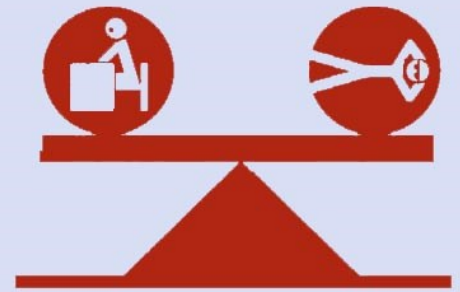


POST POLIO PACER

Conserving Strength and Energy through Pacing
July 2019 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 — This Is Our 34rd Year!



To Reconnect After 65 Years

By Kathleen Blair, Columnist

"Friends, on Thursday, August 8th at 11 a.m. we will gather at the 'Hill of Beans' Restaurant to once again connect with each other,"— a message that appeared in my mailbox early in June. It was an invitation to my 65th high school class reunion that reminded us that we are all 82/83 years old. I read further, "The restaurant is located in the Oge-ma area near Timm's Hill." (Timm's Hill is the highest point in Wisconsin and is several miles north of Rib Lake, the site of my alma mater.)



"Oh, that would be so wonderful," I thought wistfully, "but it's way too far for me to drive."

The invitation included these brilliant words of wisdom, "**There are a few things necessary in order to face this adventure of aging: a healthy spirituality, a sense of humor, things to do, joy, patience (with ourselves and others), and contact with family and friends.**"

Speaking of contact with friends and family -- at dinner with other octogenarians the following evening, I was surprised to learn someone I knew here in southern Wisconsin was familiar with Rib Lake and the surrounding area. He had gone to Medford High School 17 miles south of Rib Lake. Later that evening I telephoned my son, Ron, and told him about our conversation.

"What day is the reunion?" Ron asked.

"Thursday, August 8th"

Imagine my delight when he responded, "Okay, I will pick you up the morning of August 7. Get a reservation at a motel in Medford. We'll stay there Wednesday night, go to the reunion at Timm's Hill on Thursday, stay one more night in Medford and drive home on Friday, the 9th."

I had our reservation by 8 a.m. the following morning.

Reviewing the black and white photos and faded print and written messages from my 1953 and 1954 yearbooks, I recalled many nostalgic memories from my teenage years. It was so much fun to see the faces and read



the names and activities of all my classmates. There were even photos of the bus drivers, cooks & janitor.

A note from Marie, my loyal high school friend, recalling the fun we had roller skating and square-dancing said, *"I sure have enjoyed having you as my closest friend and hope it will always be that way."* I look forward to reconnecting with her in August, because I heard she's going to be there.

A note from another dear friend, Alice, began, *"I didn't think I could get into so much 'hot water' until I met you. But I don't regret it."* Would love to see her again.

And with a touch of sadness I recognized faded photos of my younger brother, Wayne, cousins Gracie and Shirley, and brother-in-law, Jimmy, who are no longer with us. May they rest in peace.

In the coming weeks, with the help of my old yearbooks, I plan to reflect and remember names, faces and long-gone events as I prepare for this much-anticipated adventure, **my 65th high school class reunion**. And I will share "the rest of the story" in the October issue of Pacer.

tremendous physical stress on polio-damaged, overworked neurons, muscles and joints. The wheelchair requires that you propel yourself using your arms. And you steer the scooter using your arms and shoulders to move a "T - bar" tiller that turns the front wheel while you use your hands to squeeze levers that make the



scooter move. What's more, the tiller forces you to lean forward in the seat, putting you in a forward flexed position that causes neck and back pain.

On the other hand, there is the power wheelchair. Steered by a joystick, like those used for video games, power wheelchairs have a knob attached next to one of the armrests. The joystick allows you to steer with only one hand -- or even just your fingers -- with arms at your sides and shoulders relaxed while sitting with "painless posture." Also, the new power chairs have mid-wheel drive, instead of the old rear wheel motors, that allow the chair to turn in its own space, make it smaller and very maneuverable.



Power chairs can be fitted with special rigid backs that have adjustable foam inserts to provide the right amount of lumbar curve to insure proper posture. If you have trunk weakness or scoliosis, you can get a back made from custom-formed foam to cradle and hold your body in place. And if



Power Wheelchair or Scooter?



From Dr. Richard L. Bruno, HD, PhD
 Director, International Centre for Polio
 Education

There is a Post-Polio Institute rule of thumb, or more correctly a rule of arms and legs: if you're wearing a short leg brace you need to use a cane; if you're wearing a long leg brace you need to use two forearm crutches; if you have two long leg braces you need a wheelchair.

Obviously, there are lots of polio survivors with and without braces who need assistive devices, including a wheelchair. But, after more than 35 years of experience, I no longer recommend either manual wheelchairs or scooters for polio survivors. If your arms are weak or your shoulders hurt too much to use crutches, you shouldn't be using a manual wheelchair or a scooter. Both put

you have upper back or neck pain or muscle weakness, you can order a shoulder-height or head-height back, or an additional head rest, that will allow your muscles to be supported and relaxed while driving.

Power chairs can also accommodate custom seat cushions. If one butt cheek is smaller than the other, or if you have scoliosis and your upper body tilts, an adjustable cushion that has separate inflatable air bladders or foam inserts of different heights and firmness can lift one side of your pelvis and balance your body. Those with leg swelling can get manual or electric elevating leg rests. You can even get a special power seat riser to allow you to reach high cupboards, and chairs whose backs recline and allow you to take your twice daily 15-minute rests breaks (or even a nap) without leaving the comfort of your custom-designed chair.

Now that you know power wheelchairs are the way to go, how do you get Medicare or your insurance company to pay? Medicare and most insurance companies use the Medicare rule:

You are eligible for a power chair "only if you need it inside your home" and "your arms are either too weak or you have too much pain to propel the manual chair." Your doctor and a physical therapist need to fill out the Certificate of Medical Necessity and write a separate letter of medical necessity for the power chair.

Your doctor and therapist need to clearly document, on the form and in the letter, your actual physical condition, including:



- 1) leg and arm muscle weakness/pain that prevent you from using crutches or a manual wheelchair;
- 2) if you are unable to walk more than ten to twenty feet and need to use a power wheelchair at all times inside the house;
- 3) if you are unsafe and more likely to fall;

4) if your PPS symptoms are progressing and will get worse without the power wheelchair.

If your power chair has already been denied and you are filing an appeal, it is helpful to get the name of the Medicare or insurance company doctor who will be reviewing the denial and have your own doctor give him or her a call and directly send the doctor the form and letter. A personal doctor-to-doctor chat with the medical director of the insurance company can often get you the chair. In any case, it is important to play by the rules in order to obtain a power wheelchair under Medicare regulations or your own health insurer/HMO policy.

Reprinted from the Pa. Polio Survivors Network — June 2019 <www.papolionetwork.org>

WHAT DID YOU MISS ON MAY 13, 2019?

Gail Beckwith, co-leader (with Fayth Kail) of the Madison Area Post Polio Support Group, provided information at the May meeting about keeping safe in your home and in the community. Many of these suggestions you have heard before—but maybe haven't acted on yet...

The most dangerous place in the home is not the kitchen, stairways, garage or even the living room—*it's the bathroom*. Equipment to make the bathroom safer include a nightlight, grab bars to make entry/exit from the tub safer, non-slip surface in tub, a shower seat, a hand-held shower, a raised toilet seat &/or safety bars attached to the toilet seat and good lighting.

Improve lighting—increase ambient lighting (the foundation of a room's lighting) as well as task lighting which makes reading, cooking or other tasks easier. Put LED &/or motion-activated lights at entrance ways and hallways as well as overhead lights at top and bottom of stairways.

Remove trip hazards from traffic areas—throw

rugs, pet and children's toys, shoes, newspapers, electrical cords, etc. which cause many falls.

Install a second railing on stairs with only one railing now, to provide using both hands for stability. Consider a stair lift, if feasible.

Secure your furniture—anchor wardrobes, dressers, bookcases and TVs with furniture restraints (aka anchoring kits). This not only keeps seniors safe but visiting grandchildren as well.

Kitchen hazards include cans, boxes, dishes, glasses, cups and silverware that are not stored within easy reach. Have someone help you to rearrange items so they are in easy reach. Avoid standing on a stool or chair to reach items. Using a "reacher" may help to remove light weight items from shelves beyond arm's length or items that have fallen on the floor.

Home Safety--Keep a charged fire extinguisher handy in the kitchen and know how to use it. Regularly replace batteries in smoke alarms *or* get hard wired alarms.

Food safety—check fruits and vegetables for bruises and put perishable foods in the refrigerator within 1-2 hours. Date leftovers, use as soon as possible and toss if there are changes in taste or smell.

Fall prevention—if you have fallen in the last few months, perhaps you could consider taking a "fall prevention" class which are available in many cities. Inquire at your local hospital, Aging & Disability Resources Bureau or doctor's office for information about fall prevention classes.

Last, but not least, if you have a "lifeline device" wear it at all times—it is no help if, when you fall, the lifeline is on the top of the dresser...

CARDIAC REHABILITATION

Should Polio Survivors Just Say No?

Dr. Richard L. Bruno
Director, International Centre for Polio Education

www.postpolioinfo.com

Let me begin with the conclusion: in 37+ years of evaluating, treating and studying polio survivors I have never seen one who has had a heart attack, heart bypass surgery or heart failure who has 1) been able to do exercise required for cardiac rehabilitation or 2) suffered as a result of their inability to do cardiac rehabilitation.

Cardiac rehabilitation exercises the heart muscle by exercising the "skeletal" (limb and diaphragm) muscles. The purpose is not only to exercise the heart but also to exercise skeletal muscles in order to treat "muscle deconditioning" to improve muscle strength and endurance and to reduce fatigue and shortness of breath.

First, polio survivors' muscle weakness is *not* due to deconditioning or muscle atrophy but results from a reduced number of remaining, poliovirus-damaged neurons losing their ability to function as a result of failure from decades of overuse. Adding cardiac rehabilitation exercise -- swimming, trying to work out on a treadmill, exercise bicycle or upper extremity exercise "bike" -- on top of the overuse polio survivors experience just doing their daily activities will decrease muscle strength and endurance.

Second, polio survivors' reduced muscle strength and endurance makes it nearly impossible for them to raise their heart rate into the "cardiac conditioning zone" and keep it there for 20 minutes.

There are few studies of heart exercise in polio survivors. In one study polio survivors did five minutes of bicycle exercise followed by a 60-minute exercise class twice a week for 5 months. Obviously subjects in this study did

not have Post-Polio Sequelae. Polio survivors' legs became 4% weaker while their maximum heart rate during exercise increased only by 12 beats per minute. This study demonstrates the trade-off: there is no benefit to exercising your heart slightly if you thereby stress and kill off poliovirus-damaged motor neurons.

All that being said, it's important to note that cardiac rehabilitation is not just exercise. It involves working with your doctor and a nutritionist to use medication and diet to manage cholesterol and weight, reduce blood pressure, eliminate smoking and, perhaps most important, reduce stress!

So, talk to your doctor about "Conserving to Preserve" your remaining, poliovirus-damaged neurons to treat PPS at the same time helping your heart be the best pump it can be.

Reprinted from Dr. Bruno's post on PP Coffee House, 6/24/19.

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: Onset, diagnosis, surgery
Part 2: Will be in the October Pacer

Polio Strikes

As far as I know, I was an average little boy who squirmed, cried, smiled, cooed, kicked and all the things that little boys do. I was told that I started walking when I was 10 months old.

Then in August of 1929, when I was 16

months old, I became sick. It seemed the doctors could not determine what it was until I started losing the ability to move my arms and legs. It turned out to be infantile paralysis, which is what is now known as polio. In the time immediately after they decided what was wrong, they quarantined our place. No one was allowed to come in for fear of spreading this disease to others. None of the siblings or anyone else contracted it.

They said that at one point, all I could do was turn my head a little. My mother told me that one Saturday they didn't think I would live through the day. I guess I will just have to come to the conclusion that the Lord had more in store for me. Of course, I do not remember anything about this part of my life.

My parents did everything they could, along with the doctor's suggestions, to help me. I was taken to various doctors for evaluation and treatments.

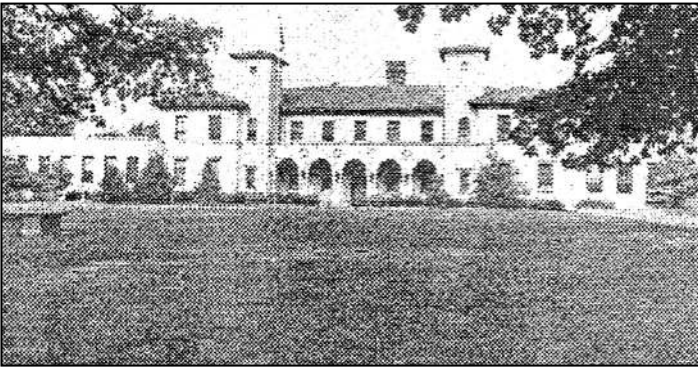
I do not know just how fast some of my movements came back, or what part of them came first, but I eventually gained enough that I could sit up and crawl around.

As time went on, I was told that, as some of the other children were pulling me around in the little red wagon, it turned over and broke my leg. While my leg was in the cast, I laid on a cot in the living room a lot of the time. When it was time for the cast to come off, Dad just cut it off with a knife. When the cast was off, they told me that I said several times, "I sure am glad to get my big leg off!"

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

Crippled Children's Hospital

In 1936, when I was eight years old, they took me to a facility called the Crippled Children's Hospital in Richmond, Virginia. As I re-



call, it was about the first part of December when we went to the hospital. One reason I think it was at that time is that I remember getting a box from back home that was filled with Christmas gifts. I don't remember everything that was in the box, but there was one that I can still see today. It was a big, red fire truck. It had ladders, and all that fire trucks have on them. I can't remember if it was a wind-up or battery operated (not many battery-operated toys back then), but it did have what sounded like a real siren. Needless to say, I thought I really had something great. Another thing that stands out in my memory is a large Christmas tree in the hall that had all the lights and trimming which was something I was not used to at home.

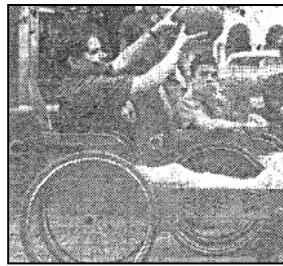
I well remember the day we arrived there. It was on Saturday about noon. They were passing out the dinner trays soon after I was there. There were only two items that I remember on the tray, black-eyed peas and milk. I liked the peas. The lady asked me if I liked milk, and I said, "No." Her answer to that was, "That's too bad, you will have to drink it anyway." And guess what, I did!

During my first stay there I had 2 or 3 operations. One was on my hips. I had sat so much the tendons in my hips were contracted. I could not lay on my back with my legs out straight. The first operation was to lengthen those tendons. Then I had to lie on my back on a raised board somewhat like the drawing,

for 6 weeks, day and night. Did you ever try to drink water (or milk) from a cup while lying flat on your back? I'm not sure when straws were invented, but we did not have them yet. I would open my mouth and they would pour the water or milk and fill my mouth and then I would swallow. They also straightened my knees.



A book could have been written by us boys on all the activities that went on there. One time there were black marks on the floor from our go-carts (the type of wheelchairs they had then) which the staff did not like. Nobody would tell who made them, so we all had to spend the day in bed. And, no, nobody ever told!



One day one of the boys got hold of a plug of chewing tobacco. During our noon school recess they tried to talk me into taking a chew. I said "Naw!" They kept trying to talk me into it, calling me a chicken, and daring me until I said I'd do it. After about five minutes, I began to get a little dizzy, so I hastily spit the stuff out. That was the first and last chew of tobacco for me!

Fifty or more years later, Mom and I were talking about me being there. She said she didn't know how she did it—take me there and leave me. I said, "Well, Mom, if it will make you feel any better, it was one of the best things you ever did for me." I have said many, many times that I learned more there in that ten months than I would have in ten years at home.

I realized more fully that I was not the only one in my shoes, and that no matter what kind of handicap a person has, life goes on and can be enjoyable and beautiful. It is largely what you make it. It is not what one has lost, but what we have left that we have to work with and make the best of.

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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!

2019 meeting dates:

July 13

September 14

November 9

Printing and postage
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 608-277-8031 tty
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<http://www.EasterSealsWisconsin.com>



LOCATION:

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

July 13—Carissa Peterson, Vice President for Camp and Respite services will speak about Camp Wawbeek and services that Easter Seals provides.

Sept. 14—Karen Lavalley, PA will discuss strokes, signs & symptoms, & how to avoid them.

