# POST-POLIO HEALTH

Summer 2016 Volume 32 Number 3

www.post-polio.org www.polioplace.org

PHI's mission is supported by its Membership.

# Why the weight? Losing a few pounds is possible ... right now. Why wait?

Sunny Roller, Ann Arbor, Michigan

Even if one uses a wheelchair full time and has a metabolism that is a bit slower due to aging, losing weight is possible. I had almost given up, but then 14 months ago, my doctor fiercely demanded that I lose 10 pounds. If I did not, she threatened to infuse me with some creepy medication. How terrifying!

At that time, since I had quit walking with braces and crutches two years before, I was close to 50 pounds overweight. And I knew that the extra weight was not only undesirable; it also made my abilities to transfer and move about so much more strenuous and dangerous. As I pushed, twisted and lifted my body around every day, my hands, arms and shoulders were at imminent risk for injury and worsening carpal tunnel syndrome.

Looking back, I started to struggle with overweight issues at the age of 11. As I

grew into womanhood with an obvious physical disability and a polio survivor's drive to succeed, losing weight was usually on my mind. It plagued me like a whispering snake, reminding me that I was too fat, which magnified my shame.

I sincerely wanted to shed the pounds, but could never figure out how to do it. Or maybe I wasn't scared enough to do it. My thoughts ranged along a scale from "why this weight?" to "oh, why not wait?" Throughout my busy adult life, I ate when the other girls were out dancing or flirting. I ate at social events with friends. It was easier to meet for dinner than to go roller skating together. I also ate poorly; grabbing fast food when I was superachieving to meet my latest professional work deadline.

But now, in my retirement years, "why not wait" had abruptly turned into "don't wait; too much weight!" For 58 long years, I had not been caring for my body properly. I didn't know how. My halfhearted attempts had always failed.

Somehow, though, I had actually hung onto hope. A spirited twinkle inside me knew that, "All things are possible." I did believe that for me there had to be a key to success. Other people lose weight, why can't I? I wasn't born overweight nor was I overweight as a little girl with a disability from polio. I wanted to get back to who I really am — innocent and unburdened — free from obesity and that incessant snake murmuring in my ear.

So, optimism in hand, with the ironically "blessed threat" of some freaky new medication propelling me forward, I began arduously searching. My deep inner resolve arose. I hunted for a logical strategy and a little magic to help guide me on a new path to weight loss. One that was feasible and effective. Delightfully,



Sunny Roller



# Family Life! WE'RE STILL HERE! 2016 Photo Contest

What activities do you enjoy with your family? What activities do you enjoy with your "disability" family?

Send us a photo that illustrates polio survivors are active participants in family life. Have you taken your grandkids on a trip? Have you participated in their school activities? Do you contribute to your family life day to day in ways that may "surprise" others who do not have a disability? Send us your photos of families in action and help us tell the world that WE'RE STILL HERE!

Help us document that people who had polio are still here, active and involved in family life.

Post-Polio Health International will select a grand prizewinner (\$150 USD) and four runners-up (free PHI Membership for two years).

The runners-up will be announced October 10-13 with the announcement for grand prize to follow on October 14th.

### **Contest Rules**

- ♦ Print or digital (JPEG with a minimum of 300 DPI/PPI) photographs will be accepted. Print photographs will not be returned.
- Color or black and white photographs will be accepted.
- ♦ Identify the location and date of the photograph and include a short statement about how polio survivors impact family life. Submitting a caption is optional.
- ♦ Each person is limited to submitting two photographs.

NOTE: By submitting the photograph to PHI you are confirming that the photograph is your property/work. You are agreeing to its limited use by PHI. PHI will state with the winning photos the following: Photo by (Name). Permission to use must be obtained through PHI. Decision of the judges is final.

Deadline to submit a photograph to info@post-polio.org is 12:00 pm CST on October 3, 2016.

### **POST-POLIO HEALTH**

Summer 2016 Vol. 32, No. 3

ISSN 1066-5331

Editor: Joan L. Headley, MS editor@post-polio.org

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

©2016 Post-Polio Health International (PHI). Permission to reprint must be obtained from Post-Polio Health International (PHI). PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

#### **How to contact PHI**

Executive Director
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 www.polioplace.org PHI sends PHI Membership Memos via email. Be sure to set your spam filter to receive emails from info@post-polio.org.

#### Moving? Change of address?

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

### Away temporarily?

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

continued from page 1

I found both — the strategy and the touch of magic.

The first step was to pay attention to the process of caring for myself. Really taking good care. What a lovely goal. Polio survivors do know how to set a goal and achieve it and I was now adamant. Focus, focus, focus. Then re-focus when focus wanes. The next step was to choose a strategy that involved a comprehensive set of tactics. I needed to go at it from all angles — exercise, healthful eating and cognitive/emotional support.

The exercise opportunity already existed. I just had to tweak it a little. I had found a gym program at our local rehabilitation center that would help me. After a time of physical therapy for an arm injury a year before, I attended what was called a "post-rehabilitation gym clinic." For a monthly fee, former patients could work out at the gym with the assistance and support of enthusiastic rehabilitation technicians. I could go every day of the week and work out on the NuStep machine or stand and walk at the parallel bars. They also would help me weigh myself to track weight loss.

Here's where the magic of kindness appeared first. When they found out I was working to lose weight, they lifted their established rule of short-term membership. They agreed to let me work out for as many months as I wished; knowing that my goal had moved from rehabilitation to weight loss. So, I keep working out at the gym.

(For more details on the reasonable high intensity interval training that my postpolio specialist, Frederick M. Maynard, MD, recommended, refer to www. sunnyrollerblog.com and search for the post of May 15, 2015 titled "Recipes for Regeneration.")

The second part of my strategy was to eat properly. This was a huge challenge because my kitchen is not very accessible and I don't like to cook. But I knew I needed to start eating clean. Eating clean is the latest buzzword young people use to mean "include whole foods like vegetables, fruits and whole grains, plus healthy proteins and fats; and exclude refined sugar and processed food."

I had been to WeightWatchers numerous times throughout my life and knew they had the most widely acclaimed sensible eating program. So for \$20.00 per month, I signed up this time for WeightWatchers Online. It was convenient and I found a huge selection of recipes that were "clean!"

Not liking to cook was a problem. One day a friend was listening to me trying to solve the challenge of not cooking, when she suggested that I ask my current housekeeper, whose contract was only for cleaning, to prepare three WeightWatcher meals for me each week.

"I needed to go at it from all angles — exercise, healthful eating and cognitive/emotional support."

Here's where the magic of kindness appeared once more. My housekeeper agreed to stretch her skills. She genuinely wanted to help and encourage me in my weight loss effort. The magic of her generosity and kindness made this part of the strategy work. And my world of "clean eating" joyfully became a reality. I choose the recipes, shop for the food and she cooks them up in my inaccessible kitchen.

I had found a way to exercise and eat healthful foods, but I knew I needed a third tactic — the psychological support to keep going and learn about my weight problem in greater depth. I asked my physician for a referral to a program at the University of Michigan called "The Hunger Within." She said, "Oh, you don't need that, but if you want to, I will."

With resolve and referral in hand, I joined the 12-week support/counseling group. It involved a therapeutic technique called cognitive restructuring, which refers to any method that helps people think differently about a situation, event, thought or belief. Cognitive restructuring

continued on page 4

continued from page 3

shifts a person from irrational destructive thought to positive and healthy thinking about any given idea.

For class members, it was all about how we see food and the meaning of food in our lives. When are we REALLY hungry, versus when do we simply WANT FOOD? We learned that with practice, we could change our thoughts about food.

I discovered that I often automatically eat when I am bored or lonely. That kind of emotional eating alone can lead to unwanted obesity. Did you know that some people want to eat a lot of bread because it brings them closer to an important person in their past lives — like a mother or grandmother, whose homemade bread was irresistible and symbolized love and nurturing? Or that some people crave a lot of sugary products because there has not been enough sweetness in their lives; but perhaps abuse or harshness from those around them?

"The kindness demonstrated by those around me has added the magical power that completes the equation."

So I have learned that I can change my distorted thinking and practice more constructive ways to alleviate boredom or loneliness as I develop exciting new interests, and build deeper and more active friendships.

The magic of kindness also emerged from the class in a powerfully different way, as I continued my weight loss journey. "The Hunger Within" ultimately teaches that we must practice being kind to ourselves. If we want to become physically healthier, it's our job to replace any self-criticism with self-compassion. As we forgive our mistakes, and nurture the inner joy and goodness that shone in our faces as little children, our thoughts about other people become kinder and more compassionate, too.

This class is only conducted at the University of Michigan, but Marilyn Migliore, the workshop's creator and leader for 20 years, relays that there is a website (www.autochair.com) associated with it. This site describes the program in detail and provides an opportunity to purchase the book. She reports that many people across the country have formed monthly reading/discussion groups with weight loss in mind. They study the book, chapter by chapter and apply its premises.

Before my physician's warning, I had nearly given up. Then I changed my mind. With fierce focus and fresh hope, I worked to adapt that three-part strategy to my unique situation. The kindness demonstrated by those around me has added the magical power that completes the equation. As others continue to teach me how to be kinder and more nurturing of myself, I believe the adipose tissue will continue to fade away. Funny how that works.

Since my physician's warning in May of 2015, I have lost 15.5 pounds. Not dramatic. Not perfect. But moving in the right direction — about a pound a month. I slowed down during the cold, winter months, but continued to lose a little. Now I am focused on shedding ten more pounds by Thanksgiving.

Losing weight is a feasible goal, even if one is a polio survivor in later life who uses a wheelchair full time. Why the weight? Who needs it? Why wait? From this experience, I can earnestly say — losing a few pounds is possible ... right now.

### When to Move

Joyce Tepley, Dallas, Texas

According to the latest study by the National Association of Home Builders, there are 48 million households headed by someone 55 or older. That's about 42 percent of all U.S. households. My husband, Phil, and I are part of that group.

I had polio in the summer of 1952 when I was 9 years old. My parents did not want me to attend a "special school" and I am grateful for the sound education I received.

I became a social worker and fully engaged in life as a tenaciously independent-minded person. Like many, I am a good problem solver, resource finder and risk taker. I have pushed myself beyond anyone's expectations and achieved much in my life.

Facing increasing physical debilitation as I age and losing what I once fought hard to regain is frightening.

I have used a ventilator noninvasively since 1986. Six years ago I got a terrible bacterial lung infection (Mycobacterium avium-intracellulare complex) that started turning my lungs into Swiss cheese. I was on three antibiotics for over a year before it cleared. Since then I have had to have two more rounds when it flared up again. Most days I am short of breath when I do the simplest things I used to do so easily — like work in my flower garden.

I use a manual wheelchair most of the time around the house and when I go out, which is less and less, I use a three-wheeled scooter. A week may go by without me putting on my leg braces and walking.

Just before my husband retired eight years ago, we looked at two cities we thought we might like to retire to — Ashland, Oregon and Ashville, North Carolina. Both had cultural amenities we were looking for but when we gave it serious thought, we just didn't want to go through moving and starting all over again in a whole new environment.

For years, my husband did all the shopping and most of the cooking for us, but he had major surgery a couple of months ago and he is still recovering. We do not have children or relatives who can help us, but our neighbors have been kind.

Between the two of us, we needed more help with grocery shopping, cooking, cleaning and all the detailed activities that keep a household and the people in it functioning.

We added more accessible equipment like extra grab bars in the shower for my husband. (We had redone the shower a while ago making it a roll-in shower for me.)

Our kitchen is not accessible for a wheelchair so I had to be clever and come up with ways to cook now that my husband can't, at least for now. I bought a convection oven and hot plate to put on our small kitchen table along with my blender. The microwave is a bit high for me but I can reach it for small things without putting myself in danger.

I cannot get close enough to the sink to get water or rinse dishes, but we bought a five-gallon industrial jug that my helper keeps full of water for cooking and my hot tea.

My cleaning lady rinses the piled-up dishes and puts them in the dishwasher once a week if my husband is too tired to tackle them any particular day.

I arranged to have packaged meals delivered and I reheat them. I also hired someone who grocery shops for us and helps with a variety of small household tasks and transportation, thereby freeing my energy to concentrate on being my husband's caregiver. (We already were paying a maid, dog walker and handyman/garden guy once a week.)

I am a supervisor of a staff now more than a doer of chores.

continued on page 6



Joyce Tepley

So far, the money my husband and I spend on hired help plus our monthly house expenses is \$1,000.00 less than what we would pay for an average assisted living arrangement in our home town.

### Other considerations:

Right now we have the money and energy to maintain our present lifestyle and home.

We guesstimate that we have five to ten more years to live at the rate of illnesses, hospital stays, emergency room visits, surgeries and number of doctors we are adding to our growing list.

If we remain in our home, we will need to increase the amount of paid help. We will probably need nursing and personal care, which is expensive. We can still drive, but when we cannot, we will need more help to fetch and carry and take us places.

Our house needs some major work and prioritizing what to spend our retirement dollars on is on our minds. Should we replace the gutters, the fence, the carpeting with wood floors? We decided against renovating the kitchen for the cheaper solution of getting tabletop appliances.

How much money should we put into the house we have lived in for 25 years that was already 30 years old? Someone who buys it will only tear it down. That's the way the neighborhood is going. We have the money to do one of the three main repair needs right now. Should we?

Moving seems too daunting a thing to face. After 25 years of accumulation (much of which I am getting rid of now I can proudly say), finding another place that will fit our needs is way beyond our imagining.

We are not sure whether we would be trading what we are able to manage now for some unknown smaller place or a place with assisted services would be better.

My husband is an introvert and cannot bring himself to move to a place that has more people near him with an expectation of socializing. We are living in a very caring neighborhood and if we moved we would lose that support and have to find and get used to a whole new set of acquaintances and places.

Most everything we need is within two miles from us and neighbors are always offering to help.

On the other hand, many of our intimate friends have died and we have to be careful about getting too isolated.

Honestly, I am not sure how we will know if and when it is time to move from our home of almost 30 years, but for now, we do not have the energy or inclination.

In a future issue of *Post-Polio Health*, Tepley will discuss "Where to Move."

### This is the third article in a series that discusses "where to live" as we age with the late effects of polio.

Karen Hagrup shared photographs of the accommodations made to her St. Louis condominium in the Fall 2015, Post-Polio Health. "Aging in place with a disability" is featured on pages 4-5 of Volume 31, Number 4. See www.polioplace.org/PNN.

Beverly Schmittgen wrote in Post-Polio Health (Volume 32, Number 1, pages 3-5) about the experience of downsizing and building a new home in a retirement community. Four years later, she and her husband have settled in as active members of a retirement community, one of the fastest growing industries in the United States. See www.polioplace.org/PNN.

## BOOK REVIEW

Daniel J. Wilson, PhD

Dr. Lauro Halstead's new memoir, *An Unexpected Journey: A Physician's Life in the Shadow of Polio*, is a reflection on his life as a polio survivor and as a physician who helped identify postpolio syndrome as a new disease. While autobiographical, this is not a year-to-year accounting of his life. Rather, Halstead considers key people in his long life and episodes that shaped his life and career.

Halstead begins with an affectionate recounting of the influence of his parents and the importance of their farm in Vermont, "Storm Acres." Following his freshman year at Haverford College, Halstead traveled in Europe. After visiting France and Portugal, Halstead developed polio in Madrid, Spain.

He describes the frightening feeling as paralysis spread and affected his breathing. Fortunately, through the intervention of a U.S. Air Force physician, he was placed in a wooden lung at a Madrid hospital. After Halstead had recovered sufficiently, this same physician arranged for him to be flown back to his home in New York for recovery and rehabilitation.

During his recovery, Halstead determined to become a physician, and several chapters detail his journey into medicine as a doctor instead of as a patient. He is open about the challenges he faced, especially those resulting from his inability to use his right arm paralyzed by polio.

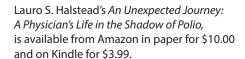
Like many polio survivors in the late 1970s and early 1980s, Halstead began to experience increased muscle pain and weakness as well as fatigue. When he became a physician, Halstead focused his clinical and research work on individuals with spinal cord injuries. But in the early 1980s he could not ignore what was happening to his body, and, as he soon discovered, to the bodies of many other polio survivors of the epidemics of the 1940s and 1950s.

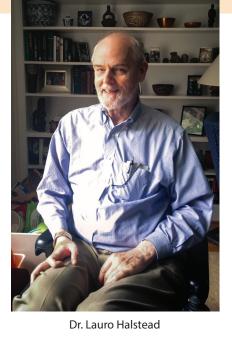
He recalls how he and other clinicians, along with polio survivors, came together in influential conferences in the early and mid-'8os to name and describe this new phenomenon, post-polio syndrome.

Halstead ends his memoir with chapters discussing men important to him, the role of music in his life, and the importance of his family.

An Unexpected Journey reveals the man behind his many contributions

to understanding and treating post-polio syndrome. We learn the various influences that shaped his decision to become a physician and later to focus on the disease that he was experiencing along with his patients. The compassion and humanity evident in Lauro Halstead's professional writing on post-polio syndrome clearly has its roots in a life well lived, even if it has been shadowed by polio.







Daniel J. Wilson is Professor of History at Muhlenberg College in Allentown, Pennsylvania. He is also the author of *Living* with Polio: The Epidemic and Its Survivors, as well as numerous articles on the history of polio.

## $\mathcal{P}_{\mathsf{ROMOTING}} \mathcal{P}_{\mathsf{OSITIVE}} \mathcal{S}_{\mathsf{OLUTIONS}}$

**QUESTION:** Sorry NO more Memberships. For years, I have been getting the newsletter and it seems that the same old post-polio stuff keeps coming around. I have been hoping in vain to obtain definitive solutions to either FIX post-polio (I am 80 years old.) or reduce the rate of on-going loss of muscles. Or, I'd like to learn of new medications and/or mechanical devices which can enhance my muscle capability, e.g., help me get up off the ground when I fall. Can you send me something useful? I will become a Member again.

### **Response from Rhoda Olkin, PhD:**

First, the bad news. There is no new cure, no new medicine, no solutions to fix polio/PPS, nor ways to reduce the rate of on-going loss of muscles. If fact, there really isn't much of anything new in the world of polio, other than the focus on eradication worldwide. So yes, we tend to recycle topics, such as light exercise, how to conserve energy, etc. But consider that there are always new members, including those from other countries, many isolated from support groups or others with polio. People with polio in other countries are generally younger than those in the U.S., as polio was still widespread beyond when it was mostly eradicated in the U.S.

And note that polio was 'almost' eradicated in 2000, but fifteen years later the task isn't quite completed, with new polio cases in Afghanistan and Pakistan. In the western hemisphere there were cases as recently as 1979 (and those folks would be about 37 now).

But you do not have to fall. In fact, falling is not a natural part of aging, even when aging with polio/PPS. The purpose of assistive devices is to prevent falls. This is very important, as falls tend to make people feel fragile. When they feel fragile they reduce activities, including socializing, which then often leads to depression. Social support is a key factor in enjoying older age, as is keeping an active mind.

The good news is that there are many devices that can help prevent falls. The simplest are grab bars placed strategically around the house. Crutches and canes can be used when fatigued, and especially if getting up to use the restroom in the middle of the night. There are knee walkers and four-wheel rolling walkers that have seats. (See, for example, one for under \$60 at Walmart.) And of course there are scooters and manual and electric wheelchairs. Repeated falling is an indication that some device should be used. I had to move to use of a scooter and wheelchair even after just one or two falls a year, because the falls were serious. Certainly if you are injuring yourself when you fall, or have fallen at least once in the past six months, you should consider using an assistive device more.

But let's not assume everything is due to polio/PPS. Be sure you have ruled out other factors that may contribute to weakness or imbalance. Sleep apnea, hypothyroid, inner ear problems — these are just a few of the many factors that might contribute to falling.

Getting up off the ground is difficult. I myself cannot do it without leaning on a chair or other firm support. Scoot on your bottom if need be, to get to a steady support to lean on when you get up, or you can fall again.

Newer very high tech gizmos are being invented, for use by those with paralysis (especially spinal cord injury). Mechanical hands controlled by thought waves, for example, are now being made experimentally, and point towards what might happen in the future. But they are still in the prototype phase.



**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.

I know that none of this is new, nor is it what you want to hear. There are workarounds for weakness and falling, but no miracles. Paralyzed muscles are not going to regenerate. But research is ongoing, including that which PHI funds (www.post-polio.org/res/index.html#awa).

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

At the risk of sounding like the shrink that I am, what I hear is frustration at the lack of a cure for PPS. It is very frustrating that nothing can be done to stop neuronal death or muscle atrophy. And that no one is trying to develop better assistive devices, or medications, or the other things that would make life better for you.

Trust me — when those things happen, you'll find out about it from us. Meanwhile, we'll be writing the same old stuff about bracing and energy conservation. Every so often we'll report something new, or something old in a new way.

Those who see the newsletter or the PHI website for the first time are excited that there is a place for people with polio and PPS. For them, recommendations for improving quality of life feel new and helpful. But for you, and others who've heard it before, it's not enough.

And you definitely don't need me to validate you by saying your frustration is normal. Often when I say this my clients assume I'm telling them they have to "accept" their condition. I'm not. That's not my place. In fact, I believe that for most polio survivors the "ideal" attitude is some balance between acceptance and denial. This balance is ever-changing, meaning that some days it will lean more heavily towards one or the other.

Living with any chronic condition is frustrating. By definition there is no "cure," only ways of managing the condition to maximize quality of life. It is important to maintain good health and treat any other conditions or issues (including psychological ones), because anything that drains your energy will only make things worse.

With chronic illness, finding positive ways of coping with symptoms AND feelings makes a difference (hence the name of this column!). At 80, you have a lot of experience coping with things you can't change. Using those skills to cope with PPS and/or developing new ones reduces helplessness, a major drain on energy.

This doesn't mean you should stifle your negative feelings. It is often said those with chronic illness should avoid negative emotions, but I believe this is unrealistic. It is true that negative emotions can fuel helplessness. But they can also lead to action. For example, frustration over the difficulty of getting up from a fall could lead you to look for a device that helps you get up when you fall. Because none exists, you develop an idea for what you need and either invent it yourself or find someone who can do so (say, in a college biomedical engineering department — often they look for projects like this).

Living well with PPS means knowing what is and isn't helpful. Organizations like PHI and its newsletters can remind polio survivors they're not alone, or they can be a reminder of daily frustration and an unknown future. Only you know which is true for you. But if you unsubscribe, check in sometimes, just in case the news changes.

**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.





# Important New Paper Published on Anesthesia and Polio

Selma H. Calmes, MD (retired), Olive View/UCLA Medical Center, Sylmar, California

A scientific paper, "Anesthesia and Poliomyelitis: A Matched Cohort Study" and my accompanying editorial "Why a Paper on Polio and Anesthesia in 2016?" appear in a prominent specialty journal, *Anesthesia and Analgesia*, in June 2016. This study was done by the departments of anesthesiology, neurology and biostatistics at one of America's most important medical institutions, the Mayo Clinic in Rochester, Minnesota.

Previous articles on polio and anesthesia in the medical literature (the place modern physicians get up-to-date and accurate information about caring for patients) have been reports of a single case of anesthesia in one post-polio patient, and there were no comparisons to patients of the same age with the same other diseases that might affect anesthesia outcome (such as heart disease) and who were having the same operations (difficult operations have increased risks for all patients). Modern medicine demands such comparisons and also demands a careful statistical analysis of study data, for accuracy and validity. Such studies are difficult to do, and no similar study on polio and anesthesia has been attempted previously.

Information on anesthesia in post-polio patients currently circulating in the post-polio community was not developed from such studies and so is not scientifically valid. So, this paper and its editorial, which advocates for more research in this area, are important steps forward, even though the study is not considered perfect because of a low number of polio survivors.

The study reports on one hundred post-polio patients having major surgery at Mayo Clinic from 2005-2009 who were identified in the Mayo Clinic's electronic medical record system. Each post-polio patient was matched with two non-polio patients of the same sex and age and with the same severity of preoperative illnesses (such as heart disease), also having the same surgical procedure. All patients' records were then reviewed by the authors, looking at other possible variables and also examining the operative, anesthetic and postoperative courses for complications.

Operation types were general surgery (39%), urology (25%) and vascular (21%). All but one post-polio patient had general anesthesia. No differences were found between post-polio patients and control patients in the following: intraoperative events (both anesthetic and surgical), pain scores (how much pain patients have after surgery), how long patients spent in a recovery room waking up from anesthesia, whether they needed to be admitted to an intensive care unit (ICU) for more specialized care postoperatively, how long they stayed in an ICU, and when the breathing tube used during anesthesia could be removed. Thirty-day mortality was not significantly different between groups.

This study did have statistical issues, identified during the pre-publication review process. Of the 100 post-polio patients, only 36% had residual neurologic damage from polio and only one of these had polio-related respiratory failure. That patient used supplemental oxygen during the day and BiPAP with oxygen at night.

Reviewers of the paper felt that the number of severely affected polio patients was too small to statistically document significance, and some criticized the statistical methods used. The low number of post-polio patients was thought to be because polio patients may have moved away from Minnesota to a warmer climate as they aged.

Although this study can be criticized on these items, its structure (2:1 matched controls) and the measures of medical care studied (common things that can go wrong) give hope to post-polio survivors that, even if they are very ill, they can undergo modern anesthesia and have the same outcomes as non-polio patients.

A word of caution, however: there is a great variability of quality of care in America's hospitals. The Mayo Clinic represents the very best quality, and whether the study can be applied to all hospitals is questionable.

Finally, this study is important as an example of how to get information on how postpolio patients *really* do during anesthesia, compared to similar patients. More such studies are needed, but this one is hopeful.

Post-polio patients can relax a little about coming for anesthesia and surgery but need to be sure they have surgery and anesthesia at a quality hospital. Check the hospital out on your state government's hospital certifying organization's website and/or the national certifying organization for individual hospitals, the Joint Commission on Certification of Health Care organization, www.jointcommission.org before agreeing to an operation.

And, post-polio patients should avoid having anesthesia in free-standing outpatient surgery centers (ones not physically located in a hospital) and doctors' offices. These are locations with little assurance of the high-quality surgical and anesthesia care post-polio patients deserve and need.

## In Appreciation

PHI thanks our donors for recognizing their loved ones and friends, listed below, with generous contributions in support of our activities.

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

### In Memory of

David Martin Graham Robert Thomas Isaeff Shirley Johnson Melvin (Mel) Lee McMullen Myrna Nielson Thacker Marge Torre Nannoe Westbrook

**In Honor of** Ann Doucette

### **Contributions to The Research Fund**

### In Memory of

David Martin Graham
Shirley Elizabeth Morse Johnson
Melvin (Mel) Lee McMullen
Bob Nelson
Esther Marie Nichols
Albert Patenaude
Stanley Rose
Barbara Marsh Steinauer
Gloria Swallow
Janet Tanaka
Myrna Nielson Thacker
Paula Webber

In Honor of Richard A. Godfrey Mobile Post-Polio Support Group

PHI acknowledges the following special contributors for 2016. PHI strives to publish an accurate list. Please contact us if we made an error.



Non-Profit Org. U.S. Postage PAID Jefferson City, MO Permit No. 210

POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard, #110 Saint Louis, MO 63108-2930 USA

### Not a Member?

**Join PHI** for just \$30 a year (Subscriber Membership) and receive your own copy of Post-Polio Health four times a year (February, May, August, November), plus PHI Membership Memos in January, March, April, June, July, September, October via email. For \$55 (Subscriber Plus Membership), join PHI and IVUN and also receive Ventilator-Assisted Living via email six times a year (February, April, June, August, October, December). You can join online at http://shop.post-polio.org or send (or fax 314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475.

### Inside Post-Polio Health

Vol. 32, No. 3, Summer 2016

Why the weight? Why wait? ... 1 WE'RE STILL HERE! Photo Contest ... 2

WE HE STILL HERE. I HOTO COINCESC III. 2
When to Move 5
Promoting Positive Solutions 8
Important New Paper Published on
Anesthesia and Polio 10

<ul> <li>\$30 Subscriber         Post-Polio Health (quarterly)     </li> <li>\$55 Subscriber Plus         Both Post-Polio Health (quarterly)     </li> <li>Ventilator-Assisted Living (kg)</li> </ul>	arterly) AND
Name	
Affiliation	
Address	
City	State/Province
Country	Zip/Postal Code
email	
Phone (include area/country co	de)
I am enclosing a check for \$_ payable to "Post-Polio Health	
Please charge \$	to this credit card:
□ VISA □ MasterCard □ I	Discover
Card No.	Exp. Date
Name on Card	
Signature	
_	