



## Acute Polio and Post-Polio - A Review

By Richard Lloyd Daggett

In our August 2015 newsletter we reported on research studies of several drugs and treatments for post-polio (PPS). These treatments and medications were thought to alleviate some of our post-polio symptoms, but the current research indicates that they are of little or no benefit. In this newsletter we are taking a basic look at polio, both during the initial attack and the causes of our current post-polio issues. This might be a repeat to some readers, but this review will be helpful to many. This review is based on the best and most comprehensive medical literature available.

### 1600 BC to 20th Century

Although cases of poliomyelitis had been described as early as 1600 BC, it was the 20th century that witnessed regular polio epidemics in North America. These epidemics peaked in 1952, with more than 57,000 reported new cases in the United States. Thanks to the introduction of the Salk injectable vaccine in 1955 and the Sabin oral polio vaccine in 1961, these epidemics were essentially brought to a halt. Poliomyelitis results from infection by one of three subtypes of this single-stranded RNA enterovirus. It is transmitted by fecal-oral spread and is extremely infectious. The virus is replicated in the gut and lymphoid tissue. Most (95%) infected individuals have no visible symptoms or may report mild flu-like symptoms. If the virus enters the bloodstream, the central nervous system is susceptible to invasion. Symptoms become more pronounced as fever and meningeal irritation develop. These individuals may later demonstrate neurologic symptoms and signs of acute poliomyelitis infection. Most common is asymmetric flaccid paralysis. The overall risk of outwardly visible paralytic polio in infected persons is 1-2%.

### Surprising Effects

The polio virus ultimately causes destruction of anterior horn motor neurons, resulting in limb paralysis. However, David Bodian, MD, PhD, and others in the late 1940s, showed that under microscopic examination, all cases had some "encephalitic" changes in addition to the typical anterior horn cell destruction. The centers most severely affected were in the brainstem and cerebellum and include the reticular formation, vestibular nuclei, and roof nuclei of the cerebellum. In addition, Bodian reported that, "There was hardly an individual who did not have lesions, sometimes of a fairly severe degree, of most of the motor nuclei of the cranial nerves as well as in the surrounding reticular formation." Bodian also reported that more than 50% of motor neurons had to be damaged before there was any visible loss of strength. This appears to indicate that many additional people had a significant polio infection, but these cases were not reported because the symptoms (fever, aches, and listlessness) were attributed to some other health issue. The clinical manifestations of poliomyelitis vary widely. Patients may report weakness in only one limb or may have rapid progression of complete paralysis and loss of respiratory function. Paralysis is more often found in the legs than the arms.

Editor: Alice Sporar

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Brainstem symptoms (bulbar poliomyelitis) occur in at least 10–15% of patients, manifesting as involvement of any of the cranial nerves; facial weakness, swallowing, and speaking. Reticular formation involvement produces impaired respiratory control, and cardiovascular instability. Occasionally, patients have lack of muscular control or, in the pre-paralytic stage, become agitated, mentally dulled, or display upper motor neuron signs.

### Then and Now

Recovery begins after two to three weeks and ranges from complete recovery to major residual dysfunction (e.g., permanent respiratory difficulties, paralysis). Younger patients who have paralytic poliomyelitis have better recovery than older patients. Recovery is said to plateau at approximately seven to ten months. Treatment is mainly supportive, ranging from breathing assistance to casts, braces, and crutches. Three factors contribute to recovery: **1.** number of recovered motor units that resume function, **2.** number of motor units that develop “sprouts” to reinnervate “orphaned” muscle fibers (graphic B and C on page 5), and **3.** Muscle enlargement induced by strenuous exercise.

Many polio survivors are now experiencing a renewal of weakness and other polio related problems, commonly referred to as post-polio syndrome or PPS. There has been considerable debate over the underlying cause of PPS. The most commonly accepted explanation for the late effects of polio is that of overuse or premature aging of polio-affected motor units. The so-called giant motor units that develop on recovery are presumed to be unable to sustain the increased metabolic demands. As such, the sprouts begin to fall off, and motor unit function deteriorates (graphic D). Measurements of the electrical activity of neurons, and their action potential, and muscle biopsy data support this theory. They suggest disintegration of function of the motor units and the terminal sprouts themselves 30–40 years after the acute poliomyelitis infection. Other explanations include musculoskeletal disuse and normal age-related loss. Persistent “low-grade” poliovirus infection or reactivation has been proposed by a few studies using a variety of tests trying to isolate the virus’ genetic material, or evidence of virus residuals in the cerebral spinal fluid of PPS patients. However, there are at least as many studies providing evidence against this persistent virus theory as there are supporting it.

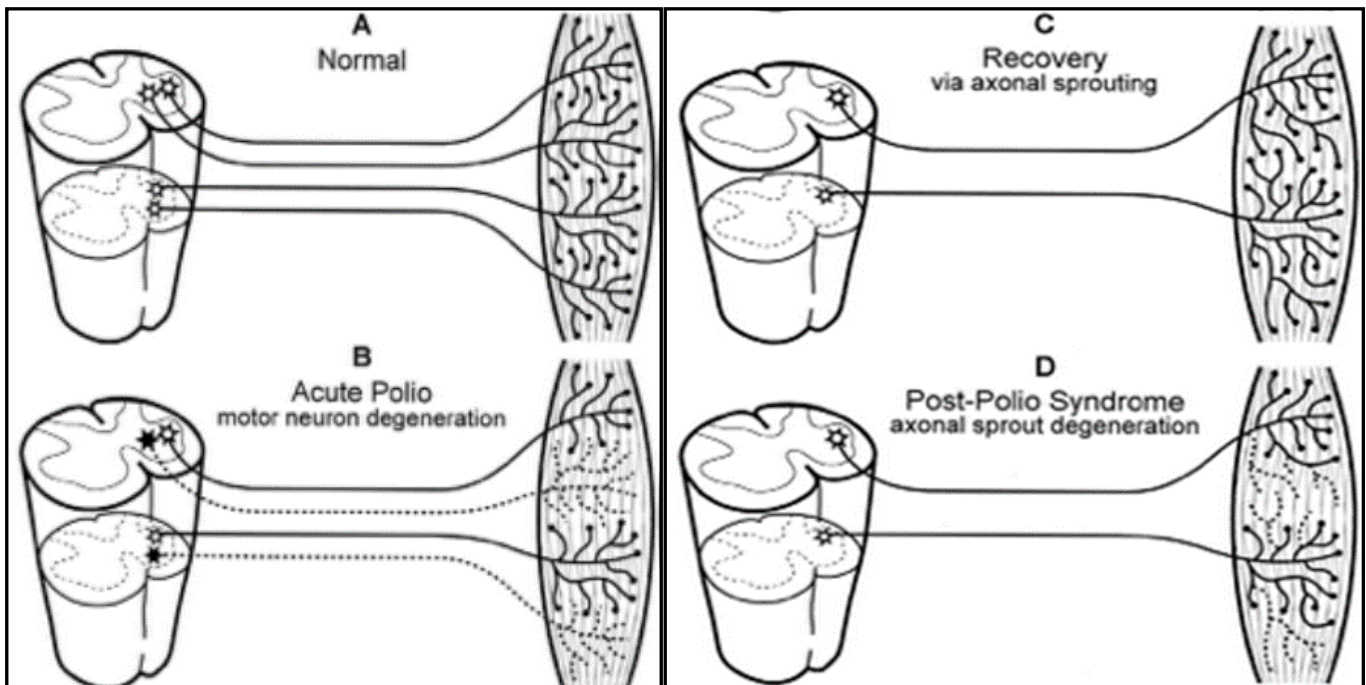
### Common Symptoms

The most common symptoms reported by PPS patients include fatigue and weakness, joint and muscle pain, respiratory difficulties, cold intolerance, plus speech and swallowing difficulties. Fatigue is the most commonly reported symptom in PPS. This includes central fatigue (sleepiness, difficulty concentrating) and peripheral fatigue (muscular weakness). Central fatigue is a nonspecific symptom given the numerous potential causes, such as sleep apnea or depression, in addition to PPS. Previous reports described extensive lesions in the reticular activating system in acute poliomyelitis patients. Investigators found very active signals in the high-fatigue group but none in the low-fatigue group. Peripheral (muscular) fatigue has also been examined using functional studies, electromyography, and muscle biopsies. All of these methods suggest that there is constant remodeling of the giant motor units, with sprouts “dropping off”. The most frequent symptom of PPS is progressive muscular weakness. The progression is slow and may occur in muscles previously affected by polio or, less commonly, in muscles previously assumed to be unaffected by the original polio attack. The extent of new weakness seems to correlate with the severity of the acute polio infection and with the amount of recovery, *i.e.*, individuals with greater recovery seem to have a greater chance of developing new weakness.

### Treatment

Treatment of fatigue, both central and peripheral, primarily involves lifestyle changes. These include regularly scheduled rest periods as well as individually tailored exercise programs, depending on the current functional level of the patient. Pain is almost as common as fatigue in PPS patients. Rehabilitation medicine specialists have proposed three types of pain in PPS patients. Type I pain is postpolio muscle pain. It is an aching, deep or superficial muscle pain described as similar to the pain experienced during the acute polio infection. It can be precipitated by strenuous activity, stress, or cold temperatures. Type II pain is part of an “overuse” syndrome, which includes bursitis, tendinitis, myofascial, and soft tissue injuries, secondary to poor biomechanics or posture. Type III pain includes degenerative joint disease, low back pain, and nerve compression syndromes. It is the result of chronic over-use, unequal loading of joints and asymmetric muscle

function secondary to weakness. For example, wrist and shoulder pain may develop in some patients secondary to long-standing use of crutches. Treatment of pain in PPS is similar to the management of chronic pain in general. Lifestyle modifications, physiotherapy, assistive devices, analgesics, and joint or trigger point injections are the most commonly used options. One of the hallmarks of the treatment of acute poliomyelitis was the negative pressure ventilator, or iron lung. When respiratory failure was present, it was the major cause of morbidity and mortality. Respiratory symptoms occur in up to 40% of PPS patients. Symptoms range from mildly decreased pulmonary function to acute respiratory failure and the need for assisted ventilation. Contributing to these symptoms are restrictive chest wall changes (scoliosis, kyphosis), altered chest wall strength (decreased maximum inspiratory/expiratory pressures), recurrent infections, and sleep-related disordered breathing.



### Probable mechanism of post-polio syndrome:

- (A) Under normal conditions, a healthy lower motor unit is composed of a motor neuron cell body (located in the anterior horn of the spinal cord gray matter), the motor axon, and muscle cells (fibers) innervated by the axon.
- (B) The polio virus infects some motor neuron cell bodies, which subsequently die, while others survive (or were never infected). The loss of lower motor units results in muscle fiber denervation and the weakness that occurs as a result of acute poliomyelitis.
- (C) Motor axon terminal sprouting reinnervates previously denervated muscle fibers, creating a “giant” motor unit. This is associated with improvement in strength in the weeks and months after an acute attack of polio.
- (D) However, after many years, abnormally enlarged motor units are no longer able to maintain the extensive sprout pattern. Sprouts start to degenerate, producing new denervation and muscle weakness (post-polio syndrome).

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(Continued on Page 4)

**Some of the resources used in this report:**

Bodian D: Histopathological basis of clinical findings in poliomyelitis.

Paul JR: History of Poliomyelitis. Yale University Press.

Dalakas MC, Elder G, Hallett M, Ravits J, Baker M, Papadopoulos N, Albrecht P, Sever J: A long-term follow-up study of patients with post-poliomyelitis neuromuscular symptoms.

Halstead LS, Rossi CD: New problems in old polio patients: Results of a survey of 539 polio survivors.

Fischer DA: Sleep-disordered breathing as a late effect of poliomyelitis.

**10 Things to Know before Traveling**

**Flying the Friendly Skies.** Whether it's for an important business trip or your next family vacation, here's what you need to know to ensure a smooth flight. The [Air Carrier Access Act](#) requires that all domestic and international flights with a U.S. destination or departure point provide certain free accommodations to people with disabilities. Fliers with disabilities aren't required to travel with another person (unless it's for safety reasons) or [notify an airline](#) about their disability. For more information about your rights as an air passenger with a disability, read the U.S. Department of Transportation's (DOT) [air travelers with disabilities](#). There are also guides specifically for [passengers with developmental disabilities](#) and those who use [wheelchairs or other mobility aids](#). All passengers, including those with disabilities, must be [screened by Transportation Security Administration](#) (TSA) officers. If you have questions or concerns about the process, contact [TSA Cares](#) by [email](#) or phone at 1-855-787-2227, or speak with a TSA officer beforehand. You may want to provide the officer with a [TSA disability notification card](#) or other medical documentation to describe your condition. If you experience disability-related air travel service problems, call DOT's [Air Travelers with Disabilities hotline](#) at 1-800-778-4838 (TTY: 1-800-455-9880) or [file a complaint online](#).

**Public Transportation.** Public transportation is crucial for people with disabilities to have access to employment, education, health care and activities in their community. [Section 504 of the Rehabilitation Act of 1973](#) and Title II of the [Americans with Disabilities Act](#) (ADA) protect people with disabilities from discrimination in public transportation services and [facilities](#). The ADA also requires public transit agencies to provide free [paratransit](#) services (also called "dial-a-ride") for people who cannot use regular ("fixed-route") services because of a disability. Your public transportation provider may provide "[travel training](#)" programs to help you learn your way around the system. Check with your local [public transportation provider](#) for information about paratransit services in your area. Other transportation choices include [accessible taxis](#) or "[share-a-ride](#)" programs that use [volunteer drivers](#). If you've experienced problems with using public transportation services or facilities, call the Federal Transit Administration's [ADA Assistance Line](#) at 1-888-446-4511 or email [ADAAssistance@dot.gov](mailto:ADAAssistance@dot.gov). You can also [file a complaint](#) online. Visit [Disability.gov's Guide to Transportation](#) or download Easter Seals' "[Everyday Travel Guide](#)" to find tips for public transportation riders with disabilities. For more information about transportation services and reduced fare programs for people with disabilities and seniors, visit the [American Public Transportation Association](#) or call the National Transit Hotline at 1-800-527-8279.

**Riding the Rails.** Railway transit can be a convenient, fast and cost-effective option for many people. For people with disabilities, there are some important things to know when traveling by train. First, you may be eligible for certain [discounts](#). Also, if you need an accommodation while in a [train station](#) or [on a train](#), you should contact your rail carrier before your trip to let them know. Amtrak offers information for people who use wheelchairs or other [mobility devices](#), [portable oxygen equipment](#) or [service animals](#). It's important to remember that rail providers may have different rules for [emotional support animals](#) and pets than for service animals.

**Winter Weather Travel.** When winter storms hit, it's important to put safety first, which means travel plans may need to be cancelled or postponed. As winter weather approaches, think of [SNOW: "Stay off the roads, Not Out in the Weather."](#) However, even in the midst of the coldest winter weather, some travel must go on. If driving somewhere in the cold or snow, plan ahead by [preparing your car for winter weather](#). Be sure to follow these [winter driving tips](#), including keeping the gasoline tank at least half full at all

times to avoid gas-line freeze up, and driving slowly during inclement weather. In case of an emergency while driving, be sure to [keep a winter emergency kit in your car](#) with items including a flashlight, food, water and warm clothing. Public transportation is often still an option during winter weather, but [be careful when taking a train or a bus by following safety guidelines](#) and dressing warmly. If you're planning to travel by air during winter weather, check for flight delays or cancellations and take the [proper steps in the event that a flight is cancelled](#).

**Adaptive Driving and Vehicle Modifications.** Learning to drive, or re-learning after a disability or injury, can mean greater independence. You might take an adapted driver training course with a [driver rehabilitation specialist](#) or add [specialized equipment](#) to your vehicle. The Association for Driver Rehabilitation Specialists' (ADED) [fact sheets](#) explain how types of disabilities or health conditions may affect a person's ability to drive and what changes can be made. Use ADED's [Driver Rehabilitation Provider](#) and [Certified Driver Rehabilitation Specialist](#) search tools to find nearby adaptive driving programs. Check out [United Spinal Association's adaptive driving guide](#) for information on driver training programs, adapting a vehicle and paying for vehicle modifications. The National Highway Traffic Safety Administration also has a helpful guide to [Adapting Motor Vehicles for People with Disabilities](#). Find a dealership for adapted vehicles with [ADED's Mobility Equipment Dealer search tool](#). When it's time to purchase an adapted vehicle or pay for modifications, many options for [financial assistance](#) are available. State [Vocational Rehabilitation agencies](#) may help fund certain modifications if they're necessary for the driver to get to work. The U.S. Department of Veterans Affairs' (VA) [Automobile and Special Adaptive Equipment Grants](#) help Veterans with certain service-connected disabilities buy an adapted vehicle or modify one. You may also wish to check with your state's [Assistive Technology Reuse program](#) to see if they have adaptive equipment that works for you. For more information, read these [tips on funding vehicle modifications](#) or visit the [Vehicle Modifications](#) section of [Disability.gov's Guide to Transportation](#).

**Organizations That Can Help.** [Easter Seals Project ACTION \(Accessible Community Transportation in Our Nation\)](#) is a program run by Easter Seals and the U.S. Department of Transportation Federal Transit Administration. Project ACTION promotes access to transportation for people with disabilities, and provides a [resource library](#) on accessible transportation topics. Travelers with disabilities can get information on [how to find and use accessible transportation](#), and transportation providers can get [guidance on legal requirements and best practices to accommodate riders with disabilities](#). Recently, Easter Seals and the [National Association of Area Agencies on Aging](#) created the [National Aging and Disability Transportation Center \(NADTC\)](#), which will promote transportation options for seniors, people with disabilities, caregivers and communities through technical assistance, information and referral and community grants. The NADTC website is currently under construction, but you can visit their [Facebook](#) page and [Twitter](#) feed or call 1-866-983-3222 to learn more.

**Pedestrian Safety.** Sidewalks and street crossings can be challenging for pedestrians with disabilities, especially when obstacles like illegally parked cars are in the way. During the winter, snow banks add to the problem, sometimes blocking [ramps and curb cuts](#) and forcing pedestrians with disabilities into the street. These barriers make it difficult and even unsafe for people to get around. The [U.S. Access Board](#) is developing [guidelines](#) for "public rights-of-way" that address issues related to [accessible signals](#) for pedestrians who are blind, [parking](#) for people with physical disabilities and accessibility of streets and sidewalks. The Federal Highway Administration's [Bicycle and Pedestrian Program](#) offers a guide on how to design [accessible sidewalks and trails](#). [Accessible Design for the Blind](#) works to make travel safer for pedestrians with visual disabilities by providing information on [travel training](#) and [detectable warnings](#). Read "[A Safety Guide for Pedestrians with Disabilities](#)" and use mobile apps like [AXS Map](#) to find accessible routes in your area. Learn how to make your community safer for all pedestrians at [America Walks](#). The U.S. Department of Justice's [Project Civic Access](#) works to ensure that all counties, cities, towns and villages comply with accessibility requirements of the ADA. You can report pedestrian accessibility issues in your area by [filing an ADA complaint](#).

**Help Paying for Transportation.** Paying for transportation can be difficult on a fixed income. Programs

such as [Charity Motors](#), [Ways to Work](#) and [Working Cars for Working Families](#) help low-income individuals and families buy a car or pay for automobile repairs. Many of them are [state-based](#), so contact your local [Independent Living Center](#) (ILC) to find nearby help. [Paratransit](#) is also a good option for people who cannot use “fixed route” public transportation services because of a disability. Check with your local [public transportation provider](#) to find paratransit services in your area. Some local organizations offer free or low cost transportation programs that help people with disabilities and seniors get to doctor’s appointments, grocery stores and community events. Check with your local ILC, [Aging and Disability Resource Center](#) or [Area Agency on Aging](#) to learn more about programs near you. State [Temporary Assistance for Needy Families](#) programs provide temporary financial help to low-income families, including assistance paying for transportation to work or job training programs. People with disabilities can save money for disability-related expenses, including transportation, through an [Achieving a Better Life Experience](#) (ABLE) account. Watch this [video](#) to learn more about ABLE accounts.

**Around the World.** International travel presents its own set of [considerations for people with disabilities](#). All U.S. travelers leaving the country should [prepare for their trip](#), [understand passport requirements](#) and know how to [manage their health while abroad](#). [Students with disabilities](#) who are interested in studying abroad can use the State Department’s [students aboard checklists](#) to stay safe and enjoy their international experiences. Once you’re in a new country, accessibility standards might be very different and an unfamiliar landscape can mean challenges to getting around. [Wheelchair users](#) may have a variety of concerns, including old city structures, lack of curb cuts and limited or no accessible transportation options. People who are blind will have to learn how to [navigate new areas](#) and find new ways of communicating direction. In addition, disability may be [viewed negatively or differently](#) because of existing stigma in a particular country. You can [download](#) Lonely Planet’s “[Accessible Travel Guide](#)” for free from the [European Network for Accessible Tourism](#) website to find accessible hotels, restaurants and tourist activities around the world. The “[Comprehensive Guide to Traveling with a Disability](#)” offers additional information. The U.S. Department of State’s [National Clearinghouse on Disability and Exchange](#) works to increase opportunities for people with disabilities in all types of travel; read the [brochure](#) to learn more.

**Rides to Your Appointments.** Getting to and from medical appointments is a critical part of maintaining a healthy lifestyle. Medicaid funds [Non-Emergency Medical Transportation](#) to and from doctor’s appointments. Contact your state’s [Medicaid office](#) to learn more. Veterans with disabilities can use the nationwide volunteer transportation network provided by [Disabled American Veterans](#) (DAV) for transportation to VA medical facilities for doctors’ appointments, medical tests and treatment. Use the [DAV Hospital Service Coordinator Directory](#) to find contact information for your local program. Often, rural areas have limited public transportation options. Contact your [state 2-1-1](#), [Community Action Agency](#) or [local public transportation service](#) to find information about rural transportation programs in your community. You can also use the [Eldercare Locator](#) or talk to one of the site’s information specialists toll-free at 1-800-677-1116. Your state’s [Department of Transportation](#) or [Department of Health & Human Services](#) may offer information about local transportation services for people with disabilities and seniors, as well as programs that can help low-income individuals and families pay for their transportation needs. For additional information, visit [Disability.gov](#)’s [Finding a Ride & Paratransit Services section](#).

For more information about transportation, please read [Disability.gov’s Guide to Transportation](#). Don’t forget to like [Disability.gov](#) on [Facebook](#), follow us on [Twitter](#) and use #disabilityconnection to talk to us about this newsletter. You can also read [Disability.Blog](#) for insightful tips and information from experts in the community.

Read [past issues](#) of the *Disability Connection* newsletter.

## Tri-Counties Independent Living Center—Triumph Awards by Bob Boyce

By way of background on myself, I caught polio way back in 1955 in the UK when I was 2 ½. I've been here in the US since 1996, working for BP in Cleveland, then Chicago and finally Houston. I retired in 2011 and came back to my adopted home of NE Ohio, and now live in Copley where I have a 14 year old daughter.

I currently serve on the Board of the Tri-Counties Independent Living Center which covers Medina, Portage, Stark, Summit and Wayne Counties. I wanted to let you, and the other Ohio Polio Network contacts copied-in on this message, know that the Center is organizing its inaugural TRIUMPH Awards this year, which will be presenting awards for an adult, a child and an advocate who have contributed by service to the disability community. We'll be sending out details of the awards, with a request for nominations, soon and I wanted to add the Ohio Polio Network contacts for the Akron, Cleveland, and Canton areas to our distribution list. The awards will be made at a dinner on May 5<sup>th</sup> to be held at St. George's Church on Ridgewood Rd. in Copley. Please let me know if there are other contacts you would like us to send the award details to.

I've copied in Rose Juriga, Director of TCILC, as well as Sharon Connor and Abby Morgan, who are also TCILC Board Members and are organizing the awards event. Just in case you don't already know it, the TCILC website is [www.tcilc.org](http://www.tcilc.org).

I look forward to being part of the Ohio Polio Network and hope very much you will be able to participate in the TRIUMPH awards

## Don't Blame Post Polio Syndrome for Everything

Oyel Times, Toronto, Canada, Published on Friday, 07 August 2015, Written by Stephen Pate

Post Polio Syndrome can mask life threatening health problems like heart disease.

Post Polio Syndrome can dominate your life but it may not be your only health problem. In fact, post polio can mask life threatening health issues. Pain, muscle weakness, fatigue and sleep disorders are common to Post-Polio and a number of other conditions.

According to the Mayo clinic, "common signs and symptoms of post-polio syndrome include: progressive muscle and joint weakness and pain, general fatigue and exhaustion with minimal activity, muscle atrophy, breathing or swallowing problems, sleep-related breathing disorders, such as sleep apnea and decreased tolerance of cold temperatures. In most people, post-polio syndrome tends to progress slowly, with new signs and symptoms followed by periods of stability.

When someone gets Post Polio Syndrome they and their doctors can tend to blame everything else on PPS. That may seem logical but it can be wrong. "As a post-polio survivor I have been fooled more than once," wrote Bruce Lambert in "Is It Post Polio or Something Else." (Post Polio Health).

The devilish thing is that Post Polio is often misdiagnosed as something else – aging, Chronic Fatigue Syndrome or a number of conditions with weakening muscles and persistent pain. However, once Post-Polio Syndrome is confirmed, it becomes the reason for every new symptom. We want to believe that because that simplifies life.

In Bruce Lambert's story, a new groin pain was not Post Polio: it was spinal arthritis which took multiple MRI's and X-rays to diagnose.

Coronary Heart Disease and Post Polio Fatigue and shortness of breath are also signs of coronary heart disease or CHD. Arteries clogged with cholesterol reduce the amount of oxygen in the blood and create weakness, shortness of breath and muscle pain in the extremities like arms and legs.

Fatigue is symptomatic of a Post Polio diagnosis. Certainly PPS can also contribute to deconditioning and more weakness. However, the cause of new weakness and pain may be "cardiovascular disease... caused by

narrowed, blocked or stiffened blood vessels that prevent your heart, brain or other parts of your body from receiving enough blood ”(Mayo Clinic)”.

An ounce of prevention is worth a pound of cure. Getting a proper diagnosis before a heart attack is better than after. First, some heart attacks kill you without warning.

Secondly, even if you survive a heart attack, the recovery process is long and slow.

If you find it hard to climb a ladder or do tasks that previously were possible, you may have CHD and be a heart attack candidate. See your doctor and get your cholesterol, blood pressure and other indicators checked.

The traditional tests for heart attack or CHD are poor predictors of heart attacks. Everyone knows someone who passed their stress test and died within months from a massive fatal heart attack. There is a new test that can more accurately predict you heart condition called the Coronary Calcium Scan. Like an MRI, it can predict if you have a build-up of plaque in your arteries and risk a heart attack.

“A coronary calcium scan is a fairly simple test. You’ll lie quietly in the scanner machine for about 10 minutes while it takes pictures of your heart. The pictures will show whether you have calcifications in your coronary arteries.

A coronary calcium scan is most useful for people who are at moderate risk for heart attacks. You or your doctor can calculate your 10-year risk using the Risk Assessment Tool (link is external) from the National Cholesterol Education Program.”

If you have Post Polio Syndrome and dependant on a wheelchair or crutches for mobility, it is highly likely you are at risk. Our bodies are meant to be in motion and that becomes more difficult for PPS survivors. There are things you can do to avoid a heart attack like take statins and blood pressure medications, get rid of the stress in your life, lose weight to shed those dangerous extra pounds and try to get into an exercise program.

Reprinted from Sacramento Region Polio Survivors Group, November 2015

# Enjoy the Spring

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*April hath put a spirit of youth in every-  
thing...William Shakespeare*

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Please forward letters and articles to the return address on the newsletter or e-mail to [amsporar@worldnetoh.com](mailto:amsporar@worldnetoh.com)

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