

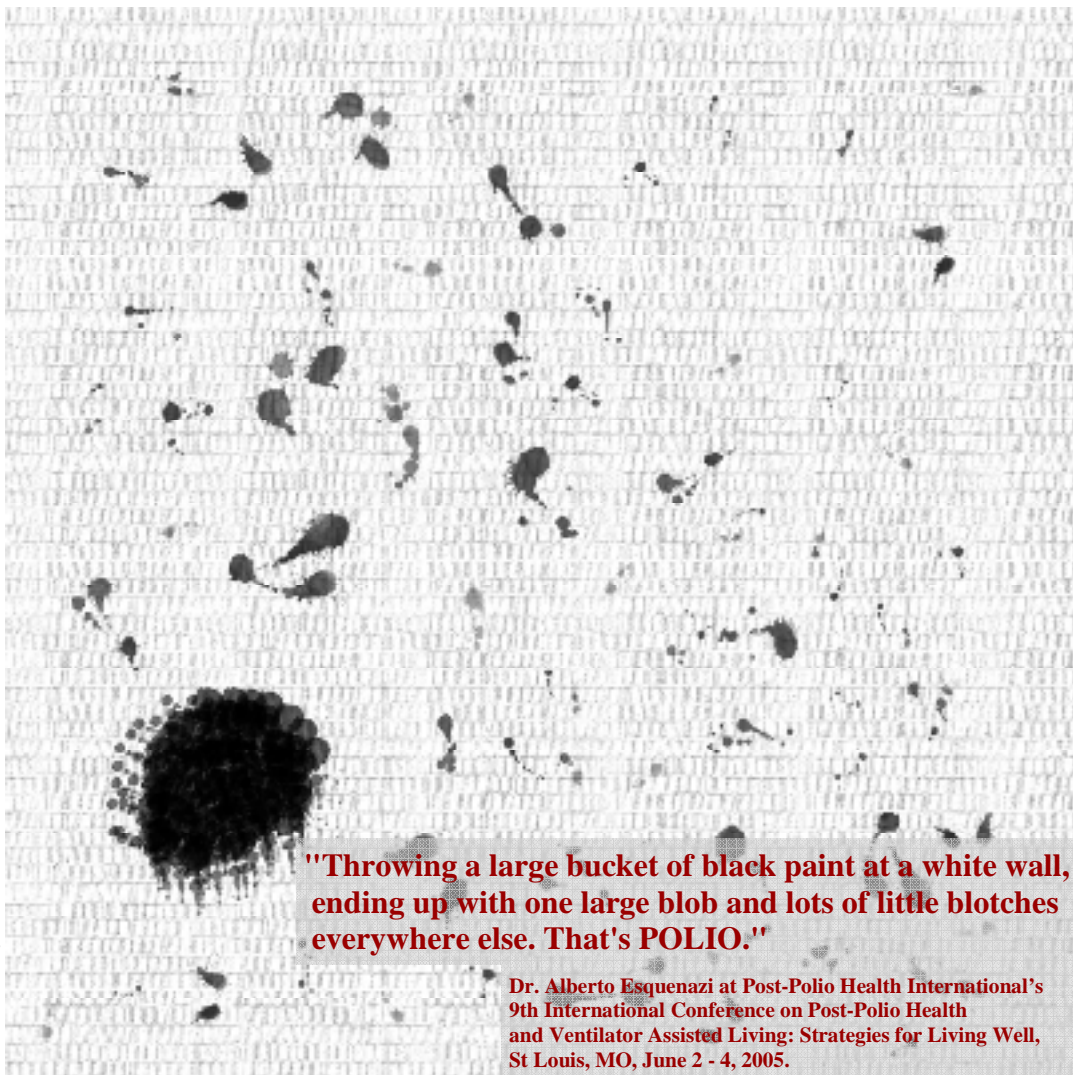


The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
Volume 5 - Issue 5 — August 2005

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

**ANNUAL GENERAL MEETING—22ND OCTOBER 2005
SEE PAGE 19 AND SEPARATE ENCLOSURE**



Art Work by Chris Salter

"Throwing a large bucket of black paint at a white wall, ending up with one large blob and lots of little blotches everywhere else. That's POLIO."

Dr. Alberto Esquenazi at Post-Polio Health International's 9th International Conference on Post-Polio Health and Ventilator Assisted Living: Strategies for Living Well, St Louis, MO, June 2 - 4, 2005.



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CONTENTS.

Page 2—Contents, Donations, Contact Information.

Page 3—Editorial

Page 4—Message from the Chair

Page 5—Treasurers Thoughts

Reports from the PHI 9th International Conference

Pages 6 to 9—Trauma Treatment, What is it and what are the benefits

Pages 10 to 18—Analysing your Gait, The role of exercise, bracing or surgery?

Page 19

Pages 20 and 21—Emotional Impact

Page 22, Letters to the LincPIN

Page 24—ICE and the ‘Southport Gang’

WE WOULD LIKE TO THANK THE FOLLOWING
FOR DONATIONS RECEIVED TOWARDS OUR WORK.

Dianne Lightfoot, Ewan Peddie, Sylvia Fortune, Jim & Jenny Rayner

Joan Deans, PAB Peacey, V. Scrivener, T. Croker, K.F. Preece,

London & Scandinavian Metallurgical Co. Ltd £150 via member Tom Croker

Anne Brown, Iris Jarvis, Barbara Anne Stevens, M.S. Kelly, A. & D. Fenner, DD&P Barr

VE Parkinson, V Holland, R.K. Staniforth, Sheila Dunnnett, Denise Carlyle, Hilary Hallam,

Mary Kinane, Robin & Pauline Butler, Di Newman, Chris Salter, Barry & Olivia Branston

Di Brennand and the phone team - Pat Hollingworth, Margaret Edmonds, Judy Barter

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

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Membership Information

Renewal dates are the first of the Months of Feb, Apr, Jun, Aug, Oct, Dec.

Please make cheques payable to ‘Lincolnshire Post-Polio Network’

Post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK

UK Membership - Life Member (LM) £150 or £5 x 30 months S.O. - Member £10 a year.

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Other Countries please contact membership@lincolnshirepostpolio.org.uk for details.

Next LincPIN Newsletter - October 2005

Articles for publication 15th September by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial by Hilary Hallam

Please note that there is an enclosed sheet with this newsletter regarding the Annual General Meeting on October 22nd 2005 to be held in North Hykeham, Lincoln, Lincolnshire. Please help us plan the event by posting the reply slip or emailing Sheila Dunnett with the information.

This newsletter contains three reports from Post-Polio Health International's 9th International Conference on Post Polio Health and Ventilator Assisted Living: Strategies for Living Well. We will be adding more reports in future newsletters. I am particularly pleased to be able to report on the presentation by Dr.'s Esquenazi & Keenan [pages 10 to 18]. This report is compiled from notes I made at the time, and an audio record, of the presentation. Specifically I would like to draw your attention to the following points that the doctors made during their talk:-

Doctor's Esquenazi and Keenan

- have learned now that Manual Muscle Testing is not a good way to assess muscle strength. They now use hand held dynamometry as a way to test strength because a grade 5 muscle—normal—could have as much as 30% weakness before Manual Muscle Testing could detect it.
- have found out that it is really difficult to truly improve muscle strength. That they do see, and can measure, some improvement in muscles strength after adjustments with bracing, lifestyle, weight etc, but they think that once people have stopped abusing their muscles they just recover their base line strength. It is very important to continue to exercise to maintain that strength and flexibility and prevent disuse weakness
- have learned that if we have weakness in our legs then we will end up with problems in our shoulders and wrists

Patients tend to

- overestimate the strength of their muscles
- underestimate the demands they place on their muscles every day

Health professionals need to

- Understand that each patient is different
- Understand the pattern of strength and weakness, and the compensations that have been developed over time.
- Look at the whole person not just the leg, or both legs, and how patients do actions of daily living.

What did I learn from this talk? I looked at my daily life and current problems. One is that after walking a few paces I become more round shouldered and unable to hold my head up straight. I know I can stand and walk straighter when wearing my long leg brace. It unlocks at the knee as I take my weight on my other leg which means I can walk normally and not stiff legged as I do when not wearing it so my knee does not collapse. I mistakenly thought that if I was going to be spending most of the day out on my scooter, or only going to be walking a few yards, then I could leave it off.... but I can see now that I was wrong. I have been putting more weight forwards and causing more strain on my neck, back and legs. I now wear this every time I go outside the house and can already see a huge difference. Amazing what we don't want to 'see'! We need to be our own medical detective and try and work out why we have changed the way we are doing actions of daily living.

Message from the Chair

Greetings readers and we hope that this edition finds our members and their families and friends well after an interesting and weather-filled summer. Whether you live on this eastern side of the pond from which we write, or on t'other side, or in the lower hemisphere, extreme temperatures and even floods will have affected some of you. We hope all our members are safe and well.

We would like to thank member Tom Croker for the donation of £150 from his former employer, the London & Scandinavian Metallurgical Co. Ltd.

In this edition, we continue to report back on topics of interest from Post-Polio Health International's 9th International Conference on Post Polio Health and Ventilator Assisted Living: Strategies for Living Well held in St. Louis, Missouri on June 2nd through 4th 2005. Unfortunately even with three of us attending we were unable to attend all the presentations as most times there were six choices. This issue I have done a report on Stephanie T. Machell's talk on Trauma Treatment, taken from my notes at the time and from the audio presentation.

One of the messages which I took home from this conference is that it is essential to continue to share knowledge and information about what works for polio survivors, what is new in the areas of alternative therapies (and there is a lot out there that is of some interest) and what some of the more traditional health professionals are saying. I would like to thank my friends and relatives who donated £450 in total towards the cost of my trip.

We were pleased while we were still in St Louis to learn of the British Medical Journal's highlighting of the issue of post-polio syndrome – Consultant Neurologist at Lane Fox. Dr Robin S. Howard's article has a good list of references (including our website - which pleases us and confirms that it is one of our strengths); this is followed by a commentary from "Alice" about her experience of diagnosis of post polio, written by member Dr. Ruth Bridgens, Sociologist. If you missed the reference in June's issue – here it is again:

<http://mt.lincolnshirepostpolio.org.uk/archives/pandpp-news/000778.html>

I look forward to seeing as many of you as can join us for the AGM. Our speakers Mark Rainey and Dr. Darren Barnes-Heath are looking forward to telling you about their work and answering your many questions. Please return the enclosed slip [or email the information] to Sheila Dunnett. This is all the news for now. Enjoy the summer days and contact us with your experiences, opinions or questions, via any of our contact details on the second page of the LincPIN.

Mary Kinane, Chair mary.kinane@lincolnshirepostpolio.org.uk

Treasurer's Thoughts August 2005

giftaid it **Your support.**

Jenni Paulger once again very kindly completed the necessary forms this year to reclaim tax through the Inland Revenue. At the end of June we received a cheque for £459.16. I would like to thank all those who were able to take advantage of the Gift Aid scheme. Gift Aid provides a great opportunity for tax-paying members to increase the value of their donations to LPPN.

I would also like to thank all those who recently sent donations either along with your responses to the questionnaire, or with membership renewal forms. All those £5 or £10 cheques really add up, helping us to continue in our work.

Newsletter Questionnaire.

A big thank you to the 54 people who responded to the questionnaire – some by post, others by email. Here are the numbers!

1. What do you feel your membership fee covers? 26% felt this was payment for their newsletter. 68% felt it covered, or should cover, both newsletter costs and support for LPPN.
2. 15% wished to continue to receive their newsletter 6 times a year, while 83% were happy to receive it 4 times a year in future.
3. 55% want to continue to receive their newsletter by post. 31% would be happy to receive theirs though email. Several members felt one way to reduce costs would be to access the newsletter through the LPPN website.
4. An increase in the annual membership fee to £12.50 suited 24% of respondents. 55% of respondents thought an increase to £15 was appropriate.

A reduction in the number of pages was thought to be a good idea by 35% (who opted for 20 pages) and 28% (who opted for 16 pages) since reduced weight would lower the cost of postage. 20% of respondents wished the newsletter to maintain its current length. 13% felt the newsletter should vary in length depending on the amount of quality information available.

Several people felt that these were editorial decisions and that it was up the committee to decide such issues. There were many excellent money saving suggestions, which the committee will discuss at their next meeting. Fundraising ideas were numerous - from holding a scrabble evening, a pub quiz or having a tabletop sale, to organising a safari supper, a local youth club non-stop event or an able-bodied/wheelchair sponsored walk. Every £5 raised helps. Several members asked if they could be put in touch with other members to help organise a fundraiser together. Many members felt unable to directly contribute to fundraising efforts due to advanced age and/or the severity of their health problems.

I would welcome any suggestions/comments you might like to make. You can contact me via email: denise.carlyle@lincolnshirepostpolio.org.uk

“Trauma Treatment: What is it and What are the Benefits?”

**A review of Stephanie Machell’s presentation
at Post-Polio Health International’s
9th International Conference on Post-Polio Health
and Ventilator Assisted Living: Strategies for Living Well,
St Louis, MO, June 2 - 4, 2005.**

Compiled by Mary Kinane from notes taken at the presentation and an audio record.

This is a personal review of a hugely interesting subject, which caught my attention as soon as I registered for the conference. All attendees had the same dilemma of having to choose which presentations would best suit their curiosity and needs, or the interests of their groups. On this subject, I decided to trust my instincts and to go for something which I thought would speak to me personally, as well as to pique my interest and even broaden my horizons. Coincidentally (or otherwise) this topic has already done all three of these things! I would like to share some of my impressions, as well as some background to the topic, with you the reader. I should point out that I am condensing a great deal of detail into this review, but I hope I have succeeded in bringing out the salient (and to me, fascinating) points in Stephanie Machell’s talk.

I knew nothing about trauma treatment, or the subject of post-traumatic stress disorder (PTSD), before June of this year. Stephanie Machell, PsyD, (International Rehabilitation Center for Polio, Framingham, Massachusetts) knows quite a bit about this subject, from both an academic and a practitioner’s point of view. Her presentation began with an overview of the last twenty years of popular therapeutic practice and belief, taking the audience through a whistle-stop tour of accepted practice in trauma therapy (and related subjects) in the U.S.A. (and perhaps in a more understated way, in Britain) for the last two decades. “Talk” therapy, giving the client the benefit of person-centred listening skills, the “how does that make you feel?” approach to modern counselling has been the mainstay of the therapy session for the last 25 years. Ms Machell went on to put the case forward for the need not just to “talk about” past traumatic experiences (even if we can remember them) but also for the need to approach them from a number of perspectives at the same time. She described how traumatic experiences, especially of a long time ago (for example contracting polio, being rushed to hospital, being separated suddenly from parents/siblings/community) can be re-stimulated in our bodies long after the polio crisis is over, and can have lasting effects on our physical, cognitive, emotional and spiritual health.

Early trauma treatment (1980’s) consisted of dredging up “horrible” memories, re-living them, pounding on pillows etc:- that was how trauma was treated. The problem with this method was that the nervous system didn’t know the difference between that experience (i.e. re-living it) and being traumatised. This re-living of a trauma meant that the patient was only being brought through the trauma all over again. Crucially, people can get addicted to this process because the body releases opiates when a person re-lives trauma. The client literally becomes addicted to the therapy because of the re-stimulation and the opiates released.

Thankfully, this is not how trauma treatment is done today. Ms Machell started using the newer approach to trauma treatment as early as the late 80's (when it was still quite controversial) and to think about trauma in a different way. "Now we have kinder, gentler trauma treatment - then again if you're the person going through the trauma treatment it may not feel gentler - it is painful to work with any kind of trauma - talking about why it might be important with people with post polio especially to deal with any potential past trauma that they may have had...."

She went on to say: "How do you find professionals (and with what techniques) in mental health who have any experience of polio or post polio syndrome?" Ms Machell's own father is a polio survivor... in his thirties, from the Boston epidemics in the 1950's. A person trying to make meaning from a traumatic event will need varying techniques which can help - "adults who had polio may recall actual events, but children deal with these things differently".

"If I experienced trauma, does that mean I have Post-Traumatic Stress Disorder? No! Not everyone who experiences trauma develops PTSD or other psychological problems. However, it may still be helpful for someone who experienced trauma to receive psychological treatment (see under *What sort of treatment is available to me?*)

The symptoms of PTSD include intrusive thoughts about the event(s), dreams, flashbacks, intense distress when faced with reminders of the event(s), avoidance of reminders of the events(s), amnesia for all or part of the event(s), sleep disturbances, muscle pain, restricted emotional range (can be coupled with a tendency to become intensely angry or a low level of constant irritability), difficulty concentrating, hyper-vigilance, and an exaggerated startle response. Some of these symptoms may alternate (e.g., intrusive thoughts with avoidance of reminders)."

"PTSD is a bi-phasic (two-sided) disorder, going from intrusive memories to the second phase of numbing out and the losing of memories". When people have had more chronic trauma, they get frozen into one of the two responses (more often the numbing response) but sometimes into feeling over-whelmed and "flooded". A good example of the flooding response (when people have lots of intrusive memories) is with Vietnam Veterans, during fireworks on the 4th of July.

Stephanie's view is that all polio survivors have high sensitivity. Various environmental triggers stimulate emotional memory. When a trigger stimulates an emotional memory, it manifests at a physical level through the production of adrenalin and cortisol, as well as other neuro-chemicals. For a polio survivor – a trigger can be the smell of wet wool, or a particular kind of hospital smell. The brace clinic can be a significant trigger for traumatic memories "...many things are associated with the brace clinic". Stephanie said she sometimes "thinks she should be stationed just outside the door of the brace clinic" as there are so many triggers which patients experience while there. Another common feature of triggering is that people will have feelings and they won't really know why they're having them. Triggers can get disconnected from the original traumatic event. This is very

common with adults, *who as children* were traumatised at early ages; trying to connect a feeling with a memory is difficult because they were too young to consciously remember the original event.

Irritability and “startle responses” are known as “autonomic hyper-reactivity”, where those with a PTSD-related condition tend to respond in very intense ways to the world in general. But, there can also be the opposite effect - (“a constricted affect”) so that a person can find expressing emotions difficult - for example; a man or woman can find him/herself unable to share their feelings of happiness with their children, and for which modern trauma treatment can help.

So, what is good trauma treatment, and how do we go about accessing it? “Linda Bieniek created an extensive list of psychological treatments for trauma describing their risks and benefits (*see Resources below*). Working with a psychotherapist who is well-trained and experienced in trauma is essential. Few will be familiar with polio or pps, but should be willing and open to learning more.” What good trauma treatment addresses is to try to teach our bodies to *re-regulate* (the biology of trauma consisting of too many “fight or flight” hormones - adrenalin and cortisol - getting pumped through your system). If the trauma wasn’t talked about (which in the main it was not where polio in childhood was concerned) you can spend years pumping adrenalin and cortisol and all kinds of other neuro-chemicals that do things to your body and sensitise you, in reaction to all sorts of events, and the parasympathetic nervous system takes a long time to work (to clean up) and while it’s doing its work you feel tired and your muscles ache. (enter pps symptoms?!).

Helping your body to self-regulate can include the following therapies and, according to Ms Machell “...you’re looking for somebody who can help you to learn a number of self-regulation techniques”, which can include the following:

1. *Meditation* helps to re-train the central nervous system; also it is the most accessible as a self-help technique.
2. *Yoga*.
3. *T'ai Chi* (this can be done to some effect sitting down)
4. *Vitamin intake and diet* (food influences on mood)
5. *Bach Flower Remedies* (working on the mental and emotional levels - homeopathic)
6. *Meridian (Energy) therapies* (acupressure, shiatsu, acupuncture, meditation)”
7. *EMDR* (Eye Movement Desensitisation and Reprocessing).

N.B.: All the above techniques help to support patients through therapy, and help to by-pass a lot of the work that used to be done in trauma treatment (memory work). Intervention on the level of the spirit/energy: if you intervene on the “energy” or energetic level, you can get a lot out of energy therapies... it works for what ails you, and there are good supportive techniques for the hard work of psychotherapy; there are techniques for pain-management; and there is EMDR (as above). Interestingly, Ms Machell sees EMDR as an energy technique... (some don’t) “hitting the right points and clearing things out”. EMDR deals with how memory is stored – (and traumatic memory is stored differently from other memory); the

memory unreels like a news-reel – when it unreels it unreels fully and completely – “once it gets going it’s very hard to stop it – EMDR helps to break down the memory and helps to re-store it as “normal” memory. It’s like taking an antacid...”.

The above is a combination of direct quotes from a transcript of Stephanie Machell’s session, or sections from the abstract provided in the programme notes to each conference participant. Otherwise, the review is in my own words. I did some follow-up reading when I got home, and have included an extra reference below. I hope that this piece will have provided some stimulating perspectives on alternative approaches to healing and treating pps. It is my view (and my experience) that while we need to continue to seek the best from our traditional medical practitioners, we also need to take more responsibility (and be more in the driving seat) for our own health - we need to explore ways to try out these techniques safely, and not at great cost (either emotionally or financially) to ourselves.

Stephanie T. Machell, PsyD.

Roots & Wings Psychological Services, Office: 5 Watson Road, Belmont MA 02478

Resources: Books & Articles:

Kabat Zinn, Jon (1990) Full Catastrophe Living: Using the Wisdom of your Body and Mind to Face Stress, Pain and Illness. (This is an excellent introduction to mindfulness and yoga exercises that might be useful with trauma survivors, and those with heart conditions and chronic pain) (U.S.)

Phillips, Maggie (2000) Finding the Energy to Heal: How EMDR, Hypnosis, TFT, Imagery and Body-Focused Therapy Can Help Restore Mind-Body Health. (an excellent introduction to some of the newer treatments available – highly recommended)

Bieniek, Linda (2001) *Emotional Bridges to Wellness* Polio Network News, Fall 2001, Vol 17, No. 4 (this and the subsequent articles are the best ones on how and why to deal with the trauma of polio).

Bieniek, Linda & Kennedy Karen (2002) *Pursuing Therapeutic Resources to Improve Your Health*, Polio Network News, Fall 2002, Vol 18, No. 4.

Useful Organisations:

Sidran Foundation (www.sidran.org) a great resource for info about trauma treatment, including therapist referrals). (U.S.)

The Association for Comprehensive Energy Psychology (ASAP)– a good source for accessing practitioners of above techniques; try a word search on the internet for ASAP’s website. (U.S)

Added Reference (writer’s note): When I got back to England I read a fascinating article by Dr Nick Baylis, Lecturer in Positive Psychology at Cambridge University, in Dr Feelgood’s “On the Science of Happiness”, on EMDR and other techniques, in *The Times of Saturday 16th July 2005*. (this is a regular weekly article in Saturday’s Times).

You can e-mail Dr Baylis on drfeelgood@thetimes.co.uk for more information on PTSD, Clinical Hypnosis and Rewind Therapy, from a British perspective). (U.K.)

**Analyzing Your Gait: The Roles of Exercise, Bracing or Surgery?
A review of Dr. Esquenazi and Dr. Keenan's presentation
at Post-Polio Health International's
9th International Conference on Post-Polio Health
and Ventilator Assisted Living: Strategies for Living Well,
St Louis, MO, June 2 - 4, 2005.**

Compiled by Hilary Hallam from notes taken at the presentation and an audio record.

Dr. Alberto Esquenazi, is a rehabilitation physician and
Director of the Gait & Motion Analysis Laboratory
at Moss Rehabilitation Hospital in Philadelphia.

Dr. Mary Ann Keenan, is an orthopaedic surgeon and
Professor of Orthopaedics and
Chief of the New Orthopaedics Service at the University of Pennsylvania.

"As you know quite well there is not a lot of expertise out in the real world in the realm of post polio syndrome. Unfortunately it's a disease that we don't learn in medical school. It is a disease that is not taught in health care in general but is one that is critical to individuals like you." [Esquenazi]

"There is no better way to treat Post Polio than to prevent it, so we are always encouraging people to think about polio prevention" [Esquenazi]

Both doctors ran the largest Post Polio Clinic in the mid Atlantic for ten years. The combination of both members of their team afforded them the privilege of dealing with many complex cases over the years. They learned much from Polio Survivors about their condition and experiences and were able to implement that knowledge into the care of other patients. Due to local politics they have ended up working in separate establishments but developed some special arrangements to continue collaborating. They have a multi disciplinary approach and encourage periodic evaluations. They educate their patients and believe peer support is critical so are always surrounded by patients only too willing to help. They counsel patients on modified exercise programs, on activity adjustments, on weight control, bracing and in a few circumstances surgery.

Dr. Esquenazi defined polio, post polio and the nature of polio muscle weakness. He explained how braces help to substitute for that weakness, and how in his clinic they optimise brace alignment and fit.

"Acute poliomyelitis is an infection of the anterior horn cells in the spinal cord and usually it will present as a febrile episode with weakness, with stiffness and with pain." [Esquenazi]

There are about 1.5 million polio survivors alive today in the U.S.A. [USA population of 297 million, about 0.5%] and about 20 million polio survivors in the world [World population of 6,455 million, about 0.3%].

PPS usually presents a variety of problems, muscle weakness, overuse syndrome, nerve injuries, joint derangement, and the natural aging process.

He stated that patients tend to overestimate the strength of their muscles and often present with pain in, say, one area. However, it is not a focal disease but a systemic disease and affects the whole body. It had a larger effect in the areas where clinical

paralysis and weakness were seen. He described polio as “throwing a large bucket of black paint at a white wall, ending up with one large blob and lots of little blotches everywhere else. That’s POLIO.”

Dr. Esquenazi went on to discuss Manual Muscle Testing, describing it as the old way that testing was done! i.e. basically grading muscles from 0 [with no muscle strength] to 5 [normal muscle strength]. “That is the way it was done and is continuing to be done in many places. We have learned now that that is not a good way to do it. We now use hand held dynamometry as a way to test strength because a grade 5 muscle—normal—could have as much as 30% weakness before Manual Muscle Testing could detect it.”

According to Dr. Esquenazi, the meat of the matter is calf weakness, and everyone needs to appreciate what this means. He explained that our calf muscles have to hold our whole body weight when we are in the stance phase, to prevent us falling. That we have to lose a huge amount of calf weakness before it is detected by strength testing. When we walk we take many steps which is what needs to be assessed, not just one step.

He explained how we also underestimate the demands that we place on our muscles every day: just sitting, keeping our head and back straight plus demands on our legs to cross them and move them around. Then add walking! Also as we get older we tend to get a little bigger, and he added that Americans tend to get a little bigger than the bigger, adding to problems and producing fatigue.

A review of the information provided by the 500 patients in their clinic showed that most patients complained of fatigue. A large number complained of muscle pain, joint pain, muscle weakness, new muscle weakness, cold intolerance, atrophy, problems with walking (almost 80%) and stair climbing.

He then talked about the consequences of trying to walk. He explained that we have been compensating for decades, and our joints pay a price for that. He showed a film of a lady with a large amount of back flexibility in her knee joint, stretching, straining and damaging not only muscles and tendons, but also skin, nerves and vessels—ending up with a complaint of pain.

He said “many of you got to the age of 17 and 18 and decided ‘No more braces’ with the thought that ‘if I can get rid of my braces then I am better.’ Unfortunately we know now that that was not a good idea. Plus you hide your braces. President Roosevelt worked endlessly to hide his so that he did not appear to be ‘disabled’.”

In their Gait Laboratory they put a series of little infra-red sensory stickers on a patient that allows them to convert the human figure into a computer animation so they can measure how we walk in great detail. This can be manipulated and rotated and viewed from any perspective. They can measure the speed, symmetry and displacement of joints and do this without and then with bracing.

He then showed a slide of a gentleman carrying a very large toolbox and asked why do you think this patient came to visit us. There was a lot of laughter when the first person called out, ‘His fingers are tired’. ‘Yes, and he is also likely to get backache and shoulder problems. Can you guess his job?’ I replied, ‘something very strenuous because he is a polio survivor’. Dr. Esquenazi told us that he is a maintenance engineer in a huge Casino with endless corridors and has to carry all that he might need with him; that he wrote to his employers and the Union to

explain that he needs to put wheels on this toolbox so that he can retain his health and job.

He then went on to explain that there are two phases to walking, the stance phase when the foot is on the ground and the swing phase when the leg is off the ground. Braces and adaptive postures can do a great job at substituting for stance phase muscles but there is nothing to help swing phase muscles so they are very vulnerable to overuse.

“There are old style and new style braces but unfortunately the new style braces, even though they are lighter and more visually appealing, have become more and more ones that are brought out from a factory and shoved on a patient. The art of making braces is dying.”

He explained that people are not going into training, that Insurance Companies do not want to pay for braces, and that dealing with polio survivors is a pain because they know what they want and it never comes out right.

What does a brace do for us? It substitutes for weak muscles. The brace produces support to the leg when standing, and when walking, where the foot is in the stance phase. In general it does nothing in the swing phase although there are a few exceptions. Braces do nothing for us when we are sitting—although sometimes they make our leg uncomfortable.

Weak calf muscles mean that the tibia bone is not held strongly, and wants to fall forward, tending to make the knee buckle. So what do we do? We use our hand to push back on our thigh, or maybe just snap our knee back into hyperextension. The next thing we do is to take short steps, which do not strain our legs as much. We may complain that we cannot keep up with our friends and are fatiguing, but it could just be taking short steps—longer ones might cause our knee to buckle. Or we may walk with our knee stiff so that it does not have to make that effort. The answer is to put a brace on it.

Braces [AFO's: ankle foot orthosis] come in all colours and shapes so the first step is to try to pick one that is visually acceptable to the patient. Although it might not seem the first criterion, they want us to wear it. Secondly it must be properly mechanically built. Thirdly it must not hurt. He asked how many patients in the room wore braces; how many have a sore or callous and a few people kept their hands up. He explained this was not unusual; that we are willing to tolerate calluses, rubbing, high pressure, because it lets us do more, but this is not acceptable and it shows how tolerant we can be. “Go back and have your brace reassessed.”

In his clinic they tend to use braces that are hinged and have movement—although that is not universal—because when the foot hits the ground it needs to get flat to make us stable. If the foot is not allowed to do that then we need to make extra effort, bend our knee early, flex our hip earlier, and do things to accommodate this, which will usually strain our thigh muscles.

Back knee deformity is another very frequent problem usually aggravated if the foot

is stuck in a toe down position. A long time ago surgery to stabilise the knee was sometimes to put your foot into a fixed position pointed down. It can be prevented but it's not easy once it's started and we tend to need a long leg brace. Long leg braces KAFO's [knee ankle foot orthosis] come in many flavours and shapes. At their clinic they like to use braces that are not locked at the knee if at all possible. Where feasible they like to allow ankle movement but this has advantages: moving the foot up and down gives a more natural gait, adding a little spring to kick the foot up if necessary— and disadvantages: it has the potential for unwanted ranges of motion; the brace can become loose, the joints not doing what they are supposed to, and they require more maintenance, replacing parts and pieces where necessary.

In their clinic they use spring assisted braces, ultra light-weight carbon graphite and the newest of all, weight activated braces that lock as your weight goes down on them and unlocks as your weight comes off. While not without problems they work for some people.

Shoulder and wrist problems when walking! Dr. Esquenazi said they have learned that if we have weakness in our legs then we will end up with problems in our shoulders and wrists, either from pushing a wheelchair, pushing ourselves up to stand, or leaning heavily on crutches. He then showed film of a patient who helped with their research, followed by an animation showing how she stood up from a chair. "She uses her head and twists her pelvis in an awkward manner. Now we can try and figure out what is causing this. Think hard of the extra problems, the extra stress and strain on her shoulders and wrists if she weighed more."

Sometimes they can make braces for upper limbs but they are a little harder to do and less effective than lower limb braces.

"Key Issues to remember.

1. The earlier you apply a brace the better because you will reduce some of these strains and problems down the line.
2. The lighter the brace the better because it will take away the strain during the swing phase when you have to 'carry' the brace.
3. Where possible have your brace optimised for alignment at least twice a year. Remember you take it off at night and stand it against the nightstand and it falls over and could now be out of alignment. If you think it now feels a little stiff, or has a kink in it, get it checked out.
4. Your relationship with your Orthotist is long term. Find a knowledgeable and preferably bracing experienced physician to work as your advocate. Take a third person with you to help ensure that you both understand what you are saying.
5. You are taking the brace home—the brace maker will tell you it looks good—but does it feel comfortable?"

"I will now hand over to my colleague Dr. Mary Ann Keenan"

[Editors note to help UK members understand some of Dr. Keenan's comments. In America you will find that many surgeons specialise in only one area of the body, so you can get a surgeon who only does knees, and one who only does feet.]

Dr. Keenan started by talking about Exercise, saying, “We have found out that it is really difficult to truly improve muscle strength.” She said that they do see, and can measure, some improvement in muscles strength after adjustments with bracing, lifestyle, weight etc, but they think that once people have stopped abusing their muscles they just recover their base line strength. It is very important to continue to exercise to maintain that strength and flexibility and prevent disuse weakness.

Their guidelines are:-

- Low resistance and low impact – not exercising against a lot of force. Water exercises sometimes are helpful as you have the buoyancy of the water to support you against the resistance of the water.
- Short duration - say two minutes - of exercise for each area of the body, rotating the different muscle groups.
- Do not exercise any group of muscles to the point of fatigue.
- Take frequent rest periods.

Dr. Keenan then went on to talk about surgery. Surgery is not a huge part of caring for people with post polio problems but if you do need surgery then it's important to have an

- Anaesthesiologist – “who understands the issues of post polio and the need to go light on all their many drugs”
- Surgeon - who accepts and practises the holistic approach to surgery, someone who goes beyond looking at the leg in question, to both legs, arms and in fact the whole body.
- Knee surgeon - who understands how the foot impacts on the knee, how a weak calf can lead to knee problems.

People who have a little weakness in their calf have to use their quadriceps in the front of their thigh more strenuously leading to kneecap problems, grinding of the kneecap and tendonitis in the thigh muscle. If the calf is even weaker with back-knee then you can have more serious problems. Dr. Keenan has seen patients who have had their knee scoped a couple of times, by good surgeons, nibbling away at their meniscus because of tears, who did not realise that the problem was being caused by the weakness in the calf. It is really important for health professionals to look for the underlying cause.

She explained that she performs surgery for pain relief, correction of deformity, on occasion redirecting some muscles' forces with tendon transfers, stabilising joints and to reshape a leg or foot so that a brace can be made which will provide good structural support. “Getting rid of that brace was a 50's and 60's idea but it is no longer appropriate”.

Dr. Keenan tells all her patients that there is a lot she can do for our legs but we have to save our shoulders, the key to our independence. We need to minimise the mechanical force we put on our shoulders, e.g. pushing up to get out of chairs, leaning heavily on crutches etc.

Dr. Keenan then went on to talk about specific problems.

Rotator Cuff Problems – caused by overuse of shoulders. MRIs are taken of the shoulder joint, but Dr. Keenan ensures that this also covers the muscles that control that joint; looking at the actual tears in greater detail, and also to get some concept of the quality of the muscles that work that joint. If the muscle is filled with fat then you know it does not have much muscle strength. To reattach the tendon there needs to be enough muscle fibre to work the shoulder again. Rotator Cuff Surgery is a big investment of patients' and family's time because during recovery you cannot use that arm whilst the shoulder is healing. It is imperative to look at what actions caused the tear so that you modify how you do the action to prevent it occurring again. Some strength can be lost but overall the results are good.

Carpel Tunnel Syndrome – surgery is not always necessary. It may be as simple as changing grips on canes and crutches, or better leg bracing so you don't have to lean so heavily on aids. Where this has been going on for some time with significant arthritis, where really severe, she might stabilise the wrist to get rid of the pain but this takes away the motion so she tries to avoid this type of surgery.

Equinus – toe down position. When you walk and your toes go down first instead of your heel. It is like having a built-in doorstop pushing you backwards and jamming your knee backwards. Here she lengthens the Achilles tendon to get the flexibility back again and get the foot flat on the floor but the trade off is loss of some strength. This tightens the toes so they snip the tendons to allow the foot to lie flat in the shoe.

Cavus – a high arched foot. To help you get a foot or foot and brace into a shoe your foot needs to be flatter. If there is no arthritis they can release the ligament on the bottom of the foot and let the bones go back into their normal position. If there is a lot of arthritis then they add a little wedge of bone. She showed a video of a patient whose foot and ankle were fused in the toe down position with the idea that it would push her knee back/stabilise her knee and so not need a brace. Now in her 50's she was having knee pain so Dr. Keenan cut through the mass of fused bone to flatten the foot and gave her a new brace, which solved her problem.

Valgus – foot that rolls over and pronates, flat foot. Having this type of foot can make it difficult to fit a brace, so realigning the foot into a better position will give a better base of support. Abnormal feet put abnormal forces on knee and hip which can cause pelvic wiggle movements and back strains, causing knock knee or valgus deformity. This can be caused by one leg shorter, weakness of hip muscles, tightness of the band on the side of your leg, or a crooked foot. A lot of different factors to be considered before treating. It may just need a lift on your shoe and a cane, or Dr. Keenan may need to release some tendons, realign the bone and sometimes if significant arthritis replacement joint surgery is necessary.

Varus – bow legs. There is no surgery to tighten up the ligament and joint capsule behind the knee. Long leg bracing can control this unless it's really severe with lots of arthritis when knee replacement is considered.

Quadriceps weakness - very common in polio survivors. The quadriceps are the muscles that help us stay upright. If our knees are flexed – not able to straighten them – then we ask the quads for more help. If we have weak quads and flexed knees then we are more vulnerable to falls and we lean more heavily on our arms. If bracing does not work then surgery is considered to lengthen some tendons, cut the bone, realign the knee or replace the joint.

Hip flexion problems - make us lean forward and put strain on our muscles and back using up an enormous amount of energy to compensate; energy which we are already short on as polio survivors and should not be wasting.

“If you let go of a plastic skeleton it collapses. It is the muscles that control the flexibility of joints and depending on where your body weight is in relation to how a joint moves normally, then you either need to have the muscles control that flexibility or a brace that controls it.”

Joint replacement – for polio survivors there are a lot of special considerations regarding all the other implications of the combinations of patients’ muscle strengths. It is imperative that patient and medical personnel work as a team. Patients need to understand the ultimate restrictions that this surgery will place on them. If you have already damaged a normal joint then you will wear out the metal and plastic joint in the same way unless you change how you do actions. Other leg deformities have to be corrected as well and it may be necessary to use a lower leg brace as well.

- Contracture of a joint - you don't have normal motion. You can have laxity in one direction or the other because of stretched out ligaments and joint capsules. With little muscle strength you need to compensate.
- Bones – if you have a lot of weakness or paralysis in a limb then bones are much weaker, and there may be more osteoporosis, making fixation of the knee or hip joint challenging.
- Hip Abductor and Hip Extensor Muscles - you need pretty reasonable strength of these muscles to keep the ball and cup of the hip joint together. There is a certain inherent stability to a ball and cup design and they can pop out of position if you don't have the muscle strength to hold it together.
- Arthritic hip and low muscle strength - make it impossible to do a hip replacement and alternatives have to be considered.
- Constrained hip joint replacements – not used with polio survivors with weak muscles because it is just going to transmit all the forces onto the bone making it weak or osteoporotic and the replacement rip out from its setting. An alternative to get some pain relief might be to control the position of the leg by cutting the pelvis making a roof over the hip joint. A video was shown of a lady who had this surgery and six years later is still walking and has pretty reasonable relief of pain.

Planning for surgery and post-op rehabilitation – Dr. Keenan coordinates with Dr. Esquenazi and the team at Moss Rehab and all treatment is pre approved. As surgery realigns the leg the brace maker comes into the operating room to make the mould and it's fast tracked so rehabilitation can proceed.

Dr. Keenan then showed short videos of two patients.

1. A 56 year old with bad deformity presenting with back pain. She has no muscle strength in left leg, significant weakness in right leg. Left arm also completely paralysed. Total knee replacement, long leg brace for left leg and short leg brace for right leg. 14 years later and she is still walking and going well. BUT she had to promise me that she would never stand on her left leg without the brace to protect it.

2. Knee bending inwards – valgus or severe knock knee, given total knee replacement. Shown walking two weeks after surgery with the knee joint locked to protect some tendon repairs. Now able to walk without the knee joint locked because as much motion as possible is wanted. This shows her 2 years post op and it is now six years later and she is still doing quite well.

Special considerations for polio survivors pre surgery - because of weakness, paralysis, osteoporosis, and/or abnormal shaped bones, there needs to be a lot of work done ahead of time.

- Look at the whole person not just the leg, or both legs, and how they do actions of daily living.
- Each patient is different and we need to understand that the pattern of strength and weakness, and the compensations that have been developed over time.
- Coordinate with anaesthesia team regarding anaesthesia and for inter and post operative pain management.
- Coordinated team approach with rehabilitation and bracing.
- Custom joints may need to be made.

As Keenan stated, “Our job is to avoid your garage or closet being filled with a bunch of failed and discarded devices”.

Dr. Keenan then told the audience that they had helped produce a booklet, freely available on the Einstein Website, to help us save our shoulders.

Booklet

Save Our Shoulders: A Guide for Polio Survivors

by Jennifer Kuehl, MPT, Roberta Costello, MSN, RN, Janet Weschler, PT.
Investigators, Mary Klein, PhD, Mary Ann Keenan, MD, Albert Esquenazi MD.

http://www.einstein.edu/rx_files/yourhealth/mrri_sos9510.pdf

Dr. Esquenazi and Dr. Keenan then answered some questions.

Question 1 - What can be done for weakness of upper spine and neck to support the head?
Answer - Surgery to stiffen the neck is a major operation which would transform the forces onto the next area of spine that was mobile and would only be done as a last resort. Bracing is the usual answer providing the patient does not have breathing problems as the brace would normally transform forces to the chest wall. Braces could be worn

intermittently. The other option to relieve pressure on the neck would be to tilt the chair back.

Question 2 – How many other medical teams like you are there in the world?

Answer - There are other centres that do polio and post polio but they tend to be more focused on the psychosocial side of things. Our strength is in the medical, orthopaedic and rehabilitation areas. Other clinics like ours that we are aware of are Rancho Los Amigos in Los Angeles started by Dr. Jacquelin Perry, one in Germany, and one in Northern Italy.

Question 3 – Can we get our ‘orthopods’ to talk with you, or do we have to come to your clinic or Rancho Los Amigos?

Answer - It would depend on the complexity of the problem. Orthopaedic Surgeons do not get a lot of training in polio and post polio and are not used to working in a team environment. We have formed a symbiotic working relationship where we have learned much from each other for the benefit of our patients.

Question 4 – Asked about pain.

Answer - They are not pain specialists; they work in the biomechanical area. They believe that pain is a sign of something else and that addressing that something else most times brings pain relief to patients. Patients will be referred to Pain Clinics if needed.

Question 5 – Can I be evaluated by you and come back to my own area for treatment?

Answer – Dr. Keenan responded that for most polio survivors she sees she does not recommend surgery and refers patients to Dr. Esquenazi. That she does see patients from far away and tries to educate her patients to go back and educate their other care givers. Dr. Keenan said “The first thing we always assume is that the patient is correct and maybe we don’t understand why you are right or what the issues are, but unlike some orthopaedic surgeons who say that the patient is an unhappy person, or a complainer, I try to figure out why whatever you have been doing is not working for you, even when I am the one that said do that. Sometimes we are wrong, or just don’t have the right alignment of braces and sometimes we have to go to a more sophisticated evaluation in a laboratory setting so we try to work through it together.”

Question 6 – I am from the UK and we rarely get a chance to be referred to a gait laboratory. We get manually muscle tested done a single time and our repetitive and sustaining problems come later than the time we are tested. Could you make a video to help solve this situation?

Answer – Dr. Esquenazi explained that gait analysis is a relatively new technology. That there are probably 20 gait labs in the UK but half are devoted to research. Dr. Keenan said she had just been to an excellent lab in the UK whose focus was on Cerebral Palsy. Dr. Esquenazi said he was in the U.K. two weeks ago at a two and a half days conference just learning about the basics of normal walking not pathology. He said “More than once I have had my Fellows and Residents look at a patient and tell me ‘normal strength’ and I say, ‘Nix, come on lets go over and look at this patient together’. This patient, not meaningfully, not in a wilful manner, has done you a nice trick and showed that the strength of the hip is 5 when the strength of the hip is really 2. So you need to be able to pick that up, and that’s experience. There is no way to learn that in a quick way. Making a video sounds lovely, but in reality you need more than that.”

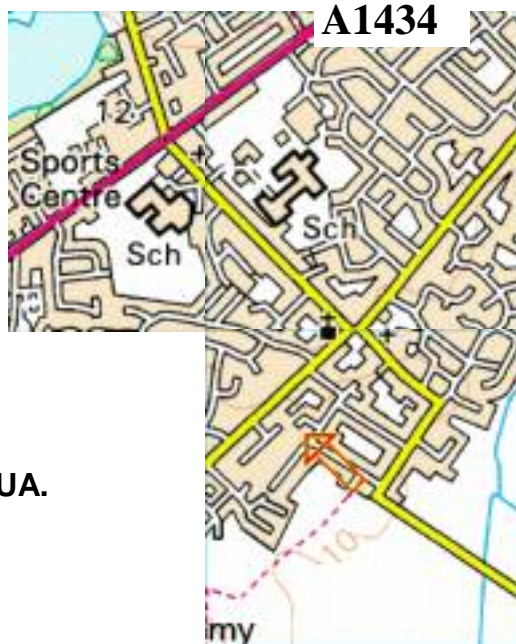
Lincolnshire Post Polio Network

Annual General Meeting

Saturday 22nd October 2005.

10.00 to 4.30 p.m.

**North Hykeham Day Centre,
Neale Road,
North Hykeham, Lincoln, LN6 9UA.
Tel 01522 689534**



From the A1434 at the Traffic Lights
turn south onto Moor Lane [between Schools]
At the traffic lights at the crossroads turn right
Take first left onto Clarke Road, Right on Perney Crescent, Right on Neale Road
and the Day Centre is on the right at the end of this cul de sac.

Plan for the Day

AGM commences 10.15 a.m.

Followed by Speaker at approximately 11.30 a.m.
Mr. Mark Rainey, Social Services, a Carer Services Co-ordinator

Lincolnshire County Council Social Services Directorate is developing a countywide service to provide information, advice and support to carers through a single point of access and a coordinated network of partner providers. Mark is asking for this to be a two way discussion. He will explain what the new service is all about and then would like to hear from members as to any problems that their carers have experienced. An ideal opportunity for us, especially our Carers, to learn more about the new Carers Assessment and bring forward problems that we have experienced.

Buffet Lunch approximately 12.30 p.m.

2.00 p.m. Speaker - Dr. Darren Barnes-Heath, BSc, D.C. C.C.E.P.
A Doctor of Chiropractic specialising in Neurological conditions in Lincoln.

Chiropractic specialises in mechanical disorders of joints, particularly those of the spine, and their effects on the nervous and muscular system. It is now State Registered and is the third largest primary healthcare profession in the world, after medicine and dentistry. Darren will explain how he assesses and treats Polio Survivors and looks forward to answering your questions.
Tea, Raffle, General Questions and Chat ending at 4.30 p.m.

PLEASE POST OR EMAIL INFORMATION FROM ENCLOSURE RE AGM.

Emotional Impact

Yesterday I was hit by a ball of anger that I have not experienced in a long, long time. Pure hard cold anger that has caused me to have a huge temper tantrum. This is the emotional impact that PPS has in my life at times. I had dealt with this anger on a large scale before I found out that I had PPS.

All I knew at the beginning was that I was losing life as I had known it and I didn't know why. When one of my Doctors talked about putting me in the hospital entirely for depression, I went into a huge rage. I knew I was angry. Big time angry but I knew I had a problem. The problem was physical. No, I couldn't explain why I would vomit so hard and long that I would end up in the hospital. (I vomit when I get extremely fatigued). I also have SLE (Lupus). Doctors blamed my problems on that until my lab reports started showing that my Lupus was coming under control.

I couldn't explain why I fell several times a day. I couldn't explain why I was so exhausted by the time I got to work that I couldn't stand long enough to look up documents in the files for the boss. My supervisor started doing the stand up stuff for me if I needed to stand when I first got to work. I couldn't explain why I reached the point during each day when I could not hold a pen and there was no way I could put enough pressure to get copies through the multiply carbons required. Then, the fastest, most accurate key punch person in the office started making errors. Why in hell was my left hand no longer working properly on the computer?? Angry?? YES!! This was in the late 80's. Thank God not all of my Doctors turned their back on me.

But it was an old friend who brought a

news paper to Robert and showed him a long article about PPS. This lady is about 2 or 3 yrs. Older than me. She was a neighbour when I had Polio. She remembered. She knew of the problems I was currently having. That was amazing. I read and reread that paper. I was reading about people who were having the same problems I was having. Doctors had treated them as the one Doctor had treated me.

There was a phone number for more information. I called. The lady who answered spoke in low tones. She had trouble breathing. After a few questions she gave me a crash course in making the best of it and resting more. She frightened me. I had a lot of but, but, but, but and she was reaching the point she couldn't talk much longer and with much irritation she explained that she could no longer wipe her own butt. She asked me if I wanted to be in the same condition!! Talk about getting my attention - she got it!

Within the same week, another friend brought me a smaller article from a magazine. It was small enough I knew my good Doctor would read this all the way through. The article and I went to the Doctor. He read every word twice! When I left his office, I had an appointment with a Neurologist who had just returned from a conference about PPS. And that was the beginning of knowledge, progress and a complete new way of life. I learned quickly. The Neurologist used me to teach others. But, I did not talk with this Doctor or any of my other Doctors about the anger I was dealing with.

I was very busy adjusting, adjusting and helping others do the same. Even so, days would come when I would struggle with the emotional impact of all of this. My response was cold, hot anger! I

learned to tell my family that I was not angry with any of them. I was having trouble dealing with all the changes in my life.

Yesterday, my son, Daughter-in-Law and Grandson came for a visit. They brought a Blackberry Cobbler that they had picked the berries on their property and son had baked the cobbler. We had a perfect visit. It was too hot, but I went outside to check on my flowers. I came inside to cool off once and went back out and did some transplanting. Yes, this kind of work is demanding but it is one of the things I love and can still do with in limits. LIMITS—LIMITS—LIMITS.

The old anger hit me hard and unexpected. Robert thought he had done something. The dogs went to another room. I explained my emotions to Robert. Robert likes to fix my problems. He was/is helpless to fix this!! My butt hurt from sitting so long in my wheelchair. My back hurt. My shoulders hurt. I could deal with the physical pain.

The emotional impact - that's another thing. You can't rub your emotions. You can't put a heating pad on them. I was dealing with too much anger to go to bed where I needed to be. This was the first time this amount of anger has boiled within me in a long, long time. I didn't see it coming. I was shocked. I was disappointed in myself.

I had a visit with myself. OK, so it's been a long time. Even so, I still remember my other life. I wanted my other life back. There was no way to get it back. I like to get what I want. Day light was about to peek upon me before I went to bed. But, me, myself and I had come to terms with each other.

I wish I could honestly say that I'm so happy & bubbly and life looks so good

this day. That would be a lie and that would be pushing my emotions in the corner instead of dealing with them. I will not push my emotions into a back corner of my mind. I will face them. I will be fine. I've fought the anger before.

Being me, I don't expect to ever be thankful that I have PPS and SLE. Being me, I will survive and laugh and play and work and enjoy life. The rocks, bugs, flowers, family, sun, rain, snow and friends and the many, many wonders of life. I will enjoy them. I will be thankful for my wheel chair and all the other items that give me such a full life.

Why do I share this?? We have some new members. I want to tell you, hey, it's ok to be upset with the changes in your life. You will react in your own way.

We are all different even though we have so much in common. I also want you to know that you can share your problems with the emotional impact just the same as you can share your physical pain and just the same as you can share your smiles.

All my love to each of you, be you new to PPS or be you an oldie.

MARGARET E. DAVIS, Arkansas.
<med43@earthlink.net>

[Margaret gave us permission to use this text from an email she posted to the St. Johns University Polio Email List. She would love to hear from other PPS'ers, especially those in the UK. If you don't have email then write via our main address and we will forward your letters. Why not add a leaflet about where you live.]

LincsPPN Members Email List—If you have email and are not subscribed [or have changed your email address since subscribing] and want to join email membership@lincolnshirepostpolio.org.uk

I can deadhead and prune again

Dear LincPIN,

Having a weak left hand, and needing to hold onto something, due to unstable legs, while deadheading and pruning in the garden, I have been searching garden centres while on holiday, or here locally, as well as newspaper advertisements for one handed secateurs—without success.

After 12 months and nearly giving up, I contacted the British Red Cross who gave me the address of a firm in Sheffield. The girl who answered my telephone call (Jo) knew exactly what I wanted and took my order.

These secateurs arrived in just over a week, are well made, and what I have been looking for, and work as expected. I can now hold onto something and do my deadheading without falling into my rose garden. Incidentally they can be adjusted to the thickness of the stem.

Barry Branston.
Chapel St. Leonards,
Lincolnshire.

I contacted the Company for a catalogue and they recommended that we also look at the following tools.

1. Topiary Shears — Hand forged in our Sheffield factory from high-carbon steel, these shears are already recognised by the Arthritis Society for their ease of use. They are used single handed, leaving the other hand free, and are suitable for all types of topiary and soft garden trimming.
2. Circlehoes — Brilliant weeding tools from the USA which make for effortless weeding and healthier plants. Suitable for general maintenance of a weed-free environment in cultivated soil - particularly in heavily planted areas.
3. Winged Weeders — Suitable for very fast and effective weeding in shrub beds (in already cultivated soil) - without having to bend over. These tools use a four bladed head to slice through the top layer of soil, consequently preventing 'dry-out'.

CUT AND HOLD PRUNER Amazing and incredibly ingenious gravity defying cutters for thorny stemmed or skin irritating plants - from roses to brambles. The action of squeezing the handles together to complete the cut also causes the gripping device to lock the stem holding it securely in place for release into a flower basket, trug or compost heap, without having to pick it up. The cutting mechanism of these pruners uses a 'bypass' action to ensure the cleanest healthiest cut. GTO/CHP



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HAVE YOU FOUND ITEMS THAT MIGHT HELP OTHERS?

Dear LincPIN,

I would like to express my appreciation for all the work that Hilary has done in the preparation of the new self assessment forms that were introduced at the International Conference in St. Louis this past June. I know how much time and effort went into it because we discussed these forms by e-mail for many months prior to their final finished product. It shows the true dedication of someone who is willing to put herself out there to help others with pps. I truly hope that people still having difficulty with their GP's will use these forms and discuss them with their doctors. Dr CarolVandenakker, who was their reactor at this conference is doing great work at her clinic at U.C. Davis in Sacramento, California and every time I visit the staff comment on how thrilled they are to have someone like her on the staff and how much her patients love her. I would not have found her if it had not been for Hilary so my hat is off to her for all her dedicated work.

I read the article in the last LincPIN about eyes but I think my problem is slightly different. My right eye weeps a lot and a doctor I saw prior to Dr. Vandenakker said that she noticed that the right eye blinks slower than the left. My vision blurs after any concentrated use e.g. reading, Knitting etc. (that is, close work). It tends to take about 30 minutes for my eyes to readjust. According to an ophthalmologist I visited a few months ago there is nothing wrong which leads me to believe that this is another result of polio (possibly bulbar). I would be interested in hearing from anyone who may have similar problems and if they have found anyone in the medical profession who has any thoughts on it. I can be reached at evh@pacific.net or write to me via the main address.

Jean in California [lived in Lincoln UK as a child.]

Another snippet from Western Australia Post Polio Newsletter,
June 2005 (Vol 16: no2):
Tessa Jupp, RN.

“Problems with SLEEP??

I keep getting people in with disturbed sleep and poor memory problems. Taking zinc before bed at night has helped so many people. If you can't turn the brain off, and you keep thinking – take 2-4 chelated zinc gluconate tablets (each tablet will be about 4mg elemental – which is 27% of the EC recommended daily allowance) – it helps with short term memory loss too”

Note from Mary: I decided to try this advice recently, and I have to say it seems to be working, and I have had no adverse reaction. I have reduced my normal 10mg dose of amitriptyline at night to 5mg, and am getting a reasonably good night's sleep. (This is also if I give myself the chance to wind down before going to bed). You could try the extra zinc at night whether or not you rely on amitriptyline (elavil in the U.S.).

Mary Kinane. Chair. mary.kinane@lincolnshirepostpolio.org.uk

Help out in a crisis - with ICE

A Cambridge-based paramedic, Bob Brotchie, a clinical team leader for the East Anglian Ambulance NHS Trust, has launched a national campaign to encourage people to store emergency contact details in their mobile phones.

By entering the acronym ICE – for In Case of Emergency – into the mobile's phone book, users can log the name and number of someone who should be contacted in an emergency, e.g. ICE daughter.

Follow these hints to get the best out of ICE:

Make sure the person whose name and number you are giving has agreed to be your ICE partner. Make sure your ICE partner has a list of people they should contact on your behalf - including your place of work.

Make sure your ICE person's number is one that's easy to contact, for example a home number could be useless in an emergency if the person works full time.

Make sure your ICE partner knows about any medical conditions that could affect your emergency treatment - for example allergies or current medication.

Should you your preferred contact be deaf, then prefix the number with ICETEXT.

For more information see <http://www.icecontact.com/>



Pictured having a get together in Southport are from right to left - Di Brennand (LincsPPN telephone team), Anne Ashcroft, Judy Barker (LincsPPN telephone team) Ann Jones and Carol Lenton.

All suffer from PPS apart from Carol who was affected with transverse myelitis two years ago. Carol's husband Dave who took the photo, also has PPS. The group get together every couple of months for a chat, coffee and exchange of news and ideas. Why not form a friendship group around where you live with other PPS sufferers? Put a note in your GP's surgery or library. It only has to be a handful of people for informal get-togethers, support and friendship. Our group is full at six, just enough for each others sitting-rooms." Di Brennand.