



GLEANINGS

ISSUE #1, WINTER 2024

Don't Do This, Do That

by Millie Malone Lill

You know how we polio survivors are. We have overcome so much in our lives that we think we are invincible. Well, we are. Sort of. We need to know how exactly to play the game to insure that we win. It's not cheating! It's strategy.



First, we need to define the goal. To beat the Polio Dragon and finish the game as close to intact as possible, that's the goal.

Do Not: Try to downplay your level of disability to avoid making others uncomfortable.

Do: Simply tell it like it is. "If I go shopping with you today and then out to lunch and maybe a movie after that, I will be in bed for two days. I would love to have lunch with you, though. Maybe we could have a pizza delivered."

Do Not: Avoid asking for help when you need it.

Do: If your store offers delivery, take advantage of it. If your neighbor is making a trip to the store and offers to pick up your needs, smile and say Thank You. You can call your order in, perhaps, so your friend doesn't have to do anything more than pick it up and drop it off for you.

Do Not: Get your feelings hurt when others do not understand PPS. I've had PPS for over 40 years, and I still don't quite get it.

Do: Explain in simple terms that you have a neuromuscular disability a little bit similar to MS. If they ask for details, say it is progressive but can be managed if you are careful. That's usually all it takes.

Millie's Column (continued on p.2)

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## Eastern Nebraska Office on Aging

As one of the nation's 622 Area Agencies on Aging created by Congress under the Older Americans Act, the Eastern Nebraska Office on Aging (ENOA) serves families in Douglas, Sarpy, Dodge, Cass, and Washington counties. Their role is to provide a continuum of services to meet the varied needs of a diverse group of older individuals. Through ENOA's nutrition programs, care management services, volunteer opportunities, and community services, they enhance the lives of older Nebraskans.

A further mission of the Eastern Nebraska Office on Aging is to assess the needs of older individuals and their families and to provide services to meet those needs. By creating unique programs that fill gaps in service, ENOA helps older Nebraskans live independently, with dignity, and to remain for as long as possible in their own home. The caring, professional support they provide to the oldest members of the family can also help relieve the burden of caregiving on younger family members.

*ENOA (continued on p.2)*

**ENOA** *(continued from p.1)***INFORMATION & ASSISTANCE (I&A)***Guiding you in the right direction*

Often the first call for help from people requesting services, the Information and Assistance lines are staffed by individuals who answer questions about ENOA programs or direct callers to the appropriate agency or community resources. I & A is the entry point for ENOA's services. Call 402-444-6536 weekdays from 8 a.m. to 4:30 p.m.



**Eastern Nebraska  
Office on Aging**

[enoa.org](http://enoa.org)

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

**Do Not:** Stress yourself by worrying about what other people will think if they see you using a walker, cane, crutches, wheelchair or whichever tool you need to live your best life.

**Do:** Realize that what other people think of you is not your business and also that the chances are they aren't thinking about you in the first place.

**Do Not:** Beat yourself up by thinking of what you used to be able to do versus what you can do now.

**Do:** Try to be grateful that at one time you could do all of that. Even able-bodied people find that time and age take away some abilities.

**Do Not:** Waste time being angry or resentful at your disability. What good does that do? You will still be disabled, but you will also be angry and upset.

**Do:** Find things in your life that make you happy. I highly recommend writing a gratitude list every evening. Every day contains something that you are grateful for if you take the time to look for it. I find ending my day with gratitude makes falling asleep much easier.

I'm no guru. I am an elderly woman dealing with PPS the best way I know how. Although having contracted polio 78 years ago, I have managed to have a pretty decent life. I try to find humor wherever possible, and I maintain an attitude of gratitude. My Facebook friends have brought me comfort and joy as we share our lives, our sorrows and our triumphs. To me, the secret of beating that Polio Dragon is to thwart his attempts at making me miserable. I find things he can't control, and my life is a good one.

*Until Next Time*

## **Aging and Disability Resource Center**

The Nebraska Aging and Disability Resource Center (ADRC) has statewide information available for you, your family, and caregivers. The ADRC is here to help you navigate through what can be a consuming and complicated maze of services and programs. They will collaborate and partner with multiple community providers to obtain and access information and services for you. All ADRC information and assistance is free and confidential. For more information, call toll free at 1-844-843-6364. The state website (<https://ne211.org/nebraska-aging-disability-resource-center/>) has information that includes:

- A library with information on health, medications, symptom checker.
- Legislation at the State and Federal level.
- Assistive devices.
- Prescription drug assistance.
- Fall prevention.
- Facts about Medicare.
- My Personal Health Record (My PHR) to help organize and store your medical and healthcare information.

## New NPSA Zoom Meeting ID and Password

As a Gleanings subscriber, you are invited to attend our monthly Zoom meetings, no matter where you live. We frequently have people from as far away as Germany, Montreal, New York, and Florida in attendance, as well as those in Nebraska and Iowa.

We meet from 2:00 – 4:00 Central (U.S.) time on the first Sunday of the month, unless it is a holiday weekend such as Independence Day and Labor Day or during our winter break. Our first in-person meeting will be Sunday, May 5<sup>th</sup>, for those in the Omaha area.

Topics will be announced via email at least one week in advance.

*You are invited to attend our Zoom meetings by:*

- Calling one of the phone numbers listed in the box **OR**
- By downloading the **Zoom App** onto your mobile device or computer.

### Topic: NPSA Monthly Zoom Meeting

Time: This is a recurring monthly meeting

#### 2024 Tentative Meeting dates:

Zoom only: April 7

“Hybrid”: May 5, June 2, July 7, Aug 4

### To join Zoom Meeting, click this link

(for Gleanings online subscribers only):

<https://us06web.zoom.us/j/89629397895?pwd=bFBhOERvWmo5M2c2VkFYeGIZbFQ1dz09>

**Or**, open the **Zoom App** on your computer, mobile phone or device and enter:

**Meeting ID:** 896 2939 7895

**Passcode:** 940274

**To call in by telephone in the US**, dial one of these phone numbers and then enter Meeting ID and Passcode when prompted:

- +1 669 444 9171 US
- +1 719 359 4580 US

## Post-Polio Resource Guide to Clip and Keep

The following organizations publish newsletters, hold online meetings, and have Facebook pages or websites that provide a wealth of information to polio survivors, their families, and health care providers.

Also listed below are links to YouTube videos.

| Resource Name & Description                                                                                                                                                             | Resource Access Points                                                                                                                                                                                                                                                                                           |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Post-polio Health International (PHI):</b> Publishes a quarterly newsletter and a directory of health care providers who are familiar with polio and Post-Polio Syndrome.            | <b>Websites:</b> <a href="http://www.post-polio.org">www.post-polio.org</a> and <a href="http://www.poliohealth.org">www.poliohealth.org</a><br><b>Email:</b> <a href="mailto:info@post-polio.org">info@post-polio.org</a><br><b>Postal address:</b> 50 Crestwood Executive Center #440, Saint Louis, MO 63126   |
| <b>Boca Area Post Polio Group:</b> Publishes monthly newsletter and holds monthly Zoom meetings.                                                                                        | <b>Send Email to:</b> <a href="mailto:bappg@aol.com">bappg@aol.com</a>                                                                                                                                                                                                                                           |
| <b>PA Polio Survivors Network:</b> Publishes monthly newsletter, including column by Dr. Richard Bruno.                                                                                 | <b>Send Email to:</b> <a href="mailto:papolionetwork@gmail.com">papolionetwork@gmail.com</a>                                                                                                                                                                                                                     |
| <b>Post-Polio Syndrome Advocacy Group (Post-Polio SAG):</b> Sends occasional polio virus updates and holds occasional Zoom meetings.                                                    | <b>Send Email to:</b> <a href="mailto:datwater@tampabay.rr.com">datwater@tampabay.rr.com</a>                                                                                                                                                                                                                     |
| <b>YouTube Links to Videos:</b> If you have access to the internet, you can search for information about polio and post-polio to locate dozens of YouTube videos on those two subjects. | <b>Traveling without a Spare: Moving the Conversation Forward with Dr. Wenzel A. Leff:</b><br><a href="https://youtu.be/2R5cEKtr87s">https://youtu.be/2R5cEKtr87s</a><br><br><b>Post-Polio SAG's Zoom meeting with Jacqueline James:</b> <a href="https://youtu.be/u32gPK72-wk">https://youtu.be/u32gPK72-wk</a> |



Easter Seals Nebraska's mission is to create solutions that change the lives of children and adults with disabilities or other special needs, and their families. Each person touched by Easter Seals Nebraska--whether a client, family member, volunteer, employee, donor or other supporter--becomes a force of change to assure all people enjoy independence, have access to participate in community activities and explore opportunities for social and economic growth.

Easter Seals offers help, hope and answers to more than a million children and adults living with autism and other disabilities or special needs and their families each year. Services and support are provided through a network of more than 550 sites in the U.S. and through Ability First Australia. Each center provides exceptional services that are individualized, innovative, family-focused and tailored to meet specific needs of the particular community served. Primary Easter Seals services include:

- [Medical Rehabilitation](#)
- [Agriculture](#)
- [Workforce Development](#)
- [Camping & Recreation](#)

***Easter Seals Nebraska***  
*12565 West Center Road, Suite 100*  
*Omaha, NE 68144-8144*  
*1-800-471-6425 or local 402-462-3031*  
*Easter Seals and its affiliate organizations are 501(c)*  
*(3) nonprofit organizations.*

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 Work: 402-995-3752  
 Email: [kkharbanda@unmc.edu](mailto:kkharbanda@unmc.edu)

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 Home: 402-339-8480  
 Email: [kjdulany@msn.com](mailto:kjdulany@msn.com)

**Executive Director/Gleanings Editor**

Stephen Jackson  
 PO Box 6076  
 Omaha, NE 68106  
 Voice mail: 402-932-5426

**Please note NEW Email address:**

[Nebraska.Polio.Survivors@outlook.com](mailto:Nebraska.Polio.Survivors@outlook.com)



# GLEANINGS

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**Get Connected. Get Help.™**

*Aging and Disability Resource Center*

# ADRC

Serving all Nebraskans

[adrcnebraska.org](http://adrcnebraska.org)

Call 1-844-843-6364 (toll free)

### 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.

Nebraska Polio Survivors Association  
PO Box 6076  
Omaha, NE 68106

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