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Donations received since last newsletter:	
<i>November 2020</i>	
Smile.Amazon	£11.31
<i>December 2020</i>	
J Underhay via PayPal Giving Fund	£50.00 + £3.75 gift aid
Galvin Donation	£12.50
Unknown via PayPal Giving Fund	£2.50
<i>January 2021</i>	
P Dunham via PayPal Giving Fund	£15.00
Y Webb Cheque	£100.00
<i>February 2021</i>	
J Barter Donation	£12.50
Total received: £207.56	

Thank you so much!

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Editorial by Hilary Boone

I am starting to write this on February 1st. Where did January go? It is so strange here we are stuck at home week after week, month after month and I would have thought the time would go slowly... Remember when you had weekdays, weekends and Bank Holidays, now each day is just the same as the next. If only those that contact us that work for Social Services, Benefits, the NHS etc realise how we wish we could reply 'I am on annual leave till x'. Since March 12th 2020, when we started our first day of Stay Home, I have not had a full day off from being Richard's Carer when the Carers we can employ from our Direct Payment funds are not working. Not only have I not had a full day off but there is no pay, holiday pay or pension. I just read this out to Richard and his reply 'But you do have fringe benefits'.

That reminds me, the other evening we were in the bedroom watching TV and as I went to put my phone on charge I spoke. A voice said, "Sorry I did not get that" I replied "Don't be nosy it was not meant for you" The voice replied "I am sorry". Richard said 'Did your Apple Watch just apologise to you?' I replied, "Yes it did" and we both burst out laughing. I find it hard to keep pace with progress, How things have changed since the start of this millennium.

I started thinking what might be good information that we really need to take on board to get the best out of our lives. We are all the most stubborn determined folks who would not be beaten by any challenge we met. Being told by a health professional - hopefully one with knowledge of polio and post polio and how it affects our lives - that you should give up work, or think about using an electric scooter, being assessed again or for the first time for a short [AFO] or long leg foot orthosis [KAFO] is very hard to hear. That triggered a memory from early 1997 at my 3rd rehab clinic appointment since finding PPS existed. I was asked, "Have you thought more about getting an electric scooter". I shook my head "No". He then said "who wrote this article about pacing and resting in this newsletter and using equipment." I was so proud to say that I had written it but got a shock when he said "Can you tell me then why YOU are not taking the advice that YOU are suggesting others do?" I replied, "Oh I am not there yet" His reply "I have news for you, you are and I would think you have been for some time. Stop being stubborn." My scooter arrived by lorry on my 50th birthday and I had to try it up and down the street. I was so embarrassed, but...!

Now at 73 I am on my third electric scooter. Rather than restricting my life it opened it up and I started to do so much more. I have travelled hundreds of miles by plane UK to USA and back. By train Lincoln to London and across America from Florida to California. Round State Parks, huge shopping Malls, Museums, Castles, Garden Centres, PPS Conferences, from home around town and back again about ten miles, all day on grass at American Pioneer Re-enactments [see photo [back page](#)], etc and I do not have to carry my bags. I will be honest and say I do not like seeing pictures of myself on it. In fact, the first time I went to Lincoln I was in Marks and Spencer and passed a little old lady on a scooter just like mine. I thought maybe she would have a chat about what it is like and I turned to go after her. I got a heck of a shock seeing myself in a large mirror!

What is the best place, event you have managed to go to once you got wheels?

Ellen and Lonnie whom we met in Texas and visited us in Florida recently bought a lovely home in Arizona. Ellen was featured on the front cover of a *PPM Newsletter Vol, 4, Issue 8* and yesterday she posted some more sunrise and sunset photos. I soaked up how they made me feel and I asked her if we could we print a couple. See [front cover](#) and [back page](#)

We recently had a photo competition but not many entries so I have another idea - we will dedicate at least one page to photos that mean something to you that you would like to share with other members/readers. Add a few words to tell us why this means so much and help us add some more 'Ah's and warm feelings to our Newsletters. Maybe an eek with a one liner?

Annual General Meeting 2021. We are again unable to meet up this year. The committee have decided to try this online, although we do understand that some may not have the internet access needed. If you turn to [page 13](#) Toni explains how we plan to have a practice run through.

Covid-19 We have included some virus information that we hope you might find helpful. I could not close this newsletter without a small tribute to [Captain Sir Tom Moore](#) - an Inspiration!

Drop, Jab and Go or how I got vaccinated

As I write this I can report that I had the Covid-19 Oxford AstraZeneca vaccine just over two weeks ago. To be honest I couldn't really care which version I had but maybe had a slight preference of the Moderna mRNA given my bias towards the slightly more novel approach. However, it was a totally painless experience and I had absolutely no after effects that I can identify. Of course, as my PPS comes in various forms of day to day variable irritations, be that various pains and/or annoying fatigue, who knows if I would have noticed anyway.

The other slightly different issue for me is that I have no upper arm muscles, and let's be honest here this is no hyperbole, I mean NO upper arm muscles and very little arm muscle anywhere else if I am being honest. So, the preferred option for an injection site is the large muscle known as the gluteus maximum, in other words my buttock. So the procedure is not 'roll up your sleeve' but 'pull down your pants'. This isn't usually an issue when getting vaccines and injections at the GP or hospital where they are used to the issue and where to inject. Also, after around 65 years of innumerable situations where I have practiced the art of remaining perfectly comfortable being either semi-naked or even naked in a room of medics, nurses or even passing curious medical students and others, it is not something that bothers me particularly. If there ever is an issue it usually arises with other people's embarrassment or difficulty which is perhaps a function of their inexperience or personal issues and attitudes.

Of course what I didn't want was to arrive at some mass public vaccination room or clinic and find some health professional or worse, volunteer, confronted with me offering to drop my pants and either not understanding why or not being able to offer the vaccine there and then, after I have been 'gagging', so to speak, to get it as soon as I could. I did attempt to plan for this and so spoke to my GP who suggested the local clinic as they use individual rooms.

I arrived and of course the rooms were not individual and there was no note about me, but luckily for me the person administering the vaccine was a GP herself. So at least no explanation of muscle mass and polio arms was required beyond stating the facts. So, all went more or less fine as we waited for the other recipients to leave the room and close the door to exclude others whilst I was 'dealt with'. She was slightly concerned that there was a large window in the door and so suggested we move to the side where there were now 3 or 4 other health professionals, but let's face it I was hardly about to strip off and do a pole dance (even if I could) and so I reassured her that I was fine with the present company and suggested we just get on with it. So, having risen from my wheelchair like some later day Lazarus, I stepped forth, bent over a convenient chair and offered the desired area for her needle skills.

That was that and in just a few seconds, with my wife's assistance, I had dropped my pants, been jabbed, pull them back up, was back in my wheelchair and on my way. So, I have had the first dose and now wait the 2-3 weeks when I will feel just a little better protected from this pesky virus than before.

Simon Parritt

Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP

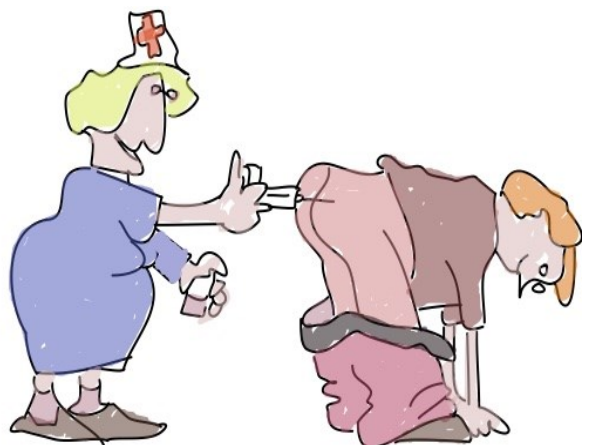
Chartered Psychologist

HCPC Registered Counselling Psychologist

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Chair - Polio Survivors Network

simon.parritt@poliosurvivorsnetwork.org.uk



Toni Writes ...

Firstly, a big thank you to members who got in touch to share their thoughts on our recent newsletter articles, I am sure that those who submitted the questions are very grateful for your input.

If you have any burning questions or any tips or experiences, you would like to share the contact details are below for you.



So as this pandemic rumbles on and seems to twist and turn I am sure you have had moments where you are just completely sick of hearing about it. I don't know about you but have had days/weeks where I have avoided the news just to create some positive head space (I have lost friends during this pandemic). I think this seems to have become quite common and has come to be termed pandemic fatigue or similar such phrases.

One definition of pandemic fatigue is that it is a 'natural response felt to the prolonged uncertainty and disruption caused by a pandemic'. Everyone is different but if you find you are experiencing symptoms of pandemic fatigue it is important to try and stay connected to people (video chats, phone calls, texts, letters, reaching out to friends) and to try to make the best of our circumstances (focus on what we can do not on what we cannot do).

A routine can help too as we can feel we are using our days/weeks to take care of the necessary things but also to set aside time to look after our own health and wellbeing. It can be hard to keep up with the handwashing, sanitising, face mask wearing, social distancing but this is what we need to keep doing for now, one day it will change. If we get fatigued by the pandemic we can be at risk of letting our guard down. Keep up the good work, it does save lives. Don't forget that I am always on the end of an email if you want to drop me a line.

As ever we are looking out for any articles you have found helpful or books that have inspired you for our online library. Please feel free to share them (contact details below).

Take care and keep safe

Toni x

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In [PPM 113](#) we had an interview including the query... "Have any members experienced tingling or pins and needles type of sensations?" Please let us know if you have experienced these and have suggestions in addition to Hilary's below.

Editors response: In PSN early years I asked a Neuro Physiotherapist at a meeting in Cambridgeshire this question. She told me that I needed to get my legs up every time I sat down as this will help stop the waste products in my blood pooling in my feet and causing this. I can confirm this really works. Days where we took a long car journey, flew UK/USA/UK and attended conferences back came these niggling painful sensations every evening/night. Days when we got our feet up this reduced by about 90%.

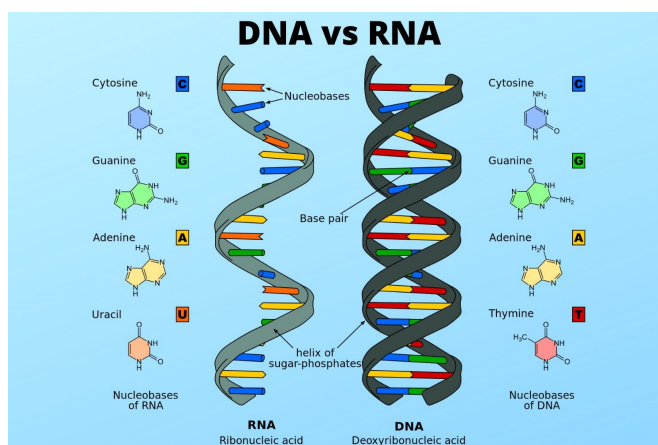
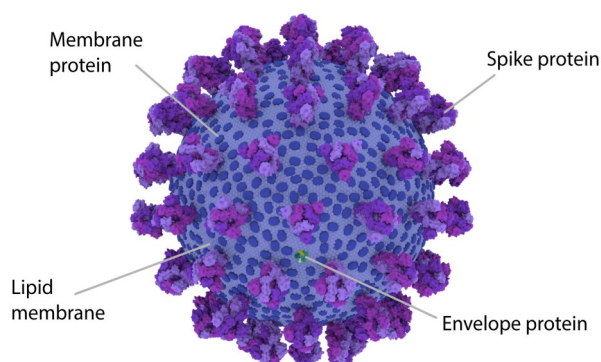
Reasons to get vaccinated against COVID-2 the disease caused by coronavirus

All living things are made of cells. Our bodies have millions of cells, each with a nucleus in the centre containing information about us in the form of very long strands of DNA, a molecule in the form of a **double** helix which is twisted to form chromosomes. They are the 23 pairs of these chromosomes or “coloured bodies” visible under a microscope when the cell is dividing to make an exact copy of itself.

Corona viruses are made of a very long, single strand of RNA, a strand of approximately 26,000 to 32,000 bases or RNA “letters” in length which are folded in a special way and surrounded by a fatty outer layer called an envelope. The virus usually appears spherical, as seen under an electron microscope, with a crown or “corona” of club-shaped spikes on their surface. Viruses can only reproduce copies of themselves by infecting a host cell. Once inside the cell they instruct it to become a “virus factory”. Mutations or changes to the RNA can only happen inside a cell. That is why it is so important to isolate, keep our distance, wear masks and wash hands.

Corona viruses are a group of viruses that usually cause mild illnesses, such as the common cold. However, certain types of corona virus can infect the lower airway, causing serious illnesses like pneumonia or bronchitis. Most people get infected with corona viruses at some point in their lives and the majority of these infections are harmless. The new corona virus, (Severe Acute Respiratory Symptom CoronaVirus) SARS-CoV-2 that causes the disease COVID-19 is a notable exception.

Read more: <https://www.newscientist.com/term/coronavirus/#ixzz6hALkUXuL#>



Each pathogen is made up of several subparts, usually unique to that specific pathogen and the disease it causes. The spike protein of corona virus is called an **antigen**. It is the part of the virus that allows it to infiltrate the cells in the lungs, throat and nasal cavity by interacting with a receptor on the cell wall called ACE2. The immune system makes **antibodies** in response to the pathogen's antigen. You can consider antibodies as the soldiers in your body's defense system. Each antibody, or soldier, in our system is trained to recognize one specific antigen. We have thousands of different antibodies in our bodies. When the human body is exposed to an antigen for the first time, it takes time for the immune system to respond and produce antibodies specific to that antigen. Vaccines train the immune system to recognise and fight bacteria and viruses so when they try to enter the body it is ready to defeat them. After recovery, memory cells remain in the blood so that next time the body meets the infection it can quickly make the antibodies to fight the infection.

Most of us don't have to worry about smallpox, polio or diphtheria. Smallpox is a thing of the past, while polio and diphtheria are very rare. The reason is found in the development of vaccines. Vaccines are a clever way to train the immune system to make us immune to a particular disease.

<https://www.who.int/news-room/feature-stories/detail/how-do-vaccines-work>

The first vaccine was developed by Edward Jenner in 1796. At that time it was noticed that dairymaids who had cowpox, a mild disease, were immune to smallpox. Jenner decided to test this idea by infecting an 8 year old boy with cowpox and a few months later he injected the boy with smallpox. Luckily the boy lived and did not catch smallpox. He was immune to it. Since then vaccines have saved the lives of millions of people by preventing or eliminating many diseases. Smallpox, which killed 300 million people in the 20th Century was finally eliminated in 1980. There were hopes of eliminating polio this way by the year 2000 but unfortunately due to misguided resistance to vaccination, it is still endemic in Pakistan and Nigeria.

The Pfizer/ BioNTech vaccine uses an artificially made copy of a small part of the messenger RNA or mRNA from the genome of the virus from the spike protein. Once inside a human cell it instructs the cell to make more special spike proteins normally found on the virus. These proteins then trigger an immune response, which in turn creates an immune memory so that next time the body encounters the corona virus with its characteristic spikes, it will be able to recognise it and destroy it. The vaccine contains merely a set of instructions to stimulate the immune system; it does not contain any part of the original virus. In extensive trials it was found to be 95% effective. Fortunately they also have the technology to alter the genetic sequence of the vaccine in 5-6 weeks to match that of the spike protein when it mutates or changes.

The University of Oxford team has used a harmless corona virus to deliver the viral genes into the cells of the body. The vaccine is based on a virus that causes colds in chimpanzees but it is made safe by modifying it so that it cannot replicate in humans. This vaccine also carries genetic instruction to make the spike protein. The immune system recognises these and raises an army of antibodies and T-cells to fight the virus. Clinical trials have shown that it is safe and induces a strong immune response and is 90% effective if given in two doses, the second dose given about 12 weeks after the first. The AstraZeneca vaccine developed in Oxford has the advantage that it is much cheaper than the Pfizer/BioNTech vaccine and it does not have to be stored at ultra low temperatures.

There are a hundred different vaccines in development against the corona virus that causes COVID-19. The Moderna vaccine developed in the US was approved recently for use in the UK for the 18+ population and has high efficacy. It is similar to the Pfizer vaccine in the way it primes the immune system to develop antibodies and memory cells. Some side effects were reported in the younger population but very few in the over 65s. The vaccine made by Janssen, the Johnson & Johnson group, is a one shot vaccine. It uses the same technique as AstraZeneca, but is given as a single injection, rather than two. It is being reviewed by drugs regulators for approval. This, combined with it needing only a fridge to store and a billion doses planned this year, means it could make a significant impact around the world. Another vaccine made by Novavax is waiting for approval. It is nearly 96 % effective against the older coronavirus and nearly 86 % effective against the new variant.

Some vaccines against other diseases use viruses which are inactivated by heat, some use viruses that are made weaker so they cannot replicate in the cells of the body. These vaccines generate a strong, long lasting immune response. This is the way the MMR vaccine is made for Measles, Mumps and Rubella. Some vaccines, like the one against flu use a small part of the virus. In order to eradicate a disease successfully a large proportion (60-70%) of the population all over the world need to be inoculated, thus producing "herd immunity", because vaccination only protects the vaccinated person from developing the disease but not from transmitting it. New versions of the corona virus are emerging in countries around the world as the virus spreads which urges us to vaccinate more people all over the globe. Fortunately the new vaccines can be rapidly tweaked to be effective against new variants.

But only if enough people immunised can the spread of the virus can be halted. Unfortunately some people are sceptical of vaccines in general. This could prevent the levels of vaccination reaching high enough levels to protect everyone.

This mistrust has been fuelled by scare stories like the one about the MMR vaccine causing autism. However all vaccines are thoroughly tested for safety before they are used widely and continue to be monitored. Large clinical trials have found no link between the MMR vaccine and

autism. Despite this many people continue to mistrust vaccines and the resulting low uptake of the MMR vaccine lead to the re-emergence of measles. In 2018 nearly a thousand cases of measles and similar number of mumps were reported in the UK. The cases of mumps increased to five thousand in the year 2019. Measles and mumps can have serious complications. Covid-19 has so far caused the death of over 100 000 people and many others who recovered had their lives changed by continuing health problems. Although we have no information yet about how long the immunity lasts after vaccination, this will become clear once the large proportion of the population is vaccinated. Another unknown is whether vaccinated people can infect others by carrying the virus from an unknown source. But please remember that neither vaccine contains any virus and cannot cause Covid-19 infection.

Immunisations prevent the death of 2-3 million people every year. When new viruses emerge vaccines are our best hope of defeating them. I have been vaccinated against Covid-19 with the AstraZeneca vaccine and my husband had the Pfizer/BioNTech vaccine. We didn't have any serious side effects apart from a slight tenderness at the vaccination site for 24 hours. We were both very happy to be immunised and I hope that I have persuaded you to do the same.

Zsuzsanna Snarey B.Sc.(Special) Chemistry

Reliable information about the vaccine can be found on the NHS website:
<https://www.nhs.uk/conditions/coronavirus-covid-19/coronavirus-vaccination/>

You could listen to BBC Sounds programme by **Tim Harford** called "How to Vaccinate the World"
<https://www.bbc.co.uk/sounds/series/m000py6s>

There is useful information from the FDA (Food and Drug Administration, USA)
on the **Pfizer BioNTech** vaccine:
<https://bit.ly/3dc1cOf>

and on the **Moderna** vaccine:
<https://bit.ly/3p7IMAf>



The British Polio Fellowship provides Covid-19 vaccination information on their website:
<https://www.britishpolio.org.uk/covid-19-vaccination-information>

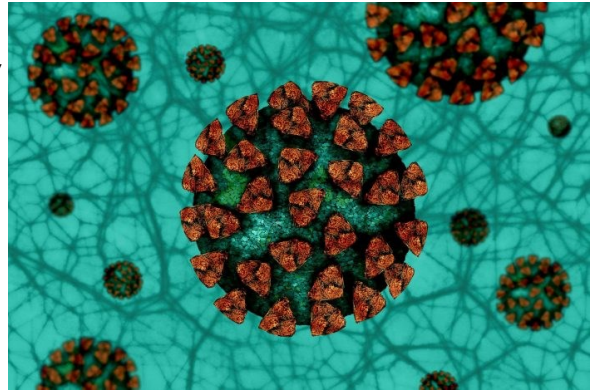
Contact the BPF on 0800 043 1935 or Email info@britishpolio.org.uk

Any day now it will be March,
Daffodils, Sunshine,
Warmer and Longer Days
and New Beginnings.
Keep going everyone, we can do this.

Variant of Covid Virus

Kindly shared with us by PSN member, Eddie Bollenbach
M.A. biology

You have probably heard of the new variant of COVID virus in the United Kingdom and also another mutant strain in South Africa with similar mutations to the UK variant. Let's constrain to the UK mutant. The reproductive number or R_0 of the wild strain is 1.1 which means 10 infected people will typically infect 11 others. It is believed that the reproductive number R_0 of the mutant strain is 1.5, which by division you can find that the new virus seems 70% more infectious. 10 people will most commonly infect 15 people.



The difference in infectivity is not enough to mean we cannot control the virus by mask-wearing, social distancing, and hand washing. It can be handled. Now, since the genetic code of the new variant differs in 6 places in the spike protein, but USA Today says 8 places, the result is that two amino acids in the spike protein are different from the wild type. A protein is a long chain of amino acids linearly bonded to one another. Then this long line of amino acids folds a couple of times to give us the shape of the protein. A change of 2 amino acids in the spike protein will result in a slightly different shape for the spike protein. In this new variant, there are a whopping 17 new mutations altogether.

Since the shape of the spike protein matters because it is the target of antibodies induced by vaccination the concern arises regarding the antibody shape combining with the new spike protein shape.

The good news is vaccinologists believe the vaccines will still be effective and work.

Continuing research is going on now in Britain to measure this. This variant will soon be all over the world if its R_0 is higher than that of the wild strain. The US hasn't closed its border to people from the UK because the strain is probably here already and it will be treated the same way as our original wild-type strain.



Two items from the Neurological Alliance latest newsletter:

1. Are YOU one of 12 million people in the UK with a neurological condition... Or caring for a person with one?

If you have had a brain or spine injury, live with a neurological condition, or are close to someone who does, [NeuroLifeNow](#) want to hear from you.

The Brain and Spine Foundation and the Neurological Alliance have come together to build **NeuroLifeNow** – an app and website that supports you to share your experiences in order to influence change. We're committed to improving treatment, care and support for every person with a neurological condition. We are tired of people with neurological conditions not getting the support they need. We believe that by coming together we can help to change that faster.

2. Association of British Neurologists (ABN) vaccines guidance

The ABN has published *Guidance on Vaccination for COVID-19 and Neurological Conditions* <https://bit.ly/3rj1jex>

This states that all COVID-19 vaccines are safe for neurology patients, and recommends patients take up whichever vaccination they are offered without delay, unless they have a specific contraindication (e.g. severe allergy, pregnancy). People with more unusual medical problems who are concerned should ask their GP, who may refer them on to their neurologist.

Vaccines Excerpts [1] Covid 2021 and [2,3] Polio from the 1950's

[1] PSN Life Member Marcia Dreisbach Falconer, PhD Cell and Molecular Biology wrote:

Here's a good article in the NY Times, by a doctor - here's a little excerpt. We should all be RUSHING to get the vaccine! I am!

Right now, public discussion of the vaccines is full of warnings about their limitations: *They're not 100 percent effective. Even vaccinated people may be able to spread the virus. And people shouldn't change their behaviour once they get their shots.*

These warnings have a basis in truth, just as it's true that masks are imperfect. But the sum total of the warnings is misleading, as I heard from multiple doctors and epidemiologists last week.

"It's driving me a little bit crazy," Dr. Ashish Jha, dean of the Brown School of Public Health, told me.

"We're underselling the vaccine," Dr. Aaron Richterman, an infectious-disease specialist at the University of Pennsylvania, said.

"It's going to save your life — that's where the emphasis has to be right now," Dr. Peter Hotez of the Baylor College of Medicine said.

The Moderna and Pfizer vaccines are "essentially 100 percent effective against serious disease," Dr. Paul Offit, the director of the Vaccine Education Center at Children's Hospital of Philadelphia, said. "It's ridiculously encouraging."

New York Times 18/01/2021 **Underselling the Vaccine** by David Leonhardt
<https://nyti.ms/3p8kshQ>

[2] **Polio is a crippling and potentially fatal infectious disease.** There is no cure, but there are safe and effective vaccines. The strategy to eradicate polio is therefore based on preventing infection by immunizing every child until transmission stops and the world is polio-free.

The Global Polio Eradication Initiative
<https://polioeradication.org/polio-today/polio-prevention/>

[3] **On April 26, 1954**, the Salk polio vaccine field trials, involving 1.8 million children, begin at the Franklin Sherman Elementary School in McLean, Virginia. Children in the United States, Canada and Finland participated in the trials, which used for the first time the now-standard-double-blind method, whereby neither the patient nor attending doctor know if the inoculation was the vaccine or a placebo.

One year later, on **April 12, 1955**, researchers announced the vaccine was safe and effective and it quickly became a standard part of childhood vaccinations in America. In the ensuing decades, polio vaccines would all but wipe out the highly contagious disease in the Western Hemisphere.

The man behind the original vaccine was New York-born physician and epidemiologist **Jonas Salk [1914-1995]**. Salk's work on an anti influenza vaccine in the 1940's, whilst at the University of Michigan School of Public Health, led him, in 1952 at the University of Pittsburgh, to develop the inactivated polio vaccine [IPV], based on a killed-virus strain of the disease. The 1954 field trials that followed, the largest in U.S. history at the time, were led by Salk's former University of Michigan colleague, Dr. Thomas Francis Jr.

In the late 1950's Polish born physician and virologist **Albert Sabin [1906 - 1993]** tested an oral polio vaccine [OPV] he had created from a weakened live virus. The vaccine, easier to administer and cheaper to produce than Salk's, became available for use in America in the early 1960's and eventually replaced Salk's as the vaccine of choice in most countries.

Polio vaccine trials begin, History.com Editors
<https://bit.ly/3tNFExg>

From our readers ... (we love to hear from you)

You will have noticed a few requests for help or advice from our readers in the last Polio Matters Newsletter. Below are some of the responses we received.



Can You Help?

A new member has reached out to ask how you cope with the cold temperatures please. A suggestion has been made to the polio survivor that they take pain medication to help with the cold but they are not keen to do this. Any tips you can share about keeping warm?

Thank you in advance.

Please email info@poliosurvivorsnetwork.org.uk or post to PO Box 954, Lincoln, LN3 4RA

A query about keeping warm in the cold - our editor and readers replied:

“Wear layers of clothing so its easy to change to my temperature needs. Plus by a woollen hat [I think I look awful in hats but now I don't care what I look like so long as I am warm].”

“I used to work outside in East Yorkshire winters & cold was no real problem. I am 75 & for the last 25 years cold has become a real problem! I wrap up warm!!! Since I stopped cycling I've started to use a recumbent, it's comfortable, 2 years ago it became impossible for me to ride it, breathing problems. So I electrified it & ridden 7000 miles since. As you are not working hard it's easy to get very cold! So I layer up!!!! Merino wool long johns, socks, long sleeve tee shirt, next a gillet of down, then a fleece shirt & finally a windproof breathable jacket. Also a fleece balaclava + waterproof breathable woollen hat, Sealskin gloves, merino wooden running socks & winter cycling boots. Always a hot drink in my flask! Waterproof trousers & hoodie in saddle bag. I know I look a sketch but I don't get too cold out on a 2 hour ride. Hope this helps. Wrap up & stay warm & exercise within your ability.”

A member is very interested to find out how polio has affected the spines of survivors as the years have gone by.

Please send your experiences to info@poliosurvivorsnetwork.org.uk or post to PO Box 954, Lincoln, LN5 5ER

A query about how spines have been affected - our readers replied:

“I am writing to you about my experiences with Ankylosing spondylitis, I have & have had for many years problems with my spine, top to bottom. As a consequence I've tried physiotherapy, too targeted & painful, Pilates to vigorous, but my teacher offered the class the option of continuing

with Pilates or trying "Melt Method" the class was split 50/50, I went to "Melt Method" doing most of the exercises. Since lockdown classes have been suspended but I do selected routines at home using "Melt equipment" I purchased. These routines I do daily for my spine, hands & feet & I find that they loosen me up in morning & release kinks in the evening. Even some headaches. These I do along with other exercises throughout the day. Along with my medication & the watchful eye of specialists I am able to mostly manage my P.P.S. quite well.

Me & Vit D3. I have over the years found that not all the medical profession recommend supplementation with Vit D3 & have been told not to take it by some. Never the less I do take a daily supplement which is supported by other medical professionals!

My experience; Proven by me on at least 3 separate occasions, I find that when my Vit D level drops below the halfway mark on the "scale/range" (150) that I start to gain weight & no matter what I do my weight continues to rise & at the same time my blood pressure rises in just the same a manner. When I become much lower in Vit D I experience pain all over & it's not like the pain from my joints! It also overwhelms all my pain relief! If I then take Vit D, my pain disappears overnight!

Once I was looking at my weight graph on my smart watch once & noticed that my weight started to gain on stopping Vit D & then started to drop off when I resumed Vit D. On noticing this I referred to my log of Blood Pressure, it followed the same graph line! My conclusion is that Vit D supplementation is beneficial to me! From June till September I take 25ugs/day. October to December I take 50 ugs/day. January to March it's 75 ugs/day. March to June 50 ugs/day. This dosage seems to work for me. Hope my experiences are of help. Thanks for an informative magazine!”

I wonder if any other members have experienced constant tingling sensations, like pins and needles.

A query about tingling sensations/pins and needles - our editor replied (we would love to hear our readers views on this too):

“A neurological physiotherapist in the late 1990s told me that if we had restless, jiffly, aching legs then we should get our feet up every time we can.”

“...The newsletter is not only informative but conveys a sense of community with those who experience PPS, something that it is difficult for people in my daily life to understand...”

Polio Survivor Ellen Riddle, now living in Arizona, writes again in our Newsletter

Twenty five years ago I was using a cane. I had decided to use my artistic talent to make it fun. I decided if people were going to stare (I felt everyone was staring) I wanted it to be because they were checking out my spiffy cane rather than staring at me using it.

This began my Cane and Staff art period. I purchased 100 unfinished canes from a source out on the east coast and began making them. Some I sold, some I gave away, a few I kept. When I stopped doing canes and walking staffs I had only a dozen or so of undone canes left. I loved working on wood. Around ten years ago I simply stopped doing my wood burning works of art. Just stopped.

I continued to draw, to paint and to write. Which evolved into my window painting stained glass period. I am toying with picking this up again. I stopped because of the RV Lifestyle carrying so much glass around... Only did this art when a friend wanted one done on an existing window.

During our RV travels I got into teacher drawing and painting more than doing my own work. Space was limited in the RV. I sketched and took photos. During the initial months of Covid 19 I took to sketching on the streets doing chalk art. The closest I've come to participating in the art world of graffiti (I think I would have loved it as I have loved it as I have always yearned to do murals, both of which are beyond my physical abilities due to polio/PPS).

More recently I have discovered rock art.. A small version of graffiti which I am enjoying exploring. Paint the rocks and just leave them somewhere for someone else to find and enjoy. But it is photography that is calling to me now.

Over the last seven years or so, thanks to the cameras on iPhones, I have resurrected my love of photography. I studied it as part of my degree in fine art some 50+ years ago. For years I always had a good camera at my side. Even had my own dark room at one point as I struggled to find my spot in the art world. I did end up as a commercial artist working in an art studio for ten of my working years. When PPS hit at age 46, carrying a camera round my neck became impossible due to the pain it caused.

As an upside down polio with pretty good legs and a very weak upper body most of my pains and limits revolve around my neck, shoulders and arms. Over the past ten years or so of owning one iPhone after another I have perfected my skills in using its camera. And I have a few 'dark room' apps that I play with. Helping nature speak for itself.

I am taken by sunrises and sunsets. I don't think I will ever tire of taking shots of them. The awe they speak to me is what I continue to work capturing.

When I agreed to write this piece I was questioning how I would tie in my art work over the years with my ongoing struggle to cope with PPS. How would I tie it in with our ways of surviving and conquering our PPS challenges?

There is an obvious connection I just didn't see it until I started to write. You see, as I wrote and got into editing and re-editing this piece; I uncovered a truth I have been dodging.

I walked away from doing canes/staffs because it became more difficult to do. The same happened with my stained glass painted windows, and other paintings. My weaker fine motor skills jump out at me as I push to do these type of works. Rock painting is more do-able as I don't look at it as fine art. I don't hold it to the standards I set with what I silently view as my 'real art'.

My salvation as an artist, with PPS, if you will, lies in my photography. And as I finish this short piece I realise I need to embrace it more. Stretching the limits of using my camera on my phone to produce quality photos. Just because I can without so much complaining by my PPS body.

I also realise that I still need to draw and paint. I need to learn how to let these reflect the limits of my polio/PPS body are setting for me and just do it. However, for now my joy is in my sunrise and sunset photos. I hope you enjoy seeing the beauty that I see in Arizona.

Ellen Riddle

Email: ariddle4you@gmail.com

We would love to meet you

When discussing possibilities for our Annual General Meeting for 2021 we thought it would be a good idea to see if our members are able to join us online.

We appreciate some of you may not be comfortable doing this or even have access to online meetings. In order to see how an online meeting would work for our members who wish to try it out (and also for us hosting it) we wondered if you would like to join us for a Polio Survivors Network virtual coffee and catch up on:

Friday March 12th 2:00 p.m GMT

Those who have provided your email addresses should see an invite with the relevant link to the meeting dropping into your inbox in the coming days.

If you have changed your email or would like to provide PSN with your email address please email info@poliosurvivorsnetwork.org.uk and we will be sure to include you.

We plan to use Microsoft Teams so if you would like a brief guide on how to use it on your device please email as above.

It is not a formal meeting and there is no need to book. We do hope that you will enjoy meeting other Polio Survivors. Even if you can only pop in for a few minutes it would be great to see you. We will keep the meeting open for at least an hour (and can run it as long as we like if we're having too much fun)!

There are certainly positives to having a meeting online as this means any of our members from all around the world would be able to attend, how lovely this would be for our AGM (if we can get the time zones to line up).



Recent PSN meeting using Microsoft Teams



23rd February – Rotary Purple For Polio Tea Party

Rotary Club UK will be hosting a Zoom on 23 February at 16:00 to celebrate, inform and inspire about their work. Their ambassador Anne Wafula-Strike will be co hosting the talk with Konnie Huq alongside many other fabulous guests including the Fellowships very own Colin Powell and Sarah Passingham.

'Working across the world, with global partners, Rotary has led the fight to rid the world of polio. Join us on our polio journey, sit back in the comfort of your home and enjoy a free online celebration of the truly amazing and lifesaving achievements so far with short stories from young and not so young, snapshots of polio activities, tributes, music and lots more.'

Tickets for this free event are available here:

<https://www.eventbrite.co.uk/e/rotary-polio-tickets-136195764197>

The LincPin Volume 4, Issue 8, February 2004

How Do You Decorate Your Canes by Ellen Riddle

<https://poliosurvivorsnetwork.org.uk/enter/wp-content/uploads/2018/10/lincpin4-8.pdf>

Australian Polio Survivors' Response to Pandemic Changes

by Michael Jackson M.P.T., B.Ed.
Polio Australia Clinical Health Educator



In late 2020, 183 Australian polio survivors responded to a survey through Polio Australia. On this survey we included a variety of questions related to the health of polio survivors and their use of health professionals. We asked the following pandemic related question to capture how Australian resident survivors were coping with the pandemic: *"COVID-19 has caused many changes in how Australian society has functioned in 2020. What have been the most notable aspects of these changes - for you as a polio survivor - living through this pandemic?"*

The question was open-ended and so there were no cues for the content of the responses, and no cues to respond positively or negatively. Responses were coded by the most emphasised aspect submitted by an individual. The question was not mandatory on the survey: 56% of the respondents chose to not answer this question, 36% reported negative experiences, and 9% reported positive experiences.

The most common positive notable aspects reported by polio survivors experiencing the pandemic were:

- Less deadlines and commitments, and so less stress
- Less pressure to travel or to participate in events
- Availability of online ordering and home deliveries
- More time for home and hobbies
- Better coping and well being

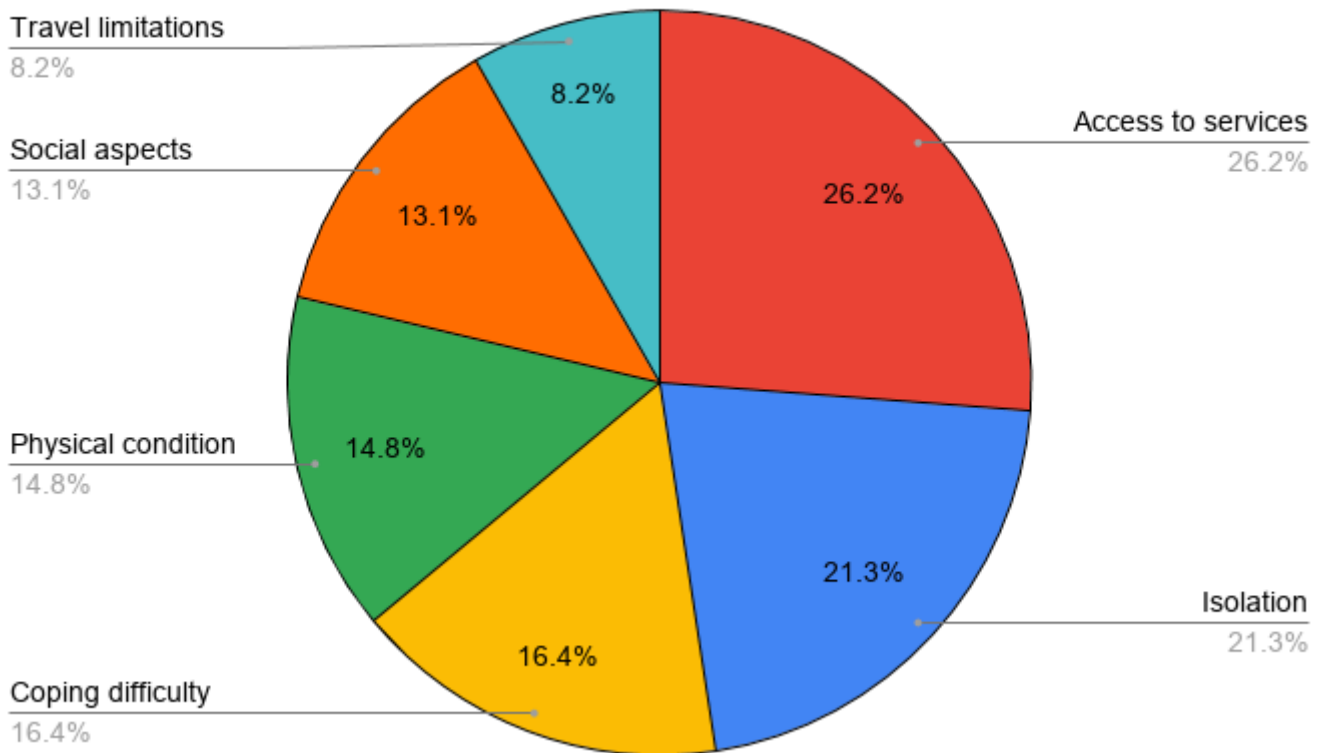
Polio survivors experiencing the Late Effects of Polio often experience varying degrees of fatigue, and yet the term *fatigue* was included in only one response. We are unable to say that these positive responses were related to respondents' fatigue experiences, but the character of these responses in context of the group being asked hint at such. There appear to be mental health benefits experienced by some polio survivors during this pandemic – perhaps by those who are less energised by or reliant on social engagement.

The most common negative notable aspects reported by polio survivors experiencing the pandemic are shown in the pie chart. Reduced or difficulty with access to services was the most reported negative aspect, and this is easy to appreciate in context of how healthcare changed during the pandemic. Isolation, coping, or a change in social aspects was difficult for half of those reporting negative experiences; this may reflect those survivors who lean on social engagement for support, care, and mental health. Negative effects on physical condition was reported by 15%, this being annotated with concerns about losing strength, endurance and general fitness that was being maintained through regular exercise. A direct example of pandemic exercise disruption was the closure of public pools, eliminating a known well-tolerated mode of exercise that could not be replicated in other environments.

It is worth comparing the positive and negative aspects reported. Themes around social preferences and needs presented strongly in both types of response. Removal from participation in social events, ability to cope, and ability to travel were reported both positively and negatively. In contrasting the reshore activity, while negatives included accessing needed services and maintaining physical condition.

As is often the case with survey questions, and what we see here, is that asking a particular question can lead to other questions needing to be asked in order to gain a fuller understanding of a topic. It is unknown how these responses might compare to what may be observed in the general Australian population, in those with disabilities, or in the polio survivor population at large. The national pandemic strategies utilised in different countries, and the nuances of

Negative Aspects of Pandemic on Australian Polio Survivors (n=64)



survivorship in each country, may additionally have an influence on the responses provided compared to this cohort.

Michael Jackson M.P.T., B.Ed.

Polio Australia Clinical Health Educator

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“I AM WEARING A PAIR OF SHOES”

I am wearing a pair of shoes. They aren't pretty shoes.. Uncomfortable shoes. Each day I wear them. Each day I wish they'd feel more comfortable. Some days my shoes hurt so badly that I do not think I can take another step. Yes, I continue to wear them and continue my journey.. I get funny looks wearing these shoes. I can tell in others eyes that they are glad these are my shoes and not theirs. They never talk about my shoes.. To learn how painful my shoes are might make them uncomfortable. To truly understand these shoes one must walk in them. But, once you put them on, you can never take them off...

I now realise that I am not the only one who wears these shoes. There are SOOOO many pairs in this world. Some women/men ache daily as they try and walk in them. Some have learned how to walk in them so they don't hurt quite as much. Some have worn the shoes so long that days will go by before they think about how much they hurt. No one deserves to wear these shoes. Yet, because of these shoes we are who we are! These shoes have given me the strength to face anything. I am a disabled person who has a lifelong disability. I will forever walk in these shoes.

Author Unknown

Posted by Polio Survivor **Constance Hanby Habakangas**

😊 Items to hopefully make you smile 😊

1. A chicken crossing the road is poultry in motion.
2. I thought I saw an eye doctor on an Alaskan island, but it turned out to be an optical Aleutian.
3. She was only a whiskey maker, but he loved her still.
4. A rubber band pistol was confiscated from algebra class, it was a weapon of maths disruption.
5. The butcher backed into the meat grinder and got a little behind in his work.
6. No matter how much you push the envelope, it'll still be stationery.
7. A dog gave birth to puppies near the road, she was cited for littering.
8. Two silk worms had a race; they ended up in a tie.
9. When cannibals ate a missionary, they got a taste of religion.
10. Don't join dangerous cults: practice safe sects.

Things native English speakers know but don't know they know:

Adjectives in English absolutely have to be in this order: opinion-size-age-shape-colour-origin-material-purpose-noun. So you can have a 'lovely little old rectangular green French silver whittling knife' but if you mess with that word order in the slightest you will sound like a maniac! It's an odd thing that every English speaker uses that list but almost none of us could write it out. So as size comes before colour, green great dragons can't exist!

Barely

Barely the day starts and it is already six in the evening

Barely arrived at Monday and it is already Friday

... And the month is already over

... And the year is almost over

... And already 40, 50 or 60 years of our lives have passed

... And we realise that we lost our parents, friends

And we realise it is too late to go back...

So...

Let's try, despite everything, to enjoy the remaining time...

Let's keep looking for activities that we like...

Let's put some colour into our grey...

Let's smile at the little things in life that put balm in our hearts...

And despite everything, we must continue to enjoy with serenity the time we have left.

Let's try to eliminate afters...

I'm doing it after... I'll say after... I'll think about it after...

We leave everything for later like 'after' is ours.

Because what we don't understand is that...

Afterwards, the coffee gets cold... Afterwards, priorities change...

Afterwards, the charm is broken... Afterwards health passes...

Afterwards, the kids grow up... Afterwards the parents get old...

Afterwards, promises are forgotten... Afterwards, the day becomes night...

Afterwards life ends... And then it's often too late...

So... Let's leave nothing for later...

Because still waiting to see later, we can lose the best moments, the best experiences, the best friends, the best family...

The day is today, the moment is now!

We are no longer at the age where we can afford to postpone what needs to be done right away.

So let's see if you have time to read this and share it... or maybe you'll leave it for "later".

Don't ignore pain!! by Verite Reily Collins

veritegreenbee@gmail.com Website: www.aftercancers.com

Do you ever get the impression the doctor isn't listening? Particularly when you say you are in pain. Well, you are not alone. Every year a major cancer conference is held in San Antonio, Texas. This year a major session highlighted that pain was often under-reported.

A recent [study by Dr. Reshma Jagsi from the University of Michigan](#), compared what patients said about the side effects they were experiencing from treatment, with what their doctors reported.

What the study found

Patients and physicians were asked to complete a questionnaire after each treatment detailing symptoms they were experiencing. The study found:

- About 30% of the patients reported **moderate to severe pain**, yet physicians reported that the patients had experienced pain at **only 1 on the scale or no pain at all**.
- For patients who said they were experiencing **itching of the breast often or all the time**: the doctors, on about 36% of their responses, said their patients **were experiencing no itching at all**.
- For patients who reported they were experiencing **swelling of the breast often or all the time**: the physicians, on 51% of their responses, said **their patients were experiencing no swelling at all**.
- Although patients reported they were experiencing **significant fatigue most of the time or always**, **about 19% of physicians said their patients were experiencing no fatigue at all**.

Patients frequently reported very significant symptoms while their doctors said these same symptoms were non-existent or very minor. symptoms. So we are not alone; pain is under-reported in other areas. During Q & A it was asked whether patients may be more comfortable reporting side effects on questionnaires, rather than "disappointing" their doctors with "complaints". Dr. Jagsi replied that she absolutely thinks that's the case, saying "we need to encourage patients that, when we tell them certain side effects are expected, it doesn't mean they shouldn't tell us if they're bothered by those side effects." She stressed that doctors need to emphasize to patients that they want to know about any side effects that they're experiencing and that there are things they can do to help support them through the experience. **Dr. Virginia Kaklamani**, MD, Co-Director of the conference, said "we need to listen more to our patients." Or perhaps learn to understand what patients are trying to say?

Implications of the findings - you are not alone

Under-recognition of treatment side effects impacts patients in at least two major ways. The first, of course, is ensuring they receive quality care including appropriate management of symptoms and side effects while undergoing treatment. Directly related to that, getting a clear picture of individuals' experiences with side effects, which can differ across populations, is an important part of addressing health care disparities.

Resources

There is no doubt that the best resource is a patient actually speaking up and making sure their doctor and medical team understand what they are saying.

What to do

Pain relief has improved dramatically in recent years. If you are experiencing pain, go back to your GP and ask for a referral - it could help to do some research on the Internet, find out what consultants specialise in, and **ask to see a named consultant**.

Pain relief is getting more attention and the Covid-19 crisis can work in our favour, as focus is being given to long-covid and the problems it is causing, including pain.



"It's our new method for determining who we should treat first. We take people in order of how loud they scream."



Editor: I am going to approach what I add here differently this month. Why? Reduced availability of carers has meant less time for me to do other stuff including opening up each item of Post Polio News to read it. I scrolled down and something caught my eye on Weekly Picks and I realised that readers may not be aware of the variety of information Chris Salter adds to PPN.

Today's Email Weekly Picks included this:

⇒ **Vincent – Lady Gaga's MIXED METER Star Spangled Banner?!**

<https://bit.ly/3a7wl37>

Lady Gaga? I thought 'I have got to see what this is' and I found it really interesting!

Here are the other items included in my email under Weekly Picks. I have included a bit more information under each item.

⇒ **Dickson – Pandemic Pivot**

<https://bit.ly/3cZUryL>

Science - Pandemic Pivot: How scientists answered the call for diagnostic tests. I am going to go back and read this once I have finished this page.

⇒ **Tuba Skinny**

<https://bit.ly/3tKHoaj>

The Quarantine Album now available. "We were scheduled to record a new album in April 2020, but postponed due to the pandemic. In the meantime we thought you might enjoy hearing some previously unreleased recordings."

⇒ **Alan – Technological challenges in vaccine rollout**

<https://bit.ly/372PDEZ>

MIT Technology Review - Pandemic Technology Project - This is how America gets its vaccines. By Cat Ferguson and Karen Hao, Jan 27th 2021. The Biden administration has inherited a web of tech systems and policies that it must navigate to meet its goal of administering 100 million doses in the first 100 days. After just a week in office, the Biden administration is already under immense public pressure to fix America's mangled vaccine rollout.

⇒ **Rich – I was lucky to find this vaccine anywhere**

<https://bit.ly/3p9ZlpT>

The Washington Post - Voices from the Pandemic - Stanley Plotkin, legendary vaccinologist, on the historic development and chaotic distribution of Vovid-19 vaccines. As told to Eli Saslow January 27th 2021.

Excerpt below:

"I've been so focused on helping to develop these vaccines that I barely thought about the mechanics of getting it myself until this month. How can our process be this complicated? I've been calling around now for the last several weeks. I could not find out where, or when, or how to receive a vaccine. I didn't get anywhere.

I'm 88 years old. I'm in the priority group, and I qualify by all the Phase One recommendations. That should be enough. I don't want to jump ahead of anyone in the line. I don't want to call somebody up on the phone and say: "You know, I actually consulted on this vaccination process. I wrote the textbook on vaccines.....!"

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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

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

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

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

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

NB Respiratory and Sleep Problems Section very informative.

GOOD ANAESTHETIC ARTICLE - English version used by many PPS Groups

POLIO PATIENTS AND SURGERY - Information for health staff.

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

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

Printed copies on our headed paper with permission are available.

Editors Note: Articles from Polio Survivors and Health Professionals welcomed



Goodnight Captain Sir Thomas Moore 13.4.1920 to 2.2.2021 and thank you.

‘Captain Tom’ a true gentleman who served his country not only in WWII but right through to 2020 where he inspired us to join with him across the UK and around the world, raising funds to support NHS Charities Together.

An amazing £ 32.79 million by the close of day on his 100th birthday.

His family tell us that the last year of his life brought events that were beyond his wildest dreams. He deserved every one.

“Tomorrow Will Be A Good Day”



Hilary's mobility scooter all dressed up for an American Pioneer Re-enactment

See [page 3](#)

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