. This year we will be doing it all again. To this end, SWD would like to take the opportunity to extend an invitation to all disabled sailors, and disabled people who would like to become involved in sailing. It's not that difficult. Our members consist of paraplegics, polio and Parkinson's victims, MS sufferers, dyslexic, sight impaired, and hearing impaired people. We've got the lot. Furthermore, we're having a ball! We have found that having a disability is about having the courage and determination to overcome it. On the yacht, a paraplegic makes an excellent winch man, a dyslexic is quite good at battling up the foredeck in stormy, rough seas, and a sight impaired person is very good on the aft, mid or foredeck. We make the most of our abilities. So, if you fit any of the above, or some we haven't thought of yet, please don't hesitate to contact us.

A major contribution to this year's training program is a J24, made possible by sponsorship funds. The J24 has a flat, unobstructed deck which makes it ideal for disabled sailing. It is an international class of yacht, which will allow us to compete at the highest levels. Furthermore, its small scale will allow us to hone in on and develop individual talents more effectively. As it were, all training has been aboard the racing yacht itself, the Adams Radford 16.5, Carpe Diem.

This year we will not only train disabled people to sail and participate in ocean racing, but we will also be holding sailing days with disabled and disadvantaged children. These days will take place on Sydney Harbour and Queensland waters. This is a new aspect of the program, and one which we envisage will be very rewarding for all parties. Again, we thank our sponsor for helping us get it started.

Our ocean racing agenda for the year will be -

Sydney - Southport	29 July
Mooloolaba - Airlie Beach	13 August
Hamilton Island Series	18 August
Sydney - Hobart	26 December

The 1995 racing program will provide us with many challenges, none more important than overcoming our disabilities, and working as a team. This year we will arrive in Hobart a bit earlier perhaps, safe and happy, and looking forward to the challenges of '96. Hope to see you with us soon!

If your have any enquiries about any aspect of the program, please contact:
Richard Bowler (Secretary) on 300-9324, Al Grundy (President) on 662-2770, or Dee Draper (PR Chairperson) on 949-7949.