



# GLEANINGS

Spring 2016

## FOR CRYING OUT LOUD

By Millie Malone Lill

Do you have a problem letting others see you cry? I've been in a discussion with other polio survivors and many of us do have that problem. For many years, I would let no one see my tears. Even when my husband of 34 years died and my heart was shattered, no one saw me cry. Why?

Perhaps it was because so many of us had polio as small children. I was four. We were torn from our families and put into isolation. Some of us did not see our parents or siblings for months at a time. The nursing staff was overwhelmed during the epidemics and some of them lost their patience with weepy children.

I was one of the lucky ones in that I was not abused in the hospital. However, many were. I heard that sometimes nurses threaten to put crying children in a dark closet if they didn't stop that caterwauling. Sometimes this threat was carried out. One little girl had nightmares and woke up screaming. The nurse did put her in a dark closet. Would you be surprised to learn that this did not stop the nightmares? One woman said that her nurse told her the plug would be pulled on her iron lung if she cried.

It's hardly surprising that so many of us have difficulty crying where others can see us. When my beloved died, I remained dry-eyed at his visitation and at his funeral. I suppose people saw me as hard hearted and uncaring. That was not the case. I cried myself to sleep many nights and always burst into tears when coming home to my empty house, the house where so many of my hours were spent caring for that dear man



*Gleanings columnist Millie Lill, with Fiona in her lap, was spotted in early March riding around Denison, Iowa, in her purple power chair. Her friend and fellow polio survivor, Sheri Rogers, joined her on this outing. Photo by Bruce A. Binning, courtesy the [Denison Bulletin Review](#).*

in the 13 years of his serious illness. But only in private. Never, ever where I could be seen.

Another reason, in my opinion, for this difficulty is that we don't want to appear vulnerable. It's far too easy for a disabled person, child or adult, to be bullied. Bullies love to see our tears. They live for that. If you are unable to defend yourself physically, you must find another way. By not letting anyone see your vulnerability, by never crying no matter what, you might seem stronger than you actually are.

Now that I am old, I have learned that it is OK to cry. It's OK to let others see my vulnerability. It does not imply that I am weak, merely that I am human. It took a long time to trust my friends enough to let them see my tears.

*(Continued on p. 3)*

Watch for the Summer 2016 issue of *Gleanings* in late July. It will include the October 2<sup>nd</sup> Reunion Invitation.

## Physical Therapist Recommends Strategies to Prevent Falls

By Elaine J. Allen

Polio survivors who seek physical therapy (PT) during recovery from injuries or surgeries should consider their physical capabilities, according to a physical therapist who has treated people with PPS and who specializes in inner ear imbalances.

Julie Whalen, a PT with Makovicka Physical Therapy in Omaha, spoke to the NPSA group on Sunday, April 3<sup>rd</sup>.

"The role of rehabilitation is to help individuals find a balance between activity demands and their abilities, and to maximize function and prevent further injury," she told those attending the monthly meeting.

Whalen has been a PT for more than 20 years, first in Pennsylvania and now in Omaha. Although her specialty is inner ear imbalances, she has treated "a handful" of polio survivors and became familiar with symptoms of post-polio syndrome, particularly those of fatigue and muscle weakness.

She encouraged polio survivors to look for a PT who might understand these symptoms. "Finding a PT who specializes in multiple sclerosis might be helpful for a polio survivor because that therapist would understand the

During her presentation, Whalen cited statistics about the dangers of falls and what steps polio survivors can take to avoid falls. In a study published in the Journal of Rehabilitation Medicine, researchers found:

- 74% of polio survivors fall at least once a year
- That's 25% higher than normal population
- 86% fell in a familiar environment
- 72% while walking
- 50% in the afternoon.



## Importance of Exercise

"Researchers found that individuals with Post Polio Syndrome who engage in regular physical activity reported a higher level of function and fewer symptoms than those who were not physically active."<sup>4</sup>



Whalen recommended several improvements to polio survivors' living environments to prevent falls and to improve their balance and strength. Her slide presentation and other references she cited are listed below.

### *Julie Whalen's Physical Therapy Presentation References*

1. Bickerstaffe A, Beelen A, Nollet F. Circumstances and consequences of falls in polio survivors. J. Rehabil Med 2010; 42: 908-915.
2. Gonzalez et al. Management of postpolio syndrome. Lancet Neurology. 2010; 9:634-642.
4. Vestibular Disorders Association of America. <http://www.vestibular.org>. Age-related Dizziness and Balance. Charlotte Shupert, PhD, with contributions by Fay Horak, PhD, PT Oregon Health & Science University, Portland, Oregon.
4. American Physical Therapy Association, Section on Neurology. [HTTP://WWW.NEUROPT.ORG](http://www.neuropt.org) . Patient Education Fact Sheet: Exercise and Post Polio Syndrome. Beth Grill, PT, DPT, NCS.
5. National Institute of Neurological Disorders and Stroke. [HTTP://WWW.NINDS.NIH.GOV/DISORDERS/POST\\_POLIO/DETAIL\\_POST\\_POLIO.HTM](http://www.ninds.nih.gov/disorders/post_polio/detail_post_polio.htm) . Post-Polio Syndrome Fact Sheet. Publication date May 2012. Updated 2/23/15.
6. Post-Polio Health International. [HTTP://WWW.POST-POLIO.ORG](http://www.post-polio.org) . Aging Well with Post-Polio Syndrome: Don't Let Fall Prevention Fall through the Cracks. Spring 2011. Vol 27, No. 2.

Julie Whalen's NPSA slide presentation is linked to Gleanings' secure site: [POST-POLIO PRESENTATION\\_NPSA\\_APRIL 2016.PDF](#)

**Millie's Column** *(continued from p. 1)*

However, because of my polio support groups and the incredible sharing experiences, and the interaction between my fellow polio survivors, now I am finally able to let others see me shed tears.

My power chair caused me a lot of problems when I first moved into my

"I have learned to stand up to bullies. Surprisingly, there are people even at my age who will try to bully those of us who are noticeably different."

independent senior housing apartment. Some of the other residents attacked me for having to use my chair when they have seen me walk. Several people insisted that I go to a nursing home. At first, I took it like a blow to the heart. For a while, I let their wrong opinion stand. Finally, though, I had enough and I had someone come and explain the Fair Housing Act to a gathering of my fellow apartment dwellers. I answered questions at that meeting and I asked some, as well.

It takes courage to let people see you cry, but I know you, my fellow polio survivors, are definitely not lacking in that trait. Take heart! We have overcome so much that letting others see we are human is absolutely OK.

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## Foundation Board Members Retire

Gene and Barbara Roth have been long-time valuable members of the Nebraska Polio Survivors Association Foundation Board of

### Nebraska Polio Survivors Association

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PO Box 6076  
Omaha, NE 68106  
Voice mail: 402-932-5426  
Email: npsa.org@hotmail.com

Directors. Gene served as President for many years and Barbara was the group's secretary.

In late March, they notified President Edward Roche of their intention to resign from the board. "We appreciate Gene and Barb for their many hours of dedicated service to the group and on the Board," President Roche said.

## 2016 NPSA Meeting Schedule

Our meetings are held from 2:00 – 4:00 p.m. on the first Sunday of the month, except in July and September, when holidays fall on the first weekend:

**May 1** Dr. Bruno's Coffee Conversation (Part 2)

**June 5**

**July 10:** Annual Ice Cream Social

**August 7:** Gretchen Bren's recent trips for Rotary International's End Polio Now polio vaccination campaign

**September 11**

**October 2** (Reunion TBA) **November 6**

We meet at the Bloomfield Forum Community Room, 9804 Nicholas Ave., Omaha, Nebraska. Meeting topics will be announced on our Facebook page, via email notification, and at the previous month's meeting. Friends and family are welcome. Refreshments are served.

## Post-polio Health International

### Online Resources:

PHI offers many helpful resources online, including videos on its Polio Place page.

**PHI's Home Page:** [www.post-polio.org/](http://www.post-polio.org/)

**Polio Place:** [www.polioplacel.org/](http://www.polioplacel.org/)

**Directory (PDF):** [www.post-polio.org/net/PDIR.pdf](http://www.post-polio.org/net/PDIR.pdf)



## Dr. Bruno Speaks During PA Polio Network Conference

NPSA members watched a video of Dr. Richard Bruno's "Casual Coffee Moments" meeting in Pennsylvania last October with polio survivors from as far away as Australia.

Gleanings columnist Millie Malone Lill shared the video with other NPSA

members during the March 6<sup>th</sup> meeting.

During the Casual Coffee Moments, Dr. Bruno answered questions and shared his experiences and opinions related to polio survivors and the challenges they face when dealing with health care providers who may not be aware of PPS symptoms and how to treat them.

One early topic in the hour-long conversation was the effect of anesthesia on polio survivors who undergo any kind of medical procedure.

Several participants described their experiences with anesthesia and asked what they should tell their doctors when they undergo tests or surgeries.



He encouraged polio survivors to carry an Anesthesia Warning card (*similar to the one that appears elsewhere on this page*) to alert health care providers how to treat them, especially in emergencies and post-op.

He also suggested that polio survivors become teachers for their health care providers, since most medical schools teach very little about polio and the late effects of polio.

Dr. Bruno is the author of The Polio Paradox, one of the most widely-read books about Post-Polio Syndrome (or Sequelae). His clinic is based in Englewood, New Jersey. His late wife was a polio survivor.

The conference was sponsored by the PA Polio Survivor Network. The card below was provided as a service from one originally developed in New Jersey.

### Cut, Fold and Carry This as a Card to Show Health Care Providers



**I am a POLIO SURVIVOR with POST – POLIO SEQUELAE (PPS)**

Unexpected midlife symptoms:

- Overwhelming Fatigue
- Muscle Weakness
- Muscle and Joint Pain
- Sleep Disorders and Cold Intolerance
- Difficulty Swallowing and Breathing

## ANESTHESIA WARNING!

### I am a Polio Survivor...

- EASILY SEDATED, difficult to wake
- Difficulty BREATHING and SWALLOWING with anesthesia
- HYPERSENSITIVE to PAIN and COLD.
- Need heated blanket and increased pain medication post-op.

**For more information visit:**

[HTTP://WWW.POLIOEPIC.ORG](http://www.polioepic.org)

Spring 2016



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### NPSA Mission Statement

The mission of 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.

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