



The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 6 - Issue 5 - May 2008

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



Annual General Meeting September 6th 2008 North Hykeham Day Centre Neale Road, Lincoln LN6 9UA

Come to the AGM and visit Lincoln.

47AD - Lindum Colonia - Roman Lincoln.
See many ruins including Newport Arch
300AD, which traffic still goes through.

Lincoln Cathedral, started in 1075 with
parts rebuilt after an earthquake and fire in
the 12th Century, finished in 1501

Lincoln Castle, started in 1068. See a copy
of the 1215 Magna Carta and a Victorian
prison, great views from the wall walks.

Jews House, 1168, Jews Court 1600's

The City Museum, see an insitu roman
mosaic, a Saxon's tradesmen's tools etc...

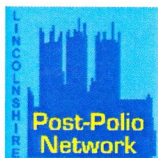
The Usher Art Gallery,

The Museum of Lincolnshire Life

Lincolnshire Road Transport Museum

Reminder

12th, 13th, 14th JUNE 2008
MOBILITY ROADSHOW, STONELEIGH PARK, COVENTRY



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Jim & Jenny Rayner, Brookvale High School, Mrs. L Cuff, John Ward, Pat Galvin, Mrs. AE Massingham, Yvonne Webb, Kay Preece, Mrs. AS Lovelock, Brenda Lynton-Escrit, Mrs. Susan Page, Mr. Allison, John Dooan, Mr. & Mrs. DA Paice, Val Scrivener and Mrs. Ann Devine. Plus all those who work so hard for us for the time, energy and financial savings donated to the LPPN from their PPS lives

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

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Next LincPIN Newsletter - August 2008

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

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Editorial by Hilary Boone.

Now we can no longer spend the winters in Florida we wondered if we would cope with winter later this year. However, when we landed back in the UK on Easter Saturday, expecting Spring, Alison drove us home through a kaleidoscope of weather and Easter Sunday we woke to 3 inches of snow.

One thing I learned this year is that I **have** to be more realistic when planning how long a task is going to take. We planned to pack up Richard's small mobile home in February and sightsee in March. You would think that I would have realised that because there is already not enough energy each day to manage daily living that this would not be possible. I did ask for help but it was not forthcoming so I just pushed myself and crashed out each day. Thankfully Julie [Ex UK] and Gerry called and realised we needed urgent help and took over during the last week. I knew I was physically fatigued but had not realised too mentally fatigued to realise that I had to find help. Now we have to complete the alterations to our new home and this is going to take much longer than we realised. I dare not comment on the delay of months waiting for Social Services to respond to our request for help. The visit was not easy. How many more weeks will I have to wait before I get the help I need?.

All our team do their best but we all have PPS and other factors influence our lives and sometimes our PPS work has to take a back seat. Our Chair, Mary McCreadie has had a major hip operation and for the most part totally inadequate post op care. I hope things improve soon because I really miss that daily contact. I know the rest of the team will agree with me on this. If you ring/write/email us and do not get a reply then we wont mind a gentle poke in the ribs. If any members would like to help with our work and have an hour or two to spare a week then please get in touch.

April 9th I attended the **Regional Neurological Alliance meeting** in Liverpool. The Government have devolved all health and social care decision making to local areas. The Neurological Alliance have received a Section 64 grant of £192,000 over 3 years to support the local neuro alliances already in being and see new ones start up across the country. Sadly there wont be any direct cash for the LNA, but tools will be developed to help with our work. 10th April, **Chester's BPF PPS Group** talk from an Anaesthetist [See page xx]. 28th April **Everyone's NHS** in Lincoln - made some excellent contacts and will again be attending important local meetings. 29th/30th April **Naidex** [Disability Equipment at the NEC]. May 12th I attended the **Independent Living Strategy Consultation**—Government launched in April to help disabled people have a greater say in how they live their lives in the future. The Office for Disability want to hear more views so see pages 5 and 6 and let us have your comments or write to them direct.

Sadly I have to end by telling you that I have just heard from Helen, daughter of member Tom Croker of Rotherham, that 'he had been unwell for a couple of weeks with a chest infection but then suffered a heart attack on Tuesday'. We have sent a card of sincere condolence to the family.

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Message from the Chair

As you already know, I recently underwent surgery on my hip – an operation known as a Girdlestone resection. Having researched it thoroughly, I thought I knew exactly what to expect, but nothing could be further from the truth. It has been a very hard journey so far, and although I am now home from hospital, it is going to be a long time before I'll be back to my usual self or able to carry out my LincsPPN duties. I hope you will understand. I would like to thank the many, many of you who so kindly sent me cards, letters and text messages – you will never know how much they meant to me during what turned out to be one of the most difficult times of my life. When I'm able, I'll tell you the full story of what happened.

Best wishes, Mary McCreadie

Mary, with Paul's help, wants to go to the Mobility Roadshow if she has recovered enough. They have booked in at a local hotel and to pace and rest will be attending on all three days. If you are going please get in touch so mobile phone numbers can be exchanged and meetings made over a cuppa.

Lynn Hobday, a past Chair, sadly lost her husband Fred recently. We send our sincere condolences to her and her family. One point Lynn has raised with us is the constant almost daily contact from a huge variety of Social Services staff, endless forms to fill in, and little understanding of her need for time to grieve. Lynn says, until something like this happens you often do not realise the little things that your partner and carer do for you so that you can manage daily life. For instance, she drives herself and uses a walker to and from the house and then a scooter to do her shopping. However, missing now is the opening and closing of the up and over garage door; loading and unloading of her scooter, bringing in and back her walker to the car and taking in the shopping. She urges you all to think about the future and make plans for different eventualities. Lynn is attending the Roadshow on Friday with her Sister to look for a vehicle that will lift her scooter in and out and near to the driving seat. Lynn has attended every AGM over the years and am sure that many of you will remember her. She has certainly got the steely determination and brimstone grit that is needed to manage PPS as you age. We do hope that she finds a vehicle that will help her continue to manage her life as she wants to.

Our AGM on September 6th 2008 is being held at the North Hykeham Day Centre on Neale Road from 10.30 to 4.30 p.m. Same venue as 2005 when Dr. Darren Barnes-Heath was our speaker. AGM will be in the morning followed by buffet lunch. The afternoon will include one speaker and time for you to bring up issues that have made your life more difficult or need help with. Please let us know these asap as it might be possible to invite someone to answer your questions. We are sorry that we cannot give you more information at this time but all of us have been coping with other personal issues and PPS fatigue. I could not delay the LincPIN any longer so will post you the Report and full information in the very near future.

Why not visit some of Lincoln's tourist attractions - if you would like us to send you some more information about Lincoln, ring/write/email.

Independent Living Strategy and Consultation

On 3 March 2008, the Office for Disability Issues launched a consultation on the Independent Living Strategy, this runs until the 20 June.

The strategy sets out a five-year plan that seeks to realise the Government's aim that all disabled people (including older disabled people) should be able to live autonomous lives, and to have the same choice, freedom, dignity and control over their lives as non-disabled people.

The Government is consulting on how to involve disabled people in the implementation and monitoring of the Strategy

For example, two possibilities are:

- setting up an Independent Living Scrutiny Group, to monitor – at a national level – annual progress on the strategy
- supporting networks of disabled people to be involved at regional and local levels in implementation and monitoring of the strategy.

The Government wants to hear disabled people's views on these proposals and welcomes other ideas for disabled people's involvement. The Lincolnshire Post-Polio Network is encouraging you to tell the Office for Disability Issues about your experiences and views.

The Independent Living Strategy is available in PDF, RTF, Easy Read, MP3, audio and Braille. To get hold of a copy of the strategy, to take part in the consultation or to find out more, contact the Office for Disability Issues at:

Web: www.officefordisability.gov.uk

Email: Independent-living-review@dwp.gsi.gov.uk

Telephone: 020 7712 2845

Textphone: 020 7712 2032

Post: Independent Living Strategy Consultation, Office for Disability Issues,
Department for Work and Pensions, The Adelphi, 1-11 John Adam Street,
London, WC2N 6HT.

[Editors Note:- I [Hilary] attended the Consultation in York on 12th May 2008. It was extremely interesting and I had good input during the workshops. I raised the point that many disabled groups have been 'talking' for years and that our biggest problem has been an unwillingness for some to 'hear' what we say. Many at the meeting commented on attending meetings and just being there so that the box could be ticked [have consulted with users]. I said 'It is not just our problems that need discussing but also the problems being experienced by those we meet from local and national government offices. It is a two way process and essential for round the table talks with a genuine willingness from both sides to share, discuss and implement ideas to see an improvement in services. I suggested Statutory Disabled Awareness Courses for all local and national government staff to experience what it is really like to live in our shoes, and for more than a few seconds, would provide greater understanding. I worked for Education/Social Services and had empathy but did not have understanding till I became disabled.

Summary document in PDF format, 26 pages:-

<http://www.officefordisability.gov.uk/docs/ilr-summary.pdf>

Full document in PDF format , 135 pages:-

<http://www.officefordisability.gov.uk/docs/ilr-executive-report.pdf>

Continued overleaf

Consultation Question 1:

We would welcome views on how best to involve disabled people, at a national level, in the monitoring of progress on implementation of the Independent Living Strategy, for example, by setting up an Independent Scrutiny Group.

18. The new local government performance framework will encourage the involvement of disabled people in the commissioning and delivery of local services. In addition, the Disability Equality Duty (DED) promotes the ongoing involvement of disabled people. The Department of Health {DH} work to establish a user-led organisation in every locality by 2010 could provide local focal points for engaging disabled people in the implementation of the Strategy. Other initiatives, such as Local Involvement Networks [LINKs], aim to promote local people's involvement in shaping services.

Consultation Question 2:

We would welcome views on current arrangements for promoting the involvement of disabled people and their organisations and the contribution these arrangements may make to the monitoring of the Independent Living Strategy.

19. There are many existing networks of disabled people which could be drawn together to provide a resource for the involvement of disabled people at local and regional levels in implementing the Independent Living Strategy.

Consultation Question 3:

Is there a need for a "network of networks" to facilitate the involvement of disabled people in the implementation and monitoring of the Strategy?

Developing leadership capacity amongst disabled people

20. The Independent Living Review's Expert Panel advised us of the importance of building leadership capacity amongst disabled people of all ages. They suggested that Partners in Policymaking™ courses would be useful in promoting disabled people's involvement in implementing the Strategy. [Partners in Policymaking website:- www.partnersinpolicymaking.co.uk/index.php]

Consultation Question 4:

We would welcome views on current initiatives to build leadership capacity amongst disabled people, on whether further work should adapt the Partners in Policymaking™ model, and/or whether there are other models we should consider.

21. The Expert Panel identified a range of different mechanisms to support delivery of the Strategy. The Government Offices for the Regions play a key role and there is a need to assist them to support local strategic partnerships {LSPs} to deliver independent living policies, linking with user-led organisations, and monitoring implementation. We will be producing targeted information and guidance for Government offices for the Regions, including toolkits, as set out in the Strategy. We would welcome views on what other action may be required.

Consultation question 6:

We would welcome any other views on the Independent Living Strategy.

[Editors note - Contact information on page 5. Write to us by 18th June or send your comments direct.

26th March 2008

**BRITISH POLIO FELLOWSHIP EXPERT PANEL
DEFINITION OF POST POLIO SYNDROME**

Summary Level Definition

"Post Polio Syndrome (PPS) is a neurological condition that can occur in people who have had polio. After an interval of several years of stability, people may then develop increasing weakness, stamina problems, fatigue and pain. PPS may respond to a range of therapies which might prevent further deterioration".

Symptoms include the onset of new weakness or abnormal fatigue in previously or unaffected muscles; a general reduction in stamina; muscle and/or joint pain; muscle atrophy; breathing, sleeping and/or swallowing problems; or cold intolerance. Symptoms may lead to loss of endurance or function.

A diagnosis of PPS assumes the absence of any other conditions that could explain the above symptoms. Such conditions should be considered and excluded by appropriate investigations".

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Operational Definition

The following operational definition of Post Polio Syndrome supports and expands upon the summary definition above. It is derived from consensus statements based on the extensive review of various medical and scientific literature, studies and previous definitions.

As there is no diagnostic test for Post Polio Syndrome it is commonly defined by a symptom complex that includes new muscle weakness, decreased endurance, pain and fatigue.

The onset of PPS may be gradual or it can occur suddenly. It occurs irrespective of ageing. Symptoms may sometimes appear to be triggered by various events like surgery, falls or immobility.

The following are the main criteria that need to be considered in making a diagnosis of "Clinically Definite PPS" or "Clinically Possible PPS" and are also shown graphically in the table below:

Clinically Definite PPS

"Based on various consensus statements, a diagnosis of "Clinically Definite PPS" comprises a confirmed history and/or physical evidence (however slight) of polio, a period of functional recovery and stability, new muscle weakness, or abnormal muscle fatigue, with evidence of neurogenic change, and the exclusion of any other possible conditions".

Clinically Possible PPS

It is recognised that there are patients who have PPS symptoms, but there is less diagnostic certainty. This would include patients with the following characteristics - a possible history of polio where there may be no previous physical manifestation,

new muscle weakness, or abnormal muscle fatigue, (with no evidence of neurogenic change), a complex of symptoms that are generally recognised to be those for PPS, and the exclusion of any other possible conditions.

1. Definite History of Polio / Physical Evidence

Diagnostic criteria (See below for more detail on each criteria)	Clinically Definite PPS	Clinically Possible PPS
1. Definite history / physical evidence of polio	✓	
2. History of possible polio		✓
3. Period of recovery and stability	✓	✓
4. New muscle weakness - with evidence of neurogenic change	✓	
5. New muscles weakness - no evidence of neurogenic change		✓
6. Appropriate complex of symptoms	✓	✓
7. No other disorder / medical explanation.	✓	✓

The patient's original medical records, history and/or physical evidence provide a confirmed diagnosis and history of the original polio illness.

2. History of Possible Polio

Some people may not have confirmation of prior polio or a physical manifestation of the illness, but do have some history and/or current symptoms, which taken together, indicate a possibility of polio.

For example, this could apply to a patient in whose family, or circle of friends, there was an incidence of polio, or who is known to have come from an area where there was a polio epidemic or outbreak, and/or who suffered an illness that at the time was not diagnosed as polio.

3. Period of Recovery and Stability

Partial or fairly complete neurological and functional recovery after the original polio illness followed by a period of neurological and functional stability. As guidance only, the period of stability will generally be 15 years or more.

4. New Muscle Weakness – with evidence of Neurogenic change

Muscle weakness may be confirmed clinically by the presence of clear lower motor neuron features. When and if available / appropriate, EMG testing may confirm this and establish a baseline for repetitive testing or offer alternative diagnosis. Other tests that may be useful are nerve conduction tests to assess nerve damage, Manual Muscle Testing (MMT), reflex and exercise testing for endurance. Other causes of neuromuscular weakness will also need to be excluded by appropriate tests.

Although it is accepted that electro diagnostic testing has limitations in confirming neurogenic weakness, and will not provide a definitive diagnosis of new weakness, it may help to exclude some of the other common causes of neurogenic weakness as well as other, more rare, conditions.

5. New Muscle Weakness – No evidence of Neurogenic change

A patient who has a possible history of polio may be experiencing new weakness that testing cannot confirm to be neurogenic (see Point 4) but is consistent with the symptoms of PPS.

6. Appropriate complex of symptoms

These may include two or more of the following health problems occurring after the stable period: extensive general fatigue, abnormal muscle fatigue, decreased endurance, muscle pain, joint pain, new weakness in muscles previously affected or unaffected, new muscle atrophy, functional loss, breathing or swallowing problems, cold intolerance.

7. No Other Disorder / Medical Explanation

Exclusion of medical, orthopaedic, and known neurological conditions that might cause the health problems listed in Point 6 above, although these other conditions may coexist with PPS. Depending on symptoms, the most obvious possible causes to rule out are orthopaedic problems related to the original polio; injuries, breathing problems, other neuromuscular diseases, and other diseases that commonly cause fatigue, such as thyroid problems, diabetes or heart disease.

EMG testing and other relevant tests (see Point 4 above) may be used as a means to exclude other known neurological conditions that may present similar symptoms.

Main symptoms of PPS

With reference to Point 6 in the criteria for diagnosis above, the following are considered to be the most common health problems resulting from PPS.

Weakness

New weakness is often seen as the most recognisable symptom of PPS.

It can sometimes be difficult to separate weakness from muscle fatigue, which could be thought of as 'weakness that develops over time' or through usage. Recent definitions of PPS usually include both weakness and muscle fatigue (also known as peripheral fatigue, or stamina or endurance problems) as essential symptoms. Both symptoms can occur not only in muscles previously known to be affected by polio, but also in muscles where no damage has been apparent until now.

Studies have varied in their findings but have shown for example: weakness in around 2/3 people with polio, weakness in previously affected muscles in up to 85% of people with polio, and weakness in previously unaffected muscles in up to 58% of people with polio.

Fatigue

Post Polio fatigue is often experienced as two separate types of fatigue: a general, sometimes overwhelming, exhaustion (which may include mental fatigue), and localised muscle fatigue, often described as increasing physical weakness, loss of strength and endurance during exercise, and a heavy sensation in the muscles.

Muscle fatigue after even minimal exercise can lead both to increasing weakness and the aching that is common in PPS. It may lead to general exhaustion or fatigue

at the end of the day or it may even last for several days. Muscle fatigue can be a result of the muscle overuse that is thought to play a large part in PPS.

General fatigue is an overwhelming feeling of exhaustion and weakness. Sometimes mental fatigue can be the result of muscle fatigue and muscle overuse. Fatigue can also result from sleep disturbance, sleep apnoea (stopping breathing for intervals) or breathing problems.

Rest usually relieves fatigue, unless it has been building up for days or more, when it may take longer to feel better.

General fatigue has been found in around half of people with polio¹⁴, increasing to 80% for fatigue during exercise.

There is also a theory that any brain stem damage during the initial polio illness can cause increased lack of energy and alertness, sleepiness and concentration problems later on.

Muscle pain

Muscle pain is very common and is usually described as aching, especially after activity, or felt as burning, spasms or cramps. This pain may be the result of muscle overuse and may occur with twitching or fasciculations, especially later in the day or at night.

Research has shown pain can relate to activity levels, and particularly the intensity of activities, which is usually higher in people who had polio as they are using their muscles at their maximum much of the time.

Joint pain

Where joints are no longer held in place by strong muscles, they may become unstable, resulting in joint pain. It may also be caused by injuries to the tendons or ligaments due to overuse of unstable joints. Weakness and injuries around joints may also lead to the pain of compressed nerves.

Muscle loss

Also known as muscle atrophy, this loss of muscle bulk has been found in 20-30% of people with PPS.

Sleep disturbance

Sleep disturbances are common and may relate to sleep apnoea, breathing difficulties, pain, muscle twitching or general overtiredness. Sleep apnoea (lack of oxygen because of not breathing well or often enough) can be due to repeated shutting of the airway from throat weakness, sometimes made worse by weight gain. It can also occur when there are brief interruptions in the brain reflex that triggers breathing.

Breathing problems

Breathing problems are more common in people who needed help with their breathing when they had polio, but can occur later on in anyone with polio. They are caused by muscle weakness of the diaphragm and chest muscles, scoliosis or sleep apnoea.

Breathing problems may develop very slowly. Early signs may be frequent waking from sleep, sometimes with choking or gasping; nightmares, snoring, morning headaches, coughing, daytime sleepiness, difficulty speaking at length, lack of concentration and breathlessness with exercise.

It is extremely important for both doctors and people with polio to understand there may be breathing problems later on, and these need thorough assessment.

Swallowing problems

Weakness in the muscles used for chewing and swallowing may lead to frequent choking, gagging, or food becoming stuck in the throat. There may also be voice and speech changes, such as hoarseness or a nasal sounding voice, especially after speaking for a while or when tired.

Research into swallowing problems has shown slowly progressing new weakness even in some people who were not aware of any change and had not originally had bulbar polio. Swallowing muscles do not usually weaken over time², so this convinced many doctors that PPS occurs irrespective of ageing.

Most often, swallowing problems stay mild and progress only very slowly. Advice from a speech and language therapist may prove helpful.

Cold intolerance

Sensitivity to cold, like many PPS symptoms, may be felt in one area of the body for example in an arm or leg which may have a poor blood supply, or may be felt as a general cold intolerance, or intolerance to any large temperature change.

Other symptoms

As there has not been enough research into PPS, there are many other symptoms that may or may not be related to polio. When other possible causes are ruled out, polio is sometimes thought to be the cause. These symptoms may include balance or dizziness problems, face or eye muscle weakness, digestive or urinary problems relating to polio damage.

If the autonomic nervous system (the part of the nervous system controlling muscles people do not have to think about moving, like the heart, stomach or bladder) has been affected by polio, then generalised cold intolerance, blood pressure and heart rate problems may occur.

Further sources of information

As well as the clinical publications, studies and papers on the subject of Post Polio Syndrome, further information can be obtained from The British Polio Fellowship, FREEPHONE 0800 018 0586; Website: www.britishpolio.org.uk or email: infobenefits@britishpolio.org.uk.

References - include:

Farbu E, Gilhus N E, Barnes M P et al. EFNS guidelines on diagnosis and management of post-polio syndrome. Report of an EFNS task force. European Journal of Neurology 2006.

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Jubelt and Agre. Characteristics and Management of Postpolio Syndrome. JAMA 2000.

Ramaraj R. Post-poliomyelitis syndrome: clinical features and management. British Journal of Hospital Medicine, Dec 2007.

The British Polio Fellowship. Post Polio Syndrome. Guidelines – summarising clinical guidelines for primary care 2007.

Expert Panel Members

The Expert Panel members who contributed to the above definition are:

Sir Bert Massie (Chairman) Chairman of the Disability Rights Commission

Dr Steve Sturman MBChB (hons), FRCP Consultant in Neurology & Rehabilitation Medicine, City Hospital, Birmingham

Dr Craig Davidson Consultant Physician & Director of the Lane Fox Respiratory Unit, London

Ms Alex Curtis Senior Physiotherapist, the Lane Fox Unit, London

Mr Robin Luff BSc MBBS, FRCS, FRCP Consultant in Rehabilitation Medicine, Kings College Hospital, London

Dr Joseph Cowan MBChB, FRCP Consultant in Rehabilitation Medicine, Royal National Orthopaedic Hospital, Middlesex

Dr George Kassianos GP in Berkshire. Spokesperson on vaccination for the RCGP.

Dr Ros Sinclair Chartered Psychologist and British Polio Fellowship Trustee

Ms Pam Jones Retired Occupational Therapist and British Polio Fellowship Trustee

Ms Mary Kinane BA (hons) Chair of the Lincolnshire Post Polio Network

Dr Ruth Bridgens PhD Medical Sociologist

Graham Ball Chief Executive of the British Polio Fellowship

Tess Mitchell BPF Service Development Manager

Editors Note:- As you know Mary Kinane was invited to join this panel and has contributed information towards this definition. She would appreciate hearing from you if you have any comments regarding the definition.

Please email her at mary.kinane@lincolnshirepostpolio.org.uk

Or write to her, Mary Kinane, Lincs PPN, PO Box 954, Lincoln, LN2 5ER.

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n.b. Blue Badge holders can obtain a free copy by simply paying £1.99 for postage and packing.

Tel: 0800 953 7070 or visit the guide's website.

THE THINGS GRANDKIDS SAY

1. She was in the bathroom, putting on her makeup, under the watchful eyes of her young granddaughter as she'd done many times before. After she applied her lipstick and started to leave, the little one said, "But Grandmamma, you forgot to kiss the toilet paper good-bye!"
2. My young grandson called the other day to wish me Happy Birthday. He asked me how old I was, and I told him, "62." He was quiet for a moment, and then he asked, "Did you start at one?"
3. After putting her grandchildren to bed, a grandmother changed into old slacks and a droopy blouse and proceeded to wash her hair. As she heard the children getting more and more rambunctious, her patience grew thin. Finally, she threw a towel around her head and stormed into their room, putting them back to bed with stern warnings. As she left the room, she heard the three-year-old say with a trembling voice, "Who was THAT?"
4. A grandmother was telling her little granddaughter what her own childhood was like: "We used to skate outside on a pond. I had a swing made from a tire; it hung from a tree in our front yard. We rode our pony. We picked wild raspberries in the woods. "The little girl was wide-eyed, taking this all in. At last she said, "I sure wish I'd gotten to know you sooner!"
5. My grandson was visiting one day when he asked, "Grandma, do you know how you and God are alike?" I mentally polished my halo while I asked, "No, how are we alike?" "You're both old," he replied.
6. I didn't know if my granddaughter had learned her colors yet, so decided to test her. I would point out something and ask what color it was. She would tell me and was always correct. It was fun for me, so I continued. At last she headed for the door, saying sagely, "Grandma, I think you should try to figure out some of these yourself!"
7. When my grandson Billy and I entered our vacation cabin, we kept the lights off until we were inside to keep from attracting pesky insects. Still, a few fireflies followed us in. Noticing them before I did, Billy whispered, "It's no use, Grandpa. The mosquitoes are coming after us with flashlights."
8. A second grader came home from school and said to her grandmother, "Grandma, guess what? We learned how to make babies today." The grandmother, more than a little surprised, tried to keep her cool. "That's interesting," she said, "how do you make babies?" "It's simple," replied the girl. "You just change 'y' to 'i' and add 'es'."
9. A nursery school teacher was delivering a station wagon full of kids home one day when a fire truck zoomed past. Sitting in the front seat of the truck was a Dalmatian dog. The children started discussing the dog's duties. They use him to keep crowds back," said one child. "No," said another, "he's just for good luck. " A third child brought the argument to a close. "They use the dogs," she said firmly, "to find the fire hydrants."

The following are items that I receive due to my subscribing to a variety of medical News Services. I hope that you find them interesting.

Science Daily - Biological Link Between Pain And Fatigue Discovered

<http://www.sciencedaily.com/releases/2008/04/080407153037.htm>

University of Iowa. Reported in Science Daily (Apr. 9, 2008) — A recent University of Iowa study reveals a biological link between pain and fatigue and may help explain why more women than men are diagnosed with chronic pain and fatigue conditions like fibromyalgia and chronic fatigue syndrome.

Working with mice, the researchers, led by Kathleen Sluka, Ph.D., professor in the Graduate Program in Physical Therapy and Rehabilitation Science in the UI Roy J. and Lucille A. Carver College of Medicine, found that a protein involved in muscle pain works in conjunction with the male hormone testosterone to protect against muscle fatigue.

Chronic pain and fatigue often occur together -- as many as three in four people with chronic, widespread musculoskeletal pain report having fatigue; and as many as 94 percent of people with chronic fatigue syndromes report muscle pain. Women make up the majority of patients with these conditions.

To probe the link between pain and fatigue, and the influence of sex, the UI team compared exercise-induced muscle fatigue in male and female mice with and without ASIC3 -- an acid-activated ion channel protein that the team has shown to be involved in musculoskeletal pain.

A task involving three one-hour runs produced different levels of fatigue in the different groups of mice as measured by the temporary loss of muscle strength caused by the exercise.

Male mice with ASIC3 were less fatigued by the task than female mice. However, male mice without the ASIC3 protein showed levels of fatigue that were similar to the female mice and were greater than for the normal males.

In addition, when female mice with ASIC3 were given testosterone, their muscles became as resistant to fatigue as the normal male mice. In contrast, the muscle strength of female mice without the protein was not boosted by testosterone.

"The differences in fatigue between males and females depends on both the presence of testosterone and the activation of ASIC3 channels, which suggests that they are interacting somehow to protect against fatigue," Sluka said. "These differences may help explain some of the underlying differences we see in chronic pain conditions that include fatigue with respect to the predominance of women over men."

The study, which was published in the Feb. 28 issue of the American Journal of Physiology -- Regulatory, Integrative and Comparative Physiology, indicates that muscle pain and fatigue are not independent conditions and may share a common pathway that is disrupted in chronic muscle pain conditions. The team plans to continue their studies and investigate whether pain enhances fatigue more in females than males.

"Our long-term goal is to come up with better treatments for chronic musculoskeletal pain," Sluka said. "But the fatigue that is typically associated with

chronic, widespread pain is also a big clinical problem -- it leaves people unable to work or engage in social activities. If we could find a way to reduce fatigue, we could really improve quality of life for these patients."

In addition to Sluka, the UI research team included Lynn Burnes, a research assistant and lead author of the study; Sandra Kolker; Jing Danielson; and Roxanne Walder. The study was funded in part by grants from the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

PubMed, A service of the US National Library of Medicine and the National Institutes of Health. www.pubmed.gov

1: Parkinson's Related Disorder, 2008 Mar 26. [Epub ahead of print]

Restless legs may be associated with the post-polio syndrome

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Restless legs syndrome (RLS) has been described in association with a number of conditions including iron deficiency, neuropathy and Parkinson's disease. Here we report a patient who developed RLS concurrent with the development of classic post-polio syndrome (PPS), 40 years after recovery from an episode of paralytic poliomyelitis. PPS is still frequently encountered in neurological practice, and clinicians should be aware of the possibility of associated RLS.

PMID: 18374619 [PubMed - as supplied by publisher]

Note: full text can be accessed for US \$ 31.50 via <http://tinyurl.com/2xzudw>

British Polio Fellowship

Chester PPS Support Group Meeting - April 10th 2008.

I [Hilary] was in Liverpool for the Regional Neurological Alliance meeting on 9th April and was told that the Chester group were having a Consultant Anaesthetist speaker the next day. When I expressed interest I was invited to attend. Richard and I enjoyed meeting Carol Neale [also at Naidex] and Guido d'Isidoro again. I found the first half of the talk about how polio survivors issues helped develop anaesthesia during those outbreak years very interesting. The second half was about anaesthesia in general and whilst interesting, along with others present who had read many medical articles on PPS and anaesthesia, we were not 100% happy with his responses that our concerns would not be an issue. We then asked how many Polio Survivors he had anaesthetized and he stated that as far as he was aware he had not anaesthetized a Polio Survivor with or without PPS. Much to everyone's amusement he smilingly said 'I am quite happy to anaesthetise you' and I replied 'but only after we have had a long talk about issues I am concerned about'.

He is a very approachable doctor with a willingness to listen. I spoke to him after his talk, explaining that the comments made are made all over the world at other PPS group meetings. He took information from me and said he would be doing more research into this. We have been in correspondence since and I hope to have more information from him for the next LincPIN.

KAFOs for Patients with Neuromuscular Deficiencies

Mark K. Taylor, MLS, CPO, FAAOP

ABSTRACT

Patients with neuromuscular deficiencies who require knee-ankle-foot orthoses (KAFOs) for stability now have available a growing range of knee joints and materials that reflect new technology. This article emphasizes the influence of patient evaluation on KAFO component selection and design and the important distinction between patients whose growing musculoskeletal system has been affected by neuromuscular disorders versus those who were skeletally mature before diagnosis. "To understand motion is to understand nature." [1]

The orthotic profession has been trying to understand the motion of human lower limbs for decades. Not only do the motions themselves need to be understood, but outside forces that react on these motions also need to be comprehended. Neuromuscular disorders such as Charcot Marie Tooth, congenital hypotonia, Frederick's ataxia, Kugelber Weldander, muscular dystrophy, Werding- Hoffman, polio, Guillain-Barre, amyotrophic lateral sclerosis, femoral neuropathy, and others can lead to lower extremity weakness or paralysis that can be devastating to the infant, young child, adolescent, adult, and geriatric patient. Neuromuscular deficiencies present over an extended time can induce musculoskeletal abnormalities, which in turn lead to abnormally directed forces on skeletal structures, in addition to leaving muscles weak and paralyzed.

Technical advances combined with a better understanding of biomechanics have enabled scientists, engineers, and orthotists to develop new and improved methods of orthotic treatment. For centuries, orthotists were limited to two basic knee joint types: free motion and manually locked (in full extension). Over time, many variations of the locked joints were developed. Very recently, stance control knee joints have become available for orthotists to incorporate into knee-ankle-foot orthosis (KAFO) designs. The challenge is to make the right decision, based on thorough evaluation of each patient's unique constellation of biomechanical deficiencies.

Orthotists today have a good understanding of basic mechanics and physics and can use that knowledge, along with medical/anatomical knowledge, to reduce the forces that orthoses apply to persons with neuromuscular deficiencies, thereby minimizing the risk of causing damage to the structures of their musculoskeletal system. It is important to realize that "...disturbances of the neurological control mechanisms, motor input, and structural skeletal alignment can have a significant effect on dynamic stability..." [2] The purpose of orthotic intervention must be clearly understood and is typically to provide stability for the limb at risk for further damage in the sagittal, coronal, and transverse planes. For this population, proprioception is an important consideration. Some neuromuscular deficiencies, such as poliomyelitis, involve only the anterior horn cell of the spinal cord. So long as the posterior horn cell is intact, these patients retain proprioception. Having a sense of where the limb is in space seems to help in mastering ambulation with a KAFO.

In addition to providing safety and stability, KAFOs must provide sufficient comfort for a full day of activities. "Knee stability during standing is normally achieved by alignment. The normal knee extends slightly beyond a straight line so that the center of knee rotation can be displaced behind the weight-bearing line.... Muscle

activity is not required (not even quadriceps) unless the knee center is displaced anterior to the weight bearing line" [3]; Patients who were skeletally mature before developing a neuromuscular disorder can often benefit from an orthosis that maintains the knee center behind the weight-bearing line. Because of their mature skeletal development, their knees tend to be stable in the frontal/coronal plane and the transverse planes. They can often learn to recruit muscles such as hip extensors or ankle plantar flexors to assist in pulling the knee posteriorly, thus aiding in standing stability.

Patients who developed neuromuscular disorders as children commonly have tri-planar musculoskeletal abnormalities that must be considered in KAFO design to ensure unflinching stability in all environments and may not be able to utilize ground reaction forces as readily. These patients are very challenging to fit and require highly skilled orthotic care to manage their complex deficiencies. Recommendations about orthotic options are based on four types of information: (1) an understanding of the patient's diagnosis and prognosis; (2) a thorough assessment of gait, muscle function and motor control, range of motion, and alignment of the limb; (3) an understanding of the patient's general medical condition and level of fitness; and (4) discussion of the patient's typical or desired vocational and leisure activities." [4] Once these four issues are well understood, the patient and caregiver can work together to formulate a design/protocol that provides quality of life/stability that might not otherwise be present.

SUMMARY

Patients who need orthotic care are often interested in new technology, hoping it can offer them a better quality of life due to improved gait, stability, and independence. However, not everyone can benefit from the latest innovations. The role of stance control orthoses for persons with neuromuscular deficiencies is not fully clear at this time but seems promising. However, many will remain best served by less sophisticated orthoses. The challenge for rehabilitation professionals in the next few years will be to obtain sufficient clinical experience and scientific evidence to determine the optimal KAFO designs to enable people with neuromuscular disorders to achieve the highest level of independence and the greatest quality of life with an orthosis that is safe and comfortable and allows participation in the full range of normal daily activities.

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[Editors note - I first met Mark Taylor in St. Louis at the GINI PPS Conferences in 2000 {now Post-Polio Health International, www.post-polio.org}. He told us of the lady that came back to say. 'This new orthosis helps me walk better but I cannot sit on the piano stool with it on'. So, they examined her sitting on the stool and altered the top of the orthosis and she returned to playing in public.

This is the sort of help we need in the UK. When we say that what has been designed for us does not work, why does it take months and sometimes years, or never, to get something that does work. How many times are members going to tell us of endless return visits for orthoses and shoes that are a waste of NHS money, let alone the stress that this puts on us and our bodies? .

Aware that at least three members are having current problems with their Orthotic Service - orthoses and shoes - I repeat a couple of paragraphs that might help you, from an earlier article by Mark Taylor. February 2000 LincPIN.

www.ott.zynet.co.uk/polio/lincolnshire/linkpin/lincpinvol02issue09.html#Orthotically

Post Polio Syndrome. What does it mean Orthotically. [Excerpt]

...From a survey conducted in 1987 by the National Commission on Health Statistics, there were 1.63 million polio survivors with 641,000 having some type of paralysis (6). If you divide this by the approximately 1,000 ABC facilities, there are about 600 patients per facility who will need some manner of care. Even if this number were cut in half, there would still be a substantial population for each facility. A recent problem that has arisen from this group is that many of them who require orthotic care have felt reluctant to confide in their orthotist.. Many orthotic professionals have told them that they (polio patients) are hard to deal with, they are set in their ways and take a considerable amount of time to provide care. The orthotic profession must be careful not to prejudge these patients as all difficult type "A" personalities (7). Many of them have expressed offense as they have shared their feeling in the many seminars and support groups which I have had the privilege of presenting. We as professional practitioners, need to take the time to listen and to properly evaluate these patient's conditions. It is imperative that orthotic practitioners become familiar with the polio patient's history. Practitioners need to understand exactly what they are dealing with. Polio survivors are the type of patients that practitioners need to evaluate hands on and to know "first hand" the muscle weakness and range of motion and how the patient is substituting for the weakness to be able to function.

The polio patient is the most important member of his/her rehabilitation team. He/she must be allowed to assist in the design of the orthosis. He/she needs to understand that orthotic practitioners are not sentencing them to 24-hour orthotic wear but are trying to provide a system that will protect and stabilize. Be flexible with these patients. Leave options in the treatment plan. Provide patients with a choice and lead them in the right direction. Let them know that your abilities and expertise can help eliminate unwanted range of motion and allow for a more normal function. By all means, don't lock their joints unless you absolutely have to. If you do, you may find that your carefully designed orthosis will end up in their closet, not because of your design, but because you have taken away from them the simple

motions that they use to substitute for muscle weakness and joint deformity.

When assessing a post polio orthotic patient, consider all design options, which are available. Some of these options may be a combination of two or more orthotic designs. For example, you may have a patient that needs additional knee stability due to weakened quadriceps but is unable to tolerate the weight of conventional designs. One idea is to provide a hybrid orthosis consisting of a leaf spring design orthosis with a pre-tibial shell which provides minimum quadricep support and give just enough feedback to prevent the knee from buckling. Younger and stronger patients [40-60] can accept more aggressive designs and seem to have a willingness to try harder in allowing time for adjustment to new designs. They seem to have a better understanding of what the intended outcome is and will work to make it happen if possible. Older polio ambulatory [60-75] are often more complicated due to additional muscle and joint fatigue. They seem to be more apprehensive about change. Orthotic practitioners need to realize that these older patients have experienced much in dealing with past orthotic challenges. These patients need to lead the way in their orthotic care and are the ones who need options to choose from. Elderly ambulators [75+] usually need lightweight orthoses. They want little change and practitioner listening skills need to be especially keen for this group. You must let these elderly patients know that you care about them and you also must learn to take their criticism with a smile.

What drives many of these patients to their physicians and eventually to orthotic facilities is pain. Polio patients with post polio syndrome will have pain. There is a reason for this pain. Pain is good: it is a tool by which a patient can be protected from further damage if he/she respects it (8). Pain is the, "Personal Awareness of Internal Notification" system. It is important to identify the source of the pain. Orthotic professionals need to focus on the musculoskeletal issues. If possible, joints need to be protected to prevent further damage while allowing the patient to continue to have mobility. By providing stability and more normal biomechanical function, joint destruction and muscle fatigue and stress can be reduced.

Many new and amazing materials are becoming available to orthotic professionals. This allows for lighter and stronger orthotic designs. New techniques are also available through modern technology by surgeons. Some joint deformities can now be improved dramatically, relieving stress and pain around joints and surrounding tissue. Keep your polio patients informed and don't be afraid of the challenges. Many of you have been trained professionally to handle these types of conditions. Please remember that your area of expertise is greatly needed and polio survivors will be relying more on your professional services. **End of Excerpt**

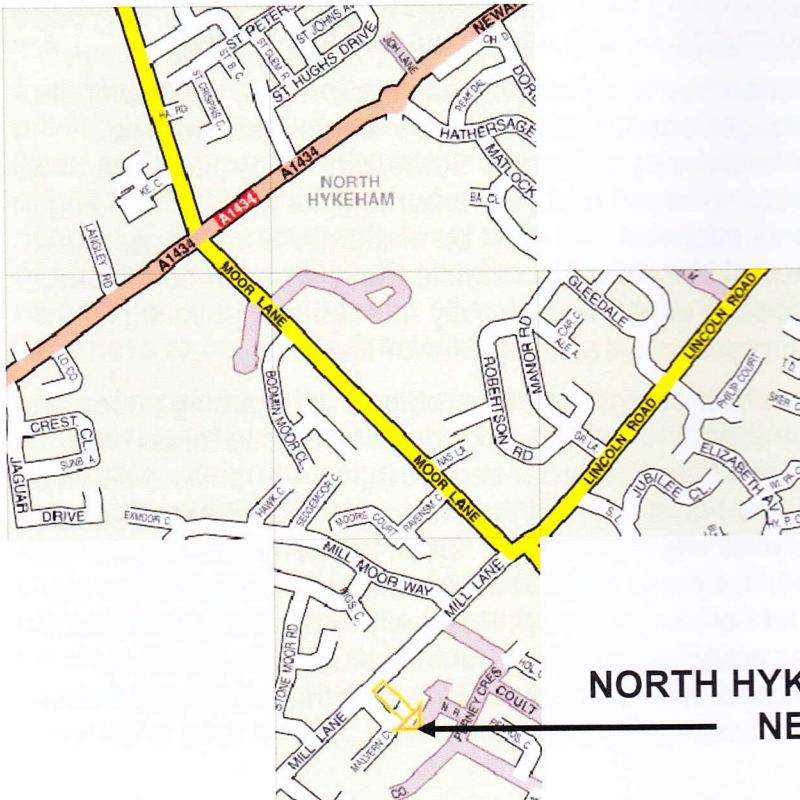
Editors note:- If you have or are still experiencing problems with getting shoes and orthoses that fit, do what is needed, and are comfortable then please let us know. As long time members will know I have had poor service in the UK, brilliant service from Canada, fitted first time and left me almost pain free, and then due to a couple of accidents sadly broke it beyond superglue repair. Back to poorly fitting, pain from lack of pressure relief UK AFO's. I wrote to our local hospital endorsing the issues raised by another member and detailing my own. Positively I suggested that round the table talks from both sides could iron out some of the issues and provide a better service. I await further contact following their reply that this was a good idea. Why not try this with your local hospital?



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