



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.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:

Allergies, Cold, COVID or Flu ?: Sniffles, coughs, fever ? What is this thing that is making me feel sick? How are they different? Primary Care physician [Marny K. Eulberg, MD](#) is here to explain.

I think I'm Cured of PPS: "I feel GREAT. I got a cane, watch my steps and have less pain". [Richard L. Bruno, HD, PhD](#) explains why it's not a good idea to go back to the gym to start losing weight just yet. His article "The PPS Roller Coaster" explains why it's important *not* to fall into the "I feel great now" trap.

She's Truly Living a Good Life: Survivor Shirley Smith lived 100 miles from her family farm, in a special school and rehabilitation facility for five years. Rather than a life of loneliness and abandonment, she discovered a "new" family, fell in love with the man that would become her husband, raised two daughters, defied the system when she couldn't get a teaching job with a disability and taught middle school for 35 years. She has never let braces and crutches stop her from living. Hers is a remarkable, polio survivor story.

We ARE Making a Difference: Rotarians and their partners across the globe are working non-stop to rid the world of polio. We know that many survivors are not actively engaged with a Rotary Club and are seeking a way to be part of the solution to this massive eradication effort.

So often we think "What can I do? I have only a minimal amount to give." We know that through the honor and credibility of the [Rotary Foundation](#), even the smallest donation can make a difference and we invite gifts to "Team Survivor" of *any* amount. We are happy to report that in just five years, Team Survivor has donated enough to the Rotary Foundation to vaccinate an est. 87,000 children. The 2021 contributions (100% of which went to the Rotary Foundation) are featured on the [Team Survivor](#) page of our website. We ARE making a difference in children's lives.

Your Generous Donations to PPSN: We are truly grateful for your thoughtful contributions to our network. These generous gifts are what allowed our work to continue serving *all* polio survivors for the last seven years. You can see our 2021 contributors and those whose lives we celebrate In Memoriam on the Donations page of our website.

It's January: The new year is the perfect time to –

- Prepare for unexpected winter weather.
- Change all your online passwords and make them more secure.
- Change your fire alarm and carbon monoxide alarm batteries.
- Pull out your Home, Health and Auto Insurance policies. Remind yourself as to deductibles. Do they speak to your current needs?



WINTER WEATHER SAFETY TIPS

- Stay indoors as much as possible
- When going outside:
 - dress warmly and stay dry
 - keep trips brief
 - don't ignore shivering—it's a sign your body is losing heat
- Know the symptoms of hypothermia and frostbite
- Use caution when doing activity outdoors, like shoveling snow

Source: PA Dept of Health

Living a Good Life

Shirley Smith



Shirley Bowery was born July 2, 1938 in Wilkes Barre, Pa, and lived on what she describes as a “subsistence” farm. She is the fourth of five children, having two older brothers and a sister, who was 9 years and 364 days older than her. Her sister Thelma, the youngest of the family, was born three years after Shirley. It was like two families, with the older siblings taking care of the younger ones.

Shirley was strong willed as a child and was very determined to get her way, sometimes with tantrums. During one of these episodes she was offered a penny to stop crying, but she held out for a nickel (which back in those days was enough to buy an ice cream cone).

She has many happy memories from those days on the farm. They loved *real* hay rides, jumping in the hay, and climbing trees. Shirley made pets of the farm animals (including a nanny goat). Kindergarten was not required and transportation was not provided, as a result, she started school at first grade, having been taught all the nursery rhymes by her older brothers and sisters. She was a good student and enjoyed school. Always competitive, Shirley remembers taking the first seat for spelling from a child who had a disability (that she now realizes was probably from polio). She always felt badly about it.

Once they were old enough, everyone on a farm had to help. Just like her older brothers and sister, Shirley had chores on the farm. Her job was to feed the chickens. She remembers the day she felt too tired to feed those chickens, and was too tired to hold her 9-month-old niece. Finally, the family doctor was called and her parents were told she had the “the flu or gripe” and was given 7-Up to keep her stomach settled. When she was unable to walk she was taken to the Contagious Hospital. A spinal tap

determined it was polio. She had spinal polio - from the waist down there was minimal movement. The family was quarantined, but no one else got the virus. During the quarantine period at the Contagious Hospital, Shirley could only see her family through a window. Her diversion was a radio and a pile of books.

After three weeks (or so) she was moved to the Home of the Merciful Savior (HMS) in Philadelphia, which was a residential facility for polio patients. She remembers receiving better care there. Having minimal movement from the waist down, she was happy she could wiggle her toes !

HMS was founded in 1882 by Helen Innes. Helen and her husband, an Episcopal minister, had custody of a boy with disabilities. They could not find an appropriate home for this child so Helen took on the task and thus began a special rehabilitative facility where all children were accepted, without a fee. HMS pledged, “the care, support and maintenance of children crippled by disease, accident or any other way.” Children received the best medical and surgical treatments at the time. Through the years, classrooms and a school program were added. The instruction was in the basics and in trade skills. (Although HMS was a

residential facility for polio patients, it is now a residential facility for children with Cerebral Palsy.) When Shirley arrived there in 1950, she saw what looked like a typical ward with beds lined up side by side in rows. That’s where she met Annie, an older girl also rehabilitating from polio, “who frightened her with her gruff voice”. Annie still walked with crutches. Shirley *hoped* to walk without crutches. She also remembers the nurse in charge, Miss Knee, “who ran a tight ship”.

She lived at HMS until she was 17. Every Sunday, her parents made the 200-mile round trip to visit to see their daughter. As Shirley grew she “moved up” upstairs where the “big girls” lived. She never felt abandoned. In fact, she created a new family for herself. Annie, “with the gruff voice” became one of her dear friends.

(continued . . .)

Shirley’s treatment included the “Sister Kenny” method. Australia’s Sister Kenny had some success with her controversial method of treatment for polio survivors (which was adopted in the US in 1940). The treatment involved using moist hot compresses to ease muscle spasm pain and gentle exercise of the affected limbs to reeducate the muscles. She remembers the use of heavy, wet, woolen army blankets on her weakened legs as well. She started using crutches and was fitted with KAFOs (long leg braces).



Fun loving Shirley at HMS

Little did she know, but HMS would have a far more special connection for the young teen than “just” polio recovery. A boy named Fred Smith, from neighboring Glenside, had also rehabilitated at the same location. He was there from ages 3 to 6, many years before Shirley’s arrival. Their paths would cross much later.

From HMS, Shirley went to a school for children with disabilities, the Widener Memorial School on



Source: widener.philasd.org

Olney Ave in Philadelphia. Upon admission, Shirley skipped a grade and entered high school. That’s where she would meet and fall in love with fellow student and polio survivor, Fred Smith. Although he left Widener and graduated from suburban Cheltenham High School, he would return for visits at his alma mater.

The Principal of Widener toured the country to find the best practices in education for children with disabilities and the result was the development of state-of-the-art facilities. Shirley arrived while it was still under construction.

Shirley has fond memories from her days at the Widener School. One is of a dedicated teacher, Daniel Werlinsky. He had an “inspiration board” in his classroom that featured fellow polio survivor, Franklin Delano Roosevelt. Mr. Werlinsky was a hero for all the children at the Widener Memorial School for Children. Another happy memory for Shirley was when her class at Widener was given free tickets to see the Philadelphia Phillies. They were playing in Shibe Park (which would later become known as Connie Mack Stadium). It was a 3-mile trolley ride down Broad St. “We all got to the ballpark on the trolley car.” “We were a sight to be seen, a group of students with crutches



Widener students champion the March of Dimes (Shirley 2nd from left)

all piling up into the trolley to go to a Phillies game.” At Widener there was a model Trolley Car, but the challenges of getting onto a *real* trolley car left them in giggles, not making the trolley car operator very happy !

Shirley graduated from Widener and went on to Temple University in Philadelphia. She lived in a dormitory made from an old brownstone that the University had gutted, making the building accessible for students in wheelchairs (unusual in the 1950’s). There was a ramp in the alley to the first floor, where they had rooms. Graduating in 1959, she was ready to start teaching. It didn’t take long for her to discover that a person with disabilities was not to be hired by the Philadelphia School District. She *was* hired at her old alma mater, Widener. Shirley taught for four years and received her Special Education Certification in 1963.

Shirley and Fred were married in June of 1959. The newlyweds started out living in an apartment close to Widener

and eventually settled in Fred’s home community of Glenside. After the birth of her first child, she was a full-time mother enjoying her two daughters. She stayed active outside the home, tutoring and teaching Sunday school.

They enjoyed their new home, and discovered that two parents with disabilities was an exciting new frontier. In spite of them *both* requiring crutches and braces, neither Shirley or Fred were one to shy away from new adventures with their children. The family went camping every summer, traveling to many places, ranging from Prince Edward Island in Canada to Disney World !



When both of the girls were in school she went back to work at Widener, teaching middle school students. She received her Master's degree in the Psychology of Reading in 1976, teaching full time until 2002. One memorable student, living with severe Cerebral Palsy, used head gear to push the keys of the typewriter. One day she wrote "It is good to have a teacher that is handicapped, because they understand." Recently Shirley told her minister, who also has a disability, how much it means to have someone as a pastor that truly understands. Her minister replied "It is *because* of you and Fred that the church was ready to have a Rector with a disability". They had paved the way.



HMS sisters – "the Big Girls" comparing braces in 1954. Shirley 4th from left.

All throughout her life, she has seen her glass as being "half full". In the 1950's there were no polio support groups. Beginning at HMS (the "Home" as she describes it) Shirley and her dear friends became like sisters. Annie, Sonia, Mary-Lou, Mary, Alice, Nancy became a family. While at Temple, polio survivor Judy joined the sisterhood. They were an extraordinary group of support for each other. Always present, the "sisters" shared a lifetime of events that surpassed the pain and disability that came with polio. They shared: weddings, births, child-rearing, employment and everything life had to offer.

The couple were active participants at their church, with their family, and in their local community. They both became engaged with an Abington, PA based Post-Polio Support Group. They were both visible volunteering at the "Casual Coffee Moments" Post-Polio Conference, with Dr. Richard Bruno, HD, PhD in 2015. Given that she taught middle school for 35 years, Shirley Smith doesn't shy away from a challenge. She has served on the Task Force on Disabilities and on the Episcopal Church Steering Committee distributing grants from endowments to designated causes foreign and domestic.

Both Fred and Shirley worked full time until retirement. Fred maintained his home-based tax business until 2017. Their daughters blessed them with seven grandchildren, sharing family vacations and frequent celebrations.

Although it came on more quickly for Fred, PPS has been gradual for Shirley. They are fortunate to have a PPS knowledgeable rehabilitative physician locally and sought his care. Shirley is determined to stay as active as possible, naps and rests when she needs to and stays safely active. The use of a scooter, has expanded her range like using it for nature walks. She also uses it when she is not wearing her braces. She is reluctant to use it for everyday use, and walks as much as she is able realizing that



it is good for her wellbeing.

Now in her early 80's Shirley remains active. After losing Fred in 2019, she now enjoys the company of one of her granddaughters on a full-time basis. She credits her positive attitude on the resilience she developed of having been raised on a farm and being nurtured as a child. Shirley displays a "can do" attitude and is a problem solver, viewing barriers only as "challenges to be overcome". She would always problem solve with her ever practical husband and together they approached things as a united front. She can do most things and thrives by not having to do any of them alone. She approaches



Fred and Shirley. Two "Yankees" on an accessible tour of Great Britain

everything she does with passion and enthusiasm and has thrived in her accomplishments. You are living a good life, Shirley Smith.





The Post-Polio Roller Coaster

[A Bruno Byte](#)

From Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

Question: I followed the plan in the Polio Survivors Handbook and I feel much better. I got a cane, can walk further and my pain and fatigue are much less. I think I'm cured! So I'm getting rid of the cane and going back the gym to get on the treadmill to lose some weight.

Answer: Sometimes it's actually not helpful for polio survivors to feel better because some go back to denying that they have PPS or are convinced that they have been "cured." They once again do all the Type A things they'd done before and PPS symptoms return as they ride the "post-polio roller coaster:" Overdoing, crashing, recovering and then overdoing again.

Sometimes our patients intentionally tested their limits, to prove that they actually had PPS, and to see whether they really need to take care of themselves. Other times survivors made a conscious choice to use their energy and risk increasing symptoms, possibly sacrificing some neurons to do something physically taxing. That's their choice. After all, the fundamental tenet of The Post-Polio Institute's program was for polio survivors to turn off their autopilot and decide for themselves what to do with their increased energy, muscle strength and remaining motor neurons. However, it's important to know that remaining, poliovirus-damaged neurons are breakable and that there is no "cure" for PPS, only symptom management.

But, regardless of the reason for overuse, getting off what we call "the post-polio roller coaster" and managing PPS for many polio survivors, if not most, will be the most difficult battle they will ever wage - even more difficult than fighting polio itself. Sadly, it is a battle that some polio survivors will never join. In the early 1990s when PPS was "new," 12% of Post-Polio Institute patients left the program, overwhelmed by the anxiety and guilt of decreasing activity, the fear of looking disabled and of being abused as they had been as children. We always kept the door open for them to return.

Unfortunately, only 10% of all patients who left treatment returned to The Post-Polio Institute. Typically, they returned about four years later, always in much worse shape than when we first met them. Some of those who limped out were rolling when they returned. Even more unfortunate, 80% of those who returned *quit treatment* again! It will be no surprise to you that these patients were 25% more Type A and 20% more sensitive to criticism and failure than patients who completed treatment.

Bottom line: Getting off the post-polio roller coaster, looking PPS in the eye and changing your lifestyle ain't for sissies.

**It's Time to Get off the PPS
Roller Coaster.**

Warning:

"Looking PPS in the Eye and
Changing your Lifestyle,
Ain't for Sissies."



Richard L. Bruno, HD, PhD

[The Encyclopedia of Polio and Post-Polio Sequelae](#)

contains all of Dr. Richard Bruno, HD, PhD's articles, monographs,
commentaries and "Bruno Bytes"
www.polionetwork.org/encyclopedia

Are you looking for a specific topic?

The Encyclopedia Index makes 500 topics easily available.



Is it Allergies? A Cold? COVID ? Influenza? Oh My !

(Part 1)

[Marny K. Eulberg, MD](#)

Every fall, going into winter, people who have sniffles, coughs, and/or fever ask themselves and their health care providers, “What causes that?” or “What is this thing that is making me feel sick?”. Fortunately, after the first killing frost, many of the allergies to plants go away until next growing season, but indoor allergens can bother people all year. Now, COVID-19 gets thrown into the mix. Colds, flu, allergies and COVID may have many of the same symptoms. And yes, it is even possible to have allergies and COVID, or flu and COVID, or allergies and the flu, etc. etc. etc. COVID seems to be the only malady out of this list that can cause a person to have a new loss of the sense of taste or smell, but not all people infected with COVID lose their sense of taste or smell. Therefore, no one can say with certainty that because you can still taste and smell that you do not have COVID !

If the problem is only due to allergies it is very, very unlikely that the person affected will have a fever but will have bothersome sneezing, stuffy or runny nose, and itchy eyes.

Web MD put together a chart of possible diagnoses for those with respiratory symptoms to help determine whether a person might have a cold or influenza.

The best preventative for both COVID and the Flu are the vaccines that are now easily available. Additionally, frequent handwashing, wearing face coverings when outside one’s home, and maintaining a distance from others that do not live in your household can be very effective. And, there is the old rule that applies whether it be Colds, COVID and Flu – if you are sick? Stay home! These hygienic measures likely will decrease your risk of getting and spreading these contagious respiratory infections.

There is a very important vaccine for Influenza and January is *not* too late to get it. Since the vast majority of us in the US who had polio are 65 years or older, it is generally advised that we be given the “high dose” flu vaccine.

Note: This is not based on the fact we had polio but is purely based on our chronologic age. The “high-dose” vaccine has four times the amount of flu antigen to the four different flu viruses (hence called a quadrivalent flu vaccine) that are expected to be currently causing influenza compared to what is in the quadrivalent flu vaccine given to younger individuals. According to an article in the New England

WebMD				
COLD vs. FLU vs. ALLERGIES vs. COVID-19				
SYMPTOMS	COLD	FLU	ALLERGIES	COVID-19** (can range from mild to serious)
Fever	Rare	High (100-102°F), Can last 3-4 days	Never	Common
Headache	Rare	Intense	Uncommon	Can be present
General Aches, Pains	Slight	Usual, often severe	Never	Can be present
Fatigue, Weakness	Mild	Intense, can last up to 2-3 weeks	Sometimes	Can be present
Extreme Exhaustion	Never	Usual (starts early)	Never	Can be present
Stuffy/Runny Nose	Common	Sometimes	Common	Has been reported
Sneezing	Usual	Sometimes	Usual	Has been reported
Sore Throat	Common	Common	Sometimes	Has been reported
Cough	Mild to moderate	Common, can become severe	Sometimes	Common
Shortness of Breath	Rare	Rare	Rare, except for those with allergic asthma	In more serious infections

Sources: National Institute of Allergy and Infectious Diseases. CDC. WHO.

**Information is still evolving

Continued . . .

Journal of Medicine, the high dose flu vaccine was shown to be 24% more effective at preventing flu in persons 65 and older than the standard flu vaccine. Nevertheless, *no* flu vaccine is 100% effective at protecting recipients from getting the flu if they are exposed to someone with influenza. Reminder: It takes two weeks after you've had the vaccine for it to be fully effective.

In the past several years, flu vaccines have been shown to be about 40-50% effective. So-o-o, it *is* possible to get flu even if you got the flu shot, but it is thought that, in that case, you will have a less severe case of flu than if you never received the flu shot. Those who should *not* get the flu vaccine are those with severe allergies to eggs and those who are sick with fever or any suspected infection including possible COVID.

Persons who are sick with fever or have been recently exposed to COVID should delay getting the vaccine primarily to avoid exposing the vaccinators and staff to whatever you may have. Initial treatment for colds, flu, and COVID are pretty much the same - fluids, rest, and symptomatic treatment such as acetaminophen (Tylenol) or ibuprofen (Advil, etc.) for treatment of fever and body aches. Stay home to minimize the risk of you transmitting these respiratory viruses to others. More as it specifically applies to COVID next month in Part 2 of this article.

Are There Delays In The Availability Of Flu Vaccine?

Currently, there aren't any delays being reported regarding accessibility of the Flu Vaccine. A record number of flu vaccine doses have been manufactured this year. The CDC will continue to provide weekly updates on total flu vaccine doses distributed throughout the 2021- 2022 flu season.

Can I Have Flu And COVID-19 At The Same Time?

Yes. It is possible have flu, as well as other respiratory illnesses, and COVID-19 at the same time. Health experts are still studying how common this can be. Some of the symptoms of flu and COVID-19 are similar, making it hard to tell the difference between them based on symptoms alone. Diagnostic testing can help determine if you are sick with flu or COVID-19.

Should A Flu Vaccine Be Given To Someone With Suspected Or Confirmed COVID-19?

No. Vaccination should be deferred (postponed) for people with suspected or confirmed COVID-19, regardless of whether they have symptoms, until they have met the criteria to discontinue their isolation. While mild illness is not a contraindication to flu vaccination, vaccination visits for these people should be postponed to avoid exposing healthcare personnel and other patients to the virus that causes COVID-19.

When scheduling or confirming appointments for vaccination, patients should be instructed to notify the provider's office or clinic in advance if they currently have or develop any symptoms of COVID-19.

Additionally, a prior infection with suspected or confirmed COVID-19 or flu does not protect someone from future flu infections. The best way to prevent seasonal flu is to get vaccinated every year.

SOURCE: CDC

<https://www.cdc.gov/flu/season/faq-flu-season-2020-2021.htm>

Edited by Dr. Eulberg from the original published by the [Colorado Post-Polio Support](#), Fall 2020



Do you have a question for either

[Dr. Richard Bruno, HD, PhD](#) -or- [Dr. Marny Eulberg, MD](#) ?

Feel free to contact us - info@polionetwork.org

The answer to YOUR question could help others.

Over the last six years, we regularly received marvelous comments and jokes to share with all of you from polio survivor, friend, grandfather and proud veteran William "Bill" Johnson of Jonestown, PA.

Just weeks before his death in December, he sent what would be his last.

Bill ? We will miss your warmth, sense of humor and veteran's pride.

The internet connection at my farm was really poor, so I moved the modem to the barn. Now? I have a stable WIFI !

What do you call a female superhero with a bad sense of direction?
A Wander Woman !

I just finished a book about the greatest basement to ever exist.
It was a best cellar !

Did you hear the news about the corduroy pillows?
They made headlines !

What did the fish say when he hit a concrete wall?
DAM !

What do you call a bee that never quite made it in the hive?
A Wanna Bee !



Thank you to our friend and fellow survivor Bill Peacock for this cartoon.



Always feel free to contact us.

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