



Polio Survivors Serving Others

Information & Inspiration
For All Polio Survivors and their Families

The PA Polio Network

www.polionetwork.org

December, 2023

Our Mission:

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

Inside this Issue:

Iron Lungs:

The sounds they made keeping children alive, inspired the development of the polio vaccine. [Dr. Julius Youngner](#), a key member of the research team working in the University of Pittsburgh lab directed by Dr. Jonas E. Salk, was one of the Unsung Heroes of the polio vaccine. Their lab was located below a ward of polio patients who couldn't breathe on their own. He said: "Machines, iron lungs did it for them." "The ward was enormously loud. The machines created a terrible din and drove home the reality of the disease. We had motivation right there in the building. I never worked so hard in my life. I worked seven days a week." Survivors whose lives were saved by these amazing machines tell an amazing tale.

- **Staying Positive in the Face of Adversity:** Thomas Fetterman recounts his experience with polio in 1953. His three months in the hospital included an iron lung, a rocking bed and painful physical therapy. Despite the permanent disability that has come as a result, Fetterman reflects on how his experience with polio shaped his optimistic outlook, sense of adventure and desire to design crutches for others with disabilities.
- **The Last of the Iron Lungs:** In this fascinating article, survivors Martha Lillard, Mona Randolph and Paul Alexander tell their stories and share the same dream: that every child will be vaccinated for polio.

Preventing Falls at Home: Survivor Thomas Fetterman guesses that he's fallen more than 500 times. Marny Eulberg, MD reminds us that the risk of falling increases with age – regardless of whether or not we had polio. Laura Vittorioso [spoke up](#) about the correlation between vision issues and the risk of falling. We have an article from the National Institute on Aging that can help.

We're "getting more mature": It happens to all of us . . . If we're lucky enough ! But what if we had polio? In her presentation "How does having had Polio Interplay Between Polio Residuals, Aging and Common Health Problems", primary care physician and polio survivor Dr. Marny Eulberg explains that many things have happened since we had polio, and that very few of us are a "pure case of our polio" anymore. In the latest of their 2023 Lecture Series, Post-Post-Polio Health International brought us a fascinating topic that highlights how difficult it can be to identify only ONE cause of a polio survivor's symptoms.

Our Network Team – What a year it has been.

We've grown and so has our amazing working team. Four amazing women joined us this year.



Barbara

Survivors – Pediatric Vaccine Advocates



Joyce

Thank You –
PA Chapter, American Academy
of Pediatrics
and the
PA Immunization Coalition
for funding our many
2023 Advocacy Projects.

More about these special projects
in the new year.



Carolyn

Administrative Project - Support



Patricia

Staying Positive in the Face of Adversity

Thomas Fetterman

By Carol Ferguson and Thomas Fetterman

Based on the 2023 interview with Meredith Sellers from the [Mütter Museum](#) of the College of Physicians, Philadelphia.

It was 1953, Tom was eight. “I was running races in the schoolyard with friends, and I kept on falling down. I had a bad headache and went to the nurse. My mom picked me up and took me home. Every time I lifted my head up in bed, it hurt like the devil.” The family doctor came out to the house and he thought I had what they called “grip”, which was a kind of viral cold. It got worse and worse and I began having breathing issues and pain in my body so they took me to Hahnemann Hospital in Center City, Philadelphia. They didn’t really know what I had and I was put in a children’s ward. They thought I had spinal meningitis and gave me a spinal tap, but it wasn’t definitive. They started giving me these “big honker” penicillin shots every two hours, day and night, for two weeks (to this day, I’m not very fond of injections). I knew something was wrong. I was very thirsty so I climbed out of bed and my legs just crumpled underneath me. I ended up on the floor and stayed there until they did their rounds and found me. Then they finally got the diagnosis, I had polio.

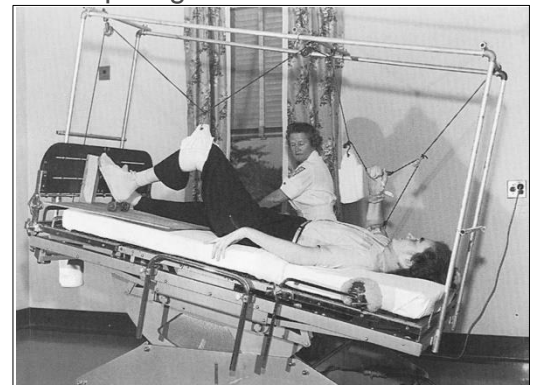
They sent me off to an isolation ward in Montgomery Hospital where put me in a glass room. I was laid on what was nothing more than a stretcher. It seemed as though my whole body had rigor mortis - I was completely stiff - like a board. I couldn’t lift my head up, I couldn’t move my arms, legs. Nothing. I was only eight and I lay there thinking “What the heck is this?” It was worrisome and deep down I thought something serious was going on. My parents came, but they were not allowed in. They had to stand outside in a gown and look at me through a window. Everything that I owned was burned. All my clothes, all my books, and all my toys, including my prize Daniel Boone, Davy Crockett coonskin hat. I guess now I would call it “traveling light” but then, it was awful. After couple of weeks, I was no longer contagious. I was moved to Sacred Heart Hospital in Norristown, which is a Catholic hospital where nuns were the nurses. I was not a Catholic and hadn’t ever interacted with nuns. It turned out they were terrific and they took very good care of us all.

My body was still very rigid and I was still having trouble breathing. That’s when they put me in an iron lung. I remember even without any activity, I was short of breath. Just laying there, I’d be short of breath. I remember that big machine being soothing because it just pushed and pulled . . . pushed and pulled . . . pushed and pulled having it’s own special rhythm. It was actually relaxing, a little hypnotic, and once you got used to that sucking and blowing sound, it was calming and reassuring. I would think to myself “Thomas, you’re still breathing and that’s a good thing.” Inside the iron lung next to me was a lovely adult woman. She had three small children. As we lay there, with our heads sticking out, we could both speak. She was very maternal toward me, which was quite amazing. She was in there the whole three months that I was there. Her husband and her three kids, little toddlers, would come every day and she would look at them through the mirror above her and talk to them. Even with the positive memories, it was frightening. I’m glad I was only in there for a short time.

After couple of weeks, they finally moved me out of the iron lung. By that time, I could move my head and I could move my arms a little. I was quite worried about what was going on with my body. I was in a room with another boy - Wesley Davis. He and I were about the same age and we became quite good friends.

I did better in the iron lung than I did on the rocker bed – it was a bed that I just was strapped onto. It would very slowly go back and forth and push the weight and lift the weight off the diaphragm. This eight year old thought it rocked on and on for way too long. It was supposed to help me sleep, but I had a hard time sleeping and was not relaxed at all. They had these draw shades that came down and covered the complete window. I remember that it wasn’t until I saw the little crack of light at the very bottom, when I knew the sun was coming up, that “bam, I was asleep”. I could finally relax for a minute. It wasn’t dark, “I’m not afraid. I’m just going to take a little nap . . . for a while.”

I wasn’t in the iron lung 24/7. I was taken out and my body was moved and stretched by the therapists. I was treated with the Sister Kenny method, where the therapist put very hot, wool pads around my arms and legs.



Rocker Bed. Photo courtesy of Michael Alexander, MD, Thomas Jefferson University

continued . . .

Then once they got you warmed up, Ms. Van Horn would come in. A lovely woman, she was a very sweet, but no-nonsense person. She would stretch me . . . really stretch me. She'd put you into these horribly painful positions. One thing I remember clearly, was everybody screaming out because it hurt so much. She would do it to one child at a time as she moved down the hallway.

My muscles were stiff, like a board. I remember they had this thing with blankets, that had hot pads in it. They'd go room to room, plugging them in. You'd lay there and hear this progression of screams getting closer and closer and closer until it was your turn to scream. But, it limbered up my joints, and very, very slowly, they made me bend a little bit further each day. It worked. We all became much more limber and that was great. It gave us more mobility, and with more mobility, we had a *lot* more fun.

Wesley and I would go up in the elevator and feed the monkeys they had in the science department. They took us on trips. We got to go to the local zoo and we started swimming therapy at the Norristown YMCA. We became like a family. I was lucky to have people around me in the same situation; we shared everything, and I think that made it easier on everybody, at least it did for me.

The nuns made a leg brace for me. Then they gave me wooden Kenny armband crutches. They took me into the rehab room with gym mats on the floor. The therapist would get me walking around and around the mats doing all kinds of maneuvers. After I got pretty good at it, they would sneak up behind me, kick a crutch out from underneath me, and watch me fall to the ground. This is how they taught me how to fall. As hard as it was, I'm glad for the lesson - I've probably fallen more than 500 times in my life. If I hadn't learned how to fall, I'd be in really bad shape.



"Many hours of exercise and skilled care are needed to help Tommy Fetterman, in his fight against polio." "The training of physical therapists and physicians is part of a large program paid for by the March of Dimes Funds. The drive to fight polio is on." Source: The Herald

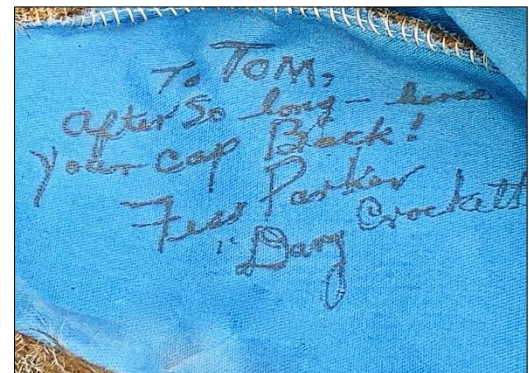


My Mom and Dad were absolute troopers. They lived forty-five minutes away and visited me every single day for the whole time I was in Sacred Heart Hospital. One day, they had not one, but two flat tires, and there was no spare. They called and said, "We are so sorry, we can't make it." I didn't mind. I have a wonderful family, and they were very, very caring. I have two brothers who visited along with friends that my Mom would drag along.

And for me, it was my first traveling experience and my first experience away from home. Initially, I was afraid, but after I got a hold of what was going on I realized that I was meeting wonderful, supportive people. The parents that came to visit their children were wonderful, and they would visit everybody. It was quite amazing. At the

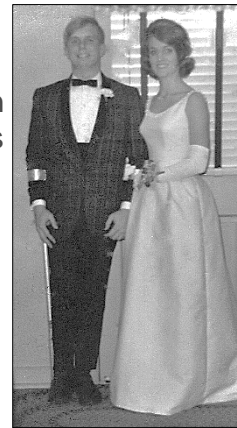
same time, my community where I grew up was very generous. They would send me special cards - a train that had dimes in the wheels, and one that had quarters in the engine. They built a little HO train track for me for me, so I could play in my bed. I look back and realize what a gift it was. Perhaps it was because given the number of children who got polio, I could have been any one of their children. At only eight, I realized I had to be heroic, even though I didn't feel so. They wanted me to have a stiff upper lip, they wanted me to be a smiling little guy who appeared to believe "I'll be all right, don't worry about me." So, I rose to the occasion. That has served me well, as I was, and continue to be, upbeat and personable.

When they burned everything, that included my Daniel Boone Davy Crockett coonskin hat. In 1953, that was the big rage, Davy Crockett (played by Fess Parker) was on everything. Some years ago, I sold a patent of mine to a medical company, and they wanted me to come to Santa Barbara, California to demonstrate it. Santa Barbara was where Fess Parker owned a business. I saw him walking into the hotel. I walked up next to him and I started singing one of his songs as he walked by. He stopped and finished the song. We sat down and we talked, and I told him about the polio and the coonskin cap. Shortly after I got home, I got a box, and it had a coonskin cap, signed by Fess Parker - Daniel Boone. It was a sweet ending to a lovely experience.



I missed three months of school. When I was ready, they let me go back to my class. They thought it was continued . . .

important that I stay with my peers. To this day, I can't read Roman numerals. I missed that. Of course, the schools were not at all handicap accessible. With all I had learned, I had never been taught how to go up and down stairs. I remember being in class and realizing that the next class was upstairs. The teachers were kind and let me out five minutes early from class so I could struggle up those steps. In the beginning, I went up on my butt. I sat down on the second step, and then I pushed myself up and pushed the crutches up a step and on to the next one. Within a week, I was walking up and down steps. After a couple of months, my upper body kicked in. I started developing muscles in my upper body while I was doing two steps at a time on my crutches. I wanted to stay up with the other kids. I still have a lot of those friends and that's a good thing.



I was only eight when I realized how fragile life could be. Now, I look back on my life with a disability. Next to my lovely wife and daughter, and now granddaughter, polio was one of the best things that ever happened to me. It drew me out, it gave me a very optimistic feeling about people, and also a great sense of adventure. I was no longer afraid.



When I was 18 or 19, I realized that my mobility would always be limited. I was strong. I knew I wasn't going to be strong forever and wanted to really live.

My wife and I have lived all over the world - in India, Bali, Indonesia, and Greece. We've been around the world four times. I've climbed Borobudur, and I've climbed up to the Acropolis twice. Back in the 70s, I went overland from Germany to India, spending six months on the road. I don't think I would've done any of that if I hadn't had polio.

I do remember when the polio vaccine came out in the sugar cube. I would have been 15 and in Junior High. I remember asking the doctor, "What are the chances of me getting polio again?" "Oh," he said, "Probably one in a million." My response? "Give me that sugar cube." I got vaccinated. I wasn't going to take any chances – and *never* wanted to go through it again.

Since 1988, I've been working with people with every possible kind of disability. As a result of my struggling with shoulder pain from having used crutches since I was 8, I invented and patented a new crutch tip technology with a built-in shock-absorbing system. Regardless of where in the world we live, disabled people are the most amazing people I've ever met. It's just remarkable to me how people thrive under adversity.

Unless noted, photos provided by Thomas Fetterman.

Thomas's business - [Fetterman Crutches](#) was inspired by his own disability.

Thank you Meredith Sellers and the [Mütter Museum](#) of the College of Physicians, Philadelphia for your inspiring video about Thomas's life.



Thomas's story and video are available on our website under [Survivor Stories](#).

Look in the Index for Thomas Fetterman.

The Last of the Iron Lungs

By [Jennings Brown](#) for [Gizmodo](#)

“Martha Lillard spends half of every day with her body encapsulated in a half-century old machine that forces her to breathe. Only her head sticks out of the end of the antique iron lung. On the other side, a motorized lever pulls the leather bellows, creating negative pressure that induces her lungs to suck in air.”

“ ‘The period of time that it took the nurse to get out of the chair, it seemed like forever because you weren’t breathing,’ ” Lillard said. ‘You just laid there and you could feel your heart beating and it was just terrifying. The only noise that you can make when you can’t breathe is clicking your tongue. And that whole dark room just sounded like a big room full of chickens just cluck-cluck-clucking. All the nurses were saying, ‘Just a second, you’ll be breathing in just a second.’ ”

“I wanted to be a ballerina. That was my big wish. I started walking on my toes when I was one, and I just constantly was after ballerina dolls.” “She was infected with polio at her 5th birthday party.” “I think now of my life as a ballet. I have to balance so many things. It’s a phenomenal amount of energy I have to use to coordinate everything in my life.” Martha Lillard 2017

“Mona got polio at the age of 20 in 1956. At the time, she was a skilled pianist planning her wedding. She needed an iron lung for the first year, until she went to rehab in Warm Spring, Georgia, where she was able to wean herself off. But 20 years later, in 1977, she had a series of bronchial infections - possibly due to post-polio syndrome - and her doctors told her she needed to start using an iron lung again.”

“The ‘yellow submarine’ is my necessary, trusted, mechanical friend,” she told me. “I approach it with relief in store at night and thankfully leave it with relief in the morning.” “They lift Mona into the iron lung using a mechanical arm attached to their ceiling.” *

Paul Alexander “ . . . spends nearly every moment in his iron lung in the center of his living room, which is decorated with degrees, awards, pictures of family, and a drawing of the Scottish folk singer Donovan, who had polio. When people enter the front door a few feet away from him, he usually greets them with a warm upside-down smile, reflected in the mirror above his head.”

“Alexander, who got polio in 1952 when he was 6, is almost entirely paralyzed below the neck but that hasn’t stopped him from going to law school and becoming a trial lawyer. ‘When I transferred to University of Texas, they were horrified to think that I was going to bring my iron lung down, but I did, and I put it in the dorm, and I lived in the dorm with my iron lung.’ ‘I had a thousand friends before it was over with, who all wanted to find out what’s that guy downstairs with a head sticking out of a machine doing here?’ ”

It is now “nearly impossible for him to get out of the iron lung for a few hours like he used to do when he went to court and represented clients in a wheel chair.”



“Martha Lillard inside her iron lung, which has been modified by mechanics over the years.” Photo: [Jennings Brown for Gizmodo](#)



“Mona Randolph spends six nights a week in her iron lung.” Photo: [Jennings Brown for Gizmodo](#)



“Paul Alexander spends almost every moment of the day inside his iron lung.” Photo: [Jennings Brown for Gizmodo](#)

Vaccine Advocates:

Something they all had in common is a desire for the next generations to know about them so we'll realize how fortunate we are to have vaccines.

Mona: "When children inquire what happened to me, I tell them the nerve wires that tell my muscles what to do were damaged by a virus, and ask them if they have had their vaccine to prevent this. No one has ever argued with me."

Paul: "Now, my worst thought is that polio's come back." "If there's so many people who've not been - children, especially - have not been vaccinated . . . I don't even want to think about it."

Martha: ". . . is heartbroken when she meets anti-vaccine activists. Of course, I'm concerned about any place where there's no vaccine, I would just do anything to prevent somebody from having to go through what I have. I mean, my mother, if she had the vaccine available, I would have had it in a heartbeat."

*Mona Randolph died on February 18, 2019 at age 82.

Read the [Complete Article](#) (that contains numerous photos and two videos): [The Last of the Iron Lungs](#)
Published November, 2017



As we bring 2023 to a close, we say "Thank You" to Post-Polio Health International for their 2023 Lecture Series.

Their latest presentation is a fascinating presentation by Marny K. Eulberg, MD
"The Interplay Between Polio Residuals, Aging and Common Health Problems"

[PHI](#) Director Brian Tiburzi introduces the speaker at the beginning of the video.

We are happy to be able to share this series in the [Living with Post-Polio Syndrome](#) section of our website.

You can easily find the series in the Index under: Post-Polio Health International (or) Video

We're "getting more mature":

It happens to all of us . . . if we're lucky enough !

But what if we had polio?

In her presentation, primary care physician and polio survivor [Dr. Marny Eulberg](#) explains that many things have happened to us since we had polio, and that very few of us are a "pure case of our polio" anymore. She highlights how difficult it can be to identify only ONE cause of a polio survivor's symptoms.

Dr. Eulberg's many articles are easily available on our website under: [Primary Care Perspective](#)
(Look under the Heading Articles/Resources)



Thank you for your kind words and generous [donations](#).

Your words inspire us and your donations pay for the many expenses required to continue this work.

Please don't hesitate to contact us:

info@polionetwork.org (NOTE – this is a new email address)

PO Box 557, Doylestown, PA 18901

Preventing Falls at Home: Room by Room

Many falls happen at home, where we spend much of our time and tend to move around without thinking about our safety. There are many changes you can make to your home that will help prevent falls and better ensure your safety.

Floors, Stairways and Hallways

- Ensure there are handrails on both sides of any stairs, and make sure they are secure. Hold the handrails when you go up or down stairs, even when you are carrying something. Don't let anything you're carrying block your view of the steps.
- Ensure there is good lighting with light switches at the top and bottom of stairs and on each end of a long hall. Consider using motion-activated lights that plug into electrical outlets and automatically turn on when you walk by them to help illuminate stairwells and pathways.
- Keep areas where you walk tidy. Don't leave books, papers, clothes, or shoes on the floor or stairs.
- Check that all carpets are fixed firmly to the floor, so they won't slip. Put no-slip strips, which you can buy at any hardware store, on tile and wooden floors.
- Don't use throw rugs or small area rugs.
- Don't walk on slippery, newly washed floors.



Fall hazards in the home, including a scatter rug, dog, and empty slippers. Source

Bathrooms

- Mount grab bars near toilets and on both the inside and outside of your tub and shower.
- Place nonskid mats, strips, or carpet on all surfaces that may get wet.
- Remember to leave a light on in the bathroom at night or use a night light that turns on automatically in the dark.

Bedrooms

- Put night lights and light switches close to your bed.
- Keep a flashlight by your bed in case the power goes out and you need to get up.
- Place a landline or well-charged phone near your bed.

Kitchen

- Keep frequently used pots, pans, and kitchen utensils in a place where they are easy to reach.
- Clean up spills immediately.
- Prepare food while seated to prevent fatigue or loss of balance.

Outdoor Spaces

- If you have steps leading to your front door, make sure they are not broken or uneven.
- Add non-slip material to outdoor stairways.
- Keep the lawn, deck, or porch areas clear of debris, such as fallen branches.
- Consider installing a grab bar near the front door to provide balance while you are locking or unlocking the door.
- Turn on your porch light at night and if you leave during the day but plan on returning home after dark.
- In the winter, treat outdoor walkways with an ice melt product or sand to make them less slippery.

Other living areas

- Keep electrical cords near walls and away from walking paths.
- Arrange your furniture (especially low coffee tables) and other objects so they are not in your way when you walk.
- Make sure your sofas and chairs are the right height for you to get in and out of easily.
- Keep items you use often at waist level or within easy reach.
- Don't stand on a chair or table to reach something that's too high - use a "reach stick" instead or ask for help.

(continued . . .)

- Reach sticks are special grabbing tools that you can buy at many hardware or medical-supply stores.
- If you use a step stool, make sure it's steady and has a handrail on top. Have someone stand next to you.
- Don't let your cat or dog trip you. Know where your pet is whenever you're standing or walking.
- Keep a list of emergency numbers in large print near each landline phone and save them under "favorites" on your mobile phone.

If you have fallen, your doctor might suggest that an occupational therapist, physical therapist, or nurse visit your home. These health care providers can assess your home's safety and advise you about making changes to lower your risk of falls.

Tools To Get Help

Six Tips To Help Prevent Falls

More than one in four people age 65 years or older fall each year, yet many falls can be prevented.



Español

Other Options

- Carry a well-charged cordless or mobile phone with you as you move throughout the house.
- Have close friends and family on speed dial.
- Consider setting up a smart home device (a small speaker that listens and responds to commands when you call its name) that can quickly connect you to contacts or emergency response teams.
- Some smartwatches can be set up to make emergency calls at the push of a button and others can even detect sudden fall-like movements and automatically call for help. Ask family and friends for help setting up these tools.

Home improvement resources

Many state and local governments have education and/or home modification programs to help older people prevent falls. Check with your local health department, search the Eldercare Locator, or call 800-677-1116 to find your local Area Agency on Aging to see if there is a program near you.

Read this article in Spanish. Lea sobre este tema en español.



Calling For Users of Negative Pressure Ventilation:

Norma M. Braun, MD is looking to interview more Post-Polio patients (and others) who can describe their experiences while they were using negative pressure devices such as an Iron Lung or Chest Cuirasses.

In addition, she's hoping to interview those who may have needed ventilatory support in later years.

Dr. Braun is a pulmonologist in New York, New York and is affiliated with Mount Sinai Morningside and Mount Sinai West Hospitals. She received her medical degree from Columbia University Vagelos College of Physicians and Surgeons and has been in practice since 1982.

- Medical School - Columbia University College of Physicians & Surgeons
- Internship - Medicine & Surgery NYU/Bellevue Hospital Center
- Residency - Internal Medicine NYU/Bellevue Hospital Center
- Fellowship - Pulmonary & Critical Care Saint Luke's-Roosevelt Hospital Center
- Certifications – Pulmonary Disease and American Board of Internal Medicine

Dr. Braun is a Clinical Professor in the areas of Pulmonary Medicine, Sleep Medicine and Critical Care.

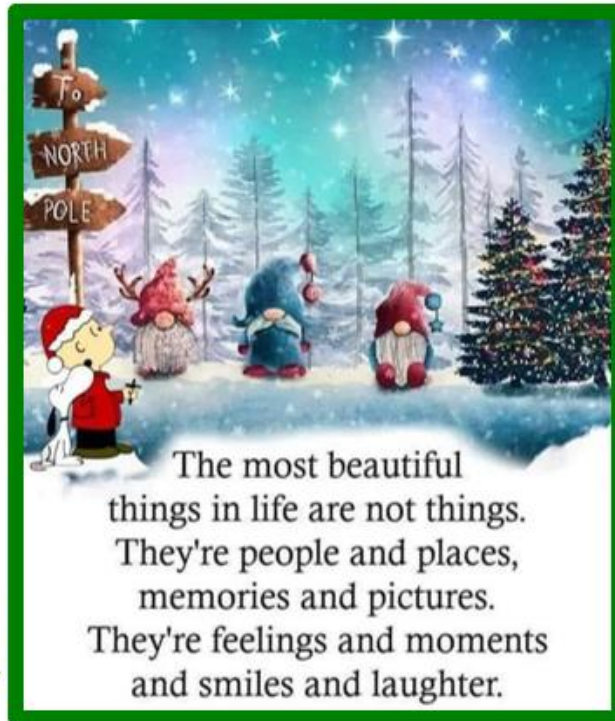
If you are interested, she wants you to know that she will protect your privacy.

She will do the interviews by either Phone or Zoom.

You can familiarize yourself with Dr. Braun in multiple ways.

- Her [Biography](#)
- Her Article: [Preparing for Surgery for Post-Polio or Other Chronic Respiratory Disorder Patients](#)
- Her Video with PHI: [Non-Invasive Ventilation](#)
- The [Questionnaire](#) she will be using.

Please contact Dr. Braun by email: norma.braun@mountsinai.org



Unless noted with the article, feel free to copy and share what you see. Always give credit to the original source, include a visible, working link to our website: www.polionetwork.org and email us a copy of what you "share". THANKS.



Email: info@polionetwork.org

215-858-4643

We are a Registered 501C3 organization