

# GLEANINGS

Spring 2018

## What If...

By Millie Malone Lill

The doorbell rings. I answer the door and stare. I realize that most of my friends are, shall we say, unique, but this person has silver hair in an elaborate Updo, a tutu, ballet slippers and wings! Yep, those transparent fluttery things indeed are wings!

"Hello, dear!" she warbles. "I am your fairy godmother and I'm here to grant your wish!"

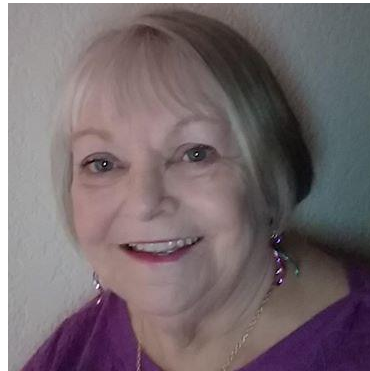
"OK, just one? If I talk-really-fast, can you count this as one wish? Tall-Thin-Rich!"

"Oh, no, sweetie. You don't get to choose your own wish, and besides, really, that is three wishes anyway! It's not cool to try to fool a fairy. No, your wish is that you never had polio." She begins waving a stick around. Well, OK, it's a wand. I know, but really this is getting to be just a tad bizarre.

"Wait! Before you grant that wish...can you show me a little preview of what that would be like?"

Sighing, she taps her toe on the floor and finally says, "Well, OK. I can do that, but you are one tough customer. The usual protocol is to say 'Thank You' and just accept the granted wish. But, here you go."

She waves her wand and "Swish swish swish..." my TV comes on. It shows me as a little girl, age four. I'm telling my Mom that my leg feels funny. Then I laugh and finish getting ready for Sunday School. Then the scene fast forwards to me, a year or so later, begging my big brother to teach me to read. I have to wait 'til I'm almost six to start school because of my



late September birthday. "Go away, Millie," he says. "You'll learn next year in school. I'm busy."

My mother is not a nurturing person. Mom's standards are purposely too high for any of us girls to achieve. She does not like girls, never has. Grandmother didn't like them either. Only boys have value. When I had polio, I'd had the support of the entire town. But

now, it seems, I am just an ordinary little girl.

As I watch my life unreel, I see myself playing softball with the other kids at recess. None of the boys are fighting over who gets to run for me in the unlikely case of my hitting the ball. Nope. It's "do it yourself time" for me. I see my awkward, ungainly self with my thick eye glasses and big teeth, my crazy hair, and no friends. I'm not good at sports. I keep trying, though, and the results are that I am failing in my classes and still not any good at sports. I'm not crazy about running around and getting all sweaty and still not being an athlete!

My few friends graduate from school and move away. I marry to get out of the house and to limit the amount of time my mother can spend telling me that I am big, ugly, clumsy and lazy. Soon I have children, but they are no excuse to keep me from learning to drive the tractor.

*Millie's Column (Continued on p. 2)*

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- Outreach Foundation Mission: Syria
- Online Post-polio resource list

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

I can feel how lonely I am in this scenario because my husband and his family are all beer drinkers and I can't stand the taste. I am not invited along to any parties. I'm only there to work. Chores, housework, child raising.

I grow older. My husband dies. I have no fun hobbies to fill my time. My time is spent working, eating or sleeping. I've never heard of post-polio, so I am not writing my column, I'm not going to support group meetings. I am very bored and very lonely.

"Wait!" I protest to the fairy. "Don't grant that wish! Having polio was not fun, but it led to a lot of things that were lots of fun. I met so many wonderful people through my polio groups. Not being able to be so active, I spent my time reading and studying, making good grades, writing and doing other sedentary things. I don't want to lose that!"

I hear a "Swish, swish, swish," and I'm screaming, "NO! NO! NO!" I wake up to find the swishing was Fiona wagging her tail, as she tried to wake me from my nightmare.

Whew! Yes, my legs are their usual mismatched, barely-functioning selves, but that's OK. My life without polio would only have been different, not necessarily better.

**Post-Polio Online Resources****Post-polio Health International:**

PHI offers many helpful resources online, including links to videos on its Polio Place page and a Provider Directory.

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

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

**2017 Provider Directory (PDF):** [www.post-polio.org/net/PDIR.pdf](http://www.post-polio.org/net/PDIR.pdf)

**NPSA's website:** [www.ne-polio.org](http://www.ne-polio.org)

**Find Us on Facebook:**

[www.facebook.com/NebraskaPolioSurvivorsAssociation/](http://www.facebook.com/NebraskaPolioSurvivorsAssociation/)

**Nebraska Polio Survivors Association  
Foundation Board of Directors**

**President:**

Edward B. Roche, Ph.D.  
117 Bellevue Blvd S  
Bellevue, NE 68005-2440  
Home: 402-292-3781  
Work: 402-559-4645  
Email: [ebroche@cox.net](mailto:ebroche@cox.net)

**Vice President and Secretary:**

Kusum Kharbanda, Ph.D.  
770 N. 93rd St., Apt. 4B4  
Omaha, NE 68114-2674  
Work: 402-995-3752  
Email: [kkharbanda@unmc.edu](mailto:kkharbanda@unmc.edu)

**Treasurer:**

Larry Weber, CPA  
Weber & Thorson PC  
11205 Wright St., Ste. 220  
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Work: 402-330-9900  
FAX: 402-330-4022  
Email: [larry@weberthorson.com](mailto:larry@weberthorson.com)

**At-Large Members:**

Karen Dulany  
8027 S 69th St  
La Vista, NE 68128-4372  
Home: 402-339-8480  
Email: [kjdulany@msn.com](mailto:kjdulany@msn.com)

Charles "Chip" Mackenzie, Ph.D.  
14601 Laurel Ave  
Omaha, NE 68116  
Mobile: 402-212-0152  
Email: [chipmackenzie@gmail.com](mailto:chipmackenzie@gmail.com)

**Executive Director**

Elaine J. Allen  
PO Box 6076  
Omaha, NE 68106  
Voice mail: 402-932-5426  
Email: [npsa.org@hotmail.com](mailto:npsa.org@hotmail.com)

## She's on a Mission to Help Syrian Widows and Children

In April, Syria was in the news, first because of a poisonous gas attack on innocent civilians, and then, a week later, because of the joint target airstrikes of military installations in Syria.

A few days following the air strikes, an Omaha woman made a planned trip to Lebanon, as a member of the Presbyterian Church's Outreach Foundation to help Syrian refugees.

Julie Prescott Burgess spoke to NPSA members at the August meeting. She described the mission of the Outreach Foundation and why she feels called to go into such a dangerous region.

"Why do we go? We're going to be a living letter of Saint Paul," as Burgess explained the relationship of Saint Paul to the people of Damascus.

Although Christians are in the minority in Syria, the Presbyterian Church in Syria began a ministry several years ago, as ISIS was gaining control of the region, to help refugees from Iraq. Now some of those Syrians who helped the Iraqi refugees are refugees themselves, she said.

Syrian refugees are mostly widows with children. The widows create beautiful hand needlework to help make money to live on. The Outreach Foundation's "Hook and Thread" ministry was formed for about 75 Muslim women who meet weekly to do needlework and do Bible study, Burgess said. "The church does not discriminate. They help everybody!"

During her presentation, Burgess handed out samples of the women's needlework to NPSA members and welcomed them to keep any of the samples they liked.

In Tyre, Lebanon, the Outreach Foundation has set up schools for Syrian children, teaching them the Syrian curriculum so if they

go back to Syria, they'll be caught up. Some of these children were born since the war broke out and they haven't had the stability of an education. "The school is

transforming these kids," Burgess said.

For more information about the Outreach Foundation's work in Syria and Lebanon, here's the web page:

<https://www.theoutreachfoundation.org/hope-for-syrian-students>



### 2018 Meeting Schedule

NPSA's meetings will be held from 2:00 – 4:00 p.m. on the following Sundays in 2018:

May 6                      June 10

July 1                      August 5

September 9      November 4

**October Reunion:** Time and Date TBD

We meet in 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.

## Rehabilitation Doctor Advises Polio Survivors to Choose Health Care that Makes Sense to Them

During the April NPSA meeting, members viewed a video recorded during the PA Polio Network's "Post-Polio Care – Past Present and Future" Conference, held in August 2017 in Pennsylvania.


Dr. William DeMayo spent 43 minutes of the conference describing the present and the future of Post-Polio care from the perspective of a Rehabilitative Physician.

He made recommendations on how to work with a Primary Care Physician to find the kind of care and treatments that best fit the needs of the polio survivor.

"Shop around and find someone you can trust," Dr. Mayo said of choosing a primary care physician. "Do NOT focus on their lack of understanding of polio. Thank them and ask them for help. You'll get better advice and better care," he urged the conference attendees. Also, he encouraged them to "look for the Heart of a Teacher."

### "We are all alike" & "We are all different": The impact on delivery of health care.

- The common history of Polio connects survivors
- The impact of even "mild" polio symptoms on the aging process.
- The Shoulder
  - A very common source of disability in Polio Survivors
    - Anatomy, injury, and basic management is exactly the same for Polio survivors and others.
    - Some shoulder problems more likely due to weakness
    - Rehabilitation approaches may need to be modified somewhat.
  - Excessive focus on the Polio rather than the shoulder can lead to mistreatment or no treatment.



### The Present: Healthcare for the Polio Survivor

- How to navigate the Healthcare System
  - Working with your Primary Care Physician (PCP)
    - Find one you trust!!!!
    - Organize your questions, be respectful of time
    - Be thankful and encouraging.
    - Do NOT focus on lack of understanding of Polio.
  - The role of Consultations
    - A consult should provide advice, YOU maintain control in decision making.
    - Neurologists – Tend to be more diagnosticians.
      - VERY helpful at ruling out other causes of neurologic decline.
    - Physiatrists (Physical Medicine & Rehab specialist or "PM&R")
      - Functionally oriented – will look at biomechanics, bracing needs, exercise, etc.
      - Wide spectrum – some do comprehensive Rehabilitation some do Sports Med.
- Be organized and focused on what you need – communicate it clearly.
- Say "I need your help..."
- Look for "The Heart of a Teacher", consider other opinions IF questions not answered or answers not logical.

(Slides taken from Dr. DeMayo's Conference Presentation video)

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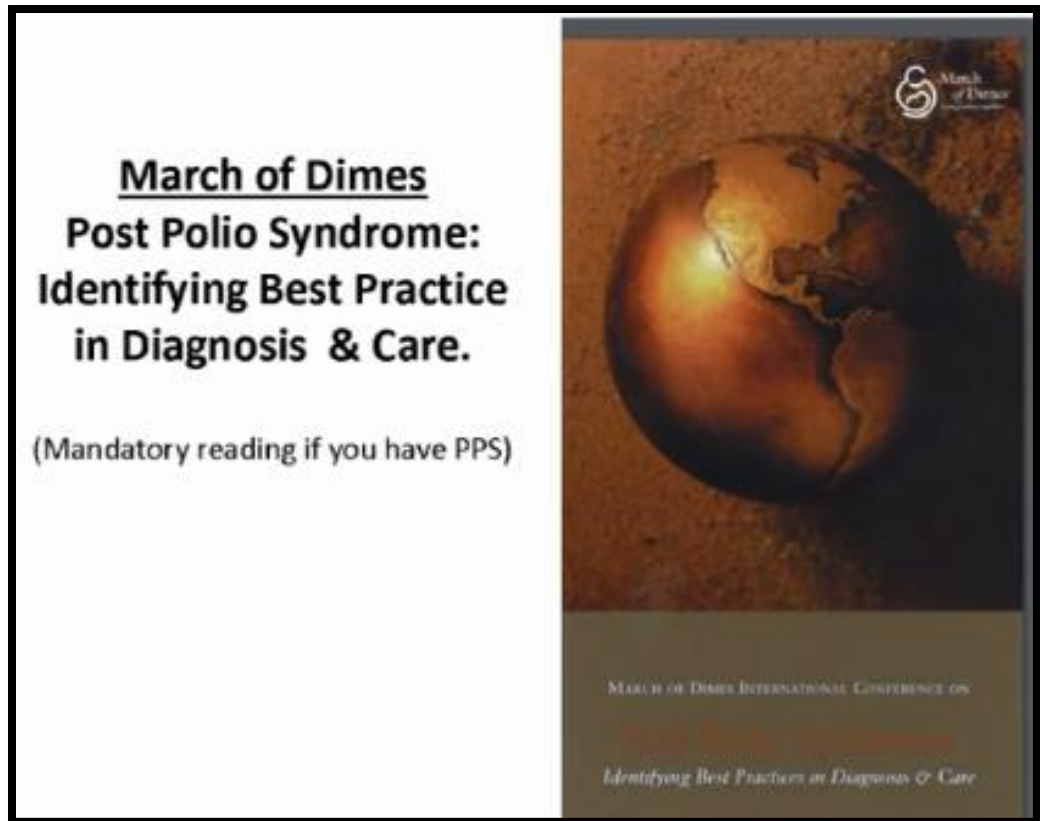


Because of their overuse from walking on crutches, the biomechanics of the shoulder is a very common source of disability in polio survivors. But Dr. DeMayo advised polio survivors to allow their doctors to provide options for the treatment of the shoulder injury, not on the polio.

As for the health care system in general, he described the Electronic Medical Record (EMR) this way: "What a quagmire!" He recommended that at each visit, provide a bullet point list or executive summary for the health care provider to input into the EMR.

In addition to primary care physicians and medical specialists, Dr. DeMayo said psychologists and counselors "can be a Lynch pin," in a polio survivor's health care decisions. "They can help to provide input and direction to help you decide what you want."

Dr. DeMayo recommended a brochure published by the March of Dimes as "mandatory reading for all polio survivors: *Post Polio Syndrome: Identifying Best Practices in Diagnosis & Care.*"



A full CD of the Post-Polio Care Conference is available by sending \$10, making checks payable to:

**Pa. Polio Survivors  
3365 Lace Leaf Dr.  
Doylestown, Pa. 18902**

The videos can be viewed or purchased online at this web page:

<https://www.papolionetwork.org/post-polio-care-conference-20171.html>

## NPSA Mission Statement

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.

NPSA  
PO Box 6076  
Omaha, NE 68106

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