



# POST - POLIO NETWORK (NSW) INC.

## NEWSLETTER

Editor: Gillian Thomas  
Email: [polio@fastlink.com.au](mailto:polio@fastlink.com.au)  
Website: [www.post-polionetwork.org.au](http://www.post-polionetwork.org.au)

PO Box 888 Kensington  
NSW AUSTRALIA 1465  
Phone No: (02) 9663 2402

### President's Corner

Gillian Thomas

At the Network's tenth Annual General Meeting held on 31 October 1998, the following members were elected to the Management Committee. The incoming Committee is already working hard to further the Network's goals.

Gillian Thomas	<i>President / Newsletter Editor</i>
Merle Thompson	<i>Vice-President</i>
Alice Smart	<i>Secretary</i>
Peter Preneas	<i>Treasurer</i>
Carmelita Bongco	<i>Minutes Secretary</i>
Anne Buchanan	<i>Information Bulletin Co-Compiler</i>
Jan Burgess	<i>Publicity Officer</i>
Bernie O'Grady	<i>Support Group Co-ordinator</i>
Anne O'Halloran	<i>Funding Co-ordinator</i>
Allan Quirk	<i>Committee Member</i>
Mary Westbrook	<i>Seminar Program Co-ordinator</i>
Ruth Wyatt	<i>Office Co-ordinator</i>

On 27 October I and three other Network members (Hazel Atkinson, Bernie O'Grady, and Allan Quirk) presented a session on Post-Polio Syndrome in an *Orthopaedic Nursing Course* conducted by the *Northern Sydney Area Health Service*. This gave us an opportunity to relate our polio stories and speak directly to nurses about how individual our polio-related disabilities are, and the implications this has for nursing care. Our session was very well received and plans are in progress for Network members to participate in similar courses run by other Area Health Services.

Post-Polio Awareness Week was held from 1-7 November. Thanks to your magnificent support in promoting the Week, we received many new enquiries, and several members told their stories via their local radio stations and newspapers. We also had national coverage on *ABC News Radio*.

Office Co-ordinator Ruth Wyatt recently convened a meeting of members who have volunteered to staff the Network's office within the *Royal South Sydney Community Health Complex*, Joynton Avenue, Zetland. We are planning to officially open the office from 2 February 1999, with two volunteers rostered to staff it from 10:00 am to 2:00 pm, Monday to Friday. To achieve this we still need more volunteers, so if you can help, please contact Ruth on (02) 9416 4287 or Alice on (02) 9747 4694.

The following are included with this *Newsletter*:

- \* A 1999 Calendar which features some of the Network members who attended this year's Conference in Canberra. If you don't need the Calendar, please don't throw it out - pass it on to a friend or put it up somewhere in your local community. We must all try to bring the Network to the attention of polio survivors who may not be aware of our existence.
- \* An Order Form for the 1996 Conference Proceedings and audio tapes, the 1998 Conference audio tapes, our membership survey report *Polio - A Challenge for Life - The Impact of Late Effects*, and our popular Network T-Shirt.

Finally, if your address label still reads "Renewal Due on 1 July 1998" we have not yet received your membership renewal. In this case, you will find a Membership Renewal Form enclosed. Please help us to help you by sending in your membership subscription as soon as possible.

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# Orthotics Outlook

**Michael Gurry B.Prost.&Orth., M.A.O.P.A.  
Orthotic Consultants Asia Pacific Pty Ltd**

In the first edition of *Orthotics Outlook* an introduction as to who an Orthotist is and where you can find additional information regarding your orthoses was covered. In this edition the way in which orthoses are described will be covered as well as the basics of foot and ankle foot orthotics.

## Nomenclature

The way in which an orthosis is described is by which parts of the body the orthosis covers and which joints it encompasses. For example an AFO is an Ankle Foot Orthosis, a KAFO is a Knee Ankle Foot Orthosis, an LSO is a Lumbar Sacral Orthosis and a TLSO is a Thoracic Lumbar Sacral Orthosis. As well as these broad descriptions of the orthosis, a more specific breakdown of the type of orthosis may be described by the function and type of materials and components used. For example an AFO may be plastic or metal. It may have an ankle joint or be fixed. It may assist function or resist movement. So in a description of an AFO we may say: "a thermoplastic AFO with Tamarak ankle joints and posterior adjustable plantarflexion stop".

## Foot Orthoses

Foot orthoses is an area where orthotists and podiatrists overlap in terms of treatment. You are probably aware that for many years there has been a fundamental difference in the way in which the two professions approach them. Orthotists have for many years fabricated what are classed as semi-rigid style foot orthoses while podiatrists have fabricated more rigid styles. Neither are right or wrong. In fact we are finding that there is much common ground in the middle using some of the podiatry alignment techniques with orthotists' material selection and fabrication know-how. It is a fast evolving area with many podiatrists using more flexible materials. Foot orthotics can play a major part in changing the alignment of higher body components. They can therefore have a beneficial role to play. However great care is required at the time of assessment to ensure that the body hasn't rigidly adapted to a set alignment, in which case the orthosis may aggravate, or even cause, other pains or complications. Not everyone needs foot orthoses.

## Ankle Foot Orthoses (AFO)

As mentioned above AFOs may take many forms. The thing to keep in mind is the outcome you are trying to achieve. The functional requirements will determine the style of components used. The physical condition of the limb will determine the materials to be used. The size and weight and activity level of the individual may influence the strength required. Plastic AFOs can be light weight, moved easily between shoes, are cosmetically sensitive and if fitted well can provide excellent control. The contra-indications for plastic are those people with decreased or no sensation, or thin papery skin, diabetics and those whose limbs swell a lot during the day. Metal AFOs are indicated where plastic is a contra-indication. The metal can be heavier, less cosmetic and requires all shoes to be modified, but does have minimal contact with poor skin and does allow for fluctuating swelling in the limb. Your orthotist in the course of his/her assessment can discuss the needs and outcomes you wish to achieve and formulate a realistic and achievable treatment plan.

If you have any questions ring your local orthotist or contact me on Phone: (02) 9553 6669, Email [orthcon@hutch.com.au](mailto:orthcon@hutch.com.au). I look forward to your correspondence and wish you all a safe and happy Christmas and New Year.



# Recognising the Effects of Non-Polio Health Problems on Post-Polio Symptoms

**Frederick Maynard MD**

*Frederick Maynard, MD, is Medical Director and Clinical Director, Department of Physical Medicine and Rehabilitation, MetroHealth Center for Rehabilitation, and Faculty, Case Western Reserve University, Cleveland, Ohio.*

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I want to talk about problems unrelated to a polio history and polio residuals: the co-morbidities, or other medical conditions that have nothing to do with one's polio condition but that may occur during the course of living and growing older.

Polio survivors can and do develop common medical problems like diabetes and heart disease, for example, that accelerate the decline in their nerve conduction velocity and further disrupt the functioning of their polio damaged motor units. Such an "extra" medical problem has a bigger effect on the ability of survivors to walk, to care for themselves, or to work than it would in people who have the same degree of diabetes and nerve conduction problems but did not have any original weakness in their muscles from polio nerve damage.

Secondary disability is another name for new medical conditions that can occur during the life of a person with a disability (see *Polio Network News*, Vol. 11, No. 1, p. 3). If we consider previous paralytic polio as the primary disabling condition, and then add in the influences of individual lifestyle and behaviour, of the environment, of intrinsic genetic biology, we have the mediating factors that determine whether new pathologies (like coronary artery disease or diabetes or intestinal problems) will progress to result in new impairments (greater weakness) or greater functional limitations (more trouble walking). If you have an initial primary disability (polio), and then you get something else (diabetes), you may develop secondary disabilities of greater impact more quickly than someone without polio. Of course, the degree of impairment and disability can influence one's quality of life.

There are a lot of different trajectories or downhill courses for functional capacity over the lifespan of a person with polio. I believe that the biggest determinant of the polio survivor's slope is whether they do or do not develop other medical conditions: how many and how severe they are. These conditions lead to the disabling weakness and fatigue associated with the name "post-polio syndrome". Loss of function can occur quickly if you have an injury or a severe, sudden onset of a medical condition. For example, after a heart attack, you have such reduced heart function that you cannot exercise or remain active for very long. This will quickly result in greater muscle weakness and more trouble walking. When such conditions come on, they can rapidly sap your strength and make life much more difficult.

When Lauro Halstead, MD, National Rehabilitation Hospital, Washington DC, interviewed some 10 injured post-polio survivors, regarding how long it took them to recover from an injury as compared to people without polio, he estimated that it took approximately 12 times as long. A rule of thumb is that for every one day "normal" people spend in bedrest and



undergo deconditioning of muscle, heart, and lung function, they must spend at least two or three days working to regain the lost functional capacity of these organs. Polio survivors may have to spend 10, 12, or 15 days fighting to recover from every one day of forced inactivity.

When my research colleagues and I at the University of Michigan studied co-morbidities, or "other medical conditions", in 120 polio survivors, we found that 35% of them - an amazingly high percentage - had other medical conditions. Furthermore, there was a high correlation between survivors with other conditions and those reporting reduced ability to remain active and do their usual activities, that is, those who demonstrated functional decline. A common secondary condition associated with functional decline was obesity, and we used 30% over optimal body weight as our definition of obesity, not just a few extra pounds.

Elevated cholesterol ratio was another secondary condition associated with functional decline. I am not sure exactly what this finding means other than that polio survivors are probably more at risk for hardening of the arteries and coronary artery disease, conditions associated with elevated cholesterol levels, because they are less active.

Our study also indicated that polio survivors are at a very high risk for neuromusculoskeletal impairments: more than half had shoulder pain, 58% had abnormalities in conduction velocity of the median nerve at the wrist, and at least 30% had carpal tunnel syndrome. Arthritic changes in the bones of the hand were higher, of course, among people using crutches, or using their hands to move themselves about in a wheelchair.

Another important co-morbidity is depression. Contrary to some previous studies, we did not find an overall increased incidence of depression: only about 18% of the entire sample were depressed, a percentage actually lower than it is for non-disabled groups of people. Living alone and having new health problems were among the strongest correlations with depression. Post-polio people who did not seek out information or professional help, possible indicators of poor coping skills, also were more likely to be depressed.

Overall, I am urging people to not look at post-polio syndrome as a new disease entity in and of itself. Rather, I am suggesting that they consider it from a life-course perspective as an "at risk" condition that results from the original polio and its resultant disability, and that is triggered by the onset of other medical co-morbidities, whether obesity, depression, heart disease, diabetes, stress, or something else. How polio survivors respond, both psychologically and behaviourally, as well as medically, to the onset of this other condition will determine their course of possible functional decline during the rest of their lives.

Consider a person who has been walking with crutches for years and begins to have shoulder pain. There are two ways that one could view this condition. The first is: as the crutch walker gets older and the collagen tissue that supports the structures of the shoulder joint become stiffer and less elastic, the shoulder begins to wear out. This view considers shoulder pain as an age-related, reduced load-bearing ability of the shoulders that causes them to hurt more than they once did. The second viewpoint is: as the shoulders grow less resilient, they are used less and their muscles become weaker. There may be some shoulder muscle atrophy along with the changes in shoulder joint tissues. At this point, the polio survivor may say, "Oh, my goodness, I am developing post-polio syndrome; my muscles are getting weaker, and, therefore, my shoulders are now hurting because my muscles aren't strong enough to support them any longer. Post-polio syndrome has caused my new pain and inflammation in the shoulder tissues."



These two viewpoints differ in their attribution of causation for shoulder pain. "Attribution theory" suggests that our emotional responses to negative events in our lives is largely determined by our explanation for why the negative event occurred. Did I develop cancer because God is punishing me? ... because I ate the wrong foods? ... because they polluted my water? or ... because cancer sometimes develops by chance? Similarly, how survivors explain their individual situations can be very important to what they do about their new symptoms.

**Figure 1**  
**Contrasting Paradigms for Evaluating Post-Polio Syndrome**

	<b>Traditional Medical</b>	<b>Life-Course</b>
<i>Viewed as</i>	Disease / Illness	At-Risk Life Event
<i>Goal</i>	Cure	Prevention
<i>Orientation</i>	Treatment	Management
<i>Etiology</i>	Unknown	Known
<i>Promotes</i>	Fear	Self-Awareness
	Anger	Emotional Growth
	Hopelessness	Information Seeking
	Dependency	Life-Style Change
	Multiple Medical Evaluations	Health Promotion

When I put together Figure 1, *Contrasting Paradigms for Evaluating Post-Polio Syndrome*, for the National Institutes of Health scientists, I wanted to offer that there are advantages in looking at post-polio syndrome as a condition that occurs in the life course of people who have had previous paralytic polio (the holistic model) rather than as a condition that views post-polio syndrome as a new disease and illness (the traditional model).

The medical model expects a cure and prescribes treatment, as opposed to the life-course model, which focuses on prevention and management of problems as they occur. On the one hand, we have an unknown cause for a new disease of post-polio syndrome; on the other hand, we have age-related factors and other medical conditions occurring in people with prior polio. I think that the traditional medical model of post-polio syndrome promotes fear, anger, dependency, hopelessness, and feelings that lead to multiple expensive medical evaluations, whereas the broader perspective of "post-polio syndrome" as a life-course event helps promote self-awareness and emotional growth.

## **Vale - Elizabeth Hastings**

We were deeply saddened to learn of the death of Elizabeth Hastings in Melbourne on 13 October 1998 of breast cancer, aged 49. Elizabeth contracted polio as a two-month old baby and used a wheelchair throughout her life. Appointed in 1993 as Australia's first Disability Discrimination Commissioner, Elizabeth's contribution to the promotion of the rights of people with disabilities was significant; she was never afraid to push forward into controversial areas and did so with profound awareness and critical insight. In August 1994, Elizabeth spoke to Network members of her ground-breaking work. We have written to Elizabeth's family to express the Network's condolences.

## **Wanted To Buy**

**Dick Ronan** (Tamworth) wishes to buy a 3-wheel rear-wheel-drive wheelchair with a chain-driven hand crank. If you have such a wheelchair and are willing to part with it, Dick would love to hear from you on (02) 6765 6858.



## Dr Henry writes ...

*Henry Holland MD, is a polio survivor, a board certified psychiatrist and an associate clinical professor of psychiatry at the Medical College of Virginia who has led the Central Virginia (Richmond) PPS (Post-Polio Syndrome) Support Group for the past two years.*

*He had a serious case of polio at age 11 in 1950 and accepted a permanent tracheostomy in 1970. His PPS symptoms started in 1990, and he was recently forced by them to give up his practice.*

*Dr Holland writes "I have learned a lot from reading the postings to the (Internet) Post-Polio Mailing Lists. I have noticed considerable questioning about medical matters in regard to PPS, various pros and cons of medications, and a variety of alternative and non-traditional treatments for PPS which may help some but not others. As a physician, I have observed a fair amount of doctor bashing, much of which may be justified. I have decided to begin posting to possibly be of some help to other PPSers and hopefully to provide some medical balance."*

*A series of Dr Holland's posts appears on the Internet on the Lincolnshire Post-Polio Network's Web site [www.zynet.co.uk/ott/polio/lincolnshire/](http://www.zynet.co.uk/ott/polio/lincolnshire/) under the title "Dr Henry Writes ...". Dr Holland has generously given us permission to reproduce his articles in the Newsletter and the first one I have chosen addresses a topic we are all familiar with. Dr Holland's permission must be sought to reprint any articles published in this series.*

### Massive Denial

**Henry Holland MD**

**Richmond, Virginia, USA**

**23 April 1998**

Denial is a word that is frequently overused in American life. We hear it used as it pertains to the method in which many substance abusers or their co-dependent spouses cope. Elizabeth Kubler Ross identified denial as one of the early stages in the process of dying from a terminal illness such as cancer. In the book of Matthew in the New Testament, even Jesus advocates self-denial as a virtue when he says, "If any man will come after me, let him deny himself, and take up his cross, and follow me." The dictionary offers several definitions for denial such as rejection of a request, refusal to admit the truth of a statement or charge, disavowal, and restrictions on one's own activity or desires. Perhaps all of us, at one time or another, have exercised denial in these four ways. In the psychodynamic world, denial is recognised as a defence mechanism. What is a defence mechanism? A defence mechanism is defined as an unconscious intrapsychic process serving to provide relief from emotional conflict and anxiety. Conscious efforts are often made for similar reasons, but most defence mechanisms are unconscious, meaning that their use is not a rational, wilful cognitive function of our personalities. Denial is one of at least 17 recognised unconscious defence mechanisms of our personalities. As a defence mechanism, denial is defined as an unconscious process used to resolve emotional conflict and allay anxiety by disavowing thoughts, feelings, wishes, needs, or external reality factors that are consciously intolerable.

Polio survivors have exercised denial to a massive extent for years and have demonstrated how successful this defence can be. Everyone is different in personality, but massive denial has been remarkably incorporated into the lifestyle of countless polio survivors. For those who survived polio with some identifiable residual damage from the disease or displayed an outward sign such as a brace, a limp, atrophy of an extremity, spinal



curvature, brace, crutches, or wheelchair, this reality set them apart from their able bodied peers. For anyone, but particularly a child, this awareness, self-consciousness, or feeling was unacceptable in order to feel normal. To consciously feel abnormal, crippled, or deformed was very anxiety provoking. The thought or feeling of being different from one's peers in the classroom, at play, or within the family was unbearable and frightening. To regain some sense of selfhood and a healthier identity, many polio survivors began a process of unconscious denial. At the same time, many were also regaining some use of previously paralysed muscles. With the encouragement of family, friends, doctors, nurses, physical therapists and many others, measurable improvement occurred and the denial process became even easier to adopt.

How often did crippled polio children secretly entertain "what if" wishes or fantasies? I would estimate that the majority did at least for several months if not years after the polio event. To be surrounded by peers who took walking and running for granted, one would naturally wonder "what if I had never had polio?" In time as this wishful thinking would only produce anger and anxiety, one would gradually adapt to the denial defence and in time, the frequency of such unrealistic wishes subsided. "Why punish myself with such fantasies and wishes, it does not do me any good, it only makes me feel worse."

Polio survivors clearly had many identifiable needs unless they completely recovered or were able to pass for normal. Some were severely damaged and needed wheelchairs or even iron lungs. Others needed braces, corsets, crutches, or canes. Many others underwent painful orthopaedic surgery and rehabilitation. The overwhelming goal for polio survivors of the 20s to the 50s was to find some way to get back on one's feet. The world would be greatly limited or nearly inaccessible to those who could not get back on their feet. Needs were hard to deny, especially if a crippled polio fell and could not get back on his/her feet without assistance from another individual. Falling was frightening to so many, not so much because of possible injury, but more so from the fear of being an object of pity and "needing" help to simply get up. How many polios, whether walking with braces or even rolling in wheelchairs, were stubbornly aggressive about opening their own doors or carrying their own objects? Most of us, not only denied, but also resented our obvious need for the assistance that would have made our lives simpler. Many of us became automatic in our refusal to accept the help of others rather than graciously accept the good intentions of others. To admit to ourselves that we had needs was intolerable. We were extremely vulnerable to become absorbed into a life of massive denial. We did just that, became masters of massive denial.

Our massive denial has resulted in a scattered group of variously handicapped individuals who have achieved, contributed to the work force, married, raised families, have done everything humanly possible to be normal, and have successfully denied our polio realities, thoughts, feelings, wishes, and needs. We were fully expecting to complete our life's course with our denial defence intact and die of natural causes like our normal peers. Polio was past history, and then came the unexpected.

A little over a decade ago, post-polio syndrome (PPS) became a new reality. Our well-oiled denial defence initially seemed to be helpful with PPS. We could simply convince ourselves that this was something that was only happening to a few polios and it would not happen to me. Or, even if it did happen, it was just a matter of "pushing through" the pain, fatigue, and weakness. The "no pain, no gain" strategy had worked so well in the past, why wouldn't it work now? Our massive denial was still operant. We all know what happened next. PPS began happening to me, as well as you, and finally to the majority of us. Some of us went to many doctors before getting a proper diagnosis. Some of us went to a support group meeting and did not like what we saw or heard and did not go back with eagerness. To go to a support group meeting was a direct insult to our denial armour. One



might see a mirror image of oneself across the room. What would we likely see? We would likely see a person with needs and realities that we did not want to accept in ourselves. Again, our denial armour might be chipped or cracked.

The whole experience of PPS is like a boomerang or a déjà vu experience. We have been caught off guard and our massive denial defence has been invaded and penetrated. What has been the result? Many of us have experienced overt anxiety, depression, anger, physical and emotional pain, loss of jobs and self esteem, family stress, and eventual resignation to an unfair fate. For those who had been "passers", the whole PPS experience has been an old nightmare or a regression back to an experience they had assumed they had beaten. Massive denial had not been necessary for most passers, but they too were unprepared for PPS and its realities.

Massive denial, was it good for us or not? Do we still need it? Will our minds find an unconscious replacement? These are questions to ponder. I doubt that we will relinquish massive denial. It has been so good to us. Even with PPS, if we have a good day, do we not entertain thoughts and feelings that we can overcome again? Do we not search for more knowledge about PPS, try many untested remedies, share information with each other, and try to gain some semblance of autonomy, even when it is compromised by undeniable realities. Becoming a burden is the last thing we want to be. We must have control of our existence. Denial of our control will likely be our demise.

Only as a result of PPS have we discovered each other. We have helped each other uncover and share our polio pasts, and now we should be better able to support each other, as we grow old in our polio futures. With the knowledge of having and knowing each other, may massive denial go on a much needed and long recess?

## **Abnormal Movements in Sleep as a Post-Polio Sequelae**

**Richard L Bruno, PhD**

**The Post-Polio Institute**

**Englewood Hospital and Medical Center, Englewood, New Jersey USA**

This paper was published in the *American Journal of Physical Medicine and Rehabilitation*, 1998; 77: 1-6, and is reprinted here with permission of the author. The paper is quite technical in parts but is certainly worth reading by you and/or your doctor.

### **Abstract**

Nearly two-thirds of polio survivors report abnormal movements in sleep (AMS), with 52% reporting that their sleep is disturbed by AMS. Sleep studies were performed in seven polio survivors to objectively document AMS. Two patients demonstrated Generalised Random Myoclonus (GRM), brief contractions and even ballistic movements of the arms and legs, slow repeated grasping movements of the hands, slow flexion of the arms and contraction of the shoulder and pectoral muscles. Two other patients demonstrated Periodic Movements in Sleep (PMS) with muscle contractions and ballistic movements of the legs, two had PMS plus Restless Leg Syndrome (RLS) and one had sleep starts involving only contraction of the arm muscles. AMS occurred in Stage II sleep in all patients, in Stage I in some, and could significantly disturb sleep architecture even though patients were totally unaware of muscle contractions. Poliovirus-induced damage to the spinal cord and brain is presented as a possible cause of AMS. The diagnosis of post-polio fatigue, evaluation of AMS, and management of AMS using benzodiazepines or dopamimetic agents is described.



# New !!!

## ***Managing the Late Effects of Polio*** **Canberra, 29 August 1998**

1. ***Post-Polio Syndrome - Management of Symptoms*** \_\_\_\_\_  
Dr Pesi Katrak, Rehabilitation Specialist, Prince Henry Hospital
  2. ***Let's Go Shopping - Sourcing the Right Mobility Solutions*** \_\_\_\_\_  
Chris Sparks, Dynamic Living Designs  
***Be Kind to Your Feet***  
Richard Lee, The Walking Clinic
  3. ***Breathing, Voice and Swallowing*** \_\_\_\_\_  
Trish O'Sullivan, Speech Pathology Department, Concord Hospital  
***The Late Effects of Polio - Ask The Panel***  
Dr Pesi Katrak, Ron Bennett, Jac Cousin, Ian Neering, Trish O'Sullivan
- 

## ***Living with the Late Effects of Polio*** **Sydney, 8 - 10 November 1996**

1. ***The State of Knowledge of Post-Polio Syndrome Today*** \_\_\_\_\_  
Dr Stanley Yarnell, St Mary's Hospital and Medical Center, USA
2. ***The Latest Research Findings on Polio*** \_\_\_\_\_  
Dr Elizabeth Dean, University of British Columbia, Canada
3. ***Experiences in Treating People with Post-Polio Syndrome - Practical Implications of Clinical Research*** \_\_\_\_\_  
Dr Stanley Yarnell and Dr Elizabeth Dean
4. ***A Panel Discussion of the Australian Experience and Research into Post-Polio Syndrome*** \_\_\_\_\_  
Dr Robert Adler, Rehabilitation Specialist  
Professor Simon Gandevia, Prince of Wales Medical Research Institute  
Dr Jill Middleton, Senior Staff Specialist, Prince Henry Hospital Polio Clinic  
Amanda Piper, Royal Prince Alfred Hospital Sleep Clinic
5. ***Where Do We Go From Here? A Panel Discussion*** \_\_\_\_\_  
Dr Mary Westbrook, Assoc Prof of Psychology, Sydney University  
Dr Stanley Yarnell and Dr Elizabeth Dean  
A representative from each Australian Polio Network
6. ***Overcoming Isolation*** \_\_\_\_\_  
Edith Morris, Counsellor and Teacher, Japan
7. ***Respiration Matters!*** \_\_\_\_\_  
Dr Elizabeth Ellis, Sleep Disorder Centre Australia Pty Ltd
8. ***Well-Being for People Who Have Had Polio*** \_\_\_\_\_  
John Smith, Researcher, Western Australia
9. ***Footloose and Fancy Free*** \_\_\_\_\_  
Jill Fogarty OAM, Senior Podiatrist, Sydney Institute of Technology



# ORDER FORM

Name: \_\_\_\_\_

Address: \_\_\_\_\_

## HOW TO ORDER CASSETTE TAPES (SEE OTHER SIDE)

The tapes detailed on the reverse side of this form cost \$12.00 for a single tape, or \$11.00 each if two or more are purchased. Against each tape that you would like to purchase, write the number of copies required in the space provided. Packaging and postage is extra. For one tape add \$4.00, for 2 tapes add \$6.50, for 3 tapes add \$8.50, and for 4 or more tapes add \$10.00.

I wish to purchase _____ tapes @ \$_____ each	Total	\$ _____
Plus packaging and postage		\$ _____
Total amount enclosed		\$ _____

## REPORT : SURVEY OF MEMBERS (November 1998) 54 Pages **POLIO - A CHALLENGE FOR LIFE - THE IMPACT OF LATE EFFECTS**

I wish to purchase _____ Reports @ \$12.00 each (including postage)	\$ _____
<i>(NB: This is a special price for Network members - cost for non-members is \$22.00, including postage)</i>	

## CONFERENCE PROCEEDINGS (November 1996) 170 Pages **LIVING WITH THE LATE EFFECTS OF POLIO**

I wish to purchase _____ Conference Proceedings @ \$29.00 each	\$ _____
(including postage)	

## POST-POLIO NETWORK (NSW) T-SHIRTS



**Post-Polio**  
Network (NSW)

The Network has white T-shirts available in large and extra large sizes. On the front centre of each T-shirt is a graphic design of a single polio virus particle and the name of our Network. The four-colour (red, yellow, green and blue) design is very striking. A black and white version of the design is shown at the left.

The T-shirts cost \$15.00 each. Packaging and postage is extra, and costs \$5.00 for the first T-shirt and \$2.00 for each additional T-shirt.

I wish to purchase _____ T-shirts @ \$15.00 each	Total	\$ _____
Size(s) required (large / extra large) _____		
Plus packaging and postage		\$ _____
Total amount enclosed		\$ _____

**Please make cheques payable to Post-Polio Network (NSW) Inc and send to:  
Post-Polio Network (NSW) Inc, PO Box 888, Kensington NSW 1465**





Despite numerous late-onset symptoms reported by polio survivors - fatigue, muscle weakness, pain, cold intolerance, swallowing and breathing difficulties - one symptom was totally unexpected: abnormal movements in sleep (AMS). As early as 1984 our post-polio patients were reporting muscle contractions as they fell asleep. The 1985 National Post Polio Survey included two questions about AMS: "Do your muscles twitch or jump as you fall asleep" and "Is your sleep disturbed by muscle twitching?" [1]. It was surprising that 63% of the 676 respondents reported that their muscles did twitch and jump during sleep and that 52% - a third of the entire sample - said that their sleep was disturbed by twitching.

These percentages are markedly elevated as compared to the incidence of AMS in the general population. In one survey only 29% of those without neurological disease who were at least 50 years old reported AMS, versus 63% of surveyed polio survivors who were 52 years old on average [2]. In another survey only 34% of those older than 64 reported AMS, slightly more than half the incidence of AMS in the younger post-polio sample [3]. Given the apparent increased prevalence of AMS in polio survivors, and with daytime fatigue the most commonly reported Post-Polio Sequelae (PPS), we were interested in objectively documenting AMS, relating them to possible disturbances in sleep architecture and identifying an effective treatment for AMS [1].

## Methods

**Subjects.** Seven polio survivors were referred for sleep studies to a sleep disorders center. This was a sample of convenience, in that the subjects were patients presenting with PPS who themselves knew (three patients) or whose bed mates knew (four patients) that AMS were occurring. Patients were on average 54 years old and 44 years post acute polio which occurred at age 10. The patients had had AMS for a mean of eight years which was on average 35 years post acute polio. Patients reported moderate-to-severe difficulty sleeping at night and moderate-to-severe daytime fatigue that did not respond to the treatments of choice for post-polio fatigue, that is, pacing of activities, daytime rest periods, energy conservation and use of appropriate assistive devices [4]. In addition to fatigue, patients reported an average of two limbs having late-onset muscle weakness.

**Procedure.** Patients underwent a standard polysomnographic evaluation with EEG and facial EMG recorded for sleep staging [5]. Blood oxygen saturation, measured using a finger pulse oxymeter, chest and abdominal wall excursion and nasal air temperature were also recorded; video monitoring of sleep was also performed. Surface EMG was recorded from patients' legs as well as from limbs in which AMS were reported.

## Results

Four types of AMS were seen. Two patients presented with what has been called Generalised Random Myoclonus (GRM) [1] [6], two patients had Periodic Movements in Sleep (PMS), two had PMS plus Restless Leg Syndrome (RLS) and one had Sleep Starts (also called "hypnagogic massive myoclonic jerks").

**Generalised Random Myoclonus.** GRM was seen in two patients. One had had bulbar polio with little or no arm or leg involvement acutely, while the other has been diplegic since polio but had no bulbar or respiratory symptoms acutely. These patients had random contractions of muscles throughout their bodies. One had such violent contractions of the trunk muscles that she was pulled into the foetal position during the night. This patient had been very aware of GRM for about 10 years.

However, the other patient had been completely unaware of GRM until they were noticed by her husband. Random, rapid muscle contractions were noted in all four limbs, jaw and



pectoral muscles, in addition to slow repeated grasping movements of the hands, slow flexion of the arms and movement of the shoulders. The presence of bilateral toe flexion was notable since the patient's right leg has always been totally paralysed except for a minimal ability to flex her toes; the toes of her right foot contracted numerous times during the night.

In both patients, GRM occurred during Stage II sleep; the latter patient also had GRM in Stage I. The patient with violent trunk flexion had muscle contractions, causing a severe disturbance of sleep architecture, only during the first third of the night. She also had a few episodes of obstructive apnoea that were not related to the muscle contractions but did disturb her sleep. She was prescribed clonazepam, 0.5 mg B.I.D., which eliminated her GRM. The other patient had GRM throughout the night but had no disturbance of sleep architecture and was not treated pharmacologically.

***Periodic Movements in Sleep.*** Two patients demonstrated PMS with contractions only of the leg muscles of which neither patient was aware. Both had limb and respiratory involvement with the acute polio and had PMS during Stage II sleep with one patient also having muscle contractions during Stage I. The former patient had nearly continuous EMG activity in his legs throughout the night and had a severe disturbance of sleep architecture. He also had some central episodes of apnoea early in the night as he was falling asleep that did not disturb his sleep. The latter patient had PMS occurring only during the first half of the night which caused no disturbance of sleep architecture. However, he had frequent hypopnoeas which did severely disturb his sleep. Both patients were prescribed lorazepam, 1.0 mg H.S., which eliminated the PMS.

***PMS plus Restless Leg Syndrome.*** Two patients had PMS plus Restless Legs Syndrome. RLS is characterised by the subjective feeling that the legs must be moved. This feeling increases during the evening, often preventing sleep onset because patients feel as if they must get up and walk. The patients with PMS plus RLS had been very little affected by the acute polio, one having no polio residual and the other having one leg weakened. PMS were seen in both legs and occurred during Stage II in both patients and during Stage I in one patient. One patient's leg muscle contractions were so violent that she was propelled one to two inches off the surface of the bed. Although her PMS occurred only during the first half of the night, her sleep was severely disturbed and she was very aware that she had had PMS for about 5 years. She was prescribed L-dopa/carbidopa (Sinemet) 200/50 mg, 1/2 tablet B.I.D., and clonazepam, 0.5 mg H.S. and at 3 A.M., which reduced the RLS and PMS by about 80% and allowed her to have a restful night's sleep.

The other patient did not know he had PMS which were continuous throughout the night and did moderately disturb his sleep architecture. He was prescribed L-dopa/carbidopa, 200/50 mg H.S., which eliminated his RLS and PMS.

***Sleep Start.*** One patient was diagnosed as having a Sleep Start, her arms ballistically abducting as she began to fall asleep. She was very mildly affected by the acute polio and had no AMS in the legs, even in the leg in which she reported new muscle weakness. The patient's sleep was markedly disturbed since her arms would move as she started to fall asleep and prevent sleep onset. She was prescribed alprazolam, 0.125 mg H.S., which eliminated her AMS.

## **Discussion**

Sleep studies in this sampling of post-polio patients objectively documented three different types of AMS. Whether other types or combinations of AMS occur in polio survivors



cannot be determined from this study, nor can this study or the 1985 National Post-Polio Survey state the actual incidence of AMS in polio survivors, since neither sample was random or population-based. However, the objective documentation of AMS in these post-polio patients, and the Post-Polio Survey finding that 63% of polio survivors reported muscle "twitching or jumping" as they fell asleep, suggest that AMS may in some way be related to the pathophysiology of the original poliovirus infection.

In 1964, Loeb coined the phrase "hypnic myoclonus" to describe muscle contractions during sleep onset in healthy individuals without neurological disease [7]. Loeb described the contractions as rapid (less than 0.5 seconds long), arrhythmic (occurring without a pattern) and causing a variety of movements - finger flexion, thumb adduction, forearm and foot flexion and extension, shoulder elevation and facial twitching during Stages I and II sleep - identical to those seen in the post-polio patients. However, in contrast to the post-polio patients, none of Loeb's subjects demonstrated contractions in more than one muscle group and in none was sleep disturbed by hypnic myoclonus.

Loeb thought that hypnic myoclonus resulted from an abnormality at the level of the brain stem reticular formation causing decreased descending inhibition of anterior horn motor neurons during sleep. Martinelli [8] thought PMS also resulted from an increase in anterior horn cell excitability, with Walters [9] finding that PMS decreased with the administration of an opiate receptor agonist.

Loeb and Askenasy suggested that AMS were also related to abnormal discharges from the thalamus, cerebellum and basal ganglia [7] [10]. The implication of the basal ganglia in the generation of AMS is interesting since PMS are common in patients with Parkinson's disease, whose decreased dopamine production impairs basal ganglia functioning, in patients with narcolepsy, who have an increased number and sensitivity of dopamine receptors in the basal ganglia, and have been found to decrease with the administration of dopamine receptor agonists [9] [11] [12].

**AMS, Polioencephalitis and Poliomyelitis.** All of the CNS regions implicated in the pathogenesis of AMS are known to have been lesioned by the poliovirus. The anterior horn motor neurons, cerebellar nuclei and reticular formation were frequently and severely damaged by the poliovirus [13]. The periaquiductal gray, paraventricular hypothalamus and lamina II dorsal horn neurons were all lesioned by the poliovirus (cf. [9] [13]); damage to these opioid peptide-secreting neurons may be evidenced not only by AMS but also by polio survivors' doubled sensitivity to pain [14] [15] [16]. Finally, the thalamus and basal ganglia (the substantia nigra, putamen and globus pallidus) were also damaged by the poliovirus, damage that has been implicated in the pathogenesis of post-polio fatigue [16] [17] [18]. Given the distribution and extent of poliovirus lesions in all of the CNS areas implicated in the pathogenesis of AMS, we should not have been surprised in 1985 that a majority of polio survivors reported muscles that twitch and jump during sleep.

**Clinical Implications.** PPS remains a diagnosis of exclusion. All possible causes for new symptoms in polio survivors, especially causes for late-onset fatigue, must be ruled out before the diagnosis of PPS is made. Therefore, it is important to rule out a sleep disorder as a cause of late-onset fatigue. Clinicians need to take a thorough sleep history from their post-polio patients, asking not only about symptoms of sleep apnoea, which occurs frequently in polio survivors, but also about AMS [20]. The patient's bed partner must also be asked about AMS since the majority of polio survivors will not know that they have AMS.

Patients are referred for a sleep study if sleep apnoea or AMS is suspected. The lowest dose of a short acting benzodiazepine will be prescribed before sleep by the Post-Polio Institute psychiatrist if a patient has AMS, since these medications seem to virtually



eliminate GRM and PMS in our post-polio patients. Treatment of sleep apnoea is deferred to the sleep disorders center as is treatment for RLS, since a dopamimetic agent in combination with a benzodiazepine may be required. However, there is a caveat to prescribing dopamimetics for polio survivors. One of our PPS patients developed vasovagal syncope with cardiac asystole during the administration of a dopamine receptor agonist [21]. We consider a history of vasovagal syncope or unexplained faints a contraindication to prescribing dopamimetics for polio survivors with AMS or RLS [22].

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# Support Group Report

**Bernie O'Grady**  
**Support Group Co-ordinator**

**Phone: (02) 9688 3135**

I am grateful to Joan Mobey whose previous writings for the Network on Support Groups provide the basis for this article.

## Why Do We Need Support Groups?

All people are influenced by the experiences of their lives and polio people, profoundly so. Many of us had extreme trauma at an early age and were separated from loved ones when we needed them most. After discharge from hospital we were told to get on with our lives as if nothing had happened. We all struggled through life with our disability but were not to tell how hard it was and so we buttoned up our lips and became determined to prove that we were just as good, if not better, than anyone else. A lot of us have gone through life with great difficulty and don't even want to talk about it; we have withdrawn into our shell which is a world of silence about what is polio.

Now later in life many of us can no longer hide our pain and disability but we still refuse to talk about it.

A Support Group gives us a chance to meet other people who have similar problems and who also have suffered in silence, and so finally you can meet and talk to others who can help you to start talking about your past and present life, and to pool and share information which will give you the opportunity to now review your life and notice that you are not the same as the average able-bodied person. We can help each other to live our lives in a more realistic way and then perhaps we can let up on the pace of our past life and set goals more realistically.

If this picture of self denial of having had polio, of not wanting to talk about new problems, of the loss of friends because you are unable to perform as good as they, of not accepting any help or advice fits you, then it may be time you broke down the barrier, admit that you have a problem, and accept the fact that there is help out there - a Support Group.

When you first join in a Group of course you will have fears, will I be accepted, will they listen to how I feel about my past and present. What will happen if my emotions get the better of me and I break down and cry. Of course people won't think any worse of you, because you are among friends. This is what a Support Group is about. You will be talking to people who have the same physical and emotional problems as yourself.

Adjusting to change is made easier as people are nourished by the sense of togetherness that is available nowhere else. Some come to the Group, receive what they need, and leave to carry on life, never to return. Others leave and return only when symptoms flare. Still others who cherish the on-going relationship with Group members continue to attend even after their initial needs have been met. As some members depart, the Group is replenished by newcomers. They are beginning their search for understanding and acceptance of new losses knowing what those who have come before them have known: some things are done more easily in a group of people with similar experiences than done alone. The cycle continues.

The Convener will make you feel welcome and introduce you to the other members who will be only too willing to listen to your story and to share theirs and so through tears, laughter and trembling this burden that you have been carrying will be greatly eased because you will be among friends, then you will say to yourself, why didn't I join a long time ago?



## **Support Group Update**

### ***Cowra Support Group***

**Convener : Vera White**

Vera is looking for members to join her Support Group. Vera is happy to set up the Group for people who would like to regularly come together on a face-to-face basis at a designated place. She will also set up a Telephone Support Group for those who find travelling difficult, and Vera will visit any member who is house bound providing the distance is not too far.

Vera is very interested in setting up a letter-writing "Round Robin" for isolated polio people to keep in touch with each other. Members write their own story in an exercise book, pass it on to the next member, they in turn read your story and write their own, and so on until it returns to the Convener to be sent on its way again.

Members, we have a Convener who is happy to help you in all these ways and so there is no excuse not to consider joining this local Support Group. Vera is waiting for your call now on (02) 6342 2647.

### ***Albury Support Group***

**Convener : Neil von Schill**

Since the inception of the Support Group network the Albury Group has operated as a Telephone Group. Mid 1998 the Group met in person for the first time and now plan to meet three or four times per year. Because of their position on the border, some of the Group are members of both the New South Wales and Victorian Post-Polio Networks. They have met to investigate how they can cater for the needs of members on both sides of the Murray River, and will continue to work to provide available benefits to them. For example, there are services available to Victorian members which Neil has been able to access. Neil would like to hear from members in his area who would like to join his Support Group. Please telephone him on (02) 6025 6169.

### ***Northern Inland Support Group***

**Convener : Barbara Chapman-Woods**

On Sunday 18 October, Barbara convened a meeting at the St Andrews Village Hall, Tamworth, which I attended. Polio members and friends travelled from Sydney, Newcastle, Armidale, Coffs Harbour, as well as from Tamworth and its outlying areas. The day commenced at 11 am with Barbara welcoming and introducing members and reading letters of apology from those members not able to come on the day.

Barbara (telephone (02) 6766 5093) successfully operates a "Round Robin" for her members because of the isolation and distances between towns, and shared with us many of the stories written by members of her Group. Following this, Barbara invited six members to tell their story from the time they contracted polio, and of their personal coping experiences through life with their disability. Each person expressed many setbacks and hardship, but conveyed a message of determination and struggle to prove they were as good as the next person. They were all very positive and cheerful.

The day concluded at 1 pm. Lunch was provided, prepared by Barbara's friends at the Village. Thank you - we enjoyed the opportunity to meet and get to know new friends.

### ***Wollongong Support Group***

**Convener : Dorothy Robinson**

This Support Group had their first face-to-face meeting on Friday 20 November 1998, at Port Kembla Hospital at 3 pm, and Dorothy reports it was very successful. Their next meeting will be held on Friday 12 February 1999 in the Conference Room, West Wing, Port Kembla Hospital from 2 - 4 pm. Any member wishing to join this Support Group, please telephone Dorothy Robinson on (02) 4229 6221.



## Conveners Needed

We still need Conveners for: Eastern Suburbs  
Sutherland / Sylvania

If you can help, we'd love to hear from you.

This is my final Support Group Report for this year. 1998 has been a fruitful and successful year for the Network and its Support Groups. Ten new Support Groups were started, some have been revitalised and other Groups continue to be strong.

I thank all Conveners and Go-Conveners for the support you provide to our members, and wish you all the best for the festive season.

## For Sale

**Mary Le Clair** (Neutral Bay) has decided to get a smaller scooter better suited to her house and wishes to sell her current machine. It is a *Shoprider* 4-wheel model which Mary tells us is two and a half years old and in excellent condition. Mary is asking \$2,200 *or near offer* (she advises a new model costs \$4,700) and can be contacted on (02) 9953 5415.

**Dick Ronan** (Tamworth) also wishes to sell his *Shoprider* 4-wheel electric scooter which comes complete with basket and light. Dick tells us that the scooter is two years old, however its batteries and tyres are only six months old. Dick is asking \$2,500 and can be contacted on (02) 6765 6858.

## Post-Polio Seminar Program : 1999

The Program for the 1999 Post-Polio Seminars has been decided and the dates set. The Program is varied and should appeal to all. Please note the dates in your diaries so you don't miss out on some wonderful speakers. Final confirmation of dates, speakers and venues, and further details of each Seminar topic, will be given in the *Newsletter* issued prior to the Seminar.

<b>Saturday, 6 March 1999</b>	<b>Seminar :</b> Orthotics and You <b>Presenter :</b> Michael Gurry B.Prost.&Orth., MAOPA <b>Venue :</b> The Northcott Society, Parramatta
<b>Saturday, 10 July 1999</b>	<b>Seminar :</b> 2000 Paralympics / Customised Clothing <b>Presenter :</b> Speakers to be advised <b>Venue :</b> St Paul's Anglican Church Hall, Kogarah
<b>Saturday, 21 August 1999</b> <b>Sunday, 22 August 1999</b>	<b>Mini-Conference</b> (program being developed) <b>Support Group Conveners' Workshop</b> <b>Venue :</b> Coffs Harbour (actual venue to be advised)
<b>Sunday, 30 October 1999</b>	<b>Annual General Meeting</b> <b>Seminar :</b> Food For Thought <b>Presenter :</b> Dietitian - speaker to be advised <b>Venue :</b> Independent Living Centre, Ryde





*Following the Conference "Managing the Late Effects of Polio" held by the Network in Canberra in August, member Kerry Jenkin wrote to express her delight at her attendance.*

As a newcomer to the Post-Polio Network and a recently-commissioned Convener for the Hornsby area, I would like to take this opportunity of extending my personal thanks to Gillian our President, Bernie the Co-ordinator of the Support Group Conveners, and the entire ACT Support Group for presenting a wonderful Conference. I felt very elated by the enthusiasm of the participants and was astonished at the number of people including the speakers who had suffered from the virus and still went on to make the service of fellow sufferers their career. All speakers had first-hand knowledge but showed extraordinary enthusiasm in sharing their experiences with those present.

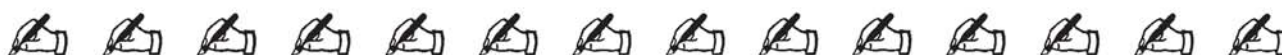
One thing I have found since contacting PPN and listening to other people is that my awareness is quite lacking and that certain demons I thought were buried many years ago have resurfaced leaving a bad taste in my mouth. I contracted polio during the war and my mother was told "you may as well let her die". As a child who suffered total paralysis, my mother had to leave two other children at home without a father in order that I be fed in Camperdown, as it wasn't the duty of the staff.

There was no suggestion of a clinic run by Sister Kenny or the Northcott Society - perhaps it was too early - but we went to the Mosman Spastic Centre newly opened where instead of fees the parents could do manual work to pay for the use of facilities and education.

I have had a wonderful career of thirty-four years and I think that my time since retirement has been the best. It is a time of no longer having to apologise or ask permission. If I'm tired or if my body is not behaving as well as usual, I can stay in bed, go for a stroll, or do nothing, it's okay.

As Convener of the Hornsby Support Group I hope to see as many members as possible from the area, as soon as possible. Not to be forgotten, thank you to all those husbands, wives and family supporting your PPS loved one.

*Roger Smith has asked me to pass on his thanks to everyone who gave him advice and information in regard to strong lightweight calipers. Roger says he will be following up your suggestions soon.*



The Management Committee wishes you a  
Happy and Holy Christmas  
and a  
Healthy and Peaceful New Year