



# PA Polio Survivors Network

Information and Inspiration  
for All Polio Survivors and Their Families

*Serving the Keystone State and Beyond*

[www.polionetwork.org](http://www.polionetwork.org)

March 2019

## **Our Mission:**

*To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.*

## **The Warmth Of Spring Will Soon Be In The Air . . .**

Even so, the PPS symptom of feeling so very cold can be overwhelming.

Can being cold all the time affect our immune system?

This month we're bringing Part 2 of our two part series from Harvard Health "How to Boost Your Immune System". That's one of the questions this article addresses.

## **Bladder Issues and Post-Polio Syndrome.**

It's one of those topics that we try to avoid, but it is one that affects so many Polio survivors. Is it Polio damage or a natural part of aging?

[William M DeMayo, MD](#) addresses this issue in one of the most thorough articles we've seen.

## **Post-Polio Health International asked us to write an article addressing "How we Began" and "What Motivates Us to Continue".**

Those of you who receive their newsletter by mail saw most of it in the Winter Issue.

We're bringing this article to you in it's entirety.

We are truly grateful to PHI for asking us to complete this project.

## **Bruno Bytes covers an enormous number of topics.**

This month, one of those topics [Richard L. Bruno, HD, PhD](#). spoke about is the need to have accurate Medical histories that are easily available.

Dr. Bruno's Original Post: So many of you have had recent medical problems, doctor and even ER visits. It's vital that everyone have a MEDICAL HISTORY & MEDS LIST with:

- Diagnoses (most recent first)
- Past surgeries
- Medications (name, dose amount and doses/day)
- SENSITIVE TO ANESTHESIA and list of drug "allergies"
- Recent blood work and test results (if you have had a recent exam)
- Names and phone numbers of your own docs

The trouble (and maybe the life) you save will be yours.

We agree. At the request of a Polio survivor, we created a "Symptom Checklist". Not long afterwards, she was grateful to have it in the ambulance when she was taken to the hospital. This year, we updated it to include "scan" codes, giving health care professionals quick access to information from various sources, about the effects of Polio. It is on the Anesthesia Warning Page of our [website](#) and is easily available for download and printing. It is also attached to this newsletter.



**We always love to end our newsletters with a positive message.**

Send us your favorite "upbeat" messages to share with our readers.



**Symptom Check List for Polio Survivors**  
**For Families and Caregivers**  
**I am a Polio Survivor with Post-Polio Sequelae.**

I can:

**Be EASILY SEDATED, and may be difficult to wake**  
**Have Difficulty BREATHING and SWALLOWING with Anesthesia**  
**Be HYPERSENSITIVE to PAIN and COLD.**

**Need a HEATED BLANKET and Need to have Increased Pain Medication post-op.**

Name: \_\_\_\_\_

I have these Symptoms of Post-Polio Syndrome (PPS) - checked:

- |  |  |
|--|--|
| <input type="checkbox"/> Overwhelming Fatigue  | <input type="checkbox"/> Muscle Weakness           |
| <input type="checkbox"/> Muscle and Joint Pain | <input type="checkbox"/> Sleep Disorders           |
| <input type="checkbox"/> Cold Intolerance      | <input type="checkbox"/> Difficulty Swallowing     |
| <input type="checkbox"/> Difficulty Breathing  | <input type="checkbox"/> Sensitivity to Anesthesia |

**\*\* Anesthesia Warning \*\***

**Preventing Complications in Polio Survivors Undergoing Surgery**

[www.polionetwork.org/anesthesia-card](http://www.polionetwork.org/anesthesia-card)



**Breathing Outcomes for Post-Poliomyelitis Syndrome**

**Breathing and Ventilation Information**

[www.breathenvs.com](http://www.breathenvs.com)



**Encyclopedia of Polio and PPS**

**Information for all Subjects related to PPS**

[www.polionetwork.org/encyclopedia](http://www.polionetwork.org/encyclopedia)



**Information on Multiple Subjects Related to PPS**

**Post-Polio Care for Families and Health Care Providers**

[www.polionetwork.org/living-with-post-polio-syndrome](http://www.polionetwork.org/living-with-post-polio-syndrome)



**Post-Polio Health International**

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



**Please take this information into account, when you are creating my treatment plan.**  
**I have added additional information, relating to my medical history, on the back side of this page. (Allergies, Current Medications, Tests Etc.)**

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Helpful Ways to Strengthen Your Immune System and Fight Off Disease (Part 2 of our two part series)

### Improve Immunity with Herbs and Supplements?



Walk into a store, and you will find bottles of pills and herbal preparations that claim to "support immunity" or otherwise boost the health of your immune system.

Although some preparations have been found to alter some components of immune function, thus far there is no evidence that they actually bolster immunity to the point where you are better protected against infection and disease. Demonstrating whether an herb — or any substance, for that matter — can enhance immunity is, as yet, a highly complicated matter.

Scientists don't know, for example, whether an herb that seems to raise the levels of antibodies in the blood is actually doing anything beneficial for overall immunity.

### Stress and Immune Function

Modern medicine has come to appreciate the closely linked relationship of mind and body. A wide variety of maladies, including stomach upset, hives, and even heart disease, are linked to the effects of emotional stress. Despite the challenges, scientists are actively studying the relationship between stress and immune function.

For one thing, stress is difficult to define. What may appear to be a stressful situation for one person is not for another. When people are exposed to situations they regard as stressful, it is difficult for them to measure how much stress they feel, and difficult for the scientist to know if a person's subjective impression of the amount of stress is accurate. The scientist can only measure things that may reflect stress, such as the number of times the heart beats each minute, but such measures also may reflect other factors.

Most scientists studying the relationship of stress and immune function, however, do not study a sudden, short-lived stressor; rather, they try to study more constant and frequent stressors known as chronic stress, such as that caused by relationships with family, friends, and co-workers, or sustained challenges to perform well at one's work. Some scientists are investigating whether ongoing stress takes a toll on the immune system.

But it is hard to perform what scientists call "controlled experiments" in human beings. In a controlled experiment, the scientist can change one and only one factor, such as the amount of a particular chemical, and then measure the effect of that change on some other measurable phenomenon, such as the amount of antibodies produced by a particular type of immune system cell when it is exposed to the chemical. In a living animal, and especially in a human being, that kind of control is just not possible, since there are so many other things happening to the animal or person at the time that measurements are being taken.

Despite these inevitable difficulties in measuring the relationship of stress to immunity, scientists are making progress.

### Does Being Cold Give you a Weak Immune System?

Almost every mother has said it: "Wear a jacket or you'll catch a cold!" Is she right? So far, researchers who are studying this question think that normal exposure to moderate cold doesn't increase your susceptibility to infection. Most health experts agree that the reason winter is "cold and flu season" is not that people are cold, but that they spend more time indoors, in closer contact with other people who can pass on their germs.

But researchers remain interested in this question in different populations. Some experiments with mice suggest that cold exposure might reduce the ability to cope with infection. But what about humans? Scientists have dunked people in cold water and made others sit nude in subfreezing temperatures. They've studied people who lived in Antarctica and those on expeditions in the Canadian Rockies. The results have been mixed. For example, researchers documented an increase in upper respiratory infections in competitive cross-country skiers who exercise vigorously in the cold, but whether these infections are due to the cold or other factors — such as the intense exercise or the dryness of the air — is not known.

A group of Canadian researchers that has reviewed hundreds of medical studies on the subject and conducted some of its own research concludes that there's no need to worry about moderate cold exposure — it has no detrimental effect on the human immune system. Should you bundle up when it's cold outside? The answer is "yes" if you're uncomfortable, or if you're going to be outdoors for an extended period where such problems as frostbite and hypothermia are a risk. But don't worry about immunity.

### **Exercise: Good or Bad for Immunity?**

Regular exercise\* is one of the pillars of healthy living. It improves cardiovascular health, lowers blood pressure, helps control body weight, and protects against a variety of diseases. But does it help to boost your immune system naturally and keep it healthy? Just like a healthy diet, exercise can contribute to general good health and therefore to a healthy immune system. It may contribute even more directly by promoting good circulation, which allows the cells and substances of the immune system to move through the body freely and do their job efficiently.

Some scientists are trying to take the next step to determine whether exercise directly affects a person's susceptibility to infection. For example, some researchers are looking at whether extreme amounts of intensive exercise can cause athletes to get sick more often or somehow impairs their immune function. To do this sort of research, exercise scientists typically ask athletes to exercise intensively; the scientists test their blood and urine before and after the exercise to detect any changes in immune system components. While some changes have been recorded, immunologists do not yet know what these changes mean in terms of human immune response.

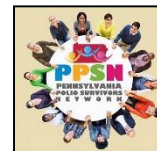
But these subjects are elite athletes undergoing intense physical exertion. What about moderate exercise for average people? Does it help keep the immune system healthy? For now, even though a direct beneficial link hasn't been established, it's reasonable to consider moderate regular exercise to be a beneficial arrow in the quiver of healthy living, a potentially important means for keeping your immune system healthy along with the rest of your body.

One approach that could help researchers get more complete answers about whether lifestyle factors such as exercise help improve immunity takes advantage of the sequencing of the human genome. This opportunity for research based on updated biomedical technology can be employed to give a more complete answer to this and similar questions about the immune system. For example, microarrays or "gene chips" based on the human genome allow scientists to look simultaneously at how thousands of gene sequences are turned on or off in response to specific physiological conditions — for example, blood cells from athletes before and after exercise. Researchers hope to use these tools to analyze patterns in order to better understand how the many pathways involved act at once.

**\*Note:** The word “exercise” has a different meaning for every Polio survivor. Talk to your physician.  
<https://www.health.harvard.edu/staying-healthy/how-to-boost-your-immune-system>



## **The Polio Survivor's Network. How We Began Our Mission of Service**



My post-polio journey was long, painful and truly confusing. Happily, in the fall of 2013, I was finally “there”. Polio was no longer defining my life. I am a Summer Grippe kid (often referred to as “non-paralytic”) polio survivor with PPS. Had I discovered the limitations that came with disability? Yes. Had I discovered new and pain-free abilities? Yes.

I had been given the gift of understanding what was happening and complete acceptance of my new limitations. I was a Polio survivor who was truly thriving. With that, came a new kind of energy.

For two years I had been writing the fascinating, joyful, painful and truly memorable survivor stories of my friends. Although active in my support group, my new energy was looking for more. I knew without question that in the end, I had been truly blessed in my care. I read every PHI newsletter from cover to cover and in early spring 2014, discovered the International Conference

soon to be held in St. Louis. I told my husband I wanted to go. He responded “you can’t travel alone”. Poor guy, I will never forget the look on his face as he dropped me off at Philadelphia airport on my bright red scooter, suitcase under my feet. From that moment, my life changed.

There was kindness everywhere I turned in the form of smiles, patience and people willing to help. Although nervous when I arrived at the conference location, I was excited as well. I was thrilled my daughter in law was joining me and that I could engage her in my “new” world. She is curious, loving, funny and kind and was the perfect companion, attending sessions one after another for two days.

The first night, while waiting outside the dining room, I met a kind gentleman, also from PA. As I was sitting and he was standing, I could not read the MD next to his name - Bill DeMayo. Little did I know he was a rehabilitative physician, one of the featured professional speakers for the weekend and an incredibly nice man. There at dinner, was [Daniel J. Wilson, PhD](#). who I had met years before, and whose advice was significant in my complex diagnosis.

The next day, when I heard [William M. DeMayo, MD](#) speak I was fascinated. His integrative treatment program for Polio survivors had the same philosophy as the one I had successfully completed in Englewood, NJ. I met, listened to, laughed with and learned so much from so many amazing people that weekend; my head was spinning. While on the flight home, I focused on how truly blessed I had been and I knew my life had changed forever. I finally found a place for my newly found energy.

While in St. Louis, I had met outstanding professionals from all over the world and fellow survivors who had become leaders in the area of post-polio support in their various states. I knew from my own experience and from the stories I had the opportunity to write, that Pennsylvania seemed to be behind other states regarding information about post-polio diagnosis and care. At that time, there were four active support groups in our state. Information for them to share was cumbersome to accumulate and had to be gathered from numerous places. Everyone was struggling with interesting and credible programing to bring survivors to meetings.

Gathering a supportive “team” became a necessity. My ever supportive husband and two close friends were my sounding board for some great (and not so great) ideas. One, who is filled with wisdom, was interested in the topic because of her love for me and for her brother who is also a survivor. The third in our initial journey was a man I met in the local support group. Paralyzed from the neck down at age 2, his journey with Polio was one that I could not imagine. His sense of humor and ability to be very “grounding” all at the same time were the perfect combination. Over the next few months, I learned how to launch a website, use Facebook and call complete strangers for advice. Our total financial investment was the \$90 we had spent for the website.

November 2014 we were ready to go. We were devoted to our mission statement: “To Be in Service Providing Information to all Polio Survivors, Post-Polio Support Groups, Survivor's Families and their Caregivers.” Our website put information from multiple credible sources in one place. Prior to launching the website, we asked every contributor for their permission to publish their work. I will never forget the response from PHI Director Joan Headley. As was typical of her work, she not only read every article but found more than one typo! I was truly grateful for her attention to detail. The idea of “[Bruno Bytes](#)” was born and our first month’s publication was uploaded. At the same time, we were truly naive as to the power of the internet.

More than four years later, our mission of service is more intact than ever. Our team has grown to be what we call a “joyful rag tag bunch” of nine volunteers. (Deb, Joe, Jim and I are survivors who are geographically spread throughout PA). We serve ALL Polio survivors regardless of where they are and charge no dues. We are funded solely on and grateful for *all* [donations](#).

- Our [newsletter](#) is published each month, all over the US and abroad, for no charge (by email). We publish in both regular and large print formats.
- Our [website](#) is updated regularly. The biographies of our regular contributors are clearly visible with a simple “click” on their name (when highlighted in red).

- With the help and support of our amazing professional contributors, we launched an updated [Anesthesia Warning /PPS Symptom Card](#). At the advice of Dr. William DeMayo, MD the information is easily maintained and accessed through a “scan code” on the card.
- At the request of survivors, we have published a [PPS Symptom Checklist](#) to share with our families and health care professionals.
- We have hosted/sponsored two conferences and a worldwide webcast. We have published the videos, thus allowing the information to be shared with all Polio survivors.
- We have communicated with and introduced ourselves to every hospital, senior residence community, neurologist, home health care agency and oral surgeon in the State of Pa.
- April is now “[Polio Awareness Month](#)”, passed unanimously by our Pa. State Representatives. Each year, we launch a new “initiative” during that month.
- We have become active on the Immunization Coalition for our State. (Two of us attended as exhibitors and speakers at the Pa. State Immunization Conference).
- We have actively engaged with [Rotary International](#), whose mission of “Service Above Self” has made it their goal (in partnership with the GPEI) to eradicate Polio. We personally visited their headquarters in Evanston, Illinois and presented a gift of gratitude from Polio survivors all over the world.
- “[Team Survivor](#)” (quite simply a means by which survivors and our families can become part of the solution) has raised enough funds to vaccinate more than 32,000 children in the most war torn areas of the world.
- We happily do presentations about the “Polio Truths” throughout the State of Pa. In 2018, we did 30+ events.
- We actively engage in the Senior Health Fairs (sponsored by our Representatives) held throughout Pa.
- In 2018, we partnered with Dr. Richard Bruno, HD, PhD, the Director of the International Center for Polio Education to edit and publish the [Encyclopedia of Polio and PPS](#). This publication contains all of Dr. Bruno’s newly updated articles (including Research articles), Bruno Bytes and videos. In addition, we have created an Index (by Subject) with more than 1,000 entries. The entries are updated regularly in a joint effort with Dr. Bruno and our volunteer team.
- We have hosted two events in the Pittsburgh area (home of the Salk vaccine). The positive press in that area resulted in a significant number of survivors and their caregivers being able to gather and renew with one another.
- Everything we publish is applicable to ALL Polio survivors and caregivers, not just those in Pennsylvania.
- We are grateful beyond words for the regular contribution(s) of our professional contributors (listed alphabetically) Richard L. Bruno, HD, PhD, William M. DeMayo, MD, Post-Polio Health International, Rotary International and Professor Daniel J. Wilson, PhD. The full list of our professional contributors is on our [website](#).

In December of 2014, we made the decision that we would continue to be active as long as it is necessary. It is our dream that post-polio care will become “main stream” for health care professionals and survivors. Until that happens, and as we venture into a new year, we are focused on answering the question from [PHI](#) Director Brian Tiburzi when he asked us to write this article. “What motivates your group to continue?”

- We are blessed to be able to work with amazing professionals who truly care about Polio survivors and the long term effects (both mental and physical) of the Polio virus. The opportunity to read and publish their work on a regular basis is something we will never take for granted and want to continue.
- The positive response from health care professionals when we talk about the “Polio Truths” has motivated us as well. When we do presentations, we encourage their questions and concerns.

We are grateful for their wanting to attend and be open to ideas. Ideas such as “non-paralytic” Polio being able to result in PPS, the reality of there being survivors seeking care who are not “aged” and “Yes”, PPS does exist. We talk about how credentialed our professional contributors are – referring to the easy access through our website to *their* biographies/websites.

- The “hits” on our website continually grow when we distribute the Polio Awareness image that encourages Polio vaccination. This image has a direct “scan” link to the Rotary International video: [Why Zero Matters](#), which is a film that explains just how easily the virus could return to all countries who are now Polio “Free”.

Most of all, it is the positive response from Polio survivors all over the US and abroad to our work that has been humbling and truly inspiring. The four survivors on our team see the effects of Polio as something that we “have” but not something that will continue to define us. The non-survivors, truly wonderful family and friends on our volunteer team, are focused on our energy not on our disability. That combination has resulted in what we believe to be a positive and encouraging message when discussing the reality of the very painful and difficult effects of Polio.

Carol Ferguson and the entire [Polio Network Team](#)



Joe Randig – all ready for the Western PA. “Live” Post-Polio Care event. Conference Photos below presentation videos.



Carol Ferguson and Deb Stambaugh exhibiting at the Pa. State Immunization Conference.



Jim Smith and Carol Ferguson at the “[Race to Zero](#)” (Purple Pinkie) to raise funds for Polio Eradication. ([Slide Show of photos](#)).



Deb Stambaugh exhibiting at a Senior Health Fair in Central PA

## Bladder Basics in Polio Survivors

[William M. DeMayo, MD](#)

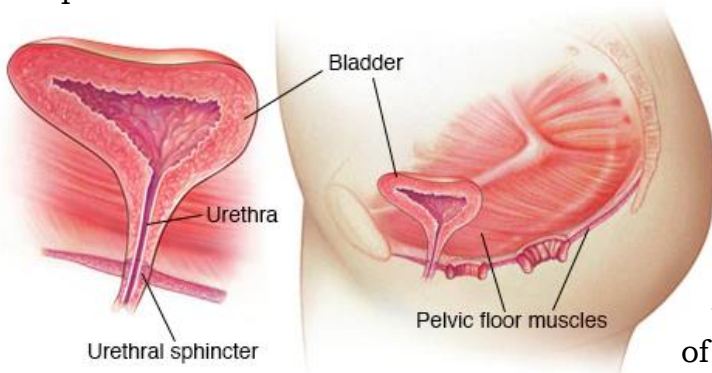
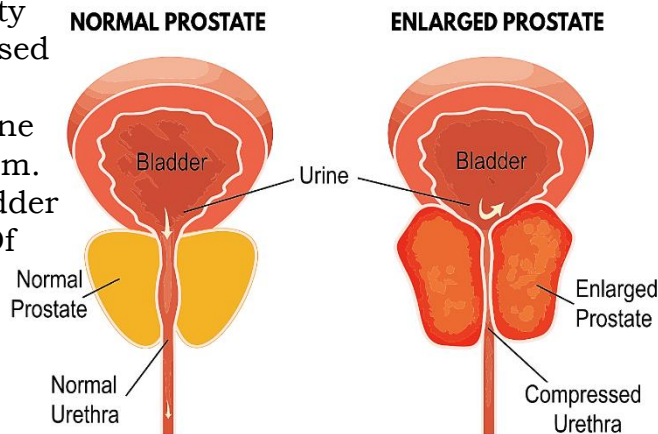
DeMayo's Q&A Clinic

*Dr. DeMayo, I have PPS. In the last few years I have experienced bladder issues. I have urine retention. On a recent CT Scan, It showed pelvic muscle atrophy. Is there a connection with Bladder problems and Polio? Were Pelvic muscles effected by the virus?*

Great Question! Unfortunately, there is not a great, short answer. Nevertheless, like most good questions, there is an opportunity to use this as a learning opportunity.

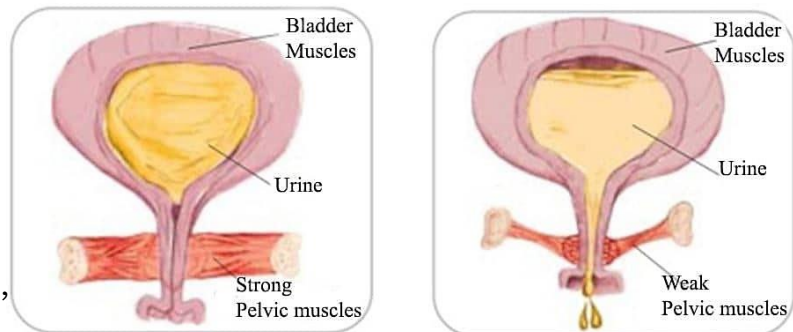
First a few basics...

- 1) The first Basic Bladder issue is that bladder issues in men are far different then in women. As the question above was forwarded to me, I don't know which gender it came from. By far, the most common source of urine retention (inability to empty the bladder) is obstruction of outflow caused by the prostate in men. PPS itself does not cause urine retention in the bladder. Having said that, one needs to be sure that retention is in fact the problem. This is usually done with an ultrasound of the bladder after a void to see if to much urine still remains. Of note, frequent urine incontinence (inability to control urine / wetting one's self) can be either due to urine retention with "overflow" leakage OR due to a lack of resistance to flow. The latter is far more common in PPS due to weakening of the pelvic floor as discussed below.



Also, incontinence is for more common in women compared to men due to multiple factors including a shorter urethra (the tube connecting the bladder to the outside), the urethra having less of a bend (especially when the pelvic floor drops), and lack of resistance of the prostate. Additionally, the bladder storage capacity in women tends to be smaller (partly due to presence of the uterus).

- 2) The second Basic Bladder issue is that neurological issues can have a major impact on urologic function. The bladder can become either over active or one can loose the awareness of bladder filling. Coordinated control of the bladder storage and emptying requires the interaction of muscles in the bladder wall, nerves from the bladder to the spinal cord, reflexes coordinated within the spinal cord and control from the brain (both with conscious awareness and without). Stroke, Brain Injury, Spinal Cord Injury, Multiple Sclerosis and many other neurological conditions can result in incontinence due to what is termed an "upper motor neuron bladder". Since Polio is a lower motor



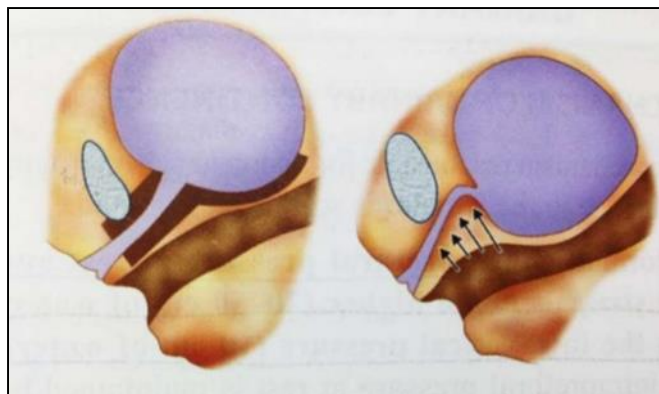
**Weak pelvic muscles causes poor bladder control and Urinary Incontinence**

(continued . . .)



neuron problem, we won't discuss these more other than to say that Polio patients are not immune from any of the above conditions so they should always be considered. Also, the normal aging process can create a "hyper reflexive bladder" that can mimic an upper motor neuron problem.

- 3) The Bladder Basic that is most pertinent to Polio survivors is that the pelvic floor muscles play a profound role in bladder function. Any older individual is subject to this issue but those who have restricted mobility or a prior reason to have pelvic floor weakness are certainly more at risk. "Stress Incontinence" results when a cough, a laugh or a sneeze increases the pressure in the abdomen and thereby increases pressure on the bladder. It occurs when the resistance to outflow is low and this is especially the case in women. Polio can certainly cause weakness in the pelvic floor muscles and this weakness can progress in cases of PPS.



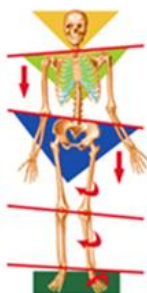
Additionally, a history of child birth, recent sedentary lifestyle and weight gain can all add to relative weakness of the pelvic floor. Weak pelvic floor muscles are directly associated with less resistance to outflow. They play an important role in supporting the bladder, directly tightening the area around the urethra as well as creating a "kinking" effect with cough, sneeze or other activity which further increases resistance.

- 4) The last Bladder Basic is that many times bladder management is NOT Basic. Urine infection, bladder / kidney stones, stress, physical activities, behavioral concerns and many other issues can significantly impact bladder function. As such, all significant symptoms that do not resolve, should be evaluated. Referral to a urologist should always be considered if symptoms fail to resolve with treatment by a PCP.

Additionally, some Physical Therapists specialize in Pelvic Floor therapy. They can often be found through your urologist, [PM&R](#) physician or GYN. Like any muscle, the pelvic floor can be over fatigued and so treatment of a patient with PPS should be individualized and not focused on just intensive pelvic floor strengthening. A good PT specializing in this area can often provide lots of tips to improve symptoms. An example would be an older person who repeatedly has incontinence on the way to the bathroom. By the time they realize the bladder is full they risk an accident because the act of moving from sit to stand causes a reflex spasm of the bladder and the pelvic floor is not strong enough to resist this. Thankfully, there is an opposing reflex that inhibits the bladder (briefly) after 3 strong but quick contractions of the pelvic floor (Kegel type contraction). Thus, if this person takes 10 seconds to do these 3 contractions prior to standing, they can sometimes counteract the reflex bladder activity just long enough to get to the toilet.

A full explanation of bladder management is obviously well beyond the scope of this brief article. At the same time, I hope I have provided some insight into the way some bladder issues arise and provided hope that there are solutions. Warm Wishes.

[William M. DeMayo, MD](#)



Rehabilitative Physician, Dr. William DeMayo has written an enormous number of outstanding articles about issues facing Polio Survivors. They are all easily downloaded for printing and sharing. You can see the full collection and watch his video presentation on our [Website](#).

What is a Physical Medicine and Rehabilitative Physician (Physiatrist) ?

Check it out [HERE](#)

Just for fun.



**What do you get when you cross a four-leaf clover with poison ivy?**

A rash of good luck on St. Patrick's Day.

**Why shouldn't you iron a four-leaf clover?**

You might press your luck!

**What's Irish and stays out all night?**

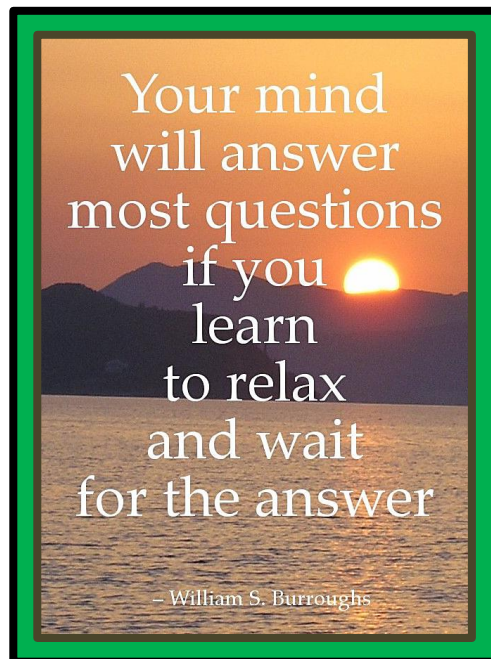
Paddy O'Furniture.



**We are truly grateful for your kind words of support**

Your generous [donations](#) are the key to helping our work continue.

Thank you survivor Jim Smith for this wonderful quote from William S. Burroughs.



**MARCH**



Always feel free to contact us.

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