POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 11/12
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

MAY 2016
Vol 8, Issue 11/12

"Life is not about finding yourself. It is more about creating yourself"

Attributed to, but not confirmed, George Bernard Shaw.

I've had to do this many times throughout my life, starting at age 7 when I got polio.. I was in 2nd grade when this happened. After I went back to school, I remember falling a lot whenever I tried to run back into the school after recess. I ended up with lots of skinned arms and knees and even a black eye one time! In 4th grade I started wearing a body brace whose purpose was to combat my scoliosis and to hold me up. I remember that shortly after getting it, I lost an important marble tournament at school because I wasn't able to get down on the ground to shoot like I'd been able to do before. …continued on page 9 including…

They all propelled me into lots of inner turmoil at first, but I have always adjusted and found comfort in the new version of myself in the end.

Carol Swedburg Maher, New Hampshire, U.S.A.

BRIDGET EVELYN LANGDON

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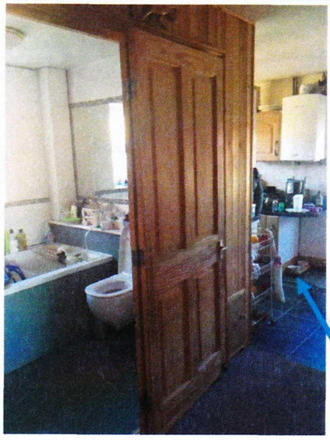
CREATIVELY MODIFYING ITEMS TO MAKE OUR LIVES EASIER

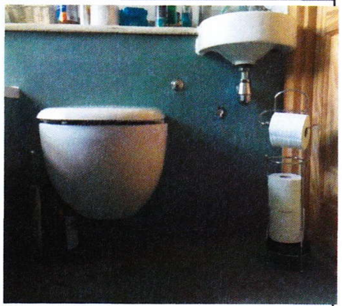
Chair Side Table with everything you might need
See page 10

Folding Door instead of Wall increases bathroom size for wheelchair and carer if needed.

No Pedestals to inhibit wheelchair footplates

'Meals on Wheels' for the Cat. See page 10





WHY NOT SHARE YOUR CREATIVE IDEAS WITH US

Home of the Lincolnshire Post Polio Library

Enter 100+ articles

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3rd MARCH 2016

John R. McFarlane

President EUROPEAN POLIO UNION

Announces Launch of PoPSCyLE

Post Polio Syndrome Centre for Life-long Excellence

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PENNSYLVANIA POST POLIO NETWORK

Introducing the 'Anaesthesia Story' Challenge

Thank you so much for the donations towards our work.

PayPal

See Page 23

Contents

New Members and Donations received.

Polio Survivors Network welcomes New Members.

Savannah Davies, Elizabeth Chipolina, Jeff Sadler,

Donations January to April 2016 received from

Tony Meladio and Clare Colfer for your generous donations.

Additional funds added to membership fees from

Susan Freeman, Ian Downing, Tony Scrace-Walters, Rose Fenton, John Ward, Janet Fowldes, Rita Unger, Diana Nash, Shirley Rose, Lynn Hobday, Christine Darlington, Yvonne Grosse, Dianah, King, Steve Clynch, Val Scrivener, Olivia and Barry Branston, Rita Nicholson and Richard Barry

£20 from Val Scriveners Photo Cards

AGM food bill donated by Dave and Margaret Marris.

Grand total for January to April 2016 is £857.00

Jann Hartman donates our 2016 membership fee to Post Polio Health International

Editorial by Hilary Boone

It is nearly the end of May and I cannot believe how fast this year is going. I have to be honest and apologise for not getting as much done for PSN as I have wanted but Richards needs since his untwist bowel operation in late December and subsequent ups and downs with his Parkinsons have had to come first. If only the healthcare support was better than it is I might not be having such a hard time.

To this end I am grateful for Dot Ives agreeing to take over the post of Secretary and taking the info@mail and to Margaret Maris for calling round once a week with the PO Box Mail and to help with other items and she never fails to make me laugh. When I burst out laughing I start choking and then you can guess where I need to go and that's when my electric chair seems to go slow. I have swallowing issues and weaker throat muscles but wonder does anyone else do this?

Many members report many issues. How many months does it take for reported symptoms that are getting worse to be adequately assessed and you helped? How many months for an assessment appointment with wheelchair services? How many months after an assessment for with adult social care or for a continuing healthcare assessment for something to happen? How many years do those of our members who receive Disability Living Allowance [DLA] and were under 65 on the 8th April 2013 have to wait for their transfer from DLA to Personal Independent Payment [PIP] forms? We have at least five members still waiting. Please let us know if you have received one and heard back or are still waiting. We had a call from a Polio Survivor in Devon who found us on the internet this week who had just received his letter with not enough points to keep his Mobility Car.. without which he can't get to work or go out socially. See page 18 for information that might be of help and please contact us if you need help because we may not know the answer but we have some great contacts.

Carol Swedburg Meyer from New Hampshire, USA posted the front page quote and a short piece on Facebook and it changed my focus of this issue to how creative have you been managing the changes in your Polio Life. When you read her story continuing on page 9 you will 'meet' the first of very inspirational polio survivors.

The second sadly no longer with us is Bridget Evelyn Langdon. See part of her amazing life story written by her daughter Deryl, dare I say it on the 'Centrefold' I can just hear her admonishing me with a wagged finger as she laughs. She would ring me regularly to update me on her respiratory support but always with some titbits that made me laugh.

Next inspirational member is Tony Scrace-Walters. Recent phone call and as usual I was soon laughing. He said 'Hils, I have to use my electric wheelchair nearly all the time now. I can still 'walk' about five metres... which for me is a marathon. I have got it down to 2 minutes now. Do you think any of the members would like to join me in late June on the Scrace-Walters Marathon?' Read more on page 9.

There is so much stress being placed on disabled people with cut after cut that I am sure many of you dread those brown envelopes that drop on the doormat. As I have said before I try and get someone else to read them first. I urge all readers that if you have to complete any forms or have any assessments that you get some help from local Citizens Advice Bureau, from AgeUK, from local User Groups [Lincolnshire Independent Living], Benefitsandwork, and other Disability Organisations. Copy all correspondence and get proof of posting to have evidence that you sent the information/forms or recorded delivery and evidence they received it. Do we stay in Europe or leave? Did you realise that if you were not registered to vote by the 18th April 2016 that you must register to vote in the EU referendum.

PAYPAL. Our Charity PayPal account is now bringing in new members and donations. See page 22 for a repeat of last issues information. On behalf of the Trustees welcome to all new members and thank you to all who renew your membership. Remember we would love to hear from you.

There is no point in reinventing the Wheel so we are pleased to support Pennsylvania Polio Survivors Network 'Anaesthesia Story' challenge. A few succinct lines about your experiences now collated by country to get the message of our possible issues out there. See page 20.

MESSAGE FROM OUR CHAIR

ADAPTING TO CHANGE - As I look through this Newsletter, the theme seems to be around adapting our lives to meet our changing needs and abilities as we age with polio. This is an ongoing process of course, one which the sooner we adopt the better. That's the theory at least and if we can incorporate change early enough, we have more time to think about it and chose what is best, rather than when there is a crisis and it is forced upon us. This is easier said than done! Pushing on regardless is a strategy many polio survivors use to cope with their impairments, and I am no exception. In my and other's defense though, this is not just because we are all brave, stoical and bloody minded, though we sometimes are happy to think of ourselves like this.

ABILITIES OR INABILITIES? - The truth is society has a very confused and ambivalent attitude towards disability. On the one hand we are encouraged to not dwell on our problems, to exploit our abilities not our dis-abilities, to push ourselves to work, exercise and be independent but on the hand we are subject to Personal Independent Payments, Employment and Support Allowance and social services assessments that requires that we concentrate on our inabilities and our worst days. What kind of madness is this?

I am not going to comment now on the chaos and shambles that is the NHS at present, as this is not any individual health workers fault and would take a whole issue. However, what does concern me is a current philosophical problem around disability. With health and social care under financial pressure, we are increasingly encouraged to manage our own healthcare and condition as much as possible. As polio survivors, most of us are quite experienced and expert at this. The problem, as I see it, is that we are still not given the kind of adequate expert information or assessment we need to do just that, and then use that information to make our own choices. How many times over the years have I heard, when I feel there is something wrong or there is a decline in my abilities – "Oh, but you're doing really well, considering!" Considering what? Considering I am a cripple? Considering I had polio? Considering I am still working? There are a million responses, I do not want to be seen as brave, courageous, doing well, this is nice to hear but what I want and need is an expert well informed opinion based upon full examination and experience of my condition. I want to know, what might or might not be possible and, if the medical professional I am seeing has limited knowledge, the best result is when they tell me that and then listen to what I have to say and discuss it with me collaboratively. This isn't innovative thinking or practice as the HEE states:

"Health Education England exists to help improve the quality of care delivered to patients and HEE is committed to ensuring that patient and public voice is at the centre of what we do. Putting patients at the heart of the education, training and workforce planning process will ensure a better connection between the decisions and investments we make and the quality of care and experience patients receive?"

INFORMED HYPOCHRONDIA - I would hate to misquote, but I seem to recall a very experienced polio consultant say the best approach for a polio survivor is 'informed hypochondria'. Meaning that you should monitor your health more than most and seek advice with speed, whilst having scepticism of both your own fears and the medical opinion.

The NHS cannot do everything and cannot afford to offer every test and expert. However what it should, and can offer, is to share knowledge with us, and let us decide if, and how, to pursue it. Ultimately we may decide to pay for it where and if we can. After all, rather than time limited interventions in times of acute crisis, it is often ongoing massage, counselling and a range of complimentary treatments that may actually be most beneficial and preventative, but this is not available through and acute focused NHS. If I were a top footballer, world politician or opera star, what would I be offered by way of keeping me at my best? I don't expect the NHS to offer all or much of this, though it might prove cost saving over the long-term. I do however expect them to tell me what I might need by investigating the problems, explaining the benefits and downsides of all interventions and treatments and not base consultations and suggestions on uninformed opinion, or what is available within their particular service, expertise or budget.

KNOWLEDGE IS POWER - Sadly, it comes down to the old adage 'Knowledge is power' but it also gives us a sense of being free to choose. I can't help feeling that we may sometimes not be offered access to the whole story, deliberately. Not all patients are easy or nice, neither are health-professionals but if only we could be more honest and have more respect for each other there might be a better outcome for all.

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>

PSN WORKSHOP - AGM Saturday 9th April 2016

The format of the AGM was slightly changed this year but the venue remained the same.

After the AGM a workshop was planned whereby the PSN members in attendance could meet with medical and social work students sharing experiences and perspectives of care in the community, voluntary organisations and by the NHS.

Due to unforeseen circumstances the timing of the AGM and the Workshop had to be alternated – this may have led to not as many professionals and students as had perhaps been expected being able to attend.

Nevertheless for those attending the feedback was positive and everyone who attended felt it was a worthwhile thing to do.

We split into two mixed groups and attempted to focus our attention on the following questions aimed at the members with post polio:

1. Which health professional has helped you most in order: GP, Neurologist, Orthopaedic Consultant, Rehab Consultant, Physio, OT, Other?
2. If you could go anywhere to see any health professional who would you want to see and what assessment/ tests would you like to have done?
3. Have you had any difficulties with Out patient appointments?
4. Have you had any difficulties as an In Patient?
5. Have you had any problems with benefits (Incapacity, DLA, PIP, ESA, Council Tax etc)?
6. Have you had any contact with Social Services and how would you rate their help?
7. Any other questions you would like to add?

As may be expected, we did not have time to discuss all the questions fully and we did have a tendency to divert occasionally – everyone keen to 'share their story' with the professionals who were there. Equally the experiences and professional perspective was very helpful and useful for us to hear and to consider.

Summary:

Overall, both groups felt that the 'support staff' in the form of nurses, physios, OT's were the most helpful as they were keen to find out more about our condition and once 'informed' were a great asset to our well-being and continuing health. We all seemed to have 'someone' we could not do without! Specialist organisations such as Neurological Alliance and PSN of course were also helpful.

It was felt that a diagnosis by a Neurologist was essential but also needed ongoing support and understanding following diagnosis. It was generally felt that our GP(s) were the least helpful and needed to be guided by us. However, it was discussed that once this happened, support and treatment improved.

All were concerned by treatment and tests as an outpatient and that tests and questions did not help in finding out the 'whole story' and that test results do not collaborate the 'real picture' and thus not appropriate for PPS patients. Linked to this is the overwhelming feeling that our medical and physical needs are seen in isolation by different professionals who only focus upon their own specialism or area. We are not seen holistically. Of concern was the overlap between different conditions (co-morbidity) and that the affect of PPS is not taken into consideration.

Accessing services is a concern and varies widely from region to region and not helped by the economic climate we are now in with services being chopped and changed. It was agreed that a way forward was to join patient participation groups, expert groups to give PPS a 'voice'. Improvements also include integrated care teams although experience and expectations varied within the groups.

Continued overleaf

Lastly, of great interest and useful to know, we were informed that if we are on any medication that ends in a 'lil' or 'pril' (as in ramipril, perindopril) need to be stopped prior to surgery.

I think the workshop was successful and achieved it's aims. Hopefully if we do it again more professionals will be able to attend.

Dot Ives, Secretary and Trustee, dot.ives@poliosurvivorsnetwork.org.uk

You get what you pay for by PSN Member Verité Reily-Collins

The old saying "You get what you pay for" is so true - and explains why the NHS has problems.

Sadly, we get the NHS the majority of us deserve. When everything goes well, we think it's the best service in the world (rest of world may not agree).

Here, when things go wrong, people complain loudly to ward cleaners, friends, nurses etc. - but seem scared to approach the people who can actually do something to improve matters. Talking to a Hospital Governor in a meeting, she told me she had had a dreadful time in hospital. So I asked what the hospital had done when she reported it? "Oh nothing. I couldn't possibly complain because I am a Governor". And she was elected to give her the power to sort things out on our behalf!

You can't blame the NHS - they don't have enough money. Our taxes and National Insurance contributions add up to around £2,500 pp in employment for our contribution each year to NHS coffers. And most people will be paying in from their late teens until they reach their 60s, without making much use of the service. So the NHS should build up a huge fund.

However, they haven't been very careful with these funds, spending money on "initiatives"; like £450,000 per year for office accommodation with a 'chill out room' for our local hospital, etc. etc. But now the pot is empty, and the NHS are running around like headless chickens trying to rob Peter to pay Paul. The answer lies in making us pay what countries with better care will pay e.g. French patients pay abound 2% more - and look what an incredibly good health service theirs is (many say it's the best in the world). But to increase our contributions to the NHS would be political suicide; no politician is brave enough to do this. So 'self-funding' by patients is becoming more prevalent.

At a meeting at our City Hall to talk about cancer, 21 of the 30 locals present had paid for some of their care. It seems sad that we have paid in all our lives, and now when we need more attention we have to pay extra, or wait at the end of a long queue. But paying for some care privately means we get what we are paying for. For me this meant when I needed an operation, i had a long appointment with the anaesthetist about what type of polio I had had - so the op went smoothly. (Not like my cancer op, when anaesthetist took no notice of me having had polio, and I ended up with massive problems that delayed recovery).

At the City Hall meeting people said they paid for their care by taking out mortgages, Equity Release, Bank Loans, etc. and generally it had been their kids who made parents spend money on their health.

At other times I have paid for a private nurse to come to my home; this meant I could leave hospital two days earlier, which was worth its weight in proper food and peace and quiet! And I set up a website www.cancersurvivorships.com which details services which are worth paying for, such as charities that offer subsidised lymphoedema massage.

Or next time you go on holiday in Europe just pop in to the local hospital and ask what it would cost to tidy up your bits that need attention. !!! And enjoy the fantastic care their patients are given. I love the French and German idea that massage is crucial to health - good idea!

Verité Reily Collins verite@greenbee.net

HAVING FUN AFTER CANCER! Cancer Side Effects https://after-cancer.info/

Margaret , Trustee and Carer writes.... About my Hubby.

David my husband was born in Edinburgh the first of two siblings. When he was a few months old he came to live in rural Lincolnshire in a small village. It was an idealistic village with a school, village hall, playing field, church and a small shop.

At the age of 5 he was not well and the GP was informed, he came to the house and told his parents that he would have to be admitted to the local isolation hospital as he had Polio.

His stay was about a month and he remembers his Mother looking at him through a window. In those days visiting times were once a week on a Sunday.

On his return home he remembers how he walked with difficulty, his ankles knocked together, this resulted in him stumbling and falling over, and he also started with a stammer. Life began to get back to a normal routine and he returned to school in the village

There were very few cars in those days, his father cycled 12 miles every day to work and back, so the family moved to the local town where his father worked, this enabled him to be home earlier and spending more time with the family. David started junior school, enjoyed helping his father in the garden growing vegetables and looking after the roses.

David went to the local Technical College where the tutor was kind and understood that he had a speech problem. He helped to arrange a speech therapist, this opened a door for David the stuttering stopped and only returned when he was tired.

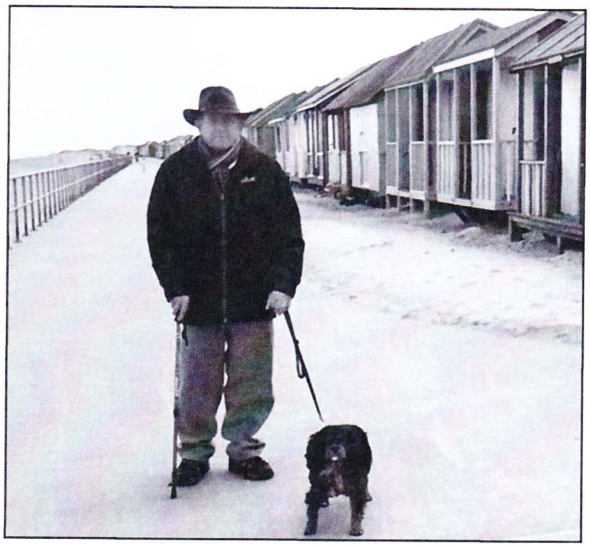
At the age of 16 he was an apprentice and was sponsored to go to the Outward Bound School in Aberdovey gaining 5 Honours. This experience boosted his confidence

In the early 1970s we met and married. He had to have a small operation. In those days it was carried out by a general anaesthetic, the anaesthetist found it hard to bring David round, no question asked we just accepted it. [Just in case you were wondering the operation was once we had a two year old daughter :-)]

Going to the Dentist was a nightmare for David even if it was just a filing as he needed a local anaesthetic. Changing NHS Dentist was no solution. The only thing that helped was seeing a private dentist who had more time to take it at David's pace, but it’s an 80 mile round trip. We at this time were not aware of PPS. After David was finely diagnosed with PPS he informed his dentist who had not heard of PPS but was more than happy to learn He still goes there now.

Margaret Marris, Margaret.marris@poliosurvivorsnetwork.org.uk

David age 5 just after discharge from the polio isolation hospital in Scunthorpe and last year out for the day in Sutton-on-Sea, Lincolnshire.



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 2015 (I cannot believe it is now a year ago)! So, back last 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 as soon as possible.
Occupational Therapist would visit in a few days.
Appointment letter for Outpatients Dept. would be received with appointment to see specialist in two weeks

Being a faithful admirer and devotee of 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 Occupational therapist (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 front porch tiles also!

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. Ten 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 in October 2014. 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 1st 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 15th 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: Apologies for no reference to PPS in this article apart from the frustration etc – the omnishambles that appears to be my 'lost notes' or even 'unwritten notes' in the NHS does not bode well ……… no wonder PPS never gets a look in!!

Fast forward to now – I would like to say I am fully recovered but that would not be quite correct. I am much much better and it all could have been a lot worse! Just another 'ailment' to add to my list! **dot.ives@poliosurvivorsnetwork.org.uk**

Continued from Front Page - Carol Swedburg Maher.

Furthermore, I was no longer able to take physical education. All of these things emphasized that I wasn't like the other kids. To compensate I developed my sense of humor; part of which was self-deprecating. It helped me get through many otherwise embarrassing moments and endeared me to my classmates. Between 8th and 9th grades I discovered a great need to re-create myself again. By that time my scoliosis had become quite noticeable and monstrous in my mind, and I saw myself retreating from others. This was a big problem in my life because I love people and love to interact with them. I made a decision to put myself out there whenever I felt afraid to be seen or to be heard. At the time I didn't realize I was creating a leader!

Therefore, in high school I was active in all kinds of organizations, and as a senior I was the president of many of them, including the Student Council. I forced myself to take public speaking, I became the student director of two different theater productions, and I was inducted into the National Honor Society.

I chose to go to the University of Missouri in Columbia because it was far from home as well as being handicapped accessible. I wanted to develop my independence! I majored in Education and minored in speech. The speech minor put me in front of the class doing interpretive readings, delivering speeches, and debating. Next step: teaching! Standing in front of 30 high school juniors and seniors is not for the timid. I had to develop the organized, prepared, compassionate teacher inside of me.

Most of my needs for creating a new side of myself since have been the result of medical issues. In 1978 I had a spinal fusion in Minneapolis, MN. I learned then that while I valued my independence so much, there were also times that required being dependent on others. My first taste of this was going back home in a halo body cast, which I had to wear for 9 months while my back healed. I had to rely on my mother and sister to do "cast care" and "pin care" for me and to take me places. I became friends with 2 retired neighbor ladies of my mom's. We did crafts together, and that really helped during those long months when I wasn't able to work.

After I married, in 1981 I discovered that all pregnancies don't always go as planned! I had to have an emergency C-section a month before our daughter Rachel was to be born because I couldn't breathe. I was in and out of ICU, and finally my pulmonary specialist got an iron lung out of a Minneapolis hospital basement, cleaned it up, repainted it, and stuck me in it! It saved my life at that time; however, the pregnancy and health problems afterwards took a big toll on my health. I could no longer teach as I had planned. The sudden switch from high school teacher to stay-at-home mom was a difficult one for me at first; however, I adapted quite well and came to love my new role as Rachel's mom.

Another major re-creation of myself came in 1989 when I was admitted into the ICU with pneumonia. I had to be intubated which I had hoped wouldn't be for very long. However, once again, things don't always go as planned. I was not able to be weaned off life support. I finally decided to have a tracheotomy which was one of my best decisions. I was able to go home with a vent which I used only at night for many years. But once again my health took another short dive and I found myself needing to be on the vent full time. With that, I also had to give up driving.

Besides all of the polio and medical-related experiences there have been many other times requiring me to re-create myself, such as becoming motherless and fatherless, becoming an empty-nester with my husband, and aging. These all required courage and imagination to turn lemons into lemonade. They all propelled me into lots of inner turmoil at first, but I have always adjusted and found comfort in the new version of myself in the end!

Because I've been able to re-create myself over and over throughout the years, I have been able to keep up with the kind of lifestyle that I love. Yes, I have slowed down some; after all, I am 71-years-old! Although I am on vent support 24/7, I am still able to lead a huge life. At home I push my portable vent, the external battery that runs it, and my canister of liquid oxygen around in a small grocery cart. When I go out to eat or shop, I pull these same items in a black bag on wheels. My husband Chuck is so supportive, encouraging, creative, and helpful. Two years ago we travelled to St. Louis to attend Post-Polio Health International's conference, where we were delighted to meet up with Hilary Boone again. Several years earlier, we got together in Boston when she was visiting the U.S.

Last spring Chuck and I made a huge move half-way across the U.S. from Iowa to New Hampshire so that we could live closer to our daughter. Just 2 months after that we made a coast-to-coast (and back again) road trip. Later in September while visiting Newport, RI for a few days, I fell in front of a restaurant and broke my left hip. I had surgery on it the following day and was in the hospital for a week before heading to a rehab hospital closer to my home. After 3 weeks of very intensive rehab, I came back home where I continued my physical therapy with the help of the Visiting Nurses Association. Today I am walking again and doing all of the things that I enjoyed before my fall. I hosted a Thanksgiving dinner in November; I admit instead of cooking it all myself, I ordered a lot of it from a grocery store. I did prepare a big Christmas Eve dinner here for my daughter and her boyfriend and did all of my shopping online. I enjoy politics and cooking, and combined the two early this year by cooking for Hillary Clinton's volunteers who spent many weekends canvassing my town and working the phones! Last week my husband and I hosted a good friend from Maine; we kept her very busy by making day trips to a popular kitchen store in Vermont, into Boston to meet our daughter and her boyfriend for lunch, to a winery for Sunday brunch, and lots of shopping.

Thus life goes on, and I want to continue to be very much a part of it all! I guess I will probably have more opportunities to re-create myself several times yet. I am looking forward to the challenge with optimism and a smile!

Continuing from Front Page - Creatively Modifying Items to Better Manage our Lives.

Hilary rang Member Tony Scrace-Walters to talk about some information he had sent to be considered for a newsletter. The theme for this issue is about creativity to better manage our lives. Tony said "Hils, things have changed since we last talked and I now use my electric wheelchair most of the day so the cat dish stand with a rail to hold onto whilst you bend down is rarely used now. I do have another piece for this newsletter though… I wonder if any members would like to join me in the Scrace-Walters Marathon at the end of June? 5 metres is now a marathon for me but I have got it down to just under two minutes. ☺

After Hilary stopped laughing Tony continued… I found trying to pick stuff up with a Reacher quite hard from my wheelchair then found that you can get them in different lengths, from 15 to 35 inches. Now I ride next to an item and using the 15" Reacher from the Complete Care Shop and I can pick things up easily. Oh and let me send you a picture of the side table by my armchair. I put cup hooks at regular intervals round the top. You can see all the items I might need are there. They have to have some sort of loop added. I have four main methods, string, split rings like on your keyring, large 3 inch paperclip, and even just a normal one cut leaving an oval. Bulldog [Binder for our American readers] clips can be very useful too. In fact if you look on the Internet there is a page with loads of useful things you can make from Bulldog clips. http://lifehacker.com/5927857/top-10-diy-miracles-you-can-accomplish-with-a-1-binder-clip.

Hilary writes.. Tony kept me laughing right through the conversation. He is another inspirational Polio Survivor who after recovery from polio trained to be a Bandmaster in the Royal Tank Regiment and as you had to have another skill he joined the 'small arms' section. He was stationed at Kneller Hall during training strangely about a mile from where I lived in my youth. I used to go to the monthly outdoor concerts but we think about a year after he left. He was also a top tenor in the Scunthorpe Male Voice Choir - the only one in a wheelchair - but sadly lung cancer and the removal of half his right lung made changes to his voice, but it does not stop him talking the hind leg off a donkey.☺
Tony Scrace-Walters <wheelie666@me.com>

Other front page photos. Our bungalow is quite small. In the kitchen we did not put cupboards under the end 18 inches of the work surface so that the cats dishes could go under there and hopefully him eating so that I did not trip over him. We forgot to allow enough room for his tail!!! Wayne made a little tray on wheels so its easy to reach down and pull it forward to get to the dishes and I push it back with my foot. Our bathroom is only 7'6" square but can be made bigger, useful if you need a Carer in their as well as an electric chair. We took the wall out and put double folding doors in so the hall can become part of the bathroom if needed. The bathroom is directly opposite the bedroom door so a ceiling rail could be fitted if needed in the future to hoist from bed to bath. A toilet bowl and sink were purchased without pedestals so that the wheelchair footplates go underneath easily. Plus we had the toilet fitted at the height we wanted so no need for that 'hard to clean raised seat!!' You cannot tell from the photo but the bath is a metre wide so when sitting on the bath lift the hot water from the middle fitted taps does not touch your legs.

If you look at the front page of our website you can see Kathleen Burrell using simple metal coat hangers that she had modified one to pull small bottles from the back of her table and another to turn the bathroom sink tap on and off. See Newsletter Volume 5, Issue 10, August 2006.
www.poliosurvivorsnetwork.org.uk/lincpin5-10.pdf

Members please lets hear from many more than the 14 who replied to the questionnaire. How have you modified how you do actions of daily living; what items have you purchased or modified to make tasks much easier? If we get enough responses we could put them in the newsletter and maybe a handout.

QUESTIONNAIRE On Self Perceived Disability of the Upper Limb in Polio Survivors Part 1

This was included with your February 2016 Newsletter. A medical article came out, two days before posting the newsletter, which included a questionnaire on self perceived disability of the upper limbs which got me thinking. I have for many years been concerned about the different perceptions that can occur between how clinicians record and readers 'see' the polio survivors who take part in studies for medical articles. Can comparisons always be made?

Firstly, what does a polio survivor look like? At my first PPS Conference in Atlanta in 1997 there were about 300 participants. I thought I could identify the polio survivors as those using canes, crutches, wearing braces, using wheelchairs or scooters and on ventilators. I had no idea till the audience was asked to identify themselves that there were as many others who to me did not show any outward sign who had also had polio, many of them health professionals. But then I did have a letter with me from Consultant to GP commenting that I had no medical evidence of having had polio and nothing physical to support it. [See Letter to a Polio Survivor in the Lincolnshire Post Polio Library. www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/kessler/letter.html]

Secondly, we need to think about the medical professionals [both writer and reader]. How many facts about polio in its first instance have they been taught and how much experience of how we have lived and are living our lives do they have? We are all so different. [apart from possibly our 'strong will, determination to succeed, I am not there yet, don't need any help thankyou. How many recognise yourself?] We are such a mishmash of where we were paralysed, weaker, showed no weakness at the time of polio, were unaffected. How old were we; how much had our bodies developed; to what level did we recover; how have we lived our lives; are there any other factors or illnesses that might need to be considered. Do we use any aids; do we live alone or with a partner; do we live in a city or in the country; have we moved far from the place where we had polio; have we accepted PPS or are we still in denial, are we seeking help for problems and if we are, are we getting adequate and timely assessment, treatment and aids. Are we self funding; reliant on a level of private health insurance; living on benefits and probably more.

Thirdly there is the way questions are worded asked and responded to. From my research into questionnaires on other medical articles, it is very difficult for a Polio Survivor to answer a question such as 'Can you do housework?' with three choices. A. No difficulty or mild difficulty, B. Moderate or Severe Difficulty or C. Unable. What is included in the word housework? Some people will be able to do some tasks sitting in a wheelchair; some will be able to do the cooking but not peel the vegetables; some can walk but can't carry or reach up to hang washing on a line; some could answer mild difficulty to do the washing up because they have a dishwasher but if that goes out of action then they night change their answer from A to B. Then there could be people that do not do any housework because there is a partner to do it, so would you be sure that answers that were nearly all A's were because they had no or mild difficulty or they use an aid, or someone else does the task, or they are still in denial? There is also difficulty with a question like 'Carry a shopping bag or briefcase' when there is no mention of how large it is, or how much it has in it or how far you have to carry it.

More information in the next newsletter after we have had the opportunity to talk to the authors of the medical article. In the meantime here is some information from the 14 people that did respond [responses will still be accepted till end June] The age range was from 57 to at least 84 as one person just said '80's. 11 were Female and 3 Male. Where our polio survivors differed was that 8 of our 14 did not have any known upper body involvement at the time of polio. Six had known upper body involvement. 3 had symptoms both sides, 2 left side and 1 right side. Not everyone answered each question but most did. The couple of witty quips, and you can guess which question that was, made us giggle so thanks for that. But just taking the last point.

Because of my Arm, Shoulder or Hand Pain I feel less capable or less useful.

PSN Questionnaire	Agreed 78%. Disagreed 14.2% and 7.1% neither agreed or disagreed.
Medical article.	Agreed 29%. Disagreed 61% and 11% neither agreed or disagreed.

CAN COMPARISONS ALWAYS BE MADE WITHOUT MORE INFORMATION?

Bridget Evelyn Langdon

Bridget was born in 1934 in Norton-sub Hamdon, South Somerset. She was taken ill in 1936 with what was thought to be pneumonia and the following year they realised that she was developing scoliosis. Treatments included being laced into a hard corset and wearing built up shoes during the day and a plaster bed for sleeping. Curvatures of the spine developed over the years.

During the war with her parents and her younger sister Janet she moved into the house that she died in at Westover, Lower Odcombe, to live with her grandfather. During the war occupants included four RAF chaps, a land girl and two refugee children so it was a busy household.

At the age of fifteen Bridget was admitted to Bath Orthopaedic Hospital. Bone from her hip was fragmented and grafted into the middle 5 vertebrae. During this operation she was given 8 pints of positive blood when her own was negative. Her orthopaedic surgeon diagnosed the illness of 1936 as polio. She remained in this hospital for fifteen months, much of it in an iron lung. She would recall the pleasure they got in eating cold baked beans from an envelope and waking up with the tarpaulin covering the bed being buried in snow, because they slept on verandas in all weathers, the fresh air being considered healthy. She also recalled the maggots eating into her back under the plaster cast.

Having been told that she would have to return to school a year lower than her age group she got a job in the wages department of Westlands. In 1956 she married Derrick Langdon and she was busy planning their diamond wedding party in the past few months.

Having been told she could not have children she duly produced three, carrying us all only 7 months. We were all Rhesus babies and each required exchange blood transfusions. Each involved 2 to four month stay for Bridget at Musgrove Park Hospital.

Bridget loved flowers and gardening and filled her large flower beds with many roses and clematis. She attended many evening classes in upholstery, lampshade making, soft furnishings, patchwork and dressmaking and the house was filled with her very professional handiwork. She made most of both hers and the girls' clothes as well as lots of knitting and crochet work. She played skittles from the age of 16 until she was 76, she kept up with many friends from school, work and neighbours. She was a skilled flower arranger and always did an arrangement for the Methodist Church and entered arrangements into the flower show

She acted as a driver and escort for all of the Odcombe school trips whilst her children attended the school and later attended the school to do voluntary work listening to the children read. She drove neighbours to hospital and visit relatives, she wrote letters for them and made phone calls on their behalf when they needed to complain. She could upset people, she had a tendency to say what she thought and could be direct. Others, if they were alone at Christmas or sometimes on a Sunday they would be invited to lunch. At times you learnt to eat with your elbows tucked in. She was a brilliant and adventurous cook and we grew up eating Indian, Chinese, French and Italian recipes as well as traditional British Cooking. There was a home cooked pudding every day and there were always home baked cakes in the tins. She preserved fruit and veg and made chutneys.

She had joined the village hall committee first as a representative of the youth club in 1950, after a break whilst her children were small she re-joined and remained a member for the rest of her life. She was a long term Parish Councillor and for some years was chairman and was vice chairman for many more. Bridget took over as the Royal British Legion Poppy Organiser for Odcombe and Lufton in 1973 and held that post for thirty five years. She supported the village football club and was it's president for a few years

In the sixties she ran a material stall at various markets for a neighbour. Driving his three litre Capri all over Somerset and Dorset with a large trailer which she was skilled at manoeuvring. For some years she ran an outside catering business with her friends, catering for weddings, funerals and retirements. She finally ran the kitchen at Westlands Club.

She was on several PTA's and was chair of Yeovil High School PTA for two years and served a term on the Somerset Education Committee. She also served a term as a governor of the BBC in the South West and for many years helped at their charity events. In 1999 she set up the Odcombe Luncheon Club obtaining a Millennium Grant through Age Concern. They then invited her onto their National grants board which involved regular meetings in London.

She was a life member of Somerset Cricket Club and their supporters club and until her health failed she attended weekend matches throughout the season. She obtained National and even international attention for spearheading the so called rebellion against Somerset Cricket Club's sacking of Viv Richards, Hallam Mosely and Joel Garner. Many letters she received had only partial addresses including a couple of international ones addressed only to Bridget Langdon, Somerset, England. Interviews on National news and National press ensured she got her twenty minutes of fame.

From 1970 she started having quite serious problems with fatigue & muscle aches and gradually developing a shortage of breath. The changes were quite gradual until autumn 2005 when she had a viral infection since then her back muscles have weakened and she had muscle spasms in her back and neck. Her scoliosis meant that her ribs sat on her hips, she had arthritis in most joints and weakening muscles, she became increasingly dependent on a machine to breathe for her. Severe bursitis in both knees and elbows caused more problems and an intolerance of most medication meant that she was unable to obtain either treatment or pain relief. But still she liked to concentrate on what she could do rather than what she couldn't do. A few days before she died she was still of the opinion she would be fit to attend a grandson's wedding last weekend.

Until the last few months she was a voracious reader, loved quizzes, crosswords and Suduko. As she became less mobile spent much time on her computer keeping in touch with friends and family in many countries and researching both hers and Derrick's ancestry. She was an active member of the Polio Survivors Network and regularly scanned Facebook to keep up with her friends and relatives activities. She spent hours on the telephone chatting to friends. She was also a menace of the early morning call if she wanted to know something. She would launch into her question without announcement or greeting and would often hang up just as abruptly once you had answered her question. She rarely called before 6.15am!

When I was about four I was apparently asked who my Mummy loved the best, me or my baby brother. I answered "My Mummy loves my Daddy best" and that never changed. He proved his love for her by his unending care over the past ten years. A man who had previously not boiled an egg he has learnt to cook, under her directions and became her principle carer including waking up five times a night to assist her.

She might have loved my Daddy best but she loved all of her children and grandchildren and was immensely proud of them.

Deryl Anne Rennie

Editors Note:- Bridget was also in the same hospital ward as Mary Berry and could remember every persons name and where they lived. Amazing recall. Bridget would ring me every few months to update me, on how she was getting on with her respiratory issues and her bi-level ventilator, and tell me what she and Derrick had been up to. The last call was a few days before she died, I will miss her calls.

The Hippocratic Post - Blogging on the World's Medical Stories.

Post Polio Syndrome: What is it, and Why does it matter?

Ted Hill, MBE, CEO of the British Polio Fellowship—May 13th 2016

Poliomyelitis, or Polio, as it is more commonly known, is one of the world's best known diseases. Having famously been contracted by Frida Kahlo, Neil Young and even Franklin Roosevelt, Polio was endemic throughout much of the 20th Century. However, one of the most successful vaccination campaigns in history has all but seen off Polio, with just 74 cases recorded last year, and just Afghanistan and Pakistan left as Polio endemic countries.

While the vaccination campaign is undoubtedly a huge triumph for medicine, the battle against Polio is not yet won. Members of the public and medical professionals alike are now unfamiliar with the symptoms of Polio and when it comes to Post Polio Syndrome (PPS) even less so.

Post Polio Syndrome is a badly misunderstood condition. Just seven per cent of the UK public have heard of PPS. That's despite 120,000 living with PPS in the UK today – a similar number to Parkinson's, which 86 per cent of the public are familiar with. Even more alarmingly, this lack of awareness also translates to the medical profession, where just 55 per cent of GPs feel able to diagnose the condition, and 18 per cent of GPs did not know how to manage the fever, fatigue, pain and breathing difficulties which characterise the condition when it is diagnosed.

A large part of my job as CEO of The British Polio Fellowship is to try and spread awareness of Polio and PPS – both among the medical profession and the public at large. Given that 80 per cent of people who have had Polio are likely to contract PPS, it is an important job both now and for the future, both here in Britain and abroad.

PPS symptoms include cold intolerance, increasing weakness, muscle and joint pain, stamina problems, sleep disturbance, breathing problems, swallowing problems, fatigue and pain. As you may notice, many of these symptoms cross over with other conditions, causing real problems with misdiagnosis, something which is only impounded by the similarity of the symptoms to common signs of ageing. Matters are made even more confusing by the similarities between PPS and Chronic Fatigue Syndrome, a condition which it shares much in common with.

Diagnosing PPS can therefore be extremely difficult, with symptoms often hard to separate from complications arising from the original infection. There is no laboratory test for PPS, nor are there any specific diagnostic criteria. Instead, three key criteria are required to diagnose PPS: previous diagnosis of Polio, long interval after recovery and the gradual onset of weakness.

When PPS is finally diagnosed, there is no silver bullet or magic treatment. Instead, PPS can only be managed. While this outcome is not perfect for those living with the condition, much can be done to alleviate the pain it causes, as properly managed, PPS may stabilise or only progress slowly. Much can be done to retain independence, including appropriate treatment for symptoms, self-management strategies such as pacing and energy management, appropriate use of adaptive equipment, looking after your general health, and social and emotional support.

Currently, there are no UK specific guidelines to managing PPS, which means that access to appropriate services for people with PPS can vary greatly. To help combat this problem, The British Polio Fellowship produced a new document entitled Post Polio Syndrome: A Guide to Management for Healthcare Professionals. This ground-breaking document is the first of its kind, and was produced with assistance from leading experts in the field. I hope it signals the start of a better understanding of PPS, and if just one person receives better care as a result of that document, then it will have done its job.

With the aforementioned document, and campaigns such as PPS Day, which we also run, The British Polio Fellowship take a two-pronged approach to PPS, providing both practical advice to members and helping to spread awareness of the condition. As time goes on, we are likely to see more and more people living with PPS, particularly in the developing world. I hope that by then, we will have made some serious headway into making the world aware of what has become the forgotten footnote of Polio. While Polio is one of the world's most recognised diseases, PPS sits in the shadows – and yet the reality is now, that PPS causes much more pain and suffering. The battle against Polio may be all but over, but the war is not won. It is now time for us all to focus our efforts on tackling, managing and understanding PPS.

http://www.hippocraticpost.com/muscular-skeletal/post-polio-syndrome-matter/

http://www.britishpolio.org.uk/services-information/british-polio-information/publication-library/

POST POLIO FIRST MEDICALLY RECORDED 141 YEARS AGO
British Polio Fellowship - 77th Anniversary
Polio Survivors Network - 20th Anniversary.
Why we are still waiting for adequate assessments?

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."

http://www.britishpolio.org.uk/wp-content/uploads/2016/02/PPS-Report-low-res.pdf

The European Polio Union is proud to announce a new initiative with the launch of "PoPSyCLE" - Post-Polio Syndrome Centre for Life-long Excellence - an initiative to change the lives of polio Survivors and perception of medical professionals for years to come. [March 3rd 2016]

One thing that has been very clear for many years, and has only been reinforced by the advent of social media, is the lack of training, knowledge and understanding amongst the medical profession, in general, to polio Survivors and those with Post-polio Syndrome in particular. Another fact that is staring us in the face is the increasing age range of polio Survivors in Europe, N. America, Australia etc. Equally apparent is the increasing numbers of polio Survivors that have been identified in sub-Saharan Africa, the Indian sub-continent and other specific areas of the world. In a paper last year in which the EPU was a co-author with PHI, Polio Australia and lead by Antonio Toniolo it was empirically demonstrated that there are over 15 million polio Survivors, of which it is thought 8 million are on the Indian sub-continent (the true total world-wide is probably more in the region of 28 million).

When all these factors are put together a picture emerges of the need to establish a facility to retain the existing PPS body of knowledge that is in danger of being lost in the "developed" world, and an internationally accredited training facility for medical personnel in the care, management and treatment of PPS in association with an online support and exchange facility for polio Survivor support groups.

As the last European PPS conference in Amsterdam (June 2014) closed there was a call from both polio Survivors and international medical leaders for the formation of a World Polio Alliance. That call fell on the EPU to action and most will have thought little if anything has taken place in the interim. In truth the converse is true but it is only now that tangible evidence of action can be made public - like all things some good, some indifferent and some plainly disappointing.

1. Formal letters of understanding on the formation of a World Polio Alliance have been signed with organisation's in Canada, Australia and New Zealand. A further and major international player is actively considering their position.

2. An application for funding ($6.5 million USD) has been submitted to the Bill & Melinda Gates Foundation (BMGF) in the form of a concept memo (copy attached) for the establishment of "PoPSyCLE" - Post-Polio Syndrome Centre for Life-long Excellence. This application has been made following extensive talks and discussions with clinical personnel in St. Thomas' Hospital, London and the Queen Elizabeth Foundation for Neurological Rehabilitation. It intended that the UK would be the initial location and pivot for the project and as it develops it will go on to include other established European centres such as PTU Copenhagen, AIDM Onlus Malceisne, AMC Amsterdam. (The initial location was decided on the basis of available physical facilities, NHS agreement, and after consultation with EPU medical advisors.)

3. In parallel, and concurrently, negotiations have been initiated with other major international commercial concerns who have a track record of donating to world leading initiatives such as "PoPSyCLE". These are ongoing and still have to bear fruit but to date all indicators are on the positive side. However, it has been made clear to the EPU that concerns such as these will only come on board if it is of benefit, in one way or another to them, and also they want statutory bodies at either national or European level involved. These discussions and contacts were made possible by the EPU being invited to attend the World Economic Forum in Davos, Switzerland.

4. As in all international initiatives of this nature there, by necessity, will be a be a heavy reliance on IT. Therefore, and through the EPU President's membership, negotiations are at an advanced stage with the Worshipful Company of Information Technologists (WCIT) in London. This is a city institution made up from the senior and board level personnel of companies such as IBM, Microsoft, Sun Systems, HP, CISCO, etc. The WCIT support charitable bodies through its various committees and whilst it does not make direct financial contributions it donates in kind. This is to say hardware, software, software engineering and project management skills through personnel secondment. Once again like all things negotiations are not easy and these commercial concerns want to have a "feel good factor" from their involvement. Additionally, they will not go into this alone and want to know that health bodies are involved and committed.

5. Lastly, and what has become a great stumbling block in all these matters is the current debate going on in the United Kingdom over its continued membership of the European Union - the so called BREXIT (Britain EXITs) debate. Although in essence the referendum due in June '16 should make no difference

to applications to the EU presently, there appears to be a mind-set that is stalling any initiative involving the UK that could go in for a period of over 2 years from referendum date. The reason is that the EU Treaty says exit would be in a 2-year time span and ""PoPSyCLE" start-up funding is over a period of 39 months. In effect potential access to EU funds is stalled until after June '16 at the earliest. Representation and argument against this attitude have been made both to the Commission, and EU Parliamentary authorities through our membership of the EDF but presently to no avail.

An answer to this would be to switch the pivot point of the initiative but then this would negate months of work with medical facilities, commercial funders and charitable bodies in the UK. However, this has not been and will not be discounted but if it comes about will cause a considerable delay in implementation.

6. Certain key medical personnel to head up the initiative have been identified and are committed to it dependent upon funding. Physical facilities have also been identified and found to be fit for purpose.

As I said earlier all of this work on behalf of polio Survivors and those with PPS has been going on in the background and it is only now with the concept memo going into the BMGF that we are able to make progress to date public. Members of the EPU of organisation have been requesting this type of action for some considerable time but it takes time. The EPU has become a world force in the PPS movement with its participation and assisting in the organisation of two European PPS conferences, it is also co-operating in the organisation of the first PPS conference in the Southern Hemisphere in Sydney Sept. '16. It is looked to by polio Survivors groups from all over the world for advice and support, these range from Brazil to Vietnam - well outside its original sphere of operation. World bodies, e.g. United Nations, WHO, etc. include it in consultative meetings and operations on polio in all its aspects.

The EPU Facebook posts and feeds draw thousands of hits and requests for help every week, currently one person is dealing with all this. It is also intended that an active Twitter feed be added - but it takes people to moderate, research and answer the resultant queries from social media portals - and many need multi lingual skills. (We are getting there - can now respond in French, German and Spanish - even if badly.)

"PoPSyCLE" - Post-Polio Syndrome Centre for Life-long Excellence is the next logical step for the EPU. However, it cannot come into existence without the membership of the EPU being on board. To date all that has been related above has been carried out by a very small number of dedicated volunteers and often at great cost, both in well-being and financially, to themselves. If this is to succeed more people are needed to assist. The British Polio Fellowship has offered both office space and clerical assistance for the project at it's brand new facilities in Watford, outside London. Now more than ever is the time to parody the famous quote from John F. Kennedy "Think not what the EPU can do for you, but what you can do for the EPU" and in fact for polio Survivors everywhere.

You have asked, we have responded, now to go further help is needed, without it "PoPSyCLE" - Post-Polio Syndrome Centre for Life-long Excellence will fail. What can or are you prepared to offer to this initiative either personally or on behalf of your association. ***This appeal is not only to EPU member organisation's but to all those who care for and support polio Survivors and those with PPS.***

John R McFarlane, President of European Polio Union

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Advice from a Patient.

This may be a normal day for you but it's a big day in my life.
The look on your face and the tone of your voice can change my entire view of the world.
Remember, I'm not usually this needy or scared.
I am here because I trust you, help me stay confident.
I may look like I'm out of it, but I can hear your conversations.
I'm not used to being naked around strangers. Keep that in mind.
I'm impatient because I want to get the heck out of here. Nothing personal.
I don't speak your language well, You're going to do what to my what!
I may only be here for four days, but I'll remember you the rest of my life.
Your patients need your patience.

©The Health Care Assistant 17 December 2014.

Informative Items.

1. Disability Living Allowance [Mobility] **walking distance rule was 50 metres.**

Reduced to 20 metres for Personal Independence Payment

Baroness Grey Thompson said… "How can we reasonably expect people who can walk only 20 metres not to require some sort of assistance?"

Some excerpts from DisabledGo News Item 19th May 2016. Government figures have predicted that, with the criteria set at 20 metres, the number of people receiving higher rates of mobility support - and therefore eligible for a Motability vehicle - will plunge from 1,030,000 [if DLA had not been replaced by PIP] to just 602,000 by 2018.

Baroness Thomas told fellow peers that

between 400 and 500 Motability cars a week are being handed back by disabled people

who have been reassessed for PIP and "whose condition may not have improved but who are losing not just their car but in many cases their independence"….. "To be told that the bill for PIP is too high and

must be cut by more than halving the walking distance tests
is a real slap in the face for thousands of disabled people,
particularly those of working age with lifetime awards under DLA"

Baroness Altmann, the pensions minister, claimed that PIP claimants who can walk more than 20 metres but less than 50 metres can still receive the enhanced mobility rate of PIP if they cannot walk the distance "safely, reliably, repeatedly and in a timely manner"…… Although it does depend on the assessment."

2. Benefits and Work - benefitsatwork.co.uk.

Get the benefits you're entitled to. Don't lose out just because the system isn't fair.

Are you being transferred from Incapacity Benefit to Employment and Support Allowance [ESA]? Or from Disability Living Allowance [DLA] to Personal Independence Payment [PIP]? Are you making a fresh claim or renewal claim? Or pursuing a mandatory reconsideration or appeal for ESA, PIP, or DLA? Are you worried that the forms are complex and unclear, the medicals may be rushed and inaccurate and the decisions unfair? If so, use our expert, step-by-step guides and give yourself the best possible chance of getting your legal entitlement. We'll warn you of pitfalls, offer you specialist tips and tactics and guide you through every part of this bewildering process.

3. Transport if you're disabled [UK] - www.gov.uk/transport-disabled

Split into categories. 1. Trains, 2. Planes, 3. Cars, buses and coaches, 4. Taxis and minicabs, 5. Ships and 6. Wheelchairs.

4. Disability Rights Handbook 41st Edition April 2016 to April 201 - https://crm.disabilityrightsuk.org/benefits-information/disability-rights-handbook-edition-41-2016-17.

Handbook is now out. £33.50 including post and packing**.** £18.00 if you are on benefits. Updates by email bi monthly throughout the year add £5.00. The handbook provides in-depth information on the benefits system and social care services and includes invaluable guidance, tactics and tools. Disability Living Allowance, Personal Independence Payments and Attendance Allowance including simple guidance how to complete the forms. It explains the new Universal Credit, but still covers the six benefits it is due to replace {Income-related Employment and Support Allowance, Income Support, Income based Jobseekers Allowance, Child Tax Credit, working Tax Credit and Housing Benefit. [Hilary has just received her copy]

5. Independent Living Survey 2016.

This survey is for Disabled and Older adults who need help and support with independent living. In Control - We are a national charity working for an inclusive society where everyone has the support they need to live a good life and make a valued contribution.

http://puttingpeoplefirst.limeask.com/index.php/171426/lang-en

6. **Independent Age.** - http://www.independentage.org/

Are a charity that is an established voice for older people founded 150 years ago. We are experts in what we do and all our services are free. Advice Line 0800 319 6789

7. **Third Thursday Webinars from Michael J Fox Foundation** for Parkinson's Research.

Listen and see the Slides 5 to 6pm UK Time. Added here because you can listen to the previous ones online and we know of six people who have both PPS and Parkinson's. Some of the info, e.g. on Constipation, there is low motility with Parkinson's patients which many polio survivors also suffer from including both Richard and myself.

https://www.michaeljfox.org/page.html?hot-topics-webinar-series&navid=webinar-series

8. **Servicecall and Pinpoint.**

These are two systems which can be used by the elderly and or disabled to be served at Self Service Petrol Stations. If they have one of these two systems you simply point your system remote or key fob at their receiver. It should light up and buzz and hopefully someone will come and serve you. It is much nicer than 'pipping your hooter and flashing your lights'. Chris Marsh from Lincolnshire posted this information and suggests wouldn't it be great if every town in the country had one service station with a disability friendly system. [Editors comment. I did not know this and Google showed that every Tesco and most Sainsbury's Service Stations are fitted with this facility.

www.service-call.net/companies_using_service-call.html [31 companies listed]

www.pinpointbycontacta.co.uk/ - 01732 223900

www.disabledmotoring.org/campaigns/refuelling-at-petrol-stations

9 **NHS England - Accessible Information Standard [AIS]**

AIS tells organisations how to make sure disabled patients receive appropriate information and support. By 31st July 2016, all organisations that provide NHS or publicly funded adult social care need to conform to the Accessible Information Standard. Offering Large Print, Braille, Easy Read, Via Email, and how to support people's communication needs, for example by offering support from a British Sign Language [BSL] interpreter, deafblind manual interpreter or an advocate.. http://www.hscic.gov.uk/isce/publication/scci1605

Five rules to remember in life.

1. Forgive your enemy but remember the 'persons' name.
2. Money cannot buy happiness but it's more comfortable to cry in a Mercedes than on a bicycle.
3. Help someone when they're in trouble and they will remember you when they're in trouble.
4. Many people are alive only because its illegal to shoot them.
5. Alcohol does not solve any problems, but then again, neither does milk.

'A woman is like a teabag - you can't tell how strong she is until you put her in hot water'
Eleanor Roosevelt {1884—1962] Diplomat.

If Plan A does not work the Alphabet has 25 more letters

The best doctor in the world is the veterinarian. He can't ask his patients what is the matter - he's got to just know. *Will Rogers*

If you trust Google more than your doctor than maybe it's time to switch doctors. *Jadelr and Cristina Cordova*

NO POINT IN Polio Survivors Network REINVENTING THE WHEEL

PENNSYLVANIA POST POLIO NETWORK, U.S.A.

We are introducing the "Anesthesia Story" Challenge.

We have discovered something really interesting. Doctors have begun listening to the "truth" that so many polio survivors react very easily to anesthesia and pre-op anesthesia prep meds. (Carol Ferg told her story in their April Newsletter).

We would like to accumulate these brief stories, and put them on our Anesthesia Warning Page. In 3 to 5 lines (doesn't have to be long at all) write your story. Sign it with your initials only and the year you had polio - Here's an example: Minor, outpatient surgery. They told my wife we'd be on our way home by 11:00. At 5pm I woke up to discover the nurse annoyed that she had to stay overtime. J.M. Class of 1951

If one of us has a doctor who ignores the information re: Anesthesia Warning? We can easily print out and share the page of stories with them.

POLIO SURVIVORS NETWORK would appreciate it if you would email your story to us at: hilary.boone@poliosurvivorsnetwork.org.uk and please add your permission for us to forward them onto Carol for their Initiative on Anaesthesia. They are going to record the responses by Country. We will then include this link - and some of the stories - in each newsletter.

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

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 August 1st 2016

Editors Note:-

Articles from Polio Survivors and Health Professionals
Welcome for future issues

European Region successfully withdraws trivalent oral poliomyelitis (polio) vaccine

WHO Regional Office for Europe. 18th May 2016

The largest ever globally coordinated switch of vaccines in routine immunization programmes took place from 17 April to 1 May 2016. This was the first step in a phased withdrawal of all oral polio vaccines (OPVs) as part of the global Polio Eradication and Endgame Strategic Plan 2013–2018.

With the switch, 19 Member States in the WHO European Region were among the 155 countries and territories across the world that stopped using trivalent OPV, which protects against all three strains of wild poliovirus. Each country either began using bivalent OPV, which provides stronger protection against the remaining two wild poliovirus strains, or switched to a schedule that includes only the inactivated form of polio vaccine (IPV). Of the 19 European Member States, 17 switched to bivalent OPV (Albania, Armenia, Azerbaijan, Bosnia and Herzegovina, Georgia, Kazakhstan, Kyrgyzstan, Montenegro, the Republic of Moldova, the Russian Federation, Serbia, Tajikistan, the former Yugoslav Republic of Macedonia, Turkey, Turkmenistan, Ukraine and Uzbekistan) and two moved to an IPV-only routine immunization schedule (Belarus and Poland). The remaining 34 Member States in the Region had already adopted an IPV-only schedule.

Health authorities in each country are expected to submit a formal report to WHO validating the successful completion of the switch. The next step will be to destroy any remaining trivalent OPV stock according to national guidance.

WHO/Europe has worked closely with countries over the past two years to ensure that all mechanisms and supplies were in place to withdraw one vaccine and introduce another in every health facility by the designated day for the switch. "The extensive preparations clearly paid off, as the process was implemented successfully in each country without any major challenges," said Dr Nedret Emiroglu, Director, Division of Communicable Diseases and Health Security. "Member States' great efforts and the strong commitment of everyone involved have contributed to a historic global public health achievement."

Rationale for the switch

While OPV is extremely safe and effective, the live attenuated polioviruses within OPV can, on very rare occasions, cause cases of circulating vaccine-derived polioviruses (cVDPVs) or vaccine-associated paralytic poliomyelitis (VAPP). Over 90% of cVDPV cases and approximately 40% of VAPP cases result from the type 2 component of trivalent OPV. This component also interferes with the immune response to poliovirus types 1 and 3. Withdrawal of the type 2 component of OPV was made possible by the worldwide eradication of this type of wild poliovirus in 1999.

Safety precautions

To mitigate any risk associated with the withdrawal, all countries continuing to use bivalent OPV are expected to introduce at least one dose of IPV into their routine immunization programmes to maintain population immunity against the type 2 virus. A stockpile of monovalent OPV type 2 will be maintained for use in the event that any cases of cVDPV type 2 emerge after the switch. Global efforts are also under way to identify, destroy or safely contain all potentially infectious poliovirus samples in all laboratories and manufacturing sites worldwide.

One critical step closer to global polio eradication

The OPV switch represents a milestone in the comprehensive long-term strategy to achieve a polio-free world. Key lessons learnt will contribute to planning the withdrawal of all OPVs once the remaining two strains of wild poliovirus have also been eradicated. All countries and territories in the world still using OPV at that time will switch to an IPV-only routine immunization schedule.

Source article. http://www.euro.who.int/en/health-topics/communicable-diseases/poliomyelitis/news/news/2016/05/european-region-successfully-withdraws-trivalent-oral-poliomyelitis-polio-vaccine

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

Ken Loach Film, I, Daniel Blake, wins the coveted Palme d'Or at the Cannes Film Festival - Film critics reduced to tears.

The film depicts the failings of the UK welfare system.

Ken Loach says...
"There is conscious cruelty in the way we organise our lives now which means the most vulnerable people in society, such as the disabled, are caught in this unfair situation. They are often unable to live with dignity, and instead suffer pain and deep despair.
It's deeply shocking that this is happening at the heart of our world."

RELEASE IN UK LATER IN 2016

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Sold in aid of **POLIO SURVIVORS NETWORK**
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