

## Polio Survivors Serving Others

Information & Inspiration For All Polio Survivors and their Families

## The PA Polio Network

www.polionetwork.org

October, 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:

October is Polio Awareness Month all over the world. What IS World Polio Day?

World Polio Day was established by Rotary International, one of the earliest participants in the Global Polio Eradication Initiative, to commemorate the birth of Jonas Salk, who led the first team to develop a vaccine against poliomyelitis. World Polio Day (celebrated each year on October 24) provides an opportunity to highlight global efforts toward a polio-free world and honor the tireless contributions of those on the frontlines in the fight to eradicate polio from every corner of the globe.

"As long as wild poliovirus continues to circulate in Afghanistan and Pakistan, all countries are at risk of wild poliovirus being imported. Outbreaks of poliovirus variants – which emerge when not enough children are vaccinated against polio – present an additional and pressing challenge in multiple countries.

On World Polio Day, the CDC commemorates this progress and joins its GPEI partners in the call to overcome the barriers to Make Polio History once and for all." (CDC)

"Today, the world is closer than ever to eradicating an ancient disease thanks to proven tools and brand-new innovations." This article "Polio Eradication Through Innovation" from the Johns Hopkins Bloomberg School of Public Health explains why, through the use of these extraordinary tools available in 2023, the eradication isn't as far away as we think.

Rotary Magazine has featured our friend, advocate and fellow survivor Ina Pinkney in their <u>October issue</u>. Her powerful story "Polio Survivor Ina Pinkney Reflects On Life's Pains And Pleasures" is a "must" read.

We celebrate this amazing effort. "After 35 Years, Polio Has Been Cornered. We Must Finish the Job." Survivor Joe Randig has written from the perspective of those of us who understand first hand WHY this must end. <u>Join us</u> and become a part of the solution. If polio exists anywhere it is a threat to children everywhere.

**Accessible Travel for Polio Survivors:** A part of their fascinating 2023 Lecture and Town Hall series, Post-Polio Health International has shared their information filled conversation with travel professional Candy Harrington.

**Exercise and Polio Survivors – Could Anything New be Published?** Richard L. Bruno, HD, PhD recognizes that this article may surprise many of you. His latest article: "Is Exercise Okay In Polio Survivors After Surgery or Immobility?" Has an interesting "twist" to the conversation.

Marny Eulberg - Polio Survivor, Physician & Humanitarian: We've had the marvelous opportunity to work with <a href="Dr. Eulberg">Dr. Eulberg</a> since 2019. We share her work in these newsletters and on our website under the heading: Primary Care Perspective. Now, the table has been turned. PPSN's Helen Urban had the opportunity to interview and write about HER. We are happy to bring you the story of this amazing woman.

The Polio Vaccines - IPV, OPV, cVDPV, nOPV2: This is all so confusing. What ARE they? What's the difference? We have multiple, easy to access resources to help.

- Our <u>August 2022 Newsletter</u> featured: "Vaccine-derived Polioviruses: Managing the risks
  What are vaccine-derived polioviruses and vaccine-associated paralytic poliomyelitis?" And "Updated
  Statement On Report Of Polio Detection In United States"
- Our <u>July 2022 Newsletter</u> featured: "Wild Poliovirus vs Circulating Vaccine-Derived Poliovirus What's The Difference?" And "Vaccine-Derived Poliovirus (VDPV2) Detected In Environmental Samples In London, UK"
- Our September 2021 Newsletter featured: "The Virus" (one of our favorites).

We are grateful to the Rotary Foundation and the <u>Global Polio Eradication Initiative</u> (GPEI) for these clear explanations of this topic that means so much to polio survivors.





# Is Exercise Okay In Polio Survivors After Surgery or Immobility?

By Richard L. Bruno, HD, PhD

Director, International Centre for Polio Education

Polio Education New weakness can be caused by a leg, arm, hip or shoulder being immobilized or after having had surgery. Is exercise okay to treat new muscle weakness after surgery or immobility, say having your leg in a cast for six weeks? I'm sure you think my answer is no. But the answer is a very qualified "possibly".

Let's first talk about muscle strength, which is measured on a six point scale from 0 (paralyzed, having no strength) to 5 (muscle so strong that the therapist can't "break" your muscle's contraction).

Say you have a knee replaced and your quadriceps (thigh muscle) strength drops after surgery from 4/5 to 3/5, from "pretty strong" to just being able to raise your lower leg against gravity. This loss of strength likely is not due to new post-polio muscle weakness and neuron failure, but to the effects of surgery. Is it okay to exercise to bring your strength from 3 back to 4?

Score	Description
0	No contraction.
1	Flicker or trace of contraction
2	Active movement, with gravity eliminated.
3	Active movement against gravity.
4	Active movement against gravity and resistance
5	Normal power

Canadian physiatrist Rubin Feldman developed a protocol for just this situation: 50% non-fatiguing exercise (Orthopedics. 1985 Jul;8(7):889-90).

• 50% non-fatiguing exercise is when a patient does *half* the amount of exercise that causes any symptom: be it muscle weakness, fatigue, shaking or pain.

Polio survivors are amazed when this often piddling amount of exercise increases muscle strength and endurance following immobility or surgery. But, Feldman warns never to perform even 50% non-fatiguing exercise in muscles with less than antigravity strength – muscles graded less than 3/5 that can't lift their limb's weight against gravity - and is not intended to treat post-polio muscle weakness.

Why is non-fatiguing exercise okay after surgery but not recommended for treating post-polio muscle weakness? Think of your muscle strength as a bucket of water. Surgery or being in a cast scoops water out of the bucket and non-fatiguing exercise puts the water back. Post-polio muscle weakness is like having a hole in the bucket that is draining off your muscle strength and exercise will just make the hole in the bucket bigger.

Take this article with you to your first session with the physical therapist, explain that you are a polio survivor and must only do non-fatiguing exercise to prevent further motor neuron damage. Count the number of repetitions of exercises that you are given to identify the point where you feel any symptoms: muscle weakness or shaking, fatigue or pain. Then, talk to the therapist about doing only half of the number of symptom-causing repetitions to protect your neurons.

Please know that the success of 50% non-fatiguing exercise completely depends on polio survivors being aware of their symptoms, stop exercising when symptoms are felt and not being cowed by therapists demanding that you "push through and feel the burn".

Richard L. Bruno, HD, PhD

Source: The use of strengthening exercises in post-polio sequelae. Methods and results

This article is easily available in the <a href="Encyclopedia of Polio and PPS">Encyclopedia of Polio and PPS</a>.

Look in the Index under the topic: Exercise. Scroll through those articles.

"Is Exercise Okay In Polio Survivors After Surgery or Immobility?" will come up as a choice.



## Marny Eulberg Polio Survivor, Physician & Humanitarian

By Helen Urban



Marny Eulberg (lower right) sits on a tricycle during her hospital stay for polio infection in 1950. She recovered, became a physician and ran one of the first dedicated PPS clinics in the US.

Source: <u>Undark Magazine</u>

Marny Eulberg grew up in northeast South Dakota on a family farm. In 1950, at the age of four, she contracted polio. At the same time, one of her two younger siblings (a sister who was 14 months old) also contracted polio. They were both hospitalized the same day - Marny for six months and her sister for 6 weeks. There were few polio cases in their community that year, but in 1955 the number grew. Like some of the other Polio children at the time, Marny was a March of Dimes poster child.

Marny's mother suspected that her younger son had it at the same time, but he never developed any paralysis. At the time, the testing was inadequate to determine exposure to the virus. Her family was poor and their house had running water but no sewage system. This could possibly have been the source of the virus. Her parents had previously purchased a health insurance policy which covered "Eight Diseases". Fortunately, Polio was one of them. The policy coverage was for 3 years or \$10,000. It covered her six-month stay in the hospital and three of her surgeries. (She would have six surgeries before she entered high school). The March of Dimes also offered further financial assistance.

When she was released from the hospital, she was wearing one leg brace and using crutches. She was told that if she worked hard enough, she wouldn't need the brace to walk anymore. By the time Marny entered junior high, she was free of the brace. Her pediatrician was a polio survivor and felt that wearing the brace did more psychological damage than there was value from the brace. She stopped wearing the brace until her late 30's when the weakening in her muscles became so severe, she actually needed the brace once again.

As a result of having Polio, the sisters were each left with one leg shorter than the other. They were opposite legs - Marny's was her left leg and her sister's was her right leg. Their mother made their clothes for them and would customize their outfits for their shorter, thinner leg. Having learned to sew from their mother, the girls made clothes in 4-H and would customize them accordingly. Since this also affected their shoe size on one foot, they had difficulty buying shoes. Of course, they figured it out - they would buy 3 pairs of the same shoe in 3 different sizes. Once they mixed and matched them, they would each come away with one new pair of the correct fitting shoes!

With her awkwardness and limp, Marny experienced some bullying and felt left out - especially with sports. She was always the one left after the teams were picked on the playground. That was when she decided to put all of her efforts into academics and set her sights on becoming her high school class valedictorian. Unfortunately, it did not happen (she narrowly missed it) but her strong academic skills would pay off throughout her career. In addition to her academics, she learned to play the saxophone. Thanks to an amazing band director and her supportive parents, when she got to high school, Marny joined their awardwinning high school marching band – playing while sitting down and in full band uniform! She was even able to travel with them and get to enjoy being part of the band.

From the time she was in 8th grade, Marny wanted to be a nurse. Her parents felt that her physical challenges would limit her in that line of work, so they introduced her to a local medical technologist (lab tech) to discuss career opportunities. It must have worked. Marny went on to attend South Dakota State University and graduated with a BS in Clinical Laboratory Technology. She spent three of those years on campus and one year in a hospital lab. Upon graduation, she worked for two years in a medical lab in Tucson, Arizona. Always grateful for thoughtful, caring parents, she wrote a letter to her mother acknowledging and thanking her for all that she had done for her through the earlier years of her life.

In 1970, she was one of ten women admitted to the University of Arizona School of Medicine. The knowledge and experience she gained while working in the hospital lab was most helpful to her in her first year. In an effort to reduce her medical school expenses, she worked on weekends as a medical technologist at Tucson Medical Center. A large one floor building, the lab was a one mile walk to the furthest patient's room. When necessary, Marny would get in her car and drive around to the other end of the medical center to make sure the patient was taken care of in a timely manner. She tried as best she could to fit in as a "normal" student. She was determined not to be treated differently or to let her handicap hold her back.

She served her residency in Family Medicine at Mercy Hospital in Denver where she was the only woman in the class. Her first surgery that she attended as a medical student was an eight-hour heart surgery. She stood through the procedure, without any breaks. She was determined not to be treated differently because of her disability, but in reality, she felt there was more prejudice towards her as the only female resident.

Upon completion of her residency in 1977, she served as a family physician in the small town of Hot Springs, South Dakota. As a small town doctor, she did everything from delivering babies (140 babies and 10 C Sections) to visiting patients in the hospital and taking care of the elderly.



1974 Medical School Graduation Photo Source: Marny Eulberg

In 1980, she moved back to Denver. In 1986 she was offered a full-time professorship at Mercy Medical Center (where she served her residency). She was excited about the challenge of teaching new residents and accepted the position – one she stayed with until her retirement in 2016. During her time at Mercy Medical Center, she opened the (1985) Mercy Post-Polio Clinic (later renamed the Mountain & Plains Post-Polio Clinic).

In 2014, she started seeing Polio patients in her own wheelchair accessible home. Prior to the pandemic, she was seeing 40 - 50 patients per year. Now only seeing 25 patients/year, she would love to see the number grow. Marny does not charge the patients, but will accept donations to Rotary, Colorado Post-Polio Organization and PHI.



The view from her mountain retreat. Photo Source: Marny Eulberg

She loves spending time at her cabin in the mountains. Until recently, she would snowshoe 0.3 miles once a month in the winter, using two different sized snow shoes and forearm crutches that were modified with a basket and a point on the end to be similar to cross-country ski poles.

A Rotarian, Dr. Eulberg is the District 5450 Polio Plus committee chairperson. From July 2023 through June 2026, she will be one of two End Polio Now Coordinators for Rotary's Big West Zones 26 & 27.

Marny is also a volunteer with the Presbytery of Denver. Their

organization has a relationship with the Presbytery of Zimbabwe.

As part of their Mission Partnership Projects, they raise money to maintain a clinic there. This money pays for five staff members at the clinic. They also help support the drilling of wells where there are schools and support orphans by making sure they have enough food and can get to school. Marny was part of a delegate exchange and went to Zimbabwe for two weeks. While she couldn't help at the clinic (due to government regulations) she was able to meet with the staff and bring them supplies. She receives updates and monthly reports from the clinic which helps with

accessing any possible wants/needs they may have.



Pictured here in 2019, Eulberg traveled to Zimbabwe as a delegate for her church. Source: Undark Magazine

She has served on the Board of Post-Polio Health International since 2002. She serves on the Executive Committee as secretary and on their medical advisory committee.

Marny helps run a Post-Polio Camp/Retreat every other summer for 3 days at the <u>Easter Seals Camp</u> outside of Denver. Hosting about 40 people, and open to polio survivors all over the US, it is attended by the polio survivors from Colorado and across the nation.

Dr. Eulberg is a regular contributor to the monthly <u>newsletter</u> of the PA Polio Network (PPSN). Her full series of articles are featured under the title "<u>Primary Care Perspective</u>". Her thoughtful contributions bring a joyful approach along with a special perspective as a polio survivor and a practicing primary care physician. She regularly answers questions from polio survivors and their families.

Marny may have retired, but she is far from finished with her volunteer and humanitarian efforts. She is proving day by day, that anything is possible, no matter what physical limitations you may have.

Helen Urban



It was special for us to be able to interview her and publish Marny Eulberg's story. After working with her for 4 years, we have discovered her smile, sense of humor and dedication all to be a winning combination for a physician with her background. Dr. Eulberg's complete inventory of articles are available on our website. You can easily find them. From the <a href="Home Page">Home Page</a> you can easily see the six Headings across the top.

- If you look under "Professionals" the names of our contributing professionals are listed alphabetically.
  - "Click" on her name. Her Biography and contact information are easily visible.
  - There you will see her inventory of articles and videos.
- Look under "Articles/Resources". You will easily find "Primary Care Perspective".
  - · Her articles and videos are all listed there for easy scrolling.

Are you looking for a particular topic? "Click" on the Index button. You will see the complete Index of topics she's written about, listed alphabetically. Click on your topic of interest.

#### Of Note:

Her articles on the topics of <u>Gabapentin (Neurontin)</u> and her 3 part series on Post-Polio Osteoporosis are of great interest to many polio survivors.

We get lots of guestions regarding vaccines. In her very thorough article:

"Immunizations are for Everyone: Not Just for COVID and Not Just for Kids", Dr. Eulberg explains each of the vaccines that are typically recommended for adults.

She is clear at the end, when she states: "Please talk to your primary care physician about staying up to date on the vaccines YOU may want or need."

THANK YOU Dr. Eulberg for your generous contributions.

Dr. Eulberg's <u>story</u> is easily available In Survivor Stories – under the Heading Articles/Resources.



## After 35 Years, Polio Has Been Cornered. We Must Finish the Job.

Since 1988, Rotary and its partners in the Global Polio Eradication Initiative have reduced polio cases by 99.9% worldwide. The wild poliovirus is now circulating only in Afghanistan and Pakistan. That's why we celebrate <u>World Polio Day</u> on October 24<sup>th</sup>.

The World Health Organization estimates there are 15+million polio survivors worldwide, the vast majority of whom are realizing the permanent disability caused by the poliovirus. We encourage pediatric vaccine acceptance and share factual vaccination information. Together we must continue the march toward global eradication and do our part to prevent polio outbreaks in our own communities. Very few Americans realize that polio paralyzed a 20-year-old man in NY last summer. Polio was eradicated in the US in 1979, yet as a result of lack of vaccination, we have been added to this list of Polio Outbreak Countries, along with Canada, Israel and the UK (also previously declared "Polio Free").

One lesson learned during the polio epidemics is that there are hundreds of asymptomatic poliovirus infections for each paralytic case, meaning that many of those infected with polio were so mildly affected that they didn't know they'd had the virus. Just because someone had no or minor flu-like symptoms, showing no obvious weakness or paralysis, doesn't mean that the poliovirus didn't do damage to neurons in the brain and spinal cord.

The safety and efficacy of the inactivated Salk polio vaccine is well documented. It is the only vaccine given in the US since 2000. As evidenced in the State of New York in 2022, for those who have not been vaccinated, the time for action is now.

We have an opportunity to make history by ending polio, making it the 2<sup>nd</sup> disease in history to be eradicated through the use of vaccination. For us it's deeply personal because we're polio survivors and we understand that it will NEVER be over. Survivors of this disease, all over the US and abroad will <u>always</u> remember:

- The terror, sadness and loneliness that came with being so sick.
- Lonely months and years of hospitalization, surgeries and painful rehabilitation all while separated from parents and siblings.
- The frightening reality of an iron lung and the lack of human touch.
- The sorrow that came with discovering wheelchairs, leg braces and crutches were ours for life.
- The loneliness that came as we returned home, and were forced to accept that everyone around us knew that it was the home of a "cripple", and parents kept their children away.
- It will never over, as we realize the shock that has come with the reality of the late effects of polio, when those of us who thought we escaped or recovered from paralysis find ourselves with new weakness, fatigue and pain as we age.

We are asking everyone to help us finish the job and end polio for good, so that this paralyzing disease does not return to polio-free countries, putting children everywhere at risk.

Get involved. Vaccination for smallpox is no longer necessary. It was eradicated in 1980. Thanks to the passion and raw determination of Rotarians and their partners in the Global Polio Eradication Initiative (GPEI), Polio will be the 2nd disease in history to have that marvelous distinction. This enormous effort is the basis for our dedication to support that Initiative. Donations to the Rotary Foundation can be made through <a href="Team Survivor">Team Survivor</a>. For every dollar you donate, the Gates Foundation will turn it into three.

Our PA <u>Polio Network</u> was founded in 2014 by polio survivors who were searching for current and accurate information on post-polio syndrome. We are grateful to have attracted a dedicated group of thoughtful, professional contributors and volunteers who are dedicated to the advocacy of bringing forth information about managing the lifelong, disabling effects of the poliovirus.

Please join us and become a part of the solution. If polio exists *anywhere* it is a threat to children everywhere.



"Today, the world is closer than ever to eradicating an ancient disease thanks to proven tools and brand-new innovations.

For thousands of years, poliovirus spread unchecked, paralyzing children and sowing fear in communities around the world. Just 3 decades ago, hundreds of thousands of children were paralyzed by polio annually. Since then, the global polio eradication initiative, along with governments, donors, and frontline health workers, has committed to ending polio worldwide - by protecting all children with polio vaccines.

Promising trends suggest that poliovirus is finally on its last leg. 2 out of the 3 strains of wild poliovirus have been wiped out, and so far this year, just 7 cases of the remaining wild virus strain have been reported across 2 countries, Afghanistan and Pakistan. Actions taken now will decide whether today's and future generations can grow up in a polio-free world. To get there, we must use everything at our disposal, including proven solutions and innovative new tools.

Delivered by a simple dropper, the oral polio vaccine (OPV) is as proven a tool as exists in global health. It's inexpensive and easy for vaccinators to transport and administer. Because it can both protect the individual child and stop person-to-person transmission, OPV has brought poliovirus to its knees.

But in areas where not enough children receive OPV, the weakened strain of poliovirus it contains can pass amongst the community. And over time, that strain can revert to a variant form and spread like the wild viruses to cause paralysis.

Stopping variant polio outbreaks is essential to achieving eradication, which is why a next-generation oral polio vaccine, nOPV2, has been developed and rolled out. So far, nOPV2 has proven to be significantly less likely to revert to a paralytic form. Close to 700 million doses have already been delivered in more than 30 countries, helping protect millions of children in the highest risk communities.

In the face of variant polio outbreaks, some scientists have called to stop the use of oral polio vaccines immediately and instead use the inactivated polio vaccine (IPV). IPV is excellent at preventing infection of the nervous system, which causes paralysis. There is no doubt that high IPV coverage through routine immunization is key to sustaining a polio-free world, especially after eradication is achieved. And because IPV does not contain the live virus, it does not carry the same risk of reversion as OPV.

However, IPV is not as effective in stopping person-to-person transmission, particularly in low-and-middle income countries with poor hygiene and sanitation, where the fecal-to-oral spread of poliovirus is known to be the predominant mode of transmission. In contrast, OPV is much better at breaking chains of transmission between people in such settings.

Additionally, some regions facing variant poliovirus outbreaks, like eastern DRC and northern Yemen, are experiencing serious humanitarian crises, which can limit vaccine delivery efforts. Administering an injectable vaccine like IPV in an outbreak response setting, which requires trained health workers and strong health infrastructure, is often impossible. No matter the type, a polio vaccine sitting on a shelf is of no use to a child. That's why countries around the world are implementing new strategies to meet local challenges and stop further transmission.

In Pakistan, dozens of mobile vaccination teams are helping protect nomadic populations in border regions and at transit points, where risk of encountering the virus is high. In parts of several African countries with unreliable

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census information, geospatial data experts are helping estimate population sizes and locations to inform immunization campaigns.

In other areas, an overall lack of health infrastructure makes outbreak response difficult. To ensure all children are reached in such settings, polio campaigns also deliver other essential services, including measles vaccines, vitamin A supplements, and other routine immunizations. In Somalia, authorities are constructing new public health emergency response centers to coordinate everything from outbreak response activities to food security efforts.

From proven and next generation vaccines to improved ways to reach children, it's clear that the tools and strategies needed to cross the finish line on polio are in hand. We can't afford to stop now.

To finish the job, we need bolstered political and financial commitments at all levels—both from affected and polio-free countries. Such commitments are essential to achieve high polio vaccination coverage where it's needed most and protect the incredible progress made so far.

Only then will we be able to ensure no child is paralyzed by this preventable disease again. But as long as polio exists anywhere, the entire world will remain at risk."

Johns Hopkins Bloomberg School of Public Health

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### Please join us and become a part of the solution.

If polio exists anywhere it is a threat to children everywhere.



"In the effort to end Polio – every vaccination counts.

National Immunization Days reach all children and educate parents.

Outbreak response stops the spread of poliovirus.

Routine immunizations protect children for life.

Cross border immunizations protect children on the move.

Every vaccination helps to safeguard a child's life . . . and deliver a world without Polio."



Click to watch video.

## "Polio Survivor Ina Pinkney Reflects On Life's Pains And Pleasures."

"My earliest memory is the sound of pain. Mine."

"Strips of wool cut from a St. Marys-brand blanket, which my father had to find on the black market since it was wartime, were lifted from a pot of boiling water, wrung out, and wrapped around my thin, flaccid leg." "My father said I didn't cry. He did."







Illustrations by Sol Cotti. Rotary Magazine – October, 2023

#### **Accessible Travel for Polio Survivors**

A part of their <u>2023 Lecture and Town Hall series</u>, Post-Polio Health International has shared their fascinating conversation with travel professional <u>Candy Harrington</u>

PHI Director Brian Tiburzi will introduce the speaker along with her credentials at the beginning of the video.

We are happy to be able to share outstanding series on The <u>Living with Post-Polio Syndrome</u> page of our website. Look for it under the heading "Post-Polio Syndrome". www.polionetwork.org

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





### All over the world, October is Polio Awareness Month

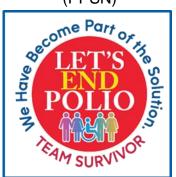
Polio Australia

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