



POST POLIO MATTERS

Polio Survivors Network Newsletter
June 2022 — Volume 10 Issue 10 of 12 [118]

The Neurological Alliance

#BackThe1in6

It raises awareness of how many people are diagnosed with a Neurological Condition

“The stress being caused trying to get the mental health care I need is exacerbating the symptoms of my neurological condition

#BackThe1in6



1 in 6 people in the UK live with a neurological condition but there simply isn't the workforce or services in place to support them. Join us in calling on governments across the UK to back the 1 in 6 and set up a Neuro Taskforce to deliver real change.

Sign the petition today <https://tinyurl.com/BackThe1in6>

Finding out you have a neurological condition is scary and confusing. Receiving the right information and support can make a real difference.

2 in 10 reported not being given an explanation of their diagnosis.

Almost 40% of adults were not given any information at all. This must change!

Polio Survivors have experienced years - some decades - of not receiving an early diagnosis because most Colleges of Medicine were either not aware of or not teaching enough facts about the later stage of Polio. Post-Polio Syndrome. This too must change!

[Lincolnshire](#)
Post-Polio Library
100+ articles

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

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<u>Donations and Charity Incentives Paid</u>	
<i>(since last newsletter)</i>	
Donation (J Barter)	£12.50
Smile.Amazon payment	£12.92
Donation (V Scrivener)	£30.00
Donation (D & J Shaw)	£12.50
HMRC Gift aid payment	£106.05
Donation (K Lagwi)	£12.50
Smile.Amazon payment	£7.34
Donation (PayPal Giving Fund)	£8.89
Donation (G Ross)	£25.00
Donation (PayPal Giving Fund)	£1.00
Total	£228.70

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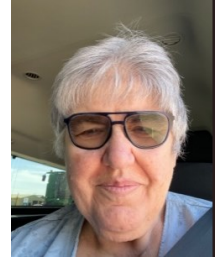
Thank you so much!



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Editorial by Hilary Boone



I must apologise for the very late delivery of this Newsletter and explain the reasons.

I started research into PPS on 25.11.1995 and have given up a major part of my life to this and my work for PSN which includes editing the Newsletter. This helps me feel, despite my ongoing disability, that I can still be a useful member of society and doing something in return for the benefits I receive. For nearly three years I have been forced to spend a huge amount of my time, and available energy for my own post polio life, dealing with an ongoing issue with Continuing HealthCare [CHC]. This has been instrumental in a faster decline in my physical ability and increase in the struggle to manage the stress of the decline of both our lives. My Charity and University work has had to take a back seat.

I/We have been in receipt of funding to help us manage our lives at home for over 23 years. Without this we would not be managing and we are very grateful that the system exists. Despite the slow deterioration of our neurological conditions at a review 2.5 years ago half Richards funds were removed. It took 19 months to obtain the necessary medical assessments and start new paperwork that were instrumental funds being reinstated from 27.9.2021. Would you expect me to tell you that we are still struggling to obtain a properly worded Agreement? Hot off the press. Saturday's post brought a Recorded Delivery offer of a meeting.

Once we learn more about Post-Polio we begin to understand why we are having problems and learn how the best way to manage our lives is by 'Pacing and Resting Activities' and using any aid or assistive device [including human] to not waste energy on something we do not have to do. Energy Tokens. Ten a day and Seventy a Week and no more. Spread £10.00 out over an average day. Extra activities like attending a medical appointment/doing some gardening etc will take more and that has to come from not doing some of things you would do on a normal day. You have to decide do I do this or that? How many of you have pyjama days saving the energy to get dressed to fit something else into your day? I have to allocate some of my ten energy tokens towards helping my husband every hour we are unable to employ Carers. The minute Carers arrive I raise the foot end of my recliner chair, pick up my laptop, and add a neck cushion to support my head and deal with the never ending paperwork all this entails. I am being forced to experience far too many pyjama weeks and I hate it.

Services for those with Neurological Conditions in Lincolnshire have been extremely poor for decades as I am sure our long time readers will remember. Lincolnshire Neurological Alliance [founded in January 1998] learned in 2000 that Lincolnshire Health Authority believed that employing ONE visiting Neurologist ONE Day a Month at the County Hospital was enough for the 634,300 population. LNA proved the statistics that LHA were using were flawed.

We campaigned for better services and it was not long before our County had its first resident neurologist and other staff. A huge increase in clinics. Sadly after a few years this Neurologist decided to move to another County and we started to see a decline in local services and a failure to provide adequate neurological services in the Community.

We continued to campaign for improved statistics to prove the need. **The Healthy Aging Group of the University of Lincoln** were asked by the County Council to undertake an independent health needs assessment for people living with neurological conditions in the county. This is a way of reviewing the current resources available to meeting the needs of a specific population.

They surveyed service users, carers, voluntary sector organisations and health professionals.

All four groups agreed that service provision does not meet demand.

<https://harg.blogs.lincoln.ac.uk/2018/08/13/developing-a-health-needs-assessment-for-people-living-with-neurological-conditions-in-lincolnshire/>

The LNA continued to campaign and then Co-production became the buzz word and we hoped that at last our input would become more than just the far too often 'we consulted box ticking' and our views being ignored.

Co-production is an approach to decision-making and service design rather than a specific method. It rejects the traditional understanding of service users as dependents of public services, and instead redefines the service/user relationship as one of co-dependency and collaboration. Just like users need the support from public services, so service providers need the insights and expertise of its users in order to make the right decisions and build effective services.

In practice, it means that those who are affected by a service are not only consulted, but are part of the conception, design, steering, and management of services.

When Co-production happens like this it saves time, stress and money for all involved. Problems raised by Users/Carers, and any other section of people involved, can be sorted before they happen.

When Co-production does not use the on the ground personnel from every section then we continue to see an increase in the number of complaints and appeals. Staff time is now taken up dealing with them and everyone involved is put under increasing stress. Time and money that could be better spent is wasted. And now another new title for another new system comes on statute on the 1st July 2022. Will this be any better? LNA have seen many changes over 24 years and sadly problems raised repeatedly over the years still remain....

Integrated Care Systems are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area.

“The proposed NHS Lincolnshire Integrated Care Board (ICB) will, subject to the passage of legislation through Parliament, be fully established on 1st July 2022 to oversee the commissioning, performance, financial management and transformation of the local NHS”

Polio Survivors Network are members of the Neurological Alliance and recently became members of the Continuing Healthcare Alliance. The CHA is a group of 20 charities and organisations who believe that NHS continuing healthcare needs to improve. Who aim to make continuing healthcare fairer and easier to access for those who need it most. This is run from Parkinson's UK. www.parkinsons.org.uk/get-involved/continuing-healthcare-alliance

We would love to hear from any of our readers, their family or friends who have been/are involved with Direct Payments/Personal Health Budgets, Continuing HealthCare and with the new Integrated Care Systems in your County. Any information regarding the processes and paperwork both good and bad would provide more facts for our database of information to support discussions

Our website is continuing to grow thanks to the hard work of Toni Dunlop. The more items you share the more information we have to base our response to those who ring and email us for information. If you would like to check with us first if we have a copy of something please do, but remember we would rather have ten copies than none.

We continue to share information with many other PPS Support Groups around the world.

We would love to feature more stories or snippets of your life and items for a Make You Smile Page in forthcoming issues. Your Newsletter Needs You.

A Timely Reminder. When working on something special please do not forget to save it regularly. Yesterday afternoon after working on the Newsletter for five hours I really needed to stop for the day. I started closing down pages I had open on Google. Tired as I was when I clicked on the fifth open page and it said 'Do you want to save?' I clicked 'No' because I had finished with that page... what I had not noticed was the mouse had slipped down onto Publisher and I had just lost five hours work.

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. You do not have to have the Internet we can pop items in the post and can add you to a meeting via your telephone.

MESSAGE FROM OUR CHAIR



PPS – TIME TO BE THE FIRST

Not the second, last or never mentioned condition!

The received wisdom has been that PPS (Post Polio Syndrome) is a diagnosis by exclusion. Is this the wrong approach for you the patient now, should it be a diagnosis FOR INCLUSION.

It may be true from a medical reductionist stance, that exclusion is the way to go, but it certainly shouldn't be what drives your assessment and treatment. If you have had polio or even if you are unsure if it was polio, the probability is that polio could and probably is having an impact on all of your health care and life. You may be unaware of it, perhaps just coping well, deliberating minimising or ignoring it but this is the ostrich position. By adopting an approach that doesn't allow for PPS until everything else is excluded, the result is that, especially if something else is discovered, it is often then ignored, overlooked or just not assessed or factored into all your current and future healthcare.

Multidisciplinary versus Holistic?

We have to recognise that the NHS, medical and health professions even before the current problems, more or less abandoned the term 'holistic' care in favour of an approach that divided our bodies and minds into separate compartments, conditions and specialties. You hardly hear or read the word 'holistic' anymore in mainstream healthcare narratives or contracts and sadly it has taken the feel of an alternative at worst, or complimentary health care approach at best.

So, we are left with the term 'multidisciplinary' which of course emphasises the fact of our health needs are divided up into different parts, separate disciplines and so are left with few adopting an overall holistic care approach. It appears MDTs (multidisciplinary teams) are the closest these days. This is despite the fact that we are whole and complex integrated and interdependent systems making us uniquely who we are. People who have had any degree of previous polio are not well served by that fact being ignored even when it appears symptom silent or 'coped with'.

Try to set the Polio agenda

In an ideal world it should not be a binary choice between bottom up or top down medical and psychological care. The reality of the situation is that the traditional GP role as the holistic care manager of you and your family is no longer what it was, and we have to take control and put it on the agenda ourselves. There are lots of resources and information out there from polio groups around the world and of course us and our library, please take advantage of this before not after there is a problem.

Adequate is NOT optimum

So, your new best policy is always mention you had polio, don't let it be dismissed with the retort, but this isn't anything to do with your polio or PPS. Whilst it may or may not be directly, the chances are the treatment, prognosis and the outcomes will be affected without it being assessed and factored into who you are. Much of the acute care is good but having a chronic condition means vigilance and seeking OPTIMUM not just adequate healthcare for you as a previous polio patient with or without, a formal PPS diagnosis.

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

Chartered Psychologist. HCPC Registered Counselling Psychologist

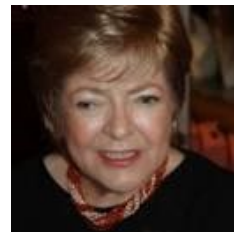
Chair Polio Survivors Network

simon.parritt@poliosurvivorsnetwork.org.uk

Verite Reily-Collins

PSN Trustee, Health Journalist and owner of aftercancers.com

Jeremy Hunt - May 24th 2022.



Six years as Minister and what did he have to show for it?

Jeremy Hunt was Secretary for Health from 2012 to 2018, probably one of the most elusive Health Secretaries ever. Finally he challenged Bojo for the PM ship, but lost out. However, with his new book just out, signs are he is keen to challenge again for the leadership in the near future.

One thing that could be said about Hunt's 6-years in post was that it was pretty undistinguished – after six non-productive years – he did manage a strike – and the waiting lists grew longer during his time. Now, the House of Commons has appointed him Chair of their Health and Social Care Committee (HSCC), Strange – like asking a schoolboy to mark his own homework, as the HSCC would effectively be commenting on work done by Hunt when he was officially the Minister.

He now has the cheek to write a book about what's wrong with the NHS, called :

Zero: Eliminating unnecessary deaths in a post-pandemic NHS.

Judging by reviews already out, it won't need me to point out that there were innumerable 'adverse incidents (the polite word for deaths) during his tenure of office,

It's not all down to Hunt but much of what's wrong in today's NHS stems from systems emanating from his six years. During his time, he must have been working diligently away eroding what efficient systems were still in place, so today patients are 'served' by Appointment Call Centres that could have a waiting list that has soared up to anything from 6.4 million to over 13 million (depending on which source you go to). According to a report by Policy Exchange, NHS bureaucracy has doubled since the pandemic; knowing how slowly the Dept. Health moves, this increase must have started off under Hunt.

Amongst the "highlights" under Hunt was a months-long clash over contracts, culminating in junior doctors staging a series of walkouts, the first all-out strikes in NHS history. This resulted in newly-qualified doctors, with their training having cost the NHS millions, going off to work in Australia and America, leaving the NHS short of qualified staff.

Then there was trouble at Lewisham Hospital, where Hunt's battle to drastically cut services and close departments – including vital maternity, A&E and intensive care units – reached the High Court, where he lost. Judges found he had acted outside his powers after the Save Lewisham Campaign Group pushed the case to victory.

In 2013, [Hunt announced a fundamental review of emergency care following waiting times that were the worst in almost a decade.](#) A year later he was criticised by a health watchdog for claiming in the Commons that median waiting times to be seen in A&E departments had halved since 2010; 2015 revived the 2013 statistic – this time, seeing the worse A&E waiting times in a decade; and in 2017, [Hunt admitted that the NHS must do better when it comes to waiting times](#) after failing to miss targets for cancer care, A&E and routine operations over 18 months.

Underfunding caused the next crisis – the worst ever winter crisis, – caused by systemic underfunding: the Minister failed to ask for enough money to keep the NHS going efficiently. Do you remember this involved the Red Cross saying there was a '[humanitarian crisis](#)' in winter care caused by 'systemic underfunding' following the record-low A&E waiting time performance?

Yet under Hunt front-liner staff numbers went down, but readers might be pleased to know that numbers of Admin. staff increased! After La la had left, it was very obvious that the NHS needed more front-line staff, NOT Administrators. Yet in his six years I can't remember any initiative from Hunt to try and increase numbers, Now, Hunt's smiling photo no doubt will greet us from windows of bookshops, encouraging us to buy his book. But as far as I can see, this is just a way of getting us to vote for him – I seem to remember he ran against Bojo for leader, and I am sure he still has ambitions to be Prime Minister.

The final comment comes from NHS expert, Roy Lilley

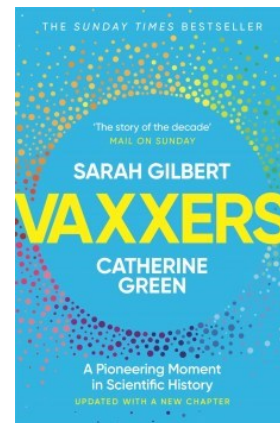
"\has Hunt learned enough to be the next PM?"

Holiday Read

If you are looking for something to read on holiday, why not pick up "Vaxxers", the story behind developing the Astra Zenica Vaccine. Written by Sarah Gilbert and Catherine Green two people who really go on with serious work.

[Editors comment <https://fabnhsstuff.net>]

Roy Lilley is an NHS writer, broadcaster, commentator and conference speaker. The Academy of Fabulous Stuff. A social Movement for sharing Health and Social Care ideas, services and solutions that work.]



Another Important Point

Warning! if a doctor asks you "Can you climb stairs", do **not** jump in with YES!, Be cautious - I've learned to reply "on my bum".

This blunt statement concentrates doctors' minds and ensures they get the picture from our side. It jolts them out of their comfort zone, and makes them see that ordinary tasks are often difficult if you have to factor long-term effects from polio into the equation. ..

Once you have got their attention, and they start to realise you won't fit in their tick boxes, I hit out with "but I do have trouble with xxxxx" and ask for help with whatever is bothering me. Controlling the appointment means less of your time is wasted, and appointments are more productive - for me, anyway.

Today, I've discovered one often has to take on the role of teacher when dealing with NHS staff. They are lucky enough to have grown up in a fully-vaccinated-against-polio-world. But, this has made the NHS complacent and can give them ideas - at my last physio appointment I didn't think the physio had much clue, so looked on their lanyard. It gave their job title as 'Assistant Practitioner' . I asked, and was told "I'm a trainee - started eight months ago".

No wonder the poor kid hadn't a clue what polio was, or what it did to our muscles.

The NHS seems to have decided, in its wisdom, that we polio survivors have all died off (in its dreams) and therefore they don't need to train staff about our needs.

Recently it even tried to cut us off completely; the ONLY mention of Polio on its website was about Post Polio Syndrome; totally ignoring polio survivors who DON'T have PPS.

World Health Organisation, were not amused and they, and PSN, have made the NHS re-write the webpage. In another cost-cutting exercise, hospitals across the UK have made Covid-19 an excuse to close hydrotherapy pools down, and are resisting attempts to get them re-opened.

Recent scandals such as the Paterson case, the Shrewsbury and Telford Hospital Ockenden Report, etc. etc., have bought out what the NHS tried to hide, but carpets were too small. Common to all of the reports was the comment that patients aren't being listened to -- which means YOU just have to open your mouth and comment - loudly.

Case study Valerie, a PSN member, was offered a telephone appointment instead of her usual six-monthly review by her surgeon. She knew she needed to show him how her mobility was failing, so stuck to her guns and said NO - she wanted to see him face-to-face.

Much to her surprise, she has been offered a proper appointment in his hospital for the same time and date - so if we ask - we do get!

With this in mind, try being assertive - and see if it works!

Verite Reily Collins

veritegreenbee@gmail.com

www.aftercancers.com

Polio and me: how my father's illness shaped our family



Sarah Passingham with her father, Push, in the Sixties;
the author today

Sarah Passingham
Thursday June 23 2022, 5.30pm
The Times

The disease is back in the headlines after poliovirus was found in sewage samples in London. For Sarah Passingham, this news has personal significance.

When I was a child I dreaded going to play with friends whose fathers would be there. Granted, this was the Sixties, when fathers were often at work, but it went further than unfamiliarity. They frightened me. Their stilt-like legs, dangling arms and the way they loomed over me all served to intimidate and unnerve. I've heard of a similar experience from people who grew up with single mothers, but my parents were happily married and furthermore my father often worked from home. Push, as he was known, was a big character and very much the centre of our household, so a male presence was hardly unknown to me, but in my little world fathers used a wheelchair to get around.

Push was totally paralysed from the waist down in the terrible polio epidemic of 1952. He relied on his arms and his chair for all independent mobility, so I never saw him upright. He was 6ft 4in but sat at about 4ft tall and so, by the time I was six or seven, I had outgrown him. Being seated was a great leveller. To the family and close friends his chair did not identify him. But it did define him, and by association it defined us as a family. His Everest & Jennings wheelchair literally marked out the physical limits and boundaries of his body, and had to be allowed for.

Push used to say three things happened in 1952: one wonderful, one terrible and an almost. He was a world-class oarsman and disappointed to narrowly miss rowing in the Helsinki Olympics, but at just 26 his sights were set on 1956 in Melbourne, Australia. He married our mother, Diana, in September but six weeks later he caught polio. In hospital he contracted TB, another disease for which there was no vaccination at the time, and the combination kept them from starting their marriage properly for nearly seven years. Their lives changed for ever.

My brother and I knew where those wheelchair boundaries lay from toddlerhood. We could haul ourselves upright against the big back wheels ready to be swung up onto his lap, but we learnt never to kick his legs or jolt his chair as this caused him great pain. The giraffe-like men that I met when I left our house didn't have strict boundaries. They didn't stay in one shape. They moved around too much and I didn't know where to stand. I had to crane my neck to check their faces. Their arms and hands swung about alarmingly. They were an unknown quantity. Until I was considerably older, I was too nervous to see beyond their differences and get to know them. Later still, if I forgot my usual little preparation speech, I saw that same anxiety reflected in the eyes of my school friends when they met my father for the first time.

There were other boundaries that we should never cross and one was talking about his illness; a generational hangover from the war perhaps, but my imagination ran wild. After reading Winston Graham's *The Walking Stick* at an age when I was too young to comprehend that every survivor has an individual experience, I terrified myself reworking the scenes of Deborah in an iron lung, imagining my adored father

suffering dreadfully with the fear of suffocation at every breath.

The reality was bad enough. Constant and appalling pressure sores, a gut that didn't behave reliably — you really don't want to catch a stomach bug when you have very little control over your own body — and pain. So much pain. As well as the sores on his backside, sometimes the size of a dinner plate, his legs ached, his shoulders were overworked, he suffered with chilblains and he developed scoliosis of the spine. Occasionally he fell out of his chair and was horribly bruised. He almost never complained, but we saw it in his eyes when we had suddenly to leave an outing we were on, or a party that we were enjoying and simply go home so he could lie on his side on the sofa, or just go to bed. Then there was the waiting. My brother and I learnt to wait for England. It took so long to get ready to go anywhere that spontaneity was never a part of our lives.

It feels disloyal to suggest it, but at a time when small children usually take centre stage in a family, we always came after Push in the pecking order. Perhaps we learnt something valuable about life, but it certainly changed us, the way we process emotion and find it hard to express our needs. Able-bodied members in a family where there is disability are always affected too, and recent research shows that trauma gets passed into subsequent generations.

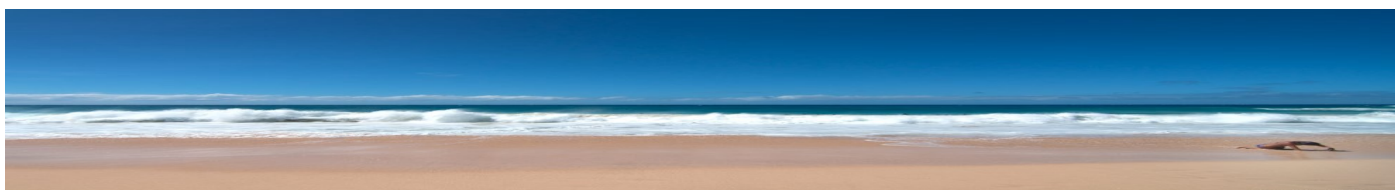
Then there's the whole issue of identity. Occasionally Push referred to himself as a cripple, which definitely halted further conversation. What he chose to call himself was not up for grabs by the rest of the population. All my life I've struggled to find an acceptable word for not walking, but in the end I always resort to "using a chair".

In the past two years we have become familiar with another virus that has changed lives, and the expression "long Covid" is familiar to almost everyone. But how many have heard of PPS (post-polio syndrome)? This cruel condition began to make itself known to Push during the last ten years of his life. Thanks to [Post-Polio Health International](#) we know more about why older polio survivors start losing hard-won muscle tone, experience even more pain and can succumb to something that almost feels like the disease taking hold all over again.

Push died peacefully at his home in 2003. He made it to 76 thanks to a lifetime of care and dedication from my mother — who was only 23 when her husband was driven off to an isolation hospital one desperate Sunday morning in October. Polio doesn't often kill, but complications of polio are a life sentence. And not only for the person affected.

The shock of reading today's headlines about live polio virus being found here in the UK froze me to the marrow. I have a grandson about to turn two and our daughter has another on the way. I felt panic rise as it must have in other mothers during the years of the "summer plague". We should remember that we are all only a sugar lump away from another epidemic and fear beyond anything we've experienced with Covid.

Sarah Passingham's family memoir, *PUSH: My Father, Polio and Me*, is published by Story Machine



I had polio - its legacy has lasted all my life!

*Hilary Boone, 75, founder of the Polio Survivors Network
(as told to Elisabeth Perlman)*

I caught polio in Benghazi, Libya, when I was five years old. It was 1952. They'd brought my father out there because he was in the Royal Corps of Signals during the war. He worked for what was then GPO Telephones (now British Telecom) and took a contract to repair the phone system.

My brother and I got whooping cough first. But then I contracted polio from a girl I'd played with on the beach. She'd also come over with her family because her father was in the Lincolnshire regiment.

I became paralysed from the waist down. I was very ill. My mother called the doctor a few times and was dismissed. They thought it was flu. Finally, she was told to bring me to the army hospital straight away. They didn't say why, but the other girl had already been admitted with polio and they realised they had an outbreak on their hands. I was kept in isolation for a couple of weeks. I remember my mother telling me that she had to stand at the doorway of the room. She wasn't allowed in and had to wear a mask. She was worried sick. She wanted to know what I'd do if I needed the toilet. And I said, "Oh, I just click my fingers and say 'Jeeves', and an orderly brings me a bedpan." It was then always the family joke.

As soon as I was let out of isolation, my parents inquired about hydrotherapy. The hospital said they didn't do that. So my mother asked if she could take me swimming every day. They picked me up from the hospital every afternoon. Lady Mountbatten actually came to visit the poor polio children at the hospital one afternoon, but she couldn't see me because I was off swimming.

Anyway, I gradually started to learn to walk again. It took six months. I was always falling over but was much more mobile, just a bit dodderly.

It was shocking for my parents to experience. My father wrote back to his mother making light of my condition because he didn't want to worry her, but he really was worried. Many years later, when I told my parents I had post-polio syndrome (PPS), they were both absolutely distraught because it opened the box on how they'd felt when I was a child.

They'd just shut it off. That's what I've done with so many of my memories from the time. If I don't want to remember it, I don't remember it.

In 1953 my father's contract ended and we moved back to the UK, settling in Hounslow, Middlesex. As far as I was concerned, I had polio but I went to school and tried to function normally. I was just always falling over.

Things really improved when I was 12 because I had a transplant on tendons in both feet. After that I wasn't tripping over. I wanted to do every sport I could that didn't involve running. I completed lifeguard training a few years later and got as far as an orange belt in judo. If I'd gone to a higher belt, people would have beaten me all the time, because if I bent my left knee more than four inches, my leg would collapse.

Tell me I can't do something and I'll prove you wrong. I did the Lyke Wake Walk across the North York Moors when at training school for the police at RAF Dishforth. I served four years in the police and then moved to Lincolnshire and worked as a swimming teacher and lifeguard.

However, in 1988 I had a fall, which left me with fatigue and a weakened body. In seven years, no diagnostic testing picked up PPS. My muscles were tested using single actions only, which did not confirm that they were weakened. My prior polio was not in the equation till I mentioned it. Then I learnt there was another stage following the stable period after recovery. I started researching that day and have not

stopped since. The British medical establishment needs to understand the extent to which this disease can have lasting effects.

The polio vaccine was not successful until April 12, 1955, three years after I caught the virus. Regardless, that day is a special date for me as my only grandson, Dain, was born on April 12, 2011.

- Article featured in *The Times Health Supplement* 24 June 2022

You may have seen some of these articles regarding polio virus being found in London recently:

- ⇒ <https://www.gov.uk/government/news/poliovirus-detected-in-sewage-from-north-and-east-london>
- ⇒ <https://www.bbc.co.uk/news/health-61896411>
- ⇒ <https://www.bbc.co.uk/news/health-61900915>
- ⇒ <https://www.bbc.co.uk/news/health-61915794>
- ⇒ <https://www.science.org/content/article/poliovirus-in-london-sewage-sparks-alarm>
- ⇒ <https://www.theguardian.com/commentisfree/2022/jun/27/polio-detected-uk-outbreak-infectious-disease>
- ⇒ <https://time.com/6190607/polio-in-london/>

Is there anything you would like to know about this issue from the relevant organisations?

We are here to support our members who are concerned/have questions about these findings?

If we can be of any help and support please let us know.

Contact us by email to psnadmin@poliosurvivorsnetwork.org.uk

By phone on 01522 888601

Or write to PO Box 954, Lincoln, LN5 5ER

and we will do what we can.

MY POLIO LIFE - <https://poliosurvivorsnetwork.org.uk/new/my-polio-life>

A Self Assessment Patient Questionnaire to assist you with collating information on your Life as a Polio Survivor to help when attending medical appointments.

I have taken many phone calls and emails over the years PSN has been in being mostly asking for information on post polio syndrome and secondly asking for advice on attending your first appointment with a new health professional.

You have probably spent many months if not longer wondering about issues but done nothing about them. Often your family and friends can see a difference in how you are managing but you don't because you don't want to see it.. If you do not voice the issue out loud then it does not exist. [Anyone recognise that?]

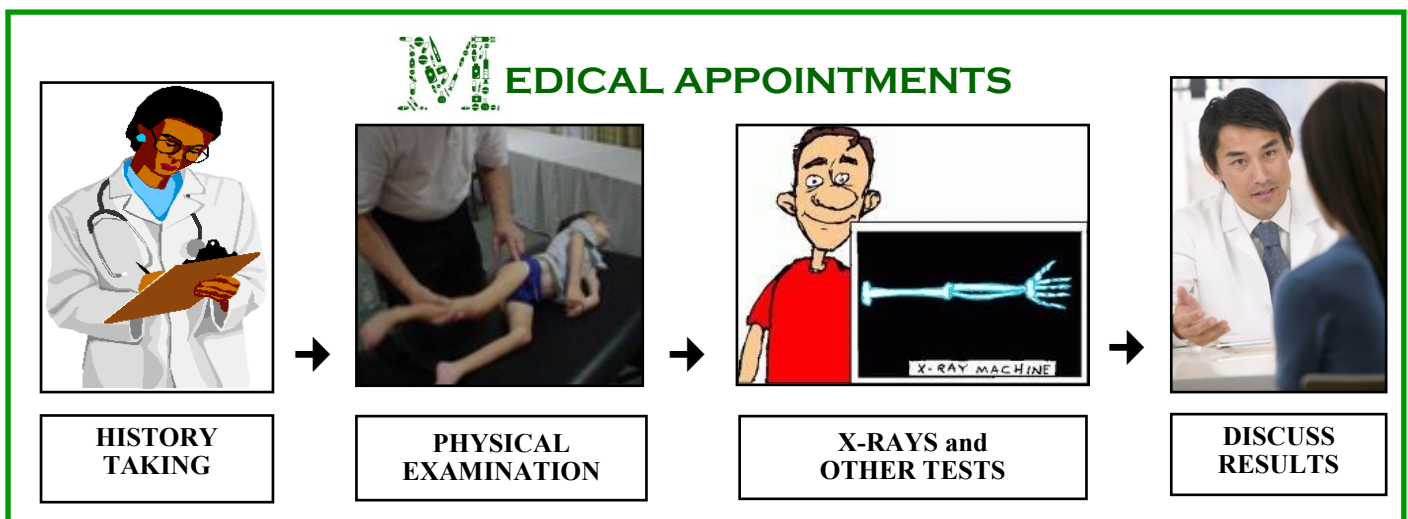
We developed My Polio Life so that you could quickly record a lot of basic information about your life. What equipment, symptoms, diagnoses etc you had and now have. We then suggest that you start an A4 Ring Binder split into sections adding pages to increase the amount of information where you need to. Sections like; what you and family members remember about your polio and recovery. More information on the equipment you had and now have; the qualifications you have and include certificates or awards for anything. We have led varied and comprehensive lives and all achievements are important. Remember most health professionals hearing you had polio will have no idea how well you recovered or what you achieved from looking at you now. Add a few photos and see the 'Oh I had no idea you could recover that much from having paralysis.'

These files are for you to use as an aide memoire to prepare information for appointments. We do not suggest that you produce either at an appointment, firstly because there is no time to read it and secondly it can be a bit intimidating for those whose training has been minimal wondering if your knowledge of polio is greater than theirs. A page or two and few photos is fine.

All your Committee have been through this and we know having to think in depth about your issues is not easy and speaking the facts out loud even harder. About 20 years ago I was given permission by a PPS specialist in America and her patient to sit in on his third yearly examination. I had spent the previous evening chatting to him when he told me that he was also having problems with his arms now. The doctor examined his arms and said "this seems to be much the same as last year but have you noticed anything". He said "No".

I obviously could not say anything but I could see myself a few years earlier doing the same. A bit later that day I asked, "why did you say no when you told me you were having similar problems to me?" His answer, "Her examination did not appear to find anything and I did not want to be worse than last year"

What does an average new medical appointment consist of?



Preparing for the appointment.

Unless we have seen the health professional before they will start with taking some history. Then they will do a physical examination and possibly send us for an x-ray or some other tests before we return to be told the results and the next steps. In the UK with free healthcare and limited time for appointments the speaking time could be as little as ten minutes. Make every word count.

We recommend that, if at all possible find out from the secretary of the Department, who has the appointment been scheduled with [the Consultant or a Registrar] roughly how long do the appointments usually last, how many polio survivors have they seen, are they aware if any x-rays, blood or other tests have been scheduled. You now have more idea of how long you have to speak about your issues. Start with the most important one and have one or two more ready if there is time. You can always ask for another appointment to discuss the rest

We recommend you start with Page 10 and Actions of Daily Living. Add another sheet if you need to add more actions. Now for each action How did you this at Best Recovery and we suggest that if you did this as normally accepted then write 'Normal' if you had your own way of achieving the task then write 'My Way'. Now think about how you do that action now. There is only room for a few short words. You can expand on this on the page in your A4 Ring Binder.

No.	Action of Daily Living	Best Recovery	How I do that action now
3.1	Roll over in bed.		
3.13	Going up Stairs.		

I wonder how many of you will read 3.1 and have to go back to bed and roll over to be able to write down how you do this. [www.thesnoozle.com is a brilliant aid to help you turn more easily].

Once you have completed the list put them in order of importance. What is the action you are having most problem with. For me it was 3.13 Going up Stairs. My issues started after a Fall and I had problems and pain in my neck and left arm. During the next 7 years I answered their questions. I explained I would come home from work and crash out in the chair exhausted. I assumed that their physical examinations of me would confirm what I was reporting. All their single action Manual Muscle Tests showed I had good strength and it was not till years later that because they found nothing they thought I was making it all up. My prior waist down paralytic polio was not in the equation.

Where did I go wrong? I had had good recovery from paralytic polio. Prior to my fall I was an RLSS Advanced Teacher, Senior Lifeguard, Training Officer, Grade II Examiner. Eight months later I went back to work and had to take my basic Bronze Medallion again and failed. Why did it never occur to me to ask for another appointment and say 'I can no longer swim fast enough over 4 lengths or pull myself and my body out of the water at the deep end of the swimming pool.'

In 2004 I was referred to a Senior Physiotherapist who had heard of PPS having found our Website. After she graded my arm muscles saying how strong I was able to ask "If my arms are strong can you please tell me why I am using elbow rotation not wrist rotation to scramble eggs?" The physio examined my wrists and found the right one had extremely weak supinator's. She then watched me do actions of daily living My Way. Getting up from the floor, getting in and out of a low saloon car. She was able to see where my weaknesses were and examine those muscles specifically. She tested more than once and saw how quickly some muscles weakened. It had taken 16 years but now my varied polio virus weakened muscles were graded correctly.

Don't make my mistake. Be honest even if it is hard to hear yourself say the words. You have to be more specific and tell it like it really is.

The most important question to ask the Health Professional you are Consulting.

I used to be able to do 'X' this way but in the last ____ have had to modify the way I do it.

Please can you tell me what has changed in my body to cause this.

They can now see that the ability of other muscles need assessing.

Two pages from twenty years ago LincPINs

I was searching the old Newsletters for the photo I have added on page 16 when I saw the following and did not realise at first that it was from my own daughter. [Volume 4, Issue 8, Page 7, February 2004](#)

A Daughters Dream. I have always had so much respect for my mother. She has always been so strong and independent, I could ask her anything and she would know the answer. For years and years she has been my support system, teaching me how to cope with the things in life. Then suddenly she started to have problems that she could no longer shield me from. It was like a slap in the face!

"What do you mean you're struggling? You can do anything" My rock was starting to crumble and I hadn't even noticed the cracks. The person I wanted to be like could no longer cope, so how the hell was I going to cope? I had been so sure I knew what my future held, but not anymore.

What sort of relationship was I going to have with my mum and she with her grandchildren.

Picture the scene..... It's Christmas Day and the whole family are sat together opening their presents. My mum is sat on the floor playing with the grandchildren and their new toys. "Come on kids get dressed we're going outside to build a snowman! "When they finally come back inside cold and tired mum gets on with cooking the dinner. After dinner we watch the Queens speech and then go for a walk round the park and feed the ducks. We get back to a nice warm house and mum flops in the chair exhausted, but satisfied that everyone has had a great day.

I know this might sound selfish but that's how I imagined things. Not only is mum unsure of her future but so am I. My mind starts racing... Will she get worse? Who will help her? What help does she need? Why is this happening to me?

So as time goes on mum finds out what things she can do to help herself and comes to terms with her illness. She hasn't really spoken to me about the future and what she thinks will happen, so I make my own mind up. I don't want to accept what's happening, I'm angry and upset, but most of all I'm scared.

THE REAL QUESTION IS:- Is she the only one living with her illness

I wrote - We really need to learn more about how others view what is happening to us and how we cope with life, medical appointments, worries about our future and the arrival of brown enveloped benefits and other correspondence!!

Thinking back.. I needed a disabled bathroom and had been sent a Disabilities Facilities Grant Booklet. Pages and pages and I started to read through it... so much financial info on benefits etc. needed yet again on another form. It is hard to see in black and white how little you are now getting on benefits now unable to work. I got upset and threw the form across the room. About twenty minutes later my daughter came in and could see I had been crying and asked why? I was not going to tell her but she saw the corner of the large form/booklet and picked it up. She told me 'Social Services have just told me I am your official carer [news to me] so I will fill this in for you, in pencil, and I only want answers, no discussion.'

She started name, address, etc. and turned the page over and the next question was "Is this a benefice of an ecclesiastical estate?" What on earth is that? I explained that ecclesiastical related to a church.. I cant repeat her response.

On she went page after page and then she asked "Do you have an in valid carriage, what on earth is that?" I tried not to laugh as I responded that she had misread the word invalid as not valid and that it referred to a mobility vehicle. "They have not called them that for decades.. How old is this form?" The benefit for me was that now I saw what I must have looked and felt like when I opened the envelope and read the form. I made the following decision and have stuck to it ever since.



Every time I receive an envelope



see that I am not going to like reading the contents....



I get someone to read it and tell me which pages will annoy me the most



REST, PACING AND TIMING Grace R. Young, MA, OTR

Material Copyright © 1997 Grace R. Young

Fatigue and pain must be respected. Overuse to muscles is not always apparent while it is occurring. Muscle pain is a warning signal that the muscles have been overused. The damage accumulates over a period of time and may not become obvious until you lose the ability to do an activity which was previously possible.

REST

Try to rest at least one hour during the day. If you work and resting at lunchtime is not possible, take a one-hour rest immediately after work. This will make your evening activities more productive and enjoyable. Lie down to rest so your back doesn't have to support your body weight. Sitting takes 1/3 more energy than reclining. If you want to read use an overhead book holder so your hand and arm muscles won't stay tense. You can listen to music, practice visualization, or meditate; the point is to allow all the muscles in your body to relax.

PACING

Have you had days when you felt so good that you took on an ambitious project and kept pushing yourself so you wouldn't lose momentum? Were you incapacitated for a few days after that? It is tempting to overdo on your good days. However, you'll be more productive over-all if you plan your activities for a balanced lifestyle. Prolonged activities such as cleaning house or gardening, can leave you exhausted for the rest of the day unless you break them up into short segments with rest breaks in between. Before starting an extended activity, decide how long you will work at it and allow a 15-minute rest break every 30 minutes. Use a kitchen timer to let you know when to stop working and when to start up again. Alternate light and heavy tasks throughout the week. Split your ambitious projects into daily segments throughout the week, and stick to your plan no matter how good you feel on any particular day. Plan fewer activities for the days when evening activities are on the agenda.

TIMING

You may have different levels of pain and fatigue at various times of the day. Activities which are simple to perform in the morning may be difficult later in the day, or vice versa. For example, if cooking supper in the late afternoon is too stressful, prepare most of it in the morning, to be reheated later.

HOW CAN YOU JUDGE IF AN ACTIVITY IS TOO STRESSFUL?

The easiest sign is a feeling of fatigue while you are in the midst of the activity. This seems obvious but many of us do not pay attention to our body.

If the level of fatigue is out of proportion to the level of activity, the activity may be too stressful even if your mind says it should not be.

If there is a change in the quality of movement. For example, you develop a tremor or "jerkiness" in your motions while performing the activity.

If there is a change in the quantity of movement; that is, decreased range of motion. For example, you can usually lift your arm to a certain height but that height lessens as you continue the activity.

If you start to use compensatory movements. For example, you "hunch" your shoulder in order to raise your arm, or you swing your leg out to the side instead of flexing at the hip.

My young grandson called the other day to wish me a Happy Birthday. He asked me how old I was and I told him I was 62. He was quiet for a few minutes and then he asked, "Did you start at One?"

Two hairy caterpillars were sitting on a garden path having a chat when a butterfly flew past. One caterpillar said to the other one, "You'll never get me up in one of them."

Post-Polio News Daily is published early to late afternoon, GMT/UTC.

Post-Polio News RSS Feed Daily Digest is published at 23:00 hrs GMT/UTC.

The above editions, in addition to being notified on publication via Twitter, Facebook and LinkedIn are now announced on a new Post-Polio News Telegram channel:

<https://t.me/postpolionews>

For information on Telegram see <https://telegram.org/>

Chris Salter. Owner/Editor/Gopher/General Factotum.

Ultra-long-acting antivirals as chemical vaccines to prevent viral diseases | Future Microbiology.

[Received 4 October 2021; Accepted 6 May 2022; Published online 6 June 2022] [Ahead of Print]

Abstract.

For two centuries, vaccines have been successful in the fight against viruses, triggering immune protection. Indeed, the elimination of smallpox, the only infectious disease eradicated to date, was made possible through vaccination. For measles, polio and hepatitis B, vaccines are available but significant challenges exist for universal coverage. For other viruses, such as HIV and hepatitis C, vaccines have remained elusive.

Recent advances in medicinal chemistry have resulted in the production of antivirals that can extend activity for months. We envision the use of ultra-long-acting antivirals for the prevention of certain viral illnesses, halting either contagions or reactivations under immunosuppression. Such 'chemical vaccines' would fill an immediate need in providing protection when classic vaccines do not exist, responses are suboptimal, escape mutants emerge or immunity wanes.

Original Source Article: <https://www.futuremedicine.com/doi/10.2217/fmb-2021-0254>

Polio this week as of 8 June 2022 | GPEI | ReliefWeb.

[Source: [GPEI](#)] [Posted: 9 Jun 2022] [Originally Published: 9 Jun 2022] [Origin: [View original](#)]

Headlines.

- One case of circulating Vaccine Derived Poliovirus type 2 (cVDPV2) has been reported in Eritrea and the government has immediately declared detection of this strain to be a national public health emergency. See 'Eritrea' section below, for more information.

A new WHO report entitled, '[Role of the polio network in COVID-19 vaccine delivery and essential immunization: lessons learned for successful transition](#)' describes the contributions of the polio workforce to COVID-19 vaccine rollout and essential immunization, and makes the case to sustain the network through integration and transition, in order to strengthen immunization programmes, protect against outbreaks, and deliver essential health services to communities.

Join the United Nations Foundation from 15:00 – 16:30 UTC on June 16th for a special webinar to mark Day of the African Child. The webinar, titled [Preparing for a Polio Free World: Civil Society Contributions to Polio Integration and Transition Planning](#), will highlight the vital roles of polio eradication, transition and integration in supporting child health.

Rotarians from around the world are gathering this week in Houston, USA, for the annual Rotary International Convention. More than 1.2 million Rotary members around the world remain committed to the goal of polio eradication, raising awareness and critically-needed funds for the effort.

Summary of new polioviruses this week:

- ⇒ **Pakistan:** two WPV1 cases
- ⇒ **Djibouti:** two cVDPV2 positive environmental samples
- ⇒ **Egypt:** one cVDPV2 positive environmental sample
- ⇒ **Eritrea:** one cVDPV2 case
- ⇒ **Ghana:** two cVDPV2 positive environmental samples
- ⇒ **Madagascar:** four cVDPV1 cases
- ⇒ **Nigeria:** two cVDPV2 cases and five positive environmental samples
- ⇒ **Yemen:** 28 cVDPV2 cases

Original Source Article: <https://reliefweb.int/report/world/polio-week-8-june-2022>

Describing post-polio syndrome (PPS)| Neurología (English Edition).

[Open Access] [Accepted 5 March 2019, Available online 5 May 2021, Version of Record 4 June 2022]

Introduction.

Patients presenting [sequelae](#) of [poliomyelitis](#) may present new symptoms, known as PPS.

Objective.

To identify clinical and functional profile and epidemiological characteristics of patients presenting PPS.

Patients and methods.

We performed a retrospective study of 400 patients with poliomyelitis attended at the Institut Guttmann outpatient clinic, of whom 310 were diagnosed with PPS. We describe patients' epidemiological, clinical, and electromyographic variables and analyse the relationships between age of poliomyelitis onset and severity of the disease, and between sex, age of PPS onset, and the frequency of symptoms.

Results.

PPS was more frequent in women (57.7%). The mean age at symptom onset was 52.4 years, and was earlier in women. Age at primary infection > 2 years was not related to greater poliomyelitis severity. The frequency of symptoms was: pain in 85% of patients, loss of strength in 40%, fatigue in 65.5%, tiredness in 57.8%, cold intolerance in 20.2%, [dysphagia](#) in 11.7%, cognitive complaints in 9%, and depressive symptoms in 31.5%. Fatigue, tiredness, depression, and cognitive complaints were significantly more frequent in women. Fifty-nine percent of patients presented electromyographic findings suggestive of PPS.

Conclusions.

While the symptoms observed in our sample are similar to those reported in the literature, the frequencies observed are not. We believe that patients' clinical profile may be very diverse, giving more weight to such objective parameters as worsening of symptoms or appearance of weakness; analysis of biomarkers may bring us closer to an accurate diagnosis.

Original Source Article: <https://www.sciencedirect.com/science/article/pii/S2173580821000614?via%3Dihub>

Toni Writes ...

At a recent Polio Survivors Trustee meeting it was commented that we have received interesting queries via our website over the last few months. In the last year we have had queries from the UK and around the world regarding:

- * AFO & KAFO advice due to weakening legs
- * Are there any clinicians who are aware of polio survivor breathing issues?
- * Help in getting a diagnosis of Post Polio Syndrome
- * Knee replacement in polio affected leg
- * Pain management
- * Experiences of polio as a child
- * Prognosis regarding weakening legs and use of wheelchair
- * Help in educating health care professionals treating relatives who are polio survivors
- * Advice regarding anaesthetic and antiemetics
- * Neck vertebrae issues - could they be related to PPS?
- * Sleep problems
- * Is there any information on children of polio survivors having medical issues?

Maybe some of these themes resonate with you? Maybe you have some experience, tips or advice to share? As ever please feel free to drop me a line with your thoughts, or absolutely anything else on your mind. Take care

Toni

Email	psnadmin@poliosurvivorsnetwork.org.uk
Post	PO Box 954, Lincoln, LN5 5ER
Website	www.poliosurvivorsnetwork.org.uk
Phone	01522 888601

P.S. Hilary just took a call from Portugal seeking information on UK and USA post-polio knowledgeable health professionals they might consult on a visit to either country.

Westpoint, Exeter

Saturday 23 July

Yorkshire Event Centre, Harrogate

Saturday 13 August

Royal Highland Centre, Edinburgh

Saturday 17 September



Motability

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<https://motabilityonebigday.co.uk>

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- Powered wheelchairs and scooters

Specialist advice from

- Motability Scheme Advisors
- Adaptation specialists
- Wheelchair Accessible Vehicles specialists
- Kwikfit
- RAC
- RSA Motability
- Disabled Motoring UK
- Driving Mobility

JAMES (age 4) was listening to a Bible story.

His dad read: 'The man named Lot was warned to take his wife and flee out of the city but his wife looked back and was turned to salt.'

Concerned, James asked: 'What happened to the flea?'

'Dear Lord,' the minister began, with arms extended toward heaven and a rapturous look on his upturned face, 'without you, we are but dust....' He would have continued but at that moment my very obedient daughter who was listening leaned over to me and asked quite audibly in her shrill little four year old girl voice, 'Mom, what is butt dust?'

Two men were approaching each other on a sidewalk. Both are dragging their right foot as they walk. As they meet, one man looks at the other knowingly, points at his foot and says "Polio 1950". The other hooks his thumb behind him and says "Dog Poop, 30 feet back."



If only you could buy these trailers.

Richard and I were at Discovery Cove in Florida in 2004 on our electric wheels when we passed this couple. We had to ask them about this brilliant idea.

His wife said that she got so fed up with not being able to keep up with him that she jokingly asked for a trailer. Her husband decided to make something and told us that this one is version 3.

I can see our Carers asking us to make one for Richards wheelchair.

[The LincPin Volume 4, Issue 5, August 2003](#)

Management Committee [Trustees]

Chair - Simon Parritt - simon.parritt@poliosurvivorsnetwork.org.uk
Secretary, Zsuzsanna Snarey - zsuzsanna.snarey@poliosurvivorsnetwork.org.uk
Treasurer, Newsletter Editor - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk
Trustee - Verité Reily-Collins - verite.reilycollins@poliosurvivorsnetwork.org.uk

Trustee/s - Vacancies please contact Toni for more information

Operations Team

Phone Enquiries - Hilary Boone - **01522 888601**
PSN Admin, Enquiries and Website - Toni Dunlop - 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

Write to us at PO Box 954, Lincoln, LN5 5ER, U.K.

Email psnadmin@poliosurvivorsnetwork.org.uk

Phone us on 01522 888601 - will ring you back when we access 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



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

Printed copies on our headed paper with permission are available.

Editors Note: Articles from Polio Survivors and Health Professionals welcomed

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Baroness Tanni Grey-Thompson - 14.00 to 14.30

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<https://www.accessable.co.uk/the-nec>

Richard and Hilary will be at the NEC from about Noon on the 6th July 2022

to about 2pm on the 7th July.

Let us know if you are going to be there so we can say 'Hi'



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