



GLEANINGS

October - November 2015

Joan Headley Speaks about 'PHI and You' to Reunion Attendees

By Elaine J. Allen

The speaker for NPSA's 31st reunion said Post-Polio Health International (PHI) operates with a philosophy of "building bridges and bonds, not bureaucracy. We promote participation and process, not personalities."

Executive Director Joan Headley gave a brief history of Post-Polio Health International (PHI),



referring to it as "55 years in 55 seconds." Joan Headley began working for PHI in 1987, when the organization was still known as International Ventilator Users Network. The current name change occurred in 2003.

She told 45 attendees that PHI's four-fold mission is "to enhance the lives and independence of polio survivors and home ventilator users through education, advocacy, research and networking."

The educational mission takes several forms. In her role, Joan has coordinated International Conferences and participated in medical and professional conferences, nationally and internationally, the most recent one in Lyon, France.

PHI hosts several websites, including www.PolioPlace.org, where videos and a Living with Polio section includes polio survivors' stories. "Why are stories important? Because we are preserving our legacy," she said. "Our story is not finished. We are writing our story each day."

PHI's research fund, provided by generous donors and endowments, has awarded nine research grants of \$50,000 a year. The most recent research grant is a two-year study of the "Poliovirus genome in patients with post-polio syndrome (PPS)". The researcher is based in Italy but four clinics in four different U.S. cities are participating in the study: Philadelphia, Syracuse, St. Louis, and Los Angeles.

As part of its advocacy mission, PHI recently concluded another "We're Still Here" week from October 11 – 17th. This year's theme featured a photo contest of polio survivors "out and about" in various venues.

Post-polio Health International Online Resources:

PHI's Home Page: www.post-polio.org/
Polio Place: www.polioplace.org/
Directory (PDF): www.post-polio.org/net/PDIR.pdf

Inside This Issue:

Millie Malone Lill's Column, p. 2
List of Donors, p. 3
Photos from 2015 Reunion, p. 4 -5

Scooter Ho!

By Millie Malone Lill

I was invited to attend a conference in Philadelphia on October 4th. It was just one afternoon, but the main focus was Dr. Bruno. “Oh, I want to go,” I thought when I read the invitation, “but the airports are so big and I haven’t flown since 9/11. How much hassle will check in security be? I’ve seen what the airlines can do to a power chair, backs ripped off, arms destroyed. What might happen to my little travel scooter?”

I seesawed back and forth until a new friend, Alice, said she wanted to go but didn’t want to go alone. She could drive to the airport, no problem. I decided I’d go.

I went to my local travel agent to set this all up. Previously, I’d booked tickets online, but I thought I should have some professional help to make sure there were no slipups with my scooter. I was pleasantly surprised by the fact that my agent could save me \$200 by booking us on a Weekend Getaway flight with Southwest airlines. She took care of all the details, too, like checking us in 24 hours ahead of time and making sure everyone knew I would be taking the scooter right to the door of the plane and that I would need it again when I changed planes in Chicago.

On Friday night, Oct 2nd, my travel companion, Annie, and I checked into the Holiday Inn right across from the Des Moines, Iowa, airport. It’s a really nice place and had a shuttle that would take us and the scooter over to the airport for our 6:00 a.m. check-in time. My grandson took us to dinner that evening, too, adding a bit of frosting to this cake. Far too early the next morning, we were at the airport, checked our baggage, and headed for the gate. We found coffee and breakfast sandwiches on the way. Loading was so easy.

We changed planes at Midway in Chicago, but everything went smooth as silk. For me, at



least. Poor Annie had to do far too much walking. She refused a wheelchair, though. From Chicago to Philadelphia, the cloud cover was complete. We flew between layers of clouds so it looked as if we were floating on sudsy water.

Arriving at the airport, we contacted our shuttle and were driven through sporadic rain to the hotel. What a lovely place that was! The Delaware Valley polio group had made all the plans and everything was set up perfectly for all of us. There were 100 attendees from all over the place; the farthest one traveled from Las Vegas.

Quite a few of us gathered for cocktails (mine was coffee) and then for dinner in the hotel dining room. It was so great to meet so many online polio friends, some of whom I had met before, but many of whom I’d only spoken to online.

We had breakfast the next morning with Dr. Bruno, who is my idol. He does so much for polio survivors and does it for free. We had a nice visit, with many others there to meet. Then on to the conference, which was named Casual Coffee Moments with Dr. Bruno. It was essentially a question and answer session. There were lots of round tables where we were served our lunch. Then the conversations started. Everyone had questions and Dr. Bruno often had answers. He has a wonderful sense of humor, although his answers were very clear and easy to understand.

It was a wonderful weekend with lots of information that I am still sorting and digesting. However, this column is intended to reassure anyone who thinks travel is no longer an option. It most definitely is! My little scooter and I had a wonderful time. Knowing that I can once again go visiting opens the door to much more travel in my future. Look out World! I’m back.

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2015 NPSA Reunion Attendees Met for Fellowship and Food on October 4th



NPSA founder Nancy Baldwin Carter was able to attend this year's reunion after missing the 30th Anniversary celebration last year because of her husband's health.



Featured guest speaker Joan Headley talks with NPSA's Foundation Board President Dr. Ted Roche.



The reunion was attended by 45 polio survivors, family members and friends. This was the first reunion for several of the attendees.

The buffet luncheon was held at The Thompson Alumni Center on the west edge University of Nebraska – Omaha's Dodge Street campus.





Dr. Vickie Roche talks with Deb Walker, friend of Nancy Baldwin Carter and her husband, Bill.

Sandra Moore and Jackie Devaney
chat during the luncheon.



Judy Eades, a monthly meeting attendee, speaks with Lois Givens, who attended her first reunion.

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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.

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