

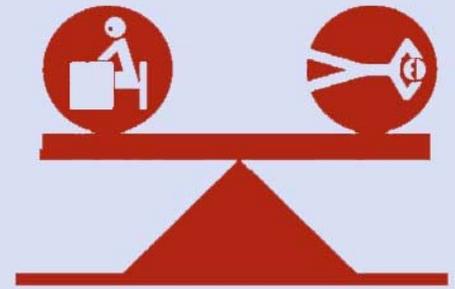
POST POLIO PACER

Conserving Strength and Energy through Pacing

January 2015 — Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter

MAPPSG formed in 1985 — This Is Our 30th Year!



Let the Light In

By Kathleen Blair

Most, if not all of us, probably remember Bing Crosby and the Andrews Sisters singing “You’ve got to accentuate the positive, eliminate the negative, latch on to the affirmative . . .” during the 1940s. That song has been ringing in my head the last couple of days – maybe because I need to pay closer attention to it.



At this time of year – with the cold, snow and ice; my reduced freedom to get out of the house; the lack of daylight with such short days and long dark nights – I find that I tend to accentuate the negative. It’s not that I have seasonal mood disorder, I just feel better inside when the sun is shining.

To paraphrase Emily Dickinson’s poem, “There’s a certain slant of light,” the lack of light in winter is like a weight that touches us internally where meaning can be found. It depresses us. I, for one, am affected.

I knew I was grumbling and complaining too much when my granddaughter, Britney, told me, “Grandma, there are always bumps in the road.” At the tender age of 13 she was telling me that life is good even if bad things happen.

Her teen-age wisdom made me realize I needed to find the light, eliminate the negative, and accentuate the positive. I needed to

make the decision to change my way of thinking. But how was I to do this?

Almost two thousand years ago St. Paul gave the answer, “Whatever is true, whatever is honorable, whatever is just, whatever is gracious...think about these things.” (Philippians 4:8) In other words, I needed to dwell on good things, happy things, everything in my life for which I am grateful – my family, friends, good neighbors, faith, hobbies and the blessings I receive every day. I should be latching onto the affirmative, not all the bumps in the road. By doing this an internal light will brighten these dark, dreary winter days.

I have no problem finding the light during the evenings that I can get to my grandson’s basketball games. After a short, cloudy day and sudden darkness, just getting into the gym – where we have to stop in the entrance and wipe the snow off the tires of my wheelchair – happiness washes over me. The bright lights in the gym, sounds and sights of enthusiastic athletes, happy fans and parents, friends and acquaintances, make my heart sing. It helps me “Latch on to the affirmative . . .”

The words of that song continue to resonate with me. I went online and looked up the rest of the lyrics. The second verse struck a chord:

“You’ve got to spread joy up to the maximum.
Bring gloom down to the minimum
Have faith or pandemonium
Liable to walk upon the scene.”

Spreading joy...this is the second key to finding that internal light and beating the winter

doldrums. When I can bring a little sunshine into another person's day, we both bask in the light. Making a phone call to someone who is home-bound, writing a letter to an old friend or distant relative, and spreading smiles wherever we go are simple ways to make someone's day brighter.

May I now spread some joy by sharing with you delightful moments I've experienced recently from two other granddaughters?

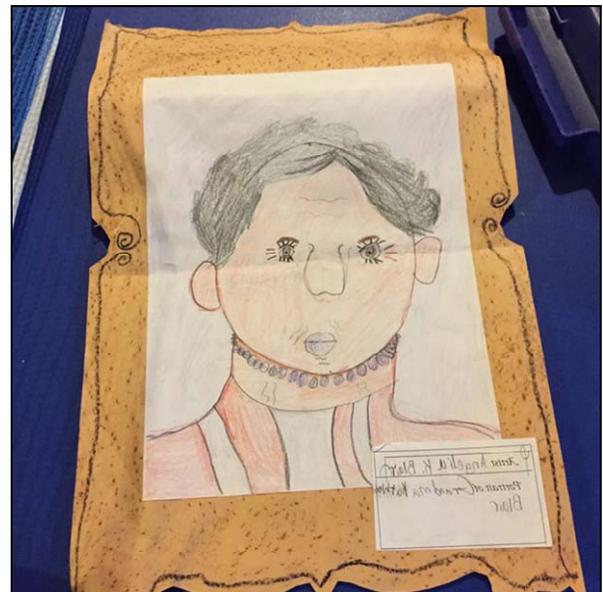
Kame graduated from UW on December 21st. Soon after Christmas she traveled to the other side of the world to spend thirty days with the Reach Out Volunteers Program teaching English to children in Cambodia. Knowing I was nervous about her leaving – after all I'm a grandmother and the news on that side of the world hasn't been all that comforting – she emails me regularly to reassure me she's safe, and loves the adventure.

There's also a website with photos and posts from the volunteers that I follow daily, <<http://rovolunteers.com/Cambodia-village-immersion-blog>>, and she has created her own website that I enjoy even more, <kameblair.weebly.com>.



Kame & her new friend riding a tuk tuk in Cambodia

Angelia, home on Christmas break from Winona State, sent an email telling me she was going through old school yearbooks and found an art project she did in third grade. That would be 10 years ago. Attached to her email was her drawing of me with wrinkles and all. I have to share it with you. No, she



is not an art major, but I love the drawing.

Moments like these bring comfort and happiness into my life; they are priceless.

Throughout 2015 I plan to take St. Paul's advice, keep my thoughts on the affirmative and spread the joy. I will let the light in. After all, faith, joy, peace, hope, happiness, love and laughter keep us healthier in both mind and body in these later years.

To all our Post-Polio Pacer readers – May you have a joyful, peaceful and Happy New Year with plenty of light.

If you want to listen to Bing and the Andrews Sisters sing "Latch on to the Positive" copy this URL, exactly as it is, into your browser: <<https://www.youtube.com/watch?v=9-8phUuifjo>>

In Memoriam

Helen Dresen, who wrote her "polio story" which was published in the July 2014 issue of the Pacer, passed away on January 3, 2015 due to heart complications. This lovely lady will be missed by her friends and family who have had her in their lives for 93 years. Our condolences to the family.



Part 2 of Mary Herness' "polio story".

Part 1 is in the October 2014 Pacer.

RED LIGHTS AND SCREAMING SIRENS

The next day I was moved into a larger room in the isolation wing. My bed was situated in between two iron lungs. Those hulking, huge machines made a sighing, hissing, working sound that never quit. An oxygen tube was inserted up my nose and taped down. It hurt! I hurt! I was thirsty and confused. I hated that room! And where was my Dad? I have no idea how many days later he was finally allowed to come in to see me. Time was all blurred! He looked very strange dressed in a long white hospital robe with a mask covering his mouth and a white cap covering his familiar bald head. He told me that he had a hotel room nearby, and that he had eaten breakfast at a restaurant. He was going to ride the bus home later that day. I cried when he left after his brief five-minute visit. Now I was really all alone listening to the foreboding humdrum sounds coming from the laboring iron lungs.

Delirious and depressed, I repeatedly yanked out the oxygen tube. Why couldn't they just let me breathe? Each time they scolded and unceremoniously shoved the tubes back into my nose. I begged for a drink of water. One kind nurse would come with a wet washcloth and touch my parched lips. She also wiped off my face. It was the only comforting thing I can recall. She sat beside my bed talking with me about where I lived, what grade I was in at school and things I liked to do. She was an angel, and an exception to the way

the majority of the nursing staff treated me.

Nights were the worst! When I called out for a wet cloth, the crabby mean nurse whom I dreaded would come. She looked tough and stern, never smiling. The wet washcloth was thrown at me, stinging my face as it came flying over the bed railings. "There," she scolded, "Now be quiet." She must have hated teenagers who had polio as well as her nursing job.

The lady lying in the iron lung on my left turned her head toward me. She told me to never mind. She confided that this crabby nurse treated everyone badly. Later I learned that kind lady in the iron lung was from New Mexico and was expecting a baby. I would turn my head to watch as the nurses brushed her teeth, combed her hair, fed and bathed her through open hole-like vents on the sides of the iron lung. She was unhappy, too. I could not see the person in the other iron lung. Thankfully, I never did have to be placed in an iron lung. The oxygen tubes helped me survive those first critical days until my lungs were able to function at nearly full capacity.

The bulbar polio that had stricken my body weakened my throat muscles. That is why I could not swallow, even a tiny sip of water. The intravenous feeding needle in my arm kept me alive. I would watch those bottles of liquid slowly go down. Ever the optimist, I would keep reassuring myself that when this bottle gets empty, they will remove the needle. Each time I was disappointed when the empty bottle was replaced with a full one. It was my lifeline, but no one explained that.

Near the end of my stay in isolation, my parents came to visit. They were barely recognizable in the white long gowns, face masks and white caps. But their eyes were a welcome sight. It occurred to me that hospital rules and regulations are extreme and unnecessary. After all, I lived with these two people. We had shared any germs floating around. I did not consider that they may bring germs into the ward, infecting other patients. They listened to my account of the

crabby nurse who threw the wet washcloth at me, how they kept sticking that oxygen tube back in my nose and how hungry and thirsty I felt. Ma's eyes were teary-looking, and Dad had to blow his nose. A nurse came and told them their time was up. I emphatically told them to bring my clothes and shoes next time they came, because I was coming home! They did not respond.

At about that same time in the isolation ward, I was able to scoot myself up in the bed with my right arm as a lever. A glass of water on a stand nearby got my attention. By hoisting myself up and reaching through the bed railing, I managed to grab the glass. After the first tiny sip of that wonderful cool liquid, I gulped down the entire glassful, excited and pleased that I could swallow. When I informed the nurse, I expected a reprimand. But rather, she noted it on my chart and soon returned with a small dish of applesauce. That simple dish of applesauce might just as well have been an exotic serving of lobster! It was the finest cuisine in my eyes, as it slipped easily down my polio-damaged throat. That day was the turning point in my long battle toward recovery.

A few days later, I was moved from the isolation ward and the pumping, hissing sound of iron lungs to a children's ward. At age thirteen and one-half, I was the oldest person in the ward filled to capacity with eight children ranging in ages from two to my age. I felt like I did not belong, but had no other option. The one thing we all had in common was the struggle to regain use of our afflicted bodies. The sounds of crying from the youngest children were almost always present. One child had a feeding tube in his throat and cried pathetically when the rest of us received a treat of ice cream. It was a sad room.

Most of the time in the children's ward, I lay flat on my back. The bed head was raised up, so I could feed myself. Even though my left arm hung quite useless, I improvised and used my right arm for eating, drinking, brushing my teeth and also as a lever to flip over onto my stomach. Going to the bathroom be-

came an embarrassing and uncomfortable ritual on the bedpan.

Just when I thought life could not get any worse, the physical therapy crew arrived pushing carts filled with steaming hot packs! My first thought was that they were about to clean, because the pushcarts resembled the kind used to squeeze out rag mops for mopping floors. Wrong! The gray-wool cloths were wrung out, and, horror of horrors, they put them on me. They folded the hot steamy cloths around my legs, thighs, arms and on my back! The hot cloths were covered with heavy rubber-like covers and fastened in place. Did I mention the strong smell of hot wool? I could not believe they were going to leave me there, burning up. After about twenty minutes, someone returned and removed the hot packs. Now I can rest, I told myself!

Wrong again! The sternest person I had ever met arrived to give me stretching exercises. As he manipulated my painful body, I could hear him canting, "foot up-down, leg up-down, arm up-down, wrist, neck and hands up-down." At first my body was not responding to this stretching approach. Throughout the session, I was in excruciating pain, but the exercise which pushed my nose down toward my knees, with legs flat was the worst. The routine of hot packs and stretching was repeated two and three times daily. Years later, I learned this was the Sister Kenny method widely used to regain use of polio damaged muscles. The hot packs loosened up the tight, shrunken muscles, and the dreaded stretching strengthened and promoted use of them. If only someone had explained the purpose for this attack on my aching body.

In Part 3 (April 2015) Mary resumes her studies lying in a hospital bed, and is transferred to Luther Hospital in Eau Claire, and takes her first wobbly steps.

Golden Rule of Post Polio Syndrome

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

Many Thanks To:

The Post Polio Group for the much appreciated gas card, and the gift certificate to Café La Bellitalia was enjoyed. Thanks also to Fayth Kail for the lovely flowered box which held a small bell with a heart shaped handle — to ring in the new year, perhaps?



All the contributors to the *Pacer*, Kathleen Blair for her columns, Gail Kempfer, Kathleen B. and Sandy Person 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 expenses for our speakers. Without the support of Easter Seals, we would not exist! We need to support them in return, either by monetary donations or donating to &/or shopping at **Savers**.

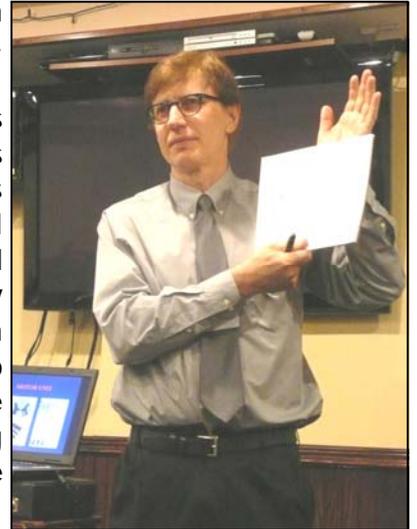
This group continues to be a labor of love for all involved.

Marcia Holman

What did you miss at the November 8 meeting?

By Marcia Holman

About 20 people gathered to hear Dr. Andrew Waclawik, Prof. of Neurology, UW School of Medicine & Public Health discuss “Evaluation of a patient with suspected post-polio syndrome”. Although he was unable to use his power point slides due to technical difficulties, he did discuss many questions which were submitted to him from the March meeting and some from the audience:



Restless leg syndrome (RLS): may be due to an iron deficiency, be genetic, or drugs such as those for Parkinson’s, e.g. Sinemet, or anti-depressives, but is not a result of post-polio syndrome.

Exercise: He recommended *for those who are able* to use a stationary bike for leg exercise; use 2-5 pound dumb bells to increase arm strength and gradually increase the number of repetitions and sets, but don’t use more than 10 pounds.

Stress: Everything gets worse with stress— anxiety, sleep deprivation, memory, reading, etc.

Sleep: Take power naps—not more than 15 minutes or you may not sleep well at night. If you wake every 2 hours or so, does this mean you do not have enough oxygen? Answer: Maybe. Check with your doctor re: oxygen desaturation. For those with sleep apnea—to improve oxygen levels CPAP is good for snorers; Bi-PAP better for individuals with post-polio syndrome. Treatment of sleep apnea can markedly decrease complaints of fatigue.

Swallowing: The muscles which control swallowing also control speech. Drinking water is a difficult task which requires many muscles in sequence. He also advised “don’t talk with food in your mouth” to avoid aspirating food.

In my email conversation with Dr. Waclawik after the meeting re: a list of physicians who specialize or have interest in the post-polio syndrome, he replied:

“I am not sure if there are any physicians in the Dane County who specialize, or have interest specifically in the post-polio syndrome. If there are diagnostic questions then one should ask for a neurologist with subspecialty training in neuromuscular diseases. With regard to management, physicians from the Physical Medicine and Rehabilitation subspecialty are probably most helpful. Also, if there are any breathing problems a pulmonologist should be asked for help and if patients have difficulty swallowing they should see a dysphagia specialist. Each person needs to decide whether diagnosis or management is what is needed.”

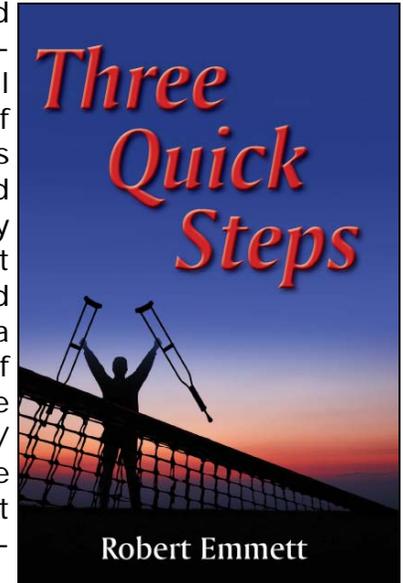
In spite of the computer glitch which precluded Dr. Waclawik from projecting his Powerpoint presentation onto the large TV, people were very pleased at the information provided and having their questions answered.



The Book Shelf

An e-note from Robert Emmett about his book “Three Quick Steps”.

I am writing to tell you about a memoir I just published on Amazon/Kindle. “Three Quick Steps”, deals with my experiences with polio (age 9 in 1952) and now post-polio syndrome (PPS) until my current age of 70. Its main focus is how I was shaped as an individual by a wonderful support group of family and friends. It was a perfect example of the famous phrase of Abraham Lincoln/Peter Drucker...“The best way to predict the future is to create it.”



I think your organization and its members will relate to this and find much in common. From 1954 (year before Salk vaccine) and back we are now a generation, that upon close examination, contributed greatly to society due to our mostly driven and introspective personas. I welcome feedback and comments. Having shown this to some PPS survivors it was real joy to discuss our feelings and parallel lives.

Thanks,

Robert Emmett, Polio Survivor 1952

If you have any questions, I can be reached at <RobertEmmett@3quicksteps.net>.

Editor’s Note: *Three Quick Steps* by Robert Emmett is available at Amazon in paper back for \$9.45 and Kindle for \$1.99.

Check out the many reviews on Amazon—“an interesting read” according to one reviewer.

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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 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.



Happy Valentine's Day



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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 14, 2015

Open Discussion:
**How has the cold weather affected you
this year compared with past years?**

•

Saturday, May 9, 2015

**Kris Jensen, accompanied by a dog,
will talk about her business,
“Journey Assistance Dogs” .**

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