

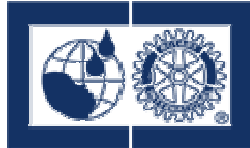


The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
Volume 6 - Issue 6 — September 2008

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

PolioPlus



Rotary International

Rolf Sperr,
Rotary International
District 1270
District Governor
2006 - 2007

speaks at our AGM about Rotary International's new Polio Plus program END POLIO NOW. Closer ties are being formed between Post Polio Support Groups and Rotary throughout the world. For more information read the reproduced text from their leaflet and report from the meeting on pages 10 and 11.

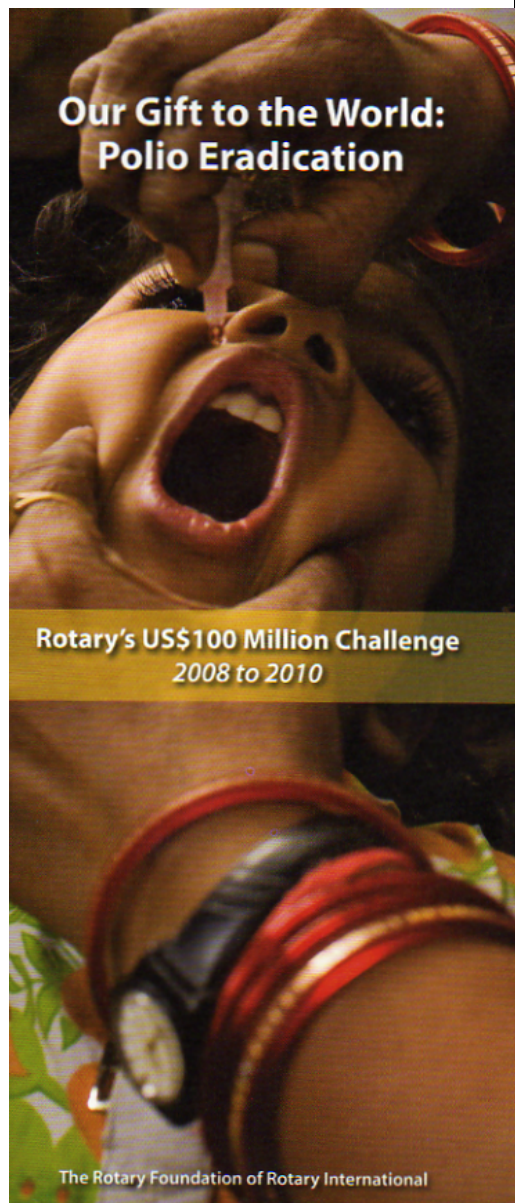
Councillor Barry Fppard MBE

speaks at our AGM about local government help for disabled people. He listened to each members views on their locality which showed a variety of service levels. He was not surprised to hear that there could be huge variations depending on which side of a local boundary you lived. He is going to be doing some research into the issues that were raised and will report back to us for the next newsletter.

Member Dr. Ruth Bridgens

reports on New PPS Studies from Montréal and the Lane Fox Unit, page 6.

Contact and membership information reformatted see pages 14 and 15.



This publication is provided as a service to those seeking such information. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Lincolnshire Post-Polio Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177

CONTENTS

- Front Page - Front of END POLIO NOW
Rotary International Leaflet
- Page 2 - Contents, Donations and Results of AGM voting.
Page 3 - Editorial
- Page 4 - Message from the Chair
- Page 5 - A letter from Lynn Hobday, Vice Chair
- Page 6 - New PPS Studies from Montréal and Lane Fox Unit
By Trustee Dr. Ruth Bridgens
Includes Editors Notes
- Page 10 - Text from Rotary International's Leaflet
- Page 11 - Report on talk by Rolf Sperr, Past District Governor, District 1270.
r.sperr@ntlworld.com
- Page 12 - TipBits
- Page 13 - PLAUTEAU's by Viola Pahl
- Page 14 - Membership form
- Page 15 - Contact and membership information.
- Back Page - Text about Lincoln Cathedral on Presentation Certificates

Our thanks to the following who have donated funds towards our work

Jim & Jenny Rayner; JM Deans; Yvonne Grosse; Miss C Forrester & Mr. LM Lundblad;
Mrs. P Minnitt; Mrs. M Pearson; Stuart Tanfield; Claire Colfer; CM Murray;
Jennifer McGowan; Nicolas Harvey; Pauline Dunham; Mrs. BPM Bowles; DV & RM
Palmer; AJ Healey; Mrs. E Hobday; SN Jupp; Val Scrivener; CJM & JY Curtis;
Mrs. BJ Bradley; Margaret Edmonds.

Plus all those who work so hard for us for the time, energy and financial savings
donated to the LPPN from their PPS lives.

RESULTS OF VOTING AT OUR ANNUAL GENERAL MEETING ON SEPTEMBER 6TH.

The Management Committee Trustees voted in at this meeting are as follows.
Mary McCreadie was returned unopposed as our Chair. Lynn Hobday [who
served as Chair in our early years] has been voted in as Vice Chair. As last year,
Denise Carlyle is Treasurer and Hilary Boone is Secretary. Dr. Ruth Bridgens will
serve again this year to be joined by Jim Pullin and Glenna Tomlin.

CONTACT INFORMATION IS NOW ON PAGES 14 AND 15

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Editorial by Hilary Boone.

Firstly I have to apologise for the delay in your receiving this newsletter. This is because we are having alterations done to our home which means stuff is being moved from one room to another and then back again. This type of disruption [and there is more to come] on top of daily living is so exhausting, both physically and mentally. My best times to work are first thing in the morning whilst the few brain cells still working still have some oomph 😊. Although I do not want to admit this, I must, that it takes me longer to be happy with the wording and setting out of the LincPIN than it did a year ago.

Thankfully I have at last obtained some help from Social Services and the Direct Payments I have been awarded are paying for the help in the home we so badly needed. In fact it has shown me that our lives would have been far less stressful had I applied some years ago and not continued to be a 'pig headed, determined, 'I can manage', 'I am not there yet' Polio Survivor.

Lynn Hobday, now our Vice Chair, has asked that I reformat the contact and member information so that it is easier to pick out what you are looking for. She also suggested that we include a membership form [which could be cut out or copied] alongside this making it easier for other people reading our copy or online to join. I have moved this permanently to the end of the newsletter. Pages 13/14.

Annual General Meeting - This was held on September 6th 2008 and I would personally like to thank those that were able to attend, most traveling long distances. Due to unforeseen circumstances 9 members contacted me in the last week to say that they were now not able to attend. It was a shame as we did miss seeing you all but we do understand that living with PPS and aging means that if something unexpected happens then something else we planned has to go. The minutes are enclosed with this newsletter.

Discussion took place on the date of next years AGM. Our financial year ends on the 31st March. The accounts have to be finalised and audited, the Annual Report written and posted to members six weeks prior to a meeting date. Other meetings in September have prevented some members attending so it was decided to try early October for next year. The IBIS hotel only have small meeting rooms which has meant us using another nearby venue. Those attending felt that the time has come to consider the extra effort in loading and unloading wheelchairs/scooters to change venue. It was therefore decided that we should hold next years AGM at a hotel. This would make it easier for those attending to rest when necessary and have more time to socialise with others. We will be give you more information in the next newsletter.

Polio and Post Polio Support Groups are working together. We now have Polio Canada, Polio Australia, the European Polio Union [next meeting October 22nd to 26th near Berlin] and Polio World that was started at the 2006 Miami PPS conference and relaunched this summer.

Rotary International's END POLIO NOW campaign has started to forge more links as they learn more about Post Polio Syndrome and accept the need to add this information to their leaflets and work in Nigeria, Afghanistan, India and Pakistan.

Working together across the world should speed up an improvement in services.

Message from the Chair

I would like to thank all members who sent cards and messages - and I loved the funny ones - whilst I go through this awful time of trying to sort out the results of the operation that I had in mid April. Unfortunately about eight weeks ago the pain increased so much that I was taken to A&E and admitted to hospital. I have been in three hospitals and as this newsletter is being checked for the last time am in an ambulance on my way to an appointment at RNOH Stanmore. The saga too much to go into at the moment, although I can tell you that the stress some of the medical professionals have caused me has been far worse than the pain I am trying to cope with.

I was able to 'attend' part of the AGM by phone and was heartened to be voted in again as Chair. After the voting here is what I said... I would like to thank Hilary, Denise and Ruth for continuing in post. I would like to welcome Lynn Hobday who has taken the post of Vice Chair and Jim Pullin and Glenna Tomlin who have joined as Trustees. Our hard working Operations Team remains the same as last year and I thank you all for everything you do on our behalf. Mary Kinane decided to take a break from the committee but agreed to continue attending the British Polio Fellowship Expert Panel whilst I am indisposed for which I am most grateful. I would also like to thank Sheila Dunnett for dealing with the post whilst Hilary was out of the country and for looking after us at our AGM's. Sheila was not able to attend this year as she was on holiday with her new boyfriend. She was missed but we were all so pleased to hear the news.

Last years committee decided to purchase hand coloured personally signed copies of Lincolnshire Cathedral by John Bangay to be presented to members who work so hard on our behalf . Sadly I cannot present these in person but the following have received these with heartfelt thanks. Mary Kinane, Chris Salter, Robin and Pauline Butler, Barry and Olivia Branston, Di Brennan, Margaret Edmonds, Judy Barter, Robert Price and Sheila Dunnett.

The certificate on the back of each picture, printed on parchment paper, is as the back page but with the inclusion of the following piece.

Presented to:-

***In recognition of many years of voluntary service to
The Lincolnshire Post-Polio Network***

***Mary McCreadie, Chair.
September 6th 2008.***



Best wishes to you all, Mary McCreadie

Letter from Lynn Hobday, Vice Chair.

My name is Lynn Hobday and many of you will know me from when I was Chair and at each annual meeting in Lincoln.

You will recall how, when LPPN was formed, I was walking. Since then, due to ill health, and PPS bone breakage, I am in a wheelchair. I can only manage a few steps on a walking frame. But, as always, you continue to adjust and adapt - and life is (you believe) still fairly independent.

In February this year, my dear husband died.

As well as overwhelming grief and loneliness, I became aware of just how much my husband did for me. Gradually, over the years, he had taken over various tasks in the home and arranged our social life so I could continue to believe I was coping.

The past six months have been horrendous.

In spite of a very good neighbour and several friends, I have been clutching at straws - trying to maintain my independence.

The situation has not been helped by the "authorities".

I have been hassled and pressured by everyone - Social Services, Local Authorities, Wheelchair Service, Pension Service, financial queries, building work, adaptations - and on and on. As many as eight officials called on one day!

Orders and advice come from all directions as well as being treated like someone with mental problems who cannot understand a simple question. ALL I NEED IS TIME.

O.T. Specialists have been helpful but they want to reconstruct the inside of my bungalow - changing doors and adding ramps. Can I bear all this disturbance, noise, damage, etc.? I think not.

Shall I opt for a suitable apartment with care provided when required? Maybe. One has to take into account the emotion and upset involved when leaving one's home.

As I am sure PPS will cause more physical problems will I be able to cope alone?

You will realise from this that my husband's death produced a double blow and I am still reeling.

I have yet to find an organisation (including those dealing with polio) who deal directly with the person needing help. The usual answer to a request is 'have you tried xxx? - it's called passing the BUCK.

What can we, as polio survivors, do to avoid this and what happened and is still happening to me?

Lynn Hobday

Since writing this I have offered myself once again to be part of the Committee to highlight the issues that we are experiencing and hopefully see an improvement in services. If you would like to write to me please do so care of the LPPN main address because I do not have a computer. If it would help you to write by email then send it to lynn.hobday@lincolnshirepostpolio.org.uk which will go to Hilary who will print it out for me.

New PPS studies from Montréal and the Lane-Fox unit

Dr Ruth Bridgens — pb.rb@virgin.net

Fordyce CB et al (2008) Elevated serum inflammatory markers in post-polio myelitis syndrome. *Journal of the Neurological Sciences* (online before print)

This is a fascinating article because it not only says something potentially new about PPS, it says something illuminating about doctors as well. The research was carried out by Daria Trojan at the Montréal Neurological Institute, who has conducted several studies trying to understand individual PPS symptoms, particularly pain. In 2002, her team conducted a study on who was most at risk of developing muscle or joint pain and found that the risk factors were different, suggesting different pathologies for the two types of pain. They found that women were most likely to get any type of pain, and that only the joint pain was related to initial and recent weakness. Muscle pain was more common in those who had polio at a younger age and those who had had both general and muscle fatigue for longer. As I understand this, joint pain relates to the weakness around joints, and muscle pain to increasing fatigability, which might increase the likelihood of overuse.

The new study continued this research by investigating whether immune system (inflammatory) markers in the blood might relate to the pain, which could lead to new treatment ideas. The focus of the research is pharmacological treatment for PPS, which has possibly influenced the interpretation of the results. The study found increased inflammatory markers (TNF-alpha, IL-1beta, IL-6, and leptin) in blood serum compared to controls. Associations were found between TNF-alpha and leptin with muscle pain. There were no associations with age, disease duration, or fatigue. In the discussion, the authors describe how increased inflammatory markers, which are found in many neurological diseases, can damage neurons themselves and could possibly be controlled with immune modulating agents. The authors then describe other PPS research in which inflammatory markers and poliovirus genomic sequences were found in the spinal fluid of PPS patients. The genomic sequences can possibly cause the production of increased inflammatory markers and this has led to the theory of PPS as an autoimmune response. Animal research has also shown that inflammatory markers themselves can increase pain perception, and that decreasing the markers can diminish pain.

The authors acknowledge that the inflammatory markers could have arisen from either the central or peripheral nervous system, but they do not mention that the cause of the inflammation could be peripheral muscle damage due to overuse. Being able to measure these inflammatory markers from a simple blood test could be very useful for PPS patients in helping them diminish their pain, if the relationship between the markers and the pain was understood. Is the inflammation being caused by overuse, poliovirus sequences or the markers themselves? There is no mention in the study of whether the pain people experienced was constant or fluctuated with activity. If the researchers had been thinking in terms of overuse, a further study could show whether the markers decreased when activity levels and pain were lowered. The authors end by saying that they "do not wish to overstate

potential causal relationships or links between inflammatory markers and PPS symptoms", but, in their quest for a drug treatment, that is more or less what they have done. Whereas they conclude that the inflammatory markers cause PPS pain, it is actually more plausible that the overuse from PPS muscle fatigue and weakness cause damage resulting in pain and raised inflammatory markers, as most PPS pain is activity-related.

Davidson et al (2008) Prolonged benefit in post-polio syndrome from comprehensive rehabilitation: a pilot study. *Disability and Rehabilitation* (online before print)

This pilot study of the Lane-Fox PPS rehabilitation programme has produced some very interesting results, but before discussing them, it is important to look at who participated in the study and what aspects were being evaluated. The programme is designed for those who are independently mobile with or without orthotic devices, and the patients chosen were able to take part in the physical testing aspect of the study. They also had the stamina to take part in a nine-day (three days per week for three consecutive weeks) intensive programme of individual assessment, testing, discussions, exercise and social interaction. Interestingly, although most PPS clinics see about twice as many women as men, only 10 women took part in the study compared with 17 men. They were tested at the beginning, after three months and after six months. There were three physical tests (walking at increasing speed, a timed test of getting up from sitting, and grip strength), plus tests for anxiety and depression, an illness perception questionnaire, pain and fatigue questionnaires, and an occupational performance measure.

The most pronounced improvement was in the endurance measures. The average distance walked with increasing speed rose from 77 metres to 99 metres. At baseline the average number of times participants could stand from sitting was 21 times and this improved to 25 times. There was no change in the grip strength, but there were significant improvements in the walking, getting up from sitting tests, and the perceived exertion of doing these tests. However, a study group with more women, with more severe PPS symptoms, or with those more severely affected by polio, might not improve in these measures. And although a pain questionnaire was administered at the beginning showing, on average, mild to discomforting pain, no mention is made of any pain follow-up, even though this is one of the most important considerations for patients. Interestingly, although non-fatiguing exercise, stretching, and hydrotherapy were part of the rehabilitation programme, the final aim was "to provide participants with realistic and achievable daily home activity targets", indicating that there was no expectation for participants to carry on with any exercises.

The study had a large psychological component and because there was a correlation between anxiety/depression and symptom reporting, it was assumed that the psychological symptoms were causing the PPS symptoms (somatisation) [see editors notes page 8]. However, as depression significantly decreased without a decrease in symptom reporting, the somatisation theory was rejected. Anxiety (found in 30% of the sample) was found to have significantly decreased at the three-month follow-up but had increased again by six months. It would have been interesting to know the participants' thoughts on why their anxiety increased after six months. There were also improvements in the performance of leisure activities followed by more moderate improvements in self-care and productivity. A significant

change in performance was found in five participants (21%). The authors felt that people were more likely to use aids for leisure activities like gardening and were more reluctant to change the way they did things in the house or at work. They came to an interesting conclusion about the value of fatigue and strength testing: "Although Dalakas recommends the use of validated fatigue scales and quantitative muscle testing, considering the effort needed to fully assess muscle strength and endurance, we would suggest that functional outcomes, in the form of questionnaires, may be more valuable." I would add that good listening to patients' descriptions of symptoms and functioning is of crucial importance for rehabilitation programmes to be successful. For the patients, it was noted that simply meeting other people with the same problems was very important, as was sometimes talking for the first time about childhood memories and fears.

Editors Notes:-

Reference 32. Westbrook MT. Changes in post-polio survivors over five years: Symptoms and reactions to treatments. International Federations of Physical Medicine and Rehabilitation held in Sydney, March 1995. Accessed 1 June 2005 from the website: <http://www.ott.zynet.co.uk/polio/lincolnshire/library/westbrook/mw707.html>

Member Norman Jones attended the first Lane Fox Unit Course and reported this in the April 1999 LincPIN. [Excerpted].

During the nine days we covered a variety of topics. Firstly there were one-on-one physiotherapy assessments to establish a baseline of muscle movement and strength as well as one-on-one sessions with dieticians, occupational therapists and psychiatrists. These sessions were to establish what problems we individually experienced and to give the medical team some insight into how we coped with them.

There were a series of talks on diet, nutrition, exercise, footwear, stretching, sleep disorders, pacing, posture, relaxation, joints, chronic fatigue syndrome, energy conservation, stretching, aromatherapy, work and leisure and finally goal setting. This was interspersed with sessions in the gymnasium, the hydrotherapy pool and numerous group discussions. The latter being one of the more valuable aspects of the programme.

I attended the presenting of the results of this Course to those attending and later at the PPS Conference at St. Thomas Hospital. At the Conference the Psychiatrist stated that they had seen 30% improvement in the psychological scores but that they did not know why. I responded that I believed I had an answer. 'Personally and from taking calls from other polio survivors seeking help the response to finding out that 'you are not alone and that many other polio survivors are experiencing similar issues' brings a huge sigh of relief. Plus the majority of us have not had the benefit of the extensive assessment and talks or the chance to socialise with our peers like these Polio Survivors.'

I then looked up the definition of Somatisation I thought the following might be of interest. How many of you have reported physical symptoms/levels of physical symptoms that have not been corroborated by testing and you have been told or it has been suggested/implied that what you are reporting is 'all in your mind'?

Excerpted from 'A Symptom Checklist to Screen for Somatoform Disorders in Primary Care' by Kurt Kroenke, M.D., Robert L. Spitzer, M.D., Frank V. deGruy, III, M.D., and Ralph Swindle, Ph.D.

Psychosomatics 39:263-272, June 1998

© 1998 The Academy of Psychosomatic Medicine

- "Somatoform symptom is a physical symptom that lacks an adequate physical explanation"...
- "These 15 symptoms are stomach pain; back pain; headache; chest pain; dizziness; fainting; palpitations; shortness of breath; bowel complaints (constipation or diarrhoea); dyspeptic complaints (nausea, gas, or indigestion); fatigue; trouble sleeping; pain in joints or limbs; menstrual pain or problems; and pain or problems during sexual intercourse. The symptoms are prefaced in the Patient Questionnaire by the query: "During the past month, have you been bothered a lot by 1) stomach pain? 2) back pain? etc..."
- "The clinician is asked to decide: "Based on your clinical judgment, does the symptom have a physical explanation that is adequate to explain its severity and associated disability?"

The majority of us have and still are experiencing genuine reported physical symptoms with a physical explanation but they go uncorroborated because the form of assessments and/or recording of the results does not go far enough.

20 years ago following a fall at a school where I was teaching I reported pain and that 'my arms were weaker'. 3 weeks in hospital and many further appointments over five months failed to find a reason. The clinician/s judged that the strength of my upper body was normal and it was suggested that I return to work to see how I got on. I had 3 part time jobs as a swimming teacher and lifeguard. A requirement of employment was a current Life Saving Bronze Medallion. Despite training hard I could no longer reach the required standard to renew this and lost these jobs within four months. 'My arms are weaker' got me nowhere.

Do you think if I had explained... that part of the Bronze entails swimming 50 metres and towing a body 50 metres in under 3 minutes followed by getting that body out of the pool and performing artificial respiration. That for 7 years prior to my fall I had regularly passed higher awards and specifically the Life Saving Bronze timed swim in 2 mins 50 seconds. That the best time achieved was now 3 mins. 45 seconds and that now I could not pull the towed body out of the water because I could no longer pull myself out.... .that further testing other than the single action manual muscle assessment that did not pick up the weakness might have taken place?

During my early research I was given access to my GP records and found I had another syndrome. I read 'Has Lloyd George Syndrome' and was devastated but was told it was a minor issue, nothing to worry about. 2 years later I read that 'practices still using the Lloyd George Envelope record system'... and had confirmed to me that my Lloyd George Syndrome referred to too much 'all in the mind' symptoms on the paperwork in my envelope.

Ensure your physically explainable reported symptoms are not wrongly labelled as psychosomatic be explaining and demonstrating examples of the **CHANGE** in the way you are now performing actions of daily living.

Our gift to the world: Polio Eradication

Rotary's US\$100 Million Challenge 2008 to 2010

"Eradicating polio will be one of the most significant public health accomplishments in history, and we are committed to helping reach that goal with Rotary as one of our key partners".

Bill Gates, Co chair, Bill & Melinda Gates Foundation.

The Rotary Foundation of Rotary International Our Commitment

Not long ago, the world was paralyzed by the fear of polio. More than 125 countries were polio endemic, and thousands of families watched in anguish as the disease killed or crippled 1,000 people a day, most of them children.

In response to this suffering, Rotary began planning in the early 1980's for one of the most ambitious humanitarian programs ever undertaken by private entity. In 1985, it launched Polio Plus, a multimillion dollar initiative to immunize all the world's children against polio. Rotary's commitment was so great that the World Health Assembly resolved in 1988 to wipe out the disease that had killed and paralyzed for 5,000 years.

For the 20 years since, Rotary and its spearheading partners - the World Health Organization, UNICEF, and the U.S. Centres for Disease Control and Prevention - have worked tirelessly to rid the world of the wild poliovirus. Thanks to the generous support of Rotarians worldwide, Rotary has been able to contribute nearly US\$700 million to keep alive the dream of a polio free world.

Our Progress

Since 1985, more than two billion children have received the oral polio vaccine. Five million children destined to be polio victims are walking today and enjoying a better life because of global immunization. Reported polio cases have dropped 99.8% - from 350,000 a year in 1988 to fewer than 2000 a year today - and only four countries - Afghanistan, India, Nigeria and Pakistan - remain endemic. Due to the efforts of Rotary and its global partners, the world is on the threshold of eradicating the wild poliovirus.

Our Challenge

Although tremendous progress has been made, the world is not yet polio free. The poliovirus knows no borders; it can spread from an endemic country into polio-free areas. As long as one case of polio remains in the world, no child is safe from this deadly disease.

The greatest challenge in the battle against polio today is financial. Despite the enormous resources already committed, more money is urgently needed to reach the children in the four remaining polio-endemic countries. Recognizing Rotary's resolve to eradicate polio and its extensive volunteer network, the Bill and Melinda Gates Foundation awarded Rotary a US\$100 million grant. In return Rotary is committed to matching the \$100 million over a three year period beginning 1 January 2008.

Our Legacy.

There is now an unprecedented opportunity to finish the job and eradicate polio. Consequently, every Rotary, Interact and Rotaract Club is being asked to organize a public fundraising event for each of the next three years to help meet this challenge. All members of the family of Rotary, especially newer Rotarians, are also invited to join Rotary's legacy by making a personal gift.

Eradicating polio means that no child ever again will be paralyzed by or die from the wild poliovirus. Additionally the \$1 billion spent annually on polio could be used to address other public health concerns. Now is the time to respond.

In 1985, Rotary made the historic decision to immunize all the world's children against polio. A little more than 20 years later, the world is nearly polio free. With your help polio will be defeated.

Be a part of the legacy. More than one million Rotarians worldwide have contributed to the success of the polio eradication effort. Join the fight at www.rotary.org/endpolio.

United States

The Rotary Foundation
14280 Collections Centre Drive
Chicago, IL 60693, USA

Great Britain & Ireland

Rotary International
Kinwarton Road
Alcester, Warwickshire, B49, 6PB, UK

Rotary International Talk after our AGM on September 6th 2008

Wendy Watson of Rotary International was unavailable at the last minute to speak at our Annual meeting. We are really grateful to Rolf Sperr, a Past District Governor, for calling in on the way to another meeting. He told us that he and many of his colleagues were unaware that Post Polio Syndrome existed till he met me at the Lincolnshire Show in June. I had explained that for many years Polio Support Groups around the world had contacted Rotary with the hope that information on PPS could be added to their published literature without success. As you all know one of our biggest stumbling blocks is the lack of awareness of our condition not only with the general populace but also the medical profession. Time and again we heard groups being told that once Rotary had managed to eradicate Polio, then they would look towards helping on PPS.

Having read more on PPS from the information that I sent him he told us that he had forwarded this to all Rotary Districts and that Rotary now want to forge more contact with other polio groups and individuals around the country. We were pleased to tell him that in the last few months we are seeing more and more emails from areas around the world where polio support groups are giving talks to their local Rotarians. He suggested that members contact their local Rotary club and offer a talk on what it is like to live with Polio and Post Polio Syndrome.

I joined the Lincoln Rotarians on Saturday 14th August for their END POLIO NOW street collection. Sadly most people under 50 passed by without a glance. I thought this sad then realised I had had typhoid and paratyphoid inoculations as a teenager and have little knowledge of those conditions. A few elderly folks stopped for a chat.

Rotary District 1270's Disability Games - 26th April 2009 in Lincoln.

Rolf said it would be good to see polio survivors joining in the fun. I will be obtaining more information and forms from the local club - see next Newsletter.

TipBits

Getting up at night and ensuring your safety as you get to the facilities.

Now this is common sense but there is an issue. If you put the light on it wakes you up more and it is harder to get back to sleep. My father, who immediately took items to pieces to see how they worked and if he could improve on them, had some solutions.

He fitted a little light onto a plug [now automatic night light plugs] for the socket in the long corridor from bedroom to bathroom. When you opened the bathroom door there were two pulley cords, one higher than the other and with different cord pull ends on them. The lower one switched on the normal light and the higher one switched on a red bulb which my Dad said was enough to 'do' by but not enough to wake you up fully, just like on submarines.

Shading eyes from the sun.

Wear a sun hat or a cap with a peak is the obvious answer but what do you do if the sun is coming in from the side. My grandfather wore just a peak on a band and we used to laugh when he wore it on the side. However, he was not as crazy as we thought. He just moved it from side to side and front depending on which way the sun shone. Smiling, I don't think he ever wore it back to front!

Eye sight not so good on seeing the difference between black/grey/brown.

Again we used to smile at Grandpa when he said, 'I think I will wear my number 1 suit to this event and number 2 suit to that'. He also wrote a code on the back of each tie as to which suit it would go with. We used to put this down to eccentricity. We have now changed that view because if your eyesight is not so good you might not be able to tell which jacket goes with each trousers by colour but it is simple by number.

Deciding when to use electric wheels.

Now for most polio survivors the thought of using 'wheels' is a downward step. The same happened with my father when he had problems with arthritis and three new knees [yes three, one did not work properly]. He point blank refused to try a scooter saying he was not bad enough. ?How many recognize that statement?

He struggled on two sticks and resting on seats as he walked the 100 yards from bungalow to the Pub each lunchtime. As it got more difficult folks would drive him back up the hill. 8 years ago I met them in Torquay when they were on a coach holiday and my father not only had more opportunity to see me using mine on the daytrip but had his eyes opened when someone else on the trip said to him, 'I think your daughter is very selfish using that scooter to get about when you are far more disabled than she is.'

He never said anything at the time, but two months later he told me 'I have bought a large scooter to use on the odd days I am bad'. When we sneakily read his diary for that week we smiled because he used it every day but the day it rained and he had been all over the village, 2 miles from the top to the seaside where they lived. He eventually admitted that he should have got the scooter years earlier.

PLATEAU's

www.pahl.ca/fredandviola - viola@PAHL.CA

On the 20th of Aug. I will be "celebrating" my 60th anniversary as a polio victim. And in September, I will have my 83rd birthday.

The first time I observed "plateaus" was in the years 1981-1985 when my husband was chaplain at a seniors' residence - both Independent Living as well as a wing for Intermediate Care. I was in my late fifties, and I observed the "plateaus" older people experienced. Some of the seniors were very active, and then suddenly - the "aging" process robbed them of some energy, and they went to a lower plateau. Then for a time they managed at this lower plateau - but - again, the "aging" process robbed them of more energy - and on and on - until they had to move from independent living to intermediate care.



And so it is with those of us with polio. We have TWO factors working against us - the weakening of the polio muscles combined with the aging process. In the last several months, after having wrenched my left arm accidentally, I have gone down to a lower plateau, and I will not revert to a higher plateau. The experience I had with seniors in 1981-1985 certainly has prepared me to accept my circumstances.

One of my sayings that works is..

'Don't COPE with the inevitable
CO-OPERATE with the inevitable.

I reached 83 on the 13th of September, I accept the lower plateaus - it's just a part of life, polio or no polio.

I now live at this seniors' residence - Evergreen Baptist Home in White Rock, British Columbia, Canada - and I can observe this phenomenon around me all the time - including the plateaus occurring now more often in my own life.

I have just revised the link on my website entitled WOW WHEELCHAIRS and IRON LUNGS. There are quite a few chuckles there, and "fun" pictures. Sixty years! Unbelievable! I've had a great life in spite of the disability.

Picture from TOILETS WITH PIZZAZZ - from Viola's Website.

NOTE THE TWO PLATEAUS 😊

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why not support our work by joining us**

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If you do not wish to cut the newsletter
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A Post-Polio Information Service for Polio Survivors and Medical Professionals
Registered Charity No. 1064177

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WRITE P.O. Box 954, Lincoln, Lincolnshire, LN5 5ER, UK
PHONE UK 01522 888601 From Abroad +44 1522 888601
FAX UK 0870 1600840 From Abroad +44 870 1600840
EMAIL info@lincolnshirepostpolio.org.uk

JOIN or RENEW Membership Secretary,
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Newsletters - The LincPIN - Next Issue November 2008

Articles/Items/Tipbits/Letters/Questions must be received by 21st October 2008
Post or email:- newsletter@lincolnshirepostpolio.org.uk

Management Committee [Trustees]

Chair & Email List Facilitator - Mary McCreddie mary.mccreadie@lincolnshirepostpolio.org.uk
Vice Chair - Lynn Hobday - lynn.hobday@lincolnshirepostpolio.org.uk
Secretary - Hilary Boone - hilary.boone@lincolnshirepostpolio.org.uk
Treasurer - Denise Carlyle - denise.carlyle@lincolnshirepostpolio.org.uk
Committee Members - Ruth Bridgens - ruth.bridgens@lincolnshirepostpolio.org.uk
Jim Pullin - jim.pullin@lincolnshirepostpolio.org.uk
Glenna Tomlin - glenna.tomlin@lincolnshirepostpolio.org.uk

Operations Team

Membership Secretary - Robin Butler - robin.butler@lincolnshirepostpolio.org.uk

Phone Team - Di Brennand (Leader) di.brennand@lincolnshirepostpolio.org.uk
Margaret Edmonds and Judy Barter

Administrative Support - Sheila Dunnett, Pauline Butler, Barry & Olivia Branston

Internet Services Administration - Chris Salter - netadmin@lincolnshirepostpolio.org.uk

REMEMBER - DONATIONS TOWARDS OUR WORK, LARGE OR SMALL, ARE WELCOME

LINCOLN CATHEDRAL from the south west

‘Thou, Lincoln, on thy sovereign hill’ so Wordsworth hailed the noble church and this is the first view which visitors get of its great cathedral



Due to the deliberate occupation policies of William the Conqueror, Lincoln was chosen as a new site for a cathedral church and a Norman monk, Remigius, having contributed to the invasion expenses, was rewarded with the Bishopric of Lincoln. He chose to build on the commanding hilltop site in the middle of this medieval city, still surrounded by the walls of the Roman town from which it grew, and began the building of the cathedral of the Blessed Virgin, dying just before its consecration in 1072.

The building of 1072 did not, however, last long. In 1141 the roof was destroyed by fire and Alexander the Magnificent reconstructed it in stone (1123 - 1148), adding embellishments to the western doors and inserting the carved frieze. In 1185, partly on account of an earthquake, much of the building collapsed. In 1186, a priest called Hugh was elected Bishop (at the Kings behest) and in 1192 work on the new cathedral began.

From this viewpoint, it is easy to see how the great west front dominates the walking tourist rather than the three towers which first greet the traveler from a distance. Grouped around the west door are the crude Norman arches (1) of the first church, then the decorative additions of the Norman 12th century restoration (2), and finally the high and richly carved Gothic wall (3) serving as a screen and framing and fortifying the Norman work which has always needed support. The two western towers (4) and (5) extensively damaged in the 1185 earthquake, have frequently required repairs, often drastic in nature, to avoid further collapse. On the two pinnacles at the north and south ends of the great frieze are set important stone figures. On the south end (6) sits a statue of St. Hugh, probably erected in the days of his successor Robert Grosseteste, while at the north end sits and equally fascinating figure, the Swineherd of Stowe (7). He is said to have brought all his savings—a hornful of silver pennies—to St. Hugh to help with the building of the cathedral, and was rewarded with this stone effigy, carved in such a way that, if the wind blows from a certain direction, a sound is said to come from the horn.

For most of the cathedral's history, the western towers were capped with slender spires, only being removed in 1810, amid great controversy. The central tower (8), rebuilt after collapse in 1237, also had a massive spire which, while it lasted, made the cathedral the tallest building in Europe (525ft). The weight of the tower was too great, however, and it came crashing down in 1549. Nevertheless, the tower still stands 171ft high, with an internal vault of 125ft (compared with Boston Stump's 272ft and 137ft vault). Most of the cathedral's bells are hung in the south west tower (5) but Great Tom hangs in the central tower and is rung on great occasions—as an ordination, or when the judge comes. Lower to the right is the south transept of the cathedral and projecting from this is the Galilee porch which was built as a state entity for a bishop (9). Just around the corner from the porch can be seen the circular window, known as the Bishop's Eye (10), constructed with fragments of medieval glass.

Opposite the west front stands Exchequergate (11), one of the ancient gates which divided the cathedral precincts from the city.

Hand coloured

and signed by JOHN BANGAY

the original artist who gave us permission to use his picture.

