



GLEANINGS

February - March, 2014

POLIO MOMS SACRIFICED A LOT

By Millie Malone Lill

It's about time we gave our moms some credit, don't you think? A large number of polio survivors contracted polio before they were old enough to go to school.

I was four. It was awful for us, of course, being taken from our homes and stuck into hospitals. At the time I was incarcerated, children were not treated as they are now. The wards were crowded, the nursing staff overwhelmed, the patients sick, frightened and homesick. Many of us didn't get to see our families for weeks or months on end. Sometimes the nurses lost their tempers with us. Some, not many, but some, were downright mean.

I was lucky. My mom got a job working in the hospital cafeteria. She came to see me every day once I was out of isolation. She found a rooming house nearby and walked back and forth from the rooming house to the hospital. Mom didn't drive and even if she had, we lived on the other side of the state from the hospital. We only had one car and Dad needed it. He came as often as he could, but I was the ninth of ten children so he had responsibilities at home, too. Luckily, the older children in my family were quite a bit older so my two older sisters were able to care for my younger sister who was only two.

It had to be hard for my mother to leave her two-year-old child and stay with the four-year-old. Mom was a house-proud woman and I know she worried that my sisters would not be able to keep the house as spotless as she required. Add to this the fact that she had been by the bedside of

her four year old son when he got hit by a truck, developed spinal meningitis and finally died. This was long before I was born, but a mother never gets over something like that. So many children died of polio, too, so the familiarity of the situation had to be very stressful for her.

Later, when I came home from the hospital, there were the daily exercises that Mom had to help me do. They hurt and I know I sometimes cried. More stress for Mom. My little sister needed attention that she likely didn't get, the

logistics of running a household, cooking, cleaning, laundry...life doesn't stop because one little girl gets sick.

As I grew, there were trips to Iowa City, a six-hour drive at that time, for braces, check-ups, a couple more surgeries. Mom was always there. She was not a woman given to displays of affection, but she was there.

My story is far from unique. I bet your mother was much like mine. She worried, she helped you recover, and she made sure you did your exercises. She probably winced when you fell and hurt for you when other children made fun of you. Our mothers went through as much pain as we did. I didn't realize that until I became a mother myself. It is nearly as difficult to watch a loved one in pain as to be the one, yourself, in pain.

If your mom is still alive, I think you should give her a call. Tell her "Thank you" for being there, for caring, for worrying. She deserves it. Better yet, go visit her and give her a big hug while you thank her. We moms eat that stuff up.



**INSIDE: Results from our 2014
Reader Survey**

GLEANINGS READERS RESPOND TO 2014 SURVEY

By Elaine J. Allen

The results of our recent reader survey have helped us learn more about you and understand what kinds of topics you would like to read. More than ten percent of Gleanings readers (113 out of 915) responded to the short survey that appeared in the December-January issue. Some of the surveys were filled out online. The results are summarized in graphic form on the following pages.

Almost all readers, 92 out of 113, like to read Millie Malone Lill's column. More than half read all features in each issue. One reader commented, "I think the information that has been shared in Gleanings has been worthwhile, some makes you smile, some makes you think and some let you know that we are all in this together. Keep up the good work." The following is a summarized list of the topics that readers said they would like to read in Gleanings.

Gleanings Topics Suggested by Readers	Count
PPS symptoms, tests for and effects of	9
Stories about other polio survivors' experiences and strengths	8
Medical research and developments	7
Names of doctors and PPS specialists	7
Physical therapy, exercise, pain management and medications	7
Assistive devices and tips on how to do daily tasks	6
More humorous columns like Millie's	6
International polio news, including vaccination efforts	3
In-depth stories about meetings	2
Where is Nancy Baldwin Carter? Biographies of officers	2
Home health care, in-home assistance	1
Articles that help other people understand our plight	1
Information about the plug (sometimes referred to as staple) surgery on a leg to stop or slow down the growth	1
Research ways to simplify ADLs	1

2014 Survey Responses (continued on p. 3)

Mark Your Calendars! 2014 NPSA Meeting Schedule

March 2: Hearing Loop Technology with Sheryl Butler

April 6: Dr. Byron Oberst, retired Omaha pediatrician who treated children infected during the 1952 polio epidemic

May 4: Siebert Mobility

June 1: To be announced

July 13: History of Polio Website & Ice Cream Social

August 3 and September 7: To be announced

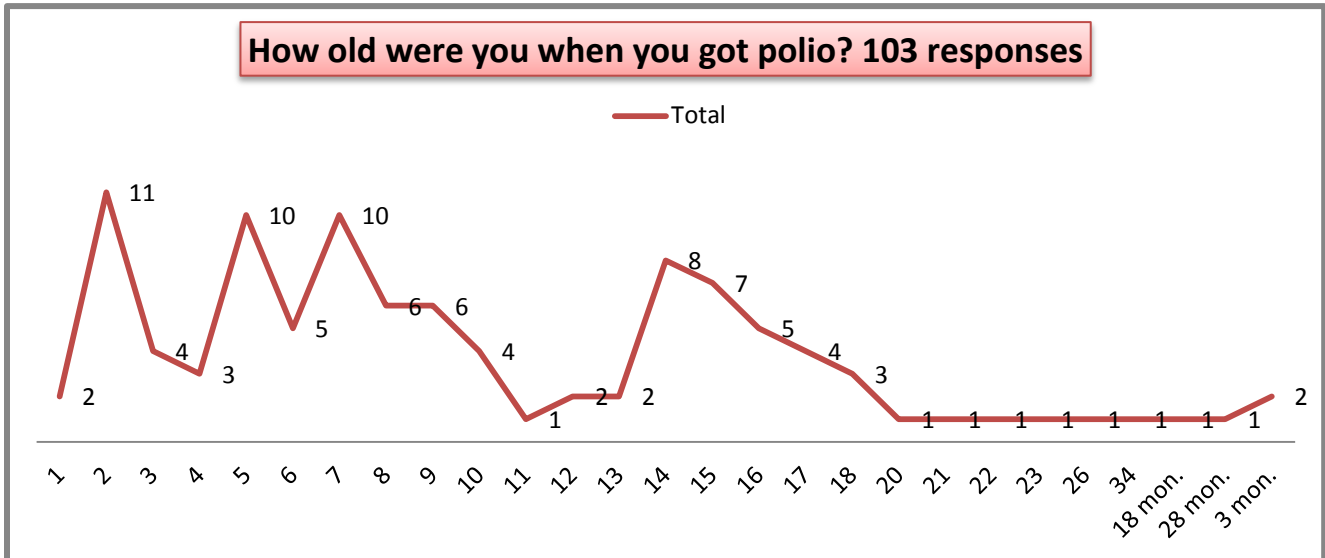
October 5: Tentative date for 30th Annual Reunion

November 2: To be announced

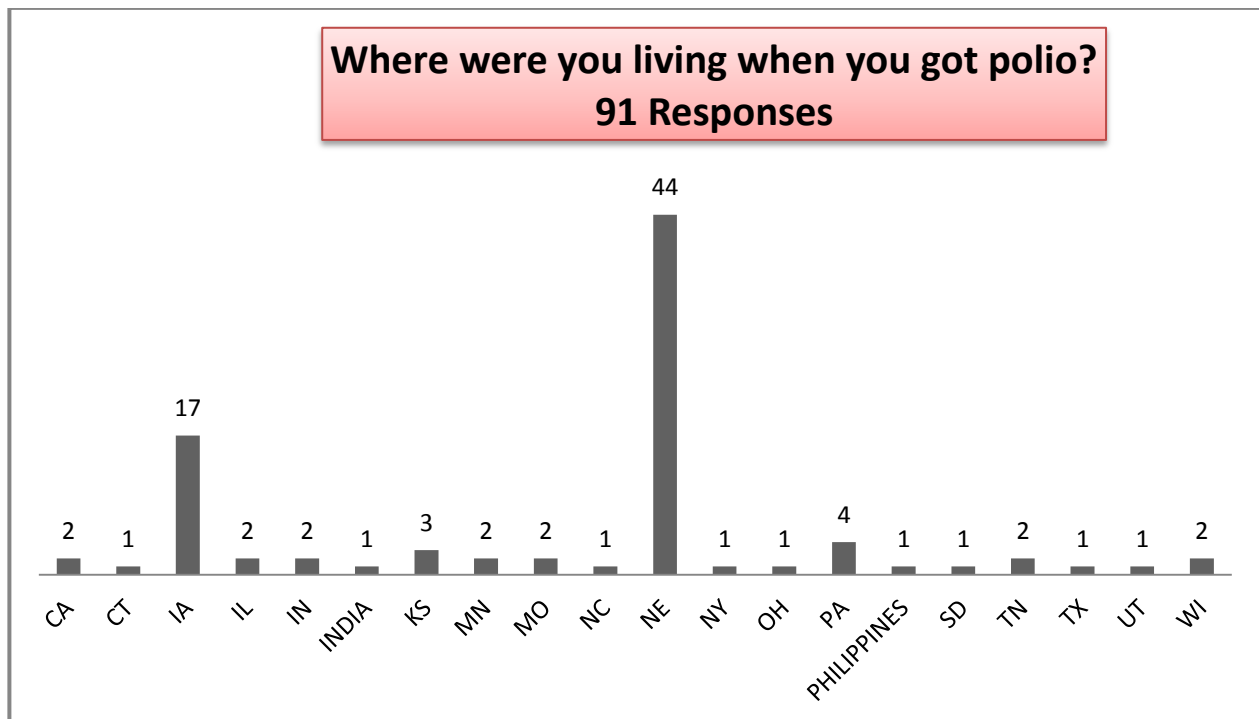
Except for the Annual Reunion, we meet Sunday afternoons from 2:00 – 4:00 p.m. at the Bloomfield Forum Community Room, 9804 Nicholas Ave., Omaha, Nebraska. Everyone is welcome to attend. Coffee and refreshments are served. Please join us.

2014 Reader Survey Responses (Continued from p.2)

The survey asked you to tell us a little about yourselves: Several respondents have survived with Post-Polio into their late 80s and early 90s. One survivor, who is 90 now, was infected with polio in 1925 as a two-year-old, making the respondent the reader who has lived with the effects of polio and post-polio for the longest period. Two other respondents were the youngest to be infected at 3 months old. One person contracted polio at the age of 34.

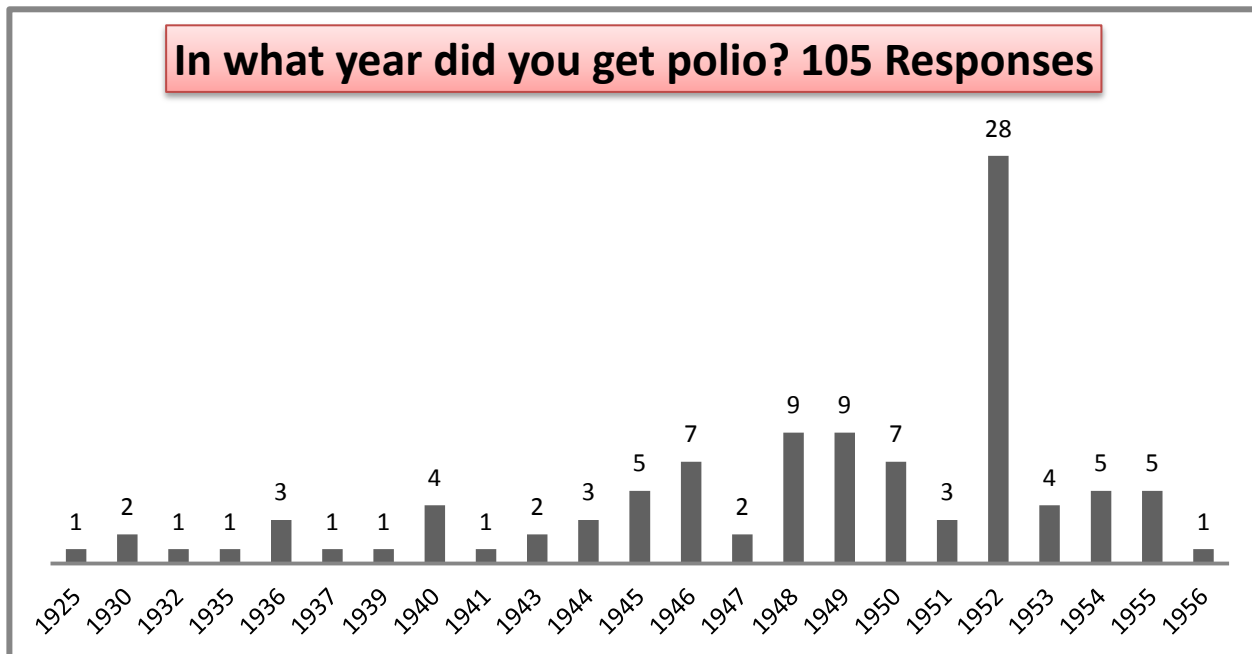


The largest majority of Gleanings readers live in Nebraska and Iowa. But readers who responded to the survey were living in many states and even two countries when they got polio. Twenty-two respondents reported other family members were also infected with polio, including one person whose parent died within two days in 1945.



2014 Reader Survey Responses (Cont. from p.3)

The largest number (28) of respondents to the survey reported they were infected during the polio epidemic of 1952. The next highest groups were infected in 1948 and 1949 (nine in each year). As mentioned above, one respondent contracted polio in 1925, and the person infected the most recently got polio in 1956.



Readers who responded to the survey reported what parts of their bodies were originally affected by the polio virus.

Body Parts Originally Affected	Count
Legs	63
Arms	29
Back, spine, paralyzed	19
Both arms, legs	17
Throat, Lungs, including being in an iron lung, Bulbar	10
Entire body	3

In 2014, the most common Post-Polio Syndrome symptoms for the survey respondents include weakness, fatigue and becoming tired easily, followed by pain, and use of mobility devices.

Most Common Post-Polio Symptoms	Count
Weakness, fatigue, tire easily	84
Pain	25
Use of wheelchair, walker, crutches, braces	22
Cold intolerance or sensitivity	6
Fall easily, balance problems	6
Problems breathing, swallowing, reduced lung capacity	5
Fusions, surgeries	5
Heart, stroke	2
Broken bones	1

Annual Gifts Received December 10, 2013 -
February 10, 2014

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

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Consider NPSA for Memorials, Honorariums
or Planned Gifts

In addition to annual gifts, there are other ways to
give to the Nebraska Polio Survivors Association. You
might want to honor a polio survivor who you admire
or respect. Memorial gifts honor a family member or
friend who has passed away.

You may make one through your estate plan
without giving any money right now, or you can make
a gift that will return an income to you, such as an
annuity. All of these gifts are referred to as planned
gifts, because you are planning to provide the gift at a
later date.

If you would like to consider a planned gift to
NPSA, please contact one of the NPSA board
members listed on this page.

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We're celebrating 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.

We love hearing from our readers. If your address has changed from the one listed on the mailing label, fill out this form and return to the address below.

Name: _____

Street Address or PO Box: _____

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

Please send all address changes, comments or inquiries to:
 NPSA Executive Director
 PO Box 6076
 Omaha, NE 68106

Or, leave a message on our voice mail: **402-932-5426**. If you'd like to receive an electronic version of **Gleanings** instead of a paper copy, send us an email to NPSA.org@hotmail.com.