



GLEANINGS

February - March 2013

"WHAT DID YOU DO TO YOURSELF?"

By Millie Malone Lill

Have you ever gotten that question? When I first gave up the idea of keeping my brace covered by pants all the time, I was asked that question a lot. I was waitressing at the time. In Iowa. In the summer. In a building too old and drafty for A/C to be reliable. I decided to wear walking shorts. It was a good decision in one way because it was so much cooler.

Nevertheless, people who had known me for years and surely must have noticed that I listed noticeably to port and limped when I walk, had never seen my brace. I often wonder what reason they gave themselves for my obvious handicap.

"I didn't do anything to myself," I would say, somewhat affronted that people would think I'd deliberately damage my body, causing all this bother. "I had polio when I was four. Now I have Post Polio."

This usually got a strange stare. Sometimes, if we weren't busy, and since it was a small café in a

small town we often weren't, I'd try to explain PPS. "Look," I'd say, "when the polio virus attacked my spinal cord, it destroyed about half or more of the motor neurons that send messages to the brain. Kind of like a spark plug wire. New little neurons sprouted from the remaining neurons and sorta-kinda worked for awhile. Then the old

neurons got worn out from doing all the work and the newer ones were not that strong to begin with, so here I am. I've come unplugged." That was usually all I had time to say. These people were my neighbors and casual acquaintances. I didn't want to offend them by getting huffy, but neither did I want to go into a lot of detail to people who most likely weren't all that interested to start with.

Sometimes someone would see me using my power chair and would be puzzled because they'd seen me walking earlier that day, week, or month. Then I'd get, "Oh no! What did you do to yourself?" I would have to explain that I can only take a limited number of steps a day and that I was saving them for when I could not use the chair.

As far as that part about looking better without the chair...come on, how could I look better with my face squinched up in pain, breath coming in gasps, sweat running off my brow?

(Millie's Column continued on Page 2)

2013 NPSA Monthly Meetings

Mar. 3	April 7	May 5	June 2	July 7	Aug. 4
Sept. 8	Oct. 6 (Annual Reunion)	Nov. 3			

No January or December Meetings

Please join us for informational programs and lively discussions. We meet from 2:00 – 4:00 p.m. in the Community Room of the Bloomfield Forum, 9804 Nicholas Avenue (northeast of the Westroads Mall) in Omaha, Nebraska.

DON'T MISS MARCH'S PROGRAM: GRETCHEN BREN



Gretchen Bren, Executive Director of the Rotary Clubs of Omaha, returns to tell us about her polio vaccination trip to Africa with Rotary International's End Polio Now campaign.

In recent news, nine polio vaccination workers were murdered in northern Nigeria by extremists who claim the polio vaccine causes infertility in women. Gretchen will talk about the precautions they took.

MILLIE'S COLUMN *(continued from Page 1)*

And then there would be times when I couldn't get my power chair in the store because of a step or too high threshold, so I'd park the chair and walk in. At that point, I got the "It's a miracle!" reaction. "I'm so glad to see you don't need that awful chair anymore. You look so much better today. I bet you are glad to get rid of that chair!" I think this reaction is harder to take than the what-did-you-do-to-yourself stuff.

It seems so self-pitying to tell people that you are walking because you have to, being unable to get into the store otherwise, and that you would be paying for this little walk big time.

As far as that part about looking better without the chair...come on, how could I look better with my face squinched up in pain, breath coming in gasps, sweat running off my brow? I would love to say that once I'd explained all of this to people, they'd understand and I wouldn't have to do it again. Not so.

Oh, wait. I'm forgetting. We polio survivors are so well trained in hiding our pain and difficulty that it is entirely possible no one can see how bad I'm hurting. Of course, there is no way they can

tell that tomorrow or more likely the day after, I will be screaming in agony from leg spasms or, alternatively, woozy and disoriented from pain pills.

It isn't just ordinary people who react this way, either. I've had mixed responses to the use of my chair from medical professionals and their staffs, as well. One time, I'd had a new brace made and came back in to the office for an adjustment. I was in my power chair. The receptionist, a perky little gal with, I want to emphasize, no medical training at all, told me to get out of that chair at once! "Excuse me?" I said.

"We made you a brace so you don't have to use that chair anymore. Now get out of it at once!"

Now, here's the thing: I've been a Mom for a very, very long while and I don't take disrespect sitting down, even when I am sitting down. As you can imagine, this did not go over well. Lead balloon type of going over.

"Little girl," I told her, maintaining eye contact, "I am a polio survivor with about 200 steps a day at my disposal. I've used them all up by now. Furthermore, where I sit and how I get around is not your problem."

She got a bit red in the face, but she did back down. She was extremely lucky that my mother gave me a good bringing up, although I often think that was a bigger handicap than polio provided.

I've heard all the "use it or lose it" nonsense I ever want to hear. I've had PPS for about 30 years now and I think I am a better judge of what works for me than someone who either just met me or has seen me only a few times. I do as much as I can, but I've learned when to quit.

If someone asks you, "What did you do to yourself?" you have my permission to smile and say, "I learned how to live with PPS, whatever it takes."

If you should happen to back over someone's toes during your retreat, absolutely by accident, of course, well...stuff happens, doesn't it?

Millie Malone Lill is a humor columnist who lives in Iowa. You may write to her in care of Gleanings, or npsa.org@hotmail.com.

NEW FOUNDATION PRESIDENT ATTENDS MEETING VIA SKYPE

Newly-elected NPSA Foundation Board President Edward Roche, PhD., talked with members online during the February 3 NPSA meeting. Because PPS limits his ability to get around without assistance, Roche attended via a Skype call to introduce himself to members and to discuss the Foundation's by-laws, management and objectives.

Roche explained the Foundation's purpose. "The Board supports NPSA's mission by providing stewardship of the endowment which funds some of its operating expenses," he said. "Those expenses include the Executive Director's part-time salary and the cost of workers who help produce Gleanings."

However, Roche emphasized the need for voluntary contributions from those across the U.S. who receive Gleanings, NPSA's bi-monthly newsletter. To maintain its 501 (c)(3) status nonprofit status, NPSA must receive a significant amount of its funds from public support.

Nonprofits are also required to keep the articles of incorporation, by-laws, and annual financial reports on file with the Nebraska Secretary of State's office. He explained that the current by-laws were written more than 20 years old and need to be updated to reflect NPSA's current operation and board composition. Roche invited those who attended the February meeting to consider forming a committee to rewrite the by-laws.

Roche announced some long-range goals for the NPSA and the Board:

- Solicit requests for starter grant proposals to fund neuromuscular diseases
- Adopt more electronic delivery methods for Gleanings
- Build the board membership to include medical professionals who can help review grant proposals
- Organize a seminar for health care professionals to help meet its mission of educating the medical community about Post Polio Syndrome

RIDING ON A SEGWAY INSTEAD OF IN A WHEELCHAIR

Polio survivor George Blessing attended the February 3 NPSA to demonstrate how he gets around – his Segway. He says he likes it better than using a wheelchair because he stands above the crowd. He modified this two-wheeler with a seat so he can sit if his legs get too tired.



Blessing has posted 18 videos of him riding or pulling his Segway on YouTube.

You can search for the videos in YouTube by entering **Segway river j rat**.

To search in Google, enter **Segway pull 1** or **Segway pull 2**.

ANTIBIOTICS: DON'T USE THEM TO TREAT COLDS OR THE FLU

(From the www.U.S.A.gov Weekly Digest Bulletin)

If you're suffering from a cold, the flu, or another virus, there are things you can do to help [relieve the symptoms](#), but taking antibiotics will not help. Antibiotics only treat bacterial infections, such as strep throat.

[Antibiotic resistance](#) is a serious public health problem that is primarily being caused by the repeated and improper use of antibiotics.

You can help prevent antibiotic resistance by taking these actions:

Don't take antibiotics for viral infections, such as colds or the flu.

- If you are prescribed antibiotics for a bacterial infection, take the full course of treatment even if you begin to feel better after a few days.
- If you need to stop taking a course of antibiotics for some reason, [discard leftover medication](#)--do not save it for a future illness.
- Do not take antibiotics prescribed for someone else.

If your healthcare provider determines that you do not have a bacterial infection, ask about ways to relieve your symptoms. Don't pressure your provider to prescribe antibiotics.

More Health Related Internet Links:

New on the MedlinePlus [Polio and Post-Polio Syndrome](#)

(www.nlm.nih.gov/medlineplus/polioandpostpolio/syndrome.html) :

[Polio: Information for Parents](#)

<http://www.cdc.gov/vaccines/vpd-vac/polio/downloads/PL-dis-polio-color-office.pdf>

Source: Centers for Disease Control and Prevention, American Academy of Pediatrics, American Academy of Family Physicians - PDF

Scam Awareness: *Phishing, Pharming, Visiting and Smishing*

Scam artists try to obtain sensitive information such as your Social Security Number, driver's license, credit card or bank account information. Whatever the method used, criminals attempt to scare or excite you into divulging confidential and financial account information. The names distinguish the medium used for the attack. The most common forms of scams are:

Phishing: refers to criminal activity that attempts to fraudulently obtain sensitive information through e-mail.

Pharming: a scam where a hacker installs malicious code on a personal computer or server. Installation of malicious code is usually accomplished through Phishing.

Vishing: relies on social engineering techniques to trick the victim into providing information over the telephone.

Smishing: uses cell phone text messages to lure consumers in. Often the text will contain a URL or phone number. The phone number often has an automated voice response system. **Types of commonly seen scams:**

Your account or card has been suspended. This message warns that suspicious activity has been detected on your account and your card has been frozen until you verify your account or personal information. A real financial institution would not call you and ask for your account or personal information. Hang up and call your financial institution at a number that you know is legitimate.

You've won something big and awesome! We all have dreams we'd love to see come true, and scammers prey on our wish lists. Making you excited about something is another way to make you vulnerable. If you receive an email, phone call or text message telling you that you've won something amazing and all you have to do is confirm your identity, then it's probably too good to be true. Don't let your excitement cloud your judgment. Always do your research before you respond to a notice like this, especially if you don't remember entering a drawing in the first place.

I REMEMBER...ROBERT J. ZEMAN

By James V. Zeman *(Editor's note: This is a copy of the actual letter which accompanied his gift.)*

I am making my contribution larger than usual in memory of my brother, Robert J. Zeman. Bob was afflicted with polio in high school while playing basketball, falling to the ground never able to walk again without braces and crutches. He did rehabilitation at Warm Springs, where he proudly snapped a picture of FDR in the swimming pool. While serving as Dawes County judge he went up to his third story office each working day using the stairs as no elevator was available. He loved hunting and fishing, where I often accompanied him. My polio was less physically destructive and I avoided walking help, except for canes, until the last few years when I needed to get around in a wheelchair. Bob was finally freed recently after a nearly seventy year period of braces and crutches.

SHARE YOUR MEMORIES

If you have a memory of a loved one who survived polio, or would like to share your polio story, please send it to us at the address listed below.

We will print it as space allows as part of our "I REMEMBER" series.

NPSA THANKS YOU!

The following donors contributed to our mission from December 10, 2012 – February 10, 2013:

Annual Gifts:

Mary L. Ferguson, Norfolk, NE

Marjorie Huelman, Carroll, IA

Frank Johannsen, Bayard, NE

Susan Kneten, Wilson, NC

Donald Osentowski, York, NE

Linda Randig, Butler, PA

Lucille Rolfes, Bella Vista, AR

Memorial Gifts:

James V. Zeman, Deadwood, SD

NPSA is a 501(c)(3) organization. As a non-profit organization, we rely upon and are grateful for the generous, voluntary support of our members, their family members, and friends. Every gift helps us fulfill our mission. Your gifts are fully tax-deductible, as allowed by law.

If you would like to become a donor, you may send a check to:

**Nebraska Polio Survivors Association
PO Box 6076
Omaha, NE 68106**



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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.

NPSA was founded in 1984 by Nancy Baldwin Carter.

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