

**OCTOBER  
2015**

**Vol 8, Issue 9/12**

**07.10.2015**

**PRESS  
RELEASE**

from the  
European  
Polio Union  
and  
Rotary  
Action Group  
Page 6

**WE'RE  
STILL  
HERE!**

October 11-17, 2015  
[www.post-polio.org](http://www.post-polio.org)

**British Polio  
announce  
PPS Day  
22.10.15  
'landmarks  
illuminated' in  
BPF Colours**

Home of the  
Lincolnshire  
Post Polio  
Library



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# POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 9/12  
n.b. Volumes 1 to 6 published under the name LincPIN.  
[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**WORLD POLIO DAY - 23.10.2015**

**POLIO NEARS ERADICATION**

**BUT POLIO SURVIVORS**

**WE'RE STILL HERE!**

October 11 to 17 2015

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

**AND WE NEED GOOD QUALITY  
Multi Disciplinary Assessment  
[physical, respiratory, orthotic, mobility  
and other equipment + coping strategies]  
So we can live life to the full**

**WE NEED IT NOW PLEASE**

**U.K. Medical Professionals**

**Sandy's death must not be in vain**

## **Polio Survivors around the World send Condolences to the Family and Friends of Polio Survivor and Grandmother SANDY GLYN**

Grandmother Sandy Glyn aged 62, a Chef and Housekeeper lost her job and home in late 2014. She moved 100 miles to live with one of her daughters but became increasingly concerned about her rapidly deteriorating health. Sadly her body was found on Mudeford Beach on 16.2.2015.

Friend Lynn Hart told the inquest Sandy was concerned about delays in transferring her medical care from Cirencester to Bournemouth and added, "She was crying out for help. She was adamant she was not going to be a burden on her two daughters."

Recording a verdict that Sandy took her own life, [The Coroner] Sherrif Payne reports "This is a terribly sad case of a woman who overcame polio as a child. She had a successful career and brought up two daughters who she clearly doted on. She had difficulty getting ongoing care when she transferred to Bournemouth. It would appear that the hurdles that were presented to her just became too much for her". Excerpted from the Bournemouth Echo, 9.10.2015

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**Mobility  
Roadshow**

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

**POLIO 2015**

**> 30/09/2015**

**Afghanistan**

**32**

**Pakistan**

**12**

**TOTAL**

**44**

**Plus**  
**circulating**  
**vaccine derived**  
**polio cases.**

**Madagascar 9**

**Ukraine 2**

**Guinea 1**

**Mali 1**

**Nigeria 1**

**Pat bear pac-**  
**erpole**

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**New Members and Donations received.**

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

**Donations since 1st June 2015 are.....**

**From members - £627.50**

**Val Scriveners Cards another - £20.00**

**And from the family and friends**

**of Peter Rawson £107.00**

**A total of £ 754.50 in four months Thankyou so much.**

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.

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## Editorial by Hilary Boone

*Where did the summer go? What has happened since the last newsletter.*

**August 4th 2015 - British Polio Fellowship Ambassador and Paralympian James Crisp** visited Lincoln's Waterside to promote awareness of Polio and Post Polio Syndrome. The Lincolnshire Branch of the British Polio Fellowship were represented by their Chair David Mitchell who is also BPF Vice Chair of the Trustees, Caroline Gordon-Wilson Secretary. Hilary and Richard Boone, David and Margaret Marris who are members of both BPF and PSN.

James Crisp is 32 and caught polio from the vaccine as a child. He was advised to take up swimming. He has attended three Paralympic Games, Sydney in 2000, Athens in 2004 and London in 2014 with a total of 12 medals. He has also taken part in IPC Swimming World Championships winning 16 medals. He brought a couple of his Paralympic medals with him which many people stopped to look at. I was surprised how heavy they were.

**October 2nd 2015 - Rebecca Colpus Development Officer for the British Polio Fellowship** South West Region put on a BPF Information Day at Medieval Dartington Hall in Totnes, South Devon.. Speakers were Professor Gareth Williams who wrote 'A Paralysed Fear' featured in a recent newsletter who spoke on the History of Polio. This was followed by me with the Title Living with Post-Polio Syndrome. I was asked a couple of questions at the time but many more during lunch. Attending events and talking with Polio Survivors by letter, phone, email, etc always brings forth more information to share. One thing I did realise was that had I had knowledge of any pre-presentation questions I could have modified my presentation to include more information on those subjects and a bit less on others.

**October 23rd 2015 is World Polio Day.**

**November 25th 2015. The 20th Anniversary of my mentioning to a Consultant 'I had Polio.' 7 years and one month after a fall that triggered new symptoms.**

**Post-Polio Syndrome exists.** The new pain, fatigue and functional decline I have had for 7 years is REAL. Contrary to my medical file 'it's not all in my mind, I am not malingering, not trying the physio exercises' is now all taken on board. My prior polio is now in the equation and I am going to get the help I have needed. NOT. 14 months later there is an assessment report to the effect that I don't have any medical records of polio, don't look as if I had polio, and have latched onto PPS to psychologically adapt myself to a new lifestyle and get benefits. I had to start again at a second hospital and after a days full tests with nothing found letter to GP says 'confidently diagnose the post-polio syndrome'. Problems continue because there is not enough knowledge and experience of Polio and PPS.

**Condolences** to the family and friends of:- Member Lesley Ann Forsyth, Peter Rawson [see page 2] and Sandy Lynn [See front page],

**Martina Desgouttes, Polio Survivor, Researcher, Speaker and Author of A Whirlwind of Change - my total transformation** rang from the USA to tell us about her new book. Martina's book is based on real life depicting the challenges as a forty-eight year old woman, obese, workaholic with poor health improved her quality of life. We chatted for nearly an hour [thank goodness for cheap transatlantic calls] about how her fatigue was reduced by losing nearly 100lbs in weight and having medical help for issues with her adrenal glands. I have now got a copy of her 92 page book telling the above story and how her faith has helped her get through this. I gave her info on PPS so she is now going to do more research into that. If you want to know more have a look at her website, [www.healthyexplosion.net](http://www.healthyexplosion.net). Remember PSN are not able to endorse [see disclaimer on page 2] We try to provide a wide selection of the information out there.

**PAYPAL.** Our Charity PayPal account is now open and we are just waiting for the final paperwork detailing and activating the reduction in commission for a charity. More information in the next newsletter but in the meantime please contact Dot Ives if you have any questions. And a big thankyou to Dot for taking on the task of sorting all this out.

## **MESSAGE FROM OUR CHAIR**

### **THE PRICE OF SILENCE**

It has been a challenging time with the sad and tragic death of Sandy Glyn. We can see the high price that lack of support and recognition of the issues we face brings. Silence is never an option. In times when money and resources are short and under pressure it is often those who suffer in silence, press on and do their best without complaining or asking for help that ultimately suffer the worst fate. Unfortunately as polio survivors we are 'trained' into this way of being. Sadly it is a 'he or she who shouts loudest world' and the softly, softly approach leads to nothing. As you probably know from your own experiences, polio people are so often misunderstood and not really heard and so often at best under-diagnosed and at worst misdiagnosed with all sorts of other physical and mental health issues. Indeed, being older we **DO** have concurrent functional and medical conditions and because PPS is a diagnosis by exclusion it allows assessors to decide we have something else and ignore the unique aspects of polio and PPS. Ignorance abounds and very few medical professionals working in today's NHS will have seen an acute case of polio and importantly have miniscule experience of polio patients in their later life when compared to colleagues from the past. Expertise is being lost and more is being lost as we are seen as an historical footnote of neurological illness. This is an error when other non-polio enteroviruses in the same chain as polio can and are causing acute flaccid paralysis displaying many similar neurological issues to poliomyelitis. They are still endemic across the world and will experience the same issues in the future.

### **CALL FOR HONESTY**

We are just not getting 'a fair crack of the whip'. Why for instance did they remove the polio pathway for care from the web for doctors despite representations by the BPF? To get things changed we need to harness and revive our 'difficult person' or 'type A' reputation and become a nuisance again. However, not by rejecting help trying to overcome our own impairments silently but by pushing ourselves to overcome those 'inherent impairments' in political policy and medical professionals. Let us start by demanding that those who offer services to us be honest about what they know, and what they don't know. Then be equally honest about what they can offer, and cannot offer.

### **ASSESSMENT IS NOT RESOURCE MANAGEMENT**

Hilary mentions later how money is always an issue. Of course it is, but assessment by medical professionals should never start with the premise of whether the hospital and, or social services can afford to meet our needs. It should start with a full and accurate assessment and then we, as the autonomous patient, can decide for ourselves what we can achieve with that information. It should be transparent so we can decide, given all available resources, what we can achieve. Whether a millionaire or a pauper assessment should be on the same basis, even if the millionaire has more options to implement and act on the assessment information. Full assessments and tests can be deemed not cost effective, not because it isn't good information and science, but because there isn't the funding to act on it because the personnel, equipment, treatment and finance is not available within that particular service.

### **CART BEFORE HORSE APPROACH**

I have a philosophical and professional problem with that approach because it is unscientific and morally flawed. A simple everyday example is orthotics and wheelchair assessment and supply which is, as we know, just terrible. The usual approach is: what can we afford – and then how can we fit this patient into it. This is cart before horse thinking, completely the wrong way around! This extends into most hospital situations and is further complicated by the hierarchical nature of the NHS and research which is full of large egos, reputations and empire building. It has always been thus and comes with the territory to some extent, but we must not just step aside and accept it as we age! Please don't let the polio reputation be tarnished by being seen as 'good patients' we owe our forebears more than that! We were known in the past for not being a push over, do not let that fight ebb away as PPS and/or aging sets in. We need to be as difficult as

ever and as ego driven as them and build on our empire. We have little to lose and everything to gain.

## RECLAIM OUR BAD REPUTATION

So my message this month is: time to take off the gloves, time to be very difficult and regain our reputation. Use all the help and assistive devices and coping mechanisms you can and then with that energy you save take the fight back to them and prove that we may not be increasing in numbers but we might just be increasing in awkwardness!

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

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Chair Polio Survivors Network.

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### PRESS RELEASE BY EPU/RAG ON CO-OPERATION TO ASSIST POLIO SURVIVORS 7th October 2015



Poliomyelitis is a disease that is on the edge of eradication in the world thanks to the combined efforts of Rotary International, the World Health Organization, UNICEF, Centers for Disease Control (CDC) and the Bill & Melinda Gates Foundation (& other generous funders), together with the thousands of volunteers and health workers who have carried out the worldwide vaccination program.

Once the disease is eradicated there will still be in excess of 15 million polio Survivors worldwide who are going to need care, support and treatment for decades to come. Without, they are destined on the large part to shortened life expectancy, poverty and destitution certainly in the sub Saharan Africa, the Indian sub-continent and surrounding countries.

That is why today the Polio Survivors Rotarian Action Group and the European Polio Union are announcing that they are pooling information, and body of knowledge resources for the benefit of polio Survivors and those with Post-polio Syndrome (PPS) around the world.

John R. McFarlane, President of the EPU, said "We all acknowledge the tremendous work that has been carried by out by Rotary and its partners in bringing this virus to near extinction, and we know the final inch will be difficult but we also have to look to the future and care for all those who were unable to benefit from the vaccine for whatever reason. They need help so that they can live their lives with dignity and independence." Ann Lee Hussey, Chair of the Polio Survivors RAG, stated "The eradication of this virus is the first part of a journey for those already affected that will last for the rest of their lives. There is much more to be done beyond eradication. We see co-operation with the EPU as the first stage in bringing the humanitarian needs of polio Survivors and those with PPS to the fore, wherever they are in the world."

Polio Survivors & Associates is a Rotarian Action Group (RAG) dedicated to the humanitarian assistance of polio survivors. The European Polio Union is a group of polio Survivors' support groups (21 organizations in 18 countries). It also arranges events to help and inform medical personnel and those affected by polio and Post-polio Syndrome on best practice and treatment of the condition. The two groups have a common goal - to help and improve the lives of polio Survivors and those with PPS.

#### **John R. McFarlane, President of European Polio Union**

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#### **Ann Lee Hussey, Chair of Polio Survivors Rotarian Action Group**

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## **LIVING AND MANAGING Post-Polio Syndrome IS NOT EASY SHARING EXPERIENCES HELPS**

**I was invited by the British Polio Fellowship South West England** to give a talk on 'Living with PPS' at their Information Day in Totnes, South Devon on 2nd October 2015. I would like to thank Rebecca Colpus for the invite as the day provided me with more information and experience of polio survivors issues. I was asked a couple of questions after my talk but many more during lunch. I always learn from those I meet, or talk to on the phone or internet, and realised that in future that if I knew any prior to talk questions before I planned my presentation slides that I could include some of the answers. Believe me if one person asks a question there are always others that want to hear the answer.

**What did I learn from the Trip.** I learned that:- Lincoln to Bournemouth Seaside Travelodge, to Monkey World to Paignton Seaside Travelodge to Totnes and back to the Travelodge and home to Lincoln was 642 miles. I love driving but have had to accept that I did not have enough energy tokens available for this, so Richards PA, Wayne, drove.

Then there is the loading and unloading of wheelchair and scooter, ventilator, luggage, battery chargers, extension lead, some drinks and snacks and items for the presentation in and out of the car and motel rooms. Wayne, did that too.

Then we have to eat, go out or bring food in. Wednesday and Thursday night we went out to Pier cafes and Wayne moved the tables and ordered for us. Friday night Richard was exhausted so Wayne got us a TakeAway to eat in the room.

Richard needs help during the night a few times. To save money, and for me to have a bit of help, Wayne is happy to stay with us in a Family Room. He does the 11pm medicines and puts ventilator mask on and gets up if needed for the next hour or so. Then he goes into a deep sleep and its my turn from about 3am, Richard's 7.00 medicines and turn him till they kick in. 8am alarm wakes Wayne and we go for breakfast and Wayne takes a tray back to the bedroom for Richard.

[There is a problem in Family Rooms in older Travelodges, the bathroom door is not wide enough for a wheelchair and whilst there are rails round the bath none by the toilet. I have to work out how I am going to get down and up again. Note to self get rooms where bathroom is on the right side of the room, right arm strongest to push up using toilet bowl. We must write to Travelodge and see if there is a way we can persuade them to have a pullout bed available for a Disabled Room, or maybe we need to look at other hotel chains.]

I have always wanted to go to Monkey World and in case this might be the only time we were nearish I put it in the plan. It was fantastic and I would love to go again. We got there at 10.00 am looked round, got some great photos, had some lunch with Wayne help. Richard had to go back to the car and rest but I took a quick scoot to the capuchin monkeys and we left for Paignton at 2.00pm. Friday I went to the BPF meeting and they had a lazy look round Totnes, sadly the boat trips were not accessible. None of this trip would have been possible if we had both not got Personal Budgets and employed people like Wayne to assist us both and be with Richard when I could not. They have made a huge difference to our lives.



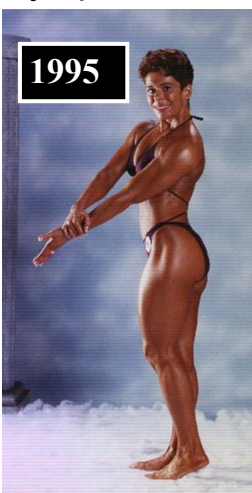
Arrived home Saturday mid afternoon and I could not stay awake. Did you realise that using muscles to keep your position in car seats can be tiring too? Oh and Richard could use a bottle on the trip but I had to use Motorway Services and wonder why oh why they have to put the Disabled Toilets so far from the Disabled Parking Spaces. Sunday I woke exhausted and again on Monday. Reality Check needed. Look back over the last 20 years and think about how many times I have had to downsize what is possible. Did I put too much into the three and a half days from Wednesday 9.30 am to Saturday 3.30pm? Yes, adding Bournemouth and Monkey World in was way too much for all three of us.

**Personal Overview.** I had waist down paralysis in 1952 with good recovery that continued after tendon transplants in both feet in 1961. I swam, life-saved, canoed and did Judo gaining many qualifications, My jobs have been a Secretary, then Policewoman, a Swimming and Life-saving Teacher and Senior Lifeguard.

In 1988 I slipped on a school corridor floor but this time when I got up the pain did not go away, and actions of daily living became harder. I could no longer pass the Pool Bronze Medallion to continue teaching and lifeguarding. Fatigue was overwhelming. Medical professionals could find nothing wrong with me. Treatment was physiotherapy exercises but no matter how hard I tried I just got worse.

My prior polio was not in the equation until I mentioned it on November 25th 1995, 7 years later. I started researching that day nearly 20 years ago. December 1997 I received a copy letter to GP that all tests were negative and 'confidently diagnose the post polio syndrome'. I was a bit shocked about five years later to read on my medical records that during those 7 years where my prior polio was not in the equation that it was believed I was not trying to do the physio exercises, that I was malingering, that all my issues were all in my mind. Worse than that, after my polio was in the equation, is a statement to the effect that I did not look as if I had had polio and I had locked onto PPS to adapt myself to a new lifestyle and claim benefits. Both my husband and I are still having difficulty trying to get some of our issues assessed by medical professionals that really do have knowledge and experience of how our bodies are affected by Polio and Post-Polio Syndrome.

Most countries do NOT have accurate statistics of how many people had damage from one of the three polio viruses in their earlier life. In the UK figures used suggest more than those with MS but whatever there are huge overlaps in the symptoms and issues with other similar neuromuscular conditions.



**Colleges of Medicine** please add more facts to your **lectures on the Polio Virus**; what it has done to our bodies; ensured health professionals understood how many recovered that well that externally we do not look like those photos in the medical books; the massive overlap of symptoms with other neuromuscular conditions; about **Post Polio Syndrome** and links to more information.

**Sincere Thanks to Gwen** for allowing us to use the 1995 photos of when she was the Senior Nurse for a 50 bed establishment and with PPS in 2003.



## TELLING IT LIKE IT REALLY IS and LOOKING AT HOW LIFE COULD IMPROVE

**I am a member of the University of Lincoln User and Carer Panel** for the Health and Social Care department. When my colleagues and I were first approached we realised that we [a variety of disabilities] now had an opportunity to tell students 'like it really is' to be on the receiving end of a Social Workers job. We are involved from interview stage for a place on a BSc or MSc course and during parts of their training where service users and carers are referred to. Comments so far are that listening to our experiences ahead of work experience is very helpful, not only from students but also through comments they have made in their work placements from our Social Workers.

Yesterday, for the first time, Tony and I attended one of the Preparing for Social Work Practice Sessions. We both agreed that learning how social workers are trained to form a relationship with us to find out exactly what our problems are has been of great benefit. They use active listening skills to help us think about what is challenging us at the moment and how we can look at this with different perspectives to help take on board what is happening to us now, where do we need to be and how are we going to get there.

Polio Survivors are known world wide to be the most stubborn, determined to push to the limits what and how we achieve, and will do anything to continue as we have always done. When a medical professionals suggest that we could give up work, start pacing and resting the activities we do, and **horror of horrors** start or go back to using aids and assistive devices and ask someone to help us do or take over a task for us. How many times have you responded 'I am not there yet' and it takes many more years before you started to take things on board?

Accepting we need to accept the changes and 'tell it like it really is' is not easy....

Social Workers are first told they need to help us talk about our problems and concerns. Some of us can do this easily but most of us find it difficult to change the habits of a lifetime. With polio we were told 'Use it or Lose it' and boy did we use it. Now the advice if you are having new issues is to 'Conserve to Preserve', and understanding why and changing old habits is not easy. They are taught to develop a set of listening skills to help us reveal what is going wrong and right with our lives. Using empathetic responses, not direct questions, they look at our experiences, behaviours and the feelings and emotions we display as we talk.

Think of something that is really difficult for you at the moment. What have you done about it? One most of us have and are still going through is to try and get some help from the NHS for new symptoms we have been experiencing for some time, often months or a year or more. An empathetic response to what we start to say and would be something like 'You are furious because you feel you are being ignored and you did not express your needs to him'. Would you then think about what happened at those appointments in more detail?



I try hard to go to appointments with a positive attitude that they will have the knowledge and experience to help me but this has not happened so many times. As soon as something demonstrates a lack of knowledge I know my facial expressions show that I am not happy and I might even say things in a way I regret afterwards. So I have not helped myself.

Students are then taught to help us develop new perspectives on our issues. What is going wrong with our lives and if there are a lot of issues putting them in order.

Taking the trying to get medical help issue, PSN points out in My Polio Life that when we look at actions of daily living that it is the change from how we used to do the action to now that is the most important fact to get across. Even if you are asked a Closed Question, "Can you do x", you must give an Open Answer as if they had used the Open Question "How do you do x?" We must tell it like it really is and those items we can demonstrate more easily should go near the top of the list. E.g. A photo from your best recovery period when you could do the action and demonstrating how you can no longer do this or how you have to do it now.

For instance going back to 1988/89 I was always examined with Manual Muscle Testing looking at my 'I am weaker' statements. We now know that Single Action Manual Muscle Testing can be invalid and unreliable if we are able to provide a strong first response but not sustain or repeat this. Testing a limb with a few actions does not necessarily show that the three strong responses mean that we can perform a pattern of movement. E.g. Arms, I can grip strongly, I can push and pull them over strongly but I cannot lift and sustain a jug of water to pour it out or bring it towards me without using my other arm and preferably standing up to do this.

Do you think if in 1989 I had said 'I have gone back to life-saving training but I can't swim as fast and can't pull myself out of the deep end of the pool anymore and have failed the basic test to lifeguard and teach and have therefore lost all those part time jobs... might I have been given further tests that would have corroborated my poorly phrased 'I am getting weaker'? I just assumed that the way we were assessed would pick up any problems we were reporting.

Wosket\*(2006) 'acknowledges that because we have lived with our difficulties for a long time we are familiar with our day to day problems' but whilst we might be familiar have we been able to look back and seriously think about how our life was, is now and how it might be? Everytime we have to change the way we do something our Norm changes and becomes our new Norm. Tongue in cheek, my 'Norm; [short for Norman] is buying far too many new outfits. 😊😊

Sally Riggall\* [author of Using Counselling Skills in Social Work, available on Amazon] lectures students that once we can accept the need to make changes that Social Workers can help us see what the future might hold if we make some changes.

We are helped to ask ourselves:-

- What would help me most at the moment?
- How would I like things to be?
- If my life was just a little bit better, what would be happening that is not

happening now?

- If I was managing a little better what would be in place that is not in place now?
- What would I like to be doing differently with the people in my life?
- If my life was more as I wanted it, what would this look like?

I add for polio survivors

- If I started using some electric wheels and equipment to save energy in the lounge, bedroom, bathroom and kitchen, and started asking people to help me do a task or do it for me what would my pain and fatigue levels look like and what would this saved energy allow me to do that I cant now?

Just a few ideas of how my life changed using different aids.

Cane with arthritic shaped handle - better but my body was lopsided.

Arm crutches, then SureFoot ones that have a foot plate on springs that walks with you, now I could go over rough grass and sand. Gradually distance reduced.

Rollator - it was my Dads and I brought it back to use then I got old [yes really old not now] but the day I brought a heavy item back into the house from garage it stayed out. Don't like how I look using it because of the 'old/disabled' person it conveys but it is much easier.

Manual Wheelchair - thought this would mean I could push myself and go back to joining in with my friends, after I all I had waist down polio, but 25 yards to the end of the road and I was wiped out. This was more confirmation that the polio virus had affected my upper body. Others could push me and that first time in Oxford being whizzed across busy roads level with bus exhausts and clonked up and down kerbs, eek. It was horrible. I went to visit the disabled early 20's now that I had pushed in my earlier life to apologise for my doing this.. But they said 'Oh its ok if you trust the pusher and we trusted you. You just gotta get used to it'.

**Electric Scooter No. 1** - The first 18 years ago - sadly the company lied that the larger 6 would be better for me than the 4 they demonstrated and confirmed it came apart. Two charities put up the funding and it arrived on my 50th birthday and the driver wanted me to try it on the street... Oh how I hated that. Two days later a friend comes round to take me out but it did NOT come to pieces as I had been told but they were strong and managed to lift the heavy end onto the back of their car and then lift and push it in. [You must try before you buy and rent one for a week if possible to ensure the seat is comfy and the distance to the tiller etc, and arm rests are right for you. Plus you need to be able to transport it. Remember the larger the wheels the rougher the ground it will go over].

**Electric scooter No. 2** - My next scooter came to pieces but I got a hoist to lift it directly into the new car that my Dad helped me purchase VAT free and that includes all repairs and servicing [when his will was read some years later I learned that the amount was to be deducted before the remainder was shared. I smiled, that was my Dad] Now I could go out alone and this scooter has been round Castles, Museums, Antique Fairs, Shopping Centres, large hotels at conferences, enabled me to re-enact Pioneer Times and its been flown free many times across the pond. Without it none of that would have been possible.

What should Polio Survivors be looking at for their future? Remember I have been there and I know that you could/can still do most of the separate tasks but not all in one day. There will be other things not in this list...

- First and most important is managing your energy levels so you have enough to do the things that you want to do by accepting that pacing and resting all activities rather than pushing till you are so tired and in so much pain that crashing out is the only option.
- having someone drive you to medical appointments so you are more rested and take notes for you,
- a reduction in falls with a saving on NHS care and keeping all the bits still working, especially shoulders without which we cant transfer as easily,
- being able to have enough energy for whatever exercise is appropriate for us starting with stretching or being stretched and moving onto basic exercise regimes worked out together with a knowledgeable Polio and PPS Neurophysiotherapist that you can fit into our daily life plan. Massage for those aching muscles can make a huge difference to an improvement in general health,
- getting help around the home for all those heavy tasks that we are struggling with like changing a duvet, using a Hoover and moving the furniture, hanging the washing out and bringing it in and ironing it, etc., getting help with the garden. Someone to batch cook you foods you love and putting them in the freezer for you, etc. This might mean you have to contact Social Services for an Assessment of Need to find out if you are eligible for a Personal Budget to employ staff to help with all this. [Try asking a local User Group for help to do this first so you have all your facts collected]
- going to Schools/Colleges/Universities to volunteer a few hours or take a course or learn a new hobby
- seeing a positive and possible way forward to spending more time with your family and friends for the rest of your life.

Thinking about the long term future is not what we want to do. There comes a time when this should be considered. For example when we moved in 2007 to our new bungalow from a house we had to consider a property where a ceiling hoist could be put in from bedroom to bathroom. We still don't need it but when we do ... Look at Disabled Refurbishment Grants to have alterations to your property and remember if you find it difficult to get up and down from a chair then a standing stair lift could work easier than one with a seat, although moving might be a better option. It could mean a granny flat with relatives, or sheltered accommodation, a retirement home and one with nursing facilities for later might be good.

It is important that you do not consider the cost to make up your list because this will give anyone helping you a true idea of how you could see your future and an improvement in your quality of life. Some things wont be possible but they cant be considered if you do not mention them.

## **Now you have a your plan for your future**

- Get someone to check out the benefits you receive to ensure you are getting what you are entitled to,
- Ask a major charity, local User Group or search on [www.gov.uk](http://www.gov.uk) to help you look through the process of applying for benefits and help to see if you qualify
- Approach Social Services for an Assessment of Need,
- Charities may be able to help with the purchase of equipment,
- A Disablement Facilities Grant from your County Council for work over £1,000 to be done on your property to make it more accessible to you in your daily life
- Churches may be able to help even if you cant attend

There is another side to all this in that once you start seeing a saving of energy, a reduction in pain and fatigue levels many members have been able to do a bit of volunteering to help others going through the same issues. [I have to admit that many of us still overdo at times but we have put this and the consequences of 'Dolittle' or 'Pyjama' or 'Low spoon' Days into our plan]

One member reads to children in Infant School, others are officers in charities and if they can go to local NHS and County Council, local User Groups and Regional Neurological Alliance meetings, others have joined local art groups, some still work part time. Some have moved into residential homes where they have found the choice between living alone and joining in when you want to makes life easier. Some are in nursing homes now and find replying to letters and emails not very easy but they love to read them.

Some of us have Direct Provision [where the Council puts services in] or Direct Payments where you are given a yearly personal budget to buy your own care.

A Personal Budget paid as a Direct Payment. If you are eligible and it is important to get support from a local User Group or Charity to help you apply, then your needs are assessed and a yearly budget is allocated. A costed support plan has to be written. This details the way you will use this money to pay for help and in fact anything that would improve the quality of your life can be considered, to meet the set outcomes that were decided during your assessment. You can do this yourself, have help, or it can be done for you. It will be much easier if you have done a plan for your future. It is important that you do not forget to include extra help to go on holiday/s and if equipment is listed then put purchase or lease. If you leave anything out or things change then you can go back and ask for that information to be included or a further assessment. You should be reviewed every year. You will have to go through a Financial Assessment to see if you have enough money coming in to pay a contribution to the amount of your yearly budget. We did not have to pay a contribution until we were awarded Pension Credit and then most of that became our contribution but there are other advantages to receiving this.

You also have to go through a Financial Assessment Review every year because Benefits go up, Pensions are expected to go up but check that the figure they have used is the right one. Council Tax goes up if you are paying this, again check the figure is not last years. Then there are Annual Statements of Set Charges

each year that you can deduct like a set cost for laundry or a gardener. If the cost to you is higher than the set charge then you can submit invoices to demonstrate this and have the higher amount paid.

Benefits and dealing with all this IS daunting and many people [me included for many years] did not go down this route because I did not want to deal with the paperwork. If you are struggling then you need to contact a local group to help you understand it all. Sadly whilst the Care Act has come into being there is still a difference in how this is interpreted and acted upon by each local Authority. Talking this over with others who have already gone down this route and how it has made a difference to their lives helps enormously.

Please share with us your views on the contents of this newsletter and ask any questions you think of. If we do not know the answer then we can advise of other organisations that can help, like the British Polio Fellowship, Healthwatch, the National Council for Volunteering Organisations, Citizens Advice Bureau, and your local User Groups.



**2016 Australasia-Pacific  
Post-Polio Conference**  
**Polio - Life Stage Matters**

**20-22 September 2016**

**Four Seasons Hotel, Sydney**

For more information call 1300 789 845  
or visit [www.postpolioconference.org.au](http://www.postpolioconference.org.au)

**SAVE  
THE  
DATE**

As the world celebrates the highly successful polio eradication program which has reduced the number of polio endemic countries to only three, the challenge to maintain high vaccination rates to prevent further outbreaks remains.

However, there is also a growing need for health professionals with the knowledge to adequately treat the estimated 20 million people world-wide, including 400,000 living in Australia, who are survivors of polio.

The aim of this International Conference is to exchange knowledge about the diagnosis and treatment of the post-polio condition across different age groups to best preserve functioning throughout life.

**2016 Australasia-Pacific  
Post-Polio Conference**  
**Polio - Life Stage Matters**

**For more information  
call 1300 789 845 or visit**

[www.postpolioconference.org.au](http://www.postpolioconference.org.au)

## **Anesthesia Specifics for PPS**

**Selma Calmes, MD, (ret) anesthesiologist**

*In the absence of any significant published information, the following is based on my clinical experience and ideas developed after extensive study of polio and PPS. As more information becomes available, these will change. These are the recommendations on the PHI web site ([www.post-polio.org/ipn/anes.html](http://www.post-polio.org/ipn/anes.html)). I reviewed them and added an additional one, #9, and a comment.*

### **ANESTHESIA ISSUES FOR POST-POLIO PATIENTS:**

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
  2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the poliovirus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.
  3. Succinylcholine often causes severe, generalized muscle pain postop. It's useful if this can be avoided, if possible.
  4. Postop pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.
  5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.
  6. Patients who use ventilators often have worsening of ventilatory function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It's useful to get at least a VC preop, and full pulmonary function studies may be helpful. One group that should all have preop PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation preop and a plan for postop ventilatory support. Another ventilation risk is obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.
- \*COMMENT: Postop respiratory failure in these patients can be difficult to manage. The patient's pulmonary physician could help by doing a preop evaluation and being involved in postop ventilatory management. This situation might call for the resources of an ICU in a major medical center.
7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred postop, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be useful.
  8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.



## \*9. NEW IDEAS/THOUGHTS:

**Spinals:** Recent studies demonstrating the presence of cytokines in the CNS of PPS patients lead me to be less enthusiastic about using spinal/epidural anesthesia. There is no data on this situation, and there are so many benefits to this regional anesthesia, and they might be suitable in some situations. Lidocaine would not be a suitable drug choice for PPS patients.

**Regional anesthesia:** Should the peripheral nerves of PPS patients be exposed to local anesthetics, especially for long periods postop? There is no data, but many PPS patients have atrophied peripheral nerves. Perhaps smaller doses of local anesthetics and avoiding continuous postop infusions would be safer.

**Above-the-clavicle blocks (supraclavicular and interscalene):** These have a high risk for diaphragmatic paralysis and should probably not be used in PPS patients, unless the patient can tolerate a 30% decrease in pulmonary function.

**SUMMARY:** PPS patients can have anesthesia and surgery safely, with careful preparation. Anesthesia and surgery is a process that involves anesthesia, surgery and hospital care. For an optimal outcome, ALL must be at high levels of performance and achievement! You, the patient, must work to be sure you get these. Remember, few surgeries are truly urgent and you usually have time to get data from the web, the state's hospital licensing department, the state's medical board and other resources. You should also research the operation and its consequences, to be sure you can deal with them. Don't rush into anything until you're satisfied you'll get the best. You deserve it.

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## **Emergency Room Precautions**

**[www.DoctorBach.com](http://www.DoctorBach.com)**

### **USE CAUTION in administering**

- \* Anesthesia (1)
- \* Narcotics (2)
- \* Stimulants (3)
- \* Supplemental O2 (4)

### **Be prepared to intubate!**

#### **Patients with neuro-muscular disease are subject to...**

- (1) Malignant Hyperthermia caused by certain anesthetics.
- (2) Restrictive Lung Disease caused by weak respiratory muscles.
- (3) Tachycardia (high pulse rate).
- (4) Hypopnea (shallow breathing) and hypercapnia (CO2 retention).

### **Supplemental Oxygen**

DO NOT administer supplemental O2 for sustained periods without CONSTANT monitoring of EtCO2 with a capnograph. EtCO2 > 43 mmHg indicates CO2 retention. Administration of O2 can cause CO2 to rise, resulting in hypercapnia, coma, and DEATH!

Sustained hypercapnia (EtCO2 > 43) requires mechanical ventilatory assistance. Use **noninvasive ventilation** via mouthpiece or nasal interface with high-span Bi-PAP (typ. 18/2, rate 10) or volume vent (typ. 1000 ml, rate 10, command/assist mode). If unconscious, intubation may be required.

### **Also see: Severe hypercapnia after low-flow oxygen therapy...**

For additional information, See: [www.DoctorBach.com/ER](http://www.DoctorBach.com/ER)  
Or call: Millennium at 1-800-269-9436 / (973) 463-1880



## The Continuing Saga of Delightedly Deleted Dot

You may recall that my retirement and plans had a minor set back when I slipped and fractured two vertebrae. The saga continues!

Back in May when I was released from hospital with back brace and crutches I hung on to their every word! At 6pm on day of despatch armed with enough drugs to keep the local smackheads in ecstasy (should I require a new source of income) I left in the faith and knowledge that:

**Discharge letter** will be posted asap. **Occupational Therapist** would visit in a few days and **Appointment letter for Outpatients Dept** would be received with appointment to see specialist in two weeks.

Being a faithful admirer and devotee of the NHS what could go wrong? They were great in A&E and very good on the ward. Discharge letter did not arrive (and I forgot about it)! The OT and student OT did arrive and visited three times with sage advice, supervision and a sucking in of breath at my plainly not, non slip bathroom floor..... more sucking in of breath at my non slip Edwardian porch tiles!

Outpatients appointment not received after 6 weeks I rang the ward as suggested by the OT. They said my notes were 'not quite complete' but they would chase up and I would hear soon. 10 weeks later I rang the main switchboard for help and was put through to the 'Appointments Bureau'. I was helpfully informed that my records said I was discharged from Consultant's clinic on October 14th. I agreed that I had been but what about my 5 day residency order in May?! There was no record of this.

This is where my PPS brain perhaps or rather my morphine induced brain let me down. I had no idea of the name of the Specialist I saw! (at this point I was beginning to think I had dreamed it all)! Tramdolly Dotty in freefall! I was put through to 'A' secretary of 'A' consultant who prowled the ward when I was there and may have come across me. I vaguely recall seeing three different 'specialists' but do not recall any names or saw any name badges – they could have been cleaners for all I know.

'A' secretary appeared helpful, said she would ring the ward and track down my notes. She promised to ring me back before the end of the week. When I telephoned 'A helpful' secretary a week later, she had forgotten but had recalled our previous telephone conversation. She would put me back on the top of her 'To Do' list on her pad and get back to me.....she didn't. When I again phoned the 'A helpful, now not so helpful' secretary. She had news. My notes were perhaps 'lost' or at Eaglescliffe (a leafy suburb not renowned for medical facilities)! She gave me the phone number of another secretary who may know of me! I duly rang. I was still not known. She would try to find my notes.....

I asked if it would be ok to remove my brace and chuck it away on 'brace removal day' – this being 12 weeks following my discharge from hospital. This was 1<sup>st</sup> August – the date etched in my brain, a day of freedom, celebration and liberation – more liberating than the bra burning days of the 60s and 70s! Today was 15<sup>th</sup> July.

"Oh, you are wearing a brace!!! Oh that's the Spinal Unit it will be Mr..... not us. I will get his secretary to phone you and make an appointment. DO NOT remove your brace!!" ..... Delightedly Deleted Dot turning quickly into Desperately Deluded Dot – more next time!!

**Footnote:-** Frustration etc – the omnishambles that appears to be my 'lost notes' - Apologies for no reference to PPS in this article apart from the even 'unwritten notes' in the NHS does not bode well .....no wonder PPS never gets a look in!! [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

**Editors Note:-** **Any more stories like this?** Richard and I can add three in the last year! How about a barium swallow that needs you to stand for ten minutes. You are in an electric w/c when referral made, the box wheelchair user has been ticked and you have provided a letter with all the information on your lack of ability specially at the time of the appointment. Your stories can help us campaign for better services.

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)

### REMINDER FOR MEMBERS

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

**Did you let us know?**

**Thanks Dianne and Ava - anyone else need to update us?**

**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.**

### © PHOTO CARDS

**by MEMBER VAL SCRIVENER**

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**Pack of 5 - £4.50 inc. P & P.**

**[sample cards on this page for this issue only  
see previous newsletters for colour copies]**

**Order by writing to PSN**

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 November 30th 2015**

### Editors Note:-

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

**Monday, October 12, 2015 WHO: Vaccine Derived Poliovirus – Laos**

The oral (Sabin) polio vaccine (**OPV**) contains three attenuated (*weakened*) polio virus strains, that activates an immune response in the body, and for a few weeks causes the weakened virus to be shed in the faeces. This is considered a 'good' side effect, for in areas with poor sanitation, this vaccine-virus can spread in the community for a limited time conveying extra immunity.

But, as the **WHO explains**, every once in awhile this can go awry.

On rare occasions, if a population is seriously under-immunized, an excreted vaccine-virus can continue to circulate for an extended period of time. The longer it is allowed to survive, the more genetic changes it undergoes. In very rare instances, the vaccine-virus can genetically change into a form that can paralyse – this is what is known as a **circulating vaccine-derived poliovirus (cVDPV)**. <SNIP>

Since 2000, more than 10 billion doses of OPV have been administered to nearly 3 billion children worldwide. As a result, more than 10 million cases of polio have been prevented, and the disease has been reduced by more than 99%. During that time, 20 cVDPV outbreaks occurred in 20 countries, resulting in 758 VDPV cases.

Statistically, a drop in the bucket. But for Polio to be completely eradicated, experts have warned that the use of the OPV must be eventually phased out, and the final push completed using the older inactivated Salk vaccine (see Nature **Vaccine switch urged for polio endgame** - [www.nature.com/news/vaccine-switch-urged-for-polio-endgame](http://www.nature.com/news/vaccine-switch-urged-for-polio-endgame))

Unlike the oral vaccine which has been the workhorse of the global polio eradication initiative, the inactivated vaccine must be delivered via an injection, and by a trained healthcare professional. It is also 10 times more expensive than the oral vaccine, but OPV must be phased out if Polio is to be completely eradicated.

Last year we saw detections of cVDPV in both **South Sudan and Madagascar**, and earlier this year 8 new cases were reported in Madagascar. Today the World Health Organization reports on another rare cVDPV event, this time in Laos.

**Circulating vaccine-derived poliovirus – Lao People's Democratic Republic**

**Disease outbreak news - 12 October 2015** - On 8 October 2015, the National IHR Focal Point of the Lao People's Democratic Republic (PDR) notified WHO of one confirmed type 1 vaccine-derived poliovirus (VDPV) case.

**Details of the case** - In Lao PDR, one case of circulating vaccine-derived poliovirus type 1 (cVDPV1) was confirmed, with onset of paralysis on 7 September. The patient was 8 years old when he died on 11 September. [continue reading source article]

<http://afludiary.blogspot.co.uk/2015/10/who-vaccine-derived-poliovirus-laos.html>

Country	2015 - WPV	Country	2015 - cVDPV
Afghanistan	12	Guinea	1
Pakistan	36	Madagascar	9
		Nigeria	1
		Ukraine	2
<b>TOTALS</b>	<b>48</b>		<b>13</b>

	To date 2014	Total 2014
WPV	221	359
cVDPV	36	56

# 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)

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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.

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**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%).

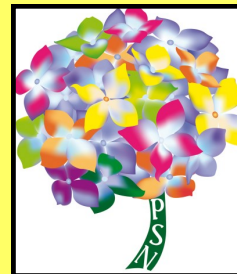


# Polio Survivors Network

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)

**British Polio Fellowship Ambassador and Paralympian Swimmer James Crisp visits Lincoln Waterside to raise awareness of Polio and Post-Polio Syndrome.**



1. James Crisp with Lincolnshire Branch Secretary Carolyn Gordon-Wilson and
2. Margaret Marris, Hilary Boone, David Marris, James Crisp, Richard Boone and BPF Vice Chair and Lincolnshire Branch Chair David Mitchell.

**British Polio Fellowship South West of England Information Day at Medieval Dartington Hall, Totnes, South Devon on October 2nd 2015.**



1. Hilary Boone giving her presentation on Living with Post Polio Syndrome.
2. South West England Members
3. Professor Gareth Williams giving his presentation on the History of Polio to South West England Members

