

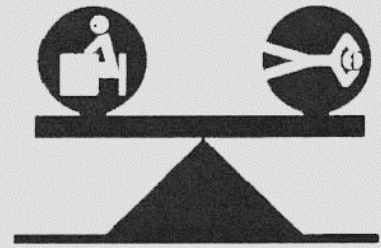
POST POLIO PACER

Conserving Strength and Energy through Pacing

April 2020 — Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter

MAPPSG formed in 1985 — This Is Our 35th Year!



POST-POLIO HEALTH
INTERNATIONAL

INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

Coronavirus (COVID-19) and Polio Survivors

Everyone seems to be talking about, worrying about and asking questions about coronavirus, and that includes polio survivors. As we have seen this is a rapidly evolving situation and what we know today may change next week or next month.

Some facts that are not likely to change are:

- Polio and the late effects of polio **do not**, in themselves, cause immune compromise. Therefore, polio survivors are **no more** likely to contract a coronavirus infection or develop serious illness from it than people who never had polio!
- Most polio survivors in the United States and Canada are over 60 years old, which places us in the "higher risk" category with a greater likelihood of developing severe disease after being infected with the virus than younger people.
- Polio survivors who had breathing

muscle involvement with their original illness and/or now have respiratory problems of any kind are at "high risk" when they become ill with **any** respiratory infection, including coronaviruses.

- Just as it is for people who never had polio, if a polio survivor has diabetes, heart disease, severe kidney disease, or are immunocompromised due to a medical condition or certain medications, then they are at high risk of developing complications if they contract COVID-19.

What you can do: follow CDC guidelines about infection control—washing hands frequently, disinfecting frequently touched surfaces, covering coughs and sneezes, avoiding large crowds especially in poorly ventilated areas, staying home if you are sick and avoiding non-essential trips, such as long airplane rides or embarking on a cruise ship.

If you do develop cough or fever (temperature over 100.4 degrees F), especially if you have had known contact with someone who has coronavirus or has recently been in some of the "coronavirus hot spots," call your doctor for advice about what to do next. If you have increased trouble breathing, you probably need to be seen by a doctor at a hospital but have someone call ahead so that the emergency room is prepared for your ar-

rival. Likewise, if an ambulance is called to transport you please let them know in advance that you may have coronavirus so they can take appropriate precautions.

For the latest information about the coronavirus, check the CDC's website at www.cdc.gov/coronavirus/2019-ncov/. If you have any specific health questions about yourself, contact your physician.

Post-Polio Health International
including International Ventilator Users Network
St. Louis, Missouri
www.post-polio.org
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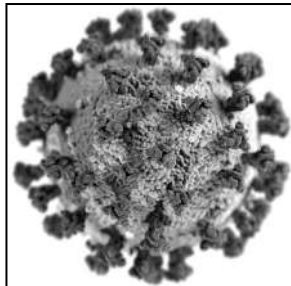
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Be Aware of Scams

COVID-19 Scams

Unfortunately scam artists take advantage of seniors by peddling fake tests for the coronavirus to Medicare recipients.



According to the Health and Human Services inspector general's office, marketing schemes offer tests for COVID-19 and "Senior Care Packages" with hand sanitizer, a sanitary kit, or a vaccine, which doesn't exist. What they *really* want is your personal information—your Medicare number or your Social Security number. Frequently, as soon as that number is provided, the caller will hang up. When a fraudster has your Medicare information,

it can be repeatedly used to bill for unwanted goods and services, which can be a problem if you ever need them in the future.

Health care is one of the most prevalent forms of identity theft.

Another scam—CDC (Center for Disease Control) employees are not knocking on doors. If someone comes to your residence and claims to be from the CDC, do not allow entry or provide any information and call your respective police department.

NOTE FROM THE EDITOR

Considering the uncertainty of the timing in lifting the "social distancing" for the coronavirus Covid19 virus, our meetings may need to be cancelled.

The 2020 meeting dates are listed on the back page of the *Pacer* however no topics/speakers have been arranged. A tentative topic for the May 9 meeting is: "Overcoming obstacles—what was your obstacle and how did you overcome it?"

You will be notified by email if meeting must be cancelled. People who do not have email will be contacted by phone. If you are not contacted during the week before the meeting, please call one of the people listed in the Planning Committee "gray box" on page 7 of your latest Pacer.

Keep well and keep washing your hands frequently.

We hope to see you sometime in the future...

Marcia Holman, Editor

**Dr. Bruno’s Original Post: COVID
"FEAR vs CONTROL COLUMNS" for
POLIO SURVIVORS**

Back in 1985 we discovered that polio survivors were Super Type A: driven, anxious, controlling perfectionists. A few years later we discovered why. Having had polio, plus the draconian ways it was dealt with -- including isolation and quarantine -- were the ideal circumstances to create anxious and controlling Type A perfectionists.

Today a virus once again has polio survivors isolated and afraid, television and the Internet continuously providing terrifying but conflicting and uncertain information about the chance of catching COVID-19, and when the quarantine will be over. How could the repetition of isolation and helplessness as happened during the polio epidemics not fuel sometimes-overwhelming fear in polio survivors?

" FEAR vs CONTROL COLUMNS "

With that said, it might help to turn off the TV, take a deep breath and write down **"Fear columns"** and **"Control columns"** listing the reality of your fears and what you already are doing to take control of your own life...

<u>Fear</u>	<u>Reality</u>
Starving to Death	Won't Happen
Losing Medicare/Medicaid, SSI/SSDI	Won't Happen
Losing Connection with Everyone	Highly Unlikely
Not Getting Needed Medication	Very Unlikely
Not Getting Needed Medical Attention	Unlikely
Broken Assistive Device (e.g., Wheelchair, Bi-Pap)	Possible
Unable to Buy Toilet Paper	Likely
Any American 65 or older (from CDC*):	
Catching COVID	.04% Chance
Needing ICU Admission	.02% Chance

*<https://www.cdc.gov/coronavirus/2019-ncov/index.html>

CONTROL COLUMNS:

List each thing you're doing to TAKE CONTROL and PROTECT YOURSELF and HOW OFTEN you are doing them:

<u>Control</u>	<u>Reality</u>
Self-Distancing	90% of time
Staying At Home	95% of time
Washing Hands After Being Outside	100% of the time
Visiting People With COVID symptoms	0% of the time
Watching TV News	80% of time

Looking at the columns, you can see how unlikely terrible outcomes are, how much you *already* are taking control to protect yourself and where you may need to make changes to prepare for problems (e.g., finding a wheelchair repair person) and take better care of yourself (e.g., turning off the TV).

List your own FEARS and their LIKELIHOOD and things you are doing to TAKE CONTROL, so fear doesn't control you. (And turn off the TV news!)

Reprinted from "Bits and Tidbits from the Post-Polio Coffee House"
Bruno Bytes - 1st Qtr 2020 Dr. Richard L. Bruno, HD, PhD <https://www.papolionetwork.org/bruno-bytes.html> March 2020

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

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:

- Part 1: In the July 2019 Pacer**
- Part 2: In the October 2019 Pacer**
- Part 3: In the January 2020 Pacer**
- Part 4: My First Car**

One day at noon, my friend, Everett went down to The Mart to get us lunch. When he came back he told me there was a good looking Chevy in the showroom just

down the street. That kind of caught my attention. I had been thinking about owning a car - you know how boys are. I suppose all boys want a car when they get to



My First Car

that age. I wasn’t absolutely sure I would be able to drive one, but I really thought I could, with the right equipment on it. I knew of people who could not use their legs, but they had cars and were able to drive with hand controls. I also knew that there were some people who didn't think I could do it.

Well, I called the dealer that afternoon and asked about the blue 1952 BelAir Chevrolet in the showroom. It was Fluid Drive (automatic transmission), which I knew I would have to have. They allowed Everett to drive me in this car to show my parents. I really had never said anything to my dad about getting a car. I had mentioned it to Mom, but I thought Dad would have questions about my driving. Anyway, we took the car down to my folks. They came out to see who was coming! I talked and tried to explain that I thought I would be able to drive with hand controls, and if I wouldn't be able to, I would feel much better asking someone to drive my car than asking to go with them. And then, I guess one other thing I was wanting to know, "Could I borrow a little money for the down payment?" Well, to make a long story short, Dad agreed to loan me the money. Then I talked to my cousin, Malcolm, about putting some hand controls on it. He thought he could do that, so I purchased the car - brand, spankin' new - for \$1800.

Malcolm got started on the hand controls. He made up a lever that was attached to the steering column, with a rod going from the lever to the brake pedal. He wanted me to try this for the brake. The car did not have power brakes. So, to try it out I had someone to use the gas pedal and I checked the brakes. I could stop it ok, but I was not sure I could stop quick enough to really feel safe.

On Thanksgiving Day in 1952, I drove solo for the first time. My parents always helped our neighbor butcher hogs that day since the neighbor worked for the State Highway Department and was off work that Friday and Saturday. I had a brainstorm. Honestly, I figured my parents would frown on the idea and if I went ahead and did it, they would probably

worry all the time I was gone. I asked my brother to go out and drill a hole in the upper end of the gas pedal, saw an old worn-out broom off the handle and drive a nail in the end. He did this for me, and I filed the head off the nail. I went out and got in the car, stuck the nail that was on the end of the broom handle in the hole in the gas pedal so it wouldn't slide off, and used that to operate the gas. I moved around there in the driveway a little, and thought things were going fine so I decided I would take a little drive. I went to Wirtz, which was 5 miles from home, and got along fine. I took it slow and made it without any problems. On the way home I decided to go by Burnt Chimney, which was just a crossroad with a gas station and a little grocery store and stop at Ezra Lee Bowman's. I even made it back home safely. I guess if a policeman would have stopped me, I would have been in trouble, since I had no driver's license, not to mention the driving equipment might not have passed inspection. This did prove to me that I could do it.

Then we got serious about getting the equipment needed to make it work properly and safely. Malcolm checked around to see if he could find some controls that would use vacuum to operate the pedals. He did find a used one from a Buick dealer. These controls had a lever that attached to the steering column but worked a lot differently than the first lever he had tried. This lever you just pulled down toward the seat for the gas and pushed up for the brake. It was much quicker and easier to operate, and I felt much more comfortable with its safety. It was getting toward the end of 1952 by this time.

Eventually, I thought I was ready to try for my license. It was a cloudy day and we had a few showers that morning be-

fore we got there. A lady went with me on my test drive. After we had driven a while, she said, "Let's see you stop really quick." I thought she meant what she said, so I pushed the lever all the way up and slid all four wheels, which made her almost bump her head against the windshield. She said, "Boy, you might upset your fruit basket that way." At least she found out that I could stop quick. I did get my license.

Then came the insurance question. Since I was handicapped, the insurance companies did not want to issue me a policy. There was a law then that someone had to write a high-risk policy. The state passed these requests out to the insurance companies and whoever got it would have to write the policy. Of course, the premiums were about double the regular ones, but after so long a time, and you proved yourself, they would give you a regular one.

After I got the hand controls on the car and got my license, I drove back and forth to work about every day. This was after I had my braces and crutches, so I could leave a wheelchair at the shop and one at home. I could get out of the car and walk to the shop and back to the car at closing time. Every once in a while as I was getting out in the morning, I would notice some people watching me. I decided one morning I would just stop and watch them for a while. It didn't take them long to turn and go on their way.

One time I had someone drive me up to Fishersville, to visit the watch repair school I had attended. We saw something a little amusing to us. Just as we were entering the town of Staunton, the older lady in front of us came to a complete stop, hand cranked her window down, put her arm out and gave a right turn signal. Then she pulled her arm back in, cranked her window back up and slowly pulled into the

service station on the right side of the street. I don't remember how much traffic she had backed up, but not as much as would have been today. Her car was back when there were no lights for turning signals. The arm signals were arm straight out level for left turn, and your arm up for right turn.

One day on the way home from work, I saw three men walking along the road just before I got to Burnt Chimney. They started thumbing for a ride. I knew one of them, so I stopped. They wanted me to take them home, as they had been fishing in a nearby pond. I told them I really didn't have time. Besides that, it was out of my way as they lived east of Burnt Chimney about three or four miles. They said just take them to a little store close to their house, and they would pay me to do that. I agreed to take them that far. After they got in and we started off, I could smell they had been drinking. They were feeling pretty good! When we got to the store, I stopped there, and they begged me to just take them to their house which they said was only another mile or so. They assured me they would pay me enough for my trouble. I wasn't really wanting to get them upset at me so again I agreed to do as they asked. I was beginning to get a little concerned by now, but I went on. When we got to their house, they started digging into their pockets and finally came up with forty-six cents. They said that was all they had. I took the money and got out of there as fast as I could. I suppose it did pay for the gas I used but nothing for the wear of the nerves!! I decided right then I was done picking up hitch hikers, even if I did know them.

**Part 5 of the story:
"Courtship & Marriage"**

will appear in the July 2020 issue.

**Have You *Thought* About Writing
Your Polio Story?**

Make notes, lots of notes to help you write your story.

Below are some topics to help you get started:

How old were you when you contracted polio? How was life different after polio?

If you were hospitalized, at what hospital? How long were you there? Hospital memories—other children, limited visitation by parents, etc.

Did you have any surgeries? How successful were they?

When you came home what adaptive equipment did you use (braces, crutches, wheelchair?)

If you contracted polio during childhood, did your school make any adjustments to accommodate your new needs?

As an adult—are/were you employed and/or do volunteer work? Were adjustments made to compensate for braces & crutches or w/c use?

More about adult life—career, marriage, children, etc.

Post Polio Syndrome—Age and your first symptom (s). How does it affect your life now?

Choose what you would like in your story and with whom you wish to share it—your family, or maybe in the *Post Polio Pacer*.

If you would like editorial help, contact Marcia Holman or Kathleen Blair. See email addresses on page 7.

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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.





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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

2020 meeting dates:

March 14

May 9

July 11

September 12

November 14

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NO MEETING IN JANUARY

LOCATION:

Monona Garden Family Restaurant
 6501 Bridge Rd., Monona
 Noon to 2:30

**Meetings on hold until the
 Covid-19 epidemic is over & we
 can meet again.**

