



POST POLIO MATTERS

Polio Survivors Network Newsletter

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DOING IT OUR WAY

POLIO SURVIVORS have lived our lives, lives that were full and often to a level way higher than initially thought possible. As we recovered there were many changes as we planned each careful step, each wheel rotation travelling along our various highways achieving more to reach our best possible.



Now our muscles weaken there are times that we bite off more than we can chew. We need to ask for aids for human help... so against our life before... so hard for us to ask out loud.

There is no doubt that we need this support, year on year, as we continue to modify the ways to do what we can manage. If you did not have polio but you have had an injury or operation that reduces how you functioned for a while then you probably found that it was not easy working out how to do some of the things you needed to do.

We know Polio Survivors are not easy patients, no two of us the same. We know there are manuals that advise things like 'how to get up from the floor' and 'this is the equipment we supply for that problem'. You have the extensive knowledge of your profession and we have decades of experience of having to continually change how we do what we need to do. Please work together with us so we can work out how to find yet another way to do it our way.

I give the following example of where I failed to provide enough information as to why I had to do the action my way.

I explained I was struggling to get up from the toilet that 12 years ago we had had fitted to a frame at 19 inches in height, 3 more than normal. I demonstrated how I got up from sitting on the side of the bath that is 5 inch higher at 24". With my hands on the side of the bath level with my bottom I lean forward and can stand with very little strain on my shoulders.

The solution was an email telling me that a frame and raised toilet seat like the one on the left would be provided. This would not work for me. I had failed to explain when demonstrating that my hands have to be at the same level as my bottom and no higher or it would put too much strain on my shoulders. It is extremely important that we [Save Our Shoulders](#) so we can still transfer.



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**Polio Survivors Network send our sincere condolences to
Her Majesty the Queen and her family
on the passing of her husband
His Royal Highness the Prince Phillip, Duke of Edinburgh.**

**THE DUKE OF
EDINBURGH**
1921 - 2021



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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</i> (since last newsletter)	
V Scrivener	£30.00
D & J Shaw	£12.50
K Lagwi	£12.50
Total	£55.00

Thank you so much!

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Editorial by Hilary Boone

One would think that with all these months of Lockdown the time would be going slowly. However, for us we cannot believe how fast the months seem to be going. It is 1st May today, the start of our 15th month stay at home.

Thankfully our carers had their second vaccine over a week ago (Pfizer) but both struggled with fatigue and pain for a few days. They are OK now over a week later. Richard and I have just had the AstraZeneca second vaccine. For us the first shots Richard did not seem to have any reaction to both shots. For me, I had hurt my left wrist about 12 hours before the first shot and the pain multiplied by at least four for a few days. I answered this to the question from the nurse on 28th April when I went for my second shot and she said, as I had thought, it had gone to the site of inflammation. This time I did not even feel being given it and I have not had felt any different from my normal level of struggling to complete the endless and growing paperwork that arrives through the letter box [laughing to myself—perhaps I should tape the letter box closed?] and by email.

How many more of our members are also a carer to a disabled partner? We manage our Post Polio Syndrome by pacing and resting and using energy tokens [10 a day and 70 a week] to plan our lives. I am having to give up some of my energy tokens to help Richard [he also has Stage 4 Parkinsons] when we are unable to employ a carer due to the loss of funding for his medical needs. Please, if you are in this position, do let us know of any issues that you have so that we can see if there is anything we, and the other neurological charities with which we are in contact, can do to help.

It is taking months to have Richard assessed by the many health professionals needed to be able to provide all the medical reports for his varied complex issues for the checklist onto multi disciplinary team meeting. I just charted the hours I have been on duty, and for the first four months of the year it is 76% of the time. Of course I am asleep some of this time but as Richard has to have medication at 10.45, 02.30, 06.30 the most sleep I get in one stretch is about 3.5 hours. I read on my iPad on night screen to try and get back to sleep.

⇒ ***Continued from front page...***

Actions of Daily Living. Have you stopped and thought how you are doing the actions of daily living? How many times have you changed the way you do them since Post-Polio started? Until I did this I had no idea because every change just became my new normal.

In 2004 I was scrambling eggs and suddenly realised that I was using elbow rotation not wrist rotation to do this. Everyone up to then had recorded my arm strength as normal. On telling this to the Physiotherapist who was giving me a full assessment she tested the muscle involved with this action. She found that whilst I had passed the normal arm strength test of grip my fingers, pull and push against her that my wrist muscles were very weak. If you give health professionals more specific information about these changes you can then ask them "Please can you tell me why I am have had to change the way I do this?"

To work in the kitchen I have to stand up as my arms work best at 45 degrees down. I used to work in the sink then when we moved 13 years ago we cut the kickboard off one cupboard to lower that work surface. I hold on with one hand as I move about the kitchen and if I need both hands to do something then I have to lean against the work surface. I am also limited to a few minutes of doing this before need to rest.. Perch on that lowered work surface.

Remember not everyone who assesses us is a medical professional and even if they are they may not have received any/enough facts about Polio and the nerve damage caused and/or Post-Polio Syndrome and the new weaknesses in those polio muscles. In 1996 when we first started our research we found that for Doctors, Polio was a half hour lecture with leprosy!!!

Help PSN build up more information on the different ways we have developed to manage our every day lives. Remember your way may help someone else manage their lives. We look forward to hearing from you.



POST POLIO MATTERS

Polio Survivors Network - 2021 Annual General Meeting

The decision has been made by the management committee to cancel the Polio Survivors Network 2021 Annual General Meeting due to the ongoing Covid-19 pandemic.

As our members are vulnerable and also to keep in line with current government advice, we are not confident at this time to plan an AGM that would be before our submission deadline of September 2021. Whilst things are slowly opening up and vaccines being administered, forward planning is not set in stone.

The management committee considered holding a virtual AGM using Microsoft Teams and hosted practice runs in the form of a virtual coffee catchups. As many of our members are older and digitally excluded this was not felt to be a good fit for our needs as a charity.

If it is possible to hold a face to face get together safely before the end of the year as the lockdown eases we will look at the options available. **Simon Parritt, Chair**



As referenced on our cover page, MossRehab developed Save Our Shoulders which is an excellent resource. It can be found https://www.mossrehab.com/upload/docs/Services/mrri_sos9510.pdf and also on Post-Polio Health International website <https://post-polio.org/wp-content/uploads/2020/01/Save-Our-Shoulders.pdf>

“Many polio survivors report new symptoms as they age, Some of the more common symptoms include loss of strength, fatigue, muscle twitching, cramping and muscle or joint pain.”

“The purpose of this manual is to help polio survivors become more aware of the behaviours that can cause shoulder overuse and some of the treatment options that are available.”

What do YOU think of USA invasion of the NHS?

After I posted an article about the American company Centene's take-over of 58 GP surgeries around Britain, plus the announcement that American Tim Ferris had been headhunted from Massachusetts's GP Organisation to be NHS National Director of Transformation, my inbox exploded.

The article is here : <https://aftercancers.com/american-revolution-in-reverse/>

Before moving out of London I was finding I had to wait three to four weeks for a GP appointment, even if I said I was in pain. My surgery had amalgamated with several others "for your convenience", but innovations copied from across the Atlantic was making my care less user-friendly.

Some years ago I was paid to sit on a Dept. of Health committee, looking in to care of the elderly, such as polio survivors. The committee was run by a firm of American Management Consultants, who proceeded to give us all a glitzy presentation about the benefits they were going to bring over looking after the needs of London's elderly.

The Americans had flown a group of NHS administrators over to their HQ in Seattle, "to see nurses in training". These then agreed to employ 200 of the trainees, at a salary of £50,000 p.a. (we wondered if UK nurses had been offered this),

Putting on my smarmiest face, I asked "I do hope we'll welcome the US nurses?" I was assured "yes". "And will we be giving them the same contracts as British nurses?" "Of course".

Anyone knowing the employment scene in the US knows that the private healthcare package is almost more important than the salary. So surprise, surprise, only six US nurses applied for the job, all that were prepared to risk long waits for NHS treatment. So British nurses were employed, but sadly I suspect on a lower salary.

NHS today

Many good ideas came out of lockdown, and giving power to those who understand the system and know what needs to be done would seem to be the way forward, but does a big conglomerate understand our GP surgery system? And does Ferris have in-depth knowledge?

Currently **Centene**, and its subsidiary **Operose Health**, are involved with 58 GP surgeries across the UK: making it the largest GP network in the UK. And the **UK boss of Centene, Samantha Jones, was recently appointed as an adviser to Boris Johnson on "NHS transformation and social care"!** **Anything ringing bells?**

Today, the NHS has 9,000 GP vacancies, and the shortest consultation time of any economically developed nation. (French GPs often ask how can our doctors give a diagnosis in 10 short minutes?). Can we really afford to let the Centene experiment continue in our GP practices?

With GPs resigning in droves, what is needed in the NHS? Do we need overseas involvement? Or do we need someone who understands the problems of an under-funded NHS reeling after lockdown? Or do we need someone who understands what the NHS needs, how to make use of the way NHS staff performed miracles, came out with new ideas, innovations and improvements, often radically changing healthcare for the better. So let's utilise this talent, instead of head-hunting across the Atlantic.

The US medical system is known to be inefficient, and possibly one of the most expensive in the world. So what do we have to learn from this? Except perhaps how to 'add value' by increasing bills? Involving outside agencies from another country will mean they have to be paid - somehow.

As Silver Voices, the very-much-on-the-ball campaigners for the elderly say, "Worrying times indeed".

Lack of contact with patients is one reason why GP's leave the profession early. Today, we have the shortest consultation time of any economically developed nation.

Ferris comes with the usual PR promises of "setting forth a strategy and overseeing the design, development and delivery of clinical and digital technologies aimed at improving health care quality, increasing productivity and ensuring convenient access to services and health information for more than 56 million people in England".

This begs the question "what's new? and what do we get out of it?" Answer - a whole lot of upheaval, changes and cut-backs.

And watch out! Ferris is coming into the role promising to look out for a "wide range of efforts aimed at improving care in the hospital and in the community for the sickest and most vulnerable patients". We all want this, but how to deliver this, in a grossly underfunded NHS, needs someone who understands how the NHS works,

This will take a deep understanding of how the health system works in Britain, which means someone who had had years to understand what is going on in Whitehall, as well as what is urgently needed in the NHS.

This video was made by a group of patients, worried about what was happening to their local surgery <https://mail.google.com/mail/u/0/#inbox/FMfcgwxwLtkZxLbGwdImMLbcMjzBdpdfg?projector=1>

Verite Reily Collins Trustee, Polio Survivors Network

www.aftercancers.com

Lessons have been learned - or have they?



When Nurses or Doctors asked me "why didn't you get the polio vaccine?" I would politely explain that this wasn't developed until after I had caught polio. Until I realised they didn't listen. Now, I just burst in to crocodile tears. These flow until I reckon the point is taken that this is an insensitive question.

I am a cynic, and not convinced everyone looking after my health has learned lessons they should. I tip-toe around a 'new' doctor, until I can work out if they know what's what. Like all of us, 'I get on with it' if there is a problem, otherwise we'd never get anything done.

I remember telling the Anaesthetist from The Royal Marsden, twice, that I had had polio. Went off for my op - and when I woke up alone in the recovery room, lying on a theatre trolley, thought "they haven't operated".

Hooking my legs under the trolley mattress, I attempted to sit up and find out what was going on. The trolley shot across the room, banging into a tsunami of other trolleys that shot off in every direction. The noise bought people running to see what was going on.

Were they concerned about me? I should cocoa. Sister bore down saying "you weren't supposed to be awake", and was obviously furious - with me. With polio you have different reactions to anaesthetics, but - of course - it was my fault that things had gone wrong!

I just hope rivalries twixt NHS and Military are sorted out today! Many years ago, a Military Ambulance transferred me from Millbank Military Hospital in London to the Royal National Orthopaedic Hospital at Stanmore to start my polio treatment. Nurses had wrapped me in sheets, as it was too painful to dress me in a nightdress or PJs.

On my journey I had a full Military escort; nothing to do with me, but you were 'nursed' according to rank (or in my case my father's), so two smart male orderlies in full khaki uniform, and two female Queen Alexandra nurses in their elegant red capes, accompanied me.



Marching me smartly on my trolley into the ward, out of the corner of my eye I saw a Sister shoot out of her office, calling up her 'troops' as she swept down to repel this invasion.

Elbowing the nurses aside, she proceeded to whip the sheets off my trolley – leaving me fully exposed and stark naked.

No doubt this made a lively tale when everyone returned to quarters, I'll always remember receiving a lovely 'care parcel' from the Military team, of delicious Meltis New Berry fruits, as a kind memento.

It was a different problem with French student doctors. In hospital, every Friday my surgeon would carry out his Ward round, trailing a group of doctors from abroad who had come to learn from the great man.

I enjoyed meeting these doctors, until one day I heard sniggering amongst the young, male group. I spoke French, and could hear my legs being discussed at length (they were long even though I was only 16). With idiomatic French (learned from dubious sources), I told them to F - off.

My surgeon suddenly found his audience were cowering in the centre of the ward, looking at me transfixed. Astonished anyone in Britain spoke French - and such words! - but my surgeon had a quiet smile on his face.

MRI Scans can cause me problems because there is no way I am able to lie on the flat metal bed without lots of padding. I explained this to the doctor in charge, several times.

Eventually, I thought she had grasped that I needed strong pain relief, and she produced some tablets for me to take. But, ten minutes into the procedure, I could feel red-hot poker starting to

dance up my spine, and had to call a halt.

Crawling out, I was met by a furious doctor, arms akimbo: "I gave you tablets for claustrophobia" she almost screamed. And wasn't too interested when I tried to tell her I didn't suffer from fear of being enclosed, but she was past listening.

Recently, it took me four months to find someone in the vast NHS network who could check if it was safe to have the Covif-19 vaccine. Previously my reactions to drugs had included losing the sight of my right eye, to a 7-hour heart operation; so I didn't want a repeat.

Finally, everything comes to he (or she) who waits! And a friend-of-a-friend introduced me to a charming Nobel medicine prize-winner (how lucky can you get) - who in a no-nonsense way talked me through what I should and shouldn't do.

Reading through the literature handed out after the vaccination, I saw the words 'chimpanzee' and 'ethanol'. Now, it's not rocket science: these words could be worrying - yet those ladling out the vaccines don't seem to have cottoned on.

Perhaps those moaning about 'anti-vaxxers' should learn some lessons, and be prepared to answer questions that concern us. Or will it take the Army yet again to step in and sort things out so we get listened to?

If anyone has the same quirky sense of humour as me, see <https://aftercancers.com/the-indoor-mountain-climbing-club/>

Verite Reily Collins

www.aftercancers.com

Editors note: Apart from chuckling a lot whilst I typed this up it reminded me of similar issues Richard and I had had. Please tell us your stories. These are important points and we need to find a better way of telling health professionals about our issues.

Waking up early in the Recovery Room. I had the same coming round early experience in the Recovery Room after a small gynae op. I woke up, I could not see any staff so I lifted my blanket to see if I had been operated on. I had. I called out and Staff came running, they were mystified and said we will send you back to the ward but you are going two ahead of what we expected. They sent the anaesthetist to see me later that day. He told me that he had researched and found I needed less anaesthetic as our polio weakened muscles cannot clear the normal dose as easily. He added that maybe he should have given me just a little bit more as I had given the Recovery Staff quite a shock.

MRI last year. I too cant lie flat I explained. They said they would sort it and laid on my back with my knees up [they were lowered over a cushion] I had my head pushed into a plastic cage and I started my journey in with my eyes tightly closed. I was in massive pain in my back due to the curvature of my spine and told them. Two minutes really important, so saying Nursery Rhymes constantly I manage the two minutes.. Then it was two minutes more and with tears rolling down my face from the pain I continued saying my nursery rhymes as the machine made its g,g,g,g,g sounds. That was over and would you believe they said just another ten minutes but I had to say please get me out of here and out I came my face wet with tears and my back killing me.

Richards story is that I had had an accident and he had come with me in the ambulance. He did not have any food at the right time and he fainted so they put him in the next bed to me. I had broken my ankle and it was wrapped up in cotton wool and my plastic Ankle Foot Orthosis put on and I was sent home at 3.00 am in a Taxi. Richard however was low on potassium so they kept him in. Next morning a Consultant arrived on the ward with a gaggle of students. The Consultant started to ask him questions about his conditions and the medication he was taking. He asked "What are you taking this Mirapex for". Richard replied "Parkinsons" The Consultant responded "I have never heard of it being prescribed for Parkinsons". Richard then asked him "Are you a Neurologist?" He tutted, spat feathers and stormed out of the room saying "Discharge this man". Richard said the students were having a hard time keeping straight faces.

COULD YOU CLAIM?

Has Covid-19 forced you to wear a mask and glasses at the same time?

If so - you may be entitled to condensation.

Polio Pioneer Helps Survivors Hold On To Strength By Joseph Shapiro

With permission from Polio Perspective April 2021, Editor Millie Malone.

Dr. Lauro Halstead is one of only a handful of doctors in the U.S. who specializes in polio - and he speaks to his patients with authority. He was one of the first doctors to publish evidence of a startling medical problem: Twenty-five years ago this month, he presented evidence that people who'd had polio as children were reporting a new weakening of their muscles as they got older. It became known as post-polio syndrome. But there's one more thing that gives him an understanding of his patients: Halstead is a polio survivor, too.

One challenge is that many doctors do not have experience treating patients with polio or post-polio syndrome, says Dr. Lauro S. Halstead in his book *Managing Post-Polio*. He recommends working with your primary care doctor to find a physician with expertise in post-polio care.

At the National Rehabilitation Hospital in Washington, D.C., Halstead comes down the hallway on an electric scooter. He is 73, and he would like to retire, but he can't. The number of aging patients who want to see him is growing. Post-polio patients - including many from around the country and even from other countries - come to his polio clinic here.

On a late April day, Edith Gerver sits in an exam room, with a bamboo cane at her side. The 83 year old explains that her daughter is moving to Florida, and she's thinking of going with her. But she's having a problem: Lately she's been losing her balance and falling, a few times a month. She has come to see Halstead, hoping he can come up with a solution.

The doctor asks her to take off her shoes. Her feet are strange: There are scars, but no ankles. Multiple childhood surgeries fused her bones so she could put weight on her feet and walk. Halstead uses his arms to press against her feet, testing the strength in her legs.

Shared Experiences

He takes a medical history and gets a sense of her active life. They share their polio stories. He was 18, a college student touring Europe, when he got sick. She was an infant in Germany, and later, when her Jewish family fled to the United States, she wasn't at first allowed in because she had had polio.

Halstead tries to persuade Gerver that it's time to start wearing a leg brace. He rolls up his pant leg and shows the one he uses. She says she tried one before, but it was too uncomfortable. He tells her she should get a scooter, like his. She says it would be too hard to get around with it.

"What I want to do," he tells her, "is be able to make any modification that you are interested in that would help you have a more comfortable, enjoyable life."

But it's not easy for his patients to do things that look like they'd be giving in to their polio. People with polio worked hard to overcome their illness, so it goes against their nature - when post-polio syndrome kicks in - to slow down.

"So you may think, you think that maybe that's like giving in?" he asks her.

"I feel that as long as I can stand on my two legs, I'm ahead of the game," the woman says. "I know that doesn't make much sense."

"No, it doesn't," the doctor replies softly.

"But it's who I am," Gerver replies. "And I think polio made me that way."

"OK," says Halstead. "I will accept that."

Survivors

But he doesn't give up. He keeps pushing her gently over the hour-long appointment. By the end, she agrees to let him call the hospital's orthotist. She'll try one more time to wear a leg brace.

Halstead can relate to patients like Gerver because he, too, is managing his post-polio syndrome. "I'm having a lot of the same issues that she is in terms of slow, progressive weakness in my legs," he explains. "So I can walk shorter and shorter distances. I continue to use a motorized scooter for longer distances, longer than 20, 30, 50 feet. I take afternoon naps to help get me through my afternoon fatigue."

There hasn't been a new case of polio in this country from the "wild" live virus since 1979. The use of the live-virus vaccine, which sometimes can cause infection, was discontinued nine years ago.

Still, there are hundreds of thousands of polio survivors alive in the United States. The National Center for Health Statistics estimates that there are more than 440,000. The leading polio survivors' group, Post-Polio Health International, puts the numbers at 775,000 or more. Many of these survivors are still paralyzed. But most aren't and, from looking at them, there's no way to know they had been infected. But all polio survivors face the threat that polio can come back as they get older — the post-polio syndrome first described in the mid-1980s by doctors like Lauro Halstead and Marinos Dalakas.

Another patient, Julie Lewis, waited six months for her appointment with Halstead. This is her first time to the clinic, so she spends two mornings seeing Halstead and his team, which includes physical and occupational therapists, and a social worker.

She has a busy and important job as a hospital administrator. She, too, finds it hard to accept all of Halstead's advice to slow down including taking a nap at the office.

After her long sessions with Halstead, she goes back to the office. Lewis, at least until now, has always been able to hide her polio. But right away, Halstead spots the one visible tip-off. He holds his hand to hers. On both of them, the usually thick muscle at the base of the thumb has withered.

That looks familiar to me, your hand," Lewis tells the doctor. "I like your hand."

Halstead laughs and says, "But it's useless to me." There's no question that the atrophied hand muscle is a sign of polio," he says.

That comes as a relief to Lewis. She's 55 now. She remembers that when she was 9, she was so sick for weeks that her mother had to hold her up in bed and on the toilet. But she's had trouble finding a doctor to confirm that early memory. Her mother has since died, and her early health records are gone. "I'd been told all my life I had polio - by my family, my early doctor," she explains. "But as I got older and I had trouble finding doctors that could recognize and confirm that, I started doubting at times. Maybe I had an injury, maybe something else happened to me that I wasn't sure about."

Diminishing Resources

Seeing a doctor who specializes in polio makes the difference. But that raises a question, says Joan Headley of Post-Polio Health International: "Who's going to replace these early champions and these early physicians?"

It was a member of her polio survivors' group that gets credit for first sounding the alarm about post-polio syndrome. In 1979, a man from Arizona wrote in the group's newsletter that, as he aged, he was having more difficulty with weak muscles and extreme fatigue. Other members wrote in to say they'd noticed the same thing. In 1982, Halstead was the first doctor to listen to the group's members, survey them, present his findings and then, with a handful of other polio doctors, spread knowledge about post-polio syndrome.

Last month, several hundred of Headley's members gathered at Warm Springs, Ga., the town whose warm mineral springs President Franklin D. Roosevelt and others with polio visited. At the recent meeting, a big topic of conversation was who would replace the generation of polio specialists like Halstead. Headley says many polio survivors say they still have difficulty finding doctors who understand polio. But there's also optimism that rehabilitation specialists - and even many family doctors - now have the expertise to treat them.

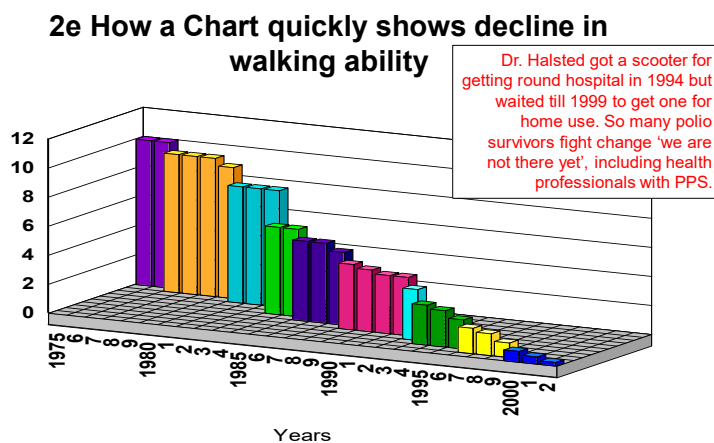
Headley says that's in no small part because of Halstead. "Dr. Halstead has certainly been the champion of the post-polio community over the last 30 some years," she says. And because Halstead spread the word about post-polio syndrome - with his research, writing, speeches and personal communication with doctors and survivors - there's reason to think, she says, that "most physicians now know about the late effects of polio and post-polio syndrome."

Halstead would like to retire. He's got a wife and teenage son, and he's got lots of interests: He

travels to Italy a couple of times a year, in part because of his love of all things Italian, but also to help polio survivors there create the kinds of support groups and clinics found in the United States. And Halstead also plays music. He had been a trombone player before contracting polio, but stopped after his illness. (Although, while in the hospital, he taught himself to play piano with one hand.) But recently, he's taken up another brass instrument, the euphonium, with a special left-handed instrument made for him. But before he can retire, he's hoping his hospital can find and hire a young doctor — one he could mentor to take over his practice.

Editors Note: I have met Dr Lauro Halstead at quite a few Post-Polio Conferences. He told me he had been to Lincoln in the UK six months before catching polio on his trip round the world.

I have also had the great honour of being invited to his house for a meal and lots of talk about how we are managing our new issues. He told me that he had had to get an electric scooter to manage the long corridors in the hospital and now some years later realised that with a young son he needed one at home too as it allows you to do so so much more. I took notes of the dates and made a slide for one of my presentations a few years later.



Progression of Symptoms – City blocks walked 1975 - 2002
Dr. Lauro S. Halstead – November 2002

Miami, April 9th to 11th 2007



Dr Halstead told me that when eating he uses a dessert spoon for carrots and brings his head down towards the plate. Less arm movements and more carrots an effort. He told me, “When working I hang a sign on my office door at lunchtime saying meeting in progress do not enter but I am taking a break on my couch and the easiest way of falling asleep is for me to listen to a medical book on headphones”. He also told me about examining a lady who told him that she uses 9 pillows to support her weakened limbs. Nine, I said was an awful lot of pillows but if it helps that is ok. Imagine my surprise he said on getting home and counting I used SEVEN.

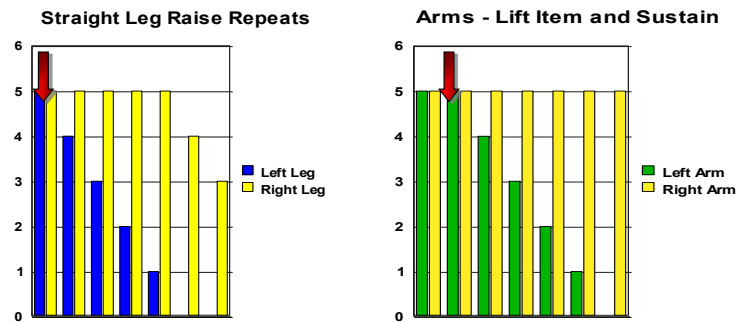
Single Action Manual Muscle Testing

Following my fall in 1988 I was repeatedly tested for my new and unexplained weaknesses and nothing found. I later learned it was thought I was malingering. In 1999 I received a copy of a medical report from a UK Neurologist that stated *the power of my left leg, hip, knee and ankle were normal*. I could not believe what I was reading as my left leg had been weaker ever since I caught polio at the age of 5 and in fact when assessed for the post of Relief Sports Hall Attendant I had been instructed on each piece of equipment in the GYM. I had to experience it first and the Instructor asked “When did you damage your left thigh?” This was because I was unable to lift the bar with my left leg on that exercise machine. I explained it was my polio but thankfully that did not stop me continuing with the job.

I got home and thought about this.... Why would a health professional write something he did not believe to be true. Then light dawned as I remembered back to 1969 when I had passed a medical for the Police. I had continued with the application on my fathers instructions as it would be a good interview experience for me but I never expedited to pass the medical.

I realised there has to be something wrong with the way we are being assessed. Single action Manual Muscle Testing. I did some self assessment tasks, made up a PowerPoint slide and sent this with a letter to Dr Lauro Halstead and to Dr Maynard, Post-Polio Health International.

3b Was the patient asked to repeat/sustain the test to the level their weakness starts?



My reported new weakness was not corroborated by a single test or two second duration.

Miami, April 9th to 11th 2007

Lauro S. Halstead MD

Director of Post-Polio Program,
National Rehabilitation Hospital,
Washington DC, USA.

May 2002

Replied: "If done only a single time, it can give an erroneous idea of the true muscle strength and endurance"

Jean Maggi, a Polio Survivor the subject of a Netflix documentary

El Límite Infinito (now on Netflix UK with English subtitles)

Aspires to go into space

<https://wsvn.com/entertainment/man-with-polio-subject-of-netflix-doc-aspires-to-go-into-space-and-a-fort-lauderdale-clinic-is-helping/>

Jean Maggi, had polio and was never expected to walk again. This documentary from his early struggles to his climb up the Himalayas also highlights his advancement of adaptive sports. Now this 58 year old man aspires to be the first disabled person to go into space and is training at NASTAR, the National Aerospace Training and Research Center in Pennsylvania, U.S.A.

A Fort Lauderdale clinic in Florida - Hangar Orthotics - is helping him to achieve this.

I saw this on a Polio Facebook page and thought our readers who can access this would be interested. Then I looked for a photograph to go with this piece and on looking at his website am astounded at his achievements. A typical do not tell me I can't because I will show you I can. Information on DualSki, HandBike, Golf, Tennis, Basketball, WakeBoard, Squash and Horseriding. He has competed in the Paralympics www.jeanmaggi.com

He has also set up a Charity, Fundación Jean Maggi

A non-profit organization, founded in 2016 in Córdoba, Argentina by Juan Ignacio Maggi and María Victoria Milano, with the unconditional support of his family.

Created to contribute and provide aid to children with disabilities through movement, sports, it has delivered more than 250 adapted bicycles, it also supports its beneficiaries through education and work. This is for children aged 4 to 18 with mobility issues who could benefit from using a hand bike. Promoting the inclusion and personal growth of all its beneficiaries www.fundacionjeanmaggi.org/

Toni Writes ...

Feedback, surveys, how did we do, what is your opinion, how is my driving ... we are often being asked our thoughts from so many organisations and services but does our feedback make a difference? Sometimes it seems to and other times we wonder why we bothered. I do question sometimes what it is that makes me feedback to some services and not to others?



Was it the tone, the length, my mood, and openness to it, was it of interest to me, was it cleverly worded? We can get a bit surveyed out - especially when we have purchased something online, the business would like to understand our experience. When data is collected and analysed properly it can inform decisions, other times it can just be a tick box exercise. When it comes to healthcare, Covid or illness the data collected means so much more, it is a very personal thing to share isn't it. Only share your data with those you want to.

One thing I have started to do more of is to personally feedback to those who do not ask for it especially when service or help has been very good. Just a simple "before I go, I just wanted to say thank you for your attitude/energy/helpfulness/politeness/etc..." - it makes a person's day. Talking of which below is some feedback from our lovely members in response to the last newsletter:

"Thank you for the PSN newsletter which was so full of interest - and humour!"

"The information you have provided is useful."

"Hello, I must send you a quick line to congratulate you on your recent newsletter 114. IT IS FANTASTIC. There you are, that's all."

"Your polio info in last newsletter is some of the best I've seen"

"All the best for moving forward into a better 2021."

Since about 1990 you have been my 'go to' source of PPS info - thank you all of your support!"

As ever we are always on keen to hear your experiences, tips, or question. Also, any articles you have found helpful or books that have inspired you for our online library. Please feel free to share them (contact details below).

Take care and keep safe!

Toni x

Email	psnadmin@poliosurvivorsnetwork.org.uk
Post	PO Box 954, Lincoln, LN5 5ER
Website	www.poliosurvivorsnetwork.org.uk
Phone	01522 888601

Polio Survivors under 65 & Covid-19 Vaccine

See 'polio syndrome' listed on page 10
of JCV Greenbook guidelines
<https://bit.ly/3buTXyk>



One of our members, Mary Kinane, spent 6 weeks and finally managed to get the attention of her GP practice - to put her finally in Category 6 for consideration as a polio survivor for the Covid-19 Vaccine.

GPs will need to search for Post Polio Syndrome on the SNOMED system but it has to be done in a specific way. It only appears when searched by:

- the *Title* postpolio syndrome
- or
- one of these synonyms:
 - Postpolio muscular atrophy
 - Post-polio progressive muscular atrophy
 - Progressive muscular atrophy following poliomyelitis
 - Postpolio syndrome

To be clear it does not appear if just “polio” or “post-polio” or “Post Polio” is searched for as these are not included in the above list of synonyms.

The SNOMED CODE for Post Polio Syndrome title, description and ID are listed below:

Name: Post poliomyelitis syndrome (disorder) See more descriptions.

Concept ID: 31097004

Description ID: 52052015

We would like to introduce you to another line of support available for those who have a neurological condition (Post Polio Syndrome) or care for someone who does.



Brain & Spine Foundation are working with the Neurological Alliance and currently offer telephone, email and peer group support.

Call the free, professional **Helpline** on **0808 808 1000** (Monday - Thursday, 9am - 4pm)

Email helpline@brainandspine.org.uk

Website: <https://www.brainandspine.org.uk/supporting-you/online-support-groups/>

Problems with my Callipers by Zsuzsanna Snarey

I have callipers for both legs to prevent the hyperextension of my knees caused by weak quadriceps muscles. Although I was paralysed by polio at the age of eight I did not have to wear callipers, or rather my mother did not agree with the doctors that I should wear them, instead she sat by my bed lifting up my limp legs and encouraging me to try and hold them. She persevered doing daily exercises with me for over a year until I finally managed to take a few steps with crutches. Then she found a physiotherapist qualified in the Sister Kenny Institute in the US who further rehabilitated me so that I was able to discard the crutches and only use one stick outdoors. In the house I did not even need a stick. I arrived in England from Hungary at the age of fifteen, finished school and university where I met my husband, got married and brought up three daughters while teaching in various schools.



I noticed some problems with my hyper-extending left knee when I was about 60 years old and found an advert in the British Polio Fellowship magazine for the ultra light UTX callipers made in Holland by Ambroise. At that time my husband had private health insurance from his work at Pfizer in Sandwich and I was able to see an orthopaedic surgeon within a week instead of waiting 9 months. He agreed that a calliper was the best solution and I was measured up by a representative of Ambroise in my home. The calliper was delivered soon after. I had to take it to the Orthotics Department where I was sternly reprimanded for jumping the queue. Eventually it was agreed that I could have a spare so that I was not left without one when it was returned for refurbishment. This had to go through RSL Steeper and took about 1-3 months.

A few years later my right knee started hurting. My GP recommended an X ray and he put me on painkillers for arthritis. But I knew that the pain was caused by hyperextension. Nevertheless it took me two years before I was allowed to have support by a UTX calliper. [The X by the way stands for Intelligent Knee Support or IKS in Dutch. The UT stands for The University of Twente where Nils Van Leerdam worked on it for his Ph.D.] Originally Dr Robin Luff told me at the Lane Fox Unit that having two callipers was not an option for me. He recommended a Chinese knee operation.

Now I had two callipers and two spares but the second calliper had to be returned several times for adjustments because the way I was measured was not accurate. In final desperation in 2018 we booked a crossing and drove to Enschede near the German border of Holland to be properly measured by Nils van Leerdam for making the callipers a better fit and for two new callipers. We stayed for 3 days while small adjustments were made.

Last November I noticed a small crack in the metal and took it in to Nottingham Orthotics department for posting to Holland. It eventually transpired that the Postal Department was not able to post it because Holland did not accept parcels. This seemed very strange and unlikely to me. So I picked it up from the hospital, found a large box, organised the postage and took it to the post office where it was accepted. A few weeks later I received it back from Holland, having been fixed.

In January when Brexit was finally forced on us with all the accompanying regulations, the same fault happened. The calliper had to be returned. This time I didn't even try to take it to the hospital as I used to do, I had the box that it came in, I had approval from the Orthotics Department and from Holland for the repair and paid a delivery company DPD £22 to pick it up from my house. It was not easy to fill in the Customs Declaration forms and I had to print out seven sheets of A4 which were to be attached to the parcel. In the box where the value of the contents was declared, I put £50 for insurance purposes and prayed that it would not go astray! Two weeks later when Ambroise searched for the delivery, they found that the parcel would not be released until the payment of 20 Euros was made! This worried me because according to the HMRC, tax is not payable by disabled persons on goods which are for their disability and especially not for repair under guarantee. I wrote to my MP to question this. Before I had

received an answer, the repaired calliper was delivered but not handed over until I paid nearly £50. I think this was calculated from the declaration on the visible label that the “value was 180 euros” while the information to customs officials that it was of no commercial value, not for resale and free of charge was folded under and not visible to them.

I have been trying to get a refund from HMRC which clearly states that I should not be charged anything as a disabled person. This has involved wading through numerous forms on the HMRC website, several telephone calls, being transferred from one department to another, having offers to ring me back, which never happened. I have spent two weeks in struggling to understand the reason why I was charged Import Duty and how to claim it back and I am nowhere near a solution. I have spoken with the Orthotics Department at the hospital and they are having similar difficulties to post things to destinations outside Britain. There is a form C285 which asks me to check regulations after January 1st 2021 with several numbers which I don't have. I am asked to send the completed form and supporting evidence to the National Duty Repayment Centre. [address not provided] and wait for the outcome within 30 working days. These problems are all the result of Brexit and are designed to frustrate and annoy people.

What I have learnt is that the correct customs declaration forms have to be filled in before posting such as CN22 for articles below £270 or CN23 for articles above £270 in value and the parcel should be clearly marked GOODS FOR PEOPLE WITH DISABILITY: RELIEF CLAIMED. Then it may have been accepted by customs and I may not have been charged. I have found out last week that even a letter to Hungary which now costs £1.70 requires a customs declaration form signed and attached to the back of the envelope. No wonder people have stopped sending letters.

https://en.wikipedia.org/wiki/Elizabeth_Kenny

<https://www.ambroise.nl/en/>

<https://www.gov.uk/guidance/pay-no-customs-duty-or-vat-on-goods-for-disabled-people>

Zsuzsanna Snarey Trustee PSN

zsuzsanna.snarey@poliosurvivorsnetwork.org.uk

As I look at the way our world has been going these days, people blaming the world for their problems, it makes me realize what it means to be a polio survivor.

We not only survived the polio virus but we survived in a world where we were different but we didn't allow that difference to define us. We didn't blame the world for our disabilities but we worked so hard to prove to the world that we could do it, and we did. in fact I believe it made us stronger.

Now we're facing another issue from having had the polio virus. And that strength is what will get us through this one. I am thankful for the doctors and the people that have worked so hard to bring attention to the world about post polio syndrome.. I am thankful for these networks online that help me understand what's going on with me and give guidance at times as to what I can do, or how to deal with it.

So in close, be proud that you are a survivor!

Kathy Hazel, Polio Survivor (Facebook polio list)

Polio Survivors do you discuss post-polio issues with your friends and family?

It is not easy for us, I am sure you will agree, but did you realise it is also very difficult for our family, our friends and even our GP's and other health professionals we had before we started with PPS issues.

In early October 1988 I was working four part time jobs to 60 plus hours a week. 12 Voluntary and bringing up two children on my own. On 10th October 1988 I slipped on a wet patch on a school floor and although previously this would not have caused issues for long this time I started to have pain, fatigue, and actions of daily living became harder and harder. I did not find PPS existed till November 1995 and at last it was added to the equation of what might be wrong with me. I started the Charity and the phone was in my home. It never dawned on me that my family only heard my side of phone conversations. They rarely asked questions and I did not discuss anything with them about what the future would hold.

It was not till 8 years later in 2003 as I was finishing a PowerPoint presentation for a PPS conference in San Francisco that my daughter walked in. I very proudly asked her to look and tell me what she thought. She read through it all and then told me to add another slide.

“Add this Mum”

She told me to type ‘These are not only your problems. They are mine as well. As you have got worse, things are more difficult at home for me.’

You cannot do the things you used to do with your family and friends and the frustration that you suffer is shared by us as well.

There is so much to do in your life, my life and our house each day that it is not possible for me to fit it all in.

There are a lot of things that you are upset about not being able to do at this age. This also applies to me. I am 27 and I still live at home... woopy do... There are life experiences that I wanted to have not living in Lincoln, working abroad and travelling...etc.’

Do we ensure we allow our family to tell it like it really is ?

I had not realised that I had not discussed anything PPS with my two children. I had not realised that they were wondering how their lives could change from what they hoped as I continued to deteriorate.

I told my kids that they should live where they wanted to and do the jobs that they wanted to do. I would manage as I had always done. My son lives in North Kent and works for South Eastern Trains and my daughter travelled to Canada to meet with a Canadian Roller Derby skater she had met online. They married and we have a ten year old grandson. Shortly they are to be moving from Alberta to Vancouver Island, British Columbia.

My daughter reminded me on this weekend's live chat about the day she came home and found me crying. I pretended that there was nothing wrong but she looked round the room and noticed a form that I had been trying to fill in that in frustration I had just thrown across the room. She picked the form up. An application for a Disabled Facility Grant that I had to complete to get the funding to apply for the wet room the NHS OT in 1998 said I needed. She started to read down the front page and said, “I will fill this in in pencil. Say nothing but answer my questions.” I was annoyed but could see from the expression on her face that I better do as she asked.

She added name and other details and turned the page over. She read out loud “Is this a benefice of an ecclesiastical estate?” And exclaimed what on earth is that [well words like that] I explained that ecclesiastical was related to churches. A few pages later she asked “Do you have an invalid [she pronounced this in valid] carriage?” “What on earth is that?” I explained she had mis pronounced it. She then flipped through the remainder of the pages stating “how many decades ago was this form developed?”!!



Current status of poliomyelitis in Latin America

Revista chilena de infectología | Scielo.

November 09, 2020; Rev. chil. infectol. vol.37 no.6 Santiago Dec. 2020

Abstract.

Oral poliovirus vaccine (OPV) has been instrumental in controlling the polio epidemic, and stands out for its safety, efficacy, ease of oral administration, and low cost. However, despite these advantages, as it is a live attenuated virus vaccine, there is the possibility of mutations that confer neurovirulence. Therefore, surveillance for acute flaccid paralysis (AFP) is important, whether associated with live vaccines (VAPP) or vaccine-derived viruses (VDPV). In this review we present important data from Latin America in recent years, where data on VDPV of community transmission, of ambiguous origin and associated with immunodeficiencies are reviewed. Due to the presence of VDPV, it is important to strengthen the epidemiological surveillance system for AFP, with data much lower than those recommended in recent years in the Americas. Additionally, it is essential to improve vaccination coverage to reduce the number of infants at risk of acquiring poliomyelitis. Consequently, we present the vaccination coverage rates with the inactivated vaccine against poliovirus (IPV) in the region and analyze the vaccination programs against poliomyelitis in accordance with the recommendations of the Latin American Society of Pediatric Infectious Diseases (SLIPE; minimum 3 doses of IPV) and the WHO Strategic Advisory Expert Group (SAGE) on Immunization (minimum 2 doses of IPV). The study concludes with recommendations from the authors for the change from OPV to exclusive use of IPV, to increase vaccination coverage and to strengthen surveillance for AFP in the region.

Original Source Article - [Current status of poliomyelitis in Latin America \(conicyt.cl\)](http://conicyt.cl)

Emerging and Re-emerging Infectious Diseases in the WHO Eastern Mediterranean Region, 2001-2018 | International Journal of Health Policy and Management.

4 February 2020; Accepted: 8 February 2021; ePublished: 6 March 2021

Abstract.

Background. Countries in the World Health Organization (WHO) Eastern Mediterranean Region (EMR) are predisposed to highly contagious, severe and fatal, emerging infectious diseases (EIDs), and re-emerging infectious diseases (RIDs). This paper reviews the epidemiological situation of EIDs and RIDs of global concern in the EMR between 2001 and 2018.

Methods. To do a narrative review, a complete list of studies in the field was prepared following a systematic search approach. Studies that were purposively reviewed were identified to summarize the epidemiological situation of each targeted disease. A comprehensive search of all published studies on EIDs and RIDs between 2001 and 2018 was carried out through search engines including Medline, Web of Science, Scopus, Google Scholar, and ScienceDirect.

Results. Leishmaniasis, hepatitis A virus (HAV) and hepatitis E virus (HEV) are reported from all countries in the region. Chikungunya, Crimean Congo hemorrhagic fever (CCHF), dengue fever, and H5N1 have been increasing in number, frequency, and expanding in their geographic distribution. Middle East respiratory syndrome (MERS), which was reported in this region in 2012 is still a public health concern. There are challenges to control cholera, diphtheria, leishmaniasis, measles, and poliomyelitis in some of the countries. Moreover, Alkhurma hemorrhagic fever (AHF), and Rift Valley fever (RVF) are limited to some countries in the region. Also, there is little information about the real situation of the plague, Q fever, and tularemia.

Conclusion. EIDs and RIDs are prevalent in most countries in the region and could further spread within the region. It is crucial to improve regional capacities and capabilities in preventing and responding to disease outbreaks with adequate resources and expertise.

Original Source Article [Emerging and Re-emerging Infectious Diseases in the WHO Eastern Mediterranean Region, 2001-2018 \(ijhpm.com\)](http://ijhpm.com)

Virtual Support for Polio Survivors

During the pandemic polio support groups from around the world have been turning to offering digital/virtual support. PA Polio Survivors Network have compiled a very useful webpage. We've converted the times for your information (information taken from <https://www.papolionetwork.org/support-group-zoom.html>).

Not all meetings are each week so please check with the group contact.

The UK times are approximate – **please check times and how to access details with the organiser** also a handy time zone converter is here <https://www.thetimezoneconverter.com/>

DAY	GROUP	UK TIME	CONTACT DETAILS
Sunday	Nebraska Polio Survivors	8.00 pm	npsa.org@hotmail.com www.nepolioorg.ipage.com/
Monday	Polio Quebec - adapted Yoga	8.00 pm	monaarsenault@gmail.com association@polioquebec.org www.polioquebec.org/eng/
Tuesday	Polio Quebec	12.00 am midnight	monaarsenault@gmail.com association@polioquebec.org www.polioquebec.org/eng/
Wednesday	March of Dimes Canada	7.00 pm	bstupar@marchofdimes.ca www.marchofdimes.ca/enca/programs/postpolio
	Marin County Polio Survivors	9.30 pm	FrancineAllen@comcast.net
Thursday	Boca Area Post-Polio Support	6.00 pm	bappg@aol.com www.postpolio.wordpress.com/
	Marin County Polio Survivors	9.30 pm	FrancineAllen@comcast.net
Friday	Polio Survivors Network	Varies	info@poliosurvivorsnetwork.org.uk
Saturday	Atlanta Post-Polio Association	7.00 pm	nicolsw@locinc.com or appaemail@gmail.com
	Land of the Sky Post-Polio Support	5.00 pm	emcanallen@gmail.com
	Polio Support Group San Gabriel Valley	6.30 pm	hopemle@juno.com www.facebook.com/1ppssgvwie/
	World-Wide fellowship of Polio Warriors	11.00 am 5.00 pm	peter@poliowarriors.org www.poliowarriors.org/

Polio Australia (steph@polioaustralia.org.au) please contact for information of events.

Polio Survivors Ireland provide a telephone conference (fsw@ppsq.ie)

Post-Polio Health provide ideas for support group discussions (info@post-polio.org)

This list is not exhaustive, other groups may exist in your local areas too.



Donate to PSN by using
PayPal donate link:
<https://bit.ly/2KzyAvE>

Joke: While cooking I
accidentally rubbed some
herbs in my eye ...
... I am now parsley sighted!



Management Committee & Operations

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

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, U.K.

Email psnadmin@poliosurvivorsnetwork.org.uk

Phone us on 01522 888601 - will ring you back when we access 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>

giftaid it

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:

Patient Plus 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

PHOTO OF OUR VIRTUAL COFFEE AND CATCHUP ON 12th MARCH 2021



Polio Survivors Network

Virtual Coffee and Catchup

Friday May 21st 11:00 a.m.

If you'd like access details please email info@poliosurvivorsnetwork.org.uk

We do hope that you will enjoy meeting other PSN members. Looking forward to seeing you there.



© PHOTO CARDS by MEMBER VAL SCRIVENER

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