

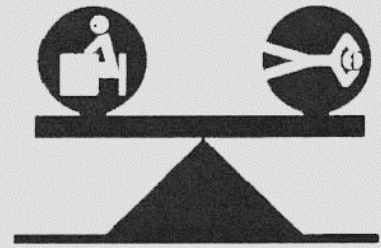
POST POLIO PACER

Conserving Strength and Energy through Pacing

January 2021 — Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter

MAPPSG formed in 1985 — This Is Our 36th Year!



So You Don't Plan to Get the Covid-19 Vaccine. Read This.

Marian Jensen



This COVID-19 pandemic is old hat for me. I lived through the polio epidemic. I never got a vaccine. In 1954 there wasn't one. Instead I got the disease, a debilitating neuromuscular disorder leading to temporary or permanent paralysis. Seventeen days in an iron lung at age seven, four months in the hospital, a year of physical therapy, and then I walked away, unlike three kids in iron lungs in the same ward who died.

So fearful of polio were adults, they said I was a miracle child. So I acted like one. Learned to run and jump like all the other kids. Made straight A's, got a scholarship to college, married, had a child and career, pushed and pushed to make every minute count.

Traveled to all the continents save one. Wrote a few books along the way. Paid no attention to the rumor that aging polio survivors were experiencing residual effects of muscle weakness, crippling physical and mental fatigue, disruption of digestive and respiratory systems. That wouldn't be me.

Then I started to get tired, really tired, and in 2019 (more than six decades after the active stage of the virus), I couldn't get out of the swimming pool after only a few laps. Ten

months later, I began using a walker to steady my once muscular legs that have lost forty percent of their motor neural pathways along with the rest of my body. I no longer travel, eat steak, drink red wine, or write novels. I must nap a couple of times a day to conserve dwindling energy, and minimize brain fog.

Post polio syndrome is considered a rare condition now (affecting less than 200,000 individuals) because polio survivors are dying off. I'm among the youngest, in the US anyway. Still no cure, drug, or treatment exists beyond the use of assistive devices and lifestyle adjustment.

Some post polio patients today were asymptomatic as children, or had such mild symptoms of the virus they didn't warrant definitive diagnosis or hospitalization. Their condition, called "non-paralytic" post polio syndrome can be equally troublesome.

So if you're thinking of skipping the vaccine, or having your children do so, consider how you/they might handle the post COVID-19 syndrome decades from now. Me? I'm getting the vaccine this time around.

<https://www.ninds.nih.gov/disorders/patient-caregiver-education/fact-sheets/post-polio-syndrome-fact-sheet>

Marian Jensen, author of the Mining City Mystery series, lives in Butte, Montana.

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FOOTPRINTS & MEMORIES OF JACOB & MARY MONTGOMERY

By Jacob E Montgomery

Editor's note: Jacob Ezra Montgomery was born in Wirtz, VA, on April 12, 1928 and passed away on Father's Day at age 89 in 2017. His daughter, Charlene Denlinger, sent me his book for "anyone who may be interested in reading it." With her permission, excerpts of the book follow:

Part1: In the July 2019 Pacer
Part 2: In the October 2019 Pacer
Part 3: In the January 2020 Pacer
Part 4: In the April Pacer
Part 5: In the October 2020 Pacer
**Last Part: Memories, Blessings
 and Growing Old Together**

One day during the summer of 1997 a brother came in the shop and said he had something outside he wanted me to see. I went out with him and there was a van and a man in a power wheelchair. This brother said he and some others had been thinking they would like to get me a van with a ramp or lift that would make it easier for me and Mary, if I thought I would be able to operate the lift and drive it. This was quite a surprise for me; in fact, very much of a shock! He told me I should think about it; I didn't have to say right then. I later told him that I really didn't think I deserved this and that I was not asking for it, but if they really wanted to do that, I would accept it.

Several weeks went by and he called me to say they had one picked out and would like us to go look at it and see what would have to be done to equip it to my needs. The van was in Akron, Ohio, so we went up one weekend to see it. We thought it looked like it would work. When they were ready to work on it, we went back up for them to fine tune everything. We were there a few days until they had it ready to go. Myrl and Judy came to drive it home. We did not think it was a good idea for me to drive it home before I had a chance to try it out a little.

It was not legal to drive from a regular wheelchair so they also helped get me a power chair. This was equipped with a bolt underneath that goes into a box on the floor of the van, and locks me in place. To get out I have to flip a switch to release the lock. I have a remote switch in my pocket I can push to open the door and let the ramp down. Then I ride up the ramp and pull up to the steering wheel. Using the remote, I again raise the ramp and close the door. All of this is done without changing seats. This made it possible for me to go places alone. Also, Mary didn't have to get the chair out and I didn't have to slide out across a board to get in my wheelchair.

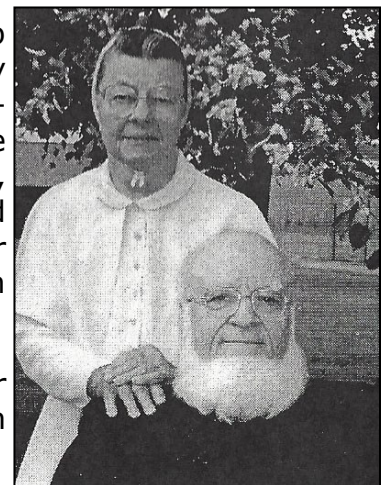
It just seems impossible for me to express on paper how much we have appreciated this act of kindness. It really did change our lives, especially mine. We just want to say, our prayer is that God will bless each and everyone who had anything to do with getting this blessing for us!

In the late 1990's we began to notice a slight change in Mary's personality. We thought perhaps it was a little touch of depression or that something was bothering her. However, as we would occasionally bring up the subject, she would always say nothing was wrong.

We decided to see a doctor about this, and after going to a couple of different ones, they both said they thought it might be the beginning of dementia.

In 2000 she had a hip replacement surgery and seemed to recover well. When the doctor dismissed her, he said she was good for 20 years or 20,000 miles, which ever came first!

We celebrated our 50th anniversary on July 9, 2003.



In 2008 we decided we needed a little more help. As a family we discussed what we should do. Kent and Charlene informed us they had a vacant building on their place that was built for a chicken house, and later was used as a hog house. It was empty and they suggested we could make part of that into a cottage, which we did. We told some folks we weren't sure whether we would 'cackle' or 'grunt' when we moved in.

We liked this idea, so the work began. Our family did most of the work, tearing out all the inside of the end of this building and making it into a cottage with an attached garage. Work started sometime the beginning of June, and it was ready to move into by November. We moved on November 1, 2008. It was an extra nice day for that time of year, and the moving went smoothly.

Sometime in the early 2000's she discovered she had arterial fibrillation of the heart. This did not seem to interfere with her daily routine. The heart doctor put her on a blood thinner to keep a clot from forming. We saw the heart doctor on a regular schedule for several years.

In the early part of 2012, she complained one night of being short of breath. We went to the doctor and after doing some testing, he told us the atrial valve in her heart was closing, restricting the blood flow, and causing a fluid buildup. They suggested open heart surgery to replace the valve.

As a family, we discussed this option, and through some research, found out that going through that type of trauma often affected individuals with dementia in a negative way. So, taking all things into consideration, our decision was not to have the valve surgery.

On Friday evening, March 22, 2012, Myrl and Judy were here for supper. Mary came from the rest room and stopped at the kitchen table. After just standing there a moment, she started reeling back and forth. Myrl and I both saw her, and Myrl jumped up in time to catch her, breaking her fall. She passed out and we thought the worst. We called the res-

cue and Kent and Charlene right away. She came to before the EMT's arrived, but we all thought she should go to the hospital to be checked out. The doctors thought that she was dehydrated because of her medication. She soon seemed much perkier and came home on Sunday afternoon. We had some company that evening, and everyone was amazed, she seemed more like herself than she had in a few years. Things went back to the usual in a few days, but she got along fine with no more problems for awhile.

About 11:30 on April 23 as we were getting ready for bed she had another passing out spell similar to a month earlier. Again, I called the children and the rescue. Again, she had revived by the time the EMT's arrived.

They took her back to the hospital. This time there were more complications. She had more trouble with shortness of breath and that continued to get worse. Her oxygen level was low and they could not get it back to normal.

On Tuesday they informed us that they had done all they could do and suggested we use the services of Hospice. We transferred her to the Hospice of Dayton on Tuesday evening. We had excellent care and support there. Mary peacefully passed away at 3:15 on Tuesday afternoon, April 26, 2012.

Thus ended our fifty-eight plus years together. Looking back they seemed so short, but I am very thankful to God for a good life together.

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

The History of 'APRONS'

I don't think our kids know what an apron is. The principle use of Grandma's apron was to protect the dress underneath because she only had a few. It was also because it was easier to wash aprons than dresses and aprons used less material. But along with that, it served as a potholder for removing hot pans from the oven.



It was wonderful for drying children's tears, and on occasion was even used for cleaning out dirty ears.

From the chicken coop, the apron was used for carrying eggs, fussy chicks, and sometimes half-hatched eggs to be finished in the warming oven.

When company came, those aprons were ideal hiding places for shy kids... And when the weather was cold, Grandma wrapped it around her arms.

Those big old aprons wiped many a perspiring brow, bent over the hot wood stove. Chips and kindling wood were brought into the kitchen in that apron.

From the garden, it carried all sorts of vegetables. After the peas had been shelled, it carried out the hulls.

In the fall, the apron was used to bring in apples that had fallen from the trees.

When unexpected company drove up the road, it was surprising how much furniture that old apron could dust in a matter of seconds.

When dinner was ready, Grandma walked out onto the porch, waved her apron, and the men folk knew it was time to come in from the fields to dinner.

It will be a long time before someone invents something that will replace that 'old-time apron' that served so many purposes.

Send this to those who would know (and love) the story about Grandma's aprons.

REMEMBER: Grandma used to set her hot baked apple pies on the window sill to cool. Her granddaughters set theirs on the window sill to thaw. They would go crazy now trying to figure out how many germs were on that apron.

I don't think I ever caught anything from an apron - but love...

author unknown

F.Y.I.

Do you have cold feet? People on Dr. Bruno's "Coffee House" on Facebook rave about Heat Holder sox. Check out www.Heatholder.com

More good sites to check out:

Polio Epic, Inc.—Serving Arizona Polio Survivors Since 1985

WEBSITE: PolioEpic.org

FACEBOOK: You can ask for membership in the Facebook Group named "Post Polio" (note: space included between words)

Youtube.com channel: [YouTube.com—Polio Epic, Inc.](http://YouTube.com—PolioEpic,Inc)

A Recollection of My Confrontation with Polio in 1952

By John Uhler

Part 1 : In the July Pacer

Part 2: Coming to Terms

Part 3: Spoiled Rotten

Spoiled Rotten

By March I was a cute, little, almost six year old - the center of attention (at least in my own mind) for seven months. I was the only child my age on the floor. Everyone else was older. The pediatric floor was on eight, one floor above. But polio patients weren't allowed there. I was cute and happy, and the nurses mostly loved me, although there was a grouch or two in the mix.



My mother came to the hospital almost every day in the afternoon and in the evening. My dad came mostly in the evening, since he was working. Our house was three blocks away, so my mother just walked over. So, if seven months was roughly 210 days, she made over 400 trips to visit me during the time I was there. That's at least two hundred miles, rain or shine. And the times she wasn't there for some reason I got mad at her and I'm sure she felt bad about that. I felt bad about it when I realized what I had done.

Every time my mother or dad came, they brought me a "surprise." The surprise was always some game, toy, book, record, etc. I guess some how they got the idea that they had to keep my spirits up, so this is what they did. So, now we're talking over 400 "surprises." My room was full of stuff. My parents had very little extra money. The thing that helped save them from financial ruin was

the fact that they had purchased a "polio insurance" policy at some point. Those policies were popular back then. It covered a lot of expenses during and after my confinement.

As for the toys, it wasn't until years later that I found out that my great uncle Ray, who was a funeral director in town was the benefactor. He apparently had visited every store in town that sold toys of any kind and bought one of each in all of them. And when he had purchased one of every toy in town, he asked the store owners to find something different in another town. He was a good man. His first child died at birth and he never had any more. I never knew until after he had died, that he had done this.

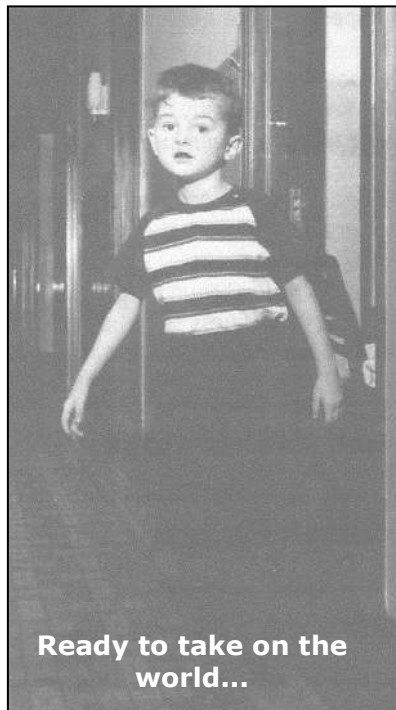
As my health improved, I was able to walk or ride around the floor on my trike watching what was going on and visiting people. One morning I spent an hour or so in the utility room on the worktable, with various nurses, over an hour or so building a flatbed truck with my Erector Set. It's a lot like Legos of today. Well, this version of the Erector Set had a small wind up spring driven motor that would power the truck using a loop of string between the motor and axle. The only problem was that the truck would only go in reverse. One of the nurses twisted the loop of string in the middle and all of a sudden the truck was going forward. Looking back, I think she was either very bright or had seen a steam engine in action and understood how drive belts were used to drive things like threshing machines.

Another time I was supposed to be taking a nap, but I was too excited about the fact that I had discovered I could wiggle my ears. I couldn't help but turn on my call light so I could show the nurses. When one finally came, she was a bit upset. I'm sure she had other things to do.

Another day a man showed up as a new patient in my double room, who was a photog-

rapher. When I finished my bath one day, I got dressed and walked out into the hall and he snapped my picture. He sent it to me at home a few weeks later. It was a great picture of me, healthy as I could be and ready to go home.

Needless to say with all the attention, visitors, and surprises, I was truly spoiled. And the problem was that I never really got over being so.



Wrapping it up

As I reflect on those seven months, there are a number of people, activities, and things of note that at the time were just normal, expected, unnoticed, or seemingly random in nature, that with the perspective of 67 years, are now appreciated and understood with an adult mind.

I had a sister, Mary Susan, who was three years old at the time. While I was in the hospital and my parents were tending to me, she was being "shipped around" as my mother would say, to any friend or relative who would take her for an hour or so. I'm sure it was unsettling for her. When I finally got out of the hospital, she was four years old and wetting the bed every night. I know it wasn't my fault, but I can't help feeling a bit of guilt for that.

And then there was Sister M. Joselind, FSPA (whose given name was Bernadette Hahn). This Franciscan nun who I'm pretty sure managed the medical unit on the 7th floor was an absolute saint who I credit with saving my life. It seemed as though she was there and

everywhere all the time. She was a St. Francis School of Nursing graduate, a few years older than my mother, who led her nursing staff by example. She did everything from suctioning me out, to feeding me, to holding my urinal for me (she got surprised, once), to saying my prayers with me every night before I went to sleep.

Her obituary said she was from Liberty, Wisconsin, a settlement with only a few houses in southwestern Wisconsin. I'm guessing she grew up on a farm nearby, which means that she probably grew up knowing how to do everything, and made nursing and prayer her life's work.

Appreciation

Every once in a while I still run into older nurses who worked during those years. And no matter where they are from, it is clear that they understand what it was like, and they remember everything. They always recognize on sight that I'm a polio survivor. And to them, the doctors and the ancillary staff who worked in those years, I and every other survivor owes a great debt of gratitude. They cared much for us, and they worked very hard—they need to be remembered! God bless them all.

A little humor...Richard Bruno: (In Post Polio Coffee House)

"I thought I was using the TV remote," polio survivor John Doe told paramedics after he found himself catapulted into the kitchen.

"I wanted a beer anyway."



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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.



A happy snowman with a bird to cheer him on...?



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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

2021 meetings on hold until the Covid-19 pandemic is over— or we all get vaccinated.

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**Why is the Pacer so late?
 Because sometimes I don't
 have all the information
 needed—like articles from
 members. Your "polio story,"
 or specific parts—i.e.,
 school, work, child care, or
 how aging related changes
 affect your life.**

LOCATION:

**Monona Garden Family Restaurant
 6501 Bridge Rd., Monona**

