

GLEANINGS



Millie Malone Lill, author, polio survivor and long-time contributor

The Dance

By Millie Malone Lill

When the polio virus hit our spinal column, it shotgunned throughout our system. It was like a bombing in a war, damaging motor neurons here, missing some over there. During the recovery stage, the motor neurons that were not killed sent out sprouts to help enervate the muscles whose motor neurons were no longer functioning. This made it seem that we had recovered. And we had, in a limited way. We worked hard to make those neighboring motor neurons run more muscle fibers than they were meant to.

This miraculous recovery led people, including doctors, to think that we were cured and that we should continue to work hard, try to be “normal.” We did. We went out for sports, we danced, we swam, we roller skated, we walked and hiked. And, in trying to prove it to ourselves and the world in general, we went overboard. We developed Type A personalities.

As time went on, the overworked helper neurons tired and started to die off. This is what post-polio syndrome is – a dying off of the motor neurons that were overworked to their limit. The virus had killed off a lot of neurons at the start of all this. If 60% of the neurons running a muscle were dead, that muscle was paralyzed, unable to function. Sometimes, only a small percentage of the neurons were zapped, but as we age, we naturally lose neurons anyway. Some of us only had about 50-75% of our neurons after the virus attack. We lose 10% a year in the aging process. If we started with 100% of our neurons, 10% would not be catastrophic, but we only had half that many to use to start with.

Eventually, polio experts like Richard L Bruno, H.D., Ph.D, started to realize what was happening and our new mantra went from “use it or lose it,” to “overuse it and you'll lose it,” and now “conserve to preserve.” For many of us, now faced with a body that was not functioning as it should, it was too late. Dead neurons stay dead.

All of this brings me to the point of this article. Garth Brooke's song “The Dance”:

And now, I'm glad I didn't know
The way it all would end, the way it all would go
Our lives are better left to chance
I could have missed the pain
But I'd had to miss the dance

Was it worth it? Maybe so, maybe so. Would I have given up the pleasure I got from working on the farm, raising my children, caring for my husband and traveling with my friend? If I had not done all of this, perhaps I'd not be using a power chair now. But I'd have missed

The Dance.

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From the Executive Director

Reflecting on the History of Polio—and Looking Ahead Together

Nebraska has a rich and important history connected to polio. Many of you know that the Nebraska Polio Survivors Association was the first support organization of its kind in the nation.

What you may not know is that Nebraska experienced some of the nation's worst polio outbreaks, and Omaha's local media played a pivotal role—first by bringing attention to the urgent need for a vaccine and later by encouraging the public to get vaccinated.

In April, I had the opportunity to speak to the Omaha QUAD organization, a group of mostly retired advertising, public relations, media and business professionals. As a newcomer to NPSA, I spent considerable time researching for my presentation, "Polio in Nebraska: The Story That Didn't End." Having grown up in Missouri and being very young during the 1950s and 1960s, I had no idea Nebraska's polio outbreaks had been such significant national news.

If you ask most people about polio today, they'll probably say, "There was a crisis, then a vaccine, and the problem was solved."

But that isn't the whole story.

According to History Nebraska, during the devastating 1952 outbreak, Nebraska recorded the highest incidence of polio in the nation, with 163.9 cases per 100,000 people. Entire communities were affected. Local newspapers and broadcasters walked a careful line between warning the public and offering reassurance. They encouraged families to avoid public gathering places, explained emerging medical guidance, and later helped build public confidence in vaccination efforts. During that same era, the widespread use of the iron lung also spurred innovations that continue to influence respiratory care today.

[Link to rest of this article on the website.](#)



Melodae Horst, APR, SHRM-SCP

NPSA Survey Highlights: Thank You for Your Feedback

By Melodae Horst, APR, SHRM-SCP

Thank you to everyone who participated in our recent member survey. Your responses are helping shape the future of the Nebraska Polio Survivors Association, and we appreciate you taking the time to share your experiences and ideas.

The survey confirmed what many of us already know—our NPSA community is looking for reliable information, meaningful connections and greater awareness of post-polio syndrome within the medical community.

Nearly all respondents identified as polio survivors, and most reported living with post-polio syndrome. Many shared that finding healthcare providers who understand polio and PPS remains one of their greatest challenges. Members expressed a strong desire for increased education for medical professionals, better referrals to knowledgeable providers and continued advocacy on behalf of survivors.

In response to a question about newsletter content, respondents overwhelmingly requested more information about PPS, managing aging with polio, medical research updates, and personal stories from fellow survivors. Most respondents also indicated they would like to hear from NPSA monthly and prefer a newsletter of moderate length that provides meaningful information without being overwhelming.

Several respondents emphasized the importance of staying connected through our monthly in-person or Zoom meetings, sharing personal experiences, and building a stronger community where survivors can learn from one another. Others highlighted concerns about maintaining independence, managing fatigue and pain, accessing adaptive equipment and navigating today's healthcare system.

One message came through loud and clear: awareness matters. Many respondents hope NPSA will continue advocating for recognition of PPS, educating healthcare professionals, and ensuring that the experiences of polio survivors are not forgotten.

As we move forward, your feedback will guide our priorities. We will continue working to provide relevant educational programs, strengthen our community, expand outreach to medical professionals, and offer resources that support survivors and their families.

Thank you for helping us look ahead together.

Ask a PT



We are starting a new regular column to answer your questions about physical therapy, occupational therapy, speech therapy and massage therapy. Send your questions to us at Nebraska.Polio.Survivors@outlook.com. Our first question comes from our recent NPSA survey. These Q's and A's will be posted in their entirety on the website.



QUESTION: I am hunting for a power travel chair that will do uneven ground and hills but is narrow (22" or less) so I can continue to go to small shops. Do you have any advice on that?

ANSWER FROM: Vicky McHugh, PT, DPT, Board Certified Clinical Specialist in Pediatric Physical Therapy (ABPTS), [Key Complete Therapies](#).

For many wheelchair users, the search for a power chair feels like an impossible trade-off: the chairs that handle hills and rough terrain tend to be wide and bulky, while the narrow chairs that fit through boutique shop doorways often lack the muscle for real-world terrain. But the good news is that that gap is closing and with the right guidance, you can find a chair that handles both.

Before you fall in love with specs on a website take one step further to find one you can trial~ the best wheelchair is the one that fits you — not just the doorway. Here's what to consider as essential when selecting a power chair:

Key Tips for Your Search for a New Power Wheelchair

- Motor power matters for hills: Higher wattage motors (500W and above) provide more power for hills and rough surfaces. (WheelerZone.com)
- Tire type matters for uneven ground: Pneumatic (air-filled) tires provide superior shock absorption and traction, and larger diameter wheels with deeper tread patterns offer better grip on loose surfaces. (WheelerZone.com)
- Braking is a safety must: Electromagnetic brakes that engage automatically when you release the joystick are essential for preventing rollbacks on slopes.
- Real-world range is less than advertised: Factors like hills, rough terrain and frequent stops can reduce range by 20–30% compared to ideal conditions.
- Try before you buy: If possible, visit a local mobility/durable medical equipment dealer to test drive.

Understanding the 22-Inch Challenge

Standard power wheelchairs typically run 25–27 inches wide. Getting under 22 inches while maintaining outdoor capability is a genuine engineering challenge, and it narrows your field significantly. However, there are a handful of purpose-built models that have solved this problem. Find additional information about **Top Power Chairs to Consider** on our **website** and read additional information from **Key Complete Therapies** go to the NPSA **Resources page:** <https://www.nebraskapoliosurvivors.com/resources.asp>

DISCLAIMER: NPSA offers this program as an educational resource but in no way is a substitute for any type of medical or allied health care by your personal healthcare provider. Our volunteer providers can only make suggestions that you, in turn, will need to discuss with your healthcare provider. Interactions in writing, verbally or by video cannot replace the value of an in-person evaluation.

Judy Eades tells her story in a way that depicts a lifetime refusing to be defined by polio. "I like to be independent," she says. "And I have been all these years."

Eades built a life marked by service, family and faith. Now 78, she remains a steady and thoughtful presence as in the Nebraska Polio Survivors Association, where she served on the NPSA Board of Directors for about a decade. She continues to support fellow survivors as the Board secretary with openness, honesty and compassion.

Eades says she grew up on a farm near Red Oak, Iowa in a large family, initially of 13 children. Though three died young, she was one of 10 who grew up together. When she was almost 5, she developed a fever and headache; both were signals of polio. Her mother recognized the symptoms immediately. Eades was taken to Omaha and spent three months at St. Joseph Hospital.

What followed was a long recovery, she recalls, with lasting weakness in her right leg. After returning home, she was shaped by determination and the care of her mother, whom Eades described with gratitude. Her mother helped her with therapy, exercises and daily treatments while balancing the demands of farm life and raising a large family. Years later, Eades publicly thanked her for that devotion.

"That woman was a saint," Eades says. View the rest of the story on the Our Stories page <https://www.nebraskapoliosurvivors.com/about.asp?key=10>



Judy Eades: A Life of Independence, Belonging and Faith

Longtime NPSA Board member reflects on resilience, community and living life on her own terms.

by Melodae Horst, APR, SHRM-SCP

[Our Stories Page](#)



Inaugural Judy Joy Award

NPSA Board Secretary, Judy Eades (center) was awarded the Inaugural Judy Joy Award "for inspiring and uplifting the NPSA community with her faith, humor, kindness and ever-present sense of joy - May 3.

Also pictured are, left to right, Karen Dulany, member-at-large; Carol Nelson, treasurer; Kusum Karbanda, president; Melodae horst, executive director.

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Have an article, photo or story idea to share?

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"Humor Heals" Sunday, August 2

1:30 - 3:30 pm CT

Indoor Picnic

La Vista Community Center
8116 Park View Boulevard, La Vista

Join the NPSA family for food, fun and lively conversation!
Reserve your space for this free event.
Email: Nebraska.Polio.Survivors@outlook.com or go to our

[Click to register](#)



Millie Malone Lill
Author and Polio Survivor

Sunday, September 13, 2-4 p.m. CT - Zoom Only

Recording artist, music therapist, music educator and motivational speaker, Dianne McTaggart Wall, "Music Therapy, Miracles & Me" and "Music Therapy and PPS."

Sunday, October 18: 2 - 4 p.m., CT - In-Person and Zoom

Annual Reunion with food and Ron Glowen Entertainment – An afternoon of music, karaoke and singing.

Sunday, November 1: 2 - 4 p.m., CT - Zoom Only

Author. Susan L. Schoenbeck, MSN, RN, "Kindness: What it is. What it is Not" explains the difference between sympathy (You poor thing!) and empathy (How can I help?) Focusing on polio survivors who may be recipients of unkind remarks.

Featured Support Group Partner



The Boca Area Post-Polio Group has been operating for 30 years, with meetings held at a church until COVID hit.

From May of 2020 to May 2026, 73 meetings have been held on Zoom with 40 - 60 people attending each "We are a fun and caring group - no pity-party," said Maureen Sinkule,

co-founder of the group. "We are here to support each other and to validate what we are feeling."

Sinkule emphasizes that there is no better place to learn about PPS and how to deal with it than a support group.

"It is a safe place to share," she said, "as long as people want to talk." Even though the meetings are scheduled from 1-2 p.m., she is known to be on Zoom until 6 p.m.

The group features one person a month who shares their polio story in 10 minutes following the discussion of an announced topic. Every other month there is a featured speaker.

If you are interested in attending one of the Boca group's events, email Sinkule to be on the mailing list to receive their monthly newsletter and Zoom link. The email is bappg@aol.com Include your name, address, phone and email. She will then reach out to you.

NPSA Events Year Begins with Respiratory Health Presentation

Physical Therapist McKenzie Dolph Explains How Belly Breathing Supports Relaxation, Strength and Stability

The Nebraska Polio Survivors Association launched its new programming/events year March 1 with a presentation by McKenzie Dolph, PT, DPT, of Key Complete Therapies. Dolph explained how diaphragmatic, or "belly," breathing supports respiratory health, pelvic floor function, and overall physical stability for polio survivors. She described diaphragmatic breathing as an effective way to activate the body's relaxation response.

"So that's another way of saying diaphragmatic breathing, breathing into your belly," Dolph said. She explained that belly breathing stimulates the parasympathetic nervous system, which helps lower heart rate, reduce blood pressure, decrease stress and ease pain.

"That's a really big word that's just saying it's going help you relax," Dolph said. "We have two nervous systems in our bodies, one is in response to stress and one is relaxation."

Dolph also demonstrated breathing exercises members could practice at home to improve muscle strength, stability and breathing efficiency while reducing the effort required for respiration.

Planning Ahead: NPSA Members Learn About End-of-Life Preparation

Survivor and Attorney Educator Focuses on Estate Planning, Healthcare Decisions and Family Communication

NPSA's April 12 meeting was held via Zoom for a thoughtful discussion on estate planning, healthcare directives and preparing loved ones for future decisions. Retired attorney and polio survivor Saul Morse guided members through important legal and financial planning topics while emphasizing that preparation can ease burdens on families.



Physical Therapist McKenzie Dolph shared breathing techniques at Key Complete Therapies on March 1.

Morse reminded attendees that this kind of planning is unavoidable.

"You know, in life, there's nothing as certain, they say, as death and taxes," Morse said.

He encouraged members to create wills, trusts, durable powers of attorney and healthcare directives while reviewing beneficiary designations on retirement accounts and insurance policies. Morse stressed that failing to prepare can create unnecessary stress for grieving families.

"There is about to be, at least in the United States, a transfer over \$120 trillion of wealth between the baby boom generation and their heirs and descendants," Morse said.

He also discussed family communication, noting that even close families can experience disagreements over personal belongings.

"Even in the best and most loving family, there's always a bit of that tension for things like who gets grandma's cake plates."

Morse explained that federal estate taxes affect relatively few families.

"Very few of us will have to deal with federal estate taxes," Morse said. "The first \$14 million of your property is exempt from federal estate tax."

He recommended working with qualified legal professionals to establish trusts and other wealth distribution planning tools.

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"In the United States, it's usually a lawyer who understands the implications and can give you advice," Morse said, "More importantly, draft documents properly in accordance with the laws wherever you live."

Among his practical suggestions was creating a personal "Death Binder" containing copies of legal documents, insurance information and routine financial records so family members can easily locate important information when needed.

Resources:

[FIVE WISHES | The Living Will With Heart & Soul – Five Wishes](#)

[CaringInfo: Resources for Serious Illness & End-of-Life Care](#)

Note: State government sites might be the most reliable source for free forms such as a Power of Attorney because the forms are created or approved by the state. Also consult your legal representative.

A Lifetime of Strength: Stanley Johnson Shares His Polio Journey

Survivor Reflects on Life with Polio, Medical History, and the Ongoing Challenges of Post-Polio Syndrome

At the May 3 NPSA meeting, Stanley Johnson shared his personal journey living with polio for more than 70 years while also presenting a history of the disease and its lasting effects.

Johnson described contracting paralytic polio at age 2, the challenges of growing up on an Iowa farm while wearing braces, and how years of physical labor may have contributed to his long-term strength.

"I did not fully realize he had polio until 7th grade when my mother mentioned it regarding football participation," Johnson said. "And polio survivors often did not discuss their condition openly during childhood."

He also traced the history of major U.S. polio epidemics, the development of the Salk vaccine, and treatment methods used before vaccines became available.

The presentation examined post-polio syndrome and the new weakness many survivors experience decades after recovery.



Following the presentation, participants enjoyed a social of ice cream and brownies.

Attendees discussed the limited awareness of post-polio syndrome among healthcare providers and shared personal experiences navigating aging with the condition.

Johnson concluded by reminding members that preserving survivors' personal histories helps educate future generations while honoring the resilience of those who lived through one of the nation's most significant public health crises.

Book Recommendation: [The Autumn Ghost: How the Battle Against a Polio Epidemic Revolutionized Modern Medical Care](#), by Hannah Wunsch about iron lung history and intensive care units.

"We're Still Here": Mike Kossove Celebrates the Strength and Resilience of Polio Survivors

International Polio Educator Encourages Survivors to Celebrate Their Achievements and Preserve Their Stories

The Nebraska Polio Survivors Association's June 7 Zoom meeting featured internationally recognized polio educator, author, microbiologist and survivor Mike Kossove, whose presentation focused on resilience, hope, and the enduring accomplishments of polio survivors.

Kossove shared his personal experience with non-paralytic polio, the later development of post-polio syndrome, and decades of research dedicated to educating others.

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Throughout the presentation, members repeatedly echoed the phrase that became the theme of the meeting:

"We're still here."

Kossove reminded survivors that their lives represent perseverance rather than limitation.

"We're not victims," he told the group. "We're survivors, achievers, role models and leaders."

He explained the science behind post-polio syndrome, describing how surviving nerve cells compensate for damage before eventually becoming overworked.

"Nobody knew any of this," Kossove explained, noting that understanding of post-polio syndrome did not begin to emerge until the 1980s when survivors began comparing their experiences and physicians started recognizing common patterns.

Kossove also discussed his book *Polio: Then, Post-Polio, And the Survivors*, which documents the experiences of survivors, families and caregivers while preserving the history of the disease for future generations.

He concluded by encouraging survivors to continue sharing their experiences.

"Our stories must be told," he said. "They remind the world what human beings are capable of even when faced with enormous challenges."

His presentation ended with members offering a toast and once again repeating the words that captured the spirit of the gathering: "We're still here."

Kossove's Book: *Polio: Then, Post-Polio, And The Survivors.*



Post-Polio Research Update

By Victoria F. Roche, Ph.D.

A video of a recent "Post-Polio Research Update" with Dr. Fred Maynard, MD [is available to view on PHI's YouTube channel](#). In the video, Dr. Maynard discusses two new clinical research studies recently published by a group of Italian investigators led by Dr. Antonio Toniolo.

◆ The first study revealed that a cohort of long term polio survivors from Northern Italy who exhibited symptoms of post-polio syndrome (PPS) had significantly higher levels of the viral genome in their blood, cerebral spinal fluid, and intestinal tissue compared to 1) stable survivors who had not developed PPS, 2) family members living with the survivor for at least 5 years, 3) individuals with non-polio neurological diseases, and 4) healthy controls. The viral DNA found in survivors was a mutated and fragmented version of the infectious wild-type virus and was not believed to be able to replicate nor be readily transmitted to others. However, its presence could result in persistent low-grade infection and inflammation that could lead to PPS symptoms. These results support the need for ongoing research and development of new polio-specific antivirals and anti-inflammatory therapies to mitigate PPS development risk and/or symptoms.

◆ The second study showed that polio survivors were more likely to have abnormalities in levels of intestinal immunoglobulins IgG and IgA than family members or controls. Blood relatives of survivors had Ig levels between survivors and controls, indicating that immunoglobulin abnormalities may have a genetic predisposition although the impact in survivors is more dramatic. This study also found that survivors had lower Vitamin D levels than the family or control groups. Almost half of the survivor group was classified as Vitamin D deficient, leading to an increased risk of osteopenia/osteoporosis and fracture.

Taken together, these studies may offer hope for how to better identify those individuals with PPS who may benefit from treatments thought to improve the immune system's ability to fight chronic viral infection.

You can learn more about these studies in Dr. Maynard's accompanying synopsis at <https://post-polio.org/pps-research-update/>. Survivors are encouraged to share the citations found at the end of Dr. Maynard's synopsis with their health care providers and may wish to ask about a Vitamin D assessment and any need for supplementation.

Victoria F. Roche is Vice President, NPSA Board of Directors and Professor Emerita of the School of Pharmacy and Health Professions, Creighton University.

Resources for Finding Medical Providers

NPSA has found a site designed to assist survivors in their search for medical professionals who work with Post-Polio Patients. The site is www.medifind.com.

The 20 Best Post Polio Syndrome Doctors Near Me | MediFind (Omaha, Nebraska example)

The above link to this page is an example of providers found by just entering Omaha, Nebraska. However, this site enables you to find providers within your city or state.

According to its website, MediFind's rankings are based on a variety of data sources, such as the number of articles a doctor has published in medical journals, participation in clinical trials and industry conferences, as well as the number of patients seen for a given condition. Note that MediFind's provider database is not based on user reviews, and providers do not pay to be included in the database.

On the website, you can create an account for further resources and chat with an online assistant. You can further define your needs through the following filters and then book an appointment online directly.

- Distance
- Level of Expertise
- Availability
- Gender
- Years of Experience
- Insurance Carrier
- Specialty
- Additional Specialty
- Language

You can also filter your search to find a Post Polio Syndrome doctor that offers video calls. There is also a MediFind "Clinical Trials" tool to learn about the latest clinical trials and research advances for PPS. MediFind also has a "Latest Advances" tool to find summaries of recent articles published in medical journals.

Are Polio and Post-Polio Survivors More Prone to Type 2 Diabetes?

As polio survivors age, many are asking whether living with polio or PPS increases the risk of developing Type 2 diabetes. In this thought-provoking article, Professor Michael Kossove examines the latest research, separating fact from myth while exploring how reduced mobility, muscle loss, and aging may influence metabolic health. Discover what every polio survivor should know—and the preventive steps that can help protect long-term health.

[Read the full article on the NPSA Resources page:](#)

Website Resources Page Update

We are in the process of updating several aspects of the NPSA website to continue to provide you with fresh content.

Be sure to visit the Resources page as we evolve the content there with more links to resources and articles.



The mission of the Nebraska Polio Survivors Association is to educate the public and the health care community concerning polio and post-polio syndrome and to respond to the needs of individuals who suffer from the syndrome through group meetings, educational programming and newsletters, financial and other support of research concerning the syndrome and the circulation of research results.

In Memory

NPSA thanks the family and friends for the donations received in memory of Katherine Mary Taylor, who passed away March 8.

According to her obituary on Legacy.com, "She contracted polio at a young age and spent nine months in an iron lung, though never letting the effects of that illness stop her in life."

Please send information about your polio survivor family members. We want to know their stories and legacy to share with others. If you wish to memorialize or honor a polio survivor with a donation to NPSA, you may send a check to the address below. We are a 501(c)3 nonprofit organization, all gifts are fully tax-deductible. We will acknowledge your gift in a future issue of Gleanings.

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