



Polio Survivors Serving Others

Information & Inspiration
For All Polio Survivors and their Families

The PA Polio Network

www.polionetwork.org

September, 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:

A Book Review: "I hope this will help people remember what it was like before the vaccine. It was an eye-opener for me to see how much advocacy comes from polio survivors."

Hannah Wunsch, MD

PPSN's Pamela Sergey is back as she describes *The Autumn Ghost: How the Battle Against a Polio Epidemic Revolutionized Modern Medical Care* by Hannah Wunsch as "an enlightening and deeply impactful story of this critical moment in medical history."

As a follow up: We have a video conversation with Hannah Wunsch, MD with the Post-Polio Syndrome Advocacy Group "Medical Advances as a Result of Polio".

Carpal Tunnel Surgery – What Should I do? [Marny K. Eulberg, MD](#) explains the diagnostic testing, surgery and recovery process of this now common surgery. Polio survivors need to make informed decisions with this (and any surgery) that requires pressure on the muscles involved during recovery due to the use of crutches and walkers.

Falling - Are you at risk? Survivor Laura Vittorioso has a reminder. Falls Prevention and Safety: As Polio survivors we are more prone to falls and have become aware of some of the strategies to prevent falls.

Valium, Its Offspring and Polio Survivors:

Valium © (diazepam) on the market for 60 years, is the great grandfather of the benzodiazepine ("benzo") of anti-anxiety drugs. [Richard L. Bruno, HD, PhD](#) explains the relationship between this and other drugs in this family of medications and that their use in small doses can be safe and effective for polio survivors.

World Polio Day (October 24): We celebrate this important event hosted by the Global Polio Eradication Initiative (GPEI) and Rotarians all over the world.

As we think about this important day, and the miracle of the polio vaccine, we are reminded of the continued . . .



"Over 650 million children in Africa have now been vaccinated against Polio, with a recent drive to vaccinate another 22 million children earlier this year. Chad is one of the countries in the region with the highest concentration of 'No Dose' children. These are kids who have never been vaccinated." Source: [Susanne Rea](#) 8/24/2023

Continued . . .

new friendships we've made through the opportunity to advocate for the eradication of polio.

Polio survivor Susanne Rea, is a Rotarian and Polio Eradication Advocate. Her [Facebook Page](#) keeps us informed of the amazing international effort to rid the world of this terrible disease. These photos are clear images of the dedication of those Involved with the GPEI.

Join [Team Survivor 2023](#). Team Survivor is a means for Polio Survivors, our friends and families to come together in a thriving, spirited way to support the Rotary Foundation and their partners rid the world of this terrible disease.

Because of the Gates Foundation 2 for 1 Match –
Your \$25 Donation to the Rotary Foundation will become \$75
NO donation is too small. That's what makes it so special.
We ARE a part of the solution.

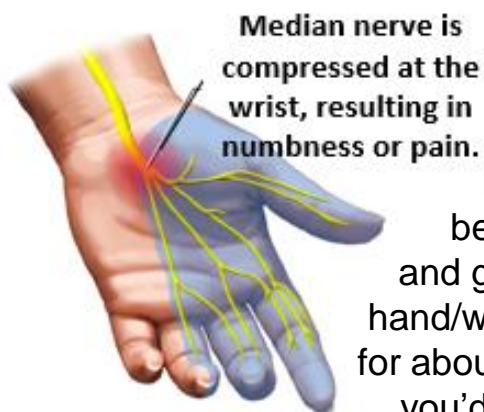


Carpal Tunnel Surgery – What Should I do? A Conversation with Marny K. Eulberg, MD

Question: I had polio when I was 5. 36 years later, I discovered I needed additional support with a full left leg brace and assistive devices. I've also been diagnosed with arthritis and carpal syndrome.

Now 80, I have tingling sensations in the first three fingers of my right hand. My Family Physician suggested I contact an Occupational Therapist. Years ago, a fellow survivor told me NOT TO HAVE Carpal Tunnel Surgery, but I didn't have a chance to learn why not. What do YOU advise?

Dr. Eulberg's Response:



It does sound like your symptoms could be from carpal tunnel syndrome. Did you have an EMG/Nerve Conduction Velocity test done? If so, and it clearly showed slowing of the nerve conduction at the wrist, the diagnosis is confirmed.

If you use a cane, a crutch or a walker with some weight bearing on your right hand or if you use your hands to push off and get from sitting to standing, you will be advised to not use your hand/wrist to do these things during the post operative period (usually for about 10-14 days). This is an important part of your recovery, so you'd need to figure out how to deal with those restrictions. One option is to get an attachment for the walker (forearm support) that allows you to bear weight on your forearm but not on your wrist. There is also a similar crutch. These are frequently used by persons who need to use a walker or crutch/cane for some leg weakness but have recently broken their wrist/forearm/hand. Here are two examples of "platform crutch attachments".

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There is no absolute reason that a polio survivor should not have carpal tunnel surgery if they have carpal tunnel syndrome. If the pressure on the median nerve through the wrist is severe enough it can lead to permanent paralysis of some muscles in the fingers and/or thumb in addition to the tingling and /or pain that occur when the nerve is partially compressed.

You need to make an informed decision, in consultation with your doctors about the pros and cons of various treatments for carpal tunnel syndrome. The one thing that is unique to polio survivors and others with leg weakness is the need to use their hands/arm for some activities that others can do entirely with their legs - that complicates how one cares for themselves as they recover from the surgery.

IF they decide to have surgery, polio survivors need to make their surgeon/anesthesiologist aware of any previous Anesthesia issues. For carpal tunnel surgery, most often the procedure will be performed under local or nerve block anesthesia and the patient will not need general anesthesia. The anesthesiologist/nurse anesthetist may use “conscious sedation” which means they will administer a mild sedative, so you are in “la-la” land but not fully unconscious. This would be similar to the “conscious sedation” used during a colonoscopy or cataract surgery. (If you have never had surgery or anesthesia of any kind, please let your surgeon know that you are a polio survivor). More information regarding surgery along with a card you can give to your physician [is available](#) for download in both English & Spanish.

I have seen several polio survivors who have had successful carpal tunnel surgery and did well, but it required some temporary change to their normal daily routine during the post-op period.



[Marny K. Eulberg, MD](#)



Dr. Eulberg’s complete inventory of articles are easily available on our website.

You will find [Primary Care Perspective](#) under the Heading: Articles/Resources – www.polionetwork.org/primary-care-perspective

Click on the [INDEX/CATEGORIES](#) Button to find everything listed by topic.

Falls Prevention and Vision

September 22 is Falls Prevention Day

By Laura Vittorioso



“According to the National Council on Aging (NCOA) every 14 seconds an older adult is seen in the emergency department for a fall related injury. The chances of falling and of being seriously injured in a fall increases with age.”

Falls Prevention and Safety: As Polio survivors, we are more prone to falls and have become aware of some of the strategies to prevent falls; i.e.: Use of a mobility device such as a cane or walker, removing loose rugs, installing handrails and being aware of slippery surfaces such as black ice in winter. Maintaining eye health as we age is also critical for preventing falls. Age related eye changes are a big contributor to falls. Some of these changes include: early cataracts, reduced contrast sensitivity, increased difficulty with glare and the need for more light.

Considerations as We Age:

Cataracts: Most of us will develop cataracts. A cataract is simply the clouding of the lens. The lens is removed and a clear, plastic lens is inserted. Cataract surgery is now routine and easily managed in the recovery period. A developing cataract can produce a blurry image, usually in one eye first; sensitivity to glare and difficulty with reading.

Reduced Contrast: Contrast is the ability to detect subtle changes in the environment. For example, seeing a black curb on a black surface, seeing the first step on a similarly colored background or in low light, finding a toothpick on a multi-colored counter top. Contrast begins to fade in our late 60's and 70's and is often a reason why driving in bad weather or at night becomes difficult.

Glare: Our ability to handle glare on a bright sunny day decreases as we age. Sunglasses are now recommended for all ages to protect the eyes from harmful UV rays from the sun. There are many different tints to choose from, some of which will increase contrast, such as amber or yellow. Yellow sunglasses improve contrast greatly for night driving and poor weather such as fog or snow. Sunglasses particularly the wrap-around or fit over styles also protect the eyes from dirt, dust and wind and can help conditions such as “dry eye” another effect of aging.

Light: It is estimated we need double the amount of light to read or perform fine motor tasks as we age. Overhead lighting in each room is an important falls preventative. In addition, task lighting such as a gooseneck-type reading lamp which can be positioned on the page of a book or a task can greatly improve function. There are a variety of lightbulbs to choose from ... bright white LEDs or softer, more natural bulbs called “daylight.” The back lighting on an iPad or Kindle provides a very comfortable light for reading.

Medicare and Medicare Advantage plans cover an annual eye exam each year with an Optometrist. The Optometrist is the professional who performs “refractions” for corrective
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lenses. An Optometrist is also trained to detect eye disease through dilation in order to see the back of the eye. If the Optometrist suspects eye disease a referral will be made to an Ophthalmologist. The Ophthalmologist is a medical doctor specializing in eye disease and can perform eye surgeries.

Maintaining eye sight is a critical factor in preventing falls and overall function. While aging doesn't mean that eyesight will be compromised there are various factors of aging that can reduce visual function. The best preventative is to see an eye specialist once a year and to call if one notices any sudden or unusual changes in vision such as a flood of floaters, or a cut in central or peripheral vision. If an eye doctor cannot be reached it is best to go to the emergency room as time is of the essence with conditions such as a vein occlusion or retinal detachment.

Laura Vittorioso
Vision Rehabilitation Therapist
[The Iris Network](#)

Thank You

Thank you, Laura, for your multiple contributions to our work bringing support to polio survivors and our families.



Valium, Its Offspring and Polio Survivors

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

Director, International Center for Polio Education

Valium is the great grandfather of the benzodiazepine (“benzo”) family of anti-anxiety drugs. Valium © (diazepam) has been on the market for 60 years. After its FDA approval in 1963, Valium became the best-selling medication from 1968 to 1982, with more than 2 billion tablets prescribed in 1978 alone. Valium was nick-named “Mother's Little Helper” after The Rolling Stones 60’s song about women becoming dependent on drugs to deal with the “drudgery and anxiety” of suburban living.

But Valium and its offspring do not necessarily cause dependence. In 2016, benzodiazepine misuse (i.e., use “any way a doctor did not direct”) was reported in 2% of the 31 million benzo users, with adults 65 or older reporting the lowest (<1%) misuse.

(See: [Benzodiazepine Use and Misuse Among Adults in the United States.](#))

So, with the less than 1% misuse potential in the back of our minds, lets look at the benzos that help treat polio survivors’ symptoms.

VALIUM © (diazepam)

Benzodiazepines not only effectively treat anxiety, but also treat muscle spasms, seizures and are used to provide sedation for medical procedures. Benzos work by stimulating receptors for the neurochemical GABA that “calms” neurons. For polio survivors, Valium's usefulness is in treating muscle spasms. Polio survivors, with their muscle imbalances, muscle overuse, leg length differences, unusual spinal curves and muscle overuse, are prone to develop painful muscle spasms, often in the back and neck.

At The Post-Polio Institute we found that a week or two of low dose (2.5 mg to 5 mg two or three times a day) could break the cycle of pain and spasm and then Valium could be stopped. As I will say several times below, we never had a patient abuse the drug. When patients got rid of the spasm and pain they also got rid of the Valium.

One important feature of Valium is its half-life (the time it takes for half the dose you've taken to leave your body) of between 20 and 50 hours. This can be a good thing since you don't have to keep taking the drug frequently during the day. But it can also be a problem because Valium is sedating and can keep you too “relaxed” for too long. So you have to be aware of how Valium and all benzos affect your attention and coordination before, as the package insert warns, you “drive or operate heavy equipment”.

XANAX© (alprazolam)

Our 1985 National Post Polio Survey found that nearly two-thirds of polio survivors reported abnormal movements in sleep (AMS), with 52% reporting that their sleep was disturbed by AMS. The survey prompted us to perform sleep studies in polio survivors to document AMS. Patients demonstrated a variety of abnormal muscle movements: generalized random myoclonus (GRM), brief contractions and even ballistic movements of the arms and legs; slow repeated grasping movements of the hands; slow flexion of the arms; contraction of the

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shoulder and pectoral muscles; periodic leg movements in sleep (PLMS) with muscle contractions and ballistic movements of the legs; and PLMS plus restless leg syndrome (RLS).

(See: [Abnormal Movements in Sleep as Post-Polio Sequelae](#))

Given the muscle relaxing properties of benzos, we trialed patients with AMS on a low dose of Xanax (0.5 mg to 2 mg) which eliminated the muscle movements. Some patients started with the 0.5 mg and moved up to 1 mg or rarely to 2 mg. But no one needed to go beyond 2 mg to get relief. In fact, once the lowest effective dose was found, polio survivors stayed on that dose, some of them for more than 25 years now.

Why did we choose Xanax rather than another benzo? Because Xanax has a half-life of between 6 and 27 hours. That means if you took Xanax 30 minutes before bedtime and slept from 10 PM to 8 AM, a half-life of six hours would have allowed your body to eliminate 66% of the drug, preventing you from being "hung over" when you got out of bed.

But the short half-life of Xanax can also be a problem **if** the drug is prescribed for anxiety. Xanax is known for its abuse potential specifically because it's short half-life requires it to be taken frequently to control anxiety. Why isn't this a problem for polio survivors with AMS? Because the drug is taken before bed. Whatever "relaxing" feelings Xanax might provide go unnoticed because you're fast asleep.

KLONOPIN © (clonazepam)

We have found over the decades that severe swallowing difficulty is rare among polio survivors. Although swallowing problems are thought to be more common in diagnosed "bulbar" polio survivors, 60% of Post-Polio Institute patients who reported swallowing difficulties did not have a clinical history of "bulbar" polio but did have slowed swallowing on a video barium swallow study. What's more, patients reported having spasm-like pain, a feeling that food was stuck in their esophagus behind the breastbone.

It was one of our patients who accidentally discovered that a very low dose (0.25 mg and rarely up to 1 mg) of the benzo Klonopin © (clonazepam), taken 30 minutes before eating, relaxed spasms in the esophagus and stopped food from getting stuck. Klonopin has a half-life between 18 and 50 hours, meaning it lasts at least three times as long as Xanax. So, as with Valium, don't drive a car or operate heavy equipment before determining your body's response to Klonopin's relaxing and sedating effects.

VERSED © (midazolam)

Versed is a benzo you may never encounter. Versed is used for sedation before procedures like a colonoscopy (often combined with an opioid such as fentanyl), preoperative sedation, for the induction of general anesthesia and for sedation of people who have an endotracheal tube and are in ICU on a ventilator.

Versed is given intravenously, not taken by mouth, and has the shortest half-life of all the benzo's, 1.5 to 2.5 hours. Even though the half-life is short you still need to be cautious about being sedated and even uncoordinated after being given Versed. If a colonoscopy takes half an hour you're still at least an hour away from just half of the dose being gone.

With any procedure using anesthesia, show your doctors/anesthesiologists/anesthetists the [ANESTHESIA WARNING CARD](#) along with the article [Preventing Complications in Polio Survivors Undergoing Surgery or Receiving Anesthesia](#)

“I’VE BEEN ON XANAX SAFELY FOR YEARS,
BUT MY DOCTOR SAYS NOW SHE CAN’T PRESCRIBE BENZOS!”

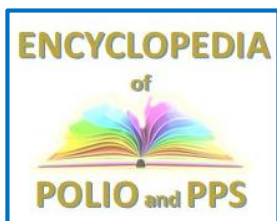
Some state and federal government policies and regulations, as well as actions taken by practice plans and payers that follow the Centers for Disease Control and Prevention’s controlled substance guidelines, have been rather draconian. To find a balance between the excessive use of benzos and a potential overreaction in terms of heavy-handed restrictions, several pragmatic recommendations include refraining from suddenly and unilaterally discontinuing benzos in the millions of legitimate users, avoiding overly restrictive regulatory policies, but especially loosening restrictions at governmental agencies such as the Drug Enforcement Administration, state legislatures medical licensing boards.

If you're having trouble finding a prescribing physician, contact your state Department of Health and medical licensing board to get copies of the latest legal restrictions on benzodiazepine prescriptions. Remind your doctors that benzodiazepine misuse (i.e., use “any way a doctor did not direct”) was reported in just 2% of the 31 million users, with adults 65 or older reporting the lowest (<1%) misuse. See: [Benzodiazepine Use and Misuse Among Adults in the United States](#).

For more information see [Walking the Benzodiazepine High Wire](#). Kurt Kroenke, M.D., and Matthew E. Hirschtritt, M.D. Nov 2022

Note: At the Post-Polio Institute we ALWAYS suggested that polio survivors treat the source of pain before asking for medications to minimize it.

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

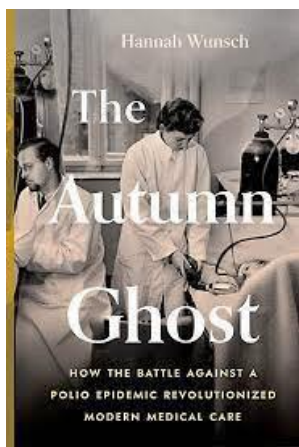


Dr. Bruno’s Complete Inventory of work is easily available in the [Encyclopedia of Polio and PPS](#).
www.polionetwork.org/encyclopedia

Click on the [INDEX/CATEGORIES](#) Button to find everything listed by topic.

The Autumn Ghost: How the Battle Against a Polio Epidemic Revolutionized Modern Medical Care

By Hannah Wunsch
A Book Review by Pamela Sergey



The COVID-19 pandemic has underscored the importance of intensive care units (ICUs) and mechanical ventilators in our medical system – but you’ve probably never given either a second thought or wondered how they were developed. Would it surprise you to know that their development was due to polio?

The Autumn Ghost: How the Battle Against a Polio Epidemic Revolutionized Modern Medical Care by Hannah Wunsch is an

enlightening and deeply impactful story of this critical moment in medical history. Through meticulous research and compelling storytelling, Wunsch, a Professor of Anesthesiology and Critical Care Medicine at the University of Toronto and a practicing intensivist at Toronto’s Sunnybrook Hospital, delves into the gripping account of the 1952 polio epidemic in Copenhagen - and how it changed the world.

During the 1950s in the US, polio usually erupted during the early summer months. In Northern countries such as Denmark, it manifested itself as an “Autumn Ghost”. At the height of the 1952 Danish polio epidemic, Wunsch transports us to Blegdam, a 500-bed infectious disease hospital in Copenhagen where medical professionals were baffled by an already high mortality rate in young patients with bulbar polio, which affects the respiratory and swallowing muscles. By the end of August 1952, 27 out of 31 patients had died. And still, polio patients continued to arrive at the hospital, up to 50 a day including 10-12 in respiratory distress. During the last five months of 1952 the hospital received roughly 3,000 patients diagnosed with poliomyelitis, about one-third with paralysis.

The hospital was woefully undersupplied with iron lungs and portable ventilators. It faced an overwhelming challenge of simultaneously caring for 70 paralyzed children who were unable to breathe on their own. With a team consisting of 1,200 to 1,500 medical, nursing and dental students, the hospital embarked on an unprecedented mission to develop and implement respirators, blood gas monitoring, and intensive care units (ICUs) to keep these children alive. The sickest patients were grouped together, and students provided 24/7 manual ventilation using a rubber bag attached to a tracheostomy tube. The hospital’s mortality of polio patients requiring ventilation fell from 87% in July 1952 to 22% in November 1952. The unusual methods implemented were working!

The narrative unfolds with a perfect blend of historical context and personal anecdotes of those involved, which allows the reader to truly comprehend the magnitude of the crisis and the extraordinary efforts undertaken by the medical community. Wunsch skillfully paints a vivid picture of the hospital's atmosphere during those harrowing times, creating a sense of urgency and empathy within the reader while highlighting the remarkable ingenuity and resilience that emerged in the face of such adversity.

One of the book's most significant strengths lies in its meticulous attention to detail. Wunsch

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went to the Copenhagen City Archives where she found the 1952 “Black Book” detailing every death at Blegdam. She provides a comprehensive understanding of the technological advancements made during that period and their subsequent adoption in the US and other parts of the world. This book is an essential read for anyone interested in medical history, as it offers both knowledge and inspiration.

Drawing on compelling testimony from doctors, nurses, medical students, and patients, “Autumn Ghost” is a testament to the power of human perseverance and ingenuity in the face of a devastating epidemic. It serves as a reminder of the transformative impact that dedicated medical professionals can have on society, and sheds light on a remarkable chapter in the ongoing fight against infectious diseases. Despite their differences, both polio and COVID-19 have resulted in outbreaks that tested health care workers while solidifying the need for ICU care, blood gas monitoring, and ventilators. With the COVID-19 pandemic technically over, it is not unusual to ask if, like polio, there will be long term health ramifications in 20, 30, or 40 years.

Pamela Sergey

SOURCES:

The Epidemic of Poliomyelitis in Copenhagen, 1952 By H. C. A. Lassen, published October 1953 <https://journals.sagepub.com/doi/pdf/10.1177/003591575404700119>

Medical Advances as a Result of Polio

A Conversation with Hannah Wunsch – the author of “Autumn Ghost: How the Battle Against a Polio Epidemic Revolutionized Modern Medical Care”

From the [Post-Polio Syndrome Advocacy Group](#)

Dr. Wunsch is a critical care physician and researcher at Sunnybrook Health Science Centre and a professor of anesthesiology and critical care medicine at the University of Toronto.

“This book is a remarkable medical story that we haven’t heard before, reconstructing the polio crisis and the heroic efforts to keep patient’s alive.” From the Autumn Ghost

What can we learn as a result of the polio vaccine?

- Since 1988 Worldwide:
 - 1.5 million lives have been saved by the polio vaccine.
 - 18 million are able to walk who wouldn’t otherwise.
- Since 1988 In the US:
 - 15 million lives have been saved by mechanical ventilation

“I hope this will help people remember what it was like BEFORE the vaccine. It was an eye-opener for me to see how much advocacy comes from polio survivors.” Hannah Wunsch, MD

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What did we learn from polio?

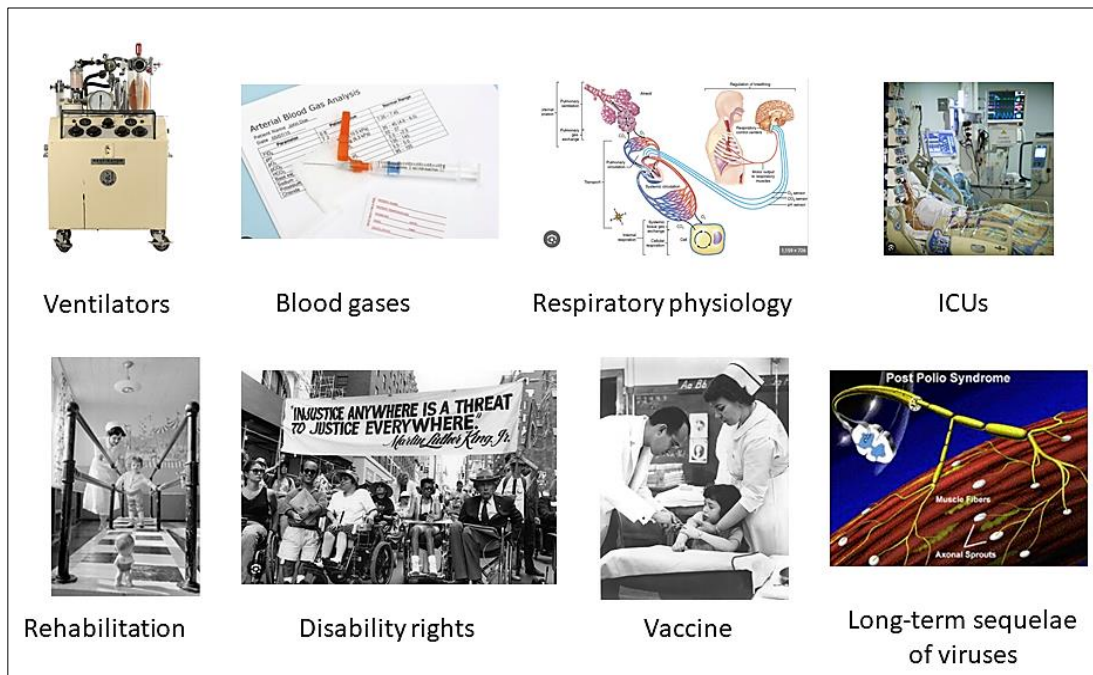


Image Source(s): Above - Hannah Wunsch, MD
Below – Ken Masson, PPS Advocacy Group

**MEDICAL ADVANCES
AS A RESULT OF POLIO**

Post-Polio Syndrome Advocacy Group

Dr. Hannah Wunsch
Professor and Author

[“Medical Advances as a Result of Polio”](#)
is available on our website under the heading: Polio History

Day in and day out, in the most war torn, hard to reach areas of the world, vaccinators in each community go house to house, vaccinating children for Polio with these precious drops. Afterwards, they color the child's little finger on their left hand. Thus the term "Purple Pinkie".



A community worker puts a mark on a child's finger after administering the polio vaccine during a door-to-door polio vaccination (nOPV2) campaign in Somalia, May 2023.



After the devastating floods in Pakistan, the vaccination campaigns continued.

Polio is still endemic in Afghanistan and Pakistan.

With the ease of worldwide travel we have today, if Polio exists anywhere, it is a threat to children everywhere.

Thank you Polio survivor and Rotarian Susanne Rea for your work supporting polio eradication.

100% of the proceeds that are sent to us for [Team Survivor](#) go to the Rotary Foundation for Polio Eradication.

www.polionetwork.org/team-survivor



"A lifetime of Disability. . . ."
"It's Imperative that we protect our children from this danger."

[Polio Awareness from the Pakistan Polio Eradication Programme](#)

This heartfelt polio ad in Pashto aims to raise awareness and support for polio eradication efforts worldwide. Together, we can make a difference and ensure a polio-free future for generations to come.



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

Search Bars, Indexes, Tags and Categories

Search Bars - are the traditional method for finding articles/information



Indexes - “Index/Category” buttons are new – and very effective.

- When you are on a page of interest: [Encyclopedia of Polio and PPS](#), [Living with Post-Polio Syndrome](#), [Newsletters](#), [Primary Care Perspective](#) (etc) and you are looking for a specific topic “Click” on the Index/Category Button.

INDEX/CATEGORIES

Tags - these are topic identifiers.

- At the bottom of each article, you will find topics listed that are referred to as Tags.
- When you “Click” on a Tag, EVERY article on the site under that topic will come up.

Categories - When you hover over the Primary Headers across the top of the page (Home, Post-Polio Syndrome, Professionals, Polio, Our Advocacy and Articles/Resources) you will see the titles of the Primary Category pages listed under that Header.

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