POST POLIO MATTERS

Polio Survivors Network Newsletter
October 2023 — Volume 11 Issue 3 of 12 [123]

WE'RE STILL HERE! WEEK — October 8th to 14th 2023






LIVES LIVED WITH HEALTHCARE LESSONS FOR THE FUTURE









HEALTH PROFESSIONALS - How we can help you?

POLIO SURVIVORS are a NIGHTMARE

PART THREE

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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Donations and Charity Incentives Paid

(since last newsletter)

Donation from VG	200.00
Donation from FM	12.50
PayPal Giving Fund	60.00
Total	**£272.50**

PayPal

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

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

Thank you so much!

Editorial by Hilary Boone

Polio Survivors are a nightmare - Part III

Well guys and gals I thought as polio survivors we can be a nightmare for health professionals in areas that have little knowledge of polio it its first instance and also post-polio syndrome. I wonder how many people with other conditions are also experiencing similar situations?

I/We, members and colleagues are contacting each other to discuss the fact that we are now receiving a far less than adequate health service compared with what we used to receive pre-Covid. Pre-Covid we might have had to wait months but we would get face to face appointments. We would receive an examination with time to discuss a few points. We would be referred for tests or to see other health professionals. There were long delays and many of us struggled to see health professionals that had enough knowledge and understanding of our PPS issues but we eventually did get to see someone.

Having experienced face to face assessments over many years at the Rehabilitation Department I wonder how it is that a new doctor who has never seen me before is going to assess me by a video call next month? Phone/Video Call Appointments. How many of you have experienced these? Have any of you been sent a format of the appointment to complete so you can prepare answers to questions and if you need to demonstrate a new issue how you can do this? Please share with us anything that you think would help more members.

We can have every other condition as well as PPS and many of us do. Our Trustee Verite Reilly-Collins [a polio and cancer survivor] runs aftercancers.com which contains a lot of helpful information and many a smile over her comments about some politicians remarks. I am sure many readers also belong to other charities/organisations seeking help for their issues. If you are getting good support from another charity we would love to add this information to a database?

However, are we more than just an NHS number with coded medical conditions? If we have never met or been examined by the health professional on the phone/video call how do we ensure that we provide enough information to get the best advice/treatment? How much more difficult is this when the condition under review is not related to a polio/post-polio issue but the fact that we are a polio survivor and having to manage our life a certain way is very relevant? I wonder how many of our members – and other polio survivors have or are already experiencing issues that are not being realised as important information needed by the new department health professional for their assessments/treatment regimes.

You receive another diagnosis and hopefully are given information or advised where to go get more information. You read down the list of possible issues and see the word fatigue but until this week I had not wondered if this fatigue would run alongside my PPS fatigue or add to that level? My PPS fatigue starting nearly 28 years ago. I made a list of symptoms from each condition. It was a long list and not easy seeing it in black and white. I was surprised how many symptoms listed were in both conditions.

The management of PPS is by pacing and resting actions and using aids/assistive devices and physical help which I have been doing for a couple of decades. I have gradually added in using more aids, asking for help for part of the tasks, employing Carers to take over some of the tasks. All I needed to do was expand on this and I would manage. Now I find that the percentage of my PPS fatigue before this new condition was added was about 60%. Then I realised since adding another condition over the last eight months how much more help I had been given by our Carers and it was about another 20%. If I did not realise this how would my new health professional understand unless I explained it to them.

Using Aids and Assistive Devices

With PPS we use many different aids and assistive devices but this will mean that we do actions of daily living a different way from the norm. Having met so many polio Survivors over the years I have seen some amazing methods of performing actions of daily living. I got a picture in my mind as I typed this of a colour co-ordinated outfit, electric wheelchair user Linda Donahue at a PPS conference. We started to discuss how do you get in and out of your wheels or up and down off an electric scooter. Linda smiled back and said ‘Well I cannot call it walking but I can get from my chair to the table to get another dessert and back again.’ I could have phrased it better but I said “Really?”. Laughing Linda got up and bent forward took a few lurching actions to the table and back again with another dessert. I was amazed and those that know me won’t be surprised to hear that I told her I had seen a duck with one leg do better than that which caused even more laughter.

For some years my spinal curve has increased and currently when I stand I am leaning right over almost looking down at the floor. Until my fall in July 2022 I managed with a walker in the home and my electric scooter when out. Now I have to use an old second hand electric wheelchair and hope it wont be too many more weeks before Wheelchair Services deliver the one I was assessed for last year. How many of you attending appointments on electric wheels have been asked if this impacts on how you do actions of daily living that might be relevant to your new condition?

Aging as a Polio Survivor

I am sure that many readers will agree that aging as a Polio Survivor is not easy and not what we expected and adding in one or more new conditions makes it even harder. Before this sounds all downhill…..

Polio Survivors in our past pre PPS issues are renowned to be so strong willed and determined to succeed, do not need any help type folks. Do not tell us we cannot because we will find a way to prove you wrong. Members - we would love to hear how you achieved things that were never expected of you from qualifications right through to having a family.

Many years ago I met Irish Polio Survivor Jim Costello who contracted polio at the age of 15 at a rugby match. He spent a great deal of his life in an iron lung in Cherry Orchard Hospital and even talked to me one night whilst in it operating the phone with his feet. As successful business man he was able to walk round the Conference but had to have someone with him to be his arms. Amazing man who was instrumental in much of the work of the Post Polio Support Group (now Polio Survivors Ireland), the organisation he helped to found. What are the most important things you achieved?

Counselling how it can help

I booked a counselling session and I was able to – for the first time this year – go through all the different problems that I/we had or were being forced on either/both of us by other agencies/people. I never stopped talking for over half an hour and it really helped just to get it all out there. When you are a Carer to another disabled person, or maybe you live alone, you cannot always do this. Then I was helped to put all this into perspective. What was really important to deal with now and what could be left until later? Who and what did I think could help me put this into practice? I had desperately been trying to keep my ‘Leaning Tower of Pisa’ issues upright and the strain was overwhelming me. Now the blocks were neatly laid along the ground and it would be up to me how and when I rebuild my tower.

Post Polio Syndrome Day 22 October 2023

This year more buildings than ever will be illuminated in the

British Polio Fellowship charity colours to mark Post Polio Syndrome Day.

Want to get involved?

Contact the BPF Marketing and Campaigns Manager on
01923 281 091

www.awarenessdays.com/awareness-days-calendar/post-polio-syndrome-day-2023/

Polio Survivors Network @NetworkPolio · 1m

Congratulations to Mick from Polio Survivors Network #poliosurvivors #postpolioadvocacy #polio #postpoliosyndrome

British Polio @Britishpolio · Sep 27

We are delighted to welcome a new trustee to the @BritishPolio Fellowship! 👋
Mick Harper joins the Board. Voted in by members, Mick has a wealth of experience in his current roles as Chair of the Lincolnshire Branch and Chair of the East Midlands Region. #polio

Toni Writes …

Thank you so much for responding to our 'lives lived with healthcare lessons for the future' project which hopes to capture the experience of as many polio survivors as possible. You will spot many experiences in this edition of Post Polio Matters.

We know how invaluable it is to read about the experiences of others in similar situations to us, we can learn new ideas, empathise, avoid pitfalls and be forewarned. So we are asking if you haven't already done so please could you think about sharing some of your experiences. We can't wait to hear your story. We are also happy for them to be anonymous. It can be as long or short as you prefer (one or two pages makes for easy reading) and can include whatever aspects of your life you wish to focus on (your recollection of having polio, your life after polio, things that you have learned which are unique to polio survivors, warnings for future generations, etc).

Send your story by:
Email to info@poliosurvivorsnetwork.org.uk
Video file upload to https://bit.ly/3D8MQKQ
Audio only file upload to https://bit.ly/3D8MQKQ
Phone me on 07480 110334 and we can arrange an appointment for me to type up your story as you talk
Writing to us at Polio Survivors Network, PO Box 954, Lincoln, LN5 5ER
We can even organise a **Zoom** chat where I can record your story (audio or video) and I don't have to be in the virtual room with you if you'd prefer

By providing your experience to Polio Survivors Network you consent to it being shared in our newsletters, on our website and in our digital library – this consent can be withdrawn anytime by contacting us.

Take care
Toni

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

From Our Readers:

Important service which offers good advice to those of us living with PPD, very best wishes.

Thanks for sending me the newsletter which I have enjoyed reading.

Thanks for the newsletter, it was very interesting and I recognise many of the issues discussed. I noticed getting up from the floor was mentioned, this was a major problem for me and I have found that an electric bath chair solves my problem. They are flat when in the down position, easy for my wife to move to me wherever I fall (even in the garden) and is battery opened (rechargeable). My wife gets it, I move onto it, it's only a few inches high in the down position then my wife operates it, keeping the button pushed until it's fully up. In the up position it's like being on a chair and therefore much easier to standup from. I bought it from Amazon for about £300. Anyway I thought I share this with you.

Can you help? I caught Polio in 1945/1946 ,which paralysed me from the waist down. I was admitted to Cuddington Isolation Hospital in October 1946 and discharged 6/7 weeks later. I do remember being in a very long ward with a lot of other young people some in iron lungs; I was lucky as I had a cloche over my lower body. I am struggling to find my old health records after emailing and telephoning many NHS departments. Any advice would be much appreciated.

My Experience

by Zsuzsanna Snarey, PSN Trustee

I was eight years old when I was diagnosed with polio in Hungary. After our failed attempt at escaping to the west I was in an orphanage where I caught the polio virus while my mother was in prison. When she was released, she set about rehabilitating me with a daily regime of exercises. It took a year before I was able to take a few steps with elbow crutches but eventually I was able to attend school.

When I was 14, I had a muscle transplant on my right foot and the following year my left ankle was fixed because it was completely paralysed. I was still in plaster when the Hungarian revolution broke out and we took our chance to leave Hungary.

Once in England I had some physiotherapy in hospital and started school. After passing A levels I went to study Chemistry and met my husband. We married and I worked in research for three years. I was able to walk with one stick but only needed it outside.

When my first daughter was born, and I had no trouble carrying her. Two years later I gave birth to her sister. At the age of 30 I was at the peak of my abilities. My third daughter was born 8 years later. I was a part time science teacher and carried on teaching for 26 years, carrying heavy books, standing in classrooms, and walking without a stick.

I was not ready to retire at 60, so I trained as a chiropodist and left teaching. At first, I was visiting patients as well as looking after them in my surgery, but gradually, I found carrying my heavy case even though it was on wheels difficult. I could work more efficiently from home. But sitting most of the day took its toll. In the beginning I would greet people as they arrived, then I left the front door open with a notice to invite them in, which meant that I did not even have to get up between patients.

I hardly noticed the deterioration over the next sixteen years as a chiropodist although I had to have first one then two callipers to stop the hyperextension of my knees. I gave up work when we moved to be near our grandchildren and now, I use two sticks indoors and an electric mobility scooter outdoors.

I can still drive my Motability car, but I have gradually lost the ability to use the stairs since I had a stairlift for the past thirteen years. Muscle loss is part of getting old and I am finding it more difficult even to stand up and to walk. My balance is very bad, and I fall easily. I have a small hairdresser’s stool on wheels in the kitchen which allows me to carry heavy pans with two hands, and to hoover and wash the floor. We have smooth floors downstairs so I can move easily. I have a stool in the shower which I take with me when visiting friends.

I shall be 82 next week and so I should be content with my life so far. I don’t know what the future will bring but I shall cope with it.

MESSAGE FROM OUR CHAIR

Busy Times . . .

As many of you know living with PPS and aging with other issues isn’t exactly a walk in the park. Recently I have been dealing with treatment for high risk prostate cancer and being asked if I wanted to stop as it might be worsening or accelerating my PPS symptoms - or is it at 73 just the PPS muscle loss? No one knows which it is, so it is up to me to choose what to do!

Also I have been trying to sort a new NHS wheelchair whilst our 17 year old dog, Pumpkin, now needs more care support from my wife, Alexa than me. Oh and not to mention our animals, 3 birds, a cat and another 3 year old dog!

So please excuse my lack of contribution to the last two issues. I am working on an article about my first months of polio and hopefully it will be in your next issue. Until then I wish you all well and hope we can find both comfort and community in sharing our life experiences as polio survivors.

Simon Parritt, C.Psychol, AFBPsS, MSc, BSc (Hon), BA
Chartered Psychologist, HCPC Registered Counselling Psychologist & Chair of Polio Survivors Network

Thank heavens I caught polio in the '50s!

by Verite Reily-Collins, a PSN Trustee, Health Journalist and owner of aftercancers.com

If I had caught it today, I can't imagine the current NHS being able to cope! Today's superior graduate nurses wouldn't be able to cope with the high level of care we needed around the clock.

In the '50s, the NHS really was 'the envy of the world'. Every Friday my surgeon, J.I.P. Janes, would sweep down on his ward round, heading up a swarm of foreign medics come to observe (and pay) to learn from Stanmore National Orthopaedic Hospital. Today, the only NHS hospital where I come across overseas doctors here to learn from the NHS is the Royal Brompton Hospital.

Recently, I had a long stint in our local hospital, the 1,000-bed John Radcliffe. A dirty injection needle into my eye had made me blind. Looked after by trainee nurses from Oxford Brookes, I was interested to see how today's nurses performed. At the start, they impressed me with their competence taking my blood pressure - every four hours they would wheel in a machine and plug it in - all going very smoothly - then read off the figures produced.

Then things started to unravel, the readings suddenly went sky high and I was alarmed - the nurses hadn't a clue what this meant and weren't about to do anything to discover what these showed. Today’s nurses aren't expected to be curious, and I began to understand how the lack of curiosity enables scandals like the Lucy Letsby case, and many others, go undetected for so long.

Eventually, it was an Agency nurse who let the cat out of the bag; apparently, the Ward sister in charge of drugs had forgotten to order blood pressure tablets, and others on the ward had the same symptoms - but I was the only one who queried readings.

I remember the cheerful way the nurses at Stanmore coped with our problems, however basic. Catching another hospital bug this time I threw up all over the floor. My bell summoned a nurse, who gave a horrified scream and told me "You've dirtied the floor. I need to call a cleaner to clean it up”. Had no-one told her nurses have to deal with life's basic problems, however gross?

Doctoring today is by remote control. The nurse takes a photo of you, sends it to the doctors, and back comes their diagnosis. This was taken to the limits when one Friday Dr. Joel (it's all First names in today's NHS) actually appeared in my room, saying he had come to take some blood tests. He wasn't much good and gave up, saying he would be back on Monday.

Monday produced a cheerful Dr. Leo, who popped in to give me the good news that my blood test results were fine and was rather put out when I queried his diagnosis. Off he disappeared, never to be seen again - this was the norm in my ward; ask a nurse a question, and off she would go to some distant hidey-hole lost forever.

|One does wonder why some nurses bother to go into the profession today. When I was admitted to the ward, I was delighted to be shown into a single room (being highly contagious had its benefits). I waited for the Ward Sister to come and 'welcome' me - but no one came. After a while, it became obvious that infection control training was sadly lacking in those supposedly looking after me, so I fumbled my way down the corridor to find Sister's office.

Once there, a voice identified itself as a Sister, so I started - only to be stopped by the voice saying "but I don't talk to patients".

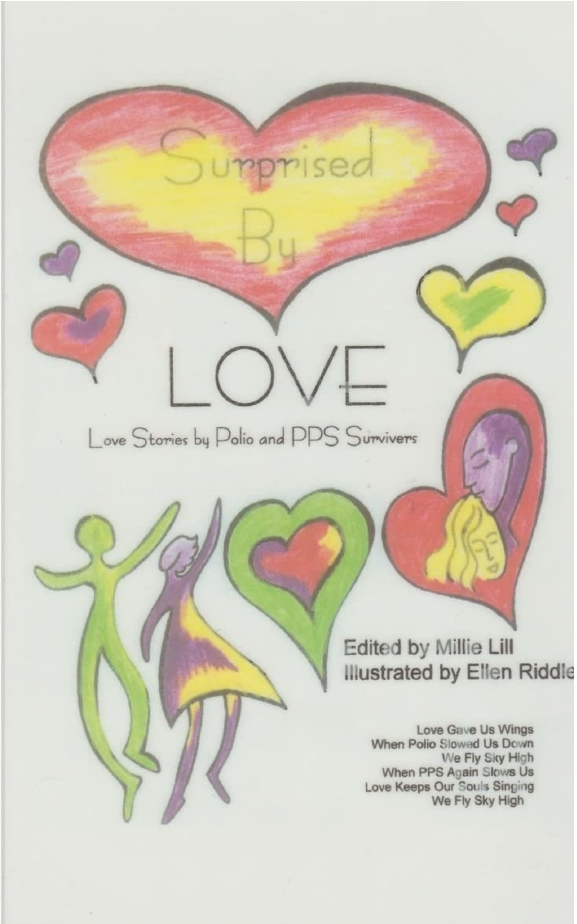
Sadly, it seems doctoring by remote control is going to be the norm in today's NHS. Although warned by the Ophthalmology Dept that I was allergic to Preservatives, backed up by me when admitted (but who takes note of patients?) the dreaded Ward Sister in charge of drugs had ordered the cheaper version of the antibiotics prescribed for me. Yes, you've guessed it - full of preservatives. I wake up one morning with a face aflame and burning itching skin all over my body.

Nurse sends over a photo of some of the rash - but no doctor appears. Eventually back comes a message to say the photo showed my 'rash' was only a bruise! The Dermatology Dept. did send down some cream for me to use, which promptly got lost because Ward Sister didn't write this down in the drugs book.

So, I self-prescribed and got my brother to buy some La Roche Posay products, which did the trick. I have booked a follow-up appointment at Guys Hospital in London, via the NHS Patient Choice scheme. It will cost the NHS as I will also need hospital transport, but this might make the hospital look more carefully at its procedures. Oh for the days of the caring nurse - I was very lucky they were around when I was being treated for polio.

I am NOT having a go at the majority of today's nurses who look after me beautifully. Just moaning at the way nurse training is becoming dependent on 'remote control doctoring'.

Verite Reily Collins veritegreenbee@gmail.com www.aftercancers.com



Surprised By Love: Love Stories by Polio and PPS Survivors

Edited by Millie Lill
Illustrated by Ellen Riddle

Stories from polio survivors on how they encountered unexpected love.

Available at: www.amazon.co.uk/Surprised-Love-Stories-Polio-Survivors/dp/1718964382

My Experience – Sylvia

My name is Sylvia. I was born in 1948 and contracted Polio in 1950/51. I was living on the Isle of Wight and, I believe, along with my slightly older brother, one of the very first people on the island to catch polio. I lost the use of one of my legs. After a spell in the isolation hospital, I recovered and certainly within my childhood memory was symptom free.

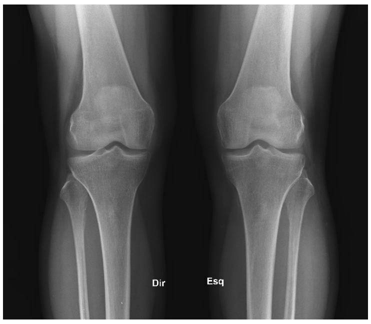
I went on to be a keen tennis player for over 19 years, playing daily during the Summer and several times weekly on hard courts during the winter, until at about the age of 42 I noticed that my legs were changing. My right calf was diminishing noticeably, although was still strong enough to support me.

Eventually I could no longer reliably run in all the directions required for tennis and I gave up. I then joined a golf club and played 18 holes regularly, usually three times a week until I no longer had the stamina to walk the course and so five years ago, I gave up golf. I then started playing lawn bowls two or three times a week and short mat bowls during the winter.

Over the last few years my "weak" leg has felt less reliable and I've been using a walking stick when out and about and this year find I now must use it when playing lawn bowls. Similarly, over the last few years I have felt unsteady with sometimes a loss of balance. I cannot walk far without considerable pain, although I'm not sure whether this is because of the late effects of polio or other problems with my spine for which I take prescribed pain medication.

To sum up, everything from my strength to my eyesight, endurance and energy seem to be reduced. I have recently purchased a mobility scooter with which I can go a bit further afield - in fact have just returned from Austria where I was able to explore, amongst other sights, those of Vienna and Salzburg. Thanks to coach travel company B D for transporting my mobility scooter and making this possible. My brother was a year or two ahead of me in his debilitation and requiring a mobility scooter and stair lift (so far I'm still managing with the banister).

I hope to soon have an appointment with an NHS neurologist, interested in PPS, as I would so love to know what I may attribute to PPS and what the future may be expected perhaps to bring. I wonder if any of my experiences will strike a chord with others.



John Hopkinson Experience

In 1958, at age 11, there was suddenly a steep downturn in my mental and physical ability. There was no obvious reason why that happened. My parents thought that the simultaneous pains were probably "growing pains" as the only real pain I had was severe cramps in my legs, particularly the left one.

My parents were the type who would stop at nothing to find out what was wrong. They had nearly lost my sister to illness during the war and were determined not to go through the same concerns with me. However nothing was diagnosed, the pains eventually eased after a couple of years and my school work and physical activity gradually improved, although I played rugby rather than my first love football as I was somewhat slower running and I had developed a slight limp. My school work was not as good as it should have been with particular problems at exam times. Previously I had been very good at this although I say it myself!

Generally speaking, despite several health problems, I managed quite well until after university and starting work, I began falling especially when walking over uneven ground. When my left leg started aching again, I was advised to see a specialist who had, by chance, considerable experience with polio both at home and abroad and, after examining me, came to the conclusion that I must have had polio some forty years or more earlier, at the time when the leg pains started at age eleven.

I was advised to wear an orthotic leg brace and other supports which I did for several years. When my left knee was replaced, my surgeon said that in the process, he would be able to lengthen my left leg which subsequently allowed me to stop using the brace and improved my mobility but the aches and pains continued because of what I now realise was PPS.

There was, and still are, constant mobility problems. However, I think myself extremely fortunate to have survived sixty five years without many of the considerable challenges that most polio sufferers have had to bear. In recent years, I have suffered from sepsis and a mild stroke and recently have had a shunt fitted on my brain as treatment for hydrocephalus. I mention these last three complaints only because my non-medical training makes me wonder if they, in any way could have been promoted by my earlier polio. Has my central nervous system suffered because of polio? Perhaps other PPS sufferers might have a view on this. Nevertheless, I consider myself extremely fortunate in that polio did not have more serious implications for me.

I enjoy being a member of the Lincolnshire branch of the British Polio Fellowship too, despite not having been to meetings recently as my recent operation means I can't drive for a while. The secretary is very good at keeping me informed.

Mike Locke’s Experience

Written on the eve of my 69th birthday, this is the story of how polio has affected my life.

It was my sister’s birthday, July 28th, but there was no party on that day in 1955 because I was being taken to St George’s Hospital, Tooting, suffering from polio.

I spent several months in St George’s and I have a vivid memory of the day I left, walking down the long corridors with my mother holding my hand. Every time I took a step with my weakened left leg, the knee gave way and I performed a little genuflection. My mother was crying.

I went back to school and got on with life, with the recommendation that I ride a tricycle to strengthen the affected muscles and have a lift built into my shoe to prevent my left foot from turning inwards. I was collected once a week by ambulance from school and taken to St George’s for physiotherapy.

For the rest of my school life, I was the kid with a limp. I walked, cycled, played football and cricket. I was not spared the hell of the cross-country run. On my journey home from school, I would often pick out a pedestrian some way in front of me and make every effort to walk fast enough to overtake them before reaching my house. This “I’ve had polio but so what” carried on into teenage years and into the world of work. I remember one manager asking me if I would register as disabled (so he could meet his quota); I refused indignantly.

Then followed marriage and parenthood. The lift on my shoe was replaced by a cork insole. I hit 30 then 40 then 50. I could walk 15 miles. I climbed Pen-y-Ghent. I walked a mile or two every lunchtime. I took up cycling again and duelled with the Range Rovers in the lanes of Surrey. This activity continued with cycling holidays in Holland (flat) and France (not flat).

Between 2000 and 2004 I completed a part-time degree course, rushing around London and hopping on and off trains and Tubes. We went on group walking holidays, which proved to be disastrous as I could not keep up with the rest. A friend recommended a podiatrist, who scorned my NHS cork insoles and had a pair made (not just the left foot) from hard plastic, which was agony until my feet adjusted to the new shape.

At about the age of 58, I began to find walking an effort. No longer was I overtaking pedestrians. My daily walk to the station went from 10 minutes to twelve to fifteen. It was as if I were willing my legs to move but they could only respond sluggishly. The lunchtime walks came to an end. The bike went in the shed.

I took redundancy/retirement at 60. The bike came out of the shed and was overhauled. I joined a gym and worked ferociously at the treadmill, rowing machine and exercise bicycle. That was perhaps unwise, as I could not stop myself going flat out – something not recommended for post-polio muscles. About this time, my ‘good’ right foot displayed an alarming tendency to collapse to the right, throwing me off balance and landing me more than once in the gutter. I had some new insoles made and started using a walking stick. I joined the BPF. The bike went back in the shed until I gave it to one of my sons.

With help from the BPF, a pain in my knee, which I mistakenly took to be polio-related, led to an appointment with a post-polio specialist at Kings College Hospital. I learnt that there wasn’t much to be done, and that my right foot had also been affected by polio to some degree. I was referred to a rehab centre where I was fitted for an ankle-foot orthosis (AFO) for the left leg and a re-modelled insole for the right foot. For 55 years, I had been walking with my left leg straight and the knee locked rigid; the AFO forced me into a more normal gait.

About 18 months ago, I became aware that my left quadriceps had become weak. It meant I could not use alternate legs when climbing stairs, not without hauling myself up on the banisters when it was my left leg's turn to do the pushing. A physiotherapist recommended some exercises but it has not been possible to regain strength in that muscle.

Most of my cars have been manual and I've been able to work the clutch, though my left foot becomes tired after repeated gear changes in heavy traffic. However, in the last month or so, I have had difficulty pressing the clutch all the way to the floor in any circumstances, resulting in some expensive-sounding grinding noises.

I can walk a mile or so, with regular rest stops to give my legs a chance to recover. Luckily my town is quite well provided with benches. I am well-known to local bus drivers, but my visits to London are rare these days. That's partly due to the fact that step-free access is still some way off and partly because I've got out of the habit of being in crowds.

I fell down some steps during a French walking holiday in 2005, and this has made me very wary of descending stairs, for fear my left leg will give way and propel me forward – and downwards. If nobody's looking, I often undertake part of the descent on my bottom. I dread leaving aeroplanes via steps, but even using BA is no guarantee of an air bridge.

Where does that leave me, at 69 with PPS? I am mentally alert, can get about at my own pace, can drive (though may need an automatic). I can't walk in a group, cycle, run up and down stairs, or swim. My mobility has worsened over the past 10 years. I have no idea what the next ten years holds, but I will deal with it, with the help of friends and family.

My Experience by Maureen Chapman

Hi, my name is Maureen l am a polio survivor. I contracted polio in the early 1950s - in them days doctors were very wary of telling the patient or their parents what they had / diagnosed with. I can remember as a small child of 3 years of age being in hospital for long spells that seem to go on for years in and out of hospitals all the time. Eventually from the age of about 8 they discharged me and told my parents what l had been suffering from - l carried on with my life as a child doing what children do but l always walked with a limp which was noticeable to other children and adults.

Post Polio Syndrome became a problem to me in my early 40s when l started to fall or trip over for no reason - after watching a documentary on TV about the latter stages of a Polio Survivor l realised that it was me. After visiting my GP, she arranged for me to have an assessment with a consultant at Kings College Hospital in London who diagnosed PPS.

I will now jump to my current daily life and how it has affected me now. At the age of 74 l have so many problems which l have to come to terms with. My right foot / ankle / leg has completely deformed, and l walk over on one side - my weight has increased as not being able to walk without pain and aids - swallowing is also a major problem where l choke on food / fluids if not chewed or swallowed completely.

Twice yearly l have steroids injections in my feet and ankle but my Consultant recommended that l have surgery as my foot is now bone on bone. With arthritis in both feet now on top the disability l have, life is not as it should be in my retirement years. My medication is Gabapentin 500mg x 4 times daily, Co-codamol every 4 hours for the pain, plus various sprays / roll ons / ointment / on feet to relieve the pain.

My Polio Story

by Dianah King

I was born in 1942 and when I was 4 I contracted polio the day after visiting Redcar beach. I was admitted to the isolation hospital in Darlington where I spent a week in an iron lung and was then transferred to the Adela Shaw Orthopaedic hospital in Kirkbymoorside in North Yorkshire where I spent a number of years having treatment. I was discharged wearing a caliper on my right leg.

At the age of 7 I was readmitted to have 2 operations to my leg and I believe the surgery was related to my Achilles tendon. At 14 I had a further 2 operations for the same thing. My right foot is 2 sizes smaller than my left and an inch shorter. 20 years ago I started wearing an AFO (ankle foot orthoses) on my right leg and a built up shoe.

I have never let my polio hold me back and have lived a normal life enjoying riding a bike, a horse and even abseiling!! I married at the age of 23 after working in London as a Nanny for a number of years. I was married for 53 years until I lost my husband just before the pandemic. I have one son however I would have loved to have more however I do believe that the polio was a factor in why this did not happen as my body is twisted.

As the years have passed I have noticed symptoms that I associate with post polio including reduced mobility and balance issues. I had an operation on my neck in 2013 which gave me back my mobility. I continue to have symptoms however I am still mobile even if I have to use a stick sometimes. I had a steroid injection in June which was fabulous and has given me several weeks pain free.

I have always lived a full life being involved in many charities including WRVS for 32 years, setting up the Alzheimer's day centre in Richmond (North Yorkshire) and being a school governor. I am rarely at home as I am either lace making, sewing, lunching or talking. I am also lucky to spend time with my extended family.

me with my family on the beach the day before I contracted polio.

I am the girl with the dark hair and plaits sat on my Granny's knee.

me with my caliper and my younger sister.

me today

fabulous at 80

(nearly 81) !!

Neill Jupp's Experience

My name is Neill Jupp and am 75 years of age and a Polio Survivor who caught Polio at the age of 3. The main part of my body that got the Polio was my right side from the right arm to my foot which was described as a club foot very misshapen and no muscle at all.

I spent most of my early years in an isolation hospital in Newhaven Sussex where my parents looked through the window from outside not being allowed anywhere near me. Most of my hospital stays were in Chailey Heritage a craft school in Sussex in the middle of nowhere making it difficult to visit as the bus service was very poor. How my mother got to visit me I will never know as she never talked about my early years as she seemed to blame herself.

Life in Chailey was difficult to say the least the regime was harsh you had to watch your back at all times as you could and would get a beating for just being in the wrong place at the wrong time.

My medical side was lots of procedures and 2 operations which have lasted for 66 years but are now worn out and no replacement in sight as nobody nowadays knows much about polio due to all the old surgeons being retired or dead, so polios get pushed out because nobody seem s to care or understand the pain you are now in.

My treatment over the last 40 years has been hit and miss some doctors will take you on then either move on or retire just as you are getting them to understand your needs very frustrating.

My life now is that I am back to walking sticks as the pain in my leg is so bad that a stick takes the pressure off my joints. The only exercise I can manage is swimming as it is non weight bearing so my joints can relax for 30 minutes. You have to keep positive and not let it beat you but I take lots of breaks so that I am not tiring myself out plenty of fresh air on the seafront sitting on a bench and enjoying the view also is good for you.

Neena Bhandari is a Sydney-based foreign correspondent and freelance journalist. Neena has a special interest in Post Polio Syndrome. She has written for the British Medical Journal and is a frequent speaker on Poliomyelitis at various international forums.

Neena has recently launched Post Polio – India, which aims to be an umbrella website for polio survivors and their families, health professionals, researchers and organisations to connect and share experiences and expertise.

https://neenabhandari.com/what-clinicians-need-to-know-when-treating-polio-survivors/

https://neenabhandari.com/why-polio-survivors-may-benefit-from-a-lung-function-test/

https://neenabhandari.com/polio-never-far-away-in-the-jet-age/

https://neenabhandari.com/the-phases-of-polio-past-present-and-future/

My Experience

By Eddie Clark

As a seven year old just nearing the end of going to infant school in Lincoln during 1957, the energies in life were endless. It must have been the final half term in April, there it was me and my friend climbing on play equipment in the local park without a care in the world, when it all started. There was me feeling very unwell. I remember the pain in my body was getting worse, so I returned home as fast as I could knowing the one person would be there for me, my Mum. With Dad at work, my twin brother out with his mates and sis as I called her then, was helping Mum in the kitchen. Mum, without hesitation seeing my condition getting no better, ask sis to stay with me whilst Mum rushed to the neighbours four doors down in our row of terraced houses to ask if she could use their telephone. With the nearest public telephone box at the post office 10 minutes away, it was a bonus, mums very seldom worked in those days as our kind neighbour answered the door and let Mum phone the doctor. On his arrival, with me on the settee stretched out, his diagnosis was swift.

He and Mum went down to the neighbour again who by this time was waiting with the passage front door open ready and concerned for them to return. A short while later the cream coloured ambulance with its bell ringing so loud came to the excitement of most of the neighbours in the street who all came out to watch while I was carried out on a stretcher to be placed in the back of the ambulance. On arrival at St George's Hospital Lincoln the Dr immediately put me in isolation in a glass cubicle with others either side. Being so young I had no idea what was going on as I was unable to move. Laying there paralysed, the nurse came in, gowned up to and said " o dear I feel it best if we changed your sheets" I'd lost all lower body feeling and control.

I remember being transferred to a room with a big box iron lung and laying there so must have had difficulty breathing at some time as Mum confirmed in later years on revisits to St George's. After a time I was transferred to a ward where children laid in bed. I recall drinking from a teapot lying flat on the bed stretching out my left arm. Mum, aunts, crying, wiping tears from their eyes, uncles looking on, all unable to verbally ask anything through the glass observation area. Over time and treatment St George's Hospital transferred me to the County Hospital in Lincoln as I regained movement slowly in the recovery children's ward.

My whole life of hard work eventually started to show areas of weakness in my late 50's. I thought its time to start having words with the Dr. Sleep apnoea was ruled out after tests. After the hospital test I had a word with the Dr who was a polio specialist. Enquiring he commented there are possible signs of PPS. I carried on with work until I felt a four day was needed so I could recover over a long weekend.

Going to see the local Dr in 1963 and asked the question again about PPS, not a chance she said, I've had no case of that in my working career but I'll get you to see a neurologist to check it out. I had to travelled to Nottingham for test only to find the young neurologist just making snide remarks of how mild my condition was at 70 years old, how I'm looking for answers nobody seems to know much about. No dedicated person at The County Hospital, my local Dr has no time to listen, even with EMG carried out by the neurologist assistant and when neurologist turned up briefly, he was constantly interrupted by a trainee neurologist.

My life goes on at the age of 73, and thankful to wake up with a pulse and plan my day around my condition now. Plan B kicks in lots of the time, with planning and adjustment it keeps my independence ticking over. With the help of my power chair this gives me a way of being able to make the days routine more comfortable, happy days.

76 and Still Adapting

by Marion D Rushing III

What a coincidence, I had just returned from a visit with the neurologist when I opened the email from Toni Dunlop asking for my polio story. I'm more than happy to share with others who have also dealt with polio, the disease that keeps on giving.

I'm 76 and had polio when I was 18 months old. That was 1949 and there was a big epidemic here in the states. I was lucky in that my grandfather was a physician. I was placed in Cripple Children's Clinic, Birmingham, Alabama. When my grandfather, "Wekkie" (short for Westcott) came to visit me and saw the conditions there, he swept me up out of the bed, put me in his car, and drove to Warm Springs, Georgia where I got state-of-the-art treatment at the Warm Springs Foundation which was well-known due it's patient, Franklin D. Roosevelt. I can't tell you what a difference it has made in my life. For all intents and purpose, it was a normal life, yet so far from it.

I played sports, not very well, but I played. In high school I lettered on the B-team basketball, and was state champion in the shot put. What a sport! It's all upper body strength, and you hop on just one leg. Luckily, it was my good left leg!

I know that I spent some time in an iron lung at age two. I don't know how much, but any time in Skinner's Box is a bunch. Here I am, a 76-year-old man and I still vividly remember that contraption. Someone ought to do a study on the psychological effect of the iron lung on infant children. I remember how frightened I was. I remember not being touched by another human being. I still don't do so very good with relationships today. I've really tried hard, but just can't make it work. Just another scarred soul due to polio.

I guess it's a triumph on my part that I don't feel guilty any longer and blaming myself. It was just the start of how polio warped my soul as well as my body.

After I got out of Warm Springs, I remained an out-patient. I started with a hip brace which gradually became shorter as I got older, and was only high-top shoes when I started first grade at age six. I started wearing non-orthotic shoes in the third grade (Just a metatarsal wedge on the soul of my right shoe).

In the fourth grade they discovered that I had scoliosis, an "S" curve in my spine. So, the docs at Warm Springs prescribed a brace for me. Their orthotic shop measured me and tailor-made a corset with stainless steel stays. It went from my diaphragm down to my hips, extending a little lower on the front and rear. I remember it was the strongest, thickest cotton I had ever touched. Down the back, there was a stay on either side of my spine with a steal loop welding the two at the top and bottom. I got refitted with a new brace every six months until the ninth grade.

Man, I can remember how the blood would drain from my face and hands with anguish when I contemplated going to junior high school wearing a bulky brace with GIRLS! Lucky again. I quit wearing the brace two months before I started ninth grade. And that was pretty much it for my treatment during my youth.

Growing up, the family never talked about me and my problems with polio. I guess it was because my mother could never fully accept it. It conflicted with her perfect life. As great as her father was, she was a bit lacking in support. Mom wasn't warped. She was just bent a little bit. Anyway, it was enough to make it hard to love her.

So, growing up was tough. I never had anyone that I could talk with about what I was going through. Too bad because I was a highly intelligent, very sensitive, very creative, ultra-shy and extremely introverted soul in the midst of a family of high achievers. I'm a little ashamed to admit it, but I felt shame. I, on the other hand, wasn't much of an achiever. I finished high school with barely a "C" average. A letter grade lower in any course, in any year, would have stopped me from graduating. Yet, I was a National Merit Scholarship semi-finalist. Interesting, huh.

Well, that's the story of my life up until now. As I said, I just returned from my latest visit to the neurologist. The good news is that a recent nerve conductivity test on my right leg compared favorably with another conducted five years ago. There's still no motor neuron activity from the knee down… dead. Oh, the pain nerves are working just fine. I'm aware of it every night when I go to bed.

My hip is withered and my toes are curled up because I can't move them. Every night I have to designate about 20 minutes of my stretching time to my poor little toes. My god, they can hurt so bad.

Remember what I said about small things? My goal in life is to stay loose. No one else knows better than us what it's like to have a part of your body in a constant, rigid spasm. It hurts.

Now pay attention because here's the part that nobody is talking to you about. On the affected parts of your body that are still running, you've got a reduced number of motor neurons due to polio. So, this means that when you have injuries, such as lower spinal injuries, you are more susceptible to injury than even you think you are. Case in point – my back.

A year ago I had a fall, and this fall was different from all the rest because I couldn't roll into the fall. My feet were tangled in the hose as I was watering my plants. I pride myself on my ability to take a fall, rolling on my shoulder where I don't get hurt, just dirty. But this time I fell straight back in a sitting position. You can imagine what this did to my spine. When I hit, the sound in my head was like a "thud" on the side of a jug. It was hard.

The shock of the impact went straight up my spine giving me a wedge compression fracture in T-12 and another compression fracture in T-11. Interestingly, the lumbar section held up just fine. That's because it was surgically rebuilt (my second back surgery) with fusions, bone grafts and titanium rods, and when they did it, they built it like a bridge. Before and after nerve conductivity tests and MRIs show an undamaged spinal column and nerve roots. Yet, peristalsis stopped when I fell.

The theory is that polio left me with a reduced number of motor neurons, and the few that remained to run my lower digestive tract were damaged in the fall. Seems reasonable. After all, I had already lost the ability to express my bladder without a catheter.

So, here I am performing a sensitive balancing act with Mira-Lax in order to keep my digestive system moving, and I've got diarrhea for the rest of my life. Oh, and by the way, I'm nearly two inches shorter than I was when I graduated from high school.

I've accepted myself as I am, not broken, just bent pretty good. Both physically and emotionally. I'm moving on with plans to remodel my bathroom and plant a peach tree in the yard. I'm moving forward. It's bound to be better than what's behind me.

I'll leave you with these words of advice. Learn how to take a fall if you haven't already. Find someone to teach you. You know that you're going to fall…sooner or later. Make the best of it.

Me, I'm going to stay loose, or loose as I can. Then I'm going to get high and bake some banana bread. Life is good, even when it deals you a bad hand. It's not the hand you're dealt, but how you play it. You can do it; you are some of the toughest people in this world. Keep on adapting!

My Polio Experience

(Anonymously provided)

I am a 75-year-old woman. I had polio when I was 18 months old in the 1949 epidemic, before there was a vaccine. I don't remember getting ill or being in hospital.

I grew up with a paralysed left arm and a slightly impaired right leg. My parents were told to put my arm in a sling. When I was four, I had an operation on my leg and a doctor decided I should be strapped into a plastic support to hold my paralysed arm bent at the elbow. The support required many tedious trips to hospital for measuring and replacements when it got cracked or I grew. I hated it so much. It prevented me from doing all the things I wanted to do, which, at that age, was playing with dolls, dressing-up, clambering about on climbing frames in the park etc. Unknown to me, my parents were very concerned about how I'd cope at school while wearing the support. Nevertheless, the rule at home was, 'You must wear the support. Doctor says'. Fortunately, one day, when I was taken to hospital for a check-up, I saw a different doctor. He had the empathy to inquire about how I found the support. When my mother explained how obstructive it was, he surprised her by saying that its sole purpose was to help me. If it didn't help, I didn't need to wear it. We threw it in the bin and life improved no end. I started school able to join in everything.

At university, I used my experience to write my undergraduate dissertation on relationships with physically disabled people. This was long before anyone had thought about disability studies. There were few relevant texts to consult. I married, but sadly, was widowed. I was left with a two-year-old son. I brought him up on my own, became a teacher and later left teaching to work in the voluntary sector. In the 2000s I did a diploma in disability studies, which I enjoyed immensely and it gave me a fresh outlook and a knowledge base from which to campaign.

I always fell over occasionally, but thought nothing of it. By the time I reached my 50s, it seemed to me it happened more often. About 15 years ago, I found that I couldn't get up by myself when I fell. It has led to some difficult situations. I realised it must be post-polio syndrome. My walking had become a bit limited. Following several bouts of infection in my leg, originally due to an infected cut, I was sent to hospital for intravenous antibiotics. On leaving the hospital, I found I couldn't walk back to the car park. My GP sought the advice of a neurologist who said that the infection could be exacerbating the post-polio syndrome. It would probably get better on its own. It did improve a bit. Now I have had a number of recurrences of the infection and each time I'm left unable to walk as well as I could before. I use a stick and can only walk about 30 metres, with my leg getting imperceptibly weaker with every step. I have to be very careful. I have not found any references, in general information about post-polio syndrome, to infections having this effect.

I have been lucky enough to enjoy much good health. Of course, women need the services of health professionals even when they're well. As I get older I've had to consult health professionals more often. I continue to be surprised and disappointed by their attitudes. It is my experience that, whatever my reason for using health services, the professionals think that, without asking any questions about my circumstances, because I have an impairment, I must be 'informed' that I 'can't do' various tasks that I've been happily doing for over 70 years and, in the guise of 'helping', they actually make life more difficult for me.

So far, I've led a fulfilling life. In my retirement, I pursue my interest in politics, support community projects and campaign, particularly around equality and disability access.

My Polio Story

by Michael Kossove, Professor Emeritus and Adjunct Professor of Microbiology

Touro University, School of Health Sciences, New York

In 1948, after returning from summer vacation in the country, I came down with polio. It was non-paralytic, and my family decided to keep it a secret. And they did and died with the secret.

In graduate school I studied Virology with Dr. John Winsser, who was a Team Leader with Dr. Albert Sabin when he developed the oral polio vaccine. I learned everything about polio, except that I was a survivor. During my early years of teaching Microbiology on the college level (I'm still teaching Medical Microbiology at 85). one of my students asked me about PPS. He saw something about it on the news the other night. I never heard about it. I visited the 3 Support Groups in my area and heard the "nightmare" stories. Each group asked me to talk about polio. I realized that survivors really had no idea about the disease, especially 3 types of viruses. At that point I changed my research from Microbiology of the Eye to PPS. With the 3 group leaders, my college, Touro College, now Touro University, sponsored the first conference on PPS. I attended a Polio Convention in St. Louis and met survivors from all over the country. I began to receive invitations to speak in person, to their Support Groups.

In the early 1980's I began to experience PPS. I was diagnosed with PPS by an Orthopedist, and a Physiatrist. On a trip to Boca Raton, Fl, to talk to the group, I stopped by my aunt. She confirmed that I had polio. Shortly thereafter, I needed an AFO (short brace) on my left leg, and over the years it became a full metal and leather brace. As the years continued, I needed an AFO short brace on my right leg, and 3 years ago, a full metal and leather brace on my right leg. During these years I developed Power-point Presentations that I presented to Support Groups, and at Polio Conference across the United States. Since COVID, I have had the opportunity to Zoom with Support Groups in the United States as well as Canada, Australia, and to a Rotary Group in London. My highlight was receiving an invitation to speak to a group of Orthopedic Surgeons, by Zoom, in Beijing, China. I continue to Zoom. I have 5 Power-point Presentations, and I continue to create others.

I am extremely lucky not to have had the early effects of polio, and I treat PPS as "a little inconvenience." I am not handicapped. I am "handicapable."

Because of this big secret, I was drafted out of college in 1958, and sent to Germany as a Senior Medical Aid Man, when Khrushchev banged his shoe on the podium of the United Nations, and walked out. We were ready for war. Thank God that didn't happen. I was released in August 1960. to return to school. If I knew I was a survivor, I would not have had to serve. It turned out that, without war, it was a blessing in disguise. The Veterans Administration made my braces, my glasses, hearing aids, and take wonderful care of me when I need them. They have accepted the fact that the service may have perpetuated PPS.

I am presently writing a book: "Polio, Then, Now, and the Survivors, I hope to complete it by December, 2023. I have met so many survivors through Zoom, and they have been the motivation for the book. I would like this book not only educate polio survivors and their families, but the Medical and Allied Health Communities as well.

My Short Story by Fred Naggs

It was 1953, I was five years old and in my first year at school. I have a clear memory of trying to get out of bed and my legs giving way under me. Our GP had seen me the previous day and told my mother to give me a couple of aspirin and I would be fine. I do not recall much of what happened after that. The paralysis was confined to my legs and I do recall being taken out in a pushchair but I was cared for at home so it must have been a relatively mild condition. I was deemed to have made a good recovery but I became a sickly child with lots of pain in my limbs. When I returned to school, I felt detached from my surroundings and the other children. I was often in trouble for daydreaming and looking out of the windows, wishing I were somewhere else. I seemed to be tired all the time and cold. I scraped along at school, just getting by.

After leaving school I had a succession of jobs and decided to redress my lack of education by pursuing an Open University degree. Married at twenty-one I had the unstinting support of my hardworking wife, who was a nurse. I secured a post at the Natural History Museum in South Kensington in 1974 and commenced a rich and fulfilling career, initially as an assistant curator and for the last 14 years before I retired as the Biodiversity & Conservation Officer in the Zoology Department. I ran international development projects throughout South and tropical Southeast Asia, mostly based on surveys in tropical rainforests. I supervised PhD students and postdoctoral researchers and followed my career dream. Problems that were later recognised as PPS began to cause problems. Episodes of brain fog were the most alarming because I had no idea what the cause might be, and I avoided public speaking, lecturing and conference presentations. Episodes of fatigue had long been a problem but they became overwhelming. I was still riding high running international projects but mobility became an increasing problem, with leg pain and weakness. Following a serious road accident on the borders of Vietnam and China in 2013 it became increasingly clear that I could not continue. All field work ended. I continued at the Museum for a further three years before retiring.

In 2021 and after 50 years in our much-loved home, we realised that a three-storey house was no longer suitable. We moved to a bungalow close to shops and amenities. It was a big step to take but proved to be an excellent decision and perfect for our current needs. I still contribute to scientific papers and write articles but productivity is low, I work around the fatigue brain fog and pain. The most important thing that I learned from the Lane Fox Unit at St Thomas' Hospital was to pace myself and be careful to work within my limitations. It is frustrating but the only way.

Urama Emmanuel Experience

My name is Urama Sunday Emmanuel, I had polio when I was 7months. I started walking at 6months and suddenly started to crawl at 7months. After two years I started walking again limping the right leg. I had no other problem apart from the partial paralysis of the right leg.

At my younger age, I could play football, table tennis, driving manual vehicles including trucks but was using the right leg only for throttle. When I purchased an automatic vehicle, I stopped engaging the right leg. At age 14, one orthopaedic surgeon suggested that I should do surgery on my right leg so that I will not be holding my right leg while walking at older age and I vehemently refused to undergo any surgery.

At age 30 after my internship at the orthopaedic hospital, I had an accident that broke my hand. I was admitted in the same orthopaedic hospital and was given a walking stick to aid movement and prevent bending towards my right leg. At that stage I remembered the doctors advice of surgery to avoid holding my right leg while walking.

Presently now, I am 47, and cannot play football or table tennis or stand up for a long time or walk for a long distance without feeling tired and breathing fast. My weight is high and I need to reduce it.

GOV.UK

Polio detection times could be halved using a scientific detection method, new research shows

New research supported by the Medicines and Healthcare products Regulatory Agency (MHRA) has shown that the time to detect polio can be halved using a technique called Direct molecular Detection and Nanopore Sequencing (DDNS), supporting the global effort to eradicate polio and help save lives.

Read the full article here:

https://www.gov.uk/government/news/polio-detection-times-could-be-halved-using-a-scientific-detection-method-new-research-shows

Have you got something to share?

Sharing your lived experience is a powerful way to make services, like health and social care, better and more inclusive. It's also a great way to make new connections, gain experience, and get paid too!

If you've got something to share but aren't sure where to start, Shaping Our Lives has launched a new guide and video which can help you.

The free My Voice Matters guide contains an overview of what involvement means, who can do it, how to have a positive and inclusive experience, and where you can go to find opportunities.

Shaping Our Lives
Inclusive Involvement Matters

Shaping Our Lives is a user-led non-profit organisation focused on empowering people, especially those who are marginalised and face barriers to being heard, to have their say.

The free guide, in both PDF and Word formats, and the video, can be found here: https://shapingourlives.org.uk/share-your-lived-experience/

Medical Advances as a Result of Polio

Among the positive outcomes of the polio virus outbreak are the significant advancements in medical treatments that have saved countless lives.

Dr. Hannah Wunsch, a well-known author, recently shared the results of her extensive research with the Post-Polio Syndrome Advocacy Group.

YouTube video and transcript available here:

https://www.youtube.com/watch?v=rn3HcMgQyOY

To learn more about The Post-Polio Syndrome Advocacy Group contact **ppsadvocacy@gmail.com**

Patient Worthy aims to publish the realities of rare disease. Your voice is integral to achieving that goal.

Would you like to contribute and share your story?

You can submit here https://patientworthy.com/contact/ **or** let them know if you'd like to work with a writer.

Polio & Anesthesia - Selma Calmes, MD

Dr Calmes is an experienced anesthesiologist, now retired as Chairman and Professor, Department of Anesthesiology, Olive View-UCLA Medical Center, Sylmar, California.

Dr Calmes has consulted on numerous surgical cases of polio survivors over the last 20 years.

The following video was produced by Post-Polio Health International, USA, in 2014 and available to view on Polio Australia's website.
https://tinyurl.com/mr2nxku4

Useful Resources

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

Management Committee [Trustees]

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, UK
Email 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
By **PayPal donate** link: https://bit.ly/2KzyAyE

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

One Day. One Focus: Ending Polio

24 October

World Polio Day is a time for Rotary members, public health advocates, and all who want a world free from polio to come together, recognize our progress in the fight to end polio, and talk about the actions we need to take in order to end polio for good.

https://www.endpolio.org/world-polio-day

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