Nebraska NPSA Polio Survivors Association

# GLEANINGS

June – July 2013

## IT'S ALL A MATTER OF ATTITUDE

By Elaine J. Allen

Gleanings readers have enjoyed Millie Malone Lill's musings for years. Attendees at NPSA's monthly meetings get to visit with her on a regular basis.

But for the June 2nd NPSA meeting, Gleanings' humor columnist was also the featured speaker, sharing with her fellow polio survivors how she manages to maintain her positive attitude.

"I spoke on this topic a few years back on a panel with an M.D. and a Ph.D. But all I have is 'BS' behind my name," Millie joked.

"I believe laughter is the best medicine." Her suggestion for the bad days: "Fill them up with fun activities like funny movies or read funny books, anything that can distract you from feeling pain."

Millie told her fellow polio survivors, "Think like a kid. Give yourself permission to feel joy." She cautioned against watching bad news, especially TV videos of 9/11, bombings, mass shootings, war coverage, etc. "Don't give in to terrorists who are trying to make you feel depressed."

*Matter of Attitude (continued on p.2)*

## "TO US, IT'S PERSONAL"

For seniors who are looking for in-home, non-medical care, Home Instead Senior Care franchisees offers 65,000 trained, insured and bonded caregivers in 18 countries.

"Our slogan is: 'To you, it's about finding a trusted partner. To us, it's personal," said a Home Instead community service representative. Amy Colwell visited NPSA's May 5 meeting to talk about the services available from the international company with its headquarters in Omaha.

In January, a new facility for seniors 55 years and older opened its doors near the campus of the University of Nebraska Medical Center. The Home Instead Center for Successful Aging is a spa and workout center affiliated with UNMC gerontologists at the Engaged and Wellness Center.

Home Instead's special programs in Omaha include Alzheimer's Care Training Program and a "Be a Santa to a Senior", a local holiday gift-giving initiative that provided over 1 million gifts to 700,000 seniors.

For more information about Home Instead, its website is www.homeinstead.com.

## Matter of Attitude *(continued from p. 1)*

To counteract bad news, she watches Abbott and Costello and Mel Brooks movies, even Shrek.

She also talked about reading humor writers and her own writing. “I read humor writers like Dave Barry and Mark Twain. And, of course, I write books, so you can read my latest book, which will be published soon as an e-book on RandomHarvest.com.”

## *TOLD YOU SO*

By Millie Malone Lill

*One night I was in bed by 6:00 and did not wake up until 8 a.m. the next day. Even so, I was exhausted. I didn't just hit the Polio Wall, I ran headlong into it and knocked myself cuckoo.*

I learned a new word the other day: *Omnishambles*. Omni means all, and a quick glance around my apartment would tell you what shambles means. That word perfectly describes what my life was during May.

As you know, I like to keep busy. During a normal month, I do the online newsletter Polio Perspective and this column for Gleanings. I do the monthly calendar, newsletter, and word search puzzle for Realife, the cooperative where I live. I belong to a book club and a poetry group, both of which meet the last part of each month. May also had me designing a new brochure for Realife in time for our May 28 Open House and preparing to present a speech at the June 2nd meeting of NPSA, as well as doing some rewriting and reformatting on my soon-to-be-published e-book version of Hot Water, Orange Juice and Kids.

Even when you add in the fact that I live pretty much in the middle of a 22-member, closely-knit family, all of whom insist on having birthdays and anniversaries from time to time and sometimes the odd potluck supper, I manage. Sometimes I manage better than other times.

This May was certainly the exception. I was doing fine with Pacing, “Conserving to preserve” and all of the stuff I keep yammering at you guys to do and which I often fail to do myself.

Then my brother-in-law died. His children and grandchildren came from New York and California to attend his funeral and to empty out his apartment and square away those things that await all of us.

First we had the funeral, then all the occasions to get together with this part of the family that we so rarely see, and I didn't want to miss out on any of it. However, deadlines were piling up. Fatigue had set up shop in my life and most of the time my ears were buzzing with it. One night I was in bed by 6:00 and did not wake up until 8 a.m. the next day. Even so, I was exhausted. I didn't just hit the Polio Wall, I ran headlong into it and knocked myself cuckoo.

Somehow, I managed to get all of it done. I'm a perfectionist when it comes to my writing and I worried that the fatigue would cause me to make mistakes. I had purchased a travel scooter in preparation to riding along to Branson, Missouri, with some friends on June 6, planning to attend our annual polio reunion there.

*Told You So (continued on p.3)*

## Told You So *(continued from p. 2)*

I'd only missed this reunion twice in the 14 years it has been going on. My registration fee was paid, my room reserved at the hotel.

Well, folks, I had to make a decision. Did I really want to go to Branson already exhausted? It would cost me between $400 and $500 all told, counting my registration fee, the hotel room, the gas and incidentals while there. That's a lot of money to spend on a three day nap, which is what it would have turned into. I wanted to go so badly, but I knew that the fatigue I was experiencing would make it a situation I endured rather than enjoyed. I canceled the trip.

June is being spent in a more relaxing fashion. I'm doing my columns ahead of deadline for a change and spreading out the rest of my activities. Please, people, do as I say, not as I do. Keep that Polio Dragon from biting you in the behind!

## I REMEMBER…RACHEL

By the late Norman L. Smith

Rachel's goals seemed far away to me as I began my physical therapy after recovering from polio. When it was possible to bend my knees and move my legs into a crouch position, I would grimace as my stretching hamstrings reached a new limit and Rachel would say, "Someday you are going to kiss your knees!"

All this as she supported my neck, head and shoulders up, pulling me toward a knee. When my face came within a foot of the goal I would stiffen to the pain while looking at the place on my knee I was to kiss someday. And to myself I'd say, "She has to be kidding." I was to learn that even a goal she set while laughing was a serious one that she intended to guide me to attain.

Rachel could take my breath away. She did so the first time she announced, "Today you are going to sit up." She held me close and told me to hug her as she brought me to an upright position and held me steady as an assistant moved my nearly-useless legs around so that they hung over the edge of the bed. My breath almost refused to come to me, and it was a short, intense, and somewhat frightening moment. She and her assistant reversed the procedure and once again I lay back in bed almost panting to recover. My lungs were weak. I could not sneeze at that time. If you told me a funny joke or story, I had no means to produce a hearty laugh, only the laughing sounds I emitted at the end of a pain outburst. Once again and in due time, sitting up became an accomplishment I could finally master with the aid of an overhead handle rigged above my bed.

Finally came the day Rachel announced, "Today we walk." And to my bedside she scooted a walker. She eased me from the edge of the bed and guided my legs so that the security strap was in place to bear my weight. I stood for a brief moment and tried to step forward only to sense my legs buckling at the knees.

That day it was but a few steps with Rachel coaching, encouraging, and laughing. In time I mastered the routine and began to take longer and longer shuffle walks in the hospital corridors. Rachel was always at hand. "Lift your foot! Hold that right hip in! Straighten up!" She commanded me like a drill sergeant, and I thought that 1 was then much like my two young sons had been when I watched them in their strollers.

One day, Rachel walked with me, assisted by a cane to the middle of a ward. She helped me down to the floor. We sat together there and talked for a moment.

*I Remember… (Continued to p. 4)*

### SHARE YOUR MEMORIES

If you would like to share your polio story, or if you have a memory of a loved one who survived polio, please send it to us. We will print it as space allows as part of our "I REMEMBER" series.

## I Remember… *(Continued from p. 3*

Then, she said, "You are down. You fell down. You aren't hurt. You must get up, but around you there is nothing to cling to, nothing you can use to pull yourself up. You must find a means to bring yourself back up to an erect standing position." Then she began to teach me the steps I must learn to master the return to an upright position.

Rachel was right. Our "love-hate" relationship continued as she had predicted. After about four months of rehabilitation. I attained the status of "outpatient." I learned that my once-friendly home setting was filled with barriers I had never noticed before. Likewise, my community was a quagmire of pitfalls that constantly challenged my mobility. As Rachel had foreseen, I would fall. In a split moment of diverted concentration, the toe of my shoe toe would snag a rough sidewalk crack, and I'd plunge forward to kiss the pavement.

Most of the time I was not hurt, but for a few moments I lay there assessing the impact damages, controlling pain, swearing oaths, and cursing my own carelessness. Then I heard her voice once again, "You must find a means to bring yourself back up erect." I'd look around, sometimes finding a friendly parking meter stand, bike rack, small tree, railing, something I could crawl to. If nothing was available I'd say to myself, "Okay, Rachel. Here we go again!" And I'd begin the methodical process of positioning my body so I could find myself

I left Bremerton, Washington in late 1952. I regret that I left Rachel then, allowing time and circumstance to separate me from her permanently. I don't believe that physical therapists receive the full recognition they so richly deserve. I know there are countless Rachels in this world. And like my Rachel, by their spirit, instill the rehabilitation of the mind as well as the physical body. They make the message plain. "If there is a will, there is a way."

Polio Survivors, Family & Friends
Health Care Professionals
Rotarians

Save the Date:

**Sunday, October 6, 2013**

## NPSA Annual Reunion Luncheon

Featured Speaker

**Ann Lee Hussey**

Polio Survivor &
Chair, Polio Survivors Rotarian Action Group

**The Thompson Center**
**University of Nebraska – Omaha**
**12:30 – 3:30 p.m.**

Registration details will appear in August- September issue of Gleanings

## NPSA THANKS YOU!

The following donors recently contributed Annual Gifts to help fulfill NPSA's mission:

Gordon Blaser, Columbus, NE
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NPSA is a 501(c) (3) organization that relies upon 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.

**News reprinted from the National Library of Medicine MedlinePlus Polio and Post-Polio Syndrome webpage:**

## MODIFIED POLIO VIRUS MAY HELP FIGHT BRAIN TUMORS, STUDY SUGGESTS

By Mary Elizabeth Dallas, (HealthDay News)

A modified version of the polio virus might one day help fight brain tumors, preliminary research suggests.

Scientists at Duke Cancer Institute said the investigational therapy, known as PVSRIPO, uses an engineered form of the virus that is harmless to normal cells, but attacks cancer cells. The therapy shows promise in the treatment of glioblastoma, the most common and aggressive brain tumor, they said.

"These early results are intriguing," principal investigator Dr. Annick Desjardins, an associate professor of medicine at Duke University School of Medicine, said in a news release. "Current therapies for glioblastoma are limited because they cannot cross the blood-brain barrier and often do not specifically attack the tumor. This treatment appears to overcome those problems." The findings were presented at the American Society of Clinical Oncology annual meeting in Chicago, from May 31 to June 4.

Researchers at Duke said they developed the therapy to take advantage of the fact that cancer cells have receptors that attract the polio virus. The virus infects and kills the tumor cells. When infused into a tumor, the therapy also triggers the immune system to attack the infected tumor cells, the researchers said.

Of seven patients involved in the preliminary study, three have responded well to the therapy. One year after treatment, one of the three patients remains cancer-free. Another is disease-free after 11 months; a third has been cancer-free for five months. Two others are also disease-free. Only two patients in the study did not respond well to the therapy, the study authors said.

In contrast, the researchers noted that about 50 percent of glioblastoma patients have a recurrence of their disease within eight weeks of traditional treatments.

Studies presented at meetings should be considered preliminary until published in a peer-reviewed medical journal.

## *Remaining 2013 Monthly Meetings:*

July 7 Aug. 4 Sept. 8 Nov. 3

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. (*Please note: We do not meet in January or December.*

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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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