POST-POLIO HEALTH

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Mitchell Wice, MD

Why You Should Consider Seeing a Geriatrician

Mitchell Wice, MD

What is a geriatrician? What exactly does a geriatrician do that is different from my primary care physician? Geriatricians treat those 65 and older, a population that has grown by over a third in the past decade and, by 2050, will be one in five adults. This population tends to be more medically complex. Many have special needs. Just as children are followed by pediatricians to address children's special needs, geriatricians are physicians who have undergone extra training to treat the specialized needs of older adults.

For example, as one ages, the body undergoes transformations that can cause chronic diseases to change course. Acute illness may present differently as compared to a healthy younger person. Older individuals may react differently to medications as compared to younger adults, including having different or more severe side effects and drug interactions, all of which require very careful medication adjustments.

Older adults are more prone to develop what are called "Geriatric Syndromes." These include dementia, delirium, falls, incontinence, frailty, osteoporosis, fractures and polypharmacy. A geriatrician has specialized training to treat these issues.

Geriatricians are trained to evaluate and treat the whole person. They often assess a person using a tool called the "comprehensive geriatric assessment." Here the geriatrician takes a complete history of not only one's acute and chronic medical issues but also of one's social issues, including the home environment, mobility, support system, finances/ benefits, nutrition, the ability to do basic daily tasks like chores, cooking, transportation, bathing, dressing, feeding, etc., along with understanding a person's beliefs, spirituality and wishes. This is followed by a complete physical exam including evaluating a person's ability to walk and his or her cognition.

The geriatrician uses all of this information to develop a comprehensive care plan to maximize healthy aging and to address older adults' needs by identifying the medical, functional and social problems, coordinating care with other specialties and providers, and minimizing health risks before they occur. A geriatrician will subsequently continue to do serial complex assessments, constantly updating everyone's care plan.

Does everyone over 65 need a geriatrician? Why can't my PCP do this? That

answer is not so simple. One of the biggest obstacles to finding a geriatrician is a severe shortage of geriatricians in most areas as, unfortunately, healthcare does not prioritize the healthy aging of complex older adults. Thus, few healthcare providers go into the field of geriatrics.

Furthermore, complex assessments like the geriatric comprehensive assessment have been shown to be beneficial for older adults with multiple complex medical issues and medications but are not as advantageous for older adults with minimal health issues. In addition, some people have had their current primary care physicians for decades and

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www.post-polio.org www.polioplace.org have developed a strong connection and rapport with them.

If one feels their current physician provides excellent care and is being well managed medically, switching providers and all the complexity that comes with it might not be advantageous.

What if one's PCP recommends you see a geriatrician? Keep in mind your PCP is not abandoning you. As we get older, we become more complex. General practitioners see patients 18 years old and above and their expertise is not always in complex older adults.

Additionally, most primary care providers only get 15 minutes per patient, while traditionally geriatricians can spend longer times. One of the most common reasons for a geriatrician referral is a PCP not feeling that they can adequately treat you with their current time constraints.

Moreover, unlike PCPs, geriatricians work as an interdisciplinary team with not only other physicians, but with social workers, nurses, physical and occupational therapists, and case managers. This helps maximize successful complex care.

Mitchell Wice, MD, is a practicing geriatrician in Providence, Rhode Island.

Lastly, what about the person who has a good rapport with their current PCP and wants to continue with them? Can one see both? In most instances, the answer is yes.

Geriatricians can see you for a geriatric consultation where they perform their comprehensive assessment and then pass along their recommendations to your primary care provider like any other specialists you would see.

This practice is common in places where there are few geriatricians and is done to maximize the number of people a geriatrician can see. In this case, the geriatrician would see you yearly or twice a year with your primary care provider doing routine care and coordinating your care, just as one sees a cardiologist or gastroenterologist.

Lastly, one does need to check with their insurance provider as some do not allow patients to be seen by "two" primary care doctors.

In the end, if you are considering transferring your primary care to a geriatrician or are seeking consultative care with a geriatrician, you should discuss this with your current primary care provider. Realize that this is a decision that might differ for each individual older adult.

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How to contact PHI

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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.

Paulette Bergounous

Behind every polio survivor is a story each unique yet containing important lessons for everyone. Here are two stories that changed my life.

But before I begin, I want you to think about what it is like to be a two-year-old. As two-year-olds, we are not built to sit, our hands to ourselves, keeping quiet. A two-year-old needs to move, feel, touch and smell in order to learn about their world and body. Imagine what life is like when that is taken away, even for a short time.

I'm going to take you back to 1946. It's a Sunday morning. A little two-year-old girl wakes up, only to find that part of her body has gone limp. She screams, and her parents come running. Remember that back then doctors came to your home. So, her parents immediately call the doctor. The doctor arrives, examines her, and says to her parents that they must take her immediately to the hospital.

At the hospital, her parents hand her over to the doctors. Two hours later, the doctors come out to speak to them. They say, "We are sorry to tell you that your child has polio. It's a contagious disease and it can result in paralysis and in some cases death." But, that isn't the worst of it. The doctors tell her parents that they cannot say goodbye and that they have to leave her and will not be able to visit.

There she is in a drab, cold environment in the arms of a stranger. The nurse takes her into a ward with glass-enclosed cubicles. She is placed in a cubicle with just a bed. There are no other children she can play with and no toys. In fact, even the clothes she came in are taken and burned.

During the day she undergoes painful treatments, which at the time consisted of taking hot wool strips of cloth and wrapping them around the affected areas. At night, she cries, she hears other children crying, but no one comes. And in the quiet times at night, she can hear the sound of iron lungs pumping away in the other room. There is no one there to comfort her and make her feel secure. The doctors and nurses are too busy just trying to keep other polio patients alive.

Well, it turns out this was my story, and that was what life was like—day by day, week by week, for almost two months at Cook County Contagious Hospital in Chicago.

It wasn't until 2008 that I learned the significance of that early life experience. My parents didn't talk much about my polio experience. It certainly wasn't something that people did back then.



Paulette Bergounous

I do remember them telling me that I was difficult when I came home from the hospital. They said that I screamed a lot in my bedroom. Eventually, they had to move my crib into the bathroom until I adjusted to a larger space.

My mom also told me I would have horrible tantrums, screaming and yelling. She didn't know what to do, and she just wasn't going to touch me. Then one day she got a glass of water and threw water on my face. It worked. I haven't had a tantrum since then.

Because of my age at the time, I don't personally recall many of the details I've

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recounted here. I learned much of it only later from the seven-year-old boy in the cubicle next to mine. My family had maintained a relationship with his, and when I was mature enough, he shared these details with me.

It wasn't until I was going through my second divorce that I sought out counseling and some answers. It was there that I learned about the impact of that experience on my life. I learned about feelings of abandonment, the lack of nurturing physical contact, trust issues, and guilt at a very young age.

At that moment, I resolved that when I returned to the States, I was going to do everything I could to raise awareness about polio and post-polio syndrome and make people aware of the importance of eradicating this disease worldwide.

> I remember going home from that counseling session and for that entire weekend I cried. I cried not because I was angry or sad, but, for the first time in my life, I felt whole. I had always felt different inside but never knew why. It didn't seem to matter what I achieved professionally or what material goods I had. Even love from someone close to me could not fill the emptiness I felt. It was never enough.

The last twelve years have been filled with challenges. I had to learn how to love myself, trust others, and not carry around a lifetime of guilt. But these have also been the best years of my life. My first life lesson is that the greatest gift you can give yourself and your loved ones is to make peace with your past.

Starting around 2000, I noticed that my right arm was getting weaker. It was then that I sought out medical advice. I reached out to the University of California–Davis in Sacramento. It was there that I met Dr. Carol Vandenakker Albanese, who is the head of the postpolio clinic. She introduced me to the late effects of polio and its impact on my daily life.

My second life lesson came unexpectedly on a trip. Even though I was semiretired, I had an opportunity in 2009 to travel with a group of 33 speechlanguage pathologists, along with Dr. Alex Johnson, Past President of the American Speech-Language-Hearing Association. We were invited to Cambodia and Vietnam as Ambassadors in Communication Disorders. It was part of the People-to-People Program, an educational and cultural exchange program established during the Eisenhower Administration.

In Ho Chi Minh City, we had an opportunity to visit not only the rehabilitation hospital but also the Children's Hospital. I remember walking through one floor and looking into one of the rooms where I saw a young boy who had a cast on both of his legs. I asked our interpreter, the head doctor of the hospital, "What happened to him?" She replied, "Oh, he had polio." Can you imagine how I felt at that moment? I had not seen a child with polio in probably 50 years. It broke my heart.

I remember asking the doctor to tell him I had polio, too. I showed him my subluxation in my shoulder and the atrophy. I will never forget the amazed look on his face as he smiled with delight. At that moment, I resolved that when I returned to the States, I was going to do everything I could to raise awareness about polio and post-polio syndrome and make people aware of the importance of eradicating this disease worldwide.

The reality was that up until then, I had hidden behind my polio. I never talked about it, and I did everything I could to cover up my arm. Now I was going to have to step out of my comfort zone to follow through with my mission to raise awareness.

One Christmas, I shared with a friend that I felt I had more to do, and she suddenly responded, "Paulette, I have watched you prepare an entire meal using primarily one hand. Do you realize how many people come home with a broken arm, surgically-repaired shoulder or severe arthritis and suddenly find they can no longer cook for themselves?" Well, that was just the start.

There I was at 70 years of age starting a new business, One-Handed Solutions. Then in late 2019, I wrote my second book, *One-Handed Cooking Secrets,* a book that contains some words of inspiration, products I use to cook, tips on organizing the kitchen, and even some recipes.

Later that year, I became a board member of Post-Polio Health International. I am so proud to be part of this amazing organization providing information and resources for polio survivors, their caregivers, and the medical profession.

It wasn't until recently that I learned about the driving force in my life. I had an opportunity to listen to Dr. Paul Offit, a well-known pediatrician specializing in infectious disease, virology and immunology. He spoke about his early life experience.

He had clubfeet, and, at the age of five, his father wanted him to have surgery. It turned out the surgery was not successful and Dr. Offit found himself in a care facility filled with polio patients. He was unable to see his family and was haunted by the cries of the children with polio. He said the experience scarred him. But he also said, "The passions of our adulthood come from the scars of our childhood." I don't know the driving forces in your life or if you are still searching for your purpose, but my second life lesson is quite clear. "No matter your age or your condition, you can always find your new purpose." Look into your past, present and future for ideas. I have found mine; I hope you find yours.

My message to you is to live your life like daylight savings: fall back and make peace with your past, and spring forward and find your new purpose.



Paulette and her mother.



Mitchell J. Freed, MD, Orlando, Florida

NOMINATED BY DIANNE WALL: As most of my fellow polio survivors can attest, we know good doctors when we meet them. I have been blessed to be treated by a wonderful physiatrist for twenty-six years—Dr. Mitchell Freed. He initially evaluated me in 1996 at the Orlando Post-Polio Clinic at Florida Hospital (now known as AdventHealth Orlando). Knowing that my new fatigue and muscle weakness had to be followed by a doctor who understood PPS and the impact it could have on my future health, I became one of Dr. Freed's patients at his outpatient practice.

Dr. Freed not only understood PPS, but he taught me how to maintain my active life with wise boundaries. As the years went by, he listened patiently to my Type A personality and gently reminded me to "conserve to preserve." Of course, I didn't always follow his advice, but then I'd show up at an unforeseen appointment after a fall. He never said, "I told you not to …" but he would look down at his notes and smile at me, suggesting I needed to start making better choices and factor in the measurement of risk involved. I knew he was right. His medical knowledge has prepared me to face my future with PPS.

Dr. Freed is by far the most compassionate doctor I have ever had the privilege of knowing. I am honored to nominate him for the PHI Shining Star listing.

ABOUT DR. FREED: Dr. Freed is a Board-Certified Physical Medicine and Rehabilitation specialist in private practice in Orlando, Florida, since 1988. He has served as Medical Director for AdventHealth Rehabilitation & Sports Medicine since 1991. As a proud Florida native, born and raised in Miami, he received his Bachelor of Science from the University of Florida and his medical degree from Vanderbilt University School of Medicine. He completed his residency in Physical Medicine and Rehabilitation at Johns Hopkins/Sinai Hospital program. Dr. Freed has been practicing both outpatient and inpatient rehabilitation where he has specialized in Post-Polio Care, Stroke Rehabilitation, Sports and Musculoskeletal Medicine, Dysphagia and Electrodiagnostics. He has been privileged to assist so many polio survivors and thrivers to live at their highest level of functioning.

With the closing of his outpatient practice this past year, his primary focus is medical directing the new state-of-the-art 60-bed Inpatient Rehabilitation unit at AdventHealth Winter Park. His greatest passion is being a loving husband to his beautiful wife, Holly, while supporting and facilitating the hopes and dreams of the lives of their seven amazing children.

To spotlight your Shining Star:

PHI's Shining Star campaign invites readers to honor the health professionals, past or present, who have made a positive difference in their lives. It's an excellent opportunity to honor these extraordinary individuals in a meaningful way and support your post-polio cause.

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

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

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

Judy Heumann, 1947-2023

PHI mourns the passing of polio survivor and disability rights activist Judith Heumann. Known as "the mother of the disability rights movement," Heumann fought for decades to expand the rights of individuals with disabilities and advocate for their independence. She was instrumental in the development and implementation of key disability rights legislation, including Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and the UN Convention on the Rights of Persons with Disabilities.

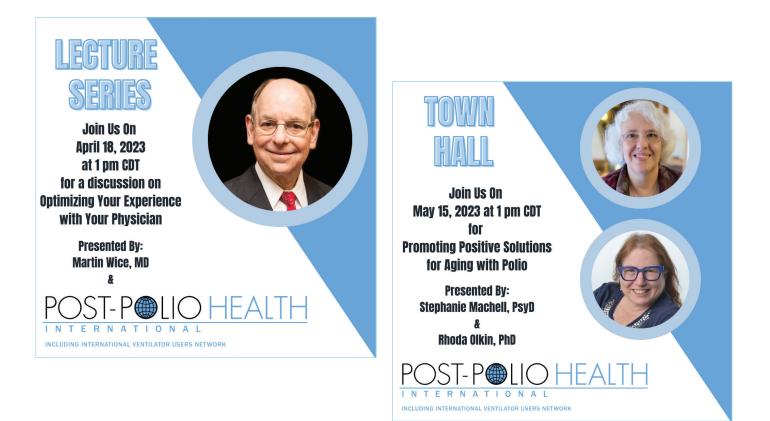


An early leader in the Independent Living Movement, she was a founding member and served as deputy director of the Center for Independent Living in Berkeley, California. She later co-founded the World Institute on Disability along with Ed Roberts and Joan Leon. Heumann served as the first Special Advisor for International Disability Rights at the Department of State during the Obama Administration, and was the first Advisor on Disability and Development at the World Bank.

In her 2020 memoir, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist,* Heumann noted: "Some people say that what I did changed the world. But really, I simply refused to accept what I was told about who I could be. And I was willing to make a fuss about it." Her impact on the polio and disability community cannot be overstated. She will be greatly missed.

UPCOMING PHI WEBINARS

Past webinars in PHI's 2023 Educational Series can be viewed on our YouTube channel at www.youtube.com/@post-poliohealthinternational.



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

Question: I was reading a column on a popular disability website recently that basically advised people with disabilities to "find joy in their pain." I do mostly try to take an optimistic view of things, but there are days where I have a lot of physical pain, it's hard to get around, and, well, I find it pretty hard to find the joy in that. I can also feel it drag my close family members down (even if they'd never blame me for it). Is it wrong on those days to just be okay with not being okay? Should I try harder so it doesn't affect those around me? Please advise.

Response from Stephanie T. Machell, PsyD:

Being told to find "joy" in pain smacks of the New Age version of the moral model of disability. The person with a disability who is unable to do so may be left feeling ashamed, guilty and/or generally flawed. For polio survivors who were indoctrinated in the importance of overcoming and passing as much as was possible, this feels especially egregious and damaging.

Being optimistic and positive is different from being joyful. "Joyful" is an emotion and emotions change. No one is joyful all the time. Optimism is a personality trait that, while usually stable, can change with time and circumstances. While you may ordinarily be an optimistic upbeat person, being in pain can make it difficult to feel positive about anything, or even to remember what it's like to be pain-free.

You don't intend to drag your family down. But emotions are contagious. Pretending you're joyful may fool acquaintances, but close family will see through the act. Knowing you feel the need to protect them from your true feelings may make your family members feel worse. Also, it may not be your attitude that drags them down. Knowing someone they care about is in pain can evoke feelings of helplessness and discouragement.

When you're having a bad day, it's okay to not be okay. It can be liberating to let go of the need to pretend that you feel better than you do. It's also okay to let others know you're not feeling okay, especially if it helps reassure them that it's not about them, or if there is something concrete you can ask them to do that might help (including leaving you alone).

There's a difference between owning that you're not okay and becoming focused on it to the exclusion of everything else. On a truly bad day, this may be unavoidable. Ruminating and complaining about everything you can't do may provide some temporary relief. But staying focused on your pain will make your bad day worse. Unless you're having the type of pain that only improves when you lie still in a darkened room, it's better to do something that can (at least temporarily) distract you from how awful you feel. Seeing you taking good care of yourself and enjoying something may have the added benefit of reducing your family members' concerns.

Response from Rhoda Olkin, PhD:

I think the advice about finding "joy in your pain" could come from someone who does not live with chronic pain. It feels patronizing and blaming if you are somehow feeling less than optimum when dealing with pain. At the same time, we all know we don't want pain to be the principal driver of our daily lives. So, let's tackle the issue of chronic pain.

First, how do we assess our own level of pain? Medical professionals have adopted the one-to-ten scale, with ten being the most pain you can imagine. Most people



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.

I know hate this scale, and, frankly, I find it ridiculous. A Novocain shot at the dentist hurts like crazy; but it's very brief, so that makes it tolerable. But a mild toothache that lasts for days and keeps you up at night might be a three to begin with, but after a few days feels less tolerable, even if the absolute pain level has not increased. So we see that pain has many dimensions: severity level, duration, constancy or intermittent, location (eye pain might be worse than toe pain), and type (stabbing, sharp, burning, etc.).

There are other ways to measure pain. Consider the following scale.

✤ Level One: Pain is there but out of my conscious awareness unless I stop and focus on it. But I could then carry on with my day, and the pain would recede from consciousness again.

★ Level Two: Pain is still out of awareness, but it is affecting my mood and behavior. My children might say, "Mom, you're crabby. Are you in pain?" And then suddenly I would be aware that I have been. They noticed the association between pain and mood before I did.

★ Level Three: I am conscious of the pain but consider it useful information or feedback that tells me to change my behavior. I need to use ice or heat, rest more, postpone an activity, or change position, all in the interest of not having the pain increase.

★ Level Four: I am now very conscious of the pain, and at this level, pain is dictating more of what I do that day. I might have to cancel plans, refrain from certain activities or movements, rest, take off my shoes, use ice/heat or a TENS unit. When pain is at this level, I "give in to it" and recognize that my day is now more about pain management than anything I might have had in mind. I might read a book, watch something absorbing on TV, listen to a podcast or music, eat my favorite foods—a bit of pampering that feels like a treat despite the pain.

✤ Level Five: Pain is now the driver and commands attention as I take steps to ameliorate the pain. More serious medications might be used.

The factors here are the effects of pain on my awareness, mood, activities, plans and sociability. For me, levels one and two are manageable (i.e., I can continue my day), level three is tolerable (my day continues but may be curtailed in length), level four is a fight to keep the pain manageable (my day gets rearranged or canceled), and level five is unmanageable (cancel everything that can be canceled).

The person who wrote the questions asks: "Should I try harder so it doesn't affect those around me?" No. Your pain is a part of the family system, it is not yours alone, and the system will have to find ways to manage the pain. What you can do is clue the family in to your level of pain and your plans to manage it. For example: "Today is a level four, I suggest you all go about your day without me, and I won't be making dinner, so order in." You don't always have to take care of them as well as yourself. ■

Further reading:

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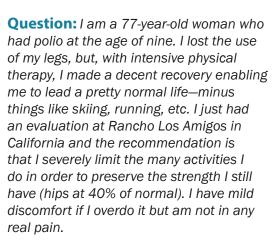
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Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.



Frederick M. Maynard, MD



Hsk Dr. Maynard

Recently I read an article about the use of acupuncture therapy in polio cases. Do you know if there have been any studies in the US about this? The article refers to pain but also the effectiveness of muscle stimulation.

Dr. Maynard: Thank you for your question. Acupuncture can be helpful in controlling muscle or joint pain, but I am unaware of any evidence that it can be helpful in improving strength in postpolio weakened muscles not inhibited by pain. Similarly, muscle stimulation has not been shown to be helpful for improving strength in post-polio weakened muscles.

I would encourage you to remain active in spite of your apparent weakening as long as you have no signs of overuse. These would include sharp or aching pain in your muscles after a lot of use or strenuous use and/or severe fatigue or exhaustion after activities. Polio survivors like you have to walk the fine line between overuse of muscles leading to acceleration of age-related deterioration of polio damaged motor nerves and underuse of muscles that can also lead to weakness by accelerating disuse atrophy.

Question: I understand that "good" limbs (those thought to be unaffected by polio) commonly show EMG evidence of prior Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/living-with-polio/ articles-post-polio-health#AskDrMaynard

poliovirus damage to motor nerves. Is it now commonly accepted that polio actually affected all of the muscles in the body?

Dr. Maynard: It is not accepted that a paralytic polio survivor has residual damage to all the muscles in their body; but they could have residual involvement in any of them, and this is common. This opinion is supported by studies that showed the mean strength of lower limb muscles of polio survivors who did not think they had involvement of the lower limb was significantly less than the mean strength of age/gender-matched controls without a history of polio.

Question: Does PPS cause muscle loss later in life or is atrophy caused by the initial polio attack?

Dr. Maynard: Initial polio infection damage to nerves may result in a muscle's atrophy (smaller or shrunken size) if a sufficiently large percent of nerves to an individual muscle died off. However, further dying off of damaged but not dead nerve cells from PPS can lead to new muscle atrophy in either or both muscles that were thought to be unaffected but had subclinical involvement, as well as muscles that were known to have been affected and weakened (this is known as 'progressive muscle atrophy' or further/ additional atrophy).

An anecdotal story might help illuminate the answer above. A woman who was known to have had polio as a young child grew up to be an Olympic gold medalist. In later years, she developed PPS, which confirmed that she did have some residual nerve loss or damage from polio. Just think how fast a runner she might have been if she had not had polio. Or maybe she wouldn't have tried so hard to develop her maximal strength.

European Polio Conference to Be Held in May

The European Polio Conference, organized by Polio-France in cooperation with the European Polio Union (EPU), will be held May 25–27 in Nancy, France.

Registration details and further information can be found at <u>https://www.polio-france.org/european-polio-conference-nancy-2023/</u>.

From the organizers:

"This congress will not be a congress like any other, with a learned society that addresses its colleagues. It will be organized by a patient association that wishes to create the necessary conditions for the exchange of knowledge in order to perpetuate its dissemination, but above all to motivate research and innovation in care.

This congress is aimed at people with polio and post-polio syndrome from all over the world, and health professionals concerned by the management of polio and post-polio syndrome."



Jn Appreciation

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

Please contact us if we made an error.

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