August 2026 www.poliosurvivorsnetwork.org.uk

POST POLIO MATTERS

Polio Survivors Network Newsletter — Volume 12 Issue 1 [Edition 133]

A Voice for Polio Survivors

This edition explores:

- *Why lived experience still matters*
- *Navigating healthcare and a PPS diagnosis*
- *How you can shape the future of PSN*
- *Travel, access and dignity*
- *The emotional reality of chronic pain*
- *Research updates & disability politics*

and more ...



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

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Donations, Charity Incentives, Grants, etc Received (since last newsletter)	
PayPal Giving Fund Grant	0.50
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Donation JU	75.00
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We Are Not a Story of the Past



I contracted bulbar polio in January 1956, aged five. It was a very different Britain. The Salk vaccine had already begun changing the course of the epidemic in the United States, yet here vaccination was introduced more slowly and many children, including me, fell into the gap between what was medically possible and what was politically deliverable.
Like many of my generation, I spent years in hospital, paralysed and separated from my family. I depended upon an iron lung to breathe and a feeding tube for food and water. Those experiences left lasting memories,not always compassionate or caring,but they were not unique. Many polio survivors remember prolonged hospital stays, rehabilitation units, splints, operations and a society that largely viewed disabled people through the lenses of a tragedy, charity, pity and low expectations.

Yet our generation's story is not simply one of survival. It is also the story of how disabled people helped change society.

When I was growing up, the expectation was that disabled people adapted themselves to institutions and services. Decisions were made for us rather than with us. Professional authority came first, and independence was often seen as unrealistic or even unnecessary.

During my lifetime I have witnessed one of the most remarkable social transformations of the twentieth century. After studying art and design, I later became a Chartered Counselling Psychologist and psychosexual therapist. Along the way I had the privilege of seeing, and occasionally working alongside, some of the pioneers who helped shape the modern disability rights movement.

Their central insight became known as the Social Model of Disability. Disability was not simply something that resided within an individual's body. Much of what disabled people experienced arose because society created barriers through inaccessible environments, discriminatory attitudes and inflexible systems. From that thinking grew the Independent Living Movement.

Its central principle was simple but revolutionary. Disabled people should have the same freedom as everyone else to decide where they live, how they live, who supports them and how they participate in society. Support should be organised around people's lives rather than requiring people to fit around existing services.

A philosophy that transformed lives
Accessible transport, anti-discrimination legislation, direct payments, personal assistance, inclusive education and the recognition of disabled people as equal citizens were not gifts generously bestowed from above. They were won through decades of persistence, campaigning and political change.

Many of us who grew up with polio lived through that transformation. We became professionals, parents, partners, volunteers, leaders and active members of our communities. Independent living was never simply a policy objective. It became our lived reality.

Are we are forgetting those lessons
No one can ignore the enormous pressures facing health and social care. Local authorities struggle with limited resources. NHS Continuing Healthcare increasingly finds itself carrying responsibilities that extend beyond its original purpose. Rising care costs, workforce shortages and an ageing population place genuine pressures on every part of the system. Most of this is not the fault of the many dedicated professionals working within those services. Most are trying to do their best under exceptionally difficult circumstances. The danger lies elsewhere.

When resources become stretched, systems naturally seek efficiency through standardisation. Individuals become categories. Needs become assessment scores.

assessment scores. Lives are reduced to pathways and service models. Gradually, almost unnoticed, the fundamental question changes. Instead of asking: **"What support does this person need in order to live the life they want?"** we begin asking: **"Which available service or funding box can this person be fitted into?"**

At first glance the difference appears small, in reality it changes everything. The disability rights movement fought the assumption that disabled people should adapt themselves to the convenience of others and institutions. Are today's systems recreating that same institutional thinking in different forms. The language remains person-centred, but is it just now lip service, as the practical reality and application becomes system-centred.

This is not simply a philosophical concern
Support organised around the realities of people's lives often produces better outcomes, greater independence and, in the longer term, uses public resources more effectively. Human-centred support is not merely more compassionate; it is frequently more economical as well. The principle remains as true today as it was fifty years ago: ***The system exists to serve people. People do not exist to serve the system.***

Perhaps the greatest misunderstanding about our polio generation is that we are viewed simply as survivors of a disease that has largely disappeared from Britain if not quite the world. But our real legacy could surely be much greater than that.

We were amongst the first large generations of people with significant physical impairments who sought power and demanded education, employment, relationships, sexual identity, parenthood and full participation and citizenship in society. We demonstrated that impairments need not mean dependency, segregation or withdrawal from community life. Many of us are now living into our seventies and eighties. We continue to work, volunteer, create, teach, campaign, care for others and contribute to our communities. We remain living evidence that, given appropriate opportunities and support, disabled people can continue to lead rich and productive lives long after society often expects us to fade quietly into the background.

As governments grapple with ageing populations, rising care costs and increasing demands upon health and social care, perhaps our generation has something vitally important to contribute once again.

The answer to an ageing society is not simply more care. It is more enablement.

It is creating the conditions in which people retain choice, maintain relationships, contribute to their communities and continue exercising as much control over their own lives as possible. Frailty and illness are genuine challenges, but so too are loneliness, exclusion, dependency and the loss of purpose. Independent living remains one of the most effective ways of addressing all of these.

Human beings are never simply the sum of their diagnoses, impairments or care needs. Health and wellbeing emerge from the interaction between bodies, minds, relationships, opportunities and communities.

- The polio generation helped establish that understanding.
- We remain living evidence of it.
- We are not simply a story of the past.
- We should also be the torch bearers for the future.

The challenge now is not merely to remember what previous generations achieved. It is to ensure that future generations inherit a society that values independence, dignity, participation and citizenship just as strongly as those who fought to establish them. Because some principles never become outdated. **Systems exist to serve people — not the other way round.**

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Sharing my Thoughts by Zsuzsi Snarey



I have recently read a book called "The Polio Paradox: what you need to know" by Richard L. Bruno, an expert in neuromuscular rehabilitation, published in 2002, often referred to as the "polio survivors' Bible" for understanding and managing Post-Polio Syndrome (PPS) and chronic fatigue. Sadly Richard (Dick) L Bruno died on the 14th of October 2024. I was so impressed by his advice in The Ten Commandments of PPS that I wanted to pass it on.

1. Listen to Your Body
Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs kept that relate activities to their symptoms. Sometimes, however, you can listen too much: to salesmen who say some herb or supplement will "cure" PPS, to fellow survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members (and the voices in your own head) saying you're getting lazy. Polio survivors need to listen to their own bodies, not to busybodies.

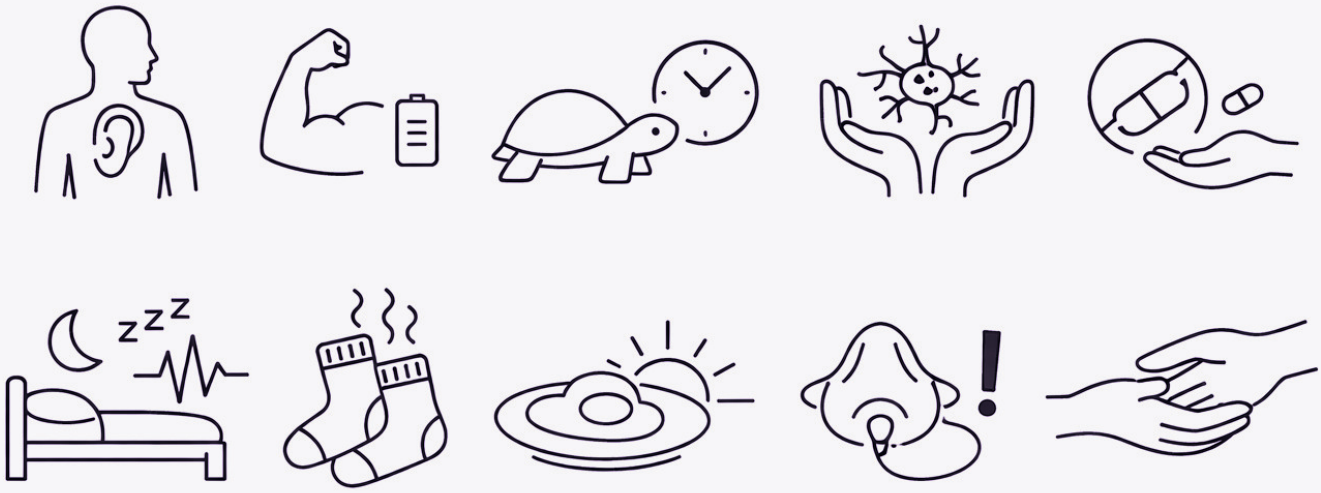
2. Work Smarter, Not Harder
Many polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: The more you overuse your muscles, the more strength you lose. Muscles affected by polio lost at least 60 percent of their motor neurons; even limbs you thought were not affected by polio lost about 40 percent. Most disturbing is that polio survivors with new muscle weakness lose on average seven percent of their motor neurons per year, while survivors with severe weakness can lose up to 50 percent per year! Forget about "use it or lose it." You need to "conserve it to preserve it." Stretching may help with pain, and non fatiguing exercise for specific muscles can prevent you from losing the strength you have, after you get a brace. But polio survivors need to work smarter, not harder. Remember the Golden Rule for polio survivors: If anything causes fatigue, weakness or pain, don't do it. Or do less of it.

3. Go Slow and Steady
The follow-up study of patients showed that taking two 15-minute rest breaks per day (doing absolutely nothing for 15 minutes) is the single most effective treatment for PPS symptoms. Another study showed that polio survivors who pace activity (who work and then rest for an equal amount of time) can do 240% more work than if they push straight through. Patients who take rest breaks, pace activities and conserve energy have up to 22% less pain, weakness and fatigue. But polio survivors who quit or refuse therapy have 21% more fatigue and 76 % more weakness. For polio survivors, slow and steady wins the race.

4. Be Kind to Your Neurons
Using crutches or braces are not signs of failure or of "giving up." You use one third of the energy--and look better walking--using a short leg brace on a

weakened leg. Muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches--dare we say even a wheelchair or scooter--if they decrease your symptoms and make it possible to finally take that trip you always wanted? We know, you'll slow down and take care of yourself "when you're ready." And you'll use a wheelchair "when there's no other choice." You don't drive your car until it's out of petrol. Why drive your body until it's out of neurons?

5. Say No to Drugs, Unless ...
Five studies have failed to find any drug that treats PPS. And no studies show that herbal remedies or magnets reduce symptoms. Don't think that you can apply a magnet or pop a pill to make your PPS disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done. Masking symptoms--with magnets or morphine--will not cure the damage. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury.



6. Sleep Right All Night
The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders such sleep apnoea or twitching muscles. However, you may not be aware that you stop breathing or twitch. If you awaken at night with your heart pounding, anxiety, shortness of breath, choking or twitching, or if you awaken in the morning with a headache or not feeling rested, you need a sleep study. "Post-polio fatigue" may be due to a treatable sleep disorder.

7. Turn Up the Heat
Polio survivors have cold and purple "polio feet" because the nerves that control the size of blood vessels were killed by the poliovirus. Your nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of synthetic fabrics like breathable fibre polypropylene that hold in your body heat.
(This does not apply to the recent heatwave! But I find that my muscles work better in the heat. Z. Snarey)

8. Eat Breakfast
Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When patients follow a "hypoglycaemia diet" (16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your midday yawning.

9. Anesthetise with Care
Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. They also stay anesthetized longer and can have breathing trouble during and after anaesthesia. Even nerve blocks using local anaesthetics can cause problems. You should have lung function tests before having a general anaesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist--and especially your anaesthesiologist--long before you go under the knife. You should never have same-day surgery or outpatient tests (like an endoscopy) that require an anaesthetic.

10. Do Unto Yourself as You Have Been Doing for Others
Many polio survivors were verbally abused, slapped, or beaten by therapists or family members to "motivate" them to get up and walk. So, polio survivors took control, becoming Type A super achievers, doing everything for everyone except themselves. Many polio survivors do for others and don't ask for help because they are afraid of being abused again. Isn't it time you got something back for all you've done for others? Accepting assistance is what can keep you independent. Appearing "disabled" by not doing for others and asking for help may be frightening, but they are also the best ways to manage your PPS.
(This last statement is one that I disagree with. I had nothing but encouragement during my rehabilitation, and yet I have a Type A personality. I am very determined, I like to achieve and I hate asking for help, not because I mind appearing disabled, but because I don't consider myself being disabled. Z.Snarey)

Physio Function
Maximising Independence

If you're anywhere near Northampton, you might already know about PhysioFunction and their work to help survivors managing post-polio syndrome.

https://physiofunction.co.uk/conditions/neurological/post-polio-syndrome

They offer hands-on support and therapies. Their website advises that if you are interested in the Post Polio Syndrome group classes please either contact the Northampton Branch of the British Polio Fellowship or PhysioFunction 0800 043 0327 for more information.

Editor's note: *We're always keen to hear from our readers, so if you've tried their services, tell us what your experience was like. Your voice helps strengthen our community.*

Toni Writes ...

IT IS A SORRY STATE OF AFFAIRS WHEN POLIO SURVIVORS AROUND THE WORLD MUST GIVE UP HOURS OF THEIR TIME TO RESEARCH THEIR MEDICAL CONDITION

Hilary Boone

What keeps a community alive? I've been thinking about that a lot lately. Maybe it's because of the conversations I've had with a few of you lovely members recently or perhaps it's the way our network continues to show such humour and heart even when life throws its challenges. Gratitude, as I wrote recently, is a powerful thing but so is responsibility, sometimes, the two walk hand in hand.

Our little charity has always been powered by people who care. Members who share their stories or views and trustees who support one another while working hard for our members. But here's the truth and it's not an easy one to say; we are running on the smallest team we've ever had. Just three trustees! Three wonderful, dedicated people who each juggle complex lives, health challenges and the everyday realities that so many of know all too well. They keep going and giving so that members can benefit from our community and regular information.

Can I ask you to think about something for us? Could you be a trustee? Not because you have endless time or perfect health. Not because you have all the answers. Not because you've done something like this before but because you care and understand the importance of what we do.

Being a trustee is about bringing your perspective, your lived experience, your ideas and ensuring that your network has a future. There's something meaningful about contributing to a cause that has shaped your life, or the lives of those you care about. Something that reminds you that even small acts can ripple outward in ways you may never fully see. Please think about it.

If you feel you might want to explore the idea, even just a little, reach out. Ask questions. Have a chat. No pressure, no commitment, just a conversation.
We need you and the future of our charity depends on people like you stepping forward, even tentatively and with doubts.

Thank you for being part of this polio survivor community.

Take care

Toni x

psnadmin@poliosurvivorsnetwork.org.uk

Thinking About Becoming a Trustee? Your Questions Answered

What exactly does a trustee do?
A trustee helps guide the charity, making sure we stay true to our mission and use our resources wisely. It's less about paperwork and more about offering your perspective, your lived experience and your common sense. Trustees help shape decisions and ensure the charity can continue to serve polio survivors well into the future.

Do I need special qualifications?
No. You don't need a legal background, financial expertise, or years of committee experience. If you have those, wonderful but what matters most is your understanding of the community and your willingness to contribute. Lived experience is one of the most valuable qualifications of all.

What kind of time commitment is involved?
We know everyone has health challenges and unpredictable days. Being a trustee is designed to fit around real life. Most of the work is done remotely and meetings are planned with plenty of notice. A few hours a month is often enough to make a meaningful difference.

My health is unpredictable, can I still be a trustee?
Yes. In fact, that's exactly why we need you. Our charity exists for people living with the long-term effects of polio and our leadership should reflect that reality. We understand fluctuating health, fatigue, mobility issues and the need for flexibility. You will never be expected to push beyond your limits.

What support will I get?
Current trustees will guide you, answer questions and you'll never be left to decide anything alone. We work as a team and with plenty of understanding.

I'm not sure I'm "trustee material." What if I'm not good enough?
If you care about the future of the charity, you are trustee material. Many people underestimate what they can offer, you just need to be willing.

Why is this so important right now?
Because we currently have only three trustees, all managing complex lives and health issues. They are doing their absolute best, but no charity can thrive or even survive with so few people carrying the load. We need more hands and more voices. Without additional trustees, our future becomes uncertain.

Can I just ask questions without committing?
Absolutely. A conversation is not a contract. If you're even a tiny bit curious, please reach out. Send a message to psnadmin@poliosurvivorsnetwork.org.uk and we'll arrange a friendly chat over the phone or Zoom.



From Our Readers

SH doesn't usually share much on open forums but felt compelled to share their experience going through Bristol Airport. SH wondered if other readers might be interested and warned of subtle changes that are happening.

SH explains …

Last Monday my partner and I were flying home to Edinburgh from Bristol. We'd been to see friends and had had a great visit. I seldom complain publicly, but I feel that I should alert others to the experience in Assistance and Security that I had in Bristol airport that night.

I had Polio as an infant, and now suffer from Post Polio Syndrome. Now retired, I require assistance more and more. I have never been able to walk without some sort of assistance e.g. an orthotic, stick or elbow crutch and now use a full KAFO and elbow crutch. I can't walk unaided even with the orthotic and my balance is very poor these days.

It was pouring with rain when we were dropped off and my partner found an abandoned wheelchair and pushed me to the Assistance desk. The lady there asked if he could push me and, in surprise and ignorance, he agreed. She proceeded to issue us with rapid fire instructions/directions. She spoke very rapidly and flashed a couple of photos at us. Due to her heavy accent and rapid delivery, I asked her to repeat the instructions. She delivered them again at machine gun speed. She did not supply us with written instructions or a copy of the photos. We asked if there would be refreshment facilities after we got upstairs. She said yes and we were dismissed. It wasn't busy, but she was done. At no time did she instruct us to check in anywhere else. We found our way upstairs and went to find some refreshment and wait for directions on the check-in gate.

We left before the instructions had come up and thought to make our way to Security. We went back the way we had come and recognised the lift and gate from the photos. We then found ourselves in front of another Assistance desk with 3 people. One of these, a young lady, proceeded to literally scold us like children. She was angry because we had not come directly to the desk to check in with them. We explained we had already checked in downstairs and did not know we had to come to this desk. She continued to scold us and went into ''broken record''. Repeating it again and again. She then dismissed us, sending us to another desk, where a lovely gentleman told us quietly and politely we needed to go to Security. A very pleasant lady then took us up to Security. She escorted me on to the plane and I could not fault her.

As we approached Security my partner asked a lady if this was the correct lane and she was very officious and rude to us, saying she was not there to direct us. She had to watch all around, not direct us. The area was almost empty. Her manner was awful, but worse was to come.



From Our Readers (continued)

When I got up to the Security gate, I submitted my goods, coat and my elbow crutch as I always do. The x-ray machine is a new experience for me, but I'd managed it in Edinburgh I I said yes, but only for a moment or two. Anyway, I stepped in and after a brief wait asked for my elbow crutch. This request was ignored, and instead an officer took both my hands and led me forward. This is the worst way for me to have to try to walk and in fact is dangerous. I got into the wheelchair again with relief. Naturally, my orthotic showed up on the X-Ray. She then leant down and felt my right leg, as is usual, and asked to see it. Normally they proceed to swab it. However, I pulled up my trousers to the knee and showed her the orthotic from the knee down, as I usually do, and had done in Edinburgh. She was unsure and left me for a moment or two. She brought another woman, presumably her manager, and she said they needed to see all of the orthotic. She was very cold and austere. I asked if she expected me to take my trousers down in the open area. I'll admit I wasn't prepared to strip in a public area, but I spoke in a calm voice and merely as an inquiry to clarify what she was asking. She responded crossly that I'd have to go to a room with them. She looked at me with irritation and disdain. I said I'd need a bench or bed to show her all of the orthotic. I said it twice. She totally ignored me. I also said I had travelled the world, both for my work and pleasure and had never had to do this. Not even in the US.

She unlocked a room which was tiny. It had a desk against a wall and 2 or three chairs in it, plus her, the original officer and me in my chair. Glad I didn't have a cat, as no danger of swinging one! I was then told to take my trousers off. I managed to wriggle out of my trousers in the chair and pull them down to my knees. Then she wanted the orthotic to be unfastened so her assistant could run her hands round my leg. She couldn't do this at the second fastening on my thigh. She then asked if a swab had been taken. By this time I was getting very distressed and frightened by her manner and don't recall what was said in reply. I didn't know what they were looking for, or expected to find. Again there was no explanation. She told the assistant to fasten it up, but I would not allow that. My orthotic is expensive and brand new. They had no idea what they were doing. They hadn't even asked what my disability was or if they were causing me pain and so I was not prepared to let them cause me more discomfort and anxiety. I managed to fasten it and pull my trousers up. As I had to do this sitting down, not on a bed as usual, it was not in the right place and I had to suffer unnecessary pain until I got home. This was some two and a half hours later.

I was then taken back out to my partner. He had no idea what was happening as I'd been taken without being able to speak to him. The officers then left. There was no explanation nor apologies from the senior officer as to her behaviour. Frankly, I was left feeling humiliated, intimidated, frightened and near to tears.

As a law abiding member of the public, I'm all for security. However, what threat can a 74 year old, partially paralysed woman, travelling from Bristol to Edinburgh be? An organisation is only as good as the employees facing the public. It's not what you say, it's the way that you say it. Explanation and communication is everything. It wasn't even busy, so I couldn't even give the benefit of the doubt to her. She was just rude, officious and a terrible representative of the business.

I hope to visit Yoevil again soon, but will be looking for flights to perhaps Bournemouth or Exeter. I also wanted to warn my fellow disabled of the experience. Social Media can be a powerful force when used correctly. Overall, my visit to the airport was an appalling experience and has left me shocked and sad, and spoilt an otherwise wonderful weekend with friends. I have sent a strong letter of complaint to the CEO and await a reply with interest!

From Our Readers (continued)

Good evening, thank you for your excellent newsletter. I think we all could relate to the stories regarding the NHS and how they are not receiving the training to support a great deal of patients. JF

I have been meaning to write and say how much I enjoyed the last magazine. CG

I found 3 articles of particular interest, MS



We Need You!

2026 Polio Survivors Network Annual General Meeting

In order to meet our charity legal obligations we need 10 members to be present at our Annual General Meeting. We currently have 7 who have responded expressing their interest in attending. Can you join us? We are also providing time to chat together after the formal meeting which will allow time for informal discussion, and the chance to speak openly with others who 'get it'.

We are holding our 2026 Polio Survivors Network Annual General Meeting on

Monday 03 August 2026
online using Zoom

1:00 - 2:30 pm
(British Summer Time)

Join Us Virtually!
Send your name and email address to us at
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 **Wednesday 29 July** to ensure your voice is heard.

We look forward to seeing you there
PSN Management Committee

Supporting Your GP Appointment for a PPS Diagnosis

Getting an appointment can be a challenge let alone from a GP or consultant that knows about polio can be challenging for individuals seeking assessment for possible Post-Polio Syndrome (PPS).

One practical step that can make a meaningful difference is taking printed copies of reputable medical information to appointments. Two particularly valuable resources are the clinical overview of PPS on Patient.info (https://patient.info/doctor/post-polio-syndrome) and the Mayo Clinic's summary of the condition (https://tinyurl.com/kb82sc3v).

For our Scottish readers please consider taking along the NHS Inform information (https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/post-polio-syndrome)

Presenting these alongside a clear description of your symptoms and how they affect daily life can help ensure that PPS is considered as part of the diagnostic process.

"Post poliomyelitis syndrome" is formally recognised in the NHS coding systems used by GPs and hospitals

In primary care, PPS appears in SNOMED CT, the coding system used by GPs, under the identifier 31097004 and is officially classified as "Post poliomyelitis syndrome". The World Health Organisation also recognises PPS and the NHS uses the WHO's ICD-10 classification for health records and mortality statistics, where PPS is listed under code G14, a designation valid throughout the United Kingdom. Mentioning these codes during your appointment can reinforce that PPS is an established and internationally recognised medical condition.

UK-based polio survivor support organisations can provide practical advice

The British Polio Fellowship offers a range of resources, including a benefits and entitlements guide (https://britishpolio.org.uk/support-for-you/practical-legal-advice/benefits-entitlements-guide/) and information on lifestyle, exercise, and mobility (https://britishpolio.org.uk/support-for-you/lifestyle-well-being-advice/exercise-mobility/).

Editor's Note: *If you would like us to print out and send copies of any information referenced in our newsletters please let us know and we can post these to you.*



European Polio Union - Updates

Last month the EPU held a successful Conference and AGM in Copenhagen and Malmö. We are sure you will find the President's letter of interest.

Last weekend we had a wonderful EPU Conference and AGM in Copenhagen and Malmö! For all those who were with us, I hope your journey back home was as smooth as possible. For those who could not attend, we hope to see you in London next year.

I am sure I speak on behalf of everyone when I say that the organising team deserves our warmest thanks and congratulations. Gurli Nielsen, Vice-Chair of PolioForeningen Denmark, together with Fredrik Canerstam, Head of Office Personskadeförbundet RTP Sweden, did an amazing job with their teams. We will circulate the presentations to our members as soon as we receive them. But in order to share our enthusiasm quickly with those who could not be with us, I would like to pass on some of the immediate feedback I heard during these two days.

The bus that picked us up at the hotel on Friday was a true surprise for most of us. Equipped with a platform deployed from its side, it lifted those of us who needed it from the pavement, one by one, almost one metre into the air, and brought us safely to the bus level, where our wheelchairs, scooters or simply ourselves and our walking sticks were then calmly and comfortably installed. The "POLIO" sign at the entrance of the specialised hospital we visited in Copenhagen created a very positive feeling of recognition for many of us. The facilities we were introduced to showed a very high standard of rehabilitation know-how and equipment. Furthermore, an atmosphere of kindness, care and expertise was immediately obvious throughout the hospital.

We had outstanding presentations by medical experts: Dr Majbritt Almer spoke about the specific characteristics of fatigue in polio survivors; Dr Natallia Suhak presented recent research on neurophysiological dysfunctions related to PPS; Kari Lofthus, physiotherapist, shared her experience in treating polio survivors; the Danish Healthcare System was presented by Nana Rømer Jørgensen, Head of Occupational Therapy; Professor Kristian Borg gave a presentation on immunoglobulin treatment in PPS; and Dr Eva Melin completed this overview with a presentation on polio care capabilities in Sweden for postpolio patients. Many thanks to all of them for their time and efforts. Meghala Karlsson, Board member of Personskadeförbundet RTP concluded the day.

On Saturday, we then held the traditional General Assembly of the European Polio Union. This was an opportunity to refresh our ideas for the future of our association. We all face the same challenges linked to ageing and to insufficient resources to meet the increasing needs of polio survivors. Our EPU statutes set out very clear missions: to encourage medical experts to share their expertise at European level, to help establish the prevalence of post-polio in Europe, to actively share information among ourselves, and to support polio vaccination. Fulfilling these missions effectively in the future will certainly require new resources. This will be our target.

We also decided that in 2028, after the 2027 AGM in London, we will hold our AGM in Brussels. The purpose will be to take this opportunity to engage with our national MEPs and promote the need for appropriate medical expertise and services in each country for the treatment of polio sequelae and PPS. We should be in a position both to acknowledge the excellent services available in Denmark, Belgium, the UK and other countries, and to draw attention to the serious gaps that still exist in some European countries.

This was my first AGM as President of EPU. I am still learning the role, but I was efficiently helped and guided by Macrina Clancy, our Vice-President, and by the Board of Directors: Frances Quinn, Daniel Koller, Michal Haindl and Concepcion Garcia-Anton. Caroline Gordon-Wilson, who is now our administration volunteer, did a huge amount of work in preparing this whole event and also guided me throughout the process. My deepest thanks to her. To conclude, I was amazed by the energy and shared commitment we all have to build a better future for EPU, for our member associations, and above all, for polio survivors across Europe. This is very encouraging.

The minutes of the meeting and the presentations will be shared later in dedicated documents and newsletters. Take care, and I look forward to seeing, reading and writing to you soon.

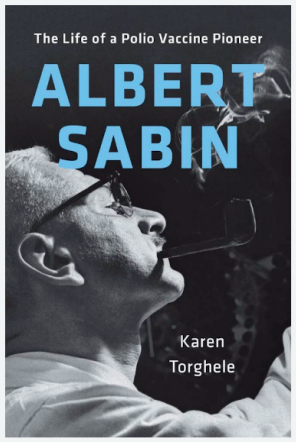
Pierre Parrot EPU President
European Polio Union

The Life of a Polio Vaccine Pioneer

A new biography of Albert Sabin offers a concise, engaging look at the scientist behind the oral polio vaccine and the challenges that shaped its development. A worthwhile read for anyone following polio history and eradication efforts.

- Available from Amazon UK: https://amzn.eu/d/02d1T5ah

- Interview with author Karen Torghele on This Week in Virology: https://www.microbe.tv/twiv/twiv-special-torghele/



🦔 Hedgehog Conservation

Hedgehogs which were once a common little rustle in gardens across the UK are now in serious trouble. Back in the 1950s, Britain was home to around 30 million hedgehogs. Today, we're down to fewer than 1 million! This decline is so steep that hedgehogs are considered vulnerable to extinction in Britain. Urban hedgehog populations are beginning to stabilise, thanks to gardens, green corridors, and community action but rural hedgehogs continue to decline sharply

These charming creatures, known by old names like hedgepig, urchin, furze-pig and hedgy boar (do you have any local names that they are known by?) are an important part of our natural heritage. Their disappearance is a warning sign: shrinking habitats, busy roads and dwindling food sources are all taking their toll. A new National Hedgehog Conservation Strategy has been launched to address these threats.

If you'd like to learn more or help make your own patch of garden a safe haven or to know how many hedgehogs are reported in your area, these organisations are a brilliant place to start:

- Hedgehog Streethttps://www.hedgehogstreet.org A fantastic project from PTES and the British Hedgehog Preservation Society, full of practical tips and community initiatives.

- British Hedgehogs https://www.britishhedgehogs.org.uk/ A great resource for information, rescue contacts, and ways to get involved in protecting hedgehogs across the UK.

Even small actions like adding a gap in your fence, avoiding pesticides, leaving out fresh water (esp in summer), creating a safe nesting space can make a real difference. If we all do a little, we can help ensure hedgehogs remain part of Britain's wildlife for generations to come.







POST-POLIO HEALTH
INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

PHI are excited to introduce two new resources on their website bringing together years of trusted guidance from two of their most popular newsletter columns.

You can now explore all past entries from "Ask the Doctor" and "Promoting Positive Solutions" in one convenient place. Whether you're seeking medical insight or practical strategies for navigating the emotional and social aspects of living with post-polio, these collections make it easier than ever to find answers and support.

Ask the Doctor: https://post-polio.org/education/ask-the-doctor-list

Promoting Positive Solutions: https://post-polio.org/educ.../promoting-positive-solutions

These resources reflect the expertise and real-world experience that have supported our community for years—now organized and accessible whenever you need them.



Post-Polio Health International
(including International Ventilator Users Network)

www.post-polio.org
www.polioplace.org
www.ventnews.org

Post-Polio Syndrome: A Silent Sequela Challenging Medicine

Understanding the Long-Term Impact of Post-Polio Syndrome

Post-polio syndrome (PPS) is a late-onset condition that affects individuals decades after an initial poliomyelitis infection, often emerging quietly and without immediate recognition. In this article, Dr. Carles Fontcuberta and Dr. Martha Castilleja explore the clinical, neurological, and social dimensions of PPS, highlighting its progressive nature and the challenges it presents for both patients and healthcare systems.

Although global efforts have brought the world closer to eradicating polio, the long-term consequences of the disease continue to impact millions of survivors. PPS illustrates how the effects of past health crises can persist across decades, requiring ongoing medical attention, awareness, and research. Its symptoms, ranging from severe fatigue to progressive muscle weakness, often overlap with other conditions, making diagnosis complex and frequently delayed.

Beyond its clinical aspects, PPS raises important questions about long-term care, accessibility, and quality of life. The article emphasizes the need for interdisciplinary approaches, patient-centered care, and greater awareness among professionals and society. As we move forward in global health, PPS serves as a reminder that eradicating a disease does not necessarily mean ending its impact.

Is it the same as polio? The answer is no, but their histories are deeply intertwined.

Post-polio syndrome (PPS) is a late-onset neurological condition that affects exclusively individuals who have previously had poliomyelitis (infantile paralysis or polio). In other words, it cannot exist without a prior infection by the poliovirus, which defines not only its conceptual relationship but also its biological origin.

While poliomyelitis is an acute infectious disease caused by an enterovirus, PPS appears decades later as a progressive neurodegenerative process. Unlike the initial infection, there is no evidence of viral persistence in this late stage, and its exact mechanism remains under investigation.

The most widely accepted theories point to progressive deterioration of hypertrophied motor neurons that survived the original infection and have worked for years under metabolic overload, low-grade inflammatory processes, and possible alterations in central regulation of exertion. However, none of these hypotheses has been conclusively proven.

A Problem from the Past... Still Present

At the same time, the world has made extraordinary progress in eradicating wild poliovirus thanks to a global alliance led by international organizations: the Global Polio Eradication Initiative (GPEI), which includes WHO, UNICEF, CDC, GAVI, the Bill & Melinda Gates Foundation, and Rotary International. This coordinated effort has eliminated wild poliovirus serotypes 2 and 3 and restricted serotype 1 circulation to very specific regions of Afghanistan and Pakistan.

However, a significant epidemiological challenge remains: circulating vaccine-derived polioviruses (cVDPV), which can spread in populations with low vaccination coverage.

This risk is substantial and requires continued vigilance, as these viruses have even been detected in wastewater in countries where polio was considered eradicated. Environmental surveillance, constant epidemiological monitoring, sustained vaccination, and a gradual transition to inactivated vaccines are essential to prevent outbreaks.

Decades of Silence Before Symptoms

PPS was recognized as an independent clinical entity in 2010 and classified by the WHO under the International Classification of Diseases (ICD-10) with the code G14.

Its prevalence is increasing due to the long interval between the initial infection and symptom onset, which can range from 40 to 60 years. This delay means many patients seek care at older ages, often with comorbidities that can mask PPS.

The course of PPS is slowly progressive and irreversible, without direct life-threatening impact, but with significant functional consequences.

Symptoms Beyond Fatigue

Common manifestations include:

- Severe fatigue disproportionate to effort
- Progressive muscle weakness
- Musculoskeletal pain
- Cold intolerance
- Restrictive ventilatory disorders due to respiratory muscle involvement
- Difficulty swallowing
- Emotional disturbances

These symptoms can lead to high levels of physical disability and emotional distress, reflecting the biopsychosocial complexity of PPS.

A Diagnosis of Exclusion

Diagnosis is primarily clinical and requires ruling out other conditions with similar symptoms, such as hypothyroidism, fibromyalgia, chronic fatigue syndrome, autoimmune diseases, chronic inflammatory processes, neoplasms, and amyotrophic lateral sclerosis.

Electromyography (EMG), which measures electrical activity in muscles, can provide useful information about chronic nerve damage caused by polio, detect signs of denervation and reinnervation, and help exclude other diseases. However, it is not specific for PPS.

Currently, there are no laboratory tests, imaging studies (MRI or CT), nuclear medicine tests, or biomarkers that confirm the diagnosis, contributing to delays and variability in management.

The five currently accepted diagnostic criteria (Halstead, Dalakas, March of Dimes, European Federation of Neurological Societies) are:

- A clear history of poliomyelitis
- At least 15 years of neurological stability after the initial infection

- Gradual onset of new musculoskeletal symptoms lasting at least 1 year
- Progressive deterioration after that year, with fatigue, pain, muscle weakness, cold intolerance, and sleep disturbances
- Exclusion of other underlying conditions

Treatment: Support, Adapt, Improve

There is no cure or specific pharmacological treatment for PPS. Management is comprehensive and individualized, focusing on:

- Specialized rehabilitation programs following neuromusculoskeletal evaluation
- Controlled physical exercise, avoiding overexertion (including tailored physical and aquatic therapy)
- Pain management through combined approaches and medication when needed
- Use of orthoses and biomechanical aids such as canes, walkers, crutches, and powered wheelchairs
- Respiratory support when necessary (including evaluation for sleep apnea or diaphragmatic weakness)
- Psychological support and patient education; support groups are highly beneficial

Exercise prescription must be handled carefully, as overly intensive programs can worsen fatigue, accelerate strength loss, and reduce quality of life. Care should always be guided by professionals experienced in PPS. The goal is not to cure, but to preserve function and improve quality of life.

An Ongoing Challenge for Medicine and Society

Recent literature highlights the need not to overlook polio survivors in the context of global eradication. Anthropologist Nora Ellen Groce, in correspondence published in The Lancet, warned that eliminating the virus should not overshadow the millions living with its long-term consequences.

Assuming PPS will disappear in the coming years may be a serious miscalculation. Lack of awareness among healthcare professionals, along with the absence of standardized protocols, contributes to delayed diagnoses and inconsistent care. In this context, it is essential to promote continued education on PPS, improve interdisciplinary coordination, and encourage research into its pathophysiology, biomarkers, and therapeutic strategies. We are facing a complex condition that requires collective commitment.

For healthcare professionals, this means recognizing PPS as a real, prevalent, and disabling condition that demands a comprehensive, evidence-based, patient-centered approach. A key question during medical history-taking remains: “Did you have polio in childhood?”

Looking Ahead

It is crucial to strengthen medical training, improve coordination among specialties, and promote research in pathophysiology, diagnosis, and treatment. PPS reminds us that eradicating a disease does not necessarily mean ending its consequences.

Dr. Carles Fontcuberta
Dr. Martha Castilleja

*The Rotary Club of World Disability Advocacy (**RCWDA**) brings together members from more than 30 countries to build a world without barriers. Founded in 2021, the club is led by Rotarians, professionals, and advocates — many with disabilities — united by one belief: “Nothing About Us Without Us.”*

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Understanding Pain as a Polio Survivor

When people hear that I had polio as a child, they assume it's something I "got over" ages ago. I wish it was as simple as that! For many who survived polio, the story didn't end with recovery and for me post polio syndrome first started with pain.

Pain in the late effects of polio/post polio syndrome isn't just a physical sensation. It is a strange thing to feel your past catching up with you, the virus has gone but its impact hasn't. Pain is also something that many survivors quietly endure and is often misunderstood by those around us.

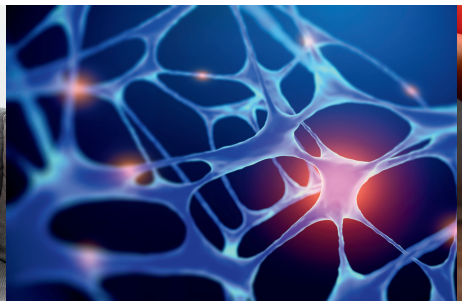
For a long time, I didn't understand why my body seemed to be wearing out faster than others of my age. The muscles that polio damaged in me never fully returned to normal I suppose they just learned to cope so now, decades later, they're tired.

The pain I live with is not simple or predictable and it comes from a mix of things that have built up over my lifetime. Muscles that were weakened long ago now struggle with everyday tasks and even the simplest movements can feel as though I'm asking far too much. My joints have gone through years of walking differently or relying on my stronger limbs which has left some of my joints overused and others underused. My nerves don't always behave as they should either and there are moments when the pain turns sharp or burning, as if the wiring inside me has frayed with time. Then there is the cold which affects my limbs and once that sets in it can take ages to get warmed up again.

Simon's last article was so true. I agree that the emotional side of chronic pain is rarely talked about yet it is just as real as the physical. There are days when I feel frustrated, when I wish my body would simply cooperate. I grew up being told to "keep going," "stay strong," and "never give up." Those messages helped me survive childhood polio but they don't really help me much now. If I push too hard, I pay for it. If I don't move enough, I stiffen up and feel worse. Finding the middle ground is a daily battle.

I've learned to try to break tasks into smaller chunks and rest before I feel exhausted. I use mobility aids and accept that my energy is limited. Some days I get it right but other days I don't but I do now try to listen to my body rather than fight it.

While pain may be part of my life, I try not to let it define me. I've learned to work with my body and think about the strength that has got me this far. Asking for help... well, that is something I still struggle to do.



Bread & Roses: The politics of Rest & Free Time (in, against, and beyond Disabling Capitalism)

Phase One: Questionnaire - Open Now!

Members of the Polio Survivors Network are invited to participate in this project. At a time when disabled people are doing more (paid and unpaid) activities than ever before, access to meaningful rest and free time is increasingly denied and scrutinised. This study explores the politics of rest and free time by asking questions about how rest and free time are experienced, regulated, and denied to disabled people in the UK.

Publications: One of the publications of this project will be a report in the form of a Manifesto for Rest and Free Time from a disability politics perspective, which will be shared with campaigning groups and other relevant collectives.

Phase 1: ***completing a questionnaire*** https://breadrosesdisability.uk/questionnaire

- the questionnaire linked above can be completed via an online form or a Word Document version (which can be sent to ioana.chis@glasgow.ac.uk)
- if you prefer to submit audio-recorded responses, this can be done via the online form
- you can choose which questions to respond to and which ones to skip
- collective submissions can also be done – or, alternatively, network members can select the most important questions for them, to then discuss them at a meeting among members only, followed by a meeting with the researcher (as participation in the project).

You can participate if you:

- self-identify as being disabled and/or chronically ill, learning disabled, neurodivergent, d/Deaf, having impairments, experiencing mental distress (or use other similar self-identification terms) **and**
- are over the age of 18 and live in the UK

Phase Two: *collective discussions/focus groups*
In autumn 2026, recruitment for collective discussions/focus groups will begin (up to 2 hours, compensated with a £40 Love2Shop voucher/participant). The discussions will take place mostly online – and, when logistically possible, face-to-face.

For any questions about the project, please **email** Ioana Cerasella Chis at ioana.chis@glasgow.ac.uk. **Website**: breadrosesdisability.uk
This 2026-2028 project is funded by The Leverhulme Trust & The University of Glasgow.



Far Fetched - Vic Baxter



Our member, Vic Baxter has written a series of articles entitled "Far Fetched" on the topic of "Dodgy Wheelchair Transfers" in faraway airports. Please enjoy the sixth one entitled...

A First Class Meal At Minus 40 Centigrade In Almaty

Undertaking a dozen two-week trips to KIMEP University in Almaty to deliver a localisation program which entailed selecting and developing enough Kazakh members of staff to take over some thirty expatriate positions within Tengiz Chevron Oil, had been a great privilege and I was ready for home.

It was therefore with some concern that I heard the check in clerk say the ambi-lift was broken and boarding in a wheelchair would not be possible.

Solution: board the wheelchair via the catering containers. Not something which would ordinarily be permitted – but where there's a will, there's a way.

I was unceremoniously rattled into an open food container, populated by a number of very well built Kazakhs and the scissor jack activated to raise us to the freight door of the aircraft.

All ran very smoothly until the cabin crew advised that they were not yet ready to receive the catering and we should await further instructions.

Dressed in a light suit I began to shiver a little and in an instant was offered a high visibility insulated jacket which I accepted. After some twenty minutes or so the lead guy decided we should all be fed.

The trolleys were therefore opened up and the most amazing fare handed around the container, complete with some Black Sea caviar and a rather special Champagne.

I "won" an insulated Jeltex jacket that day and was finally boarded in a Champagne haze totally unfazed at having dined at minus 40 degrees centigrade.



Polio Survivors & Surgery: What Healthcare Professionals Need to Know

Polio may feel like a disease of the past, yet a significant number of survivors continue to live with the long-term neurological and systemic consequences of their original infection. Many are now older adults who require surgical procedures and their care presents challenges that modern clinical training rarely covers. When clinicians understand the unique physiology of polio survivors, surgical outcomes improve and preventable complications become far less likely.

The poliovirus damaged motor neurons in the spinal cord and brainstem, leaving survivors with fewer functioning nerve cells to support breathing, swallowing and movement. Even those who appeared to regain full strength often did so by relying on a reduced pool of motor units working at high capacity. Over time, these surviving neurons fatigue and previously stable muscles may weaken. Joint instability, arthritis, respiratory compromise and cold intolerance are common and these issues can become more pronounced during surgical procedures. Even individuals who never required ventilatory support during childhood may have subtle respiratory impairment that only becomes apparent under surgical conditions.

Respiratory assessment is a critical part of pre operative planning. Weakness in the diaphragm or chest wall may not be obvious during routine activity but can become significant under sedation. Pulmonary function testing helps identify those at risk of postoperative complications such as pneumonia or difficulty clearing secretions. Early involvement of respiratory specialists is especially important for survivors with a history of bulbar involvement, scoliosis or previous ventilator use.

Anaesthetic management is one of the most critical areas where polio survivors differ from other patients. Because the reticular activating system was often damaged during the original infection, sedatives and anaesthetic agents can have exaggerated and prolonged effects. A routine pre-operative sedative may keep a survivor asleep far longer than expected and standard anaesthetic doses can lead to extended unconsciousness or delayed emergence. Careful titration, reduced dosing and close monitoring are essential. Same-day surgery is rarely appropriate, as these patients may remain sedated well into the evening and are at heightened risk for falls, aspiration and unnoticed complications once discharged.

Autonomic dysfunction adds another layer of complexity. Many survivors struggle to regulate body temperature or maintain stable vascular tone. As a result, they may experience intense shivering, cold intolerance or vasovagal episodes during recovery. Maintaining warmth, using heated blankets and monitoring for hypotension can significantly reduce discomfort and risk. Nausea and vomiting also require proactive management, since these patients are more prone to fainting during emesis.



Pain management deserves special attention. Polio survivors often experience amplified pain responses due to damage to endogenous opioid-producing neurons. They typically require higher doses of analgesics for longer periods, despite being notably stoic. Scheduled pain control, rather than relying solely on as-needed dosing, helps prevent unnecessary suffering and supports safer mobilisation.

Positioning during surgery is another area where complications can arise. Muscle atrophy, spinal deformities and long-standing compensatory movement patterns make certain positions unsafe. Because patients cannot report discomfort while unconscious, poor positioning can lead to nerve injuries or prolonged postoperative pain. Allowing the patient to participate in positioning before induction, when feasible, is a simple but effective preventive measure.

Recovery must proceed at a slower pace than with other patients. Residual anaesthetic effects, temporary muscle weakness and the disruption of compensatory movement strategies can make early mobilisation hazardous. A gradual progression from sitting up in bed, to dangling legs, to assisted standing is essential. Anti-embolism stockings and gentle in-bed physiotherapy help maintain circulation and range of motion without overexertion.

Preparation for discharge is equally important. Many survivors rely on aids such as raised toilet seats, grab bars, canes or wheelchairs and these supports may be even more essential after surgery. Ensuring that the home environment is equipped appropriately particularly with grab bars in the bathroom, safe transfer surfaces and mobility aids reduces strain and prevents falls. Planning ahead ensures a smoother and safer transition from hospital to home.

Finally, clinicians should recognise the emotional landscape many polio survivors bring with them. Childhood hospitalisations were often lengthy, isolating and painful. Those memories can resurface during modern medical care. Clear communication, respect for autonomy and a trauma-informed approach can transform the patient's experience and reduce anxiety.

By understanding the neurological, respiratory, autonomic, musculoskeletal and psychological complexities of polio survivors, healthcare professionals can deliver safer, more compassionate surgical care. The polio survivor population may be small, but their needs are significant and with informed practice, outcomes can be greatly improved.

Polio Survivors Network is part of the **Octopus People Power** programme, a simple way for us to raise funds just by helping our community get cheaper, greener energy.

How it works:

- Use our unique link to get a quote and sign up to Octopus Energy.
- You'll receive £50 free credit on your new energy account after your first direct debit is taken.
- Polio Survivors Network also receives £50 as a boost for our work

Octopus Energy is the UK's most awarded energy supplier, offering 100% zero-carbon electricity and outrageously good customer service. Switching is simple and usually takes just a few days with no disruption to your supply.

Ready to make the switch and make a difference?

Sign up via our link today: **https://poliosurvivorsnetwork.octopus.energy**



Please remember to use easyfundraising every time you shop online. Over 8,000 retailers will donate to us. This means you can raise FREE donations for us no matter what you're buying.

If you haven't signed up to support us yet, it's easy and completely FREE.

You can find our easyfundraising page here:

https://www.easyfundraising.org.uk/causes/polio-survivors-network

Communities Come Together

The National Lottery Community Fund believes that strong communities grow from strong connections. Projects supported by the Fund help create welcoming spaces, reduce loneliness and build trust so that everyone feels they belong. The Fund supports initiatives that bring people together, strengthen relationships and improves wellbeing.

PSN is proud to share this mission and is deeply grateful for the support of The National Lottery Community Fund, whose investment helps PSN continue building stronger, more connected communities.

It is with grateful thanks to the National Lottery Community Fund for the grant we received which has meant we have been able to provide Post Polio Matters Edition 133 in both printed and digital form to our lovely members.

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

British Polio Fellowship
https://britishpolio.org.uk

Post-Polio Health International
www.post-polio.org

PA Polio Survivors Network
https://polionetwork.org

Polio Quebec
www.polioquebec.org/eng/

Polio Survivors of Marin
www.facebook.com/groups/163909760771171

Atlanta Post-Polio Association
www.atlantapostpolio.com

Ohio Polio Network
www.ohiopolionetwork.org

Polio Australia
www.poliohealth.org.au

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Please contact us if you would like to help with our work

We currently offer FREE membership while our funds allow.

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 **PayPal** to treasurer@poliosurvivorsnetwork.org.uk
or use **PayPal donate** or **bank transfer** as below

PayPal

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

Bank Transfer
Account name: **Polio Survivors Network**
Bank: **CAF Bank**
Account: **00014980**
Sort Code **40-52-40**

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