Nebraska NPSA Polio Survivors Association

GLEANINGS

October - November 2012

“WORLD PREMIER” VIDEO HIGHLIGHTED NPSA’S ANNUAL REUNION

By Elaine Allen, NPSA Executive Director

A retired physician and polio survivor says polio survivors are “traveling without a spare” in the world premier of a video at NPSA’s Annual Reunion on October 7.

Forty people from eastern Nebraska and western Iowa gathered at The Thompson Center on the University of Nebraska-Omaha campus to attend the yearly event.

During the social hour, local musician Tom Roth sang a variety of popular music prior to the luncheon and showed a music video dedicated to his late grandmother. Following opening remarks and introductions, attendees dined on their choice of London Broil or Broiled Salmon.

Following the meal, Master of Ceremonies Chris Allen introduced the video interview with Dr. Wenzel A. Leff, author of <u>Traveling Without A Spare: A Polio Survivor’s Guide To Navigating The Post-Polio Journey</u>.

In the video, produced with an underwriting grant by the NPSA, Dr. Leff talked about his infection as a 16-year-old in Mobridge, South Dakota. During his recovery stage, he completed high school, went on to attend college and medical school. He married, raised a family, and became an internist, practicing medicine in Seattle, Washington, until his retirement.

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Mark your calendars!

NPSA Monthly Meetings

Nov. 4, 2012: The Grocery Geek: MSG and Food Additives

No meetings in Dec. 2012 and Jan. 2013

2013:	Feb. 3	Mar. 3
	April 7	May 5
	June 2	July 7
	Aug. 4	Sept. 8
Annual Reunion: Oct. 6		Nov. 3

PIGEONHOLED

By Millie Malone Lill, **Gleanings** columnist

People often want to label us. I know that a few people think that if you are disabled, it has to be a mental thing. Either you are mentally challenged or it's all in your head.

But what if you refuse to stay in your little pigeon hole, or pull that label off, wad it up and toss it in the garbage where it belongs? What if, even though you cannot walk, you still believe your mind is functional? Sometimes people think that if you are in a wheelchair, you cannot speak for yourself, or hear. When you take your wheelchair into a restaurant, the wait person will ask your companion, “What will he/she be having?” Unless you are far more limber than I am, you are not sitting on your ears, nor has your tongue been captured by the cat. You can order for yourself. Or at least, if you cannot, the difficulty was not caused by contact between your behind and a wheelchair.

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MILLIE *(Continued from 2)*

One person I spoke to had been in a restaurant with a friend and the friend was asked, “She won't pee on the floor, will she?” WHAT??? This was a woman in a wheelchair, not a puppy! Had I been the woman in the chair, I'd have had to say, “No, but she might bite.”

I've run into the oddest kind of prejudices in my life as a wheelchair user. Maybe I should say 'preconceived notions' rather than prejudices. For instance, many people think that if you once sit in a wheelchair, you will never get out of it again. I use my power chair for any distances more than a few yards, but I still walk a little. I've seen some people almost yell “It's a miracle!” if I get out of my chair in the grocery store to reach something on a top shelf or in the refrigerated case.

There will always be people who want to label us, jam us into a pigeonhole and expect us to stay there. I never will. My handicap is part of me, but it isn't ME. I'm far more than that! And so are you!

Another one: If once you start using a wheelchair, you won't want to get out of it because “everything is just so much easier in the chair.” Have these people ever had to do dishes from a wheelchair? Or cook a meal? Or get into a normal bathroom and back out again without help? I doubt it. Of course, some things are easier to do from a chair. If you cannot walk, getting from Point A to Point B is much easier if you use a wheelchair, just as hammering a nail is easier if you use a hammer instead of your fist. My chair is a tool. Even able-bodied people will use a car, another tool, to get from point A to point B if the distance is too far for them to walk. It’s simple: My Point A is much closer to Point B.

Some people think there’s nothing worse than 'ending up in a wheelchair.' Believe me, many things are worse. Struggling along on crutches or not being able to go anywhere at all is much worse. It really isn't depressing, truly, it is not. I think some people believe that if you are in a wheelchair, your life is barely worth living and you surely must be depressed. At least, I think that's what an acquaintance I happened to run into meant. We hadn't seen each other for years and were never really friends, merely acquaintances. He said, “Oh, Millie, you are looking so good!” I was pleased, thinking it was a compliment. He shattered that illusion when he went on to say, “You look so good, are you sure you really need that wheelchair?” It dawned on me that he perhaps meant I looked healthy and happy. Not surprisingly, I am healthy and happy. I just can't walk. Once I got over the shock of his saying that, I thought, “Hmm. Maybe if I didn't do my hair, wore sloppy clothes, didn't wear any makeup, and perhaps whimpered now and then, I would qualify for wheelchair use.

My first mother-in-law was not pleased that her son married a cripple. At that time, I wasn't even wearing a brace, as PPS was 25 years or so in the future for me. However, I was small and I was not robust. I limped. I got tired easily. I could not lift a 100 lb. bale, since I only weighed slightly more than that myself. When our first son was born, she told my husband that I should not have more children, as I was far too retarded to raise a family. Excuse me? My brain isn’t in my leg, “Thank-you-very-much!” Ever the obedient daughter-in-law, I bore two more children, who turned out quite well, too, I believe.

There will always be people who want to label us, jam us into a pigeonhole and expect us to stay there. I never will. My handicap is part of me, but it isn't ME. I'm far more than that! And so are you! I'm a writer, a mother, a grandmother, a great-grandmother, and much more.

Our tools may be different from those who are able-bodied people. We may use a power chair, walker, a cane or a brace, but those are merely tools. They don’t define us.

Live your life with joy and happiness and nail a board over that pigeonhole. Or buy a pigeon to put in it.

ANNUAL REUNION *(Continued from page 1)*

The video contains Dr. Leff's simple-to-understand description of the four stages of polio, in addition to vivid graphic illustrations of the damage caused to the neuromuscular system by the virus, and how the nerves reattach themselves to muscles during the recovery stage. It even contains a cartoon of how polio survivors begin to "travel without a spare" as they age and Post-Polio symptoms begin to appear.

Dr. Leff said he hoped his book will help polio survivors understand what they can do to take care of themselves and how important it is for them to become their own best advocates in their health care.

Following the video, several attendees bought a copy of Dr. Leff's book for themselves or their health care professionals to read.

The afternoon's program wrapped up with a raffle including the three main prizes: an autographed copy of Dr. Leff's book, a beautiful quilt and a tote bag, both made by NPSA member Penny Jewell.

I LEARNED TO WALK IN A GARBAGE CAN!

By Marjorie Farris

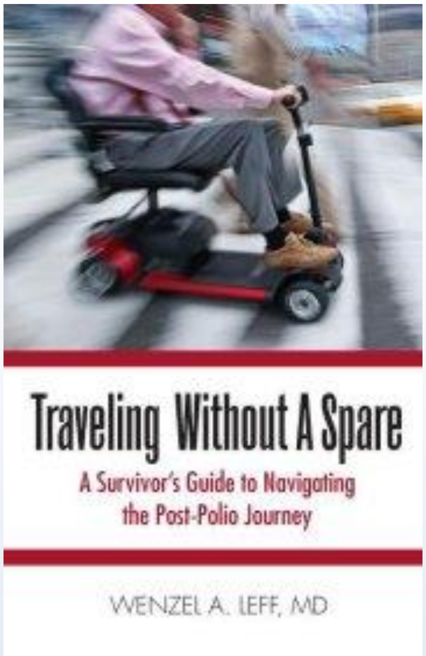
My parents were married near Sioux City, Iowa, in May 1936, during the Great Depression drought that destroyed many farm crops that year.

I was born June 17, 1937. In October, my mom told me I became fussier than usual and, when she picked me up out of my basket, realized that I was unable to use my body from the waist down. My daughter recently asked me what my parents must have thought when they realized the problem, and truthfully, I have no idea. I just know that as a parent myself, I would have been petrified, and I am sure they were also.

First, they took me to the local country doctor who had delivered me. He gave them a tentative diagnosis of "infantile paralysis" and referred me to Dr. Arch O'Donoghue, one of the finest

(Continued on page 4)

How to Order



Traveling Without A Spare

A Survivor's Guide to Navigating the Post-Polio Journey

WENZEL A. LEFF, MD

Mailing address:
Lori Leff Mueller
WAL Publishing
641 33rd Ave East
Seattle, WA 98112

Prices:

1-4 copies:	$15
5-9 books:	$13.50
10 book or more:	$12.50

Facebook page:
https://www.facebook.com/TravelingWithoutASpare

Website:
http://www.travelingwithoutaspare.com/

Dr. Leff's video: "Carrying the Conversation Forward" will be available soon on YouTube.

FARRIS *(Continued from page 3)*

orthopedic doctors in the region, who concurred with the diagnosis.

He told my parents that most likely, I would not be able to sit up or walk, but that if I were to ever be able to do those things, I would need warm water therapy every day, preferably twice a day. Since President Franklin Delano Roosevelt had also contracted polio and used the therapeutic waters of Warm Springs, Georgia, I think the doctor was thinking along those lines. However, my parents didn't have the money or opportunity for a warm water spa, so they did the next best thing: they bought a garbage can, carried water from the well twice a day, warmed it on the old wood stove, and dangled me in the water. The buoyancy of the water allowed my legs to move in a way that I couldn't outside the water, and by the age of two, I had grown tall enough and strong enough to take my first steps in the garbage can. I think that will make an interesting title for an autobiography, should I ever write one: <u>*I Learned to Walk in a Garbage Can!*</u>

> ***My parents didn't have the money or opportunity for a warm water spa, so they did the next best thing: they bought a garbage can, carried water from the well twice a day, warmed it on the old wood stove, and dangled me in the water.***

After four surgeries to correct abnormalities and the use of leg braces to the age of nine, I was able to walk without braces or the use of canes or crutches. Walking was always difficult, and I walked with a limp, but I walked, was mainlined in elementary and high school, and led a mostly normal life. After attending college at Wayne State Teachers College, I taught both kindergarten and upper elementary in Iowa public schools. I taught and worked as a secretary in Kentucky during my married years and then raised our daughter as a single mother when my husband died in 1990.

In 1969, during a European tour with three teacher friends, we were in a bad car accident. I suffered a broken hip, broken pelvis and broken shoulder and spent a month in the hospital in Amsterdam. Although we all recovered enough to begin teaching by the beginning of the fall semester, I believe that this accident caused the onset of osteoporosis which I've had for over twenty years, resulting in 29 broken bones. But who's counting? The last broken bone was the fifth one for my right leg, and at that point, I realized I would be safer and would be able to do a lot more if I used my electric wheelchair full time. In 2010, I was given a new electric chair, and I bought a van that had a side ramp – the best thing since sliced bread. Now, I am able to go anywhere at any time without worrying about wet floors or icy sidewalks.

Although I retired at 70, I am now working on my second Master's degree, this one in history, at Eastern Kentucky University. I celebrated my 75th birthday in June with a big party. Over 100 people attended, including six of my co-teachers from the Sixties. The purpose of the party was to thank the attendees because every single person there has contributed to my life and helped me in some way.

Today, life is good. I live alone in my own home. I have friends who check on me and who are just a phone call away if I need help, but I am able to do everything for myself that is necessary. In the summer, I thoroughly enjoy planting, watering and weeding a few flower beds, and on many summer evenings I enjoy sitting on the deck and reading.

I've been asked how my life would have been different had I not contracted polio at the age of three months. Of course, it would have been different, but I doubt that it would have been better. Because I couldn't always rely on my body to accomplish things, I had to think of other ways to do what I wanted to do, and as a result, I believe that I feel a greater sense of accomplishment in my life than I might have otherwise.

(Ed.: Marjorie is the cousin of NPSA Exec Dir. Elaine J. Allen)

NPSA THANKS YOU!

The following donors have sent gifts during the period May 16 – October 7, 2012:

Annual Gifts:

Joan Bredehoft
Genevieve Conway
Jim McCormick
Patricia Meierhenry
Kathleen Mensching
Bethyne Hirsch Noble
Linda Rehberg
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Susan Thorson
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Reunion Donations:

Marie R. Galda
Tom Plummer

United Way Contributions:

Linda K Hunter
Dr. Edward (Ted) B. Roche

We are a 501(c)(3) organization. As a non-profit organization, we are grateful to and rely upon the generous support of our members, their family members, and friends. Every gift helps us fulfill our mission. If you would like to become a donor, you may send a check to:

Nebraska Polio Survivors Association
PO Box 6076
Omaha, NE 68106

Your gifts are fully tax-deductible, as allowed by law.

I REMEMBER: JEAN Y. LOVE

By Marie Galda

Each of the names listed under Memorial Gifts has a story behind it. Here's one that has spanned over a century:

1910's: Anna Skvor (my mother) and Mrs. Yeager become friends while members of a church in the Corapolis, PA, area. Anna is a bi-lingual church organizer of immigrant laborers in the area's coal mines. Mrs. Yeager is a parishioner. Anna marries J. Galda (my father) and moves to Omaha, while the Yeagers remain in PA.

1920's: Both women have daughters who become polio survivors: Jean Yeager and me.

1930's: Jean is eager to go away to college so she's permitted to spend a year at the University of Nebraska in Lincoln because of its proximity to Omaha. My sister Helen and I take a bus to visit her at her dorm and tour the campus. Jean visits Omaha. She returns to PA and marries Robert (Bob) Love. Jean and I become sporadic pen pals.

1980's: In 1985, Jean and Bob tour the Midwest, especially Omaha. Jean and I increase our correspondence as we realize the reality of Post-Polio Syndrome and witness the emergence of organizations and publications dedicated to spreading the word. Jean gets on the Gleanings mailing list and becomes a donor.

2010: As Jean and I begin to age, our correspondence diminishes. When I get no responses from my cards to Jean, I wonder if I will ever hear of what happened to Jean and Bob. I get the answer when I read in the June-July Gleanings of her nephews' donations to NPSA in memory of Jean Yeager Love.

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Find us on **Facebook:**
www.facebook.com/NebraskaPolioSurvivorsAssociation

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.

Gleanings: October-November 2012

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