



THE LINC-PIN

Lincolnshire's Post-Polio Informative Newsletter No. 4 - March 1997

When did you first hear about PPS - 1980, 1990, 1995, 1997?

Dr. Henry Holland, Richmond, Virginia, USA writes.....

Even though I am a physician and a clinical faculty member of the School of Medicine of the Medical College of Virginia, I did not learn about PPS until 1991. When I began experiencing the first significant signs and symptoms of PPS in early 1991, I went to three different doctors who did every test known to medical science and they found nothing significant.....

.... Read the full article and Bruce Cottingham's on page 3.

Where are the 'My Doctor told me'? - In this Country for our members it has been..

Read an article in *The Independent* - *The Times* - *Daily Mail* - *Lincolnshire Echo* - *You Magazine* in *The Mail on Sunday* - *SAGA Magazine* - *Rural Links*. Heard it on the *Radio*, 'Does He Take Sugar?' - on *Radio Lincolnshire* in 1996, on *Radio Lincolnshire's Breakfast Show with Chris Jones* in 1997. Over heard the remark 'Old Polio' at the *Rotary Disabled Games* in Lincoln in May 1995. Surfing the *Internet* typed in 'Polio' for old times sake and found your Web Site.

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Hint. For those reading this newsletter online with their browser displaying graphics, every Lincoln Cathedral separator below, including the bars, hides a link back to the above list of contents.

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



Editorial

Spring is here, daffodils and tulips are flowering, leaves are appearing, many changes are taking place. The Lincolnshire Post-Polio Network is just the same. You will note that we have added the word Post to our name. 'Polio' is something you are vaccinated against with a lump of sugar. Adding the word Post- has already caused many people to look again and ask 'What is Post-Polio?' Likewise it was pointed out that our newsletter title is spelt incorrectly and we have agreed and changed it to Linc-PIN.

We have a new committee of seven. The role of Chairman is being shared by three of the Committee members as time and energy allow. Lyn Hobday, Yvonne Webb and Jean Tapper - see her article [The Humble Walking Stick](#). Vice Chairman and Web Administrator is Chris Salter - see his article [Letter from Kemow](#). John Fotherby has taken on the role of Treasurer. Hilary Hallam remains Secretary. Phil Bilton has taken on the role of doing the physical jobs that we can't manage. As new members are joining - from this County and around the Country - with many different qualifications - we hope to build on our level of expertise in different fields. If you have expertise that could help our cause, or would like to help - there are many little jobs to do - then please get in touch. It's not always what you know, but who you know? Do you know any top medical personnel, anyone famous who might help us? We need more money to continue our work, grants, sponsorship, donations. Every penny counts, can you help?

We are a self help group of Polio Survivors, not Doctors, providing an Information Service for Polio Survivors and the Medical Profession. We are collecting all the information on PPS that we can and making it available. Our Web Site on the Internet - details on back page - is the most cost effective way of providing this information, unfortunately this is only accessible to those with computers. We have a paper copy of this, which has already grown to two full A4 files in three months, plus lots more which can be viewed in Lincoln, ring us for details.

We publish our bimonthly newsletter to pass on some of the information. This newsletter is a few days late and it has been very difficult to decide what to put in and what to leave for next time. Much has arrived in the last few days, medical articles from Lane Fox, letters and emails from French and European PPS Support Groups. New members have been ringing wanting articles to take to Doctors they are seeing and the days seem to whiz by. If we have asked your permission to print and its not here then sorry but its still in the newsletter file for another time. Three OT students from Australia contacted us for information and when they told us about their project we asked them to write us an [article](#). They are only just learning about PPS, if you would like to pass on anything then write to us and we will email them. We have also included one page from the Catalogue on our Site to give you an idea of the articles. *[Postal version only]* Please do not hesitate

to contact us if you think we might have information that could be of help with your particular problems. If we do not have any relevant articles then we will do our best to find some. Feedback would be nice from those we send our Newsletters to for information.

A recent survey by the [The British Polio Fellowship](#) in London found that 73% of GP's had not heard of PPS and they now have [page 185 in the Guidelines](#) issued to GP's. The BPF now have an email address, british.polio@dial.pipex.com and the Lincolnshire Branch Chairman, Martin Joy, can be contacted on 01522 595401. Social meetings are second Monday of the Month at Ancaster Day Centre, Lincoln.

To those of you who are Medical Professionals, or in Government Departments and reading this then please can we assure you that we know PPS is by diagnosis of exclusion and we accept that we are getting older. What we do not accept is that we can 'age 25 years overnight'. We ask that the fact that we had Polio and initial considerable nerve damage to our bodies, regardless of how well we have recovered (a minimum of 75% of Polio Survivors have no easily visible signs of polio damage), be taken into consideration and that all the information that is available from around the World is brought into the equation when assessing, advising and treating us. We want to get the most out of the rest of our lives, and with your help can achieve this. Without your help and without the knowledge that PPS exists, many Polio Survivors will deteriorate at a much earlier age than is necessary and the financial implications of this are tremendous. A little money spent now could save a lot in the future. We need British Research, British Specialists, British Post-Polio Clinics, and British Medical Articles and we need them now please.



When did you first hear about PPS? - 1875, 1980, 1990, 1995, 1997?

Dr. Henry Holland, Richmond, Virginia, USA writes.....

Even though I am a physician and a clinical faculty member of the School of Medicine of the Medical College of Virginia, I did not learn about PPS until 1991. When I began experiencing the first significant signs and symptoms of PPS in early 1991, I went to three different doctors who did every test known to medical science and they found nothing significant. One day, my mother in law who attends a large church told me that there was a lady in her church who wore a brace from polio in childhood and that she was going to a support group for people who were having new problems with polio. I found out about the support group and its meeting time. I went to my first meeting in September '91 and learned more in that first meeting than I could ever have found through medical channels. My knowledge and participation in the support group quickly increased and for the last four years we have a busy POST POLIO CLINIC here in Richmond. The polio lists on the Internet have also been a most helpful source of information and I have passed on some of what I have learned here to my local support group. I have also successfully educated my four doctors, a primary care internal medicine doctor, a neurologist, a pulmonary specialist, and my physical medicine and rehabilitation doctor who did already know a lot about PPS.

Bruce Cottingham from Arkansas writes.....

I learned about PPS in 1986 in a newspaper article. Through [GINI](#) I learned that PPS had first been noted in the medical literature in the late 19th century! It is sad to note that in medicine, as in my own discipline, few read the classic literature. There seems to be an attitude that, "Those people couldn't possibly have known anything way back then". This squares neatly with what one physician asked me some years ago. "You say you had polio in 1951. How did they know that back then?" I informed him that the diagnosis was the result of spinal fluid samples and symptomology and that the physicians in 1951 had a good deal more familiarity with polio than those today. I also asked if he had ever heard of Hippocrates and his diagnostic techniques. I resent this sort of

patronizing behaviour and, with increasing age and irritability don't tolerate much any more. I am sorry that there is not more attention paid to the literature these days. There are some real gems in older works - or maybe I'm just prejudiced because I one of these "older works".

Say hello to the Lincolnshire "Yellow Bellies" for me - I have Cottingham penpals in Lincolnshire.

From Australia

The Australian Government have announced legislation that means parents who wish to participate in the Federally funded Family Allowance Scheme (parents get paid a pension per child), will have to fully immunise their children to receive the allowance. Also children will have to be fully immunised to be allowed to go to any Government funded school or kindergarten.

This is in response to the alarming news that immunisation rates in this country are less than the rates in most third world countries (we were down to about 27%). The Post Polio Association by the way has been telling them about the poor response to immunisation for years.



Politically Correct from Dan Miller in Washington State

In the 1950's they called me crippled.
In the 1960's I was handicapped.
In the 70's the term was disabled.
Then in the 80's I was physically challenged.
Now in the 90's I am mobility impaired.
I wonder what I will be next?



"Pressure, But She Never Knew" by Connie M Ingram

She's tiny for a two and a half year old, and she's in isolation, the hospital is unfamiliar and she is cold. She is placed on her stomach and brick shaped weights are on her back in hopes that the spine won't curve from the disease ravaging her little body. She now weighs nineteen pounds, the nurses put her back in diapers, they don't realize her age, but she can't move to use the bathroom anyhow. She is not allowed visitors with the exception of Sunday afternoons. What visitors? She is behind a locked door, for fear of spreading the disease, they can see her through a two way mirror, they can watch her dark curly mopped hair and see her new habit, one she never did before as she sucks violently on her little thumb, it's company to her now. She looks back and does not see them, she sees a tiny girl with a thumb in her mouth, and she lays very still. The Mother remarks to the Father and Grandmother, "look how still she is, look how good she is being, she doesn't cry and she doesn't fight her circumstance." The Grandmother says.....she's too sick to fight or cry, her body is trying to heal"..... There is pressure in the little girl's brain, the doctor explains to the frightened parents, there is pressure in her spine, she will not walk the rest of her life. Then suddenly the pressure shifts to the parents who wonder what will become of their child, what kind of life is in store for her and her future? They pray day after day, feeling like they are trapped in a vice of worry and fear.

On day 67, visiting day, they look through the glass and their child is sitting up, drinking a glass of juice. Her hands and arms are so little and her body is weak, but she is sitting up, and though pale, she looks better. The doctors tell them "she is better, but we will not know for some time if she can walk, if her brain will be normal, if she will even know who you are." He apologizes for the need to be so blunt, but they nod in understanding. The Grandmother and the Mother stifle their sobs. They can't bear to watch this, yet they know the little girl needs them.

The pressure shifts to the child, how much can she do and when? The next step is getting the child out of isolation and reunited with the parents. Will she even know them. She sees them come around the corner from her new room and new bed in the Children's hospital. There is something in her eyes, but not for the Mother, it is the Father that she first notices and the eyes change from vague to knowing. Then the Grandmother, almost an immediate response, again from the eyes. The Mother says in a quiet voice "Hi sweet girl, do you know who I am?" The child does, but now the eyes are angry. They almost say 'you left me here, why did you do that?'"

The physical therapy starts, one year after the sickness comes, the child can take little steps in her brace, she is used to her therapy, but she wants to do it her own way, she does not want to do it when they say, when she is ready she tries her own path.

The child is me, the little girl was me, I must now release the pressure of ignoring the inner child within, I want to embrace the child, love the child, and then finally let the child go. To look at old pictures is painful but a necessary resolve. This part is finally over.



Sole Solutions

Newsletter of the Orthopaedic Footwear Wearers Self-Help Group

write to Dr. Mark Edworthy , (A Polio Survivor)

Sole Solutions c/o First Call, 25 - 27 May Street, Derby. DE22 3UQ

or Fax 01332 200250



Letter from Kernow - by Chris Salter

Cornwall seems a long way from Lincolnshire. A few hundred or so years ago the distance would have been unimaginable to a good number of the population of both counties. In the intervening years there have been many revolutions in communications and almost daily the world becomes a smaller place. Perhaps the most recent revolution is the Internet. Unfortunately Media Hype, whether extolling or maligning the Internet, has tended to obscure its most important benefit. That being making it increasingly easier for individuals with a common interest to locate each other and then work together to their mutual benefit. In fact the very existence of the Internet is the result of such co-operation on a world-wide scale. The only frontiers on the Internet are those of language. If there is a negative aspect to this breaking down of barriers, it is a comment on human nature rather than on the Internet.

There is one more revolution to mention at this point, that of the World Wide Web (WWW). In the early '90s, Tim Berners-Lee was working for CERN, the European Particle Physics Laboratory in Geneva, Switzerland. He designed a system of organising and presenting information for the researchers. Good ideas travel pretty fast over the Internet. Tim's system became the foundation for the World Wide Web and has been developed and enhanced but the basic concept is unchanged. It uses the hypertext concept in that references within a document link directly to other documents. Imagine a library containing shelves of books, magazines, scientific papers, sound and video tapes etc. You pick say a magazine and begin to read a page. On that page there may be references to other items in the magazine. You touch one of the references and as if by magic the pages turn to the new page in question. You read further and come across another reference that interests you but it is a page in another magazine or perhaps a scientific paper elsewhere in the library. Touch that reference and the scientific paper appears in your hands. If you decide you don't want to read it after all you can easily go back to what you were reading before. In reality each document can be located anywhere in the world. When you select a reference within a document, the new document will be

retrieved from whichever of the hundreds of thousands of web sites in the world it resides on.

Lincolnshire Post-Polio Network's new web site represents only one part of our efforts in the provision of Post-Polio information. However, it does open up opportunities for us to reach a wider audience than we otherwise could within the constraints of our limited budget. Each day sees many new subscribers connecting to the Internet. Amongst them will be Polio Survivors. One of our priorities has been to make sure our site can be easily found. This has meant individually contacting all the major web site directories and notifying them of our site. We also have an interest in gaining the attention of Medical Professionals, particularly in the UK. We designed the layout of our site with this in mind. The [Health On the Net Foundation](#), a non-profit international organisation dedicated to realising the benefits of the Internet in the fields of medicine and healthcare, recognised this and have allowed us to display their [Code of Conduct](#) certification on our site. We are also in the process of contacting UK Medical web sites in order to persuade them to add a link to our site. Finally, we are joining forces with UK Medical and Healthcare Internet Associations amongst whose aims are encouraging all UK General Practitioner's to make use of the Internet.

I appear to have run out of time and space! The connection between Cornwall and Lincolnshire will have to wait until the next *Letter From Kernow*.

If you are printing this newsletter for others to read we would appreciate you attaching a copy of our

[Catalogue \[by content\] - For the Polio Survivor, Friends and Family](#)



PPS QUESTIONS AND ANSWERS, MARCH, 1995

by Drs Richard Bruno and Nancy Frick

Compiled by Tom Walter

From America Online computer information service PPS Bulletin Board

PLEASE NOTE: READ ME FIRST !

These general answers and our on-line discussion on 3/7/95 represent what is written in the medical literature on PPS, our newest research and how we treat patients at the Kessler Post-Polio Service. They are NOT intended as therapeutic recommendations for you personally nor as a substitute for your being evaluated by your own personal doctor and a doctor who knows about PPS.

Every polio survivor (PS) is different and prescribed treatments must take those differences into account.

Post-Polio Sequelae (PPS) is a diagnosis of exclusion, meaning a physician must evaluate you and determine that no other condition is causing your symptoms. You may have PPS alone, PPS and another problem or a condition not related to polio at all. There are no medical tests that can prove you have PPS.

Read these answers, read the journal articles listed with each, and understand them fully. Take them to your doctor or therapist and ask them to read and understand them fully. Do not apply therapeutic techniques described here (especially exercise) on your own.

We very much hope these answers serve an educational purpose and that you integrate them with your own experience, personal wisdom and doctors' recommendations so that you can thrive, not just survive, with PPS!

Best wishes, Drs. Richard Bruno and Nancy Frick

ABOUT PPS PREVENTION & PROGRESSION

There are no long-term studies of whether Polio Survivors (PS) who have no symptoms will develop PPS. Every time a study of PS is done, the percentage with new problems increases. The percentage was 22.4% in the first Mayo clinic study in 1982 and increased to 78% in a British polio hospital follow-up in 1987. At the NY Academy of Sciences Symposium on PPS April, 1994, the Mayo group and others thought that more than 90% of PS would develop some problems related to their polio.

Every PS is different. But, the rules that apply to every mortal apply to PS. Anyone who has too few overworked, damaged nerves compensating for muscle weakness for over 40 years is bound to have some problems. And, when you add PS super Type A lifestyles and the fact they work more hours of overtime than non-disabled people, something's got to give.

But, the good news is that the study cited below and our new follow-up study of all the patients we have treated show that if you listen to your body and stop doing the things that cause weakness, fatigue and pain, PPS often plateau and can even decrease (see below: Exercise & Activity). One example: 18 months after their evaluation with us, PS who completed therapy reported 22% LESS fatigue; however, PS who refused treatment or dropped out of therapy early had 21% MORE fatigue at 18 months.

References

Peach PE, Olejnik S *Effect of treatment and non-compliance on Post-Polio Sequelae*. ORTHOPEDICS, 1991, 14(11) : 1199.

ABOUT EXERCISE & ACTIVITY

Exercise has been the most hotly debated area in PPS. The studies cited below say three things:

1. Listen to your body! If you are doing things that cause fatigue, weakness or pain STOP DOING THEM!!! PS need to pace their activities, that is work and then rest about 2 times the amount they worked. Jim Agre showed that PS can do 240% more work if they PACE. You don't drive your car until it's out of gas; you shouldn't drive yourself to exhaustion, weakness or pain;
2. We only prescribe the non-fatiguing exercises devised by Rubin Feldman that have been shown not to hurt PS. But, these exercises are not given to all patients and are only prescribed after PS learn to pace and conserve energy! Patients are usually given gentle exercise after they get a new brace to keep muscle tone. The key word is NON-FATIGUING;
3. We have seen a small handful of PS who became deconditioned after surgery or illness. Pacing and resting doesn't mean sitting or sleeping all day and not moving. You should be doing what you need to do for yourself, and at your job, but in a paced, energy conserving, Type B fashion.

In our follow-up of all the patients we have treated, the three factors that were related to a significant decrease in fatigue were

1. completing the PPS therapy program;
2. doing absolutely nothing for 15 minutes twice a day;
3. using a wheelchair or scooter for distances.

References

Young GR. *Energy conservation, occupational therapy and the treatment of Post-Polio Sequelae*. ORTHOPEDICS, 1991, 14(11): 1233.

Feldman RM, Soskolne CL. *The use of non-fatiguing strengthening exercises in Post-Polio Syndrome*. In LS Halstead and DO Wiechers (Eds) *Research and Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains: March of Dimes Birth Defects Foundation, 1987.

Fillyaw MJ, et al. *The effects of long-term non-fatiguing resistance exercise in subjects with Post-Polio Syndrome*. ORTHOPEDICS, 1991, 14(11): 1253.

Agre JC and Rodriguez AA. *Neuromuscular function in polio survivors*. ORTHOPEDICS, 1991, 14(12): 1343.

ABOUT FEET & LEGS

PS are notorious for having cold and purple "polio feet," caused in part by the smooth muscle around the veins being partially paralysed by the original polio. Without muscle to control their size, veins fill with blood and cause your feet to appear purple. Your feet become cold because the heat in this pooled blood escapes into the air. Back in 1983, we found that PS's nerves and veins act as if it's 20 degrees colder than the air, making it hard for the nerves, muscles and connective tissues to work. PS lost 75% of their muscle strength when the room temperature dropped from 85 to 65 degrees Fahrenheit.

Cold is the #2 cause of muscle weakness in PS but is the easiest to treat. We suggest that our patients take a bath in the morning, dry off and put on Polypropylene socks or long johns while they are still warm. Polypropylene (trade name: Gortex, Thinsulate) is a silk-like plastic that holds heat in but allows sweating.

Also, engorged veins can cause swelling, especially when feet get hot in Summer or after a long bath. Jobst compression stockings sometimes help, as well as keeping your feet up a lot during the day. But, leg swelling must be evaluated by your doctor!

References

Bruno RL, Johnson JC, Berman WS. *Vasomotor abnormalities as Post-Polio Sequelae*. ORTHOPEDICS, 1985, 8 (7): 865-869.

ABOUT GETTING OTHER DISEASES

PS can get all the diseases everyone else gets. That's why your doctor has to exclude all other causes for your new symptoms before you settle on PPS. In our 1985 National Post-Polio Survey we discovered that PS were on average more Type A - pressured, time-conscious, overachieving, perfectionistic than any other group of Americans, including those who already had had heart attacks. However, PS were no more likely to have heart attacks or high blood pressure than anyone else.

We found that PS also had 3 to 6 times more trouble with gut problems diarrhoea, constipation, ulcer and colitis - as compared to the general population. PS also have more headaches (but not migraines) and muscle pain (often called Fibromyalgia). And, there is also one study that suggests that more PS have hypothyroidism.

Also, 66% of PS report frequent anxiety and 31% of those who see us for evaluation have a Major Depressive Episode - that's 6 times the rate for the general population. Both old and new types of antidepressants are effective if prescribed for PS. Again, your doctor needs to evaluate any and all new Symptoms!

References

Bruno RL, Frick NM. *Stress and "Type A" behavior as precipitants of Post-Polio Sequelae: The Felician/Columbia Survey*. In LS Halstead and DO Wiechers (Eds.): *Research & Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains: March of Dimes Research Foundation, 1987.

Bruno RL, Frick NM. *The psychology of polio as prelude to Post-Polio Sequelae: Behavior modification and psychotherapy*. ORTHOPEDICS, 1991, 14(11) : 1185-1193.

Halstead LS. *Assessment and differential diagnosis for Post-Polio Syndrome*. ORTHOPEDICS, 1991, 14(11): 1209.

ABOUT DRUGS FOR PPS

A number of drug studies were presented at the NY Academy of Sciences Symposium on PPS in April, 1994. Prednisone (a steroid) and Amantidine were tried without success to treat PPS weakness and fatigue. Growth hormone was not found to be helpful to treat new muscle weakness in one paper, but a multi-center study is beginning.

Neal Cashman again reported on the use of Mestinon to treat muscle fatigue. He found that a portion of PS whose motor nerves don't communicate well with muscles report a decrease in muscle fatigue while using Mestinon. However, the effect of Mestinon seems to wear off over time.

We presented our pilot study of a drug to treat PPS brain fatigue. In the 10% of our patients whose fatigue did not improve following the standard treatment for PPS (see above: [Exercise and Activity](#)), 60% reported less morning fatigue and less trouble staying awake on drug versus placebo. However, even if drugs are found that help, PS must still listen to their bodies and live their lives in a paced, energy conserving, Type B fashion. There is no magic pill.

References

Bruno RL, Frick NM, Lewis T, Creange SJ. *The physiology of post-polio fatigue: A model for post-viral fatigue syndromes and a brain fatigue generator*. CFIDS Chronicle, 1994, 7(4): 36-42.

ABOUT MUSCLE TWITCHING

In the 1985 National PPS Survey, we found that 63% of all PS report that their muscles twitch and jump as they fall asleep; 33% reported that their sleep was disturbed by twitching. This sleep disorder, called Generalized Random Myoclonus, is often only noticed by the PS's bed partner. In doing sleep studies, we found that a small dose of Ativan before bed usually stops the movements and restores sleep.

Other sleep disorders, such as sleep apnea, are not uncommon in PS. If you snore, wake not rested, with a headache or are depressed, you should talk to your doctor about a sleep study.

Many PS report another kind of muscle movement during the day: fasciculations. These are muscle twitches you can see or feel. Fasciculations are found in many non-disabled people. Usually, they are a sign, as is muscle pain, of muscle overuse. Again, talk to your doctor about any twitching.

References

Bruno RL, Frick NM. *Stress and "Type A" behavior as precipitants of Post-Polio Sequelae: The Felician/Columbia Survey*. In LS Halstead and DO Wiechers (Eds.): *Research & Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains: March of Dimes Research Foundation, 1987.

Bruno RL, Frick NM, Creange SJ. *Nocturnal generalized myoclonus as a post-polio sequelae*. Archives of Physical Medicine and Rehabilitation, 1995, (in press).

Bach JR and Alba AA. *Pulmonary dysfunction and sleep disordered breathing as Post-Polio*



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



THE HUMBLE WALKING STICK

What would I do without my walking stick? I don't use it for the purpose intended but living as I do in a wheelchair I find it invaluable. I use it to open and close the curtains and turn the television on and off.

Getting things from the top shelf of cupboards can be interesting, making sure they are not too heavy because they mostly land on your head, and also getting jugs and beakers from on high, you put the stick through the handle and catch them on the way down. Getting basins and bowls as well, make sure they are unbreakable then you can pull them down with the stick and catch them before they reach the floor, its great fun.

When I first heard about broomstick crocheting I thought I will try it on the walking stick and if it works buy a broomstick (no I didn't get a black pointy hat at the same time).

Its handy in the bedroom for pulling the duvet straight, getting anything from under the bed, especially mice the cats brought in, one end of stick pulls the mouse out from under the bed and the other end clobbers the cat...

In the garden I hook the plants towards me, then pull them out or chop them off, the same for pruning small trees and bushes.

A few years ago, before non drip paint and when pantrys were in fashion, I decided the pantry needed a coat of paint.... so binding the brush onto the end of the walking stick I started the job. It was not a good idea!! I ended up with white hair and a white floor and the pantry looking the same as before .. in need of paint... that I am afraid was the end of my decorating with a walking stick. There are so many other uses, I'll start keeping note of them and write again..... I really couldn't manage without my magic walking stick...

Jean Tapper aged 21 and never been kissed, kicked or run over....



Letter from Carol...

Hilary, I am really glad that I found both the Leicestershire Polio Network and yourselves. I think Networking is a brilliant idea and we can all put in information because we need to be part of a PPS Family, one that pulls together and shares what we have for the benefit of others. The [Gastrointestinal article](#) that you sent me was brilliant. I look forward to hearing the response to this article from my GP and the Consultants (I have sent them copies) that I am seeing in the next couple of months, as it gives answers to questions that have perplexed us for some years.



ARTHRITIS CARE in LINCOLNSHIRE

Invite you to a Thanksgiving Service to celebrate 50 years of Caring in Lincoln Cathedral on Sunday April 27th 1997 at 3.00 p.m. Why not join them?



JOKES PAGE - From Polio Survivors in the USA From Ruthie, Margaret and Marilynn

Illiterate? Write today for free information pack.	Have several very old dresses from grandmother in beautiful condition.
Auto Repair Service. Free pick-up and delivery. Try us once, you'll never go anywhere again.	Tired of cleaning yourself. Let me do it.
Dog for sale: eats anything and is fond of children.	Toaster: A gift that every member of the family appreciates. Automatically burns toast.
Mixing bowl set designed to please a cook with round bottom for efficient beating.	Wanted. Man to take care of cow that does not smoke or drink.
For sale: antique desk suitable for lady with thick legs and large drawers.	Our bikinis are exciting. They are simply the tops.

We do not tear your clothing with machinery. We do it carefully by hand.

The Gogh Family

Even the most ardent aficionados might not know that Vincent Van Gogh had a really large family. Some of his lesser known relatives were:-

Grandfather who moved to Yugoslavia	U. Gogh
Niece who wore a miniskirt and liked to dance	Go Gogh
His obnoxious brother	Please Gogh
Dizzy Sister	Verti Gogh
Brother who ate prunes	Gotta Gogh
Cousin who moved to Illinois	Chica Gogh
Uncle, the magician	Wherediddy Gogh
Cousin who lived in Mexico	Amee Gogh
Nephew who drove a stagecoach	Wells Far Gogh
Aunt who loved ballroom dancing	Tan Gogh
Uncle the ornithologist	Flamin Gogh
Cousin the astrologer	Vir Gogh
Nephew, the Freudian psychoanalyst	E. Gogh

Answers to Scripture questions.....

Adam and Eve were created from an Apple Tree.
Noah's wife was called Joan of Ark.

The Jews had trouble throughout their history with the unsympathetic Genitals.
Unleavened bread is bread made without ingredients.

Moses went to the top of Mount Cyanide to get the 10 Commandments.
The seventh commandment is: Thou shalt not admit adultery.
Solomon had 300 wives and 700 porcupines.

Jesus was born because Mary had an immaculate contraption.
The people who followed Jesus were called the 12 decibels.
The epistles were the wives of the apostles.

Salome danced in 7 veils in front of King Harrod's.
Paul preached holy acrimony, which is another form of marriage.
A Christian should only have one wife. This is called monotony.



Excerpts from Changing Your Life By Conserving Energy
by Mavis J. Matheson MD. A fellow Polio Survivor
Revised May 1995

Taken from the Mount Diablo Post Polio Network Newsletter May 1996 article forwarded by Julie Film.

Polio survivors need to learn to conserve energy if they are to control their symptoms of pain, weakness and fatigue. It takes effort and a change in attitude to learn to use energy conservation to our greatest advantage. Using our energy well can allow us to do more and do it better. This article suggests principles of energy conservation and techniques for making the necessary changes in our lives. Many of us don't have the strength and energy that we used to have so it's time we started taking better care of ourselves.

Change is not always easy. In fact many polio survivors find change very frightening. Change requires examining the attitudes and beliefs that keep us from feeling well. We can change the quality of our lives by changing the way we look at our circumstances. ...The way we see ourselves may interfere with our ability to change. One approach to the whole issue of activity is to be kind, positive, and gentle with ourselves. The person behind the pain and fatigue, the real you, is a capable, worthy individual and a beautiful human being. It's time to start treating ourselves like the wonderful beings we are. It's time to start taking care of ourselves as if we were precious possessions.

Only you can decide to be sore and tired or relaxed and comfortable. You must decide if you want your weakness and fatigue to progress. You are responsible for what you do. You have no control over anyone other than yourself, and only when you are clear about who is responsible for your activity will you have the power to master it. You have the capacity to recognize fatigue and overuse. You must decide how much you will or will not do.

Your mate, your friends, your boss, your doctor, your physiotherapist, and your occupational therapist can only advise you. ...only you can decide what works for you.

Four Principles of Conserving Energy

The main principles of Conserving Energy include:

- doing what you most want to do
 - planning activities for times when you have the most energy
 - learning what your maximum work is and respecting the signs of fatigue you experience
 - stopping before you become exhausted.
1. Before you begin any activity you should think about whether you really want to do it at all. Don't ask yourself what you should do: ask yourself what you want to do. It is important to be flexible. Let others in the house or office help you with the jobs you find tough. Delegate tasks whenever, possible.
 2. Plan your activities for when you have the most energy. Most people don't think about doing things if they are tired. Don't waste energy by trying to do more than your body can comfortably do. If you are tired by noon, plan activities for the morning. We take a long time to recover if we allow ourselves to become exhausted.
 3. Learn what you can do without pushing yourself and respect the signs of fatigue (including muscle soreness, tiredness, muscle weakness, change in quality of movement, grimacing, etc.).
 4. Work simplification is an important tool to use in reaching our daily and long term goals in life. Work at a comfortable easy pace and avoid tension. A moderate work pace uses the least amount of energy and you will make fewer mistakes. Alternate heavy with light work each

day and throughout the week. Break up heavy jobs over several days. Sit for as many jobs as possible. Allow time for yourself.

Full article available.



Doctor, Wheel Thyself **By Richard Louis Bruno**

It was a cold and stormy night after a long and stormy day. I had just spent three hours with a newly admitted paraplegic ultimately convincing her not to sign out of the hospital and throw herself under the nearest bus.

At 8 p.m., I rolled into the elevator and rode to the lobby with a visitor. She was grey and grandmotherly, somewhere in her early 70s. She looked aghast when she saw me bundled against the cold, clearly heading for the icy outdoors.

"You're not leaving the hospital," she asked. "Yes ma'am, " I muttered, desperate not to have a conversation. "Who in their right mind would give you a pass on a night like this," she said, her voice rising an octave. "I'm going home," I answered, beginning to understand where she was coming from. She smiled immediately: "That's just wonderful. How long have you been hospitalized?" "I'm not a patient," I said, "I work here." "Oh! " she beamed, "isn't it wonderful that the hospital gives its former patients jobs!"

Clinical psychologist Richard Louis Bruno, PhD., is Director of the Post-Polio Rehabilitation and Research Service at Kessler Institute for Rehabilitation, Saddle Brook, New Jersey, USA. Chairman of the Post Polio Task Force.



HOT TIP FROM HAWAII - Ron Amundsen

Dennis Lang clued me into the fact that I can save the shower water around my feet, so that they don't get cold during a shower. (He uses a stopped up bathtub; I keep my feet in a dishpan at the foot of my shower stool.) What a pleasure.....

Breathe Right Nasal Strips from Chemists - Worn at night help some Polio Survivors sleep better.

All tips like this will be gratefully received..... Read on [The Humble Walking Stick](#)



STUDENTS PERSPECTIVE OF OCCUPATIONAL THERAPY INVOLVEMENT IN THE TREATMENT OF POST POLIO SEQUELAE

Kristina Muehl, Greta Neville and Simone Richter
Occupational therapy students at La Trobe University, Melbourne, Australia
richter@labyrinth.net.au

Let us introduce ourselves. Our names are Kristina, Greta and Simone, and we are final year occupational therapy students in Melbourne, Australia. As part of our course we have undertaken a project on post polio sequelae (PPS). We have identified that a problem exists regarding lack of PPS knowledge amongst health care professionals, and as a result our project will focus on educating occupational therapy students on PPS. We ourselves are in the initial stages of learning about PPS,

its symptoms, etiology and treatment, but hope to develop an effective learning package suitable to educate fellow occupational therapy students.

In the near future we will be occupational therapists and we feel that our role in PPS will be to help develop strategies to overcome difficulties with everyday living. As occupational therapists, we can help you look at alternative methods of living energy efficient lives. Rather than just repeating the principles of intervention, we will apply them to an everyday living example.

After developing PPS, you may be experiencing difficulties due to fatigue, pain and decreased concentration. Tasks that you were capable of performing prior to developing the symptoms of PPS may now seem more difficult. While there are numerous issues here, we will focus on techniques to overcome problems faced while cooking in the kitchen. The principles can be adapted to any other situation.

The following are suggested principles and techniques: plan ahead - pace task / schedule rest periods - use correct/appropriate posture - use adaptive equipment - identify effects of the environment.

PLAN AHEAD

If possible have the kitchen set up so that food storage, preparation and cooking are performed in this order. This will help eliminate unnecessary lifting.

Organise all commonly used utensils and ingredients in easily accessible areas. Avoid storing commonly used items above arms reach.

Use one to two step recipes eg. pasta and sauce as opposed to a three course meal.

Before cooking commences get out all the required ingredients and utensils.

PACE TASK / SCHEDULE REST

Work at a moderate rate rather than trying to complete the task quickly. Take rest periods as soon as you begin to fatigue. Start the cooking early enough to allow time for rests.

Take a 5-15 minute rest for every hour of continuous work, e.g. between food preparation and cooking.

Place all items in a kitchen trolley to prevent returning to storage places. Slide rather than lift or carry items.

USE CORRECT / APPROPRIATE POSTURE

Sit whenever possible - high chairs at appropriate level to the bench can be used. Take a brief sitting break after 30-60 minutes of standing.

Remember to shift your weight to distribute weight over other muscles.

Have recipes at eye level using a book holder or taping them to the wall. This will avoid constant bending over.

Take care of your back, using correct lifting techniques e.g. bending the knees, rocking and holding the object close to your body.

USE ADAPTIVE EQUIPMENT

Use built up handles to help increase the grip, a wet cloth to help open jars, a kitchen trolley to help transport items around the work station, tap turners and/or a spiked chopping board.

IDENTIFY EFFECTS OF THE ENVIRONMENT

Place rugs on the floor if the kitchen is too cold. However, ensure that the rugs are tacked/taped well to the floor to avoid falls.

Correct temperature is important in order to avoid increasing fatigue. Try not to work next to the hot stove for long periods.

By planning ahead and conserving energy tasks, such as cooking, may be easier to complete. However, as occupational therapists we would also look at the psychological impact that these new symptoms are having on your lifestyle. Suggestions may include relaxation (breathing exercises or guided imagery), stress management, involvement in social and leisure activities including attending support groups.

Occupational therapists play an important role in the treatment of PPS and this can begin with education of occupational therapy students. At a later date we hope to inform you of the results of our learning package.



LINCOLNSHIRE WHEELCHAIR ACCESSIBLE PLACES TO VISIT

Both sites are now wheelchair/scooter accessible. Miles of paths, maybe a little bumpy in places - we have asked if they could train rabbits to fill the holes in again - lakes, birds, wildfowl, butterflies, plants, If you can only push/walk short distances then phone for details of where to access best places.

WHISBY NATURE PARK - LINCOLNSHIRE TRUST FOR NATURE CONSERVATION

TEL: 01522 500676

Access to the site is free. The park is always open, 365 days-a-year.

6 miles of way-marked walks have been set out on wheelchair accessible paths.

The Nature Park is an area of 160 acres of lakes, ponds, woodland, scrub and grassland, created by the quarrying of sand and gravel since the 1930's. It has been established for the quiet enjoyment of the countryside and its wildlife and contains a wide range of habitats supporting an abundance of wildlife.

Although the wildlife areas at Whisby are substantially man-made, they are of increasing importance to animals and plants since much wildlife has been lost in the countryside through changes in land use.

The wetlands of the Nature Park are of particular value since so many ponds and marshes in the wider countryside have been drained and lost. The Nature Park's lakes and ponds support a great variety of waterfowl, amphibians, aquatic insects and plants. The surrounding scrub and woodland are also valuable for many birds and insects, whilst grassland is rich in flowers and insects such as butterflies and grasshoppers.

Information Centre - An ex-school mobile classroom currently serves as the Information Centre, Warden's base and school room. Various organisations' calendars of events are displayed, as well as a wide range of Lincs Trust leaflets, County Council Walks leaflets and a wide range of North Kesteven District Council leaflets.

Toilets / Car Park - A toilet block is sited near the Information Centre. A RADAR key disabled toilet facility is available. The large car park is shared with the water-skiing facility, and will take up to 150 cars, so parking problems only occur on summer Sundays and Bank Holidays if the weather is good. A restaurant-bar is available on site but is not directly associated with the Nature Park.

On-site facilities - The idea of the nature park is to give access to undeveloped, "natural" countryside. To this end, 6 miles of way-marked walks have been set out on wheelchair accessible paths. A free leaflet showing these routes is available at the Information Centre. There are currently five bird hides around the site and a number of strategically placed benches. Interpretative boards are located at key habitat or species areas.

DATES

April
6 Spring Birds - 10.00 till lunch

May 4 Dawn Chorus - 4.30 a.m.

May 7 Nightingale Walk - 8.00 p.m.

May
10 Spring Fungal Foray - 10.00.

June 1 Whisby Wildlife Wanderings - 10.00.

June
21 Dusk till Dawn - 9.00pm - 9.30 am. Please bring warm drinks, sandwiches, warm clothes and a torch. What's that rustling in the grass? Using bat detectors, night vision equipment, moth lights etc. We shall investigate.....

HARTSHOLME COUNTRY PARK SWANHOLME LAKES LOCAL NATURE RESERVE

Skellingthorpe Road, Lincoln Tel: 01522 686264

SITE, CAFE AND TOILETS - WHEELCHAIR ACCESSIBLE

Complete circuit of Hartsholme Lake is 3100m. Main area of lake is 1500m.

Visitors Centre to Swanholme Lakes - 7 Lakes - entrance is 840m.

Central circular route on Swanholme is 1000m newly pathed - access by RADAR KEY.

Longer route is 2100m walkers only at present.

Hartsholme Country Park and Swanholme Lakes Local Nature Reserve provide over 100 hectares, (200 acres) of beautiful open space in the south west of Lincoln. There are lakes, woodlands, meadows and heathland to explore.

Hartsholme Country Park was once the grounds of a large hall which was demolished in the 1950's and remnants of the formal landscape garden can still be seen but the area is now more natural and supports an abundance of wildlife.

Swanholme Lakes was created by the quarrying of sand and gravel. After this quarrying was finished a rich mosaic of habitats developed. Many rare and common species of birds, dragonflies, and wild flowers.

The Visitor Centre is situated at the northern end of the Country Park is also the base for the Ranger Team who manage Hartsholme and Swanholme. Maps, nature trails and leaflets are available. We would be happy to put them in the post. The Visitors Centre is upstairs but if open then there is always someone up there who will willingly come down and help. **The toilets, including Radar one**, are always open, and the **Cafe** is now open weekends and from Easter throughout the summer open every day. If you cannot walk far, or are in a wheelchair then please ring the Wardens in advance of your visit, who will do all they can to see you get to some good vantage points.

ACTIVITY PROGRAMME

March

SUNDAY 30th **Easter Day Walk.** Starts at 10.30am from the Visitor Centre.

MONDAY 31st **The Great Egg Race.** The search begins from the Visitor Centre at 2pm.

April

SUNDAY 6th **Bird Watching for Beginners.** Meet at 10.30am outside the Visitor Centre.
 SATURDAY 12th **Spring Clean on Swanholme.** Meet at 10 am outside the Visitor Centre.
 SUNDAY 20th **Swanholme Stroll.** Begins at 10.30am at the Visitor Centre.
 SUNDAY 27th **Step into the Past.** Starting at 2pm from the Visitor Centre.

May

THURSDAY 1st **Photographic Competition.**
 SUNDAY 4th **Dawn Chorus.** Meet at the Visitor Centre at 4.15am. Join us for a warming cup of coffee after the walk.
Bird Watching for Beginners. Meet at 10.30am outside the Visitor Centre.
 SATURDAY 10th **Volunteer Day.** Meet outside the Visitor Centre at 10 am.
 SUNDAY 11th **Wildflower Walk.** Walk starts at 2pm from the Visitor Centre.
 TUESDAY 13th **The Geological Evolution of the Lincolnshire Coast.** Meet in the Visitor Centre at 7pm.
 SUNDAY 18th **Fugus Foray.** Begins at 10.30am from the Visitor Centre.



GET WELL SOON 'GRANNY' aka Viola Pahl in Vancouver, Canada

All our best wishes for a 'speedy' recovery Viola. Her son Gerhart has just emailed us 'Granny is doing well, the operation was a success, and whilst with pps recovery will be slow, the Get well wishes and prayers sent from all around the World have been wonderful'.

She wrote 'Gold in Life's Hourglass' and 'Granny's Love Hate Affair with a computer' that we featured in previous newsletters. We have both of 'Granny's' books - at present out on loan - Granny caught polio whilst seven months pregnant and has a very interesting story to tell. We look forward to updates on how you are doing and maybe Granny's next book will be 'Granny goes to hospital.....'



THE POST-POLIO HOKEY KOKEY - from Ron Amundsen in Hawaii

jockey shorts left leg, jockey shorts right leg,
 long underwear left leg, long underwear right leg,
 left sock, right sock,
 left knit dancer's legging, right knit dancer's legging,
 left pantleg, right pantleg,
 left shoe, right shoe,
 STAND,
 up shorts, up long underwear, up leggings
 [this could be done sitting, but it would require another stand cycle],
 up pants, tuck, button, zip, SIT, buckle,
 pant pant pant pant

In other words it is possible to dress the bottom half of your body without standing up several times in order to arrange your various layers of clothing. It takes a while to learn, and you can't be too groggy in the morning when you do it. But you can actually get all of your layers started on your legs, sort of telescoped into each other, and then stand up *only once* and pull them all up over your

butt. How many hundreds of standups and sitdowns I've wasted in the past seven years I couldn't begin to count.

The hazard here is that it is possible to get confused and do:

jockey shorts left leg, (etc. as above), left pantleg, long underwear right leg, right sock, jockey shorts right leg, right legging, right pantleg, STAND, up jockey shorts, tangle, fall, roll over to telephone, phone 911 for help.

A female version is being planned with left knicker, left pantyhose, and if there are enough orders then he is going to contact Jane Fonda about a Video.....



Electric Scooter - Get out more. Have control. Scoot to [a] and walk around, get back on and scoot some more and see how much more you can do and how much energy you save for other things. It carries your bags and walking stick. Mine is a Lark 6.



PARENTS BLOOD BY GINGER SAGE

is an intriguing biographical tale told by the Polio-handicapped gal who lives through it. GINGER SAGE masterfully weaves townspeople, farms and Colville Indians into the fabric of long-forgotten historical events. The intent of this biographical novel from 1938 is to bridge the gap between the deluge of Polio medical information and the general public. Injecting at-risk children with their Parent's Blood was a medical procedure from the Thirties. The End Notes and Bibliography explain this procedure as well as other historical Polio Medical facts.

Mail your USA \$30 cheque payable to Ginger Sage at PO Box 457, Entiat, Washington, USA. Ginger and her Post Polio Support Group have kindly donated us a copy - in the post - and this will be added to our library.

As it costs £8 for each dollar cheque to buy from America, Canada etc., if anyone wants any information or books from America we have a kind PPSer who has agreed to accept lump sums and post off our individual requests for us.

If anyone has books, newspaper articles etc., that could be added to our library, small items can be scanned and returned, then we would be pleased to add them to our growing collection. Give us a ring first in case we already have a copy.

If anyone knows of any other Polio or PPS authors - Tony Gould, A Summer Plague, being contacted for information now - who should be added to our Books and Periodicals Page on our Web Site then please contact us.



WHEELCHAIR TRAVEL

1 Johnston Green, Guildford, Surrey, UK.
25 miles SW of London.
Telephone 01483 233640 Fax 01483 237772

A company run by Dawn and Trevor Pollitt in Guildford Surrey. In 1979 a close friend Ron Surrage had a hang gliding accident that left him a quadriplegic. This led his friends to raise money for a tail lift vehicle with floor clamps for his chair, and RSAF Ltd a Charity was founded. They have since purchased other minibuses and wheelchair accessible vehicles for hire. Wheelchair Travel is operated in association with RSAF Ltd, but is predominantly for non-UK, hand-controlled cars,

'Chairman' and Private Hire clients. This company is a long way from Lincolnshire but does hire vehicles out for holiday purposes, and is also aimed at the visitor to this country. They have extensive knowledge of wheelchair accessible transport including conversions to new or used vehicles via an associate company Axcon. We have a collection of leaflets if you require further information or contact them direct.



We need more articles, more letters, more tips, so please write.....

Articles for publication by May 11th please. - Publicity date anticipated about 20th May 1997

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

Thankyou for taking the time to read this.

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

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

**The Secretary, Lincolnshire Post-Polio Network
PO Box 954, Lincoln, Lincolnshire, LN5 5ER United Kingdom**

Telephone: +44 (0)1522 888601

Facsimile: +44 (0)870 1600840

info@lincolnshirepostpolio.org.uk



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