



GLEANINGS

Summer 2017

It's a Wild Ride

By Millie Malone Lill

Sometimes I see our struggles with PPS as a carnival. We start out on the carousel. Not so bad, we have our ups and downs, but they are fairly gentle and not really alarming. We recover pretty quickly.



The next ride is perhaps the bumper cars. If we are much more careful than the other drivers, we can avoid the worst of the crashes. We are gaining confidence by now, right? Sure. We handled the carousel and the bumper cars. We have a handle on this!

As we wander through this carnival of life, we find we are on different rides at different times. We can't all stay on the carousel or the bumper cars. Some of us want to take the scarier rides. Not all of our friends are on the same rides at the same times.

Jane may have found that if she stays in the kiddie section, she can avoid the tough, frightening rides while still having a good time.

Joe, though, is unafraid and does more than he knows is good for him. He holds down a job and then decides to strengthen his polio affected muscles by joining a gym. He does not realize that you cannot strengthen a muscle that has no working neurons attached to it. He was planning to ride the death-defying roller coaster, but finds he can only barely manage the bumper cars.

Some of us are fearful of making our condition worse, so we skip the carnival altogether. We don't want to fail at anything, so we don't try anything. This might be better for our overworked neurons, but life can be pretty boring. Others go all out. Use it up, wear it out, make it do, then do without. It's one way of living life. A shorter time period of being able to do things, but oh the things we do! As we sit in our chairs, completely unable to do anything worthwhile, we reminisce about all the wonderful adventures we have had in our lives. Maybe we are helpless as newborns now, but back then, we did it all!

I don't know which way is the best. Being ultra-careful is not typical for polio survivors; if we were, we might save our motor neurons well into very old age. Or, having been careful all our lives, planning for a pleasant antiquity, we may get hit by a bus.

I'm wandering through this carnival the same as the rest of you. I see some of my friends enjoying the carousel, some on the bumper cars, a few lined up for the death-defying roller coaster. Some are sitting on the sidelines, living vicariously through their more adventurous friends. Which way is the best way to enjoy the fun without ruining our bodies? I wish I knew.

Here is what I do know: Whichever way you decide to go, remember that life is short and the carnival won't be in town forever, so enjoy it while you can.

In this issue:

- Yoga exercises for polio survivors
- Online Post-Polio Resources

Yoga Therapist Teaches a “Cutting Edge” Class in Fremont, Nebraska

Yoga is a practice to stay in the present moment, combining quality body movements and breathing. Beth Christopher Krause told NPSA members she feels she's on a cutting edge by teaching her adaptive yoga classes in Fremont. Her classes target men's and women's health, children, and addictive medicine issues. She also travels to people's homes when students cannot attend classes in the studio.

Her first experience teaching adaptive yoga began when she worked with polio survivors during her 3-year yoga apprenticeship in Santa Cruz, CA.



During NPSA's Annual July Ice Cream Social meeting, she demonstrated breathing exercises that polio survivors can do either seated or in bed to relieve fatigue and pain, wake up, or gain focus. “A deep belly breath is invaluable for reducing pain,” she said. Breathing through alternate nostrils helps with focus.

“Yoga should not hurt,” she told the group as she showed them how to the “Cat and Cow” exercise to stretch the back muscles.

First photo, “The Cat”: Hunch the back, like a cat, while taking in a deep breath.

Second photo, “The Cow”: Then, breathe out, pulling the shoulders back, like a cow with its back swayed. Take another deep breath.

Krause demonstrated other Yoga

exercises to help people with limited mobility increase circulation, improve breathing and reduce pain. These exercises can be found on the internet; here's a link to one adaptive yoga site:

<http://blog.ncpad.org/2013/05/21/5-basic-principles-of-adaptive-yoga/>

Beth's Chair Yoga class description and schedule can be found on this website:

<http://www.embraceyourway.com/class-descriptions/>



Passionate Philanthropy is Mission of 'Inspired Giving' Pro

Mary Bernier asked people for large charitable gifts when she worked as a development officer with the University of Nebraska Foundation. Now, in retirement, she consults with people who want to channel their charitable gifts to causes that match their passions.

Passionate philanthropy is not being emotional about giving, Bernier said. "Passionate giving is a collection of your values and beliefs. Actually, it is figuring out what is really important in your life. That's what I work on: helping people decide what causes to give to." She cited one of her clients, an inventor who has created a nature reserve. Mary met her client when began to work with University of Nebraska Foundation." And now the inventor is in the process of setting up a foundation of her own. "It's the most amazing project," she said.

Bernier also described a family that contributed a memorial gift to one of the Millard high schools using the money that they received as memorial gifts when their child died. The memorial gifts turned into a continuing scholarship for graduates.

"I have a passion for education, having experienced the transformative nature of giving," she told NPSA members who met during the May monthly meeting. Her passion for education stems from her experience as a single parent with no education. Her father helped her finance her undergraduate education and then she got a master's degree.

Now, Bernier helps fund a scholarship in her name for non-traditional students that is awarded by the UNO Women's Club, where she's been a long-time, active member and former president.



Mary Bernier, pictured with Keyla, the recipient of her scholarship in 2014.

In her consulting business, Inspired Giving, Bernier helps people to understand their passions to give. "Why does someone pay money to give a gift? You should be careful with your giving. It's a wonderful feeling to give but you can enhance that gift by knowing what you're giving to." She helps donors come up with an action plan and a mission statement for their charitable giving.

"Writing a check doesn't always give you the same satisfaction as giving to causes that

you care about." For some of her clients, what was missing was that the gift wasn't giving them satisfaction, she explained. Now these clients can say "no" because they have focused their giving. As in the Biblical proverb: "Give a man a fish, he'll eat for a day. Teach him to fish, he'll eat for a lifetime."

Bernier suggested donors should consider the following issues before giving to charitable organizations:

1. Look at what percentage of a gift amount goes to the cause that the organization represents. Even the best organization can lose its way, citing examples such as the American Red Cross after Hurricane Katrina and Goodwill Industries in Omaha.
2. Be careful of organizations that use paid fundraisers. "Your money is going to pay for the call, not the cause."
3. Check out Go Fund me sites: "Some of the campaigns are legitimate, but many are not," she cautioned.
4. Another huge issue: Donor lists that are sold to others. "Once you get on the mailing list for one organization, you get calls or other solicitation letters from other groups."
5. Recent telemarketing scam involving a medical brace company: The caller asks, "Can you hear me?" Then, the caller records your "Yes" response and uses that as permission to call you to solicit for donations.

Thank You to Our Donors

We're grateful to the following donors for their gifts received from April 28 to July 28, 2017:

Mrs. Sandy Fischer, Bettendorf, IA
Donna D. Garwood, Burwell, NE
Alyce Green, Plattsmouth, NE
Marilyn E. Mills, Benson, MN
Sisters of Notre Dame, Omaha, NE, in
honor of the 60th Jubilee of Sister Josita
Hanus, a polio survivor
James V. Zeman, Charleston, IL

Every gift helps NPSA achieve its mission. All gifts are fully tax-deductible because we are a 501(c)(3) non-profit organization.

Please consider NPSA in your charitable giving this year. You may send your donations to:

Nebraska Polio Survivors Association

PO Box 6076

Omaha, NE 68106

Online PPS Resources

Post-polio Health International (PHI) offers many helpful resources online, including videos on its Polio Place page.

PHI's Home Page: www.post-polio.org/

Polio Place: www.polioplace.org/

For Health Care Providers: www.post-polio.org/edu/hpros/index.html

Health Care Providers Directory

(download pdf): www.post-polio.org/net/PDIR.pdf

Bruno Bytes (from the PA Polio Survivor Network):

www.papolionetwork.org/bruno-bytes.html

Yoga Exercises for Polio Survivors (see article on p. 2): www.embraceyourway.com/

Remaining 2017 NPSA Meeting Schedule

Our meetings are held from 2:00 – 4:00 p.m. on the first Sunday of the month, except when holiday weekends (as in July or September or Easter Sunday).

September 10

October 1: Reunion at Millard Roadhouse – invitations will be sent separately.

November 5

Except for our October Reunion, 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.

Dear Reader:

If you'd prefer an electronic version of Gleanings instead of a paper copy, please send us an email request. In your message, include your name and postal address, along with your email address to NPSA.ORG@HOTMAIL.COM.

Thank you for helping us reduce costs and keep our mailing list current and accurate.

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Anesthesia Warning Card for Polio Survivors

Cut, and fold the information in the box below into a card that you can carry with you and show to your 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 this website:

www.polioepic.org

SAVE THE DATE

The Annual NPSA Reunion will be held in Omaha on
October 1, 2017.

If you live in the Omaha/Council Bluffs/Lincoln area, watch your mailboxes in early September for an invitation to the luncheon event.

Summer 2017



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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.

Are you moving? Do you have a friend or family member who survived polio and who would like to receive Gleanings? Return this form with your address changes or the name and address of your friend/family member.

Name: _____

Street Address: _____

City/State/Zip: _____

Email address (if you prefer an electronic copy): _____