

POST-POLIO HEALTH

Fall 2020
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PHI's mission is supported by its Membership.

**WE'RE
STILL
HERE!**

OCTOBER 11-17, 2020
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WE'RE STILL HERE!

October 11-17, 2020, marked PHI's 14th annual awareness campaign. This year has been a truly challenging and stressful one for most of us. Our normal routines have been upended. The activities we used to enjoy have been closed off to many of us. Most of us probably haven't seen family as much as we would have liked—or even at all.

But polio survivors are a resilient bunch and we've seen many of you adapt with the circumstances. Maybe you pulled some chairs out on the lawn and chatted with the neighbors from a safe distance. Instead of attending your grandkids' birthdays, you celebrated on Facetime or Zoom. Maybe you picked up some takeout and had a socially-distanced picnic outside with a couple of friends. In other words, you found ways to stay connected, to remain visible.

For this year's "We're Still Here!" campaign, PHI wanted to celebrate that. We asked our members to submit a photograph and a few descriptive paragraphs about the ways you've found to stay connected with others during the pandemic. We were wowed by what many of you came up with and are proud to announce the winning entries.

GRAND PRIZE WINNER

Paul Jeganathan, Kirkland, Washington

2020 marks 75 years since I contracted polio—fell ill on New Year's Day 1945, at the age of four and half.

On May 28th,
I turned 80 years old.
Yes, I'm still here!

We planned a big birthday celebration with international guests and a cruise to Alaska. Then COVID-19 descended and abruptly ended those plans. However, my wife and daughters organized an alternative celebration which was, in my opinion, a great success! Family and friends sent video greetings from around the world. It was meaningful

to hear from so many loved ones including my four-year-old great grandniece. My immediate family and I shared a dinner followed by curbside birthday visits where extended family drove by and greeted me from a safe distance. They dropped off gifts and received packets of delicious food prepared by my wife as party favors to make up for the fact that we weren't able to gather around a table as we normally would. I feel a great sense of gratitude to have celebrated 80 years of life, particularly when I consider the fact that I narrowly escaped death at the age of four. Hey, I'm still here!

This pandemic and resultant social distancing brings back memories of the decade-long isolation I experienced after contracting polio. Due to my diagnosis, I was denied access to school until the age of 14. I had to remain home, missing out on significant experiences: the learning, friendships and fun of school that other children my age enjoyed. Others seem to observe other parallels as well. After attending one of my presentations, a writer later reflected, "As I think about my own understanding of history in relation to Paul's lecture, there are some eerie similarities between the world of the mid-20th century, when polio had its day in the sun, and the

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A Letter from PHI's Outgoing President

With the October Annual Meeting of Post-Polio Health International, new officers were elected to lead the organization. I have chosen, after 18 years as a member of the Board of Directors, not to seek another term as President and to leave the Board.

I wanted with this note to say a partial goodbye to you, our members and readers, and to thank you and the Board for the opportunity to serve. As many of you know, PHI was the brainchild of Gini Laurie, a true force for things she believed in and especially for everyone who had had polio. She created, almost 60 years ago, the earliest information newsletters related to living with polio. Research and education about the poliovirus and disability can substantially be tied to her drive. I first met Gini as a 17-year-old college freshman in 1965. In one way or another, I have been involved with PHI since that time.

During my service on the Board, I was given the honor of serving as Chair of the Strategic Planning, Finance and Executive Committees. I served as Treasurer, Vice President and President. Thank you.

I believe deeply that new perspectives and energy betters organizations. I fully expect that the new President, Dan Wilson, will vastly improve on the results of his predecessor. I urge everyone reading this newsletter to do as I will be doing and renew your membership or, if you are not yet a member, to join so that the efforts for polio survivors and their families can continue.

*Warm regards,
Saul Morse*



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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.

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Away temporarily?

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

early 21st century, when another invisible enemy evokes great trepidation.”

We’re still here. Despite the trepidation, doubts and fear brought on by the pandemic, opportunities for connection remain. I make a sincere effort to remain in contact with others with the help of modern technology and tools. I mainly stay connected with four groups of people: my family, my post-polio support group, my church family and the people in the organizations with whom I volunteer.

Keeping in close touch with family is of great importance to me. Professor Anthony Brandt says, “Other things may change us, but we start and end with the family.” How true! The only face-to-face connection I have is with my immediate family. One of my daughters came home from out of state due to the shutdown. My other daughter and her family live nearby, and I look forward to their weekly visits. Who can blame me for being happy to see and interact with my precious grandson?!

I also regularly speak with my siblings, all of whom are also senior citizens. Four of my siblings live locally and one on the East Coast. In pre-pandemic days, our calls were somewhat simple with the routine “Hello?” and “How are you?” but the pandemic has changed all that. We do not talk about the COVID as much as we did in earlier months; now conversations are longer and cover general health and welfare, updates on daily activities, and current events.

Talking about family history is something we enjoy immensely. Mainly, we try to piece together bits of information and construct a family story which none of us fully know. There is also always some gossip, banter and teasing. Recently, I prompted my sisters to write down various proverbs and sayings from our early years in India. This has been a fun activity that has challenged our aging brains! We correct each other, share what we have written, and laugh about the funny and not so clean ones. Most conversations with my siblings end with words of encouragement and a reminder that we all should have grateful hearts for the good health and financial stability that allow us to maintain a favorable quality of life as we age.

The folks in my local post-polio support group are, in many ways, my other family. I call them my polio pals. Keeping in touch with other polio survivors is something I prioritize. Although my calls to them are somewhat sporadic, they always result in satisfying conversations. I especially value calls with our group leader, a very dedicated, empathetic person.

We share news from members of the group, discuss plans for the future, and exchange ideas for activities when the pandemic is over and we can come together again. Even with our aging and post-polio challenges, we’re still here.

I also stay connected with my church family, which is very important to me. We have online worship every Sunday and Bible Study every Wednesday. During the pandemic, volunteers make weekly calls on Thursdays to senior citizens and other church members who are considered vulnerable. I welcome these calls which are a great way to stay in touch with my church friends.

I also stay connected through my involvement in the church’s Disability Inclusion Ministry. We communicate often to discuss matters concerning our work. I also correspond with the Men’s Fellowship leader to plan our annual retreat in Spring 2021 and to recruit volunteers for a non-profit I support.

Volunteering provides a wonderful way to stay connected with my larger community. I started volunteering when I was in my twenties and over the years it has grown into a true passion, so much so that I coined the motto, “I Am Restless to Serve.” Two organizations to which I’m committed are Bridge Disability Ministries and Solid Ground.

Bridge Disability Ministries is a non-profit based in Washington that is classified as a provider of essential services and their work has continued during the pandemic. In fact, it’s more critical now than ever. I stay in contact with their staff, other volunteers and the board via Zoom. Besides regular business, we also enjoy small talk and checking on each other which helps reduce the sense of isolation. I helped with their annual fundraiser held in September, which kept me busy and connected. I am also involved in a project where volunteers prepare and deliver care packages to our clients, many of whom reside in care facilities and are experiencing increased isolation due to pandemic-related restrictions. Making phone calls to these volunteers allows me to engage with my community.

Solid Ground is one of the largest senior volunteer networks in the nation. As an RSVP Ambassador (Retired and Senior Volunteer Program) I’ve had to modify how I work with them during the pandemic by trading in-person opportunities with Zoom meetings and emails between volunteers and staff. Regular updates on Solid Ground’s activities keeps me inspired and helps me grow my volunteering network. The interactions I’ve had with

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the exceptional people at these organizations have been energizing and meaningful in the midst of an otherwise isolating time.

I am thankful I've found ways to stay connected with others during these strange times which would be impossible without my family and my various communities. I am deeply satisfied with how I'm staying involved and engaged. Inevitably, I ask myself what I can do better and how long I can keep doing it. Trying to find answers to these questions is not easy, and I tell myself to keep going as long as I can. I remind myself that the journey from 1945 to 2020 has been long and arduous, but not impossible because I'm still here. I'm certain I'm not alone in this sentiment and am sure many other polio survivors have experiences like mine—and that's why we're still here.

FIRST RUNNER-UP

John Nanni, Middletown, Delaware

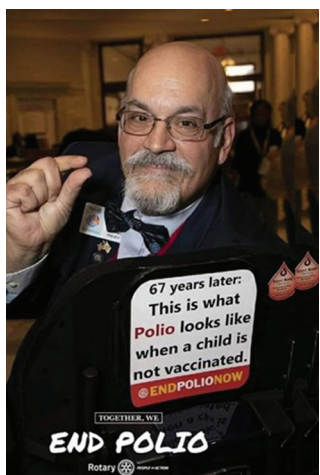
I am a polio survivor from the Class of 1953 (just months before the major Salk trial) at the age of ten months old. I was paralyzed from my neck down for six months. My mom did Sister Kenny's physical therapy on me. I walked a year later and played baseball, basketball and football in high school.

In 1992, I was diagnosed with severe post-polio syndrome. I now use a wheelchair for most of my mobility needs. However, there is very little I can't do; I just need to find a different way of doing it.

As Rotary District PolioPlus Chair, Board Member of the Polio Network of NJ/DE and Delaware State Architectural Accessibility Board Member, I have been keeping VERY busy during this COVID-19 pandemic.

Since early March, I have given over 30 Zoom polio talks—"The 3 P's in My Life: Polio, Post-Polio Syndrome and Rotary's PolioPlus"—to Rotary Clubs and Districts throughout the world, including England, Canada, Japan, Australia, Nigeria, Hawaii and throughout the United States—Zoom "trips" that I would never be able to make in my wheelchair in such a short time.

I also coordinated a major food distribution of rice. As the Rise Against Hunger Rotary Ambassador,



I found donors to purchase pallets of rice that were distributed to Food Banks and Food Kitchens throughout the Delaware, Maryland and Pennsylvania region. We were able to move over 15 tons of rice.



SECOND RUNNER-UP

Mitzi Tolman, Lakewood, Colorado

The Colorado Post-Polio Organization has been working hard during the pandemic to maintain contact and support our members. Support groups have met virtually, in person at a distance, and by phone trees. Dr. Marny Eulberg has continued to provide support in-person with individual survivors as they address their health concerns.

At the Aurora meeting in September we learned some adaptive chair yoga led by Gloria Shea, wife of Keith (polio survivor and group member). Gloria is a retired RN and taught chair yoga at the Aurora Center for Active Adults for many years. As a senior and wife of a polio survivor, she's been to our group and knows the levels of disabilities represented. It was fun and inclusive and everyone joined in. She gave me handouts to make copies of for our next meeting.

The facilitator safely served donuts with no one touching anything but their own. It was a fun treat.

THIRD RUNNER-UP

Angelia Armstrong, Smithfield, Virginia

In the spring of 2020 the world changed. Many memories came back when this first began, and I have been thinking a lot about how this feels somewhat like when I was growing up with polio. The isolation, fear, loneliness and shock that something like this could happen again in my lifetime.

My career/work stopped in a day. I am a clothing designer/artist and teacher. When the COVID-19



virus hit, my state shut down pretty quickly. All the shows, teaching dates and events that were planned for my work were cancelled.

For a few weeks I did nothing, just kind of wandering around. My husband and sons were essential workers and did not have any changes to their work schedules. The situation became a huge stressor—trying to protect them/us from getting and spreading the virus.

But then I did what I always do—I started making plans for exercise, gardening and new creative work life. My garden was my safe place, even though recent back/leg problems have limited the amount of physical activities I can do. Friends and a garden group online have been a great resource for connecting with others. Local friends doing driveway plant swaps and chatting from the porch. Discussing weather, soil, insects and other garden issues in the chat group. Mainly, I have reinvented my career self once again. An update to my website (www.angeliarmstrong.com) and new blog have given me new ways to meet and communicate with old and new friends, as well as a way to continue to make a living into the future. I am teaching new classes with Zoom and making videos for YouTube.

Another important reason I feel the world needs to know that we are still here is the current discussions the country is having around COVID-19 and the possible effects it will have on the future health of people who overcome the initial virus. It is too soon to know what this virus will do to the body as the infected children and young people grow older.

I got over the poliovirus when I was a child, but have lived my entire life with the stigma, pain and sometimes shame of getting sick. The physical disabilities as I age are only getting worse, and I wouldn't wish that on anyone.

I am happy to still be here and I am always looking forward to whatever the future holds. It seems that it is our nature as polio survivors to keep fighting and never give up.

FOURTH RUNNER-UP

Lyn Glover, Gold Coast, Australia

I have been the Facilitator for the Gold Coast Post Polio Network for 12 years now. We are under the banner of Spinal Life Australia here in Queensland of which I am a volunteer. We have Monthly Meetings and Quest Speakers, which I organize. I also outsource information on polio,



newsletters, e-newsletters and articles, which I take along to these meetings as well.

I have 40 polio survivors of which 25+ attend these monthly meetings. We are all so different. Some members have a visible disability and others don't, but we are all in this battle together. We have lost one member who was at a nursing home in this pandemic.

Gold Coast Post Polio Network are very upbeat and friendly. We care for each other, which is why these meetings are so important in accessing the community.

Our current project is collecting and recycling postage stamps and selling them to collect enough \$AUD for collared shirts with our logo to wear proudly at meetings, events and out in the community.

My Monthly Meetings were suspended due to the pandemic. My last meeting was in March. So Zoom, Facetime, Facebook, mobile and emails were my main contact with my Polio Family. I spent most days at home and only went out in the community for doctor appointments or shopping. I was able to catch up with both of my daughters and grandchildren as restrictions were lifted. I was also able to attend online church service every Sunday, which was a blessing. I also attended prayer group via Zoom on Thursdays. During the pandemic, my younger daughter got married, and we were blessed with the birth of a baby girl.

I still to date wear my face mask which my eldest daughter made for me. I also self-distance when possible, use wipes, and am very aware of my surroundings when I go out—being a polio survivor for now 62 years.

Memories I have of polio are the sound of the iron lung, being put in a cot with iron bars like a cage, my double Thomas splint, and only seeing my family once a week through a glass window. A yellow cross was put on my family's door to notify POLIO was present, that is why I wonder now what the future will hold for survivors of COVID-19. ■

Learning to Love the Way I Walk

Vaneetha Rendall Risner

Cripple! You don't belong here!

When I was seven years old, elementary school boys yelled those words as I walked by. As they laughed, they began pelting me with small stones. I was unsteady on my feet since I'd just learned to walk without braces, so I quickly fell to the ground. The boys scattered. As I sat on the asphalt, bewildered, I wondered—Why are they being so mean to me? What's wrong with me? While I wasn't physically hurt, that incident forever changed me. With my pronounced limp and weak arms, I felt different and defective for the first time.

I don't remember life before polio because I contracted it when I was three months old in India, a few months before I was to get the vaccine. The doctor assumed I had typhoid and gave me cortisone to reduce my fever. By the time the physician realized the mistake, I was almost a quadriplegic.

My parents left for England soon afterward since the doctors in India told them I would be a vegetable with no hope for any progress if we stayed. From England we moved to Canada, where I was treated at the Shriners Hospital for Crippled Children in Montréal and spent several months out of every year there. I walked without braces at age seven and had 21 operations, mostly muscle transfers, before 13.

I had just been released from the hospital when that first bullying incident occurred. Soon afterward we moved, and I hoped a new school would change things, but the taunting continued. I almost came to expect being mocked because kids frequently snickered, imitated how I walked, and asked what was wrong with me.

I assumed my parents would be disappointed if they knew what was happening, so I didn't tell them. They were so proud of the way I had adjusted and were committed to keeping me in regular school to be mainstreamed with other children. Following FDR's philosophy, they encouraged me to

succeed in the normal world by not feeling sorry for myself, walking as straight as possible, and wearing clothes that camouflaged my disability. Walking straight was actually impossible, but I tried anyway because my limp drew unwanted stares. I hated the way I walked.

At the same time, I was cheerful and outgoing and learned to adapt to my world. I found a role model in Tiny Tim from *A Christmas Carol*, who was the catalyst for Scrooge's change. He accepted whatever he was given and always thought of others. Determined to be well-liked, I tried to be a helpful friend, a diligent worker and a positive person so people would want me around.

That determination propelled me to become valedictorian of my high school class and even voted Winter Festival Queen as I worked hard to be popular. I then wondered if I could live independently, so I chose to go to college out-of-state, to the University of Virginia, where I knew no one just to see if I could do it. Since this was before the ADA, many of the buildings had steps with no railings, making them difficult to get into.



When I mentioned it to one professor, he said, “Well, I guess I could move the class if we absolutely need to. But that would involve a lot of inconvenience for everyone ... Is that what you want?” I said I would figure something out, and so every day I would ask a stranger to help me up the steps. At first, I was embarrassed but it soon gave me a sense of freedom. If I was willing to ask strangers for help, the world could open up to me.

With that confidence, after college I accepted a job in Boston’s financial district where I worked for four years and then moved to California to get my MBA at Stanford. There I met and married a classmate. Life seemed perfect, and I only thought about my disability if I glanced in the store window and saw the reflection of my gait.

But soon afterward, my perfect life began to unravel. The doctor made a mistake with my infant son’s medicine, and he died suddenly. Several years later, I was diagnosed with post-polio syndrome and told to stop painting, scrapbooking and gourmet cooking to conserve my energy. The team at the Spaulding clinic in Framingham recommended I use a wheelchair and other assistive devices to preserve my strength.

I was slowly adjusting to these changes when my husband left me for someone else and moved out of state, leaving me to parent two adolescent daughters alone. His betrayal reinforced all the painful things that I had whispered to myself over the years—You’re not enough. You’re a burden. You’ll never be fully accepted.

Painful as his leaving was, it was a pivotal point in my life. I had long been a pleaser, turning myself into a pretzel trying to please everyone. My unspoken life goal had been to fit in, but I finally saw that I didn’t need to live for other people’s approval. My faith was a critical part of that journey as I saw that I had value and dignity; I didn’t need to keep apologizing for myself.

Six years after my ex-husband left, I married an amazing man named Joel. Soon after he proposed, I mentioned that I was still self-conscious about how I walked, especially walking down the aisle. Joel looked directly at me and said, “I love the way you walk, and I’ve loved it from the beginning.”

Joel’s words have come to symbolize my current outlook. From hating the way that I walked for most of my life, I have learned to love it as Joel does. I’m grateful for polio. It has made me deeper and more compassionate. More concerned about the vulnerable and overlooked. More grateful to God and more joyful. More appreciative of community and more hopeful.

I recently heard that people who were bullied as children often believe they are not enough as adults and have three traits in common—they are high achievers, pleasers and insecure. I can identify with all those characteristics and hope my writing can help others break free from that mindset and pressure.

With my post-polio diagnosis in 2003, I cut back on the activities and hobbies that were overusing my arms and started writing with voice recognition software. I’ve had a great response to my work and have written two books. The second one, a memoir entitled *Walking through Fire*, will be released in January 2021. ■



Vaneetha Risner’s upcoming memoir, *Walking Through Fire: A Memoir of Loss and Redemption*, will be released in January 2021. However, for a limited time, if you preorder her memoir NOW at www.walkingthroughfirebook.com, you can stream the entire audiobook immediately, read by Vaneetha, for free. Vaneetha and her husband Joel live in Raleigh, NC where she blogs at vaneetha.com.

Paulette, Mark, and Ann Talk about How Life Has Shifted during the Pandemic

Sunny Roller, MA, Ann Arbor, Michigan

In late October, I interviewed three individuals who experience life with a disability from polio. They, like the rest of us, have had to manage and reinvent life during the COVID-19 pandemic. Currently living in three different American locales, they thoughtfully and candidly answered my questions about their quarantine experience. Paulette Bergounous lives in Nevada. Mark Mallinger is from California. Ann Crocker resides in Maine. Their personal introductions follow.



Paulette Bergounous

I had polio in my right arm at the age of two. I was taken from my family and hospitalized and placed in isolation in Cook County Hospital, Chicago,

Illinois. I was there for almost two months. Over the years I had gained some mobility and strength to the point that most people did not even know I had any disability. But 15 years ago, I started experiencing loss of strength and mobility because of post-polio.

I was fortunate over the years to be in a profession that gave me great satisfaction and in many cases was a lifesaver. I have a master's degree in the field of Communication Disorders and was a speech-language pathologist for over 40 years. Once I retired, I began to pursue an interest in developing a business that took my skills in another more personal direction. During the last two years, I have created a business that not only allows me to share my experience with polio but also help others who have lost the function of an arm or hand. "One-Handed Solutions" (<https://onehandedsolutions.com>) meets those two goals.



Mark Mallinger

I am a polio survivor who contracted the disease in 1951 at the age of eight. Polio affected my left leg and left me with a limp. Since the year 2000, I have relied

on a brace for support. When I initially heard the news about post-polio syndrome in the mid-'80s, I assumed I had dodged the bullet, for I experienced no new symptoms. However, by the turn of the century I began to feel pain in the affected limb and soon after it was suggested that I be fitted for a brace. I have lived in Los Angeles County for most of my life. I am a retired academic, but still engaged with Pepperdine University in a part-time capacity. Recently I've been involved with the Rancho Los Amigos Support Group in Los Angeles. The pandemic had caused them to cancel their monthly in-person meetings. For the past few months, I have been hosting Zoom sessions with the membership. Richard Daggett, the group leader, and I have collaborated to create an opportunity for members to continue their active fellowship.



Ann Crocker

In September 1952, I was diagnosed with polio just after starting kindergarten. I had paralysis from around my chin down to my toes. I was away from home for about a year, mostly at the rehabilitative

center in Bath, Maine. By that time, I only needed a lower leg brace and one cane. After a few months, the brace and cane were removed. While I never could do extensive physical activities, such as sit-ups or running more than a very few feet, I could get around adequately.

After about 25 years, I began noticing some subtle changes in my strength and physical endurance. Around 1983, my son saw an article in *Newsweek* magazine about other polio survivors experiencing changes, and Dr. Lauro Halstead was quoted in that article. I wrote to him, and he kindly responded with wonderful information and told me to contact Gini Laurie (the founder of PHI). Wow! This was an eye-opener for me and a great relief.

We got together with a few other polio survivors and went on to form our own group called the Post-Polio Support Group of Maine. At present, there is one small group around the Portland area which, before the COVID-19 shutdown, had been gathering for lunch once a month during good weather. The rest of our group members are scattered across the state. Now we all stay informed through our regular newsletter, which I edit.

During my adult life, I was lucky that I had jobs that interested me. Most of them involved helping others. Eighteen years of my career were at the State Housing Authority where I served as Director of the Homeownership Division, Manager of Special Assets, and Senior Officer for Project Oversight. Upon the strong encouragement of my physiatrist, I retired two days after my 52nd birthday. The long hours appeared to be weakening my physical condition. That was 21 years ago, and I have used my time since then doing volunteer work and helping family members. At present, walking is still possible but limited.

Each interviewee was asked the same questions about their pandemic experience. Their answers follow.

Interviewer: *Please describe your living circumstances during these lockdown months.*

Paulette: I currently live in Sparks, Nevada, with my two dogs Elsa and Mia, both rescue dogs. They have been a blessing during these lockdown months. Being able to take care of them during this time has really helped with being isolated from friends and family. They are also great listeners with no opinions! I have been on my own now for over 12 years as a result of divorce. I have been able to live independently with no assistance. But I am grateful for my neighbors, who during the winter remove snow from my sidewalk and driveway. My schedule every day is to wake up and meditate for at least ten minutes. Then I have breakfast and take my dogs out. After that I will begin to work on tasks that are related not only to my business but to my personal life, as well. This was a pattern that I had even before the lockdown. The only difference now is that I don't go out for meetings or speaking engagements. I use Zoom.

Mark: I live in a condominium on the west side of Los Angeles County with Arlene, my wife of 36 years; and I don't require outside assistance. Since the beginning of the pandemic we have lived, to some degree, in isolation. We visit the market about once a week, along with an occasional trip to Trader Joe's or Costco—obviously wearing masks while I carry a small bottle of sanitizer attached to my belt buckle. Prior to the onslaught of the pandemic, we were very active. Frequent visits to the theater, museums and getting together with friends had been our typical lifestyle.

Ann: I live in a small town near Augusta, Maine. My husband and I have lived in our current home for 40 years. Some modifications have been needed over the years, such as building another driveway in the back

to eliminate the need to climb stairs and putting in a small ramp to make entry and exit very easy, whether walking or using my scooter. We don't have any regular outside help. For the first five or six months of the COVID shutdown, our son and daughter-in-law insisted on doing our grocery shopping, but now I do about 80% of that. While the risk hasn't really lessened, I felt it necessary to restore some normalcy in meeting our day-to-day needs. We never leave the house without our face masks and hand sanitizer.

Interviewer: *What has been most difficult for you to deal with throughout this time of constraint?*

Paulette: I think the most difficult to deal with is not having opportunities to be with friends and other business owners. I have adapted very well to going out grocery shopping and to attending doctor appointments. But I miss the one-on-one contact when I was able to get together with friends. I have been creative, though, by using Zoom and by calling friends on the phone. But it's just not the same as being able to sit down in my living room and chat with them person-to-person.

Mark: I miss the freedom to get in the car and head off without concern about having to deal with the virus. Up until mid-March, there was no thought about restrictions of what I could do or where I could go. Certainly, I wish for that active lifestyle we led. However, I have found our new "life" has several benefits: I feel less rushed not having to juggle the numerous events we once planned. Again, having more time to work in the kitchen has led to us discovering a number of new recipes. With respect to the unexpected outcomes of the quarantine, having less patience with my spouse is one example. Given that we are together almost 24/7, there are times when we "lock horns," sometimes over trivial matters. Although my wife has been a wonderful partner and nurturer, spending more time together can lead to increased incidents of disagreement.

Ann: Daily living now involves careful planning to be sure we have all the essentials. My husband has been in the hospital twice this year, and his health condition is requiring more attention and care from me. Some of our grandchildren usually visit for part of the summer, and we pay them to help with seasonal and cleaning work. But this year that was not possible. I have really missed the loss of spontaneity, as we must be so careful and protective of ourselves and those around us. We can't merely decide on a whim to stop somewhere and visit or check out a new store or restaurant. The other thing that I miss very much is the abundance of hugs that

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were once in my life. Not being able to visit and hug my dear grandchildren and other family members is a big and unpleasant change for me.

Interviewer: *What has sustained you throughout these months of self-isolation?*

Paulette: My close friends and my canine companions. I talk to my best friend on the phone every day. It's not the same as when we used to meet on Sundays at my home, but it still keeps us connected. My dogs have been a godsend because I need to focus on something other than myself during this time, and the dogs require attention and affection. The routine with them has been critical in getting me through these times.

Mark: The sustainers during the past eight months include cooking, eating, exercise, streaming shows on TV, plus recognizing that the pandemic life will end sometime in the near future. My guess is that a vaccine is around the corner. It may not be available until mid to late 2021, but it will arrive.



Cooking offers a creative expression that is not only fun (usually) in the process, but in the outcome. It's a great experience to be able to enjoy my own creations. Exercise, especially swimming, for me has multiple benefits. I

like being in the water, freedom to push aside outside thoughts and concerns, and the sense of accomplishment when I reach my 30-minute goal. I do also find time for reading, either hard copy, digital or audible, but evenings are set aside for entertainment. Twenty-first century technology allows us to select from a very wide set of program content. It is not only entertaining and intellectually stimulating (depending on the choice of venue) but offers a distraction from the plight of the current environment. One evening, we especially enjoyed watching "Rising Phoenix" on Netflix.

Ann: Both my husband and I are relatively self-reliant. I always have supplies in our freezer and cabinets to maintain us for a few weeks at least. My strong faith enables me to get past some of the worst

hurdles—and I don't feel alone. Our wonderful family ties are a great comfort for both of us, and we stay in contact via phone, texting and Facetime.

Interviewer: *Upon reflection, what are three unexpected, good things that have come out of this quarantine experience—for you or others?*

Paulette: I have learned who my true friends are. I have also learned more about individuals with regard to what they value in life. I learned how to pivot my business during times like these, and in several ways the pandemic is the best thing that could have happened to my business. Now because I'm focused more on connecting via the internet, I can share information with more people than I could have by just going out and talking to groups as in the past.

Mark: The positives of the quarantine must include more available time, a greater sense of appreciation for what I have, and recognition of the importance of a loving relationship. With so many people in the US and around the world struggling with their health, their finances and their sanity, I am lucky that I do not face those challenges. My hope is that my wife and I can continue to remain healthy.

Ann: Despite all the negativity that is often portrayed in the media, I have seen goodness all around me. The kindness of neighbors and even strangers coming forward to help is so rewarding to witness. Even many businesses have stepped forward to offer free delivery services or modified production to provide much-needed medical supplies, such as face masks and testing kits.



Interviewer: *What advice would you pass along to our readers who have a disability from polio and are still forced to self-isolate? How to get through it? How to make the best of it?*

Paulette: My advice is to find a purpose and have a routine. So, how do you renew your purpose? Think about something you enjoy doing that is fun for you, which is a solitary task, obviously. Maybe you are good at knitting. Maybe you have a friend who is interested in learning how to knit. I would suggest that you google "how to teach knitting." You could



learn more about this skill; then, if they want, show your friend what the steps are involved in learning how to knit. You could then establish days and times in which you will go on Zoom to practice knitting together.

I always need to start my day with some type of reflection or silencing of my mind to focus and stay grounded. Then I can set up at least three things to accomplish that day. Maybe you'd enjoy painting; maybe you could make jewelry. It's also an ideal time to write. Do you have a book you have always wanted to write? This is the perfect time. Go for it! There are lots of hobbies out there that can get you focused and get you into a routine, but most of all, they will provide an important sense of purpose.

Mark: My three "pearls of wisdom" include staying active, committing to a positive attitude, and seeking support. Given the limitations we face, engaging in activities can be productive, while also allowing the passage of time.

I believe attitude has a huge influence on our psyche. Dwelling on the negative only exacerbates feelings of helplessness. Ask yourself, what can I do today that will make my life more meaningful or interesting. What do you like to do that is available to do? How can you incorporate that into your daily life? I'm not suggesting you deny feelings of doubt and concern, but don't let those thoughts dominate. Having supportive relationships is crucial. Those of you who live alone can be in contact with family, friends and workplace associates. Being able to share the positives, as well as your concerns, will open the space for valuable conversation that lets you know you are not flying solo.

Ann: As winter approaches, we all need to be more cautious in getting around. We can still communicate with others through so many social media outlets. Try to look for joy in our lives—it's there—we just have to value more of the little things. I'd like to sort out all my loose pictures and add them to picture

albums I already have. Reading is a big part of my entertainment, and once the wind and snows return to Maine, our jigsaw puzzles will keep us busy.

Interviewer: *Is there a question that I didn't ask that's important to answer? Please say more.*

Paulette: *What is your vision for the future?*

I've only lived in Sparks, Nevada for 2½ years. I came here to be close to family in Sacramento and to live by my dear friend and her husband of over 45 years. I thought that this was going to be my permanent residence for the rest of my life. But these last few months have forced me to look at whether this is the best place for me. I live at an elevation of 4500 feet above sea level. I've never lived at that high an elevation ever. At the beginning I adjusted, but due to the smoke from the fires in California, the high levels of ozone and UV, the winds and brand-new allergies, I am having to consider moving again. I have moved a lot over the last 12 years since my divorce. I'm quite good at the steps you need to take to make a move. It is not easy as you get older, but at the same time, my health is my priority.

Mark: *Has the pandemic brought back feelings you had when you contracted polio, in terms of helplessness, fear and anxiety?*

Following my hospitalization in 1951, I struggled with feelings of abandonment. I didn't recognize those feelings as such for many years. I did experience fear but did not understand the underlying source until many years later. At eight years old, I was taken away from my parents, friends and family. There were many episodes where fears of abandonment showed up in my life (e.g., relationships ending, parents dying). When watching TV or reading the news about COVID patients isolated in the hospital and passing away without visits from family, it brought back distressed feelings associated with my early polio struggles.

Ann: *How do we nurture our loved ones and take care of ourselves at the same time?*

All of us have stressors in our lives. These worries can be financial, environmental, family-related or include a variety of other issues. Some of us are caregivers of others or have family issues that are very taxing. Still, we also have our individual personal issues that we can't ignore. I think it is important to find a daily balance of giving others what is needed and giving ourselves some essential time, care and attention, too. ■

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