

Polio Survivors Serving Each Other

Information & Inspiration For All Polio Survivors and their Families The PA Polio Survivor's Network

www.papolionetwork.org

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Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

Inside this Issue:

This Itching Has to GO ! Are you plagued by chronic itching – especially in areas where you constantly put pressure on your skin from lying down? <u>Marny K. Eulberg, MD</u> received a question from a survivor and has written an article regarding skin care for polio survivors. She explains itching with and without a rash and of great importance to many polio survivors – pressure sores.

"Breakthrough" Infections is a term we hear frequently in these days of COVID. Did you know there were breakthrough infections with the Polio Vaccine? <u>Richard L. Bruno, HD, PhD</u> has written a fascinating article explaining this (now familiar) term. He reminds us that no vaccine for any disease is 100% effective in preventing infection in every person who receives it.

Do you let what you can't do get in the way of what you can do? Polio survivor Sharon Richardson reminds herself on a daily basis that her limitations will never get in the way of going forward and living her dreams. Our network contributor, <u>Pamela Sergey</u>, is here with a review of Sharon's memoir - *Painting Light in Polio's Shadow: One Artist's Struggles.* A true lover of fine art, Pamela enjoyed working with Sharon on this article.

Polio and COVID19 – Then and Now From Three Polio Survivors. As a result of living with this new and very destructive virus, the memories that are emerging for polio survivors have been honest and often very powerful. We were honored when the Pennsylvania Immunization Coalition featured three survivors from our network for their Blog. We have brought you a summary of their article containing the personal reflections of <u>Deb Stambaugh</u>, <u>Joe Randig</u> and <u>Shirley Smith</u>.



Survivor Stories – In Our Own Words: This <u>page</u> of our website is growing, with brief, honest stories. The PA Immunization Coalition (PAIC) saw the stories of the three survivors featured in their article and asked them to participate. The Vaccine Education Center at the Children's Hospital of Philadelphia (CHOP) chose six stories from this page to feature on their website. YOUR brief words, YOUR short story could help someone else. Many of these stories are linked to the full version on our Survivor Story page(s). www.papolionetwork.org/in-our-own-words

Email us your story, with a photo: info@papolionetwork.org (please put "story" in the subject line).



"Breakthrough" Infections and the Polio Vaccine

Richard L. Bruno, HD, PhD

Director, International Centre for Polio Education

Many people are confused by the term "COVID Breakthrough Infections," which are infections occurring even after three doses of vaccine. I think the confusion is the result of the name being wrong. The virus doesn't "breakthrough" anything. A

better name might be "Vax Miss" infections, because something about the vaccine or the recipient's body caused the vaccine to "miss" its goal of producing effective immunity. "Vax Miss" infections are not unique to COVID but are "an expected occurrence for a small percentage of those receiving any vaccine. **No vaccine for any disease is 100% effective** in preventing infection in every person who receives it." (1)

You may be surprised to learn that "Vax Miss" infections *can* occur with the polio vaccine. "Two doses of inactivated polio vaccine (IPV) are 90% effective or more against polio; three doses are 99% to 100% effective," says the Centers for Disease Control and Prevention (2). But the CDC cautions that, "There are rare cases of individuals contracting polio even with the shots" because *no vaccine is 100% effective.*

The Salk Vaccine: Not 100% effective

While "Vax Miss" infections will be exceedingly rare with the current 99% to *nearly* 100% effective polio vaccine, the original Salk vaccine was far from "100% effective", despite Salk's claim on April 12, 1955 when the vaccine trials report was announced. Unfortunately, hyperbole ruled on that beautiful spring day. First to speak, Dr. Tommy Francis, who ran the 1954 polio vaccine field trial, reported, "The vaccination could be considered to be 60 to 80 percent effective against paralytic poliomyelitis." (2)

However, the already-prepared press release stated, "Dr. Thomas Francis, Jr., Director of the Poliomyelitis

Vaccine Evaluation Center, told an anxious world of parents that the Salk vaccine has been proved to be up to 80-90 percent effective." (3) Newspapers and newsreels reported the 90% number. (4) And, ultimately, Salk himself that day announced "100% effectiveness," causing a heated backstage argument between Francis and Salk.

Polio Vaccine "Vax Miss" Infections"

When polio cases in the US began to rise again after 1957, questions arose about the "100% effectiveness" of Salk's vaccine.

In 1962, public health specialist Dr. Herbert Ratner's Polio Vaccine Status committee's findings were presented in testimony to the U.S. House of Representatives:

"In the fall of 1955 Dr. Langmuir [director of polio surveillance for the U.S. Public Health Service] had predicted that by 1957 there would be less than 100 cases of paralytic polio in the United States. As you know, four years and 300 million doses of Salk vaccine later, we had in 1959 approximately 6,000 cases of paralytic polio, 1,000 of which were in persons who had received three, four, and more shots of the Salk vaccine."

Ratner's committee estimated that Salk's original vaccine was "possibly 72% effective," a percentage in the middle of Tommy Francis' estimated range. This percentage suggests that there would potentially have been "Vax Miss" Infections" in 28% of those who received the 1950s vintage polio vaccine, accounting for the rise in polio cases in spite of widespread vaccination.

"Vax Miss" Infections" - Polio Versus COVID

Given the 90% to nearly 100% effectiveness of today's injectable polio vaccine, and the absence of poliovirus in nearly the entire world, there are likely few, if any, polio "Vax Miss" Infections".

But in spite of the 90% to 95% effectiveness of COVID vaccines, with 500 million COVID cases worldwide and 11 billion COVID vaccine doses given, at least 550 million COVID "Vax Miss" infections would be expected. Why? Because no vaccine is 100% effective.

Richard L. Bruno, HD, PhD

References: (1) <u>www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/breakthrough-infections-</u> <u>coronavirus-after-vaccination#</u>

- (2) www.cdc.gov/vaccines/vpd/polio/index.html
- (3) https://sph.umich.edu/polio/
- (4) www.youtube.com/watch?v=2LIDn_MQDkc





This Itching Has to GO ! Skin Care for Polio Survivors By Marny Eulberg, MD Primary Care Perspectives

<u>Question</u>: I have a question about skin care. I have excessive itching on on my lower extremities - specifically on hips & buttocks. Polio has affected both my right and left sides. I can sleep only on my right side and when I

sit, I do so leaning over to right side. Do you have any suggestions on what cream can be used to help stop the itching?

I do believe it could be indirectly related to polio as there is pressure on the skin because of lack of padding from missing muscles. I am now affected on my upper torso because of the way I lay and sit in my chair. My shoulder and arm are dropped on the left side. Scoliosis is very present and my stomach muscles are gone. I am barely walking with the use of a Nitro walker and have very little balance since polio onset.

Dr. Eulberg's Response:

In introducing myself, I am a polio survivor who is a retired family physician. I have seen over 1,500 polio survivors in a polio clinic since 1985.

I am so sorry that you have been plagued by the itching for so long. I know how annoying itching is for me even when it lasts for only a few minutes or hours.

First, let me say that itching or any skin problem is NOT directly related to prior polio. But, it can be *indirectly* related to polio if there is unrelieved pressure on the skin because of lack of padding from missing muscles or sensitivity or allergy to linings or paddings for braces.

However, those of us who contracted polio in the United States are mostly all over 65 years old and so the maladies that affect everyone as they age are affecting us too. Itching is common for people as they age because the skin becomes thinner and drier. It may sound like "splitting hairs" but the causes

of itching without any apparent skin rash and the causes of itching with a rash are most
often two different things.



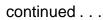
Note: You did not mention any rash so I will address itching without a rash. However, if you have a rash that shows multiple red areas with a center in each that began as a small blister and now if drying up and if it is in a pattern that follows a nerve you may blister and now is drying up and if it is in a pattern that follows the nerve you may have have shingles. Check out https://en.wikipedia.org/wiki/shingles for a description and pictures. Shingles (herpes zoster) happen in people who had chickenpox sometime in their lifetime and it only happens on one side of the body stopping in the mid-line.

Now back to itching without a rash: there are a number of causes with the most likely being dry skin (xerosis), followed by sensitivity/allergy to wool or some synthetic fibers; soap used for bathing or for laundry; a number of medications including opioid containing pain medicines, some blood pressure medicines esp. the ACE inhibitors (their generic name usually ends in "...pril") or amlodipine; amiodarone—which is used to control certain abnormal heart rhythms, some over the counter or prescription pain medications such as Tylenol (generic name acetaminophen), Motrin or Advil (ibuprofen), Aleve (naproxen), some diuretics (commonly known as "water pills" because they make a person urinate more than usual), simvastatin or niacin—used to treat high cholesterol; allopurinol—to prevent gout; or some chemotherapy drugs.

It also seems strange but some products to treat itching like Caladryl can actually make the itching worse when used for more than a few days. Then there are several systemic disorders (affecting more than one part of the body) that can cause itching without a rash and these include thyroid problems, liver disease, kidney disease, diabetes, iron deficiency, some tumors, and HIV.

Some things you can do to decrease the itching are:

• Apply cool to cold compresses,





Skin Care for Polio Survivors (continued) . . .

- Avoid drying out the skin with hot baths or showers (use lukewarm water instead),
- Use mild, non-drying soaps such as Dove or Cetaphil,
- Use a humidifier in the house especially if the air is dry,
- Keep the temperature in the house on the cool side, and
- Apply a moisturizing cream or ointment after a bath and while the skin is still damp (Eucerin or other lanolin containing creams are good but even Crisco works --but it is messy).
- You can also use over the counter hydrocortisone creams or ointments such as Cortizone 10. The ointments stay on better and may burn less when applied because some creams contain alcohol.
- If sleep is a problem due to the itching, you can try the over-the-counter allergy pills like Benadryl (generic name= diphenhydramine) or Claritin (loratadine) or Allegra (fexofenadine) or Zyrtec (cetirizine).

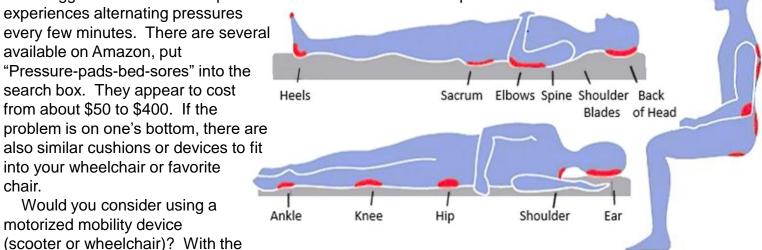
Have you seen a doctor about this? If you are going to see a doctor try *not* to use the hydrocortisone for about a week before seeing the doctor because it can "cover up" the rash enough to make a diagnosis difficult.

Also, when really tempted to scratch, it is better to use a cool to cold compress or rub the area with ice because then you don't risk breaking the skin and causing a secondary infection.

I also believe it could be indirectly related to polio as there is pressure on the skin because of lack of padding in areas where pressure happens from sitting or lying down in the area of missing muscles. These sores, referred to as "Pressure Sores" have four stages.

- Stage 1 This is the mildest stage. These pressure sores only affect the upper layer of your skin. Symptoms of a <u>Stage 1</u> Pressure Sore: Pain, burning, or itching are common symptoms. The spot may also feel different from the surrounding skin: firmer or softer, warmer or cooler.
- Stage 2 through Stage 4 are deeper -
 - They involve the deeper layers of skin going all the way down to bone in Stage 4
 - These need to be seen/evaluated by a health care professional.

A wise plastic surgeon when asked what kind of topical medications should be put on a "pressure sore" said, "You can put anything you want on it except the patient!" which emphasized the point that pressure is the problem and the primary goal is relieving the pressure. You might look into some of the pressure relieving pads/mattresses which range from foam that looks like that inside egg crates to mats that provide air or water that is blown up and then reduced so the skin



weakness of one arm and the scoliosis, a wheelchair would provide better support. But I do know polio survivors can be very stubborn about considering using any of these devices.

I am concerned about what happens if you fall and I don't want your wife to get hurt trying to help you up from the floor! I hope this helps.



Painting Light in Polio's Shadow: One Artist's Struggles Sharon (White) Richardson

A Book Review by Pamela Sergey



A passionate landscape painter, Sharon (White) Richardson writes about her own struggles with post-polio syndrome (PPS) in her memoir Painting Light in Polio's Shadow: One Artist's Struggles. On her website (www.sharonrichardson.net), Richardson expands "Most books about polio survivors focus on the direct effects of the crippling disease. Mine deals exclusively with Post-Polio syndrome (PPS) – the new muscle weakness, pain, and loss of control - that occur years after surviving the polio virus (56 years for me), and the drastic effects it had on my career as an artist."

The book is a triumph of acceptance, adjustment, determination, and persistence crucial in overcoming adversity. Richardson writes in great detail about the physical and mental obstacles that she worked through while struggling with her PPS during the last 20 years, and the many successful work-arounds she invented to continue painting despite PPS. She continues to live by the wisdom she found in a fortune cookie and taped to her easel: "Don't let what you can't do get in the way of what you can do."

In a personal email to this author, Richardson adds: "My hope is that once the reader has accepted their physical loss (a difficult and often lengthy process) and is searching for ways to adjust and adapt to their new situation, something in the book about my particular experiences will spark a "what if" idea that is applicable to their situation. Rather than acquiescing to defeat from not being able to do something they are passionate about and truly enjoy, they can visualize a way around the obstacles they face or even

explore doing something new that is similar and just as satisfying." A sixth generation Mississippian and descendent of the founders of Natchez, her current hometown, Richardson enjoys painting the lightfilled Southwest Mississippi landscape. A daughter of an artist, she graduated from the University of Georgia with a BS in entomology, but it wasn't until after graduation that Richardson took her first oil painting class. Since then, she has studied plein-air landscape painting (the practice of painting landscape pictures out-of-doors) and pastel portrait painting, with numerous accomplished artists. In her personal artist statement she admits "The way that light and the resulting shadows magically transform the dullest, most uninteresting subject into one full of excitement and charm has always fascinated me. Almost anything



Paint My Mailbox Blue © By Sharon Richardson

can be beautiful to paint if it is seen in a pleasing light. This illusive light and shadow design flowing across a landscape or still life is the focus of my oil and pastel paintings."

Her pastel paintings and her oil paintings have been accepted and exhibited in numerous local and regional competitions including the Degas Pastel Society in New Orleans, winning the Pastel Society of

America Award for her pastel painting; and three times by the Salmagundi Club in New York for her oils. Her work is included in The Mississippi Museum of Art and The Municipal Art Gallery in Jackson, Mississippi, corporations, and private collections in the United States, Canada and Europe.

In early 1946, Richardson was diagnosed with poliomyelitis. She was 8 weeks old. After a visit to Richardson's pediatrician and a lumbar puncture to confirm polio, her parents borrowed a car and drove one hundred miles from their home in Woodville. Mississippi to Mercy Hospital in Vicksburg, Mississippi. At the time, Mercy Hospital was designated a Regional Pediatric Polio Center and Richardson's stay was paid by



the March of Dimes. Richardson responded well to the intense "Sister Kenny" method of physical therapy

Painting Light in Polio's Shadows (continued) ...

treatments of hot compresses, hydrotherapy and gentle massage. After two months, she had recovered from the paralysis in her limbs and her parents were thankfully allowed to take her home. Richardson would go on to live a fulfilling life as wife, mother, avid gardener, world traveler, and ardent plein-air painter for the next 56 years, without any apparent complications from her early bout with polio.

In the summer of 2002 Richardson began experiencing muscle weakness in her arms and legs, as well as neck, jaw and tongue fatigue. She had difficulty walking and talking, and could no longer paint with her right hand. It was the onset of Post-Polio Syndrome (PPS). After seeking professional medical advice, Richardson was told that the cause of PPS is unknown, there is no diagnostic test or prescribed treatment, and no way to reverse PPS symptoms. Sharon consulted with <u>Richard L. Bruno, HD, PhD</u> (Director of the International Centre for Polio Education). Dr. Bruno helped her with strategies that would help her live with the disabling effects of the poliovirus.



In an article by <u>Marny Euberg, MD</u> published by the PA Polio Survivor's Network, Sharon learned that she is considered an "upside - downer". Dr. Eulberg explains "This term is based on the fact that the majority of observable weakness and atrophy in most polio survivors is in the lower part of their bodies. If a person has the reverse, with most of their weakness/atrophy in their shoulders, arms, and/or hands, it is 'upside down' from what is usually observed."

Sharon Richardson in her studio.

Richardson's PPS setbacks forced her to find ways to compensate "for roadblocks, and alternative solutions for dead ends." She calls them "work-arounds".

Painting Light in Polio's Shadow: One Artist's Struggles describes many of these work-arounds.

- Sharon taught herself how to paint with her non-dominant left hand, but to do this, she had to flip the arrangement of her studio so shadows wouldn't fall on her canvas;
- She created a "jacket" made of straws and duct tape to encircle the end of her paint brush making it more comfortable to hold without adding weight;
- She began painting at her easel in a seated rather than standing position;
- She added a drill to her easel to easily raise and lower the height;
- She painted smaller canvases and simplified her signature.
- Sharon purchased voice-activated computer software allowing her to continue her journal, be more active with her online PPS support group, take online writing classes, and do online shopping.

Sharon has developed a strict routine of painting for 20 minutes followed by a 20-minute rest period when she would critique her work and plan her next painting session. This arrangement has allowed her to paint three or four hours a day. Through trial and error, she learned not to exceed her rigid schedule, or she would be unable to paint for several days due to her increased "black" pain "... a burning, relentless, bottom of the barrel pain that made me feel helpless and hopeless." Unable to paint outside during COVID, Richardson switched to the centuries old tradition of still life painting and pet portraiture. She was painting, "and that was all that mattered."

continued . . .



Fire Tower Road[©] Sharon Richardson Cover Photo: Painting Light in Polio's Shadows



Country Road © by Sharon Richardson



Salado Creek © by Sharon Richardson

Painting Light in Polio's Shadows (continued) ...

Through her own PPS mantra "acceptance, awareness, and adjustment" Sharon Richardson has been able to continue to share her "enthusiasm and passion for light, color, and nature with others."

"Joyfully returning each day for new adventures at my easel, I engage my jerking arms and trembling hands. I incorporate their uncontrolled movements into my brushstrokes one spot of paint after another. Lefty paints big shapes with an amended brush, and with a regular brush, Righty paints nuances and detail. I'm grateful for this arrangement; I'm at peace painting within my bounds."

- Sharon Richardson

By Pamela Sergey

Painting Light in Polio's Shadow is available in multiple locations and formats. Amazon Archway Publishing Barnes and Noble



Scotland Farm © by Sharon Richardson



Sharon and her husband Jim Barnett at home in their fall garden.



A State Son

Polio and COVID19 – Then and Now From Three Polio Survivors By the PA Immunization Coalition (PAIC) (Article Summary)





LIVING THROUGH POLIO AND COVID-19: HISTORIC PARALLELS

"One of the most prominent similarities in the two viruses is the existence of debilitating, persistent adverse health effects in some of the exposed. Both long-haul COVID-19 and post-polio syndrome occur in a subset of survivors." "Young and old, and otherwise healthy people can still suffer from persistent COVID-19 symptoms despite recovering and testing negative for the virus."

"There are countless people who contracted and survived polio in the 1940s-50s that live with the effects of Post-Polio Syndrome today, and now they are living through yet another pandemic with COVID-19. PAIC had the unique opportunity to speak with three polio survivors from the PA Polio Survivors Network who were willing to share their extraordinary experiences and unique perspectives on COVID-19."

<u>Deborah 'Deb' Stambaugh</u> was five years old, living in Petersburg, West Virginia when she felt ill while playing outside of her family home in the summer of 1954.

<u>Shirley Smith</u> was born in 1938 in Wilkes Barre, Pennsylvania. One day, 12-year old Shirley was too tired to feed the chickens or hold her 9-month-old niece.

<u>Joe Randig</u> started school in September of 1952 when he didn't feel well two weeks later. Coming in from playing outside early, his mother grew concerned. He had a fever, headache, and stiff neck.

Polio and COVID (continued)

- <u>PAIC</u> "... Are there any significant similarities you've noticed between the Polio Epidemic and the current COVID-19 Pandemic?"
- Deb "The uncertainty of how severe the disease you have contracted will affect your body. The unknown of what was ahead."

Long stays in a hospital quarantined from everyone,

No physical contact with loved ones.

Age 5, 100 miles away from family, only to see them through a window during quarantine days. Then only on weekends for the remainder of a 6 month stay.

It was also hard on the families financially and emotionally.

Shirley – "The long-term effects. You live with the belief if you keep trying, you'll get better." I still walk with two crutches and leg braces.

People who contract COVID-19 don't know what their long-term effects will be, it is different for everyone.

Irrational fears about the epidemic and pandemic are similar. Although we lived on an isolated

farm, I still remember them closing the pools and the summer fears. The family was quarantined . . . " Joe – "I think the main similarities between the polio virus and the coronavirus would be fear."

Even though the polio virus has been around probably forever it still would bring fear to parents. A family never knew who or where it was going to strike and how severe the outcome would be.

Fear of the coronavirus was fear of the unknown. At first, we didn't know where it came from or how it was transmitted, and it spread around the world like a wildfire.

The results of the polio virus were unpredictable. There was no way of knowing if your child was going to be sick for a few weeks or never walk again or die.

TWO DIFFERENT VACCINE ERAS

"Both polio and COVID-19 are highly contagious, but some measures taken to prevent their spread differ." "Efforts for 'social distancing' were voluntary and selective in nature." "Businesses in localities would close when there was an outbreak, such as bowling alleys, movie theaters, and public pools. Interventions targeted the vulnerable, affected populations rather than on a state or even national basis."

"When Salk's vaccine underwent initial testing, approximately two million children were involved. Once the vaccine was licensed and proven effective there were massive programs launched to bring the shot, and eventually the oral vaccine, to the public via large events that families attended to be vaccinated.

"... Americans unified against polio, feeling a sense of community..." "Though the messaging may be similar, the coronavirus vaccine is more polarizing than the polio vaccine. Widespread vaccine hesitancy and misinformation have been significant markers of the pandemic."

<u>PAIC</u> - "... Are there differences that you can recall between the Polio Vaccine rollout and prevention measures compared to those for COVID-19? Was there opposition to the Polio Vaccine that you can recall?

Deb - " Everyone got in line at fire companies, schools, and clinics. People couldn't wait for that precious sugar cube to protect them from the poliovirus."

No one questioned it. This is how the Polio Vaccine is received (now) in foreign countries.

People years ago had faith in the doctors and caregivers to provide them with the latest information and people did not question as they do today."

Shirley – "I had polio in 1950, the vaccine came out in 1955. I went to a residential rehab in Philadelphia." We thought we were "the last of the kind" once the vaccine was proven effective, we believed nobody would have polio anymore. It was a welcome relief."

Even though there was one bad batch, people still believed in the science and were not discouraged. President Roosevelt was an inspiration for those that had polio.

Joe – "The development of the polio vaccine was an enormous, long-awaited achievement. Scientists worked on creating the vaccine for years followed by several years of testing."

The March of Dimes established by Franklin D. Roosevelt in 1938 was the leading force behind the research that produced a polio vaccine.

On April 12, 1955, researchers announced the vaccine is safe and effective. Total joy and relief spread

Polio and COVID (continued)

across the country. Church bells rang, newspapers had big headlines on the front page. People lined up as soon as possible to get vaccinated.

LESSONS FROM THE PAST and PROTECTING THE FUTURE

<u>PAIC</u> - "Are there any major lessons from the polio epidemic(s) and post-polio syndrome that you would like parents and other individuals to learn from? Would you consider yourself a vaccine advocate?

Deb – "It will change their lives FOREVER! As a child, other children accept you as you are. When I entered high school, the discrimination started. I stayed in my small group of friends and kept a low profile. After graduation I went to a business school and was accepted for me. I often said I preferred business school over high school any day."

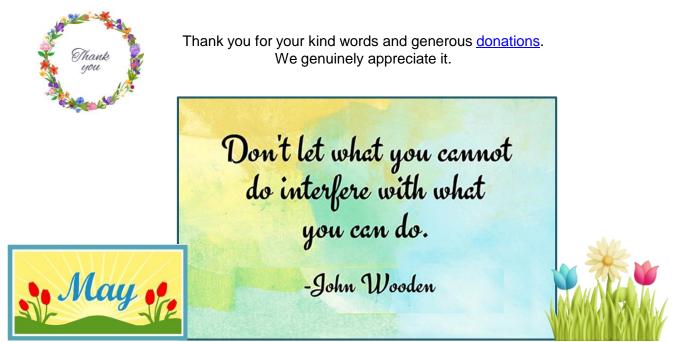
"I am adamant about vaccines" As I deal with post-polio syndrome and the inability to maneuver around as I did in the past, I feel it is most important that vaccinations are taken seriously. COVID-19 long haulers may someday face the same issues, as they deal with complications of the COVID-19.

Shirley – "The idea of herd immunity - 'I'll eventually come down with it and then I'll be immune'." People need to know there's long-term effects with these infectious diseases. You may recover, but there are long-term effects that will potentially alter the rest of your life and the quality of it. Make sure your information comes from a good source."

Most definitely, I am a vaccine advocate. All of my children are vaccinated.

Joe – "I am definitely a vaccine advocate and have been since my involvement with Dr. Salk's vaccine work." The polio vaccine monitoring continued for about 10 years. We would periodically return to the D.T. Watson Home for blood testing. My Dad made a 10-year commitment to Dr. Salk's vaccine testing program. We made the 70-mile roundtrip drive many, many times from 1954 to 1961 and that has always impressed me. "I believe that vaccines are a miracle of modern medicine, they should be understood and appreciated and accepted. Over the years vaccines have saved millions from death and disease."

This is an article summary, published with permission from all participants. The <u>complete</u> article can be viewed: <u>www.immunizepa.org/polio-and-covid-19-then-and-now-from-three-polio-survivors/</u>



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