

PHI's mission is supported by its Membership.

A Declaration of Interdependence

Sunny Roller, MA, Ann Arbor, Michigan

"Need help with that ladder, Grandma? No? *Splat!* Oh, no! Grandma fell from the ladder! She's grimacing in pain and can't get up! Call the ambulance! There goes Grandma off to the hospital. Sigh. I wish Grandma knew that asking for help isn't a cop-out. It takes courage at first, but after that, it would make life a lot easier for all of us."

It seems that many people who are living into later life resist asking others for help in the name of independence and "not wanting to burden anyone." But what might life really teach us about managing its never-ending onslaught of challenges?

Maybe sharing my experience will be useful. As a polio survivor for 67 years who has used crutches, leg braces and now an electric scooter to get around, I was taught searing lessons early on about the difference between dependence and independence.

Dependence was a bad word. It conjured up images of being shut away in a medical institution or in a back bedroom somewhere, sick and infantile, totally reliant on others. I was also taught as a child not to be a burden on others and was chastised when I was moving in that direction.

Now I wonder about that. A burden? What does that mean? I guess it means being emotionally and physically needy, being a taker, childishly weak, unable or unwilling to participate in reciprocal relationships with those around us. When we are too dependent, do we become a thorn in the side of those near us, an affliction imposed upon others?

Independence, on the other hand, was a good word. A very good word. As children of the polio epidemics of the 1950s, we were indoctrinated with the goal of becoming fiercely independent as we went through our initial rehabilitation from acute polio. "Do it yourself! You fell? Well, figure out how to get up on your own! It's a cold, cruel world out there! You will always have to prove yourself to others," were messages I often heard from my parents and therapists. And those lessons worked well for me for a long time.

Now, as a mature adult who continues to live with a physical disability, I contemplate: could it be that dependence versus independence are two unreasonable extremes? Too much dependence can lead to dysfunction and low self-esteem. Conversely, too much independence can lead to burnout—always giving, always super-achieving.

continued on page 4



PHI Adopts New Mission

The board of directors of Post-Polio Health International recently voted to adopt a new mission statement for the organization. The change was made to more accurately reflect the purpose and activities of PHI as we move forward. “As needs of people dealing with the late effects of polio change, we try to adjust our efforts to reflect current issues with which we all deal. Thus, we are pleased to share our new mission statement which reflects that change,” explains Saul Morse, PHI board president. PHI’s previous mission statement was drafted in 2003.

Post-Polio Health International’s mission is to collect, preserve, and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.

In practical terms, little will change regarding PHI’s day-to-day operations from the perspective of our members. However, we felt it important to include our recent efforts to preserve the knowledge and materials we’ve collected over the decades so that they might be available to benefit future polio survivors and researchers.

We also felt the need to highlight the role that health professionals, family members and caregivers play in maintaining the health and well-being of polio survivors. As PHI Executive Director Brian Tiburzi explains, “We often field calls and emails from concerned children, spouses, friends and caregivers wanting more information about how they can best support those in their life dealing with the late effects of polio. These people often play a key role in maintaining our members’ quality of life and independence as they age.” ■

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Editor: Brian Tiburzi, MA
editor@post-polio.org

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

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How to contact PHI

Executive Director
Brian Tiburzi, MA
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.polioplacel.org

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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.

PHI would like to extend our warmest welcome to our newest members from Polio Outreach of Washington. Following the example of the Michigan Polio Network, POOW recently made the decision to cease operations, donating their remaining assets to PHI to meet legal requirements in exchange for PHI extending one-year memberships to their remaining active members.

While PHI is pleased to offer our services to our newest members, we were also glad to hear that some of the local chapters will continue to meet and provide support informally. PHI heard from the leaders of two of those groups.

Rhonda Whitehead ♦ Everett

For 23 years I have had the honor, privilege, and joy of being a leader of a post-polio support group, and it has been one of the most rewarding experiences of my life. What can be more fulfilling than helping others improve their quality of life?

The continuing journey to reach that goal, as we move through various stages of growth and development, is both complex and rewarding for me and for the members of our group.

Recently, rather than wanting more education on polio and post-polio syndrome, we are needing to be reminded of solutions to significant problems we are still experiencing. The reassurance that there is ongoing research being conducted for the benefit of all polio survivors across the world gives great comfort to us.

Our group's membership has gone from around 43 people per meeting to around 29. I try to give assurance that no matter what changes occur in our group, we can always continue to stay in touch and give and receive support and friendship to each other.

I have found that most of the polio survivors that I have come to know are caring, accomplished individuals dedicated to accepting, learning, and adapting to whatever is needed for them to meet their physical, emotional and mental polio needs, thus improving their quality of life!

Marlys Tron ♦ Tacoma

I have chaired the Tacoma, Washington/Pierce County Post-Polio Support Group for approximately 18 years. This continues to be something I enjoy thanks to some good help.

Currently we average 15-18 in attendance and meet ten months out of the year. We have an occasional speaker, a small spring raffle, group discussions and/or a "fun" event periodically like a white elephant exchange or Bingo for a small prize.

A newsletter is sent to members twice annually announcing programs and volunteers for refreshments on non-potluck gatherings.

Distance, age and reliance on public transportation have prevented some people from attending. Also, some simply feel they know enough about polio.

Over the years, our group has had some deaths with few new attendees. As with most polio groups, we are an older group; anyone younger than 70 is rare. In the future, this group will obviously become smaller, but we will adjust to changes as needed. ■

What, then, is the most sensible way to manage our daily lives now? Our greatest American document, other than the Constitution, is our Declaration of Independence. For people who are growing older with the late effects of polio or simply growing older with the late effects of life, I say we need to draw up a more evolved document: our own Declaration of Interdependence! Not wilting dependence. Not blazing independence. But interdependence.

Interdependence. It's "the quality of being mutually reliant on each other."

Trying to be that timeworn kind of independent doesn't work as we grow into our later life years. Trying to do everything without help is not only isolating; it can be dangerous. Climbing a ladder to hang curtains? A broken hip is no fun. Traipsing in the snow and ice to my roadside mailbox instead of arranging for front door mail delivery with the post office? Let's think outside the box (or in this case, the mailbox) about that issue! Asking for convenient mail delivery wouldn't be viewed as a cop-out by anyone. It's a smart thing to do. For me, front door delivery has become an opportunity to share a smile and good words with my mail carrier. And I know by her friendly tidings that she appreciates our positive rapport. Our new arrangement may also have spared her the horror of finding me stranded and struggling in a snowbank trying to retrieve my mail the old way.

These days, painting the fence or planting a garden could easily result in a fall, and then a popped bicep when trying to push up from the ground. My Declaration of Interdependence advises me to find a few twenty-year-olds who love outdoor work. Then give them some of my best home baked cookies, some money and my full attention as they do the work, share their interests and tell me all about their life plans. This way, everyone gains from the experience.

At first it might feel humiliating or distasteful to ask for new assistance, but it can be done. In fact, in my own medical situation, I discovered the hard way that it *must* be done. When I unexpectedly faced new debilitating pain, weakness and fatigue, known as polio's late effects, I had to ditch my uninformed ways of managing medical and lifestyle challenges. Now I pace myself and take the elevator instead of the stairs.

I also make sure to tap into the advice of physical and occupational therapists regularly. Since the early 1980s, polio survivors numbering in the hundreds of thousands around the world have, in the spirit of interdependence, created and participated in our networking organization, Post-Polio Health International (PHI).

Through PHI, post-polio medical professionals and survivors have learned from each other about the late effects of polio. They have become healthcare-interdependent. Banding together, they have supported cutting-edge medical research, built an extensive library of scientific and historical information (www.polioplace.org) and continue to advocate for resources. It's powerful to witness medical professionals and their patients become each other's experts as they come together in conferencing, publishing newsletters, and linking up on a variety of web-based platforms.

Interdependence. It's "the quality of being mutually reliant on each other." Under the guidance of this new Declaration, my neighborhood buddies and I now have added opportunity to enjoy each other's company because we are more open about expressing our changing needs. As we talk, we agree to show up for each other in new ways.

In the process, we have identified one key to success. I make sure that what I ask others to help with is something they genuinely like to do. Some enjoy running errands. Others treasure their cooking skills. Still others love to help with craft or sewing projects. And they, in turn,

know what I would do best for them. Drawing upon our specific talents almost always guarantees that our exchange will be mutually rewarding.

My Declaration of Interdependence also extends to willing strangers whom I encounter in public places. Often, I ask unsuspecting shoppers at the grocery store for assistance in reaching items on high shelves. My reciprocal gift to them can be sizeable or simple. A warm hearted thank you and recognition that their kind assistance is truly valued may be the only boost they have had all day.

Adopting a renewed level of mutual exchange makes sense because we have always needed others and they have needed us. Surprisingly, I have found that life can be even more deeply gratifying as I risk receiving and giving in unexpected new ways. Living out my new Declaration of Interdependence has been different. It's also been delightful. ■



About the Author

Ms. Sunny Roller was paralyzed from childhood polio in 1952. She is semi-retired from the University of Michigan. Sunny currently serves on the Board of Directors of Post-Polio Health International. She also works as a freelance writer who may be contacted through her blog on living well into later life with a disability at www.sunnyrollerblog.com.

PHI Signs Agreement with University of Massachusetts Amherst

Post-Polio Health International is pleased to announce that we have entered into an agreement with the University of Massachusetts Amherst whereby UMass Amherst has agreed to add PHI's archives to its special collections. The agreement will ensure that material in PHI's archives—collected over several decades dating back to the 1950s—will be preserved and made available for future use.

As PHI Vice President Dan Wilson, who spearheaded the effort, describes, “The PHI archives will join a fine disability collection at the University of Massachusetts’ Special Collections and University Archives. The University of Massachusetts will preserve and digitize our archives, making them available online to polio survivors and researchers worldwide.”

UMass Amherst currently has twenty-five collections related to various disability issues. To peruse their current holdings, go to <http://scua.library.umass.edu/umarmot/category/social-change/disability/>.

In the coming months, PHI will begin the process of organizing and selecting appropriate materials from our archives for preservation. When this process is completed, the materials will be sent to UMass Amherst, where they will begin the digitization process. PHI will post a notification in our publications when the materials become available online.

We are excited to have found a permanent home for our archives so that these valuable materials can continue to educate and enlighten others about polio and its effects even beyond the life of the organization. ■

Gratitude Reframes Everything

Vaneetha Rendall Risner, Raleigh, North Carolina



Vaneetha Rendall Risner

For those of us with post-polio syndrome, sometimes it's hard to be grateful. Each year we are faced with new losses, and we're forced to give up activities and hobbies we once loved. For many of us, the life we once knew keeps shrinking. But the more we focus on what we've lost, the harder it is to enjoy what we have, which has implications for both our mental and physical well-being.

In his book *Thanks! How the New Science of Gratitude Can Make You Happier*, Dr. Robert Emmons recounts his studies on the effects of thankfulness. He conducted studies with various groups, including one solely comprised of participants with post-polio syndrome. For all the studies, he divided everyone into three groups, asking each to make weekly journal entries for 10 weeks. The first group was asked to write five things that happened the prior week that they were grateful for, the second group wrote down five hassles from the previous week, while the third group simply listed five events from the prior week.

The gratitude group often mentioned everyday events like seeing the sunset through the clouds or experiencing the generosity of friends. The hassles group mentioned things like paying taxes or coming home to a messy kitchen, while the third group just listed things they had done.

The results of the study were shocking. Those in the gratitude group were 25% happier than the other two, were more optimistic about the future, were healthier and less stressed, and even slept better. Nothing in their lives had changed—they had simply found things to be grateful for. These results were sustained weeks and even months later.

In a separate study, Dr. Emmons sent surveys out to over 300 people primarily struggling with post-polio syndrome and asked them to write about a time when they felt gratitude. He chose this group because he wondered if they'd be able to recall anything given their situation. Some like this 64-year-old woman found little to be grateful for:

My feelings of gratitude are fleeting and few and far between. I suffer from post-polio and have a great deal of anger toward this disease. It robbed me of my ability to continue my career, which I truly loved, and has had a deleterious effect on my everyday life. There is a lot of physical pain involved, to say nothing of the emotional stress. Almost any activity I want to do is no longer a spontaneous happening ... I've no intention of taking my own life, but there are days when I feel that I'd just as soon not be here.

Contrast this with this account is from a 66-year-old woman who contracted polio at age 7:

Our family was on vacation in Florida. My brother and I had been playing in the waves along the beach when I became very chilled and was shivering with a high fever of almost 107° ... For several days and nights, everyone expected me to die ... My mother said that the bobby pins in my hair rusted from the sweat when my fever broke. I clearly remember mother telling me this and also the gratitude upon her face and in her voice that I had lived. [This] made a profound impression on me, which is why I have always felt that life is a gift ... a gift to be cherished.

While most of us can relate to parts of both these women's stories, we can also see that the second one is happier; she's grateful to be alive. Dr. Emmons saw that people who could find the positive aspects of a negative situation were significantly happier than those who could not. So how can we, as polio survivors, learn to cultivate gratitude?

We can all look at the effects of polio on our lives and search for the positive things we have gained as a result. We can journal what we are thankful for each day. We can choose to focus on common blessings like a warm summer day, a hot cup of coffee, or a life-giving conversation, all of which can reframe our perspective. When we practice gratitude, we will be surprised at how much it changes us.

From all his research, Dr. Emmons concluded that the benefits of gratitude were significant and measurable. He found that being grateful magnifies our happiness and joy in everyday things and lifts our emotions. It encourages us to identify the good things in our lives and to celebrate what we have. It combats depression, makes people more resilient to stress and enables them to plan for the future. For those of us who deal with continual loss, being grateful has the power to transform our lives—if we let it. Gratitude reframes everything. ■

Vaneetha Rendall Risner is the author of the book *The Scars That Have Shaped Me: How God Meets Us in Suffering* and blogs at danceintherain.com—though she doesn't like rain and has no sense of rhythm.

A REQUEST FROM PHI

PHI is asking for your help. Do you know of financial resources available specifically for polio survivors to help purchase medical equipment? PHI and the University of Michigan Department of Physical Medicine and Rehabilitation are undertaking a project to compile a directory of these resources. Besides doing a deep search of the internet, we are reaching out to consumer and professional networks. The end goal is to create a list and publish it nationally for everyone to use and share.

More information about the project is available on Sunny Roller's blog (www.sunnyrollerblog.com/post-polio-medical-equipment-funding/). Sunny was instrumental in securing funding for this effort and is organizing the project. If you know of any resources, please send them to info@post-polio.org. We are interested in actual monetary support, not loan closets or low-interest loans. Please include the name, address, phone number and web address along with a two-sentence description of how the specific national or state resource (ex: a philanthropist or organization) would help polio survivors pay for needed medical equipment. ■

QUESTION: *I had polio when I was three. I made a pretty good recovery and have lived a full life. I'm 64 years old now and have worked my whole life. These past few years, my leg has gradually been getting weaker. I finally had to stop working this past February. I realize I'm luckier than most, and I was getting close to retirement age anyway. The time off helped my weakening leg, but the adjustment has been hard. I really did enjoy going into work, and it gave me a sense of fulfillment and usefulness. I thought I would enjoy having all this free time, but I feel like I'm adrift, in a sense. Do you have any advice? What has worked for other polio survivors?*

Response from Rhoda Olkin, PhD:

This person says that “*I finally had to stop working this past February.*” I’m going to address the question of how one knows when to retire. Is it when one “has to,” or when one “wants to” or does something else determine the decision?

Of course, finances are one of the important drivers of continuing to work or retiring. Your social security benefits are available starting at age 65, but you will get more money per month at age 70 than at age 65. When you get your Social Security Statement, they tell you what this difference in income is. If the amount is negligible, then waiting to a higher age may not be significant. The difference can be more considerable—for me it would be \$300 a month extra, which I believe is enough of an incentive for me to wait. The other part to consider is your retirement savings. If you were to take out a sufficient monthly amount (including your social security payments) to live decently, how long would your money last? For example, I have enough to get by until I’m 94, and then I really should die because I will be out of money! Given the general longevity of my family, I cannot count on that—another reason I’m still working at age 66.

Another consideration is more nebulous—what do you want out of life? If you

wait until you “have to” retire, it probably means your energy and stamina are lower, and perhaps your pain is higher. Is this how you want to retire, or do you want to do it early enough that you can enjoy retirement doing those things you love (gardening, travel, painting, pottery, visiting friends—whatever is your bliss). If the kind of job you have is part of your identity and satisfaction, then you might want to stay at it longer than if it is a McJob that you do for the income. As a psychologist and professor, my job is a large part of my identity. On the other hand, after mentoring about 100 dissertations, they have started to lose their impact on me, and most of the meetings I have to attend have an aura of déjà vu. So, it’s a mixed factor, making when to retire a more difficult question.

Retiring is not necessarily all or nothing. It might be possible to go part-time, or to retain only portions of the job and excise other parts. Considering a different type of job that is less stressful is another idea. For example, when I retire from being a professor, I will continue my private practice as a psychologist, since that allows me to sit in a chair and be wise, without commuting (and no meetings!). Volunteering is another option in retirement. The needs are great and various. If your job gave you satisfaction, then finding someone else that is fulfilling may be an



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.

important consideration. Doing *pro bono* work (using your particular work skill set) in another way is another choice.

These are hard choices, and ones only you can make. None of us knows our future, so we can only make decisions based on our *now*. When you wake up tomorrow, what would you like your day to look like?

Response from Stephanie T. Machell, PsyD:

Most of the polio survivors I've known who've had to stop working due to PPS felt physically better after a few months. Despite this, most also found it difficult to adjust to retirement. Like you, they enjoyed work and the sense of purpose and usefulness—and structure—it provides. And they hadn't been ready to give that up.

Even when it's a choice, retirement is a major life transition. When you're in transition, it's natural to feel adrift. As William Cunningham explains in his classic book *Transitions* (which you might find helpful), the period between leaving one place and arriving in another is a phase of its own that allows time to grieve what you've lost while you develop plans for what will come next. Because this phase is so uncomfortable, it's tempting to end it as soon as possible. But doing so can prevent you from making the best adjustment possible.

Transition times are good for considering what's next. During yours, you've already found out that you (like most people) don't enjoy large amounts of (unstructured) time. It is helpful to structure your time around one or more major activities. As Dr. Olkin points out in her answer, work in retirement isn't all or nothing.

Could you work part-time, even a few hours a week? Consult? Volunteer?

Seriously working at a creative endeavor like writing, art, or music can also create structure for your days, as can taking classes through your local adult ed program or college. Make regular plans to spend time with family and friends. See what activities are offered at your local senior center. Most libraries have book clubs, including some aimed at retirees. There are a variety of civic and religious organizations you can check out. Dedicating regular time to hobbies also provides structure.

Not sure what you enjoy doing? Now's a good time to find out! Think about what you were passionate about when you were younger, or what you've always thought you'd like to do if only you had time. Notice what draws your attention. Be open to trying new things long enough to discover whether you enjoy them—and feel free to drop them if you don't.

As you develop your schedule, make sure you take into account your need for energy conservation and pacing. Polio survivors often find that structuring their time to create a rhythm of activity then rest helps minimize symptoms. For some this may mean active days are followed by rest days. Others, like my dad, alternated activity and rest throughout the day.

As you move into and through your retirement years, it's likely what you want and need will change. For example, some people start out certain they want to work only to discover they enjoy having time to do other things. For others it's the opposite. Allow your plan to evolve and change as you do. ■

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.



Book Review: Polio and PTSD

Stephanie T. Machell, PsyD

Polio and PTSD: One Person's Struggle with and Triumph over the Psychological Damage of a Major Childhood Illness

by Charlene Elizabeth (Lulu Publishing Services, 2019) is a memoir focused on what the author refers to as “one large strand in the braid of my life.” She provides a spare, often harrowing description of the extreme pain of acute polio and her fear that she might die, and the ways both were intensified by isolation from those who might have provided comfort and reassurance.

Rehab provided some respite from isolation along with new discomforts in the form of Sister Kenny treatments and confinement (“I would spend the next six months confined to a space about the size of a child’s grave.”) Subsequent surgeries exacerbated her physical and emotional pain. Her parents’ reactions, especially her mother’s suggestion that she should pretend none it happened, reinforced the shame she already felt over the changes polio made to her appearance and physical abilities and further fueled the need to pass as well as the sense that she would never be loved.

Ms. Elizabeth describes how these experiences caused her to develop depression and PTSD. She identifies her own struggle around denial and ultimate acceptance of the latter diagnosis and discusses what helped (and hindered) her recovery. She is clear that while she continues to experience effects of both as well as PPS, she has been able to construct a life filled with meaning and periods of joy.

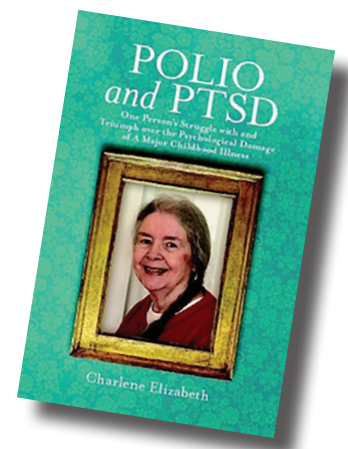
The author writes in an accessible, almost conversational, style. Polio survivors, especially those who have faced mental health challenges, will identify with her experiences. There is also much of value

for all who care for and about polio survivors, including those of us who do so professionally.

As someone who believes in and utilizes alternative and complementary medicine, I appreciated the author’s comments about its helpfulness for her, though I disagree strongly with her perspective that she (or any other polio survivor) somehow “caused” or “agreed to” her polio. And while I (obviously) agree that psychotherapy is useful for addressing the late effects of polio, I don’t believe that it follows that it might be primarily a psychological condition. As this is a memoir and not a professional treatise, the author’s hypotheses about her condition are appropriately stated and form an important part of how she has made meaning of her experiences.

At 53 pages, *Polio and PTSD* is a quick and easy read. However, I was left wanting more details about Ms. Elizabeth’s experiences. As is true for many self-published books (and increasingly so for those more traditionally published), this one would have benefitted from better editing to catch typos and other errors.

Overall, *Polio and PTSD* is a worthy addition to the polio literature. Its emphasis on psychological issues that are less often emphasized in polio narratives makes it especially important and useful. ■



PHI invites you to participate in its 2019 WE'RE STILL HERE! campaign during the week of October 6-12 by going out and spreading the word about the importance of vaccination.

You have no doubt seen stories pop up in the news this year about measles outbreaks in New York, Los Angeles and other cities. Through July 25, the CDC has confirmed 1,164 cases this year—for a vaccine-preventable disease that had been declared eliminated in the US in the year 2000.

Vaccination rates remain high overall in the US, but vaccine exemption rates among infants and school-aged children have been quietly rising, creating pockets of unimmunized individuals that put themselves and others at risk. In response, some states have begun to consider revoking non-medical exemptions.

Too many people these days underestimate the threat of vaccine-preventable diseases because they have no firsthand knowledge of their effects. In a sense, vaccines have become a victim of their own success. Most people have no idea what it's like to contract polio, rubella or the mumps.

"But what role can I play?" you may be asking.

A recent study from a team at Brigham Young University published in *Vaccines* identified talking to people who had vaccine-preventable diseases as one of the most effective ways to change vaccine skeptics' minds. "If your goal is to affect people's decisions about vaccines, this process works much better than trying to combat anti-vaccine information," said Brian Poole, PhD, a co-investigator on the study. "It shows people that these diseases really are serious diseases, with painful and financial costs, and people need to take them seriously."

PHI is encouraging you to use WE'RE STILL HERE! week to approach local media outlets, schools or other community groups to talk about your experience and why vaccinating your kids is important. PHI will help by supplying you with a factsheet containing relevant information and talking points. Once you are scheduled to speak or give an interview simply email us at info@post-polio.org or call us at 314-534-0475 and we will get you the resources you need.

So get out there and show them that WE'RE STILL HERE! ■

In 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.*

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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. 35, No. 3, Summer 2019

A Declaration of Interdependence ... 1

Gratitude Reframes Everything ... 6

Promoting Positive Solutions ... 8

WE'RE STILL HERE! 2019 ... 11

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