



## THE LINK-PIN

Lincolnshire's Post-Polio Informative Newsletter No. 1 - September 1996



**Congratulations on the formation of the Lincolnshire Polio Network** and the first edition of 'Link-Pin'. Know that the many million polio survivors throughout North America and the World stand (sit) with you.

Only through your efforts will the facts about Post-Polio Sequelae (PPS) spread from the Midlands to reach all 50,000 British Polio Survivors;

Only through your determination will those in authority take the needs of the 50,000 seriously and stop dismissing PPS because 'it was not discovered in Whitehall!';

Only through your perseverance, and the help of no lesser scientific lights than Drs. Peter Behan and Betty Dowsett, will the British medical community stop ignoring 15 years of the Worlds medical literature on PPS and begin giving you the care you deserve.

The researchers and clinicians of the international Post-Polio Task Force are ready to help you in any way we can. We look forward to being present at the opening of Britain's first Comprehensive PPS Treatment Centre and speaking at the First British Symposium on PPS.

**Dr. Richard L Bruno**

Chairperson, International Post-Polio Task Force,  
and  
Director, Post-Polio Rehabilitation and Research Service,

Kessler Institute for Rehabilitation  
and  
Associate Professor, Clinical Physical Medicine and Rehabilitation  
New Jersey Medical School, University of Medicine and Dentistry of New Jersey.

**Michael Peacock - Chairman - writes**

Welcome to the First Newsletter of the Lincolnshire Polio Network.

We are all setting off on a journey of discovery and education which will hopefully end with the creation of a dedicated clinic to treat all sufferers of the 'second phase of Polio'. To achieve this goal I am sure we will all have to put in a lot of time and hard work, raise a lot of money, and also we must change peoples minds especially those in the medical profession.

My other great hope of this exciting venture is that as many people as possible get involved in the direction of the Network. This must be a vehicle which is very responsive to peoples needs. We need feedback, serious and funny (for laughter is always the best medicine around); what more do you want to know; stories of your past and present medical forays; other items that you think we should include; etc., so please put pen to paper.

Although the dream of a clinic is some way away, in the meantime the most important piece of advice I have gleaned is that we all must 'Take it easier' and 'If it hurts stop doing it'. This will mean obvious changes to everyone's lifestyles which knowing how stubborn and determined polios are will be very difficult, but it is necessary and it does work.

**If the little voice inside you says don't - don't bully it.**

**Hilary Hallam, Secretary, writes:**

The bad news was that we did not know about Post-Polio and some of us have been deteriorating unnecessarily. The good news is that we are finding out about it now and we can see that by getting to the right medico who has all the information that informed decisions can be taken about us. Time and money will be saved. Stress from endless delays of wasted appointments and tests will be a thing of the past. The difficulties we have in the UK are that most Doctors do not even know PPS exists and for those that have heard of it they know very little about it. Very few have knowledge of Polio, or how it has affected us. There are no definitive medical articles in any British Medical Journal and what we need are Post-Polio Clinics that examine one from top to toe, assesses all our problems and refers us to the post-polio specialist Physiotherapist, OT, Speech therapist, Psychologist etc. See information on the West Park Hospital in Toronto. There are some excellent specialist units for respiratory and orthopaedic problems but no Interdisciplinary Clinic. YET! We are working on this. There are ways that we can help ourselves. There are aids and assistive devices that will make life easier. We must change our lifestyles even though it goes against the grain. There is research in many other parts of the World. By becoming part of the PPS Family of the World we can see a much better future for ourselves.

**ARTICLES PUBLISHED IN THE LINK-PIN.** *Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Polio Network. Although it does not provide an endorsement, it is provided as a service for those seeking such information. Always consult your doctor before trying anything recommended in this information or any other publication.*



**Helena Edwards - Leicestershire Polio Network**

Welcome aboard. I wrote to Professor Peter Behan who is our Honorary President, and as you know

he was delighted to become your Honorary President, and in fact has agreed to take the same post for any Network starting up provided that all correspondence is through Leicester. He is a very busy man and currently working on many projects but is with us all the way and will be writing an article in the next couple of months on PPS.

I have instigated the formation of a Post-Polio Clinic Action Group - on which you have two representatives - and we are currently recruiting a medical advisory board for this project. You will see from the [article](#) on the West Park Hospital, Toronto, that other countries are way ahead of us in looking at the polio survivor as a whole person. Our project is to open something similar in the Midlands as a National Resource for assessment, initial treatment, onward referral to specialist units, case management back to Local Health Authorities, research, training etc.....

### **John Foyster - Chairman, South Australia Post-Polio Support Group**

The Post-Polio Support Group of South Australia has a contact list of about 800 and of these just over a quarter are financial members. The main thing the support group is able to do is provide non-medical advice to callers and members, although we do lobby governments and other groups for various kinds of support.

I'm associated with the management of the group because. when I first suspected that I might be having problems of this kind, I rang a number listed in the telephone directory and received advice and help immediately. Of greatest use was a little booklet of 40 pages entitled 'A practical approach to the Late Effects of Polio' for which the group had obtained sponsorship in the late 1980's and which could therefore be distributed for the cost of the postage only. It set out all the 'facts' about post-polio as they were then known. There was also a parallel booklet for health workers who were unfamiliar with polio (and post-polio) - which of course is most of them.

I think I benefited a lot from what the group did for me through these publications (for example I immediately cut down on the number of hours I worked) and so I am now trying to give something back to the group. Post-Polio Support Groups are vital in dealing with these problems primarily because my experience is that only those who have had polio can establish an appropriate rapport with people now experiencing the longer terms effects of polio. Go-operation between post-polio groups throughout the world occurs at a high level because of our mutual experience, because we need to learn from one another, and because there simply isn't much money for dealing with this kind of problem. Good Luck to my friends in Lincoln.



Pack up your Gloomies in a Great Big Box and Sit on the Lid and Laugh  
by Barbara Johnson held in Polio Outreach Spokanes' library.

Somedays you are the bug, somedays the windshield.

Life is like an ice cream cone, just when you think you've got it licked, it drips all over you!



## **POST POLIO SEQUELAE True Answers for Friends and Family.**

**Kessler Institute for Rehabilitation, Post-Polio Rehabilitation Service, 300 Market Street, SaddleBrook, New Jersey, 07663; 1-(888)-KESSLER.**

### **What is Polio?**

'Polio' (or poliomyelitis, infantile paralysis) is a disease caused by three viruses that enter the mouth, grow in the intestines and pass along the nerves into the brain and then the spinal cord.

There are 1.63 million American polio survivors.

### **What damage did the polio virus do?**

The polio viruses entered nerves in the brain and spinal cord and took over their 'metabolic factory', causing the nerves to stop working normally just to produce poliovirus. During this invasion, the infected nerves could not function and muscles in the arms, legs, chest, diaphragm and throat became weak or were paralysed. If someone had muscle weakness or paralysis, 90% of their motor nerves were affected by the polio virus and at least 50% were killed. The remaining nerves, although damaged, were able to work again and sent out sprouts (like extra telephone lines) to turn on the muscles that were orphaned when their nerves died.

### **What are Post-Polio Sequelae (PPS)?**

Post Polio Sequelae (PPS) - new fatigue, muscle weakness, joint and muscle pain, cold intolerance and breathing and swallowing difficulty - are the 'sequel' to having had polio and occur in as many as 80% of survivors of paralytic and non-paralytic polio.

### **What causes PPS?**

PPS are caused by 'overuse abuse'. Nerves that were damaged by polio and had sprouted have been overworked for 40 years and can no longer take the strain. So too, overworked muscles ache and joints hurt after decades of doing too much work with too little muscle support.

### **Is PPS a progressive disease?**

No, PPS is neither progressive nor a disease. PPS are just the body growing tired of doing too much work with too few damaged and overworked neurons.

### **Is there any treatment for PPS?**

Yes! Since PPS symptoms are caused by the nervous system equivalent of plugging too many appliances into one electrical outlet, polio survivors simply have to unplug some of the appliances. Polio Survivors must decrease the overuse to stop the abuse of their damaged nerves, weakened muscles and painful joints.

### **What are the treatments for PPS**

Polio Survivors basically need to conserve energy to stop blowing their bodies 'fuses'. Polio survivors must walk less, use needed assistive devices (a brace, crutches, a scooter), stop working before symptoms come on, and plan rest periods throughout the day.

### **Are treatments for PPS effective?**

Yes. The worst case is that patients who stop the overuse abuse will have their PPS symptoms plateau. However, when survivors start taking care of themselves, the overwhelming majority have noticeable decreases in fatigue, weakness and pain.

### **Isn't exercise the only way to strengthen weakened muscles?**

No. Since PPS symptoms result from too many 'appliances' being plugged into an overloaded nervous system, muscle strengthening exercise would be like plugging in a dozen additional toasters. While stretching exercise can be helpful, pumping iron and 'feeling the burn' means that polio damaged neurons are burning out. Also, polio survivors typically can't exercise the way others

do to condition their hearts and try to prevent osteoporosis.

### **What can friends and family do to help?**

Polio survivors have spent their lives trying to look and act 'normal'. Using a brace they discarded 30 years ago and reducing their typically super-active daily schedule is both frightening and difficult to do. So, friends and family need to be supportive of life-style changes, accept survivors' physical limitations and their new devices. Most importantly friends and family need to be willing, when asked, to do the physical tasks polio survivors probably could do, but should not do any longer. Friends and family need to know everything about PPS and say nothing. Neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of their own bodies and ask for help when it's needed.



**Church Bloopers** - The service will close with 'Little Drops of Water'. One of the ladies will start quietly and then the rest of the congregation will join in.

#### **Answers on Test Papers**

Water is composed of two gases, Oxygen and Hydrogen....

Oxygen is pure gas. Hydrogen is gas and water.

Blood flows down one leg and up the other.

Dew is formed on leaves when the sun shines on them and makes them perspire.

The pistil of a flower is its only protection against insects.

The body consists of three parts--the brainium, the bowels and the abdominal cavity. The brainium contains the brain, the bowels contain the heart and lungs, and the abdominal cavity contains the bowels, of which there are five a, e, i, o, u.



### **POST-POLIO CLINICS.**

We have requested information on Post-Polio Clinics from the World. We have picked the West Park Hospital Post-Polio Clinic in Toronto from those that we have received already and give below some excerpts from their booklet for your visit as a patient and from their leaflet on their services to other medical professionals.

#### **West Park Hospital, Toronto, Canada - Welcome to the Post-Polio Clinic**

The staff of the West Park Hospital Post-Polio Clinic are dedicated to making your visit as stress free and comfortable as possible.....

West Park Hospital is a specialised Rehabilitation and Continuing Care facility located in the City of York.. with 17 acres of beautifully landscaped grounds for your enjoyment...

**For Your Convenience....**comfortable waiting room....has a reference library in the Post-Polio Clinic, containing many articles and books regarding Post-Polio. Videos will be available for you to watch during your break time at the clinic. Copies of tapes and written materials will be made available to you for a nominal fee.

Family members and friends are invited to accompany you to the clinic and during your assessments if you wish, or they may wait in the waiting room. An attendant will be available for all your needs, if required.

**Your Day at the Clinic** - Your assessment appointment with the Consulting Physician will be

scheduled for 45 minutes. The Consulting Physician will summarise his findings and recommendations with you, and refer you to the rehabilitation team if it is appropriate. The facts will be documented in a letter sent to you and your referring physician.

The rehabilitation team consists of a Consulting Physician, Physiotherapist, Occupational Therapist, Social Worker and a part time Psychologist. Your assessment day with the team may be spent as follows:

The duration of your clinic assessment visit with the team will be (approximately) from 10.00 a.m. till 4.00 p.m. Your day will include appointments with the Occupational Therapist, Physiotherapist and Social Worker, each one hour fifteen minutes in duration. The day will also include a lunch break from 12.45 to 1.45. You will be one of two people seen in the clinic on this day. At the end of the day you will have a brief meeting with the entire team to summarize their recommendations. This will allow you to ask any questions or concerns you may have.

*Is this what you want in this country? The Lincolnshire Health Authority have come up with three figures of the numbers of Polio Survivors that could be in Lincolnshire. 100 300, or 1200 depending on which survey you look at. Could it be even more? We believe that if we can get one National Resource interdisciplinary Post-Polio Clinic up and running then assessment, treatment, case management, research and training can take place, and then maybe others in other regions will follow, every hospital having Post-Polio Clinics is not financially practical. Tell us what you think?*

**West Park Hospital, Toronto....First** we learned diagnosis

**Next** we developed treatment.

**Now** we're dedicated to sharing our knowledge with you.

The late effects of polio is the name given to newly identified health problems affecting people who contracted viral poliomyelitis earlier in their lives. Because the symptoms resemble those of other common complaints, they are difficult to diagnose. Problems include generalized weakness, pain, excessive fatigue, diminished endurance, related respiratory problems, speech and swallowing difficulties and an overall inability to function in a regular fashion.

Because of this ambiguity, there is a need for qualified health care professionals to understand, assess and treat those who suffer from post-polio. That is why we have developed this comprehensive package. This new educational tool will give you the knowledge and resources you need to become a qualified caregiver to post-polio clinics.

Professionals in the fields of psychiatry, social work, occupational therapy and physiotherapy will be equipped to provide detailed assessment and effective treatment to those suffering from the late effects of polio. These four areas of health care are included on a single instructional video-tape in order to emphasize the interdisciplinary approach to assessment and treatment.

Each kit contains a two hour training video, assessment, treatment forms and resource information that is discipline specific. Also included are slides, photos, charts, group therapy guides and exercise programs. You'll learn about the distinctive needs of post-polio clients, such as gait assessment, bracing requirements, energy conservation methods and coping strategies.

**West Park Hospital** also offers a unique 'shadow training' program. Trainees will be given the opportunity to gain hands-on experience by following the post-polio team on their rounds as well as being included on actual assessments and follow-up appointments. Question our staff of experts and learn the intricacies of assessing and treating the late effects of polio.

Cost of Entire Post-Polio Training Package is \$1500 including (tax and shipping)

Tel. Co-ordinator Wendy Malisani in Toronto, Canada on (416) 243-3600.

*Is this what we want? It would be lovely to dream about all Hospitals, Doctors, etc. having the knowlege of Post-Polio and treating patients locally. However, we must be practical, most doctors working now know little about polio, let alone that there is a second phase to polio. Specializing in medicine takes time it does not happen overnight. For a lot of us Polio was part of our pasts, For*

*30 odd years there was no reason for us to even think about how one catches polio, what does it do to you, I only had Polio in my legs. **NOW** I learn that polio enters and affects our whole bodies and can leave some of us with hardly any visible signs of the polio. So when we have problems with other parts of our bodies no-one thinks of Polio. Without a full top to toe medical examination and assessment by a specialised team with full knowledge of polio and post-polio will we get informed diagnoses or treatment where available. Incorrect advice, operations, treatments, must become a thing of the past **NOW**. We need one clinic to start with where others can receive training and then.... Tell us what you think?*



## **Snippets from your PPS Family around the World.**

**ALBANIA** - Polio epidemic has killed seven and stricken 66. The number of cases in Albania is higher than this year's total for the rest of Europe said the World Health Organisation in a statement from its office in Copenhagen two weeks ago. Leaking water pipes are suspected of allowing the spread of cholera and polio. Officials said hundreds of thousands of children were vaccinated against polio early this year. Weakened germs were therefore in human waste that seeped into water and infected mostly teenagers and adults.

**USA - Polio Vaccine.** The new schedule for US polio immunisation recommends the use of the enhanced inactivated Polio Vaccine (eIPV) for the first two doses of the polio series followed by two doses of Oral Polio Vaccine (OPV)....With this policy change the Centers for Disease Control & Prevention is helping fulfill the vision of a polio free America first seen by scientific pioneer Jonas Salk. IPOL is an inactivated injectable vaccine that provides active protection against poliomyelitis. IPOL is as effective as the oral vaccine in preventing polio in both children and adults and is indicated for administration to those who may be at risk of paralysis associated with the live oral poliovirus vaccine. (Note - the live vaccine remains active in human faeces for six weeks)

**FRANCE - JUST ARRIVED IN MY POST.....** Groupe Francais D'entraide Post-Polio... from Nicole Richier who is in charge of the French PPS Group created in 1989 hoping that we can have worthwhile contacts in the future. The rest is in French so you will have to wait till I can get it translated. Schoolgirl french has produced the facts that it is 75 Fr for Polio's and 150 Fr for non polios a year. Their March 96 newsletter tells that their group have published booklets entitled 'Activities associatives post-polio 1989 - 1994' at 50 Fr. and 'Effets a long terme de la poliomyelitis' 1991 at 100 Fr. They are also in touch with the World. More next newsletter.

**USA - THE POLIO FOUNDATION.** This has been formed to raise funds for the following

1. Research into the causes and treatments for Post-Polio Syndrome (PPS)
2. Education of the medical community as to the nature and severity and treatment of PPS.
3. Education of the general public that polio was not an acute disease, but a chronic one whose effects have returned with new or additional disability for most survivors; that PPS is likely to affect many more in this hemisphere and the rest of the world where vaccination programs against the disease lagged those here in the U.S.
4. Provision of money and/or equipment to those with PPS who are financially unable to purchase or get reimbursed for needed life-enhancing devices such as scooters, power wheelchairs, ventilators, lifts etc.

The two main Directors are:-

President	Steven L Diamond, MD. FACP a New York gastroenterologist who was recently forced to give up his practice because of the onset of PPS.
Vice President	Lauro Halstead, MD, head of the Post-Polio and Spinal Chord Injury clinics at the National Rehabilitation Hospital in Washington, D.C. and himself a polio survivor

with PPS.

More next newsletter.

**CALIFORNIA - Tom Walter.** In recent studies in the US and Europe about 70% of those who had paralytic polio now have symptoms of Post-Polio. And probably 50% of the anterior horn cells have to be 'gone' before strength/function is affected.

According to the observations of Drs. Perry and Bruno, those who had the worst affects at the onset of polio AND who made the most recovery appear to lost the most later on with PPS.

Dr. Halstead theorizes that in each decade of this century - 1910's, 1920's etc..... the polio virus became more virulent, with more limbs affected, more bulbar polio in the 1940's and 1950's than earlier.

That could explain why we see some more mature folks in their sixties and seventies (who had polio much earlier than most of us) do not seem to be affected by PPS.

Dr. Bruno has observed that those who had the Sister Kennedy treatments seem to have more PPS - but is this because they lived and recovered more with this treatment? or because the virus was, indeed, more virulent by the time this treatment came into vogue? or?

In my own case, I was completely paralyzed and in a coma at onset of Polio at age 12 in 1954. After 10 years of surgeries and therapies, I walked for 30 years with no aids - and only a slight limp and residual paresis in the left leg. Then starting about four years ago, I went 'over the cliff with a very rapid decline from PPS - with all muscles and ioints from head to toe (including breathing and digestion) affected by pain and weakness. Within a year, arthritis set in all the joints too - probably from lack of proper muscle support. Another secondary affect we may have from lack of mucle support and exercise is osteoporosis, which was already apparent two years ago in my 'bad' (now worse) leg.

I can still 'walk' (drag myself around) short distances inside, but use an electric power wheelchair for going out. I usually have the strength and energy to get cleaned up and dressed and leave the house twice a week - and the days in between I sleep and rest and nap and rest and sleep somemore.

Curioser and Curioser.

**Athens - Gerasimos Polis.** Dear Hilary, It's was souch a pleasant surprise to see in my email an message from this "side" of the Atlantic, our own Europe. I was born in Pireaus the harbor of Athens in (dd-mm-yy) 13-12-1962. (33) I got polio at the age of four months old. My parents remember that I got very close to death since polio was about to come to the breathing muscles. Actually it did, but got off with no damage on that part of my body. It's on the "net" that I found out that PPS exists. I had no access to any kind of information on polio. Fact one: I hate doctors. Despite the severe disability I have I am a person and not a damaged material that need to be fixed. In an unaccessible city as Athens I managed to studied Architecture and now I work for the Ministry of Health and Welfare. I need you people, all the disability family and specially polio survivors. You can count upon me on any support on demanding the proper services for PPS or on whatever else on polio surviving.

**PENNSVLVANIA - Art Coburn - The Serenity Prayer - (Reinhold Niebuhr 1943)**

"God grant us grace to accept with serenity the things that cannot be changed,  
courage to change the things which shoud be changed,  
and the wisdom to distinguish one from the other.

Too soon old, too late schmart' is the saying of some folks in Pennsylvania. It fits us live a glove. Whether it is PPS or just plain day to day living, confusion reigns. Neibuhr's serenity, courage and wisdom are in short supply, but when we consciously decide that this trinity of virtues are the ones we want to exhibit, we change our world...



**Next Newsletter**, this and much much more, hopefully some from you.....

**ANCHORAGE, ALASKA - Kane W. Basie** - Information on PPS and Alaska next newsletter. In the meantime have you met Smileys. :-) and ;- ) and :-( tum the page sideways and see the faces.....the first smiles, the second winks and the third is....

**FLORIDA - Sandra Cuadra** - Information on Roosevelt Warm Springs Institute for Rehabilitation Post Polio Clinical Services.....

### **Other snips...**

I was a Principle Design Engineer at Kennedy Space Center..... I was a telecommunications systems analyst climbing up the corporate ladder by leaps and bounds.... I was a physician/psychiatrist. .... I trialed for a professional football club..... I walked out of the hospital..9 days after I entered it 'totally cured'.

### **FINALLY**

**OH! How we would love to post polio..... If only we knew where to send it.....**

We have lots of medical articles. Newsletters and emails from polio survivors and post-polio support groups around the World. Full of articles and stories of their past lives, information on lightweight braces with tennis shoes, two wheeled scooters that stand up on their own and look great, how drugs have affected them, what vitamins they take, diets they have tried, how they have been in denial that PPS existed and how they feel now, jobs they have had and how they have had to alter their lifestyles, jokes they would like to share, Franklin D. Rooseven Memorial being built that will only show one line relating to his having had Polio and the campaign to persuade the people organising it to show his disability as an example to others that one can achieve the top despite disability, and lots lots more.....

**Items for next newsletter please by October 31st 1996  
Publicity date anticipated about 20th November..**

**Bibliography of all articles and newsletters we hold will be available about 15th October  
please send sae if you want a copy. About six pages of A4.**

**Please remember that we are running on a shoe string whilst we apply for grants.  
Any donations will be gratefully received.**

**Thankyou for taking the time to read this.**

**We are only a phone call, fax or email away and we do want to hear from you.**

**All enquiries, book requests, medical article requests, membership fees, items for newsletters  
and donations to**

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