



The LincPIN

Polio Survivors Network Newsletter
Volume 6 - Issue 12 — April 2010

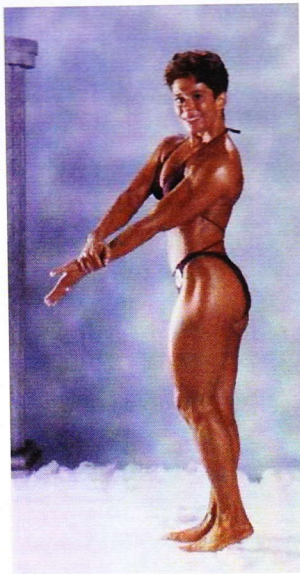
WebSite - www.lincolnshirepostpolio.org.uk

Polio Survivors Network
has been registered with the Charity Commission
as the new working name for the Lincolnshire Post Polio Network
New website coming soon - details in the next issue

Polio Survivors Network support
Post-Polio Health International - WE'RE STILL HERE!
Send us 3 photos depicting Your Polio Life
Competition Information on Page 11.

WE'RE STILL HERE!
October 10-16, 2010
www.post-polio.org

Which lady is the Polio Survivor?



The one on the left
or the one on the right
or both of them?

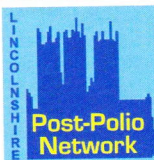
The picture on the left
was taken in 1995

The picture on the right
was taken in 2003

Professionals seeing you now,
knowing you had polio in your
earlier life, will have no idea
what you achieved
at Best Recovery
unless you show them.



Gwen - Thank you for permission to use your photos



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

- Page 2** - Contents
Page 3 - Editorial
Page 4 - Message from the Chair.
Page 5 - Our working lives and our retirement.
Page 5 - **Annual General Meeting Information and map.**
Pages 6 to 7 - **Summary of article**
Learning from the past:- reflections of two lives with polio and occupational therapy
Page 7 - Poem by Pauline.
Page 8 - RESULT study - Questionnaire available mid June.
Page 9 - Sharing Issues with other Members
Page 10 - If you had to be admitted to hospital in an emergency...
Page 11 - WE'RE STILL HERE! Photo competition.
Page 12 - Side effects of medications.
Page 13 - .Neurology Services needs Special Review says Neurological Alliance
Page 14 to 15 - Membership and Contact Information.
Page 16 - Front sheet images of information referred to in newsletter.

Donations since last Newsletter = £41.00

Our thanks to the following:-

Mrs. B Smith, Yvonne, Grosse, Cas Brown, Mrs. Darlington,
Lynn Hobday, Diana Nash, Cynthia Evans, Dinah King, Rose Fenton.

Plus we would like to acknowledge with thanks
our Committee and Operations Team
who generously donate time and energy from their PPS lives towards our work.

New Name for the Newsletter

We are extending the chance for you to rename this Newsletter to

31st May 2010

Please send us your ideas and reasons why you chose the name to

LPPN, PO Box 954, Lincoln, LN5 5ER or

Email:- newsletter@lincolnshirepostpolio.org.uk

CONTACT INFORMATION IS ON PAGES 14 AND 15

Copyright of material published in the LincPIN is retained by The Lincolnshire Post-Polio Network and/or the original author(s). Reproduction and redistribution of any material via any media requires permission from The Lincolnshire Post-Polio Network and where applicable, the original author(s). Where permission is given, original material must include a credit to the LincPIN; material from other sources should credit the original publication.

Editorial by Hilary Boone, Treasurer. Membership Secretary & Newsletter Editor.

I am sorry but this issue is only 16 pages due to the extra work our Committee are undertaking at the moment.

MEMBERS WITHOUT COMPUTERS - Write to us or Ring us if you cannot obtain information that we reference in this newsletter and we will arrange for you to receive a copy. The telephone number of the Duty Phone Team PPSer is recorded on a message on our main telephone number.

Membership. PPS with its functional decline has come upon most of our members as a complete shock. We thought our Polio was past tense and had no idea that new and unexpected functional decline years earlier than age would come upon us. Many of us have had to medically retire early and instead of a salary have found ourselves living on much lower amounts in benefits, We had no idea of the numerous hurdles that we would have to jump to complete the necessary paperwork year after year after year. We see our bills increasing way beyond the norm because of the extra costs incurred by our new and unexpected disabilities. Trying to make the pennies go further means some things have to go. I am sure the rest of the members will agree that this should not be membership of any organisation providing information that might help you manage your life. If you find yourself in this situation we would prefer you let us know rather than just not renewing your membership. We are looking into ways of sponsoring these members and any suggestions would be gratefully received.

Our Bank Details - Our Bank Details are CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ. Sort Code 40—52 —40, Account Number, 14980. The HSBC Account was closed last year mid summer. All members paying to HSBC were notified and the Renewal forms were updated with the new details.

Payment of Membership Fees by Standing Order - All members due to renew by cheque will find a S.O. form enclosed with their newsletter. If you wish to pay this way all you have to do is complete this and take or send it to YOUR bank.

Change of Address / Phone Number / Email address - Please remember if you change any of these to notify us.

Members who become ill or go into hospital. - It would also be helpful if you could let one of your relatives know you are a member and give them our contact details so they can contact us if needed.

Information by Phone or Letter - If you are looking for some information or help then please get in touch with our Phone Team Member on Duty [Ring 01522 888601 to hear the telephone number of the Duty member] or write to us. Remember we are not medically qualified and we cannot advise you what to do. We can tell you or provide you with information to help you discuss matters with your health professional.

Information by Email - We provide three choices. Information, Newsletter and Members Discussion Email List. Email membership@lincolnshirepostpolio.org.uk and let us know,

Newsletter by email - If you are happy to get your newsletter by email it would help reduce our printing and posting costs and enable us to spend the money on other work. If your circumstances change and you would like to go back to a posted copy then let us know.

Members Discussion Email List - Some members [well I am sure this is most members] find understanding all the new technology that changes daily a bit daunting. If you have a computer and would like to share stories, problems and any other issues with members you can join our Discussion Email List. See page 9.

'Meat and Greet' dates. Would you like to meet and chat with other members living near you on an informal basis? See page 9 for more information.

Message from the Chair

Dear Members, Friends and Colleagues,

Sadly, after fifteen years, Chris Salter has resigned as our webmaster. We thank Chris for all his hard work and dedication to Lincolnshire Post Polio Network and wish him much luck with all his future projects.

We put our "thinking caps" on and set about finding one of those tekkie folk who could help. And we found someone! His name is Dave Eate and he has a working life behind him in the world of computers and websites. He is donating his skills to Polio Survivors Network to help re-design our website and he will be presenting at the AGM on 2nd July when our new website will be officially launched.

Glenna, our Secretary and I attended British Polio's Expert Panel meeting held on 2nd March, 2010. Good progress is being made with the Map of Medicine and Professor Caroline Young's research into fatigue, which is, of course, work in progress. Glenna and I also attended an informal meeting with John Hooper, Chief Executive, Pam Jones, Chair (Trustees) and Tess Mitchell, Project Development Manager at British Polio's offices in Ruislip. The main reason was to discuss how Polio Survivors Network and British Polio could best work together. It is anticipated that we meet again in six months time.

I am pleased to be able to tell you that Glenna and I have started our fundraising campaign and if you have any ideas and tips please let us know.

You can email us,

glenna.tomlin@lincolnshirepostpolio.org.uk
sandra.paget@lincolnshirepostpolio.org.uk

Or write to us at the main address.

Although it is a lovely Spring day in Buckinghamshire at the time of writing we not only have the cloud of a forthcoming election but a cloud of volcanic ash floating above our green and pleasant land. What is that old saying ...every cloud has a silver lining!

Meanwhile, I'll leave you to ponder under the clouds and look forward to meeting as many of you as possible at the AGM.

Take care and live well: you are still here!

Sandra Paget,

Chair (Trustees)

OUR WORKING LIVES:

Little birds are telling us of the interesting working lives of our members. What about sharing these experiences with our readers? This can be any aspect of your working lives. You can publish using your real name or anonymously, i.e. identify yourself as much as you wish or not. Just send three or four paragraphs to Hilary about your working life experiences.

OUR RETIREMENT:

If you are retired from all that work please share with us how you fill up your time. You might have started an absorbing new hobby or have more time for a passion that's been with you for years but work, just got in the way! Your experiences may help others and no doubt interesting to read about. So, three or four paragraphs to Hilary, identify yourself as much as you wish.

Deadline for the next issue for any articles is 15th June 2010.

ANNUAL GENERAL MEETING

Friday July 2nd 2010

The Crystal Suite,

The Bentley Hotel, Lincoln

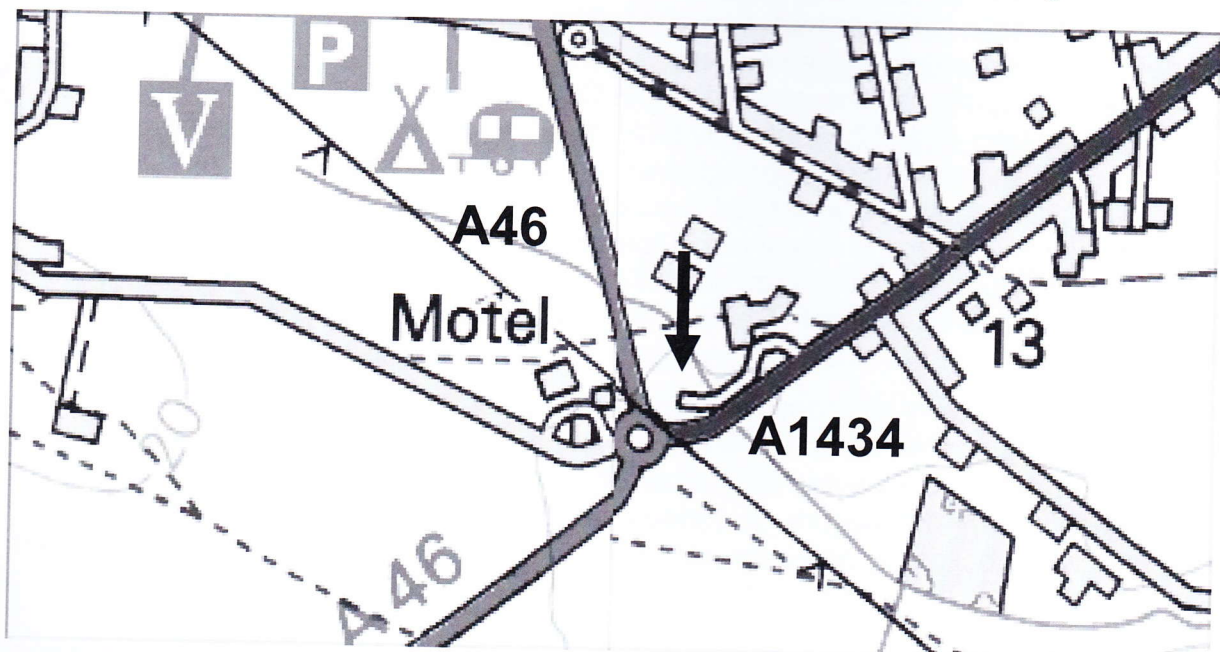
AGM commences at 1 p.m.

Speaker - 2.15 p.m.

Tea will be served at around 4 p.m with time for Questions.

Event closes at 5 p.m.

Full details of this event, including details of the Speaker/s, will be enclosed with the Trustees Annual Report in mid May. The map shows the Lincoln Bypass, the A46. Coming from either direction take the A1434 into Lincoln and immediately turn left onto the small slip road to the hotel. The motel on the map is a Travelodge



'Learning from the past: reflections on two lives with polio and occupational therapy.

By Ulla Runge and Ann Carnduff

In the British Journal of Occupational Therapy, December 2009 72(12)

A summary of the article showing a remarkably similar experience despite living in two different countries, Denmark and Scotland by two Polio Survivor Occupational Therapists. Very similar polio lives, achievements and new and unexpected weaknesses. An article by health professionals we can show to health professionals that can help confirm that our experiences with Post Polio Syndrome are 'real' and not 'all in our minds'.

Both ladies were born in the same decade and caught polio before the age of 5. Initially both considerably disabled but recovering well and for years there were few functional limitations in their family and work lives and they almost forgot about their polio. Both achieved highly in their chosen career of Occupational Therapy. Both had to retire earlier than they wished when they became users of health care through post polio.

Ann caught polio in Glasgow in 1948 and was paralysed down her right side and, for a few months, she could not talk above a whisper or sit up. However, after some months her right leg regained function and like many of us she had orthopaedic operations on her feet at 12 years of age. At 18 she started her training as an OT and qualified in 1965. When two friends introduced her to mountaineering she joined them. Ann married and had two children and during this time off work took a BA degree. She returned to work as an OT in 1980 and in 1984 became a lecturer at the Glasgow School of Occupational Therapy and from then till she retired was highly involved in many different capacities with the College of OT's and at the end of the first meeting of the European Network of Occupational Therapists {COTEC} she became their first secretary. In 2000 she was awarded a Fellowship of the College of Occupational Therapists, 'one of the most rewarding days of my life'.

Ulla caught polio in Copenhagen in 1941. She survived but could not walk. Many operations followed over the next few years and whilst she could walk now it was not far. Occupational Therapy training in Denmark became free and she qualified three years later in 1967. Her family took up skiing in Norway and in spite of her limitations she joined them although was unable to make right turns. She also took up mountain climbing. She started teaching in OT in 1971 and became Dean of Occupational Therapy in Naestved in the early 1980's. In 1989 she started her Masters in Public Health studies. In 2002 she retired from her post but continued as a supervisor and examiner in the European Master of Science in Occupational Therapy.

Both remember very long days in hospitals interrupted only by institutionalised routines, long periods of limited contact with their families, classmates and others. Coming to their rescue were OT's who focused on what they wanted to do and introduced them to craftwork. 'We made soft toys, leatherwork and baskets for satisfaction, challenge, presents, selling and fun'. Ann remember rabbits with green waistcoats and Ulla her favourite a green bambi with white spots.

For three decades they thought their disabilities had disappeared, but now, like most of us, know that they had only receded into the background. Gradually over the years as the demands from society and the health care sector changed and craft activities were replaced by work-like situations, creativity was replaced by exercising specific body parts and a 'basket full of activities' was replaced by a medical atmosphere.

The memories of their disabilities are remarkably few. They ignored the fact that their polio had an impact on their teenage years. In the 70's Ulla avoided using stairs and Ann stated 'I was sometimes slower than the others, sometimes more tired, but I always made it'.

A very important few lines are 'We can see that our disabilities must have had an impact on our view of occupational therapy. We can see from our inclusive approach towards clients that occupational therapists should act as advocates for their clients' needs and rights to be independent and that they must be aware of limitations in the environment.'

The 1990's was the decade when their polio returned and, with this, the fear of becoming old, disabled and tired, which was not easy to accept.

They were both workaholics with no time for disabilities and mention little of their new problems other than 'muscles starting to hurt causing problems with cycling, walking and driving for long distances'.

Even with the new millennium and retirement they continue with as many activities as they can. They both still have problems accepting their disabilities, remain very aware of wanting to be self-supporting and independent and continue to have much discussion about the lack of accessibility allowing participation in the environment.

Editors Note: Ann and Ulla are both on holiday on the date of our AGM but have offered to speak on another date and we are in the process of organizing this.

I WISH
by Pauline in Cumbria

I sit and watch the river flow
With no particular place to go
Flowing fast and flowing free
Oh how I wish that could be me

Meandering on who knows were
Twisting turning here and there
With no restraint it just flows free
Oh how I wish that could be me

It rages on and on without a care
Try to stop it don't you dare
No-one can stop it flowing free
Oh how I wish that could be me

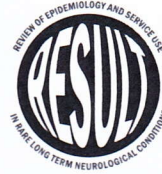
The flotsam and jetsam floating by
I think to myself as I sit and sigh
Please take the worries inside of me
With the flotsam and jetsam out to sea

I wish my life could be carefree
Like the river flowing free.

Pauline has had a leg operation that was incorrectly done, had to be redone, and she is now having to rely on her husband to do almost everything for her. She is finding life very hard whilst they try to get this sorted out. She would love to hear from other polio survivors.



UNIVERSITY OF
BIRMINGHAM



UPDATE from last newsletter

The Questionnaire will be available MID JUNE

The **RESULT** Study (Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions) is a study that has been funded by the Department of Health, and is part of the Policy Research Programme for Long Term Neurological Conditions. This study is looking at the services provided for people with rare long term neurological conditions, including post polio syndrome. The National Service Framework for long-term neurological conditions highlighted the need for quality standards in providing care and access to services. However, there is little accurate and reliable information about the views of service users and carers on the services provided. Without this information it is difficult for the service providers to make improvements. Therefore, the aim of this study is to ask people with post polio syndrome for their views and experiences of health and social care services, and identify good practice as well as any shortcomings or gaps in service provision. We will present this information to policy makers and service providers and feedback to service users and health professionals.

The questionnaire will be available by post, email, or telephone and in a number of languages (please enquire), and should take about 45 minutes to complete. If you would like some support to complete the questionnaire, a carer can help you with it, or you can contact Sonal Shah from the University of Birmingham who will be happy to assist. Alternatively, if you live within reasonable travelling distance of the University of Birmingham you can opt to have a one-to-one interview at a time and location that is convenient for you. You are free to withdraw from the study at any stage, and you do not have to give a reason. We also would welcome any comments and suggestions you may have about the study.

If you are interested in taking part in this study,
and we do hope as many polio survivors as possible will take part
or to find out more information, please contact:-

Sonal Shah,
Primary Care Clinical Sciences,
School of Health and Population Sciences,
University of Birmingham,
Edgbaston B15 2TT
Telephone:- 0121 414 8585
Email:- s.shah.1@bham.ac.uk

Sharing issues with other Members

Many polio survivors, family members, carers and friends report what a relief it can be to talk to someone who really does understand what it is like to be or have a polio survivor family member or friend with new and unexpected issues? Finding out that others are experiencing similar issues and can share with you what they have done can make life easier. There are many ways we can help with this.

1. **Write and/or reply to a short story/request for info** to the Newsletter.
2. **Become a Pen or Phone Pal** with other/s - They could live nearby or be similar in age and life experience. Contact us if you would like to do this and we will set the wheels in motion. If you prefer you can send us a small advert of 50 words or less for the newsletter, e.g. Pen/Phone Pal wanted by female polio survivor [could be carer or family member of a polio survivor] in mid 70's who worked in education and loves pottery and small dogs.
3. **MEAT AND GREET'** - Meet with other members over a meal and share stories and info. These are informal events and we hope that members, who can, will organise an event in their area. All you need to do is pick a date, find a venue that serves food [or you can have this in your home with members bringing their own packed lunch/tea]. If you would like to learn more, send us details, let us know you are in the area and would like to go etc., then write, ring or email <newsletter@lincolnshirepostpolio.org.uk>. We will send an invite with full details to all members in the area, and anyone who contacts us. We hope to hear from you and publish more dates in future newsletters.

- | | |
|-----------|---|
| May 28th | Lincoln, The Lincolnshire Poacher, 11.00 to 3.00 (Hilary and Richard) |
| June 2nd | Nr. Mablethorpe at Jean's home. Please bring packed lunch and soft drink other than tea or coffee . 11.00 to 2.30 |
| June 2nd | Bucks Herts Border [Sandra and Glenna] venue being arranged. 12.00 to 3.00 |
| June 11th | Whitehaven, Cumbria. Jim is checking the venue to ensure accessibility and the time will be 11.00 to 3.00. He plans to organize another in Aug/Sept in the Lancaster area |

And if you have a computer and are connected to the internet..

4. Become a **Computer Phone/Video Phone Pal** with others using software like Skype which is free to download and free to use between members. [www.skype.com]. Those without computers might be surprised to learn that some of us talk live with full screen video pictures with other polio survivors/ family and friends around the world.
5. **Join our Members Email Discussion List.** Technology changes almost daily and for some of us trying to keep up with it at our age is not easy at all. In case you do not know Email is an electronic letter that you type onto a computer screen and can then send immediately to one or more others who also have an email address. We set up a subscription for you and send you full details to start discussions with other members. Our list has its own email address which you use to send and reply to other emails.

If you had to be admitted to hospital in an emergency...

One of our members has ended up in hospital with an orthopaedic problem and has to decide, traction for six weeks or an operation and if an operation should it be an epidural or general anaesthetic? She did not have any information prepared to take with her and rang us asking for copies of documents to be sent to the hospital. We were thanked by the Matron of the Hospital. I am sure before I go any further on this you would all want to add your good wishes to ours for a good and healthy recovery.

Since the successful Polio Vaccine in 1955 the content of lectures on polio have reduced over the years and for some health professionals not even mentioned. In countries where polio is rarely seen most of the population under 40 know it only as one of the childhood vaccinations.

So how do we ensure that the picture we paint in the mind of the health professional we are seeing matches how we have and are living our life as near to the truth as it can be?

Over twelve years ago Hilary met Gwen [See photos on Front Page] from America via the internet. Gwen willingly gave us permission to use her photos to promote the changes that are happening in Polio Lives. Hilary has used them on slides in presentations since then with mostly 'Wow! type responses.

Hilary can tell you from a personal experience ten years ago that when a doctor and her staff at a PPS Clinic in the States were shown two photos of Richard during his best years the response was 'Wow.. Looking at you now we would have had no idea that you recovered that well had you not shown us these photos'.

I know that thinking about how polio has affected you, your life and the lives of those around you is not easy. However, if you want the best out of medical, social service and benefits appointments then it is imperative that you paint the right picture in their minds.

The following are ideas that have worked for some of our members and helped develop the information we provide.

We suggest that you make up two sets of information and keep a copy in the bag you carry with you when out, and another attached to or in the fridge.

What you Need to Know about my Condition - WYNTK - This includes contact information about you, your family and your health professions. How you manage your abilities and what help you would need in hospital, medication you take, allergies, and anything else that you feel is important. You do need to update this when things change and if you do not have a computer then we recommend that you always have at least one spare copy to hand. [See back page]

The PatientPlus article on Post-Polio Syndrome [January 2010 LincPIN]

We are in the process of updating and reproducing all our literature under our new name. The five leaflets provided when you joined and other information will be available at the AGM and sent to all members not attending.

A couple of photographs that show you have physically changed due to post polio syndrome. Have a quick look at Gwen on the front page, which leads nicely on to ...

WE'RE STILL HERE!

Photo competition

Post-Polio Health International in St. Louis, USA started a WE'RE STILL HERE! campaign in 2008 with a highlighted week each year in October. This year PPS groups from around the world have come together under the banner POLIO WORLD via a Conference Call and decided that the best way of promoting our issues is to have a photographic competition under the banner We're Still Here!

Each group will be holding their own competition and submitting their winner to Polio Canada who have offered to collect/collate/prepare the photos to find one overall winner. The judging will take place early in September 2010 so that posters can be produced for the October Polio campaigns around the world.

We are asking you to send us three photographs of your polio life. One at the age when you had Polio. One at your Best Recovery [maybe doing something no-one would suspect possible with your initial polio damage] and one showing how you are managing your life now. Like Gwen, we know that many polio survivors were never photographed showing their original polio damage so it is fine to submit a photo of you at that age.

We are asking that you provide your first name [you can give your full name if you wish] the year, age and place where you caught polio. E.g. Julie, age 2, 1947 in Exeter, and a short phrase to describe the level of polio damage - waist down paralytic polio. The other two photographs will need a short phrase to identify them, e.g. '1970 playing rugby' and '1995 back in callipers'

You can send the three photos and a letter with the information on it and we will scan and set them up using a computer. We will scan and then return your photos with a draft copy for approval before submission. Or you can stick the photos to a sheet of card adding your text to it. Or you can set them up using your computer and email the result to us. photos as you wish. We need the prepared photo's by the 20th June 2010 and if you want us to set them up for you then we need those three weeks earlier by 1st June 2010.

The best photographs will be used on posters and other literature under the banner 'We're Still Here!' and you will need to sign a permission form to enable this to happen. The winner of our competition - judging will take place at our AGM on Friday July 2nd - will be forwarded to Polio Canada.

We have realised that some of you would like to enter but DO NOT want your photographs to be used in any media reproduction. So we have decided that for our competition you can choose the level to which your photos can be used. You will find a copy of the permission sheet enclosed with this newsletter [or attached to the email for those taking copies via the internet].

GOOGLE has placed online the over ten million photos from the archives of the now defunct magazine **LIFE**. Many never published. They can be found at <<http://images.google.com/hosted/life>>. If you type 'polio' into the search option you will find several hundred photos related to the epidemics. [Info from Polio Particles by Mary Westbrook in NETWORK NEWS - Issue 77 - April 2009, the newsletter of Post-Polio Network (NSW) Inc. www.post-polionetwork.org.au]

SIDE AFFECTS OF MEDICATIONS

Recently, Members using the Members Email Discussion Forum, were discussing the side effects of medications, particularly statins. If you are concerned or think you are experiencing side effects of any medicines you are taking that trouble you the important thing to do first is discuss these with your doctor or nurse. Make a note of when you brought this to her/his attention.

You can also use www.yellowcard.gov.uk to register side effects about medicines online. For those of you without internet access you can telephone the National Yellow Card Information Service during office hours on 0808 100 3353 or write to

Pharmacovigilance Signal Management Group
Vigilance and Risk Management of Medicines
MHRA, Market Towers,
1 Nine Elms Lane
London, SW8 5NQ

Both the Medicines and Healthcare products Regulatory Agency (MHRA) www.mhra.gov.uk and the Association of British Pharmaceutical Industries have published useful information.

The ABPI has published two items which you can find here

www.abpi.org.uk/category.asp?Category=3

Taking Control: our right to information and

'Finding and Using Information About Health and Medicines 2007.'

Addresses: **ABPI**, 12 Whitehall, London, SW1A 2DY
Tel: 0870 890 433

ABPI Scotland,
Third Floor, East Crichton House,
4 Chrichton Close, Canongate, Edinburgh, EH8 8DT
Tel: 0870 890 4333

ABPI Cymru Wales,
Caspian Point 2, Pierhead Street
Cardiff Bay, CF10 4DQ
Tel: 0870 890 4333

Again, the important thing to do is to discuss any side effects that you find troublesome with your doctor or nurse and keep a note of when you brought it to his/her attention.

If you do not have internet access most libraries now have computers/internet available to you and librarians ready to help you.

If you cannot get out and/or do not have a family member to help you then please get in touch and we will help.

PRESS STATEMENT - 2nd February 2010.

**NEUROLOGY SERVICES NEED SPECIAL REVIEW,
SAYS NEUROLOGICAL ALLIANCE.**

Neurology urgently needs to be reviewed by the Care Quality Commission (CQC) the Neurological Alliance said today, in welcoming the inclusion of neurology in a list of 13 topics for consideration in the CQC special review consultation, Assessment of Quality in 2010/11.

The Neurological Alliance, which represents 8 million people with neurological conditions through 67 brain and spine charities, [Our Charity is a member] has been campaigning for the CQC to prioritise neurology for some time, including sending letters from members calling for this patient group to get the attention they deserve.

Most neurological conditions are chronic and progressive and few have cures. This means that most people receive long-term care from the NHS, local authority and independent providers, all of which are regulated by the CQC.

Yet up to this point the CQC has not looked into the provision of neurology services, despite the evidence of significant inequalities in their quality and access. A special review would mean a full examination of how neurological services are run, and would lead to better quality of care for people with brain and spine conditions.

Steve Ford, Trustee of the Neurological Alliance and Chief Executive of the Parkinson's Disease Society [now Parkinson's UK] said:

'The All Party Parliamentary Group for Parkinson's' inquiry into access to services reported significant inequalities in access to Parkinson's nurses, therapy services, aids and equipment, respite care and support for carers - with huge implication on how people cope living with Parkinson's. We are delighted that the CQC have included neurology as a topic in the consultation, but will continue our Fair Care for Parkinson's campaign to make sure neurology services are examined more closely.'

Clare Moonan, Chief Executive (External) of the Neurological Alliance said:

'We hope a special review of neurology services will act as a powerful signal to service providers and commissioners to ensure that neurological conditions are given greater priority. There is a great deal of innovation and good practice in some areas of the country but unacceptably poor care in others. We need the CQC to use all its power and influence to look at why these gaps in service exist and ensure things improve across the board.'

Nicolette Williams, Regional Development Manager of the Neurological Alliance said:

'We are delighted that the CQC has included neurology in its shortlist of possible topics for a special review, but this is only the first stage. What we need to do now is to make sure that neurology is chosen from the shortlist, so if you or your family are affected by a neurological conditions we would really encourage you to make your voice heard by responding to the consultant before 27th April' Ends.

NOTE:- Hilary is attending the Regional Neurological Alliance meeting 21st and 22nd April 2010 in Manchester on behalf of Lincolnshire Neurological Alliance and of course our members. Update in next issue

**If you have found this newsletter helpful
why not support our work by joining us**

**Sharing information with others
who know where you are coming from
is a HUGE stress reliever**

Membership provides

Our newsletter is published 4 times a year

Extensive Website including 100+ article Online Library

Members Discussion Email List

Be put in touch with other members in your area

Need an answer to a Question

**Write to us - Ring the Phone Team - Email info@
And we will endeavor to find you an answer**

Name

Address

Post or Zip Code Country.....

Phone

Email

I enclosefor membership / as a donation

I am a Polio Survivor [year] carer,/ family member / friend

Health Professional

If you do not wish to cut the newsletter
then please copy the information to a letter. Thank you.

POLIO SURVIVORS NETWORK

A Post-Polio Information Service for Polio Survivors and Medical Professionals
Registered Charity No. 1064177

Website - www.lincolnshirepostpolio.org.uk
[new website coming soon - full details in the next issue.]

WRITE P.O. Box 954, Lincoln, Lincolnshire, LN5 5ER, UK
PHONE UK 01522 888601 From Abroad +44 1522 888601
FAX [No Fax number at the moment]
EMAIL info@lincolnshirepostpolio.org.uk
JOIN or RENEW **Membership Secretary,**
P.O. Box 954, Lincoln, Lincolnshire, LN5 5ER, U.K.
Or email:- membership@lincolnshirepostpolio.org.uk
Cheques Please make payable to 'Lincolnshire Post Polio Network'
Fees **Membership is for 12 months starting Feb, May, Aug or Nov.**
UK Life Member £ 150 S.O. £ 5 x 30 [Form from Sec.]
Member £ 12.50
Europe Life Member € 300 Member € 25
Canada Life Member C\$ 550, Member C\$ 40
USA Life Member US\$ 375 Member US\$ 25
[Post US\$ checks to LPPN - c/o 4212 Blanding Blvd, Jacksonville FL 32210]
Other Please contact membership@lincolnshirepostpolio.org.uk

Newsletters - The LincPIN - Next Issue July 2010

Articles/Items/Tipbits/Letters/Questions must be received by 15th June 2010
Post or email:- newsletter@lincolnshirepostpolio.org.uk

Management Committee [Trustees]

Chair - Sandra Paget - sandra.paget@lincolnshirepostpolio.org.uk
Vice Chair - James [Jim] Pullin - jim.pullin@lincolnshirepostpolio.org.uk
Secretary - Glenna Tomlin - glenna.tomlin@lincolnshirepostpolio.org.uk
Treasurer - Hilary Boone - hilary.boone@lincolnshirepostpolio.org.uk
Committee Members - Ian Hobday - ian.hobday@lincolnshirepostpolio.org.uk

Operations Team

Membership Secretary - Hilary Boone hilary.boone@lincolnshirepostpolio.org.uk
Phone Team - Di Brennand (Leader) di.brennand@lincolnshirepostpolio.org.uk
Margaret Edmonds and Judy Barter
Administrative Support - Barry & Olivia Branston

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


June 2006 - 28 Page Newsletter on Respiratory Issues June 2006

www.lincolnshirepostpolio.org.uk/downloads/lincpin/lincpinv5i09june2006.pdf

October 2009 - 20 Page Newsletter contains

Patient UK PatientPlus Article on Post-polio Syndrome.

<http://www.lincolnshirepostpolio.org.uk/downloads/lincpin/lincpinv6i10october2009.pdf>



The LincPIN
The Lincolnshire Post-Polio Information Newsletter
Volume 5 - Issue 9 - June 2006

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

TO BREATHE we use Lungs, Diaphragm, Intercostals and Accessory Muscles.

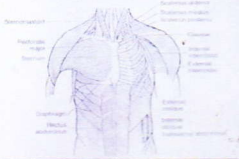


Diagram shows Diaphragm and Accessory Muscles

Do you have weakness or stiffness in any of these muscles?

Do you stop breathing to concentrate on achieving an action? If you do, is this because you are using accessory breathing muscles to assist your weak muscles to achieve that task?

AGM - September 9th 2006

See Back Page

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

© Copyright - Lincolnshire Post-Polio Network - Volume 5 - Issue 9 of 10 - June 2006



The LincPIN
The Lincolnshire Post-Polio Information Newsletter
Volume 6 - Issue 10 - October 2009

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

Patient UK PatientPlus Article



Post-polio Syndrome see inside

N.B. All mail including membership fees [except USA \$ checks] to PO Box 954, Lincoln, LN5 5ER, UK

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

© Copyright - Lincolnshire Post-Polio Network - Volume 6 - Issue 10 of 12 - October 2009

MY POLIO LIFE - Self Assessment Questionnaire to help you provide best information

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

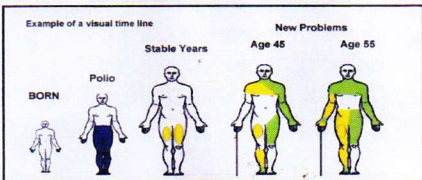
WHAT YOU NEED TO KNOW ABOUT MY CONDITION

4 Pages of information you may be asked for by Ambulance, A&E, and Ward Staff

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

MY POLIO LIFE

A Patient Questionnaire providing base line information and comparison charts on the Life of a Polio Survivor




KEY No known weakness (white) Paralysis (blue)

This Questionnaire is to help you provide pertinent information for your health professionals and could also be used to collect and collate statistics on the issues being experienced in your county/state/country.

Created by the Lincolnshire Post-Polio Network
PO Box 954, Lincoln, Lincolnshire, LN5 5ER, U.K.
Registered Charity 1064177
www.lincolnshirepostpolio.org.uk
info@lincolnshirepostpolio.org.uk

A copy of this document can be found at www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf or a completed example at www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife-sample.pdf

© The Lincolnshire Post-Polio Network, U.K. www.lincolnshirepostpolio.org.uk - Version 1.02 12/2007



Lincolnshire Post Polio Network
P.O. Box 954 Lincoln LN5 5ER, U.K.
Tel:- 01522 888601
Fax:- 0870 1600840
www.lincolnshirepostpolio.org.uk
Registered Charity 1064177

What you need to know about my condition.

I have Post-Polio Syndrome, the symptoms of which vary from person to person. This document contains key information about how Post-Polio Syndrome affects me, and will help you to understand my needs.

Full Name
The Name I like to be called by
Address
Post Code
Tel:- Mobile
Next of Kin
Tel:- Mobile
In Case of Emergency [ICE] contact
Relationship
Tel:- Mobile
GP name
GP Surgery Tel:-

I AM ALLERGIC TO:-

POST POLIO SYNDROME or PPS, is the accepted name for the constellation of symptoms including NEW weakness, muscle fatigue and/or "central" fatigue, pain, breathing and/or swallowing difficulties, a variety of sleep disorders, fasciculations, gastrointestinal problems. These symptoms can occur both in previously affected muscles and those thought not to have been affected at onset. There are no definitive tests. Diagnosis is by exclusion of other conditions. N.B. Care must be taken when prescribing any Drug or Anaesthetic that has sedative or muscle relaxant properties.