

POST POLIO PACER

Conserving Strength and Energy through Pacing
July 2015 — Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 — This Is Our 30th Year!



RED LIGHTS AND SCREAMING SIRENS

By Mary Herness

Part 4—Mary returns home, works hard on her recovery and builds her life admirably.

Parts 1, 2, & 3 are in the Oct. 2014, Jan. 2015 & April 2015 issues respectively.



My home on our dairy farm near Pigeon Falls had not changed during my absence. But I had changed! My needs had altered. Physically, I walked with a limp favoring my left side. My left shoulder had a hollow spot where the muscle had shriveled up, no longer allowing me to lift my arm to even comb my hair. A weak neck left me with limitations. I could no longer stand on my tip toes. Most bothersome, were the throat and breathing deficiencies. Choking on small crumbs, a swallow of water or a scratchy piece of food became a plague. The sound of my strangulated cough alarmed people who heard me coughing and choking. My eyesight had been damaged which led to a lifetime of wearing glasses. Dental problems were another unwelcome side effect that precipitated extractions, root canals and eventually a full upper denture. In spite of these problems, caused by the polio virus, I gained in maturity, determination and appreciation for the skills and

talents that I had. The house that was home had not changed. But my room was located upstairs! The two flights of steps never looked so steep. With Mother's help I maneuvered my way up, one step at a time. It was like climbing a mountain! According to instructions from my physical therapist, Dad had placed boards under the mattress to provide a firm support for my damaged back and legs. But surrounded by familiar territory, life was good.

Anxious as I was to return to school, anxieties and self-consciousness hung over my head. The plan was that I would return to join my eighth-grade peers on a part time basis beginning December 1. Mother drove me to school for morning classes, and picked me up at one o'clock for physical therapy in Eau Claire three days weekly. In my teenage self-centered world, it never occurred to me what a commitment this was for a mother and farm wife.

My wonderfully compassionate teacher made adjustments and special accommodations for my physical limitations. One can only imagine the "talk" she gave the students as they made ready for my return to school. They took turns carrying my lunch tray from the basement kitchen to the classroom desk where we ate noon lunch. They carried books, picked up dropped pencils and helped hang up my coat. Especially embarrassing times, when my knees gave out, causing my collapse onto the floor, quickly brought a pair of willing peers to the rescue. Bless the teacher who set the stage for that caring attitude. As the muscles in my thighs and lower legs regained strength, there were fewer of these wipe-outs.

A number of factors contributed to regaining strength and flexibility in my polio damaged muscles. Every other day trips to the physical therapist kept me on track with stretching, lifting and exercising. Peter Parisi was persistent in his demanding and coaxing requests to push my feet and hands forward to his hand, one at a time in a series of repetitions. Each session included lifting and holding my legs and arms, raising and holding my head off the pillow and touching my nose to my knees. Walking between the exercise bars left me exhausted, as the length of time was gradually extended. Physical therapy was painful, and tedious. I did not comprehend the importance or predict the long term outcome.

Physical therapy and exercise were not the complete story of my recovery. The bed on which I slept was extremely firm because of the boards that Dad had placed under the mattress. Time, rest, good nutrition and youth all contributed to the healing process. Of even greater significance were attitude and a driving type A personality, leaving little room for failure. In spite of missing half of the eighth-grade year, repeating the grade, as my classmates moved on to high school, was not an option in my mind. I would take the county eighth-grade comprehensive exam and pass on to high school. The teacher's encouragement and confidence in my academic abilities facilitated my success.

A factor that I never considered during the months of coping with recovery from polio, was the financial obligation faced by my parents. Dad had carried polio insurance for a number of years. Being a polio survivor, himself, he had the foresight to plan ahead for financial protection should this dreaded disease strike his family. Did he have a premonition? It is my opinion that rather than a premonition, he felt that by carrying the insurance, he was insuring his family from actually contracting polio! His experience as a ten-year-old boy dealing with polio had left an indelible stamp on both his body and mind.

Long range implications of this disease, both negative and positive, have been a part of my life.

He contracted the disease in 1920 which was the same year that polio ravaged the body of President F.D. Roosevelt. The parallels between this great leader and my Dad are examples of persons who never let adversity prohibit reaching high goals in life. Ironically, the disease did strike down on Dad's family, but the insurance policy was a blessing.

Long range implications of this disease, both negative and positive, have been a part of my life. Physical limitations such as weakness and paralysis on my left side, swallowing and choking problems in my throat, weak neck and foot muscles on my right side and unanticipated post-polio arthritic problems in my right hip have all required adaptations and improvisations. Emotional implications, although negative at the onset, have also resulted in some positive influences in my life.

During high school and college years, it hurt to be excluded from all physical education classes and sports. Attention caused by distorted coughing attacks in a quiet classroom, choking on a sip of water or a cracker crumb in a restaurant and/or inability to raise both arms above my head in a dance routine are a few examples of humiliating situations. These were emotional concerns during the first years following the onset of polio.

Positive influences of having dealt with polio are evident in hindsight. Never, ever did I doubt that earning a college degree and teaching may be out of reach or impractical! Rather, my drive to achieve, to acquire new skills and to reach high goals was heightened. Motivation to overcome handicaps was a driving force. I learned to ignore limitations and to improvise and adapt. Simple everyday tasks like fixing my hair required adaptations. Babies were always held and rocked on my right side. Strengths rather than weaknesses became my focus. My hands and fingers appeared to be unaffected. So I learned to play piano, acquired good typing skill, endeavored to successfully sew and quilt, and have developed some writing skills.

In my post-polio senior years there are numerous tasks and activities that are out of reach. Golfing, running in a race, participating in exercise classes, swallowing enormous pills, eating nuts or popcorn, lifting things above my head or reaching behind my back are a few examples of activities which I either must avoid or live without. Huge pills can be smashed or medications can be ordered in liquid form. Therapeutic massages, regular chiropractic adjustments and daily stretching exercises are keeping me moving and fairly comfortable. Periodic shots of cortisone in my right hip ease the discomfort. Regular doctor appointments that include bone scans, cholesterol tests, mammograms, blood pressure monitoring, and general health maintenance are a vital part of life. Being cognizant of extreme susceptibility and potentially dangerous reactions to high dosages of anesthesia, has helped me to be my own medical advocate. Participation in a post-polio support group facilitates me in keeping current and informed about special care and preventative steps that can be utilized.

Personal goals and dreams also meant marrying the man who was the love of my life. Following a difficult time in which I miscarried my first child, my husband and I were blessed with a healthy son. In the years that followed, we had two more sons. There were periods of time during the busy years that followed raising our family, teaching full time and doing the duties of a farm wife that I almost forgot that I was a polio survivor with some limitations. Few people knew or recalled that I was a polio survivor, and that was the way I preferred life to be.

When the Salk polio vaccine became available in the late 1950's, and upon the advice of our family doctor, I joined our family and lined up for the shots along with throngs of others. Since there are so many strains of polio, there may be the long shot of contracting the dreaded virus again. Thanks to medical research and experimentation of the vaccine, polio has nearly been eradicated in the United States. My children and grandchildren should never need to fear this virus. In fact, future

generations may soon forget this part of our history. The red lights and screaming sirens in the night that are still imprinted in my memory, may fade away except for stories such as I have written down for my family.

Written by Mary Hanson Herness
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 2009, edited 2014
 Dedicated to my ten grandchildren

Our sincere thanks to Mary for sharing her story with the Post Polio Pacer.

Reading this story probably brings back some of your memories that others would appreciate reading—how about writing them for your family and sharing them with Pacer readers?

Shelley Peterman Schwarz, local columnist, will be our speaker on Nov. 14. She would like topics and questions from the group so she can frame her talk to your needs.

Please email your suggestions to
 Gail Kempfer at
 <wp6838@windsorparkside.com>

Or bring written suggestions to the
 July or September meetings.

The Post-Polio Support Group welcomes Kathy Shurts, a volunteer with the Wisconsin Senior Medicare Patrol, to our July 11th meeting. Ms. Shurts will provide information on how to protect yourself from health care fraud, errors, and abuse.

It is estimated that Medicare loses \$60-90 Billion every year due to fraud, errors, and abuse. Join us to learn how to Protect yourself, Detect errors or abuse, and how to Report any suspicious charges. Don't be a victim!

A Priceless Chance to Build a Life

By *Kathleen Blair*

"Volunteers don't get paid – not because they are worthless, but because they are priceless." (Unknown)

This column was intended to "cover" the subject of volunteering – delivering meals, providing transportation, donating time and services at church, school and civic events, reading to the blind, building houses in Juarez, Mexico and other third world countries, teaching English in Cambodia, providing outdoor spring cleaning for the elderly – an endless list of worthy causes. I soon realized that covering all those admirable volunteer services was more of a book length endeavor. (Some of those services may appear in future columns.)

For this July 2015 Pacer, I want to share a McFarland community activity that touches the health, happiness and well-being of one hundred or more McFarland residents every week.

The McFarland Shared Table has just begun its fourth year of providing nutritious, free dinners on Thursday evenings to people of all walks of life. It began with months of planning by a core group of generous souls who wanted to make a difference in our community. Their mission statement found at <www.sharedtablecommunitymeals.com> includes a goal "to reach out to seniors and other area residents who may be in need of companionship and who would enjoy friendship and fellowship around the dinner table." (An implied target audience is also individuals and families who need a healthy meal for financial or other reasons.)

The Shared Table chose a centrally-located, handicap-accessible facility, the McFarland Lutheran Church, which generously agreed to cooperate in this program. Further support came from all the area churches, schools, civic, scouting, athletic teams and professional organizations who recruited volunteers to prepare and serve dinners as often as every

other month, or as few times as once a year.

I continue to be amazed at how many small groups seem to have formed for the sole purpose of participating in the Shared Table program. Kudos to them.

Each week we can look forward to the Thursday evening dinner which consists of a main dish, a variety of salads, bread or rolls, delicious homemade desserts, milk and coffee. The organizers also schedule delightful volunteer entertainment: bands, pianists, a violinist who plays while walking among the tables, sing-alongs, vocalists, etc., adding so much to the ambience. But the delicious food and entertainment are only part of the attraction. It's comforting to sit around a table while en-



joying good food (that we didn't have to cook), visit with friends and neighbors, and to meet new friends and renew old acquaintances. And the bonus is to be able to go home, relax and not have to wash dishes or clean the kitchen.

We enjoy watching little kids play in the spacious hall while their parents are either eating, serving or washing dishes. We see families come in to have dinner together after working all day; single people who would otherwise have to eat alone; elderly who want a break from cooking; elderly or disabled persons using a cane, walker or crutches, sitting in a wheelchair or riding a scooter. What makes the Shared Table work and sustains these efforts is that there is no stigma attached to the dinner, i.e. it is not just for "poor" or handicapped people. It is all ages, all walks of life sharing a healthy meal, good conversation, and relief from loneliness.

The Shared Table gives us another benefit – the opportunity to build a life. Winston

Churchill is credited with saying, “We make a living by what we do, but we make a life by what we give.” We regularly participate in and enjoy the freely-given Thursday evening dinners. But when it is our group’s turn to serve (whether church, school, civic, professional, etc.), we purchase the groceries, prepare a casserole, salad or dessert, serve the food and beverages, wash dishes and clean up. Participants also “pay it forward” by slipping checks or cash donations to core group members to help cover other expenses. This is another chance for us to “build a life.” It’s a twofold benefit – building a life and receiving a benefit. Priceless indeed.

When my church group (Christ the King) volunteers, I bake my favorite ginger snaps.

Here’s my recipe:

1 cup sugar	1 tsp baking powder
¾ cup butter	¼ tsp cloves
¼ cup molasses	½ tsp cinnamon
1 egg	½ tsp ginger
2¼ cups flour	Extra granulated sugar to
1 tsp baking soda	roll balls into

Mix well, cover and chill for 30 minutes, shape into 1-inch balls and roll in sugar. Place on oiled baking sheet and bake at 375 degrees for 12-13 minutes.

The Post Polio Pacer invites you to share your volunteer experiences. Please tell us your story so we can include it in future issues.

What Did You Miss on May 9, 2015?

Approximately 20 people heard a wonderful presentation by Kris Jensen and her dog, Nickels, who educated us about service animals and what they can do for people with disabilities.

Service animals are defined by the American Disabilities Act (ADA) as “dogs that are individually trained to do work or perform tasks for people with disabilities” which includes physical, psychiatric or other mental health disability. The work or task the dog

has been trained to provide must be directly related to the person’s disability, such as:



guiding people who are blind, alerting people who are deaf, alerting or protecting a person who is having a seizure, reminding a person with mental illness to take prescribed medications, calming a person with PTSD or a child with autism.

Under the ADA, only dogs are recognized as service animals. However, businesses must make reasonable accommodations to allow individuals with disabilities to use min-

ature horses if they have been trained to perform tasks for the individual.

Emotional support dogs are NOT considered Service Animals under the ADA. An emotional support dog may provide comfort or emotional support, may help with depression, anxiety, or certain phobias but does not have special training to perform tasks directly related to the individual’s disability. A letter from a doctor stating the individual has a disability and needs the dog for emotional support does not make the dog a service animal.

Public Facilities and Service Dogs

There are only two questions that can be asked of a person with a service dog:

- 1) Is the dog a service animal required because of a disability?
- 2) What work or tasks has the dog been trained to perform?

They cannot ask for documentation showing that the dog has been trained as a service dog or for a MD verification of the individual’s disability.

State regulations vary, but in most cases require Service Dogs in Training to wear a vest or other identification and the trainer to have documentation showing the dog is in training. Vests are optional for trained service dogs when in public.

Businesses that serve the public must allow an individual with a service dog access to any areas where customers are generally allowed. Service dogs can be excluded from a facility if it poses a direct threat to health or safety of others, or results in a fundamental alteration to the nature of the business (eg. a sterile environment). Allergies and fear of dogs are not valid reasons for denying access. Nor can a business require a deposit or surcharge as a condition to allowing an individual to bring their service dog into the facility.

Nickels responded to Kris's commands to "turn on the lights", "open the door", "pick up" (whatever is dropped on the floor) quickly and sometimes got a treat as a "thank you". Nickels name came from his ability to pick up nickels—and yes, they are slimy according to Kris, but at least they are in her hand and not on the floor.

During the Q & A Kris mentioned that service dogs are "working" and should not be petted, fed, etc. without asking for the handler's permission. That advice is worth remembering when coming upon neighborhood dogs (on or off leash) walking with their "person".

Madison Area Service Dog Groups

Custom Canine Service Dogs--

<info@customcanines.org>

Occupaws Guide Dog Association--

<info@occupaws.org>

Wisconsin Academy for Graduate Service

Dogs (WAGS)--<info@wags.net>

Editor's note: Many thanks to Kris Jensen for permission to use information from her "handout" for the above article.

An Opportunity to Participate in a Polio Genomics Study

McMaster University in Ontario, Canada is conducting a Polio Genomics study to find out whether there is a genetic reason that led some people to develop paralysis following infection with the polio virus. We are currently recruiting paralytic Polio survivors worldwide in order to meet our enrollment goals.

Key study information can be found below:

- There is no age restriction.
- There are no expenses and participants do not need to travel in order to participate in the study.
- Those who are survivors of paralytic polio (this could include spinal and bulbar) are eligible for the study.
- When a potential participant contacts us, we will arrange for a 15-30 minute telephone interview with a research nurse.
- During the interview, a research nurse will explain details of the study, obtain verbal consent and relevant clinical information.
- Upon obtaining verbal consent, a package including written consent forms and a saliva sample kit will be mailed to the participant with a postage paid return envelope so that the signed consent form and saliva sample may be sent back to our office.
- If they are interested, spouses who have not had polio will also be asked if they would like to participate in the study as a study control.
- Our goal is to enroll 5000 paralytic Polio cases and 5000 controls.

Polio Genomics Study

Dear Polio survivor,

Polio was an enormous threat to many all over the world. It is estimated that there are about 10 to 20 million polio survivors worldwide. Although vaccination fortunately eliminated polio in North America, polio is still spreading in some parts of the world.

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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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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.

An unanswered question is why some people developed complications, such as paralysis, while others did not. Most people who were infected did not develop paralysis. It is possible that there is a genetic predisposition to developing polio, that is, some people may have a variation in their genes that led to complications when they were infected with the polio virus.

Our research team at McMaster University is conducting a study to find out whether there was a genetic susceptibility that led some people to develop paralysis following infection with the polio virus. If you are a polio survivor you may be interested in taking part in this study. This would mean completing a questionnaire and sending us a saliva sample. Participating would help us to gain important knowledge and understanding about why some people developed paralysis and others did not and how the immune system may have responded to the polio virus. The information could help the development of therapies for polio and related viruses which continue to pose a threat to vulnerable people worldwide.

We started our study in Canada working with the March of Dimes Canada and expanded to include Polio survivors in the United States. As of December 9th, 2014 we have enrolled about 1,161 people. We are now hoping to enroll participants from international sites including all European countries, Australia and New Zealand and continue to welcome Canadian and American participants as well.

If you are possibly interested in participating please contact McMaster University at 1.888.541.2821 or email [<polio@mcmaster.ca>](mailto:polio@mcmaster.ca) for more information.

Sincerely,

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Please request permission from the editor to reprint articles from the Post Polio Pacer.

Madison P-P Support Group e-mail list will return in October.

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.



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Saturday, July 11, 2015

Kathy Shurts, a volunteer with the Wisconsin Senior Medicare Patrol, will provide information on how to protect yourself from health care fraud, errors, and abuse.

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Saturday, Sept. 12, 2015

A representative from SAILS will share information about programs and services the organization provides.

