



GLEANINGS

SPRING 2019

Anti-Vax?

By Millie Malone Lill

Fasten your seatbelts, folks, this is going to be a rant. Feel free to skip this article, I won't know the difference.

There are people out there who claim that vaccinating your children is not necessary or even that it is dangerous. It is true that once in a great while, someone got polio from the vaccine. Maybe one in thousands, if not millions.

However, for every person who got polio from the vaccine, there are many, many more who did not get the vaccine and got polio instead. I am one of them. The vaccine was not available when I was a child. Polio is a crippling, often deadly disease.

Lot of its victims died, many were paralyzed, some never recovered. A lot of polio survivors recovered to a remarkable extent only to develop Post-Polio Sequelae years later, losing strength and stamina, having pain and extreme fatigue. Polio can be a life ender, but it is always a life changer.

We can equate this to something else, perhaps, to make it easier to understand. How many of you wear your seat belt when riding in a car? Yes, it is confining, and yes, if you are in an accident, that seat belt is going to make one heck of a big bruise on your body and yes, again, there are a few incidents where the seat belt itself caused death. If you are strapped in and can't get the seat belt unlatched and your car is underwater, you could die. These things happen. However, many lives are saved by seat

belts, so they are a good safety measure. We seldom question their use.

We live in a very small world now. It is so easy to fly in and out of countries, some of which do not demand that their citizens be immunized. People could come into our country carrying diseases they may not even know they harbor. If our children are not immunized, they are at risk.

It is not just the polio vaccine I am ranting about. Measles are spreading, too. We thought measles, mumps, chicken pox were all things of the past, but without vaccines they can quickly become things of the here and now. I know people who have lost their hearing due to these childhood diseases and if a child contracts more than one of them at a time, there can be

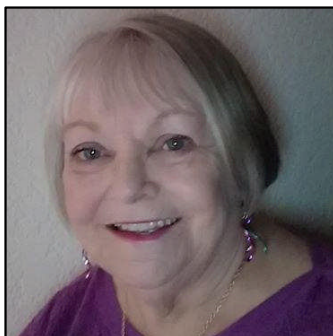
disastrous results.

I am glad Rotary International, along with the Bill and Melinda Gates Foundation, are doing their best to eliminate polio. But I worry that by saying that polio is "this close" to being eliminated, they are making us complacent and lax about immunizing our children.

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- The Story of Iris: Story of a Polio Mother
- Online Post-Polio Resource List



Millie's Column *(continued from Page 1)*

I am not a scientist, but I do know that the polio virus can live in water. Until every person on the planet has clean drinking water, until no one ever dumps raw sewage into a river, lake or ocean, until no child or adult ever swims in water that may be contaminated, polio will not be eradicated. We can and must, therefore, immunize our children. It's the least we can do.

2019 List of Donors

Thank you to our donors who sent gifts to NPSA from January through April. As a non-profit organization, we rely on the gifts from our members and other generous donors who support our mission.

We encourage anyone who finds value in this newsletter, or anyone who wants to honor a polio survivor or memorialize a departed loved one or friend, to send a tax-deductible gift to the address listed below.

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Your gifts to NPSA can be sent at any time during the year to this address:

Nebraska Polio Survivors Association
 PO Box 6076
 Omaha, NE 68106

2019 NPSA Meeting Calendar

June 2: Madonna Rehabilitation Foundation
July 7: Ice Cream Social and Exoskeleton and Robotics Research at UNO's Biomechanics Lab
August 4: Topic to be announced

We meet at Bloomfield Independent Living, 9804 Nicholas Ave., Omaha, NE, from 2:00 - 4:00. Refreshments are served. Family and friends of polio survivors are welcome.

New Study on AFM And Polio

Researchers at Johns Hopkins University are currently recruiting polio survivors to participate in a new study concerning acute flaccid myelitis (AFM) and polio. The study objective is described as follows:

“We are trying to understand why some people get better quickly after an infection and others may have breathing problems, and still others may have neurologic symptoms or paralysis. We would like to compare the cells and DNA of persons with severe symptoms with those who may have been exposed to the same virus but did not have the same severe outcomes. We plan to compare the DNA sequence of people with paralytic poliomyelitis to the DNA sequence of people with acute flaccid myelitis (AFM) following a viral infection diagnosed from 2012-present. We are looking for genetic variants that both groups share that can help explain why a virus can cause mild symptoms in some people (respiratory symptoms or non-paralytic polio), but severe outcomes like paralysis in others like you have experienced.”

Polio survivors are encouraged to participate.
 You will be asked to fill-out a questionnaire and submit a saliva sample by mail.

Contact information:

Dr. Priya Duggal (Co-Principal Investigator):

E-mail: pduggal@jhu.edu

Phone: 410-955-1213

Betsy Dee (Research Assistant):

E-mail: edee1@jhu.edu

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(Found on the Polio Place website, posted on 3/11/19.)

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Post-Polio Online Resources

Atlanta Post-Polio Association:
www.atlantapostpolio.com

NPSA Website: www.ne-polio.org
Facebook page:
[www.facebook.com/NebraskaPolioSurvivors
Association](http://www.facebook.com/NebraskaPolioSurvivorsAssociation)

PA Polio Survivors Network:
www.papolionetwork.org

Post-polio Health International:
PHI offers many helpful resources online.

Home Page: www.post-polio.org

Provider Directory (PDF): The 2017 Post-Polio Directory can help you find a list of health care professionals familiar with treating Post-Polio: www.post-polio.org/net/PDIR.pdf

Polio Place contains links to videos:
www.polioplace.org

Caribbean Cruise 2020

Join BAPPG (Boca Area Post-Polio Group) on its 17th annual trip. Various category, accessible cabins reserved for BAPPG group. Newly-built ship sails out of Port of Miami on January 26, returning February 2, 2020. Cabin rates start at \$1168 per person. Contact Judith, TravelGroup International for booking; perks; hotel; air; transfers 561-447-0750 x102; or Judith@travelgroupint.com

(Reprinted by request of the BAPPG)

THE STORY OF IRIS

By Kurt Sipolski

I suppose the first memory of her was when I was about 5. We were sitting on the bathroom floor, and I was crying. My older brother, Jim, had dressed and had run out into the warm Illinois sunshine.

My mother, Iris, was trying to put my steel leg brace on, tying the orthopedic shoe, the leather calf strap, the knee pad, the thigh strap and buckling the steel belt around my waist. The room was hot and the heavy belt bit into my hips as she struggled to pull up my jeans over the shoe and the brace.

“Why me, Mom? Why did I have to get polio?” She stopped and took my hands in hers. She was then about 30, beautiful with wavy chestnut hair to her shoulders, and hazel eyes. “But Kurt, Jesus only chooses the bravest boys. God picked you above all the boys in town.”

Our little town was once known as Hardscrabble. It is now Streator. The three of us – she, my brother, and I – had returned there from the East Coast to live with her mother when my father died suddenly after World War II.

It was there, while working as a secretary at the newly completed Pentagon, that she met my father, a young soldier. It was there she met President Franklin D. Roosevelt. The awe of reaching down to shake his powerful hand never left her.

I bit into my lower lip in an attempt to live up to her words. “Am I brave?” I asked. “Of course, you are. And God will always watch out for you.” She pressed her handkerchief to my face and ran her hand through my blond hair.

“Now you go and play with Jimmy and close the door because I want to do some sewing.”

Our bathroom consisted of a toilet, a yellow linoleum floor, a big closet and a Singer sewing machine. A bathtub and hot water out of tap were yet to come. I closed the door and expected to hear the tap of her foot on the pedal of the machine. I heard sounds but knew I shouldn't open the door. When I came back into the house, she was just walking out of the room. The machine was still covered, and she avoided my eyes while touching at hers with a handkerchief.

Eventually, she married again and was there through my therapy and operations, the wheelchairs and crutches, stoic and accepting. And she was there with her arms crossed in front of her chest, all 5 feet of her, when she made me crawl into the raspberry bushes where I'd thrown my brace in frustration one day. “Don't you want to get well?” she cried out.

By the time she had a new baby boy she named Pat, and my older brother was studying physics at Virginia Military Institute, I had left the braces behind.

For quite a while, things went well. But at my brother's graduation, like all mothers who never stop being mothers, she pushed when she saw fit.

“Now you get that mole on your neck looked at, Jim.” At the end of two years, Jim had a wife and a one-week-old girl named Felicia, and he lay dying at home with melanoma. On weekends from college, I would help him into his wheelchair and sit by the side of his bed, talking.

Mom prepared her youngest as he faced the wall, his eyes tightly shut. “Pat, the doctors say that Jimmy is going to die.” He whirled around, furious. “No, he's not! They're only people – what do they know?” It was the indefatigable logic of a 9-year-old. She was resolute. “Jimmy's going to die, and you have to be brave.” *(Continued on Page 5)*

Iris *(Continued from Page 4)*

On a cold February morning, he was buried. It was, except for one time in the future, the only time I would see her cry. She faced the church, the chilly wind at her back, her chin against her chest, arms at her sides, and cried like a little girl. Same God, different son.

I was about to graduate in journalism from Northern Illinois University. She held my hand at the reception after the funeral. "Well, I have you and your brother Pat," she consoled herself. "But Mom," I began. "I've accepted a job in Australia. I'm leaving right after graduation. A man named Rupert Murdoch has hired me to be a reporter."

Again, the hazel eyes. Maybe she thought of her young dead husband and her young dead son. "Yes, you go."

We wrote through the years. She and my stepfather visited me once in Sydney but had no interest in coming to Paris when I moved there. By then, they were happy and had settled in Sycamore, and were busy with a new life and new friends. She wrote of them, including a Mrs. Crawford, whose granddaughter, Cindy, wanted so much to be a model. Life was good.

And then her second husband died suddenly. It was later remarked by friends how strong she was, how she didn't cry. But there was a crust now. She never talked about bad things. She had developed an ability to store those things someplace in her mind where they were not touched and could not touch her.

Again, she prospered. Back in Streator, she rented a split-level garden apartment and began dating an old friend, a widower. There were dances and dinners and visits to me here in Palm Desert, Calif. She celebrated her last birthday, her 80th, here with those closest to her.

Then a car crash near Springfield, recovery, confusion. Then a fall, a broken hip and more confusion. My brother and I headed back to our hometown.

We got her settled, hired caregivers and rearranged the furniture so her walker would not catch on a rug or table. My brother headed back to Inverness.

I stayed to help Mom walk again. Her hip ached; her unused legs ached. Her mind was not sharp now. We had to tackle the stairs. "No, it'll hurt," she said. I guided her forward. "Don't you want to get well?" I cried out. I stood at the top and watched her pull herself up by the railings. She pulled and rested again and again. Tears filled her eyes. Eventually she made it to the top, exhausted.

She started to cry. "Why me, Kurt? "Why did this have to happen to me?"

The words barely left her lips as she looked at me with those hazel eyes, clouded now, and we both went back to that room at my grandmother's. I took her hands in mine. "Mom, there's no answer. Bad things happen, and it's not anyone's fault."

Could she have thought that of herself all these years? We sat at the top of the stairs for a long time, saying nothing, thinking. Doctors discovered cancer soon after.

She died on Nov. 30, 1998. It was 50 years to the day I was diagnosed with polio.

Kurt Sipolski is a freelance writer living in Palm Desert, Calif. This memoir is the basis for his novella, Too Early for Flowers: The Story of a Polio Mother, available at Amazon and local libraries. Reprinted with the author's permission.

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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