



Polio Hero News



We Appreciate Your Support.

FALL 2020



POST-POLIO HEALTH INTERNATIONAL has NEW ADDRESS :

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May 1, 2020 Web #73 - What Jonas Salk would have said about Covid-19: THE HILL - "Johnathan Salk, son of Jonas Salk, elegantly opines on how his father would have viewed the COVID-19 pandemic: 'He would have recognized the COVID-19 pandemic not only as something to be feared and fought, but also as a moment to embrace wisdom. He would have seen this crisis as an opportunity to shift from individualism to interdependence. He would have told us that fighting the pandemic demands replacing the 'us first', win/lose mindset with a 'we together', win/win mindset, and he would have advised that, paradoxically, self-interest in this case is best served by generosity.'"

POLIO EXPERT NAMES TO REMEMBER

Many times our Newsletter has articles from different sources. These are a few who we often quote. This list is not to exclude others, but to let you be more knowledgeable about some of them we rely on for current PP information.

Dr. Frederick Maynard, MD - Medical Advisor to Post-Polio Health International. Writes a regular column in their Newsletter "Ask Dr. Maynard". His association goes back decades. Did much research on PPS at the University of Michigan with **Sonny Roller**.

Dr. Richard Bruno, PhD - Clinical psychophysicologist who started treating polio patients in 1982. Dr. Bruno and his late wife, **Nancy Frick**, (polio survivor) wrote many articles without medicaleese for polio patients to understand what was happening in this PPS phase. Author of **THE POLIO PARADOX**, the "polio survivor's Bible" - a **MUST** for polio survivors. He is the Director of the International Centre for Polio Education, International Post-Polio Task Force. website: <http://postpolio.info.com>

Dr. Carol Vandenakker, MD - Board certified in Physical Medicine and Rehabilitation. Serves on the Board of PPHI and Medical Advisory Committee. Established a PP Clinic at the U. of Miami in 1993, moved to California in 2001 and established a clinic at UC Davis Health.

Dr. John R. Bach, MD - Doctor of Physical Medicine and Rehabilitation and a fellow of the American College of Chest Physicians, and is currently a professor of Physical Medicine and Rehabilitation and Neuromuscular-Pulmonary Rehabilitation in the Neurosciences Department at University Hospital, Newark, NJ and Co-Director of the medical Schools' Jerry Lewis Muscular Dystrophy Association Clinic. He is widely recognized as an expert on polioventilation and breathing problems.

Dr. Selma Calmes, MD (Retired) - Dr. Calmes and her two brothers had polio. She became the leading expert on Anesthesiology and polio patients. She retired in 2007 from the UCLA School of Medicine and Medical Center. She has written numerous articles for PPHI on Anesthesia, Swallowing and related subjects that are so valuable to polio survivors needing surgery.



Dr. William DeMayo, MD - Doctor of Physical Medicine and Rehabilitation (Physiatrist) for more than thirty years. Currently in Johnstown, PA website: <https://www.papolionetwork.org/demayo-articles.html> (Source information: Ohio Polio Network 2020 and Boca Area PP Group, Boca Raton, Fla. 8/2020)

FROM THE SISTER KENNY FOUNDATION 11/2010: "For many who survived polio, they have vivid recall of the distinctive odor of hot, wet wool. THE SISTER KENNY METHOD, developed by **Sister Elizabeth Kenny**, including placing steaming hot woolen strips with added layers of insulating wraps around affected limbs. Once the body absorbed the heat from the hot packs, the packs would be removed and pained muscles stretched by therapists. The innovative Kenny Method provided life-changing results for those whose bodies were ravaged with muscle spasms associated with polio." (PHTN Note: Turner Classic Movie Channel sometimes airs the movie "THE SISTER KENNY STORY".)



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Q. - I have trouble swallowing but no one believes me. Food doesn't get stuck in my throat, but lodges somewhere behind my breastbone. I had a normal swallowing study and the doctor doesn't believe I have a problem. Food sticks and it hurts when it does! Do other polio survivors complain about this?

A. - They surely do. It's hard enough to "swallow" having PPS without doctors refusing to believe you're having trouble swallowing. Most Post-Polio Institute patients report having only occasional, mild problems swallowing. The problem is usually high in the throat: not being able to get down pills, largish pieces of meat and, maybe even difficulty clearing their own secretions. A barium swallow study (where you eat and drink food containing barium and "video" is taken with an x-ray camera) usually shows mild muscle weakness in the throat or, as in your case, no problem at all. This "negative" finding is just like a muscle test of an arm or leg not showing weakness in the doctor's office, even though you feel weaker or even stumble at the end of the day as you get more tired. Polio survivors also have swallowing problems below the throat.

What you describe- food getting stuck behind your breastbone in the esophagus (the tube connecting the throat to the stomach) is not uncommon in polio survivors. The muscles of the throat and esophagus should contract in a coordinated sequence, like a snake, to move the food downward and into the stomach. Food gets stuck when the esophagus doesn't contract and its muscles go into spasm, not unlike when back muscles go into spasm when your leg muscles are too weak to hold you up. Food usually gets stuck right behind the top of the breastbone. And, stuck food is painful and scary! Even if food does make it down to the bottom of the esophagus, in some polio survivors the "valve" at the bottom of the esophagus doesn't open and prevents food from entering the stomach, a condition called *acalasia*.

Why do polio survivors have trouble with muscles from their throats to their stomachs? Fifty years ago, Dr. David Bodian discovered that every polio survivor had some damage to neurons in the brain stem, the so-called "bulb" of the brain. When brain stem damage was severe and "breathing neurons" stopped working, "bulbar polio" was diagnosed. The most common bulbar polio symptom was trouble swallowing, not trouble breathing; because the poliovirus also damaged the bulbar neurons that control the vagus nerve, the nerve that activates and coordinates muscles from your throat down to your stomach.

Unfortunately, 99% of gut doctors have never seen food get stuck in the esophagus and don't know what to do about it. We've found that a low dose of muscle relaxants Klonopin and Bentyl, taken 30 minutes before eating, can relax the esophagus and allow food to slide down to its intended destination. But wait! Vagus damage likely explains our first Post-Polio Survey finding that diarrhea, colitis, ulcers and constipation are as much as 6 times more common in polio survivors than in the general population. Some polio survivors report that their stomachs don't empty, a condition called *gastroparesis*. Others have their intestines abruptly stop moving - as a side effect of medication, surgery, a gall bladder attack, or for no reason at all - a condition called *paralytic ileus*. Often, the muscles of the stomach and intestines get moving again on their own. Sometimes the drug Reglan is needed to jump-start the stomach and intestines. Reglan can have bad side effects, since it enters the brain. Domperidone, a drug that does not enter the brain (or the US, so you have to buy it from Canada) is the better choice if you can take it by mouth.

Polio survivors need to try to prevent gut slowing by being careful when taking drugs that are anti-cholinergic (drugs that have dry mouth as a side effect) since they block the activity of the vagus nerve.

Finally, Polio survivors who have a chronic sore throat, husky voice, or burning in the chest should be evaluate^{3d} for reflux by an ENT doc, who'll look at the upper throat and vocal cords, and a GI doc, who may do a gastroscopy, make sure that the doctor goes light on the anesthesia and uses the anesthetic Propofol, since it's short-acting and allows polio survivors (usually) to wake quickly.

(Source: Boca Area PP Group News, Boca Raton, Florida, Oct. 2018)

Note - PHTN - *Experience tells us that if food is stuck in the esophagus, the stretching of the esophagus may be required to ease the situation. This procedure is called an Endoscopy. It may be that polio survivors should request a pediatric scope as the physician may have trouble introducing a regular size scope. Food stuck behind the breastbone will not effect breathing, but even saliva may not pass. This is considered an emergency to a GI doctor or ER. - NLSL*



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Wins Fight Over Polio



Ben Jones, Jr. League Paper 1937

We continue to collect old photos, Jr. League papers and newspaper articles about members of our support group. You may send them to: Nickie Lancaster, 529 Albany Dr., Hermitage, TN 37076-1422 or email to smlphn@att.net We can return the originals to you upon request.



CORONAVIRUS by Prof. Michael Kossove 3/12/2020, Touro College, NY

The public associated with Coronavirus brings back memories of the 1950's, and the polio epidemics where 50,000 people were paralyzed each year, and several hundreds died. It's impossible to predict how many people had the virus and didn't know it. Had they been tested (there were no tests then), they would have tested positive. Oh, the panic in the summers associated with polio. You have to be a polio survivor, or a family member, to remember that time. Now, we have the Coronavirus. We've always had the Coronavirus. Approximately 10% of the common colds are Coronavirus. This is a "Novel" Coronavirus because it's different. It's a mutation. Influenza virus mutates every year, millions get it, and thousands die. In our age, the ones that get it were not immunized, or if they were, had mild cases. Here we are again. A new virus and no vaccine. By next

winter, there will be one. While polio infected people in the warm weather, Coronavirus, unlike the Flu, infects people in late Fall, Winter and early Spring. We know that people over 60, with underlining conditions, are most vulnerable. That's us. It can be scary. They talk about respiratory conditions and diabetes. That covers many of us.

Let's talk about this crazy virus. This disease is called a Novel CoV. It was officially named Covid-19 on Feb. 11, 2020 by the WHO. The provisional name of the new virus stemmed from the year it was first seen (2019), the fact that it is new, and a member of the CoV Family. It's called corona because it is shaped like a crown. Symptoms can include the same as a cold, such as a runny nose, fever, fatigue, and respiratory symptoms.

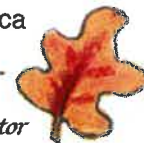
Bats are known to harbor a wide range of viruses including many that are highly pathogenic to humans. Bats can carry the virus without getting sick. Initial cases occurred in people who worked at or visited the Hunan seafood market in Wuhan, China where a variety of wild animals were sold. China has a long tradition of eating wildlife, especially in Southern provinces, including bats. They hunt bats in caves, bring them to the market live, and bats shed excrement in the market.

It's hard to say how long the virus can exist outside the body. On copper & steel it's about 2-9 hours, cardboard or plastic longer. Transmission can occur when a person touches contaminated objects/surfaces, then touches their mouth, eyes and inside their nose, or by sneezing or coughing, sending the virus into the air.

What to do to stay healthy? 1) Wash your hands often with soap and water for at least 20 seconds. An easy way to mark the time is to hum "Happy Birthday twice while scrubbing.. 2) Use an alcohol-based hand sanitizer with at least 60% alcohol. 3) Avoid touching your eyes, nose, and mouth with unwashed hands. 4) Avoid close contact with sick people. 5) Stay home when you are sick/becoming sick. 6) Cover your cough or sneeze with a tissue (not your hands) and throw the tissue away in the trash. 7) Clean and disinfect frequently touched objects and surfaces. 8) Getting a flu shot is recommended. (Addition: For a vaccine - We didn't have the biotechnology during the Polio era to develop a vaccine in a very short time like for the Coronavirus. When the polio Vaccine was released, the decline in cases became very apparent. - Colorado Connection, Spring 2020)

If you have to shop, do it early morning or at supper time when there are fewer people in the store. Stockpile essential items that you use daily. Make sure you have enough medication to last you about a month. Since polio survivors are seniors, with underlining conditions, especially respiratory, stay home. Read books, watch TV, walk or wheel around the outside of your house. Whatever you do, **there's no need to panic. Epidemic does not mean Panic.** It tells us to take precautions. (source: Boca Area PPSG April 2020)

FIRST "ZOOM" WITH BOCA RATON POST POLIO GROUP - August 10, 2019 Nickie Lancaster (PHTN) was invited to join the Zoom hosted by Maureen of the Boca Raton, Florida PPSG. Numerous others joined from several States, Canada, UK and India. Dr. Carol Vandenakker, MD (California) spoke on "Aging and Pain with PPS".. Barbara Goldstein (Florida), who for 20 years managed the East Coast Fla. PPSG, and was an old friend from the St. Louis conferences going back to the Gini Laurie days, also participated. After Dr. Vandernakker's presentation there was a general discussion and interesting interaction among participants. It was a great experience with everyone having a chance to voice their views. Maureen did a great job, but Nickie had to be reminded that Boca Raton is on Eastern time.....



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STEM CELL THERAPY IS NOT FOR POLIO SURVIVORS
by Dr. Richard L. Bruno, PhD, Chairperson, International Post Polio Task Force

(Several inquiries have been made about stem cells. This article by Dr. Bruno addressed this issue in 2015.)

Stem cells are remarkable, embryonic “baby cells” that will grow up to be any kind of cell the body makes. With all the excitement about stem cells curing spinal cord injury, many polio survivors are asking if stem cell could cure PPS, or even reverse the damage caused by polio itself. The hope with spinal cord injury (SCI) is that stem cells, injected into the spinal cord, would “bridge the gap” in cut spinal cord axons, which are like long telephone wires that connect brain motor neurons to spinal cord motor neurons and allow the brain to “tell” muscles to move again. This notion requires intact motor neurons below the cut in the cord.

Here lies the problem with stem cells “curing” polio or PPS. Even in “mild” cases, the poliovirus killed off at least 50% of neurons throughout the spinal cord. Stem cells injected into a polio survivor’s spinal cord would not have to just bridge a gap, but have to become new, functioning motor neurons. What’s more, those new neurons would have to send out their own axons to find and activate the specific muscles that were paralyzed when the original axons disappeared 50+ years ago after poliovirus infected neurons died, by burrowing inches, or in the case of the leg three feet, through the tissues inside the arms and legs.

Finally, the brain’s motor neurons would have to send out new axons as well, since the brain’s neurons and axons also died. These axons would have to burrow through the entire brain, the brain stem and down through the spinal cord to get to the newly-implanted motor neurons, indeed a tremendous tunneling task! The idea of rebuilding a polio-damaged spinal cord would require a “hat trick” of creating new brain and spinal motor neurons, new axons tunneling from the brain to the spinal cord and from the spinal cord to the muscles. Reconnecting a spinal cord that has been cut, would only require the physiological “goal” of bridging the gap between cut axons.

A possible use from stem cells would be to inject them into the brain, as is done in Parkinson’s disease patients, where they could produce the main brain activating neurochemical, dopamine, which is decreased in polio survivors and causes post-polio fatigue. But, such injections are not widely accepted even in Parkinson patients yet. If stem cells aren’t the answer, is there anything polio survivors can do to help their remaining poliovirus-damaged neurons? Recently, there has been research on “neuro-protective” drugs (medications that protect neurons’ innards from overuse-abuse that causes post-polio symptoms). Several studies have focused on degenerative diseases, such as Parkinson’s and Huntington’s diseases, which involve damaged dopamine neurons. Minocycline, a common antibiotic used to kill a variety of bacteria, and creatine, which helps to provide energy to muscle cells, have been given to Parkinson’s patients, who showed a less rapid decline in function compared to those taking a placebo.

However, a study comparing creatine and placebo in 60 Parkinson’s patients found that, while their mood improved and their need for medication decreased, their symptoms did not lessen. Vitamin E has been found in studies to have some neuro-protective effect in Parkinson’s, while Vitamin C and beta carotene were not helpful. Some research even links coffee’s ability to limit blood vessels from opening to protecting neurons against Parkinson’s, with one cup a day cutting the risk of developing Parkinson’s by as much as fifty percent. Another dietary supplement, coenzyme Q-10, is being tested to see if it protects Parkinson’s patients’ neurons. Huntington’s disease patients have also benefited from potential neuro-protective drugs. Huntington’s patients given minocycline had slower progression or no decrease in physical ability, thinking and memory. Creatine had similar beneficial results in Huntington’s.

Should polio survivors take minocycline, creatine and Vitamin E, or order a Starbucks’ Grande, threeshot cappuccino to prevent post-polio brain fatigue? Not yet. There aren’t enough studies to prove that any of these is truly neuro-protective in Parkinson’s or Huntington’s disease, let alone helpful for polio survivors, in which these substances haven’t been studied at all. double-blind, placebo-controlled studies of potential neuro-protective medications are warranted in polio survivors. For now, the only neuro-protective that we know works in polio survivors is :”*The Golden Rule: If anything causes fatigue, weakness or pain - DON’T DO IT or DO LESS OF IT!*”
www.postpolioinfo.com

OTHER NAMES TO REMEMBER



1989 Dr. James Little, MD and Karen Haynes, RPT named TN Health Care Providers of the Year for their work with Polio survivors.

Dr. Marny K Eulberg, MD - Polio Survivor and Family Practitioner in Colorado. Founded a polio clinic in 1985. 2005 Colorado Family Practitioner of the Year. Dr. Eulberg has a traveling Polio Clinic in Colorado and is Medical Advisor to Easter Seal’s Colorado Connections. marnyeul@me.com

Prof. Michael Kossove - Professor Emeritus and Adjunct Professor of Microbiology, Turo College, School of Health Sciences and Polio Survivor, N.Y.

Dr. Daniel Wilson, PhD - Professor Emeritus of History, Molenberg College Pennsylvania. Contributor to Post-Polio Health International News and Polio Survivor.

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Happy fall ya'll