



Polio Survivors Serving Others

Information & Inspiration
For All Polio Survivors and Their Families

The PA Polio Network

www.polionetwork.org

January 2024

Our Mission:

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

Inside this Issue:

It's a New Year . . . With New Resolutions: We're bringing up an old subject – Exercise.

As we enter our 10th year of service to Polio Survivors and their families, this topic is definitely in the top three. Rehabilitative Physician, [Carol Vandenakker Albanese, MD](#) wrote an outstanding article for Post-Polio Health International - Exercise Guidelines for Polio Survivors. We loved this quote: “You understand your body better than anybody else, so when you're working with a therapist or a trainer or talking to your PCP, don't be afraid to speak up and say, ‘Hey, I just can't do that’ or ‘That hurts to do that.’ “ Thank you PHI for giving us permission to publish it here.

“Life is like a river. Sometimes it sweeps you gently along, and sometimes the rapids come out of nowhere.” This quote by Emma Smith is how Theresa Wilbank begins her talk on the topic of Sustainable Caregiving. PHI ended their 2023 Town Hall series with this thoughtful presentation.

The Eradication of Polio . . . It's what we ALL want.

- The Global Polio Eradication Initiative (GPEI) has given us a brief review of 2023 and outlines their goals for 2024. We've heard a lot about the new oral polio vaccine (nOPV2), but they've given a statistic that's almost too big to grasp. A BILLION doses of the new vaccine have been administered since WHO gave it the Emergency Use Authorization in the fall of 2020.
- Team Survivor 2023. We ARE a part of the solution.

Welcome William Montgomery to our Professional Advisory Team.

A Licensed Marriage and Family Therapist (LMFT), he has been supportive of our work since we began in 2014, often providing us with interesting articles. Known as “Bill”, he has a strong interest in not only mental health, but also physical, and spiritual health.

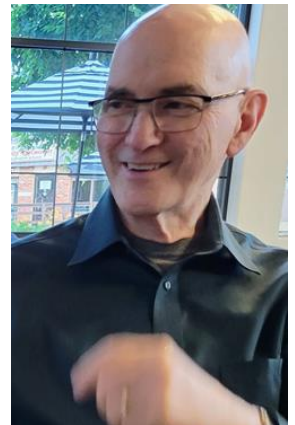
Bill began his career in engineering, with advanced degrees and a leaning towards the biomedical field. He began his path at Bell Labs, then his own consulting practice, and Dean of a Graduate School before deciding to be a therapist. He has been licensed in and practicing Marriage and Family Therapy for more than 20 years.

His interest in Post-Polio and our Polio Network, stems in part from his wife Loretta, a talented artist and curious learner who had a run-in with polio as a child.

Bill will be addressing questions and issues that arise from our readers. As he provides suggestions on dealing with issues, he hopes to provide insight and understanding of the importance of recognizing one's inner world and feelings that occur. He points out that Awareness is the first step of understanding the inner world of our Emotions, which are so strong in influencing our lives.

His book, “Become Closer” focuses on the importance of understanding one's self in order to have closer relationships.

This article: “Being Seen Only as My Disability” comes from a question sent by a survivor who struggles with wanting to be seen as a loving, caring woman who is more than “just” her struggle with the late effects of Polio.



Being Seen Only As My Disability

Counseling Corner with William Montgomery, MFT

Question: My sister has never been able to see me as anything other than my disability. She takes every conversation we have back to what I “can’t” do vs what I can. Every comment she makes, every gift she gives relates to “helping” me. After years of suffering, I have learned to accept my limitations and am enjoying life with my friends, children and grandchildren. How can I respond to someone that only sees polio affected limbs when they think of me?

Bill Montgomery’s Response: To not be seen for all you are is certainly frustrating. On one hand, you know that your sister is caring and probably means well. On the other hand, her treating you in ways that do not recognize all of you is frustrating and probably hurtful.

What to do? Let's begin by recognizing that this pattern of hers may go way back to your childhood together, and that she feels a need to help. For you today, however, you want to be treated as at equal in your own right. You probably want to be seen as the determined, devoted, family oriented person you are, who has purpose and more. Not knowing you or her, I can only provide suggestions. Perhaps you have already tried each of these. Nonetheless, I suggest you try again, and that you are as clear and calm in talking with her as possible, so she has the best chance of actually hearing you.

First, I suggest that you ask her to sit with you for a few minutes to talk. Then tell her your intention of talking, which is probably that you simply want her to hear you; and to understand. Also tell her what you appreciate, which is probably:

- That you do appreciate her caring and thinking of you.
- Then explain that you want to be seen as a regular person and appreciated for who you really are.
- She may push back, saying she does, indeed, see you, all of you. Tell her that she may think she honors the real you, but that is not how you hear it. No arguing here. It is simply not how you hear it.
- Perhaps hold hands as you talk. Also, in the future, if she begins to fall into the negative side at some point, can you simply say, “Sis, please be careful here”.

The most important point here is that you own your perceptions, your feelings. In other words, she may not mean or intend what you are perceiving, but you do experience feeling treated ‘less than’ (or whatever your feelings are). You have to own that you feel that way. Point out to her that she may not mean it, but you feel it. This is not only ‘your truth’, but also avoids, hopefully, her thinking that you are calling her a ‘bad’ person, or that you are attacking her. By having her understand that you feel unseen or diminished, you can have shorter and kinder conversations with her in the future as you kindly, firmly, say “stop”.

Finally, if she cannot stop, or reduce her behavior much, work on accepting . . . and at least in part . . . that she has some strong need, and that she may well see all of you, yet, she has a strong need to help where she can.

All the best, Bill Montgomery

Do you have a question for Bill Montgomery? Email us: info@polionetwork.org



Post-Polio Health International presented their final Town Hall in their 2023 [Lecture Series](#).

Their latest presentation “Sustainable Caregiving” features Theresa Wilbanks. A writer, speaker, podcast host and Certified Caregiving Consultant, she is the founder of Sustainable Caregiving. She is the author of Navigating the Caregiver River: A Journey to Sustainable Caregiving.

We are happy to be able to share this entire series in the [Living with Post-Polio Syndrome](#) section of our website.

**You can easily find this series in the Index under these topics:

“Post-Polio Health International” (or) “Video” **

www.polionetwork.org/living-with-post-polio-syndrome



www.youtube.com/watch?v=eN8zQ9JDDXo

Carol Vandenakker Albanese, MD,
University of California, Davis, Department of Physical Medicine & Rehabilitation

“I’m sure most of you have heard that exercise can be dangerous to a polio survivor. You’ve heard things like ‘use it or lose it,’ that muscle strengthening contributes to overuse, that if you are feeling muscle pain, then you’re burning out motor neurons, or that you can’t do strenuous exercise. And some of that is true. There are reasons those things were perpetuated, but they’re not exactly true. The truth is that there are just as many or more dangers of not exercising as of exercising. Let’s explore some different types of exercise and how to determine what’s right for you.

Dangers of Inactivity

Let’s start with some of the dangers of not doing exercise, or inactivity. For everybody, polio survivor or not, if you are not engaging in much activity, are immobilized for some reason, or are stuck in bed for an illness or injury, deconditioning occurs. That means muscles atrophy and get weaker. It’s most pronounced in muscles that are our primary postural muscles—the spinous, paraspinals and lower limbs. Those are the muscles we normally use to work against gravity. For somebody on strict bed rest, studies have shown that muscles lose 10 to 15 percent of their original strength per week of bed rest. Over five weeks, that can add up to 50 percent. Of course, strict bed rest isn’t often used anymore.

For most medical conditions, we try to keep people as mobile as possible, so the amount of weakening that happens when you have limited activity is a lower percentage of what we see with strict bed rest. When people aren’t moving, they can also get connective tissue or soft tissue contractures where joints stop moving as well and may lose bone strength or bone density.

Health Benefits of Exercise

A major health benefit of exercise is, of course, improved cardiovascular health. Inactivity is a major risk factor for the development of cardiovascular disease, and it works in secondary prevention as far as reducing mortality for people with cardiac disease. If you go through cardiac rehabilitation programs, you can reduce the impact of whatever disease is present. Exercise helps to decrease blood pressure, decrease triglycerides and bad cholesterol, increase good cholesterol, and reduce the risk of blood clots, which can lead to other medical issues.

How much exercise do you need?

The answer to this very much depends on the individual, and, especially for someone who’s had polio, there are a lot of factors to consider. Before starting an exercise program, I recommend getting a medical evaluation. If you’re over the age of 35, the rule of thumb is that you should be exercising about 30 minutes per day. Now, this is not necessarily true for polio survivors because exercise is really just on the gradient of activity - normal daily activities versus what is done for exercise. Depending on what your day-to-day activity looks like, you may or may not need to do a lot of additional exercise. This is especially true in a polio survivor who is still ambulatory and who may have a fair amount of deficits, so that actually just walking in your day-to-day life is basically the energy equivalent of exercise for somebody who doesn’t have physical impairments. Sometimes exercise is really just increasing the activity you do in a day.

The benefits are dose-related up to a point. That means that there is a ceiling effect, and at some point, more exercise is not better. Exercise is also dependent on long-term compliance, meaning doing exercise today won’t necessarily benefit a person next year. It has to be part of a lifestyle balance and having energy for exercise or day-to-day activity versus just maintaining your life and a level of function.

Exercise Components

Below we’ll examine four main components of exercise:

- Aerobic Conditioning
- Strengthening
- Flexibility
- Coordination

Aerobic Conditioning

Aerobic conditioning is what you may think of as cardiovascular exercise. It is a lower-intensity long-duration type of activity - an activity you can continue to do over a period of time, not a sprint that you can only do for a very short period. When you’re conditioned, it’s a type of exercise you can do that won’t overly fatigue you or produce

continued . . .

a lot of painful byproducts in your system and can be maintained for long periods of time.

When we talk about prescribing aerobic conditioning, we talk about activities that are more than a resting effort but of submaximal intensity, can be done repetitively, and incorporate as many muscles as possible. The perceived exertion should be in the range somewhere between fairly light to moderate. The general recommendation is that aerobic conditioning is done for at least 20 minutes, at least three times per week, but this may be different for a polio survivor.

When you're thinking about doing aerobic exercise, you should use your strongest muscle groups as much as possible. Those are the ones that should be used for any repetitive activity. You also must be careful that whatever exercise you choose to do does not increase stress on weak muscles or overstressed or unstable joints.

Often, you should consider doing a non-weight bearing mode of exercise. My recommendation is that you start well below the suggested intensity. You can increase the amount of time spent exercising by using rest intervals or pacing. Any progression in exercise should be very gradual to prevent injuries or excessive muscle soreness, and you should always monitor for symptoms of overuse.

Strengthening

Strengthening exercises increase the strength of not just muscles but ligaments, tendons, connective tissue and bones by providing stress to and increasing demand on those structures. It increases the strength of the tissue but does so by causing some breakdown of tissue which then remodels and regrows stronger. It is very easy with strengthening exercises to overdo and overstress. If you overwork and those tissues are not able to regenerate, reform and become stronger, it will result in deterioration, weakening and injuries.

This type of exercise carries more risk than your basic cardiovascular exercise, so it should be individualized. But if you're going to do a strengthening program, how do you know which muscles you should be targeting? For all of us as we get older, and especially for a polio survivor, you want to pay the most attention to muscles that are functionally important. This is where a physical therapist may be helpful in helping you decide what you need to work on. As always, you should start with less than the recommended amount and be very careful about how much you increase that amount.

Polio survivors should set very specific goals for functional gains. You're not working on strengthening the muscle just because it's weak. If a muscle is so weak that it's not helping you functionally and doesn't have the potential to become functional, then you don't need to work on strengthening it.

You really want to be aware of which muscles are at risk of overuse and which joints are at risk of too much stress lest you exacerbate degeneration in the joint. Polio-affected muscles are going to require longer rest periods to recover between strengthening sessions. Again, you need to be very diligent about monitoring for overuse and making sure you adjust those rest periods if you do see symptoms of overuse.

Flexibility

This type of exercise is concerned with the pliability or elasticity of muscles, connective tissues, tendons and ligaments. To maximize a muscle's function, we want an ideal range of flexibility. We don't want the muscle to be too stiff, but we also don't want it too lax. When people are put on stretching or flexibility programs, the goal is to restore or maintain the full range of motion of a joint. Identifying restrictions in motion that may function or stress other tissues is important in determining how much stretching you need. If connective tissue isn't regularly stretched, it will gradually shorten, especially as you get older.

Genetics, gender, age and temperature can all affect flexibility. Excess flexibility is not necessarily beneficial and can actually put joints at risk. Flexibility is especially important for polio survivors, who have muscle function around a joint where one group of muscles that move the joint is stronger than another. Often when you see this muscle imbalance around a joint, the stronger side will tend to shorten or tighten up because it's not adequately opposed by the opposite action.

For polio survivors with stretching, we don't worry about muscle overuse, but we do worry about muscle damage. Static stretching is the safest method for polio survivors. You typically want to warm up a muscle before stretching to get the best results. If it's a muscle that's hard to warm up, warm water or a warm bath can help. Bear in mind, especially for those of you who had surgeries, bony changes, joint changes, or fusion of joints may be contributing to loss of motion. So, if something just isn't moving, don't force it because that could result in a fracture. If you have a very relaxed joint, you don't want to stretch around that joint because you can do more damage to the joint.

Coordination and Balance

This is exercise geared toward improving proprioception or awareness of the position and movement of body parts. In general, polio survivors have very good proprioception and may be more aware of body movements than the average person. However, the body's response can change as one gets older and develops arthritis, loses range of motion, or develops neuropathies that involve losing some sensation, which makes maintaining coordination and balance a lot harder.

There are certain exercises geared toward improving balance which focus on the postural muscles, which contribute to maintaining balance. Sometimes using external stimuli for proprioceptive feedback can be helpful when engaging in this type of exercise.

Symptoms of Overuse

What are some signs of overuse you should be looking for? Any fatigue that lasts more than a few hours after the activity likely signals you're doing too much. If you're doing an exercise program, you should be able to go home, rest, and a few hours later feel back to normal and not feel wiped out for the rest of the day. If you feel weaker after the activity or if you can do less later that day or the next day, that's a bad sign. If the muscles are painful, that's overstretching and breaking down tissue. If you have a sensation of muscles cramping, twitching or crawling, that's another sign of overuse. Sometimes these overuse symptoms don't come on the same day.

*“You understand your body better than anybody else,
so when you're working with a therapist or a trainer or talking to your PCP,
don't be afraid to speak up and say, 'Hey, I just can't do that' or 'That hurts to do that.'”*

Carol Vandenakker Albanese, MD

If you are starting out on an exercise program, it may be a good idea to journal your activities as well as their symptoms to look for patterns, as sometimes, when the result of an activity doesn't show up until several days later, you may not remember what you did that may have overstressed a certain muscle group.

Additional Advice for Polio Survivors

In general, low-impact, gentle exercise is best tolerated. This is true for most people as they get older. This is why we often talk about using aquatic exercise, Tai Chi or adapted yoga—exercise that really doesn't have a lot of impact involved. You understand your body better than anybody else, so when you're working with a therapist or a trainer or talking to your PCP, don't be afraid to speak up and say, “Hey, I just can't do that” or “That hurts to do that.” Give feedback and don't let anybody bully you into doing something you know you shouldn't do.

Developing an exercise program will almost always require trial and error. It's a matter of trying something, seeing how your body responds, and going from there. That's why we talk about starting slow and progressing slowly because you don't want to make big errors.

Your exercise needs and tolerance are going to change over time. Things in your body change. What you're able to do mobility-wise changes. What you need to do exercise-wise will change. A good example of that is if you go from being ambulatory a majority of the time to using a wheelchair or a scooter. All of a sudden, you're walking a lot less and may actually need to add some exercise to your daily routine.

Summary

Exercise is not the enemy. It shouldn't hurt, but on the other hand, it's not necessarily easy, either. We want gentle exercise programs, but it is going to be a little bit of work. It has to be very individualized. One of the most unique things about polio is that there's no standard recommendation for a polio survivor because everybody's different.

Getting a medical assessment before starting is important, particularly to make sure your heart and lungs are fine to stress. As far as finding somebody who really knows the ins and outs of polio and what you can and can't do, that can be difficult. It is hard to find somebody with experience, but there are some resources available through PHI (including the Post-Polio Directory which is continuously updated).

There are therapists that are always willing to talk to a therapist you're working with or your physician.

Most importantly, you know your body and you know its signals. Pay attention to that. Exercise performed with the right prescription, instruction and technique can be beneficial and improve function and well-being.”

GPEI – A Brief Review of 2023 and Full Focus on 2024

As the year draws to a close, efforts intensify against the virus in 2024

18/12/2023 – Global Polio Eradication Initiative

“The Global Polio Eradication Initiative has two goals laid out in its [current strategy](#): to interrupt all remaining transmission of endemic wild poliovirus type 1 (WPV1) and to stop all outbreaks of variant poliovirus type 2 (cVDPV2). 2023 was a critical year for progressing on each of these, and while our urgent and diligent work to end polio must continue into 2024, the GPEI achieved incredible things in the past twelve months.

Continuing work in endemic countries

Despite significant geo-political and environmental challenges in the two remaining WPV1-endemic countries, Pakistan and Afghanistan, the polio programme has continued to reach greater numbers of children with polio vaccines.

Wild polio transmission was beaten back to just a handful of districts in eastern Afghanistan and the southern area of Khyber Pakhtunkhwa province in Pakistan. In both countries, efforts are increasingly focused on reaching and vaccinating the last remaining ‘zero dose’ children – children who have received no vaccines of any kind. The number of these missed children continues to dwindle, with the success of improved collaboration with the national immunisation program, new efforts like Pakistan’s [Nomad Vaccination Initiative](#) and focused vaccination activities at border crossings between the two countries. Just one family of the virus remains endemic in each country, and coupled with this increasing geographic restriction, the situation resembles the end of wild polio eradication efforts in former virus hotspots like India, Nigeria and Egypt.

In addition, after a wild poliovirus outbreak that was confirmed in southeast Africa in early 2022, neither Malawi nor Mozambique has reported a WPV case since August 2022 thanks to a concerted sub regional emergency response across five neighbouring countries. We are hopeful that this outbreak will be officially closed in the coming months, affirming that countries have what it takes to protect children from this devastating disease and keep wild polio out of Africa. Of Africa

Progress on variant polio outbreaks

Thanks to the novel oral polio vaccine type 2 (nOPV2), strong political commitment and community-based efforts to reach more children with the vaccine, the number of cases of variant poliovirus type 2 (cVDPV2) [continued](#) to decline in 2023.



nOPV2 Vaccination at Guiding Angel School Tunga, Minna, Niger.
© WHO/AFRO



WHO Representative in Afghanistan, Dr. Luo Dapeng, vaccinating children against measles in a mobile clinic in Baba Wali Village of Kandahar province.
© WHO/Afghanistan

Nearly 1 billion doses of nOPV2, a comparably safe, effective, but more genetically stable version of the existing type 2 oral polio vaccine (mOPV2), have now been administered across 35 countries, protecting millions of children from illness and paralysis.

Emergency response to variant polio outbreaks is continuing, notably in the [most consequential geographies](#) for the programme - where children are at the highest risk of encountering and spreading poliovirus. In northern Nigeria, for example, variant polio cases have fallen by 90% since a peak in 2021, thanks to concerted commitment from government, unique community programs to improve the reach of

vaccines and the extensive rollout of nOPV2. Across these consequential geographies, the programme will continued . . .

continue to focus on increasing access, acceptance and campaign quality, which have helped make incredible progress in Nigeria, and continue to innovate until we end polio for good everywhere.

Finally, In September 2023, after a massive vaccination response in the shadow of ongoing war, Ukraine officially stopped its outbreak of type 2 variant polio that began in 2021. New York, London and Jerusalem, where high-profile outbreaks began in 2022, have not detected the virus in recent months. Still, the emergence of polio in these areas is a reminder that as long as poliovirus exists anywhere, it is a threat to people everywhere.

A global effort

Most importantly, thanks to the efforts of the GPEI and its partners, health workers vaccinated more than 400 million children in 2023, preventing an estimated 650,000 cases of paralysis from polio and saving the lives of up to 60,000 children. Building full, healthy futures was at the core of Rotary International's mission when it began this fight to end polio for good in 1985, and when the GPEI was launched in 1988 - 35 years ago.

This year, the Independent Monitoring Board (IMB) conducted a [rigorous mid-term review](#) of the GPEI's progress towards its strategic goals. This welcome counsel is already helping inform and guide the GPEI's own ongoing analysis and strengthening of its strategic approaches to achieve a polio-free world, as the programme published its [initial response](#) to the mid-term review, under the guidance of the Polio Oversight Board (POB).

Achieving and sustaining a polio-free world has proven harder – and taken longer – than anyone could have imagined. But making history is never easy, and we are confident that together we can eradicate a second human disease from this earth, and build stronger, more resilient health systems along the way. 2023 has firmly set the stage for success. With the complexities of the world today, this programme still inspires to bring about the very best in our humanity.

Thank you to all who have contributed to this effort so far and continue to do so. Let us double down and make the dream of a polio-free world a reality.”

[Article Source](#)



Team Survivor – 2023 **Together, we HAVE Become a Part of the Solution**



In the last seven years, your generous donations to the Rotary Foundation have resulted in the ability of the GPEI to administer more than 118,000 polio vaccines in the most war torn, difficult to reach corners of the world. The best part about these donations, is that none is too small. For every dollar you gave, the Gates Foundation turned it into three.

As this fight drags on, it's easy to get discouraged, but *no one* is giving up. In late 2020, while the entire world was in the fight to stop deaths worldwide from a new virus, the WHO gave an Emergency Use Authorization for the new, oral polio vaccine (nOPV2). In just three years, as we read in the article above, a BILLION doses of that new vaccine have been administered.

We are happy to support the Rotary Foundation (one of the founding partners in the GPEI) in this extraordinary action. They have been leaders in this enormous effort to rid the world of this terrible disease since 1985.

See [Team Survivor](#) on our website for a list of generous contributors.

Tips to help prevent the spread of flu



Get vaccinated



Wash your hands often



Clean & disinfect surfaces



Cover your coughs & sneezes



Avoid touching your face with unwashed hands



Stay home when sick



Flu, Fatigue and Post-Polio Syndrome

By William M. DeMayo, MD

Is it a Cold, Influenza? COVID or Allergies?

Oh My!

By Marny K. Eulberg, MD

The Flu – Don't Ignore It

By Richard L. Bruno, HD, PhD



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