

Summer 2018

Marbles

By Millie Malone Lill

I saw this meme on Facebook that said, "I may not have lost all my marbles, but there is

definitely a hole in the sack." It got me thinking. My own marbles seem to be diminishing in number, too.



I'm blaming it on age.

Yes, that's it. Over the years, I've accumulated so much knowledge and wisdom that I had to kick out a few marbles to make room for new information. (I can hear you snickering over there! Stop that! It's rude.)

How else would you explain the fact that I knowingly schedule so many things on my calendar that I am perpetually exhausted? I do recall having had polio as a child, and it seems I dimly remember someone... (was that me?) ... saying we need to Conserve to Preserve. Yet, I glance at the desk calendar and I see that I have something going on every day this week.

(Millie's Marbles, continued on next page)

Poliovirus Modified to Fight Deadly Brain Cancer

Summarized by Elaine J. Allen

Recent news stories have announced the hopeful results of medical research using a

modified poliovirus to fight glioblastoma, the form of brain cancer that U.S. Senator John McCain (Republican, Arizona) is battling.

Duke University Cancer Institute researchers presented their findings in June at the 22nd International Conference on Brain Tumor Research and Therapy in Norway and simultaneously published their findings in the New England Journal of Medicine.

According to an article on the <u>Duke Today</u> website, "the therapy includes a genetically modified form of the poliovirus vaccine, which is infused directly into the brain tumor via a surgically implanted catheter. Developed by Dr. Matthias Gromeier in his lab at Duke, the modified virus preferentially zeroes in on tumor cells, igniting a targeted immune response." (source:

(<u>https://today.duke.edu/2018/06/poliovirus-therapy-glioblastoma-has-three-year-survival-rate-21-percent</u>)

Multiple news sources reported on the research findings, including:

- Time Magazine: <u>Polio Virus Could Help</u> <u>Treat Brain Cancer. Here's How (June 26, 2018)</u>
- NPR: <u>Doctors Try Genetically Modified</u> <u>Poliovirus as Experimental Brain Cancer</u> <u>Treatment (June 26, 2018)</u>
- Washington Post: (<u>Polio Virus Treatment</u> <u>Increased Survival in Patients with Deadly</u> <u>Brain Tumors Study Shows</u> (June 26, 2018)

For more information about this research, consult your local librarian or, if you have Internet access, enter these words in your search criteria: "poliovirus glioblastoma Duke".

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Millie's Marbles (continued from page 1)

I have been an unofficial advocate for polio survivors for over 30 years. I tell people to use their assistive devices, that they are only tools, to let people stare if that's what they want to do. What other people think of us is none of our business, right? I know you've heard/read me saying that many times. Yet, I will still do more than I should myself. I will still "forget" to load my power chair when I go to the store, telling myself that I can use the store scooter, or maybe I only need one or two things, so I can just walk. Oh oh...I can hear that escaping marble rolling across the floor.

Why do I do that? I no longer care if people stare at me in my chair, so it's not that. In fact, I like to be as visible as possible. It keeps people from walking over me or reaching across me in the grocery stores, cutting ahead of me in a buffet line, stuff like that. So, it definitely is not vanity. I'm just always in a hurry. I think, "It takes so long to load and unload that chair. I can walk that little bit." Yes, it does take about 3 minutes to get my chair loaded into or out of my van. It takes a two-hour nap to replace the energy I expend walking. Wait! That doesn't compute. Another marble rolls away.

I love little kids. The other day, I was at a family wedding and saw my brother's youngest great grandchild, Danny. Danny is 8 months old and quite a chunk. I love holding his sweet little self but yesterday, I caught that marble as it was headed for that hole in the sack. Gotcha! I didn't pick Danny up, I talked to him while he was in his stroller. We had a deep philosophical discussion as to whether

I had taken his nose or if I had merely beeped it. I expended practically no energy and in

fact, I think the endorphins the baby giggles released were energizing. Saved that marble.

Now that some of my marbles are gone, I have room for common sense. Whether I'll use it or not...the jury is still out. (*Editor's note: This column originally appeared in the online newsletter*, Polio Perspective. It is being republished with Millie's permission.)

Polio Outbreak in Congo Threatens Other African Countries

As of late June, 29 children in the Democratic Republic of Congo (DRC) have been paralyzed by an outbreak of a rare mutant derived from the weakened live virus in the oral polio vaccine (OPV). This rare form, called circulating vaccine-derived polioviruses (cVDPVs), is threatening to undermine global polio eradication efforts. The latest outbreaks occurred near the border with Uganda.

"Safe and effective, OPV has long been the workhorse of the eradication effort. But a feature that makes the vaccine so powerful can also be a serious downside. For a short time after vaccination, the weakened live virus can spread from person to person, boosting immunity even in those who didn't receive the polio drops. But in rare instances, in poor countries such as the DRC where many children have not been vaccinated, the virus can continue circulating for years, accumulating mutations until it reverts to its dangerous form. The vast majority of cVDPVs are caused by serotype 2, one of three variants of the virus." Science Magazine, July 2018 (Source: www.sciencemag.org/news/2018/07/polio-outbreaks-congo-threaten-global-eradication?rss=1)

For more information, refer to the Global Polio Eradication Initiative website: (http://polioeradication.org)

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Post-Polio Online Resources

Atlanta Post-Polio Association:

www.atlantapostpolio.com

NPSA's website: www.ne-polio.org

NPSA's Facebook page:

www.facebook.com/NebraskaPolioSurvi

<u>vorsAssociation</u>

PA Polio Survivors Network:

www.papolionetwork.org

Post-polio Health International:

PHI offers many helpful resources online, including links to videos on its Polio Place

page. Home Page: www.post-polio.org

Polio Place: www.polioplace.org

Provider Directory (PDF): The Post-Polio Directory, *updated in 2017*, can help you

find a list of health care professionals familiar with Post-Polio: www.post-

polio.org/net/PDIR.pdf

Remaining 2018 Meetings

NPSA's monthly meetings and this year's reunion will be held from 2:00-4:00 p.m. on the following Sundays in 2018:

August 5 September 9

Reunion: October 7

November 4

We meet in the Bloomfield by Essex Community Room, 9804 Nicholas Ave., Omaha, Nebraska. Meeting topics will be announced on our Facebook page, via email notification, and at the previous month's meeting. Friends and family are welcome. Refreshments are served.

Our photos and events are posted on Facebook:

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Nebraska Polio Survivors Association

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NPSA Mission Statement

The mission of the 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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Dear Reader: Have you changed your address or phone number? Do you have a friend or family member who survived polio and who would like to receive <u>Gleanings</u> ? Return this form with your address or phone number changes and/or the name and address of your friend/family member. If you prefer an electronic version, please send an email request to: npsa.org@hotmail.com	
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