

# POST-POLIO HEALTH

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PHI's mission is supported by its Membership.

**WE'RE  
STILL  
HERE!**

October 11-17, 2015  
[www.post-polio.org](http://www.post-polio.org)

## WE'RE STILL HERE!

In 2007, PHI launched an annual WE'RE STILL HERE! campaign to remind the world that, while polio has been declared eradicated in most places around the globe, polio survivors are still here. They are contributing members of society and active in their communities, taking an active role as civic leaders, teachers, doctors, nurses, lawyers, artists, farmers and elected officials.

According to an analysis done by PHI, there are more than 900,000 survivors in the United States, with more than half experiencing new problems in maintaining their quality of life. Some are experiencing new weakness that may require new assistive devices, such as new bracing, custom-made shoes, wheelchairs and scooters. Some are in need of home health care and new breathing machines, such as bi-level devices and ventilators. Additionally, aging polio survivors are in need of health professionals who understand how to manage their health issues.

With a goal of increasing public awareness of the existence of polio survivors and their needs as they age, PHI's WE'RE STILL HERE! campaigns focus for one week in

October on various ways that members and polio support groups, friends and families can get this message out.

Strategies have included letters to the editor, letters to elected officials (WE'RE STILL HERE! ... and We Vote), calling attention to accessibility issues in the community and places of worship, speaking to civic and school groups, and sharing experiences and artifacts on PHI's PolioPlace website ([www.polioplace.org](http://www.polioplace.org)).

### 2015 Photo Contest Winners Announced

In 2015, the theme for WE'RE STILL HERE! was Show Me Accessibility! Members were urged to help document in photographs that polio survivors are active and involved thanks to laws such as the Americans with Disabilities Act or the UN Convention on the Rights of Persons with Disabilities. Photos had to feature activities that were previously impossible to access or places visited that were not accessible before.

We are pleased to announce the five winners of the 2015 WE'RE STILL HERE! Photo Contest.

#### The Winner: Jim Smith

Jim and his wife Mary were able to get all the way to the top of the viewing platform this past September at Mount Rushmore National Park in South Dakota. The park has installed an elevator that is fully accessible, which made it easy for them to reach the viewing platform. They were thrilled – especially because it allowed them to experience the beauty together!



*Jim and Mary Smith at Mount Rushmore National Park.*

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**First Runner-Up:  
Dena Marie McBride Oden**

“I am continually amazed at how much the world has changed for me in California since the ADA was enacted. Monthly, I find new ways to maneuver on my Buzz-Around Golden Technologies scooter with my husband and granddaughter.



The picture above shows me on the accessible playground equipment at Griffith Park, California, September 2015. Devised by Shane’s Inspiration Group, the equipment is totally usable and enjoyable on my scooter. Here, with my granddaughter Vianne Rose, we are having a wonderful time together. Not only was the playground equipment accessible, but the entire park had wonderful ramps, wide sidewalks and paved paths for my usability.

I had polio in 1947. I was paralyzed from the neck down, and then regained use of arms and upper body. I have had post-polio for twenty-five years. I can no longer stand on either leg even with braces and crutches ... and yet the ADA enables great adventures for the likes of me! I am grateful!”

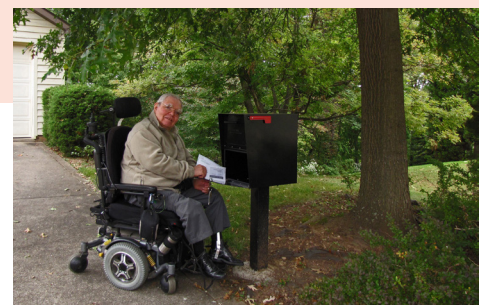
**Second Runner-Up: Audrey King**



“Thanks to the accessibility of so many cruise ships these days – thanks to ADA and/or the influence of ADA on other countries – Dorothy Willis and I have enjoyed several recent cruises to the Caribbean and Alaska. Here we are in Skagway, having just enjoyed the accessible White Pass and Yukon Railway, and in Juneau the day before, a trip to the top of the mountain in Mount Roberts Tramway.

Think we’d pass as modern day “ladies of the night?”

**Third Runner-Up: Warren Peascoe**



“Thanks to the ADA, I now have home delivery of my mail. Previously the mail was delivered to a cluster box which was not accessible. My initial attempts starting about 2001 were turned down. On the advice of the state ADA compliance people, I tried again in 2014 without success. This year I succeeded. Our mailman is delivering mail to my home. I had polio as a child and currently use a power wheelchair as a result of post-polio syndrome. A note from my doctor indicating the necessity for the wheelchair and that my condition is permanent was included in my first letter.”

**Fourth Runner-Up: Jann Hartman**

“This photograph shows me using an accessible bus at the airport in Honolulu, Hawaii, in 2007. Similar buses are now becoming commonplace. I was pleased to also find out last year that the buses from the Amtrak Stations are also accessible. Still more needs to be done, but I have found lots of progress and that allows me to continue to travel by plane, train or cruise ship.” ■



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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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**Moving? Change of address?**

Notify PHI before you move by calling 314-534-0475 or email 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.

# POLIO SURVIVORS IN TURKEY

Prof. Dr. Arzu Yağız On, Ege University Medical Faculty,  
Department of Physical Medicine and Rehabilitation, Izmir, Turkey

## ERADICATION HISTORY OF POLIO IN TURKEY

In 1963, oral polio vaccination started in Turkey and covered about 20% of the children, but by 1985, this rate increased to about 70%. In 1989, Turkey joined the global eradication program of the World Health Organization. In 1995, mass vaccination campaigns started and were repeated every year. With these efforts, vaccination coverage increased to 100%, meaning that polio vaccine was administered to all children in the target group.

Europe's last case of wild poliomyelitis occurred in eastern Turkey in 1998. However, Turkey is surrounded by polio active countries and is traversed by emigrants to Europe.

Turkey's most severe threat of polio comes from the 600,000 Syrian refugees because polio re-emerged there three years ago. Extensive vaccination campaigns have been conducted since 2012 not only at the Syria camps but also in the regions threatened by the disease, even in Istanbul. No new polio cases have been reported so far.

## CURRENT STATUS OF POLIO SURVIVORS IN TURKEY

With such a strong focus on eradicating polio, insufficient attention has been paid to the individuals living with polio residuals and their subsequent health and rehabilitation needs, as well as their lifetime social, financial and psychological needs.

The number of polio survivors living in Turkey, where they are living or how old they are is unknown. It is extremely challenging not only in Turkey but all over the world to estimate the number due to inaccurate diagnosing and reporting of the cases during the epidemics.

According to the national reports of case numbers for polio between 1961 and 1999, about 13,000 cases were reported. If we consider that only 10% of the polio cases were captured through the national surveillance system, we could estimate that there are 130,000 thousand survivors living in Turkey and many of them are younger than 50 years old.

These young patients challenge the healthcare, rehabilitation and education systems as they strive for employment, social integration and economic self-sufficiency.

Moreover, the possibility of post-polio syndrome in the future challenges the younger polio survivors. Such health problems not only affect employment, but also have psychosocial implications and possible limits to independence and social participation. Polio survivor needs will be a concern for at least another generation and will make additional demands on Turkey's national health systems.

## POST-POLIO CLINIC IN EGE UNIVERSITY HOSPITAL, DEPARTMENT OF PM&R

Our team mainly includes one or two physiatrists, a physiotherapist and an orthotist. Many professional members required for an ideal team such as occupational therapist, psychologist, social worker, nurse specialist, speech and language therapist and dietitian are lacking. Available team members assume those responsibilities as well. On the other hand, we have facilities to consult the patients to the other departments such as neurology, psychiatry, respiratory medicine and endocrinology when necessary.

### Assessment protocol

Polio patients are evaluated every Thursday. First, the patients complete a detailed medical history form, regarding their original illness and subsequent sequel, including the use of orthotics and/or walking aids, social situation and lifestyle. Patients are asked about new neuromuscular and musculoskeletal symptoms including pain, perceived fatigue, weakness and changes in function.

The physiatrist reviews the patients' medical history and performs a thorough neurologic and musculoskeletal examination. Validated scales are used to measure presence, severity and impacts of fatigue and health-related quality of life. A physical therapist measures range of motion, strength and assesses mobility status. An orthotist works with the rehabilitation physician and the therapists to determine the need for orthosis and ambulatory aids.

All patients are evaluated with detailed needle EMG (electromyography) and when necessary, further evaluations and referrals are arranged. Following confirmation of poliomyelitis, the extent of subclinical involvement is determined or a diagnosis of post-polio syndrome is made using established criteria.

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# Aging in place with a disability

Karen Hagrup, St. Louis, Missouri

Although I was only three-and-a-half when I contracted polio, I was 51 years old before I actually started investing in making my living space accessible and functional for my needs and daily living activities. Sixteen years and four living spaces later, I moved into my current apartment, and, for the first time ever, I live in a place where I would like to stay for the rest of my life.

It took a good chunk of money to transform a condo in a 90-plus-year-old building into a comfortable and accessible home. But more important than the money, was the support I received for “bucking conventions” when organizing my space. The result is an apartment where I can expect to age in place with my disability. While adapting to inevitable functional changes over time, in this space I expect to remain independent doing my daily life activities for years to come.

Some of the basic accessibility features are shown in these pictures from my living space.



The doorway to the patio was replaced with a wider door.

The door has been removed between the bedroom and kitchen. Some doorways have been widened to accommodate a chair. A small ramp from the kitchen to the living area was installed.

A pocket door was installed between the bedroom and the bathroom and the doorway was also widened.

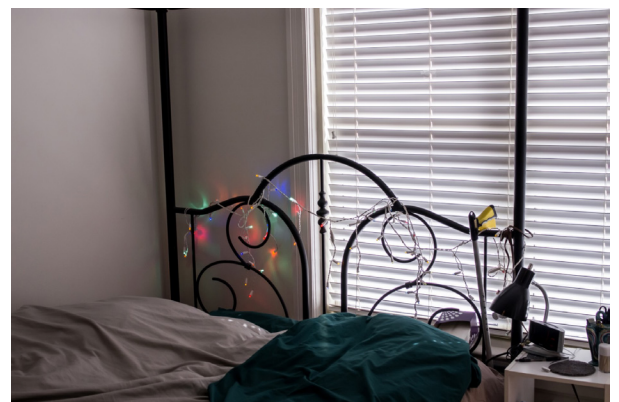


The most important area in an accessible living space is the bathroom. Because it fits my needs, I have a roll-in shower with a shower bench and also a flexible shower head and lots of grab bars.



I have a raised toilet seat and the pedestal sink has room underneath for my chair. A large cutting board provides counter space

when needed. The tall mirror allows me to view myself sitting down as well as others standing.



Providing easy mid-night access, my bed is located about eight feet from my toilet. Having a bed frame that you can grab and hold onto when you turn around in bed can be very helpful. I also have multiple reachers strategically placed throughout.

In my world, the second most important space is the kitchen. While moving into my kitchen, I spent some time figuring out how often I tend to use the dishes, utensils, pots and gadgets. The items I use most often are kept in the most convenient places. Dishes for special occasions go in harder to reach places. After several weeks I made a few changes because I had been wrong about how frequently I used some of the items.



The counter has been lowered. The garbage can is on wheels making it easy to store underneath the counter. I have a free standing stove-top that is at the same level as my main counter.

Cups are stored in a lower cabinet drawer.

I created extra surfaces to store items that I use a lot, so I don't have to get things in and out of cabinets too often.



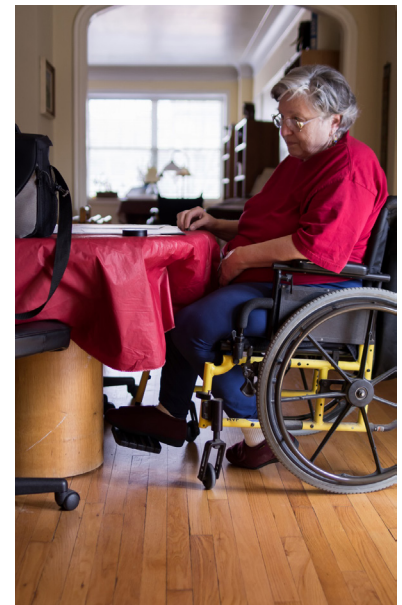
The condo has a lot of storage cabinets, but many of them reach up to the ceiling so most of those spaces are completely empty. Instead I have installed open shelves at a lower level throughout the apartment. I tend to remember better the things I can see than the ones that are covered up. I give every item a specific place where it belongs and where I always return it after use. That way I can remember where to find things. Since I may also gradually lose my central vision, this level of organization is especially important.

There are no carpets to be found anywhere in my condo. A round table with a pedestal provides easy access from all directions in a chair.

Small wheels on chair make it easier to maneuver in the house around furniture, between doorways, etc. I use the bigger wheels outside the house.



Having lived a long life already with polio and post-polio, I have had to incorporate multiple new mobility and functioning aids over time. One important lesson that I have learned is how crucial it is to take on new equipment and behaviors as early as possible. If you want to maintain your independence as you age, do not wait till it is too late to learn how to use the new tools, or establish the new habits. ■



### **Demographic data the patients admitted to our clinic**

A total of 247 patients with a history of polio have been admitted to our clinic since 1997. Confirmation of polio was made in 90% of the patients. The remaining 25 patients had been misdiagnosed as polio, when the correct diagnosis was encephalitis, stroke, cerebral palsy and other upper motor neuron syndromes.

The mean age of our 222 patients is 39 which is quite young. Most of the patients are women and most of them are married. It is not surprising because marriage is almost universal in Turkey, even for polio survivors. The educational level is high for Turkey and most of them are employed. Among the not employed patients, most of them were housewives. As an unexpected feature, the patient's sociocultural level was high compared to the general population.

However, our data does not represent the current status of all polio survivors in Turkey, since most of our patients are from the west part of Turkey, where most of them have access to our center via internet or email.

Sixty-seven percent of the patients met the criteria of post-polio syndrome. Forty-eight patients had concomitant neurological, rheumatologic, cardiovascular or thyroid disorders that could cause symptoms of post-polio syndrome.



**Prof. Dr. Arzu Yağız On** first became interested in polio while doing a fellowship at Uppsala University in Sweden. After moving back home, she established a post-polio clinic at the Ege University hospital, one of the largest and oldest hospitals in Turkey with more than 4,000 inpatient beds.

### **Clinical management program**

Our program is established according to the specific needs of the patients and covers all aspects of life.

The first step of the treatment is to educate the patient about polio, post-polio syndrome and the problems associated with them, and to provide individual and family counseling. This may include instruction in energy conservation techniques and work simplification, as well as suggestions for adaptive techniques and equipment to maximize the individual's participation in home and work activities and to assist in learning to adjust to necessary lifestyle changes. Sometimes patients are referred to a psychiatrist or psychologist to provide such assistance.

Based on the orthotic assessment, older orthoses are repaired or modified. More frequently, new custom orthoses are fabricated.

Nutritional counseling is provided to assist patients requiring therapeutic or weight-reduction diets.

A new exercise program is established that is specifically designed for the individual. Exercise programs emphasize the prevention of overuse. The program is supervised for at least two months, and carefully monitored and modified when necessary.

As education is the key part of management, the clinic staff has developed handbooks explaining the late effects of polio, work simplification, energy conservation, home exercise programs and orthoses. We provide them both to the patient and their primary care physician. (See [www.polioplace.org/sites/default/files/files/Turkishpoliobooklet.pdf](http://www.polioplace.org/sites/default/files/files/Turkishpoliobooklet.pdf))

Although medications have been used with only partial success, we usually prescribe lamotrigine for treatment of symptoms related to post-polio syndrome, based on the results of our study indicating that this drug relieves the symptoms and improves quality of life. ▶

▷ The patient usually returns for a follow-up in one to two months to assess the success of the program and the efficacy or side effects of medical treatment; for example, the exercise program may be modified based on the exercise logbook.

### WHAT SHOULD BE DONE FOR POLIO SURVIVORS IN TURKEY IN THE FUTURE?

To assist in national policy-making, more accurate estimates of regional prevalence of polio survivors and the degree of residual disability are needed to design effective programs and policies to meet educational, social and economic needs of young middle-aged adults.

Given the complexity of diagnosis and management of post-polio syndrome, care strategies for polio survivors should involve coordination of multiple-skilled professionals, and these strategies should be adopted for resource-poor areas.

Healthcare professionals, largely unaware of post-polio syndrome, should be educated. Publishing information or research in open access national journals is much more important for educating health professionals than publishing in international journals.

Perhaps the most important issue in Turkey is that there is no organization or support group specifically for polio survivors. Although many of the challenges faced by polio survivors are similar to those faced by people with other disabilities, post-polio syndrome is a unique situation because of its clinical picture, diagnostic difficulties and management approaches. Such an organization should be established immediately. It is also important to place information in Turkish on the internet for when patients Google polio and post-polio.

### Positive aspects of Turkey regarding treatment of polio survivors

As a result of family life and cultural structure of Turkey, families and friends give strong social support to the people with a disability. This social support, especially from family mediates most of the challenges polio survivors face in Turkey.

More importantly, general public insurance covers most of the rehabilitation services (physiotherapy at the state hospitals and private clinics) in Turkey. Even the poorest people may have access to these services. It also covers modification or fabrication of custom orthosis every two years (about \$600). However, if the patient needs more expensive orthosis such as lightweight carbon orthoses to increase comfort (about \$2500), then the patient has to pay the price difference. If the patient has polio at only one lower extremity, general public insurance covers a certain amount of manual wheelchair expense every five years (about \$300). If the patient has polio at both lower extremities, then the insurance pays a certain amount for an electric wheelchair every 5 years (about \$850). ■



## 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.

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

#### In Memory of

Ray Berkenbile	James C. Sailor
Edie Elterich	Constance Salidis
Martha Lou Howe	Carlos Vallbona, MD
Gail Bakken Johnson	A.C. "Sonny" Whetten
Thomas S. Reed, II	Hilda Wright

### Contributions to The Research Fund ...

#### In Memory of

Rose Marie Brooks	Janet L. Putz
John M. Clark	Elizabeth Rutledge
Gail Bakken Johnson	James C. Sailor
Walter Solomon Lindsay	Constance Salidis
Lloyd Ben Patrick	Hilda Wright

#### In Honor of

Ann Doucette	Thomas Ringhofer
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### Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

#### In Honor of

Monday Mahj Group

**QUESTION:** *I participate in a Facebook group for polio survivors. I want to contribute honestly, but many times my response isn't what others "believe." I have felt bullied a few times in the past, and just backed off. I find that I gain from it, so I don't want to leave the group. Do you have suggestions as to how to respond in these instances?*

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

Unfortunately, this is a common problem in groups. Opinions and experiences that differ from what the group as a whole believes threaten one or more members, triggering an attack on the person expressing them. Members become reluctant to share. Some leave.

Have other group members been bullied when they've said things others don't "believe?" Or are they careful to stay within the parameters of accepted beliefs? The group "norm" may be total agreement and avoidance of controversy. Or members, aware that there are one or more group bullies, may have just stopped commenting.

Because social media brings out the "trolls" (e.g., those whose posts are vitriolic attacks on those with whom they disagree) as well as the "troll" in otherwise decent people, Facebook groups usually have rules that are posted as part of the group description. Groups may have a moderator who among other things takes responsibility for insuring that the rules are followed. Often the moderator posts reminders of these rules, especially after they've been violated.

A common group rule is that posts and comments should be respectful. If your group has this rule and a moderator, send her/him a private message describing your experience and requesting that s/he communicate with the bully about this. You might also request that the

moderator post a reminder of the group rules. If there are no rules or moderator, you could propose that the group consider changing this (though don't be surprised if others take this to mean you're volunteering!).

If what you get out of the group is reading what others post, remaining in the group but not commenting or posting (or only on "safe" topics) is one option. Or you could write a post about your experiences, and/or ask whether others have had the same or similar experiences and how they have handled them. Or you could post a question about how the group should respond when others have experiences or express opinions that differ from the majority.

Or you could continue to participate as you have. If you now expect to be attacked, it is important to make sure you're not coming across as apologetic or defensive, which can provoke attack or bullying. If you are attacked anyway, the best response is either ignoring it or replying with something along the lines of, "This is my experience. Please respect it." And leave it at that. Remember that the bully wants a reaction. If there is none s/he will look for more interesting victims.

Before you post anything, consider the risks and benefits of doing so. Does the opportunity to share and the positive feedback you may get about what you want to say outweigh the possibility that you will be bullied? Then post to



**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.



the group. Will the bullying cause you to feel invalidated, even if you also receive positive responses? It might be best to post in a more supportive venue.

Different groups provide different benefits. And there is no reason to limit yourself to one.

**QUESTION:** *I see people on Facebook and other online groups who have a made-up name (Bracing Bill, Polio Paul), who may be pretending to be survivors. And there are groups like "Women in Braces." Some are way too interested in braces and other hardware, and it's getting creepy. On Facebook, one person with a pseudonym posts lots of pictures of braces; no one knows if s/he is a polio survivor or not (and could lie if asked). Perhaps people trust that everyone on FB is a good person. Is there anything our group can or should do?*

**Response from Rhoda Olkin, PhD:**

This is an excellent question but one that requires us to make some assumptions without being able to verify if our assumptions are correct. There are two possibilities here as I see it. Let's start with the benign possibility: this is a person with polio who believes that s/he is contributing to the archives by posting pictures of braces. Perhaps s/he believes that someone is collecting these, or that persons with polio are a diminishing group, one that calls for documentation.

The second possibility is less benign. The man (and it will be a man) has a sexual fetish that is attached to braces. He finds them sexually stimulating, and by posting them on Facebook he is hoping to entice similar persons to post more pictures. Sexual fetishes by themselves are generally harmless, but can be harmful to others when a person masquerades as a person with polio and others are seduced into responding as if this is accurate when it is not. The responses may feed the fetish. And those who respond may feel used, or, as you said, creepy. The other aspect here is the masquerade as a polio survivor. One would like to be able to assume that Facebook "friends" are authentic, and that sharing the

experience of polio is genuine. Obviously not friending someone with a pseudonym is one way to reduce the risk of including someone who is in it for the thrill.

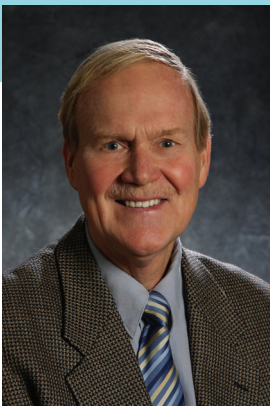
Readers may be surprised to know that there is a very large group of "devs" – short for devotees, i.e., people who experience sexual attraction to very specific types of disabilities. For example, one person might be attracted to persons with a left leg amputation above the knee. Notice how specific that example is – the attraction often is that specific. Similarly, there are "wannabes" – i.e., persons who want to have a disability and who may behave and present themselves as if they do, when in fact they do not. There are hosts of internet sites related to devs and wannabes: Google "disability devs" and "disability wannabes" and you will find definitions, and many sites and listservs. Most of the sites are very upfront about what they are and who they cater to. That is very different than going to a specialized listserv (e.g., persons with polio) and masquerading.

Trust your instincts. If something feels creepy, stay away, unfriend, disengage. Any responses may only feed the person's appetite. ■

**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.





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:** *I am 82 years old and have PPS. Two years ago I fell backward down the stairs and broke my C2 and C3 vertebrae. I still can't turn my neck enough to drive myself. I get worn out doing nothing, and I am tired all the time. I had two chair lifts installed, which does help, and I can walk with a walker, so I am able to get to church. Do you have any suggestions for me?*

**A:** I am glad that you are still on your feet with a walker at age 82 after neck fractures. The only way to regain further strength and endurance for activity is through exercise. It would be best to do this under the professional guidance and supervision of a physical therapist, probably three times a week. You will need a physician referral and obviously their permission to exercise.

Any progress is always slow in polio survivors, and especially will be at age 82. You likely were forced to be less active for several months after the fractures which led to disuse atrophy of your post-polio muscles and deconditioning of your cardio-pulmonary systems, both of which happen more quickly and to a greater degree in polio survivors. Try to muster up your determination and perseverance in order to stick with a vigorous (for you) program for at least three months minimally before thinking your activity capacity is the best it can be.

Continuing a therapeutic strengthening and endurance training program even longer may be appropriate and can be done through many community-based facilities such as senior centers, YMCA's, health and fitness clubs, etc. The challenges are accessibility, affordability and staff and equipment appropriate for senior citizens with chronic limitations (post-polio weakness and fused neck and possibly others). I hope these thoughts are helpful.

**Question:** *I had what was termed a "mild" case of polio in 1951 at age 7. Other than a barely noticeable curvature of the spine and temporary weakness in the neck, I had no ill effects and was back in full action within a couple months. I played sports throughout high school and have run a variety of races since my early 30s, including marathons and, yesterday, at age 71, I completed a nine-mile race.*

*A friend made me aware of PPS in 1985. Reviewing the literature, I saw that avoiding strenuous exercise was recommended, but I have continued to run on and off through the years without apparent PPS issues or serious structural problems.*

*I do have questions about two conditions. One is Restless Leg Syndrome, which I've experienced on and off since about the time I had polio, and I wonder if polio survivors are especially prone to it.*

*My other concern is with random "muscle tears" in my lower and upper legs, which I have experienced since my early 40s during times when I am running frequently. Curiously, the tears don't happen when I am in the act of running, but more likely when I am rambling through the house. I have worked with a sports physical therapist who does not believe I have PPS. Do you see any relationship between these two conditions and polio or post-polio? Thank you for your ongoing commitment to helping polio survivors. It is remarkable and deeply appreciated.*





**A:** Congratulations on remaining in such good physical shape at age 71 – my age! I am impressed that you have pursued many good strategies to get help with your concerns. Here are my thoughts about the two issues you raise.

Restless Leg Syndrome (RLS) remains a poorly understood condition and probably represents a spectrum or variety of conditions in regard to etiology or cause. A number of studies on polio survivors suggests that RLS is more common and particularly in relation to sleep apnea syndromes. I would also say that strenuous use and possible “overuse” does lead to muscle aches and restlessness in anyone. If you have experienced some of these symptoms ever since your childhood polio, then it makes sense that you would experience it more during periods of long distance running. If it does not persist when you are not running a lot and your overall leg muscle strength has not declined over the years more than expected with aging (hard to judge but certainly modest), then I would not be concerned about your polio history in relationship to these RLS symptoms.

Regarding your “muscle tear” symptoms, I think stretching exercises are probably the best strategy to manage them. Again, they probably relate to your strenuous use of the muscles which is normally followed by microscopic muscle-damage changes and make muscles more vulnerable to minor injuries during unplanned non-focused normal-activity related contractions. I would say that if you have had these for a long time, the soreness subsides/ resolves fairly quickly and your overall leg strength has been maintained, I would not be particularly concerned about the relationship of these symptoms to your polio history.

Overall, I would agree that you do not have PPS. I think it is fine for you to remain involved in running as you like and enjoy it and to continue to vigilantly monitor your symptoms and their intensity vis-a-vis the intensity and duration of the strenuous running-related use of your leg muscles. Clearly these activities continue to keep you happy and healthy. ■

**Correction** *Post-Polio Health*, Vol. 31, No. 3, Summer 2015, Page 3: Montreal was inadvertently left off the list of cities in Canada where there is a center involved in the Multicenter, Multi-country study of the Efficacy and Safety of Immune Globulin Intravenous (Human) Flebogamma® 5% DIF in Patients with Post-Polio Syndrome.

## Not yet a Member?

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POST-POLIO HEALTH INTERNATIONAL  
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## Happy 55th Anniversary to PHI!

While it is difficult to pinpoint the exact date that PHI was founded, in September 1960, the International Iron Lung Polio Assistance, Inc., was incorporated as a nonprofit entity by Gini and Joe Laurie.

Gini volunteered on a polio ward at the Toomey Pavilion, a city hospital in Cleveland, Ohio, and since the late 1950s had produced a publication chronicling the stories of those polio patients after they moved home. By the 1970s, the publication had grown in size and circulation and was known as the *Rehabilitation Gazette*. In 1983, the name changed to reflect the organization's larger scope and international reach – Gazette International Networking Institute, Inc. – whose acronym, GINI, played off the name of the founder.



By 2003, the name Post-Polio Health International, including International Ventilator Users Network, had emerged as a straight-forward, easily understood description of what the organization represents.

As we mark 55 years of advocating for polio survivors, we take pride in our accomplishments and continue to fulfill our mission of working to enhance the lives and independence of polio survivors and home ventilator users worldwide through education, advocacy, research and networking. ■

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