



# The LincPIN

The Lincolnshire Post-Polio Information Newsletter  
Volume 6 - Issue 11 — January 2010

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

This issue is dedicated to the life of member  
Pamela Elisabeth Minnitt  
25th February 1929 to October 3rd 2009

## Lincolnshire Post Polio Network

is changing its name to

# Polio Survivors Network

What we have - What we are - What we do

See pages 4 to 7

### Take part in PPS Research

Info on Pages 10 & 11

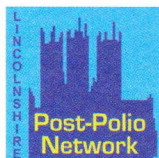
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### **Donations since the last newsletter - £1,330.00**

In memory of Pamela Elisabeth Minnitt, The Rotary Club of Sleaford, B Smith, V. Holland, ML Holland, R. Fenton, L. Forsyth, H. Boone, P. Fanutza, C. Murray, M. Lamb, W. West, B. Taverner, N. Jupp, D. Lightfoot, V. Gabriel, N. Jones, P. Dunham, O. Branston, B. Branston, W. Hyam

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 looking for suggestions for a new name for our Newsletter.  
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](mailto:newsletter@lincolnshirepostpolio.org.uk)

### **CONTACT INFORMATION IS ON PAGES 18 AND 19**

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

**Pamela Elisabeth Minnitt**, a member living near Lincoln, sadly passed away on October 3rd 2009. Anyone who has attended an AGM over the years is likely to have met her and her husband Denis. Pam might have been a 'little lady' but she had a huge smile and determination to succeed even larger. We would especially like to thank her family and friends for the generous donation of £500 in her memory. See page 8. .

**Donations** - The Committee are really grateful for the increased number of donations that we received in the last few months. We are now 'out of the woods' for this financial year BUT we need to raise more money if we are to continue to provide and improve on the level of service we plan. We will be submitting requests for grants and sponsorship in the next few months but if you, or your family or friends, can spare a few pounds/dollars to help build up a reserve we would be grateful.

**Talk on PPS for the Rotary Club in Sleaford.** I was asked to give a short talk on Polio by the Rotary Club in Sleaford at their yearly frugal lunch. [home made soup, bread and cheese]. I was able to include information from old newspaper cuttings. As I was leaving I was presented with a cheque for £100 towards our work.

**Late Payment of Membership Fees** - How many of you, like me, think 'must do x' and later think of it again and believe that you did it? There are quite a few apology letters on file because of late payment of membership fees. I wonder if it would be possible for any member not already paying by Standing Order to consider this method of payment. (S.O. form enclosed).

**Newsletter by email** - If you have a computer and have not already agreed to receive your copy of the newsletter by email, and would like to do so then please email [newsletter@lincolnshirepostpolio.org.uk](mailto:newsletter@lincolnshirepostpolio.org.uk) and I will add you to the list.

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

**Two Queries** - We have been unsuccessful in tracing a member who paid a few £5.00 monthly payments to us through the Woolwich Building Society. Whilst we got the money there was no name attached to the payment and the Building Society were unable to divulge the name. Also there is a payment recorded as Forrester/Lundblad, again we would like to match this donation to a member.

**Annual General Meeting 2010** - Requests to have the meeting during the summer months with longer days has been taken on board. It will be in Lincoln on Friday 3rd July 2010. More details in the next newsletter.

**Surveys** - There are currently 4 research surveys that Polio Survivors and or Carers can take part in. Information on pages 10 and 11. Over the last fourteen and a half years we have been going rarely do more than a few members respond to our requests for letters/tips/etc. These researchers need your help if you want to see an improvement in the services you receive.

**Members Email List** - To get the most out of this list we need members to take part. If you have a problem, issues, good or bad experience then why not share this with other members. Jim Pullin is going to look after this list. If you have not already asked to be subscribed to the Polio Network Lincs Members Email list and would like some more information please email [jim.pullin@lincolnshirepostpolio.org.uk](mailto:jim.pullin@lincolnshirepostpolio.org.uk)

**'Meat and Greet' April and May** - If you would like to hold a meeting in a pub/venue that serves food for members in your area then please let us know by the end of February. Dates and venues in the next newsletter. So far we have events being planned in Lincolnshire [Lincoln and Mablethorpe], Bucks, Herts, and Cumbria.

# Message from the Chair

Dear Members, Friends and Colleagues,

This is my first letter to you as your Chair and thank you for your show of support in voting for me at LPPN's recent election. I feel honoured that you did and privileged to have the opportunity to give my skills to enable LPPN to build on all its past work. I can only do my best by everyone and that is what I will do.

As you know unfortunate events at the Annual General Meeting held a couple of months ago led to an Extraordinary General Meeting held on 28th November, 2009 in Lincoln. At that meeting a new Management Committee [All Trustees] was voted in as follows:

Sandra Paget	:	Chair
Jim Pullin	:	Vice Chair
Glenna Tomlin	:	Secretary
Hilary Boone	:	Treasurer
Ian Hobday	:	Trustee

There are three vacant places on the committee and if anyone [including family members] is interested in joining us then please get in touch. All the new amendments to the Constitution were voted in which means that members unable to attend the AGM will be now be able to participate via teleconferencing or video conferencing. Our constitution now allows formal Notices to be sent by email to members who have an email address and agree to this.

Ian, who is the son of Lynn Hobday, polio survivor and former Trustee, donated his skills as a Management Consultant and gave us a "sit-up and listen, take note" presentation analysing LPPN's current situation. Ian informed the meeting that there is an urgent financial need for LPPN to review its expenditure. As he said, 'when the breadwinner in a family loses his/her job the family must trim back its outgoings and/or increase its incomings'.

Over the coming months the Trustees will be working to do that by looking at all LPPN's outgoings, raise funds via a fundraiser, re-design the website and importantly re-visit LPPN's mission, particularly raising awareness of post polio syndrome. It is important that we attend to these things so that LPPN can continue to use the knowledge it has acquired during the past to influence the daily lives of polio survivors in the future.

In the short term to reduce printing and postage costs we would like to increase the number of members who receive an electronic copy of the Newsletter. Not all members have a computer but if you do and you are happy to try this method then please email [newsletter@lincolnshirepostpolio.org.uk](mailto:newsletter@lincolnshirepostpolio.org.uk) and we will add you to the list.

If you have a look at the table on the next page you will see that 88% of the membership lives outside Lincolnshire. This led to discussion about changing our name to something that more accurately reflects our membership.

The following name was suggested at the EGM and the transition will be completed on the day of the Annual General Meeting, 2nd July 2010.

## **POLIO SURVIVORS NETWORK**

### **What we have - What we are - What we do**

We also discussed ways in which we could be more effective at local level. There are ten Strategic Health Authorities (SHA) in England and our members live in all of them. An idea discussed was for at least one, preferably two members in each SHA to become appointed contacts for our network, to join with us to help raise our issues locally. We need to ensure that all the local government departments know that there are polio survivors, with issues and concerns similar to many other neurological conditions in their area. This need not be too much of a task could just be as little as being our local contact for Polio Survivors Network. Myself and the other Trustees feel that a local member representing polio survivors will be better placed to keep polio issues on the local map. If you would like to help please get in touch.

As well as the ten SHAs another avenue to raise our particular issues and concerns is by members joining a Regional Neurological Alliance. LPPN is a member of the Neurological Alliance, which was awarded a Department of Health Grant in 2008 to build up a sustainable network of Regional Neurological Alliances (RNA) around the country and, again, LPPN has members in all the areas covered by RNAs. In January 1998 Hilary and Lynn Hobday attended the first meeting of the now named 'Lincolnshire Neurological Alliance', affiliated to the NA but also a registered charity. Another avenue could be to join a Local Involvement Network [LINK] These are independent statutory bodies with legislative powers and open to local people [free to join]. There should be one where you live, for example Hilary is a member of her local LINK. [[www.communityvoicesonline.org](http://www.communityvoicesonline.org)]. Have any other members joined their local LINK's? If you do not have access to the internet most local libraries will have facilities you can use. Have you any other ideas about how we can work at local level? We're waiting to hear them!

Meanwhile, I would draw your attention to LPPN's website which has required and received tremendous commitment from Chris Salter, our Webmaster from its conception to present day. There is a wealth of knowledge and information to be found there and is used by many from all over the world. This is one very good reason to keep our organisation going.

I am looking forward to meeting as many of you as possible at the next AGM which is going to be held the first week of July 2010. At the moment we are looking at Monday 5th or Friday 9th July 2010. The final date and venue will be announced later on the website and in the newsletter.

Wishing you all a healthy, peaceful and prosperous New Year and you can contact me anytime at [sandra.paget@lincolnshirepostpolio.org.uk](mailto:sandra.paget@lincolnshirepostpolio.org.uk). Write to me via the Charity address, or ring the phone line 01522 888601 to find out which Phone Team member is on duty this week who will pass on your message.

Best wishes, Sandra Paget, Chairperson

## Number of LPPN Members in each Strategic Health Authority/Board

ENGLAND There are 10 Strategic Health Authorities		
Strategic Health Authority	Number of Primary Care Trust's and where to find more information	No. LPPN Members
North East SHA	12 PCT's <a href="http://www.northeast.nhs.uk/your-local-nhs">www.northeast.nhs.uk/your-local-nhs</a>	4
North West SHA	24 PCT's <a href="http://www.northwest.nhs.uk">www.northwest.nhs.uk</a>	18
Yorkshire & The Humber SHA	14 PCT's <a href="http://www.yorksandhumber.nhs.uk/local_nhs">www.yorksandhumber.nhs.uk/local_nhs</a>	12
East Midlands SHA	9 PCT's <a href="http://www.eastmidlands.nhs.uk/the-local-nhs/nhs-organisations">www.eastmidlands.nhs.uk/the-local-nhs/nhs-organisations</a>	32
West Midlands SHA	16 PCT's <a href="http://www.westmidlands.nhs.uk">www.westmidlands.nhs.uk</a>	8
East of England SHA	10 PCT's <a href="http://www.eoe.nhs.uk/page.php?area_id=5">www.eoe.nhs.uk/page.php?area_id=5</a>	14
London SHA	31 PCT's <a href="http://www.london.nhs.uk/your-nhs-in-london/nhs-in-london">www.london.nhs.uk/your-nhs-in-london/nhs-in-london</a>	10
South East Coast SHA	8 PCT's <a href="http://www.southeastcoast.nhs.uk/localnhs/pcts/index.asp">www.southeastcoast.nhs.uk/localnhs/pcts/index.asp</a>	16
South Central SHA	7 PCT's <a href="http://www.southcentral.nhs.uk/page.php?area_id=2">www.southcentral.nhs.uk/page.php?area_id=2</a>	26
South West SHA	14 PCT's <a href="http://www.southwest.nhs.uk/interactivemap.html">www.southwest.nhs.uk/interactivemap.html</a>	11

### Wales

As of Oct 2009 there are 7 Health Boards plus three national NHS Trusts that cover the ambulance service, public health and specialist services. For more information go to the Health of Wales Information Service at [www.wales.nhs.uk.caorgs.cfm#2](http://www.wales.nhs.uk.caorgs.cfm#2)

There is a Wales Neurological Alliance for more information go to [www.wames.org.uk/wnasaesneg.htm](http://www.wames.org.uk/wnasaesneg.htm)

We have three members living in Wales.



### Northern Ireland

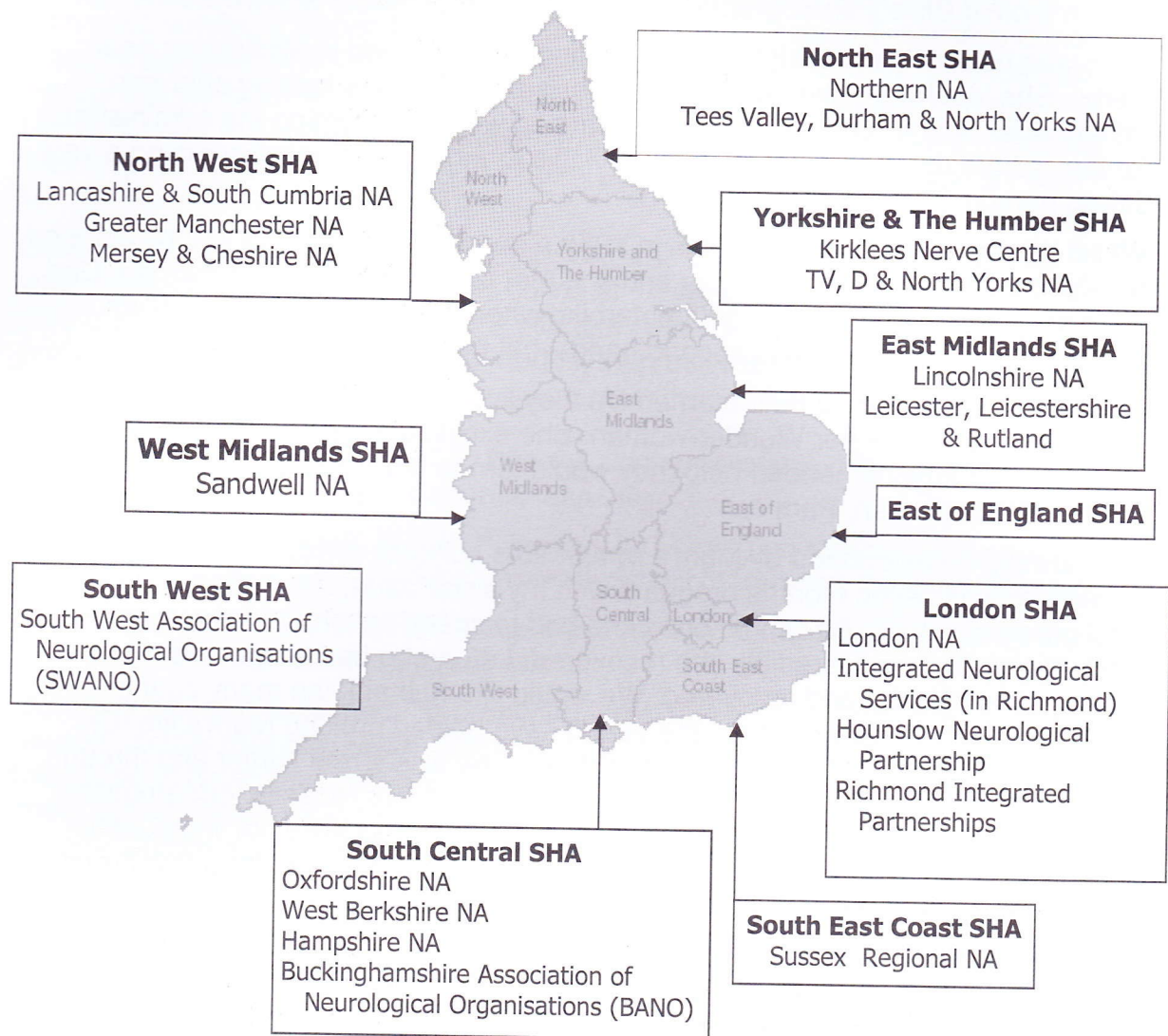
There are 5 Trusts in Northern Ireland providing health and social care services to the Northern Ireland public. Services are provided locally and on a regional basis. For more information go to [www.hsci.net/index.php?link=trusts](http://www.hsci.net/index.php?link=trusts)

We have not found any neurological organisations to date.

We have two members living in Northern Ireland.



**Map of England showing the 10 Strategic Health Authorities**  
 Regional Neurological Alliances and Organisations in the SHA's  
 affiliated to the Neurological Alliance. For more info, [www.neural.org](http://www.neural.org)



**Scotland**

There are 14 Health Boards broadly equivalent to the other UK regions. They also have a role providing information about local services and health improvement.

There is a Neurological Alliance of Scotland for more info go to [www.scottishneurological.org.uk](http://www.scottishneurological.org.uk)

Affiliated to the Neurological Alliance are the Glasgow Alliance of Neurological Groups, Caithness and North Sutherland Neurological Group. We have eight members living in Scotland.



**Rest of the World.**

We have 39 members living in Europe, the United States of America, Canada, Hong Kong and the Dominican Republic with a variety of different health systems. Members in those areas are encouraged to tell us about their healthcare systems and issues.

## Celebrating the life of Pamela Elisabeth Minnitt

25th February 1929 to October 3rd 2009

Excerpted from the Eulogy written by Pam and Denis Minnitt son Clive. Denis says have a look at Clive's photographic artistry and love of nature at [www.minnitt.com](http://www.minnitt.com)

Mum was born in West Bridgford near Nottingham and lived in Mickelover near Derby. She lost her mother at 12 years of age and took over looking after her father, older brother and two younger sisters as well as becoming the administrator for her fathers driving school business. All this toughened her into becoming a very strong person.

Whilst staying with her aunt in Paris in 1950 a good friends son and friends stopped by whilst on a motorcycling holiday and she met Denis who she later married. Dad reluctantly had to sell his AJS 500 motorbike when they needed a pram. Mum wasn't at all happy that it was second hand—but it was a Silver Cross!

For the first four years of their married life they lived with my grandparents and Grandpa used to call her Wonder-woman. She excelled at gardening, cooking and sewing and if anyone needed help they would turn to Mum and we had a family phrase 'If anyone can, Pam can'.

I will always be astounded by Mum's remarkable ability to withstand great adversity. When she was seven months pregnant with my sister Jane, she suffered almost total paralysis when she caught polio and had to spend several months lying on her back in an iron lung. Incredibly she recovered. Later, she had suspected legionnaires disease and recovered. We would like to thank the many caring medical professionals who, over the years, have helped prolong Mum's life. On several occasions we thought we had lost her. She was a real fighter and through her tremendous resilience bounced back each time. More recently, our emotional visits to see Mum in hospital as she gradually deteriorated were not without their lighter moments. It was a major triumph for her to leave the ward for a few hours and celebrate her 80th birthday at home.

She also survived the grocery shop, the chicken and pig farms and almost 58 years of Marriage!! Dad's blossoming wormery business introduced Mum into a fascinating world of subterranean wriggling. She reveled in her role as Plonker Picker which involved collecting suitably sized dollops of horse manure from a nearby field to help feed the worm's insatiable appetite. She was the first on hand to respond to Dad's cries for help when he discovered thousands of worms had done a runner (or should that be a slither) after he accidentally left the garage light on at night. The car and garage walls were covered in them and a mammoth rescue plan had to be put into operation.

She loved fashion but we nearly came to blows when she kindly ironed my jeans putting a crease down the middle of each leg and cutting off the frayed bits and sewing up all the holes.

On another occasion I remember her lifting up several drain covers whilst dressed in her nightie and wellies - in an emotional yet unsuccessful attempt to rescue her husbands false teeth.

[Editors note. Pam used a bi-level ventilator for the last 14 years. The LPPN would like to express huge thanks for the £500 donation made in memory of Pam's life.



**Breathing and Sleep Symposium**  
**Salk Institute for Biological Studies, La Jolla, California, November 2009.**

This symposium, co-sponsored by ResMed Corp and the Salk Institute for Biological Studies, was organised by Gladys Swensrud and Rick Van Der Linden, both polio survivors whose PPS brought on respiratory issues. They have done massive amounts of research for themselves and share what they have learned throughout the polio world. Both featured in our specially extended 28 page LincPIN, volume 5, Issue 9, June 2006 on respiratory issues. We have members with respiratory issues who have benefited from this knowledge including Pam Minnitt featured on the previous page.

Gladys wrote to me saying, 'The symposium was a resounding success. The videoed presentations are available online at - [www.poliotoday.org](http://www.poliotoday.org) - I believe they are worth their weight in gold. If you can't use them to convince your medical professionals about our respiratory issues, then there is no convincing them.

There were three speakers:-

Geoffrey Sheean, MBBS, FRACP, Director, Neuromuscular Division, Clinical Professor of Neurosciences, University of California, San Diego.

Noah Lechtzin, MD, MHS, FCCP, Pulmonary & Critical Care Medicine, Assistant Professor of Medicine, John Hopkins University School of Medicine, Baltimore, Maryland.

Louis J. Boitano, MS, RRT, RPFT, Northwest Assisted Breathing Centre, University of Washington Medical Centre, Seattle, Washington.

**Geoffrey Sheean** explained the breathing mechanism and how this is affected by neuromuscular disease. **Noah Lechtzin**, focused on how pulmonologists determine the cause of breathing problems, i.e. what tests are used, and the importance of coughing and other ways to get rid of secretions in the lungs. **Louie Boitano** provided information on solutions to breathing problems citing several case studies.

**We highlight two major statements made during the symposium.**

Louis Boitano began his presentation by saying 'little is understood worldwide about neuromuscular respiratory compromise, and this is an understatement'.

Noah Lechtzin was challenged to explain in one sentence why using oxygen alone is not recommended for people with neuromuscular compromise. He took seven sentences which you need to print out and keep with your medical records.

'We all rely on the concentration of CO<sub>2</sub> levels in the blood to stimulate breathing. If someone has weak breathing muscles, he or she may be chronically under ventilated, which results in a chronically high CO<sub>2</sub>. Over time the ability to sense elevated CO<sub>2</sub> diminishes.

'We all rely on a lesser degree on low oxygen levels to stimulate breathing. However, someone with weak breathing muscles and chronically elevated CO<sub>2</sub> may rely on low oxygen levels to stimulate breathing. If oxygen is given without close monitoring and ventilatory support, the breathing rate may slow, or even stop.

Most patients with neuromuscular conditions, in the absence of underlying lung disease, don't need supplemental oxygen. If someone has underlying lung disease, oxygen absorption may be hampered and oxygen may be needed but should be added to the bi-level device or ventilator."



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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.

**As part of the study will be asking people with post polio syndrome to complete a questionnaire.** The questionnaire will be asking about your experiences and views of health and social care. The questionnaire will be available from March 2010 and should take approximately 45 minutes to complete. The questionnaire will be available by post, email, or telephone and is available in a number of languages (please enquire). 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.

**The service user questionnaire** has been developed as a result of some pilot work that was carried out earlier in the study. The Delphi Technique (a consensus method) was used to find out what was important in the care and management of the conditions. The Result Study Reference Panel is a group of service users and carers who are helping to identify what is important in care to help formulate the questionnaire. The first round had a group of 50, and in the second round, 32 out of the 50 responded. [Hilary Boone is on this panel] The Delphi highlighted a number of areas that the group agreed with, such as support and information at diagnosis, multidisciplinary care, respite (replacement) care, and adjusting to the diagnosis (for both service user and carer). With this information, the questionnaire was developed.

If you are interested in taking part in this study, 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

Overheard conversation at hospital

We could provide ambulance transport for your next appointment.

The mans face lit up and he said, 'With the two tone and blue light?'



Do you spend several hours a day caring for an adult aged 18 to 65 years old with polio or post polio syndrome? Would you like to influence change in services that allow carers to take a break? If the answer to both these questions is 'YES' then we would like to hear from you.

We are a team at King's College London and have been commissioned by the Department of Health to find out about carers need for and experience of replacement care services (also known as respite care). We would like carers to complete a survey to help us do this. If you are interested further details are available on our website at

[www.kcl.ac.uk/schools/medicine/depts/palliative/arp/eval/carers.html](http://www.kcl.ac.uk/schools/medicine/depts/palliative/arp/eval/carers.html)

Or contact David Williams on 020 7848 5418 - or at [kclcarestudy@kcl.ac.uk](mailto:kclcarestudy@kcl.ac.uk) or write (there is not need to use a stamp):

Freepost RRLJ-JXEA-HYAS,  
LTNC Care Study,  
Kings College London,  
Palliative Care, Policy and Rehabilitation,  
Weston Education Centre, Cutcombe Road, London SE5 9RJ



british polio



The British Polio Fellowship have published two new booklets in the last few months.

**Post Polio Syndrome. A guide to understanding and living with the condition  
And**

**Orthotic Services. What I have a right to expect from my Orthotic Provider.**

The Orthotic booklet includes a one page survey 'How my Orthotics provider performs'. All UK members will have a copy of this survey included with this newsletter. If you are able to complete and return this to the BPF it will help give this panel more information with which to campaign for an improvement in services.

The BPF are also collaborating with the Walton Centre for Neurology and Neurosurgery in Liverpool on a new research study on fatigue and quality of life for people with Post Polio Syndrome. The questionnaires will only work well if they have been carefully tested on hundreds of volunteers. Anyone can volunteer providing they can read and tick the questionnaire pack and think they have PPS. If you would like to receive more information regarding this study, without any obligation, please return the slip provided with this newsletter by post to Professor Caroline A Young at the Walton Centre for Neurology and Neurosurgery, Lower Lane, Fazakerley, Liverpool, L9 7LJ.

British Polio Fellowship

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Email:- [info@britishpolio.org.uk](mailto:info@britishpolio.org.uk)

Website [www.britshpolio.org.uk](http://www.britshpolio.org.uk)

**Two snowmen were standing in a field in England last week.  
One snowman replied to the other, 'That's strange I can smell carrots too.'**

## The logical steps to higher outcomes in the application of modern dynamic KAFOs

By N.G.A. van Leerdam, MSc., PhD, Ambroise

[Editors Note - KAFO stands for Knee Ankle Foot Orthosis, a long leg brace

The referenced pictures (Figures 1, 2, 3) are on the back page]

For polio survivors new technology might bring improvements in functional outcome as well as in the quality of life. However, despite the often promising claims made by developers of new technology, introducing new technology that can truly offer improvements in functional outcome, is not without its challenges. New technology often asks for new treatment protocols, but the proper use of these treatment protocols require proper insight in how the product really works and how to best couple technology to anatomy.

One area where new developments have generated interest of polio survivors is that of modern dynamic Knee Ankle Foot Orthoses (KAFOs). For many generations of polio survivors a KAFO has meant a heavy locked knee brace that enabled walking with a stiff leg. Since the introduction of the UTX<sup>®</sup> orthosis (Figure 1), 15 years ago, there has been a light weight dynamic alternative. Since a couple of years there are more joint systems for KAFOs that allow for a stable knee in stance, but a free knee in swing, now often referred to as 'stance control' KAFOs

This article will inform the reader on the experiences with new dynamic KAFOs. Special attention is given to the indicators for success. Based on our 15 years of experience we've been able to distinguish a number of logical steps that improve the chance on a high outcome of the application of a dynamic KAFO. An important element of implementing these steps is forming a proper team: The physician, a good orthotist, an experienced physical therapist and last but not least: the potential user of the brace. Yes, you're reading this correctly: the user of the product is part of the team, rather than the object of the team

### First step: *Intake*

A proper intake starts with characterising both the practical and clinical needs of the individual who is experiencing a problem. The outcome might be that we think that an orthosis might be of benefit. For the UTX<sup>®</sup> we have developed a protocol (available in PDF on request) that, based on the lower extremity characteristics and rest function on a muscle and joint level determines if a UTX<sup>®</sup> is suitable, and if yes, which type. This is very important. We must never forget that no matter how brilliant new technology is, if we apply this to the wrong patient, than it's a poor application. The trick is to find the most suitable option for the individual patient. So far the dry theoretical and clinical part of intake.

If we go one step beyond theory, we have to realise that on top of that it's important to properly inform the patient. The potential user should be informed on both the product and the process (what steps can he expect, what is expected of him, reasonable expectations on outcome and time frame, be informed on any negative aspects of using a brace etc). On the other hand, the potential user has an obligation to properly inform the clinicians as well: what are his expectation levels, what sort of use is intended etc. The reason for this is that it is vital to start the process to matching expectations (on both sides) to

options as soon as possible. A well informed user of a new product is so much easier to train and will generate better outcome more quickly with less disappointment. A well informed clinician will make better judgements and offer more appropriate solutions.

The final part of intake is to start up the financial/administrative process. In that phase good communication is vital also. If a proposed solution is out of reach because of financial, legal or administrative barriers, it's better to know quickly and it's better to all know that. On the other hand, if the first part of the intake is properly done, a well balanced file is already present to make clear to the system why the proposed product fits the individual needs of the patient. That could (should?) facilitate the system to quickly decide on the application. If the system approves (that is, if such approval is necessary) then we come to step 2.

### Second step: *Collect Anatomical data*

All dynamic KAFOs on the market today are individually made (custom made) orthoses. The better the fit of these products, the more direct the control of the body on the brace and vice versa. Various techniques are used nowadays to collect the necessary data that the company needs to make the individual orthosis. Based on the chosen system, this can be measurements and tracings, measurements and digital photographs or a full leg cast (see Figure 2).

Collecting this data requires a well trained orthotist present. The essence of this process is that if you send in high quality information to the producing company, you'll get a high quality product back. Unfortunately the opposite is true too: If you send in a mess, you'll get a mess back. Modern health care systems allow orthotists less and less time to do this part of his job, leading to a higher chance of getting the latter of the two options, which is a nice example of 'modern' not being necessarily 'better'.

Unfortunately all too often incomplete data is sent to the producing company. The company then has to start chasing this info, which is time consuming, a constant source of errors and annoying to everyone. A call for orthotists to carefully collect, write down and provide all necessary data and send this to the one making the brace is therefore in order, but not without a call to health care systems to allow the orthotist enough time to properly do that. You can not expect an orthotist to do any of the measurement processes (tracings, casts and not even digital photographs) in 7 minute slot times per patient (at which he quite often has to do the intake (step one) as well).

When finally all necessary data (including financial go-ahead) is present the producing company can start to manufacture the brace. With Ambroise this process takes a maximum of five working days. After the brace has been cleared by inspection, it can be sent to the customer, ready for the third step.

### Third step: *Fitting and accustomisation.*

The modern dynamic KAFOs require a lot more insight from the orthotist in the biomechanics of walking and how the orthosis influences that than conventional KAFOs do. As a result fitting a dynamic KAFO like the UTX<sup>®</sup> is a lot more than helping the patient to don and doff the brace. It is our experience that tiny differences in alignment or fit of the brace can lead to huge differences in performance of the combination of brace and leg. The orthotist needs to know

how to do these tiny adjustments, but even more important: he needs to know how to analyse which action will lead to the best result. The role of the orthotist in this process is therefore of vital importance: fitting a stance control KAFO requires a well trained orthotist, which is something different from (but not necessarily conflicting with) being an orthotist for over 20 years! Orthotics is a very broad field and you cannot be expert in every section of that field.

At this point I need to repeat my statement about allowing the orthotist sufficient time to do his work. I've personally fitted hundreds of UTX<sup>®</sup> orthoses and it's a job that requires close attention to the patient as well as sufficient time. Sometimes you're lucky and the patient puts it on and instantly walks away with it, but more commonly you'll require a good 45 minutes for an initial fitting session. And it isn't over after that.

An orthosis is not a wonder pill that changes your life overnight. It requires the user to get accustomed to. In case of a stance control brace this also means: training. People need to learn to walk with the orthosis, learn tricks for easy donning and doffing, how to sit down, walk stairs safely etc (see Figure 3). That's hard work and requires a good physical therapist for guidance. Today it is considered standard practice to give a patient that gets a leg prosthesis a proper PT [physical therapist] program, because we know that patients have to learn to walk with their new leg and that clinical results are far better than without a PT program. Unfortunately we're not doing the same with leg orthoses, whereas the challenges for the user of the product are at least as demanding. In our many years of experience at Ambrose we have recognised the superior outcome of centres where they do have a proper PT program lined up for their UTX<sup>®</sup> patients.

People furthermore need to learn to accept and trust the brace. The latter is perhaps the most challenging task for the user of the brace. This sometimes requires a lot of time and endurance. The negative aspects of wearing a brace (and let no one tell you that there aren't any) are always instantly there. The positive aspects sometimes require more time to expose themselves. And even if you rationally accept that the brace is doing his job, that's still different than your body telling you that you feel safe to use it.

The orthotist and physical therapist should be your advisor in this process. A regular check with the orthotist to see if the alignment and settings of the brace still fit your progress wouldn't hurt. You don't want to change the settings too often nor too quickly, because it will make it more difficult to get used to the brace, but you also don't want to struggle with a brace that can work so much easier after just a tiny alteration. The duration of this process is very individual, but you shouldn't be surprised if it takes you even up to a year to get fully accustomed to your orthosis. On the other hand, if after two months of extensive training you still haven't mastered the trick of making the brace unlock, there's probably something seriously wrong.

If you think that after the training you can finally forget about visiting the orthotist, you're wrong. You'll need him for step four as well.

#### Fourth step: *Checks, maintenance and repairs*

We consider it logical to do maintenance on our motor vehicles. In fact, we've recognised the correlation between safety of the device and doing regular

maintenance and as a result we've created laws to enforce that (MOT). Strangely enough this all changes if we talk about orthoses. Although there are many sound technical reasons why doing regular maintenance is not only increasing safety, but in the end also decreasing overall cost, most health-care systems do not pay for maintenance, although they do pay for repairs. So we wait until the orthosis is completely broken and then phone the orthotist.

Despite healthcare regulations, it's probably smart to phone your orthotist (a lot) earlier than that. We would advise you to consider a regular visit to your orthotist (at least once a year, preferably twice a year). The orthotist could do some maintenance on your orthosis, but perhaps even more important, he can evaluate if the orthosis that you're using still is the best clinical solution for you. You mustn't forget that the body is not a static thing, it changes constantly. You might increase in muscle function, because you're more active than before, but you also might decrease in function. Sometimes changes happen so slowly that we personally don't always experience the difference. Furthermore you might be positively surprised about new developments that your orthotist has to offer, although we all recognise that new developments happen even (a lot) slower than changes in the body.

Sometimes your orthotist might spot a tiny problem with your brace even before you have. A quick repair can then prevent serious problems. This sometimes means that your brace has to be sent back to the manufacturer. You can be sure that the bigger the problem, the higher the chance that it has to be sent off. It is therefore not very smart to wait until your brace has completely fallen to pieces. Although it's very understandable that if the brace is still working (despite the tiny problems) it's easier to walk on than to make an appointment with your orthotist, we all know how it works: it'll fall to pieces two days before Christmas.

If your brace needs to be altered or repaired, it is of vital importance that all necessary information is sent to the one doing the job. Although this may seem too logical to even mention, we are quite often confronted with orders for repairs or alterations without all necessary data. A request like 'make fit of top band or alterations without all necessary data. A request like 'make fit of top band better', without the necessary additional information such as 'how much', 'up or down', 'in or out' etc, is not really helpful in getting your brace back quickly. It's the orthotist's job to write the order for any repair or alteration as clear as possible, but it's the brace-user's job to explain to the orthotist as clear as possible what is hampering him. Please do not only mention the big issues. If we're working on the brace anyway, it's usually not so difficult to pay attention to the little annoying things too.

At Ambroise we have a procedure to ensure a quick repair or alteration of a brace. The procedure is as follows: once an orthosis has arrived to us, members of our staff have to examine the orthosis within three hours after arrival. If cost to the customer is involved in the required actions with the brace, a quotation is made and send to the customer by fax or email the same day. After written approval of the quotation, the brace leaves Ambroise at the latest the following day. In a perfect world this would mean that a UTX send back to Holland could be back with the customer well within the week. However, there are three major 'buts' to that procedure. The first 'but' is that we cannot start if we haven't got the brace. This may seem trivial, but our experience unfortunately tells us it is

not. The second 'but' is about money. According to the procedure we sent a quotation for the cost involved in a repair or alteration (if any). We do not start the actual work on the brace before written approval (either by fax or email). This can sometimes take a lot of time. The third 'but' is about information. If it is unclear to us what it is that we need to do, or if measurements, photographs, directions etc are missing, we need to chase that information with delays and frustration on both sides as a consequence.

We cannot change the financial pressure on health care systems, but we do realise the difficulties that patients are experiencing because of this. We can only try to minimise additional burdens, such as unnecessary waiting. We would advise you to be polite but very persistent in chasing the status of your brace. Start at where you left it and work your way down the system to keep track. We would furthermore like to advise any LPPN member that knows, thinks or suspects that his/her brace might be with us, to send us an email at [info@ambroise.nl](mailto:info@ambroise.nl) to request the status of their brace. We will try to be as responsive as possible to provide the requested information.

Although these four steps seem very logical and easy to follow, it is our experience that there can be huge differences from centre to centre in how treatment protocols follow these four steps. We hope, however, that health care professionals are always looking at ways to improve the outcome of their hard work. This article might be of use to them and show some insight in the clinical relevance of our 15 years of experience that we have in developing, producing and fitting light weight dynamic KAFOs. The many successes that we had during these 15 years are bundled in these four steps, but we're not afraid to also say that some of our disasters have helped us to formulate better procedures as well.

We furthermore hope that this article gives potential new users of orthoses some guidance in what they can expect during the process of getting the brace and what they can do themselves to improve the process. As said, a brace is not a wonder pill: it's hard work, takes time, has draw-backs, but if the system fits your clinical needs it can also offer improved functionality that can change your life.

N.B. Diagrams are on the back page.

### **How the LPPN and 'My Polio Life' [LPPN self assessment questionnaire] has helped me move forward with my PPS issues**

[My Polio Life - <http://www.lincolnshirepostpolio.org.uk/downloads/extra/mypoliolife.pdf>]

**By Loreen from Oregon, USA**

I would like to thank the LPPN for the information and help your charity provides. This has given me new ways to think about all my issues. To find that I am not alone in experiencing test results that come back negative when I really do have issues is a huge relief. I am getting somewhere at last, even more relief, and as Hilary explained things to me using her own and others personal experiences I would like to add mine in the hope that it will help others.

Most of the health professionals I have seen think I am making all my issues up because the tests come back negative. I get frustrated and although I try not to get angry or upset when I talk to them, their continual dismissing my statements means that I do. I used to dread going to the next appointment because I already had in my mind that this appointment is going to be just like the last. I try not to do it, but as soon as I got an everything fine comment, I got angry.



Let me set the scene, I had spinal-bulbar polio at age 11, the year after I entered puberty. I remember it all vividly. I came home from the hospital on a liquid diet, not walking and barely talking. My respiration was severely compromised. I avoided an iron lung supposedly due to shortage of equipment. I got polio in Alaska in the middle of a big epidemic. They had a shortage of equipment, which all had to be flown in from other places. My understanding at the time was that by the time they got to me I had improved enough to escape the lung. I wore a back brace for several years. I graduated from bed to a wheelchair, then to crutches. I was measured for long leg braces but by the time they got to me for those, it was decided just to put me in high top shoes and crutches.

Recently I was having a lot more trouble with swallowing - the back of my palate trapping stuff there, including liquids - so I eventually sought medical help. I had a battery of tests by a Speech Therapist who reported 'everything works fine' but agreed to further testing and did a 'modified barium swallow test' that involved swallowing different textures and substances with imaging. The result of this test was also 'fine'. I was then referred to an ENT guy who started by saying that he was only going to look at a lesion the barium deal found. He reported this as a tonsil remnant. Because the swallowing tests had found nothing I had written out in detail for this appointment what was happening when I swallowed. He did not want to talk about it and made no effort to read it either. When he said 'You can speak, you can breathe, you can swallow, get over it' you can imagine how incensed I was.

I had a similar experience with a sleep study two or three years ago. It always bugged me because I got that "normal, nothing's wrong except you have poor sleep hygiene habits", "you're an idiot" response. When I saw my physiatrist last month I asked him to look again at my sleep study, explaining why and giving him a copy of Hilary's presentation 'When test results do not match reported symptoms'. He reread my report and gave me a copy which admits to difficulties that include some low oxygen and restless sleep episodes and 'this situation bears watching'. He is going to look into this and see me again next month.

I saw my internist this week on a regular visit and I told him about the appointments. He looked at the ENT report of the tests and apparently the doctor must have read what I wrote after I saw him because he believes that I have vagus nerve involvement, given my symptoms and bulbar-spinal polio. My most severe polio damage was on my left side. The swallowing problems are mostly on the right side. He says these facts are consistent with vagus nerve involvement and left side muscle involvement. Also, he said that kind of damage doesn't show up on testing. It doesn't matter, he said, because there is no treatment for it either.

I told the internist that my big concern was that my upper level swallowing was getting significantly worse and I worried about aspirating. According to him the testing shows that's not happening. All good news to me.

How can these guys say in their reports that I have verifiable difficulties and not tell me? All I got was the "there, there", pat you on the head, don't worry your little head about it routine. All that did was make me crazy. So now I find that I am not 'fine'. There is nothing much that can be done at the moment but there are issues that can have long term implications for intervention and they need regular reviewing. That I can understand. That I can live with. I am now going to take more care when eating. I will record more about my daily life and what I was doing when I experience symptoms in future so that I can give examples when I report issues.

As Hilary said, the crux of the matter is to ensure that the picture you paint in their mind, with the words that you say, matches what actually happens to you. I plan to have a serious discussion with my physiatrist when I see him next month and hope that together we can work out how to approach health professionals with my symptoms so that I can get the answers I now have in the first place.

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## Newsletters - The LincPIN - Next Issue March 2010

Articles/Items/Tipbits/Letters/Questions must be received by 15th March 2010  
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**REMEMBER - DONATIONS TOWARDS OUR WORK,  
LARGE OR SMALL, ARE WELCOME**

**The logical steps to higher outcomes  
in the application of modern dynamic KAFOs**  
By N.G.A. van Leerdam, MSc., PhD, Ambroise, Netherlands

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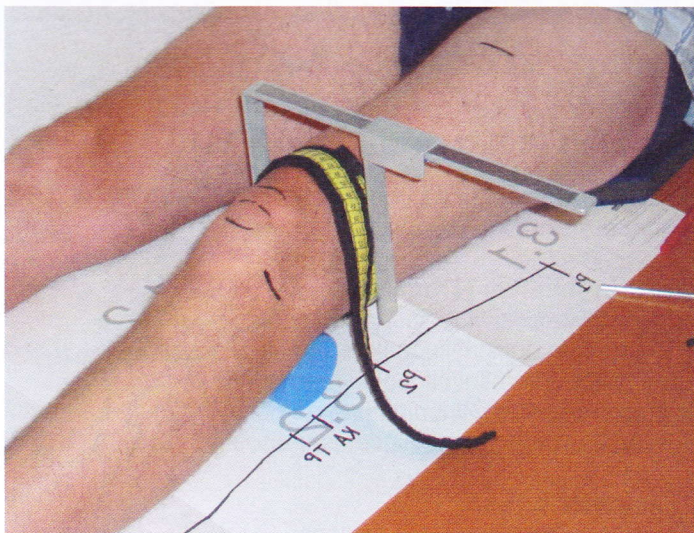
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**Figure 1.**  
The UTX<sup>®</sup> orthosis.  
A dynamic light weight Knee Ankle Foot Orthosis.

Text of the article is on pages 13 to 16.

**Figure 3**  
Training is an essential part of the process of getting a UTX<sup>®</sup>. In this image a UTX<sup>®</sup> user is training to safely walk up and down stairs.



**Figure 2.** There are various techniques to collect anatomical data, necessary for production of a custom made KAFO. This figure shows the two techniques used with the UTX<sup>®</sup> orthosis. On the left image a tracing (combined with measurements) is made of the patient's leg. On the right image a digital photograph (combined with some measurements too) against a scaling background is the basis for collecting the necessary information