

## What Having Had Polio Causes, Might Cause and Does Not Cause

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**Introduction:** As time has elapsed since the major poliomyelitis epidemics ended, following the widespread introduction of the polio vaccines, persons affected by polio, their families and their health-care providers seem to have less and less clear understanding about what symptoms are caused by polio, which are associated with polio and which are not. Many healthcare providers in practice today have had little experience or training in the care of polio survivors, and they studied the basic pathology that the poliovirus causes years ago.

Organizations, such as Post-Polio Health International, which exist to provide information to polio survivors, are frequently asked questions about various symptoms and the relationship to the acute polio. Post-polio groups and expert professionals have indicated that many individuals have been given incorrect or confusing information.

Attributing symptoms or changes in functioning to one's previous polio when the symptom is, in fact, due to a disease or condition that should be treated by an entirely different medical regime than polio/post-polio is not only not helpful but may be dangerous. Polio clinics can help with symptoms that are polio related and can help a person sort out what is and is not related to polio. The primary care physician can treat the non-polio related symptoms, and can also manage polio-related symptoms with guidance from knowledgeable post-polio professionals.

The intent of this article is to provide basic information about what the poliovirus does to the human body and to provide a general framework to guide patients, families and health-care providers as they encounter new

symptoms and try to understand them. Often a symptom can be caused by many different mechanisms and sometimes even by a combination of factors.

This article is *not* meant to be all-inclusive and list every possible cause/disease but to discuss the most common and most frequent conditions. As polio survivors age, especially as they approach the second half of their lives, other medical issues can emerge that may make it difficult to determine *exactly* what is causing what. Polio survivors should inform their healthcare providers about their prior history of polio because it can directly or indirectly affect their current medical condition.

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*PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.*

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**Away Temporarily?** Send us your "second" address and dates you will be there, and we'll do our best to send your newsletter.

## WE'RE STILL HERE! ... AND WE VOTE!

It sounds a little threatening, doesn't it?

Not voting or expressing our opinions about our countries' policies can threaten us. We must vote, knowing that in some countries polio survivors can't.

People with disabilities are of all political persuasions. Some are liberal, some are conservative. A few of my post-polio friends are libertarians. Many others declare their independent status to be sure politicians of one party or another won't take our collective support for granted or just write us off.

How you vote is your decision and yours alone.

But, how do we know what we hear in a sound bite or read on the Internet is true? Who does the talking-head expert really represent? Will one party cut Medicare more than another? How will the candidates' ideas affect those with pre-existing conditions?

It is up to each of us to vote, armed with the confidence that our selections are based on facts and that they represent our personal philosophies. Our choice will help determine who will be the decision makers about our future quality of life as polio survivors and as citizens of the world.

Take the time to search for information from reputable non-partisan groups. For example, in the United States, Factcheck.org carefully analyzes claims made by candidates and elected officials. The League of Women voters ([www.vote411.org](http://www.vote411.org)) focuses on registering people to vote and to educating voters about national, state and local elections.

Polio survivor Justin Dart used to remind us: "Vote as if your life depends on it. Because it does." PHI agrees and strongly encourages you to be involved in the process in your country.

We want to help you take action.

The August issue of *Post-Polio Health* will include an eye-catching form letter that you can mail to your sitting legislators and hopeful candidates. It will inform them about polio and its survivors and enumerate the major issues facing the post-polio population worldwide.

Help us create the list. What is your greatest concern? What issues should we list to educate our legislators about our needs? Send them to info@post-polio.org or call 314-534-0475 by July 2, 2012.

You will be able to add your personal message and let the people in power know that WE'RE STILL HERE! Watch [www.post-polio.org](http://www.post-polio.org) and the *PHI Membership Memo* for updates.

Joan L. Headley, Executive Director, PHI



### What does the poliovirus do (pathology)?

The diseases that were called “infantile paralysis,” acute poliomyelitis or acute polio encephalomyelitis, or simply “polio” were all caused by one of the three polioviruses (type 1, type 2 and type 3). The exact virus causing a person’s disease can now be identified in the laboratory but each of the viruses can cause a similar pattern of disease when they infect an individual. As used here, poliovirus or virus refers to one or more of the three polioviruses.

The virus causes a “flu-like” illness with nausea/vomiting/diarrhea, a fever and perhaps a headache and muscle aches, and, in a small percentage of individuals, varying degrees of paralysis. The majority of persons infected with the virus had only the flu-like illness, did not develop any paralysis and were thereafter immune to that virus.

Less than 5 percent of all individuals that were infected with the virus developed paralysis of muscles ranging from a few muscles to nearly all the muscles of their body; some people died as a result of the infection. The virus circulates in the cerebrospinal fluid all around the brain and up and down the spinal cord. In the spinal cord, the virus attacked the anterior horn cells (the nerve cells that go out to the muscle and tell the muscle what to do) but did not affect the nerves that go back to the spinal cord with messages about touch, pain, temperature sensation or position sense (where the body part is in space, i.e., “is

my foot on the floor or in midair? Or is my foot on a flat surface or a slanted surface?”)

The poliovirus primarily affected nerves leading to voluntary muscles. Those are muscles that you can control with thought, such as, “I think I’ll point with my right index finger.” This may include the muscles involved in taking a deep breath, in swallowing, of the face, of the trunk and abdomen and the limbs. There is lack of consensus among medical professionals about how much the poliovirus affected non-voluntary muscles such as those in the bladder or gastrointestinal tract. The poliovirus did not seem to cause permanent damage to the heart (cardiac) muscle.

### What symptoms/signs are likely related to polio (primary effects)?

■ **Atrophy (muscle wasting).** The “skinny arm” or “skinny leg” is a result of the muscle or part of the muscle not getting the message from the nerve that it should contract or move. Related to this is the possible shortening of the limb. In a growing child, bone grows as a result of the muscle pull on it and/or weight bearing. Therefore, many who contracted polio as a growing child may have one arm or leg or foot that is shorter and smaller than the non-affected/less affected limb.

■ **New weakness.** In the more than 40 percent of polio survivors who develop post-polio syndrome, increasing muscle weakness in muscles previously affected or

new weakness in muscles that were thought not to have been affected is one of the defining features of the condition.

■ **Loss/absence of reflexes at a joint.** For example, when the healthcare provider hits your knee with the reflex hammer and it does not “kick” out. But rarely, a polio survivor may have an exaggerated response or hyperactive reflex.

■ **Muscle fatigue/decreased endurance.** When a muscle does not have a full supply of “motor units” it may still be able to function for a limited number of repetitions but it “wears out” sooner. The person may be able to “sprint” but could not run a mile and certainly not a marathon.

■ **Muscular pain.** Polio survivors generally describe this as an “achy, burning or sore feeling.” It is thought to be due to overuse of the muscle(s) in the area. Individuals who had acute polio when they were old enough to remember the event say it feels similar to the muscle pain that occurred with the acute polio. Others describe it differently, but polio-related muscular pain is rarely sharp and stabbing.

■ **Biomechanical problems.** These are problems related to abnormal positions of a limb around a joint, e.g., one leg being shorter than the other or abnormal curvature(s) of the spine. This can cause mechanical low back pain, increase the likelihood of “wear and tear” arthritis in a joint or a

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chronic tendonitis/bursitis or even nerve compression problems.

■ **“Polio cold” leg or arm.** There are several theories about what causes it, but it is real! Generally the person doesn’t perceive the limb as feeling as cold as it feels when it is touched. It occurs when the environment is cold – such as in winter or in an air-conditioned room. Unless the person has other reasons such as poor arterial circulation from diabetic vascular disease or severe hardening of the arteries that causes poor blood flow in the arteries, “polio cold” leg or arm will not cause delayed healing of fractures or injuries. It is mostly an inconvenience to the individual and his/her bed partner.

■ **Some problems with breathing.** These include decreased ability to move enough air in and out to get ample oxygen into the lungs or to exhale enough carbon dioxide due to new respiratory muscle weakness or from residual muscle weakness from the initial polio. Medically this is called “restrictive lung disease.” Problems include “remembering” to take a breath or to take enough breaths per minute. This is broadly called sleep apnea (central apnea). Paralysis of some muscles of the throat can also cause intermittent blockage of the air passages in the throat, which may also be termed sleep apnea (obstructive).

■ **Certain problems with swallowing.** These can cause choking while swallowing, especially thin liquids such as water, and sometimes some of the swallowed material will go into the lungs instead of

down into the stomach causing a pneumonia known as aspiration pneumonia. Some people lose weight and have difficulty maintaining adequate nutrition because eating is so time consuming or difficult.

*Note:* Many people over age 50 have other problems unrelated to polio that can cause problems swallowing. Various tests can determine the exact cause of the dysphagia.

■ **Osteoporosis/osteopenia.** Weight bearing exercise is necessary for bone to become and remain strong. In persons who had paralytic polio the affected limb(s) may have bone that has less than the normal mineral (calcium) content. The terms osteoporosis and osteopenia refer to decreased amount of normal bone tissue; osteoporosis is more severe than osteopenia. These conditions can mean the bone is more “brittle” and may break more easily than normal bone. (Generalized osteoporosis/osteopenia can also occur in certain medical conditions and with increasing age and is usually not related to polio.)

### **What symptoms/signs may be related to polio (secondary effects)?**

■ **Increased wear and tear on joints including osteoarthritis, tendonitis, tendon tears, bursitis.** When a person has a weak limb, the unaffected or lesser affected leg or arm does more work to compensate, and weakness from polio can lead to arthritis problems in the good limb as well. People who use their arms in place of their legs (crutch walkers, users of canes,

manual wheelchair users) put more stress on the joints of the upper extremities than someone who has normal use of their legs, and this can result in damage to cartilage, tendons and ligaments in the wrists, elbows and shoulders.

■ **Nerve compression.** Carpal tunnel syndrome can be caused/ aggravated by pressure on the heel of the hand and palm from crutches and canes or from propelling a manual wheelchair. Other nerves may also be compressed by abnormal positions of joints and of the vertebrae in the spine. Symptoms of nerve compression are usually a numbness or tingling, an “electric shock” sensation and sometimes progressive weakness in the area of the body supplied by the particular nerve that is being pinched.

■ **Increased respiratory problems** from increasing curvature of the spine resulting in less room for the lungs and internal organs.

■ **Fatigue from increased energy expenditure.** Walking with an abnormal gait, use of crutches and propelling a manual wheelchair all require more energy than unimpeded walking. For example, walking with a locked knee can use up 20 percent more energy than walking with an unlocked knee, and walking with two crutches can burn up to twice as much energy as a nondisabled person would use walking the same distance.

■ **Headaches.** These can be “muscle contraction” headaches that may be caused by chronic overuse of neck muscles, unusual use of





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▷ neck muscles when doing daily tasks or related to abnormal positions of the neck from muscle imbalance or scoliosis. Headaches, especially upon awakening, can be from inadequate ventilation (breathing) overnight that may be due to respiratory muscle weakness and/or sleep apnea that may or may not be connected to prior polio.

■ **Emotional issues.** These can include post traumatic stress disorder associated with hospitalizations and medical procedures and/or teasing by childhood peers or dysfunctional family interactions with the person who contracted polio.

### **What symptoms may be compounded by having had polio (tertiary effects)?**

■ **High blood pressure and/or coronary heart disease** aggravated by weight gain and decreased exercise that were related to limitations imposed by polio.

■ **Weight gain** (including overweight and obesity) linked to decreased exercise/activity. Significant obesity, can, of itself, lead to obstructive sleep apnea and restrictive lung disease plus other problems including diabetes, osteoarthritis of hips and knees, etc.

■ **Diabetes**, in susceptible individuals, related to decreased activity and/or weight gain.

■ **Skin breakdown, or pressure sores**, from prolonged sitting without shifting position, from sleeping in one position due to

difficulty turning in bed or from poorly fitting supportive devices (corsets, braces).

■ **Situational depression** associated with decreased functioning and independence.

More important than establishing the relationship between a condition and prior polio is finding a treatment or solution for the medical problem. Post-polio experts agree that in most instances the management or treatment plan for the secondary and/or tertiary problems are the same as for people who did not have polio.

### **What symptoms/signs are NOT related to polio?**

■ **Tremor of arm, leg or head** especially when that body part is at rest.

■ **Problems with “sense organs” – vision, hearing, taste, smell.**

■ **Seizures.**

■ **Allergies to medicines or to things in the environment.**

■ **Dizziness or vertigo (“the room spinning”).**

■ **Sharp, shooting pains or severe burning pain with numbness.**

Generally, polio does not cause numbness, but nerve compression can result from abnormal positions around a joint or from crutch/cane walking or propelling a manual wheelchair and cause these symptoms.

■ **Inability to know the position of a part of the body** or where it is in space (decreased proprioception).

■ **Food getting stuck in the lower esophagus** (in the midchest or lower).

■ **Abdominal pain or diarrhea.**

■ **Cancer of any kind.**

■ **Liver disease.**

■ **Kidney disease.**

■ **Most infectious diseases**, except perhaps pneumonia in a person with a weak cough or who has swallowing problems and is “aspirating” food into their lungs.

■ **Skin rashes**, but unrelieved pressure on areas of the skin can skin breakdown and redness.

■ **Diabetes**, but weight gain and decreased activity often worsen blood sugar control in persons with other risk factors for diabetes.

■ **Hardening of the arteries** (atherosclerosis) in the heart, legs, neck, brain, although lifestyle changes induced by polio may increase the likelihood of developing this when added to other risk factors. ▲



Stephanie T. Machell, PsyD

# Promoting Positive Solutions

**QUESTION:** *I read the article in my local paper by syndicated columnist Dr. Donohue about having had polio. Who would ever be proud that they had polio? I wish it had never been published.*

**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

## Response from Stephanie T. Machell, PsyD:

It sounds like that column brought up a lot of feelings for you. Many polio survivors do feel shame about having had polio. Polio was a shameful disease and those who had it (and their families) were often shunned, even after there was no possibility of contagion.

Those who had it as very young children often didn't understand what was happening to them or why their parents had left them sick and miserable in the care of strangers. Young children believe they cause things to happen and so might be left with a sense that they had done something very bad indeed. That polio was often not discussed when they came home added to the sense that something very shameful had happened.

There are three basic models for how we make sense out of disability. Broadly stated and with apologies to my co-columnist (who explains them in far more detail in her writings) the moral model implies that if bad things happen to us we somehow deserve them.

The medical model says that disability is a medical condition and therefore value-neutral. In both of these models being proud of having a disability makes no sense.

In the minority model, it makes complete sense. In this model, people with disabilities are part of a minority.

It is the largest minority and the only one we are all eligible to join at any time. Having a disability is part of the person's identity. In this model being proud of being disabled would be the same as being proud of being a woman, or African American, or gay – all attributes that majority culture might consider unlikely reasons for pride.

What is your model of disability?

Those who had polio and couldn't pass as nondisabled were the pioneers of the disability rights movement. They struggled with society's perceptions of themselves and with the ways they had internalized those beliefs, coming to a place of recognition that part of their identity was that of being a person with a disability. Those who were able to pass never had to identify themselves as having a disability. When these "passers" developed PPS, their identity was called into question.

The "Encyclopedia of Disability" defines disability pride as follows:

***Disability Pride represents a rejection of the notion that our physical, sensory, mental and cognitive differences from the non-disabled standard are wrong or bad in any way, and is a statement of our self-acceptance, dignity and pride. It is a public expression of our belief that our disabilities are a natural part of human diversity, a celebration of our heritage and culture and a validation of our experience.***

Please send questions for Drs. Machell and Olkin to [info@post-polio.org](mailto:info@post-polio.org).



Rhoda Olkin, PhD

Can you as a polio survivor relate to this? If not, perhaps you can feel proud that you did survive polio. If you still feel only shame about having had polio, it would be helpful for you to address this in some way. Shame takes up energy that you as a polio survivor can't afford to waste.

### **Response from Rhoda Olkin, PhD:**

I can understand not being proud of having polio – it was a random event for which one can take neither credit nor blame. But I do think it is possible to be proud of being a polio survivor.

There are many possible psychological and emotional responses to having a disability such as polio. One can be depressed, angry, blaming and bitter, or determined, persevering, optimistic, even grateful. And these responses are not random events, but daily choices one makes over and over, in all the little things we do.

If life had shown me a menu of health options and offered me an array of choices, I don't imagine that I (or anyone) would choose polio over not-polio. But none of us get that menu. We only get to decide how to live with the menu item given to us.

Polio brings with it a lot of baggage. There is the diminishment of mobility that many of us experience, the attitudes of other people, the inaccessibility of many public arenas, the fatigue that limits activities, the aches and pains and swelling and so on.

Again, I wasn't given a menu from which to choose. And do those things sometimes get me down? Absolutely! But all any of us can do is take what we are handed, and make the best of it. And if we do make the best of it, that is something of which we can be proud.

I don't mean to imply that polio survivors have to be cheerful and peppy all the time. Making the best of it doesn't mean ignoring the real disadvantages that disability incurs. But it does mean not letting polio ruin the rest of our lives.

The same things that make everyone happy apply to polio survivors as well: family and friendships, meaning, love, purpose, nature. Some people get to pursue these goals with able bodies and excellent health. Others have to pursue these goals with disadvantages.

Be proud of how you have circumvented the disadvantages to attain your goals in life. When I hear people say they are proud of having had polio, what I hear is, "I am proud of what I have done, given the plate that was handed to me." It may not be the menu item you would have chosen, but still, you gotta eat. ▲

**Dr. Rhoda Olkin** is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

## Aging Well with Post-Polio Syndrome: The *Promise* of PROMIS

Rehabilitation Research and Training Center (RRTC) on Aging with a Physical Disability,  
agerrtc@uw.edu

Many aspects of a chronic condition cannot be measured with a tape measure, a blood test or an x-ray. Only the people living with the condition can tell, for example, how severe their fatigue is or how much pain interferes with their ability to do the things they value. It's these subjective measures that are often collected through someone's responses to a questionnaire or what we call a "Patient-Reported Outcome" (PRO).

In 2004, the National Institutes of Health (NIH) ([www.nih.gov](http://www.nih.gov)) funded a project to develop a set of PRO measures that doctors can use in their practices or researchers can use in clinical trials of new interventions. The project is called **PROMIS – Patient Reported Outcomes Measurement Information Systems** ([www.nihpromis.org](http://www.nihpromis.org)) and seeks to develop questionnaires that measure what patients are able to do and how they feel about important issues.

PROMIS covers three areas or domains: physical, mental and social health. Specific PROMIS measures include physical abilities, fatigue, pain, depression, sexual function and satisfaction with social participation or interactions.

PROs are important when studying conditions that have no cure, as the goal of treatment or therapy is to improve patients' abilities to function and to reduce symptoms associated with the condition.

PROMIS is being developed specifically for use in research on chronic health conditions.

Many readers of *Post-Polio Health* are participants in the RRTC's longitudinal survey that is also sent out to people with multiple sclerosis, muscular dystrophy and spinal cord injury. We use PROMIS measures in our survey, and our researchers were the first to have a larger group of people with post-polio answer these questions.

Whenever a new questionnaire is developed, it must be proven to work and also proven that it works in each population separately (e.g., post-polio, multiple sclerosis, etc.).

Dr. Karon Cook and our colleagues in the Department of Rehabilitation Medicine at University of Washington have

just reported the results of a study addressing this issue in an upcoming edition of *The Archives of Physical Medicine and Rehabilitation*. They administered the short forms of six PROMIS measures to more than 2,000 people (part of this from our RRTC survey). Results support the use of PROMIS measures across different chronic conditions and across all ages.

The use of carefully designed and rigorously tested measures has several important advantages:

**Short** – The use of short forms – often just four questions – reduces the burden on patients because they need only answer a few questions.

**Creates a Profile** – When combined with traditional clinical measures, these questionnaires allow doctors to better understand the range of symptoms that their patients are experiencing. This understanding can be used to design treatment programs and to enhance management of chronic conditions. The questions can also be used to measure symptoms important to patients in research investigating the benefits of new treatments.

**Flexible** – PROMIS measures can be used face to face, in writing or by computer online. ▲



# IVIg Update

Joan L. Headley, Executive Director, Post-Polio Health International, St. Louis, Missouri, [director@post-polio.org](mailto:director@post-polio.org)

Currently, the most talked about treatment for a subgroup of polio survivors is IVIg (intravenous immunoglobulin), a blood product that is administered intravenously. Opinions vary from “the most promising treatment in years” to “very doubtful it will prove to be of benefit.”

The March 27, 2012, issue (Vol. 78, No. 13; 1009-1015) of *Neurology*<sup>®</sup> featured “Evidence-based guideline: Intravenous immunoglobulin in the treatment of neuromuscular disorders.” The article, a Report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology, can be accessed at [www.neurology.org/content/78/13/1009.full.html](http://www.neurology.org/content/78/13/1009.full.html)

The recommendation for post-polio syndrome is that “Evidence is insufficient to support or refute IVIg use in the routine treatment of postpolio syndrome.” They further note “There is presently no effective treatment for postpolio syndrome.”

The subcommittee based its comments on the review of two Class I studies that evaluated IVIg efficacy in patients with postpolio syndrome. (*Neurology* defines a Class I study as a randomized controlled clinical trial of the intervention of interest with masked or objective outcome assessment, in a representative population. Relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical adjustment for differences.)

Their conclusion was that “One Class I study (Gonzalez) showed a significant difference, but the difference

was not clinically important for IVIg use on the most affected muscle in postpolio syndrome. One underpowered Class I study (Farbu) showed an effect of IVIg for pain in postpolio syndrome but no effect on strength or fatigue.

Dr. Kristian Borg, Professor and Chair, Division of Rehabilitation Medicine, Department of Clinical Sciences, Karolinska Institute, Stockholm, Sweden, author on the Gonzalez study and numerous articles, tells PHI that “at the moment, we are analyzing data from an open clinical study with IVIg treatment trying to determine which patients are *responders*.”

“Preliminary data suggest that they are characterized by age below 65 years, paresis in the lower extremities and no concomitant disorders, as well as low quality of life for the SF-36 subdomains of vitality and pain. These individuals are in ongoing studies to receive IVIg treatments to help determine who will benefit from the treatment.”

All experts agree that post-polio syndrome is not just one problem that will be solved by one answer. As for IVIg, it is too early to tout or dismiss the benefits. More research needs to be done, published and duplicated. ▲

**MORE on** [www.post-polio.org](http://www.post-polio.org)

For more about IVIg, see:

[Intravenous Immunoglobulin Treatment for Improving Muscle Strength](#)

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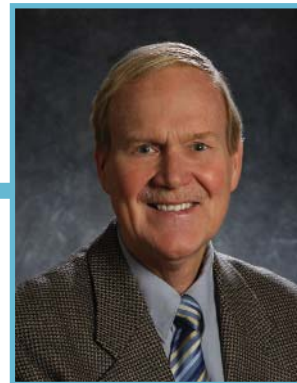
[Recent Experience Using Immunoglobulin to Treat Post-Polio Syndrome](#)

*Post-Polio Health*  
(Vol. 26, No. 3) 2006

[More About IVIg](#)  
*Post-Polio Health*  
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Frederick M. Maynard, MD

**Question:** *I am now 76, had polio when I was 4. Since post-polio syndrome (PPS) hit me, I needed a leg brace and walk with two canes. I can never remember a day without pain, but now it seems to have spread all over my body, not just my legs. My question is: How do you feel about the pain patch, Duragesic®, 12mcg to start. My internist feels that this will help. I would just like to get an OK from someone who has experience in treating PPS.*

**A:** Pain control in people with post-polio problems is highly individualized because there is no one source of pain. I would NOT endorse the use of a Duragesic patch (fentanyl transdermal system) for long-existing pain in a person with PPS because I think it is a “dead end” in regard to long lasting relief from pain. It is probably safe but can lead to dependency and less tolerance and awareness of pains that it is helpful to be aware of (so the pains can be “honored and have actions taken on.”)

I would definitely have a comprehensive evaluation by a “post-polio expert or clinic” before trying to merely “suppress your awareness of pain” by using a Duragesic patch. There are many alternatives. Maybe “giving up” regular walking and using a scooter for usual mobility would lead to a major reduction in pain levels. A thorough evaluation may tell you that and/or other alternatives.

PHI’s *Post-Polio Directory* ([www.post-polio.org/net/pdirhm.html](http://www.post-polio.org/net/pdirhm.html)) of clinical resources for post-polio survivors can help you locate regional options for an evaluation by a post-polio rehabilitation and pain control physician, preferably a specialist in Physical Medicine and Rehabilitation.

Good luck in finding help and relief.

**Question:** *I had paralytic polio 64 years ago at the age of 13 months. My left leg had major paralysis and a small amount to my right leg. I always walked with a severe limp. I was diagnosed 25 years ago with PPS as I was developing new weakness in my legs. Four years ago, swallowing began to bother me and also volume when blowing breath. In the past two years, my left fingers have “clawed,” and now my tongue muscles are weak causing speech problems as are my vocal cords somewhat. I recently saw a neurologist who thinks I have ALS. Do you know of any cases of people with PPS and ALS?*

**A:** Yes, I know of people who are post-polio survivors who have developed ALS. The majority expert opinion on this subject is that polio people are not more likely to develop ALS than other people, but the diagnosis of ALS, as opposed to, Progressive Post-Polio Amyotrophy (Post-Polio Syndrome) is very difficult and at times impossible to distinguish with certainty. Given you have had some slow progressive weakness problems for over 25 years, your condition sounds more like a post-polio condition mimicking ALS. Unfortunately there is no definitive test for either diagnosis.

SEND YOUR QUESTIONS  
FOR DR. MAYNARD TO  
[INFO@POST-POLIO.ORG](mailto:INFO@POST-POLIO.ORG).

## Thank you

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

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Alice Bindbeutel  
Nancy Judkins

### Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

Sid Stone

Given how severe your new symptoms have become, you may be an appropriate candidate to try one of the more aggressive new treatments for progressive post-polio weakness, such as intravenous immunoglobulin therapy as shown to be helpful by researchers at the Karolinska Institute in Sweden. (See page 9, *IVIg Update*.) I suggest you consult with the neurologist who diagnosed you and together pursue possible new treatment options to slow down progression of symptoms.

There are many rehabilitation strategies to minimize risks from the swallowing and breathing problems and to maintain function and quality of life.

Also, please see *Swallowing Difficulty and the Late Effects of Polio* (Vol. 26, No. 3) and *New Swallowing Problems in Aging Polio Survivors* (Vol. 12, No. 1). ▲

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## Inside *Post-Polio Health* (Vol. 28, No. 2, Spring 2012)

What Having Had Polio Causes ... p.1 ■ IVIg Update p.9 ■ Ask Dr. Maynard p.10 ■ and more.

### **PNNJ Establishes Memorial Fund at PHI**

The Polio Network of New Jersey (PNNJ) has established The Joyce and Arthur Siegfried Memorial Fund to underwrite the PHI program that supplies braces and custom-made shoes to eligible individuals with an initial gift of \$7,500.

The Memorial honors the late PNNJ leaders Joyce and Arthur Siegfried, who were pioneer advocates for polio survivors. Mrs. Siegfried attended the 1987 PHI (GINI) conference and took “pages and pages of notes” back to the Raritan Valley Post-Polio Support Group, which she founded that year. She helped organize the first New Jersey Conference on the Late Effects of Polio in 1990, which led to the creation of the Polio Network of New Jersey in 1991. She died in 2004, after many years as the organization's treasurer and leader of the Raritan Valley Support Group. Mr. Siegfried was a longtime PNNJ board attorney and also served as president, retiring in 2010 a year before his death.

PNNJ President Veliko “Lee” Bekir said, “This gives us the opportunity to bring the names of our friends, Joyce and Arthur, into a larger sphere of philanthropy and service, thus helping many polio survivors and at the same time honoring this outstanding couple in a more permanent way. We see our gift as ‘seed money’ that would encourage other groups and individuals to contribute to grow the fund. PNNJ will, within its means, make an annual contribution to maintain our commitment.”

“This generous gift assures that PHI can continue to assist polio survivors in living independently by granting funds for shoes and bracing,” said PHI Executive Director Joan L. Headley. “We are grateful to PNNJ and excited about the collaboration that helps both of our organizations fulfill their missions.” ▲

*To receive an application, call 314-534-0475 or email [info@post-polio.org](mailto:info@post-polio.org).*



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