



The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter
Volume 5 - Issue 10 — August 2006

WebSite - <http://www.lincolnshirepostpolio.org.uk>



Kathleen Burrell
from Lincolnshire.
Continues on back page.



As the Hudson Bay blanket is placed around their shoulders by Best Man Bill Westfall, Hilary and Richard become one married by 'Walking Owl' on March 25th 2006



AGM
Sept. 9th 2006
Main Speaker
Helen A. Kent, BS, RRT

PLEASE SUPPORT THIS EVENT
Full Flyer Page 15.



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A Big Thank You for the Donations received from:-

Norman Jones, David and Jane Shaw, Michael Horton, Roy Prentice, Pamela Minnitt, Val Scrivener, Robin Butler, Margaret Edmonds, Patrick Peacey, Jacqueline Williamson, Angela Johnson, Margaret Lamb, Barry Branston, Steve Clynch, Clare Colfer, Agnes Walker, Joan Deans, Thomas Croker, Kathleen Burrell, Jeffrey Edwards, Lynne Hobday, Robert Price, Jann Hartman, Jean Hill, Beverly Buccellato, Lena Jennings, Susan Sonski, Jim & Jenny Rayner, Sylvia Fortune, and the Operations Team and Committee.

Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

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Articles for publication 4th August by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial by Hilary Boone.

Quite a few people have contacted me asking for a photograph of our Wedding and I realised that I had not put one in the last issue. The one on the front page is special to us as it is the moment when Richard and I became husband and wife. As part of the Native American ceremony I had to bring a basket of fruit and corn to show that I could feed 'my hunter' and he had to bring a blanket to show he could provide shelter for me. This blanket is then used in the ceremony and put round our shoulders to join us as husband and wife.

"Grandfather, they came to you as two and they leave as one" said the Reverend Walking Owl lifting his bearded face to the sky. "Never again shall they walk alone in the world. Walking Owl is a fellow Florida Frontiersman and Spiritual Leader of the Métis nation. Richard introduced me to Re-enacting the Pioneer/Mountain Men life of the 1700's to 1840 We joined the Florida Frontiersmen and with their help we have participated for five years.

Thank you to the folks who contacted me regarding the last newsletter, commenting that they could relate to some of the phrases, e.g. 'Do you run out of breath before you finish a sentence. Others reported that they too had answered Epworth Scores for a good day and had also received low scores and two told that there was no further need to be tested. **Remember that you have a marvellous opportunity to be respiratory tested, free of charge, on the day of our AGM. Saturday September 9th 2006.** Even if you do not think you have any problems now you will have a base line assessment for the future. 22 of the 25 tested at the San Francisco PPS Group meeting had figures below the norm.

Dr. Darren Barnes-Heath, A Chiropractor with specialism in Neurology and our speaker last year, is coming to our AGM to hear Helen Kent and meet up with Dr. Betty Dowsett [a Life Member and one of the UK's prominent ME/CFS Specialists] and has agreed to answer questions. He asks that you put them in writing as soon as possible. Your AGM return slip has an area for questions on it, and we would be so grateful if you could return these, ring or email the information as soon as possible.

The Committee decided to do a smaller issue early with the AGM information as new postal rates on size come into effect on August 21st. It is mainly information from other PPSers because we know how much we learn from reading about someone else's symptoms and problems. Maybe you have problems like another PPSer but thought you were alone in this.

At an East Midlands Strategic Health Authority Meeting this month all seven tables placed Number 2 on the NSF for Neurology and Long Term Conditions list at the top of the list. Assessment and Diagnosis. Nearly all the neurological support groups there reported that the current system of assessment is failing their members and for similar reasons. I am taking this further to other meetings and hope to have more news for you next issue.

Mary Kinane and Denise Carlyle worked extremely hard on preparing the Annual Report and Accounts that are enclosed with this newsletter. Your Committee would like to remind you that all the hours spent on our work are voluntary and that nearly all of us are Polio Survivors with PPS. Like you we live on reduced energy tokens. If any members, or family or friends can spare us a few hours a month to share the workload then do get in touch. We could do so much more with more help.

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I was so Lucky. I had a “Full Recovery from Polio”

Something very interesting seems to happen when various discussions come up on the different pps email groups I am on. Some just lend to my stopping and looking at my own polio story focusing on a particular facet or two which in sharing often clarifies it just a bit more for myself while, at the same time, seeming to help other's clarify points of their own story.

Recently on one such list a writer pondered this thought. How could any of us have 'fully recovered' when we are now finding that with pps we are loosing anywhere from bits of this 'recovery' to major pieces of it. He pointed out how in his own life he is finding he is getting progressively weaker with the passing years.

Something many of us do not want to think about but if we are honest we can definitely identify with.

So I pondered his question. And in sharing this facet of my polio, post polio, and now PPS story this is what I came to see as a possible answer.

For this sharing I will start at the end of my hospital stay. I will remind those who are familiar with the basics of my stories (and those of you not) that I had polio in the fall of 1950 at the age of 4. I don't remember any of it and rely on the stories told over the years by my mother and my older sister.

When I left the hospital walking, the doctor lifted my left arm and he and my mom watched as it collapsed to my side. He looked at my mother and told her that polio had destroyed all the nerves and muscles and not to bother spending money on any physical therapy. Instead, he told her to just help me learn to adjust to it. Then, he smiled and said, two things, 'besides, she is lucky to be walking out of here and very lucky to be alive.'

So, in answer to part of the writer's inquiry I never received any real physical therapy for my left arm.

Part one of my story... the early years after polio.

My left arm was useless, but my left hand seemed 'good'. So I used it a lot. I had a rubber ball that I always carried with me and squeezed constantly. this 'developed' muscles in the lower half of my arm.

Then, later when I was in high school I insisted on learning to type. Succeeding at that I next insisted on learning to play piano. I started this in my junior year and continued taking lessons right through my college years. Both activities helped me gain lower arm development. Yet, I never did develop any upper arm or shoulder muscles. (And still have not up to this day).

I always had to lift my arm and place my hand where I wanted it to work. [Even now I type with the palm of my left hand resting on the keyboard while my fingers stretch to reach the keys. All the while my right hand 'floats' as it should.]

Part two of my story... corrective surgery on my left arm at age 29.

Before the two operations I had an EMG of my left shoulder and upper arm so the surgeon would know what he was working with. This test showed what I already knew. There was almost zip on the nerves in the shoulder and upper arm with the same results on muscles. Actually, there were a few very tiny useless ones hanging

around there.

The first surgery was on my elbow. In order to give me the ability to bend my arm he cut a piece of my elbow bone and pulled my largest lower arm muscle over my elbow and pinned it almost dead center to my upper bone. This shortened my arm further as it no longer can extend completely straight to my side. I didn't mind this one bit as it was and still is wonderful to be able to bend it.

The second operation was on my shoulder. Here the doctor put in a plate bent over my shoulder and down my arm about three inches using five pins to hold it in place. One is very large and goes deep into my scapula bone. The result is that this is sort of an under the skin brace. It allows me to use my back and side muscles to lift and move my arm. While this is simply miraculous to me in reality it's actually very limited in what this allows me to do. Yet, I no longer have to place my arm, it simply moves to where I want it to be. It is as 'close' to normal as this will ever be.

Part three of my story: now enter my PPS years

This is when I came to find out that my legs had also been affected. This was when I had that awful EMG experience in 1995. This is electrical testing of the nerves by inserting needles and stimulating them electrically and recording the results. This was done by a neurologist. He did both of my arms and both of my legs at the same time. He used both the small needle and the dreaded large Teflon needles.

I was told that I have fewer nerve cells and have over-developed more muscles in my left leg than my right. But the surprise, to me, was that I had the same damage in both my right leg and arm. It was to a little lesser degree, but the bottom line was that I have damaged nerves in all limbs.

When I got to my best recovery from my polio to my mind I only had problems with my left arm. The rest of me was fully recovered. So I got on with my life, pushing myself to the limits and beyond [as so many of us have done] not realizing that the recovery in my other limbs was not complete but enough for me to do what I did. But, since I was able to do so much of what was what normal then you could say I fully recovered. In fact, until PPS woke me up both my doctors and I agreed I had (except for my left arm) made a full recovery. I was lucky.

This is something many pps experts outline in their books and articles. This is part of the problem with pps. In short, these over-extended and over-developed muscles that enabled me to pass so well for so long; these muscles that lent to the picture of 'full recovery' are now simply wearing out.

It is why learning to pace and conserve is the key of my life today. It is why I have been using a power wheelchair about 60 to 70% of the time now. I am doing all I can to preserve the strength and ability to walk and stand as needed and to be able to use my good arm for as long as possible. Disuse is bad for us, Overuse is bad for us, it is finding that line in the middle that is important.

My hope is that I am doing well. My hope is that even though, like so many of us I still can see a gradual continuing of weakening that I manage to keep enough to stay independent till the end of my life. But, if I don't I will be able to accept it better as I know I have done all I can to do it.

The Texan One Armed Bandit.

Ellen Riddle moonshadow2@lonellen.com

Hints, Bits and Tips from other Polio Survivors.

They used to wait for me, now I wait for them.

I could lean against a pole, a wall, a building, but finding something to sit on was just heaven, low walls were the best. I never said I was tired or asked them to walk slower.

I was always able to keep up with them in the beginning but soon would be a couple of steps behind, when they realized that they would stop and wait or walk back to me and we would start out again at my pace. But soon I would again be behind them. I do remember being angry at myself that I could not keep up, but they never showed by word or gesture that it bothered them to walk at my pace or to wait for me to catch up.

Now in my chair I am the one who has to slow down and go at their pace, and it is so hard and frustrating. I think my friends and family were fantastic in the way they never showed their frustration. Margaret Campbell.

People rushing in to help

I fell more often due to my brace leg slipping on something. Once I was down, it was always a problem when people came over to help, and tried to pull me up by my arms. I learned quickly to ask them to please release my arms and assured them I was okay (even though I wasn't always). I had to get myself up even if it wasn't too good looking to do... bottom up first (probably why I started wearing slacks more and more).

It's the same with doors when I had to open them myself, and some kind hearted soul trying to help, pulled it out from under me...making me fall, unless I caught myself. It took a lot of learning to keep people from helping too much, but it also took some practice to ask for help (especially now with PPS when I really need the help).

With the onset of PPS, I found standing to be agonizing, and the scooter to be wonderful because now I always have a seat and do not have to hunt for one all the time. Jann Hartman. [now in Seattle]

'I know how you feel'.

One reason I feel that I get comfort from other pps-ers agreeing with how I feel, when what has happened etc is that they ARE in the same boat with me. When someone who isn't, who I see as 'normal' tries to identify with me, too often I go immediately back to when I was a child and got the pats on the head ..'there there its really ok'. type thing. Even if they have similar pains or fatigue I am more 'suspicious' of their saying they understand. this isn't fair to them. but there it is that is how I feel, and like so many of us I go to great lengths so they don't know I feel this way at all.

I think it is also especially hard to be honest with anyone in a white (medical) jacket as we were praised so much for being that good non complaining soldier as children. It is difficult to get it through on a deep gut level that letting them know we hurt is not complaining, whining or being weak. For me.. often I don't even let myself know how much I hurt. I am very good at psyching my pain to the background and ignoring it. In some ways this is a good thing (I need less pain

killers) but in many other ways it can be more harmful than good.

I find before I go to a doctor I have unpsych my pains. I have to allow myself to feel them so I can tell them what is really going on with me. Those health professionals who know me well can see it in my face/eyes, but most don't.

I was never taught how to fall, as those around me as a child blamed it on my being lazy. Instead I had to learn not to fall. Somehow I did. Now, whenever I feel the least bit unsteady or overly fatigued, I use a cane or hang onto someone, or use my wheelchair, whichever is nearest.

Oddly enough for not falling much after the age of 12 or so (except for going up stairs which lasted many years longer). I have a deep seated fear of falling. Ellen Riddle.

How much of our body was affected?

Today, after three early mornings and a visit from my sweet but tiring granddaughters, I absolutely believe that not one muscle in my body was unaffected. Even my eyelashes are tired! Millie Malone.

Wheelchair bound.

- Wheelchair-bound. "This is the worst tabloid-speak phrase. Are pedestrians classed as shoe-bound? Are cab drivers taxi-bound?"
- Wheelchair-bound is used in the press all the time - usually when a wheelchair user has been swindled in their own home by a phoney salesman. The Press does not do compassion well.
- As far as I know there is nowhere called Wheelchair, so how can you be wheelchair-bound?"
- Wheelchair-bound is beaten only by 'confined' ... (to a wheelchair). It sums up people's fears that disability is indeed a confinement, and this in itself gets in the way of acceptance. I'm only bound to my wheelchair when I ask to be tied up on a Saturday night, so long as my partner has the feather duster handy!
- "My wheelchair does not 'bind me'; it frees me."
- "I want to shout out loud, I am wheelchair-independent. I am wheelchair-liberated!" Marsha Coleman

Kitchen tip

A pull-out shelf can be installed below a wall oven or microwave with a Side-Hinged-Door. This helps wheelchair users to insert or remove items from the oven and partially protects them from spills during the process. Marsha Coleman

How do you cope with phrases said to you?

Life is tough moving to wheels where once you used to walk. So it is not surprising that we find it a little difficult to answer those well meaning folks who say things like, "You really do manoeuvre that thing well".

On one of the polio lists many comments came back as to things you could say, and had said, and some were really funny. One lady stopped us in our tracks when she said that "surely most people meant well but just had a hard time in phrasing something. At least they have spoken to you." Hilary Boone.

Mary McCreddie's Kitchen Saga

Why is it, that immediately you have a big project to contend with, everything else seems to either go wrong, happen at the wrong time, or generally make life even more difficult than usual?

I am the Members Email List Facilitator so those of you on the Internet will know that I was given a Disabled Facilities Grant to make my house wheel-chair friendly. The main problem being the step down into the kitchen. It took a great deal of effort to get the grant sorted out and agreed, and 8 months after getting the OK, work was finally able to begin. **I hope the following will help others of you who may be considering getting such a grant, to remember to get EVERYTHING in writing, all i's dotted and all t's crossed, and make sure that every eventuality is accounted for.**

I was extremely lucky to be able to have the builders I wanted to do the work – heaven knows what state I'd be in now, if the tender had gone to anyone else! The job entailed ripping out my existing kitchen, and raising the floor by 6 and a half inches. Not too bad so far.....but the back door and window also had to be taken out, the lintel raised by the same amount, and a new door and window put in. As the electric meters were installed above the original back door, they had to be moved. Nightmare! The electrical work somehow managed to involve every single room in the house – carpets and floorboards up everywhere – and even though these were the tidiest builders you could wish to have in your house, the mess was unbelievable! After that, the door into the hallway had to be widened considerably, and then the kitchen walls made good and decorated, before the new kitchen units were installed.

And that's where the problems (apart from the sheer difficulty of coping with all the noise, lack of electricity and mess) started. It had been agreed (verbally – and therein lies the problem) that it would be not be possible to re-install the old units – especially as I had a lot of high-level cupboards which I could only reach with extreme difficulty when on my feet, and would be impossible to reach from a wheel-chair.

It was just as the builders reached this point in the work that the Man from the Council arrived. Now the chap I'd been dealing with prior to this was very helpful; he truly understood the difficulties and was more than happy to agree the necessary new units. This new one informed me that my original chap was on long-term sick leave, and that he was taking over, and was decidedly miffed that he 'had to do someone else's work'. Very much looking down his nose at me, he looked over the job so far, and pronounced it excellent. Then he dropped the bombshell. Apparently no actual figure for new kitchen units had been specified in the Schedule, and therefore I could not have ANY new units. He insisted that I have the old kitchen put back – even the sink! "Nothing wrong with it – perfectly OK for *you*." The fact that it had only been kept operational by the nifty addition of hose pipes, and shifted around daily – sometimes even outside! – and had been used as a repository for everything from hammers to drills, screws, nails, bags of plaster and everything in between did not seem to register. I was absolutely furious. Perfectly OK for *ME*? Why? Does a disabled person somehow not know the difference between a decent sink and one that has been completely wrecked? And does a disabled person need fewer cupboards than an able-bodied one? Then he said that on consideration, he

supposed I could have *one* cupboard replaced, but that the old units still in one piece (a small cupboard and a drawer unit) would be perfectly all right to use. As it was impossible to match the doors on the one new cupboard I was so graciously being given, I would have to put up with odd ones. I was completely devastated. To have the floor raised was wonderful – but at the expense of not having a functional kitchen at all? And with no warning? I immediately rang my OT (Occupational Therapist) who had been out to see me the week before, and had said how thrilled she would be to see my new kitchen, and was totally thrown by the way she completely back-tracked and said it was nothing to do with her. In the end, I had no option but to buy the new units I needed myself. My builder was fantastic to say the least – the nonsense with not getting a proper go-ahead from the council meant that all the other work had been done, and there would have been nothing for them to do unless we could get the new units quickly. He pulled out all the stops, went and fetched the units instead of waiting for them to be delivered, and got them installed in double-quick time. Knowing that money is a real problem, he has let me have them at cost-price. Even so, paying for them will mean that I have to tighten my belt for the best part of some time to come.

So the upshot of it all is, I have a beautiful new kitchen, and a completely level ground floor! Absolute heaven! I'm still a little short on space, so I have to dispense with anything not absolutely necessary, but it is a kitchen that works for me in my electric chair. The work surface level is two and a half inches lower than normal, which makes it very easy for me to reach into the sink, or to the back of the work surface, yet is high enough to be easy to work at when I am able to stand, and also to support myself on. I have drawer units where most people would have cupboards; I have two 'pull-out' units for easy access; two enormous deep drawers under the hob, and a normal cupboard under the sink. I also have an ordinary corner unit. I can't reach the back of it, so I shall be storing things I don't need very often in there, and will probably have to wait for someone to get things out for me when I do need them. Interestingly, the much-vaunted 'train carousel' which can be used in these corner units, and which the manufacturer's make so much of for disabled people, I found to be completely useless. There is NO way I can actually get close enough to the thing when I'm in the wheel-chair to actually get anything out! Ah well.....!

There was one problem – my washing machine would not have fitted under the lowered work-surface, and I have no outside place I could put it. To get over this, my builder has made a sort of 'mini utility' room for me under the stairs! Talk about ingenuity!

In the midst of all this mayhem, I had a bit of a relapse from an operation I had a couple of years ago, which meant that I had to go and stay with a friend - one simply cannot be ill when there are builders in the house. But I'm almost back to my normal self now, and I have another 4 weeks to recover before the builders return to start on the outside work of providing me with a ramp to get me down into my garden. Won't it be wonderful *not* to have to carry my cup of tea out through the front door, round the side of the house and through the back gate in order to sit at the patio table any more? I can't wait!

Mary McCreadie

mary.mccreadie@lincolnshirepostpolio.org.uk

The old Chinese proverb 'Be careful what you wish for – you might just get it', struck a chord with me the other day. When I was young, I used to wish that I wasn't so big and tall. Why couldn't I be a delicate 5' 1" or so and 6 stone in weight to go with it? Well now I have my wish in part.....in my wheel-chair I'm only 4' 7" – pity the genie forgot about the 6 stone bit!

E-mail Forum

Huge apologies, but it has simply not been possible for me to write the usual E-mail column this time, due to both building work and illness. The list has been very busy, with lots of ideas, information and a bit of humour too, which is really good. Look out for an extended column in our next issue.

Mary McCreadie mary.mccreadie@lincolnshirepostpolio.org.uk

Two patients limp into two different American Medical clinics with the same complaint. Both have trouble walking and appear to require a hip replacement. The first patient is examined within the hour, is x-rayed the same day and has a time booked for surgery the following week. The second sees the family doctor after waiting a week for an appointment, then waits eighteen weeks to see a specialist, then gets an x-ray, which isn't reviewed for another month and finally has his surgery scheduled for 6 months from then.

Why the different treatment for the two patients? The first is a Golden Retriever. The second is a Senior Citizen.

Translating Medical Terminology - The following email enquiry was received... I suffer from sequels of poliomyelitis. I'm writing you since in Italy the orthopedic ateliers have given up making laminated outhouses for polio sufferers. The reason is that polio is a disease in extinction and they made up their minds not to invest in this activity. [A serious enquiry and one we know only too well, but what a wonderful visual picture. If you know of anyone who can draw cartoons for our newsletter, please contact us]

This exercise is suggested for seniors, to build muscle strength in the arms and shoulders. The article suggested doing it three days a week.

Begin by standing on a comfortable surface, where you have plenty of room at each side. With a 5-lb. potato sack in each hand, extend your arms straight out from your sides, and hold them there as long as you can. Try to reach a full minute, then relax. Each day, you'll find that you can hold this position for just a bit longer. After a couple of weeks, move up to 10-lb potato sacks. Then 50-lb. potato sacks, and then eventually try to get to where you can lift a 100-lb. potato sack in each hand and hold your arms straight for more than a full minute.

Once you feel confident at that level, put a potato in each sack.

Old Harold In The Hospital - Harold was an old man. He was sick and in the hospital. There was one young nurse that just drove him crazy. Every time she came in, she would talk to him like he was a little child. She would say in a patronizing tone of voice, "And how are we doing this morning", or "Are we ready for a bath", or "Are we hungry?"

Old Harold had had enough of this particular nurse. One day, at breakfast, Old Harold took the apple juice off the tray and put it in his bed side stand. Next, he was given a urine bottle to fill for testing. So, you know where the juice went!

The nurse came in a little later, picked up the urine bottle and looked at it. "My, it seems we are a little cloudy today ." At this, Old Harold snatched the bottle out of her hand, popped off the top, and drank it down, saying, "Well, I'll run it through again. Maybe I can filter it better this time." The nurse fainted! Old Harold just smiled!

Never take a pill that has more side effects than you have symptoms

Excerpt from Kathleen Burrell's chronicle of her life.

CHAPTER ONE

MY CHILDHOOD

I was born on 14th February 1912, a healthy little girl and the only daughter of George and Edith Burrell. I had three older brothers, Frank who was born nine months and two weeks after my parents were married, Stanley, who followed two years later and Artie who arrived two years after that. I came hot on his heels a year later. With three elder brothers I was probably in danger of becoming a tomboy, as I followed them around trying to do all the things they could, when at the age of five and a half I was struck down with poliomyelitis, or infantile paralysis as they called it then.

We lived in a small village in Lincolnshire called Bicker, nine miles from our nearest town. of Boston. Bicker was, and still is, a pretty village with a stream running through it, and we lived at Sycamore House, which is near the centre of the village. However, when I was young Bicker was rather isolated having no railway or bus service and very few people had cars, so my father earned his living with a carriers cart which he took to Boston twice a week on market days. Mother would go with him and their route took them via Swineshead, Drayton, Blackjack and Kirton End, arriving in Boston by the London Road and High Street. Father would also collect along the way, both passengers and goods that people wished to sell on the market. Sometimes people would give him lists of articles they wanted my parents to purchase for them. But when the First World War started and my father was called up, he sold the carrier's cart as he expected to pass his medical and be in the army for the duration. However, father had had rheumatic fever when he was young and the doctor told him he would not pass the medical. Father was now so fit and well and confident of passing it that he had a bet with the doctor that he would pass. Unfortunately he lost his bet! However it was fortunate for the rest of the family in that he did not have to leave us to go to war.

I think as a small child I was rather shy and timid, but at times would like to 'show off' especially when I had learned a new nursery rhyme. I liked to climb on the table, which I think was my stage, and recite with eloquent actions and facial expressions, to my audience who were usually some visitors or anyone who might be around and would be kind enough to listen to me. I think I was the original Shirley Temple with my curls and bows of ribbons in my hair. My masterpiece was

'The Postman':

*Hurrah! For the postman who brings us the news,
What it must cost to pay for his shoes,
Red stripes round his hat with clothing to match it,
He walks many miles each day of the week.
If he lost any letters My! wouldn't he catch it!*

I ask you, who could ask for better entertainment?

My memory of happenings around this time seems to have been deleted by my illness and largely what I know now is of hearing Mother talking of them. One event she spoke of was when she took me to see a 1920 German Zeppelin that had been brought down by the British in some way. For many years we had a small piece of aluminium like metal that she brought back from the wreckage. She had taken me to stay for a few days with her parents at Barnet 12 miles north of London. The Zeppelin had come down some time late in the war at Potters Bar, approximately 2 ½ miles away. A pushchair was borrowed, she and some of her sisters decided to walk there and take me with them. I wish I could recall this event of such importance at the time. I remember very little of the First World War but I do recall my brother Frank saying how very frightened we all were when the enemy planes came dropping their bombs, sometimes not very far away, and he said we used to scramble under the table.

There was another occasion when I think I may have saved Artie's life. I was sitting in my pushchair on the bank of the stream that meanders through Bicker village and which ran opposite our house, when Artie, who was playing near the water's edge, fell in. He had probably been

catching sticklebacks, but I'm sure he didn't intend to get quite so close to them as he couldn't swim. He was soon being dragged down, so I called for our father who was in the yard and he quickly came and pulled out a very wet and frightened little boy. However, I received no medal for my bravery!

I was five years and eight months old when my mother, one Monday morning in 1917 getting me up to go to school, found that I was unable to stand! The family doctor was called and he diagnosed the trouble as rheumatic fever, as the symptoms were similar to polio. However he soon changed his mind when my condition worsened. Also there were other children in the village similarly affected and it was eventually realised that we were all suffering from polio. At the onset I was semi-conscious for nine days and completely paralysed from the neck downwards. After some weeks a little strength returned and I was able to feed myself. By Christmas I was able to sit up for a while. A little massage was given to me by the district nurse every day but this was the only treatment I received for five months. At this point it was decided to send me to the Cottage Hospital in Boston, where I stayed for six weeks. There they gave me mild electrical treatment to no avail. I remember very little of my stay there, except that I had my sixth birthday whilst there and that day I was taken around the men's ward and made quite a fuss of. I am almost certain that they were wounded soldiers as some of them were wearing uniform. On my return home our doctor asked my parents for permission to send me to a London hospital, but as the Great War was still raging and London was being bombed, including the hospital to which I was to be sent which had already received some damage, they refused. However they said they would like me to be admitted as soon as the war was over.

On my return from Boston Hospital I spent some time each day lying on our couch with my paralysed leg tied over the high end, taking the weight of my body on the lower end. This was done in the hope that it would straighten my bent knee, but of course it didn't. I had an operation to correct this when I eventually reached the London Hospital.

For a short while towards the later part of the war, retired schoolmasters were called out of retirement to release younger men for war duties. This had happened at Bicker, which resulted in Mr Hopkins from North Lincolnshire being billeted with us, for I believe about six months. By this stage I could sit up long enough to play board games. Mr Hopkins was a very kind gentleman and spent hours teaching me to play patience etc during the evenings.

Another example of how different things were then than they are now, was when at the age of fourteen and eleven respectively, my brother Stan and I had our adenoids removed by Dr Morris, on the dining room table. This was the same table on which my father had had his teeth removed at an earlier date!

After some time my mother had found a way to get me around the house without lifting me. I was much improved in strength, especially my right leg and arm, but I was getting too heavy for mother to carry me bodily for any distance so she had to devise an alternative method of moving me about. I was able by now to put most of my weight on my right leg, balancing with difficulty, and she would stand behind me, put her arms around my waist and sort of 'hopscotch' me along, my right leg taking my weight after each jump. This was rather ungainly and slow, but it was exercise for me and also saved her taking my full weight. Eventually a wicker pushchair appeared from somewhere and she was able to push me around the village in that. From then on I managed to lead an almost normal life at home, and although I could not walk about the house I spent many happy hours sitting on the hearth rug playing with my toys, but I still needed a wheelchair in the street.

After the first World War ended nothing was done about sending me to a London hospital and it was only after my father confronted the doctor in no uncertain terms that a place was found for me. I was very lucky to have such caring parents who were determined that I should have the best treatment available to me at that time. The hospital in question was called The National Hospital for Paralysed and Epileptic Patients, and it was in Queens Square, London. Each journey to and from this hospital is completely obliterated from my mind. We must have gone by train from Donington Station to Kings Cross, as there was no other means of travelling that distance in those days. I know

both my parents went with me, and we took a taxi from Kings Cross to the hospital. The taxi driver, presumably thinking that as it was a child he was taking, it must be Great Ormond Street Children's Hospital we wanted to be at. It was not until I was already undressed that it was found that we were at the wrong hospital! Fortunately the National Hospital was virtually across the road.

I don't remember saying goodbye to my mother and father, like many unpleasant things in life one chooses to forget them, but I'm sure I was a very unhappy little girl at being left by them so far away from home. However I'm sure I would have settled down after a few days ready to make the best of it, as I understand I was always a happy child by nature. As it was to play a major part in my early life I think I should describe the National Hospital and my life there, mainly to show the difference then and now in hospitals. It was an impressive Victorian building with large wards each with a coal burning fire at the far end. There was a cot either side of this fireplace and eleven beds for women down each side of the ward. There were no unisex wards in those days! I did not see any male patients at any time, I think they must have occupied another wing. A rather strict matron was in charge and everyone was in awe of her. She was very kind to me though and once invited me to her sitting room for tea, so that I could play with her cat which had had kittens. I think she was in charge of the whole hospital. There was a staff nurse for two wards and two other nurses to each ward. The floors were bare boards which were scrubbed once a week by two maids on their hands and knees. Everywhere was very much 'spit and polish'.

I was lucky as regards food as my mother sent me a food parcel most weeks, which included butter etc and also boxes of eggs. My grandmother, who lived only twelve miles away, visited me alternate Thursdays and brought me jars of jam etc, otherwise the hospital menu consisted of breakfast and tea which was a thick slice of bread and margarine and a small cake. Dinner most days but not Sunday, was sloppy mince, cabbage and potatoes with milk pudding to follow – this latter I detested – and this menu seldom varied. I disliked milk pudding so much that it eventually started to make me retch and finally one day I was sick over it. One of the other patients who was fairly mobile and liked to do little jobs around the ward was going to take my dish into the kitchen, when the Ward Sister, who was nearby and had seen what was happening, told her to scrape off the sick as I must eat the rest of the pudding! This lady, however, was determined that I should not have to do this and promptly ignored the Sister and took the plate to the kitchen where she rinsed it down the sink. The result of this little incident was that, although I still had to have milk pudding every day, I was allowed to have a spoonful of my grandmother's jam with it, which helped a bit with the struggle I had to get it down. You can see what the discipline was like!

Early on when I first went to that hospital I lost my little gold charm bracelet which my mother had given me when I was quite tiny. It had never been off my wrist since the day she gave it to me. A nurse was about to bath me one day when she told me to take it off, which I did. She put it in her uniform pocket and I did not see it again. When questioned she denied ever having seen it. One of the charms was of the Lincoln Imp and was rather special as my mother's friend Ivy Dawson had given it to her to put on my bracelet only a few days after I was born.

Every day our beds were tidied between 10am and noon, and again between 2pm and 4pm. Everything including toys, knitting, books etc had to be put away in our lockers. Nothing was left on the locker tops and the bed clothes were tightly tucked in with no creases. This was in preparation for the doctor's visit. On two of my stays in the hospital my doctor was a kindly man whose name was Dr Tooth. There was a park on the opposite side of the road to the hospital called Queen's Square – the Queen in question being Victoria – and I was taken with some other patients to sit on a bench for a while when the weather was good and a nurse had time to take us there. The rush of the traffic fascinated me as it was quite different to what I was used to in Bicker or Swineshead.

If you want to read more of this fascinating story, go to www.lincolnshirepostpolio.org.uk/downloads/kathleenburrell/

If you do not have access to the Internet then drop us a line and we will post you a copy for a small charge of £1.50 to cover paper and postage.

Dysphagia by Carol Bratcher, Speech Language Pathologist.

This presentation was given in 1991, but is worth an Encore.. Carol Batchers father is a polio survivor.

There are three phases to swallowing: oral (mouth), pharyngeal (throat), and esophageal (tube to stomach). Two things are important: the tongue and larynx (voice box). If either is weak, there is a problem swallowing. When the bite goes into the mouth, as you're chewing, your tongue is moving the food to each side of your cheek to form a ball. If your tongue is weak, you already have trouble swallowing, moving the ball to the back of the throat and forcing the food ball down the esophagus (slam dunk) – the tongue, not the muscles of the throat, as one might think. The throat muscles then close the door behind the food so it doesn't go back up. When this process doesn't happen smoothly, there is a swallowing problem.

The type of polio you had, treatment, your history, and breathing should be evaluated if you are choking. A video fluoroscopy is a very good test for this evaluation. In the swallow, we want to make sure there is no aspiration (food entering the airway). When a person truly chokes, something blocks the airway. As you swallow, breathing stops. If the airway is blocked, you have trouble breathing again.

Swallowing is a muscular function. The tongue is made up of 8 muscles. It must function in an organised manner. Your whole throat, uvula, soft palate, voice box, vocal cords, 20-30 muscles are involved in the swallow. The tongue must be strong to push the food through or it will stop along the way in ledges and pockets like the pyriform sinus and epiglottis. Something 'stuck' in your throat may well be in one of those pockets. Normal swallowing takes less than a second. If it takes longer, it's a sign the muscles are weak. Sometimes in polio one side of the swallowing mechanism is weaker than the other, one side is going down faster than the other.. one side is doing all the work.

If you fatigue at the end of the day, eat a light supper, take smaller bites and wash down 'the pockets' by alternating solid and liquid. Fatigued and weak muscles increases your chance of difficulty. More than half the problems of post polio swallowing can be improved with proper diagnosis and instructions.

Reprinted from FLORIDA EAST COAST POST-POLIO SUPPORT GROUP
May/June 2006 Newsletter. 12 Eclipse Trail / Ormond Beach, FL 32174
386-676-2435 / e-mail address: bgold@iag.net

Editors Note. Once again it is important to self assess so that you can give detailed information to your health professionals. Write down what happens and take this with you and remember that we can do things once, twice and more times before our weakness sets in. It is up to you to tell the health professional when this happens so that they can test you to that level.

Have you changed your eating pattern; have you stopped eating certain foods; do you eat more slowly; pause between swallows; have a drink handy to help food down; sometimes feel as if a tiny crumb of food you just ate is sitting right on the edge at the back of your throat almost as if someone is stroking it with a paint brush; choke when you burst out laughing; aspirate bits of food so that you have to cough and cough till you bring it up again; etc. **N.B. The last line above.. can be improved with proper diagnosis and instructions.**

AGM - September 9th 2006

Speaker Helen A. Kent, BS, RRT

Annual General Meeting
Saturday 9th September 2006
Memorial Hall, North Hykeham, Lincoln, Lincolnshire
Doors open 10.00 a.m. AGM starts at 10.30 a.m.
Buffet Lunch at 12.00 followed by

MAIN SPEAKER

Helen A. Kent, BS, RRT,
Owner of Progressive Medical,
Carlsbad, California, U.S.A. 92010

www.progressivemed.org

Helen will be speaking about the problems experienced by people who have neuromuscular conditions:-

1. What tests should be done and the information they provide
2. Mechanical ventilation equipment being used today
3. Support that patients should expect.

Helen is very passionate about her work, helping neuromuscular support groups in California and patients with various types of neuromuscular problems all over the world.

Her holiday plans bring her to the UK in September and she offered to fly in a few days earlier to speak to our members. She is offering all attendees some free tests which will show if they need/do not need to see a Respiratory/Sleep Consultant.

Tea, Raffle and Questions & Answers.
Please submit questions, even if you cannot attend.

Doors close at 5.00 p.m.
N.B. There will be Friday and Saturday Evening Get-togethers.

All members attending who would like to be tested please
return the enclosed slip as soon as possible
so that we can assist Helen in planning her day.



Kathleen Burrell from Lincolnshire - our oldest member at 94 years of age - wrote to tell us all about her 'Helpers'. She looked at aids on offer but they did not fit the bill for her, she cant grip very well, but she can pull and push, so she made her own.

They looked like good ideas so we asked if we could visit and take photographs. We met yet another determined polio survivor who not only showed us round her lovely home, but gave us a copy of her 'amazing life story. We enjoyed it so much we asked if we could have permission to share it with you and put on our Website. Go to page 11 to read some of Chapter One.

Here she shows us the three helpers she has made from wire coat hangers. [A] is for pulling the door to behind her and hangs on the radiator in the hall.

In her hallway there appears to be closed curtains over a window [D] but it is not a window. They hang over her open bathroom door. Now she has privacy and can get in and out easily in her electric chair.

At the bathroom sink Kathleen can only reach the tap on the right so she thought about it and came up with [B] which has a small loop that fits nicely over the left hand tap. She can pull it 'on' and push it 'off' easily and then tuck it under the right hand tap when not in use.

She has a table in the lounge with all the bits on it that she might need during the day. She made [C] with a hook size that fits round the items that stay out of the way until she needs them.

[Our youngest member, aged 9 will tell his story next issue.]

