



# POST POLIO MATTERS

Polio Survivors Network Newsletter  
July 2023 — Volume 11 Issue 2 of 12 [122]

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## HEALTH PROFESSIONALS - How we can help you?

**POLIO SURVIVORS** are a **NIGHTMARE**

PART TWO

The success of the polio vaccine  
reduced the number of facts taught by your Colleges of Medicine.

The Polio Virus Damage is scattered throughout our body  
and rarely do two of us have the same level of  
nerve damage/issues - so no set pattern

We have now developed another condition  
ending up in your department.

Our members are experiencing many issues  
PSN are looking for any ideas and suggestions from anyone  
including health professionals anywhere in the world  
for a newsletter and stand alone article  
for how we might reduce the issues  
and save our NHS and all hospitals time and resources.

Continued on [page 6](#)

POST-POLIO SYNDROME

POST-POLIO SEQUELAE



[Lincolnshire  
Post-Polio Library](#)

Polio Survivors Network is the working name of  
registered charity 1064177, The Lincolnshire Post-Polio Network

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<b><u>Donations and Charity Incentives Paid</u></b>	
<i>(since last newsletter)</i>	
Smile.Amazon	5.00
Donation (K Lagwi)	12.50
Smile.Amazon	25.20
Donation (J Smith)	30.00
Donation (M Embry)	150.00
Donation (D Brennand)	12.50
Donation (S & P Tanfield)	20.00
Donation (F Mitchell)	12.50
<b>Total</b>	<b>£267.70</b>

*This publication is provided free thanks to the generous donations of our lovely members.*

**Thank you so much!**



PayPal donate link:  
<https://bit.ly/2KzyAyE>

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## *Editorial by Hilary Boone*

I am saddened by the issues that all your Trustees, my husband and more and more members contacting me are reporting.

We are all aging and many of us have other medical issues to add into how we manage our Polio lives. This has added further burdens to us and our families and those that help care for us.

We have been strong willed, determined to succeed and achieved way more than was expected of us when we had our original polio. When Post-Polio issues started most of us ignored them for years. We continued to push ourselves and then crash out, rest up for a few days and then do it all over again. Yes, we had heard about Pacing and Resting making our lives easier but hey "We were not there yet, were we?" I have to go back to 1997 about eighteen months into having found PPS existed, starting our Network and formulating Newsletters. A registrar in the Rehabilitation Clinic in Lincoln asked me "Who wrote this article in this Polio newsletter?" I was so proud to say "I did". Then stunned when he replied, "Well can you please explain why you are not taking the advice you are giving?" I never expected his response to be, "Not there yet? You have been there for at least five years." It is not easy to be honest with ourselves is it? However in view of the issues being experienced I think it would help all Polio Survivors if we started thinking about how would we cope if.....

For at least a decade or two most of us have been Pacing and Resting and using aids and assistive devices and many of us have Carers or Family Members taking on some of the roles we can no longer manage. Covid was a big shock to everyone in early 2020 and being honest I did not expect to be alive many more months. Most of us accepted the vaccines offered to us but that is a personal choice. We accepted that obtaining appointments and treatment was going to be more difficult and take longer than the already long time we were used to waiting in our varied countries.

Your Trustees started mentioning a few issues during our post meeting chats. This triggered me to formulate the front page of the last Newsletter. What I did not expect was the level of issues that were then reported to us after publication. Please find Polio Survivors are a Nightmare Part 2 on [pages 6-8](#).

The Specialist Clinics and Wards covers Cancer, Parkinson's and other Neurological Conditions, Cardio, Orthopaedic, Respiratory, Orthotics, Ear Nose and Throat, etc. Some of whom we expected might have a little knowledge about Polio Survivors issues but reported to us is that not all do.

I am asking anyone who reads this newsletter to help us by providing more information for our database of problems that Polio Survivors are experiencing. What issues did you, or happened to patients you were treating? Please tell us good and bad how did you/they cope? What would have made your life easier at the time? What information or other idea would you prepare for the next time the situation occurs?

I am sure you will be interested in reading Zsuzsi and Verite's articles. ([pages 5 & 9](#))

[PHI We're Still Here 2023](#). It would be great if some of our members could submit items for this competition. The photos could help Polio Survivors promote the fact that there are more survivors in the world - especially those in third world countries - who are still alive today.

Prof Carol Vandenakker Albanese - See [page 14](#) for presentations that can be watched online. I have met Dr. Vandenakker at many Post Polio Conferences in the last 25 years. She has acted as Reactor to Presentations I have given. I arranged for Richard to have a PPS assessment by her when she was working in Miami in December 2000 and it was she who diagnosed Richard with having Parkinson's as well as PPS.

## Polio Survivors Network Annual General Meeting (AGM) 2023

As you will all know we held our AGM online on Thursday 29 June 2023. We were pleased to welcome members from around the world.



Our Chair, Simon Parritt, presented the Annual Report which recognised that there have been challenges faced by all since our last AGM due to the Covid-19 pandemic. It was acknowledged that it is also increasingly hard for polio survivors as we age. There were advantages from the pandemic such as being in more regular contact with polio support groups from around the globe and building on these good relationships. We provide a niche service for polio survivors; it is very specific. While we don't offer a helpline or advocacy service we support where we can. It is difficult to keep polio in the mind of healthcare professionals as post-polio syndrome is a less visible condition. We also recognise that as polio survivors age using the internet and new technologies can be hard so we will ensure we keep a telephone, mail and email option to be in contact with us as well as via our website and social media such as Twitter. We will continue to educate others and will use various means to do this. We will consider further utilisation of the media and try to build on the strategies that have been produced for long-covid to support long term neurological conditions such as those faced by polio survivors. In the future it may be that we use modern media more to help our cause and potentially we will look to fundraise as is necessary. We want to thank you all for your generosity and for your support.

A copy of the minutes is available by request to [admin@poliosurvivorsnetwork.org.uk](mailto:admin@poliosurvivorsnetwork.org.uk)

Our post AGM chat included comments about how difficult polio survivor patients can be for hospital staff to help, a theme picked up in this newsletter. There is concern that the whole person is not taken into consideration. Polio survivors are more than our PPS diagnosis. Often the handover from A&E to a ward is poor and day to day needs may not be fully addressed. Polio survivors must do what we can to help ourselves and advocate for ourselves, this is not easy when ill and there is concern for those who cannot advocate for themselves. Polio survivors are often seen as 'too complicated for our ward'. We are not a typical patient as some tasks we can do others we cannot and this can change. There is a lack of knowledge in the healthcare profession and we must fill the gaps. It is a training issue so we must be prepared. It can be tiring explaining everything over and over to each member of staff or shift change. There is often a disconnect between pharmacy and hospital ward, so we need to be aware and speak up assertively. Polio survivors are used to dealing with life in different ways and can often adapt to find work arounds to issues. Polio survivors can't be compared with their age group who are recovering from a heart attack or stroke as an example. We have complex needs. It would be good for all polio survivors to have a hospital pack ready that included simple documentation about our individual needs and maybe a larger document with more details. Don't forget that we have the 'What you Need to Know About My Condition' document which is available on our website or can be requested [by email](#). It is useful to note that information can be added to the Medical ID section of a phone. Emergency services are trained to look at this information on a mobile phone as it is easily accessible to them. You can record details of any important medical information you would like staff to know. The Apple watch can also have medical information on it.

### **Your Committee need more help please.**

We are not only managing our physical health but getting older with all the paperwork that entails. We know of at least one group where they have two people for each post. If you could spare us an hour or two a month to take on a task then get in touch. Our meetings are held on the Internet but with the facility of adding someone via their phone. All members/readers are welcome to send us any info on anything that might help us manage/enjoy our lives move fully.

## FINGS AIN'T WOT THEY USED TO BE

PSN Trustee, Health Journalist and owner of [www.aftercancers.com](http://www.aftercancers.com)



Dear Readers,

Fings ain't wot they used to be. In fact they are a darn sight worse than one could imagine.

I have just spent five weeks flat on my back in Oxford's John Radcliffe Hospital, a mega building of 832 beds. Supposedly a caring community - but I didn't find much compassion given me in hospital because of a massive eye infection, no-one helped me to fumble my way around, or even helped me to work out how to feel my way around when I couldn't see.

I remembered when I had fallen off a bicycle into a holly bush in Klagenfurt, Austria. Had been shown into a small room that had been draped in sheets from a sterile pack. Nothing like that happened in Oxford - but I was to have an injection in my eye. Three days later I was being admitted to hospital, gradually losing my sight.

Things went from bad to worse and although I told the Nurses I was allergic to Preservatives, no-one paid any notice, and I was given Eye drops loaded with preservatives. Consequently I came out in a rash all over. No-one cared.

The air conditioning blasted out (In June) across beds all day long. and one needed to have a heater pumping out hot air to counter the icy blast during the day, Doctors couldn't take blood samples. but no-one worried - they just 'forgot' you needed one.

Forget about Dignity and Privacy: Doctors discussed patients in the corridors, where anyone could overhear discussions.

Infection control was left to keep a barrier up for patients, - but not much barrier up to protect one. You just hoped there was some protection, but not much guarantee. 'Agency nurses' said they were worried about infection floating around.

When you tried to find someone in charge, Sisters said "I don't talk to patients".

Drugs weren't written up in Drug books, so went missing - eventually I gave up asking.

At the end of my stay, the only thing to do was report the hospital to the CQC (Care Quality Commission), and hope they sort them out.

**Verite Reily Collins**

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## **POLIO SURVIVORS ARE A NIGHTMARE PART 2.**

I had no idea when I formulated the front page of the last newsletter how bad things actually were for polio survivors and probably an awful lot of other people with neuromuscular conditions.

The Lincolnshire Neurological Alliance from **January 1998 to December 2022** gave up hours of our time providing the User/Carer/Neurological conditions poor experiences with the hope that we would see an improvement in services offered in Lincolnshire and a saving of NHS funds. We saw a few improvements but then things took a downturn and now...

We fully accept that each health department/ward cannot possibly know the ins and outs of every medical condition. We also accept that Covid has caused massive issues for NHS staff leading to even longer delays for appointments/treatments. If NHS funds are to be saved then we believe the only way forward is genuine Co-production with all involved providing and receiving services.

Not only did we personally experience issues but we are being contacted by other polio survivors who are reporting similar issues. We have decided to have yet one more go and with our readers help write an article for the next issue [and stand alone] outlining solutions to the problems Polio Survivors have experienced. So we are asking our readers for help. It does not matter where you are in the world. Please contact us with the issues you have experienced and how you managed [both good and bad experiences]. Plus let us know if you have any suggestions of simple alterations to procedures that you believe could save time and valuable resources.

We, and those who contacted us, suddenly found ourselves in A&E, Emergency Care, Surgical or Medical Emergency Assessment Units and some then onto a ward relating to the issue we were experiencing and discharges to our home.

As I started this article all those already contacting us had provided printed medical information on our Post-Polio. We had all our medications with us so we could take them on time and we did not have to wait for them to be ordered and collected from the pharmacy. If we had other medical equipment needed during our stay then we had taken this with us. We had someone with us to assist us when needed allowing staff to concentrate on other patients.

**The following are just some of our experiences. What ideas do you have?**

### **1. When in A&E or Emergency Care.**

- A.** Two members left sitting in their electric wheelchairs throughout the night in the waiting room for more than 16 and 18 hours.
- B.** One had provided their medication time sheet and was stunned next morning to find that nurses were unaware medication had been taken at four times and therefore not recorded. We recommend that if you do this you ensure that staff are aware each time you do this.

### **2. When on Wards the level of disability awareness by many staff.**

- A.** Arriving on the ward in an electric wheelchair to be met with 'we do not have a hoist to get you in and out of bed' I don't need one. "How are you going to get in and out of bed then?" I can self transfer.
- B.** Arriving on a ward in an electric wheelchair and immediately a call goes out for an air mattress. We have lost count of the number of times we have explained that we cannot get into or out of bed or move about on an air mattress, it would make us more disabled. 3 of 7 times we have had to agree to the change. Within a short time staff have to had to change it back again. Waste of time.
- C.** One member reports asking for help to eat his dinner was met with the comment 'But I saw you walk to and from the toilets' having to explain his main polio weakness is his upper body.

### **3. Disabled toilets/washrooms.**

- A.** Entering on electric wheelchair many are so small it was impossible to turn round to shut the door.
- B.** Canada—the room I had had a completely inaccessible washroom. The wheelchair



only would go about 1 foot from the toilet. The nurses had to climb over the chair to help in the bathroom. It was at times hilarious but sadly not at other times.'

- C. I went to the disabled toilet in A&E and although I could see the low toilet was going to be an issue I could not wait. I did what I had to do then called for help. A male nurse arrived offering his arm to help me stand and I explained I cannot pull myself up I need to push up to stand. He brings another male nurse who offers his arm. I was explaining again that I cannot pull myself up when a senior nurse arrives at the door and loudly says 'Mrs X if you do not make an effort you will be there all night.' I should not but I swore and loudly explained "for the third time the only way I can stand is by leaning forward pushing myself up and your staff helping me lock my legs at the knees" At last I had got from the toilet to my wheelchair - to then receive a round of applause from those in the waiting room not something I expected.
- D. Staff not aware the disabled toilet door could be opened outward's allowing more room in the toilet but still not enough to turn to lock the door.
- E. Told no disabled toilet available on the ward nearest is 50 yards down the corridor.
- F. Low disabled toilet and no toilet raise seat available.
- G. Given commode as the only alternative with two reporting the depth so shallow that physical restrictions meant it was not possible to clean ourselves making us even more disabled.
- H. Three report disabled toilet in a very large room. One had handrails both sides. The other two only one handrail. All report Washbasin and handtowels not in reach from the toilet.

#### 4. Eye examinations seating, X-rays and MRI's - how to get on/off tables.

- A. **Eye tests** and the little low stool on wheels. "I was told you must leave electric scooter outside the room. I managed to sit down onto the low stool and have the tests. I was unable to stand from that low height and was told they would call security. For years I had raised the issue and nothing had been done. I was annoyed so I dropped to the floor crawled out of the room and used my practiced method of getting up using my electric scooter. I was so embarrassed that I sung "I do it my way" and got a round of applause from those waiting. Funny at the time but I hate it and dread going for my yearly Diabetic eye test.
- B. **X-ray tables.** How many times have you had to explain you can only do this your way and please do not grab my arms? From electric wheelchair to table. "They wanted me to try to shimmy over myself. IMPOSSIBLE! You know me I would try after wasting energy and about 15 minutes they would get out a back board and in seconds had transferred me. In the mean time I was exhausted and in pain."
- C. **X-rays standing.** Difficult if you have a forward curving spine. "I have this problem and was unable to stand at the machine as wanted. Our Neurofunctional Chiropractor uses OptoDrum and I have the App on my phone. It relaxes my spine enough that I am able to manage at the hairdressers backwash, dentists etc. I looked at the black and white line moving screen for about 20 seconds and my spine relaxes enough for me to get into the correct position. The x-ray was quickly taken. Staff asked for information as it could help others.

**OptoDrum** is an easy to use replacement for a bulky optokinetic drum or a fraying cloth tape to elicit optokinetic nystagmus for evaluation of neurological, ontological, and ophthalmological disorders. [Do not use if you have epilepsy]



**D. MRI's. Getting on and off the table.** "I had to have 4 MRIs the Dr. ordered sedation for the one that lasted 45 min. The techs decided that I didn't need it so didn't give it to me. I had pain down my leg from my back that was so bad I couldn't keep still. They said try to keep still which had become impossible."

"I could not lie flat due to spinal curve. With my knees bent they managed to get push my head and shoulders into the MRI. Pain in back was horrendous. Crying in pain I managed a 2 minute then 3 minute scan then had to beg to come out I could take the pain no longer."

**4. Ward routines.** We fully understand that there have to be routines but not every patient can easily fit into that routine. Have you experienced issues and if so were they easily sorted?

**A. Meal Times.** Did they match your routine. Were you able to eat what was offered, e.g. any intolerances or allergies. [One example from the past was returning from a lunchtime OT appointment to be told you have missed dinner and I know you cant have dairy but we have some custard you could have. Response to how do you make custard, "I don't know I get it out of a box"]

"No the food: It was horrendous. I don't think I ate three meals other than a couple of breakfasts the whole time.... I was lucky to have people that cared. There were days near the beginning that I was hungry."

Dairy allergy. Not allowed to keep my dairy free spread and milk in their fridges. Ended up using cool box by bed and relatives bringing me freeze blocks each day.

**B. Therapy.** Physiotherapist coming onto the ward and telling you/demonstrating exercises and how many repeats you will do? Have you been asked if you have any issues or when you have explained your inability to do ten repeats have you got the 'I am sure if you try you could' response?

**C. New Medication to be added to what you already take.** Have you just been given the medications on the ward round? Was the medication/dose/timing/possible side effects/issues with timings of meds already taken etc discussed? Were you just handed them in a plastic folder/envelope on discharge without comment? All the above have been reported as issues.

**D. Mobility Aids** you take in with you. Four report electric wheels kept in another room. So you had to ask someone to bring it to you so you could get to the toilet/ bathroom.

**E. Equipment you take in with you.** Bi-levels, Cough Assist, Anal Irrigator, etc. [One example Staff Nurse "Oh you have a CPAP," You reply "No, it is a bi-level" SN response "What is that?" Explained similar to CPAP but lower level to breathe out. SN "I will have to check with the doctor that you can use this"]

**F. Having a relative/carer with you.** We have many reports of issues that have been experienced that are eliminated when you have someone with you. These include:-

Incorrect medication, dosages and/or timing errors not made. Incorrect fitting of masks of respiratory equipment even on Respiratory Ward. Mucous clearing immediately when needed. Bringing wheelchair to bed to go to the bathroom. Providing urine bottle. Assisting to use commode. Help with drinking when needed and eating whilst food hot. Obtaining food that you can eat from shop/restaurant in hospital. Assisting to move/sit up/lay down/turn over when needed. Providing verbal and printed information on post-polio issues and how you manage them.

**The saving of time and NHS resources is huge as are the benefits to the patients health and recovery. Other family members concerns are lessened.**

If you do not have anyone to be with you. What did/do you do? ***Please write/email us, all suggestions / ideas will be gratefully received.***



## Michael's Sciatica

What can happen when a polio survivor falls.

A few weeks ago, we had an appointment at Specsavers and as usual I visited the loo before we left. As I tried to stand up my foot slipped away from me, and I ended up on the floor. I tried to get up without any success and as we were in a hurry, I called to my husband for help.

I wear UTX Swing callipers on both legs. They are very helpful in supporting my hyperextending knees but in order to bend them I have to release a catch or be standing. To get up from the floor I would have to bend them and it was too difficult in that position. If I had more time, I would have removed the callipers, and then crawled to a suitably sturdy, low chair in the living room. Then I would have lifted the left side of my bottom on the chair and pushed with my right leg and with my hands on the chair, I think I would have been able to get up. I have managed to do this in the past and will have to check to see if I can still do it. But there was no time, so my husband came to lift me up from behind in the small space and as he tried to make sure I was standing he pulled a muscle in his back. Not on the left side where he often suffers from pain but on the right side. He usually wears a support when lifting heavy objects. But there was no time!

The next day he had a shooting pain down his leg and his research on the internet diagnosed it as sciatica. He did not even think of asking a doctor because getting an appointment is too difficult, but looking and searching on the internet is much simpler. You get sciatica when something presses or rubs on the sciatic nerve. The most common cause is a slipped disc. He found out there were two forms of sciatica, one when the sciatic nerve gets caught in the spine, the other when the nerve is under pressure from the piriformis muscle. when lifting something improperly. The sciatic nerve passes through this muscle and can damage it. Regardless of what type you have, the shooting pain down one side of the leg is the same and the treatments are the same. My husband decided that he had the second reason for his painful sciatica.

Ice packs and exercise seemed to help him, but painkillers did not. He also rested and tried to walk through the pain He was hardly able to walk for a few days, but he persevered with his self-care treatment and gradually got better. Of course, I felt very guilty because I was the cause of his sciatica and resolved to make sure that in the future. I can get up from the floor by myself.

By Zsuzsannah Snarey, Trustee.

**Editors Note:** A lot of polio survivors share stories on many lists/groups etc. More and more of us are falling and having to struggle to get up from the floor.

Back in 2001 Richard was to have Rotator Cuff Surgery on his right shoulder and Dr. Jaquelin Perry response was for Richard to wear his right arm in a sling as it would be post operation. Then to practice all transfers. He did this and it was really beneficial as he did not have to think how am I going to do this. It was still painful but so much easier not having to think HOW?

I recommend that we all look at how would we get up if we fell on the floor? How would we manage to do all sorts of actions of daily living if we had one arm or one leg out of action? Then there are the varied heights of couches, chairs, in our and our families and friends homes... and even more issues in public rooms. Disabled toilet heights are varied. We now carry a toilet raise seat in our vehicle and I don't go anywhere without my mobile phone.

Thinking back over the last 35 years I have had to modify the way I got up from the floor seven times and for the last 3 years the only way possible has been by Carer using a hoist. My riser/recliner chair and bed are both now raised on 3 and 6 inch wooden platforms. I recently learned that my left hip and right ankle are weaker now than they were when last tested. It is a year to the day GP referred me for an electric wheelchair and maybe a couple more months wait but with the rise facility life will be so much easier at home and when out when it arrives.



**In memory of John Graham De'Ath**, Air Commodore RAF (ret'd), MBE, MA, FIMgt, who died peacefully on 10<sup>th</sup> April 2023 aged 90.

John was an accomplished athlete and Olympic triallist before suffering from polio in his early twenties. After making what appeared to be a full recovery, he managed to return to a high standard of short and long-distance running and squash, among other sports.

In 1951 he joined the RAF as a Cranwell cadet straight from Whitgift Middle School in Croydon and, as an officer cadet, was selected to line the route at the 1953 Coronation. His RAF postings took him all over the UK, as well as Malta, the United States and Germany.



John retired from the RAF in 1986 to take up a post as Home Bursar at Jesus College, Oxford, where he had a happy and successful second career. During this time he developed post-polio syndrome, which eventually forced him to retire from his College post. During his time in Oxford he was heavily involved in various sporting organisations, including the RAF Athletics Association, Achilles Club, Oxford University Athletics Association and Oxford University Air Squadron. He was an active campaigner for women's sport.

Despite being a wheelchair-user from 2010, John continued travelling around the world with the help of his wife, Sonia. Sports, wine, music and travel were his passions.

He passed away peacefully on Easter Monday in a care home, after several happy days spent with his family, singing along to favourite songs, joking, and smiling to the last.

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## Please support The Brain Charity by writing to your MP



The Brain Charity will launch our 'It's All In Your Head' report in Parliament next month.

This report examines responses from more than 800 people with neurological conditions, who told us about their delayed diagnosis and misdiagnosis journeys. It also highlights other key themes including a lack of awareness and support, and the impact on mental health.

Please ask your local MP to attend our launch event in Parliament on Wednesday, 6<sup>th</sup> September at 1:00 p.m.

By coming to our event, MPs will hear directly from those affected, and we'll ask them to pledge their support for the 1 in 6 people in the UK living with neurological conditions.

To find more information on how to email your MP and download our customisable template letter visit <https://www.thebraincharity.org.uk/write-to-your-mp/>



Ok I am not going to hide it; I am in full holiday mode! This is our first time travelling as a family since 2019. We are flying to Germany and heading to the Black Forest (and yes it was the thought of eating copious amounts of gateau that was the inspiration!) for 10 days then flying on to Italy to spend 10 days in Tuscany. La Dolce Vita!

It got me thinking, some of you must have some amazing travel stories to tell, I imagine some are amusing for all the wrong reasons - I know ours are (husband picking up his brother's passport which we only discovered on our way to the airport for our honeymoon - oops) and other trips will hold precious memories.

Perhaps overseas travel never was your kind of thing or maybe travel may no longer be possible for you now. There are various ways to find joy and relaxation closer to home. You may have discovered your own "happy place" in a nearby location – a park, beach, a local café, or even your own garden. These places offer solace and a sense of peace, serving as a getaway from the stress and routine of everyday life. Exploring and appreciating the beauty and tranquillity of our own surroundings can be just as fulfilling as embarking on overseas travel.

For those of you with specific accessibility needs, finding a destination that caters to your requirements is crucial – have you found a great place that caters for all your accessibility needs? Do you know of a travel company that is definitely worth knowing about? In some regions, infrastructure and accessibility standards may be lacking, making it difficult to move around comfortably. It is essential to raise awareness about these issues, sharing personal experiences to highlight the need for improvement. By doing so, we can advocate for change and encourage destinations to invest in accessibility measures, making travel more inclusive for everyone. Perhaps you have strong views to share due to a bad experience in trying to get about in an part of the world that should be much better?

Why not tell us about your experiences? We would love to hear from you.

Take care

*Toni x*

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### **From our readers:**

Thank you so much for all the publications, they are very useful.

Looking forward to seeing you at the Annual General Meeting.

**K McRae shared this experience** “I had polio 71 years ago which paralysed and deformed my chest, spine and whole body. In October 1952 the NHS put me in an open air unheated TB isolation ward in Oswestry which was 60 miles (3 train rides) away from my parents in Weaverham. After year of being cold, oftentimes bullied, in a bed on wheels and multiple failed operations I was sent home in a war surplus canvas pram so someone found me a 1930s wooden wheel chair. Sir John Deanes Grammar school took me back on a trial basis. I won a Scholarship to Manchester University in 1961, worked at Ferranti computer research, I have been Financially independent since and have never received any means tested benefits, but was able to send £thousands home to repay my family. Unfortunately Manchester smog and motorway traffic along with deformed lungs forced me south to English Electric Computers Kidsgrove. The &70’s winters froze me and immobilized my wheelchair forcing me further south to Portsmouth where prevailing South West winds over thousands of miles of the Atlantic sea brought pollution and pollen free air which stopped my hayfever and breathing problems.”



Neuro Key have recently launched - the My Life Tool, led by lived experience, which has been adapted by participants living with Long Covid and is now available - along with downloadable booklets. Please take a look <http://mylifetool.co.uk/LongCovid.html>

**Website** [www.na-tvdny.org.uk](http://www.na-tvdny.org.uk)

**An interesting recording** is available of the Polio Health International meeting where Rhoda Olkin spoke on "Promoting Positive Solutions for Aging with Polio/PPS" <https://youtu.be/62B798PV1LA>

**We are sad to inform our members that** Polio Epic has now closed “After almost 40 years, we are finally closing down the Polio Epic, Inc. support group. Inside the newsletter, we give you many different resources to get your information. We will also keep <http://www.polioepic.org> website open until after the first of the year (February 2024). Please consider joining PHI (Post Polio Health International). PHI has been available since the 30s, and is the largest clearing house of information in the world about all things Post Polio ! PHI also maintains a medical group of accredited medical doctors that still treat polio survivors and keep up with all the latest research.”

To members of the Polio Survivors Rotary Action Group:

Rotary has changed the guidelines and requirements for a Rotary Action Group and unfortunately, we have not been able to keep to these new standards. At the April 2023 RI Board meeting, the board expressed their deep appreciation to the Polio Survivors Rotary Action Group for its 17 years of service and terminated our group.

We will be shutting down - any funds left will be donated to The Rotary Foundation. We may be reaching out to re-start as a Fellowship or as a Rotary Action Group with a focus on mobility and accessibility.

Thank you for your support -

Sincerely:

Ann Lee Hussey - President

Gretchen Bren - Secretary

Patricia Meehan - Treasurer



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## Dr Simon Shaw has left Lane Fox

As you will know, Dr Simon Shaw, consultant in rehabilitation medicine has now left the Lane Fox Unit at Guy's and St Thomas' (GSTT) NHS Foundation Trust. In September, he will begin his new role as Clinical Director for the National Spinal Injury Centre at Stoke Mandeville Hospital near Aylesbury, Buckinghamshire.

The Fellowship will write to the Clinical Lead for the Lane Fox Service to ask about the future, but we are aware the role of Consultant in Rehabilitation has been advertised. In the meantime, Simon will continue to work with the Fellowship on the Optimal Care Pathway (formerly known as the Healthcare Pathway).

## Castledown FM radio interview

Kripen Dhrona, BPF's Chief Exec was invited to take part in a radio interview on Thursday 20 July, for Barry Rhodes' Talk of the Town program on Castledown FM (a local Wiltshire radio station). Barry asked Kripen for an update on the polio vaccination campaign for children and about the challenges facing those living with the late effects of polio and Post-Polio Syndrome (PPS). You can hear a recording of the interview here: <https://vimeo.com/847997067/0139bd91ac?share=copy>

## Useful Resources

- International Ventilator Users Network  
[www.ventnews.org](http://www.ventnews.org)
- Disabled Motoring UK  
[www.drukdiscounts.co.uk](http://www.drukdiscounts.co.uk)
- Pain UK  
[www.painuk.org](http://www.painuk.org)
- National Voices  
[www.nationalvoices.org.uk](http://www.nationalvoices.org.uk)
- Neurological Alliance  
[www.neural.org.uk](http://www.neural.org.uk)
- Rare Disease UK  
[www.raredisease.org.uk](http://www.raredisease.org.uk)
- End Polio Now – Rotary International  
[www.endpolio.org](http://www.endpolio.org)
- European Polio Union  
[www.europeanpolio.eu](http://www.europeanpolio.eu)
- Post-Polio Health International  
[www.post-polio.org](http://www.post-polio.org)
- PA Polio Survivors Network  
[www.papolionetwork.org](http://www.papolionetwork.org)
- Polio Quebec  
[www.polioquebec.org/eng/](http://www.polioquebec.org/eng/)
- Polio Survivors of Marin  
[www.facebook.com/groups/163909760771171](https://www.facebook.com/groups/163909760771171)
- Atlanta Post-Polio Association  
[www.atlantapostpolio.com](http://www.atlantapostpolio.com)
- Nebraska Polio Survivors Association  
[www.nepolioorg.ipage.com](http://www.nepolioorg.ipage.com)
- Polio Australia  
[www.poliohealth.org.au](http://www.poliohealth.org.au)
- Word-Wide Fellowship of Polio Warriors  
[www.poliowarriors.org](http://www.poliowarriors.org)

PHI extends our gratitude to those of you who were able to help make our recent lecture with Dr. Vandenakker Albanese a success. For those unable to attend, the recording is now available to view on our website at <https://post-polio.org/education/post-polio-experts-present/>.



It is also available on PHI's YouTube channel along with many additional videos at <https://www.youtube.com/@post-poliohealthinternational>.

**Other interesting videos include:**

- **Promoting Positive Solutions for Aging with Polio - RHODA OLKIN, PhD, and STEPHANIE T. MACHELL, PsyD** <https://youtu.be/62B798PV1LA>
- **Optimizing Your Experience with Your Physician - MARTIN B. WICE, MD**
- **Non-invasive Ventilation - NORMA MT BRAUN, MD, FACP, FCCP**
- **PHI Town Hall: Bracing - MARNY K. EULBERG, MD**
- **Components of Comprehensive Post-Polio Management - CAROL VANDENAKKER-ALBANESE, MD**
- **Components of a Post-Polio Evaluation - FREDERICK M. MAYNARD, MD**
- **Polio and Anaesthesia - SELMA CALMES, MD (ret'd)**
- **Ways to Avoid Respiratory Complications of Post poliomyelitis - JOHN R. BACH, MD**
- **Sleep Hygiene - WILLIAM M. DEMAYO, MD**
- **The Importance of Posture - HOLLY WISE, PT, PhD**

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***The Lighter Side ....***

Ronny Corbett and Harry Enfield - My Blackberry is not working.  
<https://www.youtube.com/watch?v=kAG39jKi0II>

Things to ponder:

- ♦ If the No. 2 pencil is the most popular why is it still No. 2?
- ♦ Why do we press harder on the remote control when we know the batteries are getting weaker?
- ♦ Why are you "in" a movie but "on" tv?
- ♦ What was the BEST thing before sliced bread?
- ♦ Why do "Fat chance" and "Slim chance" mean the same thing?
- ♦ At a movie theatre which arm rest is yours?
- ♦ When does it stop being "partly cloudy" and become "partly sunny"?
- ♦ When French people swear do they say "Pardon my English"?



# Management Committee [Trustees]

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

**Trustee** - Zsuzsanna Snarey [zsuzsanna.snarey@poliosurvivorsnetwork.org.uk](mailto:zsuzsanna.snarey@poliosurvivorsnetwork.org.uk)

**Treasurer, Newsletter Editor** - Hilary Boone [hilary.boone@poliosurvivorsnetwork.org.uk](mailto:hilary.boone@poliosurvivorsnetwork.org.uk)

**Trustee** - Verité Reily-Collins [verite.reilycollins@poliosurvivorsnetwork.org.uk](mailto:verite.reilycollins@poliosurvivorsnetwork.org.uk)

**Trustee/s** - Vacancies please contact Toni for more information

## Operations Team

**PSN Admin, Enquiries and Website** - Toni Dunlop 07480 110334 [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk)

**Printing** - Imprint Colour Printers, Lincoln

With grateful thanks to the generous legacy from Ms A Brown, we are able to make membership **FREE** whilst our funds remain above £10,000.00

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

**Write** to us at PO Box 954, Lincoln, LN5 5ER, UK

**Email** [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk)

**Phone** us on 07480 110334 and we will ring you back when we collect our messages

UK Members - receive newsletter by post and/or email (overseas members newsletters by email only)

All donations, small or large, towards our work are gratefully received

Donate by **cheque** to Polio Survivors Network

by **PayPal** to [treasurer@poliosurvivorsnetwork.org.uk](mailto:treasurer@poliosurvivorsnetwork.org.uk)



By **PayPal** donate link: <https://bit.ly/2KzyAyE>

*giftaid it*

**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%). If you have not filled in a current Gift aid form please contact us and we will email/post you one. Thankyou.

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

## **PatientPlus article POST-POLIO SYNDROME**

Written by U.K. Doctors for Doctors

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

NB Respiratory and Sleep Problems Section very informative.

**GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups**

## **POLIO PATIENTS AND SURGERY - Information for health staff.**

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

[http://www.europeanpolio.eu/documents/13642\\_Polio\\_operation\\_eng\\_TRYK.pdf](http://www.europeanpolio.eu/documents/13642_Polio_operation_eng_TRYK.pdf)

Printed copies on our headed paper with permission are available.

***Editors Note:*** Articles from Polio Survivors and Health Professionals welcomed

## WE'RE STILL HERE! WEEK October 8–14, 2023

Post-Polio Health International's 17th annual post-polio awareness campaign will take place October 8–14, 2023. We are once again inviting you to help contribute to another successful campaign. Spread the word about the late effects of polio and remind the world that WE'RE STILL HERE!

This year's theme centres around the idea of adaptation; particularly, what adaptations you've employed to participate in your favourite interests and hobbies. Perhaps you use an assistive device to provide support and stability while engaging in activities such as walking, hiking or gardening.

If you enjoy painting or drawing, maybe you use modified brushes or adaptive grips to hold the tools more comfortably. Those who love to cook might take advantage of modified utensils or make modifications to their kitchen.

Wheelchairs designed for different terrains, such as all-terrain or sports wheelchairs, might allow you to participate in activities like sports, outdoor adventures or even wheelchair dancing. Voice recognition software, adaptive keyboards or touchscreens may help you engage in writing, blogging or creating digital art.

Polio survivors are nothing if not resourceful. When our disability throws up a roadblock, we find a way around it. We want to hear from you about the ways you've found to keep pursuing your passions.

**How to participate:** Send a picture and short description (1–2 paragraphs) of an adaptation that has allowed you to participate in a hobby or activity. **How to submit:** Email your submission to [info@post-polio.org](mailto:info@post-polio.org) (Subject: WSH 2023)

PHI will feature select submissions on our social media accounts and website during WE'RE STILL HERE! week. We will also highlight the best submissions in the fall edition of Post-Polio Health.

