



Polio Survivors Serving Each Other

Information & Inspiration
For All Polio Survivors and their Families

The PA Polio Network

www.papolionetwork.org

January, 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:

2022 was a tough year for Polio Eradication. “Polio eradication took a step backwards, but we *can* recover lost ground.” In his annual *Gates Notes*, Bill Gates emphasizes the critical involvement of the Rotary Foundation in the effort to eradicate Polio. We are happy to be a part of this effort. In just six years, survivors and family members in our network have sent donations through Team Survivor to the Rotary Foundation, providing more than 100,000 polio vaccinations to children in the most difficult to reach corners of the world.

Together, we ARE making a difference in children’s lives.

Bulbar Polio and Poliovirus Antibody Testing. What do these have in common? They are two of the most frequent topics coming the way of Richard L. Bruno, HD, PhD. He addresses two questions related to these topics in this new Bruno Byte.

Celebrating the Life of Lauro Halstead, MD. Have you ever asked yourself if polio, in a curious way, enriched your life? Dr. Lauro S. Halstead went on a personal quest to answer this question. PPSN’s Pamela Sergey read his book *Unexpected Journey: A Physician’s Life in the Shadow of Polio* and added some insight into the life of this amazing man.

Trusting the health information found on the Internet. The National Dept of Aging recognizes how complicated things have become. “There are thousands of medical websites. Some provide reliable health information. Some do not. Some of the medical news is current. Some of it is not. Choosing which websites to trust is an important step in gathering reliable health information.”

Note: When you are looking at articles on our website, you can easily find the Biographies of our generous contributors. Just “click” where you see their name highlighted. www.papolionetwork.org/our-network-team

A Wish For The New Year From Our Friends At Polio Quebec



May your eyes open to glorious sights that will make your heart beat faster
And may your breathing slow enough to embrace the meaningfulness of it all.
May your mind expand to explore new ideas and consider new possibilities
And may your thinking constrict enough to impede the inevitable kvetches and self-deprecating critique.
May your sense of self morph and strengthen as you experience what no longer is but what now just might be.
May your awareness of what is and can be expand beyond what was and what you expected.
And may the journey ahead be jam-packed with joy, joined with serious self-reflection, fullness of family and friends, amidst an abundance of fun, insight, inspiration, and more than a touch of idealism,
With love sweetened with laughter, and healthy living, working and being.
And may you interact with and as part of an increasingly haimische* humanity.
Thus may you fill your heart and soul, so that the journey ahead - into the unknown -
May be exciting, energizing, and absolutely

*www.collinsdictionary.com/us/dictionary/english/haimish

Haimische: having qualities associated with a homelike atmosphere; simple, warm, relaxed, cozy, unpretentious





Bruno Bytes

from [Richard L. Bruno, HD, PhD](#)
Director, International Centre for Polio Education

On the topic of Poliovirus Antibody Testing

Since Poliovirus has appeared in the UK and the US, I have had scores of polio survivors asking if they should be tested to see if they have antibodies to the polioviruses. In the US, commercial laboratories - including the Mayo Clinic, Quest and ARUP - test for the presence of poliovirus antibodies, but they only test for Type 1 and Type 3, since the wild Type 2 poliovirus is no longer circulating. Unfortunately it is the *mutated Type 2 oral vaccine strain* that currently is circulating. A *mutated Type 2* polio virus strain is not just being found in wastewater in the US, Canada, the UK and Israel. That *Type 2* strain paralyzed a young, unvaccinated man in southern New York State. So, even if you had commercial poliovirus antibody testing, it wouldn't reveal whether you had antibodies to the Type 2 virus that unfortunately is making the rounds.

What's more, the [CDC](#) clearly states, "Demonstrating antibodies to poliovirus Types 1 and 3 does *not* reliably indicate protection against poliovirus Type 2. In the absence of the availability of testing for antibodies to all three serotypes, serologic testing is no longer recommended to assess immunity."(1)

People who had polio but were not vaccinated are only protected against the poliovirus type(s) that had infected them. [Dr. Paul Offit](#), Director of the Vaccine Education Center at Children's Hospital of Philadelphia and internationally recognized as an expert in virology and immunology, says this about antibody testing: "If you were naturally infected and were never (fully) vaccinated, you should just get the whole series of polio vaccines. I wouldn't test. The test isn't very good; the test for polio antibodies also picks up antibodies for other enteroviruses (the family of viruses to which the polioviruses belong) which are common, and not just the poliovirus." (2)

Sources: (1) - www.cdc.gov/mmwr/volumes/66/wr/pdfs/mm6601a6.pdf

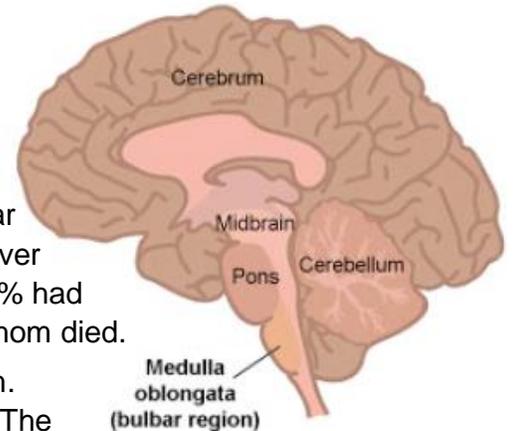
(2) - www.vimeo.com/762641842

On the topic Bulbar Polio causing death

Question: According to the WHO and CDC, most polio deaths stemmed from paralytic breathing difficulty/suffocation. Is that right?

Dr. Bruno's Response: No. The frightening image of the iron lung causes people who aren't familiar with the physiology and history of bulbar polio to assume breathing failure was "the killer." While the numbers varied from outbreak to outbreak, about 70% of those who were in an iron lung died. But even those with breathing problems could have had the two other bulbar symptoms, i.e., impaired swallowing and cardiovascular dysfunction. Just over 50% with bulbar polio had trouble swallowing, 5% of whom died. Almost 10% had trouble controlling their heart rate and blood pressure, more than 80% of whom died.

But, polioviruses always affected the bulbar part of the brain, the brain stem. Therefore everyone had bulbar polio whether there were symptoms or not. The brain stem controls many automatic functions (e.g., swallowing, intestinal movement, blood pressure, heart rate). Polio survivors having abnormalities with these functions today are showing evidence of poliovirus-damage to the "bulb" of the brain.



[Bruno Bytes](#) have been published regularly since 2014.

All issues are easily available in the Encyclopedia of Polio and PPS.

www.papolionetwork.org/encyclopedia.html



An Unexpected Journey

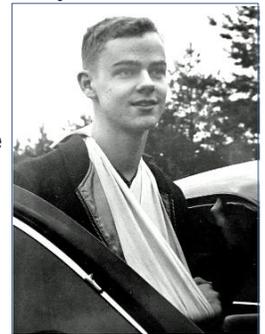
In celebration of the life of Lauro S. Halstead, MD

By Pamela Sergey

Have you ever asked yourself if polio, in a curious way, enriched your life? *Unexpected Journey: A Physician's Life in the Shadow of Polio* recounts Dr. Lauro Halstead's personal quest to answer this question.

Dr. Halstead's middle name is Storm, an old family name, but what is a storm? Chaos, fear, uncertainty, disruption and change? In a very obvious way, Dr. Halstead lived through his personal "storm". In *Unexpected Journey* Dr. Halstead speaks poignantly about both his struggles and his successes with polio. In the book's Preface, he wrote "it was a journey that seldom followed a straight and narrow path as I struggled with issues of love and career, friendships and illness." "Through the slow, demanding process of writing, I hoped to gain greater insight into how I went from one stepping stone to another - rising from a near-death experience like the mythical phoenix and gradually, through a series of hits and misses, carving out a life that had meaning and joy." (1)

A healthy 18 year old musician and lover of all things Italian, Dr. Halstead developed polio in 1954 while hitchhiking through Europe on his college summer vacation. While in Madrid he suddenly lost the use of his right arm, and his breathing became labored. Nurses at the local Catholic children's hospital stuffed his 6' 4" frame into a makeshift plywood respirator built for a much smaller child. A priest came in to administer the Last Rights to which Dr. Halstead gasped "Go to Hell". Dr. Halstead remembers thinking "I'm young. My life is just beginning. There's so many things I want to do." He wasn't going to give up! Dr. Halstead stayed in the wooden respirator for eighteen days. "I was essentially alone (without family in a strange country). And what made it worse was in those days, the dictator of Spain, Franco, in an effort to conserve electricity, turned off all power in the city of Madrid from 2 a.m. to 6 a.m. And so the respirator went dead at 2 a.m. and just by the grace of God, I managed to survive and eventually get back to the United States."(2) The teenager went to a rehabilitative hospital in White Plains, NY. "This picture was taken sometime in late September or early October, 1954 on the occasion of my first outing from the rehabilitation hospital in White Plains, New York. I remember seeing the fall colors and thinking how glorious it was to be alive. Not shown is the manual wheelchair which I used for the first six months." (3)



Source: [Polio Place](#)



Lauro Halstead (right). Source: [Polio Place](#)

"This picture was taken in the summer of 1955 approximately one year after my initial illness. A local man heard that I had played the trombone (and to a lesser degree, the baritone) for many years before polio. He was interested in the healing power of music and organized this rag-tag group to play at various senior centers, etc. in the area." (3)

Although his right arm was completely paralyzed, he learned to write with his left hand and resorted to creative ways to perform two-handed activities with only his left hand. Despite these setbacks, he decided to go to medical school. Dr. Halstead received his BA from Haverford College, an MD degree from the University of Rochester Medical School, and an MPH (Master of Public Health) degree from Harvard

University School of Public Health.

In *Unexpected Journey*, he writes passionately about climbing Japan's Mount Fuji's full 12,388 feet in 1957, exactly 3 years to the day after contacting polio; of his utopic family's summer home in VT, Storm Acres; of getting in touch with his Italian heritage while studying in Rome; of developing a technique for facilitating fertility and conception in spinal cord injured patients; and of working in a hospital in India where his parents had been missionaries. He also writes frankly and courageously about two failed marriages and his all-time rock bottom.

Dr. Halstead is credited with identifying and treating PPS (Post-Polio Sequelae), or what he called his "polio wall". In late 1982, Dr. Halstead began experiencing unexplained weaknesses in his legs. It was

continued . . .



Source: MedStar National Rehab Hospital Washington DC

misdiagnosed as ALS. But the pain was not something new: "It felt exactly like the muscle pain I'd had when I got polio almost 30 years earlier. Was my body sending me a message from long ago?" At the medical library, he found very little other than a Mayo Clinic study from 1972 which reported polio survivors developing new weaknesses that could not be otherwise explained. They called it "Frustrated ALS"; and a 1981 article on nerve conductivity in polio survivors published by Ohio State University. "Their results were totally unexpected and suggested that as polio patients aged, their muscles and nerves started to decompensate." (1)

In 1984, Halstead organized the first medical conference on Post-Polio Syndrome in Warm Springs, Ga. (the location was founded in 1926 by Franklin Roosevelt to treat polio survivors). Dr. Halstead would go on to receive many awards for his work on PPS and to improve the lives of fellow polio survivors by spreading knowledge and treatment options to those struggling with PPS.

Dr. Halstead retired in June 2012 after 50 years in the medical field. 26 of those years as Director of the Spinal Cord Injury Program and Director of the Post-polio Clinic at the MedStar National Rehabilitation Hospital in Washington DC. Dr. Halstead wrote several other books on the subject of Post-Polio:

- Research and Clinical Aspects of the Late Effects of Poliomyelitis (1987),
- Post-Polio Syndrome: Late Effects of Poliomyelitis (1995),
- Managing Post-Polio: A Guide to Living and Aging Well With Post-Polio Syndrome (2006).

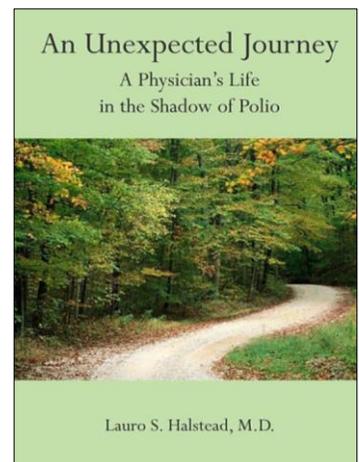
None of his books are as personal and poignant as *Unexpected Journey: A Physician's Life in the Shadow of Polio*. In *Unexpected Journey*, Dr. Halstead answers the original question about polio enriching his life this way: "I suppose that's possible. I may not have become a physician, and instead might have lived a carefree life in southern France making my own wine and perfecting my use of irregular verbs. As it is, being a disabled adult has given me a perspective on life I wouldn't otherwise have had." "So, yes. These experiences have enriched my life beyond measure. However, on balance, I can honestly say polio has been both a curse and a blessing. But what well-lived life doesn't contain a little of both?" (1)

Dr. Halstead loved music. "I don't remember how long I played the baritone that I'm holding in the photo (previous page), but, for some reason, I gave it up in favor of playing the piano with my left hand. I regret that I stopped playing the baritone because I could have been playing in bands and orchestras all these years. On the bright side, at the suggestion of a musical friend, I resumed playing the baritone three years ago and am now playing with three local groups. Last year, I had the pleasure of playing with an amateur group at the Kennedy Center in a Christmas concert." (3)

His advice to young people: "I think an important element for any young person is the whole concept of resilience and perseverance. I mean, no one's life is free of problems, of challenges, of confrontations. And I think it's absolutely critical that everybody learn how to deal with misfortune, with events that are out of their control, with challenges, whether it's physical, emotional, financial."

Sadly, Dr. Halstead passed away on January 5, 2022. Those who knew him will miss his warm sense of humor and caring ways. Dr. Lauro de Bosis Storm Halstead was the "perfect Storm".

Pamela Sergey



Article Sources:

- (1) [Unexpected Journey: A Physician's Life in the Shadow of Polio](#)
- (2) 11/2012 interview with Sabri Ben-Achour from WAMU – American University Radio - Metro Connection
- (3) [Polio Place](#)

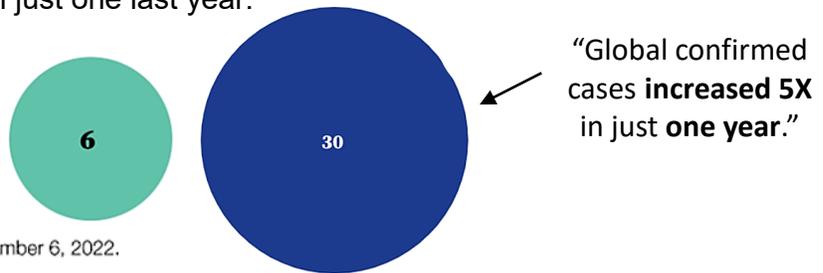


Polio eradication took a step backwards, but we can recover lost ground.

“I’ve written in previous letters (such as [this one](#)) about how close the world is to eradicating polio, and what a magical moment in history it will be when we do. Unfortunately, COVID, extreme weather, and war have made it much harder for vaccinators to do their jobs.

Between 2019 and 2021, coverage for all childhood vaccines, including the one for polio, dropped by the biggest margin in almost three decades, and not surprisingly, polio started coming back. In 2021, it paralyzed just six children in the entire world; this year, 30 children were paralyzed as of December 6. In Pakistan alone, 20 children have been paralyzed, up from just one last year.”

Polio cases in 2021 vs 2022



Source: WHO. Note: Confirmed wild poliovirus cases as of December 6, 2022.

“After several years of being limited to Afghanistan and Pakistan, wild poliovirus traveled to two countries in Africa this year. And strains of a variant polio virus were found in the sewers of London and New York. In each of these places, governments had to launch new efforts to stop the disease.

There could not be a better reminder that polio anywhere is a threat everywhere, and that we need to eradicate it. Of course, saying something is necessary doesn’t mean that it’s possible. I’ve underestimated this disease before, and I’ve been naïve about how difficult eradication would be, so I have to acknowledge that it could fail. But I don’t think it will. Earlier this year, ten eminent scientists and health experts made the case for both why this disease should be eradicated, and why it can be eradicated, in the [2022 Scientific Declaration on Polio](#). This declaration is supported by more than 3,000 signatories from 117 countries. It’s short (much shorter than this letter), to the point, and well worth your time.

Here are my own reasons for being optimistic. Despite this recent comeback, the momentum is still on our side: Polio cases are down 99.9% over the past three decades. We now have a new vaccine, called nOPV2, that will prevent outbreaks of polio variants. As of November, more than 500 million doses of nOPV2 had been administered in 23 countries. And a more detailed look at the situation in Pakistan and Afghanistan shows that while cases were up slightly this year, the overall trend is that entire families of wild poliovirus are being eliminated.

We’re also learning from the recent setbacks. In October, the group leading the eradication effort - the [Global Polio Eradication Initiative](#) - adopted a smart five-year strategy for overcoming the final obstacles to eradication. And donors stepped up to partially fund this new strategy. In October the foundation announced a new \$1.2 billion pledge, and pledges from other donors brought the total to \$2.6 billion. There’s still a long way to go—the commitments amount to a little more than half of what GPEI needs to finish the job—but this was a fantastic start. No update on polio would be complete without a big thank-you to [Rotary International](#). They were part of this effort long before the Gates Foundation was. Since we became partners on eradication, we’ve jointly raised \$1.8 billion for this work, and there’s more to come. Rotarians also lead massive vaccination campaigns to reach children all over the world. Sometime in the next few years, when polio is finally eradicated, my first phone call will be to thank and congratulate the team at Rotary International.”

[Source: www.gatesnotes.com/About-Bill-Gates/The-Year-Ahead-2023?fbclid=IwAR2EaxNxKkuEzfF_Zv0h4x5nmoS9SpTBHyuHbBbyYVaTGLJ_S_ICJINpvIE#ALChapter5](https://www.gatesnotes.com/About-Bill-Gates/The-Year-Ahead-2023?fbclid=IwAR2EaxNxKkuEzfF_Zv0h4x5nmoS9SpTBHyuHbBbyYVaTGLJ_S_ICJINpvIE#ALChapter5)

Note: Graphic Image edited due to space

Many older adults share a common concern:
“How can I trust the health information I find on the Internet?”

“There are thousands of medical websites. Some provide reliable health information. Some do not. Some of the medical news is current. Some of it is not. Choosing which websites to trust is an important step in gathering reliable health information.”

Where Can I Find Reliable Health Information Online?

“The National Institutes of Health website is a good place to start for reliable health information. As a rule, health websites sponsored by Federal Government agencies are good sources of information. You can reach all Federal websites by visiting www.usa.gov. Large professional organizations and well-known medical schools may also be good sources of health information.

Questions to Ask Before Trusting a Website

As you search online, you are likely to find websites for many health agencies and organizations that are not well-known. By answering the following questions, you should be able to find more information about these websites. A lot of these details might be found in the website’s “About Us” section.

1. Who sponsors/hosts the website? Is that information easy to find?

Websites cost money to create and update. Is the source of funding (sponsor) clear? Knowing who is funding the website may give you insight into the mission or goal of the site. Sometimes, the website address (called a URL) is helpful. For example:

- .gov - identifies a U.S. government agency
- .edu - identifies an educational institution, like a school, college, or university
- .org - usually identifies nonprofit organizations
(such as professional groups; scientific, medical, or research societies; advocacy groups)
- .com - identifies commercial websites
(such as businesses, pharmaceutical companies, and sometimes hospitals)

2. Who wrote the information? Who reviewed it?

Authors and contributors are often, but not always, identified. If the author is listed, ask yourself—is this person an expert in the field? Does this person work for an organization and, if so, what are the goals of the organization? A contributor’s connection to the website, and any financial stake he or she has in the information on the website, should be clear.

Is the health information written or reviewed by a healthcare professional? Dependable websites will tell you where their health information came from and how and when it was reviewed.

Trustworthy websites will have contact information that you can use to reach the site’s sponsor or authors. An email address, phone number, and/or mailing address might be listed at the bottom of every page or on a separate “About Us” or “Contact Us” page.

Be careful about testimonials. Personal stories may be helpful and comforting, but not everyone experiences health problems the same way. Also, there is a big difference between a website, blog, or social media page developed by a single person interested in a topic and a website developed using strong scientific evidence (that is, information gathered from research). No information should replace seeing a doctor or other health professional who can give you advice that caters to your specific situation.

3. When was the information written?

Look for websites that stay current with their health information. You don’t want to make decisions about your care based on out-of-date information. Often, the bottom of the page will have a date. Pages on the same site may be updated at different times—some may be updated more often than others. Older information isn’t useless, but using the most current, evidence-based information is best.

4. What is the purpose of the site?

Why was the site created? Know the motive or goal of the website so you can better judge its content. Is the purpose of the site to inform or explain? Or is it trying to sell a product? Choose information based on scientific evidence rather than one person’s opinion.

5. Is your privacy protected? Does the website clearly state a privacy policy?

Read the website’s privacy policy. It is usually at the bottom of the page or on a separate page titled “Privacy Policy” or “Our Policies.” If a website says it uses “cookies,” your information may not be private. While cookies

continued . . .

may enhance your web experience, they can also compromise your online privacy—so it is important to read how the website will use your information. You can choose to disable the use of cookies through your Internet browser settings.

6. How can I protect my health information?

If you are asked to share personal information, be sure to find out how the information will be used. Secure websites that collect personal information responsibly have an “s” after “http” in the start of their website address (https://) and often require that you create a username and password.

BE CAREFUL about sharing your Social Security number. Find out why your number is needed, how it will be used, and what will happen if you do not share this information. Only enter your Social Security number on secure websites. You might consider calling your doctor’s office or health insurance company to give this information over the phone, rather than giving it online.

These precautions can help better protect your information:

- Use common sense when browsing the Internet. Do not open unexpected links. Hover your mouse over a link to confirm that clicking it will take you to a reputable website.
- Use a strong password. Include a variation of numbers, letters, and symbols. Change it frequently.
- Use two-factor authentication when you can. This requires the use of two different types of personal information to log into your mobile devices or accounts.
- Do not enter sensitive information over public Wi-Fi that is not secure. This includes Wi-Fi that is not password protected.
- Be careful what information you share over social media sites. This can include addresses, phone numbers, and email addresses. Learn how you can keep your information private.

7. Does the website offer quick and easy solutions to your health problems? Are miracle cures promised?

Be careful of websites or companies that claim any one remedy will cure a lot of different illnesses. Question dramatic writing or cures that seem too good to be true. Make sure you can find other websites with the same information. Even if the website links to a trustworthy source, it doesn’t mean that the site has the other organization’s endorsement or support.

Health and Medical Apps

Mobile medical applications (“apps”) are apps you can put on your smartphone. Health apps can help you track your eating habits, physical activity, test results, or other information. But, anyone can develop a health app - for any reason - and apps may include inaccurate or misleading information. Make sure you know who made any app you use.

When you download an app, it may ask for your location, your email, or other information. Consider what the app is asking from you—make sure the questions are relevant to the app and that you feel comfortable sharing this information. Remember, there is a difference between sharing your personal information through your doctor’s online health portal and posting on third-party social media or health sites.

Social Media and Health Information

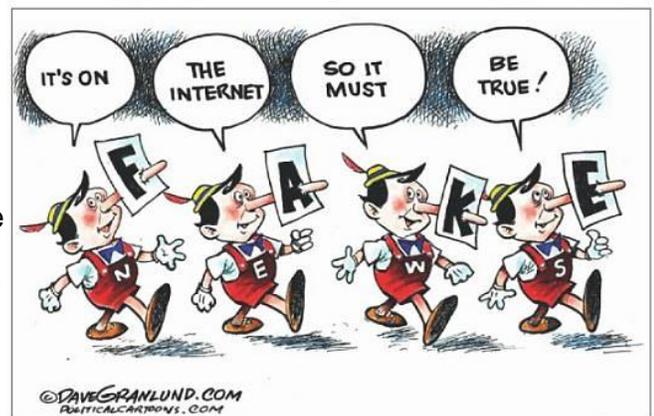
Social media sites, such as Facebook, Twitter, and Instagram, are online communities where people connect with friends, family, and strangers. Sometimes, you might find health information or health news on social media. Some of this information may be true, and some of it may not be. Recognize that just because a post is from a friend or colleague it does not necessarily mean it’s true or scientifically accurate.

Check the source of the information, and make sure the author is credible. Fact-checking websites can also help you figure out if a story is reliable.

Trust Yourself and Talk to Your Doctor

Use common sense and good judgment when looking at health information online. There are websites on nearly every health topic, and many have no rules overseeing the quality of the information provided. Use the information you find online as one tool to become more informed. Don’t count on any one website and check your sources. Discuss what you find with your doctor before making any changes to your health care.”

Source: www.nia.nih.gov/health/online-health-information-it-reliable



For Some Survivors, Polio Casts a Long Shadow

“Decades after the vaccine, adults with post-polio syndrome are struggling with symptoms — and looking for answers.”



Brad Fuller



Marny Eulberg



Carol Ferguson

Article and Photo Source: Undark Magazine

Three survivors, engaged professionals and outstanding advocates - many of whom are actively engaged in our Network, were interviewed for this article by Frieda Klotz from Undark Magazine.

Rather lengthy, this thoroughly researched article is worth the read.

We were happy to see that it was also published in: The Atlantic and Popular Science Magazines.

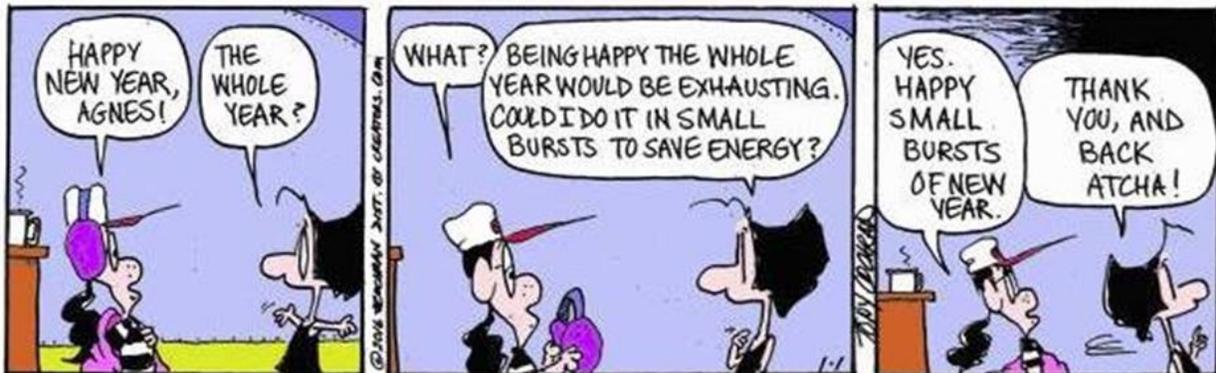


Thank You

THANK you for your kind words, generous donations and active participation.

Your monetary contributions help our work continue.

Your active participation brings forward the questions that many, MANY polio survivors are wanting to ask.



JANUARY

CONSERVE TO PRESERVE

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