



January 2026

www.poliosurvivorsnetwork.org.uk

POST POLIO MATTERS

Polio Survivors Network Newsletter — Volume 11 Issue 11 of 12 [Edition 131]



New Year, Same Courage

The new year doesn't erase the realities polio survivors face. Energy shifts and daily tasks can demand more effort than they used to.

What also doesn't change is the determination it takes to manage them. That determination is already part of you. It's built from years of adapting and pushing through situations most people never have to think about.

This issue focuses on practical information, lived experience and straightforward support from people who understand what it means to keep going when the path isn't simple.



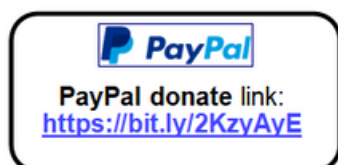
We are very grateful that this edition of Post Polio Matters has been funded by the Evan Cornish Grassroots Fund via the Lincolnshire Community Foundation.

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Donations, Charity Incentives, Grants, etc Received (since last newsletter)	
Donation M	12.50
Donation Lincoln Buffaloes	250.00
PayPal Giving Fund	31.75
Grant from Lincolnshire Community Fund	725.00
Transfer of funds from SPPN	13,697.81
Bank Interest	6.19
Total	£15,336.06

This publication is provided free thanks to the
generous donations above.

We are very grateful!



Bank Transfer

Account name: **Polio Survivors Network**

Bank: **CAF Bank**

Account: **00014980**

Sort Code **40-52-40**

Lost in the System: When Specialist Care Becomes Only Advice

By Simon W. Parritt



For decades, a small number of specialist centres in the UK offered something invaluable to polio survivors and people with respiratory failure: not just expertise, but continuity and safety. These were places where clinicians understood our physiology, our equipment, and the fragile balance that keeps us alive. They were more than tertiary services — they were a safety net. That assurance has largely gone. Today, even long-term patients are often told that direct admission is no longer possible. Specialist units increasingly function as advisory services, offering guidance to local hospitals rather than admitting patients themselves. In theory, this spreads expertise. In practice, it can leave patients stranded between systems — and sometimes falling dangerously through the cracks.

A lifetime of perspective

I write from an unusual position. I first became a patient in such a service over fifty years ago, when post-polio syndrome was still dismissed as “all in the mind.” As a young man, I was among the early post-polio patients whose lived experience helped shape what later became the Lane Fox Centre. I later played a small role, alongside far more influential figures, in supporting its establishment and philosophy: that patients with complex respiratory conditions must be treated as whole people, not isolated diagnoses.

Alongside this, I spent decades working within healthcare myself — in teaching hospitals, medical schools, primary care, and the voluntary sector. That dual perspective, as both clinician and patient, makes the changes of recent years painfully clear. Economic pressures, workforce shortages, and system reforms have gradually diluted the founding ethos of specialist, person-centred care.

Polio is now a small and ageing cohort, but the principles that underpinned those services — integrated, psychologically informed care for complex neuromuscular conditions — are more relevant than ever.

A virus, a ward, and the gap in between

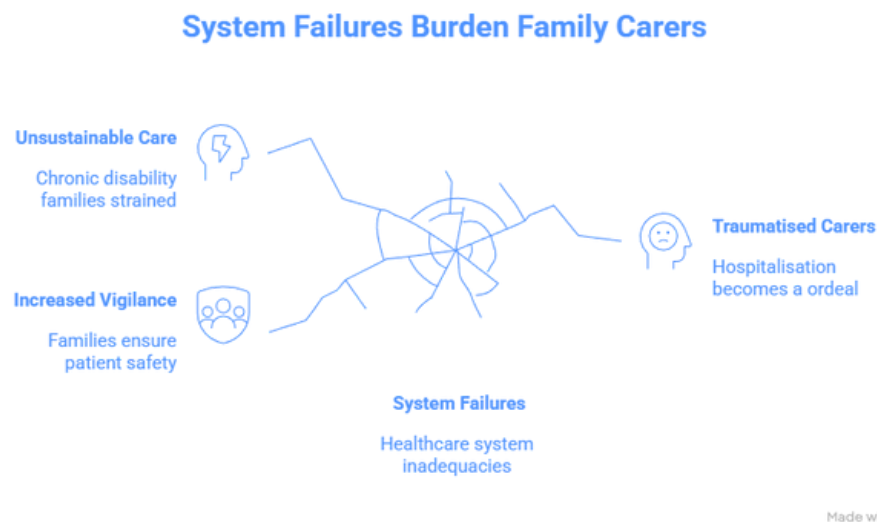
In 2024, I was admitted via A&E to a major South London teaching hospital with a respiratory virus that carried a real risk of tipping me into respiratory failure. It was my first emergency admission in over 25 years — and the contrast with earlier experience was stark.

Years ago, I could phone the specialist unit directly. If a bed was available, admission was arranged, even if it meant bypassing the nearest A&E. Today, that route simply no longer exists. Even transfers between hospitals a few miles apart are often impossible, regardless of clinical need.

After many hours in A&E, I overheard staff discussing that I was “too dependent” for the admitting ward meant to accept me. Eventually, I was admitted to a general respiratory ward, largely caring for older patients with acute conditions.

What struck me was not individual goodwill — many staff were kind — but the loss of skill mix and direct clinical presence. Much bedside care was delivered by healthcare assistants, while trained nurses were largely tied to computers. Digital systems, intended to improve efficiency, seemed instead to distance staff from patients.

Observation gave way to data entry; screens replaced eyes. For patients with complex, lifelong conditions such as post-polio and respiratory failure, this shift is not progress. It is a loss of safety and reassurance.



When advice replaces care

This experience exposed a dangerous gap between giving advice and delivering care. Specialist centres may offer excellent guidance, but if ward staff lack the training, confidence, or time to apply it, that advice becomes ineffective.

Hierarchy and professional pride can also obstruct implementation. Specialist input may sit unread or misunderstood, while patients rely on improvisation, persistence, and self-advocacy. This is not neglect — it is a system that has quietly lost the ability to translate expertise into action.

The hidden cost to carers

When systems fail, responsibility shifts to families. During my admission, my wife was at my bedside for up to eighteen hours a day, ensuring equipment was managed correctly and that I was safe. Without her, errors would almost certainly have occurred. For families already living with chronic disability, this level of vigilance is unsustainable.

Hospitalisation becomes an ordeal rather than a place of safety, leaving carers exhausted and traumatised. Families should never be expected to act as the clinical safety net.

Why specialist pathways still matter

The loss of direct admission routes for ventilator users and polio survivors is not just administrative — it is an erosion of safety. Specialist centres exist precisely because local hospitals cannot maintain deep expertise in rare, complex conditions.

NHS policy increasingly emphasises “advice and guidance” and “integrated care.” These are laudable goals — but integration fails when core competences are missing. A patient who cannot breathe unaided needs more than protocols and screens. They need teams who understand how quickly things can deteriorate, and why their bodies behave differently.

What could change

Restoring safety does not require radical reform, only practical steps:

- Shared admission pathways between specialist centres and local hospitals for known ventilator users
- Mandatory training in neuromuscular ventilation for respiratory and high-dependency staff
- Formal inclusion of family carers in care planning for long-term conditions
- Clear, actionable communication routes so specialist advice is implemented, not merely noted

The aim is not to criticise individuals, but to rebuild competence, trust, and safety.

A final reflection

Polio survivors are experts in adaptation. We have spent lifetimes making limited function work. But hospital care should not depend on our ability — or our partners' — to correct unsafe practice at our most vulnerable moments.

Universality in healthcare must include those whose needs are complex, not just common. For those of us living with post-polio syndrome and respiratory failure, the difference between advice and care is not semantic. It is the difference between reassurance and fear — and sometimes between safety and harm.

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Zsuzsi's Thoughts: My journey to the Netherlands



I have been using UTX swing callipers since 2001 when I first noticed that my left knee was hyperextending and being painful. At that time my husband had private health insurance from the company he worked for and instead of waiting 9-10 months for an appointment with an orthopaedic surgeon I managed to have one within a week. I took my copy of the British Polio Fellowship magazine, The

Bulletin, which had an advertisement for Ambroise, the company that made the lightest calliper and after a phone call to Ambroise by the orthopaedic surgeon, who agreed that it was the best solution to my problem, I had a meeting with a representative in my home who measured me up for the calliper. It arrived in about two weeks. I then had to present myself at the Orthotic department of the local hospital and maintenance of the device was taken over by the NHS. When it had to be returned to Ambroise in Holland for repairs I was without it for several weeks. So eventually a second calliper was made, but it was difficult to make the fitting right and when adjustments or repairs were needed, it took a long time to get it back because the hospital had to send it to Steepers Orthotics in Leeds, who were intermediaries in the process. Eventually we decided to drive to Holland for the fittings. This was in 2018 just before the lock down. By then I needed callipers for my right leg too and it was very difficult to persuade the NHS orthotist to provide me with a second calliper. I was told that they have not heard of anyone who needed them for both legs.

Earlier this year, in October 2025 we drove to Ambroise again, to their new premises in Enschede where we were met by Nils van Leerdam who invented the UTX swing calliper. It was his PhD thesis at the University of Twente, hence UT and X stands for IKS in Dutch or Intelligent Knee Support). This means that the knee bends in walking but locks at the end of the step.

We crossed the Channel from Harwich to the Hook of Holland taking an overnight cabin. This was a new experience because previously we crossed from Dover to Calais as we lived in Kent and then it was a long drive to Enschede on the border of Holland with Germany. This time it took less than 3 hours, and we arrived on time for the 11 o'clock appointment. The callipers were already made from the previous measurements and after the first fitting I went to have lunch at the hotel where we were booked in and returned to see Nils, at 3 o'clock wearing the callipers to have adjustments made. The same thing happened on the following day with adjustments in the morning and the afternoon. After that we said good bye and planned to travel back to the port the next day. But during the evening I still had problems and so we



returned the next morning for another tweak. We also brought with us the previous callipers that were made by Ambroise and Nils refurbished two for spare.

Enschede is a very nice clean town with a central church and pedestrianised streets radiating from the centre. They all look very similar, and it was easy to get lost. We found it hard to find our car which was parked in one of the side streets. But we did manage to find the bagel shop from our previous visit where they sell several different kinds of bagel filled with a large variety of fillings. They were delicious.

The British Polio Fellowship has the details of Ambroise representatives in England.

Dangers of Being Sedentary

An inactive lifestyle means long hours of sitting or lying down outside your proper sleeping time. Using the computer, watching television, working at a desk for long periods is going to have an impact on your health. When you don't move enough your metabolism and blood circulation slows down making you feel tired even if you get 8 hours of sleep at night. Burning fewer calories than you consume means that your body stores the extra energy as fat leading to gradual weight gain especially around your middle.

Sitting too much can also lead to muscle atrophy, loss of muscle mass and function in low back, hips, upper legs. Sitting for long periods can reduce the natural lubrication between joints and weaken muscles. Low levels of physical activity is linked to a variety of chronic diseases such as obesity, heart disease and high blood pressure.

There is a simple way to become less sedentary. Get up and start moving. Look for ways to include small amounts of activity throughout the day to break up periods of sitting. If possible, use a standing desk, and if sitting at your desk remember to stand up at least every 30 minutes. For best results choose an activity you enjoy which involves movement and do it regularly.

Remembering Verite Reilly-Collins

Verité Reilly-Collins lived a life defined not by illness but by the extraordinary courage with which she faced it. Born in Exeter in 1938, her teenage years were abruptly transformed when, at just fifteen, she contracted polio while living in Istanbul.



The disease struck with devastating force, leaving her gravely ill and dependent on an iron lung at the Royal National Orthopaedic Hospital in London. Doctors doubted she would ever walk again. Yet after two years of treatment, she defied expectations, regaining mobility and proving that determination could overcome even the harshest odds.

Her survival of polio shaped the rest of her life. Rather than retreating, she became a trustee of the Polio Survivors Network, dedicating herself to raising awareness and ensuring that others received the understanding and care she had fought so hard to secure. Her voice was clear: polio survivors deserved recognition and tailored medical support.

Years later, Verité faced another formidable challenge — cancer. Once again, she refused to be defined by suffering. She launched the AfterCancers.com website, a space filled with practical advice and personal reflections. Self-pity never appealed to her. Instead, she wrote with wit and candour, critiquing healthcare failings and urging patients to take control of their journeys. Her blog posts captured her fearless tone. In “Save the NHS – Bring Back Matron”, she declared:

“We don’t need sympathy. We need efficiency, discipline and someone who knows what’s happening on the wards.”

In another entry, “Going Private”, she wrote:

“If the NHS can’t provide timely treatment, patients will look elsewhere. It’s not betrayal — it’s survival.”

These words reflected her refusal to accept mediocrity in care. She blended humour with honesty, offering practical wisdom that reassured others they were not alone.

Beyond health advocacy, Verité was a woman of enterprise. She founded the Union Jills, a team of women promoting British goods abroad. Feminist writer Germaine Greer singled out this achievement in *The Female Eunuch*, praising it as an example of female success in business. Verité’s independence was unmistakable. She spoke five languages, travelled widely, and built ventures that reflected her resilience and vision.

She was also a prolific author, credited with writing 17 books. Her works ranged from health and beauty guides (drawing on her experience as a Beauty Editor) to broader reflections on healthcare. She even wrote about skincare for cancer survivors, restoring dignity and confidence at a time when many felt stripped of both.

Verité Reilly-Collins passed away in July 2025 at the age of 86. She left behind a remarkable legacy of resilience and compassion. Survival, for her, was never just endurance. It was turning hardship into hope and personal battles into collective progress. By sharing her experiences of both polio and cancer, she gave voice to communities often overlooked.

Toni Writes ...

We are delighted to welcome those who have joined the Polio Survivors Network following the closure of the Scottish Post Polio Network. Change can sometimes feel unsettling, but please be assured that you are now part of a community that values your experiences and stands beside you.

**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

You are not alone and our network exists to provide support and information, ensuring that every survivor's voice is heard.

Trustees within our organisation come from all areas of the UK. Meetings are held online via Zoom or Teams, so distance is never a barrier. Becoming a trustee is not a heavy commitment, yet it offers a meaningful way to shape the future of our work. We warmly encourage our new members from Scotland (or any other member in the UK) to consider joining us in this role.

We also recognise that healthcare experiences differ across the UK. The realities of being a polio survivor in Scotland, particularly within NHS Scotland, may not always mirror those elsewhere. Your insights are invaluable. If you would like to advise us on these matters, we would be grateful for your guidance. By sharing your perspective, you help us ensure that Scottish survivors receive the support they require.

If you are interested in becoming a trustee or in advising us on NHS Scotland and the unique experiences of Scottish polio survivors, please get in touch.

Also if you have anything you would like to share in our next newsletter please send it in. It can be anything - a reflection, a photo, a poem, your life story, a laugh - we'd love to hear from you.

Take care
Toni



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From Our Readers

Are there any other Polio Survivors in the Network that have had spinal anaesthetic, and were there any problems? CW

Editors Note: Please get in touch (see page 7 or Back Cover) ***with any advice or experiences we can share with CW***

Thank you very much for the extensive info regarding PPS. I will surely enjoy reading and studying the useful material. GC

Thank you very much for your emails and for the information about PSN. I look forward to hearing more about the work of PSN and how the problems with PPS can be made more available to the broader medical profession. JM

Over the past year or so, my mobility has declined significantly, and it is good to be in touch once more with a supportive group of polio survivors, many of whom will be experiencing the same problem. I am looking forward to catching up with the Newsletters. D

Please see the below link to the article I wrote in the Rotary magazine. I have spoken about the survivors and how they must never be forgotten.

<https://magazine.rotarygbi.org/jeff-hall-polio-story-october-2025>

Many thanks, EM

A lovely piece about Verite in the Telegraph:

<https://www.telegraph.co.uk/obituaries/2025/09/12/verite-reily-collins-union-jills-border-terriers-tourism/>

I have been receiving the news letter for some time & did write to you about my experiences. I found your article very very interesting as it resonated with me on several aspects. I contracted polio when I was 11 in 1946, luckily for me it only affected my body from the waist down. I have tried to find out more about the hospitals etc that I was sent to but only found out that I was in Cuddington Isolation hospital in Banstead for a short time. I remember it well as I watched the fireworks on 5th November 1946. I have been luckier than you as although I use a walking stick & recently purchased a battery operated wheel chair. Have a lot of pain but nothing that cannot be managed. If there is any one who remembers Cuddington Isolation Hospital or mayday Hospital where I went for physio then please let me know. DG

Editors Note: Please get in touch (see page 7 or Back Cover) ***with anything we can share with DG***

Psychology - The Polio Experience: A Shared Legacy

This is an extract translated from an article originally published in Polio-France – GLIP, online magazine (France). I felt it was an interesting to read what many of us know but sometimes doesn't get expressed in the UK in quite such clear and importantly psychologically clear, and maybe brutal terms – take from it that we should be kind to ourselves and recognise the journey.

Simon Parritt, Chair of PSN

Universally known and feared since Ancient Egypt, poliomyelitis—also known as “infantile paralysis”—appeared periodically in epidemic form until the 1950s (with the widespread introduction of vaccination), causing functional impairments of varying severity in young children.

Brutally separated from their families, those affected spent weeks, months, or even years in rehabilitation centres, far from home, in total dependence on hospital staff. For their very survival, these “patients” had no choice but to follow the instructions of the medical profession:

“Be good and do what you are told. It's for your own good.”



They experienced a terrible sense of abandonment, a state of total dependence, and forced, painful rehabilitation, without explanation and without their consent—leaving them with no means of controlling their own destiny. In order to survive, they had to submit to the demands of others and comply unreservedly with authority, suppressing the expression of their personal needs. They learned to live by submitting to representatives of authority, denying their physical and emotional suffering and their very identity.

Upon returning home, they had learned that submission and emotional suppression were necessary if they wished to escape mortal danger—real and/or symbolic.

They were deeply imbued with the unquestioning ideology conveyed at the time by physical therapy, which was generally continued for some ten years after the initial illness.

After striving to meet the expectations of doctors and therapists, polio survivors then sought to satisfy the social expectations of those around them, however these were transmitted through their family, school, and wider environment.

What did these social expectations consist of?

“Be good-looking and healthy, intelligent, productive, and competitive.”

In attempting to conform to the mould of Normality, former polio patients therefore learned that they had to mask their damaged bodies, maximise their remaining physical abilities to make their deterioration less visible, and optimise their intellectual potential if they wanted to be accepted in a society full of barriers to be overcome at all costs—while knowing that they would never be entirely “acceptable.”

Most succeeded in minimising the visible signs of their disability and blending into society—but at what cost?

Source Acknowledgement: This text is a freely translated extract from the original French publication. The translation has been undertaken for informational and reflective purposes and does not claim to be a literal or definitive rendering of the original text. The translator gratefully acknowledges Polio-France – GLIP for the original publication and apologises for any inaccuracies, omissions, or loss of nuance that may have occurred in the process of translation.

Important Update: Closure of SPPN

We would like to share some important news with our members. The Scottish Post Polio Network (SPPN) has now formally closed, marking the end of a valued chapter in the wider polio community. Over many years, SPPN has provided support, information and friendship to survivors. SPPN’s legacy will continue to be felt.

As part of this transition, SPPN funds have been transferred to Polio Survivors Network. This strengthens our financial position and ensures that resources dedicated to supporting polio survivors by SPPN will continue to be used for that purpose.

While it is always bittersweet to see a long-standing organisation close, we are committed to honouring SPPN’s contribution by continuing to provide information and community for polio survivors across the UK. George Reid is currently our interim Scottish Advisor, please let us know if you too would like to be involved.

On behalf of everyone at Polio Survivors Network, we extend our heartfelt thanks to SPPN and wish all a hopeful New Year.

A Welcome to our Scottish Members

This edition marks an important moment for Polio Survivors Network (PSN). Following the unfortunate closure of the Scottish Post-Polio Network, PSN has been entrusted with representing polio and post-polio survivors in Scotland, including the careful transfer of remaining funds. We want to acknowledge this openly and respectfully.

We recognise that this represents trust, continuity, and hope — and we are grateful for it. We are equally clear that representation is not something we assume, but something we must earn and build, through listening, transparency, and collaboration.

Scotland, polio, and post-polio: listening, learning, and building together

Across the UK, polio survivors are living with the long-term consequences of an infection that for many occurred in childhood or early adulthood — often more than 60 years ago.

While experiences overlap across borders, the way care is organised and delivered differs between England and Scotland, and those differences matter.

As PSN now formally represents Scottish members, we want to begin by acknowledging those differences, and by inviting conversation rather than presenting conclusions.

How many people are we talking about?

Polio is often described as a “rare” condition — but rarity can be misleading.

It is estimated that around 20,000–25,000 polio survivors are still living in the UK today. Many thousands experience post-polio syndrome or other late effects.

In Scotland, best estimates suggest several thousand polio survivors, although precise numbers are not known.

The lack of accurate data is itself part of the problem. Polio survivors are often invisible in health planning, not because needs are small, but because they are poorly counted.

Similar needs, different systems

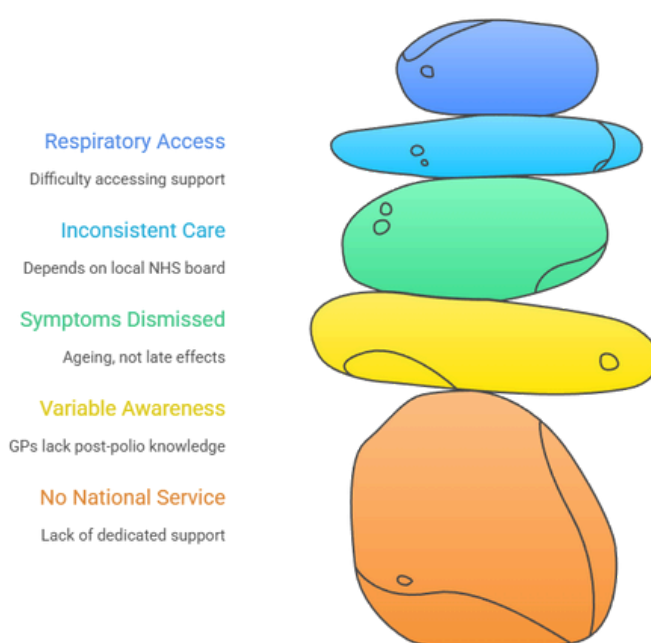
Polio survivors across the UK commonly experience new or progressive muscle weakness, severe fatigue, pain and joint problems, reduced mobility, and breathing or sleep-related difficulties. These are recognised late effects of polio, not unusual complications. However, how these needs are addressed varies.

In England — while services are far from perfect — there remains some concentration of clinical experience in post-polio and neuromuscular care, clearer (if informal) routes into specialist respiratory and rehabilitation services, and ongoing engagement between clinicians and national charities. In Scotland, many survivors describe a different picture.

What Scottish survivors tell us is missing

From long-standing accounts, and from early conversations now coming to PSN, recurring themes include the absence of any dedicated post-polio or late-effects service at a national level; highly variable awareness of post-polio syndrome among GPs and specialists; symptoms being explained as “normal ageing” rather than neurological late effects; care that depends heavily on local NHS Board knowledge and interest; and particular difficulty accessing respiratory assessment and long-term ventilatory support, despite this being a well-established risk for polio survivors.

For many, this leads to repeated cycles of having to explain their history, justify deterioration, and advocate for care while already fatigued or unwell.



Why this matters now

Most polio survivors are now older adults. The late effects of polio are not unexpected — they are a predictable outcome of long-term survival after widespread neuromuscular injury.

Without recognised pathways, informed clinicians, and coordinated care, people are more likely to experience avoidable loss of independence, crisis admissions, delayed respiratory support, and unnecessary distress.

This is not about special provision. It is about equity, consistency, and safety.

PSN's role, and our limits

As a UK-wide organisation now representing Scotland, PSN sees its role as listening before leading; amplifying Scottish voices rather than replacing them; sharing knowledge and good practice across borders; and advocating proportionately and credibly, grounded in lived experience.

We are clear that solutions for Scotland may not, and should not, simply mirror those in England. But absence of structure and visibility is not a neutral position.

An open invitation

If you are a polio or post-polio survivor in Scotland, we would very much like to hear from you. What has worked well for you within NHS Scotland? Where have you felt unsupported, dismissed, or overlooked? What would make the biggest difference to your health or daily life now? Would you like to be involved in shaping PSN's Scottish focus going forward?

You can contact PSN confidentially, contribute informally, or simply begin a conversation.

Moving forward together

The closure of the Scottish Post-Polio Network marked the end of one chapter, but not the end of advocacy, connection, or collective voice.

Our intention is that this becomes the beginning of a shared, Scottish-inclusive future within PSN, shaped with you, not just for you.

We are listening, and we welcome your involvement.



We're Still Here! This year's theme: "Protecting the Future: Lessons from Polio"

Post-Polio Health International held their annual campaign in October 2025. The campaign was established in 2007 with the goal of educating the healthcare community and the public that there are survivors of polio still in need of health care and still making the world a better place for all people with disabilities.



All week, survivors shared honest, powerful stories that cut through assumptions and showed what life with polio really looks like today. If you haven't explored the 2025 entries please click below

<https://post-polio.org/networking/were-still-here/wsh-2025-entries/>

My Name is Patrick Bird

I am Dean Emeritus, College of Health and Human Performance, University of Florida, and a 90-year-old polio survivor. I have written two historical/memoirs about my polio experience during my retirement.

A Rough Road. This book recounts my nine months of rehabilitation at the New York State Reconstruction Home after contracting polio in 1940 at age four. It is a bittersweet, often humorous story told in large part through the eyes of that child. This journey through the past is both a snippet of the history of past polio treatment and Paddy's own experiences.

The Gymnast: Disability, Sport and Romance. This coming-of-age narrative follows a working-class polio kid, Paddy, surviving the rough and tumble streets of New York City as a cripple, coping most self-consciously with the ups and downs of young love, and going on to become an All-American collegiate gymnast. Again, a heartening trip down memory lane full of humor and spirit. Accessible free at <https://hellgatetriborobooks.com/>

With the hundreds of thousands of polio cases having occurred worldwide, there are few personal books about living with the disease. I wrote these for pleasure and to also contribute to the scant polio narrative literature. Both books are available at Amazon Books, Barnes & Noble, and other book outlets.

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 fourth one entitled...



Consoling My Handler After He Lost Control Of The Chair Momentarily

I had had a long day in London and simply wanted to get home to Aberdeen and decompress. On this occasion my wheelchair handler was in his early twenties, looked little more than seven stone and his lack of interest in the job was palpable.

We made for the usual Gate 8a for the 8:00 pm flight to Aberdeen only to find the marshalling area totally deserted. As it happened the usual pontoon to the aircraft was out of service so everyone had been directed to the ground level lounge, listed as Gate 8b.

Unabashed, while texting from his airport phone, he pointed the chair at a steep ramp to the lower level, while holding only one of the chair handles. Whoosh! We were on our way towards a large window at the mezzanine level, which looked out onto the runway. Dropping his phone, he was simply a minor dead weight hanging onto an accelerating chair with my one hundred kilo body weight in it.

As we levelled out on the intermediate Level I managed to apply one of the side brakes causing the chair to spin away from the window, briefly pirouetting with a flail handler hanging onto the rear, almost throwing him through the window!

His phone was a write off and he was visibly shaken.

The approved method of descending such a ramp, I have since discovered, is to ease the chair down in reverse, with the handler better able to control the rate of descent, should the chair have no inbuilt "handler brakes" to the rear. Although I understand all current ones do.

The upshot consisted of me trying to console the handler, as we were both unharmed. Looking back, I should perhaps not have been quite so compassionate.

A Piece by Moz

Moz Copestake is a survivor who contracted polio in 1953.

Now in retirement, he accepted a volunteer role as a presenter at Radio Dacorum community internet radio

www.radiodacorum.org.uk



Doc Pomus (1925-1991)

Jerome Solon Felder was better known by his pen name as the famous blues songwriter Doc Pomus. He was the co-writer of many hit records and was posthumously inducted into the Rock & Roll Hall of Fame in 1992, having written songs for the likes of Elvis Presley, Ray Charles, Dolly Parton, Laverne Baker, Andy Williams and many more. But Doc Pomus was a polio survivor, having contracted polio, aged six, in New York. He spent a year in an Iron Lung and then walked for many years on crutches before being largely confined to a wheelchair in his 40s.

He played both piano and saxophone around the New York blues scene in the post war years with artists such as King Curtis & Milt Jackson and recorded with Chess & Gotham records. Later he befriended Bob Dylan (no less), who dedicated his book 'The Philosophy of Modern Song' to him. Many of Doc Pomus' hits were written in collaboration as the lyricist for Mort Shuman, who would write parts of the melodies. Their hits included "Teenager in Love", "Sweets for my Sweet", "Can't Get Used to Losing You" and "Viva Las Vegas"

However, the song I want to feature is his beautiful "Save the Last Dance for Me", recorded by the Drifters with Ben E King on vocals, in 1960 and inspired by Doc's wedding to actress Willi Burke in 1957. He was in his wheelchair by then and was happy that his bride should enjoy herself on her big day, so encouraged her to dance with the best man, the family and his guests, perhaps a sentiment that many readers can empathise with. It now features as the first dance in many wedding celebrations, though few will know of its origins.

It has been covered by a plethora of artists including Emmylou Harris, The Troggs, Nancy Sinatra and is reputedly the last song ever performed on stage by Leonard Cohen, as an encore in Dublin in 2013.

Doc's marriage lasted only nine years and he turned to gambling, becoming good enough to do it professionally until he returned to songwriting in the 1970's & 80's teaming up with the likes of Dr John and Willy DeVille. After his death in 1995 a tribute album, "Till the Night is Gone", was released - featuring artists such as Bob Dylan, BB King, Dr. John, Lou Reed and others. In 2012 his daughter, Sharyn Felder, put together a documentary film about his life "A.K.A. Doc Pomus".

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.



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Some excellent videos on the PPHI YouTube channel
<https://www.youtube.com/@post-poliohealthinternational>

Useful information on pain, medication and post-polio syndrome

British Polio Fellowship <https://tinyurl.com/mukktztt>

Mayo Clinic <https://tinyurl.com/3z2thsyk>

“Winter Changes Everything”

Living With Cold Intolerance as a Polio Survivor



I can always tell when winter is coming, not by the calendar, not by the weather forecast, but by the way my body reacts before the rest of the world even notices the temperature drop. For me, the cold doesn't just sting. It steals. It takes strength, energy, and ease in ways that are hard to explain unless you've lived through polio.

People assume I'm exaggerating when I say I dress for temperatures ten degrees colder than everyone else. But the truth is, my body doesn't hold heat the way theirs does. The nerves that should tighten my blood vessels and keep warmth in were damaged decades ago, back when the poliovirus swept through my system. I didn't know then that the effects would follow me into adulthood and into every winter.

When the cold hits, it hits fast. My hands turn purple. My feet feel like blocks of ice. My legs stiffen until walking becomes a negotiation between willpower and physics. Sometimes I lose so much strength that even holding a mug feels like a challenge. It's not dramatic; it's just reality.

I've learned to plan my life around warmth. Before I step outside, I layer up like I'm heading to the Arctic! I wear thin layers, thermal fabrics, wool socks, gloves even indoors sometimes. I heat my home to a level that would make most people peel off their jumpers, but for me it's the difference between functioning and fading. That comes with its own challenges with the rising cost of living though.

Hot baths are a luxury I treat with caution. They feel wonderful, but standing up afterward can make the room spin. I've learned to move slowly, to wrap myself in a robe immediately, to respect the strange ways my body reacts to temperature changes.

What people don't always see is the emotional side of it. Cold intolerance shrinks your world. It makes you think twice before going out, before making plans, before saying yes to things you'd love to do. It can feel isolating, especially when others don't understand why winter affects you so deeply. But I've also found community in other survivors who nod knowingly when I talk about cold limbs and sudden weakness. Maybe we can share more tips and remind each other that we're not imagining this but it can be managed with the right knowledge and support.

Winter still changes everything for me. But now, instead of dreading it, I prepare for it. I honour what my body needs. I stay warm before I get cold. And I remind myself that surviving polio once means I'm strong enough to face whatever the season brings.

Why Polio Survivors Feel the Cold More Deeply

Cold intolerance is a well-recognised late effect of polio. The poliovirus didn't only weaken muscles it also affected the body's ability to regulate temperature.

1. Damage to temperature-control nerves

Polio impaired the nerves that normally tighten blood vessels in the skin when we get cold. When those nerves don't work properly:

- Warm blood flows to the skin instead of staying in the body's core
- Heat is lost rapidly
- Hands, feet, and legs become cold and sometimes turn purple

This is why many survivors describe their limbs as "cold all the time," even indoors.

2. Reduced muscle mass means less insulation

Muscles generate heat. When polio reduces muscle bulk, the body simply has less natural warmth to work with.

3. Cold makes weak muscles even weaker

Research shows that when polio-affected muscles cool down, they lose strength quickly. This can lead to:

- Increased fatigue
- Difficulty walking
- Reduced hand dexterity
- More pain and stiffness

For many survivors, this is one of the most frustrating aspects of winter.

More information on Polio Survivors and the cold:

- https://post-polio.org/late_effect_polio/cold-intolerance/
- <https://www.polioaustralia.org.au/health-heat-cold-intolerance>

FOR HELP WITH THE COST OF LIVING:

England

<https://www.gov.uk/cost-of-living/disabled-or-health-condition>

Scotland

<https://costofliving.campaign.gov.scot/>

Polio eradication is within reach, experts say

Islamabad, Pakistan – November 2025

International and national experts meeting in Islamabad have reaffirmed that ending polio in Pakistan and worldwide is achievable if global efforts continue. Organised by the World Health Organisation (WHO) and Aga Khan University, the meeting brought together specialists in eradication, surveillance, and public health.

Speakers highlighted Pakistan's major progress over the past three decades. Since 1994, polio cases have dropped by 99.6%, from an estimated 20,000 annually to 74 in 2024 and 30 so far in 2025 — clear evidence that vaccination remains effective.

Despite this progress, experts warned that the situation is still fragile. The recent detection of wild poliovirus in Germany was cited as a reminder that the disease can reappear anywhere. They stressed that reducing vaccination or surveillance now would pose serious global risks and that the cost of stopping efforts would far exceed the cost of continuing them.

Several speakers described the current stage of eradication as the “last mile” — the toughest part, when fatigue and complacency can undermine success. Doctors with long experience treating polio patients urged the public not to forget how devastating the disease can be, noting that it appears milder today only because vaccination has been so widespread.

Experts also pointed to advances in surveillance, particularly in Pakistan, which now has one of the world's most sensitive polio detection systems. Modern genetic sequencing allows health teams to track virus circulation far more accurately than in earlier years.

The meeting also highlighted global achievements. Countries such as India and Nigeria have eliminated polio, and two of the three wild poliovirus strains have been eradicated. Today, only Pakistan and Afghanistan remain endemic. Representatives from Rotary International reaffirmed their long-standing commitment to eradication. Speakers concluded that polio can be eliminated, but only if governments, health workers, communities, and international partners remain committed through this final phase.

To find out more watch: <https://www.youtube.com/watch?v=jvyDMONHgko>



Lincolnshire Community Foundation's aims to create a county of thriving places where the people that live there are healthy, happy, resilient and empowered. We want to promote cohesive communities leading to a better quality of life and equality of opportunities for all, so that people are encouraged to contribute to society and fulfill their potential.

www.lincolnshirecf.co.uk

It is with grateful thanks to the Lincolnshire Community Fund for the grant we received from the Evan Cornish Grassroots Fund which has meant we have been able to provide Post Polio Matters Edition 131 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.ohiopoliionetwork.org

Polio Australia
www.poliohealth.org.au

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

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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

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