The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 2 - Issue No. 12 - August 2000

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Editorial by Hilary Hallam

It's now August as I finish this newsletter and I did think we would be in the middle of summer by now! The trip went very well, report and diary starting page 4. The only changes I would make are more days at each part of the journey to allow more time for rest to restore energy levels.

Back to the UK and as you can imagine a few days of doing virtually nothing. Gradually picking up on the workload and a little concerned to find that it is now taking me about 20% longer to do jobs compared with before the trip, e.g. more rest time needed in between parts of doing things. If you would like to help with any aspect of our work then please get in touch. There are many small jobs that can be done without coming to Lincoln, e.g. reading a polio survivors book / medical article / other groups newsletters and writing a precis on it. Or come to Lincoln and help in the office with filing / databasing / printing envelopes / making up new information packs / etc. Or maybe you have some ideas that we have not yet thought of.

The AGM is now just over 8 weeks away - information on the back pages. I would ask that all members return the nomination / voting slips as soon as they can so that we have as much advance notice as possible on numbers etc. If you would like any more information please ring. Friday and Saturday evenings at the Holiday Inn Express last year were great with lots of information being shared, and lots of laughter. Comments afterwards were that this was the first time many had been with other polio survivors and it was such a relief to know that they really were not alone with their problems and how easy it was to discuss things openly with another polio survivor that you had been keeping to yourself for a long time. Also it's good for carers to get together with other carers. We look forward to meeting more of you, your family and friends. Everyone is welcome to the events following the AGM.

Dr. Betty Dowsett to speak in Lincoln. MESH - ME Self Help - group in Lincoln have arranged for Dr. Betty Dowsett to speak in Lincoln on **Saturday 16th September 1.45 to 4.00 p.m.**, at the Ruston Marconi Sports Ground. Cost is £1 includes tea coffee and biscuits. This is on the A1434 just west of the junction with the B1190 to Doddington. This will cover ME and polio. All LincsPPN members friends, etc are welcome. Dr. Betty Dowsett is a member of the LincsPPN and at the last minute was able to join us at last years AGM for a few hours. She is a retired microbiologist who has worked with polio and ME for many years and her talks are excellent. The venue is only a mile from my house so you could meet here earlier and go together. MESH would like to know numbers so please can you ring or drop me a line if you are coming.

In the last issue I told you about our new **Polo shirts by Snickers Workwear** who donated the artwork of our embroidered logo. Richard and I wore ours at the Conference and later and they were much admired. They are white polyester cotton 65/35%, collar, three button, shirts with a breast pocket located embroidered logo of 13,500 stitches as the front of this newsletter [refers to the hardcopy edition of this newsletter]. Sizes available are S 34 - 36, M 37 - 39, L 40 - 42, XL 43 - 45, XXL 46 - 48, XXXL 49 - 51 and are priced at £10 with the Logo on, and £13.50 if you wish your Christian Name to appear below this. Please send your orders and cheques, which include postage direct to you, to the LincsPPN.

Meeting with LHA and their GP advisor. I had a meeting last week with Deborah Jaines of Lincoinshire Health and Dr. Calverley their GP advisor. He is also a co-chair of a PCG. After some discussion Dr. Calverley said that if a polio survivor went to him with symptoms of pain, weakness, fatigue and functional decline whether or not he could find weakness with Manual Muscle Testing he would refer them to see a neurologist. To get better services we would need to work with the Neurological Clinic to agree on what improvements could be made. Then formulate a business plan to put forward along with all the others coming from other departments requesting funding for the changes. We would need statistics of how many polio survivors there are in Lincolnshire, evidence on the percentage likely to need these services, what percentage this was of other neurological conditions and what this would cost.

Dr. Calverley said that initially this would be a substantial cost as most patients knowing of this new clinic would wish to be reassessed. There would be no saving on money being wasted on the 'rounds of the hospital departments' until such time as all current patients had been through the clinic.

We are suggesting a permanent and holistic Lincolnshire Neurological Assessment and Case Managing Clinic for all neurological conditions, with patients that need specialist help being referred to the appropriate specialist Neurologist / Hospital but where possible treatment being provided locally. The Neurosciences Forum has arranged for a Questionnaire to be sent out to all GP's - How many patients have you with the following conditions? Figures are hoped to be in by the end of August. At the next meeting of the NF - Aug 16th - we will be discussing the result of this meeting and requesting a meeting with the Neurological Clinic.

Remember this is your newsletter and we welcome stories, hints and tips and other bits from our members. If you have any suggestions as to subjects you would like to see articles on then add that to your AGM slip. We look forward to hearing from you.

Summary of Anesthesia Issue for Post-Polio Patients - Updated 13th June 2000*

by Selma Harrison Calmes, MD

Chair and Clinical Professor of Anesthesiology, UCLA.

Polio results in wide-spread neural changes, not just destruction of the spinal cord anterior horn cells (motor nerves) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of current literature and clinical experience with these patients.

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the polio virus actually lived at the neuromuscular junction during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which makes for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intra-op helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.
3. Succinylcholine often cases severe, generalised muscle pain post-op. It's useful if this can be avoided, if possible. There is not experience with Raplon yet.
4. Pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to 'spill-over' of the inflammatory response. Spinal cord 'wind-up' of pain signals seems to occur. Proactive, multimodal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.
5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn 'spills over' to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.
6. Patients who use ventilators often have worsening of ventilatory function post-op, and some patients who have not needed ventilation pre-op have had to go onto a ventilator (including

long-term use) post-op. The marker for real difficulty is thought to be a VC <1.0 litre. Such a patient needs good pulmonary preparation pre-op. Another ventilation risk relates to obstructive sleep apnea in the post-op period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

7. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

Please feel free to contact me if you have any questions. This brief summary may not cover everything you want to know.

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* This is an updated summary of a presentation given by the author at the GINI/IPN Eighth International Post-Polio & Independent Living Conference.

Trip to the USA 2000

by Hilary Hallam.

Firstly, can say a big thank you to all the people who helped make this trip possible. Without the donations of money, the use of Richard's truck, the meals we were given and taken out to, the sightseeing tours, comfortable beds for the night etc., this trip - as with the four previous PPS conferences I have attended - would not have been possible. Lots of discussions took place with polio survivors, PPS specialists and PPS support group leaders all sharing information on how we can help polio survivors with post polio symptoms improve the quality of their lives and the services they are getting and get this message out across the world. So as always, watch this space.

Secondly for those on the Internet I must apologise for not writing this up and posting it in sections as I travelled. I do not have a lap top computer and the first thing learned during this trip is that I had less energy available. I use an ergonomic keyboard in the U.K. and that allows me to type for longer, palm resting my left hand, with my wrists in line with my arms. Typing on a straight keyboard with twisted wrists is much harder and a few lines was all I could manage when I could borrow someone else's computer. I tried writing it out long hand but that was also tiring and I had to make do with notes on each day and as fatigued even that was difficult.

The main reason for the trip was to speak and hear others talks at the 8th GINI International Post-Polio and Independent Living Conference in St. Louis, Missouri. Having a presentation accepted at such a prestigious conference was a great privilege. I was asked to do a 12 minute summary of the presentation on the Thursday at the end of a talk by Dr. Anne Gawne <acgawne@dhr.state.ga.us> and her team from the Roosevelt Warm Springs Rehabilitation Institute Post Polio Clinic, on the roles of a multi-disciplinary PPS clinic, as well as the full hour presentation on Saturday. More on this later.

To make most use of the cost of the flight to the States I attended other PPS events, talked with many medical professionals and as many polio survivors as I could fit into the itinery. Nearly all polio survivors I met agreed that sharing information across the world is paramount to our learning about our condition. We can benefit so much from listening to and watching how others manage activities and it is easier to relate your problems to how someone else copes than it is to be told you have to do this. There is much advice out there and it is up to you when and if you take any or all of the advice given. Ultimately, you have to make your own decisions. No-one can make you do anything you are not ready to do. I would however like to comment that the more I have learned and the more I have put into practice, using aids and taking advice, the better I have managed my life and the more I get out of it, despite some deterioration. I only wish I had learned about PPS years earlier.

The main theme that came through from others every day - from PPS Specialists and Polio Survivors who are NOT in denial of the existence of their own PPS symptoms - is that we can manage our lives better doing MORE each day of what we can do and want to do, and delay further deterioration if:

- We learn about polio and its late effects and tactfully provide health professionals that we see - who probably have not had more than a few minutes lecture on the condition of polio and nothing on its late effects - with good quality medical articles on polio and PPS.
- We assess ourselves and our lives from pre-polio, through polio and recovery, our stable period of functioning, and look critically at how we do our daily activities, when these started to change, how they have changed and provide this information in an easily assimilated format, e.g. Polio Time Line and a short double spaced list of specific changes of action that show the weaknesses we are reporting.
- We use aids and equipment to prevent or lessen repetitive action and overstraining of weak and weakening muscles.
- We listen to our bodies and let the pain and fatigue we get be our guideline to what is too much at once - halving the time we do activities till we find out optimum working times. For instance this could vary from minutes when doing a repetitive action like dusting or hoovering to an hour when typing using an ergonomic keyboard and palm resting and typing in phrases.
- We then pace out our activities with working periods and rest periods with the 'working' times getting shorter and the resting times getting longer.
- We give ourselves 10 energy tokens a day and 70 a week - energy tokens are personal and only you can decide what a token, half token is for you.
- We plan our week ahead fitting in what we have to do, then what we want to do, and remembering that a 15 token day to take in a hospital appointment means that the day or days after you will have less tokens to play with.
- We communicate with our family, friends and work colleagues - and this means taking time to explain what polio and post-polio are and how with a little help you could improve your lifestyle; and not only tell them how we feel about what is happening but probably more important let them tell us how what is happening to us affects them and how they feel.
- We join support groups - to get newsletters, to go to meetings, to find penpals with similar interests to you, on the net, on the phone, by post. in person, just one or all of these. Not being 'alone' with our problems anymore and being able to 'let off steam' to someone who understands, reduces tension. We must ask questions that concern us and share the information received, it is unlikely that you are the only one with that question.
- And probably the most important of all is understanding that it is not 'giving in' to change our lifestyle and use aids that are recommended, it's sensible advice. Living with a chronic condition means managing your life to the best advantage for yourself, your family and friends. Being stubborn and struggling in pain and causing yourself possibly further unnecessary early deterioration, pain and fatigue does not help you, or help your family and friends cope watching you suffering.

BUT TO ACHIEVE THIS WE NEED A full, holistic, multi-disciplinary assessment by specialists with knowledge and experience of polio and its late effects.

Recognised PPS Clinics in many parts of the World provide this and it's well documented in medical articles on assessment for PPS as necessary.

UK polio survivors need a full assessment that categorises all our symptoms. Whether they are PPS, other conditions that affect us more because we have polio damage to our body, or other non related conditions.

PPS is by diagnosis of exclusion - symptoms that we have are also seen in many other conditions - its important that other conditions are not missed.

We need a clinic or dedicated team that can case manage us and ensure that if we are sent to other specialists that the full implications of our polio are passed on, e.g. our tolerance to some drugs and anesthetics being considerably lower than the 'norm'. Our GP's do not have the time or resources to keep on dealing with new symptoms, more deterioration, they can only refer us on to specialists. With each new symptom we seem to have to start from scratch waiting for that appointment, then the tests, then the results. We should be being referred back to the main clinic that is case managing us for a review.

The earlier we are provided with high quality advice, treatment, aids and equipment, the earlier we can start to manage our own lives to greater advantage. We all want to live as long as possible doing as much as possible but our polio and its late effects have changed the plan we had in mind. We have been lucky in that many of us did recover and have lived better lives than we would have had we stayed as we were at the initial onset of our polio but this is no consolation. We have already been through the 'mill' once with our polio and we did not know about or expect late effects to drastically alter our lives starting for many of us as early as our 40's.

Almost every UK member or Polio survivor from the UK that gets in touch with us has done the 'rounds of the hospital departments' with as much as 80% of the cost of these appointments and tests a total waste of money.

Many are contacting us with copies of reports from Consultants for Court Cases or Benefits Doctors that have assessed them. These reports show a considerable lack of knowledge of polio and its late effects and often contain inaccurate statements and where MMT has taken place grossly overgrade actual muscle ability. In some cases the Benefits Doctor's one off home visit report disagrees with that of other health professionals, including Consultants that have spent time assessing, testing and diagnosing. Many are being put through extra stress and financial hardship as they struggle with their PPS appealing decisions and going to Tribunals.

If multi-disciplinary assessment was available then correct and comprehensive medical reports would be available so that we could get the appropriate aids, equipment and benefits that we need to manage our lives.

As this is not available then together we must campaign to have the wasted money re-routed and now. We need your help to send us some good examples showing the above.

Diary of the Trip.

Outward Bound.

I left Lincoln on 23rd May 2000 handing over a huge box of paperwork to our Chairperson Christine Ayre and Committee Member Myra McManus and drove to Kingston-upon-Thames, Surrey to stay overnight with Tony Meladio. Tony came with me to Gatwick Airport the next day and valet parked my car at his house for the duration of my trip. Gatwick Airport parking would have cost £180!! He later flew to St. Louis for the GINI conference and Branson and then visited with other polio survivors in the U.S. before returning home and will be writing his story for the next issue.

I booked a British Airways flight through www.airnet-uk.com [since this was written the domain mentioned has ceased] as it was slightly cheaper on flight cost and insurance, but on checking with BA found that my taking my electric scooter had not been recorded! However with excellent help from a BA rep on the phone in Scotland, I was soon able to give them the information they needed on the scooter. I asked to use it for as long as possible and when I arrived early at Gatwick and checked my suitcases in I was allowed to retain the scooter to go to the South Terminal to collect my International Driving Licence from Europcar and thank Janine who arranged to do this out of normal hours for which I am most grateful. I then returned to the Departure Lounge to look at the shops and suddenly was surrounded by BA staff who wished to make my and their life as easy as possible in getting my scooter loaded on the aircraft. They offered me the use of the Club Lounge and asked if they could collect my scooter and me in an electric buggy 90 mins pre flight time. I agreed although in Tampa when returning we kept our scooters right to the gate and only gave them up as we pre-boarded.

In the Club Lounge I enjoyed a glass of fresh orange and was soon chatting with a lovely lady from Switzerland travelling with her grandson to America and yes - she had had polio too. At the age of 16 she became paralysed and was unable to become the ballerina she had hoped to be. She recovered well, had heard of post-polio but said she had no problems. That *was* until she read a bit of information on the symptoms and then she said she had been having days of total fatigue when she could not get out of bed, and had had swallowing problems ever since polio. A chance meeting. She was going to be staying south of Atlanta later on in the summer and I was able to give her Dr. Gawne's address and phone number.

The flight was a long nine and a half hours and I spent much of it chatting to Marion Woodward from Florida who was travelling wearing a body brace following an accident a couple of years ago. We have emailed and spoken on the phone since and Marion has passed PPS information to her relatives that are medical professionals. We did a backwards loop just before New York to wait for a thunderstorm to pass, and later many nearby had a giggle when we were coming in to land and as we hit a large white fluffy cloud there was a clunk and Marion said, "gosh that was a hard cloud", later realised to be the undercarriage.

'Base Camp' Tampa, Florida.

It took a long time to get my cases - although my scooter was back and working almost immediately. Then I was through the doors and met by Richard Boone on his scooter. He and I had been corresponding almost daily on the Internet for two and a half years and he said if you fly into Tampa we can drive to St. Louis in my truck and visit Warm Springs and others en route. This was the most cost effective way of meeting more people so I readily agreed.

Richard caught polio at the age of 6 months in 1951 and wore a long and short leg brace but as with many got rid of them by his late teens. In the last few years he has had to retire as a jeweller and as he become weaker in arms and legs get a scooter and hoist for his truck. Just over a year ago following a fall where he broke a bone in his hand he decided that he needed a full left leg caliper again. His 'better' right arm and leg are also weakening. He has also developed a benign essential tremor in his left arm which varies from nothing to moderate at different times of the day (anyone else with this please get in touch).

We drove off and within minutes we were over water and I saw a pelican fly past - something I had wanted to see - and later on the Skyway over Tampa Bay I saw many more pelicans. We were soon back at his home in Palmetto, suitcases unloaded, and we crashed out in a cool breeze thanks to the air conditioning.

Next day we went in search of some fruit juice and the day after we visited a couple of small stores. This does not sound much but we were still in 'catch up on energy tokens mode' and that was all the energy we had available, and overdoing would have meant less energy for Saturday and Sunday. Luckily chatting does not take up too much energy.

Saturday was the Florida State Muzzle Loading Championship at the Wishful Thinking Farm at Myakka City, Florida. Richard was a founding member and competed in shoots till 1996. He has built five Pennsylvania 18th Century style long barrelled flintlock rifles and three pistols and has done quite a bit of restoration work on antique originals. We had packed a few snacks and drinks in the cooler bags and off we went. The last few miles on sugar sand tracks, with many ruts. We arrived at the shoot situated in woodland and although it was about 90 degrees, the trees gave us some cover and there was a lovely breeze. We watched the competition, and spent some time talking to Steve and Jean Knight who have a Suttlers business. Steve makes arrowheads and does flint knapping and Jean makes clothes for re-enactments. Steve later gave us a demonstration of hawk and knife throwing.... No need to call the RSPCA, hawk is tomahawk... yes I wondered too. What was the most important thing I learned from this day? When you go to a Hooter on a Scooter don't leave the seat back up facing the sun. I had shorts on!!!! Hooter is a lovely name for a wooden hut placed lovingly over a deep hole. I drove back to Palmetto and was relieved to find that the measurements passed to me were correct and that the truck fitted me, leg length, steering wheel height and sitting position. We had already packed for the trip so later that evening we loaded the truck ready for the start of our 3,000 mile journey the next day.

The Road to St. Louis via Trenton, Florida.

Sharing the driving and taking breaks whenever we felt the need, we set off on Sunday and drove 4 hours to Trenton Florida to the wonderful log cabin that Art and Nancy Coburn built and had lunch with visiting family. Chicken and corn on the cob and relish... 12 oz of fresh cranberries, one apple and one orange, all finely chopped. Believe me it's delicious. Art is the polio survivor and also has many chemical and food allergies. He cannot tolerate ordinary water and has to have reverse osmosis water in the house, not eat some foods, rotate other foods and apart from taking Nancy to work and other short trips locally - avoiding tar laying etc - he has to spend most of his time at home. He has a large workshop where he makes wonderful wooden objects - like wooden goblets, banana hangers, removers for stuck toast in toasters (see page 25), items for the house and church, when energy permits.

Monday started with a turkey sausage, cranberry and strawberry pancake breakfast and then Art had arranged a surprise for us. Randy Disch arrived to give us both an hour long massage. Not having had one before I did not realise how much of me would be massaged! It was very relaxing although I explained to Randy that I would be fatigued afterwards as he was using my muscle energy. When I went to the loo (John, toilet) later I did not have the arm energy to push myself up and had to get onto the floor and crawl to the bath to get up. Much laughter at my expense which I did not mind as being with other polio survivors it really was funny at the time. It was another 'scientific overdoing' experience to add to my store of knowledge about me - oh and both Richard and I crashed out for a couple of hours afterwards. Randy later told Art that he learned a lot about PPS from us and was surprised at the fatigue we got from the massage but would be learning more and putting what he had learned into practice with other polio survivors.

Bob Vaughn, Art's Chiropractor called after lunch and we chatted about PPS. I had not put my KAFO on after the massage and I was asked to stand and walk and then put my KAFO on to see the difference. He was very impressed and came and stood behind me examining various bits of my back. He told me that my right shoe build up that I had had done was 2 millimetres too much (it should be 10mm not 12mm). He was surprised that having told the Orthotic department in January after I got my KAFO that I had realised there was a difference, that I had had to have this done myself. He explained that the difference on the leg length doubles at the hips. This, dropped feet, unnatural gaits etc that are corrected can give us huge benefits to our health and he stressed the need for correct physical assessment to pick up all these points.

Art & Nancy took us for a drive to the *'Way down upon the Suwannee River'* which is not far from their house - much wider than I expected and we saw many different types of boats go past including jet skis and water skiing. The rest of the time we spent chatting, eating and catching up on email.

Stop-off at Warm Springs, Georgia.

Tuesday we drove to the Roosvelt Warm Springs Rehabilitation Institute in Warm Springs, Georgia. We booked in to a very nice room and then crashed out for a few hours. After a snack we went on a scooter ride round the extensive grounds and lake - I got eaten by mosquitoes - and we met with Dr. Gawne and chatted PPS.

Wednesday at breakfast I followed a man who had bacon, cheesy scrambled eggs, sausage, biscuit (savoury scone), pancake and syrup on one plate and then said 'yes, cover it all with white gravy' (white sauce made with pork bits)!!! We then went to Dr. Gawne's office where she let me get my email on her computer and organised the day for us. We went and visited the Orthotics Department and saw how people are assessed and Orthosis made. They also took great interest in my Ambroise Orthosis and were soon peering into the mechanism to see how it worked, agreeing that it would help some of their clients. We then had lunch with Dr. Gawne in the restaurant, the same room where President Roosevelt held many dinners.

Myrna Whittiker and her husband from Stone Mountain Georgia arrived and we were taken on a tour round the grounds and church. It gave us a strange feeling seeing the pew in the church where President Roosevelt sat when he was there. The swimming pool is being renovated - something we would all have loved to have swum in. The four of us then went to the village of Warm Springs and had a drink watching the world go by - sitting outside of Country Cousins - owned by Phil Drummond, brother of Professor Mike Drummond from Macon GA, who is a polio survivor we correspond with a lot on the Internet. We were all given a lovely present of a teddybear - mine has twig angel wings - which will remind us of our visit. We chuckled when Phil told us that having met him we had seen the best looking of the two brothers.

We then returned to our rooms for a rest before Dr Gawne took us out for a drive over Pine Mountain in her open topped Volvo to a wonderful country style restaurant on the mountain with a breath-taking view. Being honest I could not fold myself up enough to get in the back seat of the Volvo but with the top open it was easy to step in and out. We had a lovely meal, chatting as ever about PPS.

Thursday after breakfast we went to Dr. Gawne's PPS Clinic and with grateful thanks to her first polio patient, sat in on the assessment. Dr. Gawne uses Manual Muscle Testing putting on the 50lb pressure, repeats actions that she is told cause muscle weakness. She explained that it is not always possible in the time or examining room situation to test all the symptoms reported but explained that it is imperative that "doctors listen to what polio survivors say about repeating or sustaining muscle action causing weakness" and that the other disciplines take up these points assessing the actual doing of activities that cause weakness. She was surprised when we told her that most of our difficulties occur because we only get single action MMT and this is taken as a true record of our muscle ability. She has agreed to write an article for us on how an average patient goes through assessment at her clinic. We then had to leave and sharing the driving had lunch in Tennessee, as we drove across the thin bit of Kentucky had Dinner, and stopped for the night just into Illinois.

Stop-off at Mount Vernon, Illinois.

Friday morning we drove the few miles from Marion to Carbondale IL and rang Annette Hanna who was thrilled to hear I had arrived in the States safely and then happily stunned when asked if she would like to put the kettle on for a coffee. We got directions to her house in the woods and were soon having that real live hug that is the last bit of meeting via the Internet. First it's emails, then a photograph, then a phone call and the voice, and lastly it's meeting in person. We all talked non-stop about polio, PPS, and life in Carbondale in the 70's, where all but me had been, flared trouser wearing hippie types - now that's one photo I would have loved to have seen.

We then drove on to Mount Vernon IL. where Richard was born, and where Mike his oldest friend had paid for us to stay at the Economy Inn. We unloaded the cases and went to visit Mike, his wife Vicki and son Chris. Illinois is called the land of Lincoln because Abraham Lincoln, the 16th president of the USA spent his youth and practised law there. Vicki works as a Class Assistant at the Lincoln School opposite her house and they would now like to start up regular contact with a school in Lincoln UK.

As with every part of the trip the first thing we did was nothing but chat to catch up on energy levels. The next day we had a tour round the town and visited Wal-Mart and Richard exchanged a gift voucher for two pairs of lightweight jeans.

The next day we were going to visit the country Graveyard where three generations of Richard's family are buried but he said that first the truck must be washed! We had not gone a mile down the road when some teenagers standing by a church held up a sign saying "Car Wash here today". We drove in and a bunch of kids raising money for their summer camp proceeded to wash the truck. What they lacked in skill they made up for in enthusiasm and were wet through but happy. We could not get out as there was nowhere to sit and it got very hot in the truck with the windows shut. Eventually I signalled that I had to open the window for a minute but the lad with the hose was unaware of this and I got wet too. We took a photo of them all, and hope that their summer camp was a great success and off we drove.

It was a beautiful sunny day and with Memorial Day only a few days ago nearly every grave was decorated with flowers and flags. Richard planted a flag by his dads grave - he died in 1951 when Richard was only 3 months old - and after some thoughiful moments he moved back a few feet and started to do a bit of a jig. Mystified I asked what he was doing, and he said "Dancing on my grave, it might be the only chance I get to practice." We eventually stopped laughing and drove on to visit with Uncle Charlie.

Uncle Charlie ran an oil drilling rig in Ohio and retired to live on part of the land that used to be the Boone Homestead. He has 40 acres and lives in a wooded area of walnut, hickory and maple trees on top of the hill with a large pond 50 yards from the cabin. He keeps about 30 long horn cattle and a few chickens and has accumulated many old cars and trucks from which he sells bits and tinkers with engines.

The day after, Vicki and I went shopping and I succumbed and bought myself a denim shirt with embroidery on it, something I had looked at lovingly on the last two trips. Interestingly the majority of ladies clothes in the USA have embroidery, appliqué or beads on them. Malls and stores are spread out over more area and going round in my scooter meant I could have a good look round. It was really interesting going round food stores looking at the variety of different items and prices. Richard had gone off with Mike to a creek some 25 miles away where they could do some target shooting with a flintlock pistol and cowboy revolvers - chatting and reliving their childhood days.

Another day we visited the Mount Vernon historical village which consists mainly of original log buildings from the 1820's to 50's. A church, a working blacksmiths where local blacksmiths meet every month, a general store, a school with a photo of Richards Great Aunts Class in 1900, a doctors office, and a few log cabins. A jail from 1826 that was still used untill 1936!. There was also a new museum building full of items and photos from Mount Vernon's past.

We had some great home cooked meals with Mike, Vicki and Chris each day and I was able to catch up on email using their computer. Chris is only 12 years old but whizzed about the computer like a veteran. One of his Internet friends lives in Grimsby in Lincolnshire - it surely is a small world once you get on the Internet.

St. Lousi, Missouri - The Conference.

Wednesday we drove to St. Louis Missouri, the shortest leg of the journey. Instructions to the hotel from the Internet said 'over the Mississippi bridge, bear right, bear right, left left left...' and it worked and there was the Marriott and we stopped, relieved that we had made it in one hit. We had decided on valet parking as although a bit more expensive, with the extra help you get loading and unloading, it's energy saving and money well spent. We were soon saying hi to polio survivors and arranging to meet up later for a meal in the restaurant. It really is strange talking like long lost friends to people you have only just met in real life. We started to get worried about Tony as he did not arrive as scheduled and a few hours later when he did arrive were dismayed to find that he had been re-reouted from New York via Detroit and his suitcases had not arrived with him.

After breakfast we registered for the Conference and soon were renewing acquaintances from previous conferences and meeting folks we knew by name from the Internet. Joan Headley of GINI and her staff continued to work almost non-stop to ensure that everything happened on time. At lunch it was such a pleasure to see two PPS Specialists, Dr. Jaquelin Perry and Dr. Augusta Alba being honoured for their many years of dedication to improving the lives of Polio Survivors. Retirement at 60 was not for them and although they have reduced their hours they continue to work at their PPS Clinics.

The three day GINI conference was split into Sessions and with six or seven lectures to choose from it was hard to decide which to attend, they were all so good. For example on Thursday there were 3 Sessions with 7 choices and I spoke at one session, leaving me two others to attend. I am contacting other speakers for permission to use information they provided in our future newsletters.

Much of our talk has been contained in earlier newsletters and information packs. It's really been an ongoing process as I have learned.

Assessing ourselves and how we actually do actions and how that has changed from last year, five years ago, ten years ago, is important information that we can give to any health professional we see. Doing a visual time line of our Polio Lives most people said was an excellent idea. Visual information is much easier and faster to assimilate. Remember a couple of photos can say a lot too. When I go in on a scooter with KAFO and AFO to see a new health professional they would not expect me to show them a picture of myself as a Policewoman 18 years after my waist down paralysis. We explained muscle fatigue from Eddie Bollenbach's article and many asked for copies of the slide printed in the last newsletter.

All agreed that holistic multi-disciplinary assessment was necessary to show our problems, and that exchanging ideas of how we had overcome problems could help many others. *We will publish a list of these in the next newsletter - so here is your chance to write and give us your ideas to add to them.*

We used small sketches to show that when visiting a doctor, taking a list of symptoms as long as a toilet roll and inches of medical articles off the Internet causes the Doctor to flinch in horror - trying to remember back to that 15 minute lecture about polio and thinking 'this patient might know more than I do'. HELP. Another sketch showed that asking us 'Can you?' does not encourage a polio survivor to tell it like it really is, our pride in our abilities will not let us. We ask Health Professionals to rephrase questions to 'How do you X?' instead of 'Can you do X?'. Ask ten Polio Survivors 'Can you get upstairs?' and you are likely to get ten 'Yes' answers. Ask 'How do you get Upstairs?' and get ten different replies from 'walking up normally' (waist up polio survivor) through 'one step at a time and pulling myself up with my arms' to 'going up backwards on my bottom'.

The reply Richard gave to 'How do you fix yourself a meal?' instead of his 'yes' to 'can you', caused much amusement and agreement. He replied "I eat 'ding' food now mostly. I buy processed meals and put then in the microwave and wait for the 'ding'".

As I and other members have been experiencing increasing problems with my upper body - I had waist down paralysis - I chose a lecture by Mary Ellen Brown RPT, a polio survivor herself, and Nancy L. Caverly OTR/L , "Strategies for Management of Arms and Shoulders". The first surprise was the diagram showing which muscles are used to move the arms and shoulder joints. Not only muscles in our arms but they stretch right across the front and back of our chests to our waists.

Précising their talk - we will be asking permission to include a complete article next newsletter - the advice was that we must sit and stand as straight as possible and keep our arms in good alignment to accomplish activities. Learn relaxation and breathing techniques to lessen tension and muscle stress. Make the actual doing of activities as easy as possible using any aid or assistive device that is available. Get advice on which aids are best for your particular problems. Using an incorrect aid can make matters worse. When we take breaks ensure our arms are resting too, not holding a book. Delegate tasks that are too demanding. Remember that Repetative Strain Injury occurs in 62% of the normal population when using computers, so if we are having problems with our upper extremities it is imperative that we have an ergonomic assessment to ensure our workstation is set up correctly. They finished with this reminder.

> [**A Reminder** - If you develop any pain, weakness, excessive fatigue in the upper extremities, and reasonable amounts of rest do not decrease the symptoms, get a medical evaluation and begin treatment as soon as possible. Many upper extremity problems can be eliminated with proper management, and the sooner the symptoms are addressed, the less risk you face of permanent decrease of upper extremity function. If you doctor does not suggest treatment such as physical therapy and occupational therapy, INSIST ON IT. 'Normal' people rarely hesitate to seek medical assistance when pain or weakness occurs in their arms and shoulders. Neither should you, who has much more to lose - your independence.]

To any medical professional reading this and who is using one-off Manual Muscle Testing that can grossly overgrade our actual muscle ability as an assessment, can I please ask that you now take note of the symptoms being reported to you, and ensure that the polio survivor is actually watched doing tasks that they say they are having problems with. It is 12 years since a fall and the start of weakness in my left arm and it has taken me nearly that long to convince anyone that the functional decline I am reporting is true.

I have included in this newsletter an article by Susan Calmes MD from UCLA (page 3) regarding anesthetics. Very important that you should make any health professional you are seeing that assesses or treats you with a local or general anesthetic, aware of the implications of using that on a Polio Survivor. An example being the assessment of my throat two weeks ago with camera - I was not told it was a local anasthetic and the temporary paralysis I experienced was exactly how it feels when I go to swallow and nothing happens.

We met up one lunchtime with representatives from Sweden, Panama, Switzerland and Israel and are remaining in contact. More on the GINI Conference at the AGM and next newsletter.

Bruno Mobility Europe let me down by telling me that my charger would work in the USA with just a plug socket change from British to American. The hotel loaned me a US to European Transformer that only partly worked and I had terrible problems keeping my scooter even 50% charged which made life very difficult. My advice is to check with more than one source if you are going to travel abroad with any electrical equipment.

With my scooter power draining to almost nil and a 5 hour journey ahead of us we made the difficult decision to leave the Conference a couple of hours early after the excellent ADA speech by Polio Survivor Lawyer Robert J Provan from Austin Texas. Without a working scooter I am restricted to walking just a few yards with an increase in energy use.

2nd Branson Internet Reunion.

Again sharing the driving we arrived at the city limits of Branson just as it was getting dark. Emails full of directions and hotel town plan maps are great in the daylight, but what we had not realised was that the alternative route to the south of Branson went right out into the country. I thought we must be going wrong and we headed back towards the lights and asked for directions. Turn left and left again at the lights and it's on the right. It was, but five miles further down the road. We pulled in and parked up and Millie Malone and Jerry Glass happened to be in Reception to say 'hi'. Richard headed straight for the room, luckily only two doors from reception and crashed out. My scooter had died totally on the way to the room so I borrowed Richards to get to the meeting room. I soon had a long cold drink in my hand and it was so lovely to have real live hugs with folks you have been talking to for months. Tired as I was this was good medicine but I soon decided that sleep was needed to cope with tomorrows events.

Sixty-nine folks attended the 2nd Branson Internet Reunion organised by Tommy Conrad. Carol Ann from Canada, Tony and myself from the UK, and the other 66 came from 22 different States. That's double the number who met last year and Tommy has booked the same weekend for June 2001 when they hope to double the numbers again. Sorry that I can't mention all who attended.

Next day after a good breakfast and more chatting and hugs we set off in convoy to the Duck Rides. The sight of Kathy Greulich holding up the traffic so that about ten cars could get out one behind the other, and then running back to the first car, was something I shall never forget. I was doing the same thing fifteen years earlier, except my running was a cross between a galumph and a walk.

The Duck rides are old wartime D.U.K.W.'s and 36 of us piled aboard with Captain Jerry. We were handed yellow plastic duck bills that quacked if we had enough ooomph to blow them. Most of the time we were trying to laugh at the same time. Off we set through Branson 'duck quacking' at every other DUKW that passed. A great guided tour past our hotel and out across the Dam and then up the mountain on a single track path. The company own the mountain and have purchased old wartime vehicles and they are parked at intervals and we were told their history. We arrived at the top and what a view across the lakes. We went back down the mountain and onto the slip road to the lake where Captain Jerry stopped and asked, "Do you want to go in slowly or commando style?" We all shouted "commando style" and he threw a towel towards the back and said you folks on the back seat might need this and off we set. Well we hit the water and there was a huge wave that came down the sides and over the back seat. I turned to look at Richard and he had water dripping off his nose, glasses and chin as did some others sitting on the sides, but those on the back seat got wet butts! We had not driven far when he offered the wheel to anyone who would like a go, and Dale Ryals took the opportunity to drive us about. We saw the Branson Belle Paddle Steamer and spent about a half hour on the lake. Capt. Jerry took over again and we went back up the slip road and back to the starting point with songs, jokes and stories of the past all the way. Available energy used up so it was back to the hotel and rest and chat. Quite a bit of time was spent talking with Stella Cade and Phyllis Hartke from California who run the San Francisco Bay Area PPS Group as to how support group leaders can get together more. Ideas floated are being discussed - more news next newsletter.

The next day we did a TV Interview at the hotel, to promote the awareness of PPS locally, which was shown on local tv that night. They aired one sentence of my answers, a couple of Millies and pictures of most of us on our respective wheels. Strangely at the same time on another channel was a repeat of A Paralysing Fear - the story of Polio in America. We then set off to visit Silver Dollar City. Without scooters we would not have seen anything at all, and a couple of our party hired them for the first time. Very commercialised with food, trinket, clothing, outlets everywhere. Rides for children and lots of water fun areas. Tommy arranged for us to go to the little church for 1pm to have a sing along with Barbara Fairchild. She had visited the hotel last year to sing for the first reunion. She welcomed us in to the front and we manoeuvred scooters and chairs in like a jigsaw and sang a few country style hymns.

Richard and I went on the train ride - which was stopped by a couple of rednecked farming brothers who sent the train guard off to look for baldknobbers (hillbilly bad men) who might hijack the train, and proceeded to do this themselves as soon as he was out of sight. They do this every 30 minutes!!! We left early afternoon and went back to the hotel for a long rest. We did our talk again in the evening and spent quite a bit of time discussing the ways we have changed how we do things and the novel ideas we have come up with. It's so interesting and time and time again you find things that you can try.

All too soon it was Wednesday and time to leave Branson and new and old friends. The sky was dark with rain clouds as I was loading the truck in the car park. Suddenly the heavens opened like a bath plug being removed. I took four paces back towards the hotel - the porter who had gone back for the rest of our luggage yelled for me to bring the truck over to the portico - and I did 8 paces back and got into the truck. I drove over and waited till those ahead of me had loaded and took my place under cover. I got out, totally soaked even down to the insides of my trainers, and all in 12 paces! I looked like a drowned rat much to the amusement of many.

Details of the 3rd Branson Internet Reunion in June 2001 can be found in our World-Wide Conference, Seminar and Reunion Diary, Event Card #0023.

Back to Florida with First Stop-over at Starkville, Mississippi.

We were soon loaded and as we were told the rain was likely to be set in for hours, we set off towards Arkansas. With wipers going triple speed and taking it steady we were on our way. The rain eased to normal with bouts of deluge now and then but thankfully after a couple of hours we found sunshine again.

We were heading for Starkville, Mississippi. Kenneth Rhea had contacted us in Branson and offered us a bed for the night as he could see he was not too far off our probable route to Mobile Alabama. We gladly took up his offer and arrived early evening having stopped a few times for a rest. We enjoyed a delicious meal and chatted about PPS in his area. Kenneth has had one arm that has not worked well for most of his polio life and it was interesting watching and discussing how he accomplished tasks often totally one handed. He also wears a leg caliper. Next morning we had a lovely lazy breakfast swapping more information and then were on our way again.

Stop-over at Mobile, Alabama to give 'talk'.

We arrived in Mobile Alabama with the first rain they had had in months. Charles Gollott, a USA member of the LincsPPN, lives there and had asked us to visit their PPS group. We were taken to meet our hosts John and Betty Driscoll, a lovely couple who looked after us so well. Their bungalow full of cross-stitch and other family treasures including a framed message from the Pope for their 50th Wedding Anniversary. Sylvia Bern took us out for lunch the next day and later Patsy Adams joined us and they took us for a ride round part of Mobile and then to the Easter Seals offices where we had a tour of the facilities. That night Charles and Barbara Gollott and son Britton took us out for a Mexican meal.

Saturday Patsy Adams and Margaret Brown - an English friend who has lived in the states for years - picked us up again and took us out to lunch and then for a drive round the old area of Mobile where many post civil war era houses are being renovated. The roads were lined with long-limbed branch oak trees hanging with Spanish moss touching in the centre. Some of the houses are called 'shotgun' houses as they have a front door, long hallway and back door, so you could open both doors and shoot right through.

We saw an old 18th Century fort, Fort Conde where the British got their butts whipped in the Revolution. (Richard dictated that bit - and I added it as it reminded me of 1998 when Dr. Henry asked Lynn and I on the morning of the 4th July if we were sure we wanted to go to the celebrations... "Of course" we replied. His reply, "Well, we did beat you" made us hoot with laughter).

We then went to the newer part of Mobile and saw the most hideous new building - it's ok to tell you that as the locals think the same - it's the City Hall. (For those of you who know Lincoln it's a bit like Debenhams - architecture totally out of place). We then went to the USS Alabama Memorial Park. Richard was thrilled to see his first World War II Battleship and grateful for the free 'yes you can go onboard'. There was a long slope up to the ship but we managed it and about a quarter of the main deck. Richard had his photo taken by guns he knows his father trained on during the war. He managed to look up under a large gun turret looking a bit like a giraffe drinking water, long limbs, callipers and stick, out at angles. His father was a member of a gun crew on Liberty Ships during the war so it was important to him to see some of the past associated with his father.

That evening our hosts held a 'cook out' attended by many members of their PPS group where of course we discussed polio and the differences in assessments, not only in each Country but also depending on which GP you start with. We told them about the Conference and went through our talk. Their nearest PPS Doctor is in Georgia, Dr. Peach who we had spoken to at GINI and who will be sending us more articles for our Library.

We left next morning for Florida but due to energy levels waning and the thought of Nancy's cooking we accepted Art and Nancy's offer to visit again and break the journey. We were able to tell them all about the trip and pass on things from PPS'ers in Branson for them. We left next morning after another lovely breakfast, this time blackberry and strawberry pancakes and turkey sausage, and of course Cranberry relish. Nancy had made a special tub for me.

Arrive Florida for Rest and Recuperation.

We arrived back in Florida on Monday, unloaded the truck and slept. The next two days were spent catching up on email and doing the washing. It was very hot, about 92 and with high humidity. Being outside during the main part of the day was exhausting. Thanks to a friend, Richard suddenly found himself with the offer of the cost of an airline ticket to the UK and made the decision to come back with me till after the AGM and looks forward to meeting those of you who can attend.

Thursday we went for a drive out to Sarasota, St. Armands Key and Lido Beach. White sand, blue sky, emerald sea, palm trees and a pelican or two. Bliss. We then drove back along Longboat Key to Anna Marie Island. We both agreed that it was hard seeing all the folks enjoying swimming and boating which we used to do. Now with PPS, looking was all we had energy for and sand in caliper joints was not something we wanted. It would take some planning to work out where and how we could swim in the sea again.

Another day we drove out to Myakka State Park so that I could an alligator in the wild. We stopped near a bridge across a small lake. There underneath was my real live alligator about five foot in length and further away, two more smaller ones. Beady eyes watching your every move. We drove on past the lake - not enough water for the airboats to go out, but I saw some wonderful birds, far larger than I expected. Blue and Great Herons, Roseate Spoonbills, Anhingas, Cormorants and many other wading birds.

We went to visit with Gabe and Billie in Myakka who have a two story house with a cathedral ceiling which they built themselves. Its full of items that reflect their interest in the civil war era. Gabe does cowboy, indian, civil war and mountain man re-enactments and has outfits for all of this. They also have three horses, two dogs and four cats.

Richard held a cook out for a few friends who all love target shooting with a variety of different weapons. Muzzle and breech loaders both antique and modern. Bill and Sandy worked at the same jewellery company as Richard and have been friends for 17 years. They brought over photos of the snakes that they breed - Richard has just commented that the snakes breed themselves! King Snakes. Both Bill and Sandy have flintlock muzzle loading rifles that Richard made. Bud who is a retired professor and was a sailor in WWII also visited. Richard had camped next to him at a Buckskin re-enactment two years ago.

Monday 26th June was the most awful day of weather in that part of Florida, angry dark skies, thunder and lightening, torrential rain. We packed and drove to the airport to find that the flight had been delayed five hours. After a free meal on BA and an eight and a half hour flight we arrived at Gatwick Airport to be met by Tony Meladio with my car. He drove us back to his house in Kingston where we had a quick drink and we arrived back in Lincoln at 7p.m. on Tuesday, travelling for 25 hours. Needless to say the first few days back in Lincoln were doing almost nothing.

Post-Polio Population Statistics - A Review.

Chris Salter
Vice-Chairman, Lincolnshire Post-Polio Network.
A Lincolnshire Post-Polio Library Publication.
July 2000

The starting point of this review is an extract from a recent book by Dr. Lauro. S. Halstead, one of the leading specialists in Post-Polio conditions. In "Managing Post- Polio"[1] he writes:

> "Accurate numbers of Americans who had paralytic poliomyelitis are not available and probably never will be. There is no national registry of persons who had polio. Also, there is no way, after all these years, to compile accurate figures from state and local health departments. The best estimate is based on data from the government's National Center for Health Statistics, which conducts a National Health Interview Survey each year. This survey collects data from a random sample of the U. S. population regarding various health and disability issues. In 1987, surveyors specifically asked questions about the number of persons who were given a diagnosis of poliomyelitis with or without paralysis. Based on the results of this survey, the Center calculated slightly more than 1.63 million polio survivors. Of these, 641,000 (39.2 percent) persons had paralytic polio; 833,000 (51 per-cent) had non-paralytic polio; and 160,000 (9.8 percent) didn't know. Unfortunately, some of these data have been miscopied or misrepresented and then erroneously published in the medical literature as fact. The most common error is the statement citing 1.63 million persons with paralytic polio when the correct estimate is really 641,000 as cited above.
>
> The latter figure, however, is based on a survey conducted 10 years ago. Since then, it has been estimated that 5 percent to 10 percent of the polio population has died, which means the current number of survivors is closer to 600,000. How many of these 600,000 persons with paralytic polio have PPS is unknown. Several studies indicate a large number, perhaps 60 percent or more, is experiencing one or more new difficulties related to old polio, such as muscle aches and joint pains. However, the number with PPS (new weakness with or without other symptoms many years after acute polio) is undoubtedly smaller, probably in the range of 20 percent to 40 percent. Using these figures, it is estimated that approximately 120,000 persons to 240,000 persons in this country are currently experiencing symptoms of PPS."[1]

Although the above was written as recently as 1998, it has been in part superseded regarding one significant criteria. Dr. Halstead's final PPS estimate excludes persons with a history of non-paralytic polio. For several decades there has been a tendency to require a history of paralytic polio before any diagnosis of PPS will be considered. Such a pre-requisite is not supported by medical papers written in the 1950's and earlier. Those papers report evidence of a level of neuronal damage by the polio virus that does not present any clinical signs of paralysis at the time of infection. Indeed, there can be a significant level of damage without any clinical indications. The Lincolnshire Post-Polio Network commissioned an article [2] early in 1999 to present the case for not excluding non-paralytic polio as a pre-requisite for PPS. The authors, Marcia Falconer and Eddie Bollenbach, have recently been successful in getting a commentary on the subject [3] published in the peer-reviewed American Journal of Physical Medicine & Rehabilitation and Dr. Halstead has also written on the subject in the same journal.[4] In that article Dr. Halstead writes

> "Although the diagnosis of postpolio syndrome traditionally has required a remote history of paralytic polio, many persons such as the ones described here with typical

> symptoms of postpolio syndrome have no clear history of paralytic disease and are being misdiagnosed. With this in mind, we believe that the diagnostic criteria for postpolio syndrome should be modified to include the following: a history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with poliovirus damage of the central nervous system earlier in life."*[4]*

This inevitably leads to the conclusion that an indeterminate percentage of the 833,000 persons with non-paralytic polio in the US calculation will eventually present PPS symptoms. The worst case scenario would be that all 833,000 suffered viral damage just below the clinical level.

I will now move on to the UK and specifically Lincolnshire. There are no records available of numbers of cases of prior polio being currently treated in Lincolnshire for new symptoms. A 1996 letter to the Lincolnshire Post-Polio Network from Dr. Le Geyt, Lincolnshire Health Authority, gave three separate figures for current numbers of cases of prior paralytic polio in Lincolnshire, each sourced or derived from a specific report. I have extrapolated UK figures from his figures and other sources using a Lincolnshire population of 631,466 and a UK population of 57,400,000 from 1990 National Health Service Statistics. In the case of Dr. Le Geyt's Lincolnshire estimates which are themselves extrapolations from UK figures, any difference between the original UK figure and my UK extrapolation from his Lincolnshire estimate is probably due to our using a different Lincolnshire/UK population ratio. My UK extrapolations are only intended to emphasise the significant variation found in estimated cases of prior polio.

The first figure he gave was 100. The source for this figure he quotes as a 1998 paper in the Lancet*[5]* 23,000 infections 1920 to 1950. The UK extrapolation is 8,610. (In comparison, another UK statistic, source unknown, puts UK notified polio cases from 1912 to 1961 as 74,280).

The second figure he gave was 300. The source for this figure he quotes as the British Polio Fellowship saying of 100,000 infections, 30,000 survive. The UK extrapolation is 26,404.

The third and last figure he gave was 1,200. The source for this figure he quotes as a paper by Ahlstrom *[6]* of a Swedish survey from which a figure of 186 per 100,000 population is derived. The UK extrapolation is 106,764.

From a recent Edinburgh University survey of Lothian*[7]* a figure of 200 per 100,000 population is derived, i.e. 114,800 out of a Lothian population of 750,000. Using national population statistics again, the Lincolnshire extrapolation is 1,262 and the UK extrapolation 114,800.

The Lothian survey also refers to a Norwegian survey by Gilhus*[8]* in 1998 which derives a figure of 250 per 100,000 population. The Lincolnshire extrapolation is 1,577 and the UK extrapolation is 143,500.

Returning to Dr. Halstead's US census based estimate of 270 per 100,000 population our Lincolnshire extrapolation is 1,703 and our UK extrapolation is 154,980.

It is important to re-emphasise that Dr. Le Geyt's figures and therefore our extrapolations are limited to cases with a history of prior paralytic polio. Include non-paralytic polio and the US estimate increases to 680 per 100,000 population. All the Lincolnshire and UK extrapolations are similarly affected, i.e. increased by a factor of 2.5.

As can be seen, when trying to determine the number cases of PPS in a population we are confronted with a number of problems.

1. No current statistics of persons currently diagnosed as PPS.
2. Estimates of the percentage of cases of prior polio likely to develop PPS vary considerably. Few if any take into account that a historical clinical diagnosis of non-paralytic polio does not preclude a diagnosis of PPS.
3. Although in recent years records of notified and confirmed cases of polio have been

maintained by the World Health Organization, records predating the eradication campaign are more difficult to locate and may be unreliable.

4. Estimates of the numbers of cases of prior polio vary considerably and as with PPS estimates, tend to be limited to so called paralytic polio. It is worth noting that a 'mild' polio infection may not even be diagnosed at the time of the infection but may still result in sufficient damage to cause problems in later life.

While the above observations arise from data specific to the USA, UK, Sweden and Norway there is no reason not to believe that they do not apply to all countries. As far as I am aware no individual, organisation or institution has attempted to gather statistics on a world-wide basis in order to arrive at a reasonably accurate estimate of the number of polio survivors (by definition living) in the world today let alone the number presenting or likely to present PPS symptoms. It also worth emphasising that while the polio survivor population in the polio free regions is by definition reducing in numbers over time, until the WHO eradication campaign achieves its goal, there are regions where cases of polio still occur.

ACKNOWLEDGEMENT

This review is an expansion and continuation of an analysis by Hilary Hallam referenced in *Polio Survivors Need Holistic Multi-Disciplinary Assessment Because The Standard Physical Assessment Is Not Adequate*, LincPIN Newsletter Volume 2 - Issue No. 5 - June 1999.

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

Eyelid trouble.

Mary Ellen Hemby in Marshall, Texas.
<mhemby@OURPLACE.COM>

A member of our local support group has been having eye trouble -- tired, vision loss, watering, etc. After treatment for supposed allergies and eye problems, she asked the Texas Polio Survivors in Houston and learned that another polio survivor had similar trouble. With the information from him, she has now had successful eyelid surgery and her vision problems are cured! The eye surgeons agreed that Polio had affected the 7th cranial nerve, thereby causing the drooping eyelids and loss of peripheral vision. She had only local anesthetic and is doing remarkably well. Medicare paid for this usual cosmetic surgery because it was PPS related!

So, do consider PPS when having eyelid trouble. The surgery was done by an eye surgeon in Tyler, TX. (It is usually a cosmetic procedure done by a plastic surgeon for eye lifts. It helps make you look younger!)

Dr. Jacquelin Perry’s comment on Hip replacement surgery.

Mary Clarke Atwood, Ranchos Los Amigos PPS Support Group, California, sends this reply in answer to a members query.

Question: What are your thoughts on hip or knee replacement surgery?

Answer: For an arthritic hip, total joint replacement is just fine if you have the muscles to control it. A polio survivor needs to have about grade 3+ hip muscles for this surgery to be successful. Otherwise the hip will dislocate.

The knee is simpler to handle because it can be put in a brace since it is a tubular structure. But there is no brace for a hip.

Originally published in "ASK DR. PERRY: December 1997", Rancho Los Amigos Post-Polio Support Group Newsletter, also reproduced at Post-Polio Syndrome Central http://www.skally.net/ppsc/ask.html.

Collective Ability - Information Leaflets.

Nottingham based nutrition and preventive health advisors, Collective Ability, have produced free information leaflets on managing a variety of health problems. These include:

Managing Chronic Odema.
Managing Achy Arthritic Joints.
Managing Eczema.
Antioxidants and free radicals - what are they?

These have all been written from a basis of the personal experience of one of the founders of Collective Ability - a Lincolnshire Post Polio Network member, Marguerite McElroy, and give practical advice and information which can make a real difference to all these conditions.

To receive a free copy of one or more of these leaflets contact
Dr. Paul McElroy,
Collective Ability.
194 Cator Lane, Chilwell, Nottingham, NG9 4BE.
Tel:- 0800 0 133 113.
Email:- collectiveability@ic24.net

Dr. Henry writes about "Henry's Helpful Hints for Living with

Post-Polio Syndrome"

When I was three years old, my mother became a victim of Schizophrenia. She never recovered. When I was eleven years old, I had paralytic polio. I partially recovered. These two life events were major factors in guiding my life toward a career as a physician and a psychiatrist. For at least the last decade, I have struggled with Post-Polio Syndrome (PPS). Most of you are quite familiar with all of the manifestations of that struggle. For almost six years, I have had the privilege of being the president of the Central Virginia Post-Polio Support Group, a marvelous group. As a result, I have had the pleasure and challenge to communicate with hundreds of PPSers around the world. I think I have learned a lot about PPS and the people who are living with this life changing disorder. In this article, I will attempt to share what I am calling Helpful Hints for Living with Post-Polio Syndrome. Many of these hints are similar to what is now called "mind - body" medicine. Many of them are replicated in other lists and articles. I offer these hints for your review, reflection, and response. This list represents only my opinion and is not to be interpreted as anything more than that.

1. **Sleep:** Adequate, restful sleep is a major asset in living with PPS. Successfully living with PPS usually requires more sleep than before the onset of PPS. The amount of sleep may range from 8 to 12 hours. This may be all nighttime sleep or could be a combination of nighttime sleep plus an afternoon nap. Many symptoms of PPS can interrupt the attainment of this level of sleep. Problems with pain, hypoventilation due to weakened respiratory muscles, sleep apnea, anxiety, panic attacks, and depression are common sleep disturbers. Any of these disturbers need to be evaluated and treated before sleep hygiene can be improved.

2. **Pain:** Pain and PPS are like partners of misery. Every effort should be made to eliminate or reduce pain without resorting to narcotic analgesics. A variety of pain management approaches may be tried. This might include over the counter preparations such as Tylenol, Ibuprofen, aspirin, and other non-steroidal anti-inflammatory medications. Non habit forming prescription medications may help pain and sleep problems. Low doses of the tricyclic antidepressants and/or the selective serotonin reuptake inhibitors may help to reduce the daily pain level and improve sleep. If one has made a genuine effort at managing pain by reduced activity, more rest, and the use of assistive devices, then the use of narcotic analgesics would be more appropriate. Other pain management approaches might include moist heat as obtained in a heated pool, gentle massage, magnet applications, and even acupuncture. Heated pools should not exceed 92 degrees F. Massage should not be aggressive, and a trained professional should administer acupuncture.

3. **Fatigue:** Fatigue is probably the single most commonly shared symptom of PPS. Fatigue contributes to greater pain and sleep disturbance. I believe that intermittent down time is the most effective method of managing fatigue. Down time means lying down prone or supine. Each person has to discover what is the best balance between down time and up time for each day. For example, spending an hour reclined every four hours works well for many PPSers. Medications to reduce fatigue have proven to be of minimal effectiveness in double blind studies. Also many PPSers do not tolerate medications well and have numerous side effects.

4. **Respect new weakness.** If new weakness is detected or experienced, respect this reality and do not try to restore strength by an exercise program. Exercising with this goal in mind will likely lead to more pain and a progression of the weakness. Most of us get enough exercise just trying to maintain the activities of daily living and trying to remain independent. Be sure that any physician or physical therapist who recommends exercise is fully knowledgeable about PPS.

5. **Blood pressure:** Maintaining normal blood pressure is most important for PPSers. Many of us experience elevated systolic blood pressure (the upper number on a blood pressure

reading) after exerting some physical effort. Our heart rates may also increase during times of fatigue and minimal physical effort. If this elevation of blood pressure persists, the risk for heart attack, heart failure, and stroke increase. There are many effective medications to control blood pressure. However, beta-blockers sometimes cause side effects for PPSers. The systolic pressure should be below 140 at rest and our pulse rate should be below 100 at rest.

6. **Brain power:** Utilize your brain or intellect to compensate for the increased physical limitations of PPS. This is a process that most polio survivors have been doing for years. PPS calls for an enhancement of this same process. Read more. Read some of the classics. Audio books are a wonderful way to read without tiring your brain or eyes. If your physical disability makes it difficult to hold a book or maintain a reading posture, you are eligible for the Federally funded audio (talking) books for the blind and handicapped. A simple application has to be completed by your doctor to authorize this service. I would also recommend the many benefits of owning a computer. For PPSers, the investment required to purchase a computer is usually a rewarding undertaking. You are never too old to enjoy and learn from a computer, which literally makes the world available to you.
7. **Doctors and therapists:** Find doctors and other therapists who not only know about PPS, but are interested in learning more and will listen to you. However, be cautious if a doctor tends to blame all your symptoms on PPS because we are in an age group, which is vulnerable, to many other medical/surgical problems. Your doctor should rule out other causes of symptoms that simulate PPS symptoms. Your doctor should not hesitate to refer you to an appropriate specialist if any symptoms are not explained.
8. **Herbal medicine:** Americans now live an average of about thirty years longer than our ancestors of one hundred years ago. This is largely due to antibiotics, better diagnostic and treatment techniques, improved nutrition and more prevention via vaccines. Because we have it so good, we want it even better. Thus, the herbal, vitamin, and nutrient alternative medicine business is booming. Keep in mind that the Federal Drug Administration does not have the resources to monitor these alternative products as it does prescription medications. Whether it be St. John's Wort, Ginkgo Biloba, L-carnitine, Feverfew, the various vitamins, or shark liver oil, be sure that your physician knows what you are taking and remember that with many of these products, cheaper does not always mean purity of the product. If an alternative medicine seems to be helping you, continue it. Nobody has found a consistently effective pharmaceutical treatment for PPS.
9. **Talk to someone:** Talk to someone who cares about your feelings in living with PPS. This person might be your spouse, a family member, friend, or even a professional therapist. Our support group is a healthy and welcome forum for talking about your feelings. Many polio survivors have spent a lifetime of containing their feelings of loss and even anger. To express these feelings to someone is very difficult, but the benefit is immense.
10. **Spiritual base:** Having a faith or spiritual base that transcends the daily activities and struggles of this life can be an additional source of personal and inward strength. This pilgrimage is a personal choice, but I believe provides a greater meaning to our time in the midst of the ages.
11. **Nutrition:** Enjoying good food is still one of the pleasures of life that most of us still can do. That is the up side. The down side is that we more easily gain weight, as we are more sedentary living with PPS. The practical advice is to avoid big meals, especially at the end of the day. Eat balanced meals with some emphasis on protein content. Maintain good hydration. Good hydration assists renal and pulmonary function.
12. **Keep your feet up:** When sitting, keep your feet elevated whenever possible. Another advantage of taking intermittent down time throughout the day is the benefit of preventing or

at least reducing dependent edema. Weakened leg muscles, along with reduced motor activity, contributes to dependent edema. Chronic dependent edema can lead to possible leg ulcers, deep vein clots, and phlebitis. Complications of these conditions can result in life threatening pulmonary emboli. Wearing support hose can also help prevent dependent edema.

13. **Don't ignore headaches:** Headaches are a common sign of PPS fatigue. Have your doctor rule out other causes of headache such as hypertension, tension vascular headache, or some other medical problem. A dull daily headache is often a sign of PPS fatigue and particularly brain fatigue. Brain fatigue is often marked by word finding difficulties, mental focusing, and concentration problems. These brain fatigue symptoms are usually reversible with rest. Rest and more rest is the best treatment for the dull headache of fatigue.
14. **Pace:** Approach pacing like you would an algebraic equation. The daily physiological energy expended must equal the physiological energy stored and not exceed it. Most of us are accustomed to expending more energy than we store or acquire. If you know that a particular day's activity will result in more energy expended, plan to spend more than one day to restore and recover that energy. Balancing this energy equation over time results in successful pacing. Pacing reaps results, but not in a few days. One should practice pacing for months and years.
15. **Breathe well:** Healthy breathing and good sleep hygiene are coupled together as I mentioned in #1. Sometimes, the muscles of breathing grow weaker with the progression of PPS. Thus, there could be an insidious onset of chronic hypoventilation, which could contribute to an overall feeling of fatigue. Also scoliosis, resulting from polio may advance with the progression of PPS and aging. This process could restrict the ventilatory capacity of the lungs and lead to hypoventilation. Measurements of pulmonary function and arterial blood gases can help to diagnose hypoventilation. Most PPSers with these problems do not usually need added oxygen, but simply improved ventilation, often only at night. Depending on the degree of hypoventilation, this condition can often be treated with a C-pap, bipap, or ventilator without the necessity of added oxygen. Actually, adding oxygen without improving ventilation can increase the risk of carbon dioxide retention in many PPSers with scoliosis or weakened respiratory muscles. Untreated chronic hypoventilation can lead to respiratory failure and ultimately death.
16. **Extend recovery from any stress:** Expect to take three to four times longer to recover from an infection, minor or major surgery, an injury, accident, or emotional upheaval. For whatever the reason, the physiological restorative processes of the body and brain are delayed by PPS. When any of these stresses occur, plan on taking longer to recover.
17. **Use your sense of humor:** Many survivors of polio seem to possess a witty sense of humor and an upbeat approach to life. A sense of humor is a good way to remain innovative, creative, and positive. Keep using this attribute.
18. **Sex and Intimacy:** Sexual stimulation is good for the cardiovascular system. Be creative with this stimulation. The polio virus did not damage the sensory portion of the nervous system. Feelings, both physical and emotional, are still potentially available for expression and perception. Linda Van Aken and I wrote an article about PPS and Intimacy about a year ago. That article attempts to address this issue.
19. **Be more dependent:** Not only should you allow others to help, but also you should tell them how to help you. If your spouse is your main helpmate, be cognizant that he/she also gets tired. If you ask your spouse or anyone else to fetch or fix things for you, be organized about your requests and minimize their physical effort and time consumed. Simply keeping a list of your needs or requests can help conserve your spouse or helper's energy and reduce the development of interpersonal tension. It is very difficult for PPSers to relinquish some

controls, but in doing so, avoid trying to control your spouse or helper. Communicate what you want or need, but be courteous and grateful in the process.

20. **Roll more, walk less:** When walking becomes more difficult because of new weakness or fatigue, get some wheels and roll more. If you can still walk some and rise unassisted from a chair, a scooter might be advisable. A battery-motorized scooter allows you greater and safer mobility. Scooters are great for malls, touring your neighborhood, and even in parks. If your weakness is profound, an electric wheelchair is probably what you need. Most health insurance carriers will pay for most of the cost of a scooter or electric wheelchair. Even Medicare covers these devices as long as your physician orders it. Once you learn the value of electric mobility, you may want to invest in a van and a lift to be able to take your wheels wherever you go.
21. **Use assistive devices.** Many of us have found it necessary to acquire new braces, canes, and crutches in order to keep walking and maintain balance. Accepting this need may be a step back in time for some. Don't resist this help. By all means, do anything to prevent falls. Do what is wise and necessary. Install grab bars, elevate the toilet seat, use pick sticks, and install ramps. I think it is wise to carry a cellular phone on your person (or wheelchair or scooter) at all times. Use your brain to help yourself. Only you know what you need and what may help.
22. **Never, ever give up.** During the struggle with acute polio and its aftermath, many of us were told, "No pain, no gain." We were encouraged to overcome adversity and that it was all up to us. With PPS, we know that attempting gain will bring more pain and no real gain in the process. However, we still need to retain our persevering and hopeful approach to life. Giving up will serve no positive purpose and is a sign of depression. We should press on, but pace the race. We should be more like the turtle than the hare.
23. **To be added** when a new hint comes from you.

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Originally published in the Central Va PPS Support Group (PPSG)'s newsletter, The Deja View, in the June/July 2000 issue.

Newsletter Editor's Note. The logo for the 2nd Branson Internet Reunion T shirts was a turtle in a wheelchair with the caption "Still in the Race".

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

My experience of PPS

by Janice Eary.

When Hilary suggested I write about my own experience of PPS, I readily agreed. However when I came to write this I found it much more difficult than I had expected.

I had intended it to be upbeat, how fortunate I was to have a sympathetic, supportive, GP, and to have found an equally supportive Orthopaedic Consultant. But I realised as I began to write that I didn't feel in the least bit fortunate. I was in fact full of unresolved anger and a fair amount of self pity. So although what follows isn't the account I originally intended it is at least an honest one.

I contracted Polio, age 5, in 1956. I spent 6 weeks on the children’s isolation ward of Ladywell hospital in Salford.

I had bulbar/spinal polio but fortunately, the paralysis only affected the right side of my face, and my trapezium muscle in my shoulder. Following discharge from hospital I had repeated falls. It was found that my legs were weak and the right leg was slightly shorter than the left. I wore a built up shoe and had intensive physio for 5 years. I was finally discharged at the age of 11 and although I would never be able to run or throw a ball, I could live a 'normal' life. I became a competitive swimmer and school games captain. Apart from quite severe upper back pain from the age of 15 (due to scoliosis), I put the polio behind me.

I qualified as a nurse in 1972, subsequently adding midwifery, a diploma in neo-natal intensive care and a diploma in health visiting to my qualifications. I married in 1973 and have 2 children. Although I had constant back pain, so did most nurses. Osteopaths, chiropractors, acupuncture and rather too many pain killers kept it under some sort of control.

I had always had a bit of a chip on my shoulder about not going to university like my brothers (too much missed school meant I had failed my 11 plus). This combined with an increasing dissatisfaction with the health service led me in 1991 to Sheffield Hallam University to start a combined studies degree. At the end of my second year I had a hysterectomy. Because of my studies I was not able to take enough time off to fully recover. Looking back, the symptoms of PPS began then. However I completed my degree, got a good 2-I and found a full time job, as the organiser of a charity-run weekend day care centre for Dementia sufferers and their carers.

For the first 2 years I managed OK. I was always tired, but I put this down to the stressful nature of the job. However it got worse. I began to experience pain and weakness in my arms, my back pain got worse, my feet were always blue and cold. That winter I got a bad cold, which turned into pneumonia. I had never had any problems like this before. Antibiotics didn’t work and I ended up on steroids for 3 weeks. I was off work 3 months and never felt really well from then on.

The pain increased, I couldn't pick up the heavy tea pot at work, my legs began to ache, and I started using lifts rather than stairs. Over the next 18 months I had 2 further chest infections, I developed pains in my joints and my right ankle kept giving way. From being a lively energetic person who loved her job and was very good at it, I became someone whose prime motivation was to get through what I had to do as quickly as possible so I could get home and go to bed.

What the hell was happening to me? Was this ME, cancer, MS, (we nurses always look on the bright side!] Then by chance I read an article in the Guardian about a new book "A Summer Plague" by Tony Gould. The article mentioned something called Post Polio Syndrome and outlined a few of the symptoms. It was like the cartoons! **a light went on in my head**, I knew instinctively that this was it. I bought the book. My husband searched the Internet. We were amazed at the wealth of information. Then like so many others I marched off to my GP with a pile of print outs, here I must acknowledge my good fortune My GP listened to me took the articles and actually read them! She agreed that this could be the answer.

By this time it was becoming increasingly obvious that I could not continue working as I had been. I tried to reduce my hours but my employers were not particularly sympathetic. I could hardly blame them, it was a demanding job and I was no longer able to perform physically and even worse mentally, I was just too tired. However, I was reluctant to take the decision to resign, my daughter was still at university, my son would follow in 3 years and although my husband had a good job we still needed the money. Besides, apart from a year off following the births of my children, I had always worked. I did not exactly relish the prospect of giving up my independence. Also I had never been an exactly keen housewife. However the decision was made for me, when I developed a severe attack of arthritis in my feet, which left me unable to walk for some time.

Once I had left work I made contact with the BPF and obtained a list of "sympathetic consultants". One was fairly close by and my GP was happy to refer me. I had high hopes as did my GP I would get a proper assessment, advice, treatment etc. How naive can you get!

I was given an EMG which showed evidence of long standing denervation particularly in my arms and right leg. However I was informed that this was not typical of PPS or even old polio, and anyway, what was I complaining about, he had seen others much worse than me. If this was an example of a "sympathetic" consultant then I was very glad I hadn't seen an unsympathetic one.

He recommended a MRI scan to rule out any neck injury which he felt might be the cause of the EMG findings, I was sure I had not injured my neck but agreed to the test.

I left almost in tears, I felt humiliated. Perhaps I was a wimp, who should stop moaning and get on with her life. I waited 9 months for the scan. When the results came through, I realised just how little notice had been taken of what I had to say. Quoting from the letter, he sent to my GP:

> "I am pleased to say that the MRI scan is essentially normal, but there are signs of wear and tear. In particular there was no evidence of any lumbar disc disease which was I think the main thing to exclude here. I think it is important that this lady be encouraged to be as active as possible."

He had asked for a scan of the one part of my back that gave me relatively few problems. There had never been any suggestion that I might have a lumber disc problem, it was my neck.that was suspect. I was so angry. Not only had I waited 9 months for a very expensive test, but the wrong part of my body had been scanned. I realised he had not listened to me at all. I did not fit his preconceived idea of a post-polio patient he was not interested.

I felt devastated, I had seen the "expert" and been dismissed, there was no where else to go. Fortunately my GP thought otherwise. Her attitude was we would fight this together. She had no doubts that my problems were due to the late effects of polio. She referred me back to the Orthopaedic Consultant at my local hospital who had seen me in the past. Here my reception was quite different. I was given a diagnosis of late effects of polio with new atrophy. Although he admitted he had little experience with post-polio I felt I was listened to with respect. It made such a difference.

In the 3 years since I gave up work I have continued to deteriorate at an alarming (to me) rate, so much so that I am sure I would now qualify as a bona fide post-polio patient even to the 'experts'. The knee and ankle of my right leg are both unstable, my ankle points in and my knee points out, my legs and feet are always blue, no more mini skirts for me! In fact no skirts of any description. Otherwise my symptoms are much the same as anyone else with PPS. Increasing weakness, fatigue, muscle atrophy, pain etc etc.

My GP continues to be a great support. I think it has also helped being with this practice since I was 10. All my notes relating to the original polio are available. In fact the Doctor who originally diagnosed the scoliosis in my upper back when I was 15 and who wrote numerous letters to the Matron supporting my application to train as a nurse when doubts were raised about my physical ability to nurse, has only recently retired. They know me, know what I used to be able to do. I have a sympathetic Consultant, a good specialist neurological physio, and most important a good husband and 2 wonderful children. In comparison to many others I am fortunate and should be grateful, but most of the time I am not.

I am angry and frustrated that there is still so little knowledge or acceptance among the medical fraternity and the government of the problems faced by us old polio's, Once again the UK is 10 years behind the US and some of Europe. Perhaps it is cynical of me, but one can't help wondering, if their attitude is, wait a few years and the old polio's will all die off and that will solve the problem.

But I am even more angry and frustrated with my own body for letting me down. Mind over matter no anger works. I feel guilty at the strain, financial and emotional, my condition has put on my husband and children, and the anxiety caused to my parents. Didn’t they suffer enough when I contracted polio in the first place?

Most of all I am mad at myself. I have read every thing I can get my hands on about PPS. I read the LincPIN from cover to cover, know all about pacing and energy tokens, the importance of diet adequate rest and giving up smoking! Conserve and preserve, using aids etc. I know what I should be doing to help myself, the problem is don't do it. This is partly due to the problem of many in the so called caring professions, we can dish it out but can't take it back. We can give advice, listen to peoples problems, empathise, provide support etc but find it very hard to be on the other side of the fence.

There is also denial: it is unlikely that I will be able to work again. But there is that little voice in my head that says this is only temporary, I will recover, go back to work and everything will get back to normal. If I am honest, it may also have something to do with that infamous Type A personality.

Whatever the reason, I know the answer lies in my own hands its my body, my responsibility.

I also feel bitter that the sacrifices made by my family to enable me to get my degree have resulted in only 4 years gainful employment. I also find it difficult to accept that my future is not going to be the one I planned. Even more difficult to reconcile is the fact that my husband isn't going to get the future he deserves.

As you may have gathered, I am no Pollyanna. However I must admit that there are some positives in this situation. For the first time in my life I have that most precious gift, time. I may not have worked out what to do with it yet, but I am determined not to be on the scrap heap at 48. The knowledge that others with far more difficulties than me have succeeded in turning their lives around gives me the impetus to do the same. I also know that I am very lucky. Many, if not the majority of those who contracted Bulbar/Spinal Polio either died or required artificial ventilation for the rest of the lives. When I am feeling sorry for myself try and remember it could have been a great deal worse.

Janice Eary - <Janiceeary@hotmail.com>

From Marsha in Texas <marsha@ccms.net>
WHOOHOO - http://www.whoohoo.co.uk/

This site takes an English phrase and translates it into various British accents including Geordie (Newcastle), Brummie (Birmingham), Yorkshire, Scottish and Posh dialects. There's also an Ali G translator for fans of the British TV show.

Lincolnshire Post-Polio Library

Articles added, with grateful thanks to the authors, since last newsletter and not included in this issue.

Reminder - All the medical articles printed or referenced in this section of the LincPIN’s are sourced in full in the Lincoinshire Post-Polio Library on our WebSite. For those of you without access to the Internet who would like copies of any article they are available from us for the price of photocopying. Members post free.

Title: Post-Polio Syndrome: Pathophysiology and Clinical Management

FULL TEXT HERE

Special Note: This is a long article (226K). We have also produced a multi-document version comprising fifteen separate shorter documents which reflect the section headings of the original article. Multi-document Version
Author(s): Anne Carrington Gawne and Lauro S. Halstead.
Original Publication: Critical Reviews in Physical and Rehabilitation Medicine, 7(2):147-188 (1995).

Abstract/Extract: Post-polio syndrome (PPS) is a progressive neuromuscular syndrome characterized by symptoms of weakness, fatigue, pain in muscles and joints, and breathing and swallowing difficulties. Survivors of poliomyelitis experience it many years after their initial infection. Although the etiology for these symptoms is unclear, it may be due to motor unit dysfunction manifested by deterioration of the peripheral axons and neuromuscular junction, probably as result of overwork. An estimated 60% of the over 640,000 paralytic polio survivors in the U.S. may suffer from the late effects of polio. Their physical and functional rehabilitation care presents a challenge for practitioners in all disciplines. To evaluate these symptoms, a comprehensive assessment must be done, as frequently PPS is a diagnosis of exclusion. Care of the patient with PPS is best carried out by an interdisciplinary team of rehabilitation specialists. This article reviews the epidemiology, pathophysiology, characteristics, assessment, and rehabilitation care of the patient with PPS.

Benefit Article

by Cathi Penman.

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[Newsletter Editor's Note. Cathi is a subscriber to the UKFMS - email list ukfms@egroups.com.. FM is Fibromyalgia. We monitor this list as there are many overlaps with our condition and having read Cathi's story about her Benefits Claim she agreed to write an article for our newsletter. We have members going through the minefield of Applications, Reviews and Tribunals at the moment, having similar problems to Cathi. One member awarded full mobility and high rate care has suddenly had all her benefits taken away for the second time and is now having to wait for a date for a Tribunal! Why is this allowed to happen? We believe this is mostly due to the lack of knowledge of polio and its late effects by the medical and government agency staff that assess us - and continues despite many letters and medical articles sent over many years by ourselves and the BPF.]

The Disability Living Allowance Claim Pack should come with a government health warning - 'Don't Try This At Home.' If you do, it's a case of 'Be afraid, be very afraid!'

My first application for DLA, six years ago, was turned down following a visit by a Benefits Agency GP. He was an extremely charming man, who seemed very caring and spent more time telling me of his work for the Labour Party than he did examining me. I strongly believe that this was due to a prejudice against fibromyalgia and chronic fatigue syndrome.

My first mistake had been to 'go it alone' - filling in the forms myself without aid of a safety net such as the help of a welfare rights worker, Citizens' Advice Bureau, or specialist solicitor. Luckily I clued up on this very quickly and engaged help when it came to my appeal.

It would seem that the GP's report must have been 'way off' as after appealing I went from being awarded absolutely zilch to the higher rate of both care and mobility!

I would advise anyone who is thinking of applying to first get in touch with one of the aforementioned organisations, as they have a fund of experience when it comes to filling in the interminable forms. In addition, if you have a sympathetic hospital consultant, ask him for a letter of support, stressing that it should not only detail his diagnosis, but *how this affects your daily life*. This is crucial. I've had people say to me on countless occasions - "Well you'll have no trouble, you obviously have 'physical' things wrong that can be picked up on X-ray, they can't argue with that." My reply is: "They can and they do." It is not the 'cause,' it's the 'effect' every time.

Please also remember that the Benefits Agency are not in the business of being fair, if they were, they would actively advertise benefits and there would not be so many awards made at tribunal level, it's as simple as that. They are in the business of saving the government money, whichever political colour it may be. It is often said that only the 'best actors' get DLA - whilst I wouldn't agree with the generalisation, I would say do not try to 'be brave' and do not exaggerate what you can do. The visiting GP will only write that you are 'coping well with your disabilities' and therefore don't need benefit.

If, as I was, you happen to be refused, I would first ask for a copy of their GP's report as you will undoubtedly be able to find holes you could drive a double-decker bus through. In my case, the welfare rights worker noticed the GP had written that I could easily walk "100 yds over any terrain." He had merely asked me to walk across my living room carpet and verbally noted that I had difficulties, so how he could arrive at this conclusion was beyond me - and thankfully also beyond the Independent Tribunal.

There does seem to be a definite bias, on the part of Benefit Agency hotline staff and their GPs, against conditions such as FMS and ME/CFS. A friend recently had a DLA Periodic Review. She was unhappy with the decision and rang Blackpool. The first woman she spoke to said she thought she'd had an excellent result, as she hadn't had her benefit completely taken away! Later, a gentleman who described himself as a 'graduate training officer' said it will soon be policy to take away the mobility component from FMS/ME sufferers, because 'no physical problem exists'. His atitude was disgraceful, and whether this was a personal opinion or an official one remains to be seen, as a written complaint has been sent to my friend's local MP, the Director of the DBU and Hugh Bayley MP (the Under Secretary of State for Social Security). When it comes to complaining remember: always go to the top!

My original award was for five years and I had to make a re-application last year. I had been told at the original tribunal that I would have had a 'life award' but they did not think this was appropriate due to my age - being under 40, despite my condition being diagnosed by my rheumatologist as "permanent, irreversible and degenerative" (this did not necessarily include the FMS/CFS - although he did say the FMS was incurable, but controllable).

I re-applied and after a further *not so charming* GP's visit, had all my care component taken away. When the GP arrived, I was sitting in my wheelchair, with a neck brace and bi-lateral wrist and thumb splints, yet he said I needed no help with personal care! My husband was present and we explained that I cannot chop vegetables, open tins or even get the tops off my medication bottles without help. I also suffer from the sleep disorder which in my case involves very prolific dreaming, graphic nightmares and night-terrors where I have to be woken up for my own safety. This had previously been noted by a DSS officer who stated that I categorically qualified for the higher rate of care because of this condition which necessitated care throughout the night.

We explained that because of my short-term memory loss and lack of concentration, I have to have my medication monitored as I invariably forget what I have taken. The GP was quite scathing and said: 'I hope you aren’t trying to insinuate that there's an element of dementia here?' When we told him it was down to fibro-fog it was obvious from his face and body-language that he hadn't a clue what this was. Furthermore, on examination, he pressed down with both hands and his full weight on my shoulder causing me to cry out with the extreme pain. I had residual pain for well over a month afterwards (although in his report he stated he had 'touched my clothing lightly'). I did not even wait for a decision before registering my disgust with this treatment, but nevertheless it came as no surprise to find my care component had been rescinded.

I have always believed that in dealings with the Benefits Agency, 'the best form of defence is attack' so with the invaluable help and support of my husband we mounted an all-out campaign. I partly dictated letters, my husband did the rest, to the Benefits Agency detailing my concerns and when I didn't get a reply within the stated time limit, I wrote again pointing this out. I wrote asking for a copy of their GP's report and when this didn't arrive within the promised time, I wrote again. When no reply was forthcoming I wrote to their customer services department. I also engaged the help of my local MP who in turn wrote to the Director of the DBU and Hugh Bayley MP.

The GP's report stated that my condition was "only partly due to physical factors" and it was quite evident that he thought was 'swinging the lead'. I am convinced he was of the 'old school' and thought FMS and ME/CFS was 'all in the mind'. In my letter of complaint I pointed out that FMS is recognised by the World Health Organisation and that it really isn't up to a humble GP to contradict this. I also pointed out that the diagnoses of my conditions had been arrived at by hospital specialists, with the benefit of X-rays, CT scans, Dexa scans and nerve conduction tests and their effect on my life was clearly demonstrated in the letters of support from my rheumatologist. I asked how they could possibly over-rule this overwhelming medical evidence on the opinion of a GP who had arrived late for his appointment, made a cursory examination, rushed through the form, paraphrasing my replies and showed an obvious ignorance of the conditions he was supposed to be advising them on!

I received an apology from SEMA Medical Services apologising for the GP and saying that after his report had been scrutinized by one of their doctors they had found it was "not fit for the purpose intended". My benefit was restored on review and I did not need to suffer the added trauma of a tribunal.

I am most concerned that the average applicant for DLA suffering from FMS/ME/CFS will be fighting a losing battle from the word go.

I am lucky that I am an ex-journalist and reasonably articulate. I have amassed quite a lot of information and what I don't know personally, I do know where to find the information. I also have no fear making a fuss and getting MPs and government ministers involved. I always believe in complaining at the highest level. I feel heartily sorry for those who give credence to what Benefit Agency doctors report and think that because the doctor says they don't need benefit, they must be malingering - there are people like this who give up at the first hurdle and this is exactly what the BA wants!

When I was first awarded DLA I rang the Benefits hotline to ask if I could claim Incapacity Benefit. I was told that I could not as, having been a student, I did not have the required amount of National Insurance contributions. I asked if there was any other benefit I could claim, but was told there wasn't. I found out over five years later that this wasn't the case and that being on the higher rate of care, was *automatically* entitled to Severe Disablement Allowance. The Benefits Agency advisor had, by giving me the incorrect information, wrongly denied me over £10,000 in benefit! Suffice to say, I never telephone the hotline now. I always write, then I have a permanent record of my letter to them and any reply. If I should find I've been given incorrect information in future, I will always have written evidence, rather than 'my word against theirs'. Of course in a situation like this the BA will only backdate benefit for 13 weeks. However I'm sure, had I been guilty of defrauding them for a period in excess of five years - they would certainly be looking to get more than 13 weeks benefit back from me!

Incidentally SDA is being phased out for new claimants by April 2001, so anyone who feels they may qualify should get the application pack now - let's face it, the BA are hardly likely to advertise this or any other benefit. Any private company operating in this underhanded manner would no doubt have been sued and bankrupted many years ago!

Finally, anyone who is receiving DLA and has had a 'Periodic Review' since the present government came to power please note the following important information. I have recently found that the BA in Blackpool have been using the incorrect criteria in their decision making regarding these reviews. The purpose of the Periodic Review, as stated by Hugh Bayley MP, is to review benefit to make sure that claimants are receiving the correct benefit. This means that the benefit may be increased, decreased, left as it stands, or taken away completely. However BA staff have still been using the previous government's Benefit Integrity Project rules which do not allow for an increase in benefit. This means if claimants have suffered a deterioration in condition, warranting an increase in benefit, it will not have been noted or paid. I would suggest that anyone who feels this may include them, should write directly to the Director of the Disability Benefits Unit, Mr John Sumner, at the

Disability Living Allowance Unit, Warbreck House, Warbreck Hill, Blackpool FY2 0YE, stating their case and also send a copy to their local MP and Hugh Bayley MP (Under Secretary of State for Social Security) at Richmond House, 79 Whitehall, London, SW1A 2NS.

I would also urge that anyone who comes up against prejudice towards FMS/ME/CFS or similar from the BA GPs should also write to the BA Customer Services Department, sending a copy to their MP. These conditions are recognised disabilities and prejudice against them may even be illegal.

[Newsletter Editors note - we sent an analysis of the pages in the guidance booklet for doctors assessing for benefits on polio and its late effects and requested that this be updated with some urgency. The Medical Advisor who replied asked for more information which we sent. We will chase this up.]

* * *

The teacher led the class with the Pledge of Allegiance, and instructed them to put their right hands over their hearts and repeat after him. He looked around the room as he started the recitation, "I pledge allegiance to the flag..."

When his eyes fell on Little Johnny, he noticed his hand over the right cheek of his buttocks.

"Johnny, you need put your hand over your heart."

Little Johnny replied, "It is over my heart."

After several attempts to get Little Johnny to put his hand over his heart, the teacher asked, "Why do you think that is your heart?"

"Because, every time my Grandma comes to visit, she picks me up, pats me here, and says, 'Bless your little heart,' and my Grandma wouldn’t lie."

‘Removers of stuck toast in Toasters'

1. Get a package of 5/8" craft sticks - they look just like tongue depressors.
2. Make or somehow get some pieces of wood that measure 5/8" X 5/8" X 5/8". You can cut a 5/8" dowel to 5/8" lengths if you wish. I think the tongs we have at the toaster actually have 1/2" dowel for the spacer.
3. Put white craft glue or yellow wood glue on the two opposite sides of the blocks of wood and apply one end of the craft sticks to the glue. Clamp or wrap tightly with rubber bands and then adjust so that the sticks are parallel and even. Set aside for several hours, preferably overnight.
4. Remember to turn off the electricity before trying to remove that elusive piece of toast.

Art Coburn <artinfla@juno.com>

* * *

Annual General Meeting - Saturday 30th September 2000.

Venue for meeting Ancaster Day Centre, Boundary Street, Lincoln.

Boundary Street is West off the A1434, 100 yards south of the roundabout junction with the A15 at South Park and 10 yards north of the Pedestrian Lights adjacent to DC Cook Motors on the A1434.

Ancaster Day Centre will be open from 9.00 am. when the salad buffet lunch will be prepared and stored in the refrigerated compartments. Any help towards this would be appreciated. Tea and coffee will be available during the day.

The Annual General Meeting will start promptly at 10.30 a.m. Cost for the day is £3.50 with lunch, £1.00 without lunch.

12.00 p.m.	Approximately. Talk* and question time.
1.00 p.m.	We will serve buffet salad lunch, 2 meats, quiche, green and other salads, roll and butter. Vegetarian and other diets catered for by request.
2.15 p.m.	Two talks* of 35 mins each.
3.30 p.m.	Tea and Coffee will be served. Raffle drawn. (Donations of prizes welcome) Followed as soon as possible by Question Time.
5.00 p.m.	The building will be closed.

Talks* planned are on Claiming Benefits and Appealing against decisions. Orthoses by Ken Spooner from Ambroise UK Limited and Information from the GINI Conference by Hilary Hallam. At the time of going to press we have been unable to confirm the time for the Benefits talk. Ken Spooner and Hilary Hallam will be there all day.

Anyone who wishes to stay overnight. The Holiday Inn Express have given us the rate of £35 per room, single/twin/double which includes complimentary continental breakfast for all occupants. It is the same price for single or double occupancy. Anyone wishing to share a twin room please get in touch.. This rate is for Friday/Saturday and Sunday night. Please contact the hotel direct to book rooms mentioning the Lincolnshire Post-Polio Network on Lincoln (01522 698331). The Holiday Inn Express is on Whisby Road just off the A46 Bypass behind the Pride of Lincoln.

There will be members at the Holiday Inn from 2.00 p.m. Friday to greet you. Suggested meal at 6.30 p.m. at the Pride of Lincoln adjacent - essential that you let us know by 25.9.2000 so that we can book this. Returning to the Holiday Inn Express Bar for the rest of the evening at 8.30 p.m.

Saturday we will adjourn to the Holiday Inn Express Bar for an informal evening of chat and laughter as last year. Take Away meals can be ordered and eaten in this bar or your room as the Hotel does not have a restaurant or you could eat elsewhere and then join us.

Nominations for all posts* except Vice Chair with specific responsibility for the WebSite are requested in writing by the 30th August 2000.

Currently:

Chairman	Christine Ayre	Standing down as Chairman.
Vice Chairman	Bud Robinson	Standing down as Vice Chairman.
*Vice Chairman with executive responsibility for the WebSite will remain with Chris Salter.		
Secretary	Hilary Hallam	Standing down as Secretary as nominated for Chairman.
Treasurer	Jean Tapper	Standing down as Treasurer, prepared to stand as committee member.
Committee Member	Phil Bilton	Prepared to stand again.
Committee Member	Frank Grimmitt	Prepared to stand again.
Committee Member	Myra McManus	Standing down.
Committee	Vacant.	

Member

Nominations have so far been received for:

Chairman	Hilary Hallam.	
Vice Chairman	Vacant.	
Vice Chairman	Chris Salter	Executive responsibility for the WebSite.
Secretary	Wendy Grimmitt.	
Treasurer	Vacant.	
Committee Member	Phil Bilton.	
Committee Member	Frank Grimmitt.	
Committee Member	Jean Tapper.	
Committee Member	Vacant.	

WE NEED MORE NOMINATIONS PLEASE.

Committee Meetings are held every two months in the Lincoln area to suit those attending. Recently they have been on the third Wednesday of every second month. However we are prepared to consider a weekend morning or early afternoon. We do not have the energy to have meetings in the evenings.

If any members or family members are interested in joining the committee you would be most welcome. If you would like more information about the work involved then please get in touch.

Consideration to holding committee meetings using conference phone or via the internet for anyone unable to get to Lincoln are being looked into.

N.B. Please tell us as soon as possible if your newsletter has not arrived when expected, or if you have not received anything you have requested.

AGM attendence and nomination slips were included with the hardcopy edition of this newsletter mailed to all members in August 2000.

LINCOLNSHIRE POST-POLIO NETWORK
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(US$ checks to LincsPPN c/o 4212 Blanding Blvd, Jacksonville FL 32210, USA)
Other Countries please contact for details.

All donations will be gratefully received.

LincPIN Newsletter - October 2000
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All enquiries, book requests, medical article requests, membership fees, items for newsletters and donations to

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