Nebraska NPSA Polio Survivors Association

GLEANINGS

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Scaling the Wall

By Millie Malone Lill

You can't do it. You cannot scale the wall. I'm talking about the infamous Polio Wall. You know the one. The one that you hit when you overdo. That's the one, all right. You know the drill. You bop along, feeling fine, thinking that you can do another hour's worth of whatever activity you are doing, even though you know you might be pushing it. Then, all of a sudden, there it is. The Wall. It looms large. You are totally out of strength, with no energy to go another step.

What do you do when you "hit the wall?" My friend, you crash, that is what you do. You may pay for not being aware of that wall with a few days in bed. Perhaps you will be lucky and be able to remain somewhat vertical, though sadly out of plumb, but pay you will. In my own case, I will stagger around for a few days in a zombie like state, hurting all over, ears ringing, and incoherent. Rather a high price to pay for another hour's worth of shopping, or missing a couple of hours of sleep, or any of a multitude of things that can trip the trigger that pops that wall up in front of me.

Why do we do it? There is a theory that all polio survivors have Type A personalities. Some people think that we strove so hard to overcome the original virus and its aftermath that we cannot now slow down. I don't know. I know that any sensible able-bodied person will stop when he is tired. He will call in sick if he is sick. Not your basic polio, though. Nope. Can't be thought wimpy, must keep up with the pack. In fact, we must be ahead of the pack to be truly comfortable. Comfortable being a relative term, that is. Comfortably aching in every muscle, comfortably groggy and unable to think straight. But if we slowed down, people might think we are "crippled" or in some way not as capable as our co-workers. We must outstrip everyone else. It is the Polio Rule.

The Rule must change. We are wearing out our remaining motor neurons when we overdo. We must learn to "Conserve to Preserve." If we want any quality of life, this is a lesson we must learn. I have heard it over and over again: "I am working as hard as I can to stay out of a wheelchair."

However, if we do use a wheelchair, at least for the long-distance things, we may well be able to walk around our houses longer. I use motorized carts whenever possible for shopping. It makes the difference between being able to go into one store and then drag my weary body home or being able to spend a couple of hours, leisurely browsing through all the items on display and returning home with enough strength left over to get back into the house.

(Millie's Column, continued on Page 2)

Combating Vaccine Hesitancy: Communicating "Sticky" Information

By Elaine Allen, Gleanings Editor

Health agencies and scientific experts must build trust and credibility when trying to combat Coronavirus vaccine hesitancy among people, according to a health communication researcher.

UNO Assistant Professor Roma Subramanian says interpersonal health communication between physician-patient is critical to the success of the campaign. “Finding health care professionals who will listen to you is key,” she said.

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Vaccine Hesitancy

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For the February Zoom meeting, she offered tips on how physicians can talk to patients about vaccines:

- What have you heard?
- What are your friends saying about the COVID-19 vaccine?
- What are your previous experiences?

Subramanian said it is important for health care professionals to be transparent about how the vaccine will affect their patients.

Other communication strategies include recruiting health workers who are members of minority groups as role models, and holding vaccination clinics in trusted spaces, such as churches or temples.

People in positions of influence, such as entertainers and faith leaders, cannot just share information. They must use emotional appeals and altruistic messages, she said.

Mass media messages must be tailored to different audiences. “One Public Service Announcement won't work for the entire country or community,” she said.

Subramanian says troubling vaccine hesitancy news is coming out of her native India, even among front-line health workers. She cited several reasons for this hesitancy:

1. Lack of confidence:
    - Political parties are manipulating the population.
    - Indians being used as guinea pigs by western companies.
2. Fear of sterilization:
    - The persistent misinformation surrounding the polio vaccine, especially in the Muslim minority in India, and in Pakistan and Nigeria, where polio is still endemic.
3. Trust in safety/effectiveness (not 100% safe): side effects:
    - Lack of transparency in how vaccines were approved.
    - Not enough volunteers and diversity in clinical trials.
4. Lack of accurate information and rampant misinformation, particularly with the use of the "Whatsapp" text message system that’s popular in other countries.

Millie’s Column

(Continued from Page 1)

It is so hard to "give in." To allow ourselves to use the aids that we need, such as canes, walkers, and wheelchairs. Why? No one thinks you are being a wimp if you drive your car to the store. It's too far to walk, so you drive. If it is too far for you to walk around the mall, why not use a chair? It is merely a tool, after all, just as your car is. I think we don't want to return to the days when we were struggling to get out of the braces, throw away the crutches, ditch that wheelchair. We feel we have failed if we go back to using those aids again.

We have not failed. Most of us have struggled valiantly, have gotten an education, married, raised a family, and did everything that an able-bodied person could do and, sometimes, a few things they couldn't do. It is no disgrace to use whatever tool it takes to enjoy the rest of our lives. If using a wheelchair conserves enough energy for us to be able to go to a ball game with our grandchildren, where is the harm?

Let's slow down, smell the roses, go slow enough to enjoy the view, and make our bodies last just a little bit longer. We have earned this, we deserve it, and we should not be ashamed to do it.

[*Editor’s note: This column appeared in a previous issue of* *<u>Gleanings</u>* *and in other Post-polio newsletters. Reprinted with the author’s permission.]*

> “Millie –
>
> Thanks for [your column in] Gleanings through the years. At ten years old, I was in the Scottsbluff hospital just a short time and very lucky. At 81 years old, I can still hear those iron lungs pumping and when they stopped, it was real quiet… you didn’t pop off to a nurse.”
>
> *from reader Larry L. Golden, North Platte, Nebraska*

ZOOM with NPSA!

We are meeting on Zoom until at least May 2021. With Zoom telephone/video conferences, all our members can attend safely from anywhere. As a Gleanings subscriber, you are invited to attend our Zoom meetings, no matter where you live!

We meet from 2:00 – 4:00 Central (U.S.) time on the following Sunday afternoons with topics to be announced via email and on our Facebook page at least one week in advance.

You have two options to participate in our Zoom meetings:

- Call in via one of the phone numbers listed below.
- Or, to join via video, download the Zoom app onto your mobile device or computer.

Date	Topic	Zoom Meeting Details
5/2/2021	Topic: Mindfulness and Meditation, presented by Martin Wice, MD - Center for Advanced Medicine Neuroscience Center, St. Louis, Missouri	Zoom web address: *https://us02web.zoom.us/* Meeting ID: 825 6010 0877 Meeting passcode: 661946
6/6/2021	Powers of attorney for health care, presented by Saul J. Morse - Legal Counsel, Brown Hay & Stephens, LLP, Springfield, Illinois	Call-in phone numbers (using the same Meeting ID and passcode): +1 346 248 7799 US (Houston) +1 312 626 6799 US (Chicago)
7/11/2021	To be announced	
8/1/2021	To be announced	

We encourage our readers who value this newsletter, or those who want to honor or memorialize a polio survivor, to send a tax-deductible gift to the address below:

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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.

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