

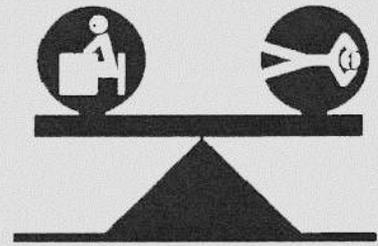
# POST POLIO PACER

*Conserving Strength and Energy through Pacing*

*January 2017 — Madison, Wisconsin*

*Madison Area Post Polio Support Group Newsletter*

*MAPPSG formed in 1985 — This Is Our 32nd Year!*

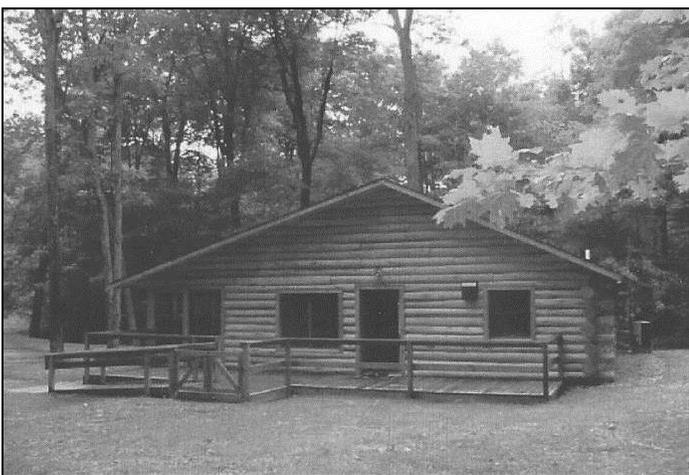


## What Did You Miss on Nov. 12, 2016?

Anyone who is interested in learning about camping or adaptive sports equipment available through the DNR missed a wonderful presentation.

Anthonette Gilpatrick, DNR Accessibility Coordinator, started working with people with disabilities at Access to Independence, and moved on to the DNR in 1989, retired at the end of 2016. We are so glad she was willing to talk with us and share her power point presentation which illustrated the accessible cabins, trails, and adaptive water equipment.

Ten accessible cabins may be reserved only by people with disabilities and their guests from May through mid-October. Reservations will not be accepted for more than four consecutive days nor more than 4 nights per year due to high demand.



Each of the eight wheelchair accessible cabins have: a kitchen with lower counter, stove, microwave and refrigerator; bedroom with two hospital beds (one is automatic) and Hoyer or

Invacare lift; living room with a full-sized sofa sleeper or futon and two cots; bathroom with a wheel-in shower, fold down shower bench and a shower commode chair; heating and air conditioning and many electrical outlets; a screened porch is attached.

Fully accessible cabins are located in Potawatomi SP, Sturgeon Bay; High Cliff SP, Sherwood; Buckhorn SP, Necedah; Mirror Lake SP, Baraboo; Kohler-Andrae SP, Sheboygan; Harrington Beach SP, Belgium; Kettle Moraine State Forest, Southern Unit, Dousman; and Richard Bong Recreation Area, Kansasville.

The cabins at Copper Falls State Park and Blue Mounds State Park are rustic—no plumbing, but have a shower/toilet in a separate nearby rustic cabin.

Adaptive equipment available include kayaks with adjustable outriggers, and raised back with side supports provide the user a comfortable and secure seat while paddling. Paddles with hand adaptations are also available for people with limited grip. These are available at Buckhorn, Council Grounds, Devil's Lake, Mirror Lake and Perrot State Parks. Beach wheelchairs with large inflatable tires are also available.

Wisconsin State Trails offer over 650 miles of accessible trails to accommodate a wide range of abilities.

For more information about accessible outdoor recreation and upcoming events offered by the DNR, check out the Open The Outdoors website at: <http://dnr.wi.gov/topic/openoutdoors/>

## Chronic Illness Masquerading as Acute Problem: Post-Polio Syndrome

Jeannette Y. Wick, RPh, MBA, FASCP  
Published Online: Friday, Dec. 30th, 2016

At a community event, a 72-year-old woman complained to her companions about pain that had developed in her leg, and various clinicians' inability to help her find relief. The conversation eventually turned toward memories from early life. The woman told a story about running in grammar school, indicating she was the fastest among both girls and boys until she developed polio. A clinician who was coincidentally engaged in the conversation made an important link—this woman's polio could be the cause of her pain. He asked if she had mentioned the polio to her physicians. She had not.

Viral polio infections peaked in the 1940s and 1950s, infecting approximately 500,000 people annually around the world. Many people suffered mild symptoms such as headache and malaise, but some developed paralysis quickly. Children were less likely than adults to be paralyzed; 1 in 1000 children experienced paralysis compared with 1 in 75 adults. During the nation's worst outbreak (the 1952 epidemic), the CDC tracked 57,628 cases and 3145 people died. More than 21,000 Americans developed mild to disabling paralysis that year.

The nation has been quick to forget polio and its disabling effects—after all, we have had an effective vaccine since 1955. However, people who were infected with polio as children are now in their 60s and 70s, and researchers have identified a lingering effect of poliovirus infection: post-polio syndrome.

Post-polio syndrome affects polio survivors 30 to 40 years after they've recovered from their initial poliomyelitis. The cause of the syndrome is unknown but seems to be related to degenerating nerve cells. It tends to progress slowly, waxes and wanes, and is potentially disabling. Up to half of people who had polio at a young age may experience post-polio

syndrome. People who are at increased risk are those who recovered from more severe polio, with greater loss of muscle function and more severe fatigue. Those who contracted polio as an adolescent or adult are more likely to develop post-polio syndrome. In addition, people who are physically active are at elevated risk.

Common signs and symptoms of post-polio syndrome include the following:

- Progressive muscle & joint weakness & pain
- Fatigue & exhaustion with minimal exertion
- Muscle atrophy
- Breathing or swallowing problems
- Sleep-related breathing disorders, such as sleep apnea
- Decreased ability to tolerate cold temperatures

Diagnosis is based on the presence of 5 factors: prior paralytic poliomyelitis with evidence of motor neuron loss; a period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval of at least 15 years of stable neuromuscular function; slowly progressive, persistent new muscle weakness or decreased endurance, with or without generalized fatigue, muscle atrophy, or muscle and joint pain; symptoms lasting at least a year; and the exclusion of other neuromuscular, medical, and skeletal abnormalities as causes.

Suspect post-polio syndrome when patients meet these diagnostic criteria. Patients may need muscle-strengthening physical or occupational therapy\*. Advising patients to rest when necessary is important. In addition to prescribing nonsteroidal anti-inflammatory drugs, a trial with lamotrigine may be helpful.

**\*Editor's note:** Only as supervised by a PPS knowledgeable PT/OT &/or Rehab. Physician.

<http://contemporaryclinic.pharmacytimes.com/chronic-care/chronic-illness—masquerading-as-acute-problem-post-polio-syndrome>

Thank you Post-Polio Health International for sharing the above interesting article – (reprinted from PA Polio Network)

## Reading – A Healthy Hobby

**By Kathleen Blair, Columnist**

I believe reading – getting my mind occupied in another world where I stay off my feet and conserve physical energy – is a healthy hobby for both my physical and mental health. And I am grateful to God for my healthy eyes.

My bookshelves are full of books by the authors I've enjoyed reading over the years – Phyllis Whitney, Rosamund Pilcher, Belva Plain, Margaret Coel, Mary Higgins Clark, Barbara Taylor Bradford, Maeve Binchy, Nicholas Sparks, Joseph Girzone – to name a few. Of those, my favorite is *The Shell Seekers*, by Rosamund Pilcher.

More recently I have spent many hours engrossed in the entire Louise Penney series from *Still Life* (2005) to *A Great Reckoning* (2016). While (impatiently) waiting for her next book to come out in August 2017, I've relaxed with mysteries by William Kent Krueger and J. A. Jance.

I particularly enjoy series of books where the author describes the adventures and experiences of the same protagonists. It's like following a family, friends and neighbors through a period of time. So reading the books is like catching up on the news of old friends.

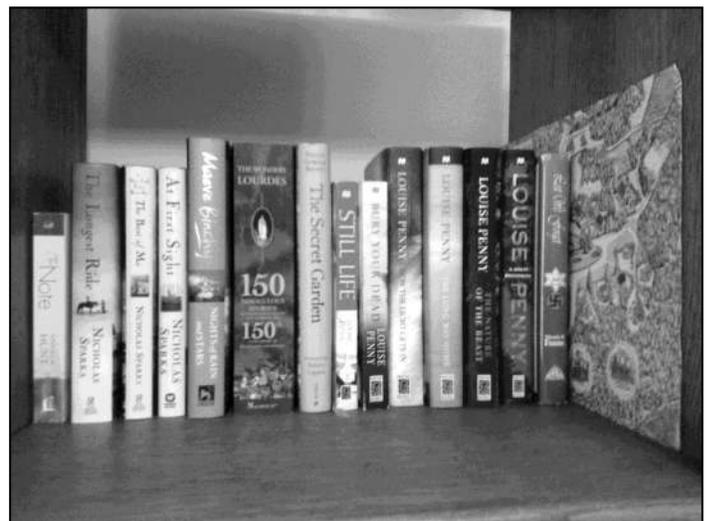
With my book shelves triple stacked, I've had to stop buying books. In fact, I'll be sorting and packing boxes of books to give away to a good home. With luck and some effort I may be able to find senior center libraries and prison libraries who might accept hard cover novels and mysteries in mint condition.

*If you have any suggestions of a place that might want donated books, please let me know.*

But I've finally gotten smart enough to make better use of our library. True, it's not possible for me to browse the hundreds of books available as I once did, especially during the

bad weather. Sometimes in summer I ride my scooter the 10+ blocks to visit the E.D. Locke Library in McFarland, but even then I find it hard to review all the titles on the very top or bottom shelves.

Gradually I have moved into the 21<sup>st</sup> century. When Ron my son, Monica my daughter, and friends who are avid readers mention an author they like, I find the author and his/her list of books on the Internet, and read excerpts of the books. Then I call the library and request the books by author, name and title.



*Some of the books I can't bear to part with...*

I am not limited to the books available in our local library; the librarian requests them from other libraries in the area. What a wonderful system! For example, many of the books I have read this winter came from libraries in Madison, Belleville, Monroe, Mt Horeb, Wisconsin Dells and other towns.

I order 3 or 4 books at a time. When they are in, I receive a computer-generated phone call and have 7 days to pick up the books. When my granddaughter, Britney and I are out with the car we stop at the library. She takes my library card in and picks up the books. After reading the book I drive up to the convenient drop box on the outside of the library building to return the books. What a convenience for someone who can't walk!

I've learned that many of the books are avail-

able in audio on CD. This would be a perfect option for those who find reading the printed page difficult. Imagine relaxing in your favorite chair or lying on the couch or in bed, and having the pleasant voice on the CD read a good story to you.

If you who are reading this column and have someone who is vision impaired, I suggest you google or call the Council of the Blind or Library of Congress in your area to learn about the free services they provide for the blind. From around 1996 to 2001 my late husband who was disabled and legally blind spent his long days listening to books we selected from the Library of Congress in Milwaukee on a tape player provided free of charge. When he had finished "reading" the audio books I shipped them back in the green plastic containers provided, postage free. After he died in 2002, I returned the tape player with a note of thanks. It's a wonderful service and an excellent use of our tax money.

After sending this column to the Pacer for publication, I will finish reading the 20<sup>th</sup> book of the J. A. Jance, Joanna Brady series, I started in October. Then I plan to research online to learn how soon the next books of my favorite authors will be published and will get on the list to be called when the books come to McFarland. And in the meantime, I may have to introduce myself to another author.

Again, thank you, God, for eyes that see well enough to read.

---

**On the topic of asking our Physicians about Medications (12/26/2016)**

**Dr. Bruno's Original Post:** A Polio Survivor's (Baby Boomer) New Year's Resolution -

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

because Less is often More! We have to take an active role and know the "why and what" before taking or changing meds. What's most important is that discussion with our physicians is VITAL.

**A Baby Boomer's New Year Resolution: Ask Your Doctor About Your Medicines**

Saint Louis University Geriatrician Says  
 "Less Is Often More"  
 Released: 26-Dec-2016 5:00 AM EST  
 Source Newsroom: Saint Louis University Medical Center

**Newswise — ST. LOUIS** -- If you're 65 or older and taking more than four medications, resolve to talk to your doctor about doing a New Year's triage to make sure too many pills aren't making you sick, advises Milta Little, D.O., associate professor of geriatrics at Saint Louis University. As people grow older, they can develop a litany of health problems and see multiple specialists who prescribe various drugs to treat common conditions such as osteoporosis, high blood pressure, diabetes, heart disease, arthritis and memory loss.

"Drugs may not play well with each other, and problems can snowball for older adults who take five or more medicines," Little said.

"As a geriatrician who quarterbacks the health care of my patients, I think six medicines usually is too many, and studies have shown mortality is higher among patients who are taking 10 medicines. I love to analyze medicines my patients are taking because reducing the number of drugs often makes them feel so much better. Many times, less is more."

Every patient is unique with different health goals and challenges that change as a person ages, which is why one-size-fits-all guidelines don't work, Little adds. She advocates an annual medicine check-up, where patients ask doctors to assess the drugs they are taking, being mindful that vitamins, supplements and over-the-counter medicines count, too.

"Supplements and other nonprescription medications, which are often less rigorously regulated than prescription medications, are a major cause of dangerous drug-drug interaction in elderly patients," Little said. "I don't recommend a multi-vitamin or ginkgo for brain health for everyone. The supplements are for specific people, and I prescribe them like anything else, only for those who need them."

Here are questions Little asks as she analyzes the medicines her patients take:

**How old is my patient?** Guidelines on what constitutes good health loosen with age. For instance, a good blood pressure for a younger adult – 120/60 – is much lower than a healthy blood pressure for an older adult – 160/90. And a person who has a blood pressure with a top (systolic) number that's too low – 130 – could fall or become dizzy, which creates additional health risks. "My prescriptions for patients who are 65 are different than those for patients who are 80," Little said. "For patients who are 100, I probably wouldn't prescribe any medicine at all. If they've lived to be 100, it's probably nothing doctors did."

**How long has the patient taken the medicine?** Prescriptions are not forever, and should be reviewed periodically to make sure they're still necessary. "It may have been appropriate for you 10 years ago, but may not be today," she says. "Under your doctor's guidance, don't be afraid to try going off your medicine." For instance, there is no evidence that shows a 76-year-old patient who has high cholesterol but hasn't had a heart attack or stroke within the last year would benefit from taking a statin, although he might have been prescribed the statin 16 years ago, when it likely could help.

**Is the dosage right?** As people grow older their bodies change. A smaller dose of medication might yield the same response as when a younger adult. Often times, a half-dose of a psychotropic medication works better in older patients than a full dose, as does a smaller dose of medicine for osteoporosis.

"Start low and go slow," Little says. "You can always give more but you can't take it out of the body once it's given."

**What are the drug's side effects?** A medicine might address one problem, but create another. For instance, antidepressants can cause frequent urination, which can lead to incontinence. Statins and blood thinners worsen frailty, which makes patient vulnerable to more medical problems. An anti-diuretic for blood pressure can worsen symptoms of gout, which is a form of arthritis.

**How well do medicines play with each other?** Drugs given for one illness could make another condition worse. Medicine given for acid reflux can reduce the effectiveness of blood thinners because of the way the medicines are broken down in the liver.

"Some older adults believe taking a pill will make them healthier, which is not always the case, particularly when they're taking many pills for different health issues. Too many medicines can make older adults feel fatigued, and undermine the quality of their lives," said Little, who is the author of an editorial on overmedication in the elderly that appeared in a 2016 issue of JAMDA.

"We have a lot of evidence that non-medical treatments, such as exercise, yoga and massages, work better in improving a person's health. But they're work."

Established in 1836, Saint Louis University School of Medicine has the distinction of awarding the first medical degree west of the Mississippi River. The school educates physicians and biomedical scientists, conducts medical research, and provides health care on a local, national and international level. Research at the school seeks new cures and treatments in five key areas: infectious disease, liver disease, cancer, heart/lung disease, and aging and brain disorders.

<http://www.newswise.com/articles/a-baby-boomer-s-new-year-resolution-ask-your-doctor-about-your-medicines>

## Post-Polio Bracing

By Marny K. Eulberg, M.D.

**Questions to ask** the orthotist (bracemaker)

1. What problem is the brace going to address?

Drop foot?

A knee that is unstable, or buckles (collapses forward)?

A deformity of foot, ankle, knee? a painful joint?

Or a combination of the above?

2. What are the credentials/qualifications of the brace maker?

3. Ask questions and get answers to YOUR satisfaction and level of understanding - examples:

"Explain to me how this brace will address/solve my particular problem(s)"

"Show me what it will look like"

"Can I try an off-the-shelf model or a sample so I can experience what it will be like to wear?"

"If it will be on the leg I use for driving (or other important activity—depress pedals on a piano, etc.) how will it impact my ability to do those activities?"

"What choices of a brace do I have?"

"What are the pros and cons of each of these brace designs?"

"What kind of footwear can I wear with this brace?"

"Will I need a different size than I am currently wearing?"

"Can I wear it without shoes?" (personal preference or cultural/religious requirement in certain situations)

4. What about the care of the brace?

Can it be worn in the water?

If there are joints, do they need to be oiled?

If so, what kind of oil should I use?

Are there springs/joints/screws that might break or fall out?

If so, can I get spare parts to have on hand and be taught how to do my own repairs?

How do I recognize a problem or impending problem with the brace? And what do I do if I suspect a problem?

5. Will gait training be recommended as part of the program?

If so, who should do the gait training, what does it entail, etc.?

6. How much will the brace cost? How much is my insurance likely to cover? How much will I have to pay out of pocket?

7. Are there any warranties or guarantees?

8. What kind of follow-up is recommended? (Note: most braces DO require some adjustments initially and over time)

Finally, technology is changing and your body may also change, especially if you have post polio syndrome, so it is a good idea to check in with an orthotist at least once every 3-5 years.

Marny Eulberg, MD, is a family medicine physician and a polio survivor. This article, complete with a video interview of Dr. Eulberg available on the PHI website: ([www.post-polio.org](http://www.post-polio.org))

Many thanks to Polio Place (a service of Post-Polio Health International) and the Pennsylvania Polio Survivors Group for providing the above article.

Visit their respective websites:

- [www.polioplace.org](http://www.polioplace.org)
- [www.post-polio.org](http://www.post-polio.org)
- [www.papolionetwork.org/](http://www.papolionetwork.org/)

### EXECUTIVE PLANNING COMMITTEE

Kathleen Blair 608-838-8773  
 Fayth Kail 249-1671  
 Nedeem Strand 222-4946  
 Sheryl Shaffer 839-4648

Do you have suggestions for speakers, topics, books to read and discuss, etc.? 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.

### POST POLIO PACER STAFF

Marcia C. Holman, Editor  
 3629 Alpine Rd.  
 Madison, WI 53704-2201  
 e-mail: mchwgh@gmail.com  
 Phone: 608-249-2233

Kathleen Blair, Columnist  
 5404 Wellington Circle  
 McFarland, WI  
 e-mail: knlmlbr@gmail.com  
 Phone: 608-838-8773

### Madison P-P Support Group e-mail list:

**Beckwith, Gail**—dbgb1973@charter.net  
 Blair, Kathleen—knlmlbr@gmail.com  
 Casper, Mary—mhcspr@ticon.net  
 duRocher, Carl—carld@gdinet.com  
 Fisk, Julie—jkfisk@hotmail.com  
**Herness, Mary**—maryherness@centurytel.net  
 Jordan, Buffy—buffyjordan@gmail.com  
 Klotzbach, Jennifer—maywoodteach@aol.com  
 Klotzbach, Marilyn—marilynkcgw@yahoo.com  
 Marsolek, Betty—bmarsolek@tcc.coop  
 Miller, Diane—welcomehome@hnet.net  
 Montgomery, Joyce—jmrm14@yahoo.com  
 Murphy, Dorothy—ddm4hymn@msn.com  
 Mylrea, Marian & Earl—mamylrea@aol.com  
 Newman, Leanne R.—roonie@charter.net  
 Post, Theresa—tjpost@charter.net  
 Purdy, Elizabeth—epurdy1@verizon.net  
 Shaffer, Sheryl—sheryls@gioffice.com  
 Schubring, Kathy Sue—kathysue@gmail.com  
 Smith, Joy—handswow7@hotmail.com  
 Strand, Nedeem—tstrand@charter.net  
**Tomter, Linda**—ltomter2@gmail.com  
 Torti, Geri—gatorti@wisc.edu  
 Wieland, Dennis—boxdodger@yahoo.com

**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.*





**Easter Seals Wisconsin**  
8001 Excelsior Drive, Ste. 200  
Madison, WI 53717

*Address Service Requested*

Non-profit  
Org.  
U.S. Postage  
PAID  
Permit No. 136  
Madison, WI

**A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP**

**Mark your calendars!**

**2017 meeting dates:**

**March 11, May 13, July 8,  
Sept. 9 & Nov. 11**

Printing and postage  
is provided by:

**EASTER SEALS WISCONSIN**

608-277-8288 voice  
608-277-8031 tty  
608-277-8333 fax  
<http://www.EasterSealsWisconsin.com>



**LOCATION:**

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

**NO MEETING IN JANUARY**

**March 11, 2017**

**Open Discussion – let's share  
our  
program suggestions**

