

PHI's mission is supported by its Membership.

## My Path to Advocacy

Grace Rossow, Springfield, Illinois, [gracerossow@gmail.com](mailto:gracerossow@gmail.com)



Grace Rossow

**M**y name is Grace, and I am a polio survivor from Nagpur, India. I was born in 1992 and adopted a year later in St. Louis. Having polio has always been a driving force in my life. I received the majority of my orthopedic care at Shriners Hospital in St. Louis—my passion for advocacy was sparked at Shriners. My two doctors were Perry Schoenecker, MD, and Eric Gordon, MD. Over the years, I had multiple surgeries such as leg lengthening and tendon releases. Thanks to them and my orthotist, Eric Crawford, I am able to walk with a KAFO brace and live a pretty independent life. Currently, I am a phlebotomist at a busy ophthalmology office!

My family was never shy about my polio diagnosis, but until I was in college, I did not necessarily understand the complexities of polio. When I was eight years old, my mom brought home *Small Steps, The Year I Got Polio* by Peg Kehret. I remember feeling terrified as my grandpa read this to me; I was too young to realize that I was not going to end up in an iron lung. Thankfully, my mom waited a few more years and read *Small Steps* to me again—I was significantly less scared the second time. Fortunately, I never experienced bullying in school, and I still am very open about living with a disability. A core belief of mine is education is key to prevention. When society forgets about polio, then we need to worry about a resurgence.

In high school, Shriners offered me a chance to be featured in their “Pre-Op Surgery” video. I’d be explaining to patients what they’d see and feel before their surgery; this is where my advocacy work truly began. I realized that I adored medical education and medical advocacy—making sure people feel comfortable and educated about their procedure, diagnosis or hospital stay is vital to recovery and long term outcomes.

This is how I became a Patient Ambassador for Shriners, speaking at the hospital and in public about my experience with polio and the importance of vaccines. I began to speak at events around St. Louis and news interviews.

Attending college and living on my own is when I truly discovered the intricacies of polio, specifically urinary tract and kidney infections due to my vagus nerve

being affected. I spent two years bouncing between specialists and undergoing testing to determine what was occurring. This caused me to begin to research and advocate for myself. I began to realize

*A core belief of mine is education is key to prevention.*

living with a disability was incredibly expensive, and I was so lucky to have parents who could help me out with the financial side of everything. I would not be where I am today without the support of my family, boyfriend and friends group.

Beyond having to advocate for myself in the healthcare system, I realized I could advocate for kids who have anti-vaxx parents. I wanted to reach these parents, and I wanted to prevent any other child

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from receiving a diagnosis of polio. I have always been active on social media and noticed that when I posted about polio, my engagement with posts would increase. This got me thinking about how I could use my social media presence to advocate for vaccines and prevent polio from coming back. I began posting on Facebook and Twitter about having polio. People noticed. In 2018, I was approached by Erin and Erin, host of

This Podcast Will Kill You, for an interview. We talked about the medical and social issues surrounding disability. I began to realize more and more just how lucky I am and how badly our healthcare system needs an overhaul.

Polio survivors have one of the most unique perspectives on vaccines and COVID-19. We have experienced a vaccine preventable disease (VPD) and cannot fathom why someone would refuse a vaccine for another VPD. During the COVID-19 pandemic, I ramped up my advocacy work, reaching out to news organizations, medical professionals, and posting in Facebook groups.

I realized that I needed to use my voice and privilege to advocate for the COVID vaccines. One of my favorite ways to network with others is an “Ask Me Anything” post in large Facebook groups. This has allowed me to meet multiple people within public health and educate people about polio.

Living with polio has affected every area of my life, but I would not change it for anything. I am honored to use my voice to advocate for children who have anti-vaxx parents, to provide education to families about vaccines, and hopefully to prevent anybody else from contracting polio. ■



## POST-POLIO HEALTH

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*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.*

### How to contact PHI

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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.

Last issue PHI rolled out a new campaign asking you to honor the health professionals, past or present, who have made a positive difference in your lives. What a great opportunity to honor them in a meaningful way and support your 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 [info@post-polio.org](mailto:info@post-polio.org). 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.

Read about our latest nominee below. And check out the complete list at [www.post-polio.org/networking/shining-stars/](http://www.post-polio.org/networking/shining-stars/)

## *Mike LaBounty, DC, Ankeny, Iowa*

**Nominated by Patti Whitham, Madrid, Iowa**

I am honored to nominate my “Shining Star,” Dr. Mike LaBounty of Bountiful Life Chiropractic in Ankeny, Iowa. He is the embodiment of grace, compassion and humility as he cares for his patients. As a deeply spiritual man, he embraces a total wellness approach toward optimal health. I was referred to Dr. Mike many years ago by a dear friend while he was in the early stages of establishing his practice. At the time, I was experiencing major symptoms of post-polio syndrome and was at my wits end with no post-polio specialist in the area to turn to. Dr. Mike and I bonded from the get-go. He soon learned my particular bodily dynamics, what adjustments were necessary to maintain ADLs, as well as balancing misalignments of the spine/hips.

As with many polio survivors, my non-polio side has overcompensated over time for a weakened polio side, causing wear and tear in those joints. When discussing these issues, Dr. Mike does not hesitate to seek opinions/treatment from orthopedic specialists. My gait/posture is often observed—we monitor leg length and discuss the importance of good, solid shoes that will sustain an ortho lift on the short polio-affected leg. X-rays and physical exams are completed periodically so, as a team, we are abreast of any changes or adjustments in treatments.

Dr. Mike has and continues to embrace the challenges of treating patients with the late effects of polio. He understands and concurs with my desire to remain physically active, even on occasions when I “overdo” it. I am appreciative and thankful for Dr. Mike LaBounty for partnering alongside me through the years. He is my healthcare HERO and “Shining Star.” ■





# NO SPRING CHICKEN:

## Stories and Advice from a Wild Handicapper on Aging and Disability

Francine Falk-Allen

I don't claim to know how life is for every person with a disability, but in my second book relating the vicissitudes of disability (and aging), I am hopeful that I've offered enough universal truths and suggestions that people will find it a beneficial—and entertaining—read. My own disability experience is this: polio at age three in 1951, with residual paralysis, weakness and greatly stunted growth in one leg. No picnic, but here I am at 73, having lived a rather remarkable life, with a lot of living left to do.



In *No Spring Chicken*, I offer my take on navigating the complications aging brings, aspiring to do so with equanimity and a sense of humor. Part of what I wanted to share with people is what I have learned about accessible travel: how to enjoy traveling even with a disability, with stories about the many places I've visited that were easy and rewarding, and also anecdotes of ridiculous experiences that I learned to avoid or work around.

When I wrote my first book, *Not a Poster Child: Living Well with a Disability—A Memoir*, I felt I could not present a lot of “self-help” material. Yet I still wanted to relate for people who are family or friends of people with disabilities some of the things we go through, or how our disabilities affect our psyches, which loved ones might not realize, and what they could alter about what they say or do that would make it easier for us to have harmonious relationships. A small example: I suggest that standing people refrain from patting us on the head when

we are seated in a wheelchair! If you've had this happen, you may have been as irritated as I (and my sister) have been; it's as if we've become a pet or a child in the eyes of the standing person. I share my own sense of how having a disability

has affected my mind and personality, and also talk about the difference for someone who becomes disabled later in life. I think, as do some other people with disabilities, that as polio survivors, we've had a lifetime to become used to accommodating a disability. But it seems to be harder for a person who had full use of his or her body to adapt to the changes aging or loss of function (at any age) can bring. So, I sincerely recount those sorts of issues, from the point of view of a person who has had a lifelong disability.

Given I've learned to manage a myriad of difficulties and am still in pretty good health, I also wanted to share for folks who are disabled or aging (or both) what I've learned that has been successful for me regarding exercise, diet, pain management, mobility, care tips, how to choose and use canes or crutches, and more. I do yoga and core strengthening every morning, so I included that practice and drew my own illustrations of the floor poses. I described the pool exercises I do a few days a week, which were taught to me by a physical therapist knowledgeable in polio. I have found support groups of many stripes to be not only encouraging but a boon to feeling known at a profound level, so I detail some of those groups and spell out how to start a group if you can't find one that already exists for the interest or problem you have.



Having done a great deal of reading on these subjects and gotten myself up to speed on disability rights, I included a chapter that's an homage to the activism of those who paved the way for the Americans with Disabilities Act.

I hope that people will find *No Spring Chicken* accessible, informative, encouraging and wryly funny. It's meant to be a spirited guide to living your best and longest life, whatever your physical challenges and whatever your age. ■

*No Spring Chicken* is available for pre-sale wherever books are sold and will be published in June 2021.

For more, visit  
<https://FrancineFalk-Allen.com> or  
[www.facebook.com/rancinefalkallenauthor](https://www.facebook.com/rancinefalkallenauthor)

## CPPO to Hold Wellness Retreat in August

The Colorado Post-Polio Organization (CPPO) will hold a wellness retreat August 15-19, 2021, at Rocky Mountain Village Camp in Empire, Colorado.

Participants will be able to choose from a menu of educational forums, exercise activities and fun. The retreat will be attended by healthcare professionals knowledgeable about the late effects of polio. Evening activities will include live entertainment and social time.

Learn more and download the application at [bit.ly/cppo2021](https://bit.ly/cppo2021) or email Mitzi Tolman at [mtolman@eastersealscolorado.org](mailto:mtolman@eastersealscolorado.org).





## PHI Is Pleased to Welcome Ann Crocker to Its Board of Directors

**Ann Crocker** is our newest member to PHI's Board of Directors. A co-founder of the Post Polio Support Group of Maine, she remains active in the group, including compiling and writing the newsletter sent to nearly 500 people. Ann's career included working as a paralegal, property manager, financial analyst and oversight manager in a number of areas at the state housing authority of Maine. While working fulltime, she completed her BS degree and MBA by taking evening classes through the University of Maine system.



Now retired, Ann pursues her interest in health-related topics, such as nutrition and research. She has been a spokesperson for the importance of protecting our children through vaccination against so many potentially diseases, such as polio. Volunteerism also included chairing public suppers and being treasurer of her local fish and game club for over 25 years.

"I value the wonderful work PHI offers polio survivors, medical professionals and the general public. PHI is a topnotch source of credible information and services," says Crocker. "I'm looking forward to working with other members of the Board to help continue PHI's quality services." ■

## Past Iron Lung Users Sought for Oral History Project

The Mütter Museum (<http://muttermuseum.org/>) at the College of Physicians of Philadelphia, one of the country's foremost medical history museums, with a mission of promoting the heritage and future of medicine and health, recently put up a new exhibit on the Iron Lung. They are looking to get in touch with those who spent time in one to record short verbal histories describing their experiences. The recording can be done via phone or Zoom.

If you are interested in participating in this project, please contact us at [info@post-polio.org](mailto:info@post-polio.org) or 314-534-0475, and we can put you in touch with the project coordinator. ■

### Did You Know?

PHI's online **Post-Polio Directory** (<https://www.post-polio.org/networking/directory/>) has links to funding resources near you. For local assistance, simply type your location into the search bar next to the map. For national resources, scan the listings below the map.

PHI also has a program to help fund the purchase (up to \$800.00) of a brace or custom-made shoes.

To learn more, go to <https://www.post-polio.org/siegfried-fund/> or call the office at 314-534-0475. ■



## Leave a Legacy

Below are a few suggested donation types that can be given now during your lifetime or set up as a planned donation to Post-Polio Health International.

1. **Donations of Cash:** This the simplest and easiest way for you to make a donation. You may receive a charitable tax deduction on your tax return.
2. **Donations of Stocks and Bonds:** A donation of appreciated stocks and bonds. You could avoid capital gains taxes that would otherwise be due if you sold them directly. Contact us to facilitate.
3. **Donations from Retirement Accounts:** If you have Traditional or Roth IRAs and are age 70½ or older, you may make a qualified charitable distribution directly from these IRAs without incurring any adverse federal income tax consequences. The distribution counts toward any Required Minimum Distribution (RMD) but is not included in calculating the individual taxpayer's limitation on charitable deductions in the year the donation is made.
4. **Donations of Insurance Policies:** This donation can be made outright for cash value, or by naming Post-Polio Health International as beneficiary. Talk to your financial advisor or attorney about these and other ways to create a meaningful way to help Post-Polio Health International continue to fulfill its mission.

## Give Back with

AmazonSmile is a simple way for to support your favorite charitable organization every time you shop, at no cost to you. Simply go to [www.smile.amazon.com](http://www.smile.amazon.com), log in, choose "Post-Polio Health International Inc" (you are only required to do this the first time) 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 <http://smile.amazon.com/about/>.

## Matching Gifts

Does your employer offer a matching gift program? Ask your HR department if your employer will make your gift have twice the impact. ■

**PHI:** *Even though my wife is eligible to receive the COVID-19 vaccine, she has yet to do so. I've shown her the information on PHI's website that encourages polio survivors to get the vaccine, but she still has some trepidation. It is still so new, she says. What if there is some long-term side effect we don't know about? I feel like the very real risks from contracting COVID-19 far outweigh any theoretical (or irrational) concerns about the new vaccines. How can I put her mind at ease and convince her to get vaccinated?*

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

People have different levels of risk tolerance. I am assuming your wife's is quite low for the unknown (like long-term vaccine side effects) while her tolerance of known risks (like that of contracting COVID-19) is higher. Research has shown that the ability to estimate risk is poor at best. Most of us overestimate the likelihood of low-probability, high-risk events while underestimating the risk posed by higher-probability, high-risk events. This is why few people hesitate to drive a car (higher probability of experiencing a serious accident) while many fear flying (lower probability). Low probability doesn't mean no probability (which is why lottery tickets sell so well). Having already experienced one low-probability event (paralytic polio only occurred in 1-5% of cases), your wife may be more fearful that she could experience another.

At this time, no one knows whether there will be any long-term vaccine side effects, let alone how high the probability of experiencing them might be. However, there is information available that might help reassure your wife. One clear but thorough explanation of the vaccines including how they work and why the risk of long-term side effects from them may well be quite low can be found at: [https://www.cdc.gov/coronavirus/2019-ncov/vaccines/different-vaccines/mRNA.html?CDC\\_AA\\_refVal=https%3A%2F%2Fwww.cdc.gov%2Fvaccines%2Fcovid-19%2Fhcp%2Fmrna-vaccine-basics.html](https://www.cdc.gov/coronavirus/2019-ncov/vaccines/different-vaccines/mRNA.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fvaccines%2Fcovid-19%2Fhcp%2Fmrna-vaccine-basics.html). If she hasn't, encourage her to speak with

her healthcare providers about the risks and benefits of getting the vaccine as opposed to contracting COVID-19.

I am assuming you and other family members have been or are scheduled to be vaccinated. Talk about how you made your decision, what getting the vaccine was like, and how you felt afterwards, including any side effects you might have experienced. Family members and close friends may also need to let her know whether they will be willing to take the risk of socializing with her (and you) if she remains unvaccinated. And you may need to let her know how her decision will affect you and your marriage.

She may still argue that it is her choice. But it's a choice with consequences for anyone with whom she comes in contact. If she remains unvaccinated, no matter how careful she is she could contract COVID-19 and spread it to you or others she loves. And if enough people make the same choice, there is a high probability that infection rates will remain high, more dangerous variants will emerge and lives will remain restricted.

Which brings me to my final thought: Is your wife's vaccine hesitancy in part due to a wish not to go back to the way things were before? Maybe the slower pace of pandemic life has improved your wife's PPS symptoms. Or maybe she has experienced more symptoms over the past year and doesn't want others to see how reliant she has become on assistive devices. If so, it might help to reassure her that once she's fully vaccinated no one will pressure her to become more active than she wants to be.



**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.



**PHI:** *I have used a wheelchair since I was in my twenties and in recent years have developed significant neurological pain in my shoulder. I have tried a number of treatment options with varying degrees of success. One thing I have noticed is that stress tends to exacerbate the pain. This past year, because of the pandemic, has been particularly stressful for me. What are some things I can do to deal with this stress?*

**Response from Rhoda Olkin, PhD:**

You are quite right that stress increases pain, in two ways: it increases inflammation which causes pain, and it decreases tolerance thus increasing our perception of the pain. This is a vicious cycle, since the pain becomes a stressor in itself. The past year (and more) of the pandemic has been stressful in so many ways, including economics, health, social isolation, contagion and illness fears, relationships. And that's true even if you never watch the news!

I wish I had a magic pill for stress. Learning to manage one's level of stress is an important life skill, and like all skills, it takes learning, practice and repetition to get better. I'm going to suggest a few ideas, all of which will not seem like they are helping one little bit until you have incorporated them more fully into your daily routine and your mindset. Remember to breathe deeply (four counts inhale through the nose, hold for four counts, let it out through your mouth for four counts).

First, accept that you are stressed. If one track in your mind is saying "I'm so stressed!" and the other track is saying "You need to stop being so stressed!" then you are compounding your stress. Second, at the end of each day, write down three things that went well that day. These can be really small things, like "I liked that new toast I tried" or "there was no line at the grocery store" or "I got a load of laundry done today" or "I worked on that project for fifteen minutes." If you

really and truly cannot find three things, it might be that you are trained to look for the negative (through upbringing or disposition or depression) and have to reprogram your perceptions. Or it might be that you really don't have three good things and your life really is out of balance, and some changes need to be made.

***Smiling makes even depressed people feel better and laughing releases endorphins.***

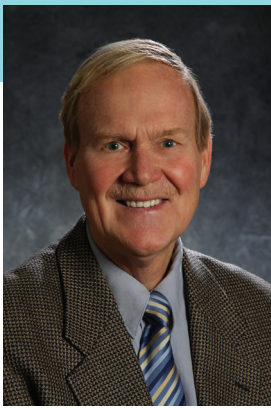
Third, do nice things for yourself. Light a candle at the dinner table, hire someone to clean the house, have a donut, drink tea in the middle of the day, get your car detailed, buy a houseplant. Fourth, socialize, whether by Zoom or phone or Facetime or however. Do this even when it might feel like you don't want to. It can be for just ten minutes a day.

Fifth, do something for someone else. Whether it's part of a nonprofit organization (hey, I just happen to know one related to polio!) or a friend, neighbor or family member, doing for others has been reliably shown to improve moods. And lastly, smile and laugh. I don't mean this ironically. Smiling makes even depressed people feel better and laughing releases endorphins. So, look for the funny wherever you are.

And thank you for writing – you are not alone in feeling stressed and your question is timely. ■

**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.





Frederick M. Maynard, MD

## Ask Dr. Maynard

Send your questions for Dr. Maynard to [info@post-polio.org](mailto:info@post-polio.org).

See other questions at [www.post-polio.org/living-with-polio/articles-post-polio-health#AskDrMaynard](http://www.post-polio.org/living-with-polio/articles-post-polio-health#AskDrMaynard)

**Question:** *I am going to have a heart stress test. Is it dangerous for a 72-year-old polio survivor who has some breathing problems to do so?*

**Dr. Maynard:** A Stress Test does involve some risks, but they are minimized by medical professionals trained and equipped to handle cardiac arrests and arrhythmia should they occur. I am unaware of evidence to say the risks are higher for those with breathing impairments or for polio survivors in general. In fact, risks may be lowered because muscle weakness limitations or breathing limitations may make it more difficult for the person being tested to reach a level of work to 'stress' the heart to its maximum. This issue limits the reliability of Stress Tests but not their risks.

The most important thing for you is to have an opportunity to explain any of your unique post-polio limitations in performing the exercise maneuvers that will be used for the Test and for you to not be pushed beyond your limits. While this may limit the value of the test results from the cardiology doctor's perspective, it will at least keep you safe from an iatrogenic new problem. And there are other ways to assess heart issues of concern.

I hope it all works out for you.

**Question:** *I'm a 69-year-old male who contracted polio in the early 1950s. My right arm was totally paralyzed from contracting polio. I was diagnosed with PPS about nine years ago. During the diagnosis, I was told that my left arm had serious muscle weakness. At the time, the doctor said my deltoid muscle was roughly 40%. When my primary doctor learned I had problems previously having a flu vaccine administered, he advised me to have my next flu vaccine administered in my thigh. When I requested this, I was told their guidelines strictly state that the vaccine can only be administered in the deltoid muscle of either arm.*

*Since then the manufacturers of both my flu vaccine and my pneumonia two-dose vaccine have changed their administration procedures to allow the shots to be administered in the thigh.*

*The problem I now face is that both Pfizer and Moderna state in their administration protocol that their vaccines are to be administered in the deltoid muscle only.*

*Not wanting to be faced with the possibility of scheduling an appointment for the vaccine, going to receive it, and then being told I can't get it in my thigh, I have tried calling both vaccine manufacturers but was not able to speak to anyone helpful.*

*Can you help me with this? Surely there are others who face the same dilemma. Can you delve into this? The thought of not being able to receive the COVID-19 vaccine has my wife and me quite worried. I would greatly appreciate your assistance.*

**Dr. Maynard:** I totally understand your frustration which reflects the difficulty our heavily-regulated health care system has for making simple and appropriate exceptions to usual procedures for people with unique disabling conditions. Vaccines do need to be given intramuscularly but any bulky muscle can be used. I would think the same steps that led to a change in administrative procedures for the other vaccines you mention will need to again occur for the new COVID vaccines. This will of course take

a lot of time unless someone in a high-up position learns of it and is willing and able to take action.

In the meantime, I would recommend you try to receive the vaccine through your primary physician, who would have the authority to prescribe the vaccine and its delivery method, including location of the injection by simply stating the reason an alternative site is necessary and why the vaccine is urgently needed. This should be no different than physicians prescribing other medications for “off-label indications” (which come from the manufacturer, usually large pharmaceutical companies who must seek FDA approval for their liability protection). ■

## 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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Questions? 314-534-0475.

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Phone (include area/country code) \_\_\_\_\_

I am enclosing a check for \$\_\_\_\_\_ made  
payable to "Post-Polio Health International." (USD only)

Please charge \$\_\_\_\_\_ to this credit card:

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