



Polio Survivors Serving Others

Information & Inspiration
For All Polio Survivors and their Families

The PA Polio Network

www.polionetwork.org

July, 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:

Anesthesia and Polio Survivor Treatment Information: Over the last 6 years, we have distributed thousands of our original cards throughout the US. At the recommendation of numerous professionals, we have updated the easy access to this information and have published newly updated and easily downloaded:

- [Anesthesia Warning Cards](#) and [Polio Survivor Treatment Warnings For Medical Personnel and Caregivers](#)

We realize many survivors struggle with downloading and printing materials. Feel free to contact us. We're happy to help provide these materials.

Note: It is important for you to replace your card with the updated version.

His Parents Would Have Given Anything For Their Son to Have Had a Vaccine to Prevent Polio: Brad Fuller isn't alone. He was an active 16-month-old toddler in the summer of 1952. It was the year that Polio reached its peak throughout the United States. His life has never been the same.

Primary Care Provider – Do I need one ? Marny K. Eulberg, MD gives us ten Reasons To Have A "Primary Care Healthcare Provider". Primary Care Healthcare Providers (PCP) can be a family physician often known as general practitioners (GPs), an internal medicine physician, a geriatrician/gerontologist, a nurse practitioner, or a physician assistant.

Searching for Specific Topics: Our new website [Tip of the Month:](#)

How do I search by a specific topic for my favorite author? This site has a "search bar" but you can do more.

The 1954 Polio Vaccine Trials: This powerful quote from Paul A. Offit, MD, Director of the Vaccine Education Center at the Children's Hospital of Philadelphia, brings back memories of the fear that came with the poliovirus.

"In 1954, 420,000 first and second graders in the United States were inoculated with Jonas Salk's inactivated polio vaccine; 200,000 were inoculated with salt water. It was one of the largest placebo-controlled trials of a medical product in history. Jonas Salk didn't want to do it. He couldn't conscience giving a saltwater shot to young children when as many as 50,000 were paralyzed by polio and 1,500 died every year.

Continued . . .

When the trial was over, the vaccine was declared “[safe, effective, and potent](#).” Church bells rang out; synagogues held special prayer meetings; department store patrons stopped to listen to the results of the trial over loudspeakers.

How did we know that Jonas Salk’s polio vaccine was effective? We knew because 16 children died from polio in that study - all in the placebo group. We knew because 34 of the 36 children paralyzed by polio in that study were in the placebo group. These are the gentle heroes we leave behind.” [Paul A. Offit, MD](#) July 1, 2023



[The Last Mile and Tommy Francis:](#)
from the University of Michigan

Are you one of the 420,000 who participated in this historical vaccine trial? We’d love to tell your story. Contact us.



Anesthesia and Polio Survivor Treatment Information

www.polionetwork.org/anesthesia-card

Polio Survivors with Post-Polio Sequelae (PPS) often have all or some of the following symptoms:

- EASILY SEDATED and can be difficult to wake
- Can Have Difficulty BREATHING and SWALLOWING with Anesthesia
- HYPERSENSITIVE to PAIN and COLD.
- May need a heated blanket and increased pain medication post-op
- In addition, Polio Survivors with Post-Polio Sequelae also can experience:

Cold Intolerance	Difficulty Swallowing
Difficulty Breathing	Muscle and Joint Pain
Muscle Weakness	Overwhelming Fatigue
Sensitivity to Anesthesia	Sleep Disorders

The QR code on our newly updated Anesthesia Warning Card goes to the following information on our new [website](#). The great advantage to this format is when new information is added (ex: Norma M. Braun, MD and Polio Denmark) the card immediately gives your physician access to the Article as well as the contributor’s biography.

Both the Anesthesia Warning Cards (available in both English and Spanish) and the newly updated “Polio Survivor Treatment Warnings For Medical Personnel and Caregivers” document are easily available for [download](#).

ANESTHESIA WARNING!

I am a **Polio Survivor**

- **Easily Sedated**, and can be difficult to wake
- Can have difficulty **breathing** and **swallowing** with anesthesia
- **Hypersensitive to pain and cold**

May need heated blanket and increased pain medication post-op



www.polionetwork.org/anesthesia-card

Anesthesia Warning Card (Front)

I am a **Polio Survivor** with Post-Polio Sequelae

Name: _____

I have these Symptoms (checked):

<input type="checkbox"/> Overwhelming Fatigue	<input type="checkbox"/> Muscle Weakness
<input type="checkbox"/> Muscle and Joint Pain	<input type="checkbox"/> Sleep Disorders
<input type="checkbox"/> Cold Intolerance	<input type="checkbox"/> Difficulty Swallowing
<input type="checkbox"/> Difficulty Breathing	<input type="checkbox"/> Sensitivity to Anesthesia

(Scan Code for Anesthesia Information - Over)
www.polionetwork.org/anesthesia-card

Anesthesia Warning Card (Back)

Caregivers can read the following information when determining the treatment plan for any Polio Survivor.

[Breathing Outcomes: Post-Poliomyelitis Syndrome \(PPS\)](#): by [John Bach, MD](#)

[Polio Patients and Surgery](#): from [Polio Denmark](#)

[Post-Polio Syndrome and Anesthesia: For Anesthesiology Magazine](#):

by David A. Lambert, M.D.; Eleni Giannouli, M.D.; Brian J. Schmidt, M.D.

[Preparing for Surgery for Post-Polio or Other Chronic Respiratory Disorder Patients](#):

by [Norma M. Braun, MD](#)

[Preventing Complications in Polio Survivors Undergoing Surgery](#):

by [Richard L. Bruno, HD, PhD](#)

[Preventing Complications in Polio Survivors Undergoing Surgery \(Dental\)](#):

by [Richard L. Bruno, HD, PhD](#)

[Summary of Anesthesia Issues for the Post-Polio Patient](#):

by [Selma Calmes, MD](#)

Polio Survivor Treatment Warnings For Medical Personnel and Caregivers

This [Document](#) was developed at the request of a survivor, who had moved into an assisted living facility. She wanted to have a single document available should she be taken to the hospital. It has a symptom checklist, QR codes to multiple resources with information regarding the late effects of Polio (PPS) and available space on the reversed side for personal notes/concerns. You can copy this easily printable document, and give it to your family and physician. Many of you have put a copy of this with your important documents.

Thank you [John Bach MD](#), [Richard Bruno PhD](#), [Selma Calmes MD](#), [William DeMayo MD](#), [Marny Eulberg, MD](#) and Richard Rosenstein DO for your advice and support in this updated project.



**Polio Survivor Treatment Warnings
For Medical Personnel and Caregivers**
I am a Polio Survivor with Post-Polio Sequelae.

I can:

Be EASILY SEDATED, and may be difficult to wake
Have Difficulty BREATHING and SWALLOWING with Anesthesia
Be HYPERSENSITIVE to PAIN and COLD.

Need a HEATED BLANKET and Need to have Increased Pain Medication post-op.

Name: _____ Date of Birth: _____

I have these Symptoms of Post-Polio Syndrome (PPS) - checked:

- | | |
|--|--|
| <input type="checkbox"/> Overwhelming Fatigue | <input type="checkbox"/> Muscle Weakness |
| <input type="checkbox"/> Muscle and Joint Pain | <input type="checkbox"/> Sleep Disorders |
| <input type="checkbox"/> Cold Intolerance | <input type="checkbox"/> Difficulty Swallowing |
| <input type="checkbox"/> Difficulty Breathing | <input type="checkbox"/> Sensitivity to Anesthesia |

**** Anesthesia Warning ****

Preventing Complications in Polio Survivors Undergoing Surgery

www.polionetwork.org/anesthesia-card



Breathing Outcomes for Post-Poliomyelitis Syndrome

Breathing and Ventilation Information

www.breathenvs.com



Encyclopedia of Polio and PPS

Information for all Subjects related to PPS

www.polionetwork.org/encyclopedia



Information on Multiple Subjects Related to PPS

Post-Polio Care for Families and Health Care Providers

www.polionetwork.org/living-with-post-polio-syndrome



Post-Polio Health International

www.post-polio.org



Please take this information into account, when you are creating my treatment plan.

I have added additional information, relating to my medical history, on the back side of this page. (Allergies, Current Medications, Tests Etc.)

Signature: _____ Date: _____

Brad Fuller

His parents would have given anything for their son to have had a vaccine to prevent polio.

Written by Helen Urban



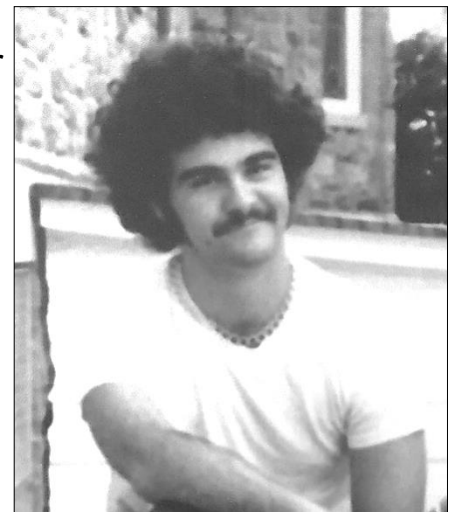
The summer he got polio.

Source: Brad Fuller

Brad Fuller was an active 16-month-old toddler in the summer of 1952. It was the year that Polio reached its peak throughout the country, affecting 58,000 children and adults, causing 3,000 deaths. That's when he contracted Polio. The northeast region of Pennsylvania, where he lived, was especially hit hard with the virus. Brad's grandparents lived on an old farm in a rural area. When his Dad was away with the Air Force, their mother would often take Brad and his siblings to stay at their farm. That's where he got sick. He was admitted to the Hospital for Crippled Children in Elizabethtown, PA - putting the toddler more than 8 hours away from his home. He stayed 9 months in the hospital, his first 4 months were spent in an iron lung. He can remember a nurse holding him in a mineral pool and instructing him to kick his legs.

His family was only allowed to visit once a month and could only speak to him through a 2-inch slot in the door. Brad was left with a weakened left leg (2 inches shorter than his right) and a weakened right shoulder, arm and hand. Luckily, his siblings were not affected by the disease. His mother always believed that he got polio from contaminated well water on the farm. Like so many other children, they never knew for sure. His parents often said that "they would have given anything to have had a vaccine for their children". Brad's childhood hero was Jonas Salk.

Up until he was in the 10th grade, Brad and his family lived at or near various Air Force bases throughout the South (Lake Charles, LA; Homestead Air Base, Atlanta, GA). He remembers his first day of school in Lake Charles being interesting. He had two things going against him right from the start - he was wearing a leg brace and he was from the North. One of his classmates decided to tease him. Needless to say, a fight broke out between Brad and the other boy. When all was said and done, the two boys ended up becoming good friends. He feels that one of the benefits of moving to different areas during his childhood is that it helped him to develop a more outgoing personality as he had no choice but to make friends in each new place. He engages easily with new people and is often told that they don't see him as disabled.



A student at Albright College

Source: Brad Fuller

When Brad was 18, he underwent ankle and knee surgery. As he came out of surgery, he was terribly cold and his body was shaking. His physician knew that this was a reaction to the anesthesia. His doctor advised him that many polio survivors have uncomfortable experiences with anesthesia and that in the future, he should inform the medical staff at the hospital that he had Polio prior to any surgery.

Continued . . .

Brad Fuller (continued . . .)

Despite his physical limitations, he felt invincible. Brad managed to play football in his youth, doubles tennis into adulthood (he had a great left hand serve) and played bass in a rock band. He received his undergraduate degree from Albright College in Reading, PA (where he met his wife, Rei). He earned two Master's Degrees from Kutztown University (one in Public Administration and one in Clinical Psychology). These degrees served as the foundation for his future in healthcare.

Brad has spent most of his career in various aspects of Healthcare administration. His duties have included overseeing community-based programs particularly helping mentally ill patients released from the State Hospital. These programs offer assistance as they acclimate back into society. He has been an administrator at hospitals, clinics, and Senior Centers, supervised social workers at runaway youth shelters and the Big Brother/Big Sisters organization.



Brad (left rear) playing the bass in his band. Source: Brad Fuller

He became a clinical psychologist and had a part time private practice where he specialized in marriage and family relationships. Brad gave up his private practice in 1990 when he was offered the opportunity to teach Health Administration at St. Joseph's University in Philadelphia. He taught there until his retirement in 2014.

It wasn't until Brad was in his forties that he was officially diagnosed with PPS. He was fortunate to have had a physician who was well read and up to date on current medical information. It was this physician who concluded that he had PPS. (Many physicians write PPS symptoms off as "normal aging").

Brad was introduced to Rotary International in an unusual way. He was Executive Director of a fairly large Senior Center in Pottstown, PA. They often hosted community groups who held meetings in their building. One evening, the Pottstown Rotary club held its meeting and Brad introduced himself to the group. After the meeting, a Rotary member, Dr. Richard Whitaker, introduced himself to Brad. He was interested in Brad's polio story as he had a brother who had passed away from the virus. The following day, Brad fell down a flight of steps at the Center and suffered a severe injury to his left knee. The ambulance took him to Pottstown Memorial Hospital. It just so happened that the surgeon on duty was Dr. Whitaker! Needless to say, after several knee surgeries and many office visits, the two developed a friendship. Dr. Whitaker introduced him to Rotary International's focus on polio eradication. As a result, Brad was invited to be a keynote speaker at several of their conferences. It comes as no surprise that Brad has become



Brad Fuller at Home. Source: Maddy Alewine for [Undark Magazine](#).

Continued . . .

Brad Fuller (continued . . .)

an avid supporter and admirer of their mission to eradicate Polio. Upon his retirement, Dr. Whitaker made a generous donation to The Pottstown Area Senior Center. In honor of his generosity, the building was named after Dr. Whitaker and his wife.

Now semi-retired, Brad and his wife Rei live in Asheville, NC where Brad volunteers as an instructor at UNCA (University of NC Asheville) in the OLLI program (Osher Lifelong Learning Center). He meets regularly with a local group “Land of the Sky Post-Polio Support” based in Asheville, NC. And if that isn’t enough to keep him busy, he also teaches Japanese History and Health Care courses in his spare time.

Although he wears a full leg brace, he struggles with frequent falls. Always one to move forward with a positive attitude, this Spring offered Brad quite the challenge. At the end of May, he was home alone getting ready to retire for the evening. His KAFO leg brace failed, and he fell. He managed to call an ambulance and went to their local hospital. Brad had a spiral fracture of his left tibia, requiring surgery. After a month in rehab, he was fully wheelchair dependent for 9 -10 weeks before he could put any weight on his leg. He sees it as one more opportunity to reflect on his parent’s wisdom. “Because God knows, they would have been happy to be able to give their son the polio vaccine.”



“Polio – A Paralyzing Fear”
(Sponsored by OLLI at UNCA)
www.polionetwork.org/archiv e/ba6b0ix4rypadj9k2qdmvi0f w4cbof

Source: Undark Magazine [For Some Survivors, Polio Casts a Long Shadow](#)



Ten Reasons To Have A “Primary Care Healthcare Provider”

By [Marny K. Eulberg, MD](#)

1. To have someone who knows about all of you - not just one portion of your body
2. To have a “coach” who heads up the team of people caring for you and helps you be the best you can be.
3. To have a “translator” who can tell you, in plain English, what the heck the specialist was saying in their report or when they talked to you.
4. To have someone who acts as “traffic controller” and knows what the difference is in knowledge and services that are offered by different specialists.
 - Example: If you have a kidney problem, should you see a nephrologist or a urologist?
5. To be a “coordinator” of care when you would benefit from care from several physicians, services, or agencies.

Continued . . .

6. To save you some expensive emergency room charges when you could get appropriate care in a different (less expensive) setting
7. To minimize the “battery of tests” that some specialists order before even talking with you and might have already been done!
8. To help you be proactive in dealing with conditions such as smoking, obesity, high blood pressure, and cardiovascular disease that can have cumulative damage over time and can add to the burden a polio survivor carries as they experience PPS.
9. Because, at least for now, preventive healthcare (in the US) is covered without co-pay/deductible with most insurances, whereas “illness-based care” is usually subject to co-pays/deductibles
10. Because your health insurance requires a referral from a PCP before you can get certain tests, see some specialists, or access care.



Primary Care Healthcare Providers (PCP) can be a family physician often known as general practitioners (GPs), an internal medicine physician, a geriatrician/gerontologist, a nurse practitioner, or a physician assistant.

The physicians who serve as PCPs may have the initials, D.O. (Doctor of Osteopathy) or M.D. (Doctorate of Medicine) after their names. Both types of medical education prepare

them to serve as PCPs. In my experience, physicians who have a D.O. degree have a better basic understanding of how the neuromuscular system functions in health and in illness. On this topic, I found this article interesting - [“Allopathic and Osteopathic Physicians May Provide Equivalent Quality of Care”](#) (“Allopathic” is another term for an M.D.).

There are different models of practice today - there still is the traditional office-based practice, there are “concierge” practices, and yes, there are even a few providers who provide most of their care in the patient’s home and make house calls routinely.

Don’t expect your PCP to be exactly like TV’s Marcus Welby (the character who played a family practitioner with a kind bedside manner, who made routine house calls and was on a first-name basis with many of his patients). Depending on where you live, most PCPs no longer go to the hospital daily to see their patients or serve as first assistant when their patient has surgery. It makes me very sad, but most insurances (in the US) will no longer pay for your PCP to be your attending physician when you are in the hospital. The PCP can come “visit” you like any other visitor but has limited authority to manage your care while you are hospitalized, in a rehab facility, or in a nursing home. This also means there is less opportunity for PCPs to truly KNOW various specialists and be able to match the patient’s and the specialist’s personalities.

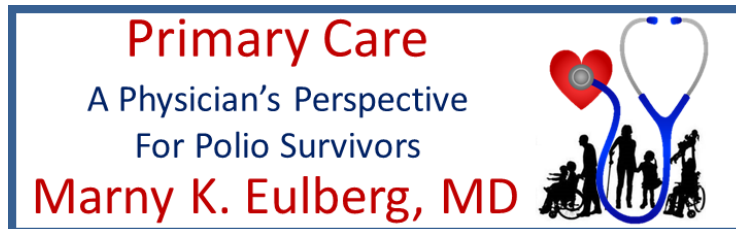
The most important factor in choosing a PCP is finding someone with whom you feel most comfortable. This does NOT mean they say “yes” to everything you want. Like a good parent, it can also mean telling you things you don’t want to hear but that are “good for you” and in your best interest (but and hopefully, said with firm gentleness and caring!). Obviously, it also helps significantly if they “participate” with whatever insurance you have!

Other factors I think are important to consider in choosing a PCP are:

- How easy it is to get into their office? Is it convenient for you to get there?
- Do you need handicapped accessibility? Is the office accessible?
- Is the practice able to accommodate your unique physical and emotional needs?
- How easy it is to deal with the office's front desk and nursing staff ?
 - Are calls returned in a timely manner?
 - Is the staff caring and compassionate?
 - Does the staff put the patient first or does it seem that their first priority is to protect the physician's time?

Choosing a primary care physician shouldn't be made without careful consideration to what YOU need. It isn't necessarily an easy decision, but can be a very important one. You do have the right to "interview" primary care providers before hiring them, similar to hiring a landscaper, plumber, etc. In the U.S. if you have an HMO or PPO the insurance may limit how one navigates the process of "shopping" for a new primary care physician.

[Marny K. Eulberg, MD](#)



Dr. Marny Eulberg has written an extensive series of articles that provide a physician's perspective on a variety of post-polio-related topics. Her goal is to better help polio survivors with their care. Featuring a mix of Q&A-style articles, as well closer looks at specific areas of interest, she provides important insights to both polio survivors and caretakers alike. Her articles are easily [available](#). Are you looking for a specific topic? Click on the Index/Categories box.

www.polionetwork.org/primary-care-perspective

Dr. Eulberg is a polio survivor (class of 1950) and is very involved in organizations dedicated to polio survivors and polio eradication. She serves on the Executive Committee for Post-Polio Health International and is serving as the End Polio Now Coordinator for Rotary Zone 26 (that includes the southwestern US and Hawaii). Her medical practice is now limited exclusively to polio survivors.



THANK YOU for your uplifting comments and your generous [donations](#).

Your words inspire us. Your donations are the means by which we are able to Continue paying for the necessary expenses to continue our work helping polio survivors and our caregivers, all over the US and abroad.





Polio Network

Polio Survivors Serving Others
www.polionetwork.org

Transitioning from www.papolionetwork.org to www.polionetwork.org

Here's our July Tip for using our new website.

Finding information by Subject/Topic

INDEX/CATEGORIES

The enormous number of articles, written by our generous, primary contributors now have easy access to an extensive index. When you are searching information, look for the Index/Category "Button". With one click on the button, every index item is listed alphabetically for easy access. "Click" on the topic of interest and the articles will come up.

<u>Article/Resource</u>	<u>Author</u>	<u>Index Entries</u>
Bruno Bytes	Richard L. Bruno, HD, PhD	483
DeMayo's Q&A Clinic	William M. DeMayo, MD	53
Encyclopedia of Polio and PPS	Richard L. Bruno, HD, PhD	572
Polio History – Putting the Pieces Together	Daniel J. Wilson, PhD	44
Primary Care Perspective	Marny K. Eulberg, MD	61

We have to thank our PA Polio Network volunteer, Denise, for her 8 years of dedication to keeping the Index that has been the basis for this outstanding tool. It supplements the standard "search bar" in that it brings the ability to seek very specific topics for the professionals who give so much to us all.



ALWAYS feel free to contact us.

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.



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