# POST-POLIO HEALTH

Fall 2022 Volume 38 Number 4

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

PHI's mission is supported by its Membership.



# Access to Knowledgeable Specialists Remain a Challenge for the World's Polio Survivors

A sWorld Polio Day approached this past October, PHI surveyed several post-polio organizations around the world and posed the question: What is the single biggest challenge that polio survivors in your country will need to address over the course of the next decade?

As one might imagine, the responses were as varied as the population of polio survivors they serve. In some places, particularly those with younger populations of polio survivors, access to education and employment ranked high in importance. In countries with older populations, issues such as access to community-based services, in-home care, transportation and affordable assisted-living were often mentioned.

One theme, however, stood out across the varied groups that responded: access to knowledgeable health care providers. Though dedicated health professionals knowledgeable about the late effects of polio can be found in most countries throughout the world, there are, perhaps, fewer of these specialists than existed ten, or even twenty, years ago. Below is a sampling of some of the responses we received that further explores this important issue.

#### **The British Polio Fellowship**

#### Kripen Dhrona, CEO

The British Polio Fellowship was established in 1939 and is the only UK national charity dedicated to supporting and empowering people living with the late effects of polio (LEP) and Post-Polio Syndrome (PPS). It is estimated there are many tens of thousands of people living today with the late effects of polio and PPS in the UK.

The biggest challenge I see for the polio community, and this has been a challenge for a number of years, is the lack of understanding of matters to do with polio and PPS. This is a problem in the wider community but is a particular issue amongst health and social care providers. This lack of knowledge is leading to the following:

• Difficulties in getting a diagnosis—appropriate diagnosis for LEP/PPS can take on average six years but can be decades for some.

- An increased likelihood of misdiagnosis, often other neurological conditions.
- People who need help not asking for it, as they fear they may be wasting their time.

♦ Most polio patients need multi-disciplinary care—this is often mismanaged or badly handled.

◆ Lack of integrated care means social care and mental wellbeing for patients is often overlooked.

Follow-up care is often not sufficient.

# (Dr. Lauro (Debosis Storm Halstead, 1936-2022

PHI is saddened to report that Dr. Lauro Halstead, an internationally renowned physician in identifying and treating post-polio syndrome, died at his home in Washington, DC, on January 5, 2022. He was 85 years old.

Dr. Halstead was born in Bronxville, New York, on February 27, 1936. He contracted polio as an 18-year-old while traveling across Europe in the summer of 1954. He survived only with the assistance of a wooden mechanical respirator at a hospital in Madrid, Spain.

His experience with polio motivated him to apply to medical school and become a doctor. He earned his medical degree from the University of Rochester in 1963. His storied career culminated with his being named Director of the Spinal Cord Injury Program and the Director of the Post-Polio Clinic at the National Rehabilitation Hospital in 1986, a position he held until his retirement.

His research, informed by his personal experience, contributed significantly to the basic understanding of post-polio syndrome and its treatment. He wrote several books dealing with polio: *Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome, Post-Polio Syndrome: Late Effects of Poliomyelitis,* and *Research and Clinical Aspects of the Late Effects of Poliomyelitis.* He also wrote a memoir: *An Unexpected Journey: A Physician's Life in the Shadow of Polio.* 

His colleagues at MedStar National Rehabilitation Hospital wrote of his career, "Dr. Halstead was a pioneer in rehabilitation medicine and one of the founding physicians at MedStar National Rehabilitation Hospital. His work in spinal cord injury, post-polio syndrome, and fertility for persons with disabilities helped thousands of patients and advanced the field of rehabilitation medicine."

In his personal life, Dr. Halstead was an avid musician. As a high school student, he played the trombone, won many awards in musical competitions and played in a swing band until his right arm was severely affected by polio. Later in life, he took up the euphonium.



In his memoir, he wrote of his complicated relationship with polio. It had certainly been a burden in many ways, he mused. Yet, it had also given him a different perspective on life. "These experiences have enriched my life beyond measure," he wrote. "However, on balance, I can honestly say polio has been both a curse and a blessing. But what well-lived life doesn't contain a little of both?"

#### **POST-POLIO HEALTH**

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#### How to contact PHI

50 Crestwood Executive Center #440 Saint Louis, MO 63126 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.



The added problem is there is a huge difference in the level of care across the UK and health and social care systems often lack the resources they need to provide sufficient care.

The Fellowship has started work on the development of an Optimum Healthcare Pathway as a tool to help in the following ways:

- Educate the health care and social profession.
- Help the polio community understand what their care journey should look like.
- Use it as a tool to raise awareness of all matters polio.
- ♦ Help identify gaps in services and resources for health and social care providers to enable lobbying to government and decision-makers.

We hope this work will benefit the whole polio community.

#### **March of Dimes Canada**

#### Kim Smith

The single biggest challenge that we see at March of Dimes Canada for Canadians who have had polio and are now experiencing post-polio syndrome or the late effects of polio is finding medical professionals who can treat them. While many of our clients report having been under the care of a medical professional knowledgeable in treating post-polio syndrome, several of these professionals have since retired.

When Canadian clients are looking for a medical professional, they have difficulty finding anyone who has been trained in caring for the effects of polio, given that the last case of paralytic polio in Canada occurred in 1977 and Canada was certified polio-free in 1994. March of Dimes Canada had a part in funding the research for the vaccine during the race for the cure in 1951.

If occupational therapists, physical therapists, medical doctors, physiatrists and other health professionals could be educated in the effects and diagnosis of post-polio syndrome, it would make it much easier for polio survivors to find the support they need. At March of Dimes Canada, we are working on updating our list of professionals knowledgeable in the field of treating post-polio syndrome so that we can help other polio survivors.

To contact the Post-Polio Canada program at March of Dimes Canada, send an email to polio@marchofdimes.ca and we will direct clients to resources.

#### **Turkish Polio Society**

Prof. Dr. Arzu Yağız On, Ege University Medical Faculty, Department of Physical Medicine and Rehabilitation, Izmir, Turkey Founding President of the Turkish Polio Society

Polio survivors in Turkey are relatively younger than patients in the rest of Europe and the United States because poliomyelitis eradication occurred much later. These young patients present different needs and challenges to health care and rehabilitation, as well as employment, social integration and economic self-sufficiency. In addition, many polio survivors are candidates for developing post-polio syndrome in the future, which will further complicate the situation and bring more challenges regarding diagnosis, treatment and rehabilitation of post-polio syndrome and have psychosocial implications.

For these reasons, there are many issues and challenges that polio survivors in Turkey will need to address over the course of the next decade. Among these, the single biggest issue/challenge for Turkey's polio survivors seems to be access to knowledgeable health professionals, as it is today. This is followed by challenges in affording necessary adaptive equipment such as lightweight orthotics or power wheelchairs.

PHI is excited to announce a new post-polio educational program available to our members throughout 2023.

Beginning in January, PHI will host a series of educational town halls and lectures centered around topics of major interest to polio survivors.

Each offering will be presented by an expert with deep knowledge on the topic at hand. We will cover important issues such as bracing, exercise, psychology, breathing and other topics related to aging with the late effects of polio.

Keep an eye out in your email and on <u>www.post-polio.org</u> for details about the specific schedule.



### **POST-POLIO TOWN HALLS**

**WHAT**: A series of six Zoom webinars organized around a specific topic in which attendees will be able to ask questions and get answers from experts on a chosen topic. Each session will start with a short overview of the topic followed by a question-and-answer portion. Each town hall will last approximately 1.5 hours.

**WHEN**: Town halls will be held in January, March, May, July, September and November. Specific dates and times will be announced roughly one month in advance.

**WHO MAY ATTEND**: The town halls will be open to PHI Members free-of-charge. (Nonmembers wishing to attend must register and pay for an annual \$30 PHI Subscriber Membership.)

**HOW DO I REGISTER:** To register for the January town hall, simply scan the QR code in the image (above) or visit <u>tinyurl.com/phi-th1</u>.

#### **PHI LECTURE SERIES**

**WHAT**: A series of four lectures held over Zoom addressing a topic of major interest to polio survivors.

WHEN: Lectures wild be held quarterly in February, April, August and October

**WHO MAY ATTEND:** The lectures will be open to PHI Members free-of-charge. Non-members wishing to attend must register and pay for an annual PHI Subscriber Membership (\$30).

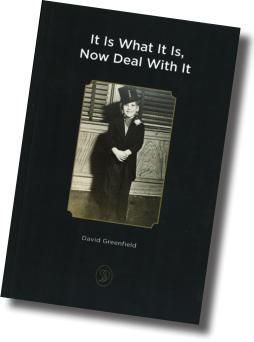
**HOW DO I REGISTER:** Registration information will be emailed to members and placed on our website and social media accounts approximately one month prior to each event.

# It Is What It Is, Now Deal With It

#### David Greenfield

*It Is What It Is* chronicles David Greenfield's journey through his life as a polio survivor, in which he describes the many steps he took with breakthrough processes some of which were painful and untested, working with various medical professionals and, indeed, even some iconic, worldwide personalities as he became part of the medical world's campaign to gain support for the proposed steps to change the course of treatment for the disease.

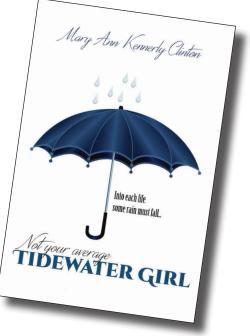
The story goes on to describe his struggle with the late effects of polio that only revealed themselves as he entered his eighties adding a remarkable dimension to the term, "long hauler." But, characteristic of his incredible attitude throughout this journey and taking the admonition of his late father: "it is what it is, now deal with it!" the author takes us on his latest step in overcoming this dreaded scourge we knew as polio.



#### Not Your Average Tidewater Girl

Mary Ann Kennerly Clinton

From the publisher: "At age six and a half, Mary Ann Kennerly Clinton was stricken with polio. This account of her 75-year journey in braces, wheelchairs and scooters reveals her resilience, determination, pluck and poise. Just challenge Mary Ann to a race and she will be sure to take you on. Why, you ask? She simply loves feeling the wind in her hair."



Keeping our aging parents safe often means making changes to their lives as well as ours. Most seniors strive to remain independent as they get older, but they eventually need more assistance, especially around the house. Here are some steps you can take to help your senior loved ones as they age.

#### When Aging in Place

If your senior loved one is independent enough to remain at home, you should make modifications to the house to ensure their safety. Some improvements are easy to undertake yourself; for others, you will need to hire professionals. There should be at least one entrance to the house that is step-free, in order to be wheelchair accessible. The main level should have a bedroom, bathroom and kitchen with easy-to-reach shelves, cupboards and cabinets.



Make sure to add grab bars in the shower to help with balance. If the house has stairs, they should be well-lit and carpeted or feature a non-slip surface to prevent falls.

Early on, if the decision is made to move, you'll need to determine whether selling the old home or renting it out is

the best option. Renting out is a popular option, as an extra revenue stream will help pay for their new home. If your loved one decides to downsize and move into a rented home or apartment, research the market in your area to see what they can afford and what neighborhoods are ideal for them. This will also give them an idea of how much they can charge renters of their old home.

#### **RESOURCES FOR CAREGIVERS**

This is the first in a series of articles written specifically for caregivers and adult children of polio survivors.

Whether they're aging in place in their current home or a new rental, don't neglect to make the outside of the house safer for your senior, too: the house number should be clearly visible from the street in case of an emergency, to help ambulances and EMTs find your senior's home. Exterior pathways should be looked at to make sure there are no holes or uneven pavement that would cause someone to trip, and no leaves or other debris that could become slippery when wet.

Hire a landscaping service if you need to modify the layout to better suit your loved one's needs. Make sure to ask if they are offering special deals in your area. If you need to finance your backyard remodeling project, landscaping loans get funded fast and have fixed interest rates and payments.

If you plan on providing more hands-on help to your senior loved one, especially if they need help with daily activities like meals, grooming and exercise as well as with their bookkeeping and finances, medications and doctor appointments, it's a good idea to be nearby. Building an in-law suite or, as REthority notes, adding a granny pod on the property will let you and your aging parent live independently from each other, but close enough that you can be there in a heartbeat should they need anything or have an emergency. Those small units offer all the comforts of home with extra safety features for seniors.

#### When Moving to a Care Home

It is estimated that one in five Americans has the responsibility of caring for an older parent, and that only 4.5% of older adults live in nursing homes according to Zippia, their care coming to an average of \$7,000 a month. If your aging parent needs skilled or nursing care that you are unable to provide, it's time to consider an assisted living facility.

There are four main types of residential care facilities according to <u>SeniorAdvisor</u>. <u>com</u>, and choosing one will mostly depend on the level of care your senior loved one needs:

 Independent or senior living, which provides transportation and entertainment, but no health care services;

 Assisted living, which provides basic health services along with daily activities;

 Skilled nursing homes for seniors who need nursing care 24 hours a day;

Continuing care retirement communities for seniors with declining health conditions. For people with Alzheimer's or dementia, a memory care facility is probably the safest option.

If your aging parents are planning on selling their home in order to move to a senior living community or a nursing home, help them get their house on the market by assessing the property's condition and making the necessary



repairs. Take time to declutter, sell and donate items and furniture your parents no longer need or want. Put a fresh coat of paint on the walls and replace or steam-clean the carpets and drapes. Also, don't forget the exterior of the house: power-wash the driveway and sidewalks, and consider repainting the front door to create curb appeal.

For our senior loved ones, safety is a priority. Take measures to prevent falls and injuries, look at the living options available (whether that's buying a new home or looking into a rental), and make an informed decision on what is best for your parents and for the whole family.

## In Recognition of Olive Nesbitt Brewster

Post-Polio Health International would like to acknowledge a recent generous bequest from the estate of Olive Nesbitt Brewster.

Olive was born on July 19, 1924, in San Antonio, Texas. She was the daughter of Charles Henry and Olive Agatha (Nesbitt) Brewster. Upon graduating from Our Lady of the Lake College in San Antonio in 1946, she went to work as a librarian for the United States Air Force, where she worked for over four decades until her retirement in 1988. A collection of historic family photographs, many taken by her, can be found today at the University of Texas at San Antonio. Olive was a longtime member of PHI and strong supporter of advancing the cause of polio survivors. She passed away earlier this year in

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

**Question:** I had polio when I was a child, but for most of my life I could do pretty much anything I wanted. I traveled, had a career, raised children, visited friends. Now I'm approaching 70 years old, and starting a number of years ago, I've noticed that I've really slowed down. I can't do many things I used to, my "good" leg is weaker, and I'm much more fatigued. I'm a bit depressed by this new state of things. Is this post-polio? Is there anything I can do?

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

Dear Writer, I am with you all the way. I understand the frustration of comparing the "now" to the "used to." At nineteen I climbed a mountain in Yosemite on crutches, 3.5 miles up, 3.5 miles down. At twenty I back-packed across the UK. In my thirties I gave birth twice.

And then ... post-polio. And since then, there has been a steady decline. Now my "good" leg is weaker, I can't go more than about 100 steps using crutches, I stopped doing wood-working once my hands seemed to slip more, and I use a wheelchair 90% of the time, having graduated from a scooter.

But I am not depressed. This is a critical piece I want to emphasize, because depression is a treatable disorder, even in the face of changes to capacity. But I don't mean to imply that these changes are easy, because they are very, very hard. At first it seems like loss, giving up things I loved to do, having to titrate my energy expenditure carefully throughout the week, saying "no" to some invitations (e.g., friends' houses with stairs; anything on a Friday night; most traveling).

But I do have some advice. First, rule out other medical conditions. I had low thyroid for several years, feeling like I was moving through jello, and attributing it to post-polio. But a magic little thyroid pill made me feel better. Getting a sleep study then using a C-PAP machine was another boost. So, check for other medical conditions that may be treatable. The synergy between symptoms of medical issues and polio can be debilitating.

Second, exercise. Oh my goodness, do I hate exercise. But using a wheelchair means muscles are not getting used, and so I have to walk with crutches sometimes, do push ups on the grab bars around my toilet, use a stretch band while I watch TV.

Third, lose weight if you are overweight. As I write this, I just ate some Halloween candy, so believe me, this one is a toughie. But extra weight is hard on the legs and heart and slows us down.

Fourth, replace things you can no longer do with new things you can. I took up knitting (and am lousy at it), painting and gardening in high planters rather than in the ground. What you're looking for is the kind of activity that takes your mind away from time and into mindlessness, where an hour goes by without you noticing.

Fifth, try not to let socializing be the thing you cut. It's tempting to say "no" when you are just too fatigued. So put social time into your calendar and cut something else so you can fit it in. You know the studies; socialization is correlated with longevity.

Sixth, take advantage of any shortcuts available. Buy ready-made; have groceries delivered; use a cleaning service once a month; put your laundry into a basket on wheels; get electric curtains; put lights on timers; have scissors, pens and paper in every room; get an automatic litterbox for your cat. Save your energy for the things



**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.

that make you feel better. Of course, if scrubbing grout makes you happy, scrub away.

Seventh, talk to someone in a post-polio support group. We all really get it; you are not alone.

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

Many polio survivors have expressed concerns about paralytic polio cases reported in New York and London. These cases appear to be caused by a vaccine-derived poliovirus that has been found in wastewater in both locations as well as in Israel and 27 other countries. As of this writing (November 2022), no further cases have been reported outside areas where wild poliovirus has not yet been eradicated.

However, cases occurring in the summer and early fall is a pattern readers of this column will find all too familiar. Though there is no reason to expect it to continue next summer, there is no guarantee it won't. As was reiterated in the World Polio Day statement by the Director and Commissioners of the European Centre for Disease Prevention and Control, "Until polio is eradicated worldwide, no one is safe."

The polio vaccine confers lifelong immunity. Anyone who has had the full series of three has no need for a booster, except for health care providers or travelers to certain areas where polio is endemic. At this time, boosters aren't being recommended for fully vaccinated people.

Does having had polio confer lifelong immunity? There are three types of poliovirus. Some polio survivors were told they had more than one, but this was based on symptoms rather than virology. Polio survivors of a certain age who received the Sabin "sugar cube" at school or know they received the Salk vaccine are fully protected. If you are uncertain of your status or have other concerns, speak with your healthcare provider about whether you need to be vaccinated/boosted.

For some the re-emergence of polio cases has triggered feelings and memories. Some may feel that yet again the lessons learned from the polio epidemics, along with those who survived them, have once again been forgotten. Those who for whatever reason went unvaccinated after the vaccine was available or who had polio shortly before that time may be especially upset that there are parents who refuse to protect their children from polio and its late effects.

The possibility of a new epidemic may trigger memories of past ones, which in turn may trigger memories of the polio experience. The news may also bring up issues related to the present and your experience of aging with polio, how you see yourself and how (and whether) others see you.

Or it may simply make you feel uneasy, anxious or angry. Rather than ignoring these feelings, it helps to find a way of addressing them. There are opportunities, both formal and informal, to educate others through writing or speaking. One polio survivor got his local NPR station to do a show on polio. You can write or make art, for yourself or to share with others, connect with a support group, or talk with family or friends. It always helps to practice good self-care, including energy conservation and pacing.

Balance being informed with not becoming overwhelmed by information. Above all, prioritize the things that give your life light and color.



**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.

# **Find Us on Facebook**

Want to keep up with the latest news and find interesting articles related to polio and aging with a disability? Check out PHI's Facebook page at <u>www.facebook.com/polioplace</u>. Here are some recent articles we've highlighted on our page:

"9 Hacks to Make Your Home More Accessible" from New Mobility (<u>https://newmobility.com/9-hacks-to-make-your-home-more-accessible/</u>)

"Google Enhances Accessibility Information" from Disability Scoop (<u>www.disabilityscoop.</u> <u>com/2022/12/08/google-enhances-accessibility-information/30164/</u>)</u>

"Employing everyday public health efforts to respond to polio's re-emergence" from STAT News (https://www.statnews.com/2022/11/09/shoe-leather-public-health-efforts-respond-polio-reemergence/)

PHI has also recently launched a private group page for our members to post and interact with one another. Simply search for "Post-Polio Health International Members" and hit the "Join" button.

# Are You a Polio Survivor in the New York Area?

The World Health Organization contacted PHI and is looking to identify people living in the New York City area who would like to be part of a photographic project.

They are looking for people:

- affected by wild polio and now consider themselves to be vaccine advocates;
- willing to be photographed by a photographer assigned by WHO, and to provide some contextual information about their experience;
- willing to participate on a voluntary basis;
- willing to sign a WHO consent form and be comfortable with WHO using the images on platforms that have a broad reach—for example our Instagram and Twitter accounts both have around 12 million followers.

located in the New York City area and available to have the photos taken in January 2023.
If interested, please contact Lindsay Mackenzie by email at mackenziel@who.int.

# **Small Ways to Give Back**

#### amazonsmile

AmazonSmile is a simple way for you to support your favorite charitable organization every time you shop, at no cost to you. Simply go to <u>www.smile.amazon.com</u>, log in, choose "Post-Polio Health International Inc" as your preferred charity, and shop as you normally would. When you shop at AmazonSmile, you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added benefit that AmazonSmile will donate 0.5% of your eligible purchases to PHI. More details are available at <u>http://smile.amazon.com/about/</u>.

#### **Give with Bing**

Microsoft Rewards lets you support PHI through its Give with Bing program. After signing up and selecting our organization, you can earn rewards points just for searching the web with Bing. Microsoft then turns those points into cash donations to PHI.

The program is free—you just need to sign up with a Microsoft account. Sign up at <a href="http://bing.com/give/">http://bing.com/give/</a>.

# **Need Help Purchasing a Brace or Shoes?**

PHI has a special fund to assist with the purchase of a brace or custom-made shoes. The Joyce and Arthur Siegfried Memorial Fund provides grants of up to \$800 to assist polio survivors with out-of-pocket costs.

Learn more about the fund and download an application at

https://post-polio.org/siegfried-fund/. Or contact the office at 314-534-0475, info@post-polio.org.

The Joyce and Arthur Siegfried Memorial Fund was established in 2012 through an initial gift of \$7,500 from the Polio Network of New Jersey (PNNJ) in honor of Joyce and Arthur Siegfried, early advocates for the needs of polio survivors. Joyce Siegfried helped organize the first New Jersey Conference on the Late Effects of Polio in 1990, which led to the creation of the Polio Network of New Jersey in 1991.

# **PHI's Shining Star Hall of Fame**

Do you know a health professional who has made a positive difference in the lives of polio survivors? Here's a great opportunity to honor them in a meaningful way and support the post-polio cause.

To spotlight your Shining Star:

• Simply donate to PHI in honor of your special health care professional. This could be a doctor, psychologist, any type of therapist, chiropractor, nurse, dentist, home health aide or someone you know that has provided exceptional care and concern and helped you with your individual needs.

• Submit a short biography and a photo of the person along with a paragraph or two about why you nominated them. Then send it to <u>info@post-polio.org</u>. We will follow up and contact you.

You will be recognized as a donor in their honor. They will receive a letter of recognition and thank you from PHI, and their story will be showcased on our website.

# **Jn Appreciation**

Thank you for recognizing your friends and loved ones with contributions to the activities of PHI and IVUN and for your generous Membership contributions.

Please contact us if we made an error.

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

In Honor of Marny Eulberg, MD Barbara Ann Hawk Caregivers

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**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

https://post-polio.org/support-us/membership/ or send (or fax 314-534-5070) this form to: Post-Polio Health International, 50 Crestwood Executive Ctr #440, Saint Louis, MO 63126 USA. Questions? 314-534-0475.

#### Inside *Post-Polio Health* Vol. 38, No. 4, Fall 2022

Access to Knowledgeable Specialists Remain a Challenge for the World's Polio Survivors ... 1 PHI's 2023 Post-Polio Education Series ... 4 Tips for Keeping Your Aging Parents Safe ... 6 Promoting Positive Solutions ... 8

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