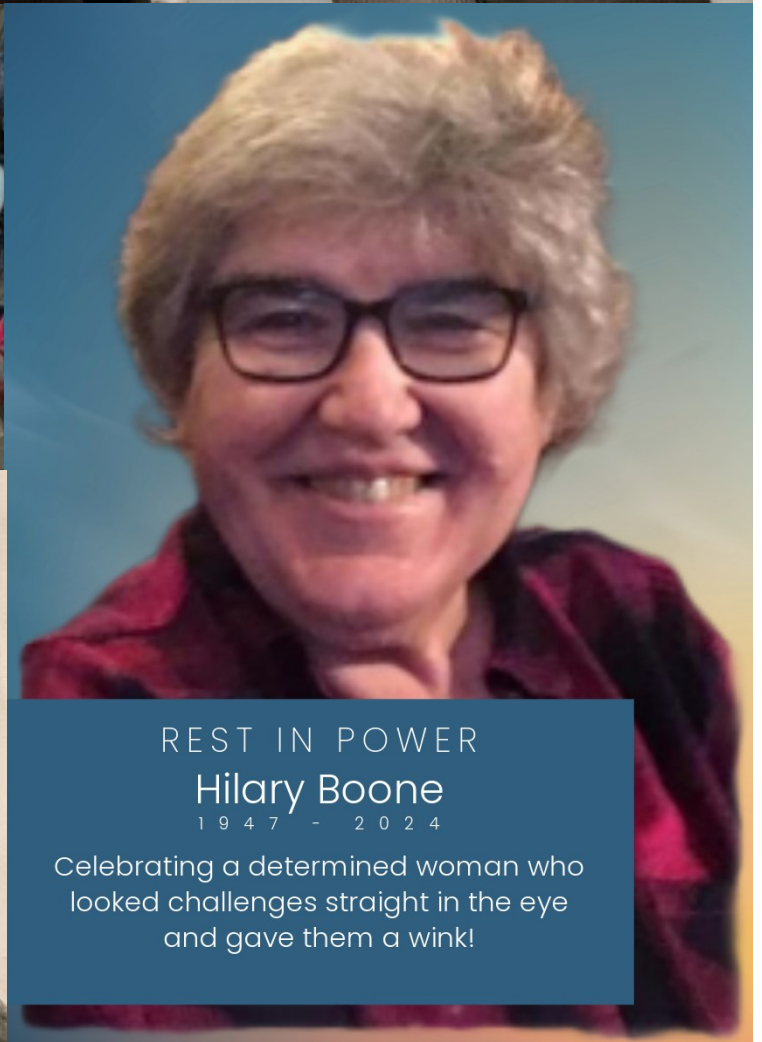




POST POLIO MATTERS

Polio Survivors Network Newsletter
October 2024 — Volume 11 Issue 7 of 12 [127]



REST IN POWER

Hilary Boone

1947 - 2024

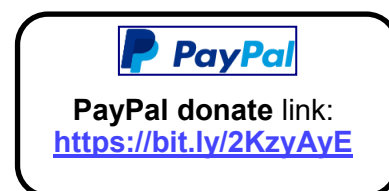
Celebrating a determined woman who
looked challenges straight in the eye
and gave them a wink!

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

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<i>Donations and Charity Incentives Paid</i>	
<i>(since last newsletter)</i>	
Donation MC	20.00
PayPal Giving Fund	10.00
Donation DM	12.50
Donation HY	20.00
Donation RB	20.00
Donation EM	210.00
Total	£292.50



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Thank you so much!



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Polio Survivors Network were very sad to announce that our founder and tireless advocate, Hilary Boone, passed away on 15 July 2024. We know many of you joined the funeral service in-person and also using the online streaming service. Many condolences were received and sent to her family and friends. We also received many kind donations in lieu of flowers as requested by the family.

We thought it only appropriate and proper to dedicate a good portion of this newsletter to the memory of Hilary, a fighter for polio survivors everywhere. Please find following the eulogy which sums up Hilary's fascinating life despite the obstacles she faced.

Eulogy - Hilary Ann Boone / Gowa Meendegaw (Dancing Owl)

Hilary was born on 16th March 1947, in Hammersmith. In 1952 the UK General Post Office offered her father Hal, a job in Benghazi, Libya to organize the rebuilding of the telephone system. Hal flew out to Benghazi, and weeks later his wife Mabel, Hilary and her younger brother Robert went out via boat on HM Troopship Dilwara.

The yellow quarantine flag was flying because Hilary and her brother Robert had caught whooping cough and then a few months later Hilary caught polio and was paralysed from the waist down after playing with a girl at the beach. Hilary was taken to the army hospital in Benghazi, her mother Mabel was told she was only allowed to talk to her from the doorway.

Once Hilary was out of isolation her parents asked if swimming would help with her recovery. An army truck took Hilary to the Mediterranean ocean to swim every day. Hilary quickly learned to swim underwater, and her father Hal would walk alongside and hold her up whilst she got her breath back.

In December 1953, Hal's work was finished, and it was time for the family to return to England. Hal wanted to make an adventure out of this so he decided rather than going home by boat he had a car shipped out to Benghazi and they would take a ferry across the Mediterranean and then drive home through Italy, Switzerland and France, with a final ferry from Calais to Dover.

While packing up the belongings Hilary's mother Mabel slipped a disc from carrying Hilary. The only treatment was to plaster cast her from her neck to her hips, it made it very difficult for her to sit in the car. On the day the ferry was due, they were waiting at the docks in Benghazi, but the captain radioed that the sea was too rough and that he was going to sail to Tripoli 600 miles down the coast. If they could reach him in 4 days' time, they could take the ferry to Salerno and then drive home through Europe as planned. The drive to Tripoli was certainly an adventure, getting stuck in the sand, haggling to buy fuel for the car, finding places to eat and even harder somewhere to sleep.

A few years later Hal was offered a job in Jordan for a year and the family visited for a few months in the summer. They visited Aqaba but the best hotel was closed because the King of Jordan was staying, as Hal was a government official the family were allowed to stay in a suite. The only other guest was an Arab actor, they had dinner with him, he was very friendly. Hal was concerned that Arabs found white women attractive and told Hilary to stay away from him. The actor was Omar Sharif, when the film came out and he became very famous Hilary jokingly said she was disappointed as she could have been seduced by one of the most famous men in the world.



Years later when the family had moved back to the UK Hilary could walk but she fell often, she had an operation to cross her tendons that enabled her to walk more easily. Hilary went on to pass her orange belt in Judo; she was a good swimmer and passed life-saving awards to distinction in the pool and open water.

Hilary's first job was as a secretary for George Wimpey, a construction company, however this was not an exciting career choice. In 1969, she passed the medical for the Police as fit and went to RAF Dishforth to start her 13-week training. On the second day she was given the timetable for the week, Friday was cross-country running. Hilary asked to see the Sergeant and explained that she could not do this. She told the Sergeant she could run enough to get around playing tennis and netball but after having polio as a child she could not run any distance.

She thought her days as a policewoman were numbered, it was decided that as she had higher qualifications in Judo and Lifesaving, she was given the weekly chance to try and complete the rest of the training. A list went up for the 40-mile Lyke Wake Walk across the North York Moors. Hilary put her name up and later saw that it was crossed off, so she put it back up again, but again it was crossed off. She complained to the Sergeant and was told as she could not run it, it had been decided that she would not be able to do this. She asked if the others had been asked if they had walked that distance before and the answer was no.



The Sergeant allowed her to attempt the walk, but her car had to be driven by someone else and had to be part of the back-up team. It was decided they would support her for the first 9 miles and then her car would be available to take her back to the training school. Her car did take someone back to the training school, it was not Hilary. Nearing the end, she had to crawl up a hill on her hands and knees, it took her 18 hours, but she did it.

She completed 4 years as a policewoman at Heathrow Airport, including 2 years in CID before marrying a colleague and moving to Lincolnshire.

In 1973 she gave birth to Michael and in 1976 Alison. Hilary continued her love of swimming and taught disabled children and adults, volunteered as a lifeguard at Chapel St. Leonards and worked as a lifeguard/swimming teacher in many pools across Lincoln.

In 1987, Hilary fell, and she struggled to recover from this point on. From 1989 to 1994 Hilary was an Occupational Therapy Aid, working at Ancaster Day Centre and then in West Lindsay running craft groups for the elderly and disabled. She continued with her education learning British Sign Language and Adult Teaching Certifications.

Finally in 1995, she was diagnosed with Post Polio Syndrome, from this day on she tirelessly searched for information.

She met Peter Jay from the British Polio Fellowship, and they organised a meeting at a local hospital, 52 people turned up and the Lincolnshire Polio Group was reformed after 20 years. Hilary met Helena Edwards from the Leicestershire Polio Network, she said she would share all their work if Hilary started a group in Lincolnshire. The first newsletter for the Lincolnshire Post-Polio Network was published in September 1996. In 1998, she became a founding member of the Lincolnshire Neurological Alliance.

Hilary did not stop researching from that day onwards, she gave many presentations, her first at the International Polio Network Conference in 2000. Her presentation at the 2nd European Polio Conference in 2014 was featured in the Journal of Rehabilitation. She put together and edited nearly all the 126 newsletters for Polio Survivors Network and has met many of the world's top Post Polio Specialists.

Hilary met Richard online in 1997, and in real life on 20th May 2000, in the first week he took her to a State Shoot. They had to drive down a road made of sand and then turned towards the edge of palm trees. They parked the truck, and Hilary got the electric scooters out of the truck and off they went towards a few signs. One pointed to a Hawk & Knife Throw, Hilary thought she didn't want to watch them throwing knives at birds. Hawk of course was Tomahawk. Then there were folks in costume of the pioneer times both cowboys and native Americans. They met so many lovely folks and nearly everyone asked Richard if he was going to get to the Rendezvous in January.

Richard took Hilary to a Rendezvous at Charley Knights place - the last before Alafia River Rendezvous bought some land at Homeland, FL. There were tents and tipis and folks living just like in the films she had watched on TV. She had not wanted to feel out of place as Richard had loads of outfits, so she had gone into a Goodwill store and purchased a curtain and made a long skirt and luckily found a white blouse that was near enough. Going round and talking to the folks was so interesting and she told Richard that she would love to do more of this, thus began her love of reenacting.



They attended the Final Ceremony a week later and standing in a circle with three Native American chiefs performing the ceremonies and the 'cowboy' elders sitting on chairs in the circle. They all went through the circle taking a pinch of tobacco from a pouch and sprinkling that on the fire saying their prayers as they were taken up to heaven, so moving. Then they passed a talking stick round the circle, and everyone was invited to say something if they wanted to. Hilary took the stick and her voice broke, it was such an emotional experience, the most uplifting spiritual experience she had ever had. They also went to Singing River, Fort Foster and a local event in Emerson Point Park where they lived.

In March 2008, Hilary and Richard settled permanently in Lincoln, where they enjoyed the British Westerners Association events, were members of the Reepham Shooting Centre and volunteering at Lincoln University for over a decade.

Read more tributes to Hilary (or add your own) here:

<https://hilaryboone.muchloved.com/>

Donations in lieu of flowers can be made here:

<https://hilary-boone.muchloved.com/>

MESSAGE FROM OUR CHAIR

Thoughts our founder Hilary's passing

***Life is never made unbearable by circumstances, but only by lack of meaning and purpose.* – Victor Frankl**



Most of us enter this world, healthy, active and full of potential. In addition, if we are fortunate, we are a welcome addition to our parent, family and society who wonder at the amazing and unique creature that has arrived, as a new human being. A kind of miracle, whether you are a person of faith or not.

Wherever, and in whoever's arms we land in, for that short period we exist on earth, we are thrust into a life with all its vibrant, beautiful and exciting possibilities and yet, also tossed into an uncertain lottery of who, where and what we are and what we may become. So much of this is random, out of our control and our particular fate, often as very young children, was to be exposed to and infected, the polio virus.

It's not that we have a short time to live, but that we waste a lot of it.' Seneca

What Seneca said so many centuries ago is certainly not true of Hilary. As I write this and reflect on Hilary, my friend and fellow traveller of many years, I think how much she was shaped, not just by birth or chance alone, of which we have no control, but how she grasped it and made meaning out of her experience and time on earth.

'After your death you will be what you were before your birth.'

Arthur Schopenhauer

Short as that is, in-between, in life, we are given the privilege and struggle of self-consciousness. We don't absolutely know, but it's worth contemplating that perhaps we are the only beings in the vastness of space and time that can be conscious in this way. So, Hilary was someone who grasped her life with both hands and used her experience of it, be that good or bad, happy or sad, pain or pleasure, exciting or, yes even boring and frustrating to make meaning out of it and used it to make a difference to others.

I first met Hilary in the mid 1990's and though we had very different experiences of polio, we were both maybe guilty of that trait that we polio survivors are accused of. Being bolshy and always questioning the received narrative, especially that handed down by 'the polio experts'. We had both reached a time in our lives when polio was obviously not a thing of the past and had become very relevant again to our current day to day life, work and increasing health challenges.

Silence isn't always golden

The disappointing thing was that few if any of the medics or polio organisations were interested in the realities of post-polio as we all experienced it. At worst the official narrative was that it was just normal aging or psychological stress reactions. Indeed, I was told at 25 that my physical issues were that I had reached adulthood and had not come to terms with my disability (or handicap as they put it) and prescribed a tricyclic anti-depressant, which I didn't take. Hilary, having been in the police force and a lifeguard was impacted later in life and began to doubt this narrative and fought to establish the truth of polio survivors lived experience.

My point is that Hilary and I came from two different experiences of polio, I was in an iron lung, couldn't swallow or move above my neck and recovered well, but with extensive muscle loss, and never fully returned to the kind of physical life I might have had, or my peers went on to have. Hilary, like many PSN

members, recovered enough and managed to do compensate enough to live her life up to a point where polio wasn't a defining issue day to day, until one day that changed and it resurfaced, with a vengeance.

There is only one good, knowledge, and one evil, ignorance – Socrates

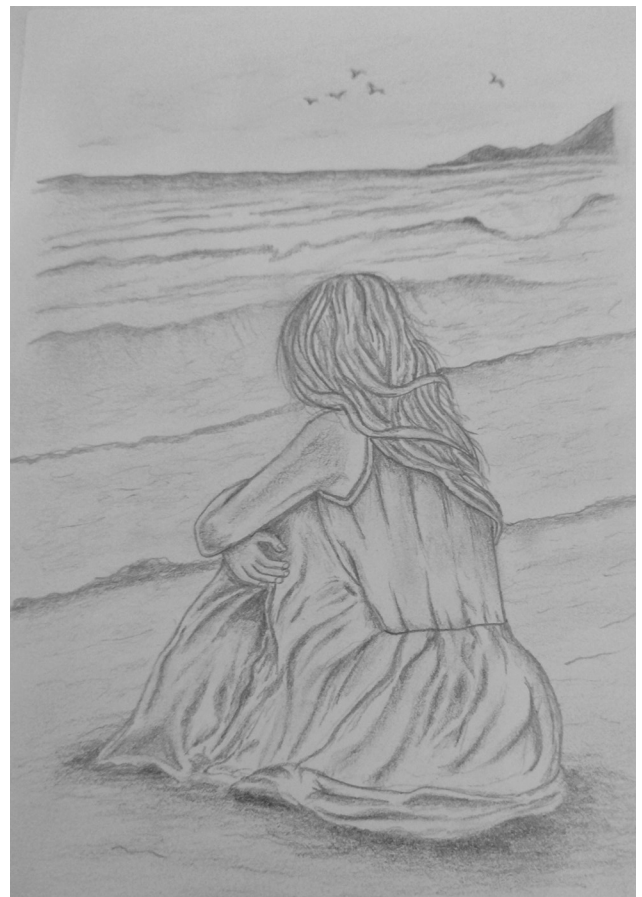
So we were different, in many ways. And, I bow to Hilary's perseverance, tenacity, stubbornness and energy in the face of so much uncertainty and push back. Sometimes she could seem a bit single minded and even dictating but I admired that in her as that was what made a difference, both in her life and of course her late husband Richard's. But this was what fuelled her to set up the Lincolnshire post-polio network which then became the charity The Polio Survivors Network (PSN) at a time when so many others just wouldn't listen.

I also want to say that whilst a big part of Hilary was a campaigning element, she was to me and many others as a kind, warm-hearted and generous person, always there to help and advise, if she could. There is more to achieve and contribute to polio survivors' healthcare and not just the lives of polio survivors but others with neurological conditions such as ME and now Post COVID. However, Hilary played a huge part in changing the narrative and closed mindedness of the medical attitude to polio.

Sometimes the smaller less visible advocates and campaigners can be forgotten. Hilary was one of those who made a difference to many people's lives, helped people across the world and though maybe she may not have fully appreciated it, changed those she helped and met in a positive way. I am sure many, will remember her with affection and appreciation and I for one will and do miss her just being here. But as the Artist Edvard Munch wrote : *From my rotting body, flowers shall grow and I am in them, and that is eternity.*" I am sure that her existence and time she spent on earth has indeed grown many flowers that have seeded and made a difference into the future.

Simon Parritt

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





Zsuzsi's Thoughts...

I was deeply saddened to learn about the death of Hilary, the founding member of the Post Polio Survivors Network. Her dedication, knowledge, and contributions have made a lasting impact on the lives of many and her legacy will be remembered with great respect and gratitude. I have met Hilary on many occasions and found her sense of humour and perseverance infectious. She is greatly missed. I send my sincere condolences to Alison and Michael hoping that you will find consolation in the cherished memories you shared and in the knowledge that Hilary's work has made a profound difference in the lives of so many.

I found the Polio Survivors Network while living in Kent and trying to get a diagnosis for my failing strength and ability to walk. I first met Hilary at one of the Annual General Meetings in Lincoln. One of our daughters lives in Nottingham and we also visited Hilary and Richard in their bungalow. When we moved to Nottingham I offered my services and for a short time, I was secretary. Later I became a trustee and Hilary encouraged me to attend the Annual General Meeting of the European Polio Union held in Budapest where I was born and where I caught polio. I will miss her contributions to the monthly newsletter, and find it difficult to imagine how we can carry on without her. May she rest in peace with her beloved Richard.



WARNING

I have been writing about the movable stool called a hairdresser's stool in past copies of this magazine. I use it for cleaning the floor, cooking and carrying large dishes where both hands are needed.

My balance is quite bad so that I always need to hold on to something stable with one hand. But while recommending the stool, I have forgotten to warn about the danger of sitting down on it until my able friend visited and tried to sit down on it. The stool slipped away from her, and she nearly sat on the floor. I have forgotten that it also happened to me once when I first had it and since then I always hold on to the seat with one hand as I sit down on it. I should have warned you of this danger. I also have to be careful when I stand up, making sure that I hold on to a chair or table with both hands.



Zsuzsanna Snarey – Trustee

From Verite

PSN Trustee, Health Journalist and owner of www.aftercancers.com

Keir Starmer announces “Ballooning NHS waiting times and delays getting vital treatment in A&E and cancer care is harming health and costing lives, according to Lord Darzi’s government-commissioned report.



It is doubtful if anything sensible will come out of this report; as implementing it will mean dismantling the multiple empires built up by the ‘new’ Admin staff that today rule the NHS, in place of Matron.

Long gone are these sensible people who ran hospitals; today there are costly levels of self-perpetuating bureaucracy that has dug itself into an impregnable position.

Today’s reality in hospital

I had been sick, so rang the bell for a nurse. As one came through the door she screamed “You’ve made a mess all over the floor”.

Yes Sunshine – that’s what nursing is all about – when there were Matrons they would have told you in their induction speech what to expect. But there is no matron today to lend wise counsel and years of wisdom to nurse training.

Instead, nurses are taught to rely on computers and smartphones, and Matron’s personal pride in running an efficient hospital has gone out the window. Pride in a job well done doesn’t have a monetary value, so today’s highly-paid CEOs who replaced Matron don’t have the same ethos.



Dumbing down nurse training

Today Matron has been replaced by highly-paid Administrators; long on theory but short on practical experience; They know all about saving money, but little about what patients really need. As I found out recently, nurses are trained how to take your blood pressure, but not how to interpret readings. Seems this has been cut out – probably to save time. and/or money.

This machine issued to trainees costs over £1,000 – replacing the small cuff machine costing a tenth. Trainees are experts at trundling these around, but seem incapable of interpreting what results show; One trainee had no idea why I was worried when my reading shot up dangerously.

And a fresh horror is appearing; Community Hospitals. These sound friendly, but basically, the NHS has looked at the number of elderly patients’ bed-blocking’ because they can’t go home, and come up with a plan that enables grannie-with-dementia to be discharged back into the community, drugged up to the eye-balls and wearing continence pads.

But if you are elderly, but have your wits about you enough not to want to exist in a drugged state, you can find it difficult to come off the drugs.

Reality today

My many long-term conditions, started when I caught polio aged 15,. These mean I have been an in-patient in 28 different hospitals. I’ve made friends with nurses in British, German, French, Italian, Austrian and Swiss hospitals, and skilled nursing helped me survive and thrive. But for the past few years I have found nurse training in the UK is being dumbed down, and **we have to advocate for ourselves if we want proper care.**

Good nursing care is vital to recovery. but it needs well-trained nurses to carry it out. If trainees don't receive proper training, things fall apart. Our new Labour government announces they aim to reduce long waits for treatment, but I think it won't work unless current nurse training is tightened up.

Everyone mentions their "wonderful doctor", but without the nursing to back up prescribed treatment we would struggle to get better.

Nurses are so important

Lying in a hospital bed in my local town, I could observe the way nurse training has changed from when I was a victim of a polio pandemic, Then, nurses worked tirelessly and got us through the worst. But today, when I ask a nurse to do something, often their response is "I must protect myself", rather than what they can do for me. Yes, safety training for staff is vitally important, but do patients need to be reminded of what should be an integral part of training? It made me feel guilty for asking.

I agree that nurses should be trained not to strain their backs, etc. But they are there to help patients, and we don't need to know what they are doing to protect themselves.

Staff Training

Once, being cared for in a major teaching hospital was a big plus. Today, it's the contrary. Recently, in Oxford's John Radcliffe teaching Hospital, the trainee nurse taking my blood pressure told me it showed a reading of 170. This was way above my normal reading, but didn't seem to concern her. Even though she could have checked in my notes and seen it is usually around the 120/130 mark. Finally, an Agency Nurse let the cat out of the bag; the sister in charge of drugs had forgotten to order my blood pressure tablets. If the trainee had done as she should, and informed a superior, this would have been sorted without fuss. But it seems nurse training is carried out at arm's length – and trainees aren't encouraged to bother superiors.

It wasn't the first encounter I had had with the Sister-in-charge of drugs. On admission, I had told the nurse doing my check-in that I was allergic to preservatives in certain drugs. This was also noted on my printed hand-over form. Hospital Caterers had picked up on this and sent a dietician to talk over what I could eat, but the 'drugs sister' hadn't bothered to read these notes, and ordered drugs for me that contained preservatives.

My face and body blew up in a painful rash and I am still being treated for this, one year later.

For the future

It is up to us, as patients, to monitor how we are nursed. If anything seems wrong it probably is, so it's up to you to alert whoever is in charge. Don't sit back and think "Nurse knows best". So often today they are a trainee and don't.

While Matron has been ousted by the new breed of Administrator/Accountants (on vast six-figure salaries), Matron on her sensible salary, with her common-sense approach to patient care, will never be allowed back into the system.

Britain has produced many innovations in medical care, from Jenner and Hunter, Lister and Fleming, to Florence Nightingale and her revolutionary nursing methods during the Crimean War.]Today, American nurses celebrate Florence Nightingale Day, and when Daddy worked in Turkey I remember going with him to represent the British Community at the Annual Nurses Award Ceremony, held in Scutari Hospital where Nightingale had worked.

The ceremony was very moving, each nurse carried a little lamp commemorating "The Lady with the Lamp", and it was obvious her legacy meant a lot.

Let's hope that today's nurses think of her legacy, and training improves to what would have been acceptable to Miss Nightingale.

Toni Writes ...

Thank you for all the messages of support and condolences which have been coming through, we have passed these on to Hilary's family. Also a big thank you for the donations and stories that you have shared, it means so much.

I have spent time reading through articles and information Hilary had written over the years and came across this fantastic definition which I want to share:



Polio Survivors – a strong willed, determined, highly motivated, hard working group of people – want to live for as long as possible, doing as much as possible. We need a full and accurate base line assessment that takes into account the endurance of our weakening muscles. We need advice, and the understanding that it takes time to accept that we have to change our lifestyle.

We need treatment where it is available, appropriate aids and equipment, and benefits so that we can financially cope in this world where anything 'disabled' has a high price label.

I can't agree more! That is exactly what Polio Survivors Network aims to advocate for. We do need your help to do this more fully – we are currently working hard to compile a list of resources (organisations, health care professionals, companies, charities, etc) that we can signpost our members and enquirers to for help.

So, have you had good experiences with any particular consultant (NHS or private)? A physiotherapist (NHS or private)? A social worker? A chiropodist? Orthotist (NHS or private)? Did you meet someone willing to listen about your post polio syndrome or someone willing to look up the late effects of polio in order to treat you more holistically? Did you have the slightly less common experience of being treated by someone who knew about polio and post polio syndrome? If so we would love to know their contact details so we can reach out to them.

Thank you in advance as I know many of you will be in touch.

Sending much love

Toni

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Phone	07480 110334

From our readers:

I found it to be a very interesting newsletter - BF

Can you help our new member with their query?

I am interested in knowing if other polio victims have experienced, like me, delayed muscle inflammation. A month after straining, my muscles became inflamed. I live in Norway. I have been diagnosed with post polio syndrome and have lived a good life until a year ago I had a severe deterioration. I mean I was exposed to too much activity during a treatment in February 2023 and suffered a breakdown, inflammation of the muscles a month after this. That is what I would like to know, in a large group that you probably are, there may be others who have experienced something similar to me. Do you know of anything that can help with the inflammation that I have in my muscles? The experts here say I have an autoimmune response. Maybe IVIG treatment will help. I am in the Norwegian association of polio victims. - LF

In August 2006, three press statements related to polio survivors caught attention:

1. *"Survivors of childhood polio do well decades later as they age"*
2. *"Polio Survivors faring well" : This statement echoed the positive outcomes observed in the study mentioned above.*
3. *"No polio effects in later life"*

Hilary was not afraid to challenge the status quo — here is a reprinted copy of her article challenging polio studies.



Polio Survivors Throw Doubt on Study

Hilary Boone, Lincolnshire Post-Polio Network

“Survivors of childhood polio do well decades later as they age” [a]

“Polio Survivors faring well” [b]

“No polio effects’ in later life” [c]

The above three press statements were made in sequence during the last ten days of August 2006. The initial statement, on the 21st August 2006, was the announcement by the News bureau of the Mayo Clinic in Rochester, Minnesota, [a] of the research findings reported in an article in the Journal of the Peripheral Nervous System, ‘Electrophysiological findings in a cohort of old polio survivors’ by Eric J. Sorenson, Jasper R. Daube, and Anthony J. Windebank. Their research used a cohort of patients that they had been studying over the last 15 years. [1,2,3,3a,4,5] A cohort of 50, reduced over the 15 years to 38 ‘old polio survivors’. Within days the findings had been reported by other media and by the time it was on the BBC News - Health there were ‘No polio effects in later life’. [c]

Polio Survivors who are NOT doing well decades after recovery; who do have polio effects in later life; who have been presenting with well documented new symptoms – including considerable functional decline in actions of daily living - to recognised Post Polio Clinics and Specialists during the last 25 years are once again disappointed that this cohort continues to be used as representative of the polio population. In the authors’ own words in the 1996 article ‘...we believe that our findings can be extrapolated to the whole population of polio survivors in the United States.’ [4]

McCarthy reviewed the 1996 article [4] in the Lancet in February 1996 [8] with the heading

Study throws doubt on post polio syndrome

Helena Edwards of the Leicestershire Post-Polio Network in her rebuttal stated, ‘We, in the UK, heard from people whose doctors were assuring them that PPS did not exist, and in some cases the doctors mentioned that their information came from an article they had read recently.’ [9]

We present the following issues that we believe need to be taken into account before conclusive statements can be made regarding findings from Sorenson et al’s research report. Authors who raise other issues with this research, and the way findings have been presented, are included in References at the end of this paper [d,e,f,g].

1. We believe the people in Sorenson et al’s study cannot be extrapolated to the ‘polio population’, because 90% of their cohort is towards one end of the scale, towards more severe deficits.
2. There are important facts from 10% [5 of 50 subjects] of their study group that appear to have been dismissed when in fact they appear to show what is happening at the other end of the scale, those of us presenting to PPS specialists and PPS Clinics; polio survivors who recovered well and now have new symptoms and considerable functional decline in activities of daily living.
3. Their use of numbers and phrases can easily be misinterpreted without the full facts from previous articles.
4. Sorenson et al make several statements of caution, regarding comparing studies with the normal population, then appear to proceed to ‘overcome’ or ‘ignore’ them in this article. Yet just eighteen months earlier they stated ‘the effects of normal aging in this cohort cannot be commented on.’ [5]
5. We question the validity and reliability of Manual Muscle Testing to grade muscles.
6. We question the reliability of a YES/NO questionnaire. Ask 50 Polio Survivors “Can you do x?” and the vast majority will say “Yes”. Ask the same number “How do you do x?” and you are likely to get a huge variety of answers.
7. The extent of recovery from paralytic polio experienced by many polio survivors is often not realised.

Issue 1

Quite simply, in the authors own words, from two of the articles, the cohort used is weighted towards people whose polio residuals were more visible

- ‘we selected those survivors from the original cohort [223] who currently reside in Rochester and the surrounding area’ [2]

- ‘we also randomly selected an equal number from those who were complaining of deterioration and those who were not.’ *This intentionally biases the study toward those with difficulty...* ‘At this time, 31 patients have completed the study.’ [2]
- ‘From the **247 survivors**, we selected 50 subjects.’ [3 - Abstract]
- ‘Fifty survivors who lived closest to Rochester were selected for the study. This group was likely to stay in the area and be available for follow-up study.’ [3]
- ‘58 subjects were called in order to recruit fifty’ [3]
- ‘Those evaluated showed a trend towards more severe deficits’ [3]
- ‘There may be a tendency for more handicapped residents to remain geographically closer to our clinic.’ [3]
- ‘These subjects were not seeking medical attention; they were invited to participate on the basis of their having had polio.’ [3]

Issue 2

Important facts in their study actually relate to the other end of the scale, of polio survivors who are experiencing new symptoms and functional decline, do not seem to have been given equal attention. Again using the authors own words. [3]

- ‘that 5 subjects who had made the greatest recovery were all experiencing new difficulties’
- ‘One of the two nearing retirement who had made an occupation change because of leg weakness was a surgeon. He had significant progressive leg weakness so that ambulation had deteriorated from requiring no aids to needing a cane and then a walker and finally a wheelchair for distances’
- ‘that nine limbs that were newly symptomatic that had not been paralyzed during the acute illness were in 4 subjects. Three of the four had purely bulbar polio but now complained of limb symptoms. The fourth had paralysis involving the legs and now complained of arm pain’
- ‘That in no case did they find new complaints in a limb that showed no electrophysical evidence of having been affected by the original disease.’

Issue 3

The use of numbers and phrases in their articles can easily be misinterpreted without reading all previous articles relating to the study. For instance the article that triggered the recent press releases, ‘Electrophysiological findings in a cohort of old polio survivors’, stated:-

- **Fifty representative subjects were randomly chosen from 298 patients** with a documented history of paralytic poliomyelitis residing in Olmsted County at the time of the infection. [6]

Compare that statement with the following quotes from the progression of articles from 1984 to 2005, referenced [1,2,3,4,5], relating to this study group. We accept that these quotes are taken in isolation and not the full context, but they do not appear to be consistent.

- 1984 Patients were required to have had established residence in Rochester prior to diagnosis for inclusion in this study.’
‘Of the 316, 201 had paralytic polio and 115 had nonparalytic polio.’
‘23 died in the acute phase of the illness.... 7 deaths in subsequent years.’
... ‘a questionnaire was circulated in April 1984 to all traceable patients who had had paralytic poliomyelitis.’
‘Of 171 potential respondents... 23 people remain untraced at the time of presentation of this data’
‘Replies have been received from 128..., three persons were unwilling to participate.’ ‘Of the 125 remaining, 97 patients indicated stability and 28 indicated deterioration since their maximal recovery from polio.’
‘This questionnaire was supplemented by a detailed telephone interview for those who indicated deterioration since their maximal functional recovery from polio.’ [1]
- 1987 ‘This group has subsequently been expanded to include all residents of Olmstead County, who had paralytic polio between 1935 and 1959. Two hundred eighty six subjects were identified, and 276 have been located for follow-up.
‘Thirty people (10.5%) died in the acute phase of the illness, and 23 died in later years.’
‘The remaining 233 formed the cohort for the follow-up. Two hundred twenty-three have been located’.
‘At this time, 31 patients have completed the study. Ten individuals reported no difficulties of any kind... Seventeen reported new, perceived, specific limb weakness.’ [2]
- 1991 ‘We identified a cohort of 300 individuals who had paralytic polio between 1935 and 1955. All lived in Olmstead County, Minnesota.’
‘Two hundred ninety-three of the 300 cases were traced. Of the 300 subjects, 53 were known to have died’.
‘Fifty survivors who lived closest to Rochester were selected for the study. This group was likely to stay in the area and be available for follow-up study.’
‘58 subjects were called in order to recruit 50.’
In response to the questionnaire, 32 individuals complained of some new difficulty (Table 4)
Table 4 – No new symptoms 18. *Types of complaints reported by 32 of the subjects with paralytic polio.
More subjects (21 of 33) complained of lower limb difficulty than upper limb problems (nine of thirty)
The cause of the symptoms is unclear but they are not attributable to age alone because the population is still relatively young (median age 49 years) [3]
- 1995 ‘Of the 300 cases, 298 identified for follow-up. 53 had died;’

‘Detailed comparisons between 50 and the other 197 survivors to ensure that the cohort was representative.’
 ‘This group of subjects was then reconstructed after five years. All gave information about their present status, and 46 underwent again the complete battery of tests described above.’
 ‘The number of subjects reporting new symptoms of weakness, pain, or fatigue remained constant over the five year interval. Of 30 individuals who had symptoms at the first study point, 23 continued to have symptoms and 7 did not. Six individuals who did not have symptoms at the first time point did have symptoms after five years.’
 ‘..(Table 1), the distribution remained similar except that more patients were likely to be complaining of all three symptoms at the second evaluation.’ [3a]

1996 ‘Three hundred individuals met the criteria for paralytic poliomyelitis. 298 of whom were available for follow-up; (n.b. 53 had died) we chose a representative cohort of 50 individuals for prospective, sequential evaluations. They were chosen because they represented the whole cohort...’
 ‘Of the 50 patients, 46 completed the detailed 5 year study. Four patients declined to complete the tests but were contacted by telephone; all four reported that they were asymptomatic and did not want to participate in further detailed physiologic testing.’ [4]

2005 ‘In 1987, we began a population-based cohort study of 50 subjects with a remote history of paralytic poliomyelitis.’
 ‘Fifty representative subjects were chosen from 298 patients who previously had well documented paralytic poliomyelitis, living in Olmstead County at the time of the infection.’ (n.b. 53 had died)
 Of the original 50 subjects of the cohort, three subjects died during the 15 year follow up period. Nine of the remaining 47 refused further participation.’
 ‘Thirty-one of the 38 subjects whom we followed for 15 years reported symptoms of progressive weakness during the study period. Only seven subjects remained asymptomatic.’ [5]

Issue 4

Sorenson et al make several statements of caution when comparing their study to others then appear to proceed to ‘overcome’ or ‘ignore’ them. E.g. Regarding the McComas study Sorenson states ‘Without such a control group, one cannot reliably compare the changes in the polio group with those in a normal aging population.’ [6]

The first paragraph of their Press Release on 21st August 2006 states:-

‘Survivors of Childhood Polio Do Well Decades Later As They Age’
 ROCHESTER, Minn. Mayo Clinic researchers have found that years after experiencing childhood polio, most survivors do not experience declines greater than expected in their elderly counterparts, but rather experience only modest increased weakness which may be commensurate with normal aging.’ [a]

Compare that to the statement in their 15 year follow-up article published in March 2005, just eighteen months earlier.

‘How the changes identified in our polio cohort compare with those of a normal aging population remains unknown. We did not include a normal control group at the inception of the cohort. In the absence of a normal control population, the effects of normal aging in this cohort cannot be commented on.’[5]

Issue 5

Manual Muscle Testing – How valid and reliable is this as a form of grading muscles?

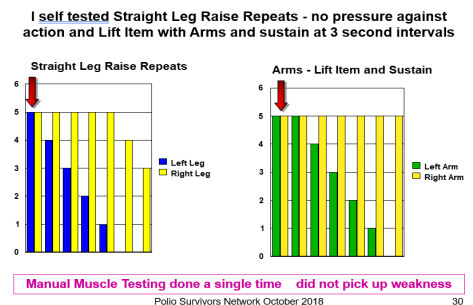
Professor W.J.W. Sharrard – a world renowned Polio Professor from the 1950’s, who wrote ‘Muscle recovery in Poliomyelitis’ [10], studied polio patients at autopsy and found that ‘muscle grades of 3 were given to individuals with 85% denervation of the muscles. In other words, profound muscle weakness must be evident before abnormal grades are given.’

The Mayo Clinic states that Manual Muscle Testing and Isometric testing across different joints were used to grade muscles. They have not used the normal MRC grading scale but used the following scale, which they state ‘has the advantage that numbers can be handled additively for additional analysis’ [2]

0	Normal strength
1	25% loss of strength
2	50% loss of strength
3	75% loss of strength
4	100% loss of strength

The issue with Manual Muscle Testing – most often performed as a single action – is that it will not tell the health professional how long the patient can sustain that action, repeat that action, or how they use that action in a pattern of movement.

According to Westbrook in her rebuttal of the 5 year study [9] Windebank et al derived their “Neurological Disability Score” from the results of manual muscle testing, a method that is notorious for overestimating polio muscle strength.[11] Polio survivors developed many trick movements; use other muscles instead of or to assist weakened ones. Important evidence of reported new weakness and compensatory strategies can be missed unless people are observed performing actions of daily living over a period of time.



Polio Survivors, who have often taken months or even years before presenting new weakness to a health professional, report again and again that ‘They say I am strong, that I have nothing wrong with me. Then why can I no longer do the things I used to a few years ago?’ To ensure this is not misinterpreted as age loss; such comments are coming from individuals in their 40’s and 50’s. The following are two responses to the Lincolnshire Post-Polio Network in May 2002:

"Regarding the MMT you are correct. **If done only a single time, it can give an erroneous idea of the true muscle strength and endurance.** In a way, the key word here is "endurance" which reflects muscle strength on multiple contractions. Many polios will have good strength on a single contraction only to get weaker on repeated contractions." *Lauro S. Halstead M.D. Director of Post-Polio Program, National Rehabilitation Hospital, Washington DC, USA.*

"You have done a brilliant job of describing a real problem for polio survivors and professionals that is, **the limitations of the Manual Muscle Testing (MMT)** scheme (a British invention, circa 1950, by the way). I quite agree with your comments and observations". *Fred Maynard, M.D. Marquette, Michigan, USA - President Board of Directors, Post-Polio Health International.*

Issue 6

Each participant completed a questionnaire of 337 items enquiring about limb and bulbar weakness, pain, fatigue and activities of daily living, in a YES/NO format.

There is an issue here that is well recognised and reported on in medical articles, [12] that polio survivors are strong willed, determined, highly capable people, who, regardless of level of disability/ability, do not need any help thank you. They are reluctant to admit that they are having new symptoms, new functional decline, and even when admitted and/or confirmed by testing, it can still be some time before they take the advice to pace and rest and use aids and equipment. Using a yes/no questionnaire does not necessarily allow polio survivors to convey to the health professional HOW they actually perform the action in question. 'Independently and with ease' for 'I could/can manage a small flight of stairs (about 10 steps) might turn out to be going up backwards sitting on their bottom.

Sorenson et al recognised 'that it had been difficult to ascertain whether limbs, apparently uninvolved by the original disease process, might become affected by progressive symptoms years later. This is because of the reliance of the memories of an illness that occurred 30 to 50 years earlier.'

The mean age at polio onset was variously reported as 9, 12 or 13 with the youngest age at one year or less. Not only is it difficult for affected individuals and family members to remember, it must also be taken into account that the youngest patients had limited language levels at the time of their polio.

Issue 7

The high levels of recovery from Paralytic Polio of some polio survivors, including some who were in iron lungs, is often not realised. Many have competed in professional or high level amateur sports, some have joined the police and armed forces, or had other highly physical jobs. The damage from their polio was not easily visible externally.

Following a presentation at St. Thomas Hospital in London by Dr. Windebank on the results of the first five years study [4], Hilary Boone asked "How many of the 50 did sport?" Dr. Windebank replied that "one man could manage three holes of golf." When asked, 'No swimmers, athletes, rugby referees, people in the police or armed forces?' he emphatically replied, 'these people had paralytic polio'. Hilary Boone replied, 'so did the people I am talking about, including myself. They all had paralytic polio and some were even in iron lungs'. The seminar restarted and Dr. Windebank did not answer a follow-up letter.

Conclusion

We believe the above throws doubt on the methods used in this study and the conclusions the authors made and continue to make from this research. The cohort steered towards those

- who had more severe deficits following recovery, [Method and Results 1991 - 3]
- who geographically still lived near to the clinic, [Method and Results 1991 - 3]
- 'These subjects were not seeking medical attention; they were invited to participate on the basis of their having had polio' [Discussion 1991 - 3]

It is highly possible that this cohort is not representative of the 608 residents of Olmstead County who had acute polio between 1935 and 1960. The results of the 50, now 38, people in this study cannot be extrapolated to the polio population of the United States. Sorenson et al's conclusions, based on a study of patients who have been chosen/selected, without a control group, believed by them to be representative of the 'polio population', can in fact be misleading.

Sorenson et al state, 'There are no confirmatory tests to reliably distinguish between the effects of the old disease from new progressive difficulties. It is a clinical diagnosis following history taking, physical examination, and test results.' [3] Therefore we believe it is essential that any study group mentioned in a polio/post polio medical article is more clearly defined to allow readers to make comparisons with their patients.

More and more polio survivors who recovered to the greatest degree from paralytic polio are now presenting to health professionals with new symptoms of weakness, pain, fatigue and considerable functional decline in actions of daily living. These are people who have often led active lives, have competed at amateur and professional sports, and who have had highly physically demanding jobs. They now find they have to:-

- Change their occupation and often medically retire early
- Return to using/start using aids and orthotics
- Go back to/start using canes, crutches, walkers, electric scooters and wheelchairs.
- Modify their homes and/or move to single story homes
- Be prescribed or purchase electrically operated chairs and beds
- Recommence using/start using respiratory aids
- Go from being very fit and active to being less able than their parents

In fact the results of this study can and should only be compared to those polio survivors who match the level of ability, disability, symptoms and lifestyle of the 50 participants, now 38.

This cohort has also been used in another article in Neurology in 2005. [7]

Where do we go from here?

Terminology: Are reported symptoms related to the late effects of polio, post polio syndrome, post polio sequelae, unstable polio, post-polio muscular atrophy, another medical condition; or a combination?

To be perfectly frank Polio Survivors already experiencing new and unexpected symptoms and functional decline do not care what label they are given so long as:-

- All our reported symptoms are accurately assessed and recorded.
- Other conditions are checked for as there are no diagnostic tests.
- We are given the medical and financial support to manage our lives.

The Mayo Clinic have been aware for ten years since publishing the results of the 5 year level of their study that other health professionals and post polio support groups do not entirely agree with all the statements made regarding their Olmstead County Polio research. It is regrettable that following such critique, they did not extend their study to include more polio survivors who had recovered like the surgeon and were now experiencing considerable new difficulties.

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. To have to continually question and research the results of testing that do not corroborate your reported symptoms because of the way it has been carried out or recorded is unjust. Struggling on year after year, often deteriorating through incorrect advice and treatment or lack of it, has to come to an end.

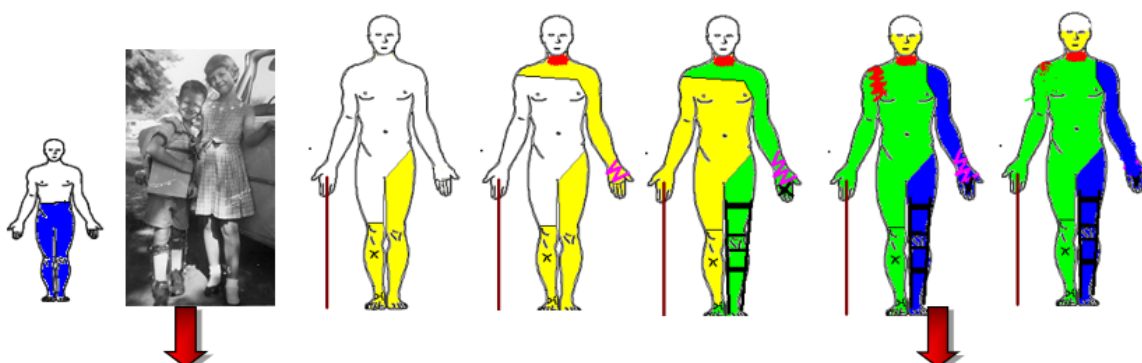
Polio Survivors – a strong willed, determined, highly motivated, hard working group of people – want to live for as long as possible, doing as much as possible. We need a full and accurate base line assessment that takes into account the endurance of our weakening muscles. We need advice, and the understanding that it takes time to accept that we have to change our lifestyle. We need treatment where it is available, appropriate aids and equipment, and benefits so that we can financially cope in this world where anything ‘disabled’ has a high price label.

References – available from PSN on request by email to admin@poliosurvivorsnetwork.org.uk

Also available from PSN is My Polio Life, a resource to help explain deterioration to healthcare professionals

‘POLIO TIME LINE’ - condensed version

[Best seen as four bodies per page with explanation underneath as 2 & 6]



Left leg KAFO Right leg AFO
 '56 Muscle transfer right foot - age 5
 '57 cyst removal same ankle - age 6
 '64 ankle fusion one foot - age 13
 '65 ankle fusion other foot - age 14

Left arm contracted tremors
 Right arm weakening
 Bad Right shoulder pain
 Neck pain - swallowing problems
 Legs weakening.
 Left muscle atrophy since brace

Tribute to Hilary Boone from Jo Cole and Deb Troops

I first met Hilary at a national Neurological Alliance (NA) meeting. Attending with the Chairman, Ginger Butler and his wife Verona, we co-founded the Tees Valley Durham and North Yorkshire Neurological Alliance (TVDNY) the year before.

I was the newbie having joined the steering group as an accredited volunteer for the British Epilepsy Association, now Epilepsy Action. Hilary and I found ourselves quietly giggling at some quite patronising material considering our knowledge. We ate lunch together and arranged to stay in touch. That was 2006.



Our friendship grew, we exchanged information regularly, meeting at Regional Alliance and NA AGM meetings in London with telephone and emails in-between. When I collaborated with a chap from West Berkshire Alliance to create Northern and Southern Regional Alliance hubs to reduce the travelling for some more disabled people, Hilary was the first to endorse and engage as a Northern member. The Northern and Southern hubs shared agenda's, were vocal, well-informed and inclusive, with the specific aim of driving actions to underpin the National Service Frameworks for Long Term Neurological Conditions.

Sadly, the NSF came to end in 2010, with a change of politics and suddenly Neurological Conditions were too expensive for the NHS. Hilary had a lot to say about that! We met Deb Troops, leading the Greater Manchester Neurological Alliance (GMNA) and the friendship grew. As 3 unpaid carers who called a spade a shovel, we understood first hand how people managed their life long conditions day-to-day, not just medical appointments once a year. Everything that Hilary, Debs and I were striving for in our individual organisations, came to the table. The Regional Alliance meetings faded away with a change of NA CEO, members felt powerless at the deteriorating services. Hilary wanted to make a difference, worked hard to keep momentum going. She was allocated a special place when we launched our Self-Management Tool and 'Open Door' series of resources at Teesside University in 2017. In turn, she introduced me to a New Zealand Researcher who piloted our Self-Management Tool with people managing post-polio and we received excellent feedback. The GMNA disbanded, TVDNY morphed into Neuro Key but conversations between Hilary, Debs and I continued to advocate to improve knowledge and understanding in services in Greater Manchester, Lincolnshire and Tees Valley. Acute Neurology Departments everywhere are in dire straits.

As with all unpaid carers, Hilary found the paper work soul destroying because it hid the reality of everyday life concentrating on process, not the impact on people. She often called to let off steam. She was a problem-solver *extraordinaire*, nothing was judged or assumed, sound reasoning and evidence underpinned everything. She knew fudged answers when she saw them and asked uncomfortable questions of senior NHS professionals that she already knew the answers to.

I had been trying to contact her for weeks, been a summer of chaos here with increased demand for our advocacy. I wanted to let her know about our latest research project in the hope she could use it at Lincoln University. As always with dear friends, when you eventually got to catch up it was joyful, except this time. I kept hearing, "wrong number" on her phone. I found the saddest of truths on the website, that Hilary had passed away. She was in hospital when we last spoke, promising to catch up. I had a few tears, how I wished I could have said goodbye. Debs and I have faith she is with us in our determination and endeavour to improve outcomes for people with neurological conditions, impairments or disabilities. She is about somewhere telling us to get on with it!

Debs and I send very best wishes to all she left behind.

Rest easy Hilary, it's been a privilege to know you.



Self-management Programme

In October 2017, a senior lecturer, Dr Stephanie Kiliñç from Teesside University and Jo Cole from TVDNY Neurological Alliance hosted an event to launch a self-management framework that was designed by people with lived experience of living with a long-term neurological condition. Taking a more biopsychosocial approach to recognise a whole person, not just a diagnosis, we enabled people to work with us to explore what meaning and purpose in life really meant to them. Publication of our co-authored paper, '*Finding Meaning and Purpose: A Framework for the self-management of Neurological Conditions*' (Kilinc, Erdem, Healey and Cole) in Disability and Rehabilitation Journal – May 2021 led to us developing a comprehensive long-term condition, self-management tool to underpin our work to promote pan-neuro conditions being included on the NHS long-term condition strategic agenda.

We launched the next phase of the project just before 2020 lockdown and discovered that the University Ethics committee had refused ethics on the ground that people with neurological conditions did not have capacity to consent. We were astounded and created peer support and training within 2 weeks to explain neurological did not mean lack of capacity. Ethics was approved but the day we were due to begin, lockdown was announced.

Undeterred, we went digital and at the end of lockdown, we created a steering group of people who lived with life-long health disabilities as peer mentors to participants in the research project. They led the work, including naming the project and during one of the sessions, we purchased the domain name too. Thus, the MyLife Tool self-management programme was realised.

www.mylifetool.co.uk

The project diversified and a resource for Long Covid was created by people living with the impact of the pandemic and Creative life to explore some of the benefits of Creative arts in improving well-being.

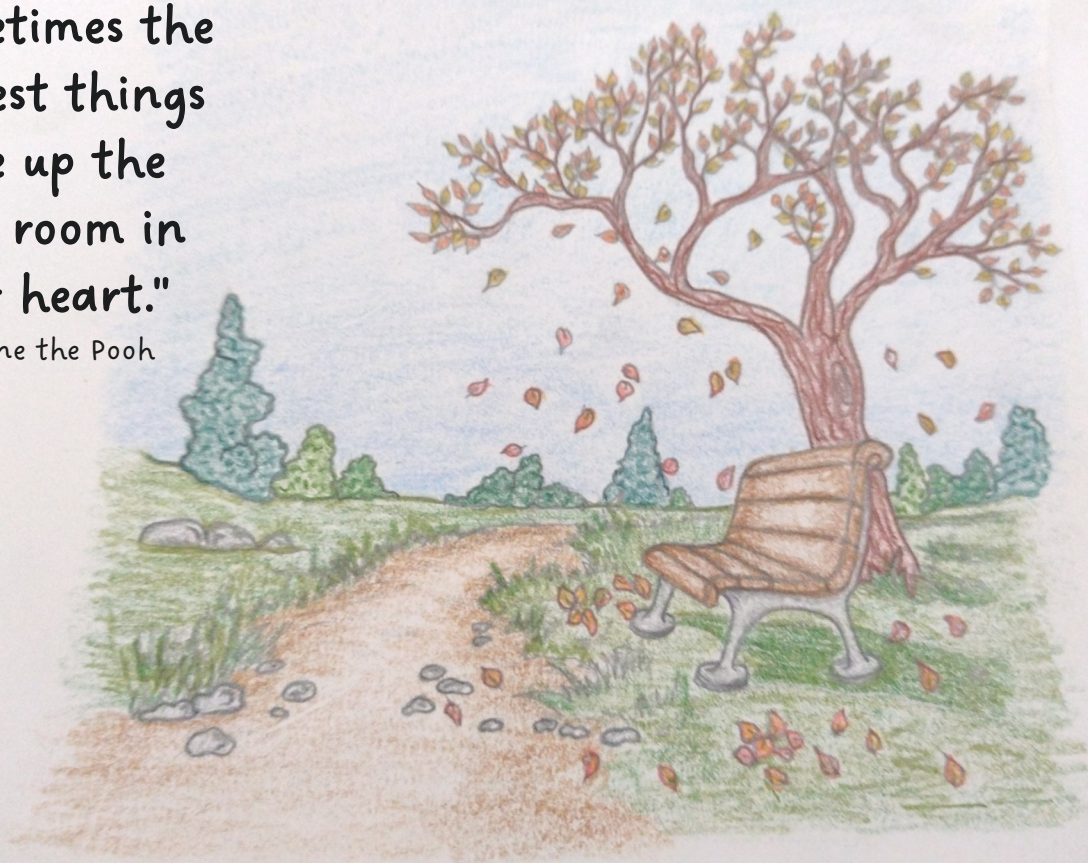
TVDNY became Neuro Key in 2023 and in 2024, the team secured funding from the University to develop the work, recruiting four people who had been Peer mentors and research assistants in previous projects. The Peer Researchers Backpack arrived in August 2024.

One of the people commented, "I am no longer unemployed, I am a Peer Researcher"

We hope we contribute to a body of knowledge that recognises the real value of lived experience in research and hope it continues to grow.

"Sometimes the
smallest things
take up the
most room in
your heart."

- Winne the Pooh



Overview of REASONS WHY IT'S HARD TO GET A DIAGNOSIS

Failure of Colleges of Medicine

to teach enough [in some cases any] facts about Polio and the late effects of polio, most commonly called Post Polio Syndrome, both initially and in continuing education, e.g. Not all polio affected muscles are atrophied, some muscles are fat with muscle striated through it. 'Guidelines' for GP's does contain information on PPS but you need to know the condition exists to look for the page.

Recovery Levels The majority of Polio Survivors recovered externally to such a level that until they have new symptoms you would not realise they had Polio in their earlier lives. Do not assume the person in front of you in callipers or a wheelchair has always been like this.

No appropriate routes of referral for GP's to send patients for assessment. Patient pathways now being developed.

Manual Muscle Testing – huge waste of money on the rounds of the hospital departments because single action Manual Muscle Testing in most cases will not confirm level of reported symptoms. Repeatedly we are told, 'nothing wrong back to GP' and off to another specialist and another and ending up with... therefore 'it must all be in our minds'.....

There are no tests to show PPS, it's a diagnosis of exclusion. There are tests that can show old polio damage, e.g. EMG, Muscle biopsy but these should only be done if necessary to diagnose. i.e. EMG's are very painful for Polio Survivors and a muscle biopsy could cause more nerve damage

Inadequate Initial assessments in consulting room with not enough time and space to allow for history taking and functional physical assessment that could corroborate the facts of functional decline being reported by the patient..

Problems with questioning. Failure of patient and health professional to ensure that the picture in their mind at question and answer match. Questions being asked 'Can you walk? Get the answer 'Yes'. Change that to 'How do you walk? And the response changes to 'I use underarm crutches and swing my legs through'.

Problems with the way we present our symptoms. We are stubborn, strong willed, determined, do not need any help and are often in denial of new symptoms for years, and reject the advise of pacing and resting, using aids etc.

Facts in medical articles. Taking and/or using facts from older medical articles on post polio without checking on the level of polio of the subjects of the research. The people involved in the research may not be representative of all polio survivors.

First phase of polio campaign concludes successfully in Gaza



Over 187 000 children under ten years of age were vaccinated with novel oral polio vaccine type 2 (nOPV2) in central Gaza during the first phase of a two-round polio vaccination campaign, conducted between 1–3 September 2024. Vaccination coverage in this phase exceeded the initial estimated target of 157 000 children due to population movement towards central Gaza, and expanded coverage in areas outside the humanitarian pause zone.

To ensure no child is missed in this area, polio vaccination will continue at four large health facilities in central Gaza over the next few days. Vaccine doses have been supplied to these sites to meet any additional needs.

“It has been extremely encouraging to see thousands of children being able to access polio vaccines, with the support of their resilient families and courageous health workers, despite the deplorable conditions they have braved over the last 11 months. All parties respected the humanitarian pause and we hope to see this positive momentum continue,” said Dr Richard Peeperkorn, WHO Representative for the occupied Palestinian territory.

The first phase of the campaign was conducted by 513 teams, consisting of over 2180 health and community outreach workers. Vaccination was provided at 143 fixed sites, including hospitals, medical points, primary care centres, camps where displaced people are living, key public gathering spaces such as temporary learning spaces, food and water distribution points, and transit routes leading from central towards northern and southern Gaza. Additionally, mobile teams visited tents and hard to-reach areas to ensure they reached families who were unable to visit fixed sites. The presence of a substantial number of children eligible for vaccination who were unable to reach vaccination sites due to insecurity, necessitated special missions to Al-Maghazi, Al-Bureij and Al-Mussader – areas just outside of the agreed zone for the humanitarian pause.

Preparations are underway to roll out the next phase of the campaign, which will be conducted in southern Gaza from 5–8 September 2024, targeting an estimated 340 000 children below ten years of age. Some 517 teams, including 384 mobile teams, will be deployed. Nearly 300 community outreach workers have already begun outreach to families in southern Gaza to raise awareness about the campaign, while 490 vaccine carriers, 90 cold storage boxes, and other supplies have been transferred to Khan Younis for distribution to vaccination sites.

The third and last phase of the polio vaccination campaign will be implemented in northern Gaza from 9–11 September 2024, targeting around 150 000 children.

At least 90% vaccination coverage during each round of the campaign is needed to stop the outbreak, prevent the international spread of polio and reduce the risk of its re-emergence, given the severely disrupted health, water and sanitation systems in the Gaza Strip. Vaccination coverage will be monitored throughout the campaign, and, when necessary, vaccinations will be extended to meet coverage targets as part of flexible strategies to ensure every eligible child receives their vaccine dose.

The two-round campaign, being conducted by the Palestinian Ministry of Health (MOH), in collaboration with the World Health Organization (WHO) and United Nations Children Fund (UNICEF), the United Nations Relief and Works Agency for Palestine Refugees (UNRWA) and many partners, aims to provide two drops of nOPV2 to around 640 000 children during each round.

“The successful delivery of the first phase of the campaign in central Gaza is a culmination of immense coordination among various partners, including the Global Polio Eradication Initiative (GPEI) and donors, and underscores the importance of peace for the health and well-being of people in Gaza. We call on all parties to continue fulfilling their commitment to the humanitarian pauses as the second phase of the campaign begins tomorrow,” said Dr Peeperkorn.

<https://www.who.int/news/item/04-09-2024-first-phase-of-polio-campaign-concludes-successfully-in-gaza>

Source: World Health Organisation, News Release, 4 September 2024

Using Fitbit for Weight Management in Post Polio

It's very important that we all manage our weight to avoid extra stress on our bodies.

In order to measure our calories we need to assess our food and drink and record it. This sounds like a challenge, but it's simple with digital scales and scanning the barcodes on food and drinks. Once an item is recorded, it can be recalled and reused. This is useful, because we tend to eat and drink the same 20% of things 80% of the time.

I use my Fitbit to show my daily calories in and out as you can see in the image from the week of the 8th to 14th July.

It's also very important that we have and maintain a healthy balanced diet with good proportions of carbohydrates, good fats and proteins. If we record our food and drink we automatically get a breakdown of the macronutrients as seen in the next image. We can also drill down into the nutrients, vitamins and minerals, salt and sugar in that food each day.

Having a log of our food and drink also helps us have an overview of our diet and the foods that are healthy and not.



This overview may help us maintain and feed a healthy microbiome which is the collection of all microbes, such as bacteria, fungi, viruses, and their genes, that naturally live on our bodies and inside us. Microbes are so small that they require a microscope to see them, but they contribute in big ways to human health and wellness.

This is my public Fitbit profile: <https://www.fitbit.com/user/25D85C>

If you have a Fitbit, you can 'friend' me and see a bit more of my real time movement information, which may be a useful benchmark to a fellow, post polio survivor. However, it's important to know we are all different individuals and your level of mobility may be very different from mine.

I have also set up an International Post-Polio Syndrome (PPS) Group on Fitbit. This group is ring fenced by invitation only, which I invite all PPS friends to join.

- Alan Lee PSN Member



What Is Post-Polio Syndrome?

Polio, or poliomyelitis, is an infectious viral disease that affects the nervous system. Between the late 1940s and early 1950s, polio crippled around 35,000 people each year in the United States alone, making it one of the most feared diseases of the twentieth century. In 1955, Jonas Salk introduced the polio vaccine, stopping the spread of the disease and eventually eradicating it from the United States.



Post-polio syndrome (PPS) is a condition that affects polio survivors years after recovery from an initial acute attack of the poliomyelitis virus. According to the National Institute of Neurological Disorders and Stroke, researchers estimate that the condition affects 25 to 50% of polio survivors.

What Are the Symptoms of Post-Polio Syndrome?

Symptoms can appear 10 to 40 years after the initial illness. The most common symptoms of PPS include slowly progressive muscle weakness, fatigue (both generalized and muscular) and a gradual decrease in the size of muscles (muscle atrophy). Pain (from joint degeneration and increasing skeletal deformities such as scoliosis) is common and may precede the weakness and muscle atrophy.

Post-polio syndrome is rarely life-threatening, but the symptoms can significantly interfere with an individual's ability to function independently. Respiratory muscle weakness, for instance, can result in trouble with proper breathing, affecting daytime functions and sleep. Weakness in swallowing muscles can result in aspiration of food and liquids into the lungs and lead to pneumonia.

How Is Post-Polio Syndrome Diagnosed?

There are no laboratory tests specific for PPS, and symptoms vary greatly among individuals. Physicians diagnose PPS after completing a comprehensive medical history and physical examination, and by excluding other disorders that could explain the symptoms. While there is no diagnostic test for PPS, physicians may use certain tests to rule out other conditions. Among the most commonly used is electromyography (EMG), which measures the tiny electrical discharges produced in muscles. A thin-needle electrode is inserted into the muscles to be studied, and an instrument records electrical activity in the muscles at rest and during contraction.

How Is Post-Polio Syndrome Treated?

Although there are currently no effective pharmaceutical treatments that can stop deterioration or reverse the deficits caused by the syndrome itself, there are recommended management strategies, including:

- Physical, occupational, and occasionally, speech therapy
- Exercise, especially cardiopulmonary endurance training, under supervision of experienced health professionals
- Equipment to help with walking, breathing, and other important functions
- Lifestyle changes to avoid rapid muscle tiring, total body exhaustion, pain and fatigue
- Education, support groups and counselling for individuals and families.

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 [Trustees]

Chair - Simon Parritt simon.parritt@poliosurvivorsnetwork.org.uk
Trustee - Zsuzsanna Snarey zsuzsanna.snarey@poliosurvivorsnetwork.org.uk
Trustee - Verité Reily-Collins verite.reilycollins@poliosurvivorsnetwork.org.uk
Trustee - Barbara Taverner barbara.taverner@poliosurvivorsnetwork.org.uk

Trustee/s - Vacancies please contact Toni for more information

Operations Team

Admin and Enquiries - Toni Dunlop psnadmin@poliosurvivorsnetwork.org.uk

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

Website www.poliosurvivorsnetwork.org.uk

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

Email psnadmin@poliosurvivorsnetwork.org.uk

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

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

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

Donate by **cheque** to Polio Survivors Network

by **PayPal** to treasurer@poliosurvivorsnetwork.org.uk



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

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

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

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

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

NB Respiratory and Sleep Problems Section very informative.

GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups

POLIO PATIENTS AND SURGERY - Information for health staff.

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

http://www.europeanpolio.eu/documents/13642_Polio_operation_eng_TRYK.pdf

Printed copies on our headed paper with permission are available.

Editors Note: Articles from Polio Survivors and Health Professionals welcomed

SIGN THE PETITION TO SAVE WINTER FUEL ALLOWANCE

Tell the Chancellor Rachel Reeves and Scottish Finance Minister Shona Robison

Don't scrap the Winter Fuel Allowance for millions of struggling pensioners just as energy bills are about to increase AGAIN.



Sign the petition here: <https://tinyurl.com/msrvep3a>

Are you a polio survivor facing challenges with fuel payments? We have collated some useful support options:

British Polio Foundation Offers guidance on accessing financial aid, including help with fuel costs. www.britishpolio.org.uk/heating-grant

Age UK Offers advice on energy efficiency, grants, and fuel payment schemes. www.ageuk.org.uk/information-advice/money-legal/debt-savings/energy/cost-of-living-payments/

StepChange Support if you're in debt with your energy bills www.stepchange.org/

Contact List of help available in each nation www.contact.org.uk/help-for-families/information-advice-services/money-debt/help-with-household-bills/

Scope Provide a list of further places to apply for grants www.scope.org.uk/advice-and-support/energy-bills-help

Ofgem Provide information on the Warm Home Discount www.ofgem.gov.uk/environmental-and-social-schemes/warm-home-discount-whd/warm-home-discount-whd-eligibility

Great advice from **Money Saving Expert** www.moneysavingexpert.com/utilities/how-to-get-help-if-you-re-struggling-with-your-energy-bills-/

Remember, you are not alone, these organisations are here to help you