

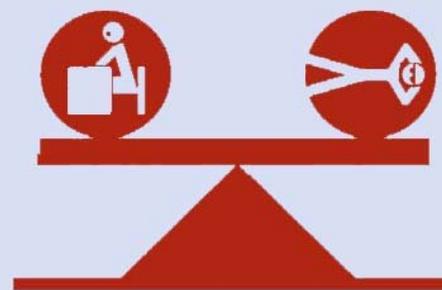
# POST POLIO PACER

*Conserving Strength and Energy through Pacing*

*July 2014 — Madison, Wisconsin*

*Madison Area Post Polio Support Group Newsletter*

*MAPPSG formed in 1985 — This Is Our 29th Year!*



## What I Have Learned

### Jean Fox Csaposs

In the 1970s, I was an avid follower of the TV series, "The Waltons." I felt close to John Boy and his West Virginia family. When Olivia, the mother, was struck down by polio and totally paralyzed, I followed her recovery with intense personal interest, as a polio survivor myself. How would they deal with her character after this disaster? When she soon emerged whole from her state of total paralysis, I was flummoxed. "That couldn't happen!" I declared indignantly to myself and anyone close enough to listen. A script-writer's fantasy, I decided, and was so disgusted, I rarely watched the show again. Was I ever wrong!

It has only been through my involvement over the past 19 years in the work of the Polio Network of New Jersey that I have learned how little I really knew about polio, at both the onset stage and later, as I began to witness the immense variations in post-polio syndrome. I learned first of all that untold numbers of people, like TV's Olivia Walton, who were totally or partially paralyzed at first, were later restored in what appeared to be a miraculous recovery – only to be affected, later in life, with post-polio syndrome.

Our Network "hotline" rings in my home. In recent years, I have seen a decided increase in the number of calls from individuals who are not only frustrated and bewildered by their new symptoms, but truly frightened by what is happening to them. Those who

apparently "did well" in life with few external effects, or perhaps one weak leg, now find they are in daily pain and often too weak to perform even ordinary household tasks. Wearable shoes have become a problem for many, and braces – discarded years ago – often re-emerge as necessary props. A recent caller was alarmed that swallowing has become so difficult for her that she has been forced to adopt a liquid diet. Fortunately, a doctor who is both experienced with PPS and "holistically" oriented (a rarity) has helped her, and she has now joined our Bergen County support group. She ended a recent note of appreciation with, "Now I feel I am not alone." I have learned that these polio survivors – whose histories are so unlike mine – are the ones most in need of our help and understanding.

Like many whose polio struck in infancy, I have no memory of its onset. In 1931, casts and bracing were the prescribed treatment. (In 2005, I donated to the Smithsonian the braces that came home with me from the hospital in New York City at seven months of age.) I pre-date the portable wheelchair and the Sister Kenny hot packs. What excitement in our house when an ad for the new Everest and Jennings aluminum folding wheelchair appeared in the NY Times. My mother immediately drove to the city and bought one—and I was free at last!! Free to wheel all over the neighborhood and call on my friends. But, I never walked without braces and crutches, and had a weak left arm and a spinal curvature. I had lots of corrective surgery, too.

As a child, I knew only one other girl in my town, Maywood, New Jersey, who had polio, a

pretty blonde who walked with a slight limp, wore her hair in a pageboy, and had lots of boyfriends. Lucky Beryl! Later, a young woman who was struck in the epic polio year of 1949 joined my college class; her involvement, like mine, was severe: both legs and some upper-body weakness—no miraculous recovery for Ellen, either. She and the late Alan Ruprecht, the founder of Drive-Master, who taught me to drive with hand controls and "put me on the road" in 1955, were my only acquaintances who'd had polio until I joined our Network.

In 1978, while living and working in Washington, DC, I saw an Amigo electric scooter for the first time. I knew right away it was meant for me. As soon as I could put together the \$900 price, I bought one. It has changed my life. Since abandoning my increasingly uncomfortable braces and crutches about 15 years ago, I have relied totally on my Amigo. Its versatility gives me the flexibility I need for all my ADLs: cooking, transferring to toilet and shower bench, hopping in and out of bed, and traveling in my van. But nowadays, I leave the driving to my capable and caring husband, Jim. Life is good.

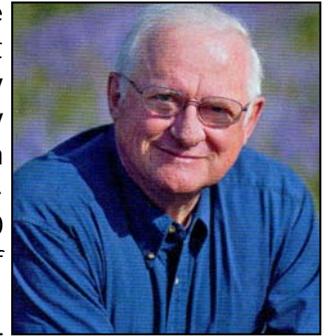
*Jean Csaposs is currently president of the Polio Network of New Jersey. The very active group organizes annual conferences--the 2014 meeting was held on Sunday, April 27th, 2014 at the Bridgewater Marriott in New Jersey. Speakers included Dr. Judith Glaser, DO, a specialist in physical medicine and rehabilitation, New Hyde Park, NY, and luncheon speaker, Dr. Peter L. Salk, son of Dr. Jonas Salk. See [www.pnnj.org](http://www.pnnj.org) for details. Questions? E-mail to [conference2014@pnnj.org](mailto:conference2014@pnnj.org).*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

Editor's note: This website has a wealth of post-polio information. See [www.pnnj.org](http://www.pnnj.org)

## The May 10<sup>th</sup> Meeting was a Great Success.

Forty people packed the banquet room at Monona Garden Family Restaurant to hear Jerry Apps, a rural historian and environmental author for more than 40 years, and the author of his most personal book, "Limping Through Life—A Farm Boy's Polio Memoir", share how polio influenced his life.



Among the stories he told was about learning to lead his 4-H bull calf, Stormy. After many days of being dragged behind the calf when the calf bolted, he told his father that the calf would never learn to lead. His father took the halter rope and said to Stormy, "Let's go". Stormy walked across the barnyard and back, doing everything he was asked to do—stop, start, go slow, go faster, turn around—amazing Jerry as he watched. His father said, "You gotta let him know who's boss." By the end of the summer, Jerry and Stormy worked well together and won a blue ribbon at the 4-H Fair. An important lesson was learned—no matter what might get in the way, hard work, patience and perseverance can make a difference, even when the challenge seems impossible to overcome.

Jerry App's talk was filled with humor, as were the questions and comments from the attendees, many who also had farm backgrounds. It was a delightful meeting with the largest group ever!



(Jefferson Meats) in Jefferson. He was a long-time member of the Jefferson Kiwanis Club and also was active with Duck's Unlimited.

Robert retired in 1988 and moved with Joyce to Lander, Wyo., where they spent a number of years as "vigorous retirees." He remained active in the Kiwanis, serving as Lieutenant Governor of the Wyoming District. Robert and Joyce returned to Wisconsin in 2001 to be closer to their family, living in Middleton and Sun Prairie. In brief remarks Robert wrote in honor of their 60th Wedding Anniversary, he told Joyce "You have provided a fantastic and interesting life for me."

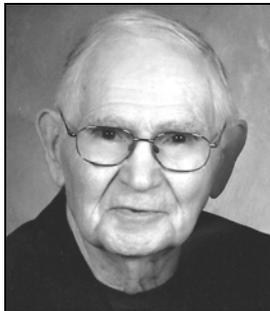
Survivors include his wife, Joyce; daughters, Pamela Montgomery Jones, Denise Montgomery Tully, Susan Montgomery Dlouhy, and Elizabeth Montgomery English; grandchildren and great-grandchildren.

The excerpts from the Wisconsin State Journal obituary are reprinted with the permission of his wife, Joyce Montgomery.

## In Memoriam

**Sun Prairie—Robert E. "Tony" Montgomery**, 87-years-old, died peacefully on April 26, 2014, surrounded by his loving family.

Robert took great pride in his multi-generational family. He and his wife of 66 years, Joyce (Streiff) Montgomery, had five daughters, nine grandchildren and 13 great-grandchildren.



Robert was born in Columbia, Ind., on Feb. 18, 1927, to Charles E. Montgomery and Catherine C. (O'Hearn) Montgomery. He moved with his parents and siblings to Jefferson, Wis., where he graduated from high school in 1944. At age 17, he enlisted in the Navy and served for two years during World War II. He often shared stories of his service in New Guinea and other Asia-Pacific locations. He spent his entire career, primarily in sales and in management, working for Stoppenbach's

**Madison—Kathleen Gratke** passed away on May 7, 2014 at age 71 after being hospitalized for pneumonia and the ravages of post polio syndrome.

Our condolences to the family and friends of Robert (Tony) Montgomery and Kathleen Gratke.

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## My Polio Story

**By Don Schiefelbein, Hillsboro, WI**

I contracted polio in the fall of 1936 when I was about 2 ½ years old. (At that time it was called Infantile Paralysis). I don't know if a doctor diagnosed it as such or not, but they did put a splint on my right arm and my mother massaged the arm. The weakness seemed to be only in my right arm and shoulder which did not develop as well as my left side. When I went for my draft physical, the doctors said my right leg and hip were also

affected. This put me as “4F”.

I got through my working years without too much trouble except I had to use my left hand and arm to raise my right arm to reach above my head.

My wife and I owned and operated a floral shop and greenhouses for 28 years. I was appointed as postmaster in our town at age 40 and didn't have much trouble with anything until age 60. Fatigue and weakness in my limbs contributed to my retirement then.

I was 80 in April and have trouble standing or walking for any amount of time. I use a wheelchair or scooter to go any distance. I also think I have some weakness in my lungs as I do not have a strong voice anymore.

## Celebrating 60 Years

*By Kathleen Blair*

June 2014 has been a special time for this aging polio survivor. In May I received two invitations to Rib Lake High School class reunions – the Class of 1953 (my late husband's) & my Class of 1954. The 1953 class was celebrating 61 years on Saturday, June 14<sup>th</sup> and my class was reuniting the following Saturday, June 21<sup>st</sup>, recalling 60 years. When I received the invitations my first response was, “Oh no, not two Saturdays in a row!” But I couldn't resist going to both of them and I'm so glad I did. It was double fun and worth each three hour drive to get there from Madison.



Thirteen members gathered at each reunion out of graduating classes of only 36 and 32. Several members of each class had passed on, but a 40% turnout after 60 years is a bit remarkable.

Of course, we shared old memories and wondered where the years had gone. And a few

of us wondered how we had lost touch with so many of our classmates. That answer is easy: college, jobs, children, bills and budgets, sleepless nights, illness, moving to a new town, aging parents, death in the family, and the list goes on. Our lives were normal – the continuous cycle of ups and downs.

One of my best friends from high school had suffered a serious heart problem two years ago, and I had only become aware of it while making plans to attend the reunion. This is not surprising since it happened in October 2012, the month my daughter was killed in a tragic car-deer accident. I'm grateful to have had this opportunity to reconnect with her now, and get her current address, telephone number and email address. Now I WILL keep in touch and I thank God for this second chance.

Another polio survivor was at the reunion, the husband of another good friend in my class. He had been completely paralyzed in 1944 and had spent several months at the Sister Kenny Institute. Three weeks before the doctors anticipated his need for an iron lung, he started to recover. Today he is strong and healthy and thanks God every day for his good fortune. It was good to see another polio survivor who does not have to deal with post-polio syndrome. And this makes me think about the many little unnoticed miracles we receive every day – sunshine, joyful moments, breathtaking sunsets, and blossoming summer gardens just to name a few.

What did we have to visit about after 60 years? The joy of retirement: some of the couples had traveled to interesting places abroad and throughout North America. We shared stories about our families, but most of all we were just happy to be together again.

We have all enjoyed special friends along the way – co-workers, friends from church and kindred spirits we have met through the years. But what a blessing to renew friendships with old classmates on a delightful Saturday evening in June in the small town of Rib Lake, Wisconsin.

## My Polio Story

By Helen Dresen,  
Cross Plains, WI

The article in the April 2014 Pacer of memories of long past winters with blizzards and frigid weather in northern Wisconsin of and living on a farm reminded me of the story of my life. My mother and dad were farmers and I was the sixth child in a family of seven children.

I became sick and couldn't walk when I was 3 years old. My parents took me to our family doctor in Cross Plains, Wisconsin. After checking me he told my parents that he couldn't help me and I was going to die shortly. So they went home heavy hearted.

One Sunday afternoon friends of my parents stopped by for a visit and the woman looked at me and said my parents should take me to a different doctor as she thought I might have infantile paralysis, which in fact I did. I credit her for my survival-I was 93 this May.

I do not remember those early years and nobody ever talked about it. I do have the brace I wore from age 3-11, but I never remember thinking of myself as a "cripple." However, at my 80th birthday party guests were invited to write a note to me of a memory or story. My older sister shared a very interesting story. One day she was asked to watch me so I wouldn't get in the way of the many men who were helping with the grain harvesting and threshing. Threshing was very hard work and in those days a large meal was prepared at noon for everyone who helped, and served in the house at the big kitchen table. I could only crawl at the time, so my mother did not want me to crawl into the kitchen while eve-



Marcia Holman, Pacer editor and Helen Dresen in her garden on a recent visit to her home.

ryone was eating and get in the way, or get stepped on. My sister and I were in an adjoining room and she was reading a book and looked up just in time to see me approaching the door to the kitchen which was only open a crack. I started to pull the door open and she said she grabbed me and said "get in here you little cripple you!" After the men returned to their work my mother said to my

sister "don't let me ever hear you call her a cripple again!" So, no one used that word again in the house and I had no idea until she shared this story with me that I was "crippled." So I was 80 and she was 86 when I first heard this story!

Because I couldn't walk the several miles to the country school my parents decided to rent the farm and move into Cross Plains to the house where my dad was raised, which was right across the street from school. They took me to a chiropractor, massaged my leg often, and fed me a lot of cod liver oil. They made a lot of sacrifices for me.

I wore the brace on my affected leg for about 8 years, and that leg is shorter and weaker than the non-affected leg. I tired easily all my life, and when I was wearing the brace as a child I would often fall- especially if I was trying to run, once breaking my arm and another time my finger. However, polio didn't prevent me from dancing and playing baseball, gardening and working hard all my life. As an adult I had to rest often, had problems sleeping, felt cold, and my back hurt because I couldn't walk without a limp. Whenever a new doctor came to Cross Plains I would go to see them for help, but they only wanted to prescribe pain killers. When a chiropractor moved into town I went to see him and finally

I was able to get some relief. I had a lift put on the heel of the shoe for the shorter leg. I still see a chiropractor regularly.

I have been diligent all my life in not gaining weight, eating healthy food, and doing exercises for an hour every other day. I love to work in my flower beds, but the last few years I have had to do that on my knees, crawling around as it is too hard to bend over and keep my balance.

Life has had its ups and downs, but I'm still here, and able to live independently, taking care of myself, enjoying my gardens and playing in several card clubs. My affected leg once again needs a brace to keep me stable - I have fallen a few times when I didn't have it on. I think I have experienced the effects of polio most of my life, but especially now in later life. I lived like Jerry Apps — tried to keep up as best I could. I thank God every night that I can still keep active and have a beautiful home to live in.



**Mary Roesler** from Holmen, WI shares this:

"It is hard to believe it will be 60 years since I had bulbar and spinal polio. I was 14 years old and it still is hard to know that people don't quite understand what polio was..."



Many thanks to all the people who took time to write their "polio story" and send it for inclusion in the Pacer. Each story is important, not only to the writer, but also to let the younger members of each family know how polio affected them and their family.

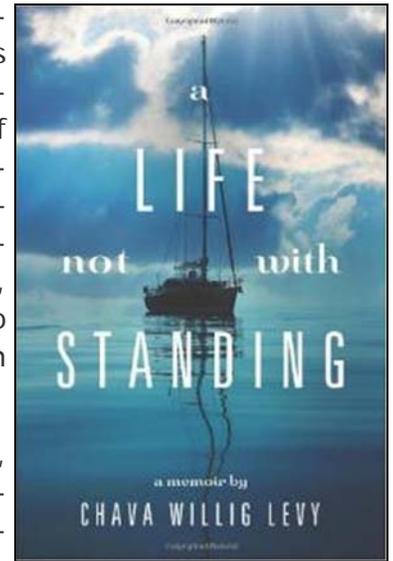
Space will always be available for *your "polio story"*—whether it is short or long, emailed, typed or hand written and sent by regular mail or handed to me at PP Support Group luncheon meeting.

*Marcia Holman, Editor*

## Book Review

*A Life Not with Standing* by Chava Willig Levy chronicles the adventures—by turns exhilarating, agonizing and amorous—of an iron lung alumna. It shatters stereotypes about people with disabilities, enabling others to view disability with pride, not prejudice.

It celebrates family, faith, music, tenacity, idealism and indignation.



But most of all, it tells a story beyond Chava Willig Levy's polio chronicle: how calamities can befall innocent people and how those calamities can evolve into and, in fact, become ingredients of and prerequisites for ensuing joy.

The print book is available at:  
<http://tinyurl.com/k6qxwo8>.

The e-book version is available at:  
<http://tinyurl.com/mos5gqr>.

**Editor's note:** The reviews of this book on Amazon.com rave about the author's writing skill and are worth reading if you are at all curious about this book. It's on my Christmas wish list.

### Golden Rule of Post Polio Syndrome

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

**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  
 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—welcomehome@hnet.net  
**Montgomery, Joyce—jmrm14@yahoo.com**  
 Murphy, Dorothy—ddm4hymn@msn.com  
 Mylrea, Marian & Earl—mamyrea@aol.com  
 Newman, Leanne R.—roonie@charter.net  
 Onsum, Chuck—chaswm@onsum.net  
 Palzkill, Marge—mppalz@yahoo.com  
 Paszkiewicz, 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—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  
**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



**Picture a field of daisies or a handful in a vase on your table.**

**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**  
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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, July 12, 2014**

**Alan Kolvin, Constituent Service Director for Governor's Office, will be our guest speaker.**

**Saturday, Sept. 13, 2014**

**Gene Salsbury, Manager of Home Health United Rehab Dept., will talk about wheelchairs, scooters and other rehab equipment & may bring some equipment to demonstrate.**

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608 -277-8031 tty  
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