

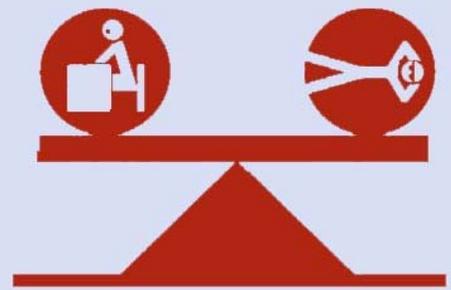
POST POLIO PACER

Conserving Strength and Energy through Pacing

October 2013—Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter

MAPPSG formed in 1985 — This Is Our 28th Year!



A View from the 89th Floor

Ray Taylor, Pinehurst, North Carolina

Now that I am halfway through my 90th year, I find myself in an enviable place. There is so much more time now. My view is so much more detached. My decisions affect so few people. I know how fortunate I am.

Obviously, I can see so much further into the past than I can into the future. And now that I have the time to do so, I can look back upon the results of my encounter with the poliovirus and ponder its effect on my body, my mind, my view of life.

The incident with the virus occurred in early 1925 when I was nine months old. I know this because my mother told me. The initial diagnosis was "intestinal flu." The misdiagnosis made no difference as there would have been nothing to do except let the virus run its course. Chalk one up to good fortune for I have absolutely no memory of the acute pain that goes along with polio.

From the height of my 90th year, memories of the past seem to flow like a ribbon of colorful strands of viscose plastic with everything blending together instead of discrete sights and sounds.

However, there is one way station that does stand out very clearly. I have no recollection that I was ever treated as "being different" by family, school or community. The one exception was my treatment at the James Whitcomb Riley Children's Hospital in

Indianapolis where I had a "tendon transplant" by Dr. Casely. In my case, the tendon that runs to my big toe was divided longitudinally up to just above my ankle and anchored on one of long bones of my right foot. It straightened my foot to an almost flat position. (It continues to work after seventy-five or so years.)

During my freshman year at the University of Missouri, my class was called up for the WWII draft. The preliminary part of the physical was not too detailed, and at the end of the day, I stood in my underwear with the rest of the guys and prepared to be sworn in to the Army. I was careful to get to the back of the pack to avoid anyone noticing my atrophied left thigh. And who should show up just as the Sergeant was instructing us to "raise the right hand," but Dr. Casely and a colleague.

He swiftly conferred with the Sergeant and stamped my file 4-F, and then proceeded to show his companion what a good job he had done on my foot. At the time I was furious and ashamed.

Without question, this episode was the most traumatic event of my life. I never thought of myself as "different," and I certainly expected to do my part in the war. To be rejected and labeled 4-F was both humiliating and disorienting to the point that I never could get organized or feel like a whole person until I fell in love with my wife to be.

It took several years for me to fully appreciate what the surgeons had done, and I eventually became grateful for the people at

Riley Hospital who labored so hard to help me lead a “normal” life.

My polio experience played almost no role in the years from WWII until the late 1990s when things began to change. We were living in North Carolina where I conducted a small marketing services business, played golf, traveled and cultivated our gardens and large yard. More frequent falls and some weakness in my arms brought the use of a cane. I do not know when I became aware of post-polio syndrome, but suffice to say that I was diagnosed by Dr. Julie Silver at her clinic in Massachusetts in early 2000. By 2004, at the age of 80, I knew we had to find a place to live that would not be as demanding as our private home. We moved to our independent living facility in 2007 where my locomotion is with a wheeled walker, arm crutches for away from home, and an electric scooter for longer distances.

And so, about 89 years after the acute phase of polio a physical recap and inventory will show the following conditions:

- Left leg, the support leg – Normal foot and calf; thigh never developed; hyperextended knee
- Right leg, the nonsupport leg – Shorter by an inch; calf always somewhat smaller with noticeable atrophy during last ten years; over-developed thigh subject to cramping; foot different shape and turned under significantly; arthritic ankle joint
- Very weak diaphragm; shallow breather
- No noticeable abdominal muscles; could never do sit-ups
- Arthritic hands becoming quite weak with numbness and little feeling when I touch
- Most noticeable nuisances: toileting and showering

I have been told many times by many people that I am the most optimistic person they have ever known. It is easy for me to see the brighter side of whatever comes along.

My view is that my polio experience has equipped me to cope with life and its varied

challenges. It helped me to understand what is valuable and important and to acquire the confidence to deal with the bad and appreciate the good.

I am the founder of the Rotary Polio Survivors Fellowship. I am active in our retirement home as librarian and organizer/discussion leader for our book club, and leader of a post-polio support group.

As I approach my 90th year, I can still read and write, talk and think, and have been happily married for almost 68 years. I am optimistic that I will continue to lead a full active life.

My view, most importantly, is that I am content.

A longer version of Ray Taylor's "A View from the 89th Floor" is available on Polio Place's Life Stories section.

Source: Post-Polio Health International (www.post-polio.org)

IN MEMORIAM

Mary E. Parks, age 74, of McFarland, passed away on Tuesday, Aug. 20, 2013, at St. Mary's Hospital.

She was born on Oct. 9, 1938, in Portage, the daughter of James Mills and Annabelle Miller. Mary married Thomas Parks on May 9, 1959, in Madison.

She worked at the Department of Public Instruction as an Educational Specialist for 47 years. Mary was a wonderful mom, wife, sister, grandma, and great-grandma.

She is survived by her children, Robin Parks



of Madison, Karile (John) Johnston of McFarland, and their children, Dalton Johnston of McFarland, Nicholas Wing and his daughter Isabella Wing of Fort Lauderdale, Fla., Christopher Parks-Johnston of Waunakee, and Alexander (Megan) Johnston and their daughter Kylie Johnston of Port Charlotte, Fla.; and sister-in-law, Marilyn Mills. She was preceded in death by son, Thomas Jr.; her husband, Thomas; her parents; and brother, Anthony Mills.

The information above was reprinted, with the family's permission, from the August 22, 2013 *Wisconsin State Journal*.

Our condolences to the family. She will be missed by her family, friends, the organizations she volunteered with and the Post Polio Support Group.

POIGNANT MEMORIES

By Kathleen Blair, Columnist

October 9, 2013, would have been Mary Parks' 75th birthday. The last time I saw Mary – six days before she left us – she told me she remembered that the first anniversary of my daughter's tragic car-deer accident was coming up soon because it had happened on her 74th birthday. So typical of Mary – thinking of someone else when her life had taken such a turn for the worse.



Mary was no longer able to get in and out of her wheelchair by herself and was dreading what lay ahead. I thought at the time she was dreading life in a nursing home, and I understood.

I remember her as a brave positive person – always finding the good and always full of gratitude. (Whenever I needed an attitude adjustment I drove my scooter over to see Mary, and she lifted my spirits.) She was

grateful for her husband, Tom, who through her working years sent flowers to her office every October 9th on her birthday. She was proud of her daughters, Robin and Karile, and so grateful to have them and grandchildren in her life. And she believed she had the most wonderful neighbors in the world on whom she could always depend. I agreed.

Yes, I, along with scores of others, do miss Mary Parks.

I remembered Mary on October 9th along with my daughter, Becky, as my son and I drove to Marathon, Wisconsin so that we could be standing at Becky's grave before 7 a.m., the time of the horrible accident that took her life exactly one year ago. We brought yellow roses, honored her memory with tears and prayers, and met other family members there who brought more flowers and shared our sorrow. Finally, we got to embrace Becky's daughter and grandsons. It was something we just had to do.

The following day, October 10th, two other families very likely remembered the unexpected but welcome telephone calls they received that evening one year ago telling them that a match had been found and the kidney they needed for a transplant was on its way.

In letters filled with genuine sympathy and gratitude that we have received from the recipients, one truth stands out – their joy in being alive. They express deep gratitude for every day and every occasion they are here to experience and enjoy. Although well aware there are no guarantees, they are happy for each day and each special event.

As I grieve my daughter, I take comfort in knowing that a part of her lives on and, because of her generosity and that of her husband and daughter, two other people have a second chance at life. I pray for their health and wish them well.

Becky and Mary will always be in our hearts. May they rest in peace.

What Did You Miss on September 14?

Our speaker, Ken Saville, Vice President of Program Development, Easter Seals Wisconsin, has been associated with Camp Wawbeek for many years. He shared historical and up to date information and photos of the camp.



Camp Wawbeek celebrated its 75th year on July 25, 2013. The 400 acres of the beautiful wooded property purchased in 1897 by Milwaukee attorney Horace Upham and his wife, Mary for a summer home near Wisconsin Dells was passed down to their daughters. The Upham sisters who wished for Wawbeek to live on as a tribute to their parent's service to others, offered the property to Easter Seals in 1938. 91 children with disabilities were the first to enjoy the "Camp Wawbeek experience."

Camp Wawbeek is the oldest continuously operating Easter Seals camp in the nation. It provides age appropriate activities and programs for campers age 7 to 97 with physical disabilities or mild to moderate cognitive disabilities. From arts and crafts, swimming, overnight camping, weekly dances to time to relax, make new friends and reminisce with old ones—it's a time to challenge themselves to new experiences.

The Wisconsin Elks/Easter Seals Respite Camp operates year around, providing overnight, individual respite care for campers as young as 3 with severe and multiple disabilities. There is no upper age limit. This camp allows parents & caregiver an opportunity to rejuvenate while the camper is well cared for.

Other specialty programs include a Day Camp for Wisconsin Dells/Baraboo area kids with & without disabilities, veterans' weekends with their families at no charge, Transition Team weekend sessions during the school year for mid-teens to 22+ to learn how to care for themselves independently, shop, cook a meal, handle money, & how to work together with their peers—all while having fun.

Twenty four hour nursing care is provided at each camp. By advertising throughout the Midwest, at camp fairs, & online for staff 18+ years of age, 125 staff members—counselors, caregivers, cooks, groundskeepers, office & support staff are hired. A large number of trained volunteers & AmeriCorps members assist staff at both Camp Wawbeek & Respite Camp.

Many thanks to Ken Saville for sharing part of his Saturday afternoon with us. Visit <http://Camp.EasterSealsWisconsin.com> for more information about Camp Wawbeek and when donating to Easter Seals make your donation specifically to "Camp Wawbeek".

Of the 17 people in the audience, 4 or 5 who had attended the Camp in their youth, responded with similar comments to the photos—"I remember the Castle; what fun we had in the swimming pool and at the campfires."



Changing Times

The needs of campers have always dictated the services Easter Seals Wisconsin provides at Camp Wawbeek. Today's campers have more severe and a wider range of disabilities; more are in need of personal care than 30 years ago. These changing needs necessitate additional staff, more in-depth staff training and changes in the camp's facilities.

Thirty years ago fewer campers had wheelchairs, and most chairs were a standard size, so accommodations for one worked for almost everyone. Not so today. Many campers have wheelchairs now—but customization alters the sizes significantly, which in turn requires more space and more customized modifications to keep camp accessible to all campers.

Adults who have been coming to camp for 30 or 40 years (or more!) truly feel at home there. That feeling is a combination of their long history with camp, having grown up in a time when there were few, if any, opportunities for them to participate in recreational activities, and living in communities where people were not as accepting and facilities were less accessible than they are today.

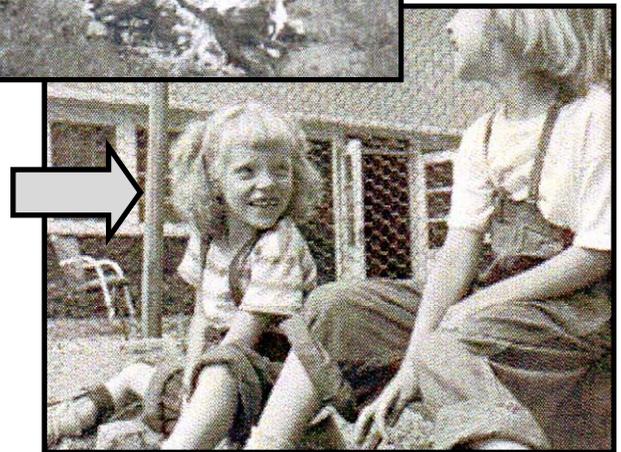
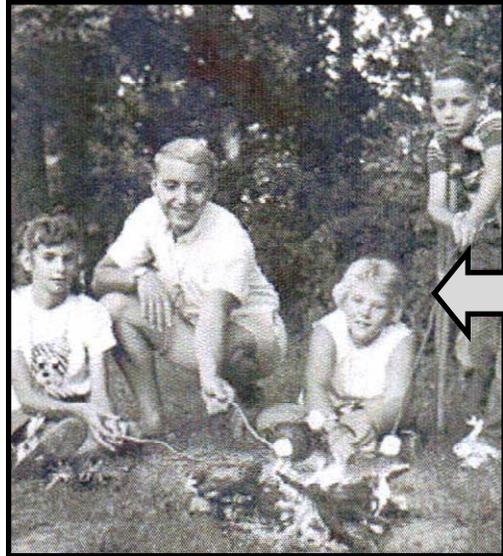
Many were (or still are) employed in their communities and used vacation time to come to camp. When they're at camp, they can relax, forget their worries and just have a good time with peers who share a common bond.

Young campers today look forward to shared experiences with other campers, too. They may have grown up with much more accessibility in their daily lives than previous generations and more options to participate in recreational activities, but they still find a unique bond at Camp Wawbeek. And for many, integrated into their public schools, Wawbeek provides their only opportunity to interact with peers with disabilities. Teens are especially eager to exchange ideas and experiences about typical teen issues. Friendships form and many are maintained year-round via phone and email. Some last a lifetime.

Reprinted with permission from Easter Seals Wisconsin.

Famous faces?

Two former campers at Camp Wawbeek were surprised to see photos of themselves in the Camp Wawbeek 75 anniversary program. Can you recognize and match the Wawbeek photo with photos taken at the October meeting?



Sheryl Shaffer



Nedeen Strand

**The Holidays Are Coming!
The Holidays Are Coming!**

And since there is no way to stop them, avoid stress and fatigue.

1. Rest before shopping.
2. Shop with a list—keep shopping time to a minimum. Shop on-line or mail order.
3. Wrap and label as you buy & sit to wrap if possible. If standing to wrap use a high table or the top of the washer & dryer.
4. Rest before going out to parties & have something to eat before leaving.
5. Enjoy small quantities of holiday treats.
6. When hosting a meal, prepare what you can in advance, ask each guest to bring a dish to pass or order a prepared meal from a grocery store.

Consider conservation of your energy as a gift to yourself.

F.Y.I.

Accessible Clothing

If shopping on-line for accessible clothing has been less than satisfactory, Accessible Wear at 11045 W. National Ave., West Allis, WI is stocked with clothing designed specifically for people who are physically challenged. They even have a seamstress, so easy alterations like hemming pants and taking in sleeves can be made right away.

Golden Rule of Post Polio Syndrome

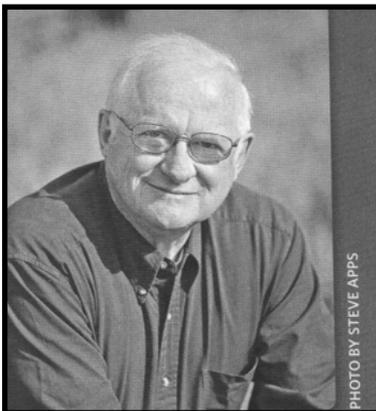
"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"

2014 MEETINGS

January—NO MEETING

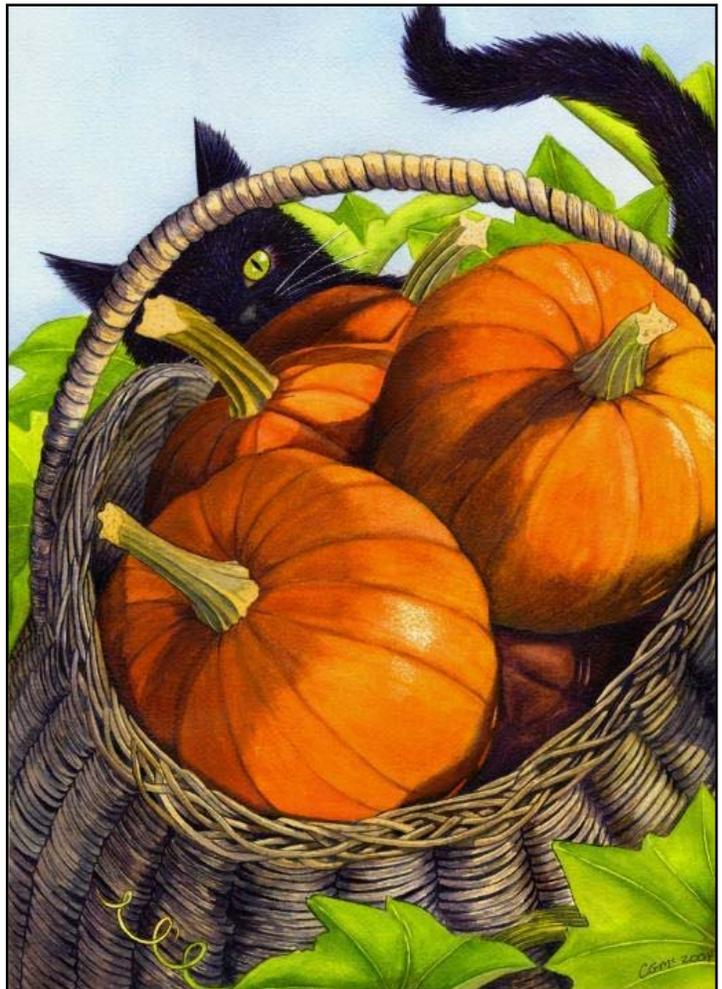
March 8—Open Discussion

May 10—Jerry Apps, a rural historian and environmental author for more than 40 years is the author of his most personal book, *"Limping Through Life—A Farm Boy's Polio Memoir"*. The book is a fascinating read.



He will share some of his experiences.

Put May 10, 2014 on your calendar and bring your friends.



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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.

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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 update your e-mail address to this list, notify Marcia Holman at: wghmch@chorus.net

Happy Holidays
 Everyone!

From
 Kathleen Blair
 And
 Marcia Holman

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.

Time flies when you are having fun—especially if you pace your activities!





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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

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November 9, 2013

**Connie Monroe & Nicole Stockbridge
will give us insight on the ADRC
(Aging & Disability Resource Center of
Dane County) program**

No meeting in January

