POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 10/12
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

FEBRUARY 2016
Vol 8, Issue 10/12

SCOTTISH POST POLIO NETWORK
15 YEARS

LINCOLNSHIRE POST POLIO NETWORK
now
POLIO SURVIVORS NETWORK
20 YEARS

POST POLIO SUPPORT GROUP IRELAND
23 YEARS

INTERNATIONAL POLIO NETWORK
now
Post-Polio Health International
31 YEARS

British Polio
77 YEARS

AGM PAGE 5

Why are Polio Survivors in the UK still struggling to get adequate and appropriate multi-disciplinary assessment, 141 years after medical recognition?

For more than 100 years
it has been recognized that new muscle weakness occurs in polio survivors many years after their initial illness.

The first descriptions appeared in **1875** when four separate case histories were reported in the French literature by Carriere,*[3]* Raymond,*[4]* and Cornil and Lepine,*[5]*.
All of these patients were young men who had paralytic polio in infancy. They developed new weakness not only in previously affected muscles but also in muscles believed to be uninvolved.

They all had physically demanding jobs
and performed repetitive activities.

Post-Polio Syndrome : Pathophysiology and Clinical Management, Anne Carrington Gawne and Lauro S. Halstead. Critical Reviews in Physical and Rehabilitation Medicine, 7(2): 147-188 (1995) [21 YEARS]
Full text in Online Library http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/gawne/ppspandcm.html

Neurological Alliance letter to the Secretary of State for Health [page 11] there are estimated **12,000,000** cases of neurological conditions which start, progress and end for a variety of reasons. There is a recognised massive overlap in symptoms and issues. We ALL need multi disciplinary staffed neurological clinics across the U.K. to assess and treat us more cheaply than waiting till we go into CRISIS.

On Friday 29 January, HRH The Duchess of Gloucester GCVO was in Watford to unveil a plaque marking the official opening of the new Central Office of The British Polio Fellowship, 77 YEARS to the day since the national charity was founded in 1939. - www.britishpolio.org.uk

Polio Survivors Network Newsletter - Volume 8, Issue 10/12
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

Printed by Elpeeko Ltd., Lincoln 01522 512111

NAIDEX

26th to 28th
April 2016
NEC
Birmingham
www.naidex.co.uk

N.B. 26th April
NOT OPEN TO THE
PUBLIC THIS YEAR

MOBILITY ROADSHOW

26th to 28th
May 2016
Silverstone
www.mobility roadshow.co.uk/

Anyone interested in meeting up at these events please contact.

Thank you so much for the donations towards our work.

POLIO SURVIVORS NETWORK AGM

9th APRIL 2016

NORTH HYKEHAM MEMORIAL HALL
LN6 9RY

South Lincoln

Contents

New Members and Donations received.

Welcome New Members

Michael Eichner and Jenny Woods

Income totals for 2015

Annual Subscriptions	£	825.00
Life Member Subscriptions	£	360.00
Members donations	£	924.00
Donation for Conference & Meeting Fund	£	445.00
Sale of Val Scriveners cards	£	110.00
Income/Donations at AGM	£	395.00
Gift Aid repayment	£	300.00

The Annual Report will be available in March 2016.

Editorial by Hilary Boone

I must apologise for the lateness of this Newsletter but family issues took priority when Richard was admitted to hospital on December 20th 2015 with a blocked bowel. I stayed with him, sleeping in an armchair because he has Parkinson's as well as PPS and there are times he cannot move and his voice drops to a whisper so making himself understood is not easy. Previous experience tells us that any delay in him getting help has aggravated the situation so I stay with him. They did not operate till 22nd December to untwist his bowel and left him unstitched for 24 hours so they could check the bowel had ‘pinked up’. Thankfully ok he was stitched up and returned to ICU but his sedation was not reduced till 24th. It was mid afternoon before he opened his eyes - relief - but he remained intubated for two days. He had many ups and downs mostly due to medication doses and changes but unexpectedly on 7th January was moved to a normal ward. Now the nursing changed to 1 to 10 so once again I stayed with him 24/7. January 18th we got the great news you can go home and Richard was ready to go in minutes but it took two hours to get all the paperwork sorted. I have to add a huge thanks to Dr. Richard Bruno who seeing a Facebook post asking for medical help contacted me and then provided ongoing daily email support, information and advice. [See page 9] Also thanks to John McFarlane, Chair of the European Polio Union. You need to be aware though that regardless of who you contact, including other hospitals where you may be a patient, that it can be very difficult to offer/discuss that information with those health professionals treating you who are going to make all the decisions.

It has taken till February 4th for me to find enough energy and spare time to start the newsletter. See page 16 at some suggestions we should have considered before this happened. See page 7 advice too.

AGM 2016 will be held on 9th April at the Memorial Hall, North Hykeham [as last year] The room will be open from 10.00 am. Tea, coffee, and soft drink available on arrival. The AGM will start at 11.00 [to allow time for people to travel]. A buffet lunch will be available for £4.00 per person [It is essential you complete and return the AGM slip enclosed with this newsletter]. The afternoon session will be a bit different this year. We are going to invite some Health and Social Care students from the University to join us for a Workshop on the problems we are experiencing. A marvellous opportunity to let Students see and hear about Polio and PPS before they qualify and to learn from them how we can help make their working lives easier.

If anyone would like to become a Trustee or can find an hour or two here and there to help us with our workload please get in touch. Maybe you belong to another organisation whose information could help our members. We are open to any suggestions to improve our work.

I was asked a good question at University of Lincoln by students regarding barriers to communication. ‘Which is more difficult when you need to be seen by a health or social care professional to get help… a physical barrier or a spoken/written barrier?’ E.g. Needing to attend an office but having a difficulty getting there, or having a problem understanding the terminology being used for completing forms. Two days later at a meeting at the Council Offices regarding a new form… The terminology is still Council speak and a lady there who is providing almost 24 hour care for her mother with vascular dementia pointed out that her days are exhausting and emotional. When she has a break and has to again give up time to deal with paperwork it MUST be easy to read and take on board or it wont get done. I agreed and said I often get down two paragraphs and have to start again and that I dread forms arriving they are very stress giving.

Newsletter. Anyone can send us information that you think other members might benefit from. Remember we would rather receive it ten times over than not at all. If something has helped you then you can bet your sweet bibby…. I wondered what that actually meant. Oh its sweet bippy not bibby and it says it is an unspecified part of the anatomy….. someone else will benefit from the information as well.

PAYPAL. Our Charity PayPal account is now open see page 5. Big thanks to Dot.

Naidex N.E.C. Birmingham. Dates are 26th to 28th April 2016, but note NEW this time is that Tuesday 26th April is for Trade and Healthcare Professionals ONLY. We’ll be there on 27th.

MESSAGE FROM OUR CHAIR

Empathy in the consulting room

As more issues come to light where our members feel we are not being listened to and marginalised, I contemplated what it was that lay at the core of this problem. Last year I was forwarded a letter from the Medical Journal, The Lancet, about empathy and the patient/doctor relationship. Written by an American doctor following his father's death in hospital, it focuses on empathy. Today doctors' training includes communication skills with patients, especially around delivering unwelcome or bad news. The author wonders though whether empathy can actually be taught? Whilst it is possible to learn what to say and the kind of words and phrases to employ in consultations and interventions, ultimately it not just about what, but how we communicate.

I mention this because as the boundary between mental and physical health grows ever closer, the psychological and emotional aspects of consultations become ever more challenging and more important for both doctor and patient. For those of us who have had a life long relationship with the medical profession as disabled people, we can no doubt all recall individual doctors, nurses and allied professionals who manage to both listen and discuss with us, not at us, in a way that makes it easier to hear, accept and more importantly, believe that they are there for us and that we have actually been listened to and heard.

Assessment and Empathy

Understanding, assessing and supporting polio survivors, as we all know, needs some specialist expertise, albeit that this is disputed in some quarters. But beyond certain basics, ultimately it is how we feel we are listened to that makes the difference. The current approach seems to have polio, relegated to an almost historical, neurological disease, soon to disappear into the history books. Within this atmosphere it is hard to believe we are getting even the basics of what we need, when we need it. At the core of this is a loss of confidence in the assessment and treatment of us as polio survivors. So often people report that after an initial consultation and the 'rush of excitement' and relief of finally being referred to a 'specialist' we are left feeling marginalised and, rightly or wrongly, that there was no follow up, understanding or ongoing sense of empathy and support. Indeed what used to be at the core of the patient/doctor relationship is now at the margins.

Are Polio Survivors the only Experts left ?

For those of us who remember being a major focus of medical interest and training, the reality today is sometimes hard to take. It can feel lonely and scary to be dismissed, knowing that polio survivors are often more knowledgeable than the 'so called' experts. Hiding lack of knowledge or funding for specialist staff development behind an empty set of 'empathic words' and a 'professional smile' does nothing to improve the situation. The importance of the patient/doctor relationship is not just academic, it is not just about getting the right answer, even if we sometimes hope for that, nor is it about cure, and it certainly isn't just 'icing on the cake' it is often that part of the cake which actually ensures survival.

All about cost benefit

We live in a cost/benefit health economy where 'evidence base' is the current religion and all else is caste into the devil's realm of placebo and financial waste. The result is that psychologically minded, person based medicine is the loser being viewed as time consuming and expensive with little 'measurable outcome'. Medicine and healthcare is not a pure science, people are not just a set of biological systems, it is an interaction between fellow human beings. Without the idea of empathy and kindness at its core, it is flawed and ultimately the real costs are high.

Simon Parritt, *C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP*
Chartered Psychologist. HCPC Registered Counselling Psychologist, www.sp-psychology.com
Chair Polio Survivors Network.
Simon Parritt <simon.parritt@poliosurvivorsnetwork.org.uk>

BRUNO BYTES - from the Facebook Post-Polio Coffee House

On Barium Test with throat paralysis - February 2015.

Question:- I am in the hospital right now with COPD. I had Bulbar polio and my throat is paralyzed. The doctor insists that I have a barium swallow test to see how thick my food should be. I do not want this test. I had it years ago and it was horrific for me. My blood pressure went through the ‘roof’. Do I have to have this done?

Dr. Richard L Bruno three part response.

1. “A video swallow study would let the Doc see what thickness of liquid you need that doesn't pool in your throat or go down toward your lungs. If you’re coughing or choking or have had pneumonia I would recommend the study but tell the Doc about your blood pressure reaction. The other option is to work with a Speech Therapist, starting with a thick liquid that you know DOES NOT cause trouble swallowing then dilute it until you find the ‘thinness’ that causes symptoms.”
2. “Speech Therapists do more than deal with speaking. They teach swallowing techniques like turning the head, tucking the chin and thickening liquids. If you’re having significant swallowing problems but don’t know what's happening in your throat with a video swallow study you cant compensate except by trial and error. It’s like bracing a leg without doing a manual muscle test. But trial and error with thick to thin liquids is better than no trial at all.”
3. “There are different kinds of swallowing problems. The ‘throat’ trouble - swallowing thin liquids - is due to the poliovirus damaging the swallowing control center in the ‘bulb’ of the brain, the brain stem. Every polio survivor had ‘bulbar’ polio, i.e. damage to the brain stem, but some had more damage than others. You may remember when you first had polio that liquid didn’t go down but came out of your nose.

   “As the woman who asked the question and her esophageal web remind us, not all swallowing problems are due to polio. Anyone can develop a pouch in the esophagus that holds liquid or food. That’s why a video swallow study is important. If you have consistent or intermittently severe swallowing issues.

   “By the way there is NO ANAESTHESIA with a swallow study. It’s not painful. Besides how could you eat or drink barium if you were asleep”

With grateful thanks to the Pennsylvania Post Polio Network you can access Bruno Bytes from their Website. Here is the link to all published at February 2015.

http://www.papolionetwork.org/uploads/2/7/7/2/27726699/bruno_bytes_(february,_2015).pdf

PayPal We have recently set up a PayPal business account. As we have charitable status this is of no cost to us. Payments, including membership renewals, can now be made via the PayPal button on our website.

Donate - There is a ‘Donate’ button at the bottom of the Home page and a further one on the ‘Support Us’ page. We are hopeful that this will generate extra donations from people who find the information on our site helpful.

Subscribe - There is a ‘Subscribe’ button with a link to membership forms that can be found from the Home Page by clicking on the ‘Join us’ button in the menu at the top of the page. Here you can pay annual, associate, one off or instalment life membership. You do not have to have a PayPal account to use this service. It accepts debit and credit card payments.

We are hoping that members and other website users may find this facility useful and easy to use. Indeed, we have already gratefully received a life membership subscription of £150. You will also need to click onto the link to the membership form to complete your details. This will then be processed by the Membership Secretary who will contact you regarding information, and newsletters.

Naturally our other methods of subscribing and donating remain easy to access and these can be found on our membership page via the ‘Join us’ button on the Home Page.

I am taking on the task of managing our PayPal Account so if you have any queries or require further information about using the PayPal facility please do not hesitate to email me.

Thanks

Dot Ives (Trustee) dot.ives@poliosurvivorsnetwork.org.uk

P.S. Remember if you move or change your email address ensure you, or a family member, let us know.

Modern Life: How [Not?] To Survive It

Does anyone, like me, ever get the feeling that modern life is conspiring against them? Let me give you some examples. Every year, I spend a week at a well-known literary festival in Wales. I stay in a comfortable guest house, which provides transport to and from the festival site. Only trouble is, as PPS is making my legs weaker and I am distinctly vertically challenged, getting on the coach is becoming a problem. The local coach company uses old-fashioned coaches which, unlike the more modern varieties, do not have a step which lowers to the ground when passengers are embarking. In the good old days, the driver would helpfully place a small plastic step underneath the step to enable those with mobility difficulties to embark more easily. When I asked the driver last year if she could provide one, she uttered the dreaded words: ‘Health and Safety won’t let us use those anymore.’

So…In other words…it is fine for me to fall off and injure myself trying to get on the coach, because that, presumably, would be my fault. If I were to fall off the step provided to help me embark without falling, that would not be all right because it would then, presumably, be the coach company’s responsibility. This I conclude has nothing to do with enhancing my or anybody else’s Health and Safety, but everything to do with the coach company protecting itself from being sued in the unlikely event of a passenger falling off a piece of apparatus put there to help them get on the coach without falling. Are you with me so far?

A similar thing happened later on last year, when I was returning by coach from a holiday in Kent. The coach itself didn’t present too much of a difficulty, because it was a modern one. The real problem came when I and my holiday companion were dropped off at a motorway service station and a courtesy car came to take us back to our home addresses. The courtesy ‘car’ turned out to be a people carrier or a minibus - not being an expert on such matters, I am not sure which category it came under. Whichever it was, I was unable to get into the thing because it was too high off the ground. ‘Haven’t you got anything I can stand on to help me in?’ I asked the driver. ‘Oh, we used to have something,’ he replied, ‘But our Health and Safety department has banned them.’ I refer you to my comments in the first paragraph. Not only that, but why do manufacturers produce brand-new vehicles which mobility-impaired people cannot access? Eventually, the matter was resolved by the driver moving the vehicle and parking it next to a high kerb which just raised me enough to get into the vehicle in a very undignified fashion, (fortunately I was wearing trousers).

My next holiday - yes, I know, it’s obviously all my fault for going on too many holidays - presented a different problem, known as the Mystery of the Missing Shower Mat. I was staying in another very pleasant guesthouse, this time near Exmoor, in an attractive en suite ground-floor room. So far, so good. Except…when I went into the bathroom, I noticed there was no rubber mat to prevent me slipping in the shower. When I asked at reception, I was told, ‘Oh we don’t provide those anymore.’ ‘Why?’ I asked, expecting it would all be down to Health and Safety. But no. ‘Because if you happened to slip when using the mat you might sue us.’ OK…So it’s fine for me to slip in the shower and possibly kill myself because there is no mat, but not OK if I were to slip on the non-slip mat they haven’t provided anyway. Is there actually any kind of logic to this? ‘You need to bring your own,’ the person at the desk informed me, helpfully. (I think he meant a mat, not logic.)

Last example. For nearly a year, I have been trying to downsize into some kind of sheltered accommodation, as I am now living by myself in a house which is too big for me, too much work and maintenance, etc. etc. I have viewed several places, but the deal-breaker has always been the lack of a dedicated parking space. I am one of those people who runs my life around my car, and I need to be able to park it close to my accommodation. Perhaps this is not very environmentally-friendly, but I find using any form of public transport is becoming increasingly difficult and exhausting. The places have I looked at have all had some parking, but provided on a (more dread words) ‘first come, first served’ basis. Fine. So I come back to my nice apartment after attending an evening concert, or whatever, only to find all the parking spaces are filled. What am I supposed to do then?

A mile or so from where I live, a well-known provider of apartments for older people is building a development which in my naivety I imagined would be very suitable for me. (I will not mention its name, but it is identical to that of a famous former Prime Minister and an insurance company fronted by an annoying dog.) I phoned them up to get some details and to ask about the parking. I was told that although there is some parking available at all their retirement developments none of them has any guaranteed or dedicated parking places and there are no disabled bays. So that effectively rules me out, and indeed anyone with mobility difficulties who relies on a car to get around. What happens when an existing resident at one of their properties has a fall, or whose mobility becomes impaired and therefore has to have their car close at hand?

The car park of another retirement development run by a different company was full up on the day I went to view, apart from one solitary empty space which I of course took. Not a very encouraging start. Inside the entrance, I noticed that the minutes of a residents' association meeting had been placed on a table in the waiting area. I read through them, and mostly they consisted of complaints about the lack of parking. The development had fifty apartments and only thirty parking spaces. When I pointed this out to the person who was showing me around she said, 'Many of our residents find they don't need a car here. We have a minibus which takes residents to the local High Street every day.' Great, I thought. But what happens when I want to visit a friend or relative? If I want to go on holiday? Go swimming? Go to a concert? Is your minibus going to be available for all those needs? Of course not. I wouldn't mind so much, but none of these places with rationed parking is exactly cheap to buy, and one would have thought it not a big ask for them to throw in a parking space to seal the deal.

Someone told me that it is now my local council policy not to demand that developers provide a parking space for each property when building flats, whether sheltered or not. If true, not only does this seem disabled-unfriendly, but neighbourhood unfriendly if flat-dwellers are forced to park on residential roads. The only winners seem to be the developers who don't have to buy so much land or spend money on underground parking. My local council has a very aggressive anti-car policy, and resorts to all kinds of devices, including Residents Parking Zones to discourage people from using and parking their cars in the city. This is all very well for those able to use public transport and get to the appropriate bus-stop, train or coach station without difficulty. I have already fallen foul of RPZs when I found to my cost that even with a blue badge I was not allowed to park in a RPZ. What one has to do, apparently, is park on a double yellow line, but as we disabled drivers all know, locating yellow lines to park on near enough to where we are visiting, which would not cause an obstruction, be dangerous to other traffic or otherwise contravene regulations is often impossible.

For me to move somewhere without guaranteed parking would only result in exchanging one set of problems for another. At least my current home has a drive. So…my search for a suitable retirement property continues. If I manage to survive long enough without falling out of a vehicle, or slipping in a shower, I will let you know what happens.

Dinah Foweraker January 2016 - dinah24@tiscali.co.uk

I [Hilary] am now in my 29th year of new symptoms - my 21st year of finding PPS exists.

Finding out PPS existed was wonderful (my symptoms were genuine). However learning more about PPS and what was happening to others and might happen to me was and still is on occasion very difficult.

From personal experience my best advice to improve our quality of life is:-

- to become a member of PPS Group/s - which can be in person and/or online
- to listen to the experiences of those who are ahead of you in learning/experiencing PPS and share with them what is happening to you and your family relationships and how you feel about it [e.g. During Richards operation in December I sat alone in a waiting room and for something to do I updated my status on Facebook. During the three hours 32 Polio Survivors from 9 different countries, responded and I had not been alone, my PPS family were there for me]
- to accept that feeling frustrated, anxious, possibly depressed about all this is normal and that counselling which can be arranged by your GP can help you 'let off steam' about all you are going through which can help you put into perspective some of what you are going through [did me]
- to accept that we are getting older and that age alone can change what adaptions and equipment we might need and that PPS and any other condition we have can add to that [Scooter for 19 years]
- to go with others, as it is more fun and less daunting, to disability stores and exhibitions and check out and try what's available for now and the future [e.g. Naidex at the NEC on 27th April 2016]
- to plan for years to come when buying or making alterations to your home [e.g. in 2007 we made sure a ceiling hoist could be fitted from our bedroom to the bathroom, not needed yet but will be]
- to accept that having physical help to manage some of the household tasks will release energy for doing more we enjoy [Personal Budgets provide us with funds to employ Personal Assistants]
- to plan the week/s ahead and ensure there is at least one event each week to look forward to [Hairdresser, Antique Fair, User support for University Lecture, Re-enactment event, Garden Centre]

Tees Valley, Durham and North Yorkshire Neurological Alliance

'Impact of Neurological Conditions – beyond clinical routines'

Report by Dot Ives

Mrs Joanne Cole, Head of Operations for TVDNY Neurological Alliance contacted me in November 2015. I was asked to contribute to this seminar at Durham University along with three other people who all had long term chronic conditions. The conditions were: Post Polio Syndrome, permanent affects of a brain haemorrhage, Dystonia and chronic pain due to multiple causes.

The targeted audience were Neuro Physio students and student nurses and this was held at the Stockton Campus.

The objectives were to:-

understand the perception of vulnerability – the future can change quickly and incidentally

understand care giving

reflect on changed aspirations and the impact of loss

Our 'brief' was to speak for 20 minutes on a brief journey through: the history of diagnosis, the psychological impact, what services are offered or used, therapeutic interventions

We each told our 'story'. Interestingly one storyteller used a phrase often used in our newsletters – *'Never judge a book by its cover'!* This seemed to fit this particular contributor perfectly as she did not 'look' as if she was disabled and in chronic pain.

Whilst our stories were very different and about very different conditions there was a recurring theme running through what we said. Lack of knowledge or understanding by professionals, services and resources varied widely and were less frequent or available in these times of economic cuts.

However, there was a 'positiveness' and an overwhelming drive and an optimism to do the utmost we can to live our lives to the full. A strong proactive attitude shone through.

Nevertheless we did also touch on the 'down' side..... a feeling that we are not listened to by health professionals; not given enough 'time' at consultations; a feeling that, at times, we don’t give the clear true story and 'tell it how it is' ourselves because we think they don't want to know or we are 'sick and tired' of saying the same thing and getting nowhere..... of bouts of depression, hopelessness and a weariness within our families that we are nearly always unwell or poorly.

I followed the survivor of a brain haemorrhage and someone with dystonia. In 'typical' fashion I explained that I 'talk down' my condition and ailments and don't see myself as being disabled although there is an ever increasing range of things I cannot do. It has been well documented in this newsletter and elsewhere that this is probably typical of many PPS sufferers and polio survivors!

I certainly felt a bit of a fraud in the present company! I began by asking for a show of hands to two questions: “How many of you have heard of polio?”… everyone put their hand up. “How many of you has heard of post polio syndrome?”.. no hands were raised.

I explained the neurological effects and onset of difficulties years and years after having polio - the muscle weakness, the fatigue, the clumsiness – the ability to constantly and always fall over and seemingly to fall over 'fresh air' at times. The respiratory difficulties others have that I am very fortunate to not suffer from as yet. The 'symptoms' that may seem like the onset of MS or be like fibromyalgia or even ME.

Linked to my diagnosis was the astounding 'luck' of seeing a clinician at the MusculoSkeletal Clinic who was a Neurologist and related to someone with PPS and who recognised the symptoms. The 'luck' that my GPs acted upon my husband complaining to his GP to talk to my GP (they were married to each other) to check me out a bit more when I next landed or limped into the surgery with injuries from a fall as he was worried about me!

Also the 'luck' that when I 'googled' this totally unknown and unfamiliar condition I came upon a BBC archive of an 'Inside Out' programme from 2002, then Polio Survivors Network, the Lincolnshire Library and newsletters galore. Of great help was **'The Polio Paradox' by Richard L Bruno.** This book described 'me' perfectly. It is an American publication and I read it on a plane returning to the UK from Washington. Seated next to me was a Medical Consultant returning to the UK after attending a conference on communicable diseases. He asked me why I was reading it. I explained that I had poliomyelitis as a baby in 1956 and had recently been diagnosed with PPS. He asked what had been affected and did I wear orthotics (shortened tendon in right leg and 'yes' to orthotics) ‘SNAP’ he said! It's a small world!

Evaluation of the seminar:

The students were asked to circle words they felt were most appropriate to describe the charity. The words included were: flexible, accessible, person centred, informative, responsive, useful, needed, positive and friendly.

Note: Respondents circled more than one word:- 100% circled 'positive; 70%+ circled 'person centred' 'informative' 'friendly'; 12% circled all the words. 100% had not heard of TVDNY and 100% thought the seminar gave useful information.

The feedback from the students was positive – when asked to describe benefit or most impact: “Hearing real life situations from the individual and the implications of the conditions, the personal stories of what people have really been through was fascinating” “Positive attitudes” “Personal experiences” “GP's being uninformed / not helpful” “Gaining exposure on individuals with REAL conditions and understanding them on a physical, social and emotional level” “Hearing service users directly tell us what they wish they had from professionals (will bear in mind)”

Information regarding the work that the TVDNY Neurological Alliance does and the services and resources available within the North East can be found on their website. www.na-tvdny.org.uk/ A useful downloadable directory regarding neurological conditions is available by clicking on the link for TVDNY-Directory-2014-1.pdf *Directory of information for people living with or caregivers of a neurological condition.* Unfortunately it does not have a directory entry for PPS!

The Polio Paradox is available from Dr. Bruno on Random Harvest eBooks www.postpolioinfo.com and also on Amazon, hard back, paper back and Kindle. Other books are available including a couple by a great PPSer Millie Malone Lill and another by Scottish Polio Survivor Vicki McKenna.

Dot Ives, dot.ives@poliosurvivorsnetwork.org.uk

N.B. Hilary writes I am a member of the University of Lincoln Users and Carers Panel. It is worth contacting your local Universities, Colleges, Hospital education departments and even Secondary Schools to ask if they have anything similar. As Users/Carers we are on the Interview Panel for prospective students for a number of Health and Social Care courses and the feedback most often contains ‘meeting users and hearing their stories’ as a positive experience and often the deciding factor in which University to pick. Hospitals can also be looking for patients to take part in training/examinations to see if their problems are being recognised. Two student Doctors visited Richard in the ward and asked if they could do a neurological examination. Single action Manual Muscle Testing was used and many of his weaknesses were not picked up. There was great interest when I pointed this out and they examined Richard again and found weakness they had not picked up before. They then examined me and even knowing the same thing happened. They assured me that ’we will speak to our Tutors about this, and thank you.’

The British Polio Fellowship's *Post Polio Syndrome:*
A guide to management for health care professionals

strongly recommends a multidisciplinary approach involving GPs amongst others when it comes to Post Polio Syndrome (PPS). Launched today, and authored by British Polio's Expert Panel and edited by Dr Frances Quinn, the report also details several key areas where further research is required and demonstrates the need for extra funding to facilitate research into these topics.

"Due to the tremendous success in eradicating Polio here and worldwide, the condition is virtually unknown in the UK and as a result little training is given to health professionals," said the editor of the guide, Dr Frances Quinn. "With the emergence of PPS, Polio survivors need informed medical care and this review aims to provide up to date knowledge and guidance."

For the first time, the guide details the specific problems of those living with PPS in the UK so that the medical community has the best chance possible of recognising and managing PPS. It is hoped that the guide will also prove useful for British Polio members and indeed anyone with PPS.

"The symptoms of PPS are characterised by new weakness, fatigue and pain in muscles which may or may not have been previously affected by the Polio infection," said Dr Robin Luff, Chair of The British Polio Fellowship Expert Panel. "One of our key recommendations is for a multidisciplinary approach involving GPs, physiotherapists and other allied health professionals. Yet there is a compelling case for further research into PPS"

A number of key evidence gaps are identified by the report's authors. Longitudinal studies following the developmental course of PPS symptoms are needed to understand the role of muscle overuse to determine the correct amount of exercise for patients. Without clinical trials it is difficult to know how much exercise is beneficial as too little exercise can be equally harmful as doing too much and must be assessed on a case by case basis. Research into this area could lead to major advancements in the treatment of PPS.

"There is a pressing need for further research in order to develop a comprehensive strategy for dealing with PPS, and this new guide makes that clear," said Ted Hill MBE, CEO of The British Polio Fellowship. "Last year our Support Service Team received 3,700 enquiries on PPS so the demand is out there and we know this is just the tip of the iceberg."

The characteristics of fatigue in PPS are also not well understood and together with cold intolerance have arguably the greatest impact on quality of life. Currently, there is only a limited understanding of exacerbating factors, and there is not a widely agreed on definition of the different types of fatigue and this is where new research could make a big difference. Improved understanding of fatigue and cold intolerance would lead to real improvements in people's lives.

"The reasons why those living with PPS are often cold intolerant are not widely understood, and so little can be done to resolve this painful symptom," added Ted. "The more we know the more chance we have to at least to manage the symptoms better. **"Overall, on a clinical level at least, we have only a fairly rudimentary understanding of PPS. While the issuing of this report is an important step forward, it is vital that The British Polio Fellowship gains as much funding as is possible to finance clinical trials and professional medical research. Only when we understand this condition much better at a clinical level, will we truly be able to help those living with it."**

NEUROLOGICAL ALLIANCES HAVE DEMONSTRATED REPEATEDLY THERE IS A MASSIVE OVERLAP IN NEUROLGOCICAL CONDITIONS SYMPTOMS AND ISSUES

POPULATION OF UK 64,000,000 - NEUROLOGICAL CASES 12,000,000

Rt. Hon. JEREMY HUNT M.P. WHY WAS THIS LETTER NECESSARY?

1st February 2016

Neurological Alliance members write to the Secretary of State for Health and The Times

Dear Secretary of State,

We are writing to you to express the concern felt by people living with neurological conditions, their families and loved ones about NHS England's decision not to retain the post of National Clinical Director (NCD) for adult neurology beyond March of this year. This is a short-sighted move which will leave no strategic leadership for neurology within the NHS at the national level and will disrupt the improvement initiatives that Dr David Bateman, the current post-holder, has led and coordinated over the past two years.

You will be aware that neurology services already lag well behind other condition areas in terms of service access and quality, with 58% of people with neurological conditions having difficulty accessing the services they need, and 40% waiting over 12 months between first symptoms and being given a diagnosis (according to a survey of almost 7,000 patients). Local commissioners have disengaged from neurology services to the point where only 15% can state how much they spend on neurology locally. Access to specialist neurology services varies hugely by both region and CCG area, with 45 CCGs (22%) offering no local neurology services whatsoever.

In the short time since his appointment, the NCD has led a range of initiatives aimed at improving patients' experience of care. He has worked with NHS England's strategic clinical networks to modernise the referral processes for headache, and to develop measurable standards to audit local provision for acute neurological emergencies and scheduled care. His work with Public Health England's Neurology Intelligence Network has allowed patients to compare and scrutinise CCGs' performance and outcomes in neurology for the first time. He has taken the lead on strengthening and developing community neurology services, including developing plans with NHS England for a community care service for patients with long-term neurological conditions.

Cutting the NCD role so soon after its creation will undermine these efforts to improve the quality and value of neurology services. Neurology is not a minor issue for the NHS. There are an estimated 12 million cases of neurological conditions in England, and NHS spending on neurology services totalled over £4.1 billion in 2013/14, including funding for 827,242 emergency admissions. Consequently it is difficult to understand why NHS England does not value clinical leadership for neurology services. In addition, it is particularly concerning that there is still no commitment from NHS England and Public Health England to fund the Neurology Intelligence Network beyond March. In conjunction with the loss of the NCD role, this would leave neurology services with no national clinical leadership, and no access to comparative national data in order to scrutinise services and hold commissioners and providers to account.

As representatives of the millions of people living with neurological conditions, we believe that the decision not to maintain the role of neurology NCD is short-sighted and damaging to patients' interests. There is enormous scope to improve neurology services, but it will require effective clinical leadership at the national level. We urge you to use your influence as Secretary of State to raise this issue with NHS England and request that they commit to maintaining the role beyond March 2016. The Neurological Alliance would be very pleased to meet with you to discuss this issue further if that would be helpful. We have sent a copy of this letter to Simon Stevens. Yours sincerely,

Arlene Wilkie, Chief Executive, Neurological Alliance [signed by 32 Charities and Regional Neurological Alliances including **Simon Parritt, Chair Polio Survivors Network and Ted Hill, Chief Executive British Polio Fellowship and Preston Keeling, Chair Lincolnshire Neurological Alliance.**

I live in Australia but joined Polio Survivors Network when I met Hilary at a PPS Conference.

I am Secretary of the Hume Polio Self-Help Group on the outskirts of Canberra in New South Wales, Australia. Hilary asked me to tell you all a bit about our Group. Well where to start… in June we celebrate 21 years since our formation. [six months older than PSN] So much has happened to our members since then. Some have passed on, others have graduated to wheel chairs and still others are walking with 'friend stick' hoping to not tumble on an invisible obstacle! Others have graduated to CPAP while others continue to wake tired but pleased to get through the night not encumbered. We all get together for a combined meeting with Albury Wodonga Polio Survivors group in November, have a knees up to celebrate Christmas and are visited by Santa complete with white beard and squeaky wheelchair!

We have a month off ‘as it is normally our hottest' although this January we had some cold rainy days! Now February has come with hot sweaty weather as we start our new Year on the second Saturday of every month sharing a meal then launching into a New Year of Meetings!.

First we have to elect a new President, a problem as the reluctant Lady feels shy! She has a loud voice and comical comments to put wayward people into order! It will be interesting.

March is a friendship and chat meeting! As Postage rose to $1 it has curtailed our mailouts so we are hoping that more rang by phone, vaguely cheaper, will come see what our group has to offer.

April our Member of the Federal Parliament will tell us what they are going to give us over 65s for National Disability Insurance Scheme. This will be very interesting with all the things Parliamentarians think we don't need? Polio Australia went to Canberra last October.

May may be a very different meeting, as the Rural Health lady will stir all up with thoughts of alternate thinking. We have a couple who live out of town (about 40 km) who have lost driver's licenses - they are finding it difficult to get to meetings - bringing friends! Also we hope to look at Wills and Powers of Attorney and the changes to the latter and planning funerals with ’Our Goodbyes’, so the family don't just put us in the ground!!!!!!!!

June is Birthday month and everyone looking to catch up with friends and have some entertainment and Cake? Muggins has to find some different cake! Last year we filled 23 tummy’s.

This year planned is a 'roll with us' in September! October is Polio month and a display at the Independence Day and local super market.

Where do we live.. Some come from Yarrawonga on the beautiful Murray River, some from Shepparton just some 20-30 km south, others from further along the Murray at Rutherglen and Corowa in Wine country, some 47 km away. Some from the Alpine shires of Myrtleford, Yackandandah (dear Bill too 'old' to drive now) and Whoroughley (Lex forced to get a driver with limited license). This area used to have massive hop fields and depleted to only speciality breweries now . Southern members come from Violet Town, Baraja, Warrendyte and Closer at Benalla. We all get together at the Wangaratta Club for food, fun, fellowship and some exchange of ideas, treatments and frivolity.

Best wishes to you all over the seas. Hope no one has grown webbed feet yet from all the floods we see on tv?

Robyn Aulmann, Secretary and dogs body of Hume Polio Self Help group.
<robynja1144@gmail.com>

How does Moses make tea? Hebrews it.
Venison for dinner again? Oh deer!
I used to be a banker, but then I lost interest.
Haunted French pancakes give me the crêpes.
They told me I had type-A blood, but it was a Typo.

I changed my iPod's name to Titanic. It's syncing now.
Jokes about German sausage are the wurst.
Why were Indians here first. They had reservations.
When you get a bladder infection, urine trouble.
I didn’t like my beard at first. Then it grew on me.

Jumma Mtuku, Artist and Polio Survivor, Nairobi, Kenya [See Back Page]

I was born on Thursday 22nd January 1981 in a small village called Timbonni in the southern coastal region known as Mwangulu. I am second last born in a family of seven children. In early 1983 I suffered Polio which led the family to migrate from Timbonni to Kinango where there was a hospital. In 1986 it was found that suffering from Polio I was taken to the Portreitz Rehabilitation Centre. Here is where I met my all time friends Abdalla Kea and Jefferson Mkala. We grew our friendship there and luckily we were enrolled in the same Port Reiz School for the physically handicapped. Mombasa Secondary School for the Physically Handicapped came next. Then College but thankfully although we went to different ones they were not too far apart and we met every evening to discuss what jobs we wanted to do. We all took Tech courses. Actually I have never seen myself as disabled rather an activist campaigning to change what is wrong.

Trustee and Carer Margaret writes…. Where Has This Year Gone

David and I have had a good summer. We sold our Motor Home last year, as David's PPS had made his mobility more limited. We decided to invest in a touring caravan and sited it on a small site on the boarders of Lincolnshire and Norfolk. This has enabled us the freedom we have enjoyed for many years of camping and not having to think about towing it. The caravan site has now closed for winter. This has given us time to catch up with our life at home and local hobbies. One of mine is researching my family tree, we both belong to the local Archaeology Group and attend as many interesting lunchtime lectures that are available at different venues within the city.

David has several health issues apart from PPS although apart from confirming he has it, he has not been offered anything else. Having been fit and well all his life it has been very hard to adjust to this life as most of you know. He has one appointment every 6 months at the Vascular Clinic another yearly at the Cataract clinic and then there is the Hearing Aid Clinic.

The 6 month vascular appointment never arrived but I didn't realize until 9 months after the previous appointment. I rang the secretary and got an answer phone and left a message. Yes, later that day I did get a reply and was informed an appointment would be sent. A week later no appointment had arrived. Rang again yes an appointment had been sent but it would be re sent, nothing. Further phone call to be informed his treatment had been transferred to another clinic within the same department. In desperation I rang the switchboard and got a really nice lady who listened, I gave the information as to what the appointment was for and immediately put me through to the right clinic and the appointment arrived the next day!! David's eye appointment due in December 2015 never arrived I rang the department, "Sorry we have a back log and don't know when you will be seen, but we are doing extra clinics"

Hearing aids: David had an appointment in September 2012. No appointment to have them fitted arrived. I rang the beginning of December "we are fully booked and do not know when they will be fitted". Since all this happened I am very mindful about appointments. I would suggest that when you leave a clinic and they say they will see you in say 6 months time that you make a note in your diary at three months. I must add some of these appointments are not at our local hospital but I find this so frustrating, there must be people out there that are not receiving care that they need. What is happening to our NHS, a service that was the best in the world? I am an ex nurse

David still finds it hard to pace himself, the mobility scooter has had many a ride in the boot of the car but not seen the light of day. He will say "I will just use my stick". (One day we may get there) maybe not.

Our Very Best Wishes for 2016 - Margaret and David Marris

This girl said she recognized me from the vegetarian club, but I'd never met herbivore.

England has no kidney bank but it does have a Liverpool.

I know a boy who is addicted to brake fluid, but he says he can stop at any time.

Did you hear about the cross-eyed teacher who lost her job because she couldn't control her pupils?

I dropped out of communism class because of lousy Marx.

All the toilets in New York's police stations have been stolen. The police have nothing to go on.

Don't worry about old age; it doesn't last.

Patient Information Forum

For everyone involved in health information and support

www.pifonline.org.uk

The Patient Information Forum (PIF) is the UK membership organisation and network for people working in, and involved with, health and care information and support.

The following Patient Information Forum [PIF] Guides that may be of interest to our members are now FREE to download.

Guide to Health Records Access

,www.pifonline.org.uk/wp-content/uploads/2014/11/PIF-Guide-Health-Access-2013.pdf

Guide to Appraising Health Information

,www.pifonline.org.uk/wp-content/uploads/2014/11/PIF-Guide-Appraising-Health-Information-2010.pdf

Dysmotility is a condition in which muscles of the digestive system become impaired and changes in the speed, strength or coordination in the digestive organs occurs. In the normal small intestine, liquefied food and secretions including digestive enzymes are pushed onwards by waves of muscular contraction. When these contractions are impaired, the contents are trapped, and cause distention with symptoms such as bloating, nausea, vomiting and even malnutrition.

Annual General Meeting of the European Polio Union

Bratislava, Slovakia, June 4, 2016

The Annual General Meeting of the European Polio Union will be held on June 4, 2016, in PIESTANY, a town in the western part of SLOVAKIA, at the **BALNEA PALACE HOTEL**, which is situated at the **SPA ISLAND** – (the reason why it is called “spa” is that from both sides it is surrounded by the Vah river) you can see the map here:

http://piestany.danubiushotels.com/destinations/piestany/about-the-town/map-of-spa-island.

The whole area of the Spa Island is a pedestrian zone (the only exemption is for hotel guests), safe, very nice, especially during this time of the year.

Stefan Grajcar <stefan.grajcar@gmail.com> John McFarlane <europeanpolio@eircom.net>

[PSN will not be attending this AGM due to cost without their also being a Conference.]

Intestinal Pseudo-Obstruction

What is intestinal pseudo-obstruction?

Intestinal pseudo-obstruction is a rare condition with symptoms like those caused by a bowel obstruction, or blockage. But when the intestines are examined, no blockage is found. Instead, the symptoms are due to nerve (visceral neuropathy) or muscle (visceral myopathy) problems that affect the movement of food, fluid, and air through the intestines. The intestines, or bowel, include the small intestine and the large intestine, also called the colon.

Members saying ‘Hi’ to Long time member Lynn Hobday who is in Lincoln Hospital as I finalise Post Polio Matters.

Do you suffer from constipation or have difficulty expelling some of your stools?

OK not an easy subject to discuss but when you do you find other polio survivors experiencing the same thing. Points to remember that nearly all health professionals have not been taught enough about polio and how it affected our bodies and are therefore not aware that we can have Gastrointestinal problems as well as Swallowing issues.

From the Lincolnshire Post Polio Online Library

Gastrointestinal Involvement in the Post Polio Syndrome [PPS] by Sinn Anuras, M.D

www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/usa/gi.html

NB. This study has not been published in a peer reviewed journal but was put together by Tom Walter from a paper delivered at the Second Texas-Oklahoma Post-Polio Symposium, September 21 to 22, 1991, at the Ramada Inn of Wichita Falls, Texas. Dr. Anuras and Terri Bozeman RN surveyed over 750 post polio patients regarding their gastrointestinal symptoms. [Excerpted selection of points]

Abstract. Gastrointestinal involvement is common in the post-polio syndrome, and it appears to affect the entire gastrointestinal tract. Unfortunately, there are only a few studies in this fascinating area. More extensive studies are needed to understand the pathologic and pathophysiologic processes in this problem, so that patients can be treated properly.

We report our survey of gastrointestinal symptoms that could affect up to 50% of the post polio syndrome patients in this service. We also propose the underlying physiologic changes, outline and diagnosis and treatment for difficulties of various parts of the gastrointestinal tract.

Introduction. Normal gastrointestinal motility is a function of the gastrointestinal smooth muscle and is regulated by both the intrinsic (myenteric plexus) and extrinsic nerves of the gastrointestinal tracts. Extrinsic nerves from the central nervous system (brain and spinal cord) connect the enteric nervous system (submucosal plexus and myenteric plexus) with the central nervous system. Therefore, any functional or structural abnormality of either the smooth muscles or the intrinsic or extrinsic nerves will result in gastrointestinal dysmotility causing gastrointestinal symptoms. The symptoms produced depend on areas of involvement. This abnormality may either involve the entire gastrointestinal tract or be limited only to certain parts depending on the underlying disease….

Symptoms produced by gastrointestinal dysmotility are variable depending on the part of the gastrointestinal tract involved…. Patients with the same disease may have different complaints that may appear to be unrelated. Patients with PPS may have difficulty with swallowing and constipation, and both symptoms can be caused by PPS….

TABLE 3	**Gastrointestinal Symptoms of 754 PPS Patients**	
Incidence %	**Symptoms**	**Organs involved**
24	Difficulty Initiating Swallowing	Oropharynx
32	Choking with Swallowing	Oropharynx
32	Difficulty with Swallowing (dysphagia)	Oesophagus
51	Heartburn	Oesophagus
28	Nausea	Stomach, Small Intestine
12	Vomiting	Stomach, Small Intestine
53	Abnormal Bloating	Stomach, Small Intestine, Colon
40	Abdominal Pain	Small Intestine, Colon
32	Diarrhoea	Small Intestine, Colon
48	Constipation	Colon, Anorectum
0.7	Intestinal pseudoobstruction	Small Intestine.

N.B. Remember that all symptoms are not caused by Post Polio Syndrome, they can be something else or a combination of both. But it must be taken into account that you had Polio in your earlier life and that could have an impact on how you manage your symptoms and issues. If you are having problems then discuss this with your GP and ensure that they are aware of the above.

THINGS TO CONSIDER BEFORE YOU GO INTO HOSPITAL.

Have you completed one of our **What You Need To Know about my Condition forms?**

Or typed up your own information.

A. Details of you and your nearest family member and your GP
B. Dates of any other diagnoses and details of any current health professionals.
C. Any allergies or intolerances and details of all your medications [need to keep updated]
D. Information on and differences from 'the norm' of your ability, mobility and equipment used.
E. Information on how you communicate, eat and drink, any issues swallowing or sleeping.
F. Any other equipment that you have bought/been given to help you manage your life.

Do you carry **a copy of the patient.co.uk article on Post Polio Syndrome** mentioned on top of next page, and the PTU leaflet on anaesthetics and any other article that you think you should carry in a file…. Remember health professionals do not have a lot of time to read but you can use them for reference. Highlight specific bits and if possible copy them with references to the full document to no more than one double sided A4 sheet. [Lincolnshire Neurological Alliance, because of our experiences are discussing a new idea but not ready for adding here but if possible will include with the posting of this issue].

Not an easy subject to write about, think about or discuss with your family.

Preparing for Future Care:- Advanced Care Planning, Advance Decisions to Refuse Treatment & DNACPR.

E.g. http://www.eolc.co.uk/uploads/Local-ACP-Guidance-LCHS-published.pdf

Richard was in I.C.U. for 16 days following his operation to untwist his bowel. As a Polio Survivor with PPS and Parkinson's and medically documented issues with swallowing and breathing there were more issues than just recovering from the operation itself. I had not prepared myself to be taken into 'the special room' by a Doctor and his dedicated Nurse to be told what the current situation was and what they expected the outcome would be and one night I felt I must ring his Sister in the States.

There are a number of issues that both of us experienced that I cannot yet report on but for my own peace of mind I need our readers to be aware that it would have been far easier for both Richard, myself and our families and friends had we discussed what we want to happen should we become ill.

I am recommending that you obtain leaflets and documents for your local hospital so that you can be better prepared than we were.

In ICU you have a dedicated nurse [although with breaks and assisting other nurses with tasks they are not with you 24/7]. I needed to get some rest and with that level of nursing Richard's needs should be picked up quickly. I provided a floppy file of information which included the above mentioned completed form, [which I call WYNTK]. The sheet of medications and times and column for what the medication is used for as sometimes this has not been known. A Day in the Life of - which includes what Richard does each day on average and a list of days out and activities that Richard does throughout the year. This is in case I become ill and we have to employ other Carers than our personal assistants employed through our Personal Budgets etc.

I thought about what else I could do to help him when I was not there and put some photographs on three A4 sheets [laminating them for easy cleaning] of special dates, and things we have done that could be used to instigate what I hoped would be happy conversations when not there. The reaction of staff to re-enactment photos was huge surprise. They were seeing the multi diagnosed person in bed, not Richard.

So I add here that the **most important fact** is that any health professional you see will **NOT KNOW** what sort of life you have out of hospital and they **MAY and DO make incorrect assumptions**. It is important that you ensure that the team are aware of '**what life is really like for you**'. In an early LincPIN I remember an article by Wendy Grimmitt about her sister in this situation where staff were stunned to learn that despite her level of disability she had recently done a tandem parachute jump.

You may or not be religious but the **Hospital Chaplains** are not just there for patients and when I eventually was taken to speak to them by **PALS [Patient Advocacy Liaison Service]** I was able to talk to them about what was happening and they encouraged me to 'let off steam' and kept in touch and I just so so wished that someone had pointed me in that direction whilst Richard was in ICU. I felt so much better.

POST POLIO SYNDROME EXISTS

Colleges of Medicine please add more facts to your lectures on the Polio Virus and the effects that it could have had on our bodies. Ensure health professionals understand how varied our nerve damage, our recovery and stable years have been. The majority of us recovered that well that externally we do not look like those photos in the old medical books. That there is a massive overlap of symptoms with other neuromuscular conditions. Tell them about **Post Polio Syndrome** and give them links to where they can find more information. Thankyou.

The most accepted articles we have found by NHS professionals are:-

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

http://patient.info/doctor/post-polio-syndrome

And in case you need an anaesthetic
an excellent leaflet translated into English
now used by many PPS Groups around the world.

POLIO PATIENTS AND SURGERY.
Information for health staff.

Lise Kay, MD, Surgeon PTU – Danish Society of Polio and Accident Victims

http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/Polio_operation_ENG.pdf

Text copies of both have been sent to members and are available on our Website link on front page

REMINDER FOR MEMBERS

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

Did you let us know?

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 March 30th 2016

Editors Note:-
Articles from Polio Survivors and Health Professionals Welcome for future issues

POST POLIO NEWS [ppn] - www.post-polio.org.uk

An online news cutting service from Chris Salter
that specialises in news relating to polio, post polio,
disability and other health related issues.

Twitter, Newspaper, RSS feed, Facebook, LinkedIn, Daily digest emails.

Excerpts from the extensive list of news items.

January 29th 2016 [See front page]

Multidisciplinary approach key when it comes to PPS | The British Polio Fellowship.

The British Polio Fellowship's Post Polio Syndrome: A guide to management for health care professionals strongly recommends a multidisciplinary approach involving GP's amongst others when it comes to Post Polio Syndrome (PPS). Launched today, and authored by British Polio's Expert Panel and edited by Dr. Francis Quinn, the report also details several key areas where further research is required and demonstrates the need for extra funding to research into these topics. Continued on page 10.

February 12th 2016

BarBara Wearne obituary | The Guardian

BarBara Wearne cycled round Malawi at the age of 70 to raise funds for leprosy treatment.

Phillip Wearne writes..

My mother, BarBara Wearne, who has died aged 89, was a polio survivor, primary school teacher and, after early retirement in 1981, an indefatigable long-haul traveller, campaigner and fundraiser.

Born in Launceston, Cornwall, to George Phillips, secretary of the local branch of the Oddfellows, and Ivy (nee Lang) who ran a café, BarBara contracted polio at an early age. But in 1938 some unorthodox surgery on her right leg allowed her to dispense with the callipers and bath chair to which she had been confined for much of her childhood. Her new freedom forged a determination to do everything, participate in anything and ask questions of everyone, while always seeing the world from an underdog's perspective.

BarBara attended Horwell Grammer School in Launceston and in 1942 started work as a clerk and typist at the Library Association, which had been evacuated from London to Cornwall to escape the blitz. When the association moved back to the capital in 1943, she went with it, serving as an air-raid warden on enlistment in 1944 and typing leaflets for the Labour party during the 1845 general election campaign.

She then travelled through Europe on a motor cycle before qualifying as a teacher at the City of Bath Teachers College in 1950. She met my father, Edwin {Ted} Wearne - an Anglican priest and former east Asia prisoner of war - in Mevagissey Cornwall, while teaching at the local primary school in 1952.

Ted's death from a brain tumour in 1966left her with four children aged from two to either. After years as a supply teacher, she spent most of her career from 1966 teaching at Caen Street primary school in Braunton, Devon.

In retirement she began 25 years of backpacker travel and activism in Latin American, African and Asia. Infiltrating a papal reception lineup in Belize in 1983, she remonstrated with John Paul II over his admonishment of the Catholic priests in the Sarndinsitra cabinet in Nicaragua. She had an audience with the Dalai Lama in Dharmsala, India in 1987, and eight years later, in Myanmar talked her way into Aung Suu Kyu's private residence in Yanon to meet the National League to for Democracy leader while she was under house arrest.

At the age of 70 she cycled around Malawi, raising nearly £5,000 for leprosy treatment. She collected money for Oxfam for 50 years, and regularly responded to emergency appeals for national disaster victims with local fundraising events. At the time of her death, four days after participating at a local climate change protest march, she was appealing for items for refugees reaching the Greek islands.

BarBara is survived by her four children, Jane, Sue, Liz and me, by two brothers and one sister and her four grandchildren.

Original article http://www.theguardian.com/education/2016/feb/12/barbara-wearne-obituary

Management Committee [Trustees] and Operations Team

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

All Forms are available on our Website,
by phoning our helpline or writing to us.
http://www.poliosurvivorsnetwork.org.uk/

Donations

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

To support attendance at National Meetings and PPS Conferences

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

Email - info@poliosurvivorsnetwork.org.uk

POST POLIO MATTERS because **WE'RE STILL HERE!**
www.post-polio.org

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

SAVE THE DATE

20-22 September 2016
Four Seasons Hotel, Sydney

For more information call 1300 789 845
or visit www.postpolioconference.org.au

L'association GLIP [new website]
(Groupe de Liaison et d'Information Post-Polio)
34 rue des Coutures 51100 REIMS, France. Tel:- +33 3 51 00 13 58
www.polio-france.org - contact@polio-france.org

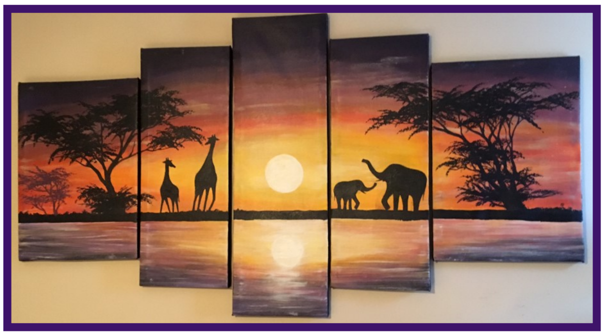
Groupe de Liaison et d'Information Post Polio

MARCH OF DIMES CANADA

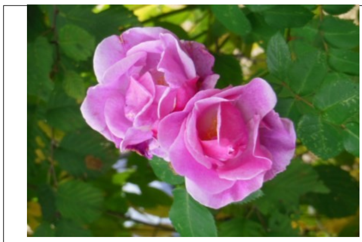
www.marchofdimes.ca/EN/programs/PolioCanada/

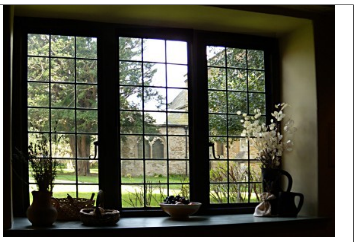
ASPr-SVG | Polio.ch
Association Suisse des Paralysés
Schweiz. Vereinigung der Gelähmten
Tél./Tel. 026 322 94 33
Fondée en 1939 Gegründet 1939

aspr-svg.ch



Painted by Kenyan Artist and
Polio Survivor Jumma Mtuku
Read more about Jumma on page 12





© PHOTO CARDS by MEMBER VAL SCRIVENER
Sold in aid of **POLIO SURVIVORS NETWORK**

Pack of 5 - £3.95 inc. P & P.

Order by writing to PSN
Emailing johnval.scrivener412@btinternet.com
Or ring Val Direct on 01234 346 397