



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

December, 2021

Our Mission:

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

Inside this Issue:

Are you particularly affected by the heat?: You're not alone. If the poliovirus damaged neurons that control body temperature, shouldn't polio survivors have trouble with heat as well as cold? [Richard L. Bruno, HD, PhD](#) realized recently that although he previously studied blood flow and the effects of cold on polio survivors, he never studied the effects of heat. His new article has some interesting discoveries.

Temperature change discomfort (most commonly seen in effects of the "cold") is not unusual for polio survivors. Dr. Bruno has additional articles, related to the cold, in the [Encyclopedia of Polio and PPS](#) on our website. They are easily available under the topic "Temperature".

It's not easy getting around in a wheelchair: During the holidays it can be especially difficult to get where we need to go. We thought we had found what we wanted to share with you, and along came the newsletter from our friends in the UK – [The Worldwide Fellowship of Polio Warriors](#). We loved their article – and coming from Switzerland, we loved the references to "sweet mince pies".

Upside Down Polio - What IS it?: We think of polio survivors requiring leg braces and wheelchairs. Polio survivors with the majority of their muscle weakness in their upper body have sometimes been called "upside down polios". [Marny K. Eulberg, MD](#) has written a fascinating article that describes how we all can learn from polio survivors living with upper extremity weakness.

Our Perspective on Vaccines: In our work regarding Vaccine Advocacy, we have had the privilege to participate in a project with the [Vaccine Education Center of the Children's Hospital of Philadelphia](#). It is a special opportunity to be working with a professional organization that understands the realities of and acknowledges the complex issues that come with the poliovirus.

One Goodbye and one Hello: We want to welcome fellow survivor May Van to our [PA Polio Network Team](#) of volunteers. We've known May for a very long time and are happy to have her positive energy around us. As we welcome May, we say "thanks" to Deborah Prewitt who was with us 7 years ago when we first began. We are grateful for her thoughtful contributions to our work.



Finding time to take care of yourself during the holidays isn't selfish.

"Winter Wellness" begins with deciding what you *really* want to do and holding off of the things that you "want" to do.

The holidays are a particularly difficult time when it comes to these activity decisions. The holidays can be especially trying during stressful periods of isolation having come from almost two years of COVID and for those who are alone. Polio survivors need to try to avoid chronic overuse activities and take some much needed time for YOU.

You can find [William M. DeMayo, MD](#)'s complete article on the topic of "Winter Wellness" on our website: polionetwork.org





IF YOU CAN'T STAND THE HEAT, YOU MAY BE A POLIO SURVIVOR.

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

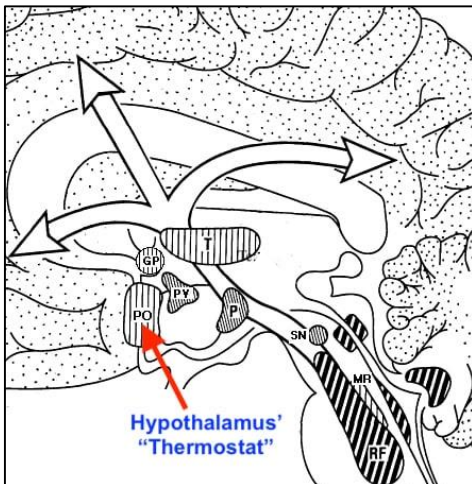
Director, International Centre for Polio Education

Question: When the temperature goes up I feel so hot, even indoors in the winter, that I sweat and soak my clothes. But sweating doesn't cool me down and, in spite of my frozen "polio feet" staying ice cold, I feel like I'm cooking inside. Is my problem with temperature a post-polio thing?

Answer: The poliovirus damaged the neurons in the brain and spinal cord that control body temperature that control the sympathetic nervous system. Your brain's thermostat (in the hypothalamus) should turn on sympathetic nerves to cause skin veins and arteries to constrict when it's cold, preventing loss of body heat. The reason polio survivors have cold and purple "polio feet" is that there isn't a signal from the brain thermostat that reaches blood vessels to tell them to constrict. So hot blood flows to the vessels near the surface of the skin, heat in the blood radiates away from your body and your skin gets cold, which passively makes the veins clamp down, trapping cold, purple blood in the little veins and, voilà, "polio feet."

But if the poliovirus damaged neurons that control body temperature, shouldn't polio survivors have trouble with heat as well as cold? Over the course of decades I had not heard one polio survivor report being overcome by heat, only that they were being frozen stiff by the cold. So while I studied blood flow and the effects of cold on polio survivors, I never studied the effects of heat. But I should have. Back in 1985, in our own first Post-Polio Survey, about 1/3 of polio survivors said that they were adversely affected by the heat.

Why didn't I study heat intolerance? Truth be told, I think I was frightened off by the first polio survivor I studied. She said that her polio-affected foot was always much colder than the other foot, even when she was in a room where others were comfortably cool. I was shocked and worried when she removed her sock to reveal a reddish-purple calf and a deep purple foot. I was afraid she had a blood clot, maybe even a clogged artery. But her veins were clear and she had bounding pulses in both feet. The real shock came when I placed an electronic thermometer on her skin. The room temperature was 75°F (24°C). I watched as the numbers on the thermometer dropped and dropped, until they stopped at 72°F (22°C). Her foot was actually colder than the room temperature! I had to put her foot up on a stool and cover it with a hot pack for half an hour before it began to warm just slightly. And when it finally did heat up, the skin became as red as a lobster. It didn't take a rocket scientist to see that there was something radically wrong with blood flow in this polio survivor's leg. So that's where our research focused, on the effects of cold.



Too Darn Hot. It's not that I wasn't interested in the effects of heat. The mechanism for sweating was one that I had studied fairly extensively when I was the autonomic nervous system fellow at Columbia-Presbyterian, before even seeing a polio survivor. The first paper I ever presented was on the mechanism of decreased sweating in Parkinson's patients. We knew that the brain's thermostat and sympathetic nerves not only control blood vessels but also control sweating, which cools your body by evaporation of sweat on your skin when opening blood vessels doesn't "dump" enough body heat via radiation. Given our finding of polio survivors' arteries not getting a signal to constrict, I would have expected poliovirus damage to the brain's thermostat and sympathetic nerves would cause polio survivors always to sweat too little. And I would have been wrong.

In a recent Internet survey, six-dozen polio survivors reported difficulties with temperature, specifically on heat intolerance. When asked about sweating, a minority reported "little to no sweating" associated with heat intolerance, while three times as many reported "hot flash-like" sweating, especially about the neck and face. "Comfortable" temperatures were reported to range from 61°F (16°C) to 72°F (22°C), while heat intolerance symptoms began from 72°F (22°C) to 85°F (29°C). The most common symptoms of heat intolerance were "nausea," "feeling faint or dizzy," being "itchy," fatigued and even anxious. Surprisingly, only three polio survivors reported that their skin became red when they felt overheated, suggesting an inability of blood vessels to open and dump enough body heat so that sweating wasn't necessary. Also surprising were polio survivors who reported having "hot flash-like" sweating from the neck up at the same time as they were experiencing painfully cold legs and feet.

If you can't Stand the Heat (continued . . .)

With these findings, we may have come full circle. We know that polio survivors have cold legs and feet ultimately because arteries clamp down and prevent hot blood from the body's core from heating the skin's surface. Perhaps the inability to get rid of excess body heat results from the same problem - surface arteries not opening - that leads to symptoms of heat intolerance and triggers sweating above the waist to try to cool the body.

So, at least for some polio survivors, cold feet cause hot heads.

[Richard L. Bruno, HD, PhD](#)
[The Encyclopedia of Polio and PPS](#)



Festive Advice To Help Any Wheelchair User At Christmas

Wheelchair access, and ensuring your environment is accessible, is a challenge at the best of times, so sprinkle a little chaos into the mix; such as that experienced over the festive period, and suddenly navigating your way through your home and the homes of loved ones can become quite a chore.

Needless to mention there's also the odd occupational hazard just waiting to rear its ugly head – such as unexpected snow storms and icy footpaths!

Snow at Christmas; it's a nightmare for Wheelchair Users!

Let's start with that last point – snow! If you're a wheelchair user yourself then you'll know all too well the perils that accompany the cold, white, powdery stuff! Wheelchair wheels (both manual and powered wheelchairs) have a tendency to get stuck in the snow and render the user completely immobile. To counter these issues, it's important to try and ensure someone is on hand to grit (*a mixture of salt and sand*) any pathways leading to your home, ahead of any impending snow storms. Likewise, if you're aware of incoming snow, it may be worth reaching out to your local authorities to remind them to clear any snowfall from public areas such as high streets, entrances to hospitals, and more. You could say that local governments have a civic obligation to ensure public services are accessible to all – regardless of uncontrollable weather fronts. Where steps can be taken to lessen the blow of such occasions, it's advisable that you yourself remain 'on the ball' and vigilant to any potential slacking.

Christmas Decorations and getting around the home as a Wheelchair User

Poor access doesn't stop there though, and it's also not reserved solely for out in public. Christmas can present obstacles for disabled people even within their own homes – with increased furniture, fixtures and fittings (such as Christmas trees, piles of presents and other ornamental decorations) wreaking havoc for those using wheelchairs, walking frames, or any other form of walking aid to get around. It's important to plan where you're going to put everything this year, and ensure that enough space is left for you to safely maneuver around the home. These same practices should be emphasised to loved ones too, or to anyone you're planning on visiting over the Christmas period. There's nothing worse than turning up at a friend's, or relative's home and realising that you can't get in for all the fancy decorations that weren't there a couple of months previous!

How to Prepare for a Christmas Party if you're a Wheelchair User

What happens if family members are planning to go to a restaurant for a Christmas meal? It may seem obvious to mention, but you'd be amazed how often we forget to call ahead and enquire about access when visiting new locations. Christmas is a busy time of year, too, so it's doubly important to ensure that there'll be no unwelcome surprises when you arrive – as there may be no opportunity to book an alternative location at such short notice – especially if it's on Christmas day! The same advice can be said for attending Christmas parties. Whether it's a work's do, or a night out with friends – cover your own back by contacting venues ahead of time to make sure they have all the necessary access requirements to suit your own personal needs. It pays to be assertive and productive in this manner, and it means you can be free from worry and ready to have the time of your life once out!

Finally (and this one goes without saying) don't forget to over indulge. Everyone does it! If you don't eat your own body weight in sweet mince pies and then fall asleep in front of the TV watching dodgy Christmas movies, then was it really Christmas at all?

Source: <https://www.passionatepeople.invacare.eu.com/festive-advice-to-help-any-wheelchair-user-at-christmas/>



“Upside Down” Polio

What is it?

[Marny k. Eulberg, MD](#)

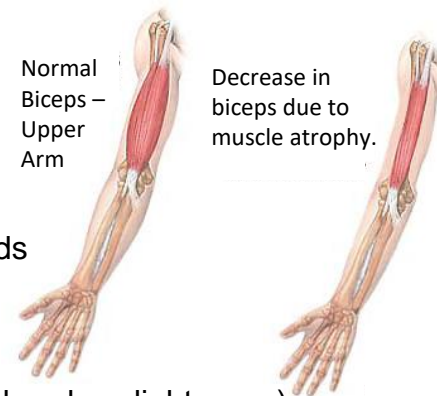
We all can learn from polio survivors living with upper extremity weakness.

Polio survivors with the majority of their muscle weakness in their upper body have sometimes been called “upside down polios”. This term is based on the fact that the majority of observable weakness and atrophy in most polio survivors is in the lower part of their bodies. Therefore, if a person has the reverse, with most of their weakness/atrophy in their shoulders, arms, and/or hand, it is “upside down” from what is usually observed.

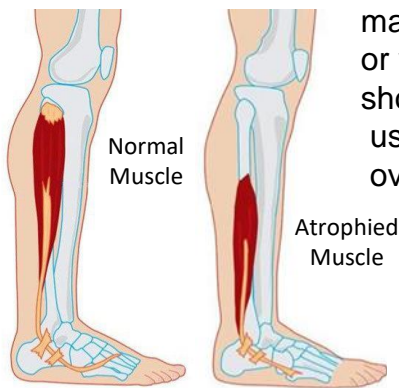
The muscle atrophy in the upper extremity may not be as obvious to the casual observer as it is in people with atrophy/weakness of their legs with an obvious limp, because the atrophy can often be hidden under clothing (ex: keeping a polio affected hand in a pocket most of the time). Upper body weakness, may take close observation in order to notice that these polio survivors perform daily tasks differently, such as using two hands to lift a glass up to their mouth or use some different movements to put on or take off a coat or sweater.

If the weakness involves a person’s right hand, they may choose to “shake hands” using their left hand or use other movements (nodding their head, a slight wave) to convey a greeting. Polio survivors with marked weakness of both arms may need someone to feed them, dress them, and perform many activities of daily living. Some who had polio at a young age may have learned to use their feet to do many of the tasks that others normally do with their hands/arms such as writing, peeling vegetables, and even doing art work; others do tasks using their mouth such as using a mouth stick to type, write and paint.

Individuals with upper extremity weakness are more likely than those with lower extremity weakness to have some respiratory muscle weakness because some of the same nerves that control the arms also control the diaphragm.

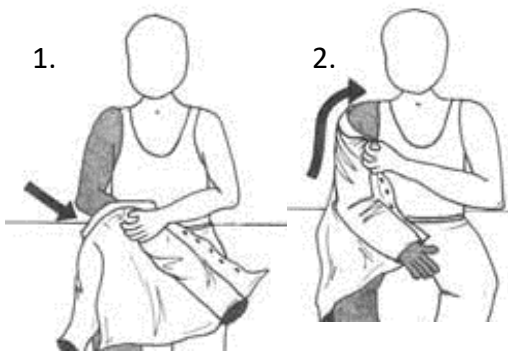


Persons who have had significant lower extremity weakness and have used their arms to assist with many activities that require leg strength (ex: getting up and down from a chair or walking with crutches) are quite likely to develop overuse problems in their shoulders, elbows, and/or wrists. Upper extremities were not designed to be used for long-term walking! This may be temporary after a particular period of overuse or can become chronic. It can be a tendonitis, a bursitis, wear-and-tear arthritis, or a tear of various tendons/muscles such as rotator cuff tears or biceps muscle rupture, etc. All of these can initially result in pain which then can lead to weakness because if it hurts to perform certain motions, people stop doing that motion or severely limit the use of muscles that effect that motion.



Bottom line: Even if a person’s initial polio primarily affected their legs, it is likely that over time they are at risk of developing some overuse symptoms in their upper body that can limit their use of their upper extremities.

Over the past few years, I began to have pain in my shoulders (right greater than left) that limits my ability to perform certain activities such as putting on or taking off certain clothing like sweatshirts, jackets, and blouses/shirts. After watching some polio survivors with upper body weakness, I learned that I could still do those activities with little or no pain. I just had to *change the way* I was doing things and use the techniques that those “upside down polios” used. So, now instead of removing a sweatshirt by crossing my arms in front of my body and grasping the lower left hem with my right hand and the lower right hem with my left hand and then pulling straight up and over my head, I now lean forward (getting my



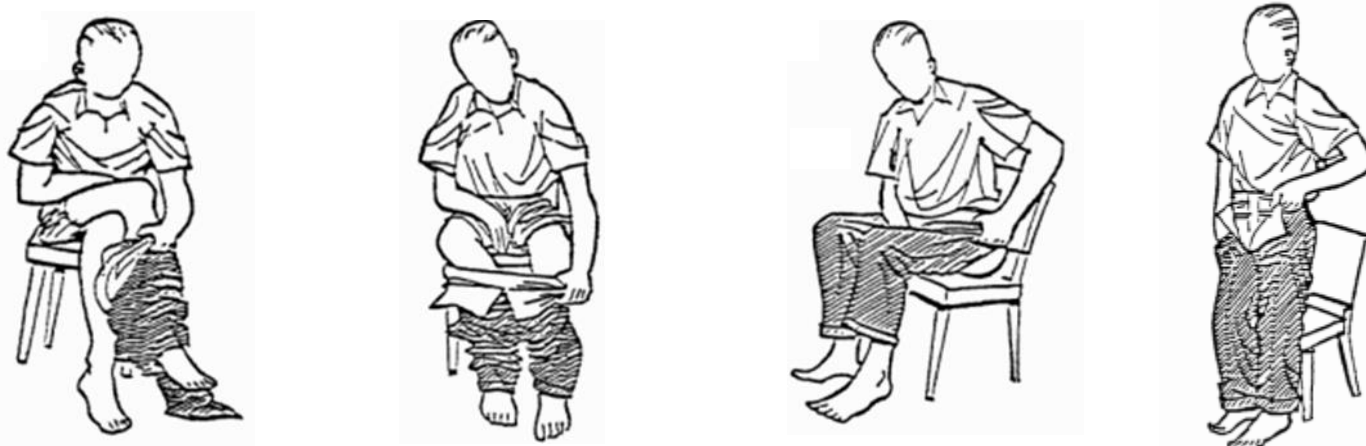
trunk nearly horizontal), grasp the back of the neck opening with one hand and pull slightly up and horizontally until the sweatshirt is over my head and off. (Note: graphic is for a jacket but the idea is similar).

Paulette Bergounous, a polio survivor with little functional use of one hand/arm, has reported that many of the people accessing her blog and videos are previously able bodied people that now are scheduled for shoulder surgery that will require little or no use of one arm for several weeks to months. A good occupational therapist can assist you with methods that work for your particular limitations.

This graphic is a good series of illustrations that shows pulling a shirt over head with the use of a single arm in detail



This graphic is a good series of illustrations showing putting on long pants with the use of a single arm.



As in many aspects of aging, there are many useful tricks and techniques that we can learn from other polio survivors. We can adapt and use what we need as we develop some of the limitations of a long life.

[Marny K. Eulberg, MD](#)

There's nothing “upside down” about the two polio survivors living with upper body paralysis, whose stories we've had the opportunity to publish. **Martha Loudder** and **Deborah Stambaugh** are determined, resilient and very much upright. Their stories are easily available on the [Survivor Stories](#) page of our website. www.polionetwork.org

You can find this article along with Dr. Eulberg's biography and additional work on our website:

[Primary Care Perspectives](#) - www.polionetwork.org/primary-care-perspective

All of her articles are available for easy download and sharing.

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". It was fun to work with such a professional organization that understands the realities of and acknowledges the complex issues that come with the poliovirus.

As of this date, three of the videos have been uploaded to their website. We have brought you a brief summary of each. Click on the arrow to watch the video. The full collection will be available on the [Survivor Stories: In Our Own Words](#) page of our website.



I can easily connect the fear of contracting polio to the fear we have been experiencing with COVID-19. An "asymptomatic" or "mild" case of the poliovirus has changed my life forever.

I "only" had the Summer Grippe (another name for flu). I got better on my own in less than a week. No need for doctors. No need for "quarantine signs" to be nailed to our door.

I had small issues that were no big deal. The word "polio" was never spoken and neighbors didn't have to know. I learned in my 40's that the summer grippe was a "mild" case of polio and that the late effects of the virus had taken over my body.

www.youtube.com/watch?v=Fcsb-QumvpA&list=PLUv9oht3hC6QvShehYb2g6JTIQvIu5SDi&index=6



No one knows what COVID long-haulers may have to go through. We did not know at the time that we were going to be going through the same thing. Having polio meant visits thru a hospital window, with no touch between child and parents. It meant long hospitalizations, painful stretching exercises, hot wet wool wraps and whirlpool exercises.

Some of the long term effects are crippling, some not so much. It meant enduring prejudice, stares and as a result of the long term effects, the uncertainty of what is ahead.

www.youtube.com/watch?v=rjing7Ey8W4&list=PLUv9oht3hC6QvShehYb2g6JTIQvIu5SDi&index=1



Parents of school aged children today don't have any idea of the fear of the poliovirus that took over during the summers of the 1940's and 50's. Movie theaters and swimming pools were closed. Birthday parties were canceled. . . . and the start of school was often delayed.

I was hospitalized for two years while I learned to live with what I had left. I am about to turn 75. That means I will have lived with the damaging, lifelong effects of this virus for 70 years . . . **70** years.

Vaccines are a miracle of modern science. When we protect our children with the vaccine for COVID, we are protecting everyone they come in contact with.

www.youtube.com/watch?v=ml6raGvpYPE&list=PLUv9oht3hC6QvShehYb2g6JTIQvIu5SDi&index=4



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

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

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

Cellphones power disease fight

Pakistan And Nigeria Replace Paper-based Reporting With Fast, Accurate Cellphone Messaging

Mobile phones and simple text messaging may be the keys to victory in the world's largest public health initiative: the eradication of polio. As the disease retreats from the global stage, thriving in only a few remote areas in two countries, it's up to health workers to deliver vaccines and share information with speed and accuracy.

Rotary and its partners in the Global Polio Eradication Initiative are strengthening the lines of communication by giving cellphones to health workers in Pakistan and Nigeria, where a single text message could save a life.

- In Pakistan, Rotary has been working to replace traditional paper-based reporting of maternal and child health information, including polio immunization data, with mobile phone and e-monitoring technology. Community health workers across the nation have received more than 800 phones through a partnership with Rotary, the Pakistani government; the country's second-largest telecommunications provider; and a data monitoring and evaluation specialist.
- Health workers can use the phones to send data via text message to a central server. If they see a potential polio case, they can immediately alert officials at Pakistan's National Emergency Operations Center. They also can note any children who didn't receive the vaccine or parental refusals – and record successful immunizations. In Pakistan, the polio eradication effort aims to reach the nation's 35 million children under age five.
- The result is a collection of real-time information that officials can easily monitor and assess, says Michel Thieren, regional emergency director of the World Health Organization's Health Emergency Program. Pakistan health workers are replacing traditional paper-reporting with accurate and timely cellphone-based reporting. "This gives governments and polio eradication leaders an advantage in the decisions we need to make operationally and tactically to eliminate polio," Thieren says.
- Beyond Polio - Health workers also are using mobile phones to monitor a multitude of maternal and child health factors. Pakistan's child mortality rate ranks among the highest in the world, according to UNICEF, with 81 deaths under age five per 1,000 live births. But mobile technology can help reduce those deaths, says Asher Ali, project manager for Rotary's Pakistan PolioPlus Committee. "Our health workers, including community midwives, are tracking pregnant mothers," Ali says. "When a child is born, they can input and maintain complete health records, not just for polio, but for other vaccines and basic health care and hygiene needs."
- They also can monitor infectious diseases, such as malaria, tuberculosis, and influenza-like illnesses, as well as child malnutrition and maternal health concerns. "If there is a problem with the baby or the mother, we can send information to the government health departments immediately, so they can solve the issue quickly and adjust their strategies," Ali says.
- Proliferation of phones - Mobile phone use worldwide has spiked recently, with about 7 billion subscribers globally, 89 percent of them in developing countries, says WHO. Even people living on less than \$1 a day often have access to phones and text messaging, according to WHO. Cellphones are used more than any other technology in the developing world. "Mobile technologies are the type of innovations that can fill in the gaps of our program and finally help us end polio for good."

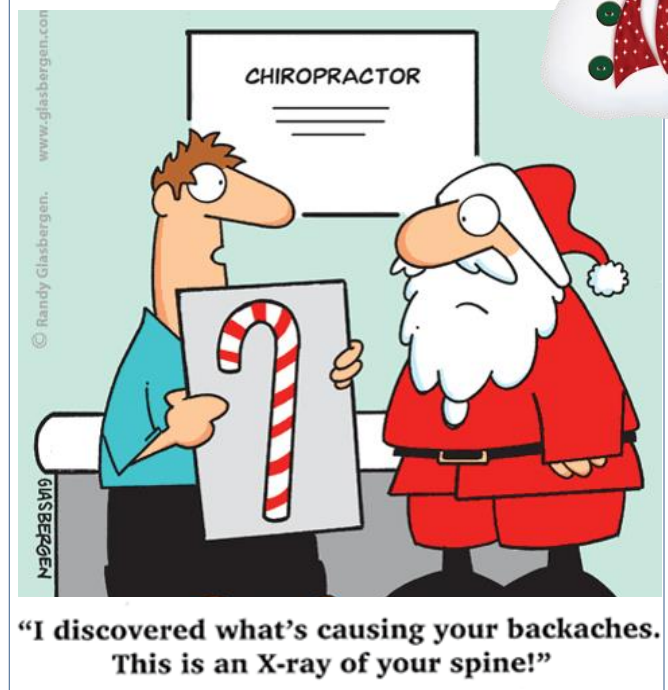


Pakistan health workers are replacing traditional paper-reporting with accurate and timely cellphone-based reporting.

Some Happy Holiday Humor . . .



Garfield / Jim Davis



"I discovered what's causing your backaches. This is an X-ray of your spine!"



Garfield / Jim Davis



Bound & Gagged / Dana Summers



Survivor Stories – In Our Own Words

This page of our website is growing with **YOUR** stories.

We are living in a world that has “forgotten” polio. There is a generation of parents who do not realize how blessed their children are to be receiving the polio vaccine as “routine” immunization. It is routine because the truth is, this terrible disease has yet to be eradicated.

We are learning to accept that the vast majority of young parents today have never actually seen first-hand the damage that can happen as a result of what are *now* vaccine preventable diseases.

As we have written scripts and participated in this project ourselves, we understand that it can be really hard to write about our own polio truths. What we have seen is that just a paragraph or two can have the powerful words that help others see the difficult realities that can come long after the live poliovirus leaves our bodies. Our words can help parents understand the complex issue of both the physical *and* the psychological symptoms of Post-Polio Syndrome.

Maybe, just maybe, a vaccine hesitant parent will change their minds when they read or listen to YOUR story.

Join us.

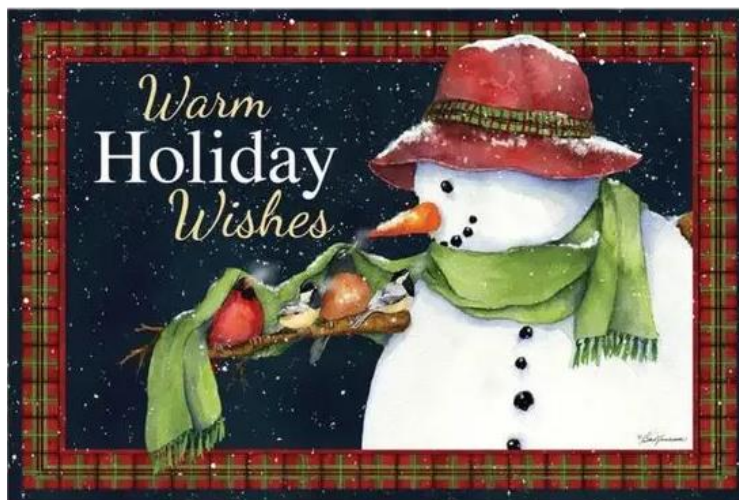
Whether it be with your written paragraph and a photo or with a brief, 2-3 minute video.

We ARE making a difference.

Email your story to: info@polionetwork.org



Thank you for your kind words and generous donations. We genuinely appreciate it.



Always feel free to contact us.

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