

GLEANINGS

Autumn 2016

Historian and Polio Survivor Speaks at Annual Reunion

By Elaine J. Allen

The polio vaccine was released in April 1955 but was in short supply in Northern Wisconsin in the fall. Because five-year-old Daniel Wilson was not attending school yet, he was not in the group of children who were given priority to receive the vaccine. As a result, Dan contracted polio during an outbreak in September 1955.

Over the years, Dan developed scoliosis and had a spinal fusion. In 1987, 32 years after his recovery from the acute phase of polio, he began experiencing Post-Polio symptoms. In 2001, he began using a Bi-pap machine to help him breathe better when he slept. In 2006, he began using a scooter to help him get around the Muhlenberg College campus in Allentown, Pennsylvania, where he is a history professor.

Dr. Wilson spoke via Skype to 25 attendees of the NPSA Annual Reunion on Sunday, October 2, 2016. He described his research into the history of polio epidemics in the US and the growing awareness of Post-Polio Syndrome in the 1980s. He has published three books on the history of polio.

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"The stigma surrounding the AIDS epidemic of the Eighties was similar to what polio survivors and their families endured in the Thirties, Forties and Fifties. It piqued my interest in doing research into polio epidemics and the stories of polio survivors," he said.

Wilson's challenge was to find voices of polio survivors. He started by digging through boxes containing over 3,000 letters that had been written to President Franklin D. Roosevelt, the most famous polio survivor. Some of these letters were written by family members of a polio patient "only a day or two after the polio diagnosis."

He found one letter that was dated December 9, 1941, asking the President for advice two days following the bombing of Pearl Harbor. "For that family, that diagnosis was their Pearl Harbor." (*Continued on p. 2*)

World Famous Writer Incarcerated

By Millie Malone Lill

Famous writer, power-chair user and well-known nag Millie Malone Lill has been locked up for the last ten days (as of this



writing). What is her crime, you ask? And, while we are in a questioning mode: "What do you mean - World Famous Writer?" I will answer that second question first. Shut up! (*Continued on p. 3*)

Historian Speaks at Annual Reunion

(continued from p. 1)

Wilson's research revealed that Roosevelt personally answered many of the letters he received in the Thirties. But after World War II broke out, his staff replied to the letters on the President's behalf.

As the Internet age began in the early Nineties, Dr. Wilson began participating on a List Serv for polio survivors. These groups stirred up many memories for the participants and helped him developed sources for his research.

"Each of us had a unique experience but I discovered people's narratives had changed from the early letters sent to Roosevelt," Wilson said. The collection of 200 narratives in his book <u>Polio Voices</u> includes the early overcoming narratives of "If Roosevelt could overcome polio, you can, too" and "I beat polio" themes. However, Dr. Wilson said the narratives began to change tone in the late Sixties to focus more on the challenges of living with the late effects of polio and overcoming obstacles.

Dr. Wilson's investigations into the subject of Disability Research revealed the key role polio survivors have played in the disability rights and independent living movement. "Polio survivors were agents of change for self-empowerment."

At the end of his talk, reunion attendees asked Dr. Wilson several questions, including why he thought there is a lack of research into Post-Polio syndrome. "Frankly, we're a dying population. PPS is not an exciting disease," he said.

Books by Daniel J. Wilson, Ph.D.

- Polio: Biographies of Disease, 2009.
- <u>Polio Voices: An Oral History from the American</u> <u>Polio Epidemics and Worldwide Eradication</u> <u>Efforts</u>, edited with Julie K. Silver, M.D., 2007
- <u>Living with Polio: The Epidemic and Its Survivors,</u> 2005

Photos from NPSA's 32nd Annual Reunion Held on October 2nd



Reunion attendees help themselves to a delicious buffet luncheon at the DC Centre.



Eunice and Fred Jalass enjoy the conversations at their table



Patti Suddeth inspect the quilted raffle items she won.

Incarcerated Writer (continued from p. 1)

As to the first question: Her crime was owning an apartment on the second floor of Realife Cooperative during a severe lightning storm. Lightning stuck a vent pipe on the top floor of the building, wreaking havoc with the fire alarm system which blared for thirty solid minutes, rendering most of the rather elderly residents half-deaf and making resident dog/mascot/hall monitor Fiona Lill shake like a leaf.

In short order, the parking lot of Realife was filled with emergency vehicles, firemen and police. Apparently, the firemen on those calendars are not the ones who actually respond to emergencies such as this one. Or maybe not to emergencies at senior housing. Oh well.

The lightning strike also damaged the panel that operates the elevator and the entry phone whereby one gets buzzed into the secure building. Since the elevator is closely allied to the fire alarm system, it went on a sympathy strike, surrendered its fried circuit board to the maintenance man and went into a deep sulk. That circuit board being nearly 25 years old, it is, of course, obsolete. An investigation is now underway trying to discover the whereabouts of either a similar circuit board or one that can be rigged to work.

Meanwhile, our heroine was invited to yet another birthday party in her honor. Her son Ted and his wife, who is without question the best cook in Crawford County, had invited her to their place for a cookout. Many of her friends and family would be there as well. Several people offered to help her down the two short flights of stairs so that she could attend. Never one to pass up a great meal with the people she loves, Millie accepted gladly. All went quite well until the party was over and the world famous writer had to go back up those two flights of stairs. Gravity is much more help going down stairs than it is going up. By the time she had hauled herself up to her apartment, said writer had used up every available neuron. Obviously, the neurons that make her brain function had gone up in smoke before she started down the stairs in the first place. The next day was spent entirely in bed and the following week was also heavily involved in nap time.

So now we wait patiently. Not one of the stellar qualities for which our heroine is noted. If you happen to drive past the Realife building, you may see someone with her nose pressed longingly to the window of a second floor window. At least, please wave.

(Editor's note: Millie has been released from her Realife "jail" and is again free to roam the streets of Denison, Iowa, and surrounding area.)

More Reunion Photos



Long-time member Karen Dulany joined the NPSA Foundation Board of Trustees in April.



Lee and Bob Hinsley carry their plates from the buffet to their table.

More Reunion Photos



Former NPSA Foundation President Gene Roth with current Foundation President Ted Roche and his wife, Vickie Roche.

NPSA Thanks Our Donors

NPSA relies on the support of its members to achieve its mission. The following donors contributed to NPSA from June 7 – October 11th. Thank you! As we approach the end of the tax year, keep in mind all gifts are fully taxdeductible because we are a 501(c)(3) nonprofit organization.

Jackie Devaney, Omaha, NE Marie Galda, Omaha, NE Larry and Eugenia Koneck, Medford, MN Edward Roche, Ph.D., Bellevue, NE Joseph and Mary Sippel, Omaha, NE Margot Sorensen, Creighton, NE Jeaninne Spencer, Lynch, NE Gary Stott, Papillion, NE

Please consider NPSA in your charitable giving this year. You may send your donations to:

NPSA, PO Box 6076, Omaha, NE 68106



Marie Galda is the most senior member of the group.



Barbara Roth recently retired from the NPSA Foundation.



This was the second reunion for Mary and Joe Sippel.

NPSA's 2017 meetings will be held on the following Sundays:

March 5, April 2, May 7, June 4, July 9, August 5, September 10, October 1 Reunion (site to be announced), November 5.

We meet from 2:00 – 4:00 p.m.in the Community Room of the Bloomfield Forum, 9804 Nicholas Avenue in Omaha. Polio survivors, family, and friends are welcome to attend.

Post-Polio Health International Online Resources:

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

Other Post-Polio Health Resources:

Hotline for Disability Services

301 Centennial Mall S, Box 94987 Lincoln, NE 68509 Toll-Free Number: 1-800-742-7594 Email: <u>shari.bahensky@nebraska.gov</u> Web: <u>www.cap.ne.gov/hotline_services</u>

Nebraska Chapter of the March of Dimes:

Mary Larsen, Director Program Services/Advocacy Government Affairs 11640 Arbor St. Suite 102 Omaha, NE 68144 Phone: 402-496-7111 Email: <u>MCLarsen@marchofdimes.com</u>

History of Polio website: http://86735198.nhd.weebly.com/

NPSA's 30th Anniversary Video: https://vimeo.com/105055161

Also, NPSA has a Facebook page, where we share links to other groups and post recent polio news items: <u>https://www.facebook.com/NebraskaPolioSu</u> <u>rvivorsAssociation/</u>

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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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|---|
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| address of your friend/family member. |
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City/State/Zip: _____

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