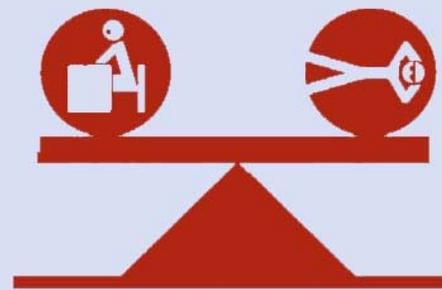


POST POLIO PACER

Conserving Strength and Energy through Pacing
January 2014 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 — This Is Our 29th Year!



WE STILL CAN - - MAKE A DIFFERENCE

By Fayth Kail

In 1971 M.O.B.I.L. (Madison Organization Behind Independent Living) formed to address awareness to the needs and concerns of people with physical disabilities. (Lack of) Legislation, housing, transportation, accessibility and personal care all were addressed in the 70's. These were accomplished through the help of Jim Wahner who was at that time in the WI Legislature, the then and now Mayor of Madison, WI, Paul Soglin who supported our efforts and developed the Citizens Advisory Commission for People with Physical Disabilities (now the Commission for People with Disabilities) to Sol Levin, to Eileen Berkeley and Kayleen (Steinhaus) Brereton who started the Independent Living Agency, "Access to Independence". We have all of these folks plus people who were involved in MOBIL and many others to thank for a big part of our independence and accessibility.



We have made great strides but there are still concerns I have, and I'll bet you do too, of the lack of accessibility with the medical providers in the clinics, doctors' and dentists' offices, and hospitals.

In the July 2013, *New Mobility Magazine*

article, "Equal Health Care: If Not Now, When?", it went on to say, "On the 23rd anniversary of the passage of the Americans with Disabilities Act, why are people with disabilities still not getting adequate and equal health care?"

My questions are:

- ◆ Can you get onto your doctor's examining table?
- ◆ If you have been in the hospital as a patient, can you access the call button and phone, use the toilet and shower?
- ◆ If you use a wheelchair, can your doctor or clinic weigh you IN your wheelchair?
- ◆ Have you thought about what you need when it comes to health care?
- ◆ Have you talked to your doctor about them?
- ◆ Do you have in your medical and dental file and carry on your person, the yellow card that identifies you as a polio survivor and has the medical alert and anesthesia warning? See card on page 5.

It's up to us to continue to make a difference. We **must** and **need** to advocate for the accessibility to better health care for our sake as well as for other people with disabilities. We cannot leave it up to the "other guy"!

Below are excerpts from the article "Wheel People are Real People" by Ellen Daly who was with the National Spinal Cord Injury Foundation when it was written in the mid 70s and

published in *The Badgerscope*—Official Publication of the American Association of Medical Assistants. The excerpts are used with her permission and may bring back memories of that time—and *some* may still be true today—almost 40 years later.

“Now, where do I put my chrome framed body? A quick glance around the waiting room reveals wall to wall furniture. There aren't many options. Sitting at the end of a row of chairs will no doubt block access for others; sitting at an end or corner table means others will have trouble getting to the magazines. I can sit in front of an empty seat or two or opt for the space behind the door or in front of the coat rack.

While searching for a place to park my body, I notice the furniture looks inviting, real comfortable and very modern (low to the floor). I also notice elderly folks trying to sit down gracefully, but what really gets me is the elderly woman who is arthritic and is struggling to get up. She shifts from hip to hip while working herself to the edge of the chair in anticipation of being called.

I begin to think about why I made this appointment and my mind immediately moves on to the next phase of this appointment. When it's my turn to see the doctor, will I be called like the others or has the nurse been told who the lady in the wheelchair is, and when it is my turn, will the nurse just simply come over and proceed to push me into the doctor's office without first indicating that it's my turn? I really react negatively to being pushed without my permission. If she just called me like she does the others, will she repeat my name as I wheel towards her in order to overcome her own surprise, will she insist on pushing the wheelchair; will she just simply ask if I need help and then let me tell her what help, how and when; will she attempt to play it cool and look through me and try to pretend the wheel chair does not exist; or will she be patronizing? I hope she will just be friendly and offer her assistance. It's always best that I navigate the wheelchair in small, tight and new surroundings, it usually

saves the walls, woodwork and furniture. You may not know this, but doctors have found that pushing a wheelchair is dangerous to one's health and doctor's offices seem to have the hardest carpeting to push over; the perfect time to see what it does to my heart rate.

Doctors' examining rooms were only meant for the "walkers". The space is usually small and filled with furniture and equipment. I have often felt like I was holding the doctor a prisoner, because in order to get out of his/her office, I usually need to back out into the hall or maneuver the wheelchair around so he/she can squeeze by. If I need to get on the examining table, wish me luck. Those tables have to be about 36" high and there's no way I can get up there without help. It's the Berlin Wall! If the table could be lowered to 16" or 18" from the floor and raised again, I and lots of others would be in luck. Now, I can use the nurses' help. It will take two people to lift me onto the table from the chair. It will be important for the individuals assisting me to ask how this should be done, so we don't all end up on the floor. If I am to change into an examining gown, I would do this before getting onto the table, it would be safer.

All I, or any other person with a disability want from the providers of health care is the same treatment as the able bodied person receives. Yes, we will need accessibility and some assistance, so it is important for the office staff to be fully knowledgeable about access to and within the office and aware of the needs and feelings of disabled people.”

I have made several copies of the original article and leave a copy in every doctor's office and clinic that I have visited because most health professional offices do not have a place for us in wheelchairs. Must we always have to stick out at the end of a row of chairs?

Fayth Kail says:

“Let's change these things –
You and Me – for Us.”

Wisconsin on Ice

By Kathleen Blair

Today, January 7, 2014, I snuggle with a heated rice bag to keep myself warm. Most of the schools in the Midwest have been closed and all events cancelled for two days. We are in a deep freeze.



With the iPad on my lap, I periodically check www.weather.com to see how far below zero it is in Central Wisconsin, Minnesota, Chicago and Philadelphia where many family members live. Then I connect with some of my loved ones on Face Time and my heart is warmed just to see their faces as I talk with them.

I think of Don (finally home after a tragic car accident and his heroic struggle to recover) and Gail (a polio survivor and Don's faithful wife) awaiting delivery of a much-needed motorized wheelchair and new (ramp-equipped) van that have been delayed because of factory shutdowns in this extreme cold.

I offer a prayer for everyone suffering from the cold – those who have to work outside to serve and protect others and those who do not have adequate housing – and I tell myself I'm okay and should just be thankful. I realize that watching the news clips on TV that show the extreme weather conditions all over the country makes me feel colder than I really am. I guess there's a lesson to be learned here about thinking more positively and limiting the external negative messages to which I am exposed.

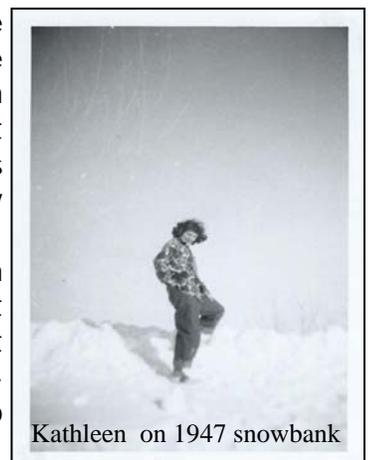
Early in December I enjoyed watching Jerry Apps on public television recount his memoirs about Wisconsin winters. He described his experiences of winters on the farm in the town of Wild Rose, Wisconsin. As I listened I relived my similar childhood experiences growing up 125 miles north of Wild Rose on a farm near Rib Lake, Wisconsin.

I recall 65+ year-old memories of brutal winter weather living in less than comfortable living conditions. In my pre-teen years living on a farm in Northern Wisconsin, I thought snow, blizzards and frigid weather were normal and sometimes exciting. Our house was heated by a wood-burning stove in the living room with a wood burning cook stove in the kitchen. Registers in the ceiling provided heat for the upstairs bedrooms. On really cold nights my mother would heat up an old-fashioned flat iron on the kitchen stove and run it over the sheets in our beds to make them warm, and we often went to bed with hot water bottles at our feet.

Of course, there was no TV, no telephone and – until the summer of 1945 when the Rural Electric Company ran electric lines to the back 40 of the farm where our house and farm buildings were located – no electricity. We listened to news and an occasional radio show on a battery-operated radio. Were those really the "good old days"?

The winter of 1946-47 was brutal. I remember windows that were so completely frosted over inside we couldn't see out. We would be snowed in for several days at a time. After a January blizzard the snow drifts were packed so hard in our quarter-mile-long driveway that, when the snowplow finally came, my dad and two other neighbors trudged ahead of the snowplow and chopped through the packed snow with shovels so the plow could get through. Snowbanks along our driveway were more than 10 feet high.

This is a photo of me on top of one of those snowbanks. I was in fifth grade and must have thought it was "cool" to take off my jacket for the picture. This photo was taken on my treasured first camera that I bought for a whopping thirty-five cents and two Wheaties box tops.



Kathleen on 1947 snowbank

Appearing in this photo is my brother, Wayne, and our dog Laddie.



Kathleen's brother, Wayne
with Laddie

“Bus service” for those who lived more than two miles from school was provided by a farmer who used his own car. My little sister, Leah Mae, often sat on my lap because, by the end of the route, four or five of us would be piled into the back seat.

One wintery day when the thermometer on the outside of our barn wall showed a temperature of minus 35 degrees – that’s temp not wind chill – we had no bus service because the cars wouldn’t start. Determined not to miss school, Wayne and I walked through the oat field, our pasture, a neighbor’s woods and their hayfield, and came out at County Highway C across from the Rib River schoolhouse. Thirty-five below and we thought it was an adventure, even when we walked back home that afternoon.

Well, they weren’t really the “good old days” but we did grow up with the inner strength to survive the ups and downs of life, move on through the hard times, and enjoy remembering - - - sometimes even getting to tell the stories.

What Did You Miss on November 8?

By Marcia Holman

Connie Monroe and Nichole Stockbridge provided an audience of 13 with information about ADRC (Aging and Disability Resource Center of Dane County) programs. The 27 people on staff average 70 phone calls per day and help connect older adults and people

with disabilities with the services and assistance they need. The trained specialists provide free individualized information, assistance and referrals. Bilingual staff and interpreters are available upon request. You may also request a home visit.

The ADRC staff can provide information about: adaptive equipment, assisted living/nursing home, benefits like Social Security, Medicare and Medicaid, caregiver support, employment programs, financial aid, health and wellness, housing options, in-home personal care, meals and nutrition programs, prescription drug coverage, rental and energy assistance, respite care, support groups and transportation.

For more information about ADRC of Dane county, contact them at:

- ◆ website www.daneadrc.org
- ◆ email <adrc@countyofdane.com>
- ◆ phone: 608-240-7400
- ◆ Request a visit at:
2865 North Sherman Ave., Madison, WI.

Each county in Wisconsin has an Aging and Disability Resource Center, so if you live outside of Dane County, check your phone book or Senior Center for your local ADRC location and phone number. Services are funded by the State of Wisconsin.

Golden Rule of Post Polio Syndrome

**"If something you do
causes you fatigue,
weakness or pain,
you shouldn't be doing it!"**

Polio Survivor Cards

Marilyn Klotzbach has provided the following information for post polio support groups in Wisconsin or other states who wish to obtain the free yellow "Post Polio Survivor (PPS)" cards to distribute to their members.

Groups may request cards by going online to <NJ.gov/health/feedback.shtml>.

More information about anesthesia concerns and Post-Polio Sequelae can be found at <PostPolioInfo.com>.

See more at:

<www.northjersey.comcommunityannouncements/83518047_N_J_State_Health_Department_distributes_polio_warning_cards_Bergen_County_.html#sthash.Qa5Mobil.dpuf>

Cards will be available at the March meeting. For those who cannot come to a meeting, send a stamped, self-addressed envelope to Marcia Holman, 3629 Alpine Rd., Madison, WI 53704.



I am a Polio Survivor with Post-Polio Sequelae (PPS) unexpected midlife symptoms:

- Overwhelming Fatigue
- Muscle Weakness
- Muscle and Joint Pain
- Sleep Disorders and Cold Intolerance
- Difficulty Swallowing and Breathing
- Heightened Sensitivity to Anesthesia

(over)

ANESTHESIA WARNING!
I am a Polio Survivor...

- EASILY SEDATED, difficult to wake;
- Difficulty BREATHING and SWALLOWING with anesthesia;
- HYPERSENSITIVE to PAIN and COLD. Need heated blanket and increased pain medication post-op.

For more information, visit:
www.nj.gov/health/cd/postpolio/index.shtml

C1510

Many Thanks To:

Everyone who contributed to the large mug I received at the November luncheon meeting.



The mug was most appropriate for Thanksgiving and the electronic, color changing angel statue, which was delivered just before Thanksgiving, added to our Christmas decor.



All the contributors to the *Pacer*, Kathleen Blair for her columns, Gail Kempfer, Kathleen B. and Fayth and Bob Kail who helped fold and put address labels on the 200+ *Post Polio Pacers* that are bulk mailed each quarter.

Our planning committee, Gail Kempfer for keeping us organized, and the faithful attendees who keep this group going—you know who you are.

Easter Seals for printing and postage for the *Post Polio Pacer* and covering meal expense for our speakers. Without the support of Easter Seals, we would not exist!

This group is a labor of love for all involved.

Marcia Holman

HELP!

Your editor needs help in finding relevant and current information pertaining to post polio syndrome, so I am asking for those who like to do research to send me such articles complete with source, title and date. *Since the next edition of the Pacer will be in April, submissions are needed by March 15.*

If you are not a researcher, how about sharing "your polio story" with the readers of *Post Polio Pacer*. Each story is unique, yet shares some aspects with other survivors.

Perhaps writing answers to these questions will help you get started:

I contracted polio in (month and year) at age____. Did you have bulbar polio? How did it affect you?

Where were you hospitalized (name of hospital, city, state) and for how long? What are your recollections about this time period?

Did either of your parents, siblings, friends or neighbors contract polio at the same time?

At the beginning of your rehabilitation, what kinds of assistive devices did you use? What devices did you use on discharge? What devices do you use now?

If you had any surgeries, what kind did you have? What types of therapy?

How did being a polio survivor affect your schooling (grade, high school, college) and work? Was the school accommodating to any new needs you had as a result of having polio or did you not return to your home school? If you were able to be employed, was your employer helpful in making needed changes for you? What types of work are you doing now or retired from?

If you have had symptoms of post polio syndrome, describe them and how they affect your daily life.

What unique methods of accomplishing every day tasks have you developed?

How does your family, children and/or friends/neighbors assist you? Do you employ people to assist? If so, what advice do you have for others who might need it? How has polio affected your family's life?

What are some positive things that have happened to you as a result of polio (i.e., the opportunity to meet stars)? What are some negatives or challenges (i.e., could no longer play football)?

Share some funny moments such as, "I knocked over a ready-made piecrust display when the wheelchair caught the display while rounding a corner."

We're not looking for an autobiography. Consider sharing a "short story" about a specific time span after you contracted polio, not only with the readers of *Post Polio Pacer*, but make copies for your family members to help them understand what you went through and accomplished as a polio survivor.

Information in addition to that from the questions above is encouraged. E-mail submissions are easiest for the editor to "cut and paste" into the *Pacer*, but hand written stories are also welcome.

Email your story or research to:

<wghmch@chorus.net>

Or mail to:

Marcia Holman, Editor
Post Polio Pacer
3629 Alpine Rd.
Madison, WI 53704-2201

EXECUTIVE PLANNING COMMITTEE

Kathleen Blair 608-838-8773
Bonnie Haushalter 233-9617
Fayth Kail 249-1671
Gail Kempfer 608-846-3776
Betty Leiser 222-8897
Nedeen Strand 222-4946

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: wghmch@chorus.net
Phone: 608-249-2233

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

Madison P-P Support Group e-mail list:

Arnold, Arthur—UncleBunks@aol.com
Beckwith, Gail—dbgb1973@sbcglobal.net
Blair, Kathleen—knlblr@yahoo.com
Casper, Mary—mhcspr@ticon.net
duRocher, Carl—carld@gdinet.com
Fisk, Julie—jkfisk@hotmail.com
Gratke, Katherine—kat3gratke@att.net
Jordan, Buffy—newacademy@comcast.net
Kail, Fayth & Bob—bandffab50sltr@yahoo.com
Kempfer, Gail—WP6838@windsorparkside.com
Klotzbach, Jennifer—maywoodteach@aol.com
Klotzbach, Marilyn—marilynkcgw@yahoo.com
Leiser, Betty—bileiser@att.net
Marsolek, Betty—bmarsolek@tcc.coop
Miller, Diane—welcomhome@hnet.net
Montgomery, Robert & Joyce—jmrm@tds.net
Murphy, Dorothy—ddm4hymn@msn.com
Mylrea, Marian & Earl—mamylrea@aol.com
Newman, Leanne R.—roonie@charter.net
Onsum, Chuck—charles_wm@onsum.net
Palzkill, Marge—mppalz@yahoo.com
Paszkievicz, Mary—mpasskey@yahoo.com
Post, Theresa—tjpost@charter.net
Purdy, Elizabeth—epurdy1@verizon.net
Schaffer, Sheryl—sheryls@gioffice.com
Schubring, Kathy Sue—kathysue@gmail.com
Smith, Joy—handswow7@hotmail.com
Strand, Nedeen—tstrand@charter.net
Tomter, Linda—tomter@discover-net.net
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 wghmch@chorus.net

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: wghmch@chorus.net

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.



Happy Valentine's Day



Easter Seals Wisconsin
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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

LOCATION:

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

Saturday, March 8, 2014

Open Discussion

**If a neurologist attended our meeting,
what would you like to ask him/her ?**

Saturday, May 10, 2014

**Jerry Apps, author of "Limping
Through Life—A Farm Boy's Polio
Memoir", is our guest speaker.**

**Family and friends are welcome to hear
this well known Wisconsin author.**

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