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www.poliosurvivorsnetwork.org.uk

POST POLIO MATTERS

Polio Survivors Network Newsletter – Volume 11 Issue 10 of 12 [Edition 130]



In this edition, we invite you to reflect on both continuity and change, as we share stories that highlight the collective strength and journey of our network. From thoughtful exchanges at this year's AGM to the arrival of a new Trustee whose experience brings valuable perspective and enthusiasm, we continue to grow in purpose and connection.

We're proud to include a vivid account of one Trustee's presentation to a distinguished group of Chartered Physiotherapists, bringing survivor experience into professional discourse and deepening mutual understanding. These moments of shared learning reinforce our commitment to awareness, advocacy and informed care.

You'll also find features that span art, history and community—from the groundbreaking Design and Disability exhibition at the V&A to the poignant closure of SPPN in Scotland and the enduring legacy of blues icon Brownie McGhee. Each story resonates with the themes of creativity, compassion and determination that define this community.

As always, your contributions—letters, articles, and reflections—infuse these pages with warmth and authenticity. We hope this issue inspires meaningful conversation and renewed connection.

We send you our very best wishes and want to say **“thank you for being part of our network”**.

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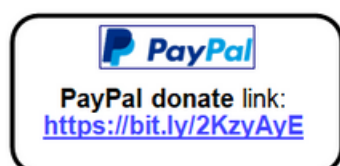
Donations and Charity Incentives Paid

(since last newsletter)

PayPal Giving fund	0.25
Donation S&P T	20.00
Donation DB	12.50
Total	£32.75

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

We are very grateful!



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2025 AGM Message From Our Chair

Simon presented the following piece at our recent Annual General Meeting (AGM) reflecting on January to December 2024.



Reflections on the Year

This year, PSN has continued to support our members with practical information, lived experience, responding to enquires, and advocacy relating to the long-term effects of polio and Post-Polio Syndrome (PPS). Our goal remains to help members live well with the evolving impact of having had polio—often decades ago.

A particularly significant and sad moment, personally and for the Charity in 2024 was the passing of our founder, Hilary Boone. Hilary's work in the late 1990s laid the groundwork for national recognition of PPS as a serious neurological condition in the face of much denial and ignorance about this now well accepted, though still sadly often an overlooked condition and an important co-morbidity to be assessed in holistic care. Her courage and determination continued to challenge medical orthodoxy and empowered countless survivors, not just in the UK but globally. We hope to continue her legacy in the coming years as best we can.

As the population of polio survivors in the UK becomes smaller and older, it is more important than ever that our voices are heard and that we work with other groups and professionals wherever possible, whilst emphasising the unique aspects of PPS. Increasingly, we find ourselves treated by services and professionals unfamiliar with polio's long-term effects, or unaware of how PPS may interact with ageing, other health conditions, and disability. Indeed, there will be few if any medical professionals in the west who have seen or treated an acute polio case or been involved in their ongoing care. PSN remains an organisation that specifically addressing these informational and education gaps in understanding. This can and does lead to polio survivors being treated according to generalised protocol and standards of care that provide sub optimal care and quality of life and in some cases lead to more serious outcomes.

Organisational Update

This past year we have worked hard to clarify our role, update our systems, and maintain our contact with members and the wider polio survivor community.

I want to extend particular thanks to Toni Dunlop our brilliant administrator. She has continued to streamline our records, oversee and rationalise the website and database, and managed both routine enquiries and compliance. Her work has been central to PSN's functioning and stability.

I'd also like to thank our trustees—Verite Reilly-Collins, Zsuzsi Snarey, for their time, input and consistent support, especially while managing their own health challenges. Their contributions have kept PSN running despite the challenges with care and commitment. I would also like to thank Ben Beck for offering to become a trustee, we look forward to him joining us.

Thanks to legacy gifts and donations, we have been able to keep membership free. However, I need to flag that this may need to be reviewed in the next year or two, as reserves are not unlimited. We remain mindful of the wider economic context and welcome any support, ideas, or fundraising suggestions.

Looking Ahead

Aside from our website and database, our newsletter remains our main tool for communication to members, offering advice, updates, and shared experience. We always welcome contributions from members and encourage you to write, however briefly, about your experiences. Whilst email digital copies remain the majority of our output, we remain committed to offering a print versions for members who may prefer them.

Finally, like all small charities PSN needs you, our members' involvement. We exist for you. Being on the committee isn't onerous—we meet virtually only a few times a year online and support one another. However, fresh energy and new ideas and perspectives are vital to keep an organisation relevant and well managed. Please do consider getting involved at any level you feel able. Thank you again for your continued support.

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Zsuzsi's AGILE Presentation 'Post Polio Syndrome'



Zsuzsanna Snarey, Trustee of the Polio Survivors Network (PSN), delivered a thoughtful and personal presentation at the Adding Life to Years conference held in May 2025 by AGILE. Zsuzsi offered a rich overview of Post Polio Syndrome (PPS) and her lived experience.

Rooted in both medical understanding and personal narrative, her talk framed PPS as the long tail of polio epidemics from the mid-20th century—a legacy that still shapes the lives of many, even as polio itself fades from public consciousness.

She began by outlining the biological impact of the polio virus, which attacks the anterior horn cells of the spinal cord, resulting in the death of some motor neurons. Recovery occurs when surviving neurons compensate by sprouting new terminal axons and re-innervating orphaned muscle fibres. However, over time, these overworked systems succumb to fatigue, age, or illness, marking the onset of PPS.

Zsuzsanna's own timeline of living with polio provided an intimate framework for understanding the condition. Diagnosed at age eight in 1949, she experienced partial paralysis and went on to recover much of her mobility during early adulthood. By 2005, however, she began experiencing significant deterioration attributed to PPS. Her journey from walking with one stick to using two sticks, callipers, a chair lift, and a mobility scooter illustrates the progressive nature of the syndrome.

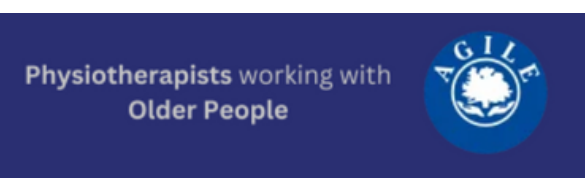
A key section of the presentation focused on physiotherapy for PPS patients, highlighting the importance of listening to individuals and adapting approaches based on their unique needs. Zsuzsanna challenged traditional models that promote the "no pain, no gain" mindset, arguing that such attitudes can be harmful for polio survivors. Instead, she advocated for targeted exercise—particularly focusing on unaffected muscle groups and incorporating cardiovascular activity to maintain general health—without exacerbating weakness or pain.



She also offered a detailed chronology of her physiotherapy experiences, beginning with childhood sessions led by her mother and a visiting physiotherapist in Hungary. At age 14, she underwent foot surgeries which led to further rehabilitation, followed by sporadic support in her adult years until a breast cancer diagnosis in 2005 prompted renewed attention to physical therapy. Her PPS diagnosis in 2007 led to more structured interventions, including referrals to neuro-physiotherapy services and hydrotherapy sessions in Margate. Since moving to Nottingham in 2018, she has utilised a blend of NHS and private services, including an exercise programme at Stapleford Care Centre and the OneStep app, reflecting a proactive and informed approach to her care.

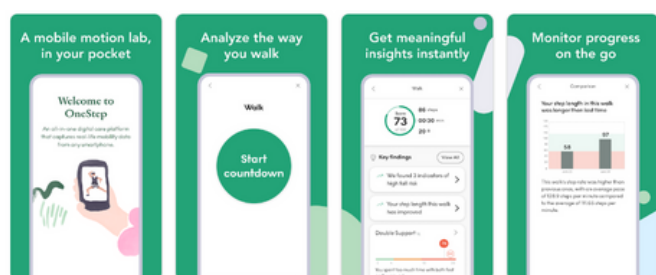
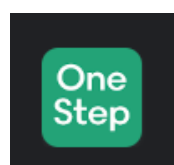
Throughout the presentation, Zsuzsi emphasised education and support as central to PSN's mission. She acknowledged the role of organisations such as the British Polio Fellowship in offering resources, but stressed the importance of providing extensive and accessible information to empower survivors and medical professionals alike.

Zsuzsi's presentation resonated with authenticity, offering a rare glimpse into how personal experience can inform advocacy, care, and understanding. It served not only as an educational tool but as a deeply human call for recognition, compassion, and continued dialogue in the treatment of PPS.



Website <https://agile.csp.org.uk>

AGILE is a Professional Network of the Chartered Society of Physiotherapy and is for therapists working with older people - whether qualified physiotherapists, assistants, students or associate members of an allied profession.

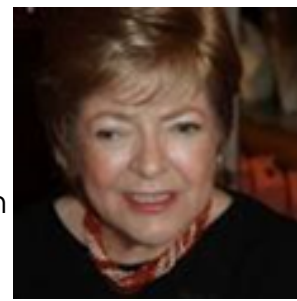


Zsuzsi used the "One Step" app for prescribed exercises and to motivate herself to stay active



Remember to avoid overexertion during daily activities and to focus on regular, gentle movement

Verite's Views-Can the V&A Encourage Better NHS Design?



The next blockbuster exhibition at London's Victoria & Albert Museum is Design and Disability, set to run until 15 February 2026. If previous exhibitions here are anything to go by, it will be well worth a visit.

Good news is that disabled visitors can purchase a free ticket – plus have a free ticket for companion/carer/wheelchair pusher. Also, there is free entrance for anyone on Universal Credit.

Design and Disability will showcase the radical contributions of Disabled, Deaf and neurodivergent people to contemporary design and culture from 1940s to now.

The V & A is the most disabled-user friendly museum I know. With Blue Badge parking for 12 cars by the Exhibition Road entrance, leading to a step-free entrance with an automatic-opening door and free wheelchairs available if wanted, they have really got what we need sussed.

The website has more on <https://www.vam.ac.uk/exhibitions/design-and-disability>



170 objects will be on display across three sections –Visibility, Tools and Living – spanning design, art, architecture, fashion, and photography. One example of the thought-provoking exhibits is the Squeeze Chaise Longue (Illustrated here), a recliner developed by artist Wendy Jacob, that embraces the sitter between two mohair arms, providing comforting sensory

feedback for those who appreciate deep pressure stimulation. Wendy was inspired to create the work with autistic animal scientist and agriculturalist Temple Grandin, inventor of the 'Hug Machine', on the design. The luxurious form of the chaise longue subverts conventional pared-back medical aesthetics.

More displays will show how Disabled people have designed for every aspect of life through their own experience and expertise, as well as trace the political and social history of design and disability. Through examples of disability-first practices showcasing the work of Disabled people and their collaborators, the exhibition will demonstrate how design can be made more equitable and accessible, and aim towards design justice.

Natalie Kane, Curator of Design and Disability says: "This exhibition shows how Disabled people are the experts in our own lives, and have made invaluable contributions to our designed world."

Hungry/Thirsty?

Afterwards, a large area in the museum is devoted to "a very nice café with a Museum attached." This has a wonderful array of what might be called Fast

Food, with lots of different main courses, tasty sandwiches, and a patisserie section to drool over. Like a canteen, you pick up a tray and fill it—but the food is far tastier. I enjoyed being wheeled around the different food stations choosing what I wanted to eat. You can eat inside in the opulent William Morris designed room, or outdoors in the Courtyard. Plenty of space for wheelchairs, and the staff are very helpful.



Design and Disability Exhibition

Design and Disability begins with a welcome and rest space for visitors to orient themselves and address any access needs. A tactile map, audio description, and BSL welcome will be available to visitors, as well as both large print, sensory map and plain English guides.

The exhibition's first section, Visibility, will explore how Disabled makers visualise and express their own identities across fashion, photography, demonstrations, graphic design and zine culture. Highlights include the hyper-visual ensemble by designer and activist Sky Cubacub, including their gender-affirming, adaptive garment Rebirth Garments Binder, which matches the Dragon Scale Head Dress that functions as a wearable weighted blanket; a handsewn Notting Hill Carnival Costume, inspired by Sandro Botticelli's *The Birth of Venus* by Maya Scarlette, a fashion designer with ectrodactyly.

Portrait photography in this section will include Marvel Harris' 'First Swim after Rebirth', a joyous self-portrait taken following gender-affirming surgery. As an autistic person who has dealt with issues of self-acceptance, well-being and gender identity, it celebrates Disabled joy. The second section, Tools, will explore the creativity of Disabled people in adapting and subverting designed objects to suit a greater diversity of access needs. This section challenges the way society views Disabled people as passive users of design, instead focusing on their inventing, breaking, adapting, and 'hacking' the designed world for themselves. Projects in this section consider how Disabled communities create design networks and work together collaboratively or individually to make new things.

On display will be the Touchstream keyboard by Wayne Westerman and Fingerworks (2005), a technology which revolutionised the tech industry and was later used in the iPhone 1. Designed to help with his severe hand pain, the

touchpad replaces a traditional keyboard, utilizing sensors to track movements like pinching, swiping and scrolling.

The finale of this section is a specially designed decompression zone for self-regulation, reflection, and rest. The area will include comfortable seats, a collection of objects designed by occupational therapists – many of them disabled themselves – to adapt existing designs, books and objects. Design, art, architecture, fashion, and photography will show how Disabled people have designed for every aspect of life through their own experience and expertise, as well as trace the political and social history of design and disability.

Who should visit?

Top of my list would be EVERY architect that bids for NHS work. Starting with the Architects who designed the Royal Marsden theatres after their recent fire. Showing the BBC TV new crew around, I winced when a Sister, showing off the special lighting, used her finger to switch on. They obviously haven't been abroad, where finger-tip switches are taboo; it's all done by elbows – they are cleaner.

Oxford's giant John Radcliffe Hospital is another where the architects and designers need educating. Recently a new set of signs were put in place – and taken down almost immediately (what did that cost?) Someone had had the “trendy” idea to paint lettering in grey on a white background. Not very sensible if you have poor vision.

But the Radcliffe classic must be the isolation room I was given when a hospital infection made me blind. My folded up clothes kept on being swept onto the floor, as I didn't have anywhere to hang them. I fumbled along the corridor to see Sister, who told me “I don't talk to patients”. Eventually I made so much fuss (I kept on tripping over clothes fallen on the floor) that Sister stomped down to my room. Told me I had a cupboard – then found the cupboard had been installed facing the wall! I could hear her bad-tempered attempts at wrenching it around, then “Oh” as she looked in and discovered there were no hooks or rails – it was bare.

Every time I have to use a loo there, I curse. The John Radcliffe loos must be the most unfriendly ones around.

Good design

Just down the road is Bicester Community Hospital, with very disabled-friendly loos. With plenty of room for wheelchairs, more than adequate sturdy grab handles, which are painted bright red – not only easy to grab but give a cheerful note. If Bicester can get it right, others should copy. Let's hope the V&A can encourage better hospital design!

Introducing Our Recently Appointed Trustee - Ben



I have known about what initially was the Lincolnshire Post-Polio Network (working name now Polio Survivors Network) for some years, having discovered for myself the value of their collection of research articles on the subject of polio and PPS.

When I learned, earlier this year, that this essential organisation now had only three trustees I immediately realised how great the need was for more people to put themselves forward. I made some initial enquiries, was invited to have a Zoom conversation with Simon, our Chair, then was duly put forward for election as a trustee at the AGM.

I was – and still am – a bit diffident about this. Although I'm a survivor myself, having contracted polio at the age of two in 1953, I've never really had any involvement in polio-specific organisations. My parents subscribed me to the BPF when it was still the Infantile Paralysis Fellowship, but as a child I hated seeing the bulletins, and was appalled when I found a photo of myself in one issue. At some point – I can't now remember when – I pulled out of the BPF, but rejoined sometime in the 80s, and happily took out a life membership. When life membership was abolished, I felt badly let down, and chose not to rejoin. My new involvement with PSN is the only direct involvement I've had since that time. Meanwhile, of course, I have experienced the increasing incursions of PPS.

I do have experience, however, of active work around disability issues. I spent the last 25 years of my working life at Southwark Council, in London, where I became active in UNISON, and for some years was chair of Southwark UNISON disabled staff self-organised group, where I was regularly involved in issues around reasonable adjustments and disability discrimination. For me personally my biggest issue as a disabled person was blue badge parking, of which there was never nearly enough to meet the needs of our mobility-impaired members.

I have also got plenty of experience in the voluntary sector. I was very active as a tenant rep in my local area, and got so involved in housing issues that I subsequently moved into housing as my job, while at the same time co-founding a tenant management organisation in New Cross, which has now been managing over 150 homes, on behalf of Lewisham Council, for over 30 years, and of which I'm currently chair. In the 90s, too, I was chair of the Deptford Tenants & Residents Forum.

I have also been chair of a primary school board of governors, member of the management committee of the North Lewisham law centre, secretary of a wrestling club (my son was the wrestler, not me!), volunteer at Huntley Film Archive, and chair of Voluntary Action Lewisham. I am currently chair of the Quaker Family History Society.

I graduated from Thames Polytechnic in 1973, then – much later – gained a master's in the history of photography, from what is now the London College of Communication.

This is probably already more than you wanted to know, but in the unlikely event you want to know more you could always visit my website, <https://benbeck.co.uk>.

We offer a warm welcome Ben as a trustee for Polio Survivors Network. We look forward to working together.

If you are inspired to think about becoming a trustee please get in touch for an informal chat.

Toni Writes ...



It was lovely to see some of you at our Annual General Meeting last month. You are such a lovely bunch (please come up with suggestions for what a collective of Polio Survivors should be called). The AGM honored Hilary's legacy and discussed the organisation's ongoing mission to support polio survivors, particularly as they age, with emphasis on raising awareness among healthcare professionals about post-polio syndrome.

The meeting covered operational updates including financial reports, trustee appointments. We are so pleased to welcome Ben Beck our new trustee.

We have always said we would review our free membership and financial position when nearing £10,000 and that time is approaching. At our AGM this was mentioned with discussion on suggestions for raising funds, possibly asking for donations of hardware or stamps and the pros and cons of reintroducing a small membership fee. All in the room were in favour of such suggestions and we will be discussing all opportunities over the coming months. Again, please let us know your thoughts.

The group shared personal experiences and challenges faced by polio survivors, particularly in accessing appropriate medical care and benefits, while highlighting the importance of tailored physiotherapy and patient advocacy.

As always please get in touch with any thoughts you wish to share.

Take care, Toni x



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From Our Readers ...

Excellent newsletter! Thank you so much! I am in America, but had my polio in the UK-
JW

SPPN to Close its Doors? PSN's sister organisation is considering its future

by George Reid, SPPN's Interim Chair

Every silver lining has a cloud.

Few know better than polio survivors the impact of the polio vaccine. We've witnessed the overwhelming eradication of the scourge of polio in just about every developed country, reinforced by the highly effective vaccine programmes of governments and agencies worldwide, as well as by key organisations such as Rotary International.

So we in Scotland can hardly complain that the residual impact of polio here is now confined - though with some important exceptions - to an ageing and declining cohort. It must have always been known, and accepted, that charities such as SPPN would have a fixed lifespan, however long that might turn out to be.

And now, frankly, time and circumstances have caught up with us. Like other polio charities throughout the world, SPPN has been struggling for some years in a number of ways. We're finding it very difficult to fill Trustee vacancies and indeed to find a permanent Chair. Membership has fallen greatly. As a formerly very active campaigning organisation, we often feel that we're now no more than treading water.

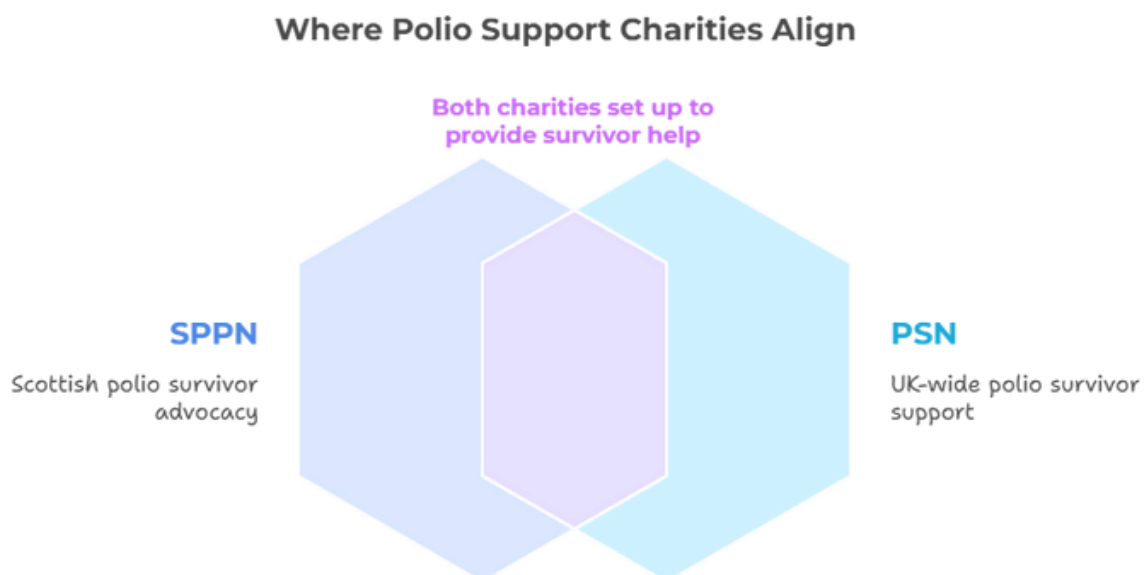
So SPPN's Trustees, with a very heavy heart, have reached the reluctant decision to recommend to members that the charity should be dissolved after 25 years of supporting and speaking up for polio survivors in Scotland. In that time, SPPN has been an important part of a 'united front' - alongside sister organisations such as PSN and BPF - in lobbying the respective governments and health services within the UK on behalf of survivors. SPPN looks back with huge pride and satisfaction on a rich history of activity and achievement. A history of compassion, dedication, and an unwavering commitment to improving lives.

So what does the future hold? It would have been far more difficult to close the doors of SPPN had it not been for our very positive relationship with PSN, which dates back to the founding of both organisations. In our own consultations with SPPN members (who overwhelmingly understand the reasons for dissolution) we have already been actively encouraging members to join and play an active part in PSN. In turn, PSN has been extremely understanding of SPPN's difficulties, and indeed has told us that it may well look kindly on options to extend its own future reach to north of the border. We hope to build on this very positive relationship as we jointly look to look at ways of providing future advice and support within PSN on Scottish issues.

It's hard to fully stave off regret when an active, campaigning charity finally runs out of steam in the way which it was always envisaged SPPN would. But those of us who intend to remain active campaigners in Scotland, even after SPPN ceases to exist, are determined to channel our enthusiasm within PSN, and to provide our friends in PSN with whatever structural and representative support they feel is helpful for the future.

And we hope to bring as many of our members as possible into PSN's world.

Editor: We're saddened by the closure of SPPN and deeply understand the challenges that led to this, as we face many of the same pressures. We offer a warm welcome to any SPPN members joining PSN and we're here to support you however we can. We share the gratitude expressed above and encourage anyone to share their story, also anyone interested in becoming our Scotland Representative or exploring a trustee role we urge to get in touch. Your voice and energy could make a real difference.



Far Fetched by 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 third one entitled...



Becoming A Hate Object In A Blizzard At Schiphol

While not as hairy as some of the other tales, this one was no less disruptive. My two ambi-lift handlers, a pragmatic, middle aged male and a vivacious, younger blonde woman, both Dutch, collected me from the terminal routinely and proceeded through a light blizzard towards the aircraft.

En route they explained that we would use a "stair-walker" for reasons unknown. These things have the appearance of a sack barrow with the wheels replaced by four prongs on the same axle. Once ensconced and duly strapped into the contraption it was activated and fairly zoomed up half a dozen of the steps then jerked to an abrupt halt, in-front of a couple of hundred passengers queuing to board – in a blizzard. In an instant I felt the heat of hundreds of eyes scowling at me. To the great credit of my handler, she very calmly explained that I was safely locked in position and she would summon a fresh battery from her colleague.

It turned out he was already on the case and they exchanged batteries on the apron. Once plugged in we were away again at a rate of knots and I was soon welcomed aboard. The five minutes or so while the situation was remedied did of course seem like a lot longer and my heart went out to those stuck at the foot of the steps in pretty inclement conditions.



Professor Mike

I am an international polio lecturer on Zoom. I am a Professor of Microbiology at Touro University in New York. I am also a polio survivor. I knew Hillary Boone (founder of Polio Survivors Network) well.

I have a list of Polio Topics I love to present. I present all over the US, and I have presented to Beijing, Australia, and Canada. Below is the list.

Polio PowerPoint Presentations

- Polio Then and Now
- Bulbar Polio and the History of the Iron Lung
- Diseases, Syndromes, and Pesticides, that Mimic Polio
- Roosevelt: Guillain-Barre Syndrome or Polio?
- The Polio Vaccine & the Cutter Lab Incident (USA only)
- How Did We Get Polio?
- Did Ice Cream Cause Polio? (10 min presentation)
- COVID Epidemic vs the Polio Epidemics
- Using Comedy to Deal With Disability
- IVIG for PPS? Your Decision



Michael Kossove is Professor Emeritus and an Adjunct Professor of Microbiology at Touro University's School of Health Sciences. He is a polio researcher, international polio lecturer, and polio survivor. He can be reached by email to professormike2@aol.com.

We hope some of you reach out to Professor Mike directly but if you would like us to organise a presentation of any of the above topics simply contact us (see back page) and we can make the necessary Zoom arrangements.

In need of funding for braces or custom-made shoes?

Apply for a grant from the Siegfried Memorial Fund by submitting a short application along with an estimate from an orthotist or custom shoe maker.

<https://post-polio.org/siegfried-fund/>

POST-POLIO HEALTH
INTERNATIONAL

About Resources Networking

The Joyce & Arthur Siegfried Memorial Fund

About the Fund
For some, living independently is curtailed by lack of funding for very personal items, such as braces and custom-made shoes. In 2012, the Polio Network of New Jersey (www.njpolio.org) established The Joyce and Arthur Siegfried Memorial Fund at Post-Polio Health International with an initial gift of \$7,500.



In need of funding for braces or custom-made shoes?
Apply for a grant of up to \$800 from the Siegfried Memorial Fund by submitting a short application along with an estimate from an orthotist or custom shoe maker.

[Download Application](#)

Brownie McGhee-Triumph Over Adversity

by Moz Copestake

The Coronavirus vaccine controversy spread into music recently when Neil Young and Joni Mitchell took steps to remove their music from Spotify, calling on the company to “take action against the mass-misinformation events which continue to occur on its platform” after it hosted a podcast by Joe Rogan in which he interviewed an alleged spreader of misinformation about the Coronavirus, the discredited scientist Robert Malone.

Mitchell and Young, like me, overcame childhood polio in the pandemic of the 1940s and '50s, as did a number of musicians of our generation; Judy Collins, David Sanborn and, from this side of the Atlantic, Donovan, Steve Harley and most famously, the late Ian Dury. The vaccine introduced in the fifties largely eliminated the disease, certainly in the developed world. It's little surprise then that these celebrities champion vaccination.

However, my focus is on a musician born a generation earlier. Walter Brown “Brownie” McGhee (November 30, 1915 – February 16, 1996) contracted his polio aged four in 1920. Different times, different culture. He was born in Knoxville, Tennessee, in the segregated Deep South and only fifty years after a bitter civil war to end slavery. Born to George Duffield and Zella McGhee (née Henley), who had married in Monroe, Tennessee in 1910, by the time the family moved to Kingsport in around 1921 his mother was no longer with them. George was a proficient guitarist and singer who accompanied his brother-in law, John Evans, on fiddle at local dances. It was John who built Brownie his first instrument, a five-string banjo, from a marshmallow box and a plank, which was given to him at the age of seven to help him recover, polio having badly crippled his right leg.

Recorded by the University of Washington in the late 1960s, Brownie said “Being from a broken home, don't know what caused my mother and father to separate. Never bothered me any. I used to be a junk boy in my day. Don't get the wrong impression. I used to pick up paper and garbage, iron and old tyres. Things like that.” Brownie had two older sisters, Ella and Verdia, who taught him to play piano and, more famously, a younger brother, Granville, who became known as “Stick” McGhee, because he was invariably seen steering Brownie around in a crude wooden cart using a pole. Stick was also a musician and wrote and recorded ‘Drinkin’ Wine Spo-Dee-O-Dee’ which got to number two in the American R&B charts in 1949 along with two cover versions that also charted that year. Jerry Lee Lewis took it into the Billboard Hot 100 in 1973 and it has subsequently been recorded by Johnny Burnette, Mike Bloomfield and Richard Thompson amongst others. Brownie would usually include the song in his sets.

In that University of Washington interview he went on to say, “I had a little one room shack, the sun shined in through the cracks, it rained in on me too.” Life was tough, but he made a fist of it as he says in his song ‘Don't Pity Me’. The first song he learnt on his home made banjo was Jim Jackson's ‘Kansas City Blues’, a tune he would often perform after he achieved fame and one which was also the basis for many other songs he would write. He liberated himself from the cart and managed to get around with crutches and sticks but, not being able to join in fully with other children, he spent time with the guitar, banjo and piano, gradually honing his style and ability. His father didn't approve too much of strumming and encouraged a finger-picking style which served Brownie well over the next fifty years. He stayed on his father's farm in Kingsport during the 1930s, helping with the farm work and singing with a local gospel band, The Golden Voices. Then he moved on to play with The Rabbit Foot Minstrels until, in 1937, he had an operation on his foot that enabled him to walk without crutches, although still with a noticeable limp. “I just wanted to pick up my guitar and start walking. And that's just what I did.”



Brownie McGhee - Born and Living the Blues



172K subscribers

Subscribe



58



Share



Download



Why not search Brownie McGhee's music on YouTube

His operation was funded by the American 'March of Dimes' programme, started by President Roosevelt that year, himself badly paralysed by polio. It was a foundation initiated to support polio victims and their families, with research into treatments and a possible vaccine. There is an interesting video on YouTube of Howard Keel singing 'You'll Never Walk Alone' in 1952 (a song written in 1944 for the musical Carousel) for the March of Dimes Campaign which illustrates just how virulent polio then was.

Here I need to introduce Saunders Terrell, (born October 24, 1911, Greensboro, Georgia, died March 11, 1986, New York). Born into a farming family and blinded by an accident aged sixteen, he was an innovative and accomplished harmonica player, taught by his proficient musical father, Ruben. In the 1930s he moved to Durham where he played the tobacco warehouses along with The Reverend Gary Davis and Blind Boy Fuller. Sonny was invited to appear in the Carnegie Hall Spirituals To Swing concerts at New York's Carnegie Hall in 1938 and 1939 just before he met Brownie and they both started recording with Blind Boy Fuller. He was inducted into The Hall Of Fame in 1986, the year he died.

Soon after his surgery Brownie and Sonny got together and played for the legendary Paul Robeson. Okeh Records' scout J. B. Long, who'd already steered Blind Boy Fuller to Okeh, recorded Brownie as a solo artist in 1940 and, following the death of Blind Boy Fuller the following year, soon paired him up with Sonny Terry to record 'Workingman's Blues'. Brownie wrote 'The Death Of Blind Boy Fuller' to commemorate their late collaborator. The partnership with Sonny proved fruitful so Brownie relocated to New York in 1942 to room with Sonny and Huddle Ledbetter, better known as Leadbelly to you and me.

Soon after this, their friend, the Reverend Gary Davis also moved there to join them in the tight knit blues folk community, which included Woodie Guthrie, Big Bill Broonzy (with whom he recorded 'Key To The Highway' and the influential Pete Seeger. However, it was Sonny & Brownie who went on to have a successful recording and touring career together. They made over a dozen albums between 1950 and 1975, putting them in the perfect place to take advantage of the sixties blues and folk revival. Brownie also released some solo albums, about half the number recorded with Sonny, but it is hard to be precise due to collaborations, compilations and dubious releases. He also opened The Home Of The Blues Music School in 1942 where he taught for eight years. They were regarded as folk artists but also played as a jump blues band (a forerunner to rock and roll) in bands with Champion Jack Dupree and Big Chief Ellis under various guises such as the Jook House Rockers or the Buckhouse Five.

He began writing his own songs including 'Sportin' Life' about the last letter he received from his mother. "My sister went and told her what kind of life I was living and she sent me a message that said, 'I want you to change your ways.'" During the war he performed with Sonny & Woody for The Office Of War Information radio shows which were often broadcast by the BBC to forces in the field. In 1947 he did his first movie soundtrack for The Roosevelt Story, acknowledging his respect for another polio survivor and his role in the surgery which allowed him to walk again. In 1948 he had a big R&B hit with 'My Fault' on the Savoy label with Hal 'Cornbred' Singer accompanying him on tenor sax. There were many 78rpm singles released in the early years but it wasn't until the start of the fifties that he got to release albums, both with Sonny and a solo artist. Many early releases were on the Folkways label and were initially mainly compilations of the forties recordings.

There were collaborations with Lightning Hopkins, Big Joe Williams and Earl Hooker. Brownie (often with Sonny) also pursued work in the theatre and films in the late fifties, appearing on Broadway in Tennessee Williams' Cat On A Hot Tin Roof and Finian's Rainbow and did a number of film soundtracks including for Face In A Crowd. Sonny & Brownie toured with Harry Belafonte and they also accepted a few invitations to tour Britain where there was some interest being shown in black American blues.

In the sixties the duo appeared on Pete Seeger's Rainbow Quest TV show and there are excellent YouTube clips of them playing and being interviewed, one including the revelation that Sonny played his harmonica upside down. This is a 'cross note' technique for the diatonic harmonica to allow it to be played in a key other than that for which it was designed. Then, in the sixties, came the blues revival boom in Britain which wholeheartedly embraced the music of Sonny & Brownie, along with so many others. They, of course, embraced it right back. It was a time when they made many concert tours in Europe and appeared on the BBC and other European stations. Into the seventies and festival appearances here included The Lincoln Folk Festival in 1971. Rob Wheeler, a friend of mine, remembers "It was an amazing line up for a small festival, I can recall these two great blues men quite well, stomping and hollering and [playing] truly great harmonica, that's what stood out for me. Great characters, having fun playing the blues for a bunch of English hippies in a rural Lincolnshire field!"

Not that Brownie and Sonny's four decade relationship was without problems. They would frequently argue and fall out, occasionally on stage and, at times, arriving and leaving venues separately, having an amnesty purely for their time on stage. In 1974 they were given their own one off In Concert show by the BBC. Playing well-honed songs, they performed 'Ride 'n' Roll', 'Livin' With The Blues', 'Conversation With A River', 'Rock Island', 'Walk On' and more. With lots of easy banter and reminiscences, the underlying tensions were skilfully contained, for a while at least. Soon after they had a big falling out whereby Sonny would appear with another guitarist and then Brownie would do a solo set.

Also in the seventies Brownie (occasionally with Sonny) made a number of TV series and film appearances, playing as the archetypal old blues performer. Many of these clips are great performances in their own right. In 1982 they were both awarded National Heritage Fellowships by The National Endowment for the Arts in the U.S. Ten years after Sonny's death Brownie died of stomach cancer on February 16th, 1996 in Oakland California, not long after one of his last concert appearances at the Chicago Blues Festival the previous June. He was an inspiration to many, especially those afflicted by polio and other debilitating conditions. I like to think that some of the musicians listed at the beginning of this piece took some inspiration from him but I have no evidence (yet) to support that idea. He overcame considerable childhood hardship to become one of the great ambassadors for the blues in this country and I always enjoy it when a band says "We'd like to do a Brownie McGee number next". His relationship with Sonny Terry may have been tempestuous but together they left an indelible mark on the second half of the last century and their music stands up today with many YouTube videos enabling us to witness their charisma.

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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



The legacy of Jonas Salk and Albert Sabin—names you may not be familiar with

by Moz Copestake

In the early 1950s, polio ran rife throughout the world, afflicting many thousands of children and killing a high proportion. It was also known as Infantile Paralysis. Doctor Jonas Salk was developing his 'killed virus' polio vaccine, testing first on animals, before moving on to limited scale trials on humans including, in 1953, on his own children – a great leap of faith. The following year extensive vaccination of around one million was carried out. The results were conclusive. Here was an effective protection against the disease. In April 1955 it was officially recognised as safe and immediately adopted by the World Health Organisation as an Essential Medicine. Inoculations began almost immediately, due to the alarming rise in cases, meaning that the disease was largely eliminated in the developed world from the mid fifties.

The project had been largely organised and funded by “The March of Dimes”, a non-profit foundation started in 1938 by American President Franklin D. Roosevelt, himself a victim of polio when aged 39 (although some historians now dispute this diagnosis), and his wife Eleanor. The name was coined as a play on “The March of Time” as a catchier title than the original “National Foundation for Infantile Paralysis”. There is a memorable YouTube of a short Howard Keel Newsreel, in support of the Foundation, singing “You’ll Never Walk Alone” from a rather grim polio ward in 1952. It gives some idea of the ages and conditions of patients of the day. <https://www.youtube.com/watch?v=wwHQ5nDWOUl>

At the same time, an alternative vaccine was being researched by Doctor Albert Sabin, based on a different technology – a live strain of the virus which did not cause paralysis but did create antibodies. This was not funded by The March of Dimes. Its clinical testing lagged a little behind the Salk vaccine. There are three types of polio virus, known as PV-1, PV-2 & PV-3. The 'killed virus' vaccine was effective against all three strains but a separate vaccine had to be developed for each of the three variants and these were proven individually throughout 1961 and 1962. They were then combined into a single dose vaccine. This had two big advantages – it was cheaper and was administered orally on a sugar cube, which most of us will be familiar with, rather than by injection.





Despite these two giant steps forward, polio persisted in inflicting its long-lasting symptoms throughout many poorer countries and those without a good health infrastructure. There were significant outbreaks in Spain and the Caribbean in the late fifties and early sixties. It continued to be rampant at times in South East Asia and Africa into the new millenium, despite the cost of the oral vaccine being well under one pound per dose. Some cultures and governments remained anti vaccine due to ignorance, superstition and cost considerations. Two of the strains, PV-2 and PV-3 have now been wholly eliminated, last recorded cases being reported in 1999 and 2012 respectively and declared eradicated in 2015 and 2019. This only leaves PV-1 at large in the modern world from the original virus strains, huge progress. However, a new strain has mutated, known as circulating vaccine-derived poliovirus, from the live virus used in vaccines. While this is not infectious in vaccinated populations, it does create infection in vulnerable populations, so that, there were more cases of the mutant reported in 2017 than of the original wild virus.

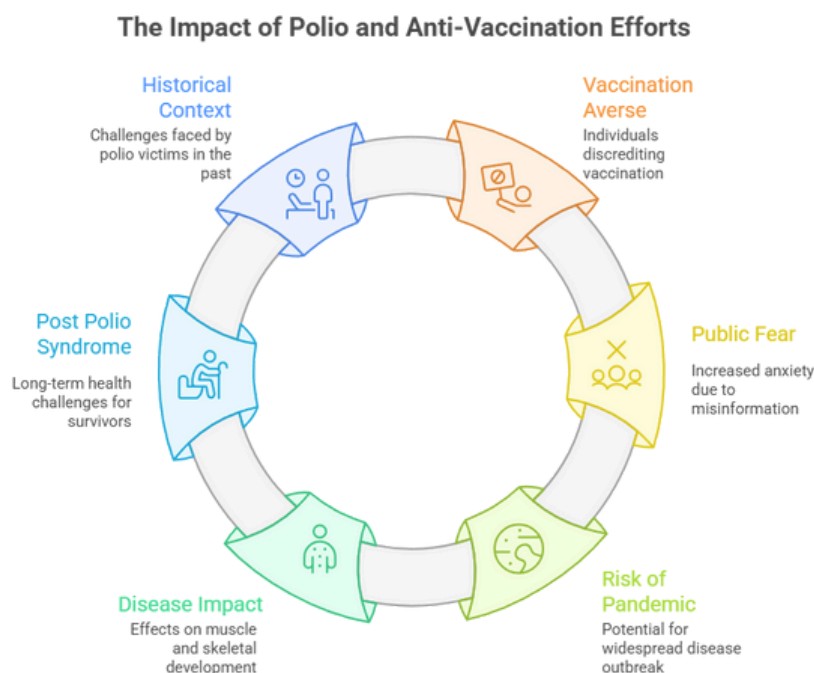
In India, the disease was finally eliminated in 2013, following a massive immunisation programme for its huge population. Zero cases were reported that year, not that the disease can ever be wholly eliminated, especially in unprotected populations, as the virus is quite resilient in sewage and untreated watercourses. Nigeria achieved a similar status in 2016. Herd immunity though, a concept we became familiar with during Covid, has reduced numbers exponentially. As of last year the 'wild' disease only remains endemic in Afghanistan and Pakistan, reporting less than 50 cases altogether – down from a high of almost 200 in 2019 – although the mutant variant also circulates in these areas.

Oral vaccinations today have become a routine part of childhood with parents protecting their families, barely aware of the suffering the virus once spread among the global population, with epidemics emerging in a constant ebb and flow throughout the world in the first half of the last century and earlier, affecting millions. While it often killed, attacking the nervous and respiratory systems after being ingested, usually through contaminated water, the survivors were left with severely wasted limbs or breathing difficulties which could confine them to an iron lung for long periods, or even the rest of their lives.

It is frustrating to see the actions of antivaxxers discrediting vaccination, raising fears in the population and risking a new pandemic. They cannot realise what's at stake and the misery that it will cause if polio again runs rampant in the world.

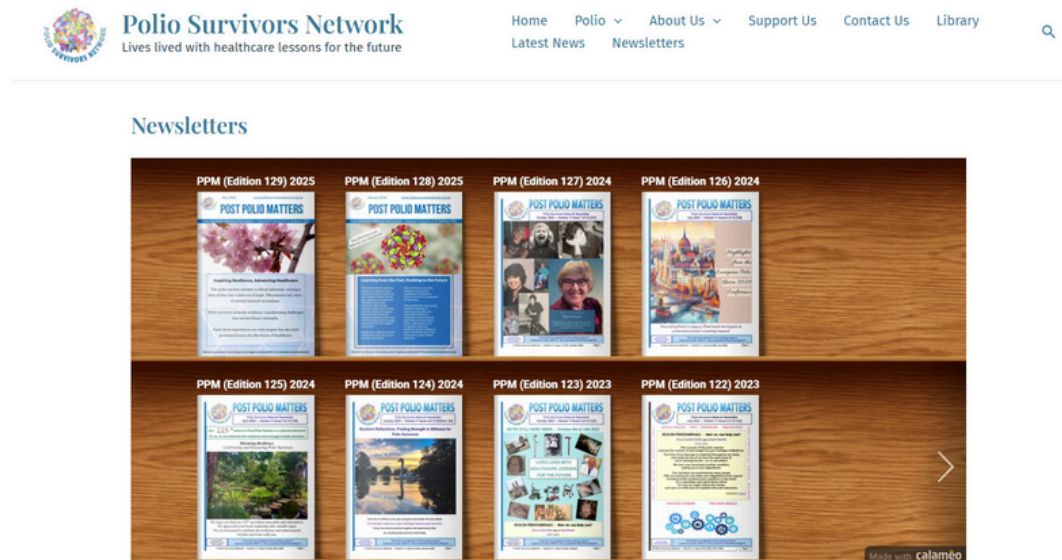
As the name 'Infantile Paralysis' infers, this is largely a disease affecting the very young, before their immune system has developed itself, although it can affect anyone. As the young are still growing, the muscle and skeletal development is impaired from the date of infection, preventing normal growth or usage, leaving victims with shorter arms and/or legs with restricted mobility. Unlike many diseases, these are not conditions which improve over time, rather they weaken so that sufferers invariably are diagnosed with Post Polio Syndrome (PPS) as they get older. As the disease has largely disappeared in the last half century, this manifests itself in the now aging population, at least those surviving.

It is impossible to understand the difficulties that polio victims have faced in their lives unless you are one of them, they are many and various with the old cliché 'Everyone's journey is different' being wholly applicable here. The Welfare State was in its infancy in Britain halfway through the last century. Those afflicted had to make their way in the world with little help, although the newly formed National Health Service was a boon, and many of them made a good fist of it, leading relatively normal lives. I can say that with some authority as I contracted polio in 1953 as a one-year-old. It has been tough at times but I am confident we had it much easier in this country than many of my contemporaries abroad. That said, PPS is ratchetting up the difficulties scale in mobility, scoliosis, fatigue and discomfort.



Newsletter Library on Polio Survivors Network Website

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www.poliosurvivorsnetwork.org.uk
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Researching vaccines that made me and friends ill in the past

by Barbara Taverner

Repeat flu vaccines may have led to death of my friend? She was with us one minute, running Devon IBS groups in Exmouth hospital, tripped over a flag stone, broke her wrist, then flu vaccine, flu, gone within weeks, a perfectly healthy woman. I and both my sons have likely been damaged with vaccines from the 1960's to 1975. Hep B vaccine 1978 caused M.S? Even the plague of Justinian 541-542 demonstrated symptoms of M.E and excessive sleeping and so on. Florence Nightingale caught flu - possibly a mild form of bubonic plague, she then only physically nursed for two years as became bed bound were she amongst other things invent the Pie chart, that is an interesting story.

I was so ill with rigours as a nurse at Royal Free in 1958. All our hospital beds were full so I was sent home. And 1963 and again 1968 ill with flu viruses and in 1975 after flu vaccine. I had polio vaccines 1955/56 as a nurse and 1961 as a midwife. Had severe tracheitis 1956 and nurses going down like flies with strep throats and being barrier nursed in a twelve bedded dormitory. That's where a doctor later thought I had had polio, whilst nursing children in iron lungs with polio, eventually flu March 1971 and I never recovered mutation of coxsackie b3 and b4 with flaccid paralysis.

As for polio vaccine 1955 some 250 cases of polio caused by some patches of polio vaccine. There was no system in place to be compensated by vaccine harm to some people.

Interesting study here

<https://www.ncbi.nlm.nih.gov/books/NBK221112/>

British Polio @Britishpolio · 7h
 Calling all photographers in the #polio community 📷 Our photo competition is NOW OPEN! Show us your best shots. Deadline 31 August



British Polio @Britishpolio · Jul 27
 Dear #polio survivors, share your fight. In poetry, step into the light. From quiet strength and silent fight, From nights endured and dreams held tight. Submit your poems before 31 August



British Polio @Britishpolio · Jul 25
 Get those paint brushes out. It's that time of year again for #polio survivors across the UK to submit their artwork to the Richard Flint Awards. Your deadline is 31 August. Good luck



Useful Resources

International Ventilator Users Network
www.ventnews.org

Disabled Motoring UK
www.dmuksdiscounts.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.ohiopolonetwork.org

Polio Australia
www.poliohealth.org.au

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