



GLEANINGS

October - November 2013

POLIO SURVIVORS URGED TO TELL THEIR STORIES

By Elaine J. Allen

The featured speaker at NPSA's 2013 Annual Reunion, Ann Lee Hussey, says the fight to wipe out polio is still being waged, and the disease is still a stubborn foe.

Ann Lee serves as the Chair of Rotary International's Polio Survivors and Associates Interest Group. Last year, she was recognized with other Rotarians by the White House as a "Point of Light".

A polio survivor who was paralyzed from the waist down in infancy, Ann Lee endured many surgeries to straighten her right leg. She began her 25-minute talk by showing slides of her leg in braces and cast. "Like many of you, I benefitted from the help of the March of Dimes to receive the care and corrective surgeries that my parents would not have otherwise been able to afford."

"As the only polio survivor in my school, I felt alone and sad."

She felt that same sadness when she made her first polio vaccination trip with Rotary International in January 2001. "I just broke down and cried on first trip to India when I saw other polio survivors, especially a little girl with leather braces," she continued, "because I was that little girl."

Since then, Ann Lee has been active in Rotary International's End Polio Now project, participating in 21 polio vaccination campaigns. In November, she will make her 22nd trip, this one to Nigeria.

"Volunteers pay their own way to go on a vaccination day trip," she said, expressing her gratitude to her husband, who encourages her to go.



Ann Lee Hussey was the featured speaker at NPSA's 2013 Annual Reunion on October 6th.

"Make the effort to tell your story. The truth of your disease will help others understand the devastating effects of polio," she said. "Write your story on paper or put them on audio or video."

She described what an amazing experience it is to know one person can make a difference. "How many lives can one person touch? In one trip, 700 surgeries were performed on 350 victims to help them straighten limbs crippled by polio.

Volunteers helped a polio survivor set up a bike shop. A polio survivor received a micro loan for a sewing machine to help provide income for her family and provide clothes for her village."

Ann Lee Hussey (continued on p.2)

Ann Lee Hussey (*from p. 1*)

But the trips are not without risk to the three countries where the polio virus is still endemic: Nigeria, Afghanistan and Pakistan. "I've lost 15 colleagues in Nigeria," she said. "And I think of the 'Angels of Karachi', who have been killed by extremist groups who use violence to resist vaccination campaigns in Pakistan."

"Has our program created conflict at times? Yes." But, Hussey believes there is always hope. "Diplomacy is key to the vaccination program in areas of conflict," she said.

For the past 25 years, Rotary International participated in global polio initiatives with the World Health Organization (WHO), UNICEF and the Centers for Disease Control. In the past few years, The Bill and Melinda Gates Foundation has become a partner in these initiatives by contributing matching funds to help with the polio eradication efforts.



Connie Russell, Chip and Mary Ellen Mackenzie (center), Diane Johnson and her sister Linda Kapple sat together at the Annual Reunion.

The polio eradication effort also raises awareness for other immunizations such as measles and malaria. To help boost children's immune systems, Vitamin A is also administered with the polio vaccine shots.

"2012 was our best year ever," for the End Polio Now campaign, she said. However, the fight is not over. A recent outbreak in Somalia was caused by people carrying the polio virus from Nigeria. "There are constant outbreaks of importation cases by nomads who carry it from one of the three endemic countries," she explained. Recent news articles report that a strain



Reunion attendees (from left to right) Judy Eades, Duane Snow, Wanda Blankenbeckler, Don Eades, and Millie Lill.

of polio virus found in Israel's sewers was imported from Pakistan.

Children in the U.S., Europe and other developed countries who have not been vaccinated or who have compromised immune systems are as much at risk of being infected as those in Nigeria, Afghanistan and Pakistan. "Global travel in places such as Europe and even North America are at an even greater risk than ever for polio to appear," she cautioned. "Polio is truly only a plane ride away. Relying on a larger population of immunized people may not be enough to protect this group of non-vaccinated children in the very near future."

Toward the end of her talk, Hussey encouraged reunion attendees to work closely with Rotary International to share their stories.

"The Rotary's Polio Survivors and Associates website, Voices of Polio, collects stories from polio survivors and we want yours," she said. <http://rotarypoliosurvivors.wordpress.com/voices-of-polio/>

Ann Lee quoted probably the most famous polio survivor, President Franklin Delano Roosevelt: "Once you spend two years of your life trying to wiggle one toe, everything else is in proportion." she continued. "It is vital for generations of any age to learn about the struggles and triumphs of those whose lives have been affected by this disease for centuries."

One of the reunion attendees asked Ann Lee if she thought polio made survivors "a stubborn lot and over-achievers." She nodded in agreement. "Absolutely! Nobody wants to say that a disease defined their life but I think the challenges that you face in illness defines what you become in your life," she said.

Dear Ms. Bea Haven-Badly

By Millie Malone Lill

Once again it is time for a visit with our resident expert on mannerly behavior. Remember, if you have a question about how to behave or how others should behave, send it to Ms. Haven-Badly's personal secretary Millie Malone Lill, mil.lill@gmail.com, and Ms. Bea just might print your letter. Wouldn't that be special?

Here are a few letters from today's mailbag:

Dear Ms. Bea,

What is the proper way to respond to a disabled person who is really, really rude to you? I thought people with a disability were required to be polite, nice, quiet and unobtrusive.

Signed, Wondering in Wisconsin

Dear Wondering,

Whatever gave you that idea? People with disabilities are just people. Sometimes they are rude, sometimes not. It has more to do with their upbringing and whether or not they remembered to take their meds than it does with the disability. Having said that, I do want to ask you: Please not get violent with him/her! That's never the answer. Treat the rude person with a disability exactly as you would an able-bodied person. Unless you are Mike Tyson, that is. Mike, biting ears is really, really rude and uncalled for! ~~~~~

Dear Ms. Bea,

The other day, I was in Wal-Mart, using their electric scooter, and picking up groceries. I was parked in front of the dairy case, trying to decide on which brand of margarine I wanted to purchase. All of a sudden, an arm materialized in front of my face and the person on the other end of that arm dragged a carton of milk under my nose, nearly hitting it. I wanted to bite the arm. Would that be a proper response?

Signed, Rabid in Rapid City

Dear Rabid,

NO!!! Never bite someone's arm. You don't know where it's been! I suggest you simply carefully back up and accidentally run over that person's big toe.

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**Dear Ms. Bea,**

I took my power chair grocery shopping the other day. The grocery store is a few blocks from my home. As I was crossing the street... with the light, I must add... a car turned the corner, and very nearly ran over me. As the car passed me within no more than 10 inches, the driver glared at me as if I were doing something wrong. She seemed to think that since she was legally allowed to turn the corner, she was also legally allowed to run over anyone in the crosswalk. What should I have done?

*Signed, Bewildered in Beebeetown*

**Dear Bewildered,**

I am assuming you screamed loudly and clutch your heart. That's certainly what I'd have done. Other than that, I guess there is not much you could do. There are some people who think people with disabilities should stay in their homes and not clog up the landscape with their presence. If she had run over you, she'd have been in big trouble, boy. But I do not advocate letting her run over you. I think you'd be in more trouble than she would, what with being squashed like a bug and all. ~~~~~

**Dear Ms. Bea,**

One day last week, I went to one of those big box stores. I can still walk a little but not enough to be able to cruise the aisles in those huge stores while shopping. I was standing in line waiting to use the last available electric scooter when an old man in a manual chair, being pushed by a young woman who was possibly his daughter, cut me off, leaped out of his manual chair and grabbed that last scooter.

I said, "Excuse me, but I can't shop here unless I can use that scooter. Could you let your pusher help you shop and let me have it?" He glared balefully at me and said, "I'll have you know my daughter is not a pusher! All my drugs are perfectly legal!" With that, he sped off in the electric scooter. Well, sped might be an exaggeration, but the point is, I had to turn around and hobble back to my car and go home.

*Signed, Resentful in Racine*

*Ms. Bea Haven-Badly (continued on p. 4)*

**Ms. Bea Haven-Badly** *(continued from p. 3)***Dear Resentful,**

I'm so sorry this happened to you. There was no excuse for that man to be so awful. He should have let his daughter continue to push him in the manual chair. However, we don't know if his daughter was one of those kids like my grandson who took me shopping in my manual chair once. He would give me a big push, take his hands off the handlebars and yell "Wheee!" Also, he went past the Clearance racks at warp speed so that I could only get what was on my list, no browsing. I can tell you, I won't let him do that again unless I have a seatbelt and airbags!

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That's it for today, Gentle Readers. Remember, if you have a question and are willing to settle for a silly answer, just email **Ms. Bea Haven-Badly** at the following email address:

mil.lill@gmail.com

Millie's new e-book, **Hot Water, Orange Juice 'n' Kids...** is now available online. All proceeds from its sale support a fundraising project for the International Centre for Polio Education.

To learn more, go to this website:

<http://www.postpolioinfo.com/index.ph>

HOTLINE FOR DISABILITY SERVICES

Persons with disabilities and their families often need to work with a variety of community and state agencies to get the services and supports they need. Navigating through these services and supports can often be complicated and confusing. In Nebraska, program helps answer questions that are encountered along the way and find resources to assist.

The Hotline for Disability Services provides information and referral services, including information about services available in a certain area, transportation, special parking permits, legal rights, and any other questions related to a disability.

Experienced Hotline staff members answer questions and provide information regarding resources via telephone or e-mail. Other information may be obtained by accessing the Hotline's website: www.cap.ne.gov

The website may be searched by entering an agency name or by selecting a category, service, county, city, age or disability. Examples of categories to choose from include: accessibility, advocacy and support, employment, financial, housing/residential, etc.

Interested individuals may call the Hotline toll-free at 800-742-7594 or, for callers in Lincoln, at 402-471-0801. Questions for the Hotline may also be sent by email to shari.bahensky@nebraska.gov

Resource List for People with Disabilities

Nebraska CAP (Client Assistance Program) / Hotline for Disability Services

301 Centennial Mall South, Box 94987

Lincoln, Nebraska 68509

Hotline Phone:

Lincoln: 402-471-0801

CAP Phone:

Lincoln: 402-471-3656 V/TT

Toll-free in Nebraska but outside

Lincoln: 800-742-7594 V/TT

<http://www.cap.ne.gov/>

HELP Adult Services

402-341-6559

1941 South 42nd, Suite 200

Omaha, NE

www.helpadulthoodservices.org

NPSA 2013 Annual Reunion Attendees



Ted and Vickie Roche, Fred and Eunice Jalass, Chris Allen



Ann Lee Hussey, Gretchen and Gary Bren, Bob Perrin, Roxy Orr



Marie Galda, Darrel and Patti Suddeth, Joan Heinz, and with husband Ron's hand only visible.



Stanley Johnson, Karen and John Dulany, Penny Jewell, Fred Henninger, and Barbara Johnson sat together at the 2013 Annual Reunion.

NPSA wishes to thanks the following donors for their generous support of our mission:

Marie Galda, Omaha, NE
 Jeaninne J. Spencer, Lynch, NE
 Barbara Waters, in memory of her aunt
 Darlene Petersen, Cumberland, IA

Reunion Raffle Prize Donors:

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We're beginning our 30th year! NPSA was founded in 1984 by Nancy Baldwin Carter.

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.

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Name: _____

Street Address or PO Box: _____

City: _____ **State:** _____ **Zip:** _____

Or, leave a message on our voice mail: 402-932-5426.

Please send all address changes, comments or inquiries to:

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