January 2025
www.poliosurvivorsnetwork.org.uk

POST POLIO MATTERS

Polio Survivors Network Newsletter — Volume 11 Issue 8 of 12 [Edition 128]

The PSN library now features over 450 articles!

Learning from the Past, Pushing to the Future

Polio survivors have overcome significant childhood illness, transforming their experiences into valuable insights. As they age, many face the additional challenge of post-polio syndrome, which brings renewed health issues. Despite this, they continue to support those in similar situations, including individuals with long COVID and advocate for greater recognition from the medical community.

Despite their resilience and the insights they offer, their voices are often overlooked.

Polio survivors are working tirelessly to ensure their experiences contribute to improve care and in preparation for the future.

Their journey from overcoming childhood adversity to becoming vital pillars of a supportive network is a testament to their enduring spirit. They strive to ensure a better understanding and recognition within the healthcare system, helping to build a world that learns from their past to create a better tomorrow.

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

Donations and Charity Incentives Paid (since last newsletter)	
Donations raised at RB’s funeral via MuchLoved	386.69
Donation VS	20.00
PayPal Giving Fund	9.66
Donation E&J P	12.50
Donations raised at HB’s funeral via MuchLoved (1st payment)	441.91
Donation A&N J	50.00
Donation EJ	20.00
Total	**£554.07**

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

We are very grateful!

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Message From Our Chair

As we enter a new year, it's a fitting time to reflect on our journey and the road ahead. It has always been my privilege to share updates, insights and personal reflections through our newsletters. These pieces of communication have been a cornerstone of our community, weaving together the stories and experiences of those living with the late effects of polio.

For many years, Hilary was the force behind our newsletters. Her dedication to producing and editing these was nothing short of remarkable. During the challenging times of COVID-19, Hilary went above and beyond, printing the newsletters herself and increasing their frequency to meet the heightened needs of our members.

However, life has its way of introducing new rhythms. Over the years, the demands and pressures of daily life have grown. Many of our members are dealing with the late effects of polio and as we age, these effects become more pronounced. Increased medical appointments, the need for personal care and the natural decline in energy levels are just a few of the factors impacted our ability to maintain the same level of newsletter production.

Advancements in digital communication have changed the way we share information. Social media, email updates and our website provide quick and more immediate ways to connect. Fellow polio support charities across the world are also sharing their latest information in this way.

It is with a thoughtful heart that I share our decision to produce newsletters less frequently. We plan to produce newsletters when we have a full newsletter to share, this will vary depending on the number and types of articles/experiences shared with us. This adjustment will allow us to better manage the realities of our daily lives and ensure that when we do connect with you through our newsletter, it is in a meaningful way.

While we may not be in your letter box or inbox as often, we are here to support and to share experience. Our online presence and resources are always available and we encourage you to reach out and share your stories.

Thank you for your understanding and ongoing support. Together, we can continue to help one another, even if our newsletters come to you at a slightly different intervals.

Simon Parritt, ***C.Psychol, AFBPsS, MSc, BSc (Hon), BA***
Chartered Psychologist. HCPC Registered Counselling Psychologist

Chair Polio Survivors Network
simon.parritt@poliosurvivorsnetwork.org.uk

Zsuzsi’s Thoughts on Ways to Increase your Bone Density

Bones need to be loaded. The saying we all know is: “If you don’t use it, you lose it.” This applies to bones as well as muscles. Maximum bone density is achieved at age of 25 for women, age 30 for men. After that the bones start to lose their mass very gradually. Astronauts lose 1-2% of bone a month because of the lack of gravity.

People who had polio are often not able to run, walk for long distances, jump or do other bone strengthening exercises and are more at risk for fractures due to osteoporosis. Bone is an active living structure. Bone is constantly being turned over. The inside of our bones is constantly being broken down and rebuilt by specialist bone cells, osteoblasts and osteoclasts. Osteoblasts form new bones and add growth to existing bone tissue. Osteoclasts dissolve old, damaged bone tissue so it can be replaced with new healthier cells created by osteoblasts. As long as this process is in balance, our bones should stay healthy and strong. But, if the process becomes out of balance, our bodies start to break down more bone than we build. This can cause the bones to become weaker and more likely to break easily. This happens with polio survivors as we age.

To keep bones strong, you need to keep in mind the following:

1. If possible, do weight bearing exercise. Try walking as much as possible, a weighted vest helps.
2. Strength training. Muscles pull on the bones and that encourages the bone building. Try doing squats, lunges, leg press, overhead press every day if possible.
3. A balanced diet is important, with plenty of protein, calcium, vitamin D, some nuts, zinc, magnesium, collagen, green vegetables, eggs. Calcium supplements with vitamin D such as Adcal.
4. Avoiding alcohol, stopping smoking, avoiding caffeine.
5. Bisphosphonates (Alendronate, Zoledronate) and also denosumab and romosozumab increase bone density. They work by slowing down the breakdown of the bone cells, but there are risks of side effects. There has been a very small incidence of atypical, or unusual fractures of the femur while on this treatment for many years. Some research has shown if 1,000

people were taking drug treatments, less than 1 person would have an atypical thigh bone fracture. For this reason, a “drug holiday” is recommended from bisphosphonates after about 5 years to prevent this happening. If you have been offered drug treatment to benefit your bones, the benefits will outweigh any possible risks. It’s important to take your drug treatment correctly. Make sure you read – and understand – the leaflet that comes with your treatment.

6. HRT has been shown to increase bone mass in post-menopausal women. It is not now recommended because of the link with breast cancer. Men can also have deficiency in testosterone. 1 in 7 men have osteoporosis.

To measure bone density a kind of X-ray, called a DEXA scan is used. You lie fully clothed on a table, having removed metal fastenings, while the scanning arm moves over your body. An X-ray detector measures how much X-ray has passed through different parts of your body. It is then compared to those of a young adult, (known as a T-score), a healthy adult of your age, (known as a Z-score). The difference is calculated as a standard deviation score. Between -1 and -2.5 is mildly reduced bone mineral density or osteopenia. Below -2.5 means it is osteoporosis. But someone with low bone density may never break a bone while another with average bone density could break several. Other factors play a part such as age, sex and type of fall.

Verite Reily-Collins Wonders … Can we learn from Royal’s Cancer Treatment?

A recent video showing the Princess of Wales playing with her family, set alarm bells jangling. This video was out-of-character and posed questions such as: were the Royal family being "used" to divert attention away from Darzi's report damning NHS cancer care? A report highlighting how cancer care in the UK lags behind what is offered to patients in other countries etc! Read more here: https://aftercancers.com/can-we-learn-from-royals-cancer-treatment/

A Few More Thoughts from Verite

Lord Darzi’s report spurs me to New Year's Resolution! 80% of us can suffer side effects from treatment, so Lord Darzi's recently published report on the NHS vindicates those of us who fight to get help with side effects; especially if we are ignored or treated like whistleblowers when we try.

It can be a constant fight for treatment; so with Darzi confirming the UK lags behind Europe for cancer care, it's up to us to fight for what we need. My New Year's Resolution is to help others get better care. Look at my website for information about products used in European hospitals to help deal with side effects of cancer drugs on our skin.

As an ex-Beauty Editor, this interests me. I developed skin problems from drug side effects, and Darzi's report confirmed I was right to be concerned. Countries, such as France, Australia, USA, Japan - even Iceland - have worked with hospitals, researchers, charities etc. developing skincare products specifically for us.

Now these are available in the UK, I can offer some via my website. I can't promise miracles, but they certainly helped me. I've looked for the cheapest prices, and Boots the Chemists seemed the best. You can order these skin care products here, and I keep an eye out for special offers.

https://aftercancers.com/dont-you-love-the-feeling-when-you-are-right/

Verite Reily-Collins
PSN Trustee, Health Journalist
Owner of www.aftercancers.com
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Toni Writes …

I couldn't agree more with the quote to the right from Hilary's article 'Polio Survivors Throw Doubt on Study'! Something clearly is amiss. Time and time again I receive queries, emails and phone calls from members or families of polio survivors who simply can't find a consultant with experience, knowledge or sometimes even an interest in polio or what it means to be a survivor.

> 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*

We need your help - have you had a positive experience with a consultant from anywhere in the UK even if this was a few years ago. We are hoping to compile a list of helpful contacts as recommended by our members. We know that not all healthcare professionals will be the right fit for each polio survivor but it's a start. Please drop me a line with anyone you have had a good appointment with so that we can reach out to them to see if we can signpost our members their way. We hope we can find a handful to start with. Also if you have had the good fortune with a sympathetic GP please let us know about your experience, we want to help share the positive news too.

Is it just me or did 2024 simply fly by? There were so many more things I was planning to do but didn't get to. I managed to book a short winter break to Budapest though so at least that broke up the dark nights a bit. You must have been to some interesting places in your time. Maybe drop me a line with a picture or a few words indicating your favourite trips and I can create a collage for the next newsletter?

Take care, Toni x

psnadmin@poliosurvivorsnetwork.org.uk

From Our Readers …

Thank you very much for your kind invitation to PSN, and the emails containing newsletters. I have been struggling with new health issues this year. I hope to find some answers and methods of coping with them. Thank you, NS

Just received the newsletter and I want to congratulate you on a most interesting and well put together copy! The pictures of Hilary on the cover are great! Thank you for all your hard work! ZS

From Our Readers (continued)

Well done - you have done a fantastic job getting all this information together in such a short time. You really did Hilary proud. VR

Can You Help Your Fellow Polio Survivor?

I retired from work 20 years ago due to me not being able to carry of full scope of my job due to pain, disability suffering breathing problems as well. I am under medical care & now that arthritis & a few other things have been excluded it would seem that Post Polio is the problem, it has been noted in my notes throughout. I take pain relief by mouth every day, not sufficient relief. So far I've had 2 injections into my back, when working it's good but there are weeks when I am in a great deal of pain & disability, next back injection is next month! I get the feeling that they will not carry on with this. Anyway this month I happened to be sitting next to to CBD liquid & I took 1 drop under my tongue early evening & slept well feeling less pain & disability next day. I've carried on with this for a week now & have felt much better!! Question: ***Do you know of other people using CBD oil in the same way for same reason & results?*** Please help me out! Thank you - AJ

Please email psnadmin@poliosurvivorsnetwork.org.uk **and we will send to AJ**

A long time member recently sent in a copy of a poem she was given when she was a nurse. It was originally written by Scottish Nurse Phyllis McCormack back in 1966. The poem is written from the perspective of an elderly patient in a nursing home, reflecting on her life. The word “crabbit” is Scots for “bad-tempered” or “grumpy” (in Lincolnshire we would say “mardy”).

https://vts.wm.hee.nhs.uk/Portals/5/Presentations/Full%20Day/Crabbit%20Old%20Woman.pdf

Can you help

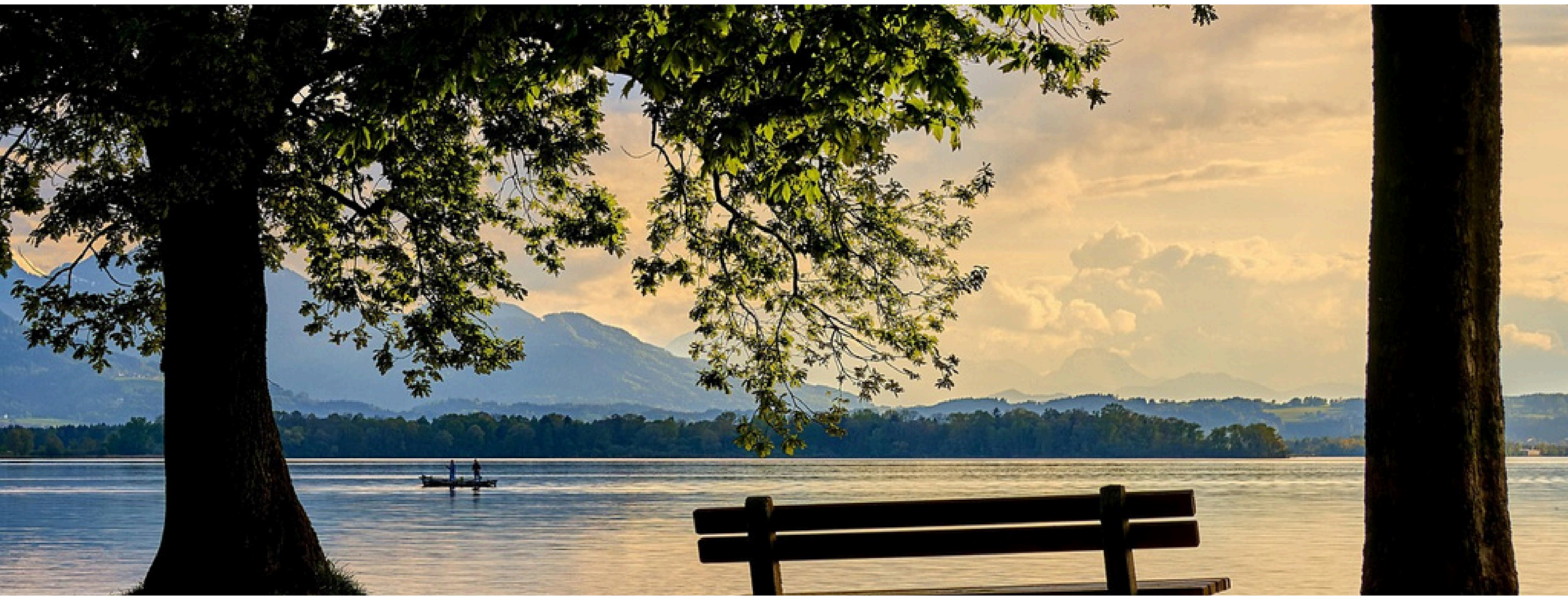
Rare Patient Voice?

CLICK HERE

for more information

Rest In Peace Dr Richard Bruno

We were sad to learn that Dr Richard Bruno, age 69, of Hackensack, New Jersey passed away on Monday 14 October 2024. His work on Post Polio Syndrome was second to none. Many of our members found his book The Polio Paradox especially helpful. Read Dr Bruno's full biography on the PA Polio Network's website https://polionetwork.org/bruno

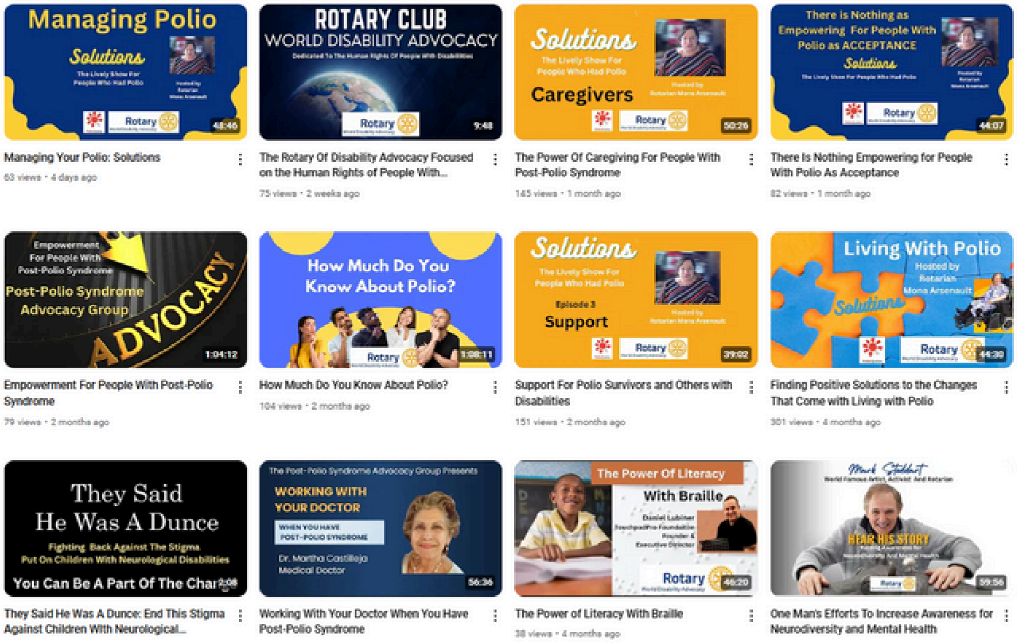


Videos from the Post-Polio Syndrome Advocacy Group

The Post-Polio Syndrome Advocacy Group has recorded many informative sessions which we would love to share with you. They are posted to the PPSAG Facebook page and also on their YouTube channel.

https://www.facebook.com/groups/postpoliosyndromeadvocacygroup/

YouTube GB https://www.youtube.com/@kenmasson4712/videos



Managing Your Polio: Solutions
63 views • 4 days ago

The Rotary Of Disability Advocacy Focused on the Human Rights of People With...
75 views • 2 weeks ago

The Power Of Caregiving For People With Post-Polio Syndrome
145 views • 1 month ago

There Is Nothing Empowering for People With Polio As Acceptance
82 views • 1 month ago

Empowerment For People With Post-Polio Syndrome
79 views • 2 months ago

How Much Do You Know About Polio?
104 views • 2 months ago

Support For Polio Survivors and Others with Disabilities
151 views • 2 months ago

Finding Positive Solutions to the Changes That Come with Living with Polio
301 views • 4 months ago

They Said He Was A Dunce: End This Stigma Against Children With Neurological...

Working With Your Doctor When You Have Post-Polio Syndrome

The Power of Literacy With Braille
38 views • 4 months ago

One Man's Efforts To Increase Awareness for Neurodiversity and Mental Health

Highlights from the Neuro Key Autumn Newsletter

With great sadness, Neuro Key had news of the loss of two much valued friends this summer, both to cancer.

NEURO KEY
An Alliance supporting people with neurological conditions

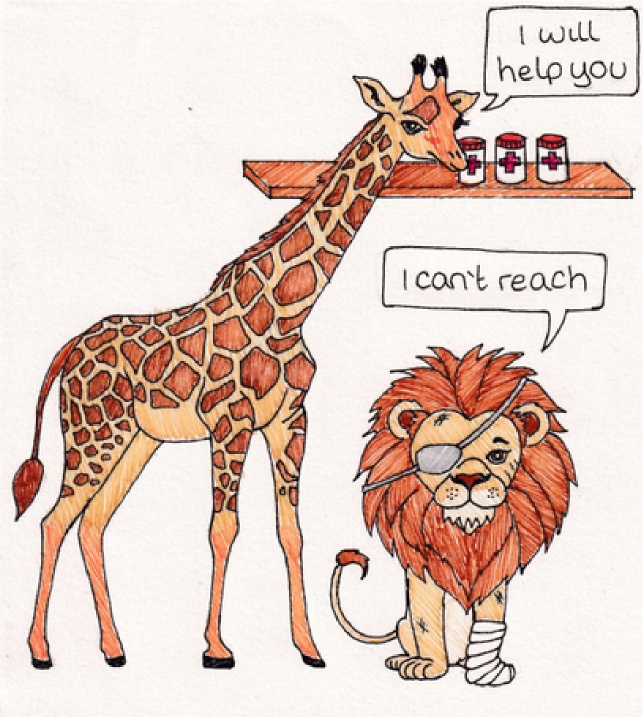
When the Lincolnshire Neurological Alliance (LNA) closed, Hilary Boone nominated Neuro Key for residue funds. Jo Cole and Hilary had been long time colleagues and worked collaboratively with the lead for the Greater Manchester Neurological Alliance (GMNA) to raise issues at national level. Now, Lincolnshire still do not have a Clinical Neurologist and Greater Manchester are to close neurology services to save money.

Hilary was a significant advocate for recognition of post-polio. Jo Cole was invited to write a tribute for the Post-polio network bulletin and the network have become neuro key Members.

Neuro Key Chairman, David Mudd and Jo Cole attended the funeral of David Harling, husband of Trustee Chris Harling and a stalwart supporter of Neuro Key to keep events going or pick up, deliver or advise on what ever was needed. Both dearly missed.

Demand for our expertise of 33 neurological conditions continues to increase and Neuro Key have been highlighting issues to regional and national networks. Neuro Key have revised the digital fundraising platform Give As You Live and set up a Just Giving page to raise funds for our advocacy service. As the leading cause of disability and the most marginalised of NHS client groups, we harness lived experience to champion a route past the almost daily barriers that people living with and caregivers of someone with a neurological condition, injury, disability or neurodiversity must overcome.

We hope you can join us in campaigning for inclusion of the neurological community to improve service delivery and support in 2025.



Neuro Key Newtown Community Resource Centre
123 Durham Road, Stockton-on-Tees, TS19 0DE
Email admin@neurokey.co.uk
Phone 01642 641825
Website www.neurokey.co.uk
X @na_tvdny
Facebook NeuroTVDNY

Far Fetched - Vic Baxter

Our member, Vic Baxter, grew up in Kenya, as his parents met there at the end of the war and stayed for thirty-five years. His father having served in India and his mother in Egypt. He was educated at the Prince of Wales School in Nairobi, moving to Loughborough in 1970, to embark on a career in engineering with Brush Electric, building turbo generators for nontourist destinations.

Several career moves followed, embracing maintenance, operations, HR, HSE, internationalisation and localisation, with multinationals, governments and his own company, Business Workout Ltd. Highlights include:
- Six years with Hawker Siddeley in heavy engineering.
- Two years with Vickers Oceanics operating mini submarines.
- A year with Wharton Williams designing diving systems.
- Twelve years with Shell in UK, USA, The Netherlands and Scandinavia.
- Assignments with Scottish, UK, Azerbaijan and Kenya governments.
- Freelancing in over dozen countries spanning the four corners of Africa, the Americas, the Caspian, both ends of UK, parts of Europe and The Middle East, on behalf of most of the oil majors.

Vic is currently back in Aberdeen, having returned from an assignment in Riyadh with SABIC, an ARAMCO company, delivering elements of Saudi Arabia’s Vision 2030, aimed at increasing Local Content and decreasing dependence on oil.

Vic has two offspring by his late wife, Dr Linda Sutherland, who keep him in order.

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

1930s Bathchair Halts Jumbo At Atyrau Airport

It had been a good journey. Aberdeen to a holdover in Amsterdam where I stayed at The Golden Tulip Hotel with Phil Hindmarsh. He had become a part of the establishment there as an oil worker on rotation. We got our customary Grolsch at the hotel bar then headed for Harlem where Piet and his wife ran a steak bar of huge repute. The group was primarily Shell folk, some of whom I had met in previous lives, who had been seconded to NAM. Palpable camaraderie ensued until our cab arrived to take us back to the Tulip.

At dawn next morning my airport limo arrived and I was wafted to Schiphol Airport in a trice. Seating onboard was adequate for the five hour jaunt to Atyrau in Kazakhstan and away we went.

KLM were often given a remote stand while Air Astana, the Kazakh national airline, were afforded a pontoon with a ramp directly into the terminal. So as I emerged from the KLM Jumbo I could see thick snow on the runway that would put the challenge into my reaching the terminal unscathed.

Waiting for me at the bottom of the stairs was something akin to a 1940s bath chair. Cream coloured with wheels all of three inches diameter. I eased myself into it and the attendant kindly introduced himself as Serik. He turned the chair towards the airport building, the snow crunching under foot as he did so, the chair wheels creakily aligning themselves with the direction of travel, hardly rotating, giving a sledge-like feel to the whole experience.

No sooner had we set off than the skies opened with a blizzard of large snowflakes falling heavily around us and across our pathway, accumulating eerily quickly as we pressed on.

Without warning the front wheels jammed bringing us to a standstill in an instant. Serik groaned and attempted to continued with locked wheels, momentarily emulating the full sledge experience, but quickly realising this would not work.

Then, to our right we saw a pair of fearsome lights peeping through the blizzard, which turned out to be an Air Astana flight heading towards a pontoon. This was fine until we realised we were between the aircraft and the pontoon.

Those of you familiar with the TV series entitled “Little Britain” will be able to envisage what happened next – Serik imagined a miracle had happened when I leapt up from the bath chair and headed for the airport on foot, emulating Bambi on ice nevertheless. Explaining to Serik once indoors that my issue was distance +/- the odd “sprint” in between.

From Carol at PA Polio Network (PPSN)

I "met" Hilary in early 2015. We chatted multiple times and had what we thought was a marvelous idea - International Pen Pals - that would include everyone, especially those survivors who were not online. Together we would create the lists for those interested and do the "matching" up so that US survivors would be able to "meet" and communicate one on one with those of you in the UK and beyond. We even created a logo image!

It didn't take off and neither one of us could figure out why it wasn't the best idea ever.

Medicines & Healthcare products Regulatory Agency (MHRA) trains worldwide laboratories in early detection of polio using breakthrough advanced technology

The Medicines & Healthcare products Regulatory Agency (MHRA) has partnered with Imperial College London, to train up multiple World Health Organisation (WHO) polio laboratories around the world on a rapid detection method for polio that can halve detection times – supporting the global effort to eradicate polio and helping save lives.

Read more here:
https://www.gov.uk/government/news/world-polio-day-mhra-trains-worldwide-laboratories-in-early-detection-of-polio-using-breakthrough-advanced-technology

Does it sometimes feel like no one is listening?

Let us know your experiences (positive and negative) of the responses you have had from GPs, Consultants, Physios, etc when seeking help as a polio survivor.

We are hoping to collate a list of sympathetic services that we can signpost our members to.

Resilience in the Face of Adversity: The Journey of Polio Survivors

Life can indeed present some formidable challenges, particularly for those who have faced the trials of polio. The narratives of these individuals serve as a powerful reminder of the strength of the human spirit and the remarkable resilience we can all embody in difficult times. Each person’s path is unique, shaped by their individual struggles and triumphs. For polio survivors, navigating physical obstacles and societal perceptions has granted them a distinctive perspective on life.

Embracing one’s journey involves viewing every setback as an opportunity for growth. Polio survivors encounter difficulties on a daily basis, yet they exhibit extraordinary determination to adapt and progress. Their experiences impart the lesson that resilience isn't merely about surviving hard times; it’s about transforming those moments into stepping stones for personal development. Each challenge they confront reinforces the notion that true strength resides within and the resolve to persevere can lead to remarkable achievements.

Consider life as a pathway with bumps and breakthroughs. For many, the highs signify victories—be it overcoming a physical limitation, achieving a personal milestone, or standing up for what is just. Conversely, the lows encompass the struggles, the doubts and the perseverance required to bounce back. It is this rich tapestry of challenges and successes that renders the narrative of resilience so profound.

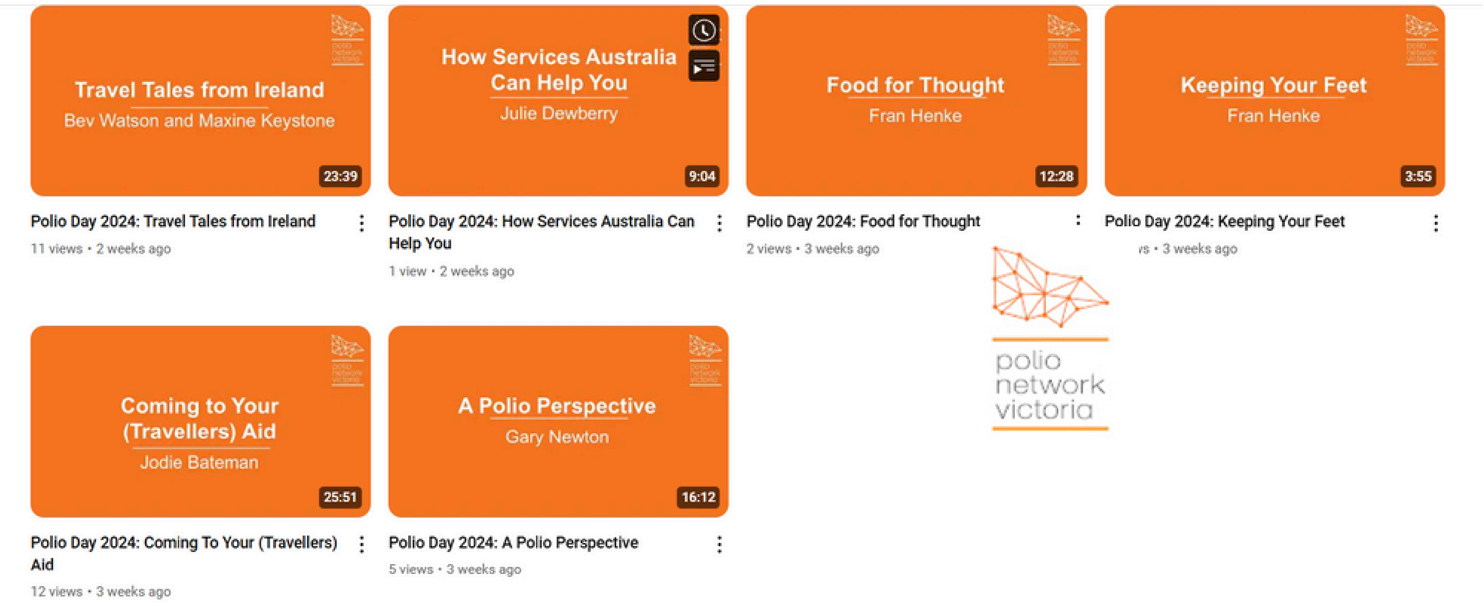
Staying motivated can provide a tremendous uplift, particularly for those who have faced adversity. It revolves around cultivating a mindset steeped in positivity and determination. For polio survivors, motivation may stem from personal aspirations, the desire to inspire others, or advocating for enhanced accessibility and inclusivity. By surrounding themselves with supportive communities, they harness collective strength and encouragement, demonstrating that we are never alone in our struggles.

Each day presents a fresh opportunity to celebrate what you’ve accomplished, regardless of how trivial it may seem. Acknowledging these victories fosters confidence and momentum. Visualising your goals can help delineate a clear path to success, aligning everyday actions with grander dreams. For polio survivors, every achievement—whether it’s taking a step or championing change—becomes a testament to their resilience and commitment.

Ultimately, the journey of a polio survivor embodies remarkable strength and inspiration. It illustrates that life is more about the experiences we gather and the growth we realise along the way than merely reaching a destination. Every step taken, every challenge faced, and every victory celebrated contributes to the richness of their powerful story. So, embrace your own journey with courage, knowing that you possess the strength to overcome challenges and forge a life brimming with purpose and passion.

Videos by the Polio Network Victoria

Polio Network Victoria has a series of videos on their YouTube channel worth a look:



Polio Day 2024: Travel Tales from Ireland
11 views • 2 weeks ago

Polio Day 2024: How Services Australia Can Help You
1 view • 2 weeks ago

Polio Day 2024: Food for Thought
2 views • 3 weeks ago

Polio Day 2024: Keeping Your Feet
vs • 3 weeks ago

Polio Day 2024: Coming To Your (Travellers) Aid
12 views • 3 weeks ago

Polio Day 2024: A Polio Perspective
5 views • 3 weeks ago

polio network victoria

https://www.youtube.com/@PolioNetworkVictoriaTV/videos

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

Nebraska Polio Survivors Association
www.nepolioorg.ipage.com

Polio Australia
www.poliohealth.org.au

MANAGEMENT COMMITTEE

Trustee Vacancies - please contact Toni for more information

OPERATIONS TEAM

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

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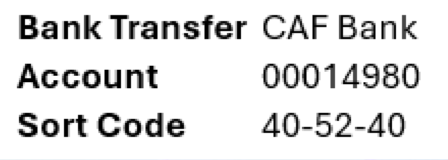

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