

Home of the  
Lincolnshire  
Post-Polio  
Library



# Polio Survivors Network

PO Box 954, Lincoln, LN5 5ER  
☎ 01522 888601

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

[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

Registered Charity No. 1064177



## HOT OFF THE PRESS - JUNE 30<sup>TH</sup> 2015

Polio Survivors Network are members of Post-Polio Health International.

LET'S PUT Polio Survivors Network Polio Survivors on the Map.

SEND PHOTO's to us and we will forward them or SEND to PHI.

A few of the photos will with your permission be in November Newsletter

Post-Polio-Health-International, St. Louis, Missouri, USA

## WE'RE STILL HERE! 2015 Photo Contest

### Show Me Accessibility!

What activities do you now enjoy that were previously impossible to access? What places have you now visited that were previously inaccessible? Send us a photo that illustrates the ability to access the activity or location.

Help us document that people who had polio are still here, active and involved thanks to laws such as the Americans with Disabilities Act or the UN Convention on the Rights of Persons with Disabilities.

Post-Polio Health International will select a grand prize winner (\$150 USD) and 4 runners up (free PHI Membership for 2 years).

The runners-up will be announced October 12-15 with the announcement for grand prize to follow on October 16.

Contest rules:

- Print or digital (JPEG with a minimum of 300 dpi) photographs will be accepted. Print photographs will not be returned.
- Color or black and white photographs will be accepted.
- Identify the location and date of the photograph and include an explanation of how accessibility laws made the picture possible. Submitting a caption is optional.
- Each person is limited to submitting two photographs.

NOTE: By submitting the photograph to PHI you are confirming that the photograph is your property/work. You are agreeing to its limited use by PHI. PHI will state with the winning photos the following: Photo by (Name). Permission to use must be obtained through PHI. Decision of the judges is final.

Deadline to submit a photograph to [info@post-polio.org](mailto:info@post-polio.org) is 12:00 pm CST on October 1, 2015.



# POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 8/12  
n.b. Volumes 1 to 6 published under the name LincPIN.  
[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**JUNE  
2015**

**Vol 8, Issue 8/12**

**178 DAYS  
AND  
COUNTING  
DOWN  
TO CHRISTMAS**

**POLIO  
CASES**  
1/1/2015  
to  
30/6/2015  
Afghanistan  
**24**  
Pakistan  
**3**



Home of the  
Lincolnshire  
Post Polio  
Library



Enter 100+ articles

**How far in time and distance  
with less pain and fatigue  
do you think you might be able to go?**



**Message from Linda Cannon Rowan to Hilary Boone, June 2015.**  
Remember when you were first online in about 1997 and you were still in denial. I thought, "this gal is crazy. She will live to regret this.'

**Leigh Lewis Trimble - page 12** - My world opened up, rather than closed down, with the use of a powerchair. There are some downsides but as a whole having the use and manoeuvrability is liberating.

**All PPS Support Group leaders at Conferences report** that so many members say 'I wish I had started using this [aids and assistive devices] before, why was I so stubborn, life is so much better now.'

Polio Survivors Network Newsletter - Volume 8, Issue 8/12  
n.b. Volumes 1 to 6 published under the name LincPIN.  
[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**Mobility  
Roadshow  
One Day Events**

**July 23rd  
Westpoint  
Exeter**

**August 6th  
Peterborough  
Arena**

**September 12th  
Stoneleigh Park  
Coventry**

**NAIDEX  
26th to 28th  
April 2016  
NEC  
Birmingham**

**Page 17 and 18  
Items from  
Post Polio  
News  
ppn  
www.post-  
polio.org.uk**

**RADAR KEYS  
Access to  
Disabled  
Toilets**

**https://  
crm.disabilityrig  
htsuk.org/radar  
-nks-key**

**Contents**

Page 2	You are reading it ☺
Page 3	Editorial by Hilary Boone.
Page 4`	Message from our Chair, Simon Parritt
Page 5/6	AGM was so much more by Trustee Dot Ives
Page 7	Member Michelle Maher writes... Disability issues.
Page 8/9	The Continuing Sagas of Dot.
Page 10	Sign my petition Member Zsuzsanna Snarey plus
Page 11	The story of Hepatitis C or is it PPS or both by Member Zsuzsanna Snarey.
Page 12	The wonder of life with a power chair by Leigh Lewis Trimble.
Page 13	New Trustee Margaret Marris writes.
Page 14	Breathing and Swallowing Problems from Post-Polio Health Care Considerations for Families and Friends.
Page 16	Punicious Punography, Mobility Show information plus.
Page 17	Post Polio News items a service by Member Chris Salter
Page 18	More Excerpts from Post Polio News.
Page 19	Contact and Membership details.
Page 20	Back page - Staybowlizer and Val Scrivener Cards info.

**New Members and Donations received.**

**Thank you to all members who have recently renewed.**

**New member Erika Gehrig, Switzerland.**

**Donations from January 1st 2015**

David Marris, Barbara Smith, Barry Branston,  
Olivia Branston, Christine Darlington, Susan Freeman,  
Tony Scrase-Walters, Dianah King, Lynn Hobday, Shirley Rose,  
Diana Nash, Yvonne Grosse, John Ward, Clare Colfer,  
Jennifer McGowan, J Dunn, Bridget Langdon, Ian Downing,  
Denise Carlyle, Michael Whitely, Maureen Allison,  
Val Scrivener for all her time making the Photo Cards.  
University of Lincoln and Dot Ives

Donations with Membership - £186.00  
Donations specifically for AGM - £287.00  
Donations towards Conference and Meeting Fund - £445.00  
Donations for buying Val Scriveners Photo Cards - £70.00

**Total to 1st June 2015 - £988.00**

Thankyou for buying Val Scriveners Photo Cards and ticking Gift Aid.

This publication is provided as a service to those seeking such information and is not intended as a substitute for professional medical care. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Polio Survivors Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

Articles in this publication may be reprinted in full with acknowledgement of this Newsletter name, volume, issue and date. Exceptions are where written by an external author/newsletter when permission must be gained from the original author/s.

## Editorial by Hilary Boone

I am really sorry that this issue has been delayed due to an increased personal workload trying to have Richards health issues addressed properly by the local NHS [started this in January] and then Lincolnshire County Council dropped a bombshell telling me my pension had been overpaid for 19 years. The good news is that the overpayment has been written off and the not so good news is that now we wait to see how much our Pension Credit will be to find out how much we now have to live on each month. N.B. Pension Credit, as a minimum you will not get a response till 28 working days after they have received your letter.

**The AGM** went very well, see Simon and Dot's reports overleaf. I would personally like to welcome Margaret Marris - A carer and ex midwife - as a Trustee and as an added bonus she lives a mile away. It is good to have a CARER on board as she sees PPS and how it affects her husband David from a different viewpoint from those of us like me who have a partner with pps or other medical conditions. Any other Carers or Family Members who would like to join us as a Trustee or just as part of the team? [See page 13]

I would also like to thank both Ann Parkinson and Maud Berneburg for giving up their time to tell us about their work. Richard and I have benefited considerably from the therapy we have received from both of them and Dr. Darren Barnes-Heath from Newland Chiropractic Clinic. It is great to have health professionals who are happy to share information, e.g. when you next see 'x' tell them that 'y'. [see pages 5 and 6]

**Front Page.** I will have 20 years - this November - of listening to other polio survivors life stories and new issues since I found PPS existed. I was responding on a Facebook post polio list to someone who new to PPS was having difficulty taking on board pacing and resting and using aids and equipment when Linda Canon Rowan responded with 'Remember when you were first online in about 1997 and you were still in denial. I thought, "this gal is crazy. She will live to regret this.' I had to admit she was right, I was in Denial for those first few years and so remember seeing a Registrar at a Rehabilitation Appointment who asked me... "Have you read your latest newsletter?" I said, "of course, I put it together". I was a bit stunned when he then said "Well why do you not take the advice that you advise others to take on board?" I said, "But I am not there yet!" He said, "I have news for you, you were there at least three years and possibly more years ago". I am sure you will all agree changing the habits of a lifetime from doing it all and more is very hard. How many of you, like me, can now say that we are managing life much better now with less pain and fatigue levels, now we pace and rest and use different aids as the event suggests or ask other people to help us with some of our tasks - although it is still not easy?

**HOT TIP.** I just realised my left shoulder is aching again. This has happened a few times recently when I have forgotten to put my recliner chair to recline and supported my neck and arms as I type on my laptop. I have also been having increased wax in my ears and it has been suggested that this is being caused by my neck muscles [scalenes] being under strain and that they need stretching/massaging on a regular basis.

**Independent Living Fund** that provides support for 17,000 closes today June 30th 2015. Scotland and Wales are not closing theirs. There are numerous reports that demonstrate a poor hand over from ILF to local Councils who will now take over the responsibility of supporting them.

**The Budget on July 8th** will be upon us shortly and we will find out what changes to Benefits are forthcoming. It is a worrying time as it comes alongside the continual Council and NHS cuts - having to save billions of pounds.

**Page 7 is a report from PSN Member Michelle Maher from the WOW Campaign.** DLA, Disability Living Allowance is closing and being replaced by PIP Personal Independence Payment for anyone over 16 born on or after 9th April 1948. You can continue to get DLA if you were born on or before 8th April 1948 if you are eligible. I am older than this but Richard was born in 1951 so we wait for the forms and yet another stressful time whilst we go through the procedure. On top of this he is now being referred for a Personal Health Budget Assessment. Have any members been through this procedure?

## MESSAGE FROM OUR CHAIRMAN - Simon Parritt

**AGM THANKS** - Firstly let me thank all those who came along to the AGM this year and apologise as Chair, for only being there in a virtual sense [Skype video call]. The AGM is a vital part of running a charity and I hope those who came enjoyed the less formal part of the day. I also wish to give a big thanks to Hilary for organising it and actually making it happen. I would also like to welcome Margaret Marris who has volunteered to join us on the trustees committee, we are always looking for people to help out in any way and new blood on the committee is more than welcome.

**RELATIONSHIPS AND ASKING FOR HELP** - This brings me onto my theme for this edition, the hidden costs of asking for help, intimacy and relationships. Many of us have led full lives and much of our philosophy as polio survivors has been to 'getting on with life' and 'make the absolute most of what we have' often at some cost be that physical and, or emotional. However, as we age we should not be fooled into thinking this is a 'normal' or any longer an ideal or a sustainable way to carry on. The problem is that help may come at a price, and I am not talking money. If we ask for help, the mere act of asking puts us in a position of being grateful, be that explicitly or implicitly. Of course we are grateful but that isn't the point, unlike many people, there is little choice as help is something we increasingly need from those around us and society in general. Those who we ask are rarely able to truly understand the psychological impact of being assisted in simple everyday tasks, the frustration of not being able to do it our way and especially having to always think of the helpers' feelings when they are helping us.

I suspect you, and almost certainly those around you, may not have thought this through, but do you ever get irritable or 'switch off' when being helped with something that non-disabled people can do for themselves, their own way, without a moments thought? Think how it feels to have someone brush your hair or shave you. It isn't easy for someone to do it right, at least not without direction and practice. Over the years we may learn to suppress feelings of frustration and 'put up with' having to accept compromise. To be grateful and to deal with the feelings of those non disabled people around us. How much do we hold back feelings of irritation, anger, frustration and, as we age with polio, does this increasing return to needing assistance make this increasingly problematic? Indeed for those of you who recovered almost completely before PPS kicked in, even the notion of being a disabled person may pose challenges as you are plunged into a whole new identity as a minority group.

When I worked in geriatric medicine in a hospital, I was struck by the way certain patients were termed 'difficult' by staff. Of course, this sometimes was a fact of their personality, but often it was a response of people whose lives had gone from non-disabled and self sufficient and the supporters of others, to being more dependent and now being expected to be 'good patients'. Ideally we all try to be polite and civil but having to say thank you every time, not show anger and frustration with how we feel and behave 'correctly' to ensure care is delivered, can take its toll.

**RELATIONSHIPS AND INTIMACY** - It is not uncommon to see these feelings when I work with couples and individuals where increasing impairment changes the dynamic of peoples' lives and need of assistance. Everything from housework, shopping, work, sex, travel, socialising and holidays become areas where accommodating to changing functional ability creeps up on us. It is still not an accessible world socially or environmentally. How do our partners and friends deal with this? How do *we* deal with how *they* deal with it? Is it ever an area of discussion? As both a counselling psychologist and a psychosexual and couple therapist, I know that sex and intimacy can be a barometer for how we are and also sadly ignored or taken for granted. So when all is well in this area of our lives it is hardly thought about or noticed. However, as things change gradually it can become a silent but increasingly major issue for some that is just not talked about. It can spill over into irritability, depression, sadness, isolation, increasing illnesses and even sometimes separation. I always like to think that as polio survivors one side effect of dealing with our body's capabilities and our lives has been to ensure we have to think and act more creatively than those non-disabled people. So potentially in our sexual and intimate relationships this can prove an especially useful skill. However, this isn't true for all due to upbringing, beliefs, family stresses, opportunities and just bad luck.

**SEXIER LIVES EQUALS HEALTHIER LIVES** - Much is talked about pacing and adapting and the use of assistive devices, but how often does any healthcare professional incorporate sex and personal relationships in their assessment? Would you ever bring it up? Do you even pay attention to it? It is worth noting that whatever your impairment, whatever your age, whoever you are there is no impairment in experiencing a healthy and fulfilling intimate relationship. OT's and physiotherapist are well placed to help with the practical issues, pain management is also something that can be addressed and psychosexual and relationship therapists can help with the relationship side. Unfortunately this is a neglected for training and funding and so once again it is left to us to be pro active and ask for what we need, in what can be a quite embarrassing area. I would just say that although many of us are aging and some sadly do not have partners anymore, research consistently shows that an intimate relationship and, or, sexual expression contributes to a longer, healthier life with less depression, and reduced experience of pain and illness.

As the last Director of charity SPOD (The Association to Aid the Sexual and Personal Relationship of People with a Disability), which closed now over 10 years ago, this has always been a special professional interest of mine. I passionately believe in this as an important part of healthcare and should be an important part of all professional training, sadly this is still rarely so. I am of course always ready to answer any queries or issues around this area of relationships and, or sexuality and intimacy in complete confidence or point people in the right direction.

**Simon Parritt, C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP**

Chartered Psychologist. HCPC Registered Counselling Psychologist, [www.sp-psychology.com](http://www.sp-psychology.com)  
Chair Polio Survivors Network.

Simon Parritt <[simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)>

### **AGM was so much more! - By Trustee Dot Ives**

Some of you may be aware that I am a relatively newcomer to PSN and AGMs and indeed to post polio really. It could be said that I am a novice and still in denial most of the time – constantly pushing my still able body to its limits!

This was my third AGM, the first with Guest Speakers – it was not to be missed. The 'day' opened with friendly smiles, refreshments, a calm Richard and a slightly, ever so frazzled Hilary! (She really needs to delegate more! ..... or even delegate anything)!

Hilary opened proceedings with her presentation: 'Painting the Same Picture Can Improve Clinical Outcomes' – more of this has been in earlier newsletter. The other Speakers were: Ann Parkinson, Neurological and Pain Specialist Physiotherapist and Maud Berneburg, Massage Practitioner, reflexologist and Reiki Master

Ann spoke knowledgeably and intuitively about her work with patients with neurological conditions focusing upon the late effects of polio. She is Hilary and Richard's physiotherapist so has no doubt earned her wings!

Ann explained what neuro-physiotherapy is and gave an excellent overview of her skills based work. She looked at specific issues, self management, goal setting exercises, respiration, pain, pacing and so much more!

I am always being told by my energetic friends that I should exercise more. Ann explained that non-fatiguing exercise increases muscle strength and decreases fatigue. That we should pace and do aerobic exercise at intervals during the day – not heavy and intensive exercise. Non swimming water based exercise may be helpful. Find what is right for you. All exercises are individual. As a general rule, avoid stretching weak, floppy areas – if it causes fatigue or pain – STOP. Music to my ears! Ann promoted a variety of exercises: gentle yoga, Pilates, tai Chi. (Tai Chi helps in reducing falls).

Too many excellent things were talked about by both Speakers. As a person who is often tense,

prone to shallow breathing and much teeth gritting I took particular notice of the fact (that I knew really) that breathing out is relaxing and if you breathe in and grit your teeth this increases tension. This puts increase pressure on your body.

Importantly, she emphasised that if you have a neurological condition you need to see a neuro – physiotherapist. Ann also promoted use of the Bobath Approach. Ann finished by talking about mindfulness approaches and demonstrated a 'guided relaxation' technique. There are different routes within the differing NHS trusts to find a neuro physio. Ann says we need to look at provision locally and get our GP to refer. Alternatively we could opt for the private option – *Physio First* would be a good starting point. ([www.physiofirst.org.uk](http://www.physiofirst.org.uk)).

This led nicely to Maud who talked about alternative therapies. Maud is a mobile therapist who uses a holistic approach. (Hilary says she has helped her to relax – so she must be good)! Her therapies include: aromatherapy, massage, reflexology, Hopi ear candling and Reiki. She provides her services within your home and tailors her treatments to your individual needs.

Maud explained that she focuses on 'healing energy' and provides a gentle approach. She explained that treatments need to be modified for people with chronic conditions.

Reflexology 'eases' conditions. Your foot is a micro-system of your body. Reflexology is now used widely in Cancer Treatment centres working on the lymphatic system to give relief and change. Reflexology is also powerful in easing the 'symptoms' of many conditions such as constipation. (It 'works' in three or four hours apparently)! It also helps relieve the tensions that scar tissue aggravates and helps with tiredness and fatigue; helping the body to re-charge and energise.

Whilst your neuro physio will have a more lasting response. Maud's treatments are 'golden time' – time for you to relax and enjoy! See bottom of page for her details. (I wonder if Redcar is within her visiting range)?

Finally, I finish with a quote from Ann at the beginning of her talk:

***“As I breathe in I am calm ..... as I breathe out I smile”***

(Members from Somerset visiting locally for a family event broke away to specifically listen to Ann's presentation. I do hope they found it useful and left more knowledgeable, relaxed and calm)!

Lincoln Neuro Physiotherapy,  
Lincoln Physiotherapy and Sports Injuries Clinic,  
8 Mill Lane, North Hykeham, Lincoln, LN6 9PD  
[www.lincolnneurophysio.co.uk](http://www.lincolnneurophysio.co.uk) - Tel: 01522 688699

Lincoln Neuro Physio is a professional, caring Lincolnshire physiotherapy practice, specialising in the treatment of neurological disorders along with posture, movement control and balance rehabilitation for those without neurological conditions. We also specialise in treating chronic pain. Through our techniques and rehabilitation programmes, we're here to offer support for conditions that affect the brain, spinal cord and nerves. When pain persists the brain and nervous system change, calming the nervous system and working to retrain the brain is a vital part of rehabilitation for those with chronic pain.

**In Touch Holistic Therapies - Therapeutic Massage and Reflexology**

[www.intouchholistictherapies.com](http://www.intouchholistictherapies.com)

Mob: 07984 592 808 - Email: [intouch123@talktalk.net](mailto:intouch123@talktalk.net)

A warm welcome to 'In Touch' Holistic Therapies, a mobile complementary therapy service for Lincoln and the surrounding villages. Enjoy your individual holistic treatment in the comfort of your own home and relax!

Choose from a range of high quality Therapeutic Massage treatments, Reflexology, Reiki and Hopi Ear Candling. Maud Berneburg MIGHT

**Member Michelle Maher writes...**  
**[WOW Campaign on Facebook and**  
**Twitter <https://twitter.com/WOWpetition>]**

Sick, disabled and carer's are well aware of the cuts to services over last five years; running the gauntlet and stress of work capability assessments and PIP. So far statistics are showing under reassessments from DLA [Disability Living Allowance] to PIP [Personal Independence Payment] , that **1 in 3 is losing the higher mobility component, and therefore their cars.**

We wait for the mini budget on the 8<sup>th</sup> July when Osborne will finally let us know where the cuts to welfare of £12 billion will fall. Leaked documents before the election and Ministers refusal to deny cuts to disabled and carer's have fuelled uncertainty. Osborne announced today [22.6.15] that they have finalised the cuts with working tax credits for poorest workers being a definite cut. The remaining billions still unspecified.

This week in Westminster Hall in a debate on the delays to PIP the new Minister for Disabled, Tomlinson, was asked more than once to confirm PIP would not face cuts. He was asked to settle disabled people's fears following rumours, he refused to answer. Hunt was asked the previous week in the House of Commons to confirm carer's would not face cuts; again there was a refusal to deny. Rumours and leaks have so far included;

**Taxing Disability Living Allowance/ PIP**

**Cutting Carers Allowance**

**Cutting Contribution based ESA.**

**£1 billion further cuts Social Care**

8<sup>th</sup> July hangs over our heads like The Sword of Damocles so we have to hope for the best. The Minister for Disabled confirmed the roll-out for reassessments from DLA to PIP will start this October despite the delays and backlogs that exist. Can I take this opportunity to advise people when completing forms, always take copies, send forms by registered post if possible, always take someone with you to any meeting and always be truthful giving full picture of your disability, I know it is hard but put pride aside because they won't. Be careful how you get there they will ask and hold it against you, if you have walked caught a bus they will count you as able. If you get a taxi you can claim it back. Be aware that are looking to take away support not give it.

I was fortunate to be fit enough to attend People's Assembly march in London yesterday, well I attended I didn't march much [because I can't] but the atmosphere was amazing. 250 000 people there and all the speakers spoke of the attacks against disabled and the cuts they face. It was hearting to know we are not being ignored and people are noticing more than ever.

Please see links below on leaks and also link from Paul Lewis Radio 4 on disabled liable for paying carer's pensions.

<http://www.bbc.co.uk/news/uk-32084722>

Potential Conservative welfare cuts revealed in leaked emails <http://gu.com/p/473j2/stw>

Cameron fails to rule out cuts to disability benefits <http://gu.com/p/49ezf/stw>

Paul Lewis Money, Radio 4: WHO WILL PAY FOR CARERS' PENSIONS?

<http://paullewismoney.blogspot.com/2015/05/who-will-pay-for-carers-pensions.html?sref=tw>

[m.maher70@ntlworld.com](mailto:m.maher70@ntlworld.com)

**The Cut off Date for Disability Living Allowance holders NOT having to change  
to Personal Independence Payment is born on or before 8th April 1948.  
PIP Date Checker for when starting in your area - [www.gov.uk/pip-checker](http://www.gov.uk/pip-checker)**





## The Continuing Sagas of Dot!

This Spring and Summer that of 2015 (not 69 as the song goes) was going to be the start of a new, eagerly anticipated era. Might not be up there with the seven ages of man but definitely a new beginning in the ages of the Ives family!

I reached a milestone birthday in April and had been looking forward to retirement for almost as long as I have been working! In the meantime, this status was to be temporarily eluded whilst the local authority service I worked for underwent a sweeping review with cuts and reorganisation. Thus came to pass, instead of retirement I found myself to be deleted instead! Delightedly deleted Dot! This was to commence from 5<sup>th</sup> June.

Meanwhile as usual, fate, fortune, the Valkyries (or even just clumsy old me) put paid to this anticipated utopia. On Bank Holiday Monday, 4<sup>th</sup> May at 9.30am I slipped on a wet bathroom floor (one foot only was on the said floor)!

### **Fact 1: PPS sufferers are prone to fall (a lot in my case)**

It wasn't an elegant slip or slide down the wall it was a full blown 'feet from under you' thwhack on your back on the floor banging head on the wall – naked beached winded whale kinda slip! I thought 'No' as I flew through the air and '*not again*' as I landed on my poor back. As the pain seared across my back, ribs and head and I couldn't breathe it did cross my mind that I may have really hurt myself this time.

### **Lesson 1: Do not lock the bathroom door**

We will cut past the braying at the door by screaming husband, the two doses of paracetamol and tramadol whilst waiting for the ambulance / the 5 hour wait for said ambulance as it was classed as a non emergency (no bleeding head, no loss of consciousness, no loss of feeling in limbs). The walk under the influence of Entonox to said ambulance.....

### **Fact 2: PPS sufferers tend to suffer pain (as used to it)**

### **Lesson 2: Cry when in agony (stop being a martyr)**

Once in A&E things moved pretty quickly considering they were busy. I was given codeine, the initial medic frowning at amount of tramadol I had taken. I was lucid enough to say how much and when. He did not ask why I was taking tramadol and I didn't offer the information at that point. Perhaps I should have? Husband had remembered to bring prescription as well as bag with nightie and toiletries. He at least had the sense to know that I was staying for a while. I naturally, assumed I would be ok and walking out albeit battered and bruised in a couple of hours and stop causing a fuss! *We didn't mention PPS at this point – not that we were thinking it was relevant to the current situation – too wound up in what was happening.*

### **Fact 3: PPS sufferers have an innate (if misguided) belief that they are indestructible**

### **Lesson 3: Listen and pay more attention to your body**

Reality checked in with a nurse popping round the cubicle curtain to straighten my legs and being told not to move – this followed x-rays..... quickly followed by CT scan.

Result: 2 fractured vertebrae – T11 wedge compression fracture (on old fracture) plus T12 fracture [T is Thoracic - between Cervical and Lumbar]

**Dr:** “Did you know you have an old fracture”?

**Me:** “No”

**Dr:** “Have you fallen previously”?

**Me:** “Often”

**Dr and Nurse** looked bemused. A silence prevailed whilst they probably assumed I was a stumbling raving alcoholic! I glanced towards Husband. He was in a catatonic state.

**Me:** “I fall, trip, stumble because I have post polio syndrome.....(no response) I had polio when I was a baby – it effected my right leg ”..... “I also have sciatica in that leg....I often trip, usually forwards onto my knees. My knees have been x-rayed”!!.... I smile weakly.

**Neither husband or I expanded on this by explaining more fully the later affects of polio and Post Polio Syndrome.**

**A missed opportunity!**

In my drugged induced pain ridden and now increasingly anxious haze I assumed they had my medical history in the buff coloured folder in their hands!

**Fact 4: A & E personal file only has your A&E history (if any)**

**Lesson 4: Do not assume anything.**

**Fact 5: A & E staff had no idea what PPS was and appeared not interested**

**Lesson 5: Have multiple copies of the Patient.co.uk article on PPS to hand.**

**Lesson 6: train catatonic husband or your carer to explain condition and implications to hospital staff (as I was in no fit state to)**

Once on the ward, I did eventually have an extreme reaction to the drugs they were giving me, this included vomiting, an allergic rash around my torso, increased temperature, increased blood pressure, decreased pulse, shallow breathing. I was moved to a side room and monitored carefully for 24 hours. I did explain to all and sundry that I have PPS and thus may have funny / increased reactions to drugs and monitor readings. Apart from an acknowledging 'sound'.....(like a cough) more in response to that they have 'heard' me rather than 'listened'; no-one asked for further information or appeared interested in PPS.

**Fact 6 and indeed 7: The staff did not know about PPS and were not interested**

**Lesson 7: Make sure you have prepared information that you carry with you and keep copies in a file attached to your refridgerator parked with large Green Cross.**

**Make sure your Carer, Ambulance Staff take this with them.**

My PPS card about anaesthetics and meds was in my purse at home. Other PPS stuff in a file!

**Summary:** 12 weeks R & R in a back brace and crutches. Holidays cancelled, life and retirement on hold. Now awaiting bone density scan – likely diagnosis of osteoporosis.

Osteoporosis is strongly linked to the anti-cancer drugs I have taken for 5 years and linked to PPS. They are now listening!

**Conclusion: I feel lucky – it could have been far worse! Lessons learned!**

**The best article to have with you when speaking to a NHS professional**

**Post Polio Syndrome - Written by U.K. Doctors for Doctors**

**[www.patient.co.uk/doctor/post-polio-syndrome](http://www.patient.co.uk/doctor/post-polio-syndrome)**

### **Please sign my petition by Member Zsuzsanna Snarey.**

A very effective new drug is denied to patients diagnosed with Hepatitis C by the NHS even though NICE has recommended it on the grounds of being cost effective.

I have written to my MP about this but I need more signatures please!

Copy and paste the link below.

<https://www.change.org/p/british-government-george-freeman-mp-and-jane-ellison-mp-department-of-health-allow-patients-diagnosed-with-the-hepatitis-c-virus-access-to-sofosbuvir-recommended-by-nice-in-january-2015>

Zsuzsanna

Author of Escape from Communist Hungary

HCPC registered Chiropodist/Podiatrist

[www.eastry-chiropody.co.uk](http://www.eastry-chiropody.co.uk)

### **11 comments many disabled people have had said to them.**

- What's wrong with you?
- It's so good to see you out in Public.
- Yes we are accessible we only have two steps.
- I was just parking there for a minute.
- Wheelchair access is round the back, through the alleyway behind the dumpster, just knock and someone will take you through the kitchen.
- You can't bring that dog in here
- Can you drive? Who do you live with?
- Where are your Carers?
- Patting you on the head as you sit in your wheelchair and saying 'you poor thing'
- Which dessert would he like, does he take sugar?
- It's good to see you in public, because I could not invite you to my house.

### **Care Quality Commission**

The independent regulator of health and social care in England  
Check out your local Hospitals, GP Surgeries, Care Homes and more...  
[www.cqc.org.uk/content/our-new-inspection-model#reporting](http://www.cqc.org.uk/content/our-new-inspection-model#reporting)

### **REMINDER FOR MEMBERS**

**Have you changed your home or email address or phone number recently?**

**Did you let us know?**

**Have you told your family and friends you are a PSN member so they can let us know if you move, become ill or go into hospital?**

**If you do not have internet access, or you do but you are unable to find what you are looking for, and you would like to learn more about any of the articles included in this or any other post-polio newsletter then give us a ring to see how we can help.**

**01522 888601 (leave a message if there is no-one available to take your call)**

## The story of my Hepatitis C, or is it PPS, or both?

By Member, Zsuzsanna Snarey

I live in England, but I was born in Budapest, Hungary. In 1949 when I was eight years old, I contracted Polio. At that time there was no vaccine and in an attempt to give me some antibodies I was given some blood from a woman who previously had polio.

I recovered slowly and led more or less a normal life eventually walking with one stick. After finishing my degree I found a job, got married and gave birth to three lovely daughters. I became a science teacher and after retiring at age 59, I took up chiropody. Ten years ago, I was diagnosed with breast cancer and had two operations. That was the beginning of problems with my health. I experienced tiredness, aches and pains in my muscles and joints which I attributed to having to stop hormone replacement therapy and side effects of Tamoxifen. But after stopping Tamoxifen the symptoms remained and I felt that it was maybe due to PPS which can start after such traumas as operations. It took several years to get a diagnosis and in the meantime I was given painkillers. My caring doctor ordered blood tests in 2007, 2013 and 2014 which showed my liver enzymes were increasingly elevated, but he was not concerned and did not take any action. Last summer I saw a lady doctor who sent me off for further investigations in gastroenterology. That was when I was diagnosed with chronic hepatitis C infection {HCV}. Further tests revealed a moderate viral load of 738,748 IU/ml. This is the blood borne virus, passed on from infected blood through a cut but I had no idea how I became infected. I have never used drugs, never had a tattoo. I have been married for nearly 50 years to the only sexual partner I have ever had. It could have been through operations for breast cancer or that blood in 1949. It is probably pointless to speculate, but I can't help wondering. Apparently the virus can lay dormant for decades but I find it hard to believe that it had been lurking within my body for 65 or even for 55 years!

I am getting more and more disabled. I have a stair lift and a mobility buggy for outdoors. I find it difficult even to walk about in my home and have to use two sticks, whereas I used to use just one stick and only for going out. Luckily, I have a helpful husband who looks after me and I can still work as a chiropodist since it is a job I do sitting down. I wonder if my health would improve if I was given the new drug Sovusbuvir (Sovaldi) or Harvoni. It has a very high cure rate in just 8 to 12 weeks.

This new drug Sovaldi was approved in England for Hepatitis C early this year by NICE but it is being held back until the end of June or July by the NHS because it is expensive. They have been negotiating a price drop. First it will be given to the more seriously affected patients with cirrhosis. I am not sure that I will be allowed to have it. I have not had a test, so I don't know if I have cirrhosis, but at least I am not diabetic, nor HIV positive and my weight is acceptable. These are all against my claim for the medicine, but I live in hope that I might still get it! In the past I drank very little alcohol and since my diagnosis I have given up even the occasional glass of wine. I have written a letter to my MP and started a petition with Change.org to the British Government to allow these very effective new drugs to become available to those diagnosed with Hepatitis C before they develop more serious conditions such as cirrhosis or liver cancer and the need for a liver transplant.

If you are on the Internet, or have a family member who is, the link to my petition is on the top of the left hand page. Thank you.

Zsuzsanna Snarey

### From English is Easy—[www.tetraplegicliving.com](http://www.tetraplegicliving.com)

And why is it that writers write but fingers don't fing, grocers don't groce and hammers don't ham? If the plural of tooth is teeth, why isn't the plural of booth, beeth?

One goose, 2 geese. So one moose, 2 meese? One index, 2 indices?

Doesn't it seem crazy that you can make amends but not one amend?

If you have a bunch of odds and ends and get rid of all but one of them, what do you call it?

## The Wonders of Life with a Power Chair

By Leigh Lewis Trimble, Kilmarnock, Virginia, USA

I had polio as a child at age four, way back in 1948. I have been able to have a nice life walking with a brace on my left leg and forearm crutches. I graduated from college walking all over the campus sometimes barely making it to classes on time, but I did it. I met my husband who was a first year professor there and we were married and had three sons.

I am now divorced. When I hit my mid fifties I found that balancing going up and down stairs became increasingly difficult. I found this odd. I was aware of Post Polio, and had started to use my manual chair as a way of trying to save my abilities. I became more and more afraid to go places alone as I seemed to fall more often. I worried a lot. I broke a bone in my wrist and still tried to walk with the pain. Finally a friend and a doctor convinced me to find a post polio doctor.

When I was diagnosed with post polio my new doctor told me that I was not to walk any more than absolutely necessary. She said that I needed to use a power chair, and the manual chair would not do as my arms were also effected by polio. I had a scooter that I had used occasionally when needed and I started using that until I could get an electric wheelchair. I felt like the scooter made me look less handicapped. I hesitated to use a power chair. Using the scooter in the house was difficult as it was large and took up a lot of room.

Once I was able to get a power chair, I found that the whole world opened up to me once more. In fact there were things that I could do from the chair that I could not do with my crutches. I had always had to have either my husband or one of my boys help me do grocery shopping. I could push a cart but getting the bags in and out of the car and into the house was impossible. For the first time with a scooter or with a power chair I was free to shop on my own. Yes, sometimes I needed to ask for help reaching things being vertically challenged sitting, but I have quickly learned that people in general are more than glad to give a helping hand. I have also found out that helping someone else makes people feel good.

I have been using my power chair for about fifteen years now. I go to work in a business that my youngest son and I own. I manage the business end doing the books and answering the emails. I paint and sell my paintings. I have even taken care of my grandson when he was a baby from my scooter, and power chair. I found it much easier to care for a baby from my chair than it was walking with crutches. Lots of things have become easier I can carry things and move items around in the house. For the first time I can actually carry a plate of food to the table.

My world opened up rather than closed down with the use of a power chair. There are some downsides, but **as a whole having the use and manoeuvrability of the chair is liberating.**

Read more at [leightrimble.blogspot.com](http://leightrimble.blogspot.com)

**Leigh Trimble - [leigh.trimble@gmail.com](mailto:leigh.trimble@gmail.com)**

### **From brainyquote.com**

My disability exists not because I am in a wheelchair, but because the broader environment isn't accessible.

### **Stella Young**

Childhood vaccines are one of the great triumphs of modern medicine. Indeed, parents whose children are vaccinated no longer have to worry about their child's death or disability from whooping cough, polio, diphtheria, hepatitis, or a host of other infections.

**Ezekiel Emmanuel**

My advice to other disabled people would be concentrate on things your disability doesn't prevent you doing well, and don't regret the things it interferes with. Don't be disabled in spirit as well as physically.

### **Stephen Hawking.**

Obviously, because of my disability, I need assistance. But I have always tried to overcome the limitations of my condition and lead as full a life as possible. I have travelled the world, from the Antarctic to zero gravity.

**Stephen Hawking.**

## Margaret Marris, New Trustee and Carer to a Polio Survivor Husband.

A little about me; more about the difficulties in finding out what was wrong with my husband David

From the age of 16 years I was employed in the National Health Service.

Firstly as a Cadet Nurse raising to a Midwifery Sister, enjoying my relationship with Mothers, Partners, Babies and Staff. I therefore have been a carer nearly all my life until my retirement.

During my career I kept myself updated to all new techniques, equipment and medication. There was no such thing as Google you asked colleagues went to the library and on study days mostly at your own expense.

David had a very active life style working abroad, Climbing, Walking, Cycling and many trips out with our Motor home.

2010/11 he was prescribed Statins. Next came the muscle pain, GP said that the Statins were the cause and to stop them. His activities got less! Fatigue, pain, irritable, not sleeping and this was having such an effect on both of us. All he kept saying was "use it or loose it" I gather a phrase you all had said to you often with your childhood polio.

I was awake one night and Googled muscle pain and there it was Post-Polio Syndrome. I knew my husband had had Polio at the age of 5 yet the GP didn't. David went to the GP to tell him what we had found, and was informed "he had never heard of it". My mistake I should have gone with him

Second GP had never heard of PPS either. I was present but more concerned about the fact he had been fainting since October 2013.

Third GP and he too had never heard of PPS but listened and prescribed Gabapentin and a Hypertensive drug. Bloods taken.

Referral to a Rheumatologist. I printed a few pages off the PSN website relating to PPS and took it with us to the appointment and she too had never heard of PPS !!! But thankfully was willing to listen.

It's taken David a long time to learn to pace himself and many a 'discussion' well we say words on my part and plenty of answers on his. I now say if I were you I would do so and so. Hilary and Richard Boone have been very helpful for him as they can tell him like it really is and what they have had to do and gradually he started trying what they suggested.

He has sold his beloved Cycle and replaced it with a mobility scooter which he now keeps in the back of the car ready for trips out.

How I regret not being more assertive at the appointments. How do polio survivors and their partners like me or that are less assertive than me get appropriately assessed and diagnosed?

David was at the GP's this week and was asked if he would see a Student who was near registration and he agreed. David asked him what he knew about Post Polio Syndrome and he said he had not heard of it. We are now finding out what College of Medicine he attends so that we can write to them.

I don't think with my NHS background I would have said that "I haven't heard of it", because in seconds you can get information on a computer screen. We live a mile from Hilary and after all the meetings she has had with the local NHS how can they still not know about PPS?

I would like to start a Carers Column in the Newsletters and would love to share your stories, hints and tips how to deal with the strong wiled determined, dare I say stubborn, polio survivors in our families.

Email me at [margaret.marris@yahoo.co.uk](mailto:margaret.marris@yahoo.co.uk) or write to me via the Charity Address.

# Post-Polio Health Care Considerations for Families and Friends.

## IV Management/Treatment Ideas

### D. Breathing and Swallowing Problems

Many of the urgent requests PHI receives are from family members who call because their loved one suddenly ends up in the hospital on a ventilator. The key is to be prepared.

It is critically important for the families to be on the lookout for sleep and breathing problems in their parent or loved one, especially those who were in an iron lung or who "just missed being in one." Symptoms to watch for include:

- sleeping best while sitting in a chair or a recliner,
- becoming breathless while doing a little extra walking, work, etc.,
- noticing that a significant curve of the spine is getting worse,
- observing extreme grogginess, confusion and/or headaches in the morning that "goes away" after an half-hour or so,
- falling asleep during the day during unusual times., e.g., at a stop light, during a conversation, and
- having repeated bouts of bronchitis or pneumonia that can be related to a weak cough or to food entering the lungs (aspiration pneumonia)

As your loved one ages, respiratory muscle (e.g., diaphragm and those connected to the ribs) strength may decrease. It is particularly evident when lying down, because in this position, the diaphragm has to work harder both to pull air in and to push the intestines and other abdominal organs out of the way. These are generally out of the way when one is upright due to gravity.

Polio survivors with weak abdominal and chest muscles can't cough as effectively and may experience more episodes of bronchitis or pneumonia. Sometimes health professionals treat the pneumonias and bronchitis as they should, but may not determine and address the cause – respiratory muscle and coughing muscle weakness. Remember that with polio, there is generally nothing wrong with the lungs themselves, but with the muscles that enable the lungs to function properly.

Testing in these situations should include pulmonary function tests, which are mostly non-invasive. They measure the forced vital capacity (FVC) and consequently the strength of respiratory muscles by measuring the maximum amount of air one can exhale. Note: Typically, a person is administered this test while sitting in the upright position, but request that it also be administered when your loved one is lying down for reasons explained above. When looking for professional medical help, look for a pulmonologist who specializes in neuromuscular diseases, i.e., ALS, MD, etc., versus one who only treats diseases of the lungs.

Unfortunately, many articles written about sleep and breathing problems in polio survivors only mention obstructive sleep apnea (OSA). In obstructive sleep apnea, the upper airway collapses and blocks the flow of air so the person stops breathing periodically. Signs of OSA are snoring and daytime sleepiness. A sleep study can detect apneas and hypopneas (breathing lapses). Four percent of women and 9% of men nationwide experience obstructive sleep apnea, and at least that many polio survivors do. (Many sleep specialists think these estimates may be too low.)

Survivors also can have central sleep apnea (CSA), a condition in which the brain temporarily "forgets" to signal breathing muscles to take a breath. This is evident during a sleep study when there is no chest movement for at least 10 seconds, indicating that the individual is not breathing. Some people have mixed sleep apnea, which is a combination of OSA and CSA.

The solution for those with only obstructive sleep apnea is a CPAP machine – a machine that continuously blows in air through a mask worn at night or during sleep. This constant airflow

keeps the airway open, so one can breathe easily.

Polio survivors who have central or mixed sleep apnea or significant respiratory muscle weakness use a **bi-level device** (one that blows air in at a certain pressure when inhaling and at a lower pressure when exhaling through a mask over the mouth or nose). Others use a **volume ventilator or one of the newer multi-mode devices**. There is a wide variety of masks and breathing devices available on the market. Experienced pulmonologists and respiratory therapists can assist in obtaining the correct treatment and equipment.

Although your parent or loved one may not have breathing or sleep problems when initially checked, periodic testing is important because such problems may develop over time.

They may begin to complain of difficulty swallowing. Complaints include food sticking in the throat, difficulty swallowing pills, coughing spells during eating, food backing up from the throat, taking longer eating a meal and unintentional weight loss.

Because many of the muscles and nerves that controls swallowing also control speech and voice, changes that make swallowing more difficult may also make speech more difficult, and quieter and harder to hear by others.

Swallowing problems that put a person at risk for aspiration – where food enters the airway instead of the stomach – can result in bronchitis and pneumonia. The two primary tests for checking swallowing are the modified barium swallow and a fiberoptic swallowing examination of the throat. Your parent's primary physician or pulmonologist can refer them to a speech-language pathologist (someone who specializes in swallowing

<http://www.post-polio.org/edu/healthcare/pt4managetreat.html>

“Reprinted from *Post-Polio Health Care Considerations for Families and Friends* with permission of Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org)). Any further reproduction must have permission from copyright holder.”

## **Those with dysphagia want drinks that taste good...**

### **Slõ Hot & Cold Drinks, Slõ Milkshakes, Slõ Medicinal Drinks & Slõ Alcohol**

*Slõ Drinks are NHS approved, used in hospitals, and prescribed by Doctors.*

You will have seen someone grimace after sipping a thickened drink. It's because it tastes sour and has left a gritty sticky residue, like un-dissolved wallpaper paste, on their teeth.

**Slõ Drinks** flow slowly so are safer for those with dysphagia to swallow. To slow them down we change their \*consistency using our unique specially formulated thickener.

It does not affect the taste of a drink and is totally tasteless so Slõ Drinks taste as good as normal drinks. **Slõ Orange** like Orange, **Slõ Coffee** like Coffee, **Slõ Wine** like Wine etc.

It dissolves quickly and completely. Consequently, Slõ Drinks are smooth and only a pleasant aftertaste remains. It's "invisibility" also means they look like "normal" drinks.

Once you've seen someone enjoy the simple pleasure of a Slõ Drink that tastes good; looks normal to everyone around and can be drunk without inducing a humiliating coughing fit – you won't make anything else.

Either make **Slõ Drinks in cups** - these are ready to use and you just add water to make them or in sachets - you add their contents to favourite drinks to change them into Slõ Drinks.

Not on the Internet, contact Pauline on 08452 222 205.

**<http://www.slodrinks.com> - sign up to receive a full report.**

**Find them on Twitter, Facebook and Pinterest.**

Slõ Hot Chocolate, Slõ White Coffee, Slõ White Tea, Slõ Orange, Slõ Lemon, Slõ Blackcurrant



## PUNICIOUS PUNOGRAPHY

I heard that OXYGEN and MAGNESIUM were going out and I was like O Mg!  
If you asked a plastic surgeon to make you look like a pelican, would you get a massive bill?

As one frog croaked to the other; "Time's fun when you're having flies!"

I bought my wife a wooden leg for Christmas. It's not her main present, just a stocking filler.

What do you call a dinosaur that smashes everything in its path? Tyrannosaurus wrecks

Why do you never hear a pterodactyl use a toilet? Because the P is silent.

There's a terrible smell in the local Apple store; it's a shame they don't have Windows

A woman said she'd recognised me from the vegetarian club, but I'd never met herbivore

I worked in a paperless office once; everyone avoided the toilets.

<http://mumblingnerd.com/2013/05/17/punicious-punography/>

## MOBILITY ROADSHOW 2015

### One Big Day Events.

Thursday 23rd July 2015

**Westpoint, Exeter**

Thursday 6th August 2015

**Peterborough Arena**

Saturday 12th September 2015

**Stoneleigh Park, Coventry**



**The Mobility Roadshow®**  
*the future of mobility*

We bring everything together in accessible locations to make finding out more about Motability as easy as possible. It's totally free and a great day out for all the family.

There will be:-

- A huge range of cars, scooters, adaptations and Wheelchair Accessible Vehicles on display.
- The opportunity to test drive adapted and non-adapted cars.
- Motability advisors to chat to
- Free Parking
- Free tea, coffee or soft drink
- Children's Play area including face painting and a chance to meet Billy the Bear.
- A free prize draw to win an iPad mini.

Your Newsletter needs your stories, hints, tips and bits

A way of doing something, or aid, that helps you might help someone else. Tell us.

**How about a recipe that tastes great on the lips but not on the hips.**

**CARERS** - Are you a Carer and would like to write and tell us how we might help Carers understand what you go through helping us manage our lives.

Articles and items for Post Polio Matters

are always welcome, by post, by email and by phone if writing is not easy for you.

**Deadline date for next issue is April 25th 2015**

**Editors Note:-**

**Articles from Polio Survivors and Health Professionals  
Welcome for future issues**

## **India Remains Polio Free, Says Government Amid Reports of Resurfacing of Virus | NDTV**

Reported by Pallava Bagla, Edited by Amit Chaturvedi (With inputs from agencies)

Updated June 20th.2015

**NEW DELHI:** “India remains polio free for the fourth consecutive year.” the Health Ministry said refuting reports that around 200 samples have tested positive to polio-like symptoms in Uttar Pradesh and asserted that its test had found all cases negative.

India has put in place a strong system for surveillance on polio and these 208 cases in Bareilly are that of the ‘acute flaccid paralysis’ a condition that presents symptoms similar to polio but the causes are not related to an infection by the polio virus, the ministry said.

Nearly 18,000 Acute Flaccid Paralysis (AFP) cases have been investigated between January and July 2015 as part of the ongoing surveillance activities in India.

“The 208 cases reported from Bareilly in a section of the media are a part of these. Reports of all AFP cases received from the laboratories polio virus,” the Health Ministry said in a statement.

The Health Ministry said that polio surveillance in India has been set up as per the global guidelines of the World Health Organisation (WHO) in which all cases of paralysis with sudden onset in children up to 15 years (which is called Acute Flaccid Paralysis or AFP) are reported and investigated by the polio surveillance.

Noting that the stool samples are tested for the virus in WHO-accredited laboratories, the ministry also said that polio surveillance in the country is considered among the best in the world and surpasses globally recognised standards.

The Health Ministry said that India has been polio free for more than 4 years and maintains ‘high’ surveillance for polio virus detection. The country reported its last case of wild polio virus in 2011.

### **Editors Note:-**

**Note the figures above, Nearly 18,000 Acute Flaccid Paralysis (AFP) cases have been investigated between January and July 2015 as part of the ongoing surveillance activities in India.**

**Acute flaccid paralysis** is defined as weakness in one or more limbs, or the respiratory or bulbar muscles, resulting from damaged lower motor neurones. **Poliomyelitis was the most important cause, but since it has declined other causes have become more important.**

Classically, in acute flaccid paralysis there is weakness with reduced tone (flaccid weakness) and reduced or absent reflexes. Differentiating from upper motor neurone weakness is usually straightforward, but it should be remembered that acute spinal shock (e.g. caused by trauma) can initially cause flaccid paralysis before spasticity develops.

**Does the WORLD need more information  
on how those in India and other countries  
who are diagnosed with Acute Flaccid Paralysis  
are assessed, treated, helped to manage their lives and  
are they likely to get Post Acute Flaccid Paralysis Syndrome?**

**Surveillance of 'silent transmission' of polio needed to wipe our virus | Medical News Today.**

The world stands on the cusp of eradicating the polio virus, but a new study examining transmission of the virus suggests that the battle will continue long after the last case of the disease is reported.

James McIntosh writes:- In the study, published in *PLOS Biology*, researchers from the University of Michigan demonstrate that the polio virus can be spread for long periods without any cases being reported, suggesting that aggressive surveillance and vaccination programs will be required to guarantee its eradication.

"Using transmission models, we show that you can have sustained chains of silent transmission in populations for more than 3 years, without a single person ever showing up as a reported polio case," explains graduate research fellow Micaela Martinez-Bakker.

Once we have eradicated polio - or think we've eradicated polio - we probably should intensify the environmental surveillance to make sure the virus is not just lurking under the hood at very low levels," She adds.

Polio is a contagious viral illness that mainly affects children under 5, with 1 in 200 infections leading to irreversible paralysis. Although the last case of naturally occurring polio in the US was reported in 1979, the World Health Organisation (WHO) reported 416 cases worldwide in 2013.

A lot of this reduction is down to the success of polio vaccination. The authors report however, that due to his success, "critical features of polio virus transmission remain obscure.

In order to investigate, the team analysed polio case reports from large epidemics in the US during the pre-vaccine era. These data included birth statistics and census numbers from every state, allowing the researchers to examine the ecology of polio infection in a world without human intervention.

**True extent of polio prevalence in 1950's in the US revealed. Copyright Medical News Today**

Polio prevalence in the US was at it's highest in 1952, with 57,000 reported cases. Mass inoculations with the new vaccine occurred just 3 years later, after the vaccine was declared safe and effective.

Incidence of the virus in the US increased greatly between the 1930s and the 1950s, and researchers initially believed that this was due to the "disease of development" hypothesis.

The hypothesis is that improved hygiene had "reduced transmission and pushed the burden of infection onto children more susceptible to paralytic polio," the authors write, therefore increasing the likelihood of clinical manifestation of the virus.

Following their investigation, the researchers now believe this hypothesis is wrong. Instead, they attribute the increase in cases in the late 1940s to rising birth rates following the end of the Second World War.

**"If you have more kindling, you can have a much larger forest fire," Martinez-Bakker explains. "The baby boom provided more kindling for polio epidemics - young children and infants over 6 months of age - so much more explosive outbreaks were now possible."**

The data obtained for the study also allowed the researchers to track the unobserved and symptomless polio infections that occurred around this time. While the reported number of polio cases for 1952 was 57,000, the team discovered that more than 3 million people were likely to have been infected that year.

According to the authors, "the regular identification of, and rapid response to, these silent chains of transmission is of the utmost importance." Their study also offers further insight into why these historical polio epidemics fluctuated, were seasonal and varied geographically.

"Reaching eradication and preventing re-emergence of polio requires intimate knowledge of how the virus persists," Martinez-Bakker concludes. "Historical epidemics that predate the use of vaccines can be used to disentangle the epidemiology of disease from vaccine effects. They allow us to establish a baseline by studying the system in the absence of intervention."

Last year, *Medical News Today* reported on a study that found an extra dose of polio vaccine for children under the age of 5 could help to speed up eradication of the virus. **Written by James McIntosh. 21.6.2015**

# Management Committee [Trustees] and Operations Team

## Management Committee [Trustees]

Chair - Simon Parritt - [simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)

Secretary - Hilary Boone - [hilary.boone@poliosurvivorsnetwork.org.uk](mailto:hilary.boone@poliosurvivorsnetwork.org.uk)

Treasurer - Gillian Bryan - [gillian.bryan@poliosurvivorsnetwork.org.uk](mailto:gillian.bryan@poliosurvivorsnetwork.org.uk)

Trustee - Dorothy [Dot] Ives - [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

Trustee - Margaret Marris - [margaret.marris@poliosurvivorsnetwork.org.uk](mailto:margaret.marris@poliosurvivorsnetwork.org.uk)

## Operations Team

Membership Secretary - Gillian Bryan - [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)

Phone and Email Enquiries - Hilary Boone - [info@poliosurvivorsnetwork.org.uk](mailto:info@poliosurvivorsnetwork.org.uk)

Administrative Support - Gillian Bryan - [gillian.bryan@poliosurvivorsnetwork.org.uk](mailto:gillian.bryan@poliosurvivorsnetwork.org.uk)

Printing and Website - Elpeeko Ltd, Lincoln.

 Please contact us if you would like to help with our work 

## Membership

**Full membership** includes voting rights and is available to polio survivors, their partners, families and friends.

**Associate membership**, no voting rights, is available to patient organisations, health and social care professionals working in the interests of polio survivors £10.00 per year

### Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.

We welcome members living in other countries and details will be sent upon request.

Please note the majority of information will be sent via the Internet.

Email:- [membership@poliosurvivorsnetwork.org.uk](mailto:membership@poliosurvivorsnetwork.org.uk)

All Forms are available on our Website, by phoning our helpline or writing to us.

<http://www.poliosurvivorsnetwork.org.uk/joinus.html>

## Donations

*giftaid it*

Donations, small or large, towards our work will always be gratefully received.

**SEE BACK PAGE - Val Scrivener is making and selling brilliant photo greetings cards**

- Some members send us a few postage stamps
- Some members take their newsletter via the internet saving us printing and posting costs.
  - Others add a donation amount to their yearly cheque, or Standing Order amount.
- Some members send us a donation with some specifying, e.g. for AGM, for Conference. Fund
  - UK Taxpayers can Gift Aid their subscription and donated amounts.

### • **NEW CONFERENCE & MEETING FUND**

**The Gift Aid scheme.** Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

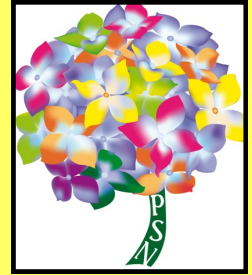
If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

# Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

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

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



**POST POLIO MATTERS** because **WE'RE STILL HERE!**

[www.post-polio.org](http://www.post-polio.org)



## staybowlizer®

### STAYBOWLIZER Seen at NAIDEX

#### Common problems - Simple solutions.

In its primary orientation {logo-side facing up}, a bowl set within the Staybowlizer is cradled with a full 360 degree of support.

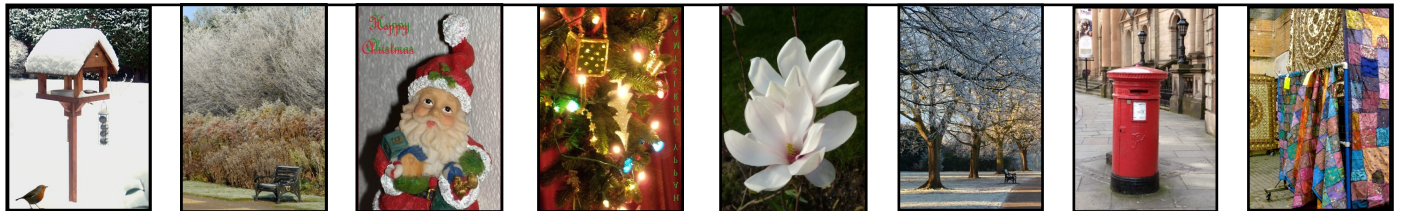
[Editors note: I keep mine by my cooker hob and also put small plates or bowls on this so that I can serve direct from pans/frying pan/slow cooker.]

Put hand inside bowl and push it down and the bowl suctions to the Staybowlizer and the Staybowlizer to the work surface.

Flip it over [logo-side facing down] place hands on opposite sides of the bowl on the saucepan, push down, and a suction lock will be formed between the bowl and saucepan.



Purchase from Amazon



© PHOTO CARDS

by MEMBER VAL SCRIVENER

Sold in aid of **POLIO SURVIVORS NETWORK**

Pack of 5 - **£4.50** inc. P & P.

[sample cards on back page of each newsletter]

Order by writing to PSN

Emailing [johnval.scrivener412@btinternet.com](mailto:johnval.scrivener412@btinternet.com)

Or ring Val Direct on 01234 346 397

