

PHI's mission is supported by its Membership.

## Welcoming New Members: PHI is taking in the Michigan Polio Network

Post-Polio Health International is pleased to announce that beginning December 1, 2018, the Michigan Polio Network (MPN) and its members will become a part of the PHI family. Since its inception in 1984, MPN has been proudly serving Michigan's polio survivors. We look forward to providing their members with the same level of quality information and services that they've received from MPN over the past three-and-a-half decades. (MPN has published a series of articles reflecting on their history in their recent newsletters, which can be read at [www.michiganpolionetwork.com/polio-perspectives](http://www.michiganpolionetwork.com/polio-perspectives).)



MPN Chairman Bruce Sachs (l) and Tim Brown, Vice Chairman and Treasurer

MPN's board of directors, acknowledging that the MPN mission had been successfully accomplished, sought a method to cease operations while ensuring that the Network's members continued to receive the latest post-polio information and support. In search of that solution, Tim Brown, MPN Vice Chairman and Treasurer, entered into a series of discussions with then PHI Executive Director Joan Headley. These discussions ultimately led to a transition agreement between MPN and PHI which was approved by the boards of both organizations.

MPN members were notified of the plan in a letter sent out by the MPN leadership last September. MPN Chairman Bruce Sachs stated in the letter that the decision was made with their members' well-being foremost in mind and only after "very thoughtful discussions and reflection into the history and mission of the MPN." Sachs explained that the decision was partly driven by a reduction in the demand among the organization's members for their services.

One exception to this was MPN's quarterly newsletter, *Polio Perspectives*, which has provided members with informative, timely articles about the late effects of polio and other polio-related topics. PHI will help fill that gap by providing MPN's former members with PHI's quarterly newsletter and electronic *Membership Memo*.

**WE'RE  
STILL  
HERE!**  
October 7-13, 2018  
[www.post-polio.org](http://www.post-polio.org)  
[www.polioplace.org](http://www.polioplace.org)

## **WE'RE STILL HERE! WEEK – October 7–13, 2018**

PHI's 12th annual awareness campaign will run October 7–13, 2018. We are inviting you to tell us why You're Still Here! Help contribute to another successful campaign by telling us what resources, people or experiences in your life have allowed you to thrive.

Write a short essay (250–400 words) about who or what has enabled you to thrive and show the world that YOU'RE STILL HERE! It may be the support of your family or friends, a piece of adaptive equipment such as a power chair or brace, modifications to your home, changes brought about by legislation such as the ADA, or a local program that has allowed you to age in place. Tell us how you've been able to age successfully with a disability.

Post-Polio Health International will select a grand prize winner (\$150 USD) and four runners-up (free PHI Membership for two years). The winning essay will be published in the Fall issue of *Post-Polio Health*.

The runners-up will be announced October 8–11 with the announcement for the grand prize to follow on October 12th.

### **Contest rules:**

- ◆ Email your submission to [info@post-polio.org](mailto:info@post-polio.org) (Subject: WSH 2018 Contest) or mail it to our office at 4207 Lindell Blvd., #110, St. Louis, MO 63108-2930.
- ◆ Include your name, mailing address, phone and/or email.
- ◆ Each person is limited to submitting one essay.

***Deadline to submit an entry is Thursday, September 26, 2018.***

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Editor: Brian Tiburzi, MA  
[editor@post-polio.org](mailto:editor@post-polio.org)

Designer: Sheryl R. Rudy  
[webmaster@post-polio.org](mailto:webmaster@post-polio.org)

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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.***

### **How to contact PHI**

Executive Director  
Brian Tiburzi, MA  
[director@post-polio.org](mailto:director@post-polio.org)

4207 Lindell Blvd., #110  
Saint Louis, MO 63108-2930 USA  
Phone: 314-534-0475  
Fax: 314-534-5070  
[info@post-polio.org](mailto:info@post-polio.org)  
[www.post-polio.org](http://www.post-polio.org)  
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***PHI sends PHI Membership Memos via email.  
Be sure to set your spam filter to receive emails  
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### **Moving? Change of address?**

Notify PHI before you move by calling 314-534-0475  
or email [info@post-polio.org](mailto:info@post-polio.org), and tell us your old  
and new addresses.

### **Away temporarily?**

Send us your second address and dates you will be there  
and we'll do our best to send your newsletter.

## Full PHI benefits extended to all MPN members

Under the terms of the agreement, all active members of the Michigan Polio Network as of December 1, 2018 will automatically have their memberships transferred to PHI. MPN members will enjoy the full benefits of PHI membership for however long their MPN membership was set to last. While the Michigan Polio Network will cease doing business as an organization, local support groups affiliated with the organization will continue to meet.

As part of the process, and to satisfy legal and statutory requirements, MPN will donate all of its assets to PHI shortly before its formal dissolution. MPN's leadership has been working closely with PHI over the past two years to make sure this is done in an orderly process and that it has the full support of its membership.

## Shifting needs create new challenges

In many ways, the dilemma faced by MPN is a common one for many state and local support groups across the country. While there are an estimated 350,000–500,000 polio survivors in the United States, only a small fraction of those are members of post-polio support groups, and those numbers have been on the decline in recent years.

Several post-polio support groups have found themselves unable to continue their mission in recent years. Texas Polio Survivors Association, Iowa Polio Survivors, Greater Boston Post-Polio Association and several others have dissolved over the past few years.

The challenges faced by support groups are many:

- ♦ declining participation
- ♦ difficulty traveling to meeting locations
- ♦ easy access to information online
- ♦ the creation of support groups on social media networks such as Facebook.

And then there is the issue of “burnout.” There are many groups where the burden of leadership has been placed on one or a few individuals to lead and run the group over many years. It can be difficult for some to find the time and energy to continually publish newsletters, arrange support group meetings, and answer members' phone calls and emails. Some may become physically and emotionally exhausted if others don't step up to share leadership responsibilities.

## MPN as a useful model to consider

While not all the reasons cited above apply to MPN's situation, their decision may still provide a useful model for other groups to follow who find they no longer have the interest or ability to continue.

In their agreement with PHI, the Michigan Polio Network has made sure that their members will continue to have access to timely, medically accurate information. Their members will also be able to get individual help by calling PHI's office with questions or by submitting them via email.

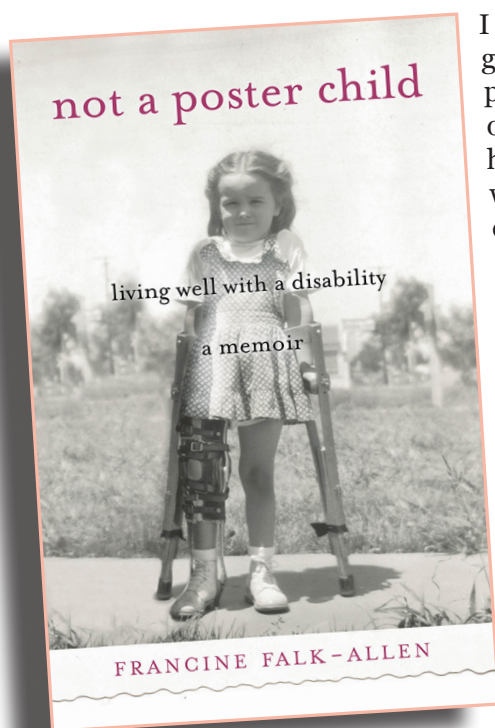
For those who value face-to-face interaction, local support groups that were affiliated with MPN can continue to hold meetings if enough people maintain an interest in doing so. MPN will continue to maintain their website to publicize upcoming support group meetings or disseminate other necessary information for those groups.

Throughout the process, PHI and MPN have tried to remain sensitive to the needs of Michigan's polio survivors. We look forward to successfully completing the transition and welcoming new members into the PHI fold. ■

# Not a Poster Child

Francine Falk-Allen

The March of Dimes was a campaign initiated to pay for polio vaccinations and patient care. Most victims of polio were small children, the most prone to severe aspects of the disease. Little children with smiling faces, braces and Kenny sticks were portrayed on coin collection placards with a hundred slots for dimes, or on posters with a jar for money attached. These promos implored donors to send in “even a dime”—the equivalent of ninety cents today.



I saw the placards in stores, gas stations, anywhere that people might be spending or receiving change. This is how the term “poster child” was born, though it has come to mean “a perfect example.”

Once an older child at church stopped me in the hallway and said, “I saw your picture on the March of Dimes poster!”

I was surprised. “I don’t think so ...”

“Yes, it was you!” she insisted. “She had brown hair just like yours!”

Not long after, a kid at school said the same thing. And then a lady in a grocery store kindly bent down and said, “I saw your picture on the March of Dimes poster, dear.”

At that point, no longer a skeptic, I thought that my picture was actually being used by the March of Dimes, and I was a little excited to learn this. I looked forward to seeing myself the next time I saw a placard around town. There I’d be, Francine Allen, the poster

child. But I soon saw that none of the posters had my picture, though the girl was about my age—around six—wore a brace, used Kenny sticks, and had hair similar to mine (although hers was not in the meticulous ringlets my mother created to draw attention away from my limp; I needed to look pretty, Mama’s reasoning went, in order to make up for my defect—a concept I have never been able to drop).

I asked my mother if I was going to be the March of Dimes girl, and she assured me that I wasn’t. I was a little disappointed, but what bothered me more was that people didn’t recognize that it was not me, that any little girl with Kenny sticks and brown hair looked the same to them. It made me a little angry that that was my identity: The March of Dimes Poster Girl. It is possible that people thought, *What a brave little girl*, when they saw that poster, and that they also thought this about me. But I didn’t think of that when I was six. I was just perturbed that I didn’t have a face to people—I was identified by a limp, a brace and crutches.

I was not a poster child—not in reality and not in terms of the smiley, optimistic, never-bothered attitude that is often wished for in disabled people. Others feel better if a crippled person reflects happy accomplishment. Certainly, winsome courage is more appealing for collecting donations! I was also not pathetic or helpless, though the poster was designed to elicit such thoughts. (I am glad people did fund polio vaccination and treatment. I just didn’t like being thought of as pitiful.)

I was not always brave, though I had to be much of the time, and I was not always accepting of my plight, and did not always bear it with a smile, though



I was told in my twenties, “You were always such a happy-go-lucky kid around the neighborhood.”

My mother was concerned that I be taught that I could be the same and do the same as other children, so I would need to try harder than others, not only physically but in all endeavors. This was good news/bad news. It was good to be encouraged, but it was a problem to think I would one day be able to run or dance as an equal, have the energy for normal activities, or be seen as the same as everyone else. There was an underlying message that I needed to be a better person than others in order to be accepted.

I believe my mother was embarrassed to have a handicapped child. If I made mistakes, my parameters were narrower, and my punishment came swifter, because I had something to make up for and there was no room for error. I needed to be perfect. And I was so very far from perfect. ■

Excerpt from *Not a Poster Child: Living Well with a Disability—A Memoir*

**Francine Falk-Allen** was born in Los Angeles, had polio at age 3, was hospitalized with paralysis for six months, and has lived nearly all of her life in northern California. As a former art major who got a BA in managerial accounting and ran her own business for 33 years, she has always craved creative outlets. This has taken the form of singing and recording with various groups, painting and writing songs, poetry and essays, some of which have been published.

Falk-Allen facilitates Polio Survivors of Marin County, and a Meetup writing group, Just Write Marin County. She was the polio representative interviewed in a PBS/Nobel Prize Media film, *The War Against Microbes*. She loves the outdoors, gardening, pool exercise, her two silly cats, spending time with good friends and her husband, Richard Falk, strong British tea and a little champagne now and then.



Francine Falk-Allen

[www.FrancineFalk-Allen.com](http://www.FrancineFalk-Allen.com); Facebook: Francine Falk-Allen, Author

*Not a Poster Child: Living Well with a Disability—A Memoir* will be released August 7, 2018 and is available to order at <https://shewritespress.com/shop>, your local bookstore or [www.Indiebound.org](http://www.Indiebound.org) (which channels funds to local bookstores), [www.barnesandnoble.com](http://www.barnesandnoble.com), or [www.Amazon.com](http://www.Amazon.com).

# The Importance of Fall Prevention

## A GROWING PROBLEM

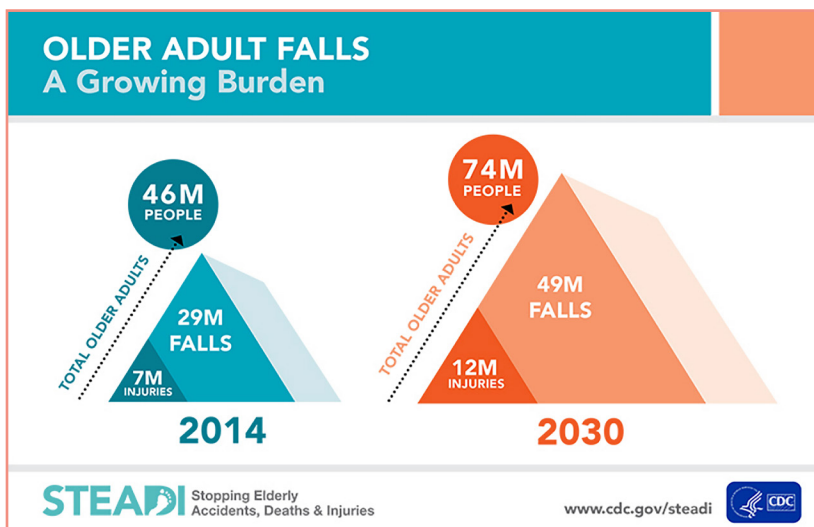
In 2015, overall health care costs in the US related to falls surpassed the \$50 billion mark. Recent estimates predict costs will reach \$67 billion by 2020, rising each subsequent year as we approach mid-century.<sup>1</sup> Among older adults aging in place, approximately 30% will experience a serious fall within a given year. Roughly one in five of these falls require medical attention, and nearly one in ten results in a fracture.<sup>2</sup>

## RISK FACTORS

Several factors put polio survivors at particular risk for falling:

- ☐ lower-extremity weakness
- ☐ fatigue
- ☐ decreased mobility
- ☐ joint pain
- ☐ poor balance
- ☐ use of multiple medications

The RRTC study mentioned previously found that 86% of those who fell were concerned about falling again, and 84% reported limiting their activity because of a fear of falling. The psychological toll of falling can lead to a loss of self-confidence in one's ability to perform routine daily activities. This can lead to social withdrawal, isolation and depression, which, in turn, can lead to further weakness, decreased mobility and an increased dependence on caregivers to complete activities of daily living (ADLs). These things can have a negative effect on one's overall health. Inactivity can raise the likelihood of developing cardiovascular diseases, diabetes, high blood pressure, obesity and depression. This can lead to a decrease in quality of life, an increase in health care costs and an accelerated mortality risk.<sup>5</sup>



Polio survivors, especially those with notable lower-leg weakness, are at an even greater risk. When the Healthy Aging Rehabilitation Research and Training Center (RRTC) at the University of Washington surveyed 2,000 individuals with various neuromuscular diseases, they found that 55% of those with PPS had fallen within the prior six months.<sup>3</sup>

Besides the associated financial burden, falls may result in injuries that have a significant impact on an individual's health years from the initial incident. More than 95% of hip fractures are caused by falling. Falls are also the most common cause of traumatic brain injuries (TBI). A new study published last month found an increased risk of death for up to 10 years after a non-hip fracture.<sup>4</sup>

## STEPS YOU CAN TAKE

Though the statistics are sobering, one needn't give in to despair. There are several simple steps you can take to decrease your risk of falling:

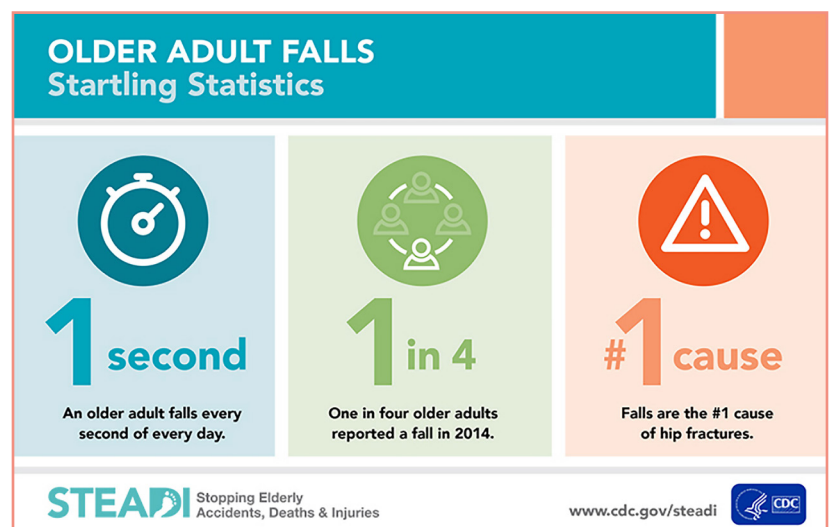
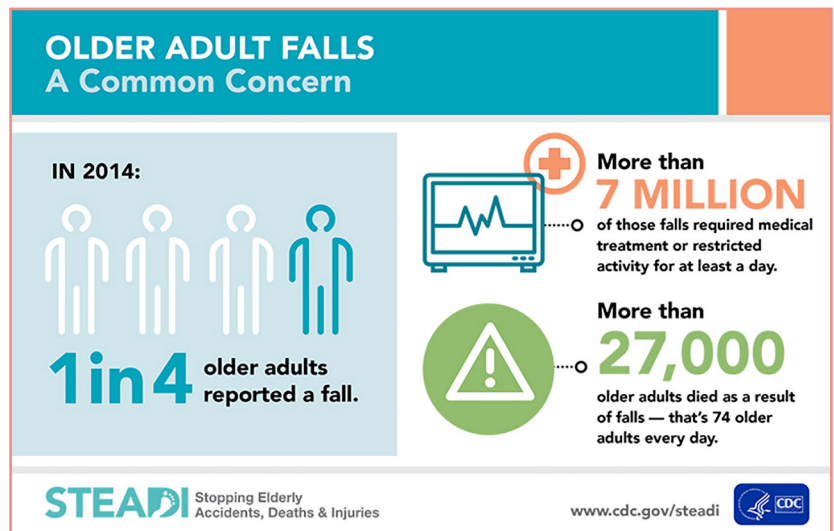
- ☐ Use appropriate assistive devices. Talk to your doctor to see if you may benefit from using a brace, cane, walker or scooter.
- ☐ Eliminate risks in your home. Remove obstructions and clutter from walkways, make sure stairs are well-lit, remove throw rugs, wear socks or footwear with grippy material on the bottom, and install handrails and grab bars where needed.

- ❑ Ask your doctor to review your medications.
- ❑ Engage in exercise that promotes better balance and flexibility, such as tai-chi or yoga.
- ❑ Take sufficient breaks between activities so that you don't become overly fatigued.
- ❑ Have your vision checked.

These steps are no guarantee that you won't fall, of course, but taken together, they may dramatically cut down on the chances of injuring yourself in a fall. ■

For more resources on preventing falls, visit the CDC's website at [www.cdc.gov/steady/patient.html](http://www.cdc.gov/steady/patient.html).

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**QUESTION:** *I'm in my 60s, and still bothered by memories of traumatic childhood experiences. When will I get over this?*

**Response from Rhoda Olkin, PhD:**

I get asked this question often by clients. The short answer is that people don't *get over* things so much as those things lose their power and emotional grip on us. Memories of previous traumas never completely disappear, they simply don't get re-awakened as often or as powerfully. And, as studies attest, we get emotionally stronger and wiser with age.

These traumas inform our early schemas, i.e., core beliefs about ourselves, others and the world. Time and therapy both address schemas. Let me give an example: I was hospitalized at ages 1, 3 and 7, for up to two months at a time. One of my core schemas is that "I have to get home because the world is too dangerous for me to survive." As an adult, I would always want to be the one to hold the car keys when I went on outings with other people so that *when they disappeared on the face of the earth*, I could still get home. Notice that this is an irrational and unhelpful belief. That is the power of trauma-related schemas—no amount of logic undoes them.

So, what pushes back against problematic schemas? Time and experiences—X happened and I survived; Y happened and I survived, Z happened and I survived. As I survive, the schema is weakened. Do I still want to hold the car keys? Truthfully, yes, but am not as insistent, and I am able to laugh at my automatic thought that others are going to disappear and strand me alone on earth.

Many facets of life that one is dealing with as one ages can reawaken memories of earlier times. For example, retirement—whether by choice or earlier than desired due to fatigue—is a powerful reminder of one's frailty. Having worked so hard in the era of "use it or lose it," retirement can seem like "giving in" to polio. Increased weakness can be a reminder that we overdid it when younger, as we were pushed to do.

Other issues also arise with age: being alone, facing mortality, losing significant others, financial strain, reduced mobility. Any new significant stressor is likely to trigger our underlying schemas. But with empathic help from friends, family and/or a therapist, schemas are weakened to a whisper. This is what it means to *get over* trauma.

**QUESTION:** *Recently, some polio survivors have mentioned to us that stories in the news related to the policy of family separation along the US/Mexican border, along with images of unaccompanied children in holding facilities, had brought up their own painful memories of being separated from their families as they recovered from polio. PHI asked our regular columnist, Stephanie Machell, PsyD, to weigh in on the subject.*

(Note from Dr. Machell: Polio survivors are a heterogeneous group with diverse political opinions. Any beliefs expressed here reflect the experiences of my clients and myself and are not intended to represent the polio community or PHI.)



**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.



**Response from Stephanie T. Machell, PsyD:**

Since the 2016 election a large percentage of my clients and those of other clinicians I know have reported higher than normal levels of distress. People with disabilities, including polio survivors, have felt threatened by legislation related to healthcare and Social Security as well as by the attitudes and behaviors of those in power.

The forced separation of children from their families has triggered memories for many polio survivors who experienced similar separations themselves. The images of crying children being taken from a parent's arms resonates with their experiences of being taken from their parents at the hospital. The lack of understanding due to age and language barriers of immigrant children bears similarities to the experiences of young children experiencing the pain and fever of acute polio with little or no explanation of what was happening to them. For both groups, confusion, terror and disorientation was exacerbated by the lack of parental comfort and support and disconnection from everything the child knew.

We don't yet know what the effects of forced separation will be for the children taken from their families at the border. Research and clinical experience, including with polio survivors, indicates that effects depend on developmental level and prior functioning, and mitigating (supportive family and environment, opportunities to talk about experiences) and exacerbating (prior/ongoing abuse, parents' stress and mental health, chaotic environment) factors.

We know that for some polio survivors, separation left scars. Those separated during their toddler years may experience

issues with attachment that linger into adulthood. Some who were older when they were separated report having felt detached from their families when they returned home, with some reporting this feeling persisting, sometimes throughout their lives. Some, especially those who were between 4 and 7 at the time, report having felt the separation was somehow their fault and that polio was a punishment.

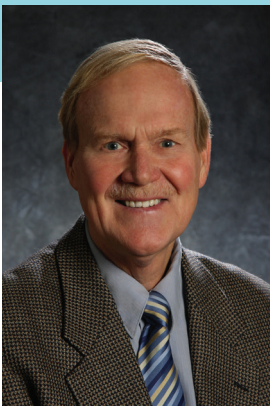
For vulnerable individuals, including some polio survivors, a history of separation can contribute to the development of depression or anxiety disorders in vulnerable individuals. Combined with other traumatic experiences, separation may be a factor in the development of PTSD and other trauma-related disorders.

Recalling the experience of being separated from parents may also bring back other polio memories. While it may be painful to remember, pushing your memories away is seldom helpful. Instead, try telling supportive others, using faith/spiritual practices and/or writing or drawing about your experiences. Practice good self-care, including avoiding or titrating your exposure to news and social media and setting limits on discussions of current events. Do things that make you feel better, including connecting with loved ones. Action in the form of relevant volunteer work can also reduce feelings of helplessness.

As always, if your memories intrude on your daily life and affect your ability to function, or if you are experiencing unmanageable levels of anxiety, depressed mood, irritability, insomnia or nightmares, you should consider seeking professional help. ■

**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.





Frederick M. Maynard, MD

## Ask Dr. Maynard

Send your questions for Dr. Maynard to [info@post-polio.org](mailto:info@post-polio.org).

See other questions at [www.post-polio.org/edu/askdrmay.html](http://www.post-polio.org/edu/askdrmay.html).

**Question:** *In cervical spondylotic myelopathy there may be muscle weakness in lower limbs and gait disturbance, so it may be confused with a post-polio syndrome in a person who has had polio. Is there some information regarding the prevalence of this pathology in elderly patients who have had polio and how to diagnose correctly and not attribute the new weakness to the evolution of post-polio syndrome? I would be grateful if you can tell me if there is any information in this regard reflected in the surveys of people with post-polio syndrome.*

**Answer:** Regarding the question about incidence and diagnosis of cervical spondylotic myelopathy (CSM) in people with a past history of polio (polio survivors), I am unaware of any survey information or population reports of incidence of these two conditions occurring co-morbidly. Nevertheless, I can confidently assure you, based on my personal experience and my frequent networking with other physicians who see many polio survivors, that they do occur occasionally in the same person. After all, CSM is a common problem among aging populations, especially those with joint and spine problems; and polio survivors, whose average age now in the US is in the early 70s, have many joint and spine problems related to their long existing residual muscle weakness after paralytic polio.

I am glad you asked about how to best diagnose these conditions since it is often not easy. CSM is a diagnosis based on cervical spine imaging and clinical exam evidence of cervical spinal cord dysfunction (myelopathy). The most common symptoms are upper extremity weakness, particularly of the hand muscles, as well as ataxic gait, hyperactive reflexes of the lower limbs with pathologic reflexes, proprioceptive loss in the lower limbs, urinary incontinence and neck pain. Many of these symptoms can also be seen in polio survivors with post-polio syndrome (PPS), especially new upper or lower extremity weakness and worsening gait (if they are walkers), but one would not expect to see lower limb hyperactive reflexes, proprioceptive sensory loss or urinary symptoms. The most important test to assess the relative contribution to primary distressing symptoms from each diagnosis may be electrodiagnostic studies performed by a physician who also examines the patient carefully. In addition to ruling out confounding peripheral neuropathies, the EMG should show confirmatory typical changes of chronic motor neuron loss in the newly weakening muscles. Additionally, one can assess the patterns of motor unit recruitment in the lower limbs for abnormalities that may be more or less typical of upper or lower motor neuron dysfunction. Unfortunately, there are no electrodiagnostic abnormalities that are completely definitive for either diagnosis.

Given the relatively high risk of complications from cervical laminectomy in older individuals, the unpredictability of symptom improvement after surgery and the unpredictability of the natural history of progression of symptoms in people with CSM, one should be quite cautious about recommending cervical decompressive surgery in a polio survivor, particularly those with sufficient evidence for a diagnosis of PPS to account for most symptoms. “Aggressive” non-surgical management of the CSM diagnosis and of the functional losses associated with PPS should be recommended first.

I hope these thoughts prove helpful to you if you are a health care provider. If you are a polio survivor with these diagnoses being considered, you may wish to share my response with the physicians you are seeing. ■

## *In Appreciation*

Thank you for recognizing your friends and loved ones with contributions to the activities of PHI and IVUN and for your generous Membership contributions.

*Please contact us if we made an error.*

### **Contributions to PHI's education, advocacy and networking activities**

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## Not a Member?

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You can join online at <http://shop.post-polio.org> or send (or fax 314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. *Questions?* 314-534-0475.

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