



# POST POLIO MATTERS

Polio Survivors Network Newsletter  
January 2022 - Volume 10 Issue 9 of 12 [117]

**HAPPY  
NEW  
YEAR**

**2022**



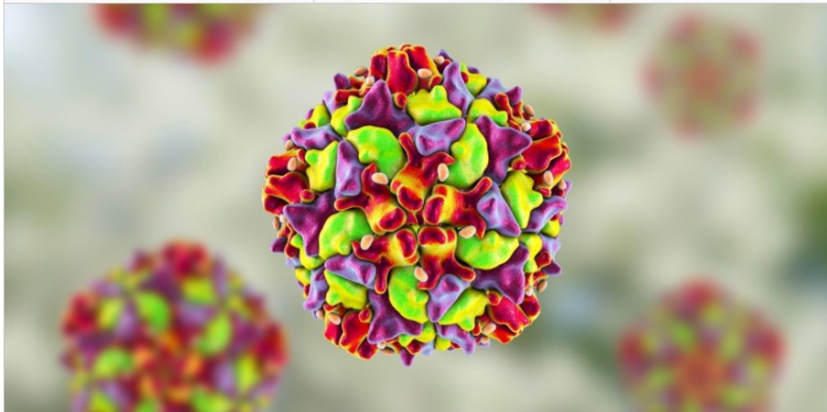
**Take a look ...**

If you get a few moments, please take a look at PSN's online library. We have been adding to the information that is available online from our paper files. All articles are searchable.

The PSN library is available from the **Library** link found at the top of our [website homepage](#) or you can go to it directly at [www.poliosurvivorsnetwork.org.uk/library/](http://www.poliosurvivorsnetwork.org.uk/library/)

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**WELCOME TO OUR LIBRARY**

RECENTLY ADDED ITEMS  
Polio victims face increasing problems

Acknowledgements:



**Photos from round the World**

**Pelicans on a Jetty**  
Hastings, Victoria, Australia.  
By Fran Henke.  
Polio Survivor, Writer, Painter, Photographer, and more....  
[www.franhenke.com](http://www.franhenke.com)

**Saguaro Cactus Dinosaur?**  
Green Valley, Arizona, USA  
By Ellen Machules Riddle  
Polio Survivor, Photographer



[Lincolnshire Post-Polio Library](#)  
100+ articles

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

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<b><u>Donations and Charity Incentives Paid</u></b>	
<i>(since last newsletter)</i>	
PayPal Giving Fund	£79.47
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P Gavin Donation	£12.50
M Grindley Donation	£20.00
<b>Total</b>	<b>£198.73</b>

*This publication is provided free to our members  
thanks to your generous donations.*

***Thank you so much!***

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## Editorial by Hilary Boone



Fingers crossed that life can return to pre-Covid sometime this year. Pharmaceutical companies are working their socks off to get vaccines out that will reduce the severity of the Covid that we could acquire no matter how hard we try to prevent it. It is hard having to add Covid rules to coping with PPS and the changes we continually have to make to manage our lives to the best we can. Having to miss out on a lot of the social life, so important to our health and wellbeing, has taken its toll of both of us and I am sure many of you as well. Trying - through constantly steaming up glasses - to read the info on some products on the shelves of Waitrose last month a lady and I bumped into one another. We both apologised almost the same words and then she added 'I never thought that leaving home to buy a toilet roll could become the highlight of the month'!

In the last four months we have managed a couple of antique fairs, cold but we were 'out out' as Micky Flanagan says and a couple of trips to a local park, the BPF Lincoln Branch Xmas Meeting, taken out for Sunday lunch by one of our carers and family, and one hospital appointment at Sheffield plus we had three nights at a disabled caravan at Saltfleetby with all three carers and we had some laughs. I can still see Richard eating a rack of ribs with only one clean finger from sauce to push his glasses back up his nose. He really did enjoy them.

I also had a bit of a shock as I used to lifeguard at Chapel St. Leonards every weekend from May to September so Barbara parked at Chapel Point where there is a viewing centre/café. We started to ride our wheels along the coastal path but I did not recognise the scenery and thought we must have joined further north. Suddenly I was asked "Well don't you want to go into Chapel St. Leonards?" I stood there perplexed. Here was the ramp that we used to run the boat down onto the beach and out on the sea for rescues but there were bush covered sandunes in the way and the sea was at least 500 yards further away. Then I was asked "Hilary when were you last here?" Oh it was the summer of 1988 before I fell and my PPS started.... eek 33 years ago. We went down into the village and I found a shopkeeper I used to know and he told me they started to work on the sea defences about nine years ago. I sent photos to both my kids and there were as surprised as me. Eight years of walking up and down the beach in my yellow t-shirt and short red pleated skirt for over a mile (picture 2), and now so different (picture 3).



### WE NEED THE HELP OF ALL READERS...

There are many new issues since Covid that as Polio Survivors/Carers of Polio Survivors we have to manage. One of the most difficult we have found is being told your review will not be face to face but by Video Consultation or by Phone Call.

We have to remember that most health professionals have been taught little about the polio virus and how it affected our body at the time, how we recovered and how Post-Polio Syndrome affects us. We have found that the NHS, Patient.co.uk, and some medical charities are providing members with information on how to manage these type of consultations. There is a massive amount of basic information on the technical side of the appointment. What we need is to provide information on how Polio Survivors with or without a diagnosis of PPS manage their lives.

The main issue coming in from members are the stock answers. To help you get up, "Take my arm" or equipment a toilet raise seat with handles. So many of us do not have the arm strength to pull up, we push up and neither of these will work for us. More information on [page 4](#) & [10-11](#)

Continued from editorial

## FACE TO FACE APPOINTMENTS changing to VIDEO CONSULTATIONS and REVIEW PHONE CALLS.

How to prepare for a telephone or video appointment . Please find some helpful telephone and video call advice here (some is specific to certain conditions but the principles remain useful):

### Basic Information

- ⇒ <https://patient.info/news-and-features/how-to-get-the-most-out-of-your-telephone-video-gp-appointment>
- ⇒ <https://www.nhs.uk/nhs-services/gps/what-to-ask-your-doctor/>

### Chrons and Colitis

- ⇒ <https://www.crohnsandcolitis.org.uk/news/blog-top-tips-for-getting-the-most-out-of-your-virtual-telephone-or-video-a>

### Dementia

- ⇒ <https://www.dementiauk.org/get-support/diagnosis-and-next-steps/getting-the-most-out-of-a-remote-consultation/>

## **POST-POLIO SYNDROME INFORMATION SHEET in process.....**

Please go to pages 10 and 11 for more information as to how you can help us provide the varied information we need as we all manage our lives in different ways.

## **MESSAGES FOR OUR MEMBERS**

### ***PSN Coffee Catchups***

As you may know (and some of you have attended) we have been running virtual coffee catchups over 2020/2021. We are moving away from this format as we have found that once lockdown started to ease demand dropped. These sessions were very enjoyable and I hope you have enjoyed meeting other PSN members.

We are now offering any PSN member (or supporter) who wishes to have a 1-to-1 with some of the trustees, or would like to bring a group together, we can facilitate a video chat. Just contact [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk) to make the arrangements.

### ***2022 Annual General Meeting/Annual Report***

Our annual report for 2021 is available to anyone who wishes in digital and printed format – please request via [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk) or phone us.

We currently do not have plans for a face-to-face annual meeting in 2022. We may consider a virtual one if there is enough support – please can we ask that you register your interest by emailing [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk)

## **Keep your pecker up** by member Janet Whitworth

This is an English expression so pecker refers to the nose. Think of a bird's beak. Another expression might be "keep your chin up." In other words: "be positive don't let bad things get you down."

My dear friend Joan said these words to me on the phone without knowing how much I needed them. I consider myself a pretty positive person but to be honest I was feeling a bit discouraged this week. Of course, we are all living through a pandemic which restricts our movements but we are all in it together and many are suffering way more than me. I got my shots and a booster, I wear a mask in Safeway, I social distance but we are still not 100% safe. Then on Boxing Day it snowed so I couldn't go out. Shucks.

My son came for a visit and he said "Mum in about 5 years I think you should sell this house and move closer to me." He means I am old and may need care. Shoot when did that happen?

Sometimes my polio friends jokingly say things like "If you have to get down be sure you have a plan to get up." I knew what they meant but those words did not apply to me. My polio affected my upper body and I always thought my legs were OK, but this week I got down on the floor to pick up petals from my drooped Christmas tulips and to my horror I realized getting up off the floor was rather a challenge. Damn what's happening?

Anyway, these things plus other news made me feel a bit down. I didn't say I was down to my friend Joan on this international call but she brightened my day chatting about family and friends. She said this Covid is just something we have to live through like people in England lived through the war when bombs were dropping destroying building and killing people. They got through it. Well not everyone of course, but when the war was over people went on with their lives and things were good again.

As polio survivors we are good at finding ways to compensate for our weaknesses. We have strong personalities and we find ways to cope.

Joan did not have polio. After our lengthy conversation I can picture her now getting up in the morning coming down stairs to put the coffee on and singing as she potters around in the kitchen. This is probably way better start to the day than turning on the news.

Chin Up.

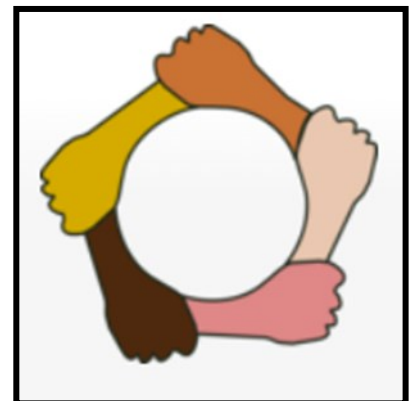
## **AN EXCELLENT NEW WEBSITE FOR Personal Health Budget holders**

We want to let you know about a website we have helped to build which arose from a research project exploring the use of Personal Health Budgets.

[www.mycarebudget.org](http://www.mycarebudget.org) has been launched it as an online, free, repository of templates and staff policy documents. So far there are over 70 documents that can be downloaded - all of them useful for anyone that holds or is gaining a care budget, especially if it used to employ staff.

All the documents come from people with lived experience of running a care budget. There's no corporation, health authority or charity running the website.

[www.mycarebudget.org](http://www.mycarebudget.org) is a wiki - so it grows by people adding and editing to it. All the input is checked before being published, so we can add confidence in what appears there. The idea is that you can browse the wiki without creating an account, but you do need to sign up for an account to download or edit the wiki. It works just like Wikipedia.



## Verite Reily-Collins

PSN Trustee, Health Journalist and owner of [aftercancers.com](http://aftercancers.com)

**Will 'lessons be learned'?** Jan 6th 2022

**The People's Covid Inquiry**, organised by **Keep Our NHS Public**, presents their finished report.



Last February, in the absence of a formal public inquiry into the pandemic, the Inquiry, chaired by the human rights barrister **Michael Mansfield QC**, started looking into all aspects of the government's handling of the pandemic.

Responding to the recent publication of the Report, **Dr Chaand Nagpaul**, BMA council chair, said:

"This report makes clear that the NHS went into this pandemic woefully underprepared and under-resourced, and the only reason the health service was able to provide care and services at the level it did was because of the unwavering dedication of frontline workers who gave their all – including their lives.

"It is clear that the Government failed to properly plan for a pandemic, with the disastrous lack of PPE supplies leading to an inability to protect frontline staff being exposed to the virus without adequate protection

"Brutal cuts to public health services ..... over the last decade left the UK without adequate testing capacity resulting in the outsourcing of test and trace operations. **This wasted £37 billion of taxpayers' money on an ineffective system that failed to identify the spread of the virus.**

### **KEY FINDINGS INCLUDED:**

1. The depleted state of the NHS and other public services prior to the pandemic was a determining factor in poor outcomes and led to avoidable deaths.
2. The government was poorly prepared for the pandemic and moved too slowly, which led to avoidable death.
3. The government adopted the wrong strategy leading to loss of life and growing mistrust in its advice.
4. The government's poor record on inequalities has put the most vulnerable at risk from illness and death from Covid-19.
5. Misconduct in public office: There has been dismal failure in the face of manifestly obvious risks.

### **What next?**

As patients, it is more important than ever that we ensure we follow guidelines e.g. to wash hands, wear masks, etc., and do our bit to protect ourselves and the NHS. The current lack of funding and staff shortages means the NHS would struggle to handle another pandemic; through no fault of its own, it does not have the resources or manpower to handle another.

To download full report go to : [https://36085122-5b58-481e-afa4-a0eb0aaf80ca.usfiles.com/ugd/360851\\_62aecaeb6944934b6c55d41708d7eeb.pdf](https://36085122-5b58-481e-afa4-a0eb0aaf80ca.usfiles.com/ugd/360851_62aecaeb6944934b6c55d41708d7eeb.pdf)

### **I've been let down by Boris Jan 13, 2022 **Be careful what you ask for****

I learned from an early age 1) you don't go out with boys who are members of the notorious Oxford Bullingdon Club, and 2) BYOB (Bring your own bottle) was a recipe for disaster – mixing drinks is never a good idea.

After the shenanigans at 10, Downing Street now coming out in the press, it seems the Cabinet Office might learn a lesson from my late teenage years. Watching our Prime Minister deliver his halting, painful apology at the Dispatch Box was cringe-making, and one can only hope when Sue Gray delivers her report that Whitehall takes note, and cleans up its act.

Apparently, 100 people were on the invitation list for the notorious email inviting people to a BYOB party in the No. 10 garden last May, but only 40 turned up. I like to think that is because 60 people had the good sense to turn down such a crass and insensitive invitation. Or was it because they discovered they couldn't claim for the bottle on expenses?

Mind you, I and thousands of others have only ourselves to blame. We voted Bojo in – me because I thought he was bombastic enough to stand up to the EU bullies; having worked in Brussels I knew what went on there – and wanted out.

## *Toni Writes ...*

I thought I'd briefly write about a lesson I learned from nature. It is always therapeutic to be out in nature or even to view nature scenes, isn't it? It has been proven that doing so improves mental health, reduces anger, fear and can even help reduce blood pressure and the production of stress hormones.



At this time of year we can't help but marvel at the beauty of the turning leaves, what a treat! Even when the leaves are dying off they produce such beauty for us to enjoy. Thinking about the leaf for a moment, have you ever stopped to consider that it is pretty much a complete food making factory, and not just any kind of factory a completely self-sufficient, self-propagating, silent factory which produces nothing which harms the environment - in fact its waste products improve the environment. Also, when the larger factory (the tree) is 'decommissioned' it even goes back to the ground and continues to give by means of the carbon cycle and in time as fuel. If only the large factories of our commercial world could learn from the humble leaf!

Well, I'm popping outside to catch the last of the good weather and collect up the impressive collection of leaves that have appeared in one corner of the garden!

As ever please feel free to drop me a line with your musings, your polio survivors' experiences, tips that you would like to share with others, something that made you smile this week or absolutely anything else on your mind.

Take care and keep safe!

*Toni x*

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<b>Phone</b>	01522 888601

### **From our readers**

*“Thank you , I like to receive the very helpful newsletters.”*

*“Thank you very much for your latest EXCELLENT newsletter!!!”*

*“I love all your help.”*

## POLIO SURVIVORS WHO ALSO HAVE PARKINSONS DISEASE

*[PSN have 3 members already and know of others around the world - If you have both conditions or PPS and another condition we would love to hear from you]*

Polio Place, a service of PHI [Post-Polio Health] International.

Dr. Frederick Maynard, Board of Directors Post-Polio Health International, St. Louis USA.

### Ask Dr. Maynard

**QUESTION.** About a year ago, I was diagnosed with Parkinson's Disease (PD). Then recently, when providing medical history to a new eye doctor and reporting that I had polio as a child, I learned from him that he and a colleague authored a letter which was published in NEJM (New England Journal of Medicine) about polio and PD. My father also had PD. I learned from the medical record of my hospital admission for polio that the doctor documented my father had polio as a child with some residual in a leg. (I remember his misshapen foot and atrophied leg.) Although Dr. Raymond Roos at the University of Chicago Post-Polio Clinic did not diagnose PPS, I believe that I definitely have some of the late effects. Some of the Parkinsons Disease symptoms are similar, as you may know. I am interested to know what experiences you may have had with others who have had a polio history and now PD. Is there a connection? There can't be many folks who fit into the category.

**ANSWER.** There have been many cases of adults with a history of childhood polio developing Parkinson's Disease.

1. One of the first reports of this is in a 1978 NEJM [Article 1] and may have been co-authored by the eye doctor you met! A relationship has long been observed between PD and a history of previous encephalitis due to several different types of viruses that may cause damage to the brain, particularly to the substantia nigra (SN) which is a small area of the brainstem that develops a deficiency of dopamine production in patients with PD and is thought responsible for most PD symptoms.
2. Bodian documented polio virus damage to the SN in autopsy cases during the 1940s, [Article 2].
3. More recently an MRI study on a child with acute wild polio in India documented changes in the SN. Therefore, it is certainly plausible that previous polio virus caused encephalomyelitis can affect the SN and predispose it to later-life degenerative dysfunction resulting in PD.
4. A 2010 epidemiologic report from Denmark actually documented a 2.3 times higher risk of developing PD among people with a history of polio compared to controls matched for age, gender and geographic location. [Article 3]

In light of these facts from the medical literature review of PD and polio that your question initiated, I think it is likely more than coincidental that you and your father both developed PD many years after having had childhood polio. I have personally seen a handful of patients with your two diagnoses, and I don't recall any unusual problems they shared in common. Both conditions can benefit from individualized exercise programs to slow down symptom progression and from rehabilitation strategies to preserve and/or enhance functional capacities.

- 1, Vincent FM, Myers WG. Poliomyelitis and Parkinsonism. N Engl J Med. 1978;298:688- 689.

To the Editor: The association between viral infection and Parkinson's disease (PD) has been of interest ever since the relation was suggested between the development of this condition and the pandemic of encephalitis lethargica. This viral origin has been assumed, but has never been proved. Cases of PD complicating infections with the arbor viruses, measles or varicella have been reported,<sup>1</sup> although these extrapyramidal syndromes are often transient and not severely disabling. We recently cared for two 69-year-old patients who as children suffered from anterior poliomyelitis (PM) and in whom, as adults, progressive PD developed. These cases prompted us to review . . .

2. Bodian D. Histopathologic basis of clinical findings in poliomyelitis. Am J Med. 1949;6:563-577.



3. Nielsen NM, Rostgaard K et al. JAMA. 2002;287:1650-165

4. Nete Munk Nielsen, MD, PhD; Klaus Rostgaard, MSc; Henrik Hjalgrim, MD, PhD; et al JAMA. 2002;287(13):1650-1651. doi:10.1001/jama.287.13.1645 b.

Abstract. To the Editor: Parkinson disease (PD), which is due to loss of dopaminergic neurons in the zona compacta of the substantia nigra and may involve both genetic and environmental risk factors. Poliovirus is believed to cause neuronal damage in the substantia nigra, and thus a history of poliovirus infection may be associated with an increased risk of PD.

\*\*\*\*\*

Information from one of my slides from facts from the mentioned article that I am sure if you have not already seen will find interesting.

**Polio Viruses I, II and III** are enteroviruses that enter through the mouth and go through the gut and in some cases go on to affect the nervous system.

“In 1948 the year in which polio viruses were first cultured specimens from two children with clinical poliomyelitis, yielded a non-polio enterovirus [eponymously called Coxsackie after the neighbourhood in which they lived]

This finding opened a Pandora’s box of some **70 previously undiscovered enteroviruses** of which **14 strains were later found** to have **neurogenic potential equal to that of polio viruses”**

**The Late Effects of ME. Can they be distinguished from the Post-Polio Syndrome?** By Dr. E.G. Dowsett MBChB, Dip Bact. Honorary Consultant Microbiologist Basildon and Thurrock Hospitals NHS Trust. <https://www.poliosurvivorsnetwork.org.uk/library/items/show/112>

Originally a Presentation to the All Party Group of MPs on ME/PPS on 31st January 2001. Lincolnshire Post-Polio Library Publication February 2001.

## PLEASE GET IN TOUCH

**IF YOU HAVE BOTH POST POLIO SYNDROME and PARKINSONS,**

or any other neurological or health condition that makes life more difficult to manage

Help us provide lots of examples of issues and how we overcome them.

Things like:-

1. Exercise advice do 30 minutes aerobic exercise daily when that is impossible for you.
2. Do ten repeats three times a day when you can only manage 3 repeats of an action before your polio virus reduced nerve supply muscles run out of oomph PSN do not advise doing nothing because there will always be something you can do if you discuss this with a PPS knowledgeable therapist or health professional. E.g. on land I can do three repeats of an action three times a day if I have enough energy tokens available from everything else I have to do. If I can use our Hot Tub regularly then I can build up to doing a few more repeats of the action because the water supports my body, the warmth relaxes my muscles and allows me to straighten my spine and stretch my limbs and breathe deeper stretching the muscles between my ribs [intercostals] and the water provides resistance to moving joints.
3. Some medications prescribed require you to discuss issues raised that polio survivors might experience - for instance possibly needing a lower dose of sedating or muscle relaxing properties of medication or anaesthetics;
4. Air Mattress offered in hospital or for home that will not work for you because whilst comfortable once you want to move to turn over/get in or out of bed you cannot do it the way you need because you need a harder surface to move on.

## Polio Survivors Share Your Experiences

**DOING IT OUR WAY.** Suggestions from readers needed of phrases to use so that people will listen and understand that we really do have to do actions our way or not at all.

This subject has been referred to in the last few newsletters but still the issues arise and on many polio lists around the world. I am sure that nearly all our readers will have experience of someone not understanding you when you made a statement about how you have to do an action because they do not have any knowledge or experience of how the polio virus has affected our muscles.

For instance you are on electric wheels and need to get through a swing door. Someone holds the door open for you but stands in your way. You take hold of the door and say "Thankyou, I've got it" but they still stand there in the way of your travelling through the gap. They think they are still helping but they are not.. What would you say in a situations like this?

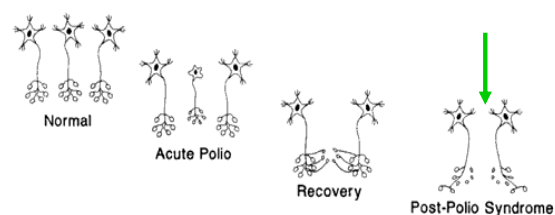
**Disabled Toilet issue from Member.** Disabled toilet not fitted out as recommended. The pan too low and single rails too high but they did not have time to look for another disabled loo so did what they had to do and then pulled the call button. A man arrived and offered an arm to pull himself up and he explained he cannot pull himself up. A second man arrives who offers another arm to pull him up. Again he explained he could not pull up, only push up. Explained I will think how can do this with their help. Swiveled sideways on the toilet and put one hand on the back of the toilet seat and the other on his disabled wheels. Leant forward and pushed up and they helped him stand and then transfer to his wheelchair. Tip. If you use an electric scooter then always use a handicapped toilet and take the scooter in with you. You will have the seat set at the right height for you and it has helped me get off the toilet quite a few times.

**Getting the Stock Answer without realising that might not work for you.** You arrive at hospital or are being assessed for equipment at home and are told we will get you an Air Mattress for the bed or Air Cushion for your armchair. However, the way you have to get in and out of a chair and turn over in bed needs a firm mattress that you can push against. Have you had this happen to you and had difficulty getting them to understand you know what you are talking about. Twice we have had to 'try it in hospital' and enjoyed demonstrating why the air mattress will not work. Richard also had a full length air cushion put on his Riser/Recliner and demonstrating it did not work they then insisted on trying just an aircushion! We hate the waste of time and money. Any ideas what we say?

**Possible explanation of why polio muscles weaken after the stable period.** Slide on right has four diagrams. 1. Normal Nerves. 2. How the polio virus has killed off one of the nerves. 3. shows how the muscle fibres that were not killed were able to grow axonally sprouted roots and take over some of those orphaned muscle fibres. 4. Our recovery. How these axonally sprouted roots are dying off. Less nerve supply means weaker muscles. As your muscles become weaker you have to change the way you do actions of daily living and this happens again and again over the years. We are all different and have many varied issues.

### Pathophysiology and diagnosis of post-polio syndrome Daria A. Trojan\*, Neil R. Cashman

Department of Neurology and Neurosurgery  
Montreal Neurological Institute and Hospital  
McGill University Montreal, Quebec, Canada



**Post-Polio Syndrome**  
One explanation is that these extra nerves are dying off  
Less nerve supply, less functional ability

Polio Survivors Network Presentation on  
9.9.2013 for Rotary Lincoln

**We are compiling an article "How we have to do actions of daily living in a different way"**

The more experiences you can share with us the more information we can include to assist health professionals understand why. Example my left leg from hip to knee is very weak and if I bend my knees more than a couple of inches I collapse to the floor, so I walk stiff legged. However my right leg is weak from knee to toes and that foot is dropped so I need to wear an Ankle Foot Orthosis that keeps my foot up.

## WHAT IS AND WHAT IS NOT WORKING IN YOUR AREA.

We know services have been affected by Covid and we know there is a huge difference depending on your Post Code but it would help all of us when discussing issues locally and nationally to have more evidence on what is and is not working in your area.

### GP Surgery.

**AskMyGP** is a service that some surgeries offer where you can log in and pick who you want support from and then provide some information and even send a photograph or file. You say how you would like a response and if it is urgent or not. They usually reply within 24 hours. Problem is that GP surgeries have a quota of how many they will take and locally we hear of some that close within fifteen minutes. Thankfully ours has been pretty good but it is not the same as having a face to face appointment now and then.

**Ringing your GP surgery** has been more difficult in our area since Covid as there are two messages to listen to before you get to the switchboard. I can recite these along with the message having listened to them so many times. Then you get through to the switchboard make your choice and have to wait whilst you are x number in the queue. I clocked just over 12 minutes a couple of months ago. **Registered Carers.** If you are a Carer have you registered with your GP Surgery as one because it might help getting support for an issue a bit easier because it would cost a lot more if you became ill and could not do the caring hours.

**Dental Services** Whilst we fully appreciate the difficulties with Covid they have had unless you are in pain there is a long wait of weeks for an appointment for a broken tooth/filling fell out. Does your dental surgery release a set number of emergency appointments each day like ours? Whilst on paper it sounds good, the problem I and other carers locally have been having is the time it takes to ring and hang on till it is your turn when you are trying to get the person you care for medicated, fed, watered, washed and dressed.

**Expectations of NHS and Social Services staff advising you can be referred to the other service for support without advising/possibly any idea how long this is likely to take.**

### REFERRALS TO THE NHS

Have you been told by Social Services to contact your GP or Hospital Consultant to get a referral for an issue you have? Did they seem to be aware how long a referral takes to process and you actually get an assessment appointment? Pre Covid this was a long time. I remember 1995 when I found out that PPS existed and was told I will refer you to a Neurologist. Six weeks later I got an appointment in the post and thought wow, only two months wait. I went to put the date in my diary to realise it was a year and two months time. I have been told that some neurology referrals are now 2 years.

### REFERRALS TO SOCIAL SERVICES

Have you been had an injury and been to A&E or an in-patient after surgery and when discharge is being planned been told you can contact Social Services for help and receive things like visits from paid home help, equipment fitted or home adaptations made like grab rails in the bathroom? This is called Reablement. We know from a couple of members in Lincolnshire that most of the items listed on their website were not offered/did not happen.

[www.lascapp.co.uk/reablement/](http://www.lascapp.co.uk/reablement/) This excerpt from the government website [www.scie.org.uk/reablement/what-is/principles-of-reablement](http://www.scie.org.uk/reablement/what-is/principles-of-reablement) gives some idea of what should happen:

In England, reablement is seen as a core element of intermediate care that: [a] promotes faster recovery from illness, [b] prevents unnecessary acute hospital admissions and premature admissions to long-term care, [c] supports timely discharge from hospital, [d] maximises independent living and reduces or eliminates the need for an ongoing care package.

From this information, meaningful functional goals and outcomes are developed with the individual, to promote wellbeing, autonomy, independence and choice. It aims to 'enable people to be and to do what they have reason to value'.

Please write or email Toni Dunlop

[psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk)



## 'He would have been shocked' - Dr. Peter Salk, son of polio vaccine's developer, speaks on COVID hesitancy.

Pittsburgh Post-Gazette 26 December 2021

Jesse Bunch writes:

When the polio vaccine was deemed safe and effective in 1955, newspapers boldly declared an end to one of the period's most-feared illnesses. But to get to that point, the vaccine went through various trials, including one where over 600,000 children were volunteered by their parents to participate. Dr. Jonas Salk, the developer of the vaccine who spent years perfecting it at the University of Pittsburgh, would even administer a trial dose to his son, Peter. Now 77 and the president of his father's namesake institute, Dr. Peter Salk told the Post-Gazette in an interview that he sees the public's widespread willingness to take the polio vaccine as a mark of more innocent times.

One year after the first COVID-19 vaccines were publicly administered, the U.S. population is just 61% fully vaccinated. According to Dr. Salk, a blend of political and cultural influences are to blame for the public's waning trust in modern medicine. Of how his father, who died in 1995, would react to vaccine hesitancy today, Dr. Salk said "he would have been shocked."

"It's such a contrast to the environment he grew up in, and to the experience with those initial vaccines," Dr. Salk said in a phone interview. In his father's day, the public tended to trust public health advice. Today, "we've got the internet," he said, which allows ideas to take hold that might seem "totally crazy and bonkers, yet people get caught up in it." "These things spread, and really that's a viral illness of its own — the disinformation that riles up these kinds of sentiments," he added.

Like his father, Dr. Salk is connected to the University of Pittsburgh, where he is a visiting professor of infectious disease and microbiology. Given his expertise, he sees the COVID-19 vaccination effort as a "mixed success." "Mixed part is the problem," he explained. "We're dealing with two things — we're dealing with the reality of this disease, and we're dealing with the reality of human beings and their behavior, beliefs, feelings and interactions." Those beliefs can directly affect people's decisions about whether to vaccinate their children. According to national KFF polling, 30% of parents with children between the ages of 12 to 17 said their child had received one dose of the COVID vaccine as of late November. In similar polls, just 16% percent of parents of children aged five to 11 said their child had received a dose — and 29% of these parents say they never will. Those figures are a sharp contrast from the polio vaccination effort in 1955, when just one year earlier, 60,000 children caught the disease and 3,000 of them died. By 1961, millions of administered vaccine doses eliminated 97% of cases. "I think the factors coming to my mind are innocence on the one hand, and need," Dr. Salk said of the polio vaccine effort. "There's no question, this was horrible, and we wanted our kids protected."

Still, Dr. Salk mentioned that anti-vaccine sentiments have been around since the first smallpox vaccine centuries ago. In the years before Jonas Salk's vaccine was approved, the media stoked concern over its use of an inactive, "killed" polio virus, as opposed to a weakened live virus that was accepted at the time to be more effective. Dr. Salk added that racially abusive studies like the Tuskegee experiment, which denied syphilis treatment to a group of Black Americans, also lowered trust among communities. "Roll back several hundred years, and you still have anti-vaxxers that were problematic, but there wasn't any organized effort," Dr. Salk said. "People might have been scared, who knows what distrust of medicine and ease of access. Nevertheless, people believed in science. They believed in the beneficence of the powers that be that were making something available that was going to make a difference."

While America's vaccination rate lags behind that of other Western nations, Dr. Salk believes a reversal of the pandemic at home is directly tied to the global vaccination effort. According to New York Times data, 48% of the world's population has received two doses of a COVID-19 vaccine as of Dec. 19, with the threat of the potentially vaccine-resistant omicron variant stoking fears of more cases and deaths. "We've got a virus that's continuing to evolve. It's evolving in part because we haven't risen to meet the needs of the world, as well as our own country, in terms of getting enough blanket immunization protection to help keep new variants from forming," Dr. Salk said.

He added that while almost half of the world may be vaccinated, distribution is unequal. In Africa, for example, the rate of fully-vaccinated individuals is just 7%. "We need to not be entirely insular in our

thinking,” Dr. Salk said. “Yes, we need to be thinking about our own country, but we also need to be understanding that we’ve got a whole world here.” Looking forward, Dr. Salk said it’s impossible to say whether COVID-19 will be mostly eradicated, like polio, or whether the world must learn to manage it. “We ought to be able to keep on top of this from the scientific side,” he said. “We ought to be able to tailor immunological interventions, vaccines that would keep things at bay in a sense. This virus is always going to be trying to get around our defenses.”

The mRNA technology used in the COVID-19 vaccines, undiscovered during his father’s time, he called “extraordinary.” Approved for the public one year after cases were first discovered, the vaccine’s mRNA technology uses genetic material from the coronavirus to train the body to recognize an attack. While the method was studied by the National Institutes of Health for some time, the COVID-19 vaccine was the first mRNA vaccine used outside of clinical trials. “Basically, pandemics in past centuries over the course of time have made changes in culture, and this is an opportunity to rethink some things,” Dr. Salk said, “for us to make some constructive changes on the deepest levels of our society, that will help to put us in a better position in all respects, not just in terms of infectious diseases.”

Dr. Salk added this kind of thinking was not lost on his father, a man who notably said “our greatest responsibility is to be good ancestors” and refused to patent the polio vaccine, forgoing any profit. “Do we need to continue to depend on the kind of things we as a species have relied on in the past to guide our lives?” Dr. Salk asked, “or is it possible that there can be some catalytic events that help us forge a new, and more constructive, interactive way of moving into the future?”

ORIGINAL SOURCE ARTICLE <https://www.post-gazette.com/news/health/2021/12/26/Jonas-Salk-polio-vaccine-hesitancy-Peter-Salk/stories/202112200087>

## **Some Covid masks are better than others. I know – I’m the Mask Nerd!**

The Guardian Mon 27 Dec 2021

**Cloth or surgical masks just don't cut it - respirators are far more effective, and they're comfortable too.**

- *Aaron Collins is a engineer who tests and reviews masks and writes.:*

As a mechanical engineer with a background in aerosol science, I often wondered why months into the pandemic we were still using cloth masks. People used similar coverings during the Spanish flu pandemic in 1919, more than 100 years ago. I knew better mask technology existed, and people needed to know about it.

So I embarked on a year-long mission to test, document, and review the best masks I could find. This eventually entailed building a mini aerosol laboratory in my bathroom, with scientific instruments capable of measuring particles 1/50,000th the width of a human hair. I have a public database for my results. And a Youtube channel. Over time I began to be known as the Mask Nerd.

With the Omicron variant spreading around the world, the most common question I get is still the most basic: what kind of mask should I be wearing?

If possible, not a cloth or surgical one. These masks are moderately effective at capturing particles coming out of your own mouth – what we engineering nerds call “source control”. But they offer little protection against incoming particles. We call this part – how well the mask protects the wearer – respiratory protection.

A typical cloth mask, while better than nothing, only provides around 30-60% protection to the wearer. Surgical masks, while better at 40-80%, lack a tight fit to the face, resulting in large amounts of leakage around the mask.

Much, much better masks exist. These are sometimes called high-filtration masks, or by the technical name of a filtering facepiece respirator. Such high-performance masks provide significant protection to the wearer at levels that are between five and 10 times that of a cloth mask, while also providing significant protection to others.

In fact, simply wearing a high-filtration mask can buy you significant time if exposed to infectious individuals. Analysis and studies suggest that with cloth or surgical masks, the risk of infection may increase within minutes of being around others with either no mask or low-performing masks. However with the use of well fitting, high-filtration masks, this same level of exposure would now take hours to become dangerous. However, it should be noted that being around a contagious person always carries some risk.

Beyond the actual increased protection from potential exposure, these masks provide a psychological

improvement in day-to-day life, as you no longer need to concern yourself with the fact that those around you may prefer to wear their cloth masks under their chin.

One might assume based on the technical name, “respirator”, that these would be some Darth Vader-style headpiece – cumbersome and difficult to breathe in. However it’s quite the opposite. These masks feature a high-tech material called electrostatically charged meltblown polypropylene (quite a mouthful). It features tightly spaced micron-sized fibres – about 1/50th the diameter of a human hair – that have an electrostatic charge applied to them to catch even smaller particles. This material can filter particles that are a just a few nanometres in size.

The most amazing thing, though, is that while providing nearly 99% protection from typical Covid respiratory aerosols, these materials also provide breathability that surpasses that of a typical three-layer cloth mask.

When picking a mask you want to look at three criteria: filtration, comfort and fit. Respirators provide not only the filtration, but comfort from highly breathable materials, and a tight sealing to the face by the design of the mask.

This is what makes respirators such an easy option: you need not worry about anything other than finding one that fits your face. This ensures that all the air flows through the mask, not around it.

In the EU and UK, the FFP2 standard is my recommendation for the general public. It features both ear-loop and headband varieties, comes in a variety of colours, and typically costs less than a pound. Regulator oversight by various EU and UK government bodies helps to ensure a quality product.

In the US, the common NIOSH N95 is a great option, but it is limited to headbands only. Ear-loop masks are available via other international respirator standards, such as the KF94 (in South Korea) or KN95 (China). However it should be noted that the KN95 is a self-reported test standard, and lacks strict government regulation by China, resulting in many underperforming and often flat-out fake masks. The KF94 is less affected by this, as it is regulated by the Korean equivalent of the FDA.

In my year of testing nearly 100 different masks, I have found over and over again that there are high-performing masks that outperform cloth masks, while still featuring many things people like about their cloth masks.

Mask makers such as Masklab and Posh have created highly decorative designed masks, with bright colours and intricate patterns. Many KF94 masks feature built-in ear-loop adjusters, making for a comfortable, but tight fit. Other mask makers such as 3M – with the 9152 (9105 in the US), a mask that helps the wearer breathe as if there were none on their face, while also providing a full range of motion for the jaw – provide great options for singers and choruses.

With ample supplies of these masks available and a more transmissible variant on our doorstep, there has never been a better time to up your mask game. I encourage people to go out and try a few different varieties, find what they like and what fits their face.

Aside from helping individuals choose the best mask for themselves, I would also encourage governments to increase the domestic production of masks, which would not only create jobs, but also allow regulatory oversight and a supply of effective, safe masks for their citizens. And good masks should be provided free of charge to the many that may not be able to afford them.

Not all masks are created equal, so it’s time to make sure everyone knows about high-filtration masks. These simple, inexpensive and super-effective masks can make a significant difference in our fight against Covid. If you wear a mask, you might as well make it count by wearing the best.

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*Aaron Collins is a mechanical engineer with a background in aerosol science who tests and reviews masks on his YouTube channel.*

**ORIGINAL SOURCE ARTICLE**

<https://www.theguardian.com/commentisfree/2021/dec/27/best-masks-covid-tests-cloth-surgical-respirators>

## **Opinion: Global development: We can vaccinate 70% of the world against Covid by mid-2022. Here's how...** The Guardian Friday 31 Dec 2021

**The WHO's vaccination goal is achievable – but it will take proper funding, better vaccine distribution and jabs with longer shelf lives.** Bipasha van der Zijde writes:

While western countries scramble with their booster rollout to deal with the Omicron wave, only 8.4% of people in low-income countries have had at least one Covid vaccination dose.

The gap in the vaccination rates between high- and low-income countries is wider than ever. We cannot keep turning a blind eye to it.

The vaccines being distributed to African countries under the Covax scheme are often close to expiry and their delivery is ad-hoc at best. In Nigeria, where only 2% of the population is fully vaccinated, they just had to destroy more than a million vaccines that were close to expiring.

Nigeria is not the only country struggling. In Ghana, where 7.4% of the population is vaccinated, Fred Osei-Sarpong, representative of the World Health Organization said: "The receipt of vaccines with a short shelf life puts excessive pressure on the staff and makes it difficult to adequately plan for effective vaccine delivery."

These short shelf lives seriously impede the delivery of vaccines to rural areas. We have worked with Benjamin Onger, health supply chain specialist with Crown Agents in Kenya – where 7.2% of the population is fully vaccinated – on the delivery of medicine for neglected tropical diseases (NTDs). He says: "There are enormous challenges in getting medicines to the last mile. We know this from years of working with NTDs. It is very hard to reach people who are most affected since they are vulnerable, often marginalised, and live in remote locations with poor roads and infrastructure."

The same challenges have slowed the uptake of Covid vaccines. And this is exacerbated by the fact that these vaccines require cold (or ultra-cold) chain logistics infrastructure that is often non-existent in these areas.

It also doesn't help that the vaccines mainly being administered in Africa are those the west has decided not to accept.

"In Ghana, at the initial stage of the vaccine rollout, a high demand was generated," said Osei-Sarpong. Then there were no vaccines. The break in the rollout affected communication efforts and this gap created the space for misinformation and rumours to thrive.

According to the WHO vaccine strategy, published in October, the goal is to have 70% coverage across the world by June 2022. How can this target be achieved?

Will freeing up intellectual property rights, often cited as a possible solution, bridge the widening gap? Neither Osei-Sarpong nor Onger believes it is the answer. For a country to start producing vaccines from scratch would be a massive challenge. According to Onger: "Countries like Kenya have begun this journey by targeting the final filling of vaccine vials locally which is still quite challenging given the need for state-of-the-art pharmaceutical manufacturing plants that will guarantee safe production with no chance of contamination."

A lot more will be required in terms of technology transfer and building the expertise needed to fully produce vaccines locally, these cannot be achieved in the short to medium term.

The answer lies in global funding mechanisms such as Covax – provided they can guarantee a pre-planned availability of vaccines. More equitable distribution of the jabs on a structural basis with longer shelf lives will allow for realistic and efficient planning. "With the provision of funds for operations and the availability of vaccines, Ghana will be able to strategise and meet the coverage set by WHO," says Osei-Sarpong.

Added to common elements such as the lack of sufficient vaccines with adequate shelf life, each country has its own unique set of circumstances that lead to a low vaccination rate. So, with funding made available, each country can tailor their efforts to combat those circumstances and make sure the vaccines can reach the last mile.

In Kenya, Onger says they need the resources to undertake door-to-door vaccination campaigns as they do for childhood immunisation. Where there exists a well-functioning delivery system, nations have high vaccine delivery rates. Kenya, for example, has an estimated 80% coverage for childhood vaccines. In Ghana, it's above 90%. The goal set out by the WHO may not be as unreachable as it appears.

It is not just in the interest of the countries with a shortage of vaccines that urgent action needs to be taken. As the UN secretary-general, António Guterres, said: "None of us is safe until we all are."

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Bipasha van der Zijde is a marketing and communications adviser at KIT Royal Tropical Institute

ORIGINAL SOURCE ARTICLE <https://www.theguardian.com/global-development/commentisfree/2021/dec/31/world-health-organization-who-we-can-vaccinate-the-world-against-covid-by-mid-2022>

**Linda Poolaw is another strong willed Polio Survivor who has dedicated her life to making a difference.** Sadly some of the issues are caused by a lack of knowledge of professionals who have not been taught enough facts and often do not have the required understanding of how people who live their lives differently through culture or disability.

### **Elder shares stories of life, laughter and American Indian health**

Connecticut Post 6 January 2022 Michael Merschel, American Heart Association News, writes:

Linda Poolaw loves telling stories. At 79, the Grand Chief of the Delaware Grand Council of North America has a few. Some are nostalgic, about growing up in rural Oklahoma, the daughter of a Kiowa father and a mother who was Delaware (also known as the Lenape). Some are painful, when she talks about American Indians' struggles. She tells stories in an Oklahoma twang, skipping from topic to topic. She talks about her father, a renowned photographer. She recalls her armed standoff with the electric company. She shares tales of Bigfoot, whom she's heard outside her Anadarko home. Her stories often end in laughter. And regularly, they express pride about her work preserving culture and protecting Native Americans' health. "When you get to be almost 80 years or so, that's all you're about anymore is the past," she said. "And I like talking about the past," celebrating the things she got to do – and relishing the experience of "being an Indian woman."

Her stories span the globe. She's known presidents of elite universities, directors of Smithsonian museums and faith leaders from the remotest parts of Canada. But she said her greatest achievement is the work she did in her home state of Oklahoma, helping researchers understand heart health among what she regularly calls "my people," before she corrects herself: "They're not 'mine.' They're 'people.'"

Native Americans have Type 2 diabetes at rates three times higher than their white counterparts, according to a 2020 report from the American Heart Association. For those who develop heart disease, diabetes is most often to blame. She knows the toll personally. Her mother, father and younger brother all died of heart issues related to diabetes. She also has diabetes and has needed six stents placed in her heart. Because of a rare eye disease, she is nearly blind. But health issues have been with her from the start. So has a determination to do things her way.

In her part of southwestern Oklahoma, the government forced Delaware people, who originally were from the region that is now New York, New Jersey and Pennsylvania, to settle on the north side of the Washita River, along with Wichita and Caddo people. The Comanche, Kiowa and Apache were forced to settle to the south. "My mother was from one side of the river, and my dad was on the other side of the river." North of the river, people grew their own food. "We had gardens, beautiful gardens, and we ate vegetables, and we learned how to preserve food like that." The people to the south had traditionally emphasized hunting. "My dad used to say he never ate so many weeds" until after he was married.

Poolaw survived polio as an infant. The brace she had to wear was not an impediment. It became a handy weapon. "All my cousins were afraid of me," she said, laughing. "Man, that thing hurt when I kicked 'em!"

The medical care she received reflected the problem of being American Indian in an unsympathetic system. When she needed to gain weight, the doctor insisted she drink milk. But "very, very few Indian people drink milk," Poolaw said, because many are unable to digest it, a condition called lactose intolerance. She faced other challenges. The school she attended was mostly white. "Growing up in an Indian and white world that neither one cared for each other – it was hard." But she grew into a fun-loving young adult. A lot of the fun centered on alcohol, which would grow into a problem. "I was kind of crazy in the early days," she said. Under pressure from her parents to clean up her act, she moved to Maine to live with her aunt, Lucy Nicoliar, who had achieved fame as a vaudeville performer under the name Princess Watahwaso. It changed her life. "Boy, nobody got in her way," Poolaw said. "And my mom was like that, to a certain extent." Lessons from her mother, Winnie, and her aunt took hold. "They taught me how not to be walking around with my head down. Be out there. Be up front."

She returned to Oklahoma, enrolled in a four-year college and earned her degree. She worked to record native speakers of the Delaware language. She wrote a play about American Indian college students. She made headlines when she and neighbors took up arms to defend their land when a gas and electric company showed up to run power lines across her property in 1986. She lost a lengthy court fight, and federal marshals arrested her. The sight of the power lines across her land angers her to this day.

Other stories have happier outcomes, such as her work to preserve the legacy of her father, Horace. When he died, in 1984, he was not widely known. Linda gathered 2,000 of his negatives and worked at Stanford University in California for a year to archive them. Thanks to that work, he's now heralded as one of the great photographers of the 20th century and has been celebrated at the National Museum of the American Indian and in exhibits around the country.

She became a spiritual leader who has helped bless and rebury remains uncovered on Ellis Island in New York



Harbor and elsewhere. But nothing put Linda Poolaw's skills to use like her quarter-century with the Strong Heart Study. Begun in 1988, Strong Heart was the first major effort to understand Native American heart health. Poolaw was hired to help recruit volunteers to sit for interviews and exams. People had been reluctant. But Poolaw began seeking them out. "I know every pig trail, every hideout, every place in southwest Oklahoma" because she had family from both sides of the river. She also had experiences that put them at ease. She estimates she helped with 1,600 interviews initially. Strong Heart Study co-founder Elisa Lee, now professor emeritus and a former dean of the University of Oklahoma Health Sciences Center in Oklahoma City, said Poolaw's hard work and enthusiasm contributed greatly to the study's success. When researchers had questions, Lee said, "very often, we would say, 'Let's talk to Linda. See what she thinks.' ... And we followed her advice most of the time." Over time, the findings reversed longstanding misconceptions about Native Americans and heart health. To date, it has been the basis of more than 450 scientific papers.

Poolaw spent 25 years working for Strong Heart. She loved "working with Indian people, getting to meet them, getting to know their history, getting to know who they are. I was kin to a lot of them. And that was the best part." The worst part, she said, was losing them. Thanks to the exams, many volunteers learned they had diabetes. Many got help. But too often, someone would spill their heart out to her in an interview, and she'd find their obituary the next week.

Generations raised on government commodities and fast food are paying for it with their health, she said. Although the study helped her learn healthy habits and lose weight, "I was a junk eater at one time. Probably that's why I have diabetes. But how are you going to educate them? We try. We try, we try, we try. But now – it's a mess." She understands the reasons behind the problem.

She recalls hearing a Navajo elder who acknowledged the challenges of eating in a world where your culture has been cut off from its traditional sources of nourishment and forced to adapt to white people's food and unhealthy government commodities. Food, the elder had said, is about more than avoiding hunger. "It is our life," Poolaw said. From birth celebrations to funerals, "whatever we do, we eat. I don't care what meeting we go to, 'What are we going to eat?' and 'Where is there a place to eat?' – it's the first thing that we think about. "It's our life," Poolaw repeated. When the Navajo woman said that, "I had big tears in my eyes."

These days, there are other problems as well. "I see things around me that hurt, that make me sad." And angry. She's been working to fight methamphetamine abuse, which she said has ravaged her area. She's chair of a group called the Consortium Against Substance Abuse that is working to build a youth activity center as a way of putting a dent in the problem. It's discouraging. But she's long had a way of coping. "I love to laugh," she said. Her mother used to say, "'Linda, are you ever serious?' And I think that's how I got through life." Love of laughter is something she's seen in tribes across the continent, from the Penobscot to the Sioux to the Navajo to Alaska Natives. "I don't care where you are – if you're in a group or a church, or if in Walmart, or wherever you are at a powwow or dance or whatever you want. You could hear us laughing. And we don't go 'hee-hee-hee-hee.' We laugh." Her theory is: "That's why we're still here."

Lately, Poolaw has been sharing laughs with other Delaware elders. She gathered them to share their memories on film. She tells them why: "Every time I go to a funeral, if it's somebody my age or older, as they go into the ground, I say, 'There go some more stories.'" She's proud of the stories people tell about her. Even from the wild days. "I'm not a saint," she said. But "everything I did – I'm not ashamed of it." One story goes back to her Strong Heart days. So many people learned they had diabetes because of her work that some started saying, "Linda Poolaw gave me diabetes." She didn't mind taking the blame, as long as it led people to get help. "They were getting good treatment," she said. "And that was the prize that I got. They started taking care of themselves."

Original Source Article: [www.ctpost.com/news/article/Elder-shares-stories-of-life-laughter-and-16754198.php](http://www.ctpost.com/news/article/Elder-shares-stories-of-life-laughter-and-16754198.php)

If you have questions or comments about this story, please email [editor@heart.org](mailto:editor@heart.org)



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**"Bruno Bytes"**

From the Post-Polio  
Coffee House



### **Carol Ferg PA Polio Survivors Network Update**

**\*\*Bruno Bytes for the 4th Quarter, 2021 are Available\*\***

Slow Bellies, Back Support, Blood Sugar, Sleep Apnoea, FDR, Heat Intolerance, Muscle Atrophy, Rotator Cuffs, Social Security Disability Insurance and Muscle Overuse.

Bruno Bytes are published quarterly,  
through a combined effort  
between Dr. Richard Bruno, HD, PhD  
and the PA Polio Survivors Network.

They are answers to questions posted in the Facebook  
"Post-Polio Coffee House" Group started in Nov 2014.

## Worldwide Online Polio Survivor Support

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/>

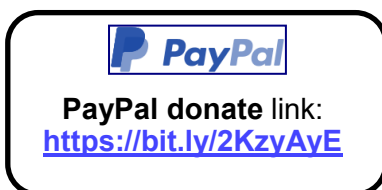
This list is not exhaustive, other groups may exist in your local areas too.

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

**Polio Australia** ([steph@polioaustralia.org.au](mailto:steph@polioaustralia.org.au)) please contact for information of events.

**Polio Survivors Ireland** provide a telephone conference ([fsw@ppsg.ie](mailto:fsw@ppsg.ie))

**Post-Polio Health** provide ideas for support group



# Management Committee [Trustees]

Chair - Simon Parritt - [simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)  
Secretary, Zsuzsanna Snarey - [zsuzsanna.snarey@poliosurvivorsnetwork.org.uk](mailto:zsuzsanna.snarey@poliosurvivorsnetwork.org.uk)  
Treasurer, Newsletter Editor - Hilary Boone - [hilary.boone@poliosurvivorsnetwork.org.uk](mailto:hilary.boone@poliosurvivorsnetwork.org.uk)  
Trustee - Verité Reily-Collins - [verite.reilycollins@poliosurvivorsnetwork.org.uk](mailto:verite.reilycollins@poliosurvivorsnetwork.org.uk)

Trustee/s - Vacancies please contact Toni for more information

## Operations Team

Phone Enquiries - Hilary Boone - 01522 888601  
PSN Admin, Enquiries and Website - Toni Dunlop - [psnadmin@poliosurvivorsnetwork.org.uk](mailto:psnadmin@poliosurvivorsnetwork.org.uk)  
Printing - Imprint Colour Printers, Lincoln

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](http://www.poliosurvivorsnetwork.org.uk)

Write to us at PO Box 954, Lincoln, LN5 5ER, U.K.

Email [psnadmin@poliosurvivorsnetwork.org.uk](mailto: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](mailto: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:*

## **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](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



*'A fire at the GP surgery?  
We're only doing online  
appointments at the moment'*

Cartoon courtesy of Matt Cartoons  
(Worth following on Twitter:  
@MattCartoonist)

## Did you know...?

***You are four times more likely to die in a fire if you don't have a smoke alarm that works***

***Around half of home fires are caused by cooking accidents***

***Two fires a day are started by candles***
















***Every six days someone dies from a fire caused by a cigarette***

***About two fires a day are started by heaters***

***Faulty electrics (appliances, wiring, overloaded sockets) cause around 6,000 fires in the home across the country every year***

## Fire Safety Advice

[www.gov.uk/government/publications/make-your-home-safe-from-fire](http://www.gov.uk/government/publications/make-your-home-safe-from-fire)

-  Fit a smoke alarm on each level of your home
-  Check smoke alarms regularly and test them at least monthly
-  Consider fire blankets, extinguishers and heat alarms
-  Take extra care if you need to leave the kitchen whilst cooking, take pans off the heat or turn them down to avoid risk
-  Don't put anything metal in the microwave
-  Try and keep to one plug per socket
-  Make sure an electrical appliance has a British or European safety mark when you buy it
-  Keep electrical appliances clean and in good working order
-  Plan an escape route and make sure everyone knows how to escape
-  Make sure exits are kept clear
-  Keep door and window keys where everyone can find them easily and nearby
-  If you have a lifeline installed, check it regularly to ensure there are no faults on the line
-  Shut all doors possible when going to bed
-  Contact your local fire department to ensure they are aware that they might have difficulty getting you out of room e.g. if you use an electric chair, have hoists fitted, use a ventilator etc (we are now registered as a three engine call out—6 fireman instead of two)!
-  Do you know how to isolate your gas and electric supply?



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