



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

February, 2022

Our Mission:

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

Inside this Issue:

COVID - It's Been Two Years. What does that mean to Polio Survivors? Last month, Primary Care Physician (and polio survivor) [Dr. Marny Eulberg, MD](#) talked about Allergies, Colds, COVID, Flu and what differentiates them. In Part 2 of this article series, she focuses on COVID while she effectively digs into the questions that we hear so often.

Pain – It Hurts. Why are polio survivors so sensitive to pain (or ARE we) ? Is it a muscle spasm or is it a muscle cramp? What's the difference? Dr. Richard Bruno, HD, PhD is here with [Bruno Bytes](#) that explain.

Our Perspective on Vaccines: In our work regarding Vaccine [Advocacy](#), we have had the honor to participate in a project with the Vaccine Education Center of the Children's Hospital of Philadelphia. Six of us had the privilege to participate in a video series titled: "Perspectives on COVID-19 Vaccine for Kids". It has been a special opportunity to work with a professional organization that has encouraged us to tell our stories of the realities that come with the late effects of poliovirus. We ARE speaking out and hopefully making a difference when it comes to vaccine hesitancy.

2021 is the Year That Set The Stage For A Polio-free World: It may go down in history as the turning point in the global effort to eradicate polio. With the ongoing COVID-19 pandemic, 2021 began with many challenges facing polio eradication efforts. But amid this new reality, countries and partners of the Global Polio Eradication Initiative (GPEI) intensified their efforts to protect children from lifelong paralysis.

Polio was an Epidemic. COVID is a Pandemic: What is the difference between an epidemic and a pandemic?

An outbreak is called an epidemic when there is a sudden increase in cases. As COVID-19 began spreading in Wuhan, China, it became an epidemic.

Because the disease then spread across several countries and affected a large number of people, it was classified as a pandemic.

- Epidemic: Sudden increase in cases of a disease.
- Epidemiology: Study of disease and other health outcomes, their causes in a population, and how they can be controlled.
- Outbreak: A higher-than-expected number of occurrences of disease in a specific location and time.
- Pandemic: Event in which a disease spreads across several countries and affects a large number of people.

SOURCE: [Centers for Disease Control and Prevention \(CDC\)](https://www.cdc.gov)



Thank you survivor John Nanni for a little humor during these trying times.

Many of us are alone during these winter months.

We must remember that we are not alone.
We have been in this together
for a very long time.





COVID and Polio Survivors - Two Years Later

[Marny K. Eulberg, MD](#)

Primary Care Perspectives

Part 2 of [Dr. Eulberg's Series](#): Allergies, Colds, COVID (or) Flu

It has now been almost two years since COVID-19 was first identified and the world began to deal with it. In early 2020, with our years of learning and all our technology, we were sure that we'd be able to conquer and vanquish this tiny "little" virus. Yet here we are, with waves of infection occurring with one variant

after another and the disease still very much in our midst and on our minds. We're *all* weary of it, but we must stay positive.

We have certainly made strides:

- We have multiple vaccines,
- We are developing new treatments,
- We are learning more and more about how the disease passes from one person to another,
- We are learning how to better monitor and treat those who become infected.

Information specific to polio survivors was published and circulated by many polio-related organizations. But, as recently as December 2021, I was still receiving occasional calls from polio survivors questioning whether they should get the vaccine. In my personal interactions with polio survivors, it appears that the majority have taken the steps to be fully vaccinated. I think this is because we are personally aware of what damage a tiny virus can do to one's body and the majority of us have wished that the polio vaccine had been available prior to our contracting polio.

There was one theory circulating that, perhaps, individuals who had contracted or been immunized for other viral infections (such as polio) might also have some immunity to COVID. In the real world, we do know that some polio survivors have indeed been infected with COVID and some have died. So **IF** there was some protection, as proposed in that theory, it certainly is *not* 100%.

It has been difficult to determine accurate information in a situation where there was no historical knowledge of this particular germ. As new information has emerged, the guidance has changed - sometimes several times! That is certainly confusing and disconcerting to all of us and can lead to misinformation.

This infection and immunity to this virus has not functioned identically as other infections/viruses have in the past. Generally, getting to a point of "herd immunity" with around 80% of the individuals who either have been vaccinated or who have contracted the disease and built antibodies to it, pretty much controls further spread of the disease, but this has *not* been the case with COVID. It has mutated *much* faster than we have been able to get to herd immunity. In addition, the immunity induced by vaccines *or* by having the disease, decreases over time and fairly quickly.

After initially believing that 2 doses of the Pfizer and Moderna vaccines and 1 dose of the J & J vaccine would confer sufficient immunity, we are learning that there have been several "breakthrough" infections even in those who have received a "booster". It may turn out that we may need yearly doses like we do for influenza.

From my vantage point, as I write this in late January 2022, this is what appears to be true:

1. The current vaccines may not prevent people from getting the omicron or other future variants, but they **DO** prevent the most severe infections and nearly all deaths.
2. Omicron is highly transmissible which means nearly all the population will be exposed to this virus at some point or another.

My hope is that contracting omicron will lead to better immunity to other COVID variants. Perhaps this will get us to enough "herd immunity" so that COVID becomes endemic instead of epidemic/pandemic. I think the best we can hope for is that COVID becomes like flu with relatively small numbers of people becoming ill with it each year and very few severe cases requiring hospitalization or resulting in death.

Continued

A review of death statistics in the United States comparing 2019 (before COVID) to 2020 show that the age-adjusted death rate increased from 715.2/100,000 population to 828.7/100,000. (As of this date, the numbers from 2021 have not been finalized). New to the listing of cause of death in 2020 death statistics, the 3rd most common cause of death was COVID, with heart disease and cancer still being number 1 and 2 respectively. Over 2/3rds of the deaths reported due to COVID in 2021 in the U.S. were in people over the age of 65 with the greatest risk in those over age 85 years. Of course, those over age 85 were at significant risk of dying from other causes too! In fact, all of us over age 65 have an increased risk of death compared to those who are younger!

Some people have been hesitant to receive the vaccine due to possible side effects. In my experience practicing medicine, I've seen that humans seem to have a big need to assign a "cause" to bad things happening and sometimes the event was purely circumstantial. It might sound absurd, but would we blame a person's death from a car crash on the COVID vaccine if they had received it a few days prior to the car crash? No. Likewise, when we hear of a death in a person who has recently received a COVID vaccine, we need to consider what their risks of dying from other "normal causes" would have been if they had not received the vaccine.

Most of the serious adverse side effects from the COVID vaccines, like blood clotting problems and Guillian-Barre syndrome, also can happen at a much higher rate in persons who contract a COVID infection.

According to a recent article in the AARP Bulletin from Jan/Feb 2022, the risk of catching COVID is six times greater for the unvaccinated than for the vaccinated AND the unvaccinated are 14 times more likely to die from COVID.

There is and was a very small risk of developing paralysis from polio from the oral polio vaccine (4-5 cases per one million doses given), but for most of us, polio survivors and our families, that did not deter us from lining up for those

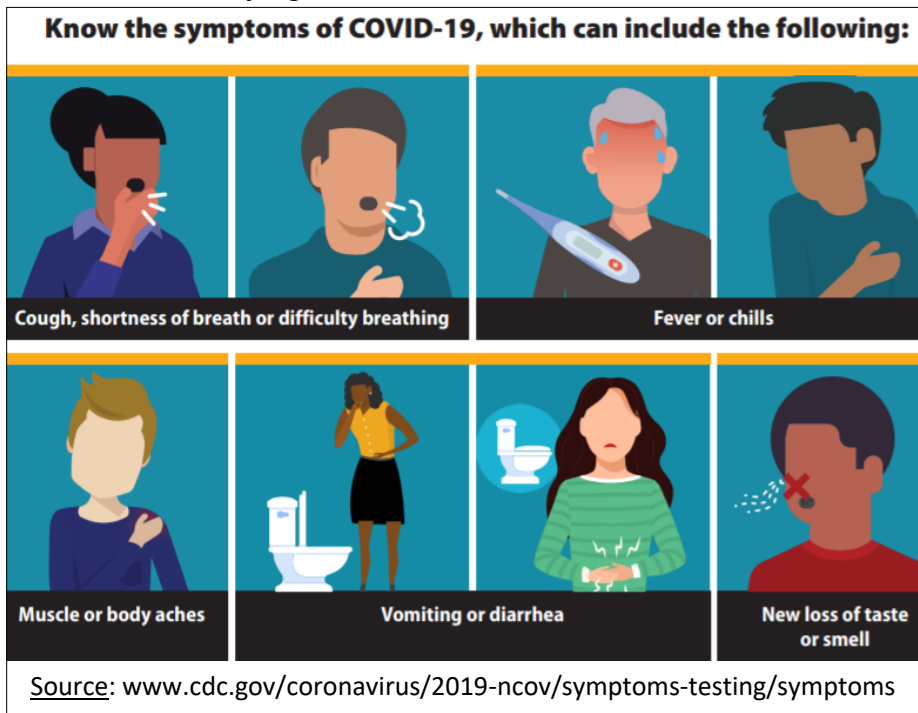
sugar cubes in the 1960s or getting our children immunized with oral polio vaccine!

Note: The oral polio vaccine has not been used in the U.S. since 2000.

Remember: "Your Immune System is like a football team. You practice all week, but you have no idea what you'll be up against on Sunday. Even with the strongest players, you don't know how well you'll play against a team you've never seen before. A vaccine gives your football team the opponent's playbook, so you're going to go out there and be more effective. It doesn't mean that the other team can't occasionally win, or that you can't still get sick. But, getting vaccinated dramatically stacks the odds in your favor, and makes any illness you DO experience, much less severe." Dr. Panagais Galiatsatos, MD, Johns Hopkins School of Medicine (2022).

There are possible side effects to ANY vaccine, this one is no different. The majority of minor effects far outweigh the significant benefits. The vast majority of polio survivors in the US are OVER 65 and beyond the ages listed for the vaccine side effects noted on this chart and the one on the next page.

If you're concerned, please talk to your primary care physician. They know your history and are there to help YOU.



continued. . . .

Note: The vast majority of polio survivors in the US are OVER 65 and beyond the ages listed for these vaccine side effects.

[Dr. Marny Eulberg, MD](#)

RARE, BUT SEVERE, SIDE EFFECTS FOLLOWING COVID-19 VACCINATION

Thrombosis with thrombocytopenia syndrome (TTS) occurs when a person develops blood clots in association with a low platelet count. TTS can be life threatening. It has been identified rarely following receipt of the adenovirus-vector-based COVID-19 vaccine.

Guillain-Barre syndrome (GBS) occurs when the immune system attacks the nervous system, causing muscle weakness that can last for months or years. GBS can occur after an infection or more rarely, after receipt of some vaccines, such as the adenovirus-vector-based COVID-19 vaccine.

Myocarditis is an inflammation of the heart, which can occur after an infection, such as COVID-19, or more rarely, after receipt of the mRNA-based COVID-19 vaccine.

Who is most at risk for these side effects?
While anyone can experience one of these rare, but severe, side effects, each tends to be more likely to occur in a specific subgroup of people. Interestingly, the three side effects are more likely in different subgroups:

Side Effect	Subgroup at Risk
TTS	30-49 yo Females
GBS	50-64 yo Males
Myocarditis	18-29 yo Males

COVIDVaccineAnswers.org

[Questions and Answers about COVID-19 Vaccines](#)

from the Vaccine Education Center at the Children’s Hospital of Philadelphia (a provider of vaccine information for ALL ages).

www.chop.edu/centers-programs/vaccine-education-center/making-vaccines/prevent-covid

[A Look at Each Vaccine](#)

from the Vaccine Education Center at the Children’s Hospital of Philadelphia (a provider of vaccine information for ALL ages).

[COVID Vaccine](#)

www.chop.edu/centers-programs/vaccine-education-center/vaccine-details/covid-19-vaccine

[Polio Vaccine](#)

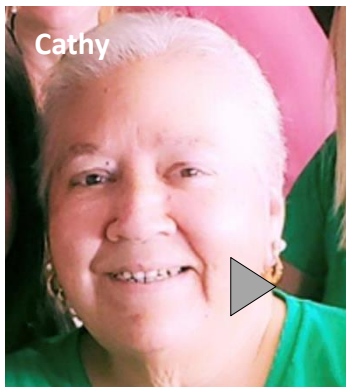
www.chop.edu/centers-programs/vaccine-education-center/vaccine-details/polio-vaccine

(There is information about 22 different vaccines on this page of their website.)

Our Perspective on Vaccines Working with the Children's Hospital of Philadelphia

In our work regarding [Vaccine Advocacy](#), we have had the privilege to be working with the Vaccine Education Center of the Children's Hospital of Philadelphia (CHOP). They are thorough, science based and trusted worldwide for their vaccine information for both children AND adults. They contacted us to see if we would participate in a video series titled: "Perspectives on COVID-19 Vaccine for Kids". Six of us enjoyed the opportunity to work with such a professional organization to tell our stories, in hopes that we could be of service helping them get the message out regarding the importance of vaccination. They truly understand the realities of, and acknowledge the complex issues that come with the poliovirus.

We brought you the first three videos in December. The final three have been uploaded to their website. You can see the video and a brief summary of each (Click on the arrow to watch the video). The full collection is on our Advocacy page. Many more of your stories, are available on the [Survivor Stories](#) page of our website.



Cathy

"Cathy talks about her experience with post-polio syndrome (PPS), which is the long-term effects of polio, and why she feels strongly about everyone getting vaccinated against COVID-19. Talking about her experience with polio, she says, 'Had I had the chance to get a vaccine, maybe my life would have been a little different. It's been very difficult, and I don't want to see another child go through something like this.'"

As a survivor with the long term effects of polio, it's increasingly difficult as you age. My muscles are getting weaker and I'm more fatigued. As a child, I had one leg brace. As an adult, I need two leg braces. The effects of this virus are very hard to deal with and have changed my life.

<https://www.youtube.com/watch?v=gnkDLkXcrdw&list=PLUv9oht3hC6QvShehYb2g6JTIQvlu5SDi&index=5>



Janis

"We were healthy, rambunctious kids, our parents abided by every single public health recommendation to try and protect us and yet, when a virus wants to hit, it's going to hit everywhere it wants to."

Polio hit my family really hard. My twin brother, Frankie died. Two of my friends died. I was paralyzed and made a good recovery. Many of us have really bad memories of how awful it was to have scabs in our head and all over our bodies from chickenpox. "I am a real vaccine advocate, as most people in my generation are." Those bad memories are the reason we are very, very thankful we have so many vaccines today.

<https://www.youtube.com/watch?v=gXL1xtmlotE&list=PLUv9oht3hC6QvShehYb2g6JTIQvlu5SDi&index=3>



Kathy

When Kathy contracted polio as a child, she was placed in an iron lung, remembers wearing braces and the pain of having to learn how to walk again.

As an adult, and as a result of post-polio syndrome, Kathy's muscle weakness and breathing issues became more significant, causing her to need a tracheostomy, ventilator, power wheelchair, and a guide dog. Kathy says, "Living with the issues of ongoing damage caused by a virus can make your life a very different place to be."

"I hate to think of the consequences for the adults and children who get COVID and end up with long term issues. I had issues my entire life as a result of a virus."

www.youtube.com/watch?v=JlwZHS1z0fM&list=PLUv9oht3hC6QvShehYb2g6JTIQvlu5SDi&index=2



COVID Vaccine Q&A Information for both Children and Adults from CHOP

Reviewed and updated regularly, this is an outstanding [resource](#).

www.chop.edu/centers-programs/vaccine-education-center/making-vaccines/prevent-covid



Bruno Bytes

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

Director, International Center for Polio Education

On the topic of Pain Sensitivity

Question: I've NEVER understood this. You say polio survivors are more sensitive to pain than non-polio survivors but have a higher pain tolerance. How is it that I can have a high pain tolerance and be more sensitive? It feels contradictory to me.

Dr. Bruno's Response: It has been known since the 1970s that the body produces its own morphine-like painkilling opiates, called endorphins and enkephalins. The problem for polio survivors is that the poliovirus killed off the brain and spinal cord neurons that produce the body's own opiates. So polio survivors can't "medicate" themselves against pain, which is why polio survivors need more pain medication than do non-polio survivors.

Our 1984 study showed that polio survivors are TWICE as sensitive to pain as non-polio survivors, likely due to the lack of endorphins and enkephalins (1) "Normal" levels of pain would be doubled in polio survivors and "intolerable" if polio survivors didn't develop a higher pain tolerance.

Here's another example of sensitivity and developed tolerance. Think about many polio survivors' emotional hypersensitivity to hospital smells (e.g., alcohol, the smell of wet wool from hot packs). As adults, polio survivors had to develop an increased tolerance to these emotional triggers or they never would allow themselves to enter a hospital again. (Sadly, many polio survivors have indeed refused to get medical treatment because they didn't develop an increased tolerance for hospitals and medical facilities). (2)

References: (1) Bruno RL, et al. Motor and sensory functioning with changing ambient temperature in post-polio subjects. Late Effects of Poliomyelitis. Miami: Symposia Foundation, 1985.

(2) Bruno RL, Frick NM. The psychology of polio as prelude to Post-Polio Sequelae: Behavior Modification and Psychotherapy. Orthopedics, 1991;14 (11):1185-1193.

For more information, please read these two articles under the topic of "[Psychology](#)" in the Encyclopedia of Polio and PPS: [Trauma and Illness as Precipitants of Post-Polio Sequelae](#) and [Psychology of Polio as Prelude to Post-Polio Sequelae](#)

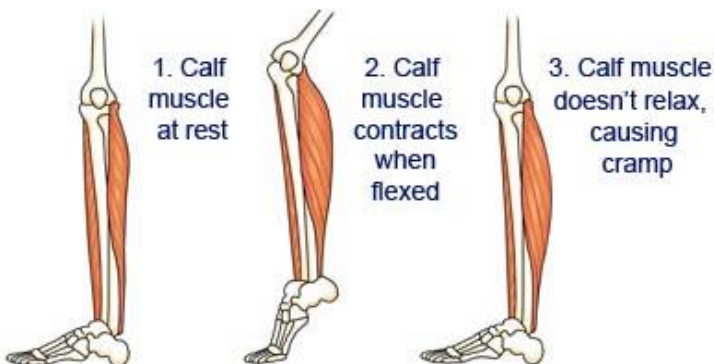
On the topic of Muscle Pain

Question: What is the difference between a Muscle Cramp and a Muscle Spasm?

Dr. Bruno's Response: A muscle CRAMP is a short-lived, very painful, involuntary contraction of an entire muscle or a relatively large portion of a muscle, usually a leg muscle and sometimes a forearm muscle. Who hasn't had a screamingly painful cramp of the calf muscle that pulls your toes downward and forces you to stand to stretch it out? A muscle SPASM feels hard, sometimes as hard as bone, and can be as small as an M&M or as big as the entire side of your neck or your low back.

No one knows what spasms are or why they can hurt so badly! Spasms seem to be muscle fibers in a small area contracting into a dense knot and usually occur in postural muscles in the neck and back. But, in a 1990 study I did, there was NO relationship between how hard a muscle spasm was, muscle electrical activity and pain. So, a small, not-so-dense spasm in a neck muscle can cause a headache that puts you in bed for hours, in a dark room after driving the porcelain bus. But a large, dense rock of a spasm in your neck or back may not hurt at all even when a physical therapist puts her thumb in it.

Bottom line: Muscle OVERUSE causes cramps and muscle MISUSE (e.g., poor posture) causes spasms.



2021 – The Year That Set The Stage For A Polio-free World

2021 May Go Down In History As The Turning Point In The Global Effort To Eradicate Polio.

“With the ongoing COVID-19 pandemic, continued wild polio transmission in the remaining endemic countries and spreading outbreaks of circulating vaccine-derived polioviruses type 2 (cVDPV2), this year began with many challenges facing polio eradication efforts. But amid this new reality, countries and partners of the Global Polio Eradication Initiative (GPEI) intensified their efforts to protect children from lifelong paralysis.

In June, the GPEI launched the new [GPEI Strategy 2022-2026](#), which lays out the roadmap to achieving a lasting world free of all forms of polioviruses through stronger community engagement, a renewed focus on gender equity and the rollout of new tools and technologies. These new tools include the [novel oral polio vaccine type 2 \(nOPV2\)](#), which began deployment under Emergency Use Listing (EUL) as part of the GPEI’s broader polio vaccine repository to curb cVDPV2 transmission. In August, the WHO African Region [celebrated one year](#) since it was certified wild polio-free, and countries recommitted to strong cVDPV2 outbreak response across the continent with the support of the GPEI.

Further critical progress took place in Afghanistan – one of two final countries endemic for wild poliovirus, along with Pakistan. For the [first time in more than three years](#), nationwide polio immunization campaigns resumed across Afghanistan reaching 8.5 million children, including 2.4 million children who were previously inaccessible.

At the same time, polio programme health workers at the forefront [continued to support](#) global COVID-19 response efforts by delivering vaccines, mobilizing communities, and countering misinformation among other activities. The use of GPEI infrastructure for health emergency response has provided critical lessons for integrating polio resources into broader health systems as more countries work towards transition and the post-certification period. Following dire predictions issued at the end of 2020, the polio programme once again proved its ability to adapt to programmatic, epidemiological and political developments. Entering 2022, there is much cause for cautious optimism – wild poliovirus transmission has slowed drastically, and cases of cVDPV2 have also declined compared to last year.

Importantly, commitment to achieving a lasting polio-free world is evident at all levels: by core GPEI partners, including among the Polio Oversight Board, which travelled to Pakistan twice in 2021; by health workers, communities and parents; and by country leaders worldwide who helped champion this year’s milestones. With the new strategy, new tools and adapted approaches, the stage is set to achieve lasting success.

To stop all forms of polio for good, the GPEI aims to capitalize on the positive epidemiological situation leading into 2022. A key opportunity to kick-start the year will be the [WHO Executive Board](#) meeting in January, where Member States plan to discuss building on the successes of this past year by fully implementing and financing the programme’s new strategy. Rotary and other key global GPEI partners are planning a renewed and intensified outreach across the broader international development community to secure the necessary financial resources to achieve success. Polio immunization campaigns will also continue in full force in both endemic and outbreak countries.

Twelve months ago, the programme was in a much different place, as WHO and UNICEF launched an [Emergency Call to Action](#) to draw attention to the need for renewed commitment. A year later, thanks to a strengthened and unified response, the GPEI is meeting the moment and is more committed than ever to end all forms of poliovirus, once and for all.”



Containment area monitoring in India. ©WHO



Vaccination team crossing river in West Garo Hills of Meghalaya. ©WHO

Some fun jokes shared with us from

[Colorado Post-Polio Support](#)

I miss the 90s when bread was still good for you and no one knew what kale was.

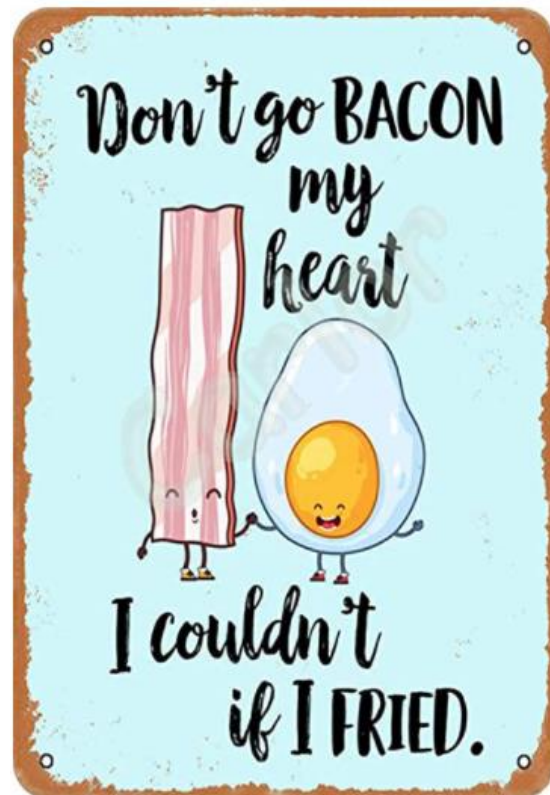
Remember back when we were kids and every time it was zero outside, they closed school?
Yeah, me neither.

I told my wife I wanted to be cremated. She made me an appointment for Tuesday.

Me: Sobbing my heart out, "I can't see you anymore...I'm not going to let you hurt me again."

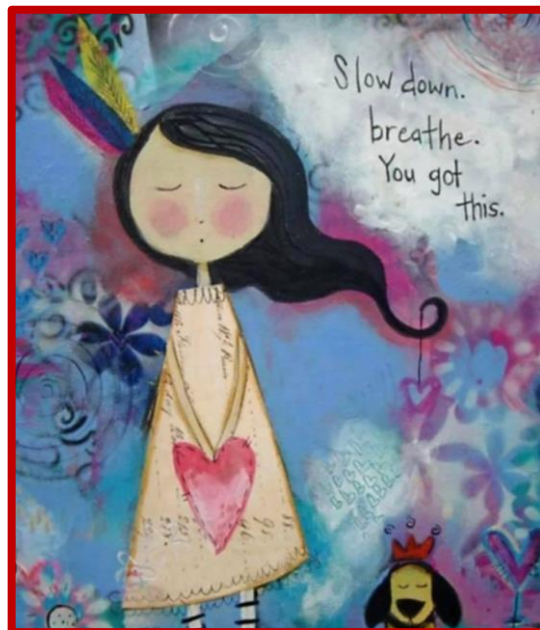
Physical therapist: "It was one sit-up. You just did one sit-up."

Remember, if you lose a sock in the dryer, it will come back as a Tupperware lid that doesn't fit any of your containers.



Thank you for your kind words and generous [donations](#).
We genuinely appreciate it.

Thank you survivor
Constance Habakangas for
this hopeful message.



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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