



# POST POLIO MATTERS

Polio Survivors Network Newsletter  
July 2024 — Volume 11 Issue 6 of 12 [126]



*Highlights  
from the  
European Polio  
Union 2024  
Conference*

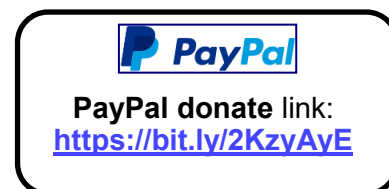
**Decoding Polio's Legacy: Peel back the layers to understand polio's lasting impact!**

[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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<i>(since last newsletter)</i>	
Donation HY	£20.00
Donation ML	£50.00
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***Thank you so much!***

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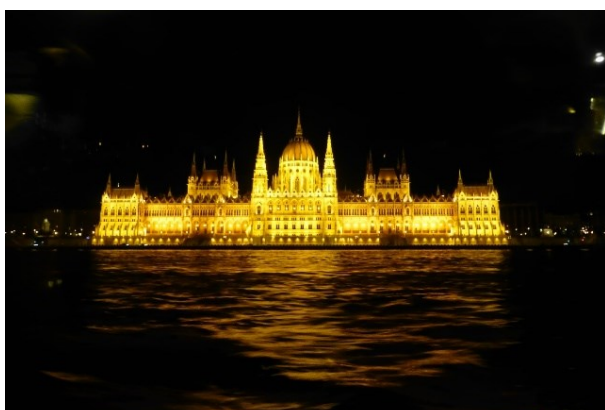
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## Zsuzsi's Trip to Budapest

I arrived in Budapest, where I was born, for the European Polio Union Conference Wednesday the 22nd of May and settled into the Hotel on the side of the Danube opposite the beautiful Houses of Parliament which was built with inspiration from the British Houses of Parliament. Budapest is a city easy to explore by electric buggy, on foot, or public transport. Some of the trams and most of the buses are accessible. The next day we met my cousin in a large indoor shopping centre and we shared a Hungarian specialty, a delicious "lángos". It is a very filling deep-fried bread dough, similar to a pizza. It is a meal by itself!



On Friday evening we had dinner in the hotel and we met several people from all over Europe attending the Conference. There were 34 people at the meeting.

Unfortunately, I became ill during the night and after listening to the introductory speeches on Saturday morning I had to go back to bed. I managed to give my presentation in the afternoon but then I felt ill again. Luckily the secretary Stefan Grajcar emailed me the PowerPoint presentations and my husband attended the talks instead of me and he also stood in for the group photo. I was able

to meet the main speaker Cathleen Davies before she left. She told me about her PhD research which will be published soon and will have a large impact on Post Polio Survivors everywhere.

On Sunday we happened to come across a group wearing 18th Century costumes walking across the Chain Bridge closed off to traffic for the day. It must have been a very hot day for them! This was the first bridge built across the Danube in 1849 by a Scottish engineer Adam Clark who first tried out the design on the Thames at Marlow. The parts were shipped out from England. The lion is the same design as that on Trafalgar Square. There are some new museums such as the House of Music where there was an exhibition of Divas from the Victoria and Albert Museum on its first stop going round the world and a permanent exhibition of the history of music which was so interesting that we spent all day there.



I had a wonderful time, and I am very thankful that I was able to represent the Polio Survivors Network.



## Assessing the Scale of the Long-term Effects of Polio. The Twin Challenges of Measuring Risk and Effective Diagnosis.

The main talk at the European Polio Union's (EPU) annual Conference in Budapest was given by the guest speaker Cathleen Davies of the UCL Institute of Epidemiology and Health.

She illustrated the importance of asking the right questions to interpret and use the answers by referring to the Hitchhikers Guide to the Galaxy in which the immense computer, Deep Thought, after working on the question for 7.5 million years, finally gives the answer to life, the universe and everything as 42. A huge disappointment because the questioners did not know what this meant. Deep Thought explained that only by understanding the question can we interpret and use the answer. We need to ask the right questions to move beyond the numbers if we are to understand the impact of polio on a global scale.



There is a difference between the Long-term Effects of Polio, the paralysis that follows the initial infection, the Late Effects of Polio (LEoP) such as pain, fatigue, muscle wasting, cardiovascular disease, and diabetes, which are the result of immobility, and Post Polio Syndrome (PPS) a neurological condition, believed to be the result of the branching of remaining motor neurons which become stressed over time.

A literature search for the number of polio survivors in the world will come across this number: **20 million Polio survivors globally**. It is repeated in many academic papers and referenced again and again. Evidence was presented that suggests that this number has no hard basis.

What is a polio survivor? Approximately 70% of polio infections are asymptomatic. The virus can be found in nasopharyngeal secretions and stool for days or weeks and can be transmitted to others. Approximately 24% of infections consist of a minor, nonspecific illness, traditionally known as 'abortive' poliomyelitis, and characterized by a low fever, sore throat, and complete recovery within a week. Nonparalytic aseptic meningitis occurs in 1% to 5% of infections. The clinical presentation includes stiffness, pain, or abnormal sensation in the neck, back, or legs. Symptoms last up to 10 days followed by complete recovery. **Less than 1% of all polio infections in children result in permanent flaccid paralysis.** These clinical boundaries are rather artificial, severity of illness lies on a continuum. Neurological assessment of poorly children is challenging and inexact, so milder or temporary paralysis is easily missed. When we start to consider healthcare systems in more challenging environments, then the diagnosis, particularly for the 99% of those who are not left with obvious lasting paralysis becomes more difficult.



PPS is a diagnosis of exclusion based on history, symptomology, clinical observation, and exhaustive physical clinical tests. PPS has been observed in siblings of polio survivors, those with much milder or asymptomatic exposure may be at a significant risk. Twins research suggested a high prevalence of PPS symptoms in twins and siblings, with a suggestion that this would have an impact on public health policy. An impact that failed to materialise. Siblings may exhibit higher rates of PPS-like symptoms' than their contemporaries because if they develop PPS symptoms, then the disease is on the list of possibilities

for diagnosis while others who may have been asymptotically exposed are simply overlooked. It would be reasonable to assume that unvaccinated siblings, living in the same household as a paralytic polio survivor had been exposed to the virus asymptotically. This gives a population of asymptotically exposed polio survivors from whom we could calculate a risk for PPS. This could be applied globally.

Whilst these may offer a clinical picture compatible with PPS, diagnosis remains at the discretion of the doctor. If polio survivors with a known history of paralytic polio struggle to get a diagnosis, those whose initial polio infection has been uncertain, ignored, or completely missed, stand even less chance of success. Studies have shown that up to 50% of anterior horn cells to a muscle could be lost whilst still retaining clinically normal strength. It is therefore quite possible to have sufficient polio damage to create a risk of PPS, without a history of clinical paralysis.

Criteria for Post Polio Syndrome as formulated by the 'March of Dimes':

1. Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography
2. A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval of stable neurologic function, usually 15 years or more
3. Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability, with or without generalised fatigue, muscle atrophy, or muscle and joint pain
4. Sudden onset symptoms may follow a period of inactivity, trauma, or surgery
5. Less common symptoms attributed to PPS include new problems with breathing or swallowing
6. Symptoms persist for at least a year
7. Exclusion of other neurologic, medical, and orthopaedic problems as causes of symptoms

Compare this with a set of criteria, proposed **by Polio Survivors Network UK** which suggests a much wider definition of primary illness, and a credible history of polio exposure whilst unvaccinated.

Diagnostic Criteria Proposed by Polio Survivors Network UK Based on Halstead 2000 :

1. A history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with poliovirus damage of the central nervous system in earlier life
2. A period of recovery
3. A stable period of functioning, from 10 to 50+ years.
4. New symptoms with no other explanation

There is a dichotomy between the clinician and the patient experience, something that needs addressing. Diagnosis of PPS is very difficult, especially for those who have no previously diagnosed history of polio infection. Around twice as many polio survivors believe that they have PPS as are formally diagnosed. In a British Polio Fellowship survey, 83% of respondents believed that they had PPS, but only 32% believed that their GP knew anything about PPS.

In the formal March Of Dimes diagnostic criteria, confirmed initial polio infection is a requirement for diagnosis. So, some clinicians are going 'off piste' to identify previously overlooked exposure and link it to the symptoms seen in later life. If they can do it, so can others.

The self-help document provided by the Polio Survivors Network helps polio survivors illustrate their symptoms and prepare for healthcare appointments. A tick box exercise clarifies the experience of the disease. Some of these are:

- Physical fatigue
- Mental fatigue
- Poor concentration
- Loss of ability to do actions of daily living
- Symptoms not believed by health professionals
- Symptoms not believed by family member
- No diagnosis but continues to deteriorate

Babies born in 1988 would be just 36 years old today when most countries of the world were affected by polio. We have no idea how many of them might be potentially susceptible to PPS. Whilst the Late Effects





of Polio are not curable, an accurate diagnosis informs appropriate treatment, often consisting of the correct advice, extra health prevention precautions, avoiding unnecessary overtreatment, or just an empathetic understanding.

The vaccination rate required to protect a given population from polio is generally accepted to be 80-85%. A quick check through WHO's latest available figures shows around 50 countries failing to meet that target in 2022. Nigeria with a population of 220 million and a vaccination rate of 62% and Ukraine with a vaccination rate of 69% suspected to be falling further due to the ongoing conflict. Lower vaccination rates increase the risk of vaccine-derived polio infections among unvaccinated individuals. Live vaccines shed by individuals receiving the oral polio vaccine enter the water supply chain, potentially mutating back to their pathological form.

It is hoped that understanding the risk of developing Post Polio Syndrome and highlighting underdiagnosis amongst all categories of polio survivors will improve understanding of the potential prevalence of the Late Effects of Polio on a global scale and improve the patient journey to diagnosis.

cathleen.davies.19@ucl.ac.uk



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## Brain & Spine Foundation

The Brain & Spine Foundation provide creative groups and activities for those with neurological conditions.

Their aim is to create a safe and supportive space for people to try a creative activity, share ideas and gain inspiration.

Click this link for more information [Creative Groups & Activities](#)

or visit

<https://www.brainandspine.org.uk/support-for-you/peer-support-groups/creative-groups/>

## *Toni Writes ...*

What are you grateful for today? Do you express your gratitude enough? Something to consider perhaps. Recently we got a beautiful kitten and his sheer joy at life and the tiny things got me thinking about gratitude. It really is a universal language that transcends all barriers, including those posed by illness or disability. It is a powerful expression that can be conveyed through various means, even the smallest gestures can have a profound impact.



Gratitude is more than just saying "thank you." It's an emotion that reflects appreciation and acknowledgment of the positive aspects of life. Non-verbal communication is a powerful tool for expressing feelings without words. A smile, a nod, or a gentle touch can convey thanks in a way that words sometimes cannot. Acts of kindness are a direct way to demonstrate gratitude. Simply sharing your time, helping, a kind word, a small gift or just being there can speak volumes. When we show our thanks or gratitude, it creates a ripple effect and fosters a community where everyone feels valued and appreciated, regardless of their abilities.

Everyday interactions can provide opportunities to show gratitude. Whether it's a nod of acknowledgment to a caregiver or a message of thanks to a friend, these small gestures build stronger relationships and a more supportive community. Studies have shown that expressing gratitude can have a positive impact on mental health. Finding ways to show gratitude can be a source of strength and resilience. By focusing on the small ways in which gratitude can be shown, we highlight the importance of every individual's contribution to a kinder, more appreciative society.

Gratitude is not confined by one's physical abilities. It is a sentiment that can be felt deeply and expressed in countless ways.

So, here's a big thank you from me for your inspiring stories, top tips, kind support and expressions of appreciation. A real testament to the enduring spirit of gratitude that exists within every polio survivor, regardless of your challenges.

Take care

*Toni x*

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From our readers:

Many thanks for this. - AL

*As an ex-journalist I am full of admiration over the latest Newsletter. You really have done an outstanding job. BIG pat on the back. - VRC*

Hilary, I was really impressed with your detailed account in the Editorial, as well as Toni and Simon's contributions. All the articles were interesting and useful. I will forward the optimal clinical pathway to my surgery. Congratulations on a great newsletter! - ZS

Thank you so much for your email and that newsletter. I found so much useful info on your website, I'm really glad I found your organisation. - SS

## Can you help our new member?

Hello and greetings from the Netherlands. I came across your network recently, and really like your intention, to educate people on polio and PPS. I am a retired physician, doing some research on Post Polio Syndrome as far as solutions and helpful treatments, and would like to hear from your members what has been proven to support their condition best. I have 2 people in my circle of acquaintances who are successfully battling the condition. Thank you! – JL

**Editor's Comments:** Please can you send any comments or experiences that you have had by email to us at [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk) so we can then pass these on.

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## A New Member's Thoughts



Hello, I contracted Polio in September 1949 at the age of 13 months whilst visiting my aunt in Southend, I was immediately put into an iron lung where I stayed for 5 months. When I came out, I could breathe for myself!!! but could only roll my head from side to side.

After a run in with sister on my ward my mother announced that she was taking me home. At this point the doctors and nurses remonstrated saying that was impossible, to which my mother replied well you're not doing anything for me here I'll exercise him myself. When asked why she was going to do this her simple reply was "because I'm his mother and that's what mothers do". My mother was a Taurus and didn't stand for nonsense from anyone. The upshot was that in September 1953 I walked into school with callipers on both legs.

I was stubborn and had to do everything for myself. I got through school with 5 O Levels and then did an OND in Electrical and Mechanical Engineering. I then went Newcastle College of Art and Industrial Design and came out of College in June 71 right into a mini recession and design jobs like hens teeth so I found an advert in the local paper for jobs at The District Valuers Office a 5 minute walk from where we were living (I was married now). So, I started there in September 71 and ended up as Rating Surveyor. After three years and not being able to see any progression, I took the Civil Service exam and became an EO Examiner in the nicely named Enforcement Office chasing Tax arrears. This lasted until early 81 when were asked anyone was interested in going into IT. At Long last I had found my ideal home up until retired as a Senior Communications and Security specialist in 2008.

All this toing and froing had left me drained because I had always listened to the Use it or Lose it mantra that we now know was the worst advice possible. I'm now wheelchair bound due the arrogance of a pair of Surgeons dismissing my protestations that my knee was also damaged. At 102 weeks I was finally given an arthroscopy of my knee!!! The result show severe damage to the anterior cartilage of my knee which was causing all the pain. But even worse all I am being offered is full knee replacement (a no no due to osteoporosis) or knee fusion locking the leg in one position. As this leg is my prime mover it's condemning me to using a chair for good.

Sorry for being so long winded but I've found writing this down quite cathartic. Thanks, GK

**Editor's Comments:** Welcome to our network, we hope you find it helpful in many ways. I am sure your thoughts will resonate with our community. I wonder if others would like to share their experiences and experience how cathartic this can be, send them to [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk) for inclusion in the next newsletter. Please see the next page for a response to your experience.



## Response to new member GK

Your account has struck a chord with me as I also caught polio in September 1949, although I was in Budapest, Hungary and I was 8 years old. Luckily, I did not need an iron lung, but I was fortunate as there was none available at that time. I had an equally determined mother, as you did, who came to stay with me in the hospital until she could take me home a few weeks later and started a regime of exercises to get me walking. It took over a year. I am so grateful for her dedication and strength of will.

I started back in school in 1953 with one crutch and my mother's arm. The school was up a steep hill. But she would not allow the doctors to put me in callipers. Eventually, I was walking with just one stick and like you, I managed to get a good education. I got a Chemistry degree and started working in research but had to give it up when I had my children and became a teacher.

PPS has also caught up with me and I find walking very hard even with two sticks. I also have callipers on both legs to support my knees. I would not have a knee fusion or knee replacement. I use an electric buggy outdoors and walk very little in the house.

So our stories are very similar. Thank you for sharing yours. Zsuzsanna Snarey

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## 2024 Polio Survivors Network Annual General Meeting

We are holding our 2024 Polio Survivors Network Annual General Meeting on **Monday 19 August** online using Microsoft Teams at 1:30 p.m. – 3.30 p.m. (British Summer Time).



Join Us Virtually! Send your name and email address to us at [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk) and we'll make sure you get all the details to log in and participate in shaping our future.

Your Voice Matters! If you're unable to join us, your vote still counts. Please complete this [Voting Form](#) by Friday 16 August to ensure your voice is heard and to help us meet our quorum.

📧 Received your newsletter by post? You'll find a printed form included for your convenience.

We look forward to seeing you there  
*PSN Management Committee*

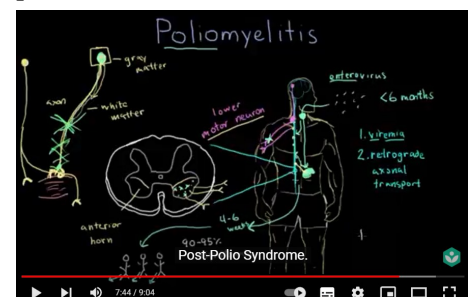
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## Want a clear explanation of Polio and Post Polio Syndrome to share with others?

Try this video from the Khan Academy Medicine (created by Ian Mannarino and hosted on YouTube)

<https://www.youtube.com/watch?v=aBBTiPsYUVA>

These videos do not provide medical advice and are for informational purposes only. The videos are not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of a qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read or seen in any Khan Academy video.



## Navigating Temperature Extremes

As the seasons shift and climate change wreaks havoc, so do the challenges faced by polio survivors. The delicate dance between heat and cold intolerance becomes a central theme in our lives.



### Our Internal Thermostat

Imagine a tiny control centre nestled deep within your brain—the hypothalamus. This unassuming region plays a pivotal role in regulating body temperature. For most, it orchestrates a symphony of responses: when it's cold, veins and arteries constrict to retain warmth; when it's hot, they dilate to release excess heat. For polio survivors, this symphony faces disruptions.

### Cold Feet and Purple Toes

Polio survivors often describe their feet as always being cold and often blue-tinged. The culprit? Damaged neurons that fail to signal blood vessels to constrict. As a result, warm blood flows near the skin surface, dissipating heat and leaving behind those infamous “polio feet.”

### Heat Waves

It seems that polio survivors also struggle with heat intolerance. Our bodies rebel against rising temperatures, sweating intensifies, clothes cling and we are uncomfortable. The brain's thermostat, once damaged by the poliovirus, also seems to struggle to orchestrate a response.

### What can help?

We must learn to dress as if it were approximately 10°C (20°F) cooler than the actual temperature. We have learned that when we lose body temperature our symptoms are triggered—muscle pain, fatigue, and vulnerability. Another tip is to try wool or polypropylene items.

In the heat wearing cooler fabrics can help and some find personal cooling devices to be helpful. Plan ahead and try to avoid going from very hot to very cold environments more than you have to as this can be very tiring on the body.

For more information check out these links:

#### **Dr. Richard L. Bruno (Polio Network):**

Inability to Manage the Heat

<https://polionetwork.org/archive/f4cig6m3ttl3i4t5bw34d9xow0qzz6>

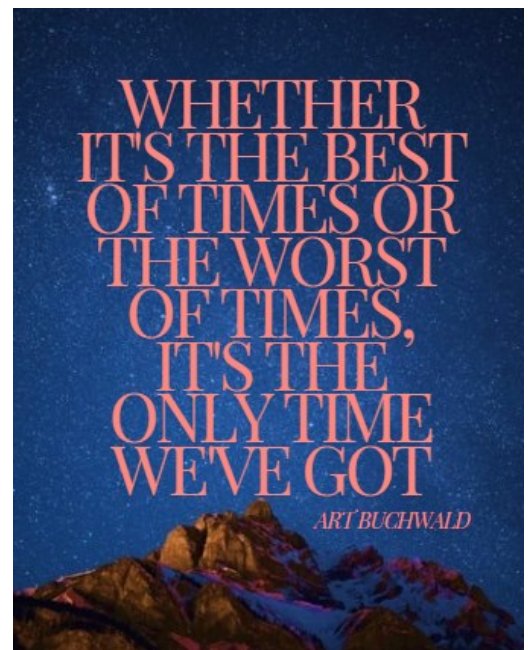
A warming winter tale for everyone who hates the cold

<https://polionetwork.org/archive/md6xsgufinqrel0vuuo07gamus4too>

#### **Polio New Zealand:**

Heat and Cold Intolerance

<https://polio.org.nz/wp-content/uploads/2021/09/Thermoregulation.pdf>



## “New” Areas of Muscle Weakness

**Question:** When I had polio, my legs were completely paralyzed but my arms were not affected. When I recovered, I walked for many years with a very pronounced limp. I now have leg muscle weakness, use a long leg brace and a manual wheelchair. But I am beginning to experience pain and muscle weakness in my upper arms. Could I have weakness where I had never had polio weakness? Is it true that paralysis or even muscle weakness weren't necessary for your whole body to be affected by PPS muscle weakness?

**Dr. Bruno's Response:** Yes, that's correct. Even if you weren't paralyzed, Dr. David Bodian showed in 1949, with 158 human autopsies of polio “non-survivors”, that if you had muscle weakness anywhere, 90% of your muscles and their motor neurons were damaged, even if not killed, by the poliovirus. Add decades of physical overuse and, wham, PPS muscle weakness! The overuse causes wearing out of remaining poliovirus-damaged neurons and produces weakness of muscles thought to be unaffected by polio.

Late onset muscle weakness can show up anywhere, regardless of the degree of initial paralysis...or none. Even "non-paralytic" polio survivors could have had wide-spread motor neuron damage but not enough in any one muscle to cause weakness initially. But those remaining, poliovirus-damaged neurons still fail with overuse abuse over time.

This article can help explain: ["Non-Paralytic" Polio Causing PPS](#)

*Written By Richard L. Bruno, HD, PhD*

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I used to be able to do cartwheels. Now I tip over putting on my underwear!

I hate it when I see an old person and then realize we went to high school together.

I told my wife she should embrace her mistakes. . . so she hugged me.

My wife says I only have 2 faults. I don't listen and something else . .

I thought growing old would take longer.

Scientists say the universe is made up of protons, neutrons and electrons. They forgot to mention morons.

The adult version of “head, shoulders, knees and toes” is “wallet, glasses, keys and phone.”

Wi-fi went down for five minutes, so I had to talk to my family. They seem like nice people.

If you see me talking to myself, just move along. I'm self-employed; we're having a staff meeting.

I came, I saw, I forgot what I was doing. Retraced my steps, got lost on the way back, now I have no idea what's going on.

*Credit to Second Time Around Publication of the Boca Area Post Polio Group*



## Decoding Polio's Legacy: Peel back the layers to understand polio's lasting impact!

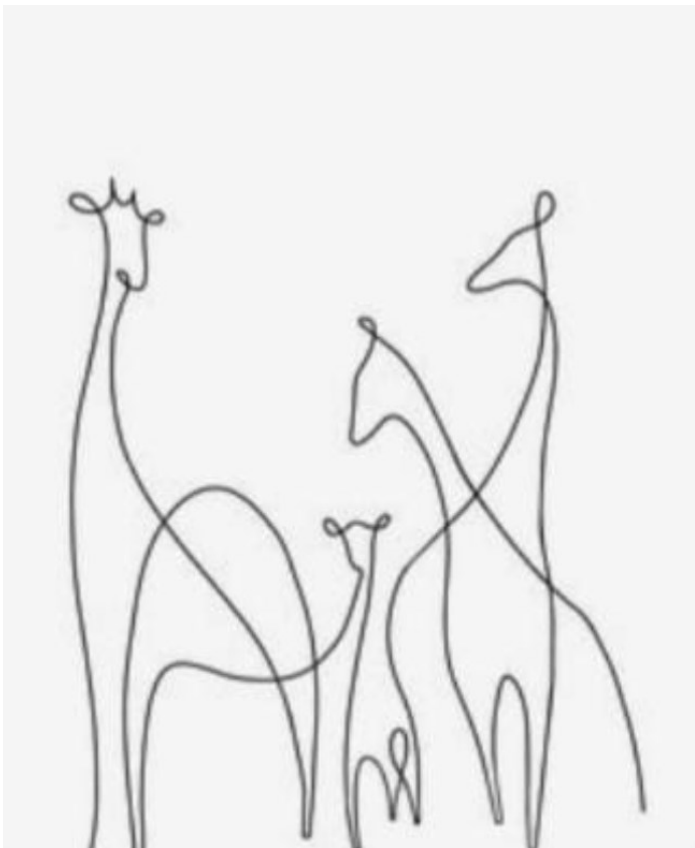
Post-polio syndrome (PPS) emerges as a companion on our shared path as survivors, quietly whispering its presence decades after our initial battle with poliomyelitis. The trio of pain, fatigue, and weakness may knock at our door and occasionally sleep disturbances, breathing difficulties, and even muscle atrophy but we stand resilient. What we experience is often an unseen struggle. It is a new strength that defines us - the gradual emergence of endurance, a testament to our never-give-up spirit.

PPS doesn't arrive unannounced but instead seems to adhere to set criteria:

1. **Polio:** Our history echoes - motor neurons lost, resilience gained. Electromyography (EMG) confirms our journey.
2. **Stable Years:** After recovery, we may tread a stable path for 15 years or more.
3. **Symptoms:** Gradual weakness, fatigue, and joint pain may now be our companions. Breathing and swallowing may be experienced.
4. **Exclusions:** We rule out other medical culprits, seeking clarity that this is likely PPS

Bracing, AFOs, KAFOs, walking sticks (canes), customized shoes, weight management, wheelchairs, scooters, walking frames, adapted homes - they're our tools. We learn to listen to our bodies, pacing ourselves. Assistive devices become our partners, and rest is our secret weapon.

PPS isn't a foe to fight; it's a companion to understand. We adapt, we learn, and we thrive. Our journey is uncharted, but our spirit remains undeterred.



### Resilience in a Single Stroke

Much like the continuous line that forms this herd of giraffes, polio survivors show unwavering strength and interconnectedness.

Our journey, marked by challenges and triumphs, echoes the unbroken spirit captured in that single stroke.

## **That Last Straw** by Millie Malone Lill Polio Perspective May 2024

Sometimes, we people pleasing polio survivors have a hard time admitting that we can't do something. By "do something," I don't mean doing something adequately or well enough. Oh no. We have to do that something better than anyone else. Good enough is simply not good enough.

In our recovery period, most of us became used to using every motor neuron in our arsenal because that is what it took to do what our able bodied peers could do easily. This became our norm. At the time, no one realized that we did not grow entire new neurons to replace the damaged or killed ones that the polio virus took. Nope, but the damaged neurons did sprout little fingers to reach out to the muscles in an effort to mimic complete recovery. We were cured, or at least that was the popular belief.

Since we were now cured, there was no excuse not to do what everyone else did. That earlier try harder philosophy was now our mantra. You can do it, come on, you aren't even trying! Stop that limping. No, you can't be tired, look at your friend, he hasn't even broken a sweat. Keep up, lazy person. This led to many of us becoming Type A personalities. We tried so hard to be normal that we left normal behind in the dust.

Looking back, we realize that many things really were harder for us. We weren't exactly cured as we thought. Those little fingers that our hardworking neurons put forth were not complete neurons after all, just extensions of other neurons that were, themselves, somewhat damaged. After so many years of trying so hard, those little fingers finally died off. This led us back to the acute stage of polio. Some of our parts no longer worked as they had. It's kind of like patching a hydraulic hose with duct tape. It works for awhile, but that tape is not a permanent fix. Under pressure, that duct tape will eventually lose its sticking power and will come off, leaving your hydraulic hose in the same condition that inspired you to put the duct tape on it in the first place. Unfortunately, duct tape isn't going to work on damaged neurons.

After a lifetime of trying so hard, we have difficulty realizing that the duct tape is no longer doing its job. We have to slow down, we have to prioritize our activities to include things we find enjoyable and things we can't avoid, things we would like to do and things we are beginning to realize we can no longer do. We can't just stop doing. At the same time, we want to avoid that last straw, the one that limits our activities to just the bare necessities of life. Added to the overworking that damages our remaining neurons, we must realize that the aging process itself kills off a few.

Does this mean our lives must be spent just enduring rather than enjoying? Not necessarily. PPS is progressive, but it can be slowed down. Listen to your body. When it signals to you that you need to rest, rest. Divide the tasks you must do into small bites. Do a little, rest a little. It might be a plan, if you can afford it, to hire someone to do the heavy stuff. Investigate benefits your insurance plan might cover. Medicare often offers services you might qualify for. Most importantly, listen to when your body says its load of straw is complete. Time to rest. Later, once you have unloaded today's load of straw, you can pick up that last single straw so much easier tomorrow.



Thinking of you...

Help PSN raise funds

Our beautiful A6 blank photocard are  
£1.75 each or £6.00 for 5 (inc P&P)





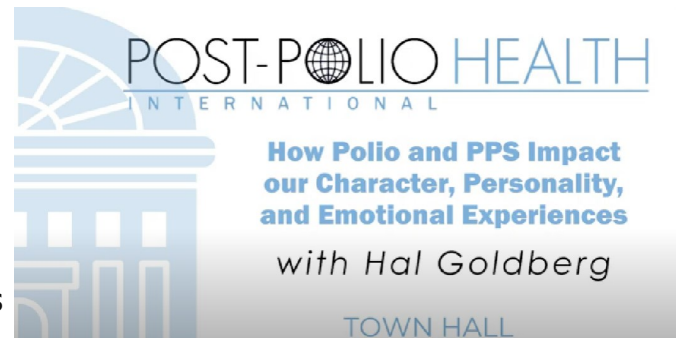
## How Polio and PPS Impact our Character, Personality and Emotional Experiences

A video produced by Post-Polio Health International (PHI) video on how polio and PPS impacts polio survivors, presented by Hal Goldberg. This video is part of PHI's 2024 Educational Series.

### Watch here:

<https://www.youtube.com/watch?v=1y2E6Be5JCU>

PHI's mission is to collect, preserve and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families and to support the health professionals who treat them. For more information about the late effects of polio visit [www.post-polio.org](http://www.post-polio.org)



### Useful Resources

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



# Management Committee [Trustees]

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

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

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

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

Trustee/s - Vacancies please contact Toni for more information

## Operations Team

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

Printing - Imprint Colour Printers, Lincoln

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

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

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

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

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

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

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

Donate by **cheque** to Polio Survivors Network

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



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

*giftaid it*

**The Gift Aid scheme.** Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year. If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%). If you have not filled in a current Gift aid form please contact us and we will email/post you one. Thankyou.

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

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

Written by U.K. Doctors for Doctors

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

**NB** Respiratory and Sleep Problems Section very informative.

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

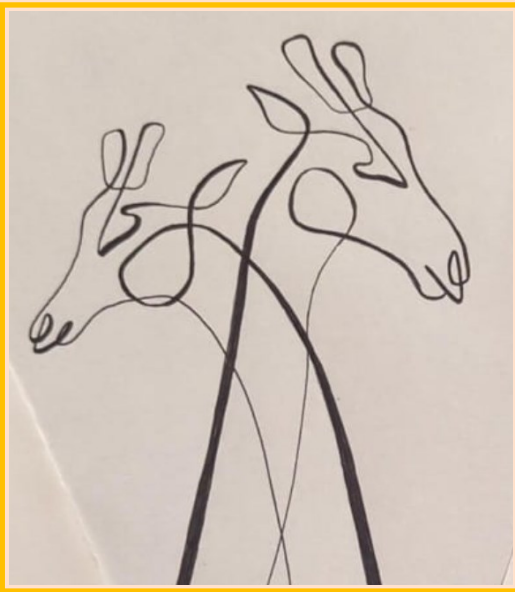
## **POLIO PATIENTS AND SURGERY - Information for health staff.**

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

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

**Printed copies on our headed paper with permission are available.**

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



Just as giraffes have long necks to adapt to their environment, polio survivors adapt by using assistive devices to maintain mobility.



Outside the EPU Conference in Budapest June 2024 –EPU Secretary Stefan Grajcar and his wife Gizka along with Els Symons from the Post Polio Group Vereniging Spierziekten Nederland (VSN) from the Netherlands



### **Polio Survivors and the Balloon of Unity**

In this whimsical scene, the elephant's gentle grasp on the balloon depicts the shared experience and community among polio survivors.

The rabbit gazes up at the same balloon expressing shared hope and the courage to journey together.