



POST POLIO MATTERS

Polio Survivors Network Newsletter
September 2022 - Volume 10 Issue 11 of 12 [119]

Thank you Ma'am for everything



© Eleanor Tomlinson



God Save The King
His Majesty
King Charles III

God Save The King - His Majesty King Charles III

[Lincolnshire Post-Polio Library](#)

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

Page 2	Contents, donations, PayPal link, AmazonSmile
Page 3	Editorial by Hilary Boone
Page 4	Message From Our Chair
Page 5	Toni Writes, From Our Readers
Page 6	Advice on Energy bills from Silver Voices by Verite Reily-Collins
Page 7	Tips When Using Your Computer
Page 8	Ten Top Things About Me/My Medical Conditions
Page 9	Rules of Etiquette for Polio Survivors
Page 10 - 12	Dr Lauro deBosis Storm Halstead, A helpful book for Polio Survivors
Page 13	More Problems With My Callipers, Covid Notes
Page 14	Polio Case Reported in the U.S. This Month
Page 15 - 17	PPN News
Page 18	A Research Project, Helpful Resources
Page 19	Management Committee, Useful Polio Articles
Back page	The Helping Hand, The Last Leg, Thank you to Val Scrivener

<u>Donations and Charity Incentives Paid</u>	
<i>(since last newsletter)</i>	
Donation (PayPal Giving Fund)	£1.00
Donation (D Brennand)	£12.50
Donation (S&P Tanfield)	£20.00
Donation (PayPal Giving Fund)	£40.00
Donation (V Gabriel)	£200.00
Donation (D Mitchell)	£12.50
Donation (C Murphy)	£10.00
Donation (PayPal Giving Fund)	£10.00
Total	£306.00

This publication is provided free thanks to the

generous donations of members.

Thank you so much!



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



This publication is provided as a service to those seeking such information and is not intended as a substitute for professional medical care. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Polio Survivors Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

Articles in this publication may be reprinted in full with acknowledgement of this Newsletter name, volume, issue and date. Exceptions are where written by an external author/newsletter when permission must be gained from the original author/s.

Editorial by Hilary Boone

Thank You Ma'am for Everything and God Save King Charles III



These last few days have been of great sadness at the sudden passing of Her Majesty Queen Elizabeth II just three months after the most wonderful celebrations for her Platinum Jubilee. Her dedication of service to her nation and her people was exemplary and inspirational.

Thanks to the invention of the television and Her Majesty's willingness to be filmed throughout her life we have the most wonderful memories. We have seen her in full regalia, in wonderful ball gowns, splendid coats and hats,

right down to a mackintosh, galoshes and a headscarf.

In 2012 we were stunned by her 'entry' to the Olympic Games but she surpassed that when we saw, and joined in with, the astonished laughter on the faces of all in the Royal Box at her Jubilee Celebrations when she produced a marmalade sarnie out of her handbag in her film with Paddington Bear. The drawing by Eleanor Tomlinson on the front and this page speaks volumes and is treasured by so many people.



Polio Survivors Network have just learned that a Celebration of Life has been held for Dr. Lauro Halstead. A Polio Survivor who researched into the new issues many of us who caught poliomyelitis in our early years were experiencing in later life. Turn to the middle pages where you will find a helpful now ten year old article that Phillipa Eckert and I wrote after his presentation at the Atlanta Post-Polio Conference 1st November 2002. I so remember the slides he showed of how he managed his life at home and work. So many ideas that may be of help to our readers.

I can hear some of you say - I am not there yet - said it myself in the first few years. Polio Survivors became strong willed and determined to succeed during our childhood recovery from polio and any suggestion of starting or restarting to use equipment is a NO, NO. Dr. Halstead happily told us that in 1994 he realised that he had to buy an electric scooter to continue working at his large hospital in Washington DC. However, just like many of us it took him till 1999 before he purchased one for use away from work.

I was lucky to meet and talk with him at many Post-Polio Conferences and super privileged to be invited to his home for dinner with his wife Jessica Scheer where he signed my copy of *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*.

Electric Wheels are not a downward step but the start of a new life being able to do more, go to many more places for longer and with less pain and fatigue. I have had an electric scooter since my 50th birthday [I was so embarrassed when it was delivered and I was asked to try it out in the road outside my home]. 25 years later and I have been thousands of miles that would have been impossible without it. Due to a bad fall two months ago I have had to use our spare electric wheelchair purchased 12 years ago off the internet. It is too small for my long legs but with a bit of 'do se do' we are managing to get round our small bungalow. We are seeking a carpenter to take a foot off one wall to give us a bit more room. I am now at the start of what I am told can be an 18 week process to get one that fits me. Please practice how you would manage if you suddenly found yourself with a limb out of action. Thank goodness it was my legs because over the last 15 years I have gradually had to use my arms more to sit, stand up and transfer. Richard has three ceiling track hoists fitted and using his sling was the only way a Carer could get me up off the floor in December and July when I fell. I had to swallow hard and ask our OT for a more suitable size sling for the Carers to use for me.

The TV is on as I type and our new King, His Majesty Charles III is about to take part in the ceremony of the Keys of the City of Edinburgh. I am amazed how many processes there are that he has to take on board during this time of mourning. God save King Charles III.

MESSAGE FROM OUR CHAIR



My Challenging Time

The past year or two has been both a challenging and complex time for me having been diagnosed with prostate cancer. Of course, it is just bad luck and affects many men as we age, irrespective of polio or any other health condition. The impact and shock of discovering I had cancer was obviously very difficult, but perhaps after the initial shock, the problems around navigating the best treatment options as a person with post-polio has proved quite stressful and challenging over and above the actual diagnosis.

As we age and inevitably have other conditions, we are all faced with questions around the quality of our lives and how this is viewed by clinicians. It is sometimes difficult to convey that despite being quite severely physically impaired, having polio, being a wheelchair user and in my case having used nocturnal ventilation for over 20 years, we do not necessarily have, with good care, a reduced life expectancy per se. The basics around the right treatment, with the right precautions can, and usually does, mitigate most problems around our post-polio issues.

Combating Misconceptions

I find the most difficult issue is achieving a balanced explanation of my medical needs, status and risks when facing a doctor who is not familiar with polio, which is virtually every medical professional these days. The first impressions as I arrive, is a 72 year old disabled man, in a power wheelchair with extensive muscle weakness, who has his wife to help him with most care needs. I am faced with small decisions such as, do I just get out of my chair and walk the few steps to sit in the chair next to the doctor or not, as I may seem overly able? Should I transfer on and off the couch with minimal support to demonstrate I am not totally incapable? These are thoughts and choices that run through my mind every time, as I don't want to underplay my needs and issues but on the other hand, I don't want to minimise them either. How much to be overly positive, a familiar trait of polio survivors, and confound initial ideas of what I can and can't do or to convey that I am quite dependent in many ways which they need to understand.

Getting the Balance Right

The danger is that when making health professionals aware of my various health and support needs, they can assume an overly negative view of my health as I suspect they have a medical/age 'norm' in their heads. It is this 'norm' that informs their thinking and of course for most of us we never were the 'norm' and so for us daily life doesn't necessarily involve the same things as it does for others. Equally most research and treatment outcomes aren't based upon disabled people's experience.

The problem is that by emphasising my polio issues I may in fact not be offered optimal or the most effective treatment. However, if I minimise them, I run the risk of having my polio issues not managed adequately thus storing up potential risks and serious side effects that could have been avoided or minimised. Whilst these have always been issues, I am finding this an even more difficult balancing issue in my prostate cancer journey when dealing with oncologists.

The Stress of Self Advocacy

I find myself, as I am sure many of us do, having to do a huge amount of personal research and facilitate communication between different specialists and services whilst feeling that I am on my own trying to explain and managing complex situations. Being diagnosed with prostate cancer has been particularly difficult in this regard as some of the treatments may or may not be harder for me because of my post-polio issues but this is unclear. The fear that lurks in the back of my mind is that I am seen as less likely to tolerate treatments because of my polio issues when this is based on what I 'look like on paper' and from a lack of knowledge about ageing with polio issues and me in particular.

The Bottom Line

There is also a wider issue here about how society sees our 'quality of life' and who has value which is based upon a non-disabled medical model. In the current climate this is becoming an even greater threat to us as we slip down the priority list. The real issues that reduce disabled peoples' quality of life are societal and environmental barriers rather than physical abilities and prowess.

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

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

Toni Writes ...

Firstly I would like to give a big welcome to the many new members who have joined Polio Survivors Network since our last newsletter, it really is good to have you with us. I hope we can be of support and help.



I would also like to say a HUGE thank you to Val Scrivener who has created beautiful photocard for purchase (proceeds going to Polio Survivors Network) over the years. Val is no longer able to do so but her hard work is much appreciated and I wish you well for the future.

Another BIG thank you to all you lovely members who have donated so generously. We are in an excellent position to continue providing our services without charge. Talking of our service, I would like you to please provide any feedback you may have on our refreshed newsletter section found on the [Polio Survivors Network website](#). Please click through the [Newsletters link](#) and have a look.

Tip: To make the text of the newsletter bigger click the + sign in the right hand corner of your screen. Also you can now search any word or phrase in each newsletter by using the magnifying glass at top of page.

As ever please feel free to drop me a line with your suggestions, tips, experiences, thoughts, any resources you have found useful or absolutely anything else on your mind.

Take care

Toni

PS: If anyone has a copy of issue 36 or 101 of our newsletter we'd love to add them to our library.

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

From our readers:

- Thank you for excellent newsletter. Thanks to all who had a hand in it.
- **Great newsletter**
- Critically important service frequently with gems of ideas which would be useful to most of us who belong in this community.
- I wish to thank you for your kind help and for the inspirational material you give to members. I am very touched by the courage and tenacity of the members and it's organisation, and the quality of the material is very high and very good indeed.

Advice on Energy bills from Silver Voices

“Put Essentials before Energy Bill”



As polio survivors, we all know how important it is to keep warm. With the horrendous increase in fuel costs, what Dennis Reed, Director of Silver Voices Charity, has to say about the horrendous bills we will soon be facing, might resonate with many of us... Silver Voices (the charity) has “had hundreds of emails on the cost-of-living crisis, seeking advice and offering comments.



SILVER VOICES

“Many members have asked for advice on what to do when they cannot afford to pay their energy bills this winter. Thousands of older people have already made all the economies they can...

Our advice is clear, do not jeopardise your health by turning off your heating, or by failing to eat and drink a sustaining diet. If the choice is between food, warmth, or energy bills then it must be the energy bills that are dropped. We are not aligning ourselves with the ‘Don’t Pay’ movement, but the responsibility must be passed back to the energy companies and the Government to provide sufficient support for the basics of life.

If you genuinely can’t afford to pay your energy bills, then the first step should be to contact your supplier saying that you need support. Ask for a hardship grant (most suppliers have a scheme) and for a reduction in the tariff. If you can afford something towards the bill without damaging your health, then show willing and make a part-payment. Do point out that you are following Silver Voices advice, to show you are part of a wider movement.

You cannot be cut off in the short-term if you don’t pay your energy bills, or be forced to accept a pre-payment meter. If you are a state pensioner, you can’t be cut off during the winter and if you have long-term health conditions or are disabled you can’t be cut off at any time. See the following Citizen’s Advice explanation for detailed information on cut-offs: [CLICK HERE](#)

Although this advice is for England, similar provisions apply across the UK. On pre-payment meters, these need to be avoided as higher rates are charged and if you run out of money, you lose your power. Suppliers cannot force people to agree to a pre-payment meter without a court order and there are many circumstances such as disability and illness which would disqualify the energy supplier from taking this action at all. Again, read the helpful Citizen’s Advice on the subject: [CLICK HERE](#)

Our advice is the only sensible response to this crisis. NHS Leaders have warned of an impending public health emergency unless the Government takes radical action. [CLICK HERE](#)

Our advice is intended to save lives. It would be a tragedy if thousands die from self-neglect because they don’t want to fall into debt. So, in the absence of measures to improve the basic income of state pensioners, we must put pressure on energy companies and, through them, the Government to show that the current situation is unsustainable, with unthinkable consequences.”

Background

I came across Silver Voices when Dennis started a campaign to ‘Gum Up The Works’, when the BBC took away free TV licenses for the elderly. Silver Voices did not advocate anything extreme, but showed simple steps one could take to legitimately question the BBC, and delay paying the fee. This was so successful at stalling matters, that I believe there are still 3/4 million who have yet to hear from the BBC about paying - and the BBC has come to an impasse!

Membership

You can apply to become a member of Silver Voices and add your voice - plus receive Dennis’s emails full of practical advice - with a bit of humour. The sub is £8 a year but anyone surviving on the state pension and benefits alone gets free membership www.silvervoices.co.uk/join-us

By Verite Reily-Collins PSN Trustee, Health Journalist and owner of www.aftercancers.com

Tips When Using Your Computer

If you're reading this on the internet you probably spend a fair amount of time at your computer. This can put you at risk for a lot of problems. Carpal tunnel syndrome, tendonitis, bursitis - all result from chronic, continuous, overuse of the hands and arms. Neck and back pain, headaches, eyestrain, tension and fatigue can also come with the territory. Before computers, people who typed for a living didn't develop these conditions. What has changed?

For one thing, we type much faster on a computer keyboard - thousands of keystrokes per hour. And there are no breaks - we don't have to stop at the end of each page to insert fresh paper. These fast, repetitive motions take their toll on your body. The problem is compounded if your computer workstation doesn't fit you.

So here are some risk-reducing recommendations from ergonomics, the science of arranging and adjusting your work environment to fit you and your body. They won't all apply to everyone, but you can utilize whatever fits your situation.

BODY AND ARM POSITION

Shoulders need to be relaxed and elbows kept close to the body. Place the computer keyboard at elbow height or 1" below elbow height to keep your forearms parallel to the floor and wrists in neutral position. A too-high keyboard is one of the most frequent flaws at computer workstations. If your keyboard height is not adjustable, change the chair height.

Be sure your chair depth is correct for you. If it is too shallow your thighs won't be supported. If it is too deep, it won't support your back.

Make sure your feet are supported. If your feet don't reach the floor use a foot rest or a 3-ring notebook binder.

You also don't want your hips flexed so much that your knees are higher than your hips. This interferes with blood flow to the legs. If you can, move your feet forward so your knees are lower than your hips and straighter than 90 degrees.

Use a lumbar pillow or a small rolled-up towel to support your low back.

To avoid over-stretching to reach objects you use often, make a semicircle with one arm to determine your comfort zone and place frequently-used objects within that area.

YOUR MONITOR

The most comfortable distance for the monitor screen is 18-25 inches from your eyes.

The top of the screen should be at eye level. If you wear bifocal or trifocal glasses the screen will need to be somewhat lower to keep your head in an upright position.

Place a document holder next to the monitor at the same height and distance as the screen as typing from a document lying on the desk causes repetitive neck motion.

TAKE FREQUENT BREAKS AND STRETCHES

Blink often. Optometric studies have shown that people tend to blink less and open their eyes wider when looking at a computer screen. This causes dryness that can lead to fatigue, a burning sensation, difficulty focusing and headaches.

Stretch your wrists and fingers. Stretch your wrists backwards until you feel a mild pull, then stretch forward. Make a fist, then stretch the fingers outward.

Put your hands on your hips and lean backwards gently, then bend side to side. Do this sitting down so you won't lose your balance.

By Grace Young <http://www.reocities.com/HotSprings/4713/>

Please also search the [Polio Survivors Network Library](#) for more articles by Grace Young

Editors note: If I don't have legs up my shoulders ache badly. Ergonomic Keyboards. These are split keyboards and allow your wrists to stay in line with your arms and reduces wrist strain. Also have a platform in front where you can rest palms. In some models Backspace and Tab keys are also duplicated in the middle. Takes a couple of days to get used to them.

TEN TOP THINGS ABOUT ME/MY MEDICAL CONDITIONS.

I have attended a couple of meetings in the last couple of weeks where the subject of patients providing information was raised. How much of a responsibility is it of the health professional and how much the patient to ensure specific information that is very important about your life and how you manage your medical conditions. How often have you had problems being assessed by health professionals in non Post-Polio knowledgeable medical situations?

It is very easy even for someone who has been attending meetings/conferences etc for over 27 years to get it wrong. **I got it wrong** when I fell on July 12th and had to attend A&E. I was triaged and sent for x-ray, told I had probably broken both ankles more so my right and was being sent home to be referred to the Fracture Clinic. Despite informing the doctor of my prior polio, post-polio and that I have to use a walker or electric scooter, none was mentioned in his report.

In excruciating pain and no longer able to walk I had to start using Richards 12 year old purchased off the internet for £75 that is far too small for me electric wheelchair with added height cushion, to get round the house. The next day two raised blisters appeared on my right ankle and I had to go to the GP surgery to have this dressed. Over the next couple of days the two raised blisters became one large one [2" x 1.5" and 1" raised] and my leg to knee remained swollen and hard. Having to stand on this completely dropped foot to transfer made life tough. I would not be able to wear my AFO's till this healed and I was told it could take months. I contacted my Rehab Consultant and she asked an Orthopedic Consultant to look at my xrays and he decided I had not broken either and therefore I was discharged from the Fracture Clinic without being seen or my current non walking situation being understood. I received extensive laser therapy on my ankle from our Neurofunctional Chiropractor and the blister became a large scab. Stuningly 17 days from the fall when the Nurse went to dress my ankle she raised the edge of the scab to find new skin underneath. It appears that daily laser therapy can accelerate healing far faster than anyone expected.

However the lack of recording or understanding of the physical issues that my Post-Polio causes in daily function has meant long delays to get to appropriate health professionals that I need to see to start trying to walk again. I accept that A&E doctors are unable to know everything about all conditions. I obviously failed to ensure the problems I would now have were understood and recorded for when other health professionals looked at my records.

I am now in the process of updating my double sided sheet as the heading of this document to ensure that it contains the most important points that I need health professionals without Polio/ Post-Polio knowledge looking after me to please take on board. Remember we are acknowledged as experts in our conditions.

What would you do in similar situations? Have you thought, or practiced, what you would do if you injured a leg or arm and were now unable to sit/stand/transfer as you normally do?

What information would you include?

TEN TOP THINGS.

Front - It is important that health professionals do not look at a list of diagnoses and see you in an electric wheelchair and think you have always been in one. Pick a few small photographs that show your abilities over the years. Then start to list what you consider are important points about you.

Back - List points that are important about your polio, your Post-Polio Syndrome and other medical conditions.



We update our copy every year. We also laminate one copy and punch hole in corner so it could be hung on the bedrail by a curly cord. As staff change shifts it is not possible for them to read a lot of information you might have handed over for your file. Many have said how useful being able to have a quick look at both sides of this has been extremely helpful.

RULES OF ETIQUETTE FOR POLIO SURVIVORS

PERSONAL HYGIENE

1. Decisions about which body part to wash depend on which doctor you're seeing today, i.e., face/ears for the ENT; feet for the podiatrist; arms for blood tests; etc
2. Proper use of toiletries can forestall bathing for several days. However, if you live alone, deodorant is a waste of good money.
3. Read labels carefully. Ever notice how much the can of room freshener resembles the can of deodorant?
4. Remember to warn your spouse before kissing if you've just taken your herbal remedies, since your breath now smells like grass.

IN THE KITCHEN

1. If you can't remember what it is you're cooking in the pot, whatever it is, it can probably use more salt.
2. Do not toss that cold cup of coffee into the dryer or set the iron in the refrigerator to cool off, no matter how good an idea it may seem at the time.
3. When your husband tells you 'Don't worry about dinner, just throw some frozen chicken in the oven and forget it', DON'T forget it.
4. When everything INCLUDING the can opener is dirty, it may be time to wash some dishes.
5. It's bad manners to fall asleep at the table, especially in the food.
6. If you're having a bad day, there's nothing better than pizza and quiet.

DRIVING ETIQUETTE

1. Always place a note on the dash-board telling you where you're going. When you get there, place another on the dashboard that says HOME.
2. Never relieve yourself from a moving vehicle, especially when driving.
3. Always carry an electronic homing device with you so you can find where you parked your car

TIPS FOR ALL OCCASIONS

1. If you have to vacuum the bed, it's time to change the sheets.
2. If you take the dog for a walk, make sure he brings you back.
3. Nevermind taking one day at a time; stick to one thing at a time.
4. Try to spend at least 45 minutes each morning doing one get-up.
5. Work at learning something new everyday, like sitting up, for example.
6. Remember to breathe when napping - it's unnerving to wake up and see vultures staring at you.

7. Learn to understand your "body language":

Joints - "I ache! It's going to rain!"

Stomach - "You're getting me upset!"

Nose - "Oh, oh, I'm getting a cold!"

Head - "Stop it, all of you! I'm getting a migraine!"

mickiemc@frontiernet.net

Dr. Lauro deBosis Storm Halstead 27.2.1936 - 5.1.2022

**A Celebration of Life was recently held
for Dr. Halstead in Peru, Vermont, U.S.A.**



Dr. Halstead is an internationally known physician in the USA for identifying and treating Post-Polio-Syndrome. He received a BA degree from Haverford College and his MD degree from the University of Rochester Medical School and an Masters in Public Health [MPH] from Harvard University School of Public Health.

Reprinted from The LincPIN, Volume 4, Issue 1. December 2002

ATLANTA POST-POLIO ASSOCIATION

ONE DAY CONFERENCE NOVEMBER 1ST 2002, SHEPHERD SPINAL CENTER, ATLANTA

Main Speaker, Dr. Lauro S. Halstead.

Report by Hilary Hallam, and Philippa Eckert.

Philippa Eckert is a USA member of the Lincolnshire Post-Polio Network and has just retired as President of the First Coast Post Polio Support Group, Jacksonville, Florida. Hilary Hallam [now Boone] the Founder and Chair of the Lincolnshire Post-Polio Network [now known as Polio Survivors Network]

Dr. Lauro S. Halstead is Director of the Spinal Cord Injury Program and Director of the Post Polio Program at the National Rehabilitation Hospital in Washington D.C. He helped to organise the 1984 and 1986 Research Symposia on the Late Effects of Poliomyelitis in Warm Springs Georgia. Dr. Halstead is internationally known for his work on the late effects of post polio, and a polio survivor himself.

Additional Speakers were Dr. Donald Peck Leslie, the attending physician at the Shepherd Spinal Center which specialises in neuromuscular disorders and Dr. Anne Carrington Gawne, Director Post Polio Clinic and Brain Injury Program, Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia.

Linda Priest, President of APPA opened the event and introduced Dr. Leslie who in turn introduced Dr. Halstead. The following is a report of his presentation

Living with PPS: A Personal Perspective. Dr. Halstead gave his presentation whilst seated in his scooter. He wanted to discuss his problems in the spirit of interaction with the audience and invited questions. He fully admitted that he did not have 'all the answers' but using his experience of polio and PPS he would give us an insight into how he manages his life as a physician and polio survivor.

Living with PPS is an ongoing battle. This is not a static disease. Often the adjustments made by the polio survivor in the past, which worked then, will not work now. Dr. Halstead admitted that he used all sorts of subterfuges to fool himself and others, while his limitations became progressively more apparent. Dr. Halstead was infected with the polio virus - incidentally six months after visiting Lincoln in the UK - in 1954, aged 18, a sophomore in college. All four limbs were affected and he spent two to three weeks in a respirator. He had no dysphagia. He was in hospital for five more months used a wheelchair for five more and an ankle foot orthosis for one year. Between 1957 and 1961 he had nine reconstructive surgeries. Recovery took three years. He taught himself to write with his left hand as his right hand and arm were paralyzed. An avid walker, he climbed to the top of Mount Fuji (12,000 feet) as a testimony to his full recovery. An achiever, he did not think of himself as disabled.

His condition was stable for twenty five years. In 1979 he began to experience extreme fatigue and new leg weakness. He considers this as the beginning of his PPS. In 1983, although he could still walk, he started using an electric scooter along the very long corridors of the hospital in order to save strength and energy. This scooter was left just inside his entry point to the hospital for him to use the next day. In 1990 he was fitted with a right ankle foot orthosis supporting his dropped foot and enabling him to carry on walking. When Hilary visited with Dr. Halstead in Washington just prior to the Toronto PPS Conference, four years ago, he was just about to get a scooter for home and social use.

Dr. Halstead illustrated his progressive decline in walking ability with a chart. This shows on the left side the number of Blocks he could walk, starts in 1975 and ends in 2002. The downward slope goes from a maximum of walking over ten city blocks down to almost zero.

[Dr. Halstead purchased a scooter for getting round the NRH Hospital in 1994. He waited till 1999 to get one to use at home and when elsewhere. So many Polio Survivors fight change "We are not there yet"

including health professionals with PPS]

Dr. Halstead then showed us slides of his home and work. Illustrating the changes that he has made, aids that he uses, so that he does not waste energy, so that he can do more of what he wants to do.

He lives in a house although from the front it looks like a bungalow. All the main living areas are on the one floor, and he has installed a stair-lift (stair glide) to the basement area. This stairlift fits directly onto the stairs, not the wall, and can be, and has been moved from house to house.

In the kitchen he uses tall stools or stands leaning one knee against the cupboards for extra support. In the lounge he has had his couch raised on four six inch risers so that it is easier to rise from. In his office at home he has a cushion on the seat, all the important documents that he needs are in a box under the desk so that he only has to lean down to get at them. All the things that he needs are within short arm reach.

His bathroom has rails fitted to hold onto. He advises that if possible delay deciding where the rails for the bath should be fitted until you are wet. He has a small stool in front of the vanity suite so that he can kneel on one knee, place his arm on a cushion and leaning his head down he moves the shortest possible distance. Clothes that are on rails means raising your arm up to get them down so he has a 'butler' (stand with hangers and places for other clothes). Some years ago he found shoes with Velcro straps and that was the end of struggling to tie laces.

He made us laugh with his photographs of eating. This started with two spoons, a 5ml and a 15ml. He then showed a dinner plate including carrots and using the 5ml spoon, three carrot slices. But with the 15ml spoon he could get 15 carrot slices on board. He places his left arm on a cushion on the table and by leaning his head down there is less distance to the spoon. Better biomechanics and saved energy.

He then showed slides of how he stands up from chairs by placing his legs at a distance apart and his knees closer together. There are many tricks that we evolve to do what we need to.

He then told us about a time in his clinic when a patient said that she used pillows to support her when resting or sleeping in bed. He asked her "how many" and was surprised at her reply of five, that is till he got home and counted his six! He uses pillows to support the parts of his body that need it and so rests more comfortably. He has a fused shoulder.

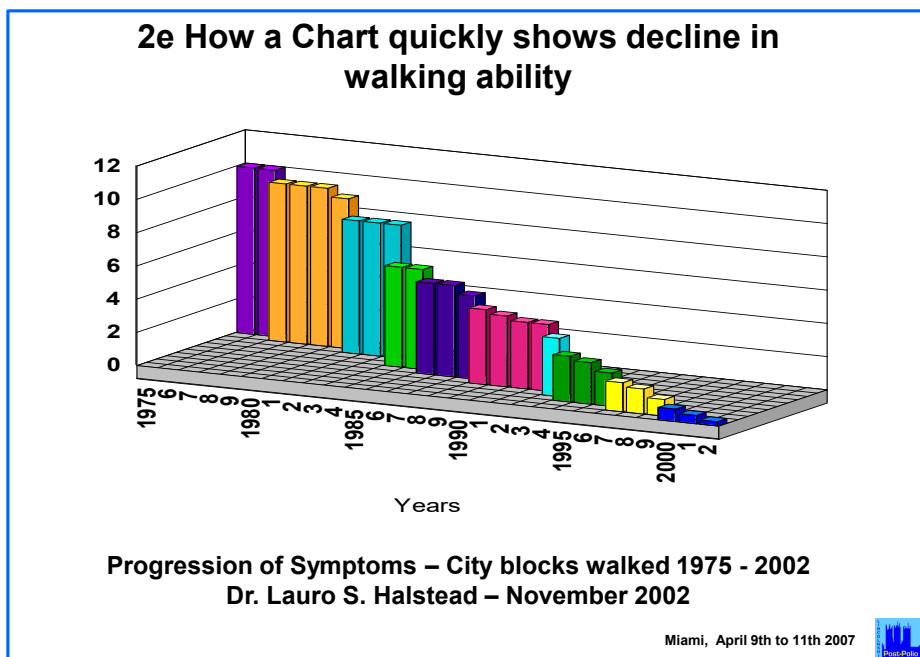
He has had to reduce his work to part time and uses a headset and voice activated software to dictate reports. All his needs at short arm lever distance. He takes an hours break during his working hours, using a recliner chair and listening to soothing tapes. The next slide showed a sign taped to his office door. Therapy Session. Do not Disturb.

He uses a small suitcase on wheels to 'carry' his laptop and office papers around. He has a Bruno Kerbsider hoist in the back of his SUV for his electric scooter.

When out and going into a shop without his scooter he uses a seat stick so that when he gets to the counter he can sit and deal with his money etc. comfortably.

He likes playing the piano and is trying to figure out a way of playing with only his left hand that would sound like he is using two hands.

Dr. Halstead does some stretching exercises every day, eats a good diet of white meat, fish, fruit nuts and vegetables. He does not smoke, but does drink socially. He takes a few basic pills necessary for his health



and one multi vitamin.

Dr. Halstead emphasized that we should avoid using pain pills unless at night to help with getting a good nights sleep. We can eliminate muscular pain by doing less. He said we should regard our energy, as Hugh Gallagher had said in his book...

“My muscle power and endurance are as coins in my purse: I have only so many and they will buy me only so much. I must live within my means, and to do this, I have to economize: what do I want to buy and how can I buy it for the least possible cost.”

Dr. Halstead defined muscle pain as pain that will subside with rest. Pain that does not respond to rest has some other origin. His open sharing of his feats and foibles resonated with us all.

This was then followed by a short question and answer session. Most of the questions in the time allowed were about exercise and pain. Dr. Halstead said that exercise for some is just getting up and dressed, but for most others, he recommends a limited program worked out with a doctor or physical therapist with pps knowledge and experience.

After lunch Dr. Halstead told us a little about current medical research, although sadly funds for research are hard to get. [omitted as 20 years old]

Of interest, the one day conference took 13 days out of the month for Hilary and Richard. Day 1 to buy food for the 13 days, Day 2 to prepare food and pack clothes, Day 3 to pack , computer, truck and rest, Days 4 & 5 to drive 500 miles to Atlanta, Day 6 Conference, Days 7 & 8 to drive back, Days 9 - 13 recovering, Day 14 go food shopping again. Many chores get left to do this, its either/or

Finally here is another

quote Dr. Halstead used from Hugh Gallagher:

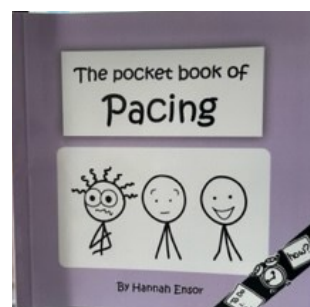
“Growing older with polio is a matter of economics... How much limited expenditure of energy for how much satisfaction. Minimise the exertion, maximise the pleasure.”



A helpful book for Polio Survivors

**The Pocket Book of Pacing
by Hannan Ensor**

96 pages - 110mm x 110mm - £5.50



Within “The Pocket Book of Pacing”, the stickmen, with their usual combination of humour, charm and honesty, fill this book with all the info and practical tips that the author, Hannah Ensor, wishes she’d been given when she was struggling to manage her conditions and the stuff she needs reminding of when things are tough.

What is pacing? How does it work? But how does that work in real life?

Pacing is a way of getting the most from the energy you have. The pocket book of pacing gives a down to earth take on how pacing can be used in practice and considers it from various angles—not just what you do and taking breaks, but also how you do things, adaptations which can help, and ways of communicating your needs to other people.

Page 58 - Treat “I’ll just finish this” with extreme caution

It feels silly to stop - you are “in the zone” “nearly done”. But in reality a short break when you need it can make all the difference. Then you can do a few shorter more effective sessions instead of one long session struggling through the fog, pain, other symptoms.

Hannah’s blog, which can be found at <https://stickmancommunications.blogspot.com> has a wealth of pacing related articles which may also be of use.

More Problems With My Callipers

Last year I have written an article about the problems I had with my callipers. It is unfortunate that I need to wear them on both legs as they have started to hyperextend. Luckily, they allow me to walk around the house without pain. There is a joint at the lower end which after a time starts to break. Last year I returned the right calliper for repair, paid for the postage because the hospital was unable to post it to Ambroise in Holland where it was made. When it was returned, I had to pay import duty in order for the courier to hand it over otherwise he refused to do so. I then spent a few months until I managed to reclaim some of the import duty, although UPS claimed that they were allowed to keep a part of it for their trouble. I also learned that if the package was marked with the words "For the disabled" no import duty was needed.

Since then, I had just the replacement part delivered so that I didn't have to send the whole calliper back and my clever husband could fix it having been given detailed instructions by Nils, the inventor of my UTX Swing calliper. Last December he even sent two, when the first shipment didn't arrive on time.

At the end of August, I noticed that the left calliper was beginning to break and asked Ambroise to send me the replacement part. This was the first time that the left calliper needed a new footplate since I had been wearing them. Unfortunately, the person who posted it forgot to write the magic words: FOR THE DISABLED on the outside of the box and it is now being held up at the hub of UPS at Castle Donnington since the beginning of September. There is a tracking number which eventually informed me that the package was out for delivery and will arrive by the end of the day. This was displayed every day for over a week but nothing arrived. I was getting desperate. In the meantime, my right calliper started to break and when I contacted Ambroise and asked them to send me a new part, I reminded them to write the magic words on the package. It arrived in two days soon after 8 o'clock in the morning. Amazing efficiency!

I have been exploring the UPS website for help and discovered that I can message someone instantly on Facebook. I know many people who are not in favour of this website, but it has some advantages. I was informed that to release the parcel they needed the invoice. Having given them my email address, telephone number and address I was contacted today by email, and I was able to send a copy of the invoice together with the government regulations regarding articles for the disabled. I am still waiting for my delivery which I am assured is in transit.

The lesson from this is that packages must be correctly labelled as required by the Brexit regulations otherwise there will be a hold up. I wonder how many manufacturers have similar problems, either exporting or importing from the continent of Europe. So far, I have not been able to discover any advantages of Brexit!

Zsuzsanna Snarey

COVID NOTES:

I know how much people are tired of even thinking of this virus but circumstances compel me to add a precept. Something significant has changed that can affect all of us if we want it to.

The new formulation of the current vaccine is the first shot available that has as its target the specific variant that is dominant now. That would be BA5. In addition, the jab is bivalent which means it has two components: the one above, BA5, and the original strain of covid that started this whole agony. Half is the Wuhan strain.

Why is this so? Because when you inoculate a person with two strains like this the effect is that the immune system reacts by producing a wide range of antibodies that may cover variants that are likely to come in the future.

Why didn't I mention BA4 which you see in the literature? This is because BA4 has exactly the same mutations on the receptor stalk as BA5 has, so it doesn't matter.

In any event, I urge all of you to make an appointment and get this. If you are dead set against it not only will you keep these variants circulating longer but you will be short-changing yourself out of the benefit mentioned above.

Professor Eddie Bollenbach. CT, USA Member

Polio Case Reported in the U.S. This Month Marny K. Eulberg, MD

By now, many in our polio survivor neighborhood have already heard the news that a case of acute polio has recently been confirmed in Rockland County, New York. More information will likely come forward, but what we currently know is that one of the United States' newest polio survivors is an adult male who was unvaccinated, developed the first symptoms about one month ago, and was infected with an oral polio vaccine-derived type 2 poliovirus.

Reportedly he had not traveled abroad, but the type of poliovirus that caused his paralysis is what is called "circulating vaccine-derived poliovirus - cVDPV" and that means it was imported into the U.S. from somewhere in the world where the oral polio vaccine is still used. It has become more common, although still rare, in parts of the world where the oral (Sabin) polio vaccine is used and where there are large numbers of unvaccinated or under - vaccinated individuals and especially where there is inadequate sanitation and access to clean water.

Globally, there were 1,113 children diagnosed with paralysis from polio caused by the cVDPV viruses in 2020, 689 in 2021, and year-to-date in 2022 two hundred thirty. These individuals, mostly children, are just as paralyzed as they would have been had they been infected with the "wild"/occurring-in-nature polioviruses. This NY case demonstrates that we, in the developed world, can still see cases of acute polio anywhere that there is inadequate herd immunity to polio. A recent report that sewage samples in London had shown presence of circulating vaccine -derived poliovirus type 2 (a similar type to that implicated in the NY case) stimulated concern that polio could show up in parts of the world that have not seen polio for decades. Organizations dedicated to polio eradication such as Rotary International and the Global Polio Eradication Initiative (GPEI) often quote the sayings, "Any form of poliovirus anywhere is a threat to children everywhere" and "Polio is just an airplane ride away."

Most polio survivors do not need to be convinced of the value of polio vaccines because they have seen the devastating effects these nasty viruses can have. A course of three doses of any form of polio vaccine has been demonstrated to be 99% effective in preventing polio.

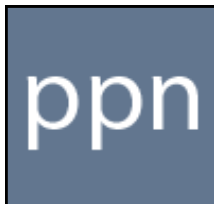
There are some advantages to using the oral polio vaccine. A novel oral polio vaccine type 2 (nOPV2) has been developed that is much less likely to mutate when out in the environment and then cause vaccine derived disease. The United States stopped using all oral polio vaccine in 2000 and switched back to the injectable (killed) (Salk) polio vaccine. There is NO risk of cVDPV when the polio shots are used instead of oral polio vaccine drops (or remember the "sugar cubes" with the polio vaccine drops were placed on a sugar cube?)

Some of you who have travelled to developing countries in the past few years may have been surprised to learn that an additional booster dose of polio vaccine was recommended before travel to certain ©Post-Polio Health International countries even though you had had the disease and had been fully immunized for polio. This is an extra precaution because of the theoretical risk of exposure to wild poliovirus or the circulating vaccine-derived poliovirus. For the past five years, wild poliovirus cases (all recently have been type 1) have been confined to Pakistan and Afghanistan. Circulating vaccine-derived polioviruses (mostly type 2) have been reported in nearly 30 countries including in many parts of Africa, Southeast Asia, Israel, Ukraine, and the Arabian Peninsula.

The bottom line is that this case presents no threat to those who have been immunized but is a reminder that polio is not yet "gone". It is unfortunate that this man now is suffering from a vaccine-preventable illness!

For up-to-date information about polio including the cVDPV go to <https://polioeradication.org>

© Marny Eulberg, MD is a member of PHI's board of directors, a family physician, and the chairperson for Rotary District 5450's Polio Committee



SERVICE NOTICE - 19th August 2022

I sincerely regret to report that I am suspending the Post-Polio News service, at least for the immediate future. This is due to my having to concentrate on my and my mothers health issues.
Chris Salter, Editor.

Polio Survivors Network and I am sure many other PPS Groups and Medical Organisations around the World will want to join with me to thank Chris Salter for his dedication in researching and passing on polio, post-polio syndrome and allied health items over the last 26 years. We send healthy vibes in your direction and hope to hear from you again in the not too distant future.

Epidemiological Alert Detection of vaccine-derived poliovirus type 2 (VDPV2) in the United States: Implications for the Region of the Americas (21 July 2022) | PAHO | ReliefWeb.

[Situation Report] [Source: [AHO](#)] [Posted: 22 Jul 2022] [Originally Published: 22 Jul 2022]

Given the identification of a case of acute flaccid paralysis related to type 2 vaccine-derived poliovirus in an unvaccinated individual from Rockland County, New York, United States of America, the Pan American Health Organization / World Health Organization (PAHO/WHO) reiterates to Member States to join efforts in order to maintain and strengthen surveillance for the detection of cases and achieve adequate vaccination coverage against poliomyelitis.

Situation summary.

No cases of wild poliovirus have been detected in the countries and territories of the Region of the Americas in over 30 years. In 1994, the Americas became the first region in the world to be certified polio-free by the World Health Organization (WHO). The early detection of cases through the implementation of surveillance of acute flaccid paralysis (AFP) in children under 15 years of age and maintaining adequate polio vaccination coverage have been key to this achievement.

On 21 July 2022, as a result of surveillance conducted in the United States of America, the New York State Department of Health reported the identification of a case of paralytic poliomyelitis in an unvaccinated individual in Rockland County. Initial sequencing confirmed by the United States Centers for Disease Control and Prevention (U.S. CDC) indicates that this is a case of vaccine-derived poliovirus type 2 (VDPV2).¹ The investigation is ongoing, further information will be shared as it becomes available.

On 10 June 2022, the Pan American Health Organization / World Health Organization (PAHO / WHO) published the Epidemiological Alert on the risk of poliovirus outbreak in the Region of the Americas, available at: <https://bit.ly/3cypDaf> warning of the risk of the emergence of vaccine-derived poliovirus and urging Member States to implement effective measures to reduce the risk of outbreaks by maintaining high and homogeneous vaccination coverage, as well as having sensitive epidemiological surveillance systems allowing for timely detection and investigation of acute flaccid paralysis cases.

In recent years, polio vaccination rates have dropped considerably, even prior to the COVID19 pandemic, polio vaccination had fallen below the recommended 95% or greater coverage goal to prevent the reintroduction of the virus in this Region. During the pandemic - which has affected health services throughout the region, including routine vaccination - polio vaccination rates have continued to decline. In 2020, only 80% of children had received the third dose of polio vaccine necessary for full immunization, a decrease of 87% compared to 2019. If this trend in vaccination coverage continues, there is a high risk of outbreaks occurring after the importation of a virus (wild or vaccine-derived) or the emergence of poliovirus derived from the vaccine, and that these are not detected in time.

[Download Original Report](#)

All children aged one to nine in London to be offered polio vaccine booster |

The Guardian. [Wed 10 Aug 2022 13.50 BST]

Nicola Davis, Science correspondent, writes:

All children aged one to nine in London should receive a polio vaccination in the coming weeks, public health experts have said as a new booster programme is announced.

The UK Health Security Agency said that, since early February, 116 polioviruses had been identified in 19 sewage samples from boroughs in north-east and central London including Barnet, Camden, Hackney, Haringey, Islington and Waltham Forest.

Experts say it is unclear how many people may have been infected but that, to date, no cases of polio – or related paralysis – have been reported.

With signs of community transmission of the virus, public health officials are hoping to curb its spread, and strengthen protection against paralysis, by ensuring all young children receive a polio vaccine in the next four to six weeks.

The newly announced booster programme for children aged one to nine, recommended by the Joint Committee on Vaccination and Immunisation (JCVI), is set to run alongside a previously announced polio vaccine catchup campaign, and will begin in boroughs of London where poliovirus has been detected and vaccination rates are low.

Parents and carers are advised that the programme will be offered via GPs, and that they will be contacted when it is their child's turn to receive a vaccination.

Dr Vanessa Saliba, consultant epidemiologist at UKHSA, said that for the majority of the population who are fully vaccinated against polio the risk was low.

“But we know the areas in London where the poliovirus is being transmitted have some of the lowest vaccination rates. This is why the virus is spreading in these communities and puts those residents not fully vaccinated at greater risk,” she said.

Saliba added that while polio was a serious infection that could cause paralysis, as a result of vaccinations the last case in the UK was in 1984.

“It is vital parents ensure their children are fully vaccinated for their age. Following JCVI advice, all children aged one to nine years in London need to have a dose of polio vaccine now – whether it's an extra booster dose or just to catch up with their routine vaccinations. It will ensure a high level of protection from paralysis. This may also help stop the virus spreading further,” she said.

While a small number of polioviruses are detected in sewage in the UK each year, the large number detected over recent months is unusual, and appears to reflect transmission of the virus in the community.

Public health experts said it appeared such transmission was asymptomatic, and was likely to have been caused by an individual recently vaccinated with live oral polio vaccine (OPV) entering the UK. OPV generates excellent gut immunity against polio; however, people who have been recently vaccinated can shed vaccine-like virus in their faeces.

While this weakened form of the virus does not cause illness, the concern is that if it circulates it can gain mutations that increase its virulence, resulting in vaccine-derived poliovirus – which has the potential, albeit rare, to cause paralysis in those who are unvaccinated.

The UKHSA said that while most of the isolates from London sewage had so far involved vaccine-like poliovirus, some contain vaccine-derived poliovirus.

The UK switched from using OPV to an inactivated poliovirus vaccine (IPV) in 2004. While IPV is very effective in preventing polio disease, it does not produce as good gut immunity as OPV, meaning it is possible fully vaccinated individuals could have an asymptomatic infection.

While public health officials believe that, combined with good hygiene, the IPV vaccine will be able to interrupt transmission, the Guardian understands that if this is not successful the use of OPV, which is not approved in the UK, may be considered.

In addition, sewage surveillance to track the spread of the virus is set to increase, with an additional 15 sites in London to begin sewage sampling this month and a similar number across England set to follow suit.

Dr Kathleen O'Reilly, an expert in polio at the London School of Hygiene & Tropical Medicine, said she welcomed the booster programme. "News of the booster vaccine against polio will add extra protection to children under 10 in London where we now have considerable evidence of poliovirus circulation," she said. "The fact that polio has been detected in sewage gives us a critical opportunity to prevent polio disease – the sewage testing and vaccination response is a really worthwhile public health action that I hope will be highly effective."

[Original Source Article](#)

SEPTEMBER 2nd 2022 - Expansion of polio sewage surveillance to areas outside London.

UKHSA, UK Health and Security Agency and MHRA, Medicines and Healthcare products Regulatory Agency are expanding polio sewage surveillance to a range of areas outside of the capital.

Following the findings of poliovirus in sewage samples collected from the London Beckton Sewage Treatment Works, which covers parts of North and East London, the UK Health Security Agency (UKHSA) working with the Medicines and Healthcare product Regulatory Agency (MHRA) are now expanding the surveillance to a range of areas outside of the capital.

This is on a precautionary basis to determine whether the virus is spreading to other areas. To date, sewage sampling has been conducted in London and Glasgow, and no polio virus has been detected in Glasgow.

The additional sites where the sampling will be rolled out are Sewage Treatment Works covering parts of Birmingham, Blackburn with Darwen, Bradford, Brighton and Hove, City of Bristol, Bury, Castle Point, Leeds, Leicester, Liverpool, Luton, Manchester, North Tyneside, Newcastle upon Tyne, Gateshead, Nottingham, Preston, Salford, Sheffield and Watford.

These areas have been chosen on the basis of an assessment of risk, which takes into consideration a number of factors. This includes demographics – population groups living in the area with links to countries overseas where wild poliovirus is still found or where live oral polio vaccine is still used; areas with low polio vaccination coverage; areas with pockets of under-vaccinated communities; and areas adjacent to the locations in London where poliovirus has been detected.

The sewage sampling strategy will continue to be reviewed and adapted as new evidence emerges. Nationally the overall risk of paralytic polio is considered low because most people are protected from this by vaccination. Dr Vanessa Saliba, Consultant Epidemiologist at UKHSA, said: No cases of polio have been reported and for the majority of the population, who are fully vaccinated, the risk is low.

We are now expanding the sewage sampling nationally to areas that are at highest risk of new poliovirus importations and areas most likely to see spread of poliovirus from London. We are in touch with public health colleagues in these areas and will work closely with local areas as the need arises.

In the meantime it is vital parents across the country check their children are fully vaccinated for their age.

Following advice from the Joint Committee on Vaccination and Immunisation (JCVI), all children aged 1 to 9 years in London need to have a dose of polio vaccine now – whether it's an extra booster dose or just to catch up. It will ensure a high level of protection from paralysis.

© **Pennsylvania Post Polio Network, USA**
An excellent USA Post Polio Syndrome Resource
www.papolionetwork.org/vaccine-information-card.html



**No Child Should Suffer From
A Vaccine Preventable Disease.**

**The Pain And Disability
Can Last A Lifetime.**

**Please Vaccinate
Your Children.**

Disease Outbreak News

World Health Organisation (WHO)

The U.S. has met the WHO's criteria to be added to the list of countries with circulating vaccine-derived poliovirus, the Centers for Disease Control and Prevention (CDC) said, which includes Yemen, Somalia, Burkina Faso, Uganda, Ethiopia, Ghana and Eritrea. It is the only country from the Americas in the list and, alongside the U.K. and Israel, one of the only wealthy nations to feature.

[Article: Detection of circulating vaccine derived polio virus 2 \(cVDPV2\) in environmental samples – the United Kingdom of Great Britain and Northern Ireland and the United States of America](#)

Your charity management committee needs help please.

We are not only managing our physical health but getting older with all the paperwork that entails. We know of at least one group where they have two people for each post. If you could spare us an hour or two a month to take on a task then get in touch. Our meetings are held on the internet but with the facility of adding someone via their phone. All members are welcome to send us any info on anything that might help us manage/enjoy our lives move fully. We have added some info from Naidex this issue (see [back page](#))

Useful Resources

- International Ventilator Users Network
www.ventnews.org
- Disabled Motoring UK
www.dmuksdiscounts.co.uk
- Pain UK
www.painuk.org
- National Voices
www.nationalvoices.org.uk
- Neurological Alliance
www.neural.org.uk
- Rare Disease UK
www.raredisease.org.uk
- End Polio Now – Rotary International
www.endpolio.org
- European Polio Union
www.europeanpolio.eu
- Post-Polio Health International
www.post-polio.org
- PA Polio Survivors Network
www.papolionetwork.org
- Polio Quebec
www.polioquebec.org/eng/
- Polio Survivors of Marin
www.facebook.com/groups/163909760771171
- Atlanta Post-Polio Association
www.atlantapostpolio.com
- Nebraska Polio Survivors Association
www.nepolioorg.ipage.com
- Polio Australia
www.poliohealth.org.au
- Word-Wide Fellowship of Polio Warriors
www.poliowarriors.org

Management Committee [Trustees]

Chair - Simon Parritt - simon.parritt@poliosurvivorsnetwork.org.uk
Secretary, Zsuzsanna Snarey - zsuzsanna.snarey@poliosurvivorsnetwork.org.uk
Treasurer, Newsletter Editor - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk
Trustee - Verité Reily-Collins - 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
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

Facebook facebook.com/PolioSurvivorsNetwork/

Twitter twitter.com/NetworkPolio

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

Email psnadmin@poliosurvivorsnetwork.org.uk

Phone 01522 888601 - will ring you back when we pick up our messages

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:

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

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

NB Respiratory and Sleep Problems Section very informative.

GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups

POLIO PATIENTS AND SURGERY - Information for health staff.

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

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

Printed copies on our headed paper with permission are available.

Editors Note: Articles from Polio Survivors and Health Professionals welcomed

Naidex

22ND / 23RD MARCH 2023
NATIONAL EXHIBITION CENTRE
BIRMINGHAM

The Helping Hand Company had a stand at Naidex this year and I purchased a Leg Up. I am able to exercise my dropped foot using this I loop it over my forefoot and lift and can push down and use the leg up to lift foot again.



'For many, especially those recovering post surgery, lifting your lower limbs or feet can be difficult and often painful. Use from a seated or lying position, a Leg Lifter is designed to help lift your leg when you need to re-position. Whether getting in and out of bed, the bath, the car, or simply putting your feet up. Leg Lifters take the strain making it easier to elevate your limbs, without having to ask for help. I can add to this. I put the Lifter over my foot in the home or the Hot Tub and can then physically push down and lift again with the Leg Up.'



THE LAST LEG, a weekly topical comedy chat show with **Adam Hills, Josh Widdecombe, and Alex Brooker on Channel 4**. The program started after the **2012 Paralympics**. Our Carer Lois obtained tickets for 13th Feb. 2022. You can see us on the left of the tier. As we left the Borehamwood Studios we bumped into **Mike the Cameraman** (see middle photo below and check out You Tube videos)

Lois also obtained tickets for their **10th Anniversary Show** on 2nd September 2022. Seated in the same place from left to right you can see Hilary, Richard, Claire and Lois. This their 25th series and **The Last Leg** have continued their **#LegUp project**. If you need or can offer a **LegUp** then please join their campaign on Twitter. Their intention, to fill a van used in an earlier programme with donated items on the last night of the series for a local charity. Adam Hills mentioned that they had already received some donations tonight. I had purchased a **couple of 'Leg Up's'** for the **LAST LEG #LegUp** as a donation from Polio Survivors Network and had handed them in as we were taken to our seats.

Due to the passing of HM The Queen they cancelled their program last Friday so we are unsure when they will screen it.



13th FEBRUARY 2022 show and 'With Mike the Cameraman'



2nd SEPTEMBER 2022

Polio Survivors Network would like to say a BIG THANKYOU
to Val Scrivener for her wonderful photo cards.
Members, thank you to you for purchasing them raising funds for our charity.