



The LincPIN

**The Lincolnshire Post-Polio Information Newsletter
Volume 2 - Issue No. 5 - June 1999**

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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.

Lincolnshire Post-Polio Network

Editorial by Hilary Hallam

Two more months into this year, and nearer to the end of the Millennium. I would like to thank all of you who have supported the LincsPPN in our work. You have written or rung with your stories and allowed us to print them. Without the openness you have shown in going into detail about all the problems that you have incurred we would not have the information that we do to push forward and ensure that the Government put money into Regional Holistic PPS Clinics. Read the article starting on the next page. We need to collate more information on this and I hope you will support us and fill in and return the enclosed questionnaire. If you know anyone else who has had polio and can photocopy this for them to complete, we would be grateful. If you want to write to any medical professional or anyone in local or national government regarding your particular problems then you are welcome to attach a copy to that.

Lecture - Post Polio Syndrome from a Polio Survivors Point of View. I have given this lecture three times so far to Physiotherapists and it has been well received. This takes about an hour and a half to two hours including questions. If you would like to arrange a talk in your area then please get in touch. I will need an Overhead Projector. There is no fee however I need my petrol costs reimbursing. If evening time or any distance from Lincoln then I would need a bed for the night. Donations to the LincsPPN are always welcome.

Membership Fees - The committee have decided to change the dates of renewal of membership to coincide with each newsletter. For example anyone joining between June 1st and July 31st will receive this newsletter plus 5 more and renewal date will be 1st June. This will be backdated to all who joined from January 1st 1999. We will be issuing membership cards with the next newsletter and date of renewal will be printed on this. Back copies of the newsletters are 75p each, postage free to members.

Sunday 1st August 1999 - Klaus - a Polio Survivor - and his wife Renate from Berlin will be staying with me at the end of July. If anyone would like to join us for a lunchtime BBQ on Sunday 1st August from 11.00 am. onwards please get in touch for details. This will be their first visit to Britain. They live in what used to be East Germany and Klaus is a retired Physicist and speaks excellent English.

Saturday August 21st 1999 - Lincoln ME Self Help Group have invited us to attend a talk given by Dr. Skinner about The Thyroid. This will be from 1.30 to 4.30 at the Ruston Marconi Sports Club on the Newark Road, Lincoln. Read 'Tears Behind Closed Door' by Diana Holmes Avon Books £7.95. A Polio Survivor and Dr. Skinners patient - who did not have ME but an underactive thyroid.

Saturday September 4th 1999 - The Lincolnshire Post-Polio Network AGM with Speakers will be held in Lincoln on Saturday September 4th 1999. There will be an informal get together on Friday night. A full day Saturday with at least four speakers, coffee breaks, buffet lunch time and informal evening get together. Pacing and resting will be fitted into the day as much as possible. We already have one confirmed speaker from Canada, Marcia Falconer PhD who wrote the Non Paralytic Polio and PPS article - LincPIN February 1999. Depending on area available we will have some disability equipment on show that you might find useful. The Venue to be announced. The main hotel will be the Holiday Inn Express where we have reserved 70 rooms. Damos as overspill or your choice. More information on page 27 including Return Slip. Please reply as soon as possible if you would like to come and where you are in the UK. Please ring if cost would be a deciding factor. We will do all we can to get as many people together as possible and to keep cost to a minimum. We will also

put people in touch with others who might have space available in cars. Enclose sae for reply if possible. Thankyou. All welcome

Sunday 3rd October 1999 - The Falcon Inn, Saltergate, Lincoln will be holding a Truck Pull outside the Pub on this day from 11.00 to 4.00 p.m. Teams of six, 3 ladies and 3 gents, will be pulling a lorry along a measured distance. Each team will donate half their raised money to the LincsPPN - the other half to a Lincoln Charity of their choice. Full details in the next newsletter. They continue to hold various fundraising events and their support is much appreciated.

We have been made aware in the last two weeks that the copies of the last issue of the LincPIN we posted to members overseas has not arrived. We are taking this up with the Post Office. Please don't delay ringing/emailing us if you do not receive your copy around the usual date or information requested does not arrive - or you have any other query. NB Receipts will be posted with your newsletter to save on postage.



**POLIO SURVIVORS NEED HOLISTIC MULTI-
DISCIPLINARY ASSESSMENT**
because
**THE STANDARD PHYSICAL ASSESSMENT IS NOT
ADEQUATE**
by Hilary Hallam

It does not show Substitution of Muscles or test our Repetitive or Sustaining Power. Also when taking our history you ask us *Can you?* when *How do you?* would produce a more accurate reply.

We are approaching the new Millennium 125 years after the first record that there are late effects of polio. When we had our first encounter with polio there were polio specialists, hospitals, treatment centres, physiotherapists and orthotists. It's 41 years since the vaccine was first used and everyone breathed a sigh of relief... Polio is over..., and the research stopped and those who were working and who have seen and worked with polio in its acute and recovery stage have nearly all retired. Much knowledge and expertise has been lost. Much of the equipment for the disabled was developed during and since those outbreaks. Now we are facing a second and unexpected encounter we find that there are only a few doctors specialising and no money available for them to expand on the minimal services they can offer. Britain is known for its medical knowledge and expertise so how can this be happening?

The lead up to making the statement above.

I had polio in 1952 with waist down paralysis. I recovered well and lived a very full and active life until a fall in October 1988. From then on I have had medically noted yet unexplained symptoms but it was not until November 1995 that I realised that my polio should be taken into the equation when examining me. I attended the Orthopaedic Clinic for the results of my MRI scan and as these were 'essentially normal' was told by the Consultant that 'I am glad you have recovered.' My reply, 'I have not recovered, I have been deteriorating over the last nine months' seemed to surprise him until I added those immortal words 'I had polio as a child. Has that got anything to do with my problems?' He then told me that there was something called the Late Effects of Polio but that he knew little about it. He had had another patient at a previous hospital presenting the same as me, and would now refer me to a neurologist.

I started my search for information and answers that day and as many of you know, have not

stopped since. I feel sure my training as a Police Officer with two years in C.I.D. has been invaluable in researching articles, listening to individual stories, charting information in reports, comparing the results, and my determination to succeed in having my own problems recognised and treated. I have been horrified to find that I am not alone and that there are thousands of Polio Survivors in this country in the same position. Many like me also have no easily visible external sign of the polio damage in their bodies till they started to deteriorate. At last I have a reason for those questions over the last ten years 'What have you done to your leg, you are limping? Why are you always falling asleep when you get in from work?' We are often the last person to realise our problems as we continue to adapt over time.

Over the last three years I have listened to stories in person, on the phone, received letters and emails, and the story is the same. Years of symptoms of pain, weakness, fatigue and loss of daily functioning ability, and no medical answers and very little appropriate help.

In Britain I have met many Polio Survivors

- who are getting little support from the medical profession;
- who are being told, its arthritis, menopause, your age, motor neurone disease and a variety of other diagnoses;
- who have weakening arms yet are still expected to push a manual chair;
- have breathing and sleep problems coping with normal daily activities;
- who are only being tested following periods of inactivity;
- have dropped feet that urgently require Ankle Foot Orthoses;
- with legs so weak they need callipers and/or an electric wheelchair;
- have badly fitting braces and callipers;
- whose houses have bathrooms, kitchens and other areas they are not able to use to their best advantage because of lack of alteration or assistive equipment.

Social Services staff also have little knowledge about polio, its late effects and our needs, and are often offering equipment that is not suitable or refusing equipment that would allow us much more control of our lives.

At the end of January 1999 I got my first clue - a report where my Quads were graded as 5 which is Normal when they have not been normal since I had my polio - and on further research I have found what I believe is a major reason why we are having such an uphill struggle to get the medical help that we are entitled to. The standard physical assessment is not adequate when examining Polio Survivors. For example, whilst lying on a couch I can lift my legs up fairly easily once. Repeat this and the loss of muscle power is quickly evident.

The assessment at present in the majority of cases (we know there are exceptions to this).

Put simply, medical professionals are taught to physically examine patients in specific ways. They use various methods of examination techniques looking for bits out of place, lumps, skin colour, weakness, pain, reflex action, or a sign or symptom that will show there is a medical condition present.

First they take our history and then ask us questions like, "Can you roll over in bed?" We say "yes." They take it that we do this as a normal person, but ask us how do we roll over in bed, and we will say "oh I have to rock my body and hold onto the headboard and it takes many movements to get there, but I can do it." We are so proud of what we can achieve but now we must learn to assess ourselves doing each action so that we can give you more pertinent information. (Our new Information Pack with Charts has been devised to help you do this. Remember whatever or however you manage a task is an achievement.)

Then we are given a physical examination which is often performed with us lying on a couch. If a good result to a request for action is seen they then move on to the next area. We are rarely asked to repeat an action or sustain it for a period of time. We are telling you that we cannot do things like

we used to but if we are not asked to repeat or sustain movements then the varied muscle fatigue we have is not seen.

The 'rounds of the hospital departments'.

Without adequate knowledge of polio and its late effects, our symptoms are recorded, a physical examination takes place and the results obtained are put in a letter of referral to a consultant. The consultant will read the letter, perform an examination and more than likely will send you for some tests to show what he thinks is wrong with you. The test results are received, most often tests are negative, and as many of us have experienced we do not have what they thought was wrong with us. We are referred on to another consultant and another and more tests, and on it goes. All this information remains on our file. This patient complains of symptoms but we cannot find any reason for them. In most cases our members tell of years of referrals to many different departments all coming back with 'we can find nothing wrong with you' and some have ended up with a diagnosis of 'it's all in your mind'.

There are no tests for PPS.

There are no tests that show PPS, it's purely a clinical diagnosis by exclusion. It is the failure of these standard assessment techniques that is wasting all the money and allowing many of us to deteriorate unnecessarily.

In the last couple of years.

In the last couple of years things have moved slightly further forward and if we fit the criteria that is quoted in many older medical articles,

- had paralytic polio (now should include non-paralytic polio as well. See Ed. note);
- had recovery period;
- had a period of stable functioning;
- are now having classic symptoms;

and the test results show no other condition, then we get our diagnosis. You have Post Polio Syndrome. We are given a pep talk and told to pace and rest and use aids and equipment but there for the majority of us it stops. There is most often no assessment by a PPS Specialist, Physiotherapist and Occupational Therapist to assess and advise on what aids and equipment we need. So we go back to our homes with far more problems than have come out at the examination and we struggle on, continuing to deteriorate and getting more and more frustrated.

Many of us are stopping breathing to concentrate on movement.

In Lincoln we have helped start an Adult Education Gentle Movement and Relaxation Class at City School on Mondays. We are three Polio Survivors, two with ME and two with MS. If you are interested in joining us please ring. We realised after a while that when Polio Survivors have to concentrate to achieve movement, especially where we are substituting other muscles, we do not breathe as normal. We hold our breath till we pause doing that action. We believe this will have an effect on our muscles and maybe if we were trained to breathe with movement we could have less muscle fatigue. The class is done sitting on a chair. We start with one minute on how we feel today and then we spend a few minutes in relaxation. Cathy Ward uses different methods each week which makes it very interesting. We then do very simple range of movements to help keep us supple. You move slowly at your own rate, and the number of repetitions that you feel safe with. For some movements it might only be once or twice.

We need a holistic multi-disciplinary approach to bring out the whole picture.

In most hospitals we are only getting part of the physical assessment necessary. We are not being offered an assessment by a Physiotherapist and Occupational Therapist where we would be asked to show how we do various tasks. This should be, watching us walk the corridor not across the room, walk up a flight of stairs not three in a physio gym, get up and down from a chair or the floor, carry

a bag or heavy book saucepan of vegetables etc. Ensure that we have assessed ourselves and let us show what actions we are finding difficult. Watch for the way we substitute muscles to perform tasks - we are experts at this. This will help give a true picture of our abilities.

American Medical Article dated 1991.

The following is an excerpt from an article published in 1991 detailing the approach to Polio Survivors in the USA for the previous ten years. The full article is available on our WebSite, or please ring for printed copy. N.B. More research has taken place around the world since this article was published and many more Polio Survivors experiencing problems are now presenting, including those with a diagnosis of Non Paralytic Polio. (See later)

From the [Post-Polio Program, National Rehabilitation Hospital](#), and Georgetown University School of Medicine, Washington, DC.

Lauro S. Halstead, MD

Assessment and Differential Diagnosis for Post-Polio Syndrome
Orthopedics November 1991 Vol 14 No. 11 1209-1217

Assessment

Assumptions and Strategies. Our approach to the assessment of post-polio patients is based on a number of assumptions concerning their past health experience and present needs. These assumptions guide the format and content of our evaluation. They are based on the experience gained in assessing and managing close to 1000 patients over nearly a decade, and the lessons learned in organizing and running two major polio programs in two different institutional settings. Clearly these assumptions represent a particular bias, and we recognize that other professionals, with a different perspective or with different resources available to them, may want to use a modification of the approach outlined here. Our assumptions include the following:

1. Polio clinic attendance may be the first health care encounter for some patients in many years. For others, because of enduring negative memories of their original treatment with polio, it may be their first health encounter ever concerning polio-related problems since the acute illness.
2. Many patients--perhaps the majority--who are seen in the clinic arrive after a considerable period of indecision and ambivalence. They want information and help, but are not sure they want to deal with what they anticipate will be difficult choices and unpleasant news.
3. These patients have generally not been treated by health professionals who are comfortable or conversant with polio either as an acute paralytic illness or a chronic disabling condition with delayed manifestations.
4. Many patients have not had contacts with health professionals who understand the rather unique experience of some polio survivors who are confronting their limitations for the first time ("first disability") or others, who after a long period of adjustment and the onset of new symptoms, are now dealing with what they feel is a "second disability."
5. Older patients, because of their chronologic or physiologic age, are dealing simultaneously with issues of aging and disability, both separately and collectively

Based on these assumptions, we have developed an outpatient post-polio program at the National Rehabilitation Hospital which has the following elements:

1. *Comprehensive assessment.* Because of the number, diversity, and complexity of the problems presented by these patients, we have found that a comprehensive, coordinated assessment is required.
2. *Interdisciplinary Team.* The best way to provide a comprehensive, coordinated evaluation that looks at the medical, functional, and psychosocial/vocational issues of this population is to use an interdisciplinary team of persons with special expertise in disability and knowledge of polio.
3. *One stop shopping.* In an outpatient clinic, the kind of assessment described in numbers 1 and 2 above is best carried out in one setting where the patient encounters all members of the interdisciplinary team in a sequential fashion over a relatively short interval of 2 to 3 days, as opposed to a piecemeal, intermittent evaluation carried out over many days or weeks in multiple settings. This kind of structure is convenient and efficient as well as cost effective for the patient. For the staff it provides the opportunity for frequent face-to-face communication while the assessment is in progress, and on the spot, cross-discipline consultation which draws on the special interests and expertise of individual members.
4. *A dimension of time.* An assessment which extends over 2 to 3 days (rather than a single morning or afternoon) introduces a dimension of time. We find this allows the patient an opportunity to integrate the evaluation process, clarify questions, and begin to deal more realistically with some of the implications of a change in health and functional status. This, in turn, seems to make the patients more amenable to therapeutic recommendations.
5. *Diagnosis by exclusion.* Because post-polio related complications are diagnosed by *exclusion*, it is essential that every patient receive a careful history and physical exam, along with appropriate laboratory studies, radiographs, and diagnostic tests to rule out other medical, orthopedic, or neurologic conditions that might be causing or aggravating the presenting symptoms.
6. *The expectation of improvement.* We believe that everyone who comes to the clinic can be helped regardless of the underlying etiology or severity of disability. As a result, our goal is that everyone, even if they can implement only some of the recommendations and interventions, will feel better physically and emotionally and achieve an improved level of function. By the same token, there is no cure, and every improvement is dependent on patient commitment and cooperation.

A typical evaluation in our clinic extends over 2½ days, with the first day reserved for evaluations by team members who include a nurse, physician, physical therapist, occupational therapist, social worker, and, if needed, an orthotist.

The patient is seen initially by the nurse who makes a brief assessment of the past and current health status, clarifies the patient's goals for the clinic visit, coordinates the evaluations by the team members, schedules diagnostic tests, and assists with patient and family education. The medical evaluation consists of a comprehensive history and physical exam with special attention in the history to the details of the initial illness with acute polio and its management, and a special focus during the physical exam on neurologic and musculoskeletal findings. There is also an analysis of station and gait and of the use and need for orthoses and other durable medical equipment. In addition, the physician determines the need for radiograph, laboratory, and electrodiagnostic studies, and initiates referrals to other rehabilitation disciplines (eg, nutritionist, vocational counselor, psychologist) as well as other medical and/or surgical specialists as needed.

The physical therapist's evaluation is based on a protocol outlined by Smith,^[6] and includes a baseline manual test of major muscle groups, measurement of major joint range of motion and leg length, and an evaluation of habitual postures during standing, sitting, sleeping, and walking. It also includes an analysis of activities and positions that provoke or relieve muscle and joint pains. The occupational therapist's assessment is based on a format described by Young,^[7] and includes an evaluation of activities that produce pain, weakness, or fatigue, when symptoms occur, and how they interfere with the person's roles. Special attention is paid to the frequency and intensity of activities in the home, at work, in the community, and during travel, and to the use of or need for adaptive aids.

The social work evaluation focuses on how new health problems and functional loss impact on the patient, the family, significant others, and colleagues at work, school, or elsewhere outside the home. There is also an effort to identify coping strategies used by or available to the individual, and assess the emotional impact of the original polio experience and relate it to current feelings of having a second disability.^[8,9] In addition, the social worker facilitates referrals and access to community resources and services, including the local post-polio support group.

On the second day, we obtain any necessary laboratory studies, radiographs, and diagnostic tests to help rule out other medical, orthopedic, or neurologic conditions that might be causing or aggravating the patient's presenting symptoms.

For nearly every patient, we feel a standard electromyogram/nerve conduction study (EMG/ NCS) is essential to confirm the presence of an old anterior horn cell (AHC) disease, identify major muscle groups with subclinical involvement, establish a baseline, and help exclude certain other neurologic and myopathic conditions. We do not believe more sophisticated studies with single fiber EMG (SFEMG) or macro EMG are indicated at this time in the routine clinical setting, as they have not helped separate the symptomatic from the asymptomatic patient or proved useful in guiding clinical management.^[10] The one exception to this is the report by Trojan et al.^[11] which describes a subgroup of patients who have a positive IV Tensilon (edrophonium chloride) test during SFEMG and respond clinically to oral Mestinon (pyridostigmine bromide). The recommended dose is gradual increments of Mestinon up to 60 mg three times a day for patients who have new neurogenic weakness and can be monitored closely for response and side effects.

*The preliminary results of a more recent study by Dr. Trojan ([see GINI Press Release November 30th 1997](#)) have unexpectedly thrown some doubts on the efficacy of Pyridostigmine in PPS. "Pyridostigmine was not found to provide significant benefits with respect to quality of life, fatigue, or isometric muscle strength [of patients presenting PPS symptoms] compared with placebo, although a trend was noted towards increased strength in very weak muscles."
LincsPPN Web Administration 20th March 1998.*

A standard battery of screening tests, such as an SMA 24, thyroid panel, fasting glucose, etc, used on a routine basis are generally not helpful or cost effective, with the possible exception of creatine kinase (CK). In the Mayo Clinic study,^[3] 10 of 32 symptomatic subjects (31%) had mild to moderately elevated CK levels, while none of the 18 asymptomatic subjects had abnormal levels. However, whether it is useful to monitor CK levels on a regular basis to assist in determining long-term prognosis or as an aid in clinical management is still not clear. In patients who are relatively inactive,

overweight, or have a family history of coronary artery disease, we recommend a plasma lipid and lipoprotein concentration study. In a preliminary report of 64 symptomatic post-polio subjects, Agre et al/[12] found hyperlipidemia in 16 of 24 men (66%) and 10 of 40 women (25%). There was no evidence to suggest that this finding is related to the history of polio; more likely it is a reflection of deconditioning and the unhealthy nutritional status found in many persons with musculoskeletal problems and mobility impairments.

Patients who had respiratory involvement initially and have a history of pulmonary disease or scoliosis have a screening vital capacity measured along with their other vital signs. If the vital capacity is less than the predicted 50% or the history and clinical situation warrant, pulmonary function studies are obtained along with arterial blood gases (ABGs). If the patient has significant spinal curvature, a 36-in, gravity loaded scoliosis film is obtained to provide a baseline for follow-up exams. Patients with borderline or abnormal ABGs and/or respiratory symptoms are referred to a pulmonologist for further evaluation and management.

In addition to respiratory complications, swallowing difficulties may be more common than previously realized. In a recent study by Sonies and Dalakas/[13] of 32 patients, 14 (44%) had symptoms of new swallowing difficulties, and of the 18 asymptomatic subjects, all but one had some abnormality on detailed testing of oropharyngeal function. Patients who present to our clinic with any swallowing difficulties are referred to a specialist for further evaluation and management.

Finally, the morning of the third day of each patient's assessment in our clinic is used to complete any unfinished evaluations and hold a team conference with the patient and family. This conference is used to review the results of diagnostic tests and discuss our impressions and recommendations for interventions. Patients are given a written copy of recommendations and are then seen in follow up 6 to 8 weeks later to evaluate the effectiveness of the interventions and make any modifications or additional suggestions for management. Thereafter, patients are seen as needed and at annual intervals for a repeat functional evaluation and manual muscle test as well as a history and physical.

3. Windebank AJ, Litchy WJ, Daube JR, Kurland LT, Codd MB, Iverson R. Late effects of paralytic poliomyelitis on Olmsted County, Minnesota. *Neurology*. 1991; 41:501-507. [[PubMed Abstract](#)]

6. Smith LK. Current issues in neurological rehabilitation. In: Umphred Da, ed. *Neurological Rehabilitation*. 2nd ed. St Louis: C.V. Mosby Co; 1990:509-528.

7. Young GR. Occupational therapy and the postpolio syndrome. *Am J Occup Ther*. 1989; 23:97-103. [[Lincolnshire Library Full Text](#)]

8. Kohl SJ. Emotional responses to the late effects of poliomyelitis. In: Halstead LS, Wiechers DO, eds. *Research and Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains, NY: March of Dimes Birth Defects Foundation; 1987:135-143. [[PubMed Abstract](#)]

9. Frick NM. Demographic and psychological characteristics of the postpolio community. Paper presented at the First Annual Conference on the Late Effects of Poliomyelitis. Lansing, Mich, October 1985.

10. Kelly JJ. The electrophysiologic characteristics of the late progressive polio syndrome. In: Munsat TL, ed. *Post-Polio Syndrome*. Boston, Mass: Butterworth-Heinemann; 1991:67-82.
11. Trojan DA, Gendron D, Cashman NR. Electrophysiology and electrodiagnosis of the post-polio motor unit. *Orthopedics*. 1991; in press. [[Lincolnshire Library Full Text](#)]
12. Agre JC, Rodriquez AA. Neuromuscular function: comparison of symptomatic and asymptomatic polio subjects to control subjects. *Arch Phys Med Rehab*. 1990; 71:545-551. [[PubMed Abstract](#)]
13. Sonies BC, Dalakas MC. Dysphagia in patients with the post-polio syndrome. *N Engl J Med*. 1991; 324:1162-1167. [[PubMed Abstract](#)]

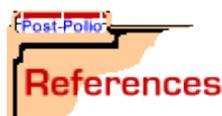


The article from which the above is extracted : [Assessment and Differential Diagnosis for Post-Polio Syndrome](#).

Canadian Multi-disciplinary PPS Clinic.

Dr. Parker runs the West Park Hospital multi-disciplinary PPS Clinic in Toronto, Canada on exactly the same lines and Joan Deverell from Wales is now holidaying in Canada following an assessment. This comment was made to her, 'Are British Doctors going to take notice of what Canadian Doctors have written in this report?' We do hope so.

I have also visited this clinic and talked to the staff and it is excellently run. There is a pre-evaluation self assessment form which is entered onto the Lap Top Computers provided to all the examining specialists. The doctor then has a good idea of who is coming into his clinic before they arrive. Appropriate tests have been pre-arranged and he performs his examination and enters the information as he works. This - including purchase of the computers - has saved an enormous amount of money and time in each specialist not having to ask the same questions over and over again. Forty-five minute appointments follow with the Social Worker, Physiotherapist and Occupational Therapist. The Orthotics Department and Workshop are adjacent to the Clinic. We are aware of many other PPS Clinics in America, Canada, Scandinavia, and others are starting up.



1. [LincsPPN Directory - Clinics](#)
2. [LincsPPN Directory - Clinics - West Park Hospital](#)

We are not asking for more money.

We are not asking for more money. We are asking that the money being spent over the years, where as much as 80% has we believe been wasted, be reallocated to Regional Holistic Centres where Polio Survivors

- can be assessed correctly,
- referred on for any other problems that become evident,
- advised and given a treatment plan,
- and case managed back to their local health authority for provision of correct aids and assistive devices,
- and where training and research can take place.

We do not need any more surveys, any more committees to look at the situation, the information is here now. Provide the funding and give Polio Survivors a reason to celebrate entering the new millennium. Any shortfall at any PPS Clinic can easily be taken up by the many other neurological conditions with similar problems.

Reasons given as to why we can't have full assessment.

What are the reasons given to us for not being able to receive the remainder of the necessary assessment -

- Our hospital does not have the money to employ PPS specialist staff.
- There is a shortage of Physiotherapists and Occupational Therapists in the country.
- There are not enough Polio Survivors alive in this country to warrant the expense.

Statistics.

There have been at least five surveys in Britain to my knowledge between 1995 and now, and they all say the same thing. Three of these UK surveys were given to Stephen Dorrell - Health Minister at the time- in 1996 by Helena Edwards of the Leicestershire Post Polio Network. Nothing happened. She did not even get the courtesy of a reply, despite many requests.

The following are excerpts from two of the surveys both available on our WebSite. Please note that these were done from questionnaires mainly from members of the British Polio Fellowship (BPF). In the majority these are polio survivors who have visibly lived with their polio all their lives and have walked with crutches, worn callipers or used wheelchairs. This we believe is only a small percentage of the actual number of people who have had polio in the UK. The majority of Polio Survivors we believe show little easily visible external sign of having had polio until they start to have symptoms. I did not know the BPF existed till November 1995 and many people who contact us say the same. Many of our members are also members of the BPF who support all people who have had polio. The BPF have an excellent Welfare set up and can help with advice and write letters on your behalf. Phone 0181 842 1898.

A Report Into The Consequences Of Living With Polio For 63,500 Years. Peter Field, 1995.

Abstract/Extract: This survey was conducted as a lay study into the impact on the lives of people who had polio earlier in life, and also to establish the frequency as well as the severity of the problems attributed to the "Late Effects of Polio".

Excerpt of The Findings - (full copy available)

The true impact of the findings are not distorted by the statistics. The message is loud and clear - having had polio is likely to have a recognisable impact later in life. The survey is clear in its message that the medical profession are not familiar with the harmful effects that having had polio earlier in life are likely to have on the ageing body. They are inexperienced as to the probability of certain outcomes, which most likely leads to the dismissive attitude sometimes referred to. This, it is suspected, is a significant contributor to the trauma often described.

Survey of the Late Effects of Polio in Lothian - January 1999. Rehabilitation Studies Unit The University of Edinburgh. D. Pentland, D. J. Hellowell, J. Benjamin, R. Prasad.

Excerpts with kind permission of Dr. Pentland.

2.1 Background & General Aim of the Survey.

The Edinburgh Branch of the British Polio Fellowship (BPF) made representations to Lothian Health Board and at public meetings of Edinburgh Healthcare NHS Trust

(EHT) expressing the concerns of members regarding the lack of specialist advice for health and related issues. People who had been affected by polio in childhood or early adulthood in the epidemic of the past reported a number of common symptoms and functional difficulties which had become apparent in their later years. In contrast to the expert advice available to them when initially affected by polio, many found that most health and related professionals (e.g. doctors, surgeons, therapists and social workers) appeared to have no or inadequate knowledge of the late effects of the condition.

They expressed a desire for a specialist service designed to address these issues. However little was known of the size or exact nature of the difficulties experienced and of how widespread was the dissatisfaction with current services.

and

5.5 Epidemiology of Polio.

It seems appropriate to add a final comment on the potential size of the likely population of polio survivors in Lothian. An extensive literature search has failed to reveal any figures as to the numbers of people who suffered polio in the past and are still alive today in the U.K. population. [Halstead \(1995\)](#) estimates 640,000¹ such people in the U.S.A. Based on an approximate population in that country of 240 million this would suggest a prevalence of 270 per 100,000. The reported prevalence in Norway is 250 per 100,000 ([Gilhus, 1998](#)). Assuming an approximate prevalence of 200 per 100,000 in Lothian whose population is almost three quarters of a million, this would lead to an estimate of about 1,500 people who had suffered polio in the past.

[De Visser \(1994\)](#) states that in this country epidemiological data about the frequency of the post-polio syndrome are based on estimates from U.S. studies which vary between 22 and 87%. Gilhus suggested that 15% of polio survivors in Norway suffered from post-polio syndrome. Taking a conservative figure of 20% and assuming that there are 1,500 polio survivors in Lothian would suggest about 300 people in the area who may be suffering the late effects of polio. Considering the limitations of our study design described above this appears a reasonable estimate. Taking account of the fact that the population of polio survivors is ageing it would be wise to plan for a larger number than this encountering problems and requiring services in a few years time.

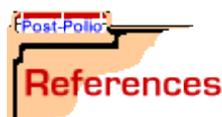
[¹ LincsPPN Editorial Note. In *Managing Post-Polio - A Guide to Living Well with Post-Polio Syndrome*, Ed. Lauro S. Halstead, M.D, NRH Press, 1998, pp11-12, Halstead states that from a 1987 survey the CDC "calculated slightly more than 1.63 million polio survivors. Of these, 641,000 (39.2 percent) persons had paralytic polio; 833,000 (51 percent) had non-paralytic polio; and 160,000 (9.8 percent) didn't know." The diagnosis of paralytic polio is a clinical diagnosis. Neuronal damage may be present sub-clinically in persons diagnosed with non-paralytic polio. Thus the potential for late-effects of polio is not limited to persons previously diagnosed with paralytic polio but includes a factor (neuronal damage) that is present in a variable degree in all polio survivors. See [Non-Paralytic Polio and PPS](#), Marcia Falconer, Ph.D. cell biology and Eddie Bollenbach, M.A. biology, A Lincolnshire Post-Polio Library Publication - January 1999. Dr. Pentland adds that the Gilhus reference also refers to paralytic cases and concurs that the extrapolation for Lothian is therefore likely to be an underestimate of the numbers suffering late sequelae.]

De Visser M. Rehabilitation of progressive neuromuscular diseases. In: Illis L.S. (ed)

Neurological Rehabilitation 2nd ed. Oxford: Blackwell Scientific Publications, 1994,p 246.

Gilhus N. Post polio: a challenge for neurological rehabilitation. *WFNR Update* Nov 1998, 6-7.

Halstead LS (1995) The lessons and legacies of polio. In: Halstead LS, Grimby G (eds) *Post-polio syndrome*. Philadelphia: Hanley & Belfus Inc, pp 199-214.



The articles from which the above extracts are sourced :

1. [A Report Into The Consequences Of Living With Polio For 63,500 Years.](#)
2. [Survey of the Late Effects of Polio in Lothian - January 1999.](#)

See also [LincsPPN Directory - Organisations - British Polio Fellowship.](#)

I met with Dr. Le Geyt, Consultant in Communicable Diseases at Lincolnshire Health in the summer of 1996. His reply to that meeting informed us that there could be 100, 300 or 1200 polio survivors in Lincolnshire depending on the survey you looked at. The LincsPPN made representation to Lincolnshire Health Authority in the summer of 1997 about the problems our members and Polio Survivors in general were having in being correctly assessed, diagnosed, advised and treated. As you are aware from earlier Newsletters, Lincolnshire Health formed the Neurological Patients Forum in January 1998 and we attended all but one meeting. We met with Dr. Bretman and Dr. Wilson in March 1999 as you know, expressing our disappointment that little had been achieved. In fact more members were having more problems. Dr. Wilson informed us that day that with regard to the Lincolnshire Health Service Specification for Neurology, the Neuro Patients Forum input was not agreed with and is only added as an addendum. The statistics that are quoted are the national figures divided by the population of Lincolnshire. Accurate figures of the numbers of each neurological condition are not known. Post-Polio Syndrome is not mentioned.

The population of Lothian is not much larger than Lincolnshire. We believe the numbers of Polio Survivors in Lincolnshire are grossly underestimated by Lincolnshire Health.

Our Newsletters have been full of information and complimentary copies have been sent to many different Government and Medical Establishments. With very little response.

Once I had confirmation from Dr. Betty Dowsett, Dr. Ali Arshad, Dr. Airey and my GP Dr. Sowerby that I am correct that the standard methods of assessment being used are not adequate for Polio Survivors I took the opportunity to once again ask for the support of our MP.

I met with Gillian Merron, MP for Lincoln, just over two weeks ago where I asked for a meeting with Frank Dobson MP. I gave her a large presentation with copy for the Minister of Health and showed her how the deterioration was not being picked up by the standard assessment. I explained that we believed that as much as 80% of the money being spent on our medical appointments and tests, and benefits appeals and tribunals was ineffectual due to the lack of knowledge of the late effects of Polio.

On our behalf Gillian Merron has written to Frank Dobson MP the Minister of Health, to Alastair Darling MP the Minister for Social Security and to Mr. Jeavons Chief Executive of Lincolnshire Health Authority. I look forward to giving you more news in the next newsletter.

We ask all those in authority in the Government, University and Colleges of Medical personnel, Local Authority Staff, Ministry of Social Security and equipment companies providing items for the

disabled, to learn about Polio and its late effects. While we continue to be wrongly assessed and sent on the rounds of the hospital departments, much of the money spent is wasted. We continue to deteriorate unnecessarily, go without aids that would allow us to conserve and preserve what we have left and use our available energy to its best advantage for as long as possible. All medical conditions should have an equal right to adequate medical assessment and care.

Paralytic* Polio Survivor Statistics taken from the Lincolnshire Health Letter from Dr. le Geyt 1996

and Edinburgh University Survey of Lothian in January 1999.

Figures in brackets are extrapolations from survey figures.

	per 100,000	UK NHS 1990	LOTHIAN Survey	LINCS figures
Total Population		57,400,000	750,000	631,466
Letter from Dr. Le Geyt, Lincolnshire Health Authority 1996, quoted 3 surveys.				
Barker Lancet 1988 - 23,000 infections 1920 to 1950 (NB UK notified 1912 to 1961 was 74,280).	15	(8,610)		100
British Polio Fellowship say 100,000 and 30,000 survive.	46	(26,404)		300
Ahlstrom survey in 1993 of 186 per 100,000	186	(106,764)		1,200
Edinburgh University survey for Lothian quotes the following surveys.				
Halstead 1995 (1987 USA estimates 640,000 paralytic polio in population of 240m).	270	(154,980)	2,025	(1,703)
Norway (Gilhus, 1998) 250 per 100,000.	250	(143,500)	1,875	(1,577)
Lothian say 200 per 100,000 of 750,000.	200	(114,800)	1,500	(1,262)
In 1987 the U.S. Department of Public Health National Health Survey calculated that there were 1.63 million Americans alive today who had had polio (paralytic and non-paralytic).	680*	(390,320)*		(4,293)*

* All figures are for Paralytic Polio cases only except for last row which includes both Paralytic and Non-Paralytic Polio.

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



What Helps Post-Polio Patients Feel Better?

with Stanley K. Yarnell, M.D.

Reported by Mary Clarke Atwood, with editorial assistance by S. K. Yarnell & L. Craig.

At the August 1998 Colorado Educational Conference Stanley K. Yarnell, M.D. was the keynote speaker. He is a well-known presenter at post-polio conferences worldwide. For the past twenty years Dr. Yarnell has been involved with disabled people both professionally and personally. He has been legally blind since 1978 due to recurrent optic neuritis.

In 1981 Dr. Yarnell established the first Northern California post-polio clinic at Saint Mary's Medical Center in San Francisco. In an effort to determine the effectiveness of treatment services at this clinic, a survey was mailed in 1994 to patients who were seen in the St. Mary's Post-Polio clinic during the preceding five years. Eighty percent of the respondents said the advice they received from that post-polio treatment team was useful. Many months after visiting the clinic, fifty-nine percent of these 130 respondents reported they felt better.

This report is based upon Dr. Yarnell's keynote address and workshop session at the 1998 Colorado Educational Conference. The focus is on five treatment options which patients credited to their improvement. It concludes with the reasons patients gave for feeling the same or worse.

Why 59% Felt Better.

The average age of the respondents who felt better was 54.5 years: their last clinic visit was 1.7 years ago.

This group experienced improvement in these health indicators:

- better coping skills,
- being more relaxed,
- increased self-confidence,
- fewer falls,
- less pain,
- less irritability,
- better sleep,
- better mobility,
- less anxiety,
- greater efficiency,
- less depression,
- better general health.

Patients were asked to indicate which treatment options contributed to their improvement.

Treatment Options:

- emotional reassurance,
- medication recommendations,
- energy conservation techniques,
- myofascial release,
- massage,
- seating changes,
- TNS (nerve stimulation),
- family education,
- heat/ice,
- change or start ventilator,
- adaptive equipment,

- bracing,
- wheelchair/scooter,
- injection,
- retirement/work cutback,
- biofeedback,
- back/joint conservation,
- swimming,
- oxygen,
- traction,
- non-fatiguing general conditioning exercise (20% rule).

What made them feel better?

- A. 79% reported energy conservation techniques.
- B. 74% reported non-fatiguing, general conditioning exercise program following the 20% rule.
- C. 59% reported retirement/work cutback.
- D. 55% reported emotional reassurance.
- E. 40% Wheelchair/scooter use.

A: Energy Conservation.

Seventy-nine percent of the respondents felt that energy conservation techniques taught by occupational therapists made them feel better. A key component to the management of fatigue is instruction in energy conservation techniques and pacing in day-to-day activities.

- Maintaining an activity diary to monitor and prioritize daily activities is often recommended. Some lifestyle changes may be essential.
- Sometimes setting limits may be necessary.
- Adaptive equipment is often helpful. Polio survivors have found motorized scooters and wheelchairs to be a great way to save energy.
- Careful analysis of gait may result in changes in orthotics so that walking will be more energy efficient as well as less painful.
- Environmental adaptations or modifications could be beneficial.

For expanded suggestions on energy conservation, see "Some Helpful Tips" by Grace Young, MA, OTR, in this same issue [of Rancho Los Amigos Post-Polio Support Group Newsletter]. This information, provided at her workshop sessions, followed Dr. Yarnell's keynote address.



1. [Lincolnshire Post-Polio Library - Young, Grace R., MA, OTR.](#)
2. [Lincolnshire Post-Polio Directory - Occupational Therapy Directory - Grace Young's Energy Conservation Web Page](#)

B: General-Conditioning Exercise 20% Rule.

Seventy-four percent of the respondents credited this non-fatigue conditioning program for helping them feel better. But polio survivors walk a fine line between overworking their delicate old reinnervated motor units and therapeutic exercise. Many polio survivors may become deconditioned because of illness, surgery, trauma, or chronic pain; convalescing may take 3 to 4 times longer when compared to patients possessing a full complement of anterior horn cells. So Dr. Yarnell has designed this non-fatiguing, general-conditioning program using the 20% rule for use when deconditioning is a factor in a polio survivor's fatigue. This program can help restore stamina for

those individuals who have continued to be bothered by profound fatigue attributable to deconditioning.

The program begins by determining the polio survivor's maximum exercise capability (MEC) with the help of the clinic physical therapist. This individual's maximum is determined to be the amount of activity/exercise that results in achy or burning muscles, or when a person feels rubber legged. When a person's muscles feel this way, they're beyond what is potentially therapeutic and have wandered into the area of potential injury.

The exercise chosen can be in a pool or on dry land, using an arm ergometer (upperbody exerciser) or exercise bicycle. The pace of exercise depends on the individual's abilities and preferences. The individual begins at twenty-percent of MEC about 3 times a week. After 4 weeks the distance or time is increased ten percent.

Most polio survivors are able to continue increasing their exercise program to the maximum exercise capability. Working gradually toward a maximum may take a full 9 months if the program is strictly followed. Exercise at a sub-maximal level allows an individual to regain a healthier sense of stamina without damaging delicate old motor units.

Additionally, it is imperative to incorporate the concept of pacing and spacing into the non-fatiguing, general-deconditioning exercise program. The 20% rule is also applied to instructions in home flexibility and stretching programs given to polio survivors, so that patients do not exercise too vigorously. This exercise program can be modified somewhat, with the supervision of a physical therapist, depending on the progress made by the polio survivor.

This program may not eliminate fatigue for all polio survivors, but it is effective for those who have a significant element of deconditioning that contributes to their sense of fatigue. For polio survivors and their treating physicians, it has been useful as an exercise guideline following illness, surgery, myocardial infarction, or trauma.

Example 1: Conditioning Exercise Swimming.

If the individual prefers swimming, then the maximum number of laps that the patient can swim is used as the maximum exercise capability. If the survivor has considerable residual weakness and is only able to swim one lap in one half-hour, then the amount of time actively swimming can be used as the maximum exercise capability, rather than the number of laps. When the maximum exercise capability has been established the polio survivor is instructed to begin his aerobic swimming program at twenty percent of the determined maximum exercise capability. He can swim 3 to 4 times per week at that level for 1 month, and then is instructed to increase by ten percent. For example, if the individual is able to actively swim in a pool for one half-hour, then one half-hour would be his maximum exercise capability. He would begin swimming just six minutes per session. 3 to 4 times per week, for a month, then would increase the amount of time actively swimming to nine minutes, 3 to 4 times per week for another month. After that he would increase by ten percent once again, so that he would be actively swimming twelve minutes per session, 3 to 4 times per week, for another month, and so on. After 3 to 4 months, patients have reported that they feel an increase in general stamina or endurance.

Pacing, or interspersing rest periods between active exercise, is essential. In the example above, the patient would be urged to actively swim for three minutes, rest for two minutes, then swim for three more minutes, then rest for two minutes. Patients are encouraged to use flotation devices, flippers, or other devices to make their swimming as easy as possible, so that they can truly rest between bouts of active swimming.

Example 2: Conditioning Exercise - Bicycle or Arm Ergometer.

Alternatively, if an arm ergometer or a bicycle is used, the same principle can be outlined, calculating distance peddled or time spent actively peddling the ergometer or exercise bicycle. The individual begins his aerobic or non-fatiguing general-conditioning exercise program at twenty

percent of maximum exercise capability, 3 to 4 times per week, for one month, and then increased the distance by ten percent. He continues with that level of activity for another month before increasing by another ten percent, so he is exercising at forty percent of maximum exercise capability. For example, if an individual is capable of peddling an exercise bicycle for one mile, or is actively able to peddle the bicycle for up to twenty minutes, then that is his maximum exercise capability. He is instructed to begin his/her exercise program at 1/5 of a mile (or if time is used, then four minutes is the beginning exercise time). This is repeated three to four times per week for an entire month before increasing the distance to 1/3 of a mile or to six minutes. Patients are encouraged to follow this same schedule for an additional month before increasing by another ten percent, and so on.

Polio survivors are reminded to always pace themselves or put rest intervals into their exercise programs. Individuals are cautioned to stop if they become fatigued during the exercise program or if they experience aching or pain in their muscles.

C: Retirement/Work Cutback.

Fifty-nine percent of the respondents reported they felt better due to retirement/work cutback. Therefore Dr. Yarnell will continue to recommend retirement or reduced workloads to patients.

D: Emotional Reassurance.

Fifty-five percent reported that emotional reassurances made them feel better. Dealing with additional disability may result in chronic anxiety and a sense of sadness for polio survivors because of grieving for losses. Post-polio support groups or self-help groups are most helpful. Sometimes individual counseling may be necessary to help a patient reduce his/her anxiety, allowing for better sleep habits, greater sense of self confidence, and a feeling of more energy.

E: Wheelchair/Scooter Use.

Forty percent of the group who felt better credited it to use of a wheelchair or scooter.

Why 23% Felt The Same.

The average age of respondents who felt the same after their clinic visit was 56 years; their last clinic visit was 1.6 years ago. These people were asked to indicate whether they felt better, the same, or worse in the following health indicators:

- level of relaxation,
- pain,
- shortness of breath,
- number of medicines,
- mobility,
- family relations,
- work relations,
- weakness,
- irritability,
- coping skills,
- energy level,
- sleep,
- frequency of falls,
- self-confidence,
- efficiency,
- stamina,
- concentration,
- fatigue,

- anxiety,
- depression,
- average weight,
- general health.

These respondents all reported no change in these health indicators. However, 43% believed they would have felt worse if they had not visited the clinic.

Why 18% Felt Worse.

The average age of the polio survivors who felt worse after their clinic visits was 64 years; their last clinic visit was 2.0 years ago. When responding to the [health indicators listed on page 1](#), on average they felt worse in nine categories and the same in the remaining areas. This groups characterized themselves as feeling worse because of:

- decreased energy,
- increased weakness,
- poor mobility,
- increased fatigue,
- more pain,
- less stamina,
- worse sleep,
- poorer concentration,
- greater anxiety.

Why 18% Felt Worse.

Why did they think they felt worse:-

76% due to PPS symptoms that progressed

48% due to age

29% due to increased stress

44% due to other illnesses.

Conclusion.

Dr. Yarnell believes that all polio survivors will NOT necessarily get worse. One key to keeping free of pain is to maintain flexibility of the trunk and spine. Dr. Yarnell suggests that each person who had polio spend 5 minutes daily on flexibility exercises.

Because of the positive response to treatment services, Dr. Yarnell's clinic will continue to

- emphasize energy conservation,
- teach exercise parameters,
- advocate early retirement or work simplification,
- provide emotional reassurance,
- encourage use of power wheelchairs/scooters and adaptive equipment,
- emphasize joint conservation,
- consider the use of medications for pain, weakness and fatigue.

Many polio survivors are having similar symptoms for entirely different reasons. The challenge for the post-polio treatment team is to design a successful, customized treatment program following careful diagnosis and analysis of primary complaints.

For More Information Contact

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Note. Articles in this [Ranchos Los Amigos Post Polio Support Group] newsletter may be reprinted exactly as written, with acknowledgement of this newsletter and the author.

Ranchos Los Amigos
Post Polio Support Group
Newsletter June 1999.

LincPIN Editors Note. We owe our thanks to Mary Clarke Atwood for sending us her newsletters. This one arrived by post just as I was finalising this newsletter. I added four more pages as I am sure this is one that you will want to read.

This Clinic also started in 1981. Why is there no Clinic like this in Britain?

Polio Survivors are high achievers. We know our own bodies. We do not like this new weakness, pain, fatigue and decline in daily functioning. We want to do as much as possible to improve the quality of our lives.

We need a holistic assessment by a multi-disciplinary team, and case managing back to our local health authorities. We need to be assessed for aids/equipment/treatment sessions. We want control of our lives and we want to do as much as possible for as long as possible within our limitations. We need electric scooters on the NHS. This should have started 20 years ago - please don't leave it any longer.



LATE EFFECTS OF POLIO THE DELICATE CHILD by Dr. G. O. Airey.

(LincPIN Editors note. Dr Airey is a member of the LincsPPN and his accompanying letter to us says

"it was good to talk to you the other day and I hope I managed to get it across to you how much I agree with your remarks (in [our last newsletter editorial](#)) and that much more should be done to make the medical and allied professions become aware of our plight and act upon it. Here is the story of my childhood days...

I find it difficult to answer the all important questions. Have you had Polio? If so, when? I was only a small boy possibly 5 or 6 when I had a long illness which confined me to bed, often in a darkened room and I remember brilliant sunshine outside.

During this time I have a very firm recollection of being nursed by my aunts (my mother's sisters) taking it in turns to sit by my bedside night and day: there seemed to be always one of them applying cloths soaked in Eau de Cologne to my brow and holding my hand, and I am told I would often say "hold my other hand too."

A frequent visitor at this time was the Minister from our church, Mr Hedgman, who would sit at my bedside and play the game called "ludo". (I remember he wore one of those flat "bowler" hats. I mention this because it may help to pin-point the date.) I have recently found that he was the minister there from 1908 to 1917.

Another date which I recall very well was when walking (yes - WALKING -) with my Mother along Broomfield Lane, Hale. We met my Grandfather coming from the station and I greeted him by saying "I'm FOUR today." (That would be 1914)

Again a very vivid memory was 1917 when my Father arrived home from business and I met him at the front door so must have been up and about by then, but he had the sad news that our eldest brother Harold had been killed.

So the illness must have been between those two dates.

They always said it had been "SUNSTROKE", this may be because they did not want to alarm everyone by using the word "Infantile Paralysis" or possibly at that time the diagnosis was only in its early stages.

I can remember the doctor who attended me was called Dr. Willson (Yes. with two LL's) and he lived at the corner of Hale Road and Queens Road. I was taken to see Mr. Telford, a consultant in Manchester: I can remember what he looked like and where his rooms were in St John Street.

I was taken regularly to a man in Old Trafford for what must have been physiotherapy and spent a lot of time in a bath chair and even threatened with one of those "spinal carriages". I can remember seeing it but yelled and would not let them put me in it.

It must have been as a result of seeing this man Telford that as a family we quite suddenly moved to St Agnes on Sea for the benefit of the sea air etc.

The war must have been over by then as Harold had been killed and [as] he was expected to go into the business, there was no longer any need to live near "the office."

It must have been a sudden move because we seemed to have got two houses in the same road. We seemed to have moved into one house when Father heard of another one fully furnished as the people were going abroad, so that is where we ended up, 34 St Thomas Road.

Those days at St Agnes I remember best and I suppose I must have been getting on for 9 or 10.

The thing that upset me most was the point of going to live there because I was not allowed to go on the sands: they had told my parents that it would not be good for my spinal trouble as I had some scoliosis and one leg shorter than the other.

Even then I must have spent a lot of time resting in bed and when I was sent to a primary school (Miss Shepherd's) I was made to lie on the floor in front of the whole class so as not to miss my rest!

I was not taught to swim or take part in any sports or games but was sent to a DANCING CLASS dressed in a white silk blouse and black velvet shorts! I wanted to learn to play the violin and went for lessons from a Mr. Peretz of the Halle Orchestra but that did not last long because they said it was bad for my back.

I remember being taken to the south of France and joining a Cunard liner called Sythia cruising in the Mediterranean with lots of American people on board.

I suppose it was after that that I was sent to a proper school King Edwards where Frank and Alan were already but I gather I could not stand "the pace" and was not there very long and was sent to a less exacting one (Kingrimol) which looking back was a pity although I made lots of friends.

It was not until we moved back to the Manchester area about 1926 that I was sent to a good school and began to learn anything Altrincham County High School for Boys, now the Grammar School.

I had a friend at St. Agnes who had an illness about the same time [Ernest Lee] who ended up with both legs in callipers but became the Town Clerk of Blackpool.

L E P?

Is that what it is?

Looking back over the years, especially having studied Medicine, and particularly the past 20 years I have always been subject to back or lower limb trouble - weakness of a musculoskeletal nature but it is only in the last 5 or 10 years that any attempt has been made to do anything about it - e.g. special shoes with insoles from Mr. Frame in Macclesfield.

I remember having treatment from an Osteopath in Cheltenham about 20 years ago.

I always seemed to drag the left leg especially when tiring, and wear the sole of the left shoe out before the other.

Even the most trivial injury would take a long time to respond to the recognised treatment.

I was subject to recurrent L-sided headache which was regarded as migraine.

Dr. G. O. Airey, Cheshire.



Learning To Skip.

By Christine Mackinnon

My name is Christine and I had Polio when I was one year old. I'm 47 now and I was one of the unlucky ones who caught it at the tail end of the 1952 epidemic. I have no recollection of that time and have relied on information from my family. My mother and Father had split up by then, but I do recall calling my oldest sister, who was only 14 years old at the time, Mum, as she walked up to my cot in the hospital, much to her embarrassment! I needed two callipers up to my waist and two walking sticks. Polio had hit my legs and back.

At the age of seven I was shipped off to boarding school, as I was getting knocked over too often at the 'normal school'. I didn't realise it at the time, but I loved every minute of it. I was taught to walk better and generally stand on my own two feet, so to speak. Better callipers were made and several operations later I became *normal*. How anyone wearing two callipers and two elbow crutches can think of themselves as normal I'll never know to this day!

The usual schooling took place and, at the ripe old age of 16, I was dropped from a great height into the big wide world. I was absolutely petrified. I had been cast out from this snug little 'pond' called boarding school where, by the way, I was quite a big fish because I was an older pupil, into the big ocean called life where I was just a little minnow and nobody knew me or wanted to know me. ("She's different, mental you know," looking at the callipers!) Luckily I had my family to lean on and soon I got into the swing of things. Life was really good. Jobs came and went, so did boyfriends and eventually I got married and had three wonderful children. The Doctors were not very keen on that bit, I can tell you!

Around 1976 I had a bad fall which started the old arthritis off and then I had to have both kneecaps removed. But on with life! Things settled down once more. When I say settled down, we all know of the usual struggles and the way we have had to push, push, push but that was a normal day, wasn't it?

Along came 1989 and I started to feel the odd twinge, back ache, leg ache, etc. but I thought nothing of it. Time rolled along and the aches and pains got worse and by 1993 things were getting on top of me. My husband was very good and helped as much as he could. I had to push harder. I was getting lazy. I must do more and I did. I was 'normal' wasn't I and no housework was going to beat me!

The year is 1997 and things are going down hill fast. What ever is wrong! I have always been able to manage, but a walk around the supermarket now and I'm really hurting and I'm bushed. And now the arguments started. I would snap at my husband and, quite naturally, he would snap back. Rows

and more rows; pain and more pain.

"It's the pain that makes you tired." "It's the arthritis that causes the pain." "There's nothing more to be done" Say the doctors. I don't know whether to use the wheelchair or just grin and bear the pain and all that goes with it. Am I on my head or my heels? I just don't know any more! My poor husband, why does he stick with me?

It's 1999 and I'm in my wheelchair and then out of my wheelchair. It's still going on and I hate being 3 foot high and invisible to all those giants who tower above me and don't see me! Why can't I do the things I used to? I'm not that old, am I? Am I imagining it? Am I a hypochondriac? I wish someone could help me, but there seems to be no one. My doctor tries to understand and I'm *under* a pain specialist. (I hate that expression). Nothing works. I am at the end of my tether and so are my poor husband and the kids. How they have stuck around for so long I don't know. I guess I am lucky to be surrounded by so much love. The trouble is their love doesn't ease the pain. That sounds really ungrateful and selfish, it's not meant that way. It's just the truth.

It is May 1999. I've been in my chair for a couple of months now continuously and because of 45 years of brain washing "You must carry on. You must exercise. You must not GIVE UP." I am feeling really guilty, but I am living with it. The pain is just too much to bear when I'm on my callipers and, in my chair, maybe I'm not quite the pain in the neck for my husband as I have been for these past years. The wheelchair has started to become a little uncomfortable, so I need to get a new jelly cushion from the wheelchair centre. All is arranged and this handsome young man arrives with my new, clean cushion. We all chat a little. Correction, I moan a little and then out of the blue this handsome young man says three little magical words, three words that have changed my whole life. NO not I LOVE YOU!!!!

"Post Polio Syndrome"

"What is that?" my husband Chas and I cried in unison.

"It is a condition that some people get about 30 to 40 years after getting Polio."

My cushion man left and my darling Chas dived onto the internet (God Bless the Internet) to find out all he could. Chas typed the word POLIO into the search engine and suddenly a whole new world of information in the form of the Lincolnshire Post Polio Network's website was there in front of us! A couple of days later we were reading like fury. Everything was falling into place. Suddenly life made sense and although I didn't really want this PPS as it is called, I was glad that this was what seemed to be up with me. I was not MAD or a HYPOCHONDRIAC, I had PPS. Having read up on PPS (and I am no expert), people were saying the opposite to what I had been told for forty odd years:

"Take it easy, get into your wheelchair, wear your callipers, use your crutches. Whatever makes you feel better or pain FREE, do it. Dust never hurt any one. The Hoover won't rot if it is not used every day and every one learns to iron, you do not have to do it."

I could not believe what I was reading at first.

"I can't do that." was my first reaction, but slowly with a lot of help and coaxing from Chas I am learning to SKIP!

Now I SKIP the ironing, I SKIP the dusting, I SKIP the washing and I'm taking a lot more rest and do you know what?

"I feel wonderful."

Please, for your own good,

LEARN TO SKIP!

Christine and Alan Mackinnon.

Law of Success:
If you want to make something good happen,
find out what action causes it,
and take that action.



Silent Night

by Christine Ayre, LincsPPN.

Living as I do in the heart of the Country, one would think all was peace and tranquillity: so it is in the Winter when the wind howls and the rain lashes down. Then I can look forward to restful nights in my snug cottage with just the sound of my ventilator purring on the bedside table and Ben my boxer dog lying in his new bed (a very fancy Victorian style bed made of pine with bun feet. Made for Ben's fifth birthday by his Uncle Barry who is a cabinet maker) and snoring loud enough to rattle the windows.

When Spring arrives all things change, gone is the peace and quiet. The Flora and Fauna erupt in a burst of frenzied energy. Frogs croak, Birds sing, Lambs bleat and Cows moo. That shiest of all creatures the tractor appears, thundering up and down the fields, drilling, harrowing and spraying. Everything seems louder in the Spring, as if trying to banish the Winter gloom.

So it was this week when I needed a peaceful night after suffering a couple of sleepless nights due to eating something that didn't agree with me. An early night sounded just what I needed, but it was not to be.

Ben and I decided to take to our beds at about ten o'clock. Ben settled down nicely and was instantly asleep and dreaming. I got into bed with my "Shorn the Sheep" hot water bottle at my side. A dressing on the bridge of my nose, slapped on my ventilator mask and prepared to drift off to sleep. Safe in the knowledge that if a burglar broke in and saw me laying in bed in my vent mask he would be frightened into leaving rapidly.

I awoke a short time later. Ben was trying to attract my attention by shoving a slipper in my ear. I cast aside my mask in a rush realising Ben was desperate to go out. He galloped down the stairs with me in hot pursuit on my stairlift. I tripped getting off the stairlift and sprawled on the hall floor. As I heave myself off the floor Ben is barking in his desperate attempt to get through the door. I get to the outer door and throw it open. Ben shoots down the driveway like a bullet and returns seconds later with his squeaky frog in his mouth, runs past me into the house and up the stairs. By the time I get back to bed Ben is already asleep with his squeaky frog in bed next to him. He couldn't possibly have had time to relieve himself. I look at the clock, it's 2 am. I settle down for the rest of the night and go off into a nice sleep.

What seems like minutes later I am awoken by the most terrible noise. That harbinger of spring "The Cuckoo" is shouting somewhere very near. It sounds as if it has a megaphone, and it goes on and on. CUCKOO CUCKOO CUCKOO. I lie listening. It's 4 am. and no bird in its right mind should be up at this time. Casting aside my vent mask yet again, I get up and put one eye through a gap in the curtains. There is the offending bird, sitting on my fence. What fool said Cuckoo's sing? I throw open the window and shout a load of abuse at the bird, it continues cuckooing, Ben puts his paws on the windowsill and adds his voice to mine. The bird gets the message and leaves, still cuckooing. We settle back to sleep.

Suddenly I'm awake again. I look at the clock, it's 6a.m. and the farmer is fetching in the cows from the field at the back for milking. This sounds like an idyllic rural pursuit and conjures up visions of a smock garbed yokel wandering behind a herd of plump milking cows. Not so at Catley. The

farmer drives down the field in his Landrover, with his dog doing the rounding up. The dog never seems to get it right, he gets side-tracked into chasing a rabbit and rolling in a cowpat. The farmer shouts at the top of his voice, swears at the dog, casts doubt on its legitimacy, telling it to go away and multiply and showers it with insults.

I open the window prior to giving the farmer a bit of verbal abuse. I shout b*****# off, the farmer waves in a friendly manner and remarks on a beautiful morning. I disagree and gesticulate rudely.

Giving up on the sleep I go down and make a cup of tea. Taking the tea back to bed with me I tread on Ben's squeaky frog. The shock makes me jump and the tray of tea lands on the bed. I go to lie on the sofa but "Aster Beagle" is there before me. Oh well such is life.

Christine Ayre at peaceful Catley Abbey

[<Catley@tesco.net>](mailto:Catley@tesco.net)

Just when I was getting used to yesterday,
along came today.

-+-

It is bad to suppress laughter;
it goes back down and spreads to your hips.



The virus that haunts its past child victims

by Barry, aged 14, from Midlothian.

LincPIN Editors note. This report came to our notice as the Online Internet Magazine Out There News for Children rang us for information on Post-Polio Syndrome.

Most children today have probably never heard of poliomyelitis - or polio, for short. But during the first half of this century it affected thousands of children across the world, many of whom died from the disease. Now, however, the virus is coming back to haunt the survivors of the illness. Known as Post Polio Syndrome, or PPS, it's estimated that about 250,000 people suffer from the condition today. Their muscles and nerves start to deteriorate, meaning they move slower and cannot lift things as easily as they could before.

Sadly, though, doctors in this country have been slow to recognise PPS, many refusing to admit that such a condition exists. People who suffer from PPS don't get special disability allowances, even though a lot of them can no longer work and require a lot of extra help at home.

Polio is a virus that enters the body orally. Once in the body it has disastrous consequences, attacking nerve cells in the spine. That means all the other cells have to work much harder and after a while they just get tired and stop working. That's when polio victims who've led normal lives start to get ill with PPS. Many lose all movement in their hands or feet, and some are even paralysed because of the disease.

Linda Dunlop is just one woman who contracted PPS recently. She contracted polio when she was five years old, but she has lived an ordinary life up until now. "Now I'm troubled with sleepless nights," she told me. She said when she was 17 she was told when she might become ill when she reached 40 or 50. "But at 17, the future never worries you, does it," she said.

Now she moves more slowly and has difficulty doing the things other people take for granted - like carrying shopping, or making the bed or walking up a hill. "Sometimes I think 'Why me?'" she says. "But that's life, I suppose."

Glossary:

Polio affected children from the ages of 0-15 during the post-war years. Polio is coming back to haunt these past victims, in the form of Post Polio Syndrome (PPS), which can be just as emotionally and physically damaging as the original virus.

PPS occurs when past polio sufferers reach the age of 50, or thereabouts. At a time when their friends are starting to retire and looking forward to spending the rest of their life without any worries, polio sufferers are having to face the virus that made such an impact on their lives yet again.

"Why is this relevant now?" I hear you ask. Well the thing is, many PPS sufferers in Britain do not realise that polio is coming back to haunt them a second time. Many of these people put their insomnia, sore joints and depression down to stress and old age.

The National Health Service does not currently advise doctors to recognise PPS. But why? In America it is a common diagnosis, with new treatments being researched all the time. In Britain today there are too many unanswered questions regarding PPS. It is about time we made sure that people with PPS (about 250,000 people in Britain are thought to suffer from the condition) are given treatment and help.

After all, would you like to go through this ordeal without any help?

Barry Preston

Out There Reports

www.outtherenews.com

AOL MEMBERS:KEYWORD:OTREPORTS

Latteeu@aol.com

If the pen is mightier than the sword, and a picture is worth a thousand words,
how dangerous is a fax?

When your pet parakeet sees you reading the newspaper,
does he wonder why you're just sitting there, staring at carpeting?

If all the world is a stage,
where is the audience sitting?



Scottish Post-Polio Network First meeting May 7th 1999

May 7th saw the first official meeting of the newly formed Scottish Post Polio Network. An auspicious day as we saw the results of the elections here in Scotland that heralded the birth of the Scottish Parliament. We however are a much smaller set up - three of us got together for lunch mid way between Glasgow and Edinburgh where we variously live. In common with the Parliament however, we aim to work towards improving the situation here in Scotland - in our case of course specifically for those with PPS.

Our aims are simple;

- to raise awareness of post polio syndrome providing information and support for people with PPS,
- to make links with other voluntary bodies and organisations,
- to encourage the formation of a PPS unit attached to a local hospital in Scotland where people can go for diagnosis and assessment of PPS,

- to open this organisation to all those interested in the above aims and objectives without discrimination.

At the moment we are only at the stage of pursuing charitable status but for further information phone 0141 4236249 or 0131 4403042.

Also see our web site temporarily on www.share.force9.co.uk
[Subsequently superseded by <http://www.sppn.org.uk/>]

Vicki McKenna,
Agnes Walker,
Billy McCreery.



A Good Enough Parent by Vicki McKenna.

Last summer I dropped my husband and our teenage daughter off at the harbour of Fionaphort on the Scottish island of Mull on their way over to the neighbouring isle of Iona. As I drove off without them there was a moment when I thought wistfully that I too would like to be clambering aboard the boat on my way to a days hillwalking on that historic island. The last time we were here on holiday nine years ago, I walked along with Steve, Katie and our other three daughters from the landing stage to the site of the Abbey with ease. I remember the wonderful sense of peace that radiated from the place and how much I enjoyed walking around it, absorbing the atmosphere. Today my health has changed and my ability to walk is now very limited.

Iona is an island that is car free and this helps to maintain its atmosphere of peace and tranquillity but my car is a substitute for my legs and without it I really cannot travel far. So it was that I left my family to a days hiking whilst I drove off to find a quiet spot to reflect and write this article. As I wrote I looked out over the bright gorse covered hills and the grey blue sea that separates Mull from Iona and thought back on the changes that have taken place over the last few years. These changes have forced me to dramatically alter my lifestyle. From being a frantically busy parent seeing to the needs of our four children I have had to slow down and develop the quieter, more reflective side of my personality. Not an easy task for one who likes to make more haste and more speed!

As a baby I contracted poliomyelitis and was lucky to be left relatively unscathed. With a partially paralysed right leg I got off seemingly lightly in contrast to many others. For the next thirty eight years I packed in a lot of living and although I wear a calliper and walk with a limp I never felt at a disadvantage in an "able-bodied" world. In all honesty I could not have described myself in the past as "disabled". As a child I found I could climb trees and ride my bike by letting my "good" leg do most of the work! I discovered that in water I was faster than the next person and so took to swimming like the proverbial fish. At school I could not join in gym classes or athletics but never had a particular yearning to walk the beam or run a race.

I never felt alienated or different through my childhood in spite of my apparent disability and can see in retrospect that having polio helped to become tougher and stronger, more adaptable than I might have been otherwise. At eighteen I left home and went to university and by the age of twenty two I had gained, alongside a degree, a husband and a baby. Over the years another husband(!) and three more children followed and bringing up my daughters has been the greatest pleasure of my life. Although the process was frequently exhausting it gave me much to laugh about and I have many happy memories of time spent with the children, playing with them, taking them swimming, enjoying their childhood alongside them.

Ten years ago, when my daughters were aged between four and fifteen years, my health began to deteriorate. At first I denied the increasing exhaustion that I was feeling and carried on as before

with a busy working and home life. Then the leg affected by polio began to give me problems and slowly but surely I started to feel disabled for the first time in my life. I became unable to walk any distance as my arthrodesed polio ankle locked causing a severe amount of pain. I found I could no longer walk my two younger girls to school, to the park or shops for if they ran ahead of me I could no longer catch up with them. In retrospect I realise this phase was a passage from being relatively able bodied to being disabled. From being able to hop on and off buses and walk all over the city I came to be unable to walk further than a few yards at a time. This was manageable in the house but going out and about was very frustrating - especially for one used to doing everything in a hurry! I came to rely increasingly on the car and without it would have been virtually housebound. Now, eight years on I realise that I, like many others afflicted by polio, am experiencing what has come to be known as post-polio syndrome. As readers will know, these symptoms include fatigue, muscle pain and weakness both in the limb affected by polio and often in the other limbs. For me PPS was and is, not only scary but also extremely frustrating.

Over the years I have come to terms with the increase in my disability but to begin with it was hard as a parent to cope. I often felt overwhelmed by my responsibilities until it gradually dawned on me that I needed to attend to my needs and fears instead of ignoring them hoping they would go away. I began to realise that I needed to learn to respect my limits. Common sense should have dictated that but I have always been one to push on ahead seeing life as a challenge. Slowly I came to see that I needed to cut back both at work and at play. I started to work two days a week instead of five and thankfully my husband earned enough to enable me to do this. Gradually I developed strategies to help me cope better with domestic chores, shopping etc. but most importantly I learnt to let go of the feeling that I had to take care of my kids twenty-four hour a day.

Slowly I began to trust that I did not have to be the prime carer and that my older girls would help out with the younger ones as would friends and family, I only needed to ask. None of this was easy - I often felt inadequate and wanted a swift return to the capable productive person I had been. My Buddhist philosophy helped me to cope with these lows as it teaches that we suffer because we cling onto the past. As I let go of the "old" me I felt much grief and sorrow but knew that it was necessary to do this and so move forward.

Over the past few years I have come to see that there are, for the children, many positive aspects to having a parent who is less able-bodied. My disability has helped them to become more independent. They have learned that it is often quicker to go and fetch something themselves than try and get me to do it! They have acquired skills of cooking and housekeeping that will stand them in good stead when they are older. They have also learned to ask others for help instead of relying solely on mum. Their father is thus given an important place in their lives which he otherwise might not have had in a family with such a bossy mother!

Our children have also learned through my "imperfections" that none of us is perfect and that life need not be about aspiring towards excellence in all things but can perhaps be about making the most of what you have. We all have different skills and talents and for some that may be reflected in a physically fit body whereas others may find that a "flawed" body enables them to pursue more introspective pastimes - it is fine to sit and stare into space! Hopefully this means that as my children go through life they will now not only realise their strengths but also accept their limitations.

Limitations can be seen as opportunities to learn how to more fully appreciate life. Being disabled has helped me to appreciate the importance of rest and relaxation. I no longer see "putting my feet up" as a weakness but as an essential part of a fulfilling day. This is a lesson that I hope I have been able to pass on to my kids and judging by the way they seem generally not to push themselves too hard I think have communicated this concept successfully to them!

Knowing our limitations does not mean that we shirk the challenges life brings. Post-polio has been a challenging experience and hopefully as the children have seen my struggles with this particular journey they will have learned how we all need to face squarely up to our difficulties - it is no use

hoping they will all go away! Thus we learn how to take responsibility for ourselves and have a sense of achievement in overcoming obstacles.

One who has faced up to his challenges - which are far greater than mine - is the unfortunate actor Christopher Reeves of "Superman" fame. I recently read how he has learnt to spend more time since his terrible riding accident being with and listening to his children. The stiller I have had to become the more I understand what he means. I too have found that I am more able to listen (hard though it is to concentrate!) and am certainly more able to be there physically for our children than I was when I was bustling about running between work, committee meetings and home! This does not mean I am always "on call" but the kids know that if they need me I am there for them. The eighties brought us that awful expression "quality time" and many working parents sadly are only able to spend this limited kind of time with their offspring - I was one of those parents. Research has shown that children thrive more when their parents are around more - not necessarily hanging on their every word, but just being there.

Children can learn from being around disability to be less selfish and more compassionate. Overall I think the experience of having a mother with a disability has helped my kids to become more caring and tolerant human beings. They have also learned the importance of being healthily selfish and when their caring and empathy run out they soon let me know! My daughters have seen how, often, I need to put my own needs first and this gives them permission to "do their own thing".

I obviously would not choose to have been "physically challenged" but as this is the hand I have been dealt then I have encouraged myself and my daughters to see the benefits in the situation. Because of my increased disability I have had to let go of the idea of aspiring to be a perfect parent and have come to appreciate being a "good enough" parent I do what I can and realise that as long as my girls know that they are loved and listened to then all is well. I may no longer be able to earn the money to buy them everything their heart desires and I cannot take them hiking on Iona but I now realise clearly that these things are not important. Helping my daughters to see that crisis is an opportunity to learn to grow into caring, tolerant, responsible adults has been the gift of my disability and, hopefully if they choose one day to become parents they will, by then, know the importance of being "good enough".

Vicki McKenna <vicki@share.force9.co.uk>



[Lincolnshire Post-Polio Library - Book Catalogue - Vicki McKenna BA. Lic Ac.](#)



Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

Title: [Stimulation frequency-dependent neuromuscular junction transmission defects in patients with prior poliomyelitis](#)



Author(s): Daria A. Trojan, Daniel Gendron and Neil R. Cashman

Original Publication: Journal of the Neurological Sciences, 118 (1993) 150-157.

Abstract/Extract: Generalized fatigue and muscle fatiguability are major symptoms of post-poliomyelitis syndrome (PPS), and may be due to neuromuscular junction transmission defects, as suggested by increased jitter on single fiber electromyography (SFEMG). To determine the etiology of this defect, we studied jitter at low (1, 5 Hz) and high (10, 15, 20 Hz) frequency stimulation with stimulation SFEMG in 17 post-polio patients with muscle fatiguability, and in 9 normal controls. In 5 of 17 PPS patients and in 1 of 9 controls, jitter was significantly higher (unpaired *t*-test, $P < 0.05$) at high frequency stimulation (HFS). In the remaining PPS patients and controls there was no significant

difference in jitter at high and low stimulation frequencies. PPS patients with increased jitter at HFS had a significantly longer time interval since acute polio (mean 48.5 years) than PPS patients without increased jitter at HFS (mean 40 years; $P < 0.05$), but were not distinguished by other historical or clinical criteria. We conclude that the neuromuscular junction defect in post-polio patients is similar to that observed in amyotrophic lateral sclerosis, and is probably due to ineffective conduction along immature nerve sprouts and exhaustion of acetylcholine stores. The appearance of an increase in jitter with HFS in post-polio patients may be dependent upon time after acute polio.

Title: [Airway Secretion Clearance by Mechanical Exsufflation for Post-Poliomyelitis Ventilator-Assisted Individuals](#)



Author(s): John R. Bach, MD, William H. Smith, Jennifer Michaels, MD, Lou Saporito, BA, Augusta S. Alba, MD, Rajeev Dayal, BS, Jeffrey Pan, BS.
Original Publication: Arch Phys Med Rehabil Vol 74:170-177, February 1993.

Abstract/Extract: Pulmonary complications from impaired airway secretion clearance mechanisms are major causes of morbidity and mortality for post-poliomyelitis individuals. The purpose of this study was to review the long-term use of manually assisted coughing and mechanical insufflation-exsufflation (MI-E) by post-poliomyelitis ventilator-assisted individuals (PVAIs) and to compare the peak cough expiratory flows (PCEF) created during unassisted and assisted coughing. Twenty-four PVAIs who have used noninvasive methods of ventilatory support for an average of 27 years, relied on methods of manually assisted coughing and/or MI-E without complications during intercurrent respiratory tract infections (RTIs). Nine of the 24 individuals were studied for PCEF. They had a mean forced vital capacity (FVC) of 0.54 ± 0.47 L and a mean maximum insufflation capacity achieved by air stacking of ventilator insufflations and glossopharyngeal breathing of 1.7L. The PCEF were as follows: unassisted, 1.78 ± 1.16 L/sec; following a maximum assisted insufflation, 3.75 ± 0.73 L/sec; with manual assistance by abdominal compression following a maximum assisted insufflation, 4.64 ± 1.42 L/sec; and with MI-E, 6.97 ± 0.89 L/sec. We conclude that manually assisted coughing and MI-E are effective and safe methods of airway secretion clearance for PVAIs with impaired expiratory muscle function who would otherwise be managed by endotracheal suctioning. Severely decreased maximum insufflation capacity but not vital capacity indicate need for a tracheostomy.

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Title: [Polio Biology III - What About If We Need The Virus Later?](#)



Author(s): Eddie Bollenbach.

Original Publication: Lincolnshire Post-Polio Library.

Abstract/Extract: Viruses are tricky creatures. We don't understand everything about them. Until recently we didn't even know how polio got inside the cells it infects. But we are learning new things all the time. Polio virus is one of the most cultured (grown) viruses for laboratory study. And yet, there are aspects of its life cycle which remain puzzling. For example, how are the virus's protein subunits assembled after they are produced, inside cells, during infection? Or, what is the effect of a mutation (change) in one of the protein subunits that assemble to produce the case inside which the genes of the virus reside?

Title: [Polio Biology IV - Polio And Limiting Variables](#)



Author(s): Eddie Bollenbach.

Original Publication: Lincolnshire Post-Polio Library.

Abstract/Extract: In the natural sciences the topic of "limiting reagents" presents a challenge to undergraduate college students. A typical problem involving "limiting reagents" goes something like this: suppose you want to produce the chemical silver iodide. You make the following two elements react: silver and iodine. If you mix 1 gram of silver and 1 gram of iodine together, and they react, which one will run out first? To find this answer calculations must be made by a student with some knowledge of introductory college chemistry. One of the two ingredients will be used up. This will stop the reaction. Some excess amount of the other will remain after the reaction has stopped. The reagent (silver or iodine) that is used up first limits the extent of the reaction because it is gone. Without it there can be no more silver iodide produced.

Title: [Dr. Henry writes about Michael's Tune](#)



Author(s): Henry Holland MD.

Original Publication: Lincolnshire Post-Polio Library May 1999.

Abstract/Extract: I have commented in previous articles how the event of polio in history has entered my life when I least expected it. Last October 30 (1998), the Rochester Cathedral Choir from Rochester England performed a concert at my church. An information sheet was provided regarding the various pieces performed and the composers. I scanned this information and noticed under the biographical sketch for Herbert Howells the following: "He was deeply affected by two events: hearing (with his friend, the composer Ivor Gurney) the first performance of Vaughan Williams' "Fantasia on a Theme of Thomas Talis" in Gloucester Cathedral; and the death from polio, at the age of nine, of his son, Michael (after whom he named his tune for the hymn "All My Hope On God Is Founded")." The death of his son from polio jumped off the page at me. I began a little research into this event in the life of Herbert Howells (1892-1983).



Security Blanket

by Judy Sander, California.

It was not a great treasure to anyone else in the world, but this piece of pink fabric printed with ballet slippers and balloons, was my "Safety Blanket". It had a pink satin edging that was cool and smooth to touch. My mother called it my security blanket. It had been mine since I was a baby and it was frayed, worn with use and love.

When I was six, I became desperately ill. In the beginning my parents thought that my complaints of pain and weakness in my legs and neck were due to over-exercise. It was early November in Colorado, and we had received a beautiful snow. My parents had purchased my first sled for my birthday and had decided to give it to me before my birthday, due to the early snow. I had sled down the creek bank over and over, all afternoon, on this shiny red and wooden sled. Then my parents realized that I had a fever and I soon started vomiting. They surmised that it probably was the flu. I became sicker by the hour so they took me to a rural hospital, hanging on to my "Safety Blanket".

The doctor on duty decided that I had appendicitis. Then with a fever of 106 degrees, my appendixes were removed. As the days went by, my fever fluctuated from 103-106 degrees, and I became weak and listless. Nothing seemed to help.

After ten days, the doctor was determined to get me out of bed to see if I could walk. I screamed in

pain. When they placed me on the floor my legs collapsed and I fell to the floor unable to get up or move. The doctor in this rural town finally ordered a spinal tap and the dreaded poliovirus was found.

My parents were devastated. I was then transported two hundred miles away to Children's Hospital, still embracing my "Safety Blanket". I do not remember the entire trip as I was in and out of a coma, but I do remember how much everything hurt, and seeing my Dad and Mom cry.

At Children's Hospital, I was confined to an isolation ward of thirty-five other "Polio's", as we were called. The ward was nothing but bed after bed of crying, hurting children, from babies to teens. I clung to my "Safety Blanket" for security.

My parents were allowed to visit me only briefly during the days and not at all at nights. They would appear as ghostly strangers to me behind white gowns and protective masks, which were required. Then they would disappear for what seemed like days to a little six-year-old girl. This continued for months, as my fever was relentless. My right side was completely paralyzed and it was difficult to swallow or breathe. I hid my head in my blanket and dreamt of dancing in ballet slippers and chasing balloons in the air.

I could see rows of iron lungs across the hall through windows in our ward. Children lay in them like rag dolls, moving their heads occasionally. I cried softly in my "Safety Blanket" day after day, and night after night. In my six-year-old mind I believed that if I was not good, if the nurses heard me cry I would be placed in one of those metal tubes for punishment. Locked in for safekeeping.

One night a little girl named Suzy in a bed next to me was crying and calling for her Mommy and Daddy. A nurse came in and told her that if she did not quiet down, she would be taken away to a room by herself. She was only three and she continued to cry for her parents. Soon the nurse returned and pushed her crib toward the end of our ward into a storage closet. Then the door was closed until morning. We could still hear her cry. Little Suzy spent many nights after that in the dark closet. I cried for Suzy. I knew that my "Safety Blanket" had softened my cries and had protected me from the storage closet and the metal tubes.

After ten months my fever dropped and I was to be released to my parents. Before I could go home, they had to be trained on my therapy treatment. They learned how to stretch the atrophy muscles and how to place the hot wet wool packs on my legs and arms, every three hours.

Finally the day came for me to leave the hospital. I clung to my "Safety Blanket" as I waited. Soon I saw my parents walking down the long hall to my ward. A group of doctors then began talking to them and pointing at me. I was terrified that they had changed their minds and I would have to stay.

A stern nurse came down through the ward, picked me up, and slammed me into a large wheelchair. My blanket dropped to the floor. I reached for it with my left hand; she pushed my hand away. I cried, "Wait, need my "Safety Blanket"." "No", she said, "It will be burned tonight. It is dirty and full of germs." I could only cry. I weighed twenty-six pounds and was too weak and fragile to complain. As she rolled me towards my parents, I turned and saw my beautiful pink blanket one last time. A little girl crying, a little girl afraid, and she no longer has her "Safety Blanket".

Written by Judy Sander,

La Jolla, CA - JSan333@aol.com

Published in the May issue of "Natural Health"



Barnsley Shopmobility.

Use of electric and manual wheelchairs and scooters is free but they do rely heavily on donations. A fleet of over 20 powered scooters of varying types, three wheel and four, powerchairs and types specifically for users who have suffered strokes and have limited arm movement gives the user a

wide choice. User propelled and escort propelled wheelchairs are available both for daily and long term loan. Holiday hire of wheelchairs is also available. The scheme is open to all people in the South Yorkshire area but as with most Shopmobility schemes any person can use our facilities regardless of where they live. Completion of registration forms and the provision of two passport photos for I.D. cards is all that is required. All users are given a thorough training prior to being allowed to take a scooter into Barnsley's lively markets and malls. Earliest loan time being 9.30 to allow for checks to be made on the fleet.

In addition to the above we are developing a Disability Information Centre where you can pick up leaflets on Social Services, appliances for the disabled, advice on buying new or second hand scooters etc. A database of holidays information catering for the disabled is added virtually every week as people return from holiday and give their opinion about their holiday spot. We have recently gone on line and our WebSite will be available shortly. A comfortable seating area is available in the shop and is well used by our users and people using the Dial a Ride facility for that all important natter prior to going home.

Opening Times are

Monday to Friday 9.00 - 4.30

Saturday 9.00 - 3.30

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Alan Lever - alever9313@aol.com



Equipment for the Less Able

About a month ago I was given a perching shower stool by Social Services. The seat on this is padded and light grey plastic. The first time I used this I slid straight off. I reported this to Social Services and the Company. Social Services have written to say they have informed all their departments. The Company sent me their newest stool but this is also slippery with just water. They are taking the matter up as urgent. They are asking that people do complain if they have problems with equipment / does not enable them to do what it says or what they need. A Polio Survivor from America suggested that I ask the company if they would provide a home demonstration where I would supply the water but they had to supply the butt (bottom). The Technical Services Manager laughed loudly and said he had just the right person for the job.

It has come to light that many of you have been given items of equipment by Social Services and that much of this is of no help. We appreciate that it has been a hard enough struggle to get them to visit. Then comes the struggle to start using the aids which mean you have accepted that you are not as able as you were. When you find they are not suitable it is too stressful to do anything about it. Please let us know if this has happened in your case.

Professor WJW Sharrard - a world renowned polio professor now retired - told me just over a year ago that if it had not been for the wonderful recovery system of axonal sprouting that took over the orphaned muscle fibres that we would have all remained at our worst. Maybe we should think about the opportunity that this gave us to learn how to adapt our lives, because adapt we did. If we could not do it one way, then we tried another, rarely giving up. This I am sure is what made us all so strong willed and determined to succeed. We are all different but we have so many qualities that are the same.

Now we are having new problems we continue to adapt, often we don't see it ourselves. All around us we see adverts for energy conservation, recycling products, look after the environment. Think of using aids and assistive devices and altering your home and work places as pure energy saving and for everyone who lives or works with you.

Hilary Hallam.



LINCOLNSHIRE POST-POLIO NETWORK - AGM & SPEAKERS

SATURDAY 4TH SEPTEMBER 1999 IN LINCOLN.
VENUE AND COST TO BE ADVISED - Sponsorship being sought.

PROPOSED FORMAT.

FRIDAY 3rd - For those arriving on Friday.	Informal Get-together.
SATURDAY 4th.	9.00 - 2.00 EQUIPMENT STANDS OPEN.
	9.30 AGM - members only.
	10.30 Coffee Break.
	11.00 Speaker - Marcia Falconer PhD.
	12.30 Buffet Lunch.
	2.00 2 Speakers.
	3.20 Tea break.
	3.40 Speaker.
	4.20 Question Time.
	5.00 End.
	7.00 - 11.00 Informal Evening Get Together.
SUNDAY 5th - If enough people are interested.	10.30 Conducted tour of Lincoln - visit Cathedral.

ROOM PRICES - These are maximum. We will get discount on numbers.

70 HAVE BEEN RESERVED for Friday 3rd, Saturday 4th and Sunday 5th September 1999.
WE NEED TO CONFIRM preferably by 11th July 1999.

Main hotel will be the Holiday Inn Express on A46 - Damons 1/4 mile away overspill or your choice.

Holiday Inn Express - Rooms £45 inc. continental breakfast. - Extra person supplement £10.00
Damons - Room only £36.50

Damons with breakfast in American restaurant - Room and Breakfast for (1) £41.00 for (2) £45.50

AGM BOOKING FORM



Lincoln ME Self Help Group invite you to attend a

Talk on the Role of the Thyroid - By Dr Skinner.

Saturday August 21st 1999

1.30 to 4.30 at Ruston Marconi Sport Club on the A1434 - Newark Road.

Read **Tears Behind Closed Doors** by **Diana Holmes** Avon Books £7.95
Polio Survivor - who did not have ME but an underactive thyroid.



MEMBERSHIP FEES.

The LincsPPN have decided to change renewal dates to fit in with the issue of each newsletter.
This will cover all memberships since January 1999.
Renewal dates are now the 1st of February - April - June - August - October - December.



LINCOLNSHIRE POST-POLIO NETWORK
Registered Charity No. 1064177

Articles for publication by July 20th - Publication date August 5th 1999

MEMBERSHIP for this financial year is £10.00 - includes 6 Newsletters

Life Membership £100 - 20 x £5 per month

All Membership fees now payable by Standing Order

All donations will be gratefully received.

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

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