



The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter
Volume 6 - Issue 2 — August 2007

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



**YOUR
NETWORK
NEEDS
YOUR HELP**

**Annual General Meeting
Speaker on Care Assessments
Afternoon Workshops
on Post Polio Issues
September 15th 2007**



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

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Map showing venue of AGM and Ibis Hotel.

Dates for your Diary: AGM -15 September

DONATIONS.

Grateful thanks for all monies received, and we sincerely apologise for not adding names as we usually do. This is due to a communications failure, and proper acknowledgements will be added next newsletter.

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

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Membership Information

Please make cheques payable to 'Lincolnshire Post-Polio Network'
Post to Membership Sec, UK, 13 Derville Road, Greatstone, New Romney, Kent, TN28 8SX
UK Membership - Life Member (LM) £150 or £5 x 30 months S.O. - Member £12.50 a year.
All UK Memberships payable by Standing Order - Forms from Membership Secretary.
Overseas Newsletters by Airmail.

European Membership - LM E300 - Member E25 a year.
USA - LM US\$375, Member US\$25 a year - **Canada** - LM C\$550, Member C\$40 a year
Other Countries please contact membership@lincolnshirepostpolio.org.uk for details.

Next LincPIN Newsletter - Nov/December 2007
Articles for publication 4th Nov. by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial by Hilary Boone

Time has flown by since the last newsletter and my husband and I are this week in the last days of moving from a large house, where we cannot use upstairs, to our new home, a compact 2 bedroom bungalow in the north east of Lincoln. Being good PPSers we paced and rested packing our things, and to ensure we were ready, we started in May! Cardboard (Stone)Henge grew and grew and recently we have been managing with a couple of pairs of trousers and t shirts and 2 plates and bowls etc.

Moving is very stressful and we have tried hard to keep our levels low but the hardest part has been asking for help. If only there was a way we could explain what 'muscle fatigue' is really like for Polio Survivors. Eventually we accept we have to say something like 'It is really difficult for me to do this and I would appreciate some help' and so often we get a 'Well just take your time' type of reply. If we could do the action taking our time, we would not have asked for help.

The new symptoms we are experiencing are occurring because something is happening in our bodies. We have all seen our grandparents or elderly family members lose their abilities bit by bit as they lose nerve supply to their muscles. They cannot lift as much weight, they cannot sustain or repeat actions for as long. Sound familiar? But at 40/50/60 we are not elderly are we?

The problem for polio survivors is that the polio virus struck all our body and started killing off nerves. A muscle has many fibres all attached to nerves. The more nerves that were killed off the less able that muscle became. Health professionals could not find weakness in a muscle until more than 44% of the nerves had died. As the percentage rose above that the weaker we became and eventually the muscle did not work at all and we were paralysed. So how did we recover? Nerves that were undamaged grew extra roots [axonal sprouts] and these attached themselves to **some** of the orphaned muscle fibres. As the percentage of nerves to each muscle increased so did our recovery level. What is tough to accept is that this percentage did not go as high as we thought and axonally sprouted nerves are not as strong. The more we did physically, the harder we pushed our muscles, and that includes muscles we knew were affected and ones we did not think were affected [e.g. arms that pushed manual wheelchairs, used crutches, pushed us up out of chairs] the earlier those axonally sprouted nerves are likely to 'medically retire'.

Your Network Needs You to come and join us on the 15th September for the AGM. Following this will be a talk by Jean Murdoch regarding Care Assessments undertaken by Social Services. The Social Worker will assess what you cannot do and provide equipment and/or finance to pay for this. An amount of time is allotted to tasks you cannot do, and this adds up to an amount of hours of care a week. Jean has been assessed/reassessed and been in receipt of Direct Payments for her care for some years now and has become very knowledgeable on the national and Lincolnshire rules and regulations. Whilst this does not happen exactly the same in each county and the Government is once again changing the rules her talk gives you a head-start on how to deal with this when the time arrives. After a buffet lunch we will then have workshops with health professionals on the issues that have and are occurring as we seek answers to our new symptoms. We will also be socializing in the bar of the IBIS hotel both Friday and Saturday evenings - a chance to let your hair down and chat with your peers, and if past years are to go by, a lot of rib aching laughter.

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Message from your Acting Chair, Mary McCreadie

I'm sure that the first thing everyone will notice, is that this issue is a little on the 'skinny' side! The reason for this is the inclusion of a Self Assessment Questionnaire entitled 'My Polio Life', as well as our Annual Report and Accounts. The next newsletter will be back to the normal size.

Questionnaire.

When seeking help for your new symptoms it is essential that you paint a detailed picture of the changes that have occurred since you caught polio, so that your health professional can see clearly what has happened to you. Consider the following example:

"I was paralysed waist down, learned to walk again and recovered well. I am only 56 but about three years ago started to find daily tasks that used to be easy for me, becoming more difficult. For instance, I drove using a manual gearbox for 30 years but three years ago had to change to automatic because I could no longer lift my left leg on and off the clutch."

This is not commensurate with age; it shows that there is new weakness in the muscles that you have been using to perform the action. What you need to know from your health professionals is what is causing the changes that are occurring, and what to do about it.

We designed the Questionnaire to help you chart the facts. It is a challenging document, and filling it in can prove to be quite an emotional experience. But seeing things 'in black and white' can also help you come to terms with your situation and move forward to managing your life to greater effect. *You need to tell it like it really is.* Too often polio survivors will answer the question 'Can you still drive a car?' with a simple 'Yes'. You may still be able to drive that car, but failing to tell health professionals that you have had to change from a manual car to an automatic means that an essential piece of information is missing, which makes it harder for them to understand your situation. You can extract relevant information from the Questionnaire and your notes for each appointment to provide a clear picture.

Inside the front cover is a detailed description of why the Questionnaire was developed, and lots of help on how to fill it in. Copies can be downloaded/printed from our Website. We have included a completed sample of 'my polio life' for information. Just enter the following url's into your browser.

www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf

www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife-sample.pdf

If you are not connected to the Internet, and need help to fill in the Questionnaire, you can ring the helpline or write to P.O. Box 954, Lincoln, Lincolnshire, LN5 5ER

Case histories of PPS to be collated into a medical article.

At the Miami PPS Conference in April Hilary discussed her findings from the Mayo Clinic Study with speaker, Dr. Walter Bradley, Professor and Chairman Emeritus, Miller School of Medicine at the University of Miami. He congratulated

her on her excellent analyses and critique of the Sorenson et al, and also the original Windebank et al, studies. Along with other delegates at the Conference it was felt important to publish a paper that presents the histories of a group of patients with post polio syndrome as a counterbalance to the papers from the Mayo Clinic. Dr. Bradley has agreed to take on this task. This is not a scientific survey but will place in the medical literature examples of our experiences. Our questionnaire is going to be used to provide this information. I would like to say thank you to those of you who, via our members email list, have already agreed to provide a photocopy of their completed questionnaire. This will be made anonymous before sending to Dr. Bradley. We are still looking for more people to take part! If you would like to help, then please e-mail me at mary.mccreadie@lincolnshirepostpolio.org.uk, write to LPPN, PO Box 954, Lincoln, Lincolnshire, LN5 5ER, or ring the Helpline - telephone: 01522 888601

Records.

A problem that we need your help to resolve, is ensuring our records are up to date. We are finding a number of people have changed their e-mail addresses, changed telephone numbers, or even moved house - which makes it very difficult for us to keep in contact and make sure newsletters are received on time. Will everyone please complete the enclosed form and return it in the addressed envelope provided as soon as possible. [If you wish you can email the information to membership@lincolnshirepostpolio.org.uk] Thanks!

The Mobility Roadshow

Hilary, Richard and I meant to be at the Show for two of the three days, but the horrendous weather rather changed our minds! Although the Thursday was a wonderful sunny day, Friday saw the beginning of the torrential rain that contributed to severe flooding in the area, which sadly prevented a number of members from coming to the show at all. Hilary and Richard spent the morning driving a 40 mile round trip to get Richard's bi-level ventilator checked out (taking 5 hours instead of the expected two) and ended up spending the rest of the day in their hotel room. I was stuck at home unable to even get out to the car without getting drowned. But that does not compare with the trials and tribulations of our Membership Secretary Robin, and his wife Pauline! They were on the road for thirteen and half hours, trying to get from their home in Kent to Cirencester - a nightmare trip. Well done both of you for not throwing in the towel, and going back home again - it was great to see you! Fortunately, the last day of the Show was kinder, (even the occasional ray of sunshine!) and we did get to see most of the stands. It really needs two days to get the full benefit of the event; to have time to discuss things in depth with the sales people, and also chat with the many visitors to the show.

Hilary missed seeing Richard testing out a motor bike which has been adapted for wheelchair users! The machine, designed by Martin Conquest, is actually a trike, and is the most remarkable vehicle we've seen. Richard drove it around the test circuit with the salesman Gary, riding pillion, and it was great to see him having so much fun! The last time he rode his motorbike was in 1980... working out routes so that he could turn right rather than left, as his left leg is paralysed and he did not want to end up on the tarmac. [The obstacles we overcome to do

what others do!] The guys from the Martin Conquest stand were terrific! Even though I'd told them there was no chance of my ever being able to buy the bike, I got taken for a trip round the circuit - and what a trip! Haven't felt freedom like that for years and years! Thanks for making the day such fun! You can see the a photo of Richard and the bike on the back page - and for any true enthusiast, you can actually buy it through Motability!

On a completely different level, one stand that gave us probably the best laugh (although it's really a serious matter) was the 'SheeWee' stand. Dressed in pink and black T- shirts with 'Stand up and take control' emblazoned across them, the staff explained how to use this strange little device. To all ladies out there who need a really easy system to cope with 'waterworks' emergencies....this little gadget really works! Sorry to be cryptic - trying to save any male blushes! If you would like to know more, just get in touch.

LPPN members had arranged to meet at 2.00p.m. at the British Polio Fellowship stand, which was manned by Lisa Nichols and Carol Neale. Thanks to both of you for making us so welcome - we'll be in touch again soon. We were delighted when Hamish and his family turned up unexpectedly. This was the first time I had met the family, and I was thoroughly impressed not only with Hamish, but also with his siblings who seem to have everything worked out to make things easy for Hamish and his parents. It was also very good to meet member Francis Ball. Francis and I have been in regular telephone contact for the last year, but had never met. Really nice to put a face to the name and voice! Member Paul Stanton was also at the show, and he and Francis came back to the hotel in Swindon in the evening, where we spent a very pleasant couple of hours chatting. Please - someone remind me not to share a bottle of plonk with Hilary again! We agreed later that neither of us can manage that amount of alcohol any more, but it was good feeling 'normal' having a drink in the evening with friends in a bar.

Annual General Meeting

Time seems to be running away at a vast rate of knots, and the AGM is nearly upon us. We want the day to be really special, and have done our best to provide you with a program that will be interesting and beneficial. But we DO need you to let us know if you are coming or not. A reply slip was enclosed with the last newsletter, but only 10% of you have replied so far. We do appreciate that many of you cannot come due to distance/ability level but we would like to know. We are very lucky to have some wonderful members who go to a great deal of trouble to make sure a good lunch is provided, and forward planning is greatly helped by knowing how many of you are likely to be there. Please help us ensure the AGM Plan is complete well before the date by returning the slip, emailing me or phoning the Helpline.

I'm looking forward to meeting as many of you there as possible.

Mary McCreddie, Acting Chair

mary.mccreadie@lincolnshirepostpolio.org.uk

Treasurer's Thoughts

Your support

Many thanks to all our members who have sent donations to help us with our work. While subscriptions are up this year, general donations are at an all time low. The enclosed Annual Report and Accounts shows a loss for the past financial year. However, this report does not include our Gift Aid tax refund. We have just had confirmation that our refund for the financial year 2006-7 will be £1756.04, massively boosted due to the generosity of Vin Murria. Vin donated £5000 earlier in the year to the Therapy Pool Fund for 9 year old Hamish Thompson, and we were able to claim Gift Aid on her contribution.



How does it work?

For each pound you Gift Aid, LPPN receives an additional 28p, thus increasing the value of your gift by nearly a third.

Who can use Gift Aid?

Anyone who has paid enough income tax or capital gains tax to cover the amount reclaimed by LPPN in the current financial year can use Gift Aid. If you are a higher rate taxpayer, you can reclaim personal tax relief of 18 percent on your donation - 23p in every pound donated.

Gift Aid provides a great opportunity for some of our members to increase the value of their donations to LPPN. Many of us are not tax-payers and therefore not eligible; some prefer to use schemes such as CAF, where tax has already been reclaimed. Please fill in a declaration form and send it to me if you are eligible. You need only fill it in once. Completing a form is not a promise to give to LPPN, but it allows us to increase the value of your subscriptions and donations that you might give us in the future.

One of our sister charities, Post-Polio UK has reverted to an informal network. Their members voted at their AGM to send their "... final funds to Chris Salter of Lincs PPN to support [our] internationally acclaimed on-line medical library... ". We have gratefully accepted a cheque from Helena Edwards for £1538.84 which will be set aside as a restricted fund to support the LPPN website.

Fundraising

We continue to hope that we might find a volunteer to help with fundraising. Thanks to Sheila Dunnett, this month we received £137.25 from Motorcise in Lincoln, raised through the ladies buying and selling on their New 2 You Dress Rail. Thank you ladies!

I would welcome any suggestions/comments you would like to make.

You can contact write to me at the main LPPN address or email: denise.carlyle@lincolnshirepostpolio.org.uk



Richard takes instruction from Martin Conquest salesman Gary, before making his trip around the test circuit. Realising a dream is a serious business! Full information about the bike (or rather, trike) is available from gary@martinconquest.com

Annual General Meeting - September 15th 2007

MEMORIAL HALL, 317 NEWARK ROAD, LINCOLN LN6 9RY
[A1434 - 100 yards west of the Station Road/Moor Lane Junction] 



Doors open 9.30 a.m.

AGM commences 10.30 a.m.

**Personal experience of Care Plans
 by Jean Murdoch at 11.30 a.m.**

Buffet Lunch 12.30 p.m.

**Workshops on PPS Issues
 2.00 to 4.45 p.m.**

**Followed by Evening Get Together
 in the Bar of the IBIS hotel**