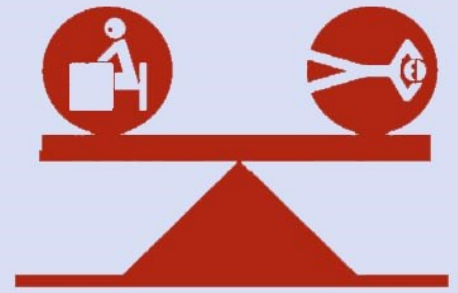


POST POLIO PACER

Conserving Strength and Energy through Pacing
July 2021 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 — This Is Our 36th Year!



Food for Thought... and Discussion

**ACCESS to Independence Inc. Facebook
Post, Monday, May 11, 2021
By Tracey Miller**

Yesterday was Mother's Day, and today we take a moment to acknowledge the story of two of the founding mothers of our local Independent Living Movement. Fayth Kail and JoAnne Ulvestad met in 1955, toward the end of another epidemic that swept our country. As young teens, they found themselves in the polio ward of the Madison Children's Hospital, dependent on iron lungs to breathe and survive. What we are going through now, echoes the experience of that time, except that these two extraordinary women were *brought together* by the polio virus, while coronavirus cruelly keeps us apart in many ways.

Fayth's and JoAnne's lives would be forever changed by polio. But they reached out and began providing peer support to one another right there in the hospital ward. They both would need to rely on wheelchairs for mobility when they left the hospital, and they found that the world was just not accessible. They banded together with others to form

the *Madison Organization Behind Independent Living*, (MOBIL) to advocate for change. ACCESS would not be what it is today without the commitment of MOBIL's members.

We can continue, despite our current challenges, to be there for one another, as JoAnne and Fayth were throughout their lifelong friendship. JoAnne is sadly no longer with us, but Fayth continues in her dedication to the cause. We salute the mothers of our local Independent Living Movement and thank them for coming together in a tough time, to make a difference in each other's lives, and the lives of so many more! They set an example for all of us of the enduring power of peer support.

Fayth Kail notes: In the early '70's, an advocacy group was created for people with physical disabilities to enter and gain independence and accessibility. 50 years later, how are we doing? Do we speak up? Do we advocate?

"No movement is a movement

if it dies with you."

**Bring *your* thoughts to the July 10, 2021
meeting at Monona Garden Family Res-
taurant, 6501 Bridge Rd., Monona. Noon
to 2:30.**

Growing Up With Polio

By Theresa Post

This is my experience of growing up with Polio:



I was born in May 1952 and was greeted by three siblings: Larry, 5; Mary, 4; and Tom, 2. I contracted polio in September 1952. Mom told me we all had flu-like symptoms at the time. One morning Mom

walked in the room to get me from my crib, and she noticed I was only kicking one leg. When she picked me up, my right leg was limp. She arranged to take me to our family doctor.

The doctor told Mom he was certain I had polio. He could have done a spinal tap to be positive but considering my symptoms and coming out of an epidemic he was sure it was polio. I don't know for sure if there was more than one treatment option presented, but the decision was made to seek treatment at the Shriner's Hospital in Minneapolis. The doctor asked Mom if she knew any Shriners because I needed to have a sponsor. Mom did not know any Shriners, so the doctor told her he would contact another doctor and ask him to be my sponsor.

Families were not charged any costs for patient care and treatments. The hospital provided for all the care I needed during my stay, including dental and shoes. I was provided an education and even entertainment.

The first time I went to Shriner's Hospital I was three years old. Outpatient day was always on Tuesday. My dad would go to work on Monday, come home and sleep for a while, and we would leave for the hospital in the middle of the night. We would come home on Tuesday so he could go to work on Wednes-

day. The trip sounds like no big deal today with interstate highway, but back in 1955 we took what we called "the old river road". The road was very narrow, hilly and winding. Today it takes about 4 hours to get to Minneapolis on the Interstate. Back then it took about 6-1/2 hours on some treacherous road conditions. My Aunt Marie would come and stay with my brothers and sister.

I was admitted to the hospital on our first trip. In those days they thought it was best to separate the kids from their parents quickly with no long goodbyes. After I was examined, someone came with a wheelchair and took me away. Mom thought they would be able to see me once I was settled into a room. That was not the case. She said hospital staff were taking them on a tour. When they got close to my room, they were cautioned to be quiet so they could get past the room without me seeing them. Well, I did see them, and I pitched a fit. It was quite upsetting for Mom and Dad. They stopped in La Crosse to eat and my Dad was so upset he wanted to go back and get me.

Visiting hours were on Sunday from 2:00 to 4:00 p.m. The administration did not recommend visiting because the patients would get upset when the family had to leave.

I had several corrective surgeries on my right leg. The stay in the hospital was seven months. When I went to the hospital, I was not able to walk. When I went home, I had long hair and was on crutches. My brother was upset because he didn't think it was me. It was quite an emotional experience for all of us.

I was eight years old when I went back to the hospital for an operation. From what I understand operations were scheduled depending on the growth rate of the patient. My stay at the hospital was three months, and I went home with a walking cast on my leg. Approximately 3 months later I went back to the hospital to have the cast removed and physical therapy. Then, of course, the drive was made again to pick me up.

Those were my childhood days, with trips to the hospital until I was 13 years old. When I was released from hospital care, I wore a long-leg brace for about 1-1/2 years; and then had enough strength to walk without the brace.

I did many of the same things as other people. I loved riding my bike. Sometimes I would ride for miles. I went to the beach, played ball, hopscotch, and tried to do all the things other kids did. My brothers and sister were highly creative in figuring out ways I could play and not need to play by all the rules of the game.

Going through high school with a disability was an emotional journey. I found friends mostly on a one-to-one basis. But, when those same people were in a group, I was treated differently. I was called names and made fun of, and just did not fit in with the crowd.

During my teen years I babysat many of the kids in the neighborhood. I usually had babysitting jobs lined up for Friday and Saturday night. Sometimes I would work for two families and had as many as eight kids to watch.

After graduating from high school, I had a summer job at the State Lab of Hygiene, labeling water samples. I was on my feet eight hours a day, five days a week. I began working full time for the state in 1973 and retired in 2003. Finding a job was not easy. Employers had more freedom to be more selective about who they hired, and most people with disabilities were not at the top of the list.

Throughout all the years, I remained active. I bowled on two leagues a week for several years. I walked long distances and climbed bleachers to enjoy concerts. I climbed to the top of the Coliseum to root for the Badgers at hockey games.

Around age 35-36, I began having difficulties with fatigue, muscle and joint pain. I dealt with it the best I could for many months. I didn't really have any reason to think some-

thing was wrong. As time went on, the way I felt began affecting my work and daily activities. I started having problems with concentration and did not think I was giving 100 percent at my job. I didn't care to do anything after work. Even making supper became a challenge. I often stopped at a restaurant to eat because I was tired. It was not all gloom and doom!

My sister, Mary, and I had a chance to just sit and visit one evening. We started reminiscing about our childhood and the things we did when we were kids. Mary said she was jealous of me when I went to Minneapolis because she wanted to go with mom and dad. I told Mary I was jealous because I wanted to stay home with Aunt Marie.

We eventually got to what we were doing at the present time. I probably brought up what was going on with my life and how much difficulty I was having. It wasn't easy to talk about. When I was younger, I just figured out a way to do something and I did it. I was incredibly determined to get things done for myself. Truthfully, waiting for someone else to help me was frustrating.

Mary was surprised to hear that I was having problems. She never pictured me as not being able to do things. She couldn't remember ever hearing me tell anyone I couldn't do whatever I wanted. That, to me, was a turning point in our relationship. We both have a better understanding of how our minds worked when we were younger. As adults, it made perfect sense.

I finally made an appointment to see the doctor. The appointment was routine with questions and labs ordered. There was no indication of anything out of the ordinary. I also had a battery of appointments with physical therapy. Ultrasound was used to hopefully give me some relief, and I was always sent home with exercises to try. We couldn't pinpoint any physical issues, so the next thought is depression, and I should seek counseling. I reluctantly agreed. My theory was I am depressed because I am in pain. Although, I gained

some healthy insights from the counseling, I only felt worse! I was using a lot of energy going to the clinic and doing my exercises at home! I am not particularly fascinated with exercising, so that was one of the first things I dropped from my list.

My coworkers started approaching me at work asking questions about polio. Some read in the newspaper or heard on the news that polio survivors were experiencing polio again. Some people wanted to know if I had been vaccinated again. I was quite confused and scared at the same time. I thought, is this what's happening to me?

I heard about a conference scheduled at Quality Inn for people interested in the theory of what was happening and plans going forward. I attended the conference in the early 80s, I think, and was shocked at how many people were there. Dr. Keith Sperling and Dr. James Agre, from the University of WI Rehabilitation Clinic talked about how polio affected the body and what their theory was at the time. It all made perfect sense to me then, but I can't explain it now. I know I left that meeting feeling reassured that good things were going to happen.

During this time period I was hearing from so many people that I should get assistive devices – cane, walker, crutches, etc. Thinking about how hard I worked to get rid of all those devices, I was not going to have any part of it! Then I heard from so many people who graduated to using assistive devices, and how much more freedom they have. So, I started out with a cane, then it was a scooter, then it was a brace and lift on my shoe. Today, I use a walker in the house and the scooter for outside longer distances.

I started attending the Post-Polio Support group meetings occasionally. Now, it's a great pleasure to be together and share with people. I also enjoy getting together with Marcia, Tim and Sandy to assemble the newsletter. All the people I have met at our meetings is very rewarding. I also want to acknowledge and give a special shout out to Fayth Kail. We

have become close friends and I am inspired by her stick-to-it attitude and her cheerful disposition. (Not only that, she makes me laugh.)

In April of 2002, I was diagnosed with Stage 3 breast cancer. The reason I think this is an important piece to my story is because of the chemotherapy my oncologist was planning on for my treatment. There were three drugs involved. I had a conversation with a lady who was on the same treatment, and she had to stop one of the drugs because it caused neuropathy in her hands and feet. My partner, Joyce, used the internet to do some research. We decided it would be best if I got a second opinion. The doctor I saw said she had not treated anyone with Polio and breast cancer, but she had patients who had Multiple Sclerosis and those patients had horrible results (she said Polio and MS are like cousins). The doctor said she would check with her colleagues, and they all had the same opinion. It all depended on the quality of life I wanted.

Fast forward to July 2020, and once again, I have the misfortune of being diagnosed with metastatic breast cancer. The chemotherapy treatment I am on has many of the same side effects as Post-Polio Syndrome – fatigue, muscle and joint pain. The side effects are on parallel tracks, but the treatment is the exact opposite. The oncologist told me to deal with the side effects of the chemo by moving, getting up and doing things, going for a walk, etc. I might not have been clear, but he didn't seem to make the connection when I told him about the golden rule of post-polio. I told him I would try to figure out a way to balance the two things on my own. The second appointment I had with him was considerably better, and he talked to me more positively about taking into consideration the effects of post-polio.

Post-Polio Syndrome has been challenging, as it is for all of us. We cannot do it alone. We all need someone to reach out to and we need people to reach back. I am extremely blessed and lucky. Since my diagnosis a year ago, we have my sister and brother-in-law, Bob, doing

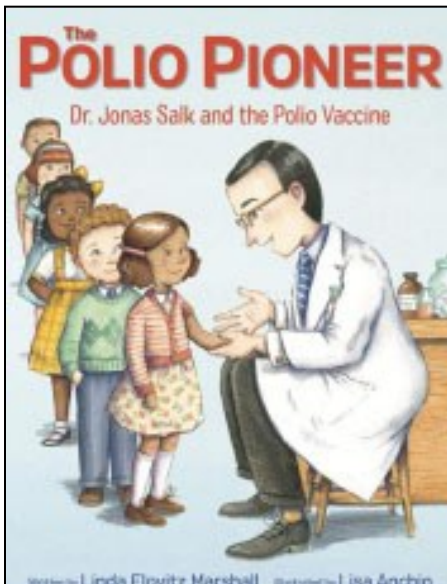
our grocery shopping, taking care of the yard work, and general maintenance jobs around the house. Mary takes me to doctor appointments.

Joyce and I have been together for over 25 years. Joyce is also having some struggles with health issues, but she does not give up. We know each other so well after 25 years, sometimes when we are having a conversation, I feel like I'm talking to myself! That's a joke!

With gratitude for all those who have reached back to me, I hope to adopt Fayth's sunny disposition as life goes on.

A Book Review

By Pamela Sergey



Both Linda Elovitz Marshall and Jonas Salk describe themselves as being curious, lovers of the written word, and embracing a desire to make the world a better place. Marshall's timely & captivating ***The Polio Pioneer: Dr.***

Jonas Salk and the Polio Vaccine, with sensitive illustrations by Lisa Anchin, recounts the story of Dr. Salk's determination to produce a safe polio vaccine during the heights of the 1940s and 50s polio pandemic in the US. The vaccine was tested in massive field trials involving close to two million schoolchildren known as "polio pioneers".

The Polio Pioneer would appeal to today's curious early-elementary child who seeks to understand the complexity of viruses, the time-

consuming process of creating a vaccine, and the importance of getting vaccinated.

When Jonas Salk (1914-1995) was a young boy, his family attended Armistice Day parades in New York City to celebrate the return of American soldiers at the end of WWI. One parade honoring the New York 27th Infantry Division, included hundreds of cars carrying wounded soldiers. It was also the year of the 1918 Spanish Flu pandemic which caused over 650,000 deaths in the US, and only a short two years after 2,000 died of polio in New York City, mostly children. These events had enormous effects on Salk. From a young age, he strongly believed in the Jewish doctrine of tikkun olam ("repairing the world" for future generations) and credited his Jewish ancestry with influencing his career and life. He graduated from Townsend High School for gifted students and entered the College of the City of New York at sixteen to study law. At some point he changed his mind and began to pursue medicine. After graduating from the College of Medicine of New York University in 1939, Salk went on to help develop an influenza (flu) vaccine, laying the groundwork for his work on the future polio vaccine. He spent his last years searching for an AIDS vaccine at his Salk Institute in La Jolla, CA.

At the head of a narrow ribbon of water in the courtyard of the Salk Institute is inscribed Salk's life philosophy: Hope lies in dreams, in imagination and in the courage of those who dare to make dreams into reality.

Linda Elovitz Marshall began working on *The Polio Pioneer* in 2016, long before coronavirus was an everyday word. When I asked her why she wanted to write a children's book on polio, she replied: "Some years ago, I realized that polio was - to my children - as distant to them as diphtheria is to me. I cannot comprehend diphtheria nor can I comprehend the fear it must have created. Because I remember polio and because I'm so grateful to the vaccine, I wanted to share my memory of polio and of the relief brought by the vaccine. It may be

hard to believe, considering what we're going through now, that back in 2016 I was thinking "if we don't share these memories with young people, young people will soon take good health for granted . . . Covid-19 changed all that."


Marshall continues: "I remembered how much polio scared me when I was a child. My mother took my brother and me from our home in the Boston area to a suburb of Hartford where my grandparents lived and where, supposedly, there was less polio. I was only four or five at the time, but it made a big impression on me. When the vaccine came out, Dr. Salk became my hero. He was such a hero to me and to my husband (a family physician) that we named our oldest son, Jonah."

Salk's vaccine quickly became a standard part of childhood immunizations in the US. Today, polio has been eliminated throughout much of the world; on their website, the CDC states "Four regions of the world are certified polio free—the Americas, Europe, South East Asia and the Western Pacific. Only three polio-endemic countries (countries that have had uninterrupted transmission of wild poliovirus) remain - Afghanistan, Nigeria, and Pakistan."

There can be no greater praise for Dr. Jonas Salk and his medical success than to hear 21st century children ask, "What is polio?"

Pamela Sergey

Reprinted from PA Polio Survivors Network
May 2021



When Franklin Roosevelt started a foundation to fight polio, Comedian Eddie Cantor came up with the "March of Dimes", asking people to mail a dime to the White House. They were soon overwhelmed with 2,680,000 dimes mailed to them, literally truckloads, mostly from children. These dimes went directly to research that resulted in the Polio vaccine. This is why Roosevelt is on the U.S. dime.

Respiratory Information Card

Normal End Tidal Carbon Dioxide (CO₂) is 30-45 mmHg
Normal Oxygen Saturation (O₂) is 95% or greater.

**Risk for individuals with Neuromuscular Disease:
Respiratory Failure**

DO NOT GIVE OXYGEN before checking end tidal or blood CO₂ Level. A low hemoglobin saturation may indicate CO₂ retention and a need for positive pressure ventilation **IF supplemental oxygen is given, continuously monitor CO₂. Non-invasive bi-level ventilation may be required. Mechanically assisted cough helps clear mucus when cough is weak and/or ineffective.**

CoughAssist by Philips Respironics is helpful to remove mucus.

Cut out & keep in your wallet. Share with your medical staff.

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Suggestions for speakers, topics, books to read and discuss, etc. are needed.

Call or e-mail (see e-mail list) one of the people listed above to suggest program topics or speakers, volunteer to organize one meeting program, share your knowledge (or find an expert) about becoming a non-profit organization or volunteer your talents (financial, organizing, etc.) as a committee member.

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To get your Pacer in color on line, set your email program to always accept messages from mchwgh@gmail.com

Names in bold are new to the list or have an address change. To add your name and/or up-date your e-mail address to this list, notify Marcia Holman at: mchwgh@gmail.com

POST POLIO PACER is a quarterly newsletter published in January, April, July & October for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.

Please request permission from the editor to reprint articles from the Post Polio Pacer.

Disclaimer: The opinions expressed in this publication are those of the individual writers and do not imply endorsement by Easter Seals Wisconsin or the Madison Area Post Polio Support Group.



Wish we could smell the flowers!

Golden Rule of Post Polio Syndrome
"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"



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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

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2021 meeting dates:

July 10

October 13

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LOCATION:

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Noon to 2:30

