The Lincolnshire Post-Polio Network
POST-POLIO INFORMATION SERVICE
NETWORKING

Reception | Library | Networking | Directory | What's New?

THE LINC-PIN

Issue No. 6 - July 1997
WebSite http://www.zynet.co.uk/ott/polio/lincolnshire/

The Web edition of this issue differs slightly from previous editions. Although previous issues have included articles that have subsequently been added to our online library, they all made their first appearence in the newsletter. For the first time this issue includes several articles from our online library (our newsletter is distributed by post to many subscribers who do not have Internet access). Rather than duplicate those articles in this online edition of the newsletter, I have instead just included links to the library articles. I have assumed that those of you who already have the articles would prefer not to have to print them again if you wish to print this newsletter for your own use. However, if you are printing copies for further distribution we would ask you to print copies of the articles as well.

Poliomyelitis - Been There, Done That
Post Polio Syndrome - Doing It All Over Again

Physiotherapists - We need your help!

Here we are in our later years, having done everything and more, to find that we are afflicted with pain, fatigue, muscles that refuse to work, reduced mobility and falls and what are we told by one doctor - PPS does not exist. Where do we go, back to the Consultants. Not likely... most have not seen or dealt with polio, and in fact even question us 'Did you really have polio?' If that's not salt in the wound, I don't know what is? 41 years of the Polio Vaccine has meant that the information in those old polio books just has not been read by today's doctors.

So where must we go now, back to our life long friends the Physiotherapists. But, and there is always a but, what do they know about PPS? Have they been trained for our special needs? If they have then who has trained them and where did they get their information from?

What we would like is British Physiotherapists to research the world-wide information, work with us, we know our bodies and how they are changing. Don't tell us Polio is old hat. We are not all in callipers and wheelchairs, many of us have little external sign of the polio but the internal nerve damage is there, and we are not all old, many of us are only in our forties and fifties.

Look at our Website - URL above - see how hard we are working to provide as much information as possible in one place to save the medical profession and polio survivors time and energy searching.

CONTENTS

Online Reading Navigation Tip - Selecting Cathedral logo will return you to the above contents.

Editorial
Hilary Hallam

Another two months have flown by and it is time for this our sixth newsletter.

We must first welcome our new members in Lincolnshire, Kent, Hampshire, Norfolk, Yorkshire, Nottingham, Derbyshire, France, to Joseph requesting help for his neighbours and Abu Dhabi in the Arab Emirates... a special welcome to Debbie and Alan. Debbie was searching on the Intemet and found out about Post Polio and contacted us. See her letter....., we were able to put her in touch with many people round the World who were able to answer her questions and send her the latest medical articles relating to her breathing problems to pass onto her doctors.

This newsletter contains letters and information that we have received which will give you some idea of the questions that want answering. **To the National Health Service Executive** we say........Is the contents of this newsletter, added to the previous ones, not enough to 'flesh out the problem'? We do not know how much more you need, to react other than your standard governmentease reply. How much longer do we have to rely on medical help from the rest of the World? This newsletter should contain British Articles, British medical opinion..... help us find Doctors and other medical professionals who will become advisors for our Network.

To the Lincolnshire Health Authority we say 'Polio did not beat us, and our present problems - whatever you like to label them - are not going to either. How much longer do we have to wait before you answer our letters and phone calls let alone agree to meet with us? Would you not like to save all the money being wasted now on inappropriate appointments and tests and work with us to define a Chain of Events for GP's so that they know what to do with Polio Survivors presenting with problems?

To Lincolnshire County Council and Lincoln City Council we say we were disappointed that you could not help with funding towards our work. Our WebSite has put the name of Lincoln and Lincolnshire on the PPS map of the World. **To Social Services** we say that we are normal people, just the same as you, we simply have some problems that need sorting out. We wait endless weeks for a visit; whoever arrives has no knowledge of our particular problems; we are talked to as if we have no intelligence at all; have to listen to reasons why we only need the most basic aids, regardless of whether they will be of any use, and then are asked to sign forms to allow you to get information from the doctor who referred us. It appears to be 'don't offer them anything over £5.00 and find some way to prolong the final decision and maybe they will either get better or pay for the alterations necessary themselves (four of us already doing this, we do not intend to deteriorate just because it takes so long to work through the red tape) or maybe even die!'

To Polio Survivors, families and friends, please ask questions, please write and tell us what you want to know. We have contacts around the World ready to help and hopefully before long we will be getting the medical assessments, advice and treatment we need, and see good British articles alongside those of the rest of the World.... Help with this work, if you have some time spare then give us a ring, you don't need to live in Lincoln, you could go and do some research at your local library for us for instance, there are a hundred different jobs that need doing. Our biggest need is funding. For our WebSite to continue to grow at the rate it is, and for all the other work involved we need more funding and sponsorship any ideas or offers of help will be gratefully received.

FUND RAISING EVENTS

If you are able to hold a coffee morning, or have a table at your Village Fete, car boot sale, etc to raise funds for our work then please get in touch with us. As soon as funds allow we will have a banner made, and be able to print off many copies of the information leaflets and posters we are finalising at the moment. Myra a member in Ruskington has donated a market stall framework and covers to us and this is available for small cost to cover maintenance. Details of these events will be included in this newsletter free of charge.

ANTI-CANDIDA DIET has helped me lose weight without difficulty for the first time. This diet has to be done under supervision of a Dietician. Article in next newsletter. Ask your Doctor for referral to dietician.

BOOK AVAILABLE NOW

Healing the Blues
Drug-Free Psychotherapy for Depresssion
An account by Polio Survivor patient and therapist.
32 copies donated to us to raise funds.
More details on Page 4

Hospital Obedience Training

by Viola Pahl,

White Rock, British Columbia, Canada

I have come to the conclusion that being in hospital is somewhat akin to Doggy Obedience Training

Class.

Have you noticed that the nurses of therapists or whoever are always talking in 'imperatives' just like animal trainers?

Roll over
Stand up
Sit up
Walk as far as the door
Take your medicine
Eat your dinner
Change your gown
and so on and so on.

Whatever happened to phrases such as 'would you like to sit up in your chair,' or 'when you are ready, we'll go for a short walk.'

At the Doggy Obedience School, the authority figures encourage the pooches with a favourite doggy tid bit to mask the distaste or the commands. Patients get these chewables, too, 'Good for you' 'That's a good girl' 'You are a sweetheart'.

And we obediently wag our tails and allow ourselves to be subjected to more commands.

One advantage nurses have over dog trainers is that generally, nurses don't get bitten by their patients. We may growl at them, be snarky, and pull on the leash in a moment of desperate disobedience, but we don't bite. Unless, of course, the doctor happens to be a dentist and has his finger in our mouth!

In some of the literature on post-op care for polio's, I think we should include a few sentences to the effect that polios' need more back rubs than most patients, because we cannot turn as often and that lower part of the back sure gets feeling as if circulation has been cut off.

At the end of the day, when nursie is weary of commanding a ward of patients, she finally resorts to unorthodox politeness: 'Would you like a back rub?' How come she is making an inquiry instead of a command? Why doesn't she follow protocol and say, 'Roll over - you're going to get a back rub'. Well nursie is tired, and so she hopes against hope that the patients will say 'No, don't bother'. Some do.

But not this lady. I want to say, 'Please nursie, I've been so good and obedient today. I'd not only like a back rub now, but perhaps several more during the night.' I daren't, of course, because the reward system for pets relies on the trainer, and if I get too sassy, by the next evening I might not even get the opportunity to choose a back rub - nursie might just pass me by.

Well, I opt for the back rub. Same equivalent as doggie getting his head patted and his ears rubbed. Or patting kitty on the head. As the blood begins to circulate and the skin tingles after a tough day at obedience school, I lay back in bed, relaxed, and if nursie had the ears to hear - she would swear she heard something or someone purring contentedly.

SHARING

My sister shared a million things
Hopes and dreams, toys and schemes
and polio

Now I am old, I share with her
Post-polio Syndrome
... wish it was MYRRH.

LaVonne Schoneman

BOOK AVAILABLE NOW

Healing the Blues
Drug-Free Psychotherapy for Depression

An account by Polio Survivor patient
and therapist.
Dorothea Nudelman - California USA
David Willingham, MSW
ISBN 0840168-316

Dorothea has kindly donated a case of her hard backed book to our Network to help us raise funds - we only have to pay the postage, they arrived this moming. She has autographed each one "Donated in support of Lincolnshire Post-Polio Network with Best Wishes, Dorothea Nudelman, July 1997."

To have psychotherapy and bring out lots of polio past ghosts is quite an experience. To write them down another, but to put into print like this takes great courage. I found this book extremely interesting, and also there were many occasions where little parts of my own polio past come flooding back, including some very emotional, tearful episodes. However, I found that this has cleared the air, and I now feel more able to cope with now and the future. If you would like a copy then please share its content with your family, friends and the medical professionals that you are seeing. It gives a great insight into how we might be dealing with our own PPS.

> "This book is a psychological peach. It is a story filled with edifying suffering, flinty fortitude, and wise and soulful humor. The immediacy of the dialogue draws us right into the heart of the consulting room. It is a bold and daring duet in which the audience is treated to the alternating voices of the healed one and the healer.
>
> *John S McGovern, PhD., Clinical Psychologist and Faculty Member, Stanford University School of Medicine, Department of Psychiatry and Behavioural Sciences.*

It is priced at $22.00 which is £13.75 plus £1.25 postage. £15.00 - please send cheque to Secretary.

We are offering this to paid up members for a minimum donation of £10.00 including postage (while stocks last).

Dorothea - our grateful thanks for this kind donation. We wish you every success with bringing out the paperback version in three months time, and thank you for including Lincolnshire Post Polio Network details in this.

Dorothea's email address is nudelman@mercury.fhda.edu

LINCOLN CITY FC
CHARITY GALA DAY

Sunday 3rd August 1997
10.00 - 4.00
at Sincil Bank, Lincoln

VISIT OUR STALL AT THIS EVENT

Pick a playing card - Item on each card on table. If anyone would like to donate any items for this - we have the cheaper items, but we need a few 50p to £2.00 items. Money, plants, toiletries, bottles and tins etc will all be welcome. Items can be brought on the day, just let us know in advance please. If you can help on day, please ring.

LINCOLNSHIRE BRANCH
British Polio Fellowship
DIARY DATES....

Saturday August 16th 1997

SUMMER BBQ
12.00 noon to 5.00
Ancaster Day Centre
Boundary Street, Lincoln.

Thursday 23rd October 1997

ORGAN RECITAL BY COLIN WALSH
Organist and Master of the Choristers at Lincoln Cathedral

Monthly Meetings
Ancaster Day Centre, Boundary St., Lincoln
2nd Monday of every Month.

September 8th Meeting
Indoor games practice for
Chess, draughts, darts, scrabble, dominoes, indoor bowls

Contact Secretary
Barry North - 01724 276676

Visit our Stand

50% to us - 50% MRI appeal

Pick a card - cakes - plants
at the
COUNTY HOSPITAL GALA
Lincoln & Louth NHS Trust

Saturday 9th August 1997
11.00 - 3.30

Fun Dog Show
Lincoln Hospitals Band
Nicola Withers School of Dancing
Uncle Ron - Children's magician
Lincoln Wrestlers
Variety of Stalls
BBQ - Pony Rides
Tombola - Raffles- Jugglers
Fireman Sam or Welephant
Restored engines and vehicles

Car Parking £1.00 Entrance Free
Proceeds to MRI 'SeeMore' Scanner Appeal

My Story - Miss Annie Wilkinson - aged 82

I read with interest 'My Story' in the Torch by Ruth Bitiman of Pottsville. (An American PPS Newsletter).

I realise how fortunate I have been over the years, considering I was completely paralysed, and I had no specialist treatment. My mother massaged my back and legs, after I had gradually got back the use of my arms. I was 11 years old and could not stand let alone walk. Then in 1938 I got into the hands of Mr. Frank Holdsworth of Sheffield (later he became Sir Frank Holdsworth) who operated on my leg, ankle and right knee, and got me walking with a calliper my right leg, and two sticks. The muscles of my right leg were very weak and the circulation very poor, resulting in chilblains on my leg and foot in winter. In 1952 I fell on frost and snow fracturing my left femur, then I got into the hands of Mr. Thomas at Lincoln Hospital. When the fracture united, he operated on my right knee, since then it has been permanently stiff. I had a job as a housekeeper in a farmhouse until I retired at 60 years of age. I walked round the house with one stick and used a trolley for a lot of things. When I retired I got a 'warden care bungalow' on the outskirts of Market Rason and carried on as usual until about 4 years ago. Swollen legs etc, which eventually got a knock resulting in one ulcer that has spread.

I had used my left hand and arm a lot with a stick in my right hand and suddenly found myself dropping plates etc. All this I put down to old age. During the last year I've had blood tests for Anaemia and Thyroid and now am on pills for both. Three months ago my thyroid dose was upped from 25mg to 100mg daily and I am beginning to feel much better. The last time I saw my Consultant, he said 'The infection in my right leg hasn't cleared up and we'd start some new treatment.' After two dressings my district nurse's remark was 'Wonderful'! It's a very painful treatment as the worst ulcers are just above my ankle. I know arterial ulcers are very difficult to heal so daren't raise my hopes too high. The Market Rasen Group of Doctors offer an annual check up to patients at the age of 75 years.

I do all my own cleaning and washing and cook for myself. I have my kitchen fitted to suit my needs. I now walk with a tri-walker, but haven't been out with it much this winter.

If anyone would like to write to me and swap stories of the past then please send them to our secretary who will pass them on.

Annie - Market Rasen, Lincolnshire.

Ask Wayne, RRT Respiratory Questions.

I am a Registered Respiratory Therapist from the great state of Tennessee, and if you had polio, the chances are, we are approximately the same age. I was educated at Duke University's School of Respiratory Therapy, Durham in North Carolina, in the mid 60's. Following the completion of my training, I spent the next 25 years becoming familiar with emergency, and critical respiratory care. Most of my experience has been in the area of the care and management of patients receiving some form of mechanical ventilatory support. Recently, I accepted a position with a large American firm, who employ therapists to provide respiratory care, and rehabilitation, in the home, and/or in nursing homes.

During my first month with the company, I found that I was tasked with providing care to a woman we shall call Miss M. She had just been admitted to our facility from the local University, and was referred to my service. She had an experience in which her airway became completely obstructed, which led to respiratory failure, requiring ventilatory support for approximately two weeks. Before that day, I'd been fairly confidant that nothing could come through the door that I hadn't experienced, yet here I was face to face with something called Post-Polio Syndrome. I 'd known about polio, as a child, and remembered the other kids that had suffered through it.... But from a professional point of view, this was a disease that no longer existed for me. I honestly had barely heard of PPS, and now I was faced with the responsibility of caring for someone with this problem. All the respiratory modalities and tracheostomy manipulations were routine, but, how would I relate to her if I didn't feel confident in my knowledge of her problems? How could I tailor a program of respiratory rehabilitation for someone, whose medical condition was unfamiliar to me? More importantly, how could I hope to gain her confidence, when my inexperience with PPS must have been terribly obvious. I decided to go to the computer, and power it up just as soon as I got home, and seek help if it was out there. Well, I did.......... and it was.

I called out to the internet, and pleaded for references, and something popped up regarding the Lincolnshire Post-Polio Network.... Never thinking such a group would be outside the US, or caring, I decided I had my help close by, and I was going to go there. My message indicated that I was now caring for a patient with PPS, and was seeking help to learn more. Well, to make a long story short, in these few months of research I have made at least one dear and life-long friend, and fairly buried myself in reams of paper on the subject. So much so, that a pulmonary physician recently referred to me as an expert on how PPS effects the respiratory system. Now, before you think I take pride in that comment, let me tell you that we should be collectively shocked by the lack of awareness most health care professionals have regarding PPS, particularly if my brief research could possibly qualify me or anyone as an expert. But I suppose I should get to the point.

I am not an expert on the subject of PPS, but I soon hope to be, for the sake of Miss M, and everyone else who may be impacted by my care. Which is why I've decided that pay-backs are due. It is time for me to pass on some help on behalf of those who spent time teaching me about PPS.

I understand from already corresponding with some of your members that you are concerned, or even frightened by the potential for future needs for ventilatory support. Even if you're in denial, the thought must have occurred to you..... It's normal... Having overcome the childhood fears, pains, and rehabilitation, ...only to be faced with these same symptoms again is reason enough to fear. Well, information is the answer to everything. The unknown is what we all fear, isn't it?

- Do you wonder why you're having trouble swallowing?
- Do you suddenly awaken after awful dreams of smothering?
- Wonder why you can't sleep very well at night, but find yourself dozing throughout the day?
- Wonder why you wake up with a sore throat in the morning, which then seems to go away by lunchtime?
- Do you sleep better on one side and not the other?
- Are you having trouble with breathing after suddenly awakening?
- Are you currently on a ventilator at night, or all the time, and have some questions?
- Are you afraid that being on a machine to assist your breathing or keep your airway open will make you less sexually attractive to your mate?

If you have wondered about any of these things, you're not alone. Large numbers of people all over the world have been concerned about such things, and somehow feel better knowing they're not alone, and there are many of us who care and will take the time to respond. Here's your chance to get some answers, and perhaps even conquer the fears.

Please send any questions you may have about these topics or any respiratory related events or areas of concern, by post, fax or email - and all will be responded to, when they arrive. We would like to print some of the questions and answers for the benefit of others reading this. Please tell us when you contact us if you would not want to see yours in print, and we will respect that. My wish is merely to be of assistance to you and nothing more. Please remember, that knowledge is the key to reducing the fears and taking control of the PPS dragon. I ask only that you let us be of assistance.

Until then, I wish you well, and the best of health......
Respectfully yours,
Wayne, RRT, Tennessee, U.S.A.

Lincolnshire Post-Polio Network

A Post-Polio Information Service for Polio Survivors
and Medical Professionals.
Website - http://www.zynet.co.uk/ott/polio/lincolnshire/

Our Website - which is like a large book and can be read, downloaded and printed by anyone connected to the Internet. It is indexed as follows:-

- Site Overview
- Library Catalogue Index
  - Quick Index
  - Library by Content
  - Library by Source
  - Other Post-Polio Libraries on the Internet
  - Other Post-Polio Articles on the Internet
  - Books and Periodicals
  - Online Journals
- Information about the Lincolnshire Post-Polio Network
- Directory Index
  - Post-Polio Organisations and Groups worldwide
  - Internet Discussion & Support Forums Newsgroups, Mailing Lists, Online Chat Room
  - Offsite Articles

What's New Page and Email Update Notification Service

NEW EMAIL UPDATE NOTIFICATION SERVICE:

If you wish to receive email notification of changes to this site please email LincsPPNUpdate@loncps.demon.co.uk with the word SUBSCRIBE in the body of the email. You will receive update notices as bcc's or blind carbon copies. This means that your email address will not appear in the headers of email to other subscribers thus ensuring your privacy.

Words that do not exist, but maybe they should...

Accordionated adj. - Being able to drive and refold a map at the same time.

Aquadextrous adj. - Possessing the ability to turn the bathrub faucet (tap) on and off with your toes.

Carpetpertuation n. - The act, when vacuuming of running over a string of a piece or lint at least a dozen times, reaching over and picking it up, examining it, then putting it back down to give the vacuum one more chance.

Disconfect v. - To sterilise the piece of candy you dropped on the floor by blowing on it, assuming this will somehow 'remove' all the germs.

Phonesia n. The affliction of dialling a phone number and forgetting whom you were calling just as they answer.

Pupkus n. - The moist residue left on a window after a dog presses its nose to it.

Michael R Well PhD. Professor,
Dept of Biology
University of Wisconsin-Eau Claire, WI, USA.

Some questions to God...

Dear God - In school they told us what to do - who does it when you are on vacation? - Jane.

Dear God - Did you mean for the giraffe to look like that - or was it an accident? - Norma.

Dear God - Instead of letting people die and having to make new ones - why don't you just keep the ones you have now? - Jane.

Dear God - who draws the lines round the countries? - Nan.

Dear God - do you really mean 'do unto others as they do unto you'? - Because if you do then I'm going to fix my brother. - Darla.

Dear God - We read in school that Thomas Edison made light. But in school they said You did it, bet he stole your idea! - Sincerely Bob.

Dear God - It rained for our whole vacation and is my father mad! He said some things about You that people are not supposed to say, but I hope You will not hurt him anyway. - Your friend (but I am not going to tell you who I am).

Dear God - Maybe Cain and Abel would not kill each other so much if they had their own rooms? It works with me and my brother - Larry.

Articles from our Online Library

The following articles are reprinted in full in the edition of this newsletter that is distributed via the *postal services. If you are printing this web edition for further distribution, please print the library articles as well and attach them to the newsletter.*

Be True To Your PPS And Your Teeth Won't Be False To You:
Preventing Complications In Polio Survivors Undergoing Dental Procedures

FULL TEXT HERE

Author: Richard L. Bruno, Ph.D.
Originally Published: PPS Monograph Series. Volume 6(1):1-8. Hackensack: Harvest Press, 1996.

Unfortunately, only a handful of specialists treat Post-Polio Sequelae (PPS) - the unexpected and often disabling fatigue, muscle weakness, joint pain, cold intolerance, and swallowing, sleep and breathing problems - occurring in America's 1.63 million polio survivors 40 years after their acute polio. However, all medical professionals need to be familiar with the neurological damage done by the original poliovirus infection that today causes unnecessary discomfort, excessive physical pain and occasionally serious complications with surgery. This is a brief overview to inform patients and professionals about the cause and prevention of complications in polio survivors undergoing dental surgery.

Dr. Henry writes.....about Bulbar and spinal polio

FULL TEXT HERE

Originally posted to the SJU Polio mailing list.

Bulbar polio involved the brain stem where the centers for the cranial nerves are located. The cranial nerves involve smell (olfactory), vision (optic), three cranial nerves control the various muscles that control eyeball movements, the trigeminal nerve and facial nerve which innervate cheeks, tears, gums, and muscles of the face,etc, the auditory nerve which provides hearing, the glossopharyngeal nerve which controls in part swallowing, and functions in the throat, another cranial nerve which controls tongue movement and taste and one that actually sends signals to the heart, intestines, respiratory(lungs) and the accessory nerve that controls upper neck movement.

TAKE A BREAK - ISSUE 30 - DATED 31.7.97

This magazine has an article about Leicestershire Post-Polio Network Member - John Splevings - and his Post-Polio problems. Name and address and 3 first class stamps to:-

Leicestershire Post-Polio Network
PO Box 30
Leicestershire LE1 7ZX

helena.edwards@virgin.net
james.mcvay@virgin.net

POLIO CONNECTION OF AMERICA
PO BOX 182 HOWARD BEACH, NY, 11414
TEL (718) 835-5536
<URL:http://www5.ios.com:80/~w1066/>

Have published 3 Yearbooks, '95,'96,'97. - 50 pages each A4

We now have one copy of each of the yearbooks and they contain many interesting and informative articles on PPS. If anyone would like copies please get in touch with us before September 3rd 1997.

These will then be ordered. Cost will be £8.00 each including postage.

Letters to the Linc-Pin

Dear Linc-Pin

I am wondering about being recommended for Physiotherapy. What will it achieve?

In the beginning it was sessions of 'try harder, stand straighter, more effort..etc...' and we did, but to what avail? Nerves knocked out by polio still resulted in deformed limbs, withered muscles, dropped feet and hands. With the best will in the world, all that effort was often to no avail.

Then came the middle - more physio after months of corrective surgery, and my original problems still existed. One of the 'ops' was to correct a dropped foot. It took 3 ops to get it fixed and stay fixed. Net result a foot fixed at such a completely flat level that it is impossible to buy shoes!!! Only flat pumps which won't stay on - no muscle power.

Now the autumn (dare I say end) of our lives we all seem to be afflicted with pain, fatigue, muscles that refuse to work, reduced mobility and falls - then I was told by a doctor 'PPS does not exist!' but no other name has been suggested for my problems. Perhaps we should hold a competition for another name.

What worries me, is if the doctors don't have the information, do the physics? Have they had any training regarding this, do they really understand my problems and why they are being caused and how will I know that what they want me to do is right for me??? So many questions but I want to know..

Flat-footed of Lincoln.

Dear Lincolnshire Post-Polio Network

I cannot thank you enough for putting together your LincsPPN website. I went to your site and found an incredible amount of information there on Post-Polio. I downloaded quite a bit to print out for some of my doctors and a few PPS folks I know to give to their doctors.

You have put a tremendous amount of work, research, and time consuming effort in order to produce this top notch newsletter, library and website. You have accomplished so much for so many.

My deepest respect and love
Eileen Revere, San Diego, California, USA.

Dear Linc-Pin

Is this all there is?

Some years ago I was the bane of my family's life! 'Why must you be so cheerful in the morning mum?! - The only answer I could give them was because that was how I felt. That was how I'd always been. Since recovering from infantile paralysis at the age of 10, everything in my life had been a challenge. I was fortunate, I felt, because I hadn't been left with any actual paralysis, just some weakness in my left arm, left leg and spine. As time went by these problems didn't seem to be serious and I grew stronger. Sadly, I had to have a long bout of hospitalisation and spinal surgery in my late teens for scoliosis - spinal curvature. Having recovered yet again, the inherent determination seemed to become stronger. Nothing was going to stop me from doing whatever I had the strength and opportunity to do with my life. I raised a family of three - who've proved to be excellent parents and I have to say a credit to their parents. They've also provided me with wonderful grandchildren.

Things went well for about 25 years, give or take, the odd pain here and there! I'm counting the years of course from the year of my spinal surgery. Then surprisingly rapid deterioration took place.

I accepted that in growing older one had to expect the symptoms that one associates with ageing - but this was all beginning to happen to me in my late forties. Muscle and joint pain, less stamina, serious pain in upper vertebrae in neck and base of skull. Occasionally, extreme attacks of vertigo accompanied by neck and head pain. Another factor was the overwhelming tiredness I was feeling - unheard of in my previous lifestyle. After hoping for quite a long time that it would all go away (of course it didn't), I broke my own code and saw a succession of consultants. Orthopaedic, neural, ears and eyes, etc. No-one could give me any answers - sometimes no sympathy or understanding either and certainly no-one mentioned the late effects of polio until fairly recently. Now in the mornings, the word cheerful doesn't enter my vocabulary. After fitful sleep I become conscious and have to seriously think about which part of me to move first as there are so many bits of me that hurt. I'm taking the only medication that's being prescribed for me, which is an anti-inflammatory tablet, without which I couldn't get through my day. Never in a million years would I have imagined I'd depend on such things. I'm still trying to achieve things in my life though by running a small horticultural nursery, but at the 'young age of 61' I'm a bit fearful for my future. All I can say for sure is that by joining and becoming involved with the Lincolnshire Post-Polio Network I've learned more about the late effects of polio that from any other source, including numerous doctors, no matter how well meaning they've been. I certainly don't know it all now as it covers such an enormous range of different problems for different people, but I am beginning to understand a bit about the changes in my own body and the reasons for those changes. The LincsPPN needs all the support it can get so all you fellow sufferers out there and any interested parties get in touch with us. You'd be amazed at the amount of information the Network has collected - some of which could help you with your own personal problems. We're hoping to expand and achieve our Charity status in the next few weeks. With more support we could do more. How about getting in touch..

Regards to you all
Yvonne Webb - Lincoln.

Editor's Story

I caught Polio at the age of 5 in 1952 in Libya, and have no medical records - Consultant asked this year 'then how do you know you even had Polio?' Imagine my parents comments when I told them my having polio was being queried, after they had had to cope with my being rushed into isolation, have a spinal tap, told I had polio and watch me over the years struggle to overcome the leg paralysis.

I had multiple tendon transfers and big toe fusion's at the age of 12/13 for dropped feet. Always falling over at school, as I tried to run, play netball, rounders, tennis. The operations made all the difference and on I went to lifesaving, judo, canoeing, lifeguarding, all sorts, all physical activities, despite my leg weakness. I never stopped. I even became a policewoman because the Doctor doing the medical had no knowledge of polio muscle testing, - of course they work once, but repeat the actions, now that is a different story. Imagine what happened at Training School when told tomorrow was cross country running and I said, I am sorry I can't run. My Chief Constable asked for me to be given a chance, and I passed out with flying colours and I later passed a CID course. I married, had two children and retook all my lifesaving awards and qualified as an Advanced Swimming and Lifesaving Teacher. I have spent many hours each week doing voluntary work, with many different disabilities. I have certificates in British Sign Language for the Deaf and Deaf Blind. I never stopped, rarely had days off work even after breaking toes and minor operations, until 1988. A fall I had then caused me major problems to my neck and left arm. Tests done at the time produced strange unexplained results, but polio was never mentioned. I had an operation in 1994 and struggled to get going again, and my neck and left arm started playing up again. In early 1995 sudden severe pain in my left leg for no apparent reason, yet I was told it is referred pain from a low back injury and exercise and build on that daily. I did that and just got worse, x-rays and MRI scans produced nothing. And I asked the question 'Does the fact that I had polio come into this?'

Light dawned, the Consultant said, 'Oh, you had polio, oh there is something called the 'late effects of polio' but I know nothing about it, I will send you to a neurologist, like another patient from my previous hospital.' Imagine how I felt, polio back again.... Stunned, frightened, worried about the future.

I went straight to the Hospital Library, and from there to the Health Information Service. Two newspaper articles and the address of the British Polio Fellowship was all I could be given - it was enough. I read a story that fitted mine, maybe here were some answers. I have not stopped searching since. I correspond daily with many many Polio Survivors around the World. I email medical professionals abroad and they reply within 24 hours....what do I get in this country... two and a half years later and I still wait for another of the rounds of the hospital appointments, this time to another hospital and a different neurologist.

The money being wasted on these appointments and tests is phenomenal..... The tests are mostly being read by persons without benefit of knowledge of polio and PPS.

I am off to America in six weeks time to a Post-Polio Conference and to visit PPS Clinics and PPS Support Groups. CarolAnn from Canada, Millie and Sparkle from the States, PPSers I have met on the Internet, are coming to pick me up in Atlanta and from there we visit Louisanna, Alabama, Tennessee, Kentucky, Illinois, and then to Niagara Falls, and possibly Montreal. Then back to Tennessee. There is much to learn, much information to share and much to bring back. This is being done on a shoe string budget and only possible due to the generosity of Polio Survivors in offering their time, cars, houses. etc.

The World's Polio Survivors and PPS Clinics are sharing their information with each other. Come on British Medical Profession - Wake Up - Time you got in on the act. Before you say it, not every symptom we have is Polio or Post Polio related but without a specialist holistic PPS Clinic how will we ever find out?

The glove is down on the table...

Dear Linc Pin

I thought the following might be of interest to new members. A few years ago I developed a very low voice and sometimes it was painful and people couldn't hear me when I called - some said it was useful...... I went to the doctor who sent me to a specialist. I had a camera put down my throat and was informed that there was nothing nasty down there and that was that. So what else could I do, nothing. Still had the low voice. Then I saw an article in a magazine about PPS. I thought that sounds like me, I might come under that...... so I asked my doctor if he would put me in touch with Papworth Hospital to see Dr. Shneerson. Dr. Shneerson said that the voice box down one side was not working... At last I had an answer to my problem, relief. He arranged for me to see a Speech Therapist and she loaned me a voice amplifier. I can now speak to my friends without raising my voice, and now after calling Bingo at the Village Hall, I have a voice - before I used to lose it for at least three days.

The Walking Stick Lady... Sturton by Stow Lincolnshire.

PS - I got some extra exercise today - moving furniture from a wheelchair which is not easy - why? - horrible smell in lounge, and yes you guessed it another dead mouse.......

Dear Linc Pin

On behalf of our group I extend our sincere gratitude for the wonderful work you are doing in collating and disseminating information regarding Post-Polio Syndrome....... may we please confirm permission to use some of the articles on your site for our future newsletters.

David Hurse, Convener.
Post-Polio Support Group, Far North Queensland, Cairns, Queensland, Australia.

Editor note:
David, thank you for your letter - yes by all means copy as per information at the end of each article

- and we would be interested in a copy of your database of articles. It is only by sharing information around the World that we will all succeed in our quest for the medical help that we need. The new Physic, Sean East at the County Hospital Lincoln, who is seeing Post Polio patients was diving in the area last year. Such a small world ....

Dear Linc Pin

What happens now? I had Polio when a child and in the last few years have had new unexpected problems. Then I found out about PPS and am soon to start taking a drug for my fatigue. I thought I was making cracks in the brick wall at last.......... Now I find no Doctor can tell me whether or not it will help. Am I just being a guinea pig?.............. So it seems as if someone has a trowel and is filling up the cracks again, and I almost feel back to square one. That old brick wall of silence... nothing can be done, you must leam to live with it, and so it goes on...

For how long?.......will I still be alive when we get our first holistic Post Polio Clinic in the UK, I do hope so, but please I am getting on in years and before I die would help.

Dear Hilary

Very many thanks indeed for your e-mail and assistance. Maybe I should give a brief background to myself? I'm 43, got polio in Hong Kong in 1954 when I was a year old. I was paralysed for a year from the shoulders down. Then movement came back, after many surgeries in Scotland got walking reasonably well etc. I have a pronounced scoliosis but until last year's operation coped well with life, happily married with 2 sons 22 and 16.

Finding out about PPS is very devastating as I feel it's now controlling my recuperation and life, especially feeling very vulnerable with my breathing problems. The stage I'm at now since Feb this year is I 'potter' about the house, can't do any heavy housework (most frustrating!), vacuuming brings on acute tiredness and breathing problems. I can only happily aim seeing friends for a coffee moming once a week, the rest of time spent recuperating from it. I can go slowly round and do the shopping on my good days, and do a lot of resting in between. In April I tried to 'build up' and went on the exercise bike for 3 days, twice a day for 15 minutes, but was floored by chest pain, breathing problems and acute fatigue only picking up feeling back to 'normal?' 3 weeks later. The breathing difficulties lasted a few days and that recovered so I was breathless only a few times in the day.

This alarmed me and I went to the Dr.'s here, a place called Gulf Diagnostics where there is a UK Internist and a USA radiologist. They only are equipped for diagnosis and not treatment. I needed to know from them how often I should exercise and when to start - I just had to get built up again from taking it easy all the time. They did a CAT scan on my lungs to see if the operation I had for collapsed lung from last year was responsible but all looked fine, so was a heart ultrasound. They sent me away with the USA radiologist saying he had heard of polio cases being troubled by past problems, perhaps that was what it was, but didn't know anything about it.

Then I went on the Internet and found data and the Lincolnshire Post-Polio Network - thank goodness. Having read the literature my first thought was they were writing about me, then it dawned I had found my 'lost tribe, family', I was not alone! Last Monday I was having my weekly coffee moming this time at my house. I cleaned the house (usually the family does it), entertained, had a lovely time but on Tuesday was flattened with fatigue; Wednesday had the worst breathing difficulties for a long time hoping all day it would go away but it just got worse, till at night I had to send an SOS to Chris Salter asking for advice. Thursday after a sleep was better with only some 'gasping' throughout the day and chest tiredness, today Friday feel a bit more breathless than yesterday. I don't know what's going on inside but I am so grateful of any help, advice you can give me to make me breathe better and give me some rest from the great effort of doing so. I will do as you suggest and go back to the Internist tomorrow after our weekend but do not think I have any infection etc. I am sorry to bother you with this long history but must tell you I feel buoyed up that someone may be able to help bring me some relief, and look forward to receiving the question sheet and information from the Respiratory Therapist and the medical articles from Dr. Bruno, and others

for my Doctor. Thank you Chris and Hilary for extending to me the life line and for the time involved! Please let me know how I may reimburse you for your time and any phone calls on my behalf.
Take care,

love Debbie in Abu Dhabi.

Dear Hilary

Wayne came bouncing in my room today and brought me an email from you telling me all about your experiences with Polio, and I look forward to hearing from the lady in Canada and the others in the States that said they would write. I am so glad to have some new Polio friends, thank you for telling them about me..

I belong to the East Tennessee Polio Survivors Organisation and get their newsletter but cannot go to the monthly meetings any more. It is held in a classroom at Port Sanders Hospital in Knoxville a few miles from where I lived for a long time with my parents. Jeanette Barnes is the founder/president and is a Post Polio herself. She had the illness about the time I did, was completely paralysed and fully recovered. She had a normal life until a few years ago when she started developing weakness, like the rest of us. East Tennessee Polio Survivors Organisation, PO Box 1527 Morristown, TN 37814.

I don't know just what Wayne told you about me, I am 56, so I'll start from the beginning of my experience with Polio. It was in late August 1954, I had been horse riding with classmates when I began having very severe pain in all of my right leg, which continued all day and night. When I went to bed I started having a headache that was the worse I had ever had by morning. When I woke I went to my mother who is a registered nurse. She gave me some aspirin and a drink but I could not hold the tumbler. She put me to bed downstairs and called the doctor. He sent me straight to a local hospital for a Spinal Tap. Some time later the lab report came back positive for Spinal Bulbar Polio. We were in shock, my father cried, I didn't know what to think. I was 14. An ambulance was outside ready to take me to the Isolation Hospital but the driver was so afraid, he would not take me and another had to be found.

My parents sat outside the door of my new room all afternoon while I twisted with pain and gradually lost the feelings, and in all muscles by night time. During the night I was put in an oxygen tent. I suffered the worst back pain I had had, hallucinated, had nightmares and could not breathe by morning.

In the early hours I was put in an iron lung, side by side with several others in a big room. We were watched and tended to by L.P.N's who treated me very well and kindly for two months. The next two months I spent in a Rocking Bed which also forced air in and out of your lungs, but you had to do some of the work.

I was given daily baths and wrapped in Hot Pads which are wrapped in towels and put on arms and legs. After this treatment, I had exercise from a Registered Physical Therapist. She was working as an R.N. at a hospital in another state when she had polio in her legs. After her own recovery Mary Lou Wilson became a P.T. and exercised Polios. We loved her. She came every day and I found out what 'tight muscles' meant. Mary Lou used her own technique of exercising weak muscles called 'Pumping the Muscle'. She really helped me.

The fifth month I was able to sit in a wheelchair and breathe by myself again. So, then I was sent to Alfred du Pont Institute in Delaware State just across the border. It is now 10pm and I am getting blurry eyed, I will start another letter soon and tell you the rest of my story.

If anyone would like to ask me questions about my treatment, or just write for fun - especially from England then I would love to hear from you, send letters via Hilary, or ask her for my address.

Love and Prayers - 'Miss M'
Loudon, Tennessee, USA

To:- St. Johns Polio List - PPS - how old are we?

I figured out my age.......

Chronologically	46	
Biologically	85	
Mentally	12	
Energetically	200+	(I hope this means TIRED)
Sexually	000	(This is irrelevant in my case!)

That all makes me 343+, but I have not figured out if a high score or a low score on this is good?

And let me tell you, for 343+ years old, I look VERY GOOD!!!!

In prayer, Sister Jean Terese

* * *

PPS CONFERENCES

Atlanta, Georgia, U.S.A.
Sep 12-14, 1997
BEEN THERE, DONE THAT, MOVIN' ON
A Post-Polio Conference Focusing on
Quality of Life
Atlanta Marriott Gwinnett Place
Contact:
Linda Sutherland at laslinda@mindspring.com
Atlanta Post-Polio Assn Inc.
APPA Conference
PO Box 250566
Atlanta, Georgia 30325
(404) 350-7631
Fax (770) 232-7178
Editors note:- Am going to this one.

Calgary, Alberta, CANADA
Sep 29 - Oct 2 1997
'97 INTERNATIONAL POST-POLIO CONFERENCE
The Coast Plaza Hotel
Featuring Drs. Yarny Eulberg, Rubin Feldman,
RL Bruno & NM Frick
"A fun conference with time for rest end sightseeing"
Contact:
Mr. Vern Hamm at hammv@cybersur.net for E-mail BROCHURE
- or -
Ms. Dodie Spittal Reny de Jong
Southern Alberta PPS Support Society
No. 7-11 Street NE

* * *

LINCOLNSHIRE VOLUNTARY CENTRE
CENTRE NEWS BACK PAGE

SPOTLIGHT ON LINCOLNSHIRE POST-POLIO NETWORK

Who are the Lincolnshire Post-Polio Network?

We are Polio Survivors (not Doctors) who, after years of stable functioning following recovery from Polio, are experiencing new deterioration. In most cases these problems have been gradual and medically noted (not explained) over the last ten to fifteen years. In May 1995 at a Disability Sports Day in Lincoln, an overheard remark relating to "old polio" and breathing problems now being experienced by people who had been in iron lungs, lodged in our Secretary's memory although its significance was not appreciated until much later. In November of the same year, following nine months of consultations without any answers, she asked a new Consultant, "could Polio be the problem?" The reply that another patient who had the same symptoms also had Polio as a child, began a trail of discovery. That observation led our Secretary to embark on a personal search for more information.

Post-Polio Syndrome (PPS) are new symptoms being experienced by Polio survivors who recovered from Polio many years ago. New fatigue, both physical and mental, muscle weakness, joint and muscle pain, cold intolerance and breathing and swallowing difficulties. They occur in as many as 80 percent of survivors of paralytic and non-paralytic Polio, typically 30 to 40 years after initial recovery from Polio.

Polio Survivors are typically high achievers who have worked hard in overcoming the initial after-effect of Polio. Many of us show little or no visible signs of having had Polio. Many of us have led very active lives. The message that we must decrease the overuse and stop the abuse of our damaged nerves, weakened muscles and painful joints is not an easy pill to swallow, even for the PPS aware.

Lack of awareness of PPS amongst both Polio Survivors and the Medical profession is a genuine problem not to be underestimated. There is unfortunately no test for PPS and therefore diagnosis can only be made after all other possibilities have been excluded and by a past history of having had polio. For the majority of us the fact that we had polio has not even been considered up to now, either by ourselves or Medical Professionals. Many who are not currently exhibiting symptoms continue life-styles that may ultimately lead to PPS.

For more information about the work of the Lincolnshire Post-Polio Network
Contact: Hilary Hallam Tel: 01522 888601 Fax: 01522 885115

<URL:http://www.zynet.co.uk/ott/polio/lincolnshire/>

IF YOUR ORGANISATION WOULD LIKE TO BE FEATURED IN THE CENTRE NEWS SPOTLIGHT FEATURE TEL: 513564

LINCOLNSHIRE POST-POLIO NETWORK

MEMBERSHIP FEES - £10.00 from 1st April 1997 to 31st March 1998
Bi-monthly newsletters - Information Pack - Please send to address below.
All donations will be gratefully received.

Articles for publication by August 30th please - Publication date September 3rd 1997
Early due to visit to USA - report on this in November Newsletter.

All enquiries, book requests, medical article requests, membership fees, items for newsletters and donations to
The Secretary, Lincolnshire Post-Polio Network
PO Box 954, Lincoln, Lincolnshire, LN5 5ER United Kingdom
Telephone: +44 (0)1522 888601
Facsimile: +44 (0)870 1600840
Email: info@lincolnshirepostpolio.org.uk

Reception | Library | Networking | Directory | What's New?

Document preparation: Chris Salter, Original Think-tank, Cornwall, United Kingdom.
Document Reference: <URL:http://www.zynet.co.uk/ott/polio/lincolnshire/linkpin/linkpin976.html>
Last modification: 10th April 2009.