POST - POLIO NETWORK (NSW) INC.

NEWSLETTER

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President's Corner

Gillian Thomas

A Happy New Year to all and I hope you enjoy the varied articles in the first Newsletter for 1999. You won't want to miss the **Seminar** to be held on **Saturday 6 March**. We have two excellent speakers lined up - full details appear on page 2. On pages 3-10 you will find a major article about non-paralytic polio and post-polio syndrome. In his *Support Group Report*, Bernie O'Grady has provided an updated listing of Network Support Groups. As usual, you will find *Post-Polio Post* on the last page.

Over the Christmas/New Year period we received many enquiries and welcomed 18 new members to the Network. The few members whose membership renewals for 1998/99 had not been received have all been personally contacted by Alice. Unlike many other organisations, the Network doesn't simply delete unfinancial members from its records. You are all important to us, and experience has taught us that most people who don't renew have simply forgotten to do so. These members are very grateful that we take to trouble to maintain contact. But remember, if you move, *please* tell us your new address and telephone number.

Member Lyn Kemp has asked me to pass on her thanks to those members who provided her with patterns for socks with grafted toes. She writes "I have passed them on to Mum who is a brilliant knitter and look forward to the results".

Work to get our office within the *Royal South Sydney Community Health Complex*, Joynton Avenue, Zetland, up and running is progressing slowly. We have held working bees to organise the files and develop some office procedures. To achieve our goal of staffing the office from 10:00 am to 2:00 pm, Monday to Friday, we need more volunteers to join the roster. **If you can give us any help at all, please contact Ruth on (02) 9416 4287 or Alice on (02) 9747 4694.** Once the office is open, members will have access to our extensive library.

An Order Form for **Dr Halstead's book *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*** is included with this *Newsletter*. Mary Westbrook's review of this highly-recommended book appears on pages 12-13. The books are on order from America, but are coming by sea freight to keep costs as low as possible (**$25 including postage**). Orders will be filled in order of receipt as soon as the books arrive.

Don't forget that the **1998 Conference audio tapes** are now available. These include a most comprehensive overview of management of the late effects of polio. This address was presented by Dr Pesi Katrak, the Rehabilitation Specialist who runs the Post-Polio Clinic. Our recently published membership survey report ***Polio - A Challenge for Life - The Impact of Late Effects*** is reviewed on page 13. Keep yourself and your doctors informed by obtaining copies of these important Network resources. The last *Newsletter* included an Order Form.

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Post-Polio Network Seminar

Date: Saturday, 6 March 1999

Time: 1:00 pm - 4:00 pm

Bring a packed lunch to eat from 12:00 noon 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 first Seminar for 1999 will feature two guest speakers.

From **1:00 pm**, **Helen Ford**, **Investigation Officer** for the **NSW Ombudsman**, will give a presentation on the work of the Ombudsman.

If you think you have been unfairly treated by a NSW public authority or public official you can tell the Ombudsman. This includes government departments, statutory authorities, public servants, police, local councils, councillors and council staff. The Ombudsman investigates conduct that may be illegal; unreasonable, unjust or oppressive; improperly discriminatory; based on improper motives or irrelevant grounds; based on a mistake of law or fact; or otherwise wrong. The Ombudsman is independent, impartial and offers services free of charge.

Helen will cover the types of complaints the Ombudsman can deal with, and how to make a complaint. There will be ample opportunity for questions and discussion.

Our second guest speaker from **2:00 pm** will be **Michael Gurry (B.Pros.&Orth., M.A.O.P.A.)** from **Orthotic Consultants Asia Pacific Pty Ltd**. Michael has written a series of articles for the *Newsletter* about orthotics, and will now bring his expertise to you in person.

Michael's talk will cover the following topics:

- Introduction - orthotics in Australia in '99 - where we are, and where we are headed
- Which orthosis for you? - metal? plastic? light? heavy?
- What to expect from an orthotist and an orthosis
- New product information - UTX Swing Orthosis
- Conclusion / Questions

If you are considering getting your first orthotic, or updating your existing one, you owe it to yourself to hear what Michael has to say.

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

Non-Paralytic Polio and Post-Polio Syndrome

Marcia Falconer, PhD - cell biology
Eddie Bollenbach, MA - biology

Marcia Falconer contracted non-paralytic polio as a child in 1949. She graduated with a B.Sc. in biology from Simmons College, Boston, Massachusetts in 1964, and received post-graduate degrees in plant cell biology (Carleton University, Ottawa, 1985) and neuronal cell biology (University of Ottawa, Ottawa, 1990). Marcia has spent many years researching cell biology, and been published in numerous scientific journals. In 1998 in partnership with other scientists she formed a biotechnology company, BioSoma where she is the scientist in charge of cell biology and animal research. Marcia received a diagnosis of "probable PPS" in 1997 and now works half time.

Eddie Bollenbach is a polio survivor and teaches microbiology, biology, and chemistry at Northwestern Connecticut Community-Technical College. He is a long time and valued contributor to several post-polio mailing lists on the Internet, and is especially noted for his knowledge and skill at communicating the current scientific understanding of the biology and biochemistry of viruses and other scientific topics relating to polio and post-polio conditions.

This article was first published by the Lincolnshire Post-Polio Network in January 1999 on their Internet site http://www.zynet.co.uk/ott/polio/lincolnshire/.

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Introduction and History

Convincing medical professionals of the reality and appropriate treatment of post-polio syndrome was and often continues to be a long, hard, up-hill struggle. Today there is general consensus in the medical community that there are late effects arising from acute paralytic polio infections of 20 to 40 years ago. An increasing number of medical doctors no longer dismiss symptoms of fatigue, pain, and increasing weakness when presented by a person with a documented history of paralytic polio. This is so even though there is no objective test available to diagnose Post-Polio Syndrome (PPS) nor is there agreement on, or a clear understanding of, the etiology of this disease. However, people with PPS symptoms and a history of non-paralytic polio have great difficulty receiving a diagnosis of PPS.

Categories of Acute Polio and the Diagnosis of Post-Polio Syndrome

During the acute polio epidemics earlier this century the following categories were used to classify the extent and seriousness of the disease:

Sub-Clinical Polio The person is unaware of infection and gains active (sometimes lifelong) immunity to infection from that strain. Sub-clinical polio usually occurred in infants and very young children.

Abortive Poliomyelitis In *Current Diagnosis and Treatment* a polio manual for physicians (Brainerd et al, 1968) the symptoms of abortive polio are described as: "Abortive poliomyelitis may simulate acute respiratory infection or gastroenteritis, and is usually not dangerous. The symptoms are fever, headache, vomiting, diarrhea, constipation, and sore throat."

Non-Paralytic Polio Symptoms, quoting again from Brainerd et al (1968), are "headache, neck, back, and extremity pain; fever, vomiting, and abdominal pain, lethargy, and irritability are present. Muscle spasm - spontaneous shortening of the muscle or hyperactive stretch reflex with limitation of extension by pain and contraction - is always present in the extensors of the neck and back, usually present in the hamstring muscles, and variably present in other muscles. Resistance to flexion of the neck is noted after a varying range of free flexion. The patient assumes the 'tripod' position on

sitting up, which he usually does by rolling to avoid flexing the back. Straight leg raising is less than 90 degrees. Spasm may be observed when the patient is at rest or may be elicited by putting each muscle through the maximum range of motion. The muscles may be tender to palpation."

Paralytic Polio The symptoms are: "Paralysis may occur at any time during the febrile period. In addition to the symptoms of non-paralytic poliomyelitis, tremors and muscle weakness appear. Paresthesias (tingling) and urinary retention are noted occasionally. Constipation and abdominal distension (ileus) are common. Paralytic poliomyelitis may be divided into two forms that may coexist: (1). Spinal poliomyelitis, with weakness of the muscles supplied by the spinal nerves; and (2). Bulbar poliomyelitis, with weakness of the muscles supplied by the cranial nerves, and variable "encephalitis" symptoms. Bulbar symptoms include diplopia (uncommon), weakness of mastication, facial weakness, dysphagia, dysphonia, nasal voice, regurgitation of fluids through the nose, weakness of the sternocleidomastoid and trapezius muscles, difficulty in chewing, inability to swallow or expel saliva and respiratory tract secretions. The most life threatening aspect of bulbar poliomyelitis is respiratory involvement due to pontile (central) involvement. Paralysis of the neck flexors is manifested by "neck drop" on lifting the shoulders from the bed. "…deep tendon reflexes are diminished or lost, often asymmetrically, in areas of involvement." (Brainerd et.al., 1968).

Part of the difficulty getting a diagnosis of PPS, arises from the current practice of strictly categorizing the acute polio illness as paralytic, non-paralytic, abortive and sub-clinical. When polio was all too common, it was generally understood that there was a wide range of damage within every patient, even though the patient was assigned to a specific diagnostic category. However as time passed, much practical and unwritten knowledge was lost. One result is that the diagnostic categories of acute polio infection no longer carry the implication that polio damage occurs as a spectrum within every patient. Now a diagnosis of non-paralytic polio raises doubts in the physician's mind that the person had any neuronal damage and even doubts that the person had polio.

Common sense dictates that it was a rare case of polio that did not blend into the adjoining category to some degree. Many sub-clinical cases probably had gastrointestinal symptoms. An abortive case with fever and headache or neck ache, along with muscle spasms, would argue for at least some involvement of the neuronal system. Autopsies on people who had non-paralytic polio, but who died from other causes, show nerve damage and some degree of neuronal death consistent with paralytic polio (Howe and Bodian, 1942; reviewed by Bruno et al, 1995). From such evidence it appears reasonably certain that there was a degree of neuronal involvement in people with non-paralytic polio (Bruno et al, 1991). The damage may have been sufficient to cause weak muscles but not enough to manifest as paralysis (Sharrard, 1955).

In acute polio, the degree of nerve involvement varies within the entire nervous system. Some areas appear clinically unaffected while, in paralytic polio cases, other regions show flaccid paralysis. In abortive polio the nervous system appears undamaged at the symptomatic level. However the symptoms listed for non-paralytic polio are suggestive of neurological involvement. For nerve damage to be visible as weakness or paralysis a threshold of damage to the neuron population must be involved (Sharrard, 1955). When few neurons are damaged or destroyed, the patient presents with no specific muscle weakness or paralysis but can have undetected neuronal damage (Dalakas (a), 1995). We do not know how this will manifest in later life. There were undoubtedly mistakes in diagnosis and misdiagnosis for many patients. Many people with non-paralytic polio probably were paralytic cases with diffuse weakness that recovered quickly (Dalakas (b), 1995).

The Non-Paralytic Polio Problem

Reluctance to diagnose PPS in symptomatic people with a history of non-paralytic polio has many reasons. The cause(s) of PPS is not completely understood. Often there is an assumption that neurological damage is the only cause of PPS symptoms. Physicians and clinicians may have unreasonable expectations of the diagnostic accuracy of electromyographic (EMG) studies as well as the accuracy of other tests. Little consideration is given to evidence suggesting that PPS symptoms can arise from damage to areas of the brain during the acute illness, from persistent polio virus RNA, from auto-immune problems, and from neuronal damage which wouldn't necessarily correlate with the expected electromyograph (EMG) readings.

One misplaced criterion for obtaining a diagnosis of PPS is the necessity for a documented case of paralytic polio. Ironically, the reason for this arises out of early research to study PPS. To be certain that test subjects had early polio, and not some other neurological disorder, researchers required that the subjects in the study group have a documented history of paralytic polio with residual weakness or paralysis in at least one limb. Unfortunately, these criteria have spilled over into the clinical area so that many physicians believe you cannot have PPS unless you have a confirmed diagnosis of paralytic polio, despite the fact that systematic studies have never been done to assess PPS in non-paralytic polio populations.

A “typical” presentation to a physician of a person with a history of non-paralytic polio and current PPS-like symptoms goes something like this. “As a child, I was very ill with a high fever and a headache. I was hospitalized for a few days (or quarantined and not hospitalized). My mother says I was never paralyzed and I was discharged from the hospital with a diagnosis of ‘non-paralytic’ polio. I had cramps and pains in my back and legs and I was very weak for some months afterwards but then I recovered completely and forgot all about polio. I wasn’t very good at sports, but then, neither were lots of other people. About ten years ago (35 to 45 years after the acute illness), I began tripping on smooth floors and occasionally falling. Now everyday jobs like vacuuming tire me so that I have to lie down for an hour or two before I can do anything else. When I’m this tired, I can’t ‘think’, can't focus or remember words. It’s difficult to put in a full day of work. My legs ache after I walk only a short distance and at night the muscles in them ‘jump’ or twitch. My feet are always cold. I can no longer climb a flight of stairs and the weakness in my legs is frightening. I saw a neurologist who specializes in PPS and he said that he saw no evidence that I ever had polio although he did not give me a thorough examination or order any tests. He says I don't have PPS and suggested that my problems are caused by arthritis or fibromyalgia.”

In one specific case of an individual earlier diagnosed with non-paralytic polio, and now complaining of new problems, the neurologist ordered two EMGs in the area the patient said was weak. According to the neurologist, both EMGs were “normal”. From this he concluded that the patient did not have polio and could not have PPS. EMG tests can miss late paralytic polio if the examiner does not find the spot where denervation occurred. With non-paralytic polio EMG positive fiber groups could be difficult to find.

Symptoms, EMGs and a PPS Diagnosis

Accepted symptoms of PPS include: progressive muscle weakness, fatigue and pain (see general review by Trojan and Cashman, 1997). One of the descriptive criteria today for PPS is progressive weakening in muscles unaffected by the original polio illness. Tests in people who had paralytic polio have shown that limbs, previously designated as unaffected, had some degree of damage (Halstead et al, 1995). Clearly, a person with non-paralytic polio could have had an equal amount of damage during the acute infection but would still be classified as having non-paralytic polio. It therefore is reasonable to assume that new weakness can occur in any muscle of a person diagnosed with non-paralytic polio.

Electromyographic (EMG) studies will not show whether or not a person has PPS or is likely to get PPS. EMGs of paretic muscles reveal neuronal damage that occurred during the acute infection and subsequently resulted in the formation of large motor units in muscle (Dalakas (a), 1995). In a person with a history of non-paralytic polio, the presence of an abnormal EMG (one that matches the typical EMG pattern produced by polio affected muscles) is considered proof of previous paralytic polio and usually results in a diagnosis of PPS (Bromberg and Waring, 1991). However a normal EMG can not prove or disprove whether a person had sub-clinical, abortive or non-paralytic polio.

A normal EMG is an indication that the muscle or groups of muscles which were tested did not undergo denervation consistent with paralytic polio. However many clinicians maintain “the lack of clear evidence for previous denervation after extensive electrodiagnostic testing is a valid means for excluding the diagnosis of PPS” (Bromberg and Waring, 1991); a view supported by Gawne et al (1995). This conclusion depends on the certainty that PPS is derived only from motor unit abnormalities and death, and no other metabolic or virological problems within intact neurons play a role - a fact which has not been established. Nonetheless, properly conducted and properly analyzed, EMG tests are valuable for ruling out other neurological conditions and may establish a

history of previous paralytic polio in people with PPS-like symptoms. They should not be used to "prove the negative" (an impossible task), that the person does not have a post viral syndrome due to poliomyelitis.

Fatigue and Non-Paralytic Polio

Severe, debilitating fatigue is another common denominator of PPS. Many people describe two types of fatigue: one relating to muscles and another relating to cognition and alertness (colloquially called "brain fatigue"). It is not known if there are two types of fatigue nor if fatigue is generated by more than one mechanism. What is known is that severe fatigue that responds to rest is found in survivors of both non-paralytic and paralytic polio and is a hallmark symptom of PPS (Bruno et al, 1991 and 1995).

A commonly supported idea is that muscle fatigue results from demands on muscles innervated by neurons damaged in the acute illness or demands on muscles innervated by relatively fragile neuronal "sprouts" which developed to replace destroyed neurons (reviewed by Dalakas, (a,b) 1995, Trojan and Cashman, 1997). There is a hypothesis that "brain fatigue" results from damage to a particular area of the brain involved in maintaining mental alertness, the reticular activating system (Bruno et al, 1991 and 1995). Extensive, post-mortem examinations by Bodian (1949) and others (see Bruno et al, 1995) indicate that some degree of damage to the brain occurred in all polio infections regardless of severity. The 30 to 40 year interval between infection and onset of fatigue could be explained by a combination of damage plus atrophy that occurs with normal aging. However, a counter argument suggests that "brain fatigue" is not a separate entity but a part of the generalized fatigue resulting from overuse of muscles during everyday living. There also is the possibility that "brain fatigue" is caused by a combination of the above factors and possibly others.

What Percentage of Non-Paralytic Cases will Develop PPS?

Estimates of the percentage of people who had acute, paralytic polio and now have PPS range from 25% to 70% or higher and there are predictions that eventually all people who had paralytic polio will have PPS to some degree or other. Statistically there is a minimum of 10 non-paralytic polio cases for every documented paralytic case. What percent of people who had non-paralytic, or possibly even abortive polio, will develop PPS? PPS support groups report that between 1 and 10% of their members had non-paralytic polio as children and now have fatigue, new muscle weakness and pain (Falconer, personal communication). However many non-paralytic cases (and even cases with mild paralysis) were never seen by a doctor and may not know that they had polio. They would not suspect that new muscle weakness, fatigue and pain were due to PPS and would have no reason to join a PPS support group.

A 1951 study of acute polio infection in twins (Herndon and Jennings) and a subsequent follow-up study by Nee et al (1995) showed that 71% of the twins diagnosed with paralytic polio had PPS symptoms. Interestingly, 42% of twins who had not been diagnosed with paralytic polio also developed PPS-like symptoms approximately 38 years after their affected twin was diagnosed with polio. Herndon and Jennings indicate that most "unaffected" twins actually had sub-clinical or non-paralytic polio. Based on this study it seems that nearly half of the people who had non-paralytic polio may develop PPS.

Tests to Determine Prior Polio Infection

Right now there are no tests that prove a person has PPS. However tests which indicate that a person definitely had polio are useful in obtaining a PPS diagnosis. There are tests to measure IgG antibody levels to polio virus strains 1, 2 and 3, as well as antibodies to other viruses including non-polio enteroviruses (Leon-Monzon and Dalakas, 1995). Everyone who was immunized will have some level of antibodies. However people who had an acute polio infection should have higher antibody levels to the infecting strain of the polio virus. Significantly higher levels document previous polio although antibody levels decrease with time, and low levels of antibody to polio virus do not rule out a previous polio infection.

By testing antibodies, a correlation was found between increased levels of a particular kind of antibody, designated as IgM, and people who had acute polio and now have PPS symptoms (Illa et

al, 1995; Leon-Monzon and Dalakas, 1995). IgM antibodies are produced as a "first response" to an infection and may indicate new antibody response to a particular condition, raising the possibility of testing IgM levels as a PPS indicator (Sharief et al, 1991; Dalakas (a), 1995).

A more sensitive test, using the polymerase chain reaction (PCR) technique on cerebrospinal fluid (CSF) obtained from a spinal tap, showed the presence of RNA, derived from polio virus RNA in people with PPS but not in CSF from people without a history of polio (Leparc-Goffart et al, 1996). While this test demonstrates a history of polio infection, the necessity for a spinal tap precludes use as a general test for PPS. Moreover, using this test to diagnose PPS must be approached with caution. Muir et al (1995) found evidence of enteroviruses closely resembling Coxsackie B4 in CSF samples from people with PPS-like symptoms but found no correlation of polio virus RNA and post-polio symptoms (Muir et al, 1996).

Polio Virus, Virus RNA Fragments and PPS

Polio virus is a "lytic" enterovirus that kills the cells it infects, and researchers long believed no virus existed anywhere in the body for more than a short time after the acute infection. However mutations to the polio virus occur readily during infections (reviewed by Blondel et al, 1998). One mutated form of polio virus can persist indefinitely in tissue culture of human neuronal origin (Colbere-Garapin et al, 1989). These infected neuroblastoma cells continuously produce polio virus into the surrounding medium and are not killed by the infecting virus. Another polio virus, with only two mutations in the virus capsid protein, persistently infects cell cultures derived from human fetal brain cells (Pavio et al, 1996). This evidence suggests that the positive PCR samples, in CSF of people with PPS symptoms and described above, represent either a persistent infection in the nervous system or the continuing presence of pieces of RNA derived from polio virus. In either case it is possible that some PPS symptoms are due to the body mounting an immune reaction to the presence of the polio RNA. This theory is supported by autopsy findings of chronic inflammation with the presence of lymphocytes in the spinal cord of a PPS patient (Miller, 1995).

There is a view that PPS patients could be divided into two groups (Hollman, 1986). "The first group has muscle deterioration from the early disease. The second group has problems in new muscle groups or those thought to be recovered from the disease. Problems in the second group are thought to have a cause other than simple aging, possibly autoimmune (in origin)". It is clear that an RNA explanation for the late problems of non-paralytic polio patients could fit into Holman's second group.

Non-Paralytic Polio - Caused by Polio Virus or by a Different Enteroviral Infection?

During polio epidemics it was known that "non-paralytic polio symptoms" were not always due to polio virus. Non-polio enteroviral infections, among others, produced the same symptoms. However, if a patient with non-paralytic symptoms had a sibling or other close contact with a paralytic polio case, then the infectious agent usually was polio virus.

Many non-paralytic cases were due to infection with a less neurovirulent variant of polio virus. Sabin and Steigman (1949) studied an epidemic of "summer grippe" in an attempt to isolate a variant of the polio with lower neurovirulence to make a vaccine. Of their "summer grippe" patients, 50% had a non-paralytic polio caused by a less virulent strain of polio, 20% developed paralytic polio, and the infectious agent of the remaining 30% of patients was not established.

To monitor the strains of polio virus causing a Washington DC epidemic, specimens were obtained from 63 paralytic cases, 87 non-paralytic cases with positive spinal taps and 5 non-paralytic cases with negative spinal taps (Shelokov et al, 1955). Of the paralytic cases, 64% had polio virus strain 1 (pv1), 33% had pv2 and 3% had pv3. Of the non-paralytic cases, 25% had pv1, 10% had pv2 and 4% had pv3 while 61% were untypable and presumably had an infection other than polio virus. Interestingly, of the 5 cases with normal spinal taps, one had pv1, one had pv2 and the other 3 were untypable.

The percentage of non-paralytic cases caused by polio virus or another virus varied enormously. During a polio epidemic in Hawaii in 1957, specimens were obtained from 38 people with paralytic polio and from 39 cases of non-paralytic polio. "Of the 38 cases of paralytic disease, type 1 polio

virus was implicated in 33, Coxsackie B2 virus was isolated in 2 and no diagnosis was established in 3. Of the 39 cases of non-paralytic poliomyelitis, only 4 were related to type 1 polio virus. There were 16 cases of echovirus 9, 7 cases of Coxsackie A9, and 4 to 5 other enteroviruses." (Johnson 1995).

Depending upon the epidemic, 70%, 39% or 10% of non-paralytic cases were caused by infection with polio virus. It is not prudent, therefore, for an examining physician automatically to conclude that a patient with a history of non-paralytic polio actually did not have polio.

PPS-Like Symptoms and Enteroviral Infections

Polio virus is one of more than 70 enteroviruses. A number of enteroviruses (Coxsackie A9 [Gromeier et al, 1997], enterovirus 70 [Gromeier et al, 1997], enterovirus 71 [Melnick, 1984], Japanese encephalitis virus [Solomon et al, 1998] and others) can cause polio-like paralysis. These non-polio enteroviral infections may cause PPS-like symptoms as well. Coxsackie virus RNA has been isolated from people with PPS symptoms (Muir et al, 1995), although it is not known if this is a common event. If PPS arises from neuronal damage, then intuitively, enteroviruses causing symptoms that are clinically identical to polio could cause similar neurological damage during the acute illness which in turn would give rise to PPS-like symptoms in later life. If PPS arises from an immune response to continuous presence of viral RNA, then finding enteroviral RNA (other than polio) in people with PPS symptoms, as was shown by several researchers, also indicates PPS-like symptoms could occur from non-polio virus infections.

Non-Paralytic Polio and PPS

With respect to a diagnosis of PPS for people with a history of non-paralytic polio and PPS symptoms, there are at least four separate possibilities:

1. The person had non-paralytic (or abortive) polio. At the time of the acute illness there was no obvious damage to the nervous system although unobserved damage was likely. There are no established figures for the minimum amount of neuronal damage which can result in PPS symptoms. Exclusion of a diagnosis of PPS on the basis of a history of non-paralytic polio is not merited.

2. The person actually had paralytic polio but was misdiagnosed. Symptoms of paralysis and/or weakness were missed or the symptoms manifested only for a short time. The patient recovered (apparently) fully within a matter of weeks. This type of polio often was labeled as “non-paralytic”. PPS will occur with the same frequency as in paralytic polio cases. Diagnosis of PPS on the same basis as for a patient with a history of paralytic polio is merited.

3. The person did not have polio but had another disease with clinical symptoms similar or identical to polio and currently presents with PPS symptoms. Some evidence supports the hypothesis that non-polio enteroviruses can have late, post-viral effects. If these people have post-viral symptoms identical to PPS, require the same management and have the same prognosis, should they be included under the PPS heading?

4. The person presents with PPS-like symptoms but the cause is not post-viral in origin. More medical examinations are required for the patient and a diagnosis of PPS is not merited.

It is vitally important that people with PPS-like symptoms see a physician since other neurological diseases can have similar symptoms. However, when these diseases have been ruled out then the doctor should consider PPS, especially if the person has an oral history of having had polio. Moreover a documented history of paralytic polio should not be the exclusive criterion obtaining a diagnosis of PPS.

Conclusions

A history, either oral or documented, of non-paralytic polio is not sufficient reason, by itself, to exclude a diagnosis of PPS. PPS symptoms may have both physical and molecular origins including neuronal damage, persistent viral RNA and immune response. In the case of non-paralytic polio, some amount of damage to neurons almost certainly took place and this may be sufficient to cause PPS symptoms of new muscle weakness, fatigue and pain. If the presence of persistent

viral RNA and/or the immune response or other molecular events can precipitate PPS, then even the absence of neuronal damage does not preclude developing PPS. A history of any kind of polio indicates the disease was severe enough to cause damage. However with only 2 years to the 21st Century we still have no objective test for Post Polio Syndrome. Considering the number of people affected and the morbidity and cost to our population, the cause of PPS should be a priority for clinical research in the next few years.

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A Conference for Your Diaries

The Network has been advised that a Neurological Care Conference for Health Professionals, Consumers, Carers and Friends, entitled

Networking Neurones - Joining The Links

will be held on **18 and 19 June 1999** at the **National Convention Centre, Canberra**.

The Keynote Speakers will be:

Professor D Burke
Professor of Neurology
University of New South Wales

Dr Meg Morris
Kingston Centre
Melbourne

The key themes of the Conference are: research and latest developments, best practice, management of your/your client's condition, and psychological and neuro-psychological management.

The Conference is being organised by the *Motor Neurone Disease Association of ACT* with support from *Alzheimers Association*, *Stroke Association*, *Respite Care ACT Inc*, *MS Society*, and *ACT Community Care Community Health Care Program*.

We are currently talking with the organisers regarding including a session on polio and its late effects, and will provide more information as it comes to hand. In the meantime, to obtain a brochure and registration details contact:

Motor Neurone Disease Association of ACT
PO Box 126
Charnwood ACT 2615

Telephone: (02) 6287 4343
Fax: (02) 6287 4344

Are You?

Are you an active member?
The kind that would be missed.
Or are you just contented,
That your name is on the list?

Do you attend the meetings,
And mingle with the flock?
Or do you stay at home
And criticize and knock?

Do you ever work on committees,
To see there is no trick,
Or leave the work to just a few
And talk about "the clique"?

There's quite a program scheduled,
That means success if done,
And it can only be accomplished
With the help of everyone.

So come to meetings often,
And help with hands and heart.
Don't be just a member,
But take an active part.

The author of this poem is *Unknown*.

The poem was published in an American post-polio newsletter called *Polio Epic* in February 1998, and reprinted in the *Rancho Los Amigos Post-Polio Support Group Newsletter* in January 1999.

The poem highlights the problems experienced by voluntary organisations: only a few members are prepared to take on the work necessary to keep the organisation functioning. All committees, including the Network's, need and welcome more help.

If you are able to assist us in any way, no matter how small, we would like to hear from you. For example, this year perhaps you could:

- help out in our office once a month,
- support our fund-raising activities,
- help to plan and organise our Tenth Anniversary celebrations, and
- help to plan, organise and/or participate in Post-Polio Awareness Week (1-7 November).

A Great Read about Coping with Post-Polio

Mary Westbrook

1998 saw the publication of *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, the most informative, readable and relatively cheaply priced book yet to appear on this topic. Dr Lauro Halstead, an American rehabilitation specialist who was responsible for early research and conferences on PPS, is the editor. Halstead has himself experienced polio and its late effects. One of his goals in writing the book was "to distil and summarise in lay terms the wealth of information presented at conferences and published in the medical and allied health literature over the past 10 to 15 years". The 13 chapters and seven personal stories are written by 20 authorities in their fields, the majority of whom are polio survivors.

Halstead describes how people who developed PPS felt anger, bitterness, and despair. "Fortunately, the feelings did not stop there. The knowledge and skills of not just how to endure but to prevail... were still intact. Our shared history of knowing how to overcome adversity led us to take action that, once again, turned our lives around and made us feel proud to be called survivors. One step was to stimulate the medical community to take our new health problems seriously. Over the years this has led to a significant increase in the attention given to polio by researchers and clinicians leading to a more precise definition PPS, a better understanding of the possible causes, and the development of more rational and effective strategies for its management".

In the first two chapters of the book Halstead gives a detailed, easily understood account of the stages of acute polio, PPS and its causes and management. There are sections on the evaluation and treatment of muscle weakness, fatigue, pain, respiratory complications, swallowing problems, and cold intolerance. These and the section," Important considerations when getting ready for surgery", would be useful to copy and give to appropriate health practitioners. Halstead comments that new muscle weakness has been the easiest symptom of PPS to research and there is now a better understanding of this than of any other symptom. The most common symptom of PPS, fatigue, is more difficult to investigate and much less is known about its causes. Halstead distinguishes peripheral fatigue, which is felt in muscles after repetitive contractions, from central fatigue which is for many people the most disabling symptom of PPS. It is characterised by "the rapid onset of mild to extreme tiredness, generalised headache, difficulty in concentrating and general malaise".

There is a long chapter on energy conservation by Grace Young, an occupational therapist. She gives advice on using your body efficiently and making your environment user friendly. Laura Smith, a physiotherapist, discusses the preservation and protection of muscle and joint capacity and how to manage injuries, pain and fatigue. She describes the abnormal forces that occur in polio bodies because of the substitution of other muscles or ligaments in compensation for muscle losses. "Substitute muscles may have had to pull at an angle and apply a greater force in a different direction. In mechanical terms, this situation would be like running an automobile on three cylinders (instead of six) with the front end out of alignment." She says that health practitioners frequently do not appreciate the complex causes of post-polio pain so they provide only temporary relief by prescribing medication and heat. Another chapter discusses starting, running and being a member of a support group. In the introduction to the book Halstead tells of the hundreds of PPS support groups that emerged overnight in the USA. He says that such support groups are not only a way reaching out to others with similar new problems but also part of a journey of self-discovery. "In my own case, it was only after I joined a local support group and began talking with other polio survivors that I started to grieve the body I had lost more than three decades earlier. Although I have still not made peace with my disability, and probably never will, I'm getting better at incorporating it into my life and the person I am."

There are two excellent chapters by psychologist, Rhoda Olkin. In the first she discusses psychosocial aspects of PPS. Because we live in a non-disabled world we are bicultural and much of our experience is only fully understood and shared by other people with a disability. Many polio survivors describe discovering the disabled community as 'coming home'. "This statement is not meant to minimise some of the emotional difficulties of identifying yourself with a group of people with disabilities. When I first walked into a room full of people in wheelchairs, little people, people using sign language... I thought, 'I'm not one them. I had polio, but they're disabled'. It took a while

to sense how comfortable this group was for me, how so much that went unsaid was understood". In her second chapter Olkin discusses how PPS effects our relationships with our families (parents, partners and children) and includes self-assessment items and suggestions for increasing well-being. Sexuality, parenting and ageing are covered. Although ageing presents additional problems for polio survivors, "We also come with some strengths; we have been members of a disadvantaged group of lower status (persons with disabilities) and hence have learnt ways of coping prior to entering a second group of lower status (the elderly). We've developed ways to cope with functional losses. Further, we've developed wisdom through experience. We've learnt that we have to prioritize *everything,* give up on some items further down the list of priorities, and make compromises."

Other chapters describe how to get the most out of visits to your doctor and strategies for coping at work as your health declines. Another is a guide to the Internet, giving information on using the Net as well as a list of PPS resources available there. The chapters on gaining social security benefits and navigating managed medical care will be of little value to Australian readers. However they will relate to polio survivors' stories of various aspects of the polio experience. For example, Hugh Gallagher describes the stress and final relief of moving from a manual to an electric wheelchair, two people write of the need to change their job or retire because of PPS, others of embracing their pasts. Carol Gill writes, "To relinquish the strain of trying to be nondisabled and to let go of it deliberately, in celebration, not in disgrace, is a truly liberating idea. Far from giving in or giving up, self-acceptance is an empowering process". There are also eight pages listing additional resources: primarily books, articles and web sites.

This is an excellent book. It is the book I would recommend to any newcomer to the post-polio scene, whether they are a survivor or a health practitioner. It also has a great deal to offer 'old hands' being full of facts and ideas to which you'll often want to refer. **The book may be purchased from Post-Polio Network (NSW) Inc for $25, including postage.**

A NEW SURVEY OF POLIO SURVIVORS

Recently the Vice-President of the Network, Merle Thompson, conducted a mail survey of members to gather up-to-date information regarding their problems and needs. The questionnaire was completed by 372 members up until October 1998. The survey revealed that although the average member is 59 years of age, members range in age from over 80 to under 30. Some members are migrants who contracted polio overseas after the vaccines were readily available in Australia. The majority of respondents (69%) contracted polio before they were 10 years of age. Nearly 80% have lower limbs affected by polio and over 50% are affected in other areas of the body. The new difficulties most frequently reported in the survey are unusual tiredness (experienced by 81% of respondents), sensitivity to cold (73%), muscle pain (70%) and joint pain (69%). The areas of the body where survivors are experiencing most new muscle weakness are their backs, hips and legs. Mobility is a major issue. Only about 50% can now walk on a level surface without difficulty and over 80% experience difficulties with uneven surfaces or stairs. Most respondents (79%) use one or more aids. Considerable concern was expressed about the cost of equipment such as scooters and wheelchairs. The majority of survivors experience problems in a range of everyday living tasks. For example, 58% have problems shopping, 37% have problems bathing or showering, and 84% say that their disability restricts them from participating in physical recreation or sport. Over half of those who are retired say that they were forced to retire early due to the late effects of polio.

A 54-page report *Polio - A Challenge for Life - The Impact of Late Effects* which analyses in detail the complete survey results has been published. With the release of the Report we now have quantitative (rather than merely anecdotal) data about the impact of the late effects of polio on people's lives. How polio survivors are living with and managing the late effects is powerfully documented. **The Report** has been widely distributed to government and community health authorities, and **may be purchased from the Network. Members pay just $12 while the cost for non-members is $22, including postage.**

Support Group Report

Bernie O'Grady **Phone: (02) 9688 3135**
Support Group Co-ordinator

This issue I am providing the yearly updated listing of Network Support Groups. If you would like to join any of these Groups, just get in touch with the Convener.

Brief meeting details for each Group are given - contact the Convener for further information. If you plan to attend a meeting for the first time, it is always wise to confirm the date and venue with the Convener.

A Telephone Support Group is a good alternative where members find travelling difficult. Some Groups meet exclusively by telephone, while for others this is but one facet of their Group. Remember that you don't need to meet in person to give support to each other.

You might also be interested in joining a letter-writing "Round Robin" where an exercise book is regularly sent around a list of members, starting and ending with the Convener. Participants read other members' contributions and add their own. The Northern Inland Support Group has two very successful Round Robins in operation.

Finally, we still have some areas which do not yet have a local Group. If you can help to get a Group started in any region not mentioned below, please give me a call.

Metro Group	Support Group Convener		Meeting Details
Blacktown / Blue Mountains	Bernie O'Grady	(02) 9688 3135	• Meetings held 3rd Monday of the month (except Jan and Dec), Kingswood Community Centre, Cnr Bringelly Rd and Baden Powell Ave, Kingswood, 11:00 am to 1:00 pm
Campbelltown	Brian Toby	(02) 9618 2279	• Telephone Support Group
Fairfield	Andreana Salapatis	(02) 9727 2323	• Telephone Support Group
Hawkesbury	Irene Alexander	(02) 4577 7685	• Telephone Support Group
Hornsby	Kerry Jenkin	(02) 9476 1468	• Telephone Support Group • 1999 Meetings scheduled: 8 March, 6 May, 12 July, 9 September, 8 November at 20/1-5 Linda Street, Hornsby, commencing at 2:00 pm
Manly Peninsula	Joan Clarke	(02) 9976 5442	• Telephone Support Group • Regular Meetings also planned once a suitable meeting place is identified
Northside	Ruth Wyatt	(02) 9416 4287	• Meetings held on the 1st Saturday of every second month, starting February
Upper Blue Mountains	Liz Lynes	(02) 4788 1170	• Telephone Support Group

Country Group	Support Group Convener		Meeting Details
ACT	Brian Wilson Roger Smith Susan Wallis	(02) 6293 2747 (02) 6247 6058 (02) 6242 0026	• Meetings held on 1st Saturday every second month, starting February, Pearce Community Centre, 2:00 pm to 5:00 pm
Albury	Neil von Schill	(02) 6025 6169	• Meetings held 3 or 4 times a year - phone for details
Central Coast	Barbara Tunnington	(02) 4369 2397	• Meetings held on the 1st Saturday of each month from 10:00 - 12 noon at Kincumber Multi-Purpose Centre
Coffs Harbour	Joan Ward-Harvey	(02) 6651 3104	• Meetings are held the 3rd Sunday of the month starting at 11:00 am, alternating between the Coffs Harbour Catholic Club and the Urunga Golf Club
Cowra	Vera White	(02) 6342 2647	• Telephone Support Group • Meetings may also be held
Grafton	Susan Stewart	(02) 6644 7789	• Re-starting after recess - ring
Hunter Area	Wendy Chaff	(02) 4957 5254	• Meetings held on the 1st Wednesday of the month (except January) starting at 10:30 am, Toronto Workers Club, James Street, Toronto
Lower South Coast	Cliff Cook	(02) 6494 4113	• Regular meetings held - phone for details
Northern Inland	Barbara Chapman-Woods	(02) 6766 5093	• Telephone Support Group • “Round Robin” letter writing • Meetings held quarterly
Northern Rivers	Rosalie Kennedy	(02) 6620 2329	• 1999 meetings at Ballina Hospital: 20 Feb and 17 April • 1999 meetings at Lismore Workers Club: 19 June, 14 Aug, 16 Oct and 4 Dec
Nyngan	Marion Wardman	(02) 6832 1350	• Telephone Support Group
Shoalhaven	Dorothy Schunmann	(02) 4448 7541	• Meetings held 3rd Friday of each month in Nowra Council building underneath Library, Berry St, from 2:00 to 4:00 pm
Wellington / Dubbo / Orange	Hugo Orro	(02) 6846 7272	• Telephone Support Group
Wollongong	Dorothy Robinson	(02) 4229 6221	• Regular meetings held - phone for details
Young	Jean Robinson	(02) 6382 4337	• Telephone Support Group

POST-POLIO POST

Member Beryl Sinton wrote to take me to task for not including a warning about taking benzodiapines when I published an article in the last Newsletter. Beryl makes the valid point that caution should be exercised when taking drugs, especially those known to cause adverse reactions in polio survivors. Remember to always advise the health professionals you consult that you have had polio, share with them articles from this Newsletter and other Network publications, and fully discuss any concerns you may have about drugs being prescribed.

Your latest Post-Polio *Newsletter*, Issue 39 - December 1998, contains an article, *Abnormal Movements in Sleep as a Post-Polio Sequelae* by Richard L Bruno PhD (page 8). The following drugs were prescribed by Doctor Bruno for various medical conditions:

Clonazepam
Lorazepam
Alprazolam
Benzodiazepine

These drugs all belong to the Benzodiazepine group. We are warned of the dangers of taking this drug. References:

A Practical Approach to the Late Effects of Polio (Charlotte Leboeuf)
Your own *Polio Medical Alert Card*

I was disappointed that there was no Postscript to this article warning of the dangers of taking this particular medication. This drug was prescribed for me 16 years ago before I was aware of Post-Polio Syndrome and the fact that we should not take, or be wary of, certain drugs but, only last year, it was prescribed for a friend in Western Australia. In both cases we took only one or two tablets and in both cases the effects were really horrific. It is obvious that some, perhaps many, doctors are still not aware of the dangers of prescribing certain drugs for us and equally obvious that some, perhaps many, post-polio people are also unaware of what drugs we should avoid. Therefore, it is incumbent upon those of us who do know what drugs to avoid to be vigilant and point to the dangers whenever possible.

Thank you for the many interesting articles and information contained in your Newsletters.

I forwarded Mrs Sinton's remarks to Dr Bruno, and asked him for any comments he would like to make in response. His reply included the following:

After about 10 years giving lowest-dose benzodiazepines (Valium-like drugs) for abnormal movements in sleep, we have had not one adverse reaction or dependence problem in a polio survivor.

Of course, as we have written, high-dose or IV benzodiazepines can be a problem, causing fatigue or prolonged sleeping after surgery or a procedure, like a colonoscopy. Please refer readers to the *Preventing Surgical Complications* article in the PPS Library.

The article referred to by Dr Bruno, The Knife Is Not So Rough If ... Preventing Complications In Polio Survivors Undergoing Surgery, was published in Newsletter Issue 31, March 1997.

For those with Internet access, Dr Bruno and Dr Frick have a Web site where you can access their PPS Library which includes all of their papers describing their research and treatment of PPS. The Internet address is http://members.aol.com/harvestctr/pps/lib.html.