The Lincolnshire Post-Polio Network
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THE LINC-PIN

Lincolnshire's Post-Polio Informative Newsletter No. 5 - May 1997

POLIO SURVIVORS STAND (sit) TOGETHER
PSSsT... Are you listening?

We are Polio Survivors.
which means we had Polio in our earlier lives
but overcame the consequences to the extent that many of us
show no obvious external signs of having had to do battle with the disease.
Most of us have been fortunate and been able to reach high standards
of achievement in our careers and personal lives.
Some of us are now experiencing functional decline,
in both polio affected limbs and those we previously thought of as unaffected.
We now have new muscle and joint pain and weakness,
breathing and swallowing difficulties.

Our very real symptoms are varied and
we accept that we could have other conditions and/or PPS.
However, most of us have not been assessed by PPS Specialists.
Our symptoms have been medically noted but unexplained for some years now.
Everyone gets a little older each day, but we are beginning to feel much older
than should be expected for our average age of late forties, early fifties.

We do not want to change jobs, give up work, retire early.
We do not want to give up sports, dancing, walking, decorating, gardening, etc.
We do not want to have to ask for help to manage our homes.
We do not want to live on less money.
We do not want to start using, or reusing aids and assistive devices.
If we can get assessed, diagnosed and are advised by PPS Specialists
that this is the right advice and it will help us to manage longer. Then we will do it.

Therefore we urgently need
A Multi-Disciplinary Holistic Post Polio Clinic - A Centre of Excellence,
staffed by Polio and PPS Specialists.
Who will physically examine us,
take note of our symptoms, read our x-rays, MRI scans, EMG and NCS and other tests.
Who will separate out our problems and manage our cases.
Who will refer us to appropriate specialists,
for treatment advice, aids and assistive devices, counselling etc.
Who will provide hands-on training for future specialists

and have the opportunities to engage in much needed broad based research.
We have deteriorated unnecessarily for far too long
and we want to live productive lives as long as possible.
We will not give up.
We will not go away,
We will succeed.
We never gave up when we had Polio.
We will not give up now.

Lincolnshire Post-Polio Network

EDITORIAL - by Yvonne Webb

Hello again to LincPin members (and those reading this via the Internet around the World). As usual we're still waiting for summer. We get a few beautiful days and we think it's here and then we could well be back into March. The gardens still get on with growing well, including the weeds!! It means lots of work for us who can manage it, of course. Being the determined breed we are most of us keep plodding away at it.

Back to LincPin business now and I'd like you to read a quote from an article written by our dedicated secretary Hillary Hallam to be included in a Physiotherapists magazine.

> 'We are not medically qualified. We are a self help group of Polio Survivors who are having problems. We know our own bodies, we have struggled with them for a number of years since the polio. We know what they did, how well they recovered and how we have used them. We know we are getting older but what we cannot explain is the rapid deterioration of our joints and muscles and our ability to carry on our normal lives. The medical profession did not understand polio back when we had it, and the same goes for now.'

I feel we can perhaps be charitable towards doctors many years ago when most of us had our polio but its disappointing to find that very little research if any, is done in this country into the late effects of polio. Britain always seemed to lead the field in scientific and medical discoveries in the past but over the last fifteen/twenty years or so the Australians and Americans seem to have taken a great deal more interest in the subject. Maybe finance has something to do with it.

I have to say though, that I don't think that its all doom and gloom as at least two consultants that I've seen recently (albeit one for a different reason) were interested in what I had to say on the subject, and I felt they acknowledged that the problem does exist. Hopefully word will get round. We do have to be optimistic; we really don't have a choice. We must keep working away steadily at getting information about PPS out to anyone who will listen to or read it. Also very important is our fund-raising efforts. Our committee group and local contacts are quite small at the moment but growing steadily. In the meantime functions such as coffee mornings, stalls at bazaars, plant sales etc., will all help in a very important way with stationery, postage and so on.

I wish all members and readers who may wish to join us, good luck and hope for the future.

PLEASE READ THE FOLLOWING -

ARTICLES PUBLISHED IN THE LINC-PIN.

Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-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.*

CONTENTS - Newsletter No. 5

LETTER FROM KERNOW by Chris Salter

As luck would have it, when the time arrived to write the third edition of this column, or to be more truthful when it was already half way out the back door, my attention was otherwise engaged. During the process of updating the LincsPPN Web Site I had noticed that some documents were not displaying correctly. Fortunately only the document details, for example the copyright notice, appear to be affected. Nevertheless it does not inspire confidence in the reader and must be resolved as soon as possible. Problem determination is a combination of diagnosis by exclusion and intuitive thinking, terms you will be familiar with in a different context. Often the exclusion part can be time consuming. It's not unlike being given a jigsaw puzzle which has all the pieces of one picture but with some of the pieces from a dozen other puzzles mixed in! Well, now you have my excuse for the rushed nature of this column. I must return to my jigsaw puzzle sooner rather than later! However, I would not want you to be mislead into thinking that it is usual for our web site to have these sort of problems. In fact this is the first event of this nature that I have had to deal with since our sites opening which is just as well as there is more than enough other work to do. I may write in more detail on particular areas of web administration in future columns but I will describe briefly the main tasks involved in keeping the LincsPPN Web Site rolling.

In one sense it is very much akin to running a newspaper or magazine. The design of the web site is constantly under review as new material is added. Sometimes a catalogue section will become too large and will need restructuring. Sometimes a new article will come along whose content doesn't sit comfortably under any of our existing headings. The latter requires careful thought in order to arrive at a heading which will encompass some future articles. The work involved in adding individual articles varies. If the source document is paper it is scanned a page at a time. Each page then has to be processed by OCR (Optical Character Reader) software to convert the image of the text into text character code that the computer can manipulate. Some errors are introduced at this stage dependent on the print quality of the source document. Some of the more expensive OCR software (in the region of £400+) has a lower error rate with poorer quality print but most of our source documents tend to be average to good quality so I get by with standard software. The OCR'd text is then transferred a paragraph at a time to a web document. This is partly due to the format of a web document but mainly to facilitate proof reading. If you proof read each paragraph immediately after inserting it in the web document you are less likely to miss any errors. The medical content of our site demands that we take utmost care not to introduce any errors. If there are pictures and diagrams these are scanned separately and then processed by image manipulation software to ensure they display properly on computer screens. Finally the web document with any associated image files is uploaded from my PC to our web site. If the document is a library article it will also require several catalogues and index documents updating and uploading. Last but not least the What's New page has to be updated and uploaded. In practice all uploads will be made at the same time as we don't want someone selecting an article from one of the catalogues only to find it's not in the library! Once I've confirmed that the uploads have been successful I send out the update notification emails to those that have subscribed to the service.

I participate in four post-polio mailing lists on a daily basis, a task I share with Hilary. Additionally I monitor one post-polio and three UK health and disability newsgroups. Mailing lists and newsgroups can be thought of as discussion forums. I also participate in five mailing lists concerned with issues surrounding medical and healthcare information on the Internet. One of the lists is the private discussion forum of the British Healthcare Internet Association of which we are a member. This is an important part of my work as Web Administrator as we have to keep abreast of developments in this area especially with regard to possible future certification schemes. An example might be an index of certified medical web sites backed by such authorities as the BMA in the UK, the AMA in the US and equivalent organisations in other countries. Such ideas are currently limited to discussion at national level but it's essential to ensure that consumer organisations such as ourselves are not excluded from any such schemes. Neither can the spinoff benefits from having

I get various emails concerning the site that require replies although thankfully only a fraction of the number that Hilary receives daily! This is probably the hardest task for me as I am a slow writer. Publicity has been relatively speaking on the back burner for a while. I have a long and growing list of medical web sites that I must check out with a view to getting our site listed where appropriate. It's time consuming but essential work.

I promised to explain the Cornish connection but I fear I have run out of space again. It will have to remain as mysterious as the Cornish landscape for a while longer! Only yesterday I looked out the window and saw a four masted square rigger anchored in the bay. Don't worry! It was the real thing...

What to do if your Walking Stick is out of reach..... Hide under the covers?

There I was all snuggled under the covers when thud, ooooh, it must be nearly morning that is the cat is back from her nightly tour. Wait..... whats that..... the sound of 'crunching'...... I took a peep over the covers and horror of horrors there was my cat with tiny feet poking out of her mouth. I looked for my trusty walking stick.... oh dear, out of reach.... Oh well, fingers in both ears and under the covers and wait. Aahhh... she is settling down for a sleep, another quick peep..... Thank goodness, breakfast is over and not a sign.

Jean, Sturton by Stow, Lincolnshire. (PS she isn't really 21, its a porky pie - little lie)

MONEY, £, $, Cash, Dosh, Ackers, Lolly, Sheckels, Bucks, Moolah.

How many other versions are there? What it all boils down to (golly gosh the Americans reading this will have fun with all the English idioms we use) we need money to carry on with the work we have started. The trouble is that there are so many self help groups and other organisations all needing money, and we are all trying to get it out of the same pot.

Unlike Leicestershire Post-Polio Network (name changed to add Post- 18.5.97) who two years ago received a start up grant of three computers and running costs for three years, we have been unsuccessful in our bid for funding from Lincolnshire County Council. No new grants to new organisations due to financial resources. We have sent out many letters asking for grants to support our work. Some have replied that they are unable to help, some are holding meetings and we await a further response, some have just not replied at all. We have more letters to write. If you know of anywhere we could apply that we might not have thought of then give us a ring. Maybe you know a firm that would sponsor some of our work, an issue of the newsletter, a Mg of space on our Website, printer ink cartridges, envelopes, etc. All sponsorship will be acknowledged on our Website and in our newsletters.

It is for this reason that the Committee have decided that we must ask for a yearly membership, and for ease of accounting have taken this from April 1997 to March 1998. We have decided on a figure of £10 and for that you will receive 6 bi-monthly newsletters containing a considerable amount of PPS information. This £10 will also cover the cost of one copy of our latest Information Pack and a membership rate for copies of medical articles not in our newsletters. See attached list *[Our library catalogue by source - LincsPPN Web Administration]*. Many of our members are now unable to work and it is not always easy to find £10 at one go, and therefore we are quite happy to have this in two cheques, the second dated up to three months later than the first. Ideally we would like to receive membership fees as soon as possible but if you wish to continue receiving the newsletter after the July issue then we must hear from you by the 31'" August 1997. We will remind you in the next newsletter.

This will give us a base income to work from but will not cover all our running costs, or allow for repair or replacement of equipment - at present personal to committee members. Jean is already having a table-top at Sturton by Stow fair on Sunday May 25th , other committee members are planning similar events in their area, which we will include in newsletters. We would like to suggest that you do a little gentle arm bending of your friends and family and see if they would organise something where you live. Collect stuff for a car boot, a coffee morning, a table at your local village fair, asking an organisation you are involved with to hold a raffle for us at one of their events, there are many ways and every £1 will count. A book of second class stamps will be just as gratefully received as a large cheque.

To give you a little idea of all that we are doing see Chris's 'Letter from Kernow' which explains all that is done via the Intemet. Then there are the newsletters to collate and send out, phone calls to take and information to be sent out to new members, letters to be sent out promoting the awareness of PPS and campaigning for appropriate PPS medical assessments and treatment, searching local and national papers for events that we could go to and articles to add to our collection, data-basing all the information that we have collected, etc. You can all join in with this, if you see something that you think we should know about then give us a ring, if you are visiting Lincoln and have a couple of hours to spare then there are many little jobs to do.

I think I have PPS. Why? Judge for yourselves.

From a lady in a hamlet in Lincolnshire.

It was in 1938 when I was nearly eleven and working for my High School Certificate. I was at a local dog show when I somehow knew, whilst queuing , that I would be unable to run with the dog around the ring. My neck hurt and I felt ill. I was taken home, put to bed and during the course of the next few days my left side became paralysed. I could not even lift my head from the pillow, and had to be 'turned' regularly by my mother (an ex nurse luckily). I still remember trying to eat mince lying on my back unable to raise my head. (I hate it now). My father called in two doctors, who proclaimed I was paralysed and should have a leg brace. Again luckily my Grandfather and Uncle were both doctors and my father had done two years training at Kings College before giving it up in favour of engineering. They all disagreed with these doctors, saying the muscles would waste. I was hauled about, put in a steel corset for my spine (no medication) and taken to a children's hospital in London. I remember my bowels being paralysed for a month. In 1939 I spent about three months in this hospital (including Christmas) was blindfolded, stuck with pins and tickled with feathers on my left paralysed side by many Interns. I was sent home, Infantile Paralysis, get on with it.

I then progressed to dragging myself round the room, clinging to any furniture available as there were no aids available. I used my Grandfathers Walking Stick, it was very painful now. Eventually my father talked to the local masseur and nearly every day for a year my mother walked me in my wheelchair to her clinic for treatment. She was very hard on me, but also kind. She managed to get me standing upright without assistance, and walking a few steps. Exercises at home every day, trying to lift myself from the prone position and raise my left leg. Sandbags on my ankles. Never achieved my goal.

Back to school at 14 in a wheelchair (I had been tutored at home meanwhile), eventually walking with bad limp and always watching out for kerbs. I was teased a lot as I could not run, the only thing I could do was walk a little, cycle eventually if placed on the bike and swim if I was lowered in a harness. I thought I was cured. I left school and found a sitting down job. Polio was never mentioned and I began to think of myself as normal, but most of all I missed dancing and running.

Between 1941 and 1987 I had no real problems apart from always a dull ache in my left leg and arm and a slow limping walk. In 1987 I suddenly experienced very bad muscle pains in both legs. Put it down to too tight ski pants, and after three months they decreased. This all happened when I found out I was being made redundant after 40 years, but after three months the boss started a new firm and took me back on.

In 1993 in the March the muscle pains returned, both legs, thighs. Trouble with stairs. In May I visited my local GP. The first time for any reason other than flu shots for over forty years. Had no tests, 'maybe its Fibromyalgia'. Previous records were all destroyed. 'How did I know I had had Polio?' I was dismissed with 'Its all in your mind.' When I could not even manage the stairs to his surgery. Three months later, still in pain, I saw another doctor at the same surgery. He was very concerned and ordered lots of blood tests, arthritis, rheumatism, etc. All negative except for 'you have abnormal muscles in your legs'. I showed him various PPS leaflets which he read with no comment. Painkillers just did not work.

In 1994 my GP referred me to a Consultant Rheumatologist. Thorough examination, endless blood and other tests, all negative. Except for 'you have abnormal muscles in your legs'. ?PPS ignored.

In 1995 another Consultant declared himself 'mystified'. I was sent to another City for tests and a registrar there seeing me walking across her room immediately said 'Polymyositis'. Which I knew was fatal. Three months later I was sent for again, the biopsy was negative and the electrical tests said 'we cannot get below the polio barrier in both legs'. Both legs, but I only had polio on one side!!! BUT it was not PPS, Polio had been wiped out in England years ago. Again they said 'We are mystified'. I struggled on for the rest of that year. Exhaustion set in and my social life was nil. Even my daily had to help me out of bed to the bathroom on odd days. I had a rail fitted in the toilet as was using the door handle to stand. It came off!!!!.

In 1996 I asked my GP could I be referred somewhere else. He said, 'No good, they don't know about PPS'. So I decided to pay privately and off I went with my x-rays and notes. One look at my spine and they pronounced 'A typical polio case'. (Like an S bend, left shoulder blade like Richard III) and said I should not be standing or walking as my spine was so bad. This had been said before, but I still had no pain in my spine. They were more interested in the fatigue, not the fact that by now both legs were affected, and I was unable to lift them from the ground whilst sitting and the pain was so intense that it made me scream.

Earlier this year I was sent for to spend three days in this hospital for tests, including a sleep study and MRI. 'You are not sleeping at the proper level, your MRI shows a nick at the base of the spine which is arthritis' (no pain there). The neurologist said 'I do not think you had Polio at all, it must have been something else. Why didn't you wear a caliper?' They made no further comment when I told them about my doctor relatives decisions. They could maybe give me injections for the pain and medication for the exhaustion. My GP has still not received a report from them, six weeks now. They now want me back for more tests for the exhaustion which they say is nothing to do with the Polio 'I say I had', and they have no answer to the abnormal muscle test results. They make nothing of the leg twitches whilst I sleep.

I am extremely frustrated. Why will all the medical profession not listen . I may be getting older - aren't we all - but I know my own body. My life style has been turned upside down and I know I had infantile paralysis in 1938. Why do I have to battle so hard for an answer?

'Mystified'
'Still mystified'
'Its all in your mind'
Fibromyalgia, no. Then Polymyositis, no. Arthritis and Rheumatism, no...
'We can't get below the Polio Barrier, but PPS does not exist.'
'X-rays show definite Polio spine, should not be walking upright'
'Did you really have Polio, maybe it was something else?'

The fact that I cannot cross my right leg over the left is immaterial. The fact that my left leg has collapsed under me three times in the last eighteen months is due to the fact that I have been overdoing it but I have only been out socially three times in the last four years because of the pain and exhaustion. The fact that I now have no control over my thighs and drop into a chair like a sack of coal is ignored.

I am so frustrated. Why will the medical profession not believe me that I had Infantile Paralysis, especially when my grandfather and uncle were both doctors and helped with my treatment?

Why will they not listen to me and take all my symptoms into account? Why were the old medical records destroyed? Why does the diagnosis keep changing? Why can't they give me a firm diagnosis for all my problems? When they do make a decision to give me some treatment how long do I have to wait before they tell my GP of their decision? Why is so much time, energy and money being wasted? Why do I have these symptoms, I have not been physically ill, this wasn't gradual like just getting old, it happened overnight, I know its not just age, I have had this body a long time and I know how it feels.

Do I have to be an Emily Pankhurst,?
Do I have to travel to America to get help'?
Are we really ready for the next millennium, or are we still stuck in the last?

This whole situation is utterly disgraceful.

Meanwhile I soldier on as I did all those years ago. At least I now have other Polio friends to talk to who understand what I am talking about. I think the idea of Polio Phone Pals is brilliant. It is wonderful to be able to offload on a bad day to another polio and in turn be the ear for their bad days. Stress does not help whatever we have wrong with us. I don' t mind what you call it, just help me manage my symptoms and live the rest of my life to the fullest possible.

* * *

Samples of other members comments:

- I was diagnosed by a top neurologist with PPS a year ago. Can you give me a list of PPS specailists in my County?
- I have had a PPS diagnosis for many years now, but still can't get treatment for my problems. Can you recommend a hospital?
- I have been told that 'the pain is all in my mind, I am imagining it, and I have been taking antidepressants for years', now I learn about PPS. Hooray, I am not nuts after all.
- I have had many appointments and tests and a continual change of diagnosis but the fact that I had polio has never been mentioned.
- I am now on my seventh diagnosis, and still they won't consider the polio, what a waste of money? Is there anywhere in this country that I can be referred to?
- As I have no records of having had Polio - I had a lumbar puncture and paralysed legs but was left without easily visible signs - they are questioning that I have even had Polio!!!!! Whatever is wrong with me they still haven't given me a firm diagnosis.
- The answer to the new pain in my legs and increased difficulty walking was 'Don't walk'.
- The doctor said 'I used to believe PPS existed but I don't anymore since reading an article six weeks ago'.
- I gave my GP the information and he threw it in the bin without reading it.
- When I mentioned PPS I was patted on the head and told not to worry about that.
- PPS is all conjecture and so is ME. They don't exist.
- My GP keeps saying 'I will refer you to a PPS specialist if you can find one'.
- After I had told my polio story, the good years in between, the problems now and replied to what I think might be the cause, the answer was 'you are probably right'.
- Physios saying 'We know nothing about this, we will have to work together on this'.
- My Dentist is grateful for the information, he says it explains why he has always had problems giving anaesthetics to people who have had polio.

* * *

The following is a depersonalised letter which may be of interest - done at the suggestion and with the permission of Professor Richard L. Bruno PhD

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Note. Professor Bruno has relocated and his new email address is PPSENG@AOL.COM. For further details see ***The Post-Polio Institute*** *Englewood (NJ) Hospital and Medical Center in our Specialist Clinics Directory.*

POST-POLIO REHABILITATION AND RESEARCH SERVICE Office of the Director
21 February 1997

Dear Polio Survivor:

1) You were asked if you have evidence that you in fact had polio.

[Fill in here your past history of Polio]

2) You have been told that one had to have significant damage from the polio and muscle atrophy to have PPS.

Neither the severity of the original polio infection nor muscle atrophy, either due to the original polio or late-onset atrophy - are required for the diagnosis nor are predictors of PPS. The postmortem studies of Professor David Bodian of Johns Hopkins University in the 1940's showed that anyone who had paralytic polio lost on average 50% of their anterior horn cells but required the death more than 60% to demonstrate any paralysis (Bodian D. Histopathological basis of clinical findings in poliomyelitis. *American Journal of Medicine*, 1949; 6: 563-578.)

However, Bodian also found that at least 90% of all anterior horn cells were in some way affected during the polio infection (Bodian D. 1947. Poliomyelitis: Neuropathologic observations in relation to motor symptoms. *Journal of the American Medical Association*, 1947, 134:1148-1154).

With regard to the prediction of PPS, our research and that of other investigations (see Klingman, et al. Functional Recovery: A major risk factor for the development of PPS. *American Journal of Physical Medicine and Rehabilitation*, 1988, 45:645-647) show that it is the degree of original paralysis plus the degree of recovery that predicts PPS. Klingman showed that 79% of the variance of PPS symptoms "could be accounted for by recovery alone."

Our research has also shown that physical overexertion is also a primary factor in triggering PPS in 96% of subjects in the first American National Survey of Polio Survivors (Bruno RL, Frick NM: Stress and "type A" behavior as precipitants of post-polio sequelae. In: Halstead LS, Wiechers DO (eds): *Research and Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains, NY, March of Dimes, 1987, pp. 145-155).

3) You have been told you must use your limbs and that, if you did not, then the muscles would wither away.

This advice is particularly inscrutable. All of the world's medical research and clinical literature on the treatment of PPS shows that persisting in physical exertion in the face of new symptoms, and especially the prescription of exercise, continue the downward progression of PPS.

The recommendations for energy conservation and assistive device use provided you are just right (see Young GR. Energy conservation, occupational therapy and the treatment of post-polio sequelae. *Orthopedics*, 1991; 14:1233-1239) . A two-year follow-up study of patients treated by the Roosevelt Institute at Warm Springs showed that patients who refuse to implement such suggestion have pain and fatigue increase and lose more than 2% of muscle strength per year (Peach PE, Olejnik S. Effect of treatment and non-compliance on post-polio sequelae. *Orthopedics*, 1991;13:1199 -1203). Patients who implemented energy conservation and assistive device use actually gained muscle strength over time.

Our just-completed follow-up study of patients treated by the Kessler Post-Polio Service since 1990 shows a 76% increase in muscle weakness over 16 months in patients who refuse to implement energy conservation and assistive device use. Patients who do implement these suggestion report a 21% decrease in muscle weakness.

4) You have been told that PPS is all conjecture and that PPS is not a problem in Lincolnshire.

I would have readily agreed that PPS was all conjecture in 1983. But after four international symposia and thirteen years of research published in journals including *Neurology, the Archives of Physical Medicine and Rehabilitation, the American Journal of Physical Medicine and Rehabilitation, the Journal of Rehabilitation, the Journal of the American Medical Association, and the Annals of the New York Academy of Science*, there is no longer any conjecture about the reality of PPS.

With regard to the prevalence of PPS in the U.K., 74,280 cases of polio had been reported to the U.K. Communicable Disease Surveillance Centre between 1912 and 1961. As in the United States, the ratio of polio cases to actual notification of the C.D.S.C. was quite low before the

> large epidemics of the late 1940's, your government describing notification as "far from complete."
>
> The cases of polio reported to our Centers for Disease Control was 480,000 during the same period, with notification also being described as unreliable since U.S. physicians were not required to notify the C.D.C. of polio cases until 1952. It is not surprising then that 1987 U.S. Department of Public Health National Health Interview Survey calculated that there were 1.63 million Americans alive today who had had polio. It is likely that the actual number of living survivors of polio in the U.K. is closer to 250,000.
>
> With regard to the prevalence of PPS, the recent survey of the membership of the British Polio Fellowship found the incidence of PPS to be 77%. Therefore, between 57,000 and 192,000 British polio survivors are experiencing the same symptoms that you report.

I cannot encourage you strongly enough to be physically examined and to immediately implement all of the recommendations made by your Doctor and your occupational therapist and any other ideas of which you can conceive to save your remaining polio damaged motor neurons.

I hope I have answered your questions and concerns. I encourage you to obtain and show the articles I have referenced herein to your physicians. Please contact me if you, your physicians or therapists have further questions.

Yours truly,
Professor Richard L. Bruno
Department of Physical Medicine and Rehabilitation
New Jersey Medical School
University of Medicine and Dentistry of New Jersey
and
Director Post-Polio Rehabilitation and Research Service
Kessler Institute for Rehabilitation
and
Chairperson, International Post-Polio Task Force.

Lincolnshire Post-Polio Library - Copy of above article with links to referenced full text and abstracts where available.

LEICESTERSHIRE POLIO NETWORK NEWSLETTER MAY 1997 has arrived.

For the benefit of those who do not get a copy and are not able to read it on the Internet we have included a copy of an interesting article very relevant to some of our members difficulties in getting appropriate medical help. We are indebted to their Editor Helena Edwards for compiling this article. We have added R.L. Bruno PhD's comment on the same article.

THE MAYO, THE LANCET, AND THE REVOLTING POLIOS.

The Mayo clinic in America has done a study in which 50 polio survivors, selected at random, were tested over a period of 5 years. The reports authors, led by Dr. Windebank, tried to measure the polios` muscle strength over that period of time, to see if they could measure new weakness. They could not. The Mayo researchers said they felt that progressive neurological deterioration was therefore rarer than previously thought.

The Lancet, is possibly Britains most prestigious magazine for doctors. It published a review of the Mayo`s findings in February 1996 under the unfortunate headline "Study throws doubt on post-polio syndrome".

Within weeks we heard from people whose doctors were assuring them that PPS did not exist, and in some cases the doctors mentioned that their information came from an article they had read recently. Three guesses which one…. One person was confidently told by a neurologist that an electrical muscle test (on one atrophied muscle, in one limb) showed no abnormalities therefore the patient did not have PPS, and anyway it had now been proved PPS did not exist!

Now regular readers of these columns will appreciate why I, along with so many other polios, have come to view some doctors with less than total admiration. Many British neurology clinics offer a grossly sub-standard service when assessing new functional decline in polios. Their patients report to us the list of ingredients that are common to the cocktail that is PPS, but the Neurologists come up with wildly variable diagnoses; everything from Motor Neurone Disease to imagination, with detours through obscure conditions with impossible names. Witch doctors casting the runes or examining chicken entrails would probably be as useful.

If there isn`t any sort of chemical or electrical test for a condition then to some "scientific" minds it can`t possibly exist. This thinking took us from B.S.E. in cattle (scientists were sure it couldn`t possibly pass to humans) to human C.J.D; brought us Gulf War Syndrome ("there is no evidence…") and is likely to be a factor in the very real M.E. problems. Fortunately there are also doctors who are not guilty of such lazy thinking, and who take the trouble to thoroughly research a subject before expressing opinions.

If your doctor is one of those relying on The Lancet to do their thinking for them (and in these pressured times G.P`s can be forgiven for doing so) you do not have to be an endlessly patient patient. Join the patient revolution. Become a revolting polio. Show your doctor the following inconvenient well qualified medical opinions.

COMMENTS : by Frederick M Maynard MD; Professor of Medicine, Case Western Reserve University; Medical Director, Metrohealth Center for Rehabilitation, USA. (From New Zealand PNN)

I have finally had a chance to see the Lancet summary of the Mayo Clinic by Windebank. I agree very much with the results of this study, that is, that true progressive nerve loss and muscle weakness (post-polio progressive muscular atrophy) is indeed a rare condition. The majority of problems in post-polio patients can be attributed to a variety of other new medical conditions, orthopedic strained conditions, arthritis, chronic overuse syndromes and so forth. *The good news of this study is that progressive neuromuscular failure is very uncommon.* The other good news is that most of the other conditions can be treated even if not completely.

Do not be too discouraged or distraught over the Lancet article, although it will reinforce many of the British medical establishment's opinion that there is no such thing as Post-Polio Syndrome. As I have said many times, the crux of this issue is the definition of Post-Polio Syndrome.

A large pharmaceutical company, INS, that manufacturers Mestinon, has recently funded a Post-Polio Task Force which includes seven experts from North America on Post-Polio Syndrome. Joan Headley and I were asked to sit with this group. We are planning to develop a consensus statement on definitions, appropriate diagnosis and management for Post-Polio Syndrome. We are also attempting to work with the American Academies of Neurology and Physical Medicine and Rehabilitation to establish practice guidelines on Post-Polio Syndrome. Hopefully you will be hearing more about this in the future."

COMMENTS : by Dr. John Petrie, MB FRACP, Consultant in Rheumatology and Rehabilitation, Queen Elizabeth Hospital, New Zealand. (From New Zealand PNN)

"Whilst the [Mayo] article is important, it does represent a purely medical model of neuromuscular failure with the expectation that particular forms of abnormality should be observable. *The fact that they were not observable does not deny the existence of post-polio syndrome, merely that the* *authors were mistaken in their initial premise.* It represents a point of view, the important issue as I have always believed is that people with post-polio syndrome do seem to be particularly prone to worsening of their disability and do require specific rehabilitation interventions. *I think that the sub-editor at the Lancet who calls post-polio syndrome into question is guilty perhaps of a little artistic license*."

COMMENT ON LANCET REPORT "STUDY CASTS DOUBT ON POSTPOLIO SYNDROME" by Associate Professor Mary T. Westbrook, Faculty of Health Sciences, University of Sydney.

"The Lancet report written by McCarthy refers to a study by Windebank et al, "Lack of progression of neurological deficit in survivors of paralytic polio: A 5 year prospective study" which appeared in the journal, Neurology in 1996*(1)*.

The main points McCarthy makes are that Windebank et al's findings show that post polio syndrome probably does not exist, that post polio syndrome is not progressive and although there is a "rare condition" called post polio muscular atrophy the symptoms that Windebank et al's subjects had can be explained by other diagnoses.

Before examining Windebank et al's actual paper I will address the first two claims that McCarthy makes. There is now a vast scientific literature which supports the existence of post polio syndrome, e.g. the recent volume of papers from the conference "The post-polio syndrome: Advances in the pathogenesis and treatment" *(2)* that was held by the New York Academy of Science.

The progression of post-polio syndrome is a somewhat more contentious issue. In a paper I presented at the 12th World Congress of Physical Medicine and Rehabilitation in 1995 I reviewed longitudinal studies of people with post polio syndrome and concluded that studies which encompassed longer time spans have usually found slow progression of symptoms *(3)*. Studies which have not found changes have typically retested after short periods, e.g. a year and/or have used small samples. When I retested 176 people with post polio syndrome (as identified using Ramlow et al's criteria *(4)*) I found that the average person had declined in that their symptoms were more severe and they experienced greater difficulty in carrying out the activities of daily life than they had five years previously *(3)*.

My findings were based on self reports. Those not convinced by what survivors say is happening to them should read several recent papers by Grimby et al. In 1994 they reported a 4-5 year follow-up of survivors who claimed to have experienced, or not experienced, increased weakness in their knees over the period. *(5)*

Grimby et al found that muscle strength had decreased significantly more in the group who said that their knees were weaker. The researchers also compared this muscle strength loss with the normal loss of strength that would be expected over this time due to aging. An able-bodied person of the subjects' age would experience a 2-5% decrease in strength whereas the unstable polio group experience 16-22% in the muscles tested.

Last year Grimby et al reported a four year follow-up of survivors *(6)*. They found a significant reduction in muscle area in subjects who reported that their legs had become weaker whereas this loss did not occur in stable legs. At the recent Post-Polio Conference in Sydney, Gandevia also reported a significant, but low, decrease in muscle strength when he retested post polio subjects. I said to him in the discussion following his presentation that as many polio survivors live at the absolute threshold of their physical ability, a slight decrease in muscle strength can have a very marked effect on the activities that can be carried out. Gandevia replied, "That is very true".

Examination of Windebank et al's paper *(1)* shows that it is one of a series that have been based on polio survivors in Olmstead County, Minnesota where full medical records of cases of paralytic polio have survived. In 1985 Codd et al *(7)* sent a questionnaire to survivors in part of the county and asked people questions as to whether they had experienced any decline in function since achieving their maximum recovery from polio. The 22% who indicated they had declined were phoned to obtain detailed information. The major symptoms reported were new pain, weakness and fatigue. This figure of 22% has frequently been cited in the post polio literature as evidence of the prevalence of post polio syndrome.

In 1987 Windebank et al *(8)* reported that Codd et al's survey had been expanded to include all cases in Olmstead county and that overall 22% reported new difficulties. From these 286 survivors Windebank et al selected a convenience sample of 50 cases for detailed examination and the eventual follow-up study referred to by the Lancet. At follow-up the sample had fallen to 46 cases. If we assume that 22% is an accurate estimate of the proportional of Olmstead survivors experiencing post polio symptoms (remember that none had been interviewed in person or clinically evaluated) we would expect Windebank et al *(8)* to have approximately 11 cases in their sample of 50, a very small number with which to study progression. In the follow-up survey referred to by the Lancet, Windebank reported that 30 patients (65% of 46 cases) had symptoms which "included combinations of pain, weakness and fatigue" which could be explained by diagnoses other than post polio syndrome. However 10 (22% of the sample) had symptoms for which there was "no alternative diagnoses". The authors then went on to suggest fibromyalgia as a possible diagnosis after rejecting the possibility that the 10 cases have chronic fatigue syndrome because they are not depressed! In a recent paper Trojan and Cashman *(9)* described 25% of the patients they had diagnosed as having post polio syndrome and as also having fibromyalgia.

My impression is that Windebank et al's decision to question the existence of post polio syndrome resulted from a) their failure to demonstrate deterioration over time and b) their failure to define post polio syndrome as part but not all that is involved in the late effects of polio. Regarding (a) I believe a contributing factor to their failure to show change may have been the lack of sensitivity of some of the instrumentation. For example, Windebank et al derived their "Neurological Disability Score" from the results of manual muscle testing, a method that is notorious for overestimating polio muscle strength *(10)*. Several of their measures were based on speed of performance rather than endurance. Regarding (b) I found the lack of definitions in Windebank et al's articles a problem. The late effect of polio are usually divided into two main groups. The first group is symptoms caused by the neurological changes unique to polio (the loss or dropout of the extra nerve fibres that reinnervated the muscles weakened at the onset of polio). These are usually described as post polio syndrome. Other late effects are caused by factors such as overuse of weak body parts, deformities such as scoliosis which may lead to pain, degenerative arthritis etc. Polio survivors may experience both types of symptoms as did many of Trojan and Cashman's patients.

In conclusion, some researchers such as Windebank et al *(1)* have not demonstrated that PPS is progressive. Others such as Grimby et al have provided convincing evidence that it is. Most researchers and clinicians comment on the enormous differences between people's rate of progression. Others such as Bruno and Yarnell have found that changes in lifestyle can slow or halt deterioration. Incidentally Ramlow et al's population based study of polio survivors from Allegheny county, Pennslyvania found that the prevalence of PPS was 28.5%.

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Our Added Comment from Richard L Bruno, PhD, West Orange NJ to the Editor of Neurology.

[The Web edition of this newsletter includes the published reply from Anthony J. Windebank to Richard L. Bruno's letter. LincsPPN Web Administration.]

November 1996 Neurology 47 1359

Post-polio syndrome

To the Editor: The article by Windebank et al was both reassuring and disturbing *(1)* Their findings support the 1984 Post-Polio Task Force rejection of the terms Post Polio Syndrome and Post-Poliomyelitis Progressive Muscular Atrophy (PPMA) and acceptance of Post-Polio Sequelae (PPS) as the generic descriptor of late-onset symptoms reported by America's 1.63 million polio survivors. *(2)* PPS would certainly include the 'mechanical' problems found to cause some of the subjects' symptoms.

However, the authors state that late-onset muscle weakness may result from 'age-related attrition of motor neurons.' The literature more often relates new muscle weakness to the metabolic failure of poliovirus-damaged neurons *(3)*. An inability to document 'progressive neuromuscular failure ' by measuring the number of motor units would be expected, because it is the size of motor units, that has been correlated with new muscle weakness. *(3)*

Further, surveys of more than 1,000 polio survivors have found an association between PPS, physical overexertion and emotional stress, not aging. *(4)*. The lack of progression of symptoms in 'unstressed' subjects also should have been expected.

The suggestion that chronic fatigue syndrome (CFS) and fibromyalgia - disorders for which there is no known etiology, effective treatment, or even agreement as to their existence - as causes of PPS in the 20% of subjects with 'no alternative explanation' for new symptoms is far from parsimonious and allows the inference that PPS does not exist. Such an inference is evidenced by the Lancet summary of the authors' paper headlined 'Post Polio Syndrome Called into Question'. Post-polio fatigue has actually been suggested as a model for the pathophysiology of CFS, because poliovirus lesions in the reticuiar activating system are well documented, and recent studies have shown lesions on MRI of the brain, neuroendocrine and neuropsychological abnormalities in polio survivors with fatigue that are identical to those in CFS. *(5)*

Polio Survivors must be assured that their symptoms are 'real', do have a physiological basis, and that a decade of clinical research has identified 'rational therapuetic approaches' based on decreasing physical and emotional stress, that do indeed 'produce substantial benefits' to those with PPS.

Richard L. Bruno, PhD
West Orange, NJ

Reply from the Author: The comments of Dr. R.L. Bruno are important. Our study identified a population-based cohort of individuals who had paralytic polio. As Dr. Bruno mentioned, these were individuals who had paralytic polio but were not 'stressed' other than by the average stresses of life and aging. We found that it was very reassuring that these individuals as a group did not have any evidence of progressive neuromuscular failure. We thought that it was also important that those individuals who had symptoms compatible with 'post-polio syndrome' also showed no evidence of progressive neuromuscular failure. We would agree that aging or interval since onset of polio are not risk factors for developing subsequent difficulties. This was reported in our first study. *(1)* We agree entirely with the conclusion that it is important to evaluate patients on an individual basis to identify specific causes for their difficulty. Most patients in the studies, had new symptoms, but most of these could be accounted for by factors not directly related to post-polio neuromuscular failure. Quantitation of fatigue is challenging because fatigue was not a major symptom in this population-based group of polio survivors. As neurologists who treat many patients who come for evaluation of post-polio symptoms, we would agree that most patients have symptoms that are real. One of the major points that we made in our first manuscript *(6)* was that the psychological profile of these individuals was completely normal. Overall, therefore, we would agree with Dr. Bruno's comments: there is no doubt that polio survivors are subject to many different types of problems. However, as a population they do not appear to be at risk for developing progressive neuromuscular failure in significant numbers. We were impressed and very reassured that in this population-based study, polio survivors as a group did not have any evidence of progressive neuromuscular failure.

Anthony J. Windebank, MD
Cleveland, OH

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Lincolnshire Post-Polio Library - Copy of above article with links to referenced full text and abstracts where available.

How To Bathe Without Getting Wet or Happy Slathering

by Ruthie

This tub gal has been unable to get in one for far too many months. I hate showers anyway, but have evolved a solution of sorts. It unfortunately always leaves me feeling less than clean because I depended on the long soak for removing every bit of grime and who knows what else. Now I sit on a bath stool and let the water rise. [Forget the yeaming to drop down I keep telling myself, at least my feet will be righteous.]

Before sitting I've slathered the unmentionable area with its own nylon puff. I've also put the Shower Gel bathtub bubbles under the now running water. The scent of my choice is the blue one [I forget what it's called]; the green one is a fair substitute. Just like the good old days I'm reminiscing.

The other nylon puff is for the rest of me except my back for which I use a looooong loofa as follows: after the soap slathering I drape it over my back and catch it with my other hand and with a seesaw motion scrub. For thoroughness drop and catch hands are reversed. After this procedure I rinse with a hand-held shower and pretend it's as it used to be -- after a long, luxurious bath. Now to the good part, my pièce de résistance.

The best slathering after-bath, bar none, lotion is Cepracil. Recommended by a dermatologist to a friend, it is better even than Nivea. All over every place it goes and until today except my back which by now must resemble a withered peach. I'm only guessing. I haven't been able to see my back for years but I did manage to apply lotion till PPS set in. Last night, a gift from God... I knew today I would finally get it properly done and thanks be to that same glorious Power, I did.

Here's how. Take one long handled bath brush [bought for back and which never satisfied now serves an unintended purpose] and affix over the brush end a plastic sandwich bag. The ones I have are the cheapest available which also pleases me. Here a little ingenuity will be needed on the part of each user, what worked for me since the brush head was small enough was to simply tie the front and back sides of the bag together. I tried cutting a hole in the top of the flap side but in use it slipped right off. I thought of scotch tape, but before I got some I managed to tie it on. Now here's the important part. Hunching over put gobs of lotion on your shoulders [yes, yes the back side] and then fast, before the lotion drips on down and out start that old plastic covered brush a rollin' back and forth. Voila! A slathered back. And I feel human again. Not to mentioned well greased and oiled and maybe even clean, but still not the same as... well, you know, grump grump grump.

* * *

We have started to compile a list of 'Internet Members' who are using our website for information.

IMPORTANT! *We do not automatically record any details of individuals accessing our web site. Nor is the list of email addresses of those who subscribe to the Update Notification Service used for any other purpose then to send out notices of web site changes. The list referred to hereunder is a totally seperate list which you will only be added to if you email your details to our Hon. Sec. as suggested.*

This will help us when statistics are asked for as we campaign for better medical assessment and treatment for Polio Survivors in the UK. So if anyone reading this newsletter via the internet anywhere in the World (including those who live in the UK who do not wish to become paid up members) would like their name, email address and town, county/state, and country added then please email us at info@lincolnshirepostpolio.org.uk. Please note that we now have an email updating service *(see our What's New section)* of changes to our site. Donations towards our work will always be gratefully received, and we have a USA 'member' who will accept $ cheques using

them to pay $-only cheque items we want from USA and Canada. Saves exchange fees.
Membership details back page.

What you should know about your Medications.
A guide for Polio Survivors.

J.M.Walker Ph.D., PT,
AM Whelan, Phar. D, 1996.

Written for Post-Polio Support (Inc)
11 Wyn Street, Christchurch 2,
New Zealand.

This is for your information - many medical professionals do not know PPS exists. You need to tell them you are a Polio Survivor and show them this.

Please note drug names are for New Zealand they may not be approved for use in the UK.
We hope to provide a UK version in the not to distant future.
Check with your Doctor, Dentist and Pharmacist before changing any of your drugs.
Lincolnshire Post-Polio Network

Why You Should be informed:

A survey in 1994 revealed that 57% of respondents, polio survivors, were over 60 years of age and 27% were over 70 years. Medications (drugs), may be by prescription, or Over-The-Counter (OTC). As a polio survivor you should become an informed user of drugs because:

- The drug effect may enhance post-polio symptoms while influencing the primary condition. Fatigue, muscle weakness, muscle irritability (cramps), ability to cough and clear secretions, anxiety feelings, may be increased so that your performance decreases.
- With increasing age the potential for interaction between drugs increases and this effect is often more severe.
- With increasing age individuals are more likely to be taking or be prescribed medications for a variety of conditions, such as hypertension, diabetes, arthritis, insomnia, indigestion, constipation....., the list can go on and on.

Who is at greater risk?

- individuals with respiratory muscle weakness or paralysis
- individuals with weakness of the muscles of swallowing
- individuals diagnosed with Post-Polo Seqeulae (Post-Polio Syndrome)
- older individuals (over 65 years)

You may have experienced a 'full recovery', Grade 5, Manual Muscle Test of involved muscles and were unaware of any involvement of your respiratory muscles, however, research has shown that these so-called 'normal' muscles are not necessarily normal and may be supplied by only 60% of the usual number of spinal nerve cells.

What you should do:

1. Change your lifestyle **before** resorting to use of an OTC drug or requesting a prescription.
2. Always inform your doctor(s) about which drugs you are currently taking regularly,

prescription and OTC drugs.

3. Ask your doctor about potential side effects, particularly those that may increase or cause
    - fatigue
    - respiratory weakness
    - muscle weakness
    - dizziness and/or drowsiness which may impede your balance and cause falls
    - increase depression thus changing your perception of pain, making it seem worse
    - insomnia, sleeplessness, will increase fatigue
    - vaso-constriction, may increase cold intolerance.

Remember

- Taking fewer medication is better.
- It is no solution to use drugs and continue to abuse your joints, overuse your muscles.
- It is your responsibility to be informed about your medications so that you can monitor the side effects.
- When certain drugs are taken for a long time you can develop a tolerance so that larger and larger doses are needed.
- Physical dependency, addiction can develop from taking certain drugs, especially narcotic analgesics.

Drugs & Their Effects.

Alcohol:- is a drug. It may

- inhibit swallowing
- decrease balance & cause falls
- decrease muscle strength

Individuals with any respiratory weakness should avoid alcohol, especially before bedtime.

Laxatives:- before medications try

Firstly change your diet and drink more fluids. Get more exercise (If advised by your PPS doctor. LincsPPN)

- bulk forming stool agents, always with fluids (e.g. bran, Metamucil, Prodiem)
- stool softeners, avoid long term use (e.g. Colace, Surfak, Correctol)
- stimulant laxatives, occasional use only (e.g. Ducolax, Castor Oil, Ex-lax)
- Osmotic laxatives, occasional use only (e.g. Milk of Magnesia, Fleet enemas)

Cough Medicines & Expectorants.

May contain alcohol or a narcotic (e.g. codeine)

These suppress coughing or loosen secretions. They also cause drowsiness, decreased co-ordination, may give a feeling of chilliness.

Antihistamines, Allergy, Motion Sickness Drugs.

E.g. Seldane, Benadryl, Gravol, Chlor-Tripolon. These cause drowsiness and can increase fatigue.

Analgesics.

These are the most abused class of drugs and long term use can cause addiction. There are two classes:

1. Non narcotic Analgesics.
   Although some may be produced over-the-counter they are real drugs, with potential side effects, interaction effects or dependency effects. Examples are: Acetaminophen e.g. Atasol, Tylenol, Excedrin. Control pain only, not inflammation.

   Non steroid anti-inflammatory drugs (NSAIDs) such as: Aspirin, Advil, Orudis, Clinoril, Motrin, Indocin, Feldene. NSAIDs can control inflammation and pain but may cause dizziness, muscle weakness, drowsiness.
2. Narcotic Analgesics.
   These may be used in dental surgery, other surgeries, or as sedatives, pain relieving drugs. Examples: Codeine, hydrocodone (Hycodan), morphine, opxycodone (Percocet), meperedine (Demerol), propoxyphene (Darvon).
    - Produce central nervous system depression.
    - Can produce physical dependency
    - Increase respiratory depression
    - May require increasingly larger doses to gain the same effect.
    - May cause postural hypotension (fainting).

Things to consider:

- Can a pudendal, spinal or epidural anaesthetic be used instead of a general anaesthetic?
- Avoid unnecessary elective surgery.
- Appropriate use of analgesics helps to control pain.
- Avoid use of analgesics helps to control pain
- Avoid taking narcotics, try aspirin, NSAIDs.
- Protect your joints! Use a cane or other ambulatory aids. Wear your orthosis.
- Try hot or cold packs, taking a shower, a bath, going to a pool to relieve muscle and joint pains.
- Change your lifestyle, practice a work-rest routine.

Stimulents

Avoid amphetamines
Some anticholinesterase drugs, e.g. pyridostigmine (Mestinon), may influence fatigue level.
Avoid over exertion, use a work-rest lifestyle.

Antidepressants, Anti-anxiety drugs.

One third to one half normal dosage may be adequate. Many of these drugs (benzodiazepines e.g. Valium, Librium, Ativan) are also muscle relaxants, sedatives and may increase fatigue, decrease strength. **Barbiturates** may be used for sedative, hypnotic or anticonvulsant activities.

- Avoid drinks and foods that may enhance effect, e.g. Alcohol, coffee, especially at night and if you have respiratory muscle weakness.
- Seek counselling for feelings of depression.
- Join a polio survivors support group, become informed, involved.
- Seek out social contacts, go on outings, volunteer, play darts, play anything, get a hobby! Find a distraction.

In Conclusion.

This is only a brief review. Drugs taken for cardiopulmonary and other problems may have important interactions with polio related symptoms.

Only you can identify yourself as a polio survivor to your doctor *(and dentist - LincsPPN)*, ensure your doctor knows what drugs you are taking, and become familiar with potential side effects.

Always remember, it is no solution to take medications and continue to abuse your joints and muscles; change your lifestyle and protect your joints and muscles FIRST.

Lincolnshire Post-Polio Library - Copy of above article with links to referenced full text and abstracts where available. UK version also available.

About my brief life in Lincolnshire

by Michael Watson, Burlington, Vermont, USA

Hilary invited me to send along a letter about my brief life in Lincolnshire. I lived in East Kirkby during 1954 and 1955, from spring to spring, a full round of the sun and seasons. Shortly after returning to the U.S. in the summer of 1955, I contracted polio. For now, I'll write about my experience of Lincolnshire and save polio stories for some other time.

Perhaps it was in Lincolnshire that I found my love of stories, places, and food. To this day I hold the taste of a savory desert pudding, steamy with the fragrance of plums, placed before me at school on the last day of class before Christmas vacation. I have searched in many cookbooks for that delight, alas to no avail. The two or three room school which contained the pudding sat on the green in the village, less than a mile from the estate on which I lived with my baby sister, mother, and father in a manor house which had been converted to apartments for military families. There were many grades in that tiny school, and I was exposed to learning by mere proximity, it was as though I could drink as fast and deeply as I wished, just by listening and thinking. I was in heaven.

Well, some of the time. I was the only school aged child in the military housing complex, and thus, the only American in the school. For months, I was challenged and scrubbled, always outnumbered. I don't know what happened to bring those frequent beatings to an end, perhaps I changed my accent, or maybe the novelty of a Yank just wore off. In the end, I sorrowed to leave my friends, especially Liz, who lived with her mother and grandmother in a thatched roofed cottage on the estate, and a boy about my age whose name I no longer remember, who lived with his family on a farm in which the buildings were laced together by thatched roofs and the pigs lived in one room adjacent to family living quarters.

Liz went on, not many years after, to become a nurse and move away. I knew her father had not returned from the war, but she seldom spoke of him and I don't know whether she much remembered him. It would be almost forty years later, during a conversation with a friend from the BBC who had lost her father in the RAF, that I would grasp the losses my friends and opponents had endured.

I was seven years of age, and Liz two or three years older. Often, after walking home from school I stopped at her house. We walked to and from school when weather permitted and that winter was snowy and we sat for what felt like weeks before the great radio adjacent her mother's pantry. We always arrived just at tea time, and a small table would be spread before us with tea, crackers, and tarts both savory and sweet. In my heart rests that table, and warms me to this day - a warmth that neither autumn nor polio can extinguish. The pastries were indescribably complexity in flavor and aroma. I have returned to England only once, and I spent my days hiking the countryside and sampling pastries from village shops, none of which came close to those which sprung from Liz's mother's and grandmother's hands.

Tea warmed the evenings of those short days, and Dan Dare roved the universe between classical music and the BBC News. When I returned to The States Dan was not to be found, but I was now convinced radio was the hearth and found sustenance with the Lone Ranger. In hospital one afternoon I listened to the Lone Ranger, a pause separating a spinal tap and the iron lung yet to come. Later, I searched the bands of my short wave radio for hours, looking for Dan; although I found the BBC, alas no Dan.

The estate was mostly wooded, with ponds and ducks, and great ferns which towered over us children. When the snow fell heavily the ferns drooped, creating houses with innumerable rooms, mansions of play. Amongst the ferns ran rabbits, or rather crawled, until the woods seemed filled with dead and dying rabbits, easy prey for small boys with air pistols and no empathy. There were the inevitable patches of briar, succulent with berries in the September sun, and nettles capable of bringing tears to adult eyes. No wonder I became a naturalist.

When I returned to walk the roads and paths around East Kirkby in 1986, a break from writing a dissertation, I discovered the fields larger and the small farms and much wildlife gone. It is much the same everywhere I go. Even here in Vermont, where large mammals such as deer and moose have been increasing, we are rapidly losing our songbirds to habitat destruction both here and in their southern wintering grounds. People, too, feel displaced from their farms and villages as global economics rewrites society and landscape.

Closer to the main buildings were lawns, peopled with statues, which relieved themselves into newted pools, fields of spring flowers, especially crocus and daffodils, and more formal gardens which interested me not at all. Inside was a spiral staircase which touched each floor, and down which I fell one day, head first, until I came to rest at the very bottom none the worse for wear. There was also a ballroom with immense frreplaces containing tree trunk sized Yule Logs at Christmas.

The ballroom was furnished with Christmas decorations purchased at the village store, which like the school, church, and post office, occupied a place on the green. I don't remember visiting it often, but one late afternoon at Christmas we stopped in for candy. The shop was so densely packed with decorations, sweets, and goods that we could barely make our ways through what had once been aisles. The glitter of lights and aroma of food filled the air, and in a corner stood boxes of fireworks. Later, some of those fireworks magically made their way to our compound where they filled the snowy New Year's Eve sky with color, as snakes crawled and fountains threw their radiance across the courtyard.

The manor house itself was an odd replica of an abbey that reflected its owner's preoccupation with status and history. Near the village school lived an ancient oak which had seen centuries of East Kirkby's history. I encountered it first while on a school nature outing. The oak lacked all pretension and simply stood by a stream in the early spring sunshine. Earlier in the day we had listened to a lecture on Mozart via the BBC. Now I stood beneath a tree which had been mature when Mozart roamed the courts of Europe. That tree, together with another which housed a multitude of rooks, became for me symbols of place and our human experience of continuity. As a seven year old, the manor house in its dream of antiquity, the trees with their ancient rooks, and the medieval farms worked to deepen my awareness of the dense weavings of place, history and ecology - an awareness which continues to hold my attention with awe. Those early awakenings were reinforced when I spent almost a year recovering from polio inside; for month after month I watched people and nature through windows, and wondered at what I saw. I believe my love of art, music, theater, anthropology, and ecology (to say nothing of gardening) is deeply rooted in my experiences in Lincolnshire. (I recently threw our household into uproar when I said I might want to return to university as a STUDENT!)

One last thought. Thanks to an RAF Commander I discovered the Wolds when I visited in the mid-eighties. Someday I'd Like to explore them, and talk to those who live there. Its odd, I vaguely remembered The Wash, and marshes and their animals and folk have always fascinated me. But the Wolds were new and magical and ancient. I must have seen them when a school boy but they have no place in the maps of memory.

The events I have shared with you took place over forty years ago; yet, the memories remain strong. I recovered from polio save for a limp and weakness. Over the years the pain has returned and I can no longer take the long hikes I love. I continue to work as a mental health counselor, although I have mostly given up teaching college. Some days I become unimaginably tired. These memories bring relief, and the lifelong interest which were kindled within me during my stay in Lincolnshire continue to illumine my world with wonder and meaning. Thanks for allowing me to share them with you.

Please feel free to share your thoughts and memories with me. Warmly,

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PARENTS BLOOD

a biographical novel by Ginger Sage M.Ed.

arrived a couple of weeks ago. Very interesting account of the flood in 1938 in Malott, Okanogan County, Washington State, USA, when Virginia (Ginger) was nearly 8, four years after having had Polio. Well written, extremely well referenced and we await copies of some of the articles she used.

A taster ....(Page 45) The roar and banging of the buildings disintegrating up the street made it impossible to hear anything. After years of soaking in the old mill pond, logs like gigantic ramrods, weighing tons, screamed and crashed against each other as they tumbled through town. Somehow the logs were glancing off of the outside store walls. Miraculously, the oblique north/south angle of the General Store on the B & O road seemed to be shunting these logs aside........(Page 60) Winifred's experiences had confirmed the advice the doctor had given Ellen and Ed after the Polio illness. 'The child is recovering now, but you can expect that she will tire easily for quite a few years. She's a smart little one, and she will probably have a productive adulthood. Still, she will need to find a knowledgeable doctor who is willing to follow her into her old age - a doctor who is willing to help her wherever he can'. 'It affects the nerves, you know,' Winifred explained. 'Many people ask me if my hand is my only deformity. I say, 'yes' but actually, polio affects the nervous system in a sporadic pattern, and then the damaged nerves cause the muscles they feed, to not develop and appear to shrivel like my hand. They tell me that the damaged motor nerves are what causes my fatigue. I've had to learn to live without overusing the nerves that weren't damaged or destroyed. If I take it easy I seem to get along fine. You don't need to feel sorry for me. ....

If you would like a copy then send a $30 cheque to Ginger Sage at PO Box 457, Entiat, Washington, USA. It costs about £8 to get a $ cheque which makes this expensive, if anyone has any contacts who could help us pay for items - often only small amounts - in $ cheques then please get in touch. Our only other suggestion is to send one cheque to one of our contacts in USA and get them to forward our requests for items.

ACTUAL SIGNS SEEN ACROSS THE USA

from Marilynn

At a Sante Fe gas station: 'We sell gasoline to anyone in a glass container'
On a long established New Mexico dry cleaners: '38 years on the same spot'
On a display of 'l love you only' Valentine cards: 'Now available in multi-pack'

Persons are prohibited from picking flowers except from their own graves.
In a New York drugstore: We dispense with accuracy.
And apparently somewhere in England in an open field otherwise untouched by human presence, there is a sign that says,
'Do not throw stones at this sign'

* * *

POLIO PHONE PALS

We have decided to start Polio Phone Pals. No-one understands the problems of a Polio Survivor better than another Polio Survivor. A few of us have the benefit of the internet and the ability to 'talk' to many Polio Survivors all over the world by email for coppers - once you have the computer equipment and Internet service, not coppers but decreasing in price monthly - and let off steam... and I can assure you that everyone who joins the Polio lists says the same thing. All of a sudden you are not alone and boy does the World shrink. So Lincolnshire Members and those in other counties who would like to join in......The idea is to put you in touch with two or three other members of similar age, experience, polio problems so that when you are having a tough time and need someone to talk to you will have 'new friends' who will understand what you mean. In turn you will be the 'ear' for them. If you want to join in get in touch by letter or phone. We can then discuss with you where other members are that have also joined and put you in touch with one another. We will not be printing any telephone numbers in newsletters. This will be entirely private and information only kept in the office in a small book. The list was started a few days ago and has five names on it already.

MEMBERSHIP FEES

£10.00 yearly from April 1997 to March 1998.
Cheques to be sent to the address below.
Payment may be sent by two cheques one dated May 1997, second postdated July 1997.

NB: Some members have already covered this fee by way of donation already received.
If you have not and wish to continue receiving the Newsletter after the July issue then please contact us by August 5th 1997.

* * *

MEDICAL and GOVERNMENT PROFESSIONALS RECEIVE THIS NEWSLETTER
free of charge as part of our campaign
'PROMOTING THE AWARENESS OF THE PROBLEMS OF POLIO SURVIVORS'

MEMBERSHIP IS OPEN TO ALL
Donations, grants and sponsorship will always be gratefully received
and acknowledged if wished in our news letters and on our Web Site.

We need more British articles, letters, tips, etc., from members and anyone else reading this.
If you would like to contribute then please get in touch before July 15th 1997.
Anticipated issue date of LincPin No. 6 will be Tuesday 22nd July 1997.

All enquiries, book requests, medical article requests, membership fees, items for newsletters and donations to
The Secretary, Lincolnshire Post-Polio Network
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