

Pressure Sores Are Painful, but Preventable

Excruciating!” That’s how Rose Marie “Rosie” Benecke describes the pain she experienced from a pressure ulcer she developed on her right buttock early last year. “I’d had them before but was always able to get over them in a few days,” she said. “This time the pain was so bad that the only comfort was to lie down.”

The risk of developing pressure ulcers, also called bedsores or pressure sores, is ever present for people who spend their days in a wheelchair or in bed. They are caused by sitting or lying in one position for too long, which puts pressure on certain areas of the body. This pressure cuts off blood supply to that area and can cause the skin and underlying tissue to die, which leads to the formation of a pressure sore.



“The Most Remarkable Woman I Know”

That’s how Beth Hughes introduced her mother, Rosie Benecke, to Peabody Energy colleagues at the company’s United Way kickoff rally that featured Rosie and Lewis, the service dog she received through Support Dogs Inc., a United Way agency.

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In the earliest stages, the skin looks red and may burn, hurt or itch, but remains intact. As the pressure sore develops, the skin breaks open and looks like an abrasion or a blister. As the sore worsens and extends beneath the skin surface, it takes on a crater-like appearance as the wound deepens. In the fourth and most serious stage, severe damage to deeper tissues may affect muscles, bones, tendons and joints. Risk of infection increases, and serious complications such as osteomyelitis (bone infection) or sepsis (infection carried through the blood) can occur.

Rosie said she regularly uses A+D® ointment, which contains lanolin, to moisturize her skin, but because of the pain, she began applying Neosporin® + Pain Relief ointment to the pressure sore. Her husband fashioned a foam rubber cushion, cutting a hole out for the affected area, and a wheelchair-user friend loaned her a Roho® seat cushion, but it proved unwieldy to

use. She realized that she needed a long-term solution.

Both her internist and a plastic surgeon confirmed that the sore was in an early stage and appeared to be improving. Anxious to speed the healing process and avoid future painful episodes, Rosie saw a physiatrist who recommended she contact United Seating and Mobility, a company offering a variety of products and services to wheelchair users.

“They recommended a Quadtro® Roho cushion [a cushion with a “memory” that adjusts itself when the user shifts positions] that I use in my power chair, but it was too squishy for my manual chair when transferring,” she said. “I don’t use the power chair in the house – it’s like driving a tank. Plus the manual chair gives me some arm exercise. A technician came out and did a seating evaluation, and a custom cushion was designed.”

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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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Editor: Gayla Hoffman
editor@post-polio.org

Designer: Sheryl R. Rudy
webmaster@post-polio.org

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How to contact PHI

Executive Director: Joan L. Headley, MS
director@post-polio.org

4207 Lindell Blvd., #110
Saint Louis, MO 63108-2930 USA
Phone: 314-534-0475
Fax: 314-534-5070
info@post-polio.org
www.post-polio.org

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Worthy of Note

We never know what we will find when we open our mail every day. Old friends updating us on their lives and accomplishments, Membership payments, questions for our *Post-Polio Health* and *Ventilator-Assisted Living* columnists, polio survivors, friends and families seeking information – no two days are alike.

Sometimes we learn that we are the beneficiary of a bequest, often from a polio survivor we've known through the years. Occasionally, as happened recently, we had never met the person who generously remembered us in her will.

Mildred Annice "Midge" Smith, 76, of Monroe, Louisiana, had been a Member of Post-Polio Health International for many years. As we learned from her brother Ed Smith, Miss Smith contracted polio when she was in the eighth grade in 1946. She spent a year in an iron lung in a hospital in New Orleans. Her mother moved there with her and volunteered at the hospital. Her father drove from their home in Delhi, Louisiana, 250 miles each way on unimproved roads every weekend to visit them.

"She went from New Orleans to Warm Springs for about a year and came home on crutches," Ed recalls. "The biggest concern was that she'd lost two years of school, but in the way of small towns back then, the teachers got together and agreed to let her stay with her class. She was a smart girl and graduated with her class."

Miss Smith earned a bachelor's degree at Louisiana Tech University and a master's degree at Louisiana State University. She taught child psychology at the University of Arkansas College of Medicine before retiring due to complications from scoliosis and post-polio syndrome. She used a ventilator at night and an Amigo for mobility.

We wish we had known Midge Smith, a lover of classical music. But she has left a legacy that will help Post-Polio Health International fulfill its mission to enhance the lives of polio survivors and home ventilator users through networking, advocacy, research and networking.

An estate gift to Post-Polio Health International can be created through a will or living trust. If you would like more information on how to create your own legacy through a bequest, please contact us at director@post-polio.org, or at 314-534-0475.

Joan L. Headley, Executive Director, PHI

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30 Years Later ... We're Still Here!

Thirty years ago, in October 1981, some 250 health care providers and polio survivors held an international symposium in Chicago to consider this question: **What ever happened to the polio patient?**

Hosted by the Rehabilitation Institute of Chicago and the *Rehabilitation Gazette* (which later became St. Louis-based Post-Polio Health International), sponsors included the March of Dimes, National Easter Seals Society, the Anesthesia Departments of Children's Memorial and Northwest University Hospitals in Chicago, and LIFECARE Services, Inc.

Rehabilitation Gazette founder Gini Laurie had an encyclopedic mind and networked – before it became a buzz word – with a vast community of polio survivors and health care professionals. This she did with no computers, email or Internet connection. For more than 20 years, she and her husband, Joe, had produced publications that chronicled the stories of polio survivors from the 1940s and 1950s.

In the late 1970s, Gini and others involved in health care for polio survivors became aware of new problems that seemed to be related to earlier polio diagnoses. In 1979, the *Rehabilitation Gazette* published a letter from a reader who said, “I find myself being able to do less and less and tire far too easily.” He suggested that the *Gazette*, “which seems to be the last polio link,” solicit names of “simpatico” doctors and publish a national directory for polio survivors to turn to for “genuine and honest advice.”

Letters poured in, and the first international post-polio conference was organized. In a summary of the proceedings of that conference, the editors note “What ever happened to the polio patient? Those survivors – the former generation that pioneered the advances – seem to be ‘prematurely aging,’ and no one really understands why.”

Writing in the August 2011 *Archives of Physical Medicine and Rehabilitation*, Lauro S. Halstead, MD, himself a polio survivor, presents “A Brief History of Post-polio Syndrome in the United States,” that tracks the increased interest in post-polio issues growing out of that first conference and others that were organized almost simultaneously in Oakland, California, and Ontario, Canada.

“At about this time, the term ‘postpolio syndrome’ was introduced, which quickly became the unofficial designation for these new health problems, although many other terms have been used as well including ‘postpoliomyelitis muscular atrophy,’ ‘the late effects of polio,’ and ‘postpolio sequelae.’”

Dr. Halstead notes that in the three decades since that first conference, “many thousands of survivors organized themselves into self-help groups, attended specialized clinics and helped energize a vigorous enterprise of basic and clinical research. More recently, as the population continued to age and the energy and enthusiasm of the early years waned, there has been a decline in published research and the number of clinics and support. Regardless of these trends, there are still thousands of survivors who, more than ever, require expert rehabilitation assistance as they cope with advancing age and declining function.”

For the last 30 years, Post-Polio Health International has focused on its mission to enhance the lives and independence of polio survivors and home ventilator users worldwide through education, advocacy, research and networking.

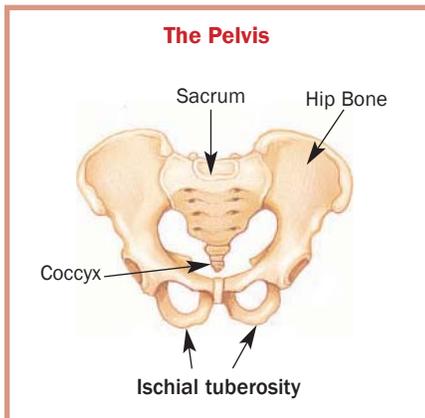
Many post-polio groups around the world can trace their beginnings to attendance at a PHI international conference and attribute their success to the work of PHI. Building on the network Gini Laurie nurtured since 1958 that connected polio survivors around the world, the solutions and achievements PHI has documented inform and motivate others to explore options to also live independently. ▲

Pressure Sores Are Painful, but Preventable

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Jamie Patton was the assistive technology professional who evaluated Rosie's seating for her custom cushion. Certified by the Rehabilitation Engineering and Assistive Technology Society, he is trained to evaluate complex mobility problems.

"Rosie's problem was in transferring laterally," Patton said. "The seating evaluation was accomplished by 'pressure mapping,' using a sensor pad linked to a laptop screen. It measures downward pressure when seated and shows exactly where the 'hot spots' are. These are typically the ischial tuberosity, the two lowest bones in the pelvis, and the coccyx or tailbone. Our solution was a Roho surrounded by a flat cushion that provided stability.



"When someone sits on the sensor pad, we see a dynamic readout on the screen and begin troubleshooting, using different cushions – gel, foam, Roho, etc. – and keep testing until the pressure is relieved and the 'hot spots' disappear," Patton said. "We also teach people

Prevention and Treatment of Pressure Ulcers

Prevention of pressure ulcers is critical because treatment can be difficult. If you spend most of your day in a wheelchair or in bed, you are at risk. Being overweight or underweight and having bladder and/or bowel incontinence also increase your chances of developing a pressure sore, as do having diabetes or a stroke, which may have numbed or decreased sensation in a certain area of your body.

You or your caregiver should check your body daily, looking carefully at areas where pressure ulcers may form – heels and ankles, knees, hips, spine, tailbone area, elbows, shoulders and shoulder blades, back of head and ears.

If you use a wheelchair, make sure it is the right size for you and have your doctor or physical therapist check the fit once or twice a year, particularly if you gain or lose weight or if you feel pressure anywhere. Sit straight and upright and shift your weight in the chair every 15 minutes by leaning forward and moving side to side.

If you transfer yourself, lift your body up with your arms and do not drag yourself. This will prevent "shearing" that removes protective layers of your skin making it more prone to break down. Avoid clothing with thick seams, buttons or zippers that press on your skin. Don't wear clothes that are too tight. Keep clothes from wrinkling or bunching up in areas where there is any pressure on your body.

Maintain a healthy diet and drink plenty of fluids to keep the skin well-hydrated. Don't smoke, and limit caffeine. Both smoking and caffeine cause constriction of the blood vessels, which decreases the blood supply to the healthy body tissues.

Take care of your skin. Use a soft sponge or cloth when bathing and don't scrub hard. Don't use talcum powder or strong soaps and use moisturizers every day. Clean and carefully dry areas beneath your breasts and in your groin. After bladder or bowel movements, clean the area immediately and dry it well. Ask your doctor about creams to help protect the skin.

If you suspect that you are developing a pressure sore, consult your health care provider right away to get specific treatment and care instructions. If the skin is broken, he or she can instruct you on proper cleaning and care to prevent infection as well as recommend special gauze dressings made for pressure sores. Medicines that promote skin healing can also be prescribed. ▲

Sources: U.S. National Library of Medicine, National Institutes of Health; *Journal of the American Medical Association*

how to keep the pressure under control. Unlike people with spinal cord injuries who have a loss of sensation, most polio survivors can feel pressure and shift their weight to redistribute it."

Even though she is still wrangling with Medicare to cover the cost of the custom cushion, Rosie is happy with the solution and has not had any pressure sores since she began using it. ▲

“The Most Remarkable Woman I Know”

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Rosie contracted polio at age 11 in 1951. “I was paralyzed all over,” she recalls. After being hospitalized and on a Monaghan respirator for six months, she came home in a wheelchair, which she’s used ever since. She received a bachelor’s degree in 1962 from Webster University in St. Louis and a master’s degree in special education from the University of Missouri–St. Louis in 1983. After a 40-year career as a special education teacher for the St. Louis Special School District, she retired in 2002. She is married and the mother of two children.

“I have used a ventilator with nasal mask at night since 1990, and I also lie down twice a day and use a vent with a mouthpiece,” she said. “I received my first service dog, Clancy, in 1991. She really increased my independence. She pulled me in my manual chair in and out of the high school where I taught, through shopping malls, grocery stores and any other place I needed to go. She’d help me fold up my chair and pull it into the back seat of the car. She opened doors for me with a door hook and picked up my glasses, pencil, shoes or whatever I dropped.”

Following the deaths of Clancy and Omni, another beloved service dog, Rosie got Lewis in 2009. “Because of post-polio syndrome, I experienced more weakness and could no longer pull my chair in and out of the car, so now I use a power wheelchair from which I can drive my van. Since I have retired from teaching, Lewis doesn’t have to do quite so much for me. Service dogs have increased my independence and added much joy to my life.” ▲



Beth Hughes, senior administrator at Peabody Energy, her mother, Rosie Benecke, and service dog, Lewis, at the company's United Way kickoff in St. Louis' Forest Park.

Photo: Brishen Combs, Obata Design.



PHI Executive Director Networks in Copenhagen

PHI Executive Director Joan L. Headley (right) participated in a panel discussion “Improving Worldwide Networking to Improve the Lives of All Survivors” at a recent conference on **Post-Polio Syndrome – A Challenge for Today** in Copenhagen, Denmark, organized by the Danish Society of Polio and Accident Victims and the European Polio Union. To see photos, PowerPoint presentations, abstracts and posters, go to www.poliocconference.com. Fellow panelists pictured with Joan are Johan Bijttebier of Belgium and Els Symons and Addje De Groot from the Netherlands.



Rhoda Olkin, PhD

Promoting Positive Solutions

QUESTION: I am not bitter because of my love of life, my family and my God, but it just gets tougher and tougher to survive and tougher on those who help me. I have children who help me and a wife who loves me but hates PPS and what it has done to her husband. How do I deal with a wife/support person who loves me but hates my PPS?

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

Response from Rhoda Olkin, PhD:

I want to respond first to the fact that it gets tougher and tougher. I presume you mean as you age – the symptoms get more pronounced, weakness from polio combines with weakness from aging and new symptoms appear. Where maybe you could walk a city block, now it seems like a big effort to go from the bedroom to the kitchen. Perhaps you have started to use assistive technology such as a scooter or wheelchair, or now you have to use crutches all the time instead of just some of the time. Yes, these are big adjustments, not only for you but for your family.

I am going on the assumption that they love you, and would rather have you around, polio and all, than not. So, if you will forgive my bluntness, everyone needs to get over it. That is, I suspect you had polio all during your marriage, and hence all during your children’s lives. This is not a new issue for the family. But I hope the family is able to talk about it openly and honestly, perhaps with the help of a professional counselor or a church elder.

Hold a family meeting, ask everyone to be honest in how they feel. Problem-solve the areas that are emotionally and/or physically difficult. For example, does your wife feel held back because you cannot do something? Would you be okay with her going some places without you? Does she feel able to do so? Is she worried that as she ages she can no longer help you in the same ways? Do some

tasks need to be doled out (to children, neighbors, church members, hired help) or even not done at all?

I want to emphasize that we polio survivors need to be careful about ascribing any new or worsening symptoms to polio when in fact they could be due to a treatable cause. For example, I went for several years thinking I had just reached a new stage of disability. In fact my thyroid hormone levels were low, and taking thyroid medication returned me to my previous levels of energy (which, admittedly, were still low and still decline with age, but are no longer debilitating).

Second, I have to wonder about your idea that it is possible to love you but hate the polio. Imagine substituting another descriptor for “polio” and see how it sounds. For example, you could never say “my wife loves me but not my gender.” They are one and the same. You are who you are as a polio survivor. There is no you, and then on the side the polio. There is only you with polio. It’s a package deal. I suspect it may be that your wife doesn’t hate what it is doing to you, but rather what it is doing to her (e.g., preventing the two of you from taking trips, or putting more responsibility on her for household tasks).

So re-read what I’ve said above, and find out what the issues really are. And remember, those vows say “for better or worse,” even if the *worse* sucks.

Please send questions for Drs. Olkin and Machell to info@post-polio.org.

QUESTION: I am a 70-year-old woman who is on Medicare. I have gotten weaker as I age and anticipate that I will need more assistive devices in the future. All of this talk about cutting Medicare has me feeling helpless and worried sick. What should I do?

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

Your fears are shared by many, if not all, of those who depend on Medicare. And they are understandable, especially when you feel so vulnerable.

I believe that those currently on Medicare, and those about to be, have little to fear. While there may be changes made to the Medicare program, these changes would probably be phased in and affect younger people more.

I believe this because seniors are the most consistent voters in this country, and politicians are aware of this. Unfortunately, inflammatory rhetoric gets the biggest share of press coverage in this age of fear-mongering, and politicians know this as well. Some organizations aimed at seniors may also stir these fears, inadvertently or otherwise.

Listening to rhetoric won't help you feel calmer or more empowered. Turn off the news, or at least the talk shows, or limit your listening and viewing. While staying informed is helpful, the sound bites and rapid-fire delivery don't tell the whole story. You may want to identify a good resource for balanced journalism or look to more than one source. The Alliance for Retired Americans (www.retiredamericans.org) is an advocacy group that has a website and weekly email newsletter that provides accurate information about Social Security and Medicare issues. While the information itself can be concerning, it is presented with a minimum of fear-mongering.

In dealing with feelings of helplessness, it helps to have support and a plan. If you don't have one already, it

might be helpful to enlist a friend or family member as an informal medical advocate. This person can not only help you assert yourself with providers but also help you identify resources. If you don't know anyone who can do this, you might find assistance through your local Council on Aging, senior center or doctor's office. Some health insurance plans have programs for providing seniors with a case manager who might be helpful as well.

Should needs arise that insurance doesn't cover, it can be helpful to know that there are resources for seniors and people with disabilities to help pay for assistive devices. For example, Post-Polio Health International provides some small grants for this purpose. If you have ever lived in Rhode Island or have family connections there, you may be eligible for help from the Rhode Island Infantile Paralysis Foundation. You or your medical advocate can research and identify similar organizations.

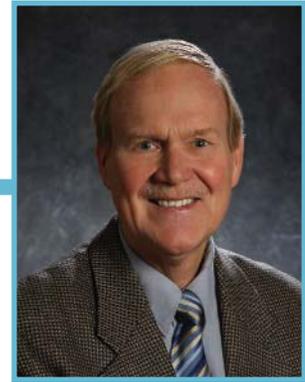
Depending on your financial situation and where you live, you may also be eligible for more help than Medicare and your Medigap insurance provide. Medicaid could be an option. Your state may also have other programs that help seniors and/or people with disabilities with some medical expenses.

Provided that it wouldn't increase your fears, it may help you to become involved in political or advocacy groups that are working to keep Medicare strong or to write letters to your representatives expressing your concerns. There are many senior action groups working on this issue. Joining with others to take action can help you feel more empowered. ▲



Stephanie T. Machell, PsyD

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.



Frederick M. Maynard, MD

Question: *I had polio in 1940. With treatment and exercise I was able to live a “normal” life and taught school for many years. At age 50, I started having new weakness. I am now 79 and my legs have shown greater weakness. I wear a full brace on my left leg and a short brace on my right leg. Lately I have been falling, even with my walker. My left leg is very swollen but medical tests do not show anything. Could the late effects of polio be causing the swelling?*

A: There are many reasons why leg swelling can occur. They all involve fluid retention, and usually the mechanistic cause is inadequate “return flow” of blood carrying fluid out of the leg and back to the heart. If you have had slowly worsening weakness now for many years and at age 79 require a left long leg brace, most likely you have swelling in that leg from inadequate muscle contraction pumping blood back out of the leg when you are upright. This is especially likely to be the explanation if the problem has developed gradually along with slowly increasing post-polio leg weakness and if it is worse later in the day than in the morning (after the leg has been elevated overnight in bed which drains out fluid).

Other common causes for leg swelling are open sores on the foot/leg which can result in lymphedema (excessive fluid production in soft tissues around the sore) and kidney or heart problems that lead to excessive salt and water retention throughout the body, especially in the legs when you are up. In the latter case, there should be swelling in

both legs, even if there is more in the weaker left leg where there is less muscle action to pump blood out. Often in older people there is more than one contributing factor to leg swelling.

If swelling appears rather suddenly in one leg only, especially if that leg also becomes painful and red, then you should see a doctor as soon as possible to test for a blood clot in a leg vein. Venous blood clots block the vein from draining blood out of the leg which results in swelling.

The mainstays of management for the symptom of leg swelling, especially when other direct causes are not found, include restricting salt intake, leg elevation as much as possible, and wearing support stockings or using leg wraps. It is important to control leg swelling because it will otherwise gradually worsen and sooner or later lead to additional problems (like open sores/ulcers, heaviness of the leg that makes it harder to get around, poor fitting of shoes and braces and blood clots, among others).

SEND YOUR QUESTIONS
FOR DR. MAYNARD TO
INFO@POST-POLIO.ORG.

MESSAGE TO PHI MEMBERS

As reported in the recent electronic *PHI Membership Memo*, our organizational report for 2009-2010 is available at www.post-polio.org/about/AnnRep2009-2010.pdf.

Members without Internet access who would like a printed copy may call 314-534-0475 to request a copy. The Board of Directors and staff gratefully acknowledge the financial support of our Members, which makes our many activities possible.

Question: *Do you know of any polio survivors who are experiencing numbness in their affected areas? I did some physical therapy recently for about six weeks using both sides of my body to improve the strength in my unaffected leg, and noticed that my left arm (the affected side) was becoming numb and then later in the day, my left leg would also become numb (just the top part of my arm and leg). My family doctor is sending me to a neurologist to see if I have a pinched nerve but he and I both think it is polio related. Since I have stopped physical therapy it has quieted down, especially if I use Aleve®, a heating pad or warm water at the pool. I'd appreciate your advice.*

A: There are many causes of numbness, but post-polio syndrome is never the DIRECT cause. Polio affected motor nerves only and, therefore, does not lead to numbness or true loss of feeling. Numbness and tingling are, however, common complaints among polio survivors because of the many musculoskeletal problems that they develop as they become older and because of other medical and neurologic conditions they may concurrently develop. A burning feeling in post-polio muscles fatigued by exercise/activity is also a common report.

Based on your description of symptoms (coming and going; located on the top of the arm and/or leg; relieved by Aleve and local heat), it is very likely your symptoms are a referred pain

from a more central spinal problem, but they could be due to a “pinched or irritated nerve,” nerve entrapments, circulatory diseases or other causes. A neurologist’s consultation is a good idea in order to rule out serious conditions. If nothing specific is found and symptoms do relate to activity/movement/exercise, then a referred pain from a musculoskeletal problem remains most likely as the cause. Working with your PT to alter your exercise program may also be successful in eliminating/controlling the symptoms.

Question: *I had all three types of polio. I was paralyzed from my throat down and was unconscious. Now I am 69 years old and have been diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS). Could polio, post-polio and POTS Syndrome have any connection and/or relationship?*

A: POTS syndrome causes the heart to race to compensate for an excessive drop of blood pressure when a person stands upright, especially suddenly from lying down position. It is considered an abnormality of the autonomic nervous system’s function to control automatic reflexes that change heart rate and the opening and closing of blood vessel size, which then affects the blood pressure. While polio may affect some

of the sympathetic nervous system cells (part of the autonomic nervous system) that control opening/closing of blood vessels, I am unaware of orthostasis (low blood pressure and faintness when standing up suddenly) being a common problem among the many post-polio patients that I have seen and know.

The name POTS is usually used to describe an unusual autonomic nervous system dysfunction in relatively young people that has no known cause. You more likely have developed “orthostatic hypotension” related to aging issues, including drug effects and fluid balance.

While polio weakness could be playing a role in making this problem worse, it is unlikely to be the primary cause. Treatment would also be the same as in people who never had polio. I would expect support hose, possibly all the way up to the waist in a “panty hose garment,” would be particularly helpful if polio leg weakness with blood pooling there when you stand up is a major factor in your POTS. ▲

Aging Well with Post-Polio Syndrome: The Benefits of Muscle Strengthening

Rehabilitation Research and Training Center (RRTC) on Aging with a Physical Disability,
agerrtc@uw.edu

Muscular Strengthening is one of the most common recommendations of physical medicine and rehabilitation for people with PPS struggling with symptoms. However, historically, any type of exercise was once thought to be bad for people with neuromuscular diseases (such as muscular dystrophy, post-polio syndrome, cerebral palsy, etc.) and this stigma has been difficult to overcome. Research has since shown exercise and physical activity to be the exact opposite – of great benefit – for people with neuromuscular disease.

In 2010, Tiffreau and colleagues published an article reviewing several studies that looked at muscular strengthening programs as a way to improve symptoms of post-polio such as fatigue, pain, sleep, muscle weakness or atrophy. This article looked at 14 different studies published from 1988 to 2008.

What types of muscle strengthening programs were studied?

Aerobic Training – Aerobic means “with oxygen” and is typically an exercise of low or moderate intensity for longer periods of time. Examples include bicycling, jogging, jumping rope, stair-climbing and swimming. In the studies, bicycling and walking on a treadmill were the most common form of aerobic training used.

Aquatic Physiotherapy – Also called “hydrotherapy” is done in warm (90–92 degrees), waist high water and the room is typically warm as well. A number of different activities can be done: balance exercises, range of movement, and strength and conditioning. Often activities are led by a specialist.

Muscle Strengthening Training – The studies used non-fatiguing progressive resistive exercises for people with post-polio. A typical program includes performing a small number of repetitions until fatigue, allowing rest between exercises for recovery and increasing the resistance as the ability to generate force increases. Activities include lifting weights, exercises that use the body as weight (push-ups or pull-ups), or using bands for resistance.

The studies reviewed typically measured how well the program worked by looking at the participants’ maximum heart rate, oxygen use, volume of muscle, blood pressure, amount of weight being lifted, walking speed, or a strength measurement (like hand grip strength). A few studies looked at electromyography (EMG), which measures the electrical potential generated by the cells in the muscles. A physical therapist can tell how healthy a particular muscle is by the EMG results. Two studies included a measure of pain. Overall, the studies supported the benefits of muscle training programs for people with post-polio:

- ◆ Main improvements were found in heart rate, increased oxygen use, blood pressure and pain reduction.
- ◆ No adverse side effects were reported for any of the studies.
- ◆ Muscle strengthening programs should focus on muscle groups which are still working and pain free.
- ◆ The programs must be individualized, moderate and regularly evaluated.

How do I start a muscle strengthening program?

- ◆ Always talk to your doctor before starting any new exercise program.
- ◆ Ask your doctor about muscle strengthening and find out if you can be referred to a physical therapist.
- ◆ Check your health insurance to see if a referral to a physical therapist or aquatic therapy is covered.
- ◆ Talk with friends and family and check out community resources (such as the YMCA). ▲

References and Resources:

Tiffreau V, Rapin A, Serafi R, Percebois-Macadre L, Supper C, Jolly D, Boyer F-C. Post-Polio and Rehabilitation. *Annals of Physical and Rehabilitation Medicine* 2010, 53: 42-50.

Taylor NF, Dodd KJ, Damiano DL. Progressive Resistance Exercise in Physical Therapy: A Summary of Systematic Reviews. *Physical Therapy* 2005, 85 (11)

YMCA of USA – www.ymca.net

Centers for Disease Control (CDC) Guidelines of Physical Activity for Older Adults – www.cdc.gov/physicalactivity/everyone/guidelines/olderadults.html

The National Center on Physical Activity and Disability (NCPAD) To Reap the Rewards of Post-Polio Exercise – www.ncpad.org/disability/fact_sheet.php?sheet=136

Letters to the Editor

I'm a 68-year-old polio survivor with some limited negative effects from post-polio syndrome, mostly in the form of increasing muscle weakness in one arm and the leg least affected by the original disease. Several years ago, I began using a wheelchair without fold-up footrests for traveling any distance over a couple of hundred feet. To rise from the chair was very difficult because my feet were further out in front of me than with a regular hospital type chair compounded by my being about 50 pounds overweight. In searching the web for assistive devices, I found the Uplift Technologies Uplift seat.

I bought the non-electric version that uses a hydraulic cylinder that compresses when you sit down and provides roughly 80 percent of the lifting effort needed to get up. There are two seats available, one for persons under 200 lbs. and one for those over. They are wonderful. My shoulder pain virtually disappeared when I started using them. I now have one in my office chair, one in my wheelchair and one in my recliner. They are very portable so they can be used in theaters and other places where a person would have difficulty in rising. Just search for "uplift seat."

Charles Hargrove

Joan L. Headley's article, "Calcium, Vitamin D and Bisphosphonates, Oh My!" (www.post-polio.org/edu/pphnews/pphnews/pph27-3p1plus.pdf) resonated with a number of readers. Here are some of the comments:

Thank you for your article in the current *Post-Polio Health*. I can relate to the osteopenia problem and Vitamin D too ... Thank you for sharing your personal story with us and best wishes.

Mary Atwood

What a good job you did on that osteoporosis article. It was thorough, succinct and with just the proper balance of authority and readability. ... I'm forwarding it to my brother who had polio in his left arm only but was diagnosed with osteopenia a few years back. He's in his late 50s and was dumbfounded because his musculature is sound. Stay well.

Joyce Tepley

Your last issue answered many of the questions I've had over the years. Primary care physicians tend to forget the post-polio people and recommend what they know. I've rejected Fosamax after reading about side effects and added specific vitamins to my routine. It's good to know Dr. Maynard supports what I decided. Thanks for a very useful issue.

Kathleen Schuerger

Send Letters to the Editor by email to info@post-polio.org or by mail to the Post-Polio Health International mailing address. All letters are subject to editing.

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News about Polio Place (polioplacement.org)

Thank you for your emails and letters about raising children as a parent (or grandparent) with a disability. If you forgot to send yours, there is still time, because PHI continually adds information to Polio Place. We want to include your ideas for "Living with Polio" (www.polioplacement.org/living-with-polio/living-polio) and make them available to younger survivors of polio and to others with disabilities. Share your wisdom in words or in photos.

Other updates: Two new features have been added to the site. In the lower right-hand corner of Polio Place, there is an option to increase or decrease the size of the print and a button to darken the color of the type.

Post-Polio Health International is committed to reaching survivors worldwide, and we are starting a new project. We invite polio survivors living in Central or South America who have an interest in post-polio issues to send a letter of introduction to PHI, 4207 Lindell Blvd, #110, St. Louis, Missouri 63108, or email it to director@post-polio.org. If you speak Spanish and English, are tech-savvy, and would like to assist PHI, contact us. ▲

PHI Members Respond

PHI Members suggest the following businesses as makers of the Hoke-type corset: Hastings Professional Medical Equipment, Cleveland, Ohio (216-898-3300), Freeman Manufacturing Company, Sturgis, Michigan (800-253-2091), Snell's Orthotics & Prosthetics, Memphis, Tennessee (901-725-7048) and C.H. Martin Company, Orthotics/Prosthetics, Atlanta, Georgia (404-525-1533).

One enterprising polio survivor found a costume maker who sews for the San Francisco opera to make her a corset. If you live in the Bay Area and can pay out of pocket, contact PHI for details. *The International Encyclopedia of Rehabilitation* describes the Hoke corset as a "Thoracolumbosacral canvas corset with front opening and multiple stays. Developed about 1930, primarily as a support in scoliosis due to poliomyelitis, by Warm Springs, Georgia surgeon Michael Hoke (1874-1944). Also called the Warm Springs corset." ▲



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