



The LincPIN

The Lincolnshire Post-Polio Information Newsletter
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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. **ALWAYS** consult your doctor before trying anything recommended in this or any other publication.*

Editorial by Hilary Hallam

Following our second AGM - we had three speakers and many questions were asked and answered. We would like to take this opportunity of thanking Marcia Falconer PhD from Ottawa Canada, Dr. Paul Ballinger from Cannock in Staffordshire, and Dr. Betty Dowsett from Essex for giving us their valuable time. Sylvia Foster, the Orthotist who was to speak - with Colin Teferrelli - had an accident whilst on holiday in France and they were unable to be with us, but have offered to speak at another occasion. We hope that Sylvia is soon on the mend. We would also like to thank those members who travelled far to join us. Our two evenings at the Holiday Inn Express were spent talking about our continual and varied forays into the minefield of 'getting a diagnosis and treatment', amongst other allied subjects. This looks like very heavy discussion but there were so many laughs that we went to bed with our ribs aching.

Marcia Falconer PhD a virologist from Ottawa Canada and LincsPPN Life Member - our first speaker after the AGM - spoke about "[Non-paralytic Polio and Post Polio Syndrome](#)". She described the categories that were used to classify the severity of the acute illness: sub-clinical, abortive, non-paralytic and paralytic, saying that these were not distinctive classifications but rather just arbitrary points along a curve with each category blending into the next. She emphasized that scientists had found the damage done to the motor neurons could be just about as severe in non-paralytic cases as it was in paralytic cases, just that the pattern of the damage varied. Considering this, it is not surprising to find that symptoms of PPS are found in people with a history of non-paralytic polio. She also talked about the criteria currently used to diagnose PPS including the use of electromyographs (EMG's). Although a useful test, having a normal EMG should not be sufficient to rule out the possibility of PPS. She concluded by emphasising that a diagnosis of Post-Polio Syndrome should not be exclusive to those with a history of paralytic polio. The talk was followed by a long and lively discussion period which was cut short only by the need to have lunch!

Dr. E.G. Dowsett, MB, ChB, Dip.Bact. is an Honorary Consultant Microbiologist with South Essex Health Trust and a LincsPPN member. In her long and varied career she has worked with patients with ME/CFS and has seen many Polio Survivors - including at least three of our members. She attended the AGM and following Marcia's talk spoke for a few minutes. She said "Marcia's talk has been very informative and she is correct in that categories of polio are names along the curve of Polio, and I look forward to long and interesting discussions with her but unlike many of you with your computers I am happy with my paper and pen." She then went on to talk about the Lincolnshire Post-Polio Network. "I congratulate you on the professional way that you present your information which means that it is being read by health professionals. Your newsletters are full of medical articles from highly respected Polio and PPS specialists and you also include articles and information from Polio Survivors who share their experiences for the benefit of others. More importantly this comes from around the World - a most important line of communication. I am pleased to see members of the local ME self help group here as you have many symptoms in common. PPS and ME/CFS are not temporary problems, they will not go away. There are also other enteroviruses (other than polio) that can and do cause acute flaccid paralysis in the world today. There is a lot that can be done to manage your lives better and by making more information on Polio and its late effects available from one source you are saving busy health professionals time in searching for good quality information. I look forward to joining with you and helping you with this valuable work."

Dr. Paul Ballinger MRCP, MRCGP, DCH, DRCOG - a GP from Cannock in Staffordshire who wrote [the Case History of a Patient](#) of his with PPS for Update - a publication for GP's - was our last speaker. A very dedicated young GP who researched for information when a Polio Survivor patient

presented with new weakness to a polio limb. He talked about the difficulty that a GP has in having to change from condition to condition every five or ten minutes as patients pass through his surgery. It is not possible for GP's to know all the latest information on all conditions and said that if we read all the information that arrives in the post then we would not have time to see any patients. He told us that in training many rare conditions are covered, but that he had not been aware that there were late effects of polio until he started to search for information. We had asked him to include in his talk how we could present ourselves and our symptoms to a GP so that the limited time available was used to best advantage.

Polio is not something that we know a lot about and you all seem to have many and very varied recovery levels, with many of you not visibly showing all the damage the polio virus did to your body. This makes a GP's life very difficult.

He suggested that we provide as much information as we can on how we were when we had polio and how we recovered. That we diary our symptoms so that we can provide a summary. He also suggested that if we find a health professional who does not know about polio's late effects that we give them copies of medical articles from peer reviewed journals. He seemed surprised that some of our members had done this and had them refused or even chucked in the waste paper bin. He answered questions on many different aspects of a GP's work and the new PCG's and his refreshing and honest replies gave us hope for the future.

The Falcon Inn Charity Truck Pull held on Sunday 3rd October raised over £700 of which we hope to get just over £500. This was 50:50 for us and the Team's own choice of Charity. Five teams entered and despite the rain starting as the Pull started, all participants pulled hard determined to win. With supporters cheering on the side lines the winners were the Falcon Inn Football Team in a time of 21 seconds. Christine Ayre our new Chairman presented a Shield to the winners and certificates to all that entered. The Falcon presented each team with a bottle of bubbly. Other teams entering were the Falcon Inn, the Perfect Strangers, North Lincs College/The Still, and the Witch and Wardrobe. The Truck was supplied by Nicholas Weaver Transport and driven 'back to the starting point' by Lee Phelan. May we take this opportunity of thanking all those involved.

The Falcon Inn Football Team play in one of the oldest Lincolnshire Leagues. Team Manager is Nick Lebbon and joining him in the Truck Pull were Nigel Lloyd, Darren Ross, Carl Barlow, Paul Wright and Sally Holding. This is their first year playing for the Falcon Inn having moved from another Lincoln Pub. They adopted the Lincolnshire Post-Polio Network as their Charity and support the Falcon Inn in all its fundraising events raising £10 a week for us from their Bonus Ball competition. Thankyou guys, your efforts are well appreciated.

Neurological Support Group in Lincolnshire. This has been reformed and the first meeting will be held in early November at Lincolnshire Health Authority Headquarters. The format of the meetings has been laid down and we look forward to giving you more positive reports in future newsletters.

Are you on the Internet? - If you are on the Internet and have an email address then do let us know so that we can ensure you are aware of all the services we offer to our members.

Reminder - we tolerate some drugs and anaesthetics differently from non polio survivors. We provide leaflets on this and there are articles on our WebSite. If you are due to have any dental work or operation that requires any form of anaesthetic then look at the following articles on our WebSite or ring or write to us for a copy.

1. What you should know about your Medications - A guide for Polio Survivors UK version J.M.Walker Ph.D., PT, AM Whelan, Phar. D. - Andrew Francis Forde MRPhami. B.Sc.Hons. [\[Lincolnshire Library Full Text\]](#)
2. Be true to your PPS and your teeth won't be false to you. Preventing complications in Polio Survivors undergoing dental procedures - Richard L. Bruno, Ph.D. [\[Lincolnshire Library](#)

[Full Text\]](#)

3. The Knife is not so rough if... Preventing complications in Polio Survivors undergoing Surgery. Richard L. Bruno, Ph.D. [\[Lincolnshire Library Full Text\]](#)
4. You are going to have surgery - A Guide for Polio Survivors - J. M. Walker, PhD, PT. [\[Lincolnshire Library Full Text\]](#)
5. Polio Survivors as Patients - Guide for Emergency Care & Surgical Health Workers J. M. Walker, PhD, PT, C. McGowan & G. Vardy. [\[Lincolnshire Library Full Text\]](#)

Reminder - to analyse how you do activities so you can show where you have problems in repeating or sustaining any movements. This will help those examining you to see the decline in muscle ability that is not evident on one off manual muscle testing.

PPS Conferences - November 13th 1999 in Atlanta, Georgia, U.S.A.; January 19th - 22nd 2000 Victoria, Australia; February 19th 2000 in Boca Raton, Florida; March 2nd - 5th 2000, Richmond, British Columbia, Canada; May 19th & 20th 2000 Warm Springs, Georgia and June 9th - 10th 2000 in St. Louis, Missouri, USA. For more information see [World Wide Conference & Seminar Diary](#) on our Website or ring for more information.

Finally. This is your newsletter and we would like to hear from you. Let's make the Christmas issue an LincsPPN members one. Have you any hints, tips or stories to tell, serious or funny? Tell us about the treatment or equipment that has helped you - tell us what you need but can't get. Have you any old fashioned Christmas treats to share with our overseas members (or from our overseas members)? Weigh our postlady down with letters, she won't mind.



Lincolnshire Post-Polio Network - 2nd AGM September 4th 1999. Chairperson's Report by Lynn Hobday.

With pleasure I welcome you to the second AGM of the Lincolnshire Post-Polio Network and thank you for giving your time to be with us. Last year, I set out our aims and objectives and told you of the work already accomplished on behalf of Polio Survivors. Let us consider another aspect of our work.

Here I would like to add personal thought on our work. When one has a problem, no matter what that problem maybe, it needs to be shared. The old adage "A problem shared is a problem halved" is as true today as it ever was! That's what LincsPPN does so well. It becomes a listener - and what's more - a listener who understands!

We all know how difficult it can be to explain the many and various symptoms of the post polio syndrome. They are different for each and every one because so much depends on how we were affected when we first contracted polio.

However, to put it very simply, there are 4 stages for everyone.

1. Polio contracted and damage done.
2. Recovery up to a point and rehabilitation.
3. Making the best of what we have left and getting on with life.
4. Slow and inexplicable deterioration of muscle power and mobility.

We all deal with these symptoms differently. Let me explain how I see it.

There is a song from the musical "Fiddler on the Roof" which begins, "Sunrise, sunset - quickly goes the day." It tells of a father's feeling on how quickly his children have grown from babies to adults - in the twinkling of an eye.

For me it sums up how quickly these problems have arrived. It seems only yesterday I was an active wife and mother, a full time professional worker with a very enjoyable social life. I would be hard

pushed to say exactly when this all changed. But change it did! I am now learning to live with Stage 4.

For many of you the experience may have been different - but what will be the same will be the frustration and anger at the indifference of the medical profession and the lack of will to help all of us cope both mentally and physically.

The Lincolnshire Post-Polio Network was formed to help polio survivors understand what was happening to our bodies, to provide information on where and how to get assistance, to link with the Establishment, to make our voice heard, to help medical professionals understand our needs - and through our WebSite on the Internet and our LincPIN newsletter, spread all this information worldwide. To the benefit of all Lincolnshire Post-Polio Network members and associates, we in return receive a current and relevant update on the work being done in other countries for polio survivors.

I do hope all I have said goes some way to explain the importance of our Charity to all polio survivors and why we must all continue to support this work in whatever way we can.

Now to the rest of my report covering 1998/1999.

Through the continuing efforts of Chris Salter, our Vice Chairman with specific responsibility for the WebSite, we have increased information available on our WebSite and this is being accessed world wide. This is vitally important work and although I have not met Chris because he lives in Cornwall. I am very well aware of the enormous input he has achieved on behalf of the Lincolnshire Post-Polio Network. My personal thanks to him for all his hard work.

Last year I told you that we were represented on the Lincolnshire Health Authority Neuroscience Group. I have to say now that in spite of attending several meetings, we have made no further progress in obtaining improved medical services for polio survivors in Lincolnshire. However, we have hopes for improvement in the coming year. With the help of the NHS Directorate in Sheffield, the Group is to be re-organised so our fingers are crossed for more positive action. We will keep you informed.

Our membership continues to grow. At present we have 29 Life members with 6 from overseas and 101 Members with 11 from overseas and memberships continue to come in.

These figures represent subscription paying members - a vital contribution to our funds. Many many more use our services - if they don't wish to join then a donation would be most welcome.

This leads me on to funds. Still we do not have sufficient funds to do all we would like to do. More funding through grants and sponsorship would enable us to pay a part time administrator to relieve Hilary of some of the secretarial work, allowing her to concentrate more on giving talks and promoting the awareness.

Alison Hallam, Hilary's daughter, the Assistant Manager of The Falcon in Saltergate, Lincoln, made us their Charity of the Year and £240 has been donated already. One of the events will be A Truck Pull on October 3rd. and we hope for good results. Anyone who can help to raise funds on our behalf would be welcomed - just talk to us today and share your ideas.

The newsletter, LincPIN, has continued to be circulated and its contents have been first class. Medical articles, personal experiences - both funny and serious, up to date information on equipment and Hilary's trips to Polio Conferences abroad to see how they are coping have all added spice to keeping us well informed.

We keep in touch with the Lincolnshire Branch of the British Polio Fellowship and exchange information useful to all polio survivors. We continue to maintain close communication with the Leicestershire Post-Polio Network. They are holding their AGM here at Ancaster Day Centre and by combining a shared date it enables more of their members to participate in the program today. By using a registration list which show the location of members of both organisations, we hope that

together we can provide a link for services especially to those who live in rural and isolated spots.

On your behalf I want to thank Hilary Hallam, secretary of the LincsPPN. It would be impossible to list the amount of work she does on our behalf. As a committee we put in our two pen'orth but it is she who makes things happen. To our committee, to our Treasurer Jean Tapper, to Christine Ayre and Phil Bilton, my thanks for your help and support throughout the year.

I am retiring this year as Chairman and take this opportunity to wish my successor good luck and best wishes for the coming year. To you all my best wishes for an improvement of quality of life and lots of laughs along the way.

The Treasurers Report was then given followed by a WebSite Report and Secretary's Report. Voting then took place for the Officers and Committee.

Your new Chairman is Christine Ayre. Vice Chairman is Councillor Bud Robinson - who was with us as Mayor of Lincoln at our last AGM. Vice Chairman/WebSite Administrator remains with Chris Salter. Hon. Treasurer is Jean Tapper, Hon. Secretary is Hilary Hallam. Committee Members are Phil Bilton and Myra McManus.



Read this sentence:

Finished files are the result of years of Scientific Study combined with the experience of years.

Now count aloud the F's in that sentence.

Count them ONLY ONCE: do not go back and count them again. [Answer at the end of this newsletter.](#)



WELCOME MESSAGE FROM YOUR NEW CHAIRPERSON - CHRISTINE AYRE.

When I joined the LincsPPN committee some two years ago, I never dreamed that one day I would be Chairperson and following in the footsteps of such an able Chairperson as Lynn Hobday.

I am very much aware of the responsibilities of heading the Lincolnshire Post-Polio Network committee and also the need to further the cause not only of our members, but also to give information and support to our great family of polio survivors throughout the world.

When I started to experience new symptoms I found myself trawling round hospitals, visiting various consultants trying to get a diagnosis. One consultant even said I had Marfans syndrome and he did that within five minutes of seeing me and never got up from his chair; is that what is called medical expertise?.

To cut a long story short, after fruitless visits to hospitals I finally found an article in the "Saga" magazine telling of an illness called PPS, the rest for me was easy. I took the article to my GP and he agreed to help. If you have a good GP it certainly makes life a lot better.

Since that time I have worked to getting things that will help me manage my life better. Some are little things, such as lightweight saucepans and ironing board, a little vacuum cleaner so that I can at least clean up things I drop on the floor and some are large things like a scooter, stairlift, electric bed and a chair with a high seat. I also have a selection of cushions and foam pads which I use to prop up my arms when in a chair or bed.

Three years ago I went for the first time to Papworth Hospital to have my breathing evaluated and

although at that time I was alright, a year later I was told that I would need treatment in the form of a ventilator. This has changed life for the better. I now feel and I'm told look better. Also I sleep at night instead of the day and wake feeling refreshed and able to get through the day.

I know that some of you are still fighting to get recognition and treatment for PPS. This is very hard and depressing when you are faced every day with increasing levels of pain and energy loss. I also know polio survivors will go on fighting, we have been fighting all our lives, so why break the habit of a lifetime. If you have not already done so then please write and tell us of your successes and failures in trying to get your symptoms assessed and treated. I look forward to hearing from you and maybe meeting you at the next AGM.

Christine Ayre <catley@tesco.net>



Rescued to the rescue.

Assistance dog partnerships can give a new lease of life both to the disabled and to former rescue dogs.

Marie-Noëlle Clifford - Dogs Today

with permission of the Publisher and Managing Editor Beverley Cuddy.

Readers of the December/January issue [Dogs Today] will already be familiar with the work of assistance dogs. Alerting people who cannot hear alarm clocks and doorbells, supplying stability via a harness to the mobility impaired, picking up or retrieving objects and using doors, lift-buttons and other objects are tasks all cheerfully mastered by the well trained assistance dog.

Many organisations, especially Guide Dogs for the Blind, train dogs before partnering them with clients. However, unlike Guide Dogs, assistance dogs for the disabled can be trained at a later stage in life (18 months to two years). Many Labradors, Golden Retrievers, German Shepherds and suitable crossbreeds in rescue shelters are given a new life through retraining for this type of work.

Christine Ayre from Lincolnshire and her four-year-old Boxer, Ben, took part in agility and obedience trials until two years ago when Christine suffered post polio syndrome. This debilitating, progressive condition affects many former polio patients in later life. Fatigue, general pain, weakness in the limbs and respiratory difficulties restrict Christine's activity.

When Christine was taken into hospital, it was the first time she had been separated from Ben for a whole week. On her return, she found that he needed time to adjust to her new limitations - and her new scooter. Ben had achieved Grade Five in obedience trials, and Christine was well-equipped to train him at home.

Boxing clever.

"Ben is always keen to help me out," says Christine. "He understands that I cannot walk as quickly as I used to and will slow down, wait for me when I have difficulty and even help me balance, as he is such a big Boxer."

Christine began training Ben slowly, allowing him time to investigate and familiarise himself with the strange machine. Then she trained him to walk beside the scooter without crossing in front or putting his paws under the wheels. Gradually they sped up, and now Ben usually runs on the verge alongside the scooter. Christine and Ben have coped well together, but Christine is sure that, with professional help and training, they could have achieved even more.

"Unfortunately, I have not been able to train Ben to retrieve items. When I attempted to get him to fetch the mail, he chucked it all in the pond with the frogs," she says.

Christine had not considered assistance dog training simply because she did not know where to get

help.

Six years ago, Josie Goodison, from Rotherham, adopted a six month-old crossbreed called Scamp, from a rescue centre. She wanted a companion for her retirement. Josie also has post polio syndrome, and as her illness progressed she found herself increasingly relying on others.

A dog-trainer suggested she contact Dog Aid, an organisation who train existing owners and their pets. Qualified last year, Scamp can now pick up items, retrieve named items, use doors, light switches, lift buttons and even empty the washing machine. He can also pull her up from a sitting position or get help if she falls.

The length of time needed for training varies according to temperament, intelligence and the tasks required. Scamp's trainer met with Josie over a couple of years for training sessions, and was flexible to take account of her fluctuating health. Apart from the trainer's travel expenses, the service was free.

'Providing you have the time and patience, training your own dog is a very positive experience,' says Josie. 'When I am ill, Scamp is a good distraction; he gives me a reason to get up in the morning and a sense of responsibility.'

Phone Assistance Dogs (UK) - c/o Hearing Dogs for Deaf People 01844 353898

Canine Partners for Independence - 01705 450156

Dogs for the Disabled - 01203 302050

Dog Aid - Delores Palmer - 01889 579103

Dogs Today - Pankhurst Farm, Bagshot Road, West End, Near Woking, Surrey GU24 9QR.

[<dogstoday@dial.pipex.com>](mailto:dogstoday@dial.pipex.com)

If you would like to write to Christine or Josie send your letters c/o the Lincolnshire Post Polio Network. If you are on the Internet then you can email them.

Christine Ayre [<catley@tesco.net>](mailto:catley@tesco.net)

Josie Goodinson [<trevor@goodinson.freeserve.co.uk>](mailto:trevor@goodinson.freeserve.co.uk)



Rambo the Ram

by Christine Ayre Catley Abbey, Lincolnshire

I've been racking my brain cell trying to think of a subject for a story. Hilary reminds me to write for the "LincPIN" and so I try not to let her down, but this time I really thought had run out of ideas. So when, out of the blue, instead of me finding a story, a story landed right on my doorstep, I was delighted.

I will warn you that this is not a story for the easily shocked. It's a story full of lust, passion and shattered dreams, so if you are faint hearted or of a delicate constitution don't read any further.

The story begins with the hay being cut in the field across the road from the cottage in which I live. After the hay was tedded and baled, my friend, who keeps a few sheep, twenty-one in all, arrived with a trailer containing the sheep and unloaded them in the field where the hay had been.

The sheep, all young and pretty, soon settled into their home; finding things to occupy the long Summer days, such as watching the baler in the next field or running over to look at the post lady as she rode past on her bicycle.

Sheep are often thought of as stupid creatures. I don't agree with this opinion. I think they are very clever animals. Anyone watching as I do most evenings what I call the lamb racing, would soon see how clever sheep are.

The lamb racing goes on in the cool of the evening. All the sheep gather, I suppose at a prearranged spot in the field. Mostly this is by the water trough. Then they all set off and race across the field,

the lambs skipping, jumping and skit-scattering along, with the old ewes trying to emulate them. Then they gather again to race back to the water trough. This is obviously their entertainment before they settle down to sleep for the night.

Back to the story. The young sheep are in the field and all is peaceful, until yesterday afternoon, suddenly all was noise and confusion. I went to the gate to see what was happening. Coming round the bend in the road was 'Rambo' the ram, from a farm a couple of miles up the road.

Rambo had obviously seen the young girl sheep pass by in the trailer and from that moment he started planning his escape. As soon as the coast was clear, he jumped the fence and with lovelight in his eyes, he set off in pursuit of the woolly lovelies. Now two miles for a little ram, on one of the hottest days of the year, is a long way.

So when he neared Catley Abbey he was just about on his last legs. Then coming round a bend in the road he glimpsed that vision of which he had been dreaming, a field full of scantily clad, nubile young girl sheep. Determined that they would see him in the best light he finished the last hundred yards at a fast trot, his yellow eyes gleaming and his little hooves beating a tattoo on the road.

The girl sheep not acting like coy young things, instead like brazen hussies, calling to him and inviting him into the field. Rambo cleared the fence like a show jumper, the girls gathered round him pushing and jostling for position, like silly teenagers round a spotty pop star. Unfortunately, Rambo is not so young now and the long journey and the last hundred yards turned out to be his undoing, his energy gone he just wanted a drink and then to get some sleep.

As the evening shadows tiptoed out to gather round poor Rambo he slept on, dreaming of ovine beauties with golden eyes and sheepish kisses, nights of passion lost to him for ever. The Spring lamb of the afternoon had turned back into old mutton.

I saw him next morning loaded up in a trailer, and on his way home I caught sight of his disappointed face as he passed the gate.

The girls have gone back to watching the baler, planning the racing for this evening and no doubt discussing Rambo and the fact that he is past his prime.

We polio survivors could take a lesson from this story. If only Rambo had rested a few times on his journey to Catley. If only he had not tried to do everything in one day. If only he had paced and rested. If only he had thought tomorrow is a day not started. If only!

Christine Ayre,
Chairperson - Lincolnshire Post-Polio Network
catley@tesco.net



Travel to and with Hilary.

written with the sweat of my brows by Klaus Kunert

Last November we got an invitation from Hils to meet her in Lincoln, when she and her daughter visited us in Berlin. My wife Renate and I readily agreed, and so we went to England, quicker than hoped before. We had much laughter already in Berlin, so we thought it could be a nice trip. But it was still much nicer than expected.

We came to the London airport and because of the wheelchair option, we met an attendant at the aircraft, who pushed us straight to Hils car. He was so quick, that it was impossible to talk to him. So we could say Hello to Hils and a friend Phil first at her car on the parking place. Then began a 3 hour ride to Lincoln. It was very funny to see all of the cars driving on the wrong side. But they all together did it very good, so we had no fear at all. Then came the first roundabout and the things seemed to be much harder, but it worked there too.

On our trip to Lincoln we saw very nice old villages and churches. It was very impressive. For a short stop we visited our first pub. By the way every second house here is a pub. It was a very old pub from the year 1640. Then the forest (Sherwood Forest) was so big it reached this area. So we exactly sat in the same place, like Robin Hood some years ago with Little John. The first explanations were about the English food. Here we only looked at Steak and Kidney pie for a further examination but ate toasted sandwiches.

After a first short sightseeing for Lincoln we arrived safely. At home we had a very warm welcome with much laughter mostly because of the different translations for some words.

The second day found us in the old city of Lincoln with houses still from the Romans. It was very interesting to see this. Here we had our first Fish and Chips meal, we very enjoyed it. It is near our kind of eating. The evening was like all evenings: resting, monitoring the Internet and watching British TV.

Next day we had our first outing: to Skegness at the North Sea. Because it was near the North Sea, we naturally eat Fish and Chips again. On the way back we had the first 5 o'clock tea in England with an LincsPPN member Miss Jean in her farmhouse with scones and butter and home-made jam.

The next day brought us the first English breakfast, what is called dinner at home. After this we went to the wonderful Cathedral of Lincoln. It very impressed us. Luckily there was an exposition of flowers at the same time, what still enlarged this impression.

The whole time we had a wonderful hot weather (about 30 degree Celsius) with no rain. We'll now call this the real English weather in the future.

A meeting with polio survivors from Lincolnshire Post Polio Network, nice ladies, brought us an exchange of experiences of us polios. We all found that the problems polios have are all the same kind. It was a good meeting also because of the BBQ with sausages and lamb chops. My wife did very well in serving us all.

On Monday we drove again to the Sea. This time Alison, Hils daughter, was the driver. She is a little younger, so the ride got a little faster. In Cleethorpes we saw again the sea, donkey ride and beach buggy ride, the last Renate and Alison enjoyed very much. Of course we had for lunch Fish and Chips. On the way we saw an exhibition of scarecrows in a little old village Faldingworth, what was very funny. One theme was about Alice in wonderland with more than 15 scarecrows.

The other days went by with sightseeing in and around Lincoln. This brought us to an heritage airfield near Boston. Here I learned that this Boston is the real Boston the pilgrims started from to the new world to found the Boston in the States, MA.

Unfortunately the times run quicker than expected. So we had to leave sooner than we wished. But we strongly hope, that we meet again in the nearer future. Either in Berlin or in Lincoln or on a place between. With this record I wish to express my thanks to Hils and her daughter for caring for us and for so much fun and enjoyment.

See you again not so far.

Bye and Tschuess from

Klaus and Renate Kunert

KlausinB@aol.com - Berlin, Germany



**A PERSONAL EXPERIENCE OF THE CONDITION KNOWN
AS SCOLIOSIS
(COMMONLY KNOWN AS CURVATURE OF THE SPINE)**

My name is Anne Proctor and I am a 58 year old Grandmother and for as long as I can remember I have had the condition called Scoliosis. I was first aware of this when I was five but only discovered in the last ten years that I was born this way.

As a child I had intensive physiotherapy and hospital checks every 3 months by a consultant. At the ripe old age of 18 I was discharged and proceeded to get on with my life.

I was more or less unaffected at this time and duly embarked on my college studies graduating some time later.

Time went by, I married and subsequently had two children. However, after the birth of my second child I started to have some problems with my back and went through a very difficult period suffering pain and numbness. I had various experiences of trying to resolve this problem and almost gave up hope of ever getting any improvement. My GP at that time realised how desperate I had become and he contacted a scoliosis specialist and asked if he would see me.

After only 3 weeks I saw the consultant and he more or less knew at once what was wrong with me. He proceeded to treat me by applying a specially made support which if successful would correct my posture and try and straighten me up a little therefore relieving the pain. Guess what after about six months it worked and after being monitored for about a year I was discharged.

A few years passed and I returned to college and resumed my career until unfortunately, I was in a major accident which left me with injuries to my back and a leg which had to be plated, which incidentally was shorter anyway from birth. I then had to embark on a series of treatments to control the pain. After seeing my consultant he referred me to the Pain Clinic at the hospital and I have to say that over the last 8 years I have had some marvellous treatment and felt that I had someone batting on my side so to speak.

The most recent treatments I have had have been Crioprobe and Radio Frequency Probes which settles the pain for months at a time, providing of course I do not overdo it as this causes the pain to come back. I have to say that this treatment does not suit everyone, however I am one of the lucky ones.

Meantime I carry on as best I can as a Regional Secretary for the Scoliosis Association UK based in Barnsley with the knowledge that we should not give up as there are treatments available out there. If after reading this article anyone wants to contact me please let Hilary know.

Anne Proctor

Scoliosis Association UK



Disabled Person's Parking Badge - Orange Badge - Information for Lincolnshire.

All new and renewal requests for disabled persons parking badges will be dealt with centrally by a dedicated team at Social Services Central Office, Wigford House, Brayford Wharf East, Lincoln, LN5 7BH, telephone number 0845 6030536.

This has been set up to deal more equitably and consistently with applications, process most applications more quickly using a dedicated team, and needing to make fewer references to medical practitioners for further information, which should also speed up the process for many applicants. Local offices will still maintain a supply of application forms and leaflets and still be a source of guidance.

Applicants must meet "Automatic Criteria" - Registered Blind, Mobility Allowance, Mobility Component of DLA, War Pensioners Mobility Supplement, DOH grant towards a vehicle or own a

vehicle supplied by a Government department.

All other applicants will be assessed under the "Discretionary Criteria" and must be permanently and substantially disabled to an extent which makes them "incapable of visiting shops, public buildings and other places unless allowed to park close to their destination" (DOT circulars 4/82 and 3.91. The disability must be such that they are unable or virtually unable to walk.



Dr. Sarah Smith - Patron of the Arachnoiditis Trust Asks how many Polio Survivors have had problems following spinal injections? and gives a short explanation of Lumbar Puncture and Arachnoiditis

Lumbar Puncture - you may find out some interesting facts about Cerebral Spinal Fluid, such as protein levels, but in essence it is still not a definitive test for PPS. (It may exclude other conditions of course). As with any test, especially ones of an invasive nature, one has to ask oneself whether or not the results will impact on the future management of the patients' condition (symptoms and signs). If the answer is not at all/slightly then any test should be reconsidered. In the case of invasive tests, especially around the spinal cord, there should be a clear and strong indication that there will be significant benefit from knowing the test results, (i.e. a significant change in treatment that might change the prognosis). It is also important to take into account any spinal pathology as mentioned (stenosis etc) both in assessing the feasibility of performing the test and also in considering the differential diagnosis. The art of diagnosis should rest on proper history taking and clinical examination.

Arachnoiditis is a chronic, insidious condition that typically causes debilitating, intractable neurogenic back and limb pain and a range of other neurological problems.

Arachnoiditis (inflammation of the arachnoid membrane) [The brain and spinal cord are covered by the meninges - a layer of three membranes - the dura, arachnoid and pia] is a chronic, debilitating, incurable condition which is not as rare as is commonly supposed. The true incidence remains unknown, but one expert has estimated approaching 2 million cases worldwide related to Failed Back Surgery Syndrome in the last 50 years: without taking into account other cases when there is no history of surgery.

Arachnoiditis is now most commonly iatrogenic [induced by the treatment itself] in origin. The majority of cases are multifactorial, so it is virtually impossible to pinpoint a specific cause. However, chemically-induced arachnoiditis: CIA (due to myelographic dyes, epidural steroid preparations etc.) is much more florid and systemic than mechanically-induced arachnoiditis: MIA. (caused by any type of trauma including surgery and multiple lumbar punctures, as well as chronic mechanical pathology such as prolapsed disc, stenosis or spondylosis). CIA is essentially a toxic condition. The syndromic clinical picture often has an autoimmune component and indeed, some patients have a diagnosed autoimmune disorder such as Sjogren's syndrome or Systemic Lupus. There is also a third subtype of arachnoiditis, due to miscellaneous causes such as meningitis or subarachnoid haemorrhage.

Arachnoiditis is substantially under-diagnosed: this is likely to be due to 2 factors: (i) doctors consider it rare and are not familiar with its clinical presentation (often they diagnose conditions such as MS/FMS/CFS/ME or even depression or at worst, malingering), (ii) the iatrogenic [induced by the treatment itself] origin may lead to a reluctance to diagnose.

This condition has not to date been systematically researched. Indeed, a leading expert has called it a "scientific orphan". Treatment thus far has been purely palliative and often only partially so. Future options must look at the condition holistically if there is to be any chance of a worthwhile degree of success.

If anyone would like more information on this condition you can give us a ring or write to Dr. Sarah Smith c/o the LincsPPN or email her directly: "Sarah Smith" <sasmith@easynet.co.uk> or contact the Arachnoiditis Trust, PO Box 27, Stoneycroft, Liverpool, L13 5RS - Tel/Fax 0151 259 0222.

You will find a long article on Arachnoiditis by Dr. Sarah Smith on

<http://www.btinternet.com/~thinkback/arach.htm>

See also [ARACHNOIDITIS INFORMATION & SUPPORT - Dr. Sarah Andreae-Jones Smith](#) and [EPIDURAL ANAESTHESIA AND ARACHNOIDITIS](#)



Atypical Coughing and Hypoventilation Syndrome in the Polio Survivor.

Deberah Nightingale <printcess@home.com>

I contracted polio in 1949 and "appeared" to have a nearly full recovery with the exception of a paralyzed left leg and I functioned in what I thought was fairly normal way until my early to mid twenties which was in the early 1970's.

Through those years I use to have frequent colds and upper respiratory infections that always seemed to lead to weeks and even months of coughing.

During a particularly active time in my life, nurses training, I was so tired all the time and thought I was just extra lazy because all my fellow students seemed to be doing just fine. And I coughed all the time. My instructors made me wear a mask while doing patient nursing and it was worse behind the mask. We know now I was building up CO₂.

Throughout the next decade the pattern was like a broken record. Nothing helped and doctors seemed baffled. I started having pneumonia several times a year. The coughing would subside once I finally fell asleep only to start again within minutes of getting up. Activity of any kind made me breathless and increased the coughing. By evening I was exhausted and talking was almost impossible.

One time is late 1991 I was hospitalized for intractable coughing. I was just so sick and exhausted but had no detectable infection. My doctor put me on nasal cannula oxygen and the coughing diminished. When the doctor saw me "getting better" he had the oxygen discontinued and the coughing returned full force.

He left town and I was seen by one of his partners who didn't know me. I talked him into dismissing me by convincing him being in the hospital wasn't helping me. There was a Polio Conference in Wichita Falls, Texas and I wanted to attend! My husband picked me up from the hospital and we drove five hours to the conference. I had a very difficult time on the trip and when I was registering, the doctor who was on call for the conference saw the physical distress I was in from coughing. He said he was ordering oxygen for me and would help make arrangements for me to be admitted to Dallas Rehabilitation Hospital Pulmonary Unit for evaluation.

Two weeks later I was admitted to DRH. They performed a complete pulmonary function tests and sleep studies done several nights in a row. It was obvious within the first two days that I was suffering from hypoventilation syndrome from polio weakened chest wall muscles. The pulmonary team recommended the use of a BiPAP ventilator supplemented with a low amount of oxygen. The remainder of my stay there was spent learning how to use the BiPAP, adjusting the settings for my optimum ventilation, trying different masks and head gear, and getting use to the whole routine.

After the testing and diagnosis, the doctor also removed me from the asthma medications I had been placed on earlier that year. He emphatically stated I did not have asthma. He said it was a common misdiagnosis by doctors who were not knowledgeable about post polio syndrome.

I slept better almost immediately. I noticed I could concentrate better and didn't wake up with the grinding headaches, And the coughing was completely gone.

The pulmonary therapists explained the coughing was from my bodies attempt to get rid of the CO₂ built up in the bottom of my lungs because I just couldn't move it out.

There is one test that is very important for a polio survivor to have done. It is called the MAXIMUM INSPIRATORY FORCE and MAXIMUM EXPIRATORY FORCE. We can often force ourselves to perform many pulmonary function tests that read as normal because they only have you do them once. If they had you do them several times in a row, the results would be very different. However, the MIF and MEF cannot be forced if you have weak chest wall muscles. It is a very simple test and does not hurt at all!

One more thing they prescribed for me was "CHEST WALL EXPANSION EXERCISES". This is done once a week with an ambu bag and a mouthpiece. I place the mouthpiece in my mouth and squeeze the ambu bag until it "hisses", releasing any air the lungs cannot hold. This fills your lungs to a normal capacity to expand the chest wall making it more flexible. I do this six times in a row, once a week. I also carry the ambu bag in my backpack to use if I start coughing while I'm away from my house. It usually clears the CO₂ from my lungs and the coughing stops.

Here are a few more things I strongly urge you to discuss with your physician: A regular flu shot as soon as they are available each year and a pneumonia shot. I have had pneumonia once in the last eight years and I recovered very quickly under my doctors care at home!

One thing that helped me just a bit before I went in to the hospital. One of our problems is we can't get the used air (CO₂) out of our lower lungs. Try breathing in through your nose as deeply as you can and then purse your lips and slowly blow out all the air you can. Try this several times and see if you feel a little clearer headed for a few minutes. No promises but it can't hurt!



Respiratory Failure in PPS - By Susan Callahan

Susan Callahan <suec@greenville.infi.net>

I am a polio survivor of 40 years. I had an experience of the most frightening kind in 1989-91. I would go to sleep at night only to awaken moments later and realize that I was not able to move my arms, hands or fingers, let alone breathe! I became so frustrated knowing my husband was laying right beside me and I couldn't awaken him to help me. After what seemed like a long time I would breathe and sit up in bed and cry. This scared me.... I didn't know why it was happening. Perhaps was it from the very emotional stress that I was going through at this time in my life? I was afraid to go to sleep or to take a nap in the afternoons. After several months of sleep deprivation. I met a dear friend who also has PPS herself that came into my life when I really needed someone that could help understand what was going on with my breathing. She suspected that my chest wall muscles were weakening by the PPS and that I should see a doctor.

I finally was able to get help from a doctor, who did a pulmonary function test and sent me to a Sleep Clinic. The Sleep Clinic is separate from any hospital and I just went in at night by 7pm. They want you to just do what you normally do on any given day. It does take time to fall asleep with all the gear on. At any rate it was hard on the first time. Where during the diagnostic procedure I stopped breathing 99 times in 1 hour. I now have had a Bi-pap machine with oxygen for 3 years. I had to go back a year and a half later and that's when they discovered I needed a oxygen concentrator with my bi-pap, which I have 4 litres. It has made a big difference to my life I have felt

so much better.

My symptoms were coughing, fatigue, sleep deprivation, headaches and overall pain in my body. I hope that this article helps someone who might be experiencing these problems. There are many people who can help you with your health problems and get equipment that will make your life easier. I am so grateful for the people and doctors that have come into my life. Now I am able to be here and do the things that I need to do at this time in my life.

A man in his 50's goes to his doctor, complaining about a pain in his leg that doesn't heal and wants a diagnosis and explanation.

The doctor checks out his leg, but can't find anything wrong. So he gives the old guy a full physical exam, and still can't come up with any possible explanation for the pain. The doctor hands the patient his bill and says, "I'm sorry but the pain in your leg is simply caused by old age, there's nothing I can do about it."

The old man replies with a look of disbelief, "That's impossible! That can't be!"

The Doctor says, "What do you mean? I'm the expert here; if you know so much, how can you say it's NOT old age?"

The patient answers, "I'm no doctor but it doesn't take a medical degree to tell that your diagnosis is wrong. Clearly you're mistaken. After all my other leg feels just fine, and it's the SAME AGE!"



HINTS, TIPS & BITS from Polio Survivors worldwide

Before I stopped walking and ended up in a scooter, I had a wheelchair I used for Malls and big stores. Otherwise, I walked. What was the turning point? I was getting weak but I pushed myself because I hated being in a wheelchair. At the end of a day when I had been to see my Dr. in Chicago, I collapsed to my knees and broke my femur. Because of THAT, I never walked again. The moral of this story is, don't continue to push yourself when you know you're getting weak. You know your body better than the doctor. If you fall and injure yourself, its no skin off his nose. YOU are the one who suffers! Not him! Listen to your body and do what's best for it.

Forget your pride and forget people who tell you to push beyond what your body can endure. A wheelchair is NOT a narcotic!! Wheelchair use or dependency simply means you've give your body permission to rest and recuperate. A polio body NEEDS rest and why people can't understand that is a mystery to me!

[Barbara Casson <Peptthewep@AOL.COM>](mailto:Peptthewep@AOL.COM)

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Scooters and Wheelchairs.

Several things to consider: Be sure there is someone in your area that is familiar with and can service and repair your equipment. I see this all the time. I'm asked to work on both scooters and power chairs that are "new" to me. It just takes more time to get parts and familiarize myself with the item.

Power chairs do get "approval" easier than scooters. [UK - wheelchairs only on NHS] If you have weakness in the arms power chairs are controlled easier (joy stick). Scooters have a tiller (like a bicycle) and require more physical effort to steer.

If seating comfort is a big issue a power chair has many more options available than scooters e.g. custom seating.

Both power chairs and power scooters are mostly 24 volts (two 12 volt batteries). Scooters usually use the smaller U1 batteries. Power chairs use U1's and two larger and heavier sizes. Batteries are either Jel (no maintenance) or lead acid (requires the addition of water from time to time). Good batteries last about a year (some longer) but a year is a good rule of thumb.

Tires come in different tread designs (some more aggressive for traction), some for quiet operation. They come in solid (one piece), tire and tube (can puncture... need to monitor air pressure... but is a softer ride), and a regular tire with a solid insert inside similar to the solid tire in ride.

Both are quite heavy. You need to consider how you can transport it. Van with lift? Station wagon, van, P/U truck with a ramp or a special hoist? A car with a LARGE trunk? Transporting is probably the biggest problem I have to help people resolve.

If you must, break them down to transport. The scooters usually break down into five components. Some power chairs fold (after removing the batteries) but most do not fold.

Scooters usually do much better outdoors and power chairs usually do much better in the house. How will you be using it most of the time?

It is a good policy to have your equipment gone over every six months by a qualified and caring service tech. Cleaning, lubing, eliminating battery corrosion, and a load test to verify the condition of the batteries will keep both you and your wheels happier.

I have been servicing all kinds of equipment for the disabled on a voluntary basis since I retired in 1994 (yes the agency is using me but I love to work with my hands and help my disabled friends in the process).

Hope this rambling(s) is of some help.

Jim in Akron, Ohio - Polio 1940 PPS 1994

[Jim Ellison <Jelli93266@AOL.COM>](mailto:Jelli93266@AOL.COM)

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Keep your extremities warm. Check them. You may not realise how cold they have become, especially if you use a wheelchair or scooter. Cold limbs do not function as well as warm ones. So think about warm clothing jackets and trousers, tights and socks, gloves, hat and scarf. Get brightly coloured ones that make a statement. I feel good about who I am.

Hilary - linpolio@legend.co.uk

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Place the cat bowls on something off the floor. I'm currently using a three-tiered wicker plant stand. The cat just stands on her hind legs to eat from the bowl placed on the 2nd shelf; she puts her front legs on the 2nd shelf by the bowl. She's been doing this for almost six yrs. and no ill effects. I never need to bend down to the floor to place or to retrieve the bowl. Feed my dog the same way - off the floor. BTW, I keep a flat pillow on the top tier of the plant stand and my cat jumps up and lies on the pillow to look out the window.

KATHRYN P ROSENTHAL, Michigan.

<KROSENTH@PRODIGY.NET>

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

I've arranged my house so I can slide out of bed onto the rug by the bed, under which is thick foam padding. So I can then crawl (no brace yet so can't walk w/o crutches, and am WOBBLY with them) into the bathroom, likewise padded. Makes morning routines SAFE and manageable. When I

go to a hotel (twice annually, with my job) I specifically ask NOT to have an accessible room, as they come with a huge bathroom with slippery-when-wet floor. I want a SMALL floor in the bathroom which I can navigate on crutches or, better yet, on the floor. I take some slabs of dense, thin foam with me to put on the bathroom floor so I can safely navigate around there, even in a hotel.

Just one home safety and mobility adjustment. I also have double railings on the basement stairs. Now that I have a brace (last 10 years, not before), I go down the stairs backwards, holding firmly to the railings. Come back up facing upstairs again. Works for me. Love those railings, installed in 1972 by my then-living husband and haven't worked loose a bit since then.

Jeanne W. Houghton, VA - [<Seacairn@AOL.COM>](mailto:Seacairn@AOL.COM)

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Does he take sugar? - A possible answer.

I've got a thought on enlightening those folks on two legs about folks on wheels. When they ask the standing person what the sitting person wants/thinks, etc, how about asking them to sit down, and then asking them whether they can still see, hear, think and talk while sitting down. Then let them know that - - to your and their amazement - - YOU TOO can think, talk, hear and see while sitting down, and can even answer questions!

Jeanne W. Houghton, VA - [<Seacairn@AOL.COM>](mailto:Seacairn@AOL.COM)

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Polio has made me what I am today.

I contacted polio in 1960. I'm beginning to realize polio also made me what I am today. I don't have a healthy body but because of this I have a strong mind and loving spirit. Aren't these attributes far more important? You sound like a fighter too. We're all survivors and it's a far greater feat to have survived the onslaught of such a major virus than to even climb Mount Everest.

Rene "Ed & Rene Butterfield"

[<joyll@centurytel.net>](mailto:joyll@centurytel.net)

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

I must tell you about myself and my experience with the Lincolnshire Polio Network. I had polio at age 3 in 1943 and lived a "normal" life with a weakened and smaller left leg. I was braced from age 3 to age 8. Surgery was performed and the brace discarded.

After suffering two falls in the 1990s and breaking a tibia and left wrist, PPS set in, presumably from the trauma and greatly lessened activity level during recuperation. I was braced on the left leg again in 1994 and must wear it daily. I also use a cane and forearm crutches when the cane is not enough.

During the past two years the PPS has worsened to the point where I had to have help in order to keep the strength and muscle tone that I still have. I was sent to a physical therapist who uses the Lincolnshire Post-Polio Library as her primary source in dealing with her PPSers. She espouses all the guidelines regarding sensible exercise and the work/rest routine. Pacing is the way to maintain what I still have without becoming an invalid. I feel fortunate in having been properly diagnosed so that I can keep functioning.

I maintain a schedule of daily activity that includes rest periods between each task or part of each task. In this way I do not suffer the extreme and debilitating fatigue that was ruling my life before I was properly diagnosed.

Please give my regards to all who have worked so hard to set up and maintain the Lincolnshire

Post-Polio Network so that people such as myself can live independently for many years to come instead of becoming a burden.

Patty Dilberto <pleed40@tdn.com>
Longview, Washington

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Getting socks and tights on and off.

Now I know some of you are going to say, getting tights/socks on and off is not the easiest of tasks when your feet are so far away from you, and you arms may be weak, but it's worth talking to an Occupational Therapist about what is available to help you. Oh! and ensure they demonstrate how they work - I well remember the fun we had when one lady brought a 'tight gutter' that she had been given, along to the handicapped club asking "has anyone any idea how this will help me get my tights on and off?". Everyone took part in the suggestions and we laughed all afternoon.

Hilary Hallam - linpolio@legend.co.uk

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Are you a Caregiver for a Polio Survivor on the Internet who would like to be in touch with other Caregivers? If the answer is yes then please email us for information about our PPS Caregivers list.

Dave VanAken <DVanAken@aol.com>

Gary Utz - <gutz@alitel.net>

[Editors note - For information on all Polio related Mailing Lists see our Website Directory - [Internet Discussion & Support Forums](#)

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

MY THIGHS WERE STOLEN FROM ME!

My thighs were stolen from me during the night of August 3rd a few years ago. It was just that quick. I went to sleep in my body and woke up with someone else's thighs. The new ones had the texture of cooked oatmeal. Who would have done such a cruel thing to legs that had been wholly, if imperfectly, mine for years? Whose thighs were these? What happened to mine?

I spent the entire summer looking for them. I searched, in vain, at pools and beaches, anywhere I might find female limbs exposed. I became obsessed. I had nightmares filled with cellulite and flesh that turns to bumps in the night. Finally, hurt and angry, I resigned myself to living out my life in jeans and Sheer Energy pantyhose.

Then, just when my guard was down, the thieves struck again. My buns [buttocks] were next. I knew it was the same gang because they took pains to match my new derriere (although badly attached at least - 3 inches lower than the original) to the thighs they had stuck me with earlier. Now my rear complimented my legs lump for lump. Frantic, I prayed that long skirts would stay in fashion.

It was 2 years ago when I realized my arms had been switched. One morning while fixing my hair, I watched horrified but fascinated, as the flesh of my upper arms swung to and fro with the motion of the hairbrush.

This was really getting scary. My body was being replaced, cleverly and fiendishly, one section at a time. Age? Age had nothing to do with it. Age was supposed to creep up, unnoticed and intangible, something like maturity... NO, I was being attacked, repeatedly and without warning.

During one spring, my attention was riveted to upper arms-female arms. I studied them from every angle, being careful not to raise mine in public nor flatten them too tightly against my body. In private I held them straight out and did endless circles that would have tightened my real arms but

did nothing for these Silly-Putty caricatures. In the end, in deepening despair, I gave up my T-shirts. What could they do to me next?

In short order, my right boob could hold a pencil (it seemed particularly cruel to take just one). And my eyes began to remind people that they needed a new pair of Hush Puppies. My poor neck disappeared more quickly than the Thanksgiving turkey it now reminded me of.

That's why I've decided to tell my story; I can't take on the medical profession by myself. Women of America, wake up and smell the coffee! That isn't really "plastic" those surgeons are using. You know where they're getting those replacement parts, don't you? The next time you suspect someone has had a face "lifted," - look again. Was it lifted from you? Check out those tummy tucks and buttocks raising. Look familiar? Are those your eyelids on that movie star? I think I finally may have found my thighs. I hope Cindy Crawford paid a really good price for them.

Author unknown. (You gotta love her, whoever she is!)

This appeared on one of the Polio lists but I forgot to copy the name of the sender and apologise for that.

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Tree cutting on the wood farm
or GETTING THE JUMP ON FALL

Well, it is a new week and I may have really achieved the impossible: I got the jump on fall!

What I really did was to hire some tree-fellers to take out four of the larger poplar trees in my yard. This gives me a substantial jump on leaf raking!!!!

These tree-monkeys knew what they were doing and the job hardly took any time at all. Of course, now I have piles of stove length firewood. FREE, COME GET YOUR FREE FIREWOOD HERE!

One aspect of having the trees removed is the excitement of watching these giants crash to the ground. It never fails to cause a momentous rush of adrenaline in me ---- the whine of the chain saw ---- the crack as the last piece breaks ---- the whooshing zing as it sings its way through the surrounding branches ---- the mighty rumbling whomp as it strikes the hard-packed driveway ---- finally, the snapping as the top splinters into pieces in a whip-lash action. Then you couldn't believe the monumental sigh of infinite relief that follows. The giant is down. All is well.

These guys can put the 50 foot downed tree anywhere they want. They attach ropes about 3/4 way up and pull the tree onto its mark. As it is cut it goes right where they want it.

The head guy couldn't come one day because (as he explained) he needed someone on the ground to pull the ropes as he cut. His ground-helper was not available on that day.

I responded, "Well, I could be your ground-helper. My cart [electric scooter] has a good electric motor and I could pull your rope."

He was very polite as he said he would wait for his regular guy, but his eyes opened quite wide in disbelief. I don't feel old or disabled. Maybe I look that way.

V. Sage <gingersg@juno.com>

<http://homestead.juno.com/gingersg/index2.html>

⚠ Currently Unavailable ⚠

P.O. Box 457, Entiat, Washington 98822

Author of 'Parents Blood', the story of her polio life with pictures of the times, and 'Entiat Remembers', pioneer stories and photographs from 1905.

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

CINQUAIN: 2

SEPTEMBER SPIDERS

Autumn
athletes falling
again, by r
a
p
p
e
l
i
n
g
down my windowpane, September
spiders.

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A SENSE OF HUMOR SOMETIMES SAVES ALL

Many a 'Depends' moment is shared when
Like broody hens, with canes in their clutches,
Folks arrive with wheelchairs, walkers, crutches
For support group meetings some saunter in
Talk, ponder, and share best tips for coping,
They network, discussing their common foe
Polio: the syndrome post-polio.
Inaccessible buildings and parking
Fret others. The war might be nearly lost
Decades after that first brutal battle
Until laughter erupts like a comet
Together, trouble-shooting... cage-rattle...
.. ing.. problem-solving.. (while counting no cost)
Inspiring... another... "Depends" moment!

[Translation - "Depends" are a trade name for incontinence pads, a 'necessity' when Polio Survivors get together and laugh too much.]

LaVonne Schoneman - © Copyright 1999 Email: [<Vonnejo@aol.com>](mailto:Vonnejo@aol.com)

HOW TO COPE - Series of Booklets.

Practical tips for Polio Survivors

16734 - 8th NE, Seattle, WA 98155



Lincolnshire Post-Polio Library Book Catalogue - [LaVonne Schoneman](#)

References TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

Inspiration, News and Knowledge from Polio Experience Network

PEN and Ink - No. 29: Summer, 1999

Eaves Droppings by Mouse in Corner - alias Marion Zoesch

Overheard at Polio Outreach of Spokane...

Those folks sure can get excited about things! One night one member, Occupational Therapist Marion Zoesch, spoke and then others shared their ideas for doing things more easily. Here is part of what they said:

Kitchen:

- Keep your small microwave or storable containers on a turntable on the counter.

- Store rarely used dishes in cupboards over the sink to be reached with a reacher.
- Put towels on the refrigerator, stove, etc. to wipe hands.
- Use basket trays, such as from dried fruit, to put hot pots on.
- Use Visionware (Pyrex pots and pans) so you can see, from a wheelchair, when things are boiling or cooking.
- If you use a wheelchair, remove the cupboard doors from the sink area if it is not an open sink.

Bathroom:

- Guardian Company makes a bath bench that sits in the tub and clamps on the side of the tub for firm support. It has a transfer end to sit down before moving over into the tub.
- A washrag you can sit on a counter can be used as a towel if you have problems hanging up the hand towel.
- To avoid having to get up during the night to go to the bathroom, use a bedpan and pour the contents into a small bowl or pan to be emptied in the morning.

Bedroom:

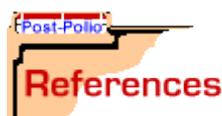
- Lower the closet rod by using a section of pipe with a chain and links hooked on the usual height rod.
- If the bed is hard to get out of, put the legs on 4x4" pieces of wood that have a depressed section to prevent it from slipping off. Keep a spare set to take with you when staying at a family or friend's house.
- In the closet or storeroom use plastic see-through boxes for storage so you won't have to look into boxes to locate things.

Miscellaneous:

- Plastic beverage bottles are lightweight to use for carrying water for plants, table, etc.
- A dog leash placed on the door is the best way to pull doors shut behind you if you use a wheelchair or crutches.
- Cover a piece of 4x4 or two 2x2s with contact paper and put it along a wall so that if you park your wheelchair against the wall you won't leave tire marks on the wall.
- Like to garden? Use raised beds, large pots or barrels to bring the garden up to easy working height.
- Have several reachers handy in various places to pick up dropped items.

Reproduced from [original article](#) in PEN and Ink - No. 29: Summer, 1999 with permission from Elinor E Young "Polio Experience Network" <polionet@polionet.org>. Elinor asked permission to use something from one of our newsletters and I asked her if she could suggest something from a current issue of their newsletter.

Newsletters from around the world arrive in our post or we are notified by email that they are online and can be read and printed off. Sharing information between groups is a great way to form links and new friendships. If anyone would like a Polio Survivor penfriend then let us know.



Lincolnshire Post-Polio Network Library - [Support Group Newsletters](#)
 Lincolnshire Post-Polio Network Library - Support Group Newsletters - [Polio Experience Network \(Spokane, Washington\)](#)

HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS HINTS TIPS BITS

ANSWER to [How many F's.](#)

There are six F's in the Sentence.

One of average intelligence finds three of them. If you spotted four, you're above average. If you got five, you can turn your nose at most anybody. If you caught six, you are a genius. There is no catch. Many people forget the "OF"s. The human brain tends to see them as V's and not F's. Pretty weird, huh? It fools almost everybody.

patty diliberto <pleed40@TDN.COM>



Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

Title: [Dr. Henry writes about Dorothea Lange](#)



Author(s): Henry Holland MD

Original Publication: Central Va PPS Support Group (PPSG)'s newsletter, The Deja View, in 1999.

Abstract/Extract: Several months ago, I was watching a program on the History Channel. The program focused on the 1930s, the Great Depression years. Dorothea Lange was the subject of the documentary. Lange achieved some fame as a result of her many photos of individuals who were directly affected by the poverty and deprivations of the economic depression. When discussing Lange's life, the narrator mentioned that Lange had polio as a child.

Title: [Polio Biology V - How To Avoid Limiting Variables While Exercising](#)



Author(s): Eddie Bollenbach MA

Original Publication: The Lincolnshire Post-Polio Library, 4th August 1999.

Abstract/Extract: It seems that we with PPS are in an awful fix. We have aches and pains and weakness which others can often counter with exercise. But we are told not to exercise. Rest is the prescription for us but often this, although necessary, results in disuse problems.

Title: [Polio Biology VI - The Polio War and Vaccine Strategy](#)



Author(s): Eddie Bollenbach MA

Original Publication: The Lincolnshire Post-Polio Library, 6th August 1999.

Abstract/Extract: The use of vaccines like the polio Salk vaccine to immunize an "individual" against a polio infection is only one of the considerations of an epidemiologist trying to eliminate the disease from a "population". The Salk vaccine produces humoral immunity so it protects the inoculated individual, but how well does it protect the "population"? How well and how fast can it diminish the prevalence of polio?

Title: [Strategies for Exercise Prescription in Post-Polio Patients](#)



Author(s): Anne Carrington Gawne, M.D.

Original Publication: Reprinted from POST-POLIO SYNDROME, edited by Halstead & Grimby, © 1995 Hanley & Belfus, Inc., Philadelphia, PA. Chapter

9, pp 141-164.

Abstract/Extract: Appropriate exercises have been shown to improve muscular strength and endurance, improve range of motion, and reduce functional deficits associated with many disabilities. In dealings with the patient with a history of polio, however, several questions arise: How much exercise is enough, and when is it too much? What kinds of exercise are best? What kinds of exercise may be harmful? And are there any guidelines to prescribe a safe and effective exercise program? To answer these questions, it is helpful to first understand the basic principles of exercise physiology, as well as the pathophysiology involved in post-polio syndrome. Following a discussion of these issues is a review of the literature on the effects of exercise in neurologically intact and post-polio individuals. Finally, a new classification system is presented, which will facilitate the prescription of exercise regimens that are both safe and effective in this population.

Title: [Dr. Henry writes about PPS and The Toddler Mystique](#)



Author(s): Henry Holland MD

Original Publication: Central Va PPS Support Group (PPSG)'s newsletter, The Deja View, in 1999.

Abstract/Extract: Several years ago at one of our support group's regular monthly meetings, we divided into three groups based on our age when we had acute polio. One group was age five and under, one was age 6 to 18, and one was over 18. We discussed our memories of the acute polio experience.

Title: [Electrodiagnostic Findings in 108 Consecutive Patients Referred to a Post-Polio Clinic - The Value of Routine Electrodiagnostic Studies](#)



Author(s): Anne C. Gawne, Bao T. Pham, and Lauro S. Halstead.

Original Publication: The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment Volume 753 pp 383-385 of the Annals of the New York Academy of Sciences May 25, 1995.

Abstract/Extract: Many patients with a history of polio develop new symptoms including weakness, pain, fatigue, and changes in function, or post-polio syndrome (PPS). Before a diagnosis of PPS is made, other diagnoses must first be ruled out. Assessment must be done in a comprehensive and coordinated manner. Therefore, as part of our routine evaluation, we do an electromyogram/nerve conduction study (EMG/NCS) on every patient. During examinations on our clinic patients we began to notice (1) electrodiagnostic evidence of polio in limbs not previously felt to be involved; (2) a normal EMG, or evidence of another disease; and (3) EMG evidence consistent with additional neurological lesions, including compression neuropathies, peripheral neuropathies, and radiculopathies. A prospective study using a routine, standardized four-extremity electrodiagnostic protocol was done to quantify the frequency of these occurrences.



The Post-Polio Institute "Protein Power" Diet
Dr. Richard L. Bruno - Director The Post-Polio Institute
Englewood Hospital and Medical Center

"Breakfast? Sorry, don't have the time. In the morning there's too much to do, like showering and

dressing and getting to work. I grab a cup of coffee (or two or three) and maybe a donut at work..."

"Lunch? Don't think so. I'm still catching up from my late start in morning. I grab a cup of coffee (or two or three) and maybe wolf down half a Big Mac..."

"Dinner? I'm either too tired or hungry as Patton's Third Army. I either defrost a piece of pizza and drag myself into bed or eat everything that isn't nailed down!"

"So why am I totally exhausted but can't stop gaining weight?"

Americans are not very good at taking care of themselves. American's with disabilities are no better, and maybe a little worse, at self-care because it takes so much time to do things non-disabled folk do in a flash, like showering and dressing. There's hardly any time or energy left for planning meals, shopping, cooking. . . or even eating.

However, people with disabilities pay a higher price for a lack of self-care than do people without disabilities. For those who use wheelchairs good eating habits and proper nutrition are essential, not only for general good health, but also to prevent bowel and urinary problems, to prevent weight gain, and to maintain a decent level of energy.

Polio Survivors vs. Breakfast. One group of people with disabilities shows the consequences of poor eating habits: North America's 1.8 million polio survivors. Nearly 76 percent of polio survivors experience Post-Polio Sequelae (PPS), the often disabling symptoms -- fatigue, muscle weakness, joint and muscle pain, cold intolerance, and difficulty sleeping swallowing, breathing -- that occur about 40 years after their original bout with polio.

PPS are requiring polio survivors to use new assistive devices or aids they discarded years ago, like braces, canes, crutches, wheelchairs and scooters, to slow down and to rest during the day. The problem is, polio survivors are Type A, hard working, pressured, perfectionistic super-achievers, who have pushed themselves beyond their physical limits and allow no time for self-indulgent luxuries, like food.

Polio survivors don't want to slow down or rest, not only because they're afraid if they are less Type A people won't like them, but also because they are afraid of gaining weight if they become more sedentary. But they shouldn't be afraid. Food is good! Eating properly doesn't lead to becoming fat, it actually reduces PPS symptoms.

Dr. Susan Creange at The Post-Polio Institute discovered that polio survivors with blood sugar levels in the low normal range have as much difficulty paying attention and concentrating as would diabetics with blood sugars as low as if they had taken too much insulin. "Polio survivors' 'Type A diet' -- three cups of coffee for breakfast, skipping lunch and eating pizza for dinner -- is actually starving their nervous systems' and causing PPS symptoms," says Creange. The relationship between diet and PPS was seen in the 1998 National Post-Polio Survey: the less protein polio survivors had at breakfast the more severe were their daily weakness and fatigue.

Why do polio survivors function as if they have low blood sugar and report more symptoms when they don't eat protein at breakfast? Because polio survivors are running their nervous systems on "half a tank of gas." About 50 percent of all brain stem and motor neurons were killed decades ago by the poliovirus. What's worse, the metabolic apparatus, the internal power plant, of the neurons that survived the original poliovirus infection was severely damaged. So polio survivors have been running their full-tilt, Type A lives on half the normal number of neurons, neurons that are less able to use their only source of fuel, blood sugar. Dr. Creange found that even normal levels of blood sugar were not enough to fuel the remaining poliovirus-damaged, metabolically impaired neurons. And that's where protein at breakfast comes in.

Protein: The fuel that keeps on giving. Protein provides a long-lasting, "slow-release" supply of blood sugar throughout the day. Polio survivors who had protein for breakfast reported less PPS symptoms because their fuel tank stayed full longer. They didn't need to "fill up" throughout the day with short-lasting sugar fixes, like soda or candy bars.

When we ask our post-polio patients to eat protein every day at breakfast, and have small, non-carbohydrate snacks throughout the day, they report an almost immediate reduction in nearly all the symptoms of PPS, especially fatigue. But "protein power" diet is neither a fad nor a miracle: it's just common sense. No engine can't be expected to run without gas!

And having protein at breakfast isn't good only for polio survivors. Mom was right: breakfast is the most important meal of the day for everyone, but especially for polio survivors, who use more energy just getting showered and dressed than does a non-disabled person who runs a marathon. We've found it's a good idea to eat breakfast before showering to "break your fast" and fill your gas tank before your neurons need the fuel.

Our patients worry that using a wheelchair, resting more and having breakfast will cause them to get fat and have more PPS symptoms. A four-year follow-up study found that U.S. and Swedish polio survivors, living their typical Type A, "use it or lose it" lifestyles without using new assistive devices or resting, lost equal amounts of leg muscle strength, about 2% per year. However, when subjects from the two countries were looked at separately, the Swedes gained only 6 ounces per year, while the Americans gained over 2 pounds; that's 220% more weight! Although weight gain alone is not responsible for the progression of muscle weakness in polio survivors, it is Americans' high fat, Big Mac diet that causes them to get fat. You can fuel your neurons, feel stronger and less fatigued without gaining weight, if you choose low fat, low cholesterol sources of protein. In fact many of our patients, even as they slow down, sit down more, and use a scooter, lose weight (about a pound per week) if they eat more protein, reduce portion size and limit carbohydrates.

We aren't recommending one of those "all protein, no carbohydrate" diets. We aren't recommending a "diet" at all, but a method for eating healthy every day. We suggest 16 grams of protein at breakfast; that's about 1/4 of the daily protein requirement (70 grams) for a 150 pound person. (Always check with your doctor, especially if you have kidney problems, before changing your diet and ask to have your cholesterol measured at your yearly check up.)

Look at the list protein-rich foods and select different breakfasts so you can have a variety throughout the week. Remember, you want foods that have more grams of protein than they do fat.

Eat well and be well!

PROTEIN-RICH FOODS: You need 16 grams of low-fat protein at breakfast		
	Protein (grams)	Fat (grams)
Great:		
Cottage Cheese Lite 1 cup	28.0	2.3
Salmon (3 ounces)	17.0	5.4
Yogurt (8 ounces)	12.0	4.0
Tofu	10.0	5.9
2% Milk (8 ounces = 1 cup)	8.0	3.0
2 Egg Whites	6.8	0.0
Bagel	6.0	1.4

	Egg Beaters (1/4 cup) [cholesterol free egg substitute]	5.0	0.0
Higher Fat:			
	Swiss Cheese (1 ounce)	8.1	7.8
	Slim * Fast "Meal On-The-Go"	8.0	5.0
	Lite 'n' Lively Cheese (1 ounce)	6.4	4.3
	Hard Boiled Egg	6.1	5.6
	Cream Cheese (Lite) (1 ounce)	2.9	4.7
Lower Protein:			
	Quaker Life	5.2	1.8
	English Muffin	4.5	1.1
	Oatmeal (1 package)	4.4	1.7
	Cheerios (1 1/2 cups = 1 oz)	4.3	1.8
	Shredded Wheat (1 ounce)	3.1	0.6
	Total (cereal) (1 cup)	2.8	0.6
Not Great:			
	Egg McMuffin	17.0	32.0!
	Bacon (3 strips)	5.8	0.4
	Peanut Butter (1 tbsp)	4.6	8.2
	Coffee?	0.1!	0.0

POLIO SURVIVOR'S POWER BREAKFASTS

12 minute breakfast: 2 hard boiled eggs (12 g) and an English Muffin (4.5 g)

8 minute breakfast: 3 scrambled egg whites (10 g) and a bagel (6 g)

6 minute breakfast: Toasted bagel (6 g), lite cream cheese (3 g) and 1 glass 2% milk (8 g)

4 minute breakfast: Yogurt (12 g) and 1 ounce of low-fat cheese (6 g)

2 minute breakfast: 1/2 cup low-fat cottage cheese (14 g)

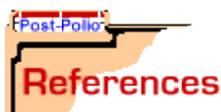
CHECK WITH YOUR DOCTOR BEFORE CHANGING OR STARTING ANY DIET!

Dr. Richard L. Bruno is Director, The Post-Polio Institute
Englewood Hospital and Medical Center, Englewood, New Jersey, USA.
and

Chairperson, International Post-Polio Task Force

Phone: +1(201)894-3724 Toll Free: +11-877-POST-POLIO Email PPSENG@AOL.COM

The above article first published at <http://www.spinewire.com/h_bruno_eat.htm>



Articles by Dr. Bruno can be found in our Lincolnshire Post-Polio Library. See the catalogue for:

[Bruno, Richard L., Ph.D.](#)

See also our Directory entries for:

[The Post-Polio Institute, Englewood \(NJ\) Hospital and Medical Center](#) Dr.

Bruno

[The Harvest Center](#) Drs. Bruno and Frick.



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The Secretary, Lincolnshire Post-Polio Network

PO Box 954, Lincoln, Lincolnshire, LN5 5ER United Kingdom

Telephone: +44 (0)1522 888601

Facsimile: +44 (0)870 1600840

Email: info@lincolnshirepostpolio.org.uk

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