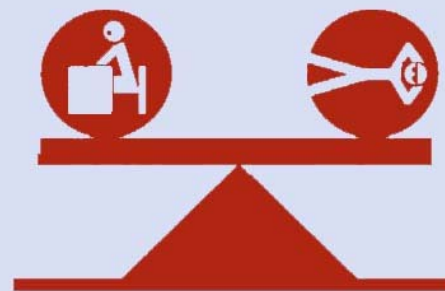


POST POLIO PACER

Conserving Strength and Energy through Pacing
April 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 3—Mary resumes her studies lying in a hospital bed and is transferred to Luther Hospital in Eau Claire, WI and takes her first wobbly steps.

Parts 1 and 2 are in the Oct. 2014 and Jan. 2015 issues respectively.



One day a kindly, smiling lady came to my bedside. She introduced herself as a teacher, whose job it was to teach homebound students, who were missing school due to illness. Her questions about my age and grade level, where I attended school and which subjects were being studied, awakened a new spark of excitement. Until that day, I had not thought much about what I was missing at Pigeon Falls School. Lying in a hospital bed in Madison, I was being left behind. We made plans for lessons to begin immediately. She returned later the same afternoon with a list of spelling words, a history book, and a writing assignment. She also brought me supplies such as paper, pencils and a clipboard. After she left, I experimented with shifting my paralyzed body around. My right arm was strong enough to manage to flip my body over onto my stomach. Even though my neck muscles were too weak to hold my head up, I

could prop my head on a pillow and write. The clipboard helped support the paper. Reading the history book was difficult, but I was motivated. I thought less about my painful muscles, and my mind was, once again, busy. My next job was a challenge! The writing assignment she had given me was to write about my hometown, Pigeon Falls. Some research was required for this task. I wrote letters to my teacher at home asking for information. My new teacher brought in books about early settlements in Wisconsin. As the days turned into weeks, visits from my bedside teacher were bright spots in an otherwise grueling routine.

The hot packs and stretching exercises continued. Slow progress was made. The physical therapist pushed and pulled my legs higher and higher. My nose could almost touch my knees while he was pushing downward, and my weak neck muscles eventually permitted me to briefly lift my head off the pillow.

The writing assignment about my hometown, Pigeon Falls, began to take shape. The title, "Pigeons, But No Railroads," led into a summary of the historical background. My bedside teacher helped with proof reading. The final paper impressed her so much she submitted it to The Badger Journal for publication. That was one of very few positive experiences during my stay at Madison General Polio Annex.

The seasons changed, the weather got colder and my days lying flat on my back turned weeks into months. Never once, did I even consider the possibility that I may never return to that familiar world of school, home,

life, family and friends.

Two months after being admitted to the polio hospital in Madison, my parents suggested the possibility of moving to Luther Hospital in Eau Claire. The long drive to Madison made it difficult for them to visit. A transfer to Eau Claire may encourage other relatives and friends to visit. I ignored the reality that people were so afraid of contracting the polio virus, they would not take the risk of visiting a ward filled with polio infected victims. I had become a part of a segregated, isolated population, almost to the same degree as patients ill with tuberculosis or leprosy!

Plans were made for my transfer from Madison to Eau Claire. Dad arranged to have the local Pigeon Falls ambulance driver come to Madison. My parents rode along to help with details. They had consulted with our family doctor. He learned that a bed was available in Eau Claire, and had given orders for my care and therapy. Being released from the polio ward, where I had experienced so much pain and frustration was like sunshine following weeks of stormy weather. Luther Hospital and Eau Claire sounded nearly as great as going home.

Dad lifted me from my bed to the ambulance stretcher. A nurse helped Mother, pack my few personal belongings, including my school notebooks. There were no sad good-byes, only a quick wave to the girl in the next bed. She was from Mauston, WI, but much younger. Therefore, we had not really had much camaraderie. The ride back to Eau Claire was long and uneventful with no screaming sirens or flashing red lights.

When the ambulance pulled into the emergency entrance at Luther Hospital in Eau Claire, I was quickly wheeled into a brightly lit room. Mother and Dad handled the technicalities of paper work. A hospital doctor did routine checks. Endless questions about what my tired, hopeless legs and arms could do, seemed very invasive. When I was finally

wheeled into a room on the fourth floor polio ward, I felt a welcome relief. Wonder of wonders; I was to share a room with only one other person. My roommate was an older teenage girl from Eleva, WI. After spending all those weeks in a crowded polio ward with all those sick little children, this was certainly a morale booster. When I fell asleep that first night, I had a feeling of reassurance that Luther Hospital in Eau Claire was going to be a step in the right direction toward conquering this debilitating disease.

Morning arrived with a host of new faces, more challenges and worries. Peter Parisi introduced himself as the physical therapist. He was the person with whom I would be working for two or three years. Nurses and aides arrived pushing those dreaded containers of hot packs! Oh, no, I thought, hot packs, stretching and new painful exercises here, too! Peter Parisi informed me

Being released from the polio ward, where I had experienced so much pain and frustration was like sunshine following weeks of stormy weather.

I needed to start sitting up on the edge of my bed, and it would not be long before he would have me on my feet walking! In the matter of a few days, I found myself facing the challenge of not only sitting on the edge of my bed, but also standing upright on my legs. My maiden voyage-walk was actually a few faltering steps with Peter Parisi on one side and a nurse on my other side. It was only after being safely tucked back in bed, that the realization of what I had just accomplished registered! "I walked! I really walked!"

My physical therapy treatments were soon transferred from the hospital room bedside to the PT room. The tedious and painful routine of stretching muscles was always combined with seemingly impossible goals. One of these goals was the continuous struggle to touch my knees with my nose. Neck stretching, foot and left arm exercises were part of the work. Never did I entertain thoughts that some activities in my teenage world may now be out of the question. It was never a consideration that lifelong limitations and residual effects from polio may become con-

straints. Indeed, that denial may have been a positive factor in my process of healing, achieving and reaching goals. My personality was profoundly impacted in that year by the culprit, polio. As a result of having to cope with this disease, I learned perseverance and sought ways to improvise when deficiencies prevented performing a simple task. I also accepted the reality that goals do not come without great effort.

After my first wobbly steps, walking opened up new avenues for me on that fourth floor polio ward. Supporting myself on the wall railing, I started roaming up and down the hallways. I made new acquaintances. These were people who were equally lonely and restricted. Other polio patients, young and old alike, were anxious to talk, sharing their backgrounds and their struggles with rehabilitation. The early evening hours became my favorite time of day, because that was when I would go for a walk and socialize. Looking back, I realize it was a shift from focusing entirely upon my problems to recognizing that other people also had problems. Many of those polio survivors had much worse crippling after effects than I had. One incident that I recall happened on one of those strolls. A patients' bathroom was located down the hall just past the nurses' station. It was not unusual for me to make a stop there. It was one more way of expressing my independence. There were handicap bars adjacent to the toilet stool. It was an effort for my weak arms to pull myself up from a sitting position on the stool, because my leg muscles were weak and undependable. One evening, I collapsed on the bathroom floor. Embarrassed and scared, I managed to crawl to the door and open it slightly. My call for help brought no immediate response. I almost panicked! Fearful thoughts haunted my mind with worries of spending the night on the bathroom floor. My Florence Nightingale, who came to the rescue, must have had to cover up her smile to save my embarrassment.

The Thanksgiving holiday loomed closer. My physical therapy routines, along with the painful stretching of shrunken and damaged

muscles, continued to progress. Finally, the goals, set jointly by Peter Parisi and me, were gradually achieved. The week of Thanksgiving was to be my homecoming! My stubborn Norwegian genes had never once allowed me to entertain any doubts regarding my chances to return home. The ride home that cold, late November day is blurred in my memory. I rode in the backseat with a blanket covering my legs according to Mother's instructions. The hour ride home was long and filled with anticipation.

In Part 4 (July 2015) Mary returns home, works hard on her recovery and builds her life admirably.

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?

Tribute to Bob Kail

No, we never saw "Bobbie" in a tux at the Post-Polio meetings, but he was a special person to more than his wife, Fayth. He supported her in all her work with this PP group, and years of volunteer work with others in attaining accessibility to housing, transportation, businesses, etc.



After a long illness, Bob passed away on February 17, 2015. His memorial service was attended by hundreds of people who went to school or church with Bob and/or Fayth, worked or motorcycled with them in years past, or needed help with transportation, repair work, etc.

Our condolences to their families.

He will be greatly missed...

Is It Post-Polio – Or Something Else?

Bruce Lambert, Hempstead, New York

Post-Polio Syndrome – oh, that devilish master of disguises & confusion!

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As a polio survivor, I have been fooled more than once. My doctors, too, even the good ones.

When I first developed post-polio syndrome, I erroneously suspected other causes for my problems. Even a neurologist scoffed at post-polio as unlikely.

But eventually post-polio was diagnosed. Then I made the opposite mistake, blaming post-polio as the root of every new problem. Wrong, again.

Take the example of my right groin, which I injured four years ago. Ever since, it was sore and stiff with limited flexibility. The nagging discomfort drastically worsened last summer as my entire leg weakened. I limped and needed a cane, then two canes. I was alarmed.

From the start, my doctors (an excellent primary physician, two locally prominent neurologists and a pioneering post-polio expert) had assumed my groin symptoms were just another part of my late-effects polio. I accepted their assessment.

They were all wrong, and so was I.

By chance, an entirely different diagnosis emerged. A neurologist had sent me to a physical therapist to strengthen my back, after multiple MRIs and x-rays had un-covered spinal arthritis. The doctor's referral didn't even mention my under-lying post-polio.

In a 20-minute exam, the therapist could not find enough back pain, weakness or stiffness to warrant treatment. I told him what I thought my real problems were: post-polio, groin injury and lame leg. "Have you had a hip x-ray – has anyone ever suggested it?"

the therapist inquired. Puzzled, I replied: "No. Why are you asking?" He said: "Your symptoms could be from a bad hip."

How right he proved to be. X-rays and two orthopedic surgeons confirmed severe hip arthritis. A cortisone injection magically banished the pain for weeks, my leg rebounded, and I put my canes aside. The shot did not repair the hip, of course, and the cortisone relief gradually wore off. So later this year I plan to get joint-replacement surgery.

"I may be your first patient who is glad he needs a hip operation," I told the surgeon. "If my problems were caused by post-polio, they can't do much about that."

There's a moral to my hip episode. Correct diagnosis is essential to health care, and polio survivors face a recurring challenge. Whenever a new problem arises, we must grapple with whether it's post-polio syndrome or something else.

We are susceptible to automatically blaming polio. Many of us were ignorant of post-polio or in denial about developing it. But once confirmed, it can bias us to see everything through that lens. Military experts talk about the mistake of "fighting the last war" – misapplying old tactical lessons to new and different situations.

For me – and my doctors – diagnosing polio was tricky from the very beginning.

While on a family trip at age 8, I started feeling sick. My mother, a registered nurse, feared polio. A local doctor dismissed my symptoms as "probably just a virus." (Some virus it turned out to be!) Still worried, Mom cut our trip short. Back home, our family doctor was reassuring, saying that many parents were needlessly panicking about polio.

Then one morning, I awakened and swung my legs over the side of the bed to get up – only to crumble to the floor. "Mommy, Mommy," I cried out. "I can't walk." So much for those oblivious doctors.

I was taken from our small Ohio town to Children's Hospital in Columbus. A spinal tap confirmed polio, consigning me to the polio ward for the next few months. At my worst, I was paralyzed from the neck down. Doctors predicted I would never walk again.

Fortunately, they were wrong again. I learned to stand and walk again and led a generally normal life, though I was never athletic, strong or coordinated.

Decades passed. Then in 1985 *The New York Times* reported that some polio survivors were developing renewed problems years after their original infection. Doctors named the condition Post-Polio Syndrome.

At the time I was 42. Concerned, I went to a support group. Other attendees had serious physical complaints. But I had no new symptoms, and my polio was a distant 34 years in the past. My conclusion: I was among the lucky ones dodging the post-polio bullet.

I was wrong. But ignorance can be bliss, and I enjoyed another quarter century of decent health before things went haywire.

At age 67, fatigue bowled me over and I drowsily drifted into long midday naps. I attributed this to changing springtime allergies. The fatigue forced me to stop my exercise routine of walking up and down 50 flights of stairs three times a week. Then I began to feel stiff and weak. Naturally, I blamed my inactivity. Or maybe this was just "old age."

It all seemed quite logical, but events proved me wrong.

On my 68th birthday I treated myself to an Asian music concert. After settling into my center seat, I belatedly realized that I had misread my ticket and was in the wrong row. By now other people had filled the seats on my left and right, and I did not want to disturb them by squeezing past.

I only needed to go back two rows, which were still empty. So I clumsily climbed over

the back of my seat to the next row, then again to the row behind that. No problem.

I thought that this exertion might make me a bit stiff or sore the next couple days. Instead, I was hunched over in pain and immobility for weeks, having a hard time getting up and down from a chair and in and out of my car.

As my symptoms piled up, I went to my doctor. We drafted a list of possibilities, including chronic fatigue, Epstein-Barr, fibromyalgia, low testosterone, hypothyroid, Lyme disease, cardiomyopathy, rheumatoid arthritis – and post-polio syndrome.

As tests eliminated other causes, post-polio loomed as the likely culprit. But a neurologist was highly skeptical, saying I was simply depressed and suffering psychosomatic symptoms. He was wrong. After electromyography and skin conduction tests, he grudgingly confirmed post-polio.

He was not much help, unaware of books on post-polio or support groups. I found both on my own. From Post-Polio Health International's *Post-Polio Directory*, I contacted the excellent clinic at the MedStar National Rehabilitation Hospital in Washington. It assessed me, designed calibrated exercises and made other recommendations. About the same time I also was diagnosed with sleep apnea, a common disorder in post-polio, and began using a breathing machine at night.

It all helped, and for a couple of years I was stabilized, albeit at a lower plateau of energy and strength.

But suddenly last summer, pronounced fatigue and napping returned. My right leg weakened drastically, requiring canes. It was obvious to me that this was a big new decline in the progression of post-polio.

Once again, I was wrong.

A sleep doctor found that I had neglected to change the silicone liner of the face mask for my breathing machine, so it weakened and leaked air, reducing the pressure needed to

ease breathing. As soon as I changed the liner, the fatigue and long naps disappeared.

For my walking difficulties, I went to a second neurologist. She focused on my spine and diagnosed neck and lumbar arthritis. She sent me to the physical therapist whose fortuitous hunch about my hip joint – the one I had strained at the concert four years before – proved to be a real breakthrough.

Ironically, the groin injury that was the last straw prompting my original post-polio diagnosis apparently wasn't caused by post-polio after all.

My doctors and I have been wrong many times. They thought I didn't have polio to begin with. Once it was diagnosed, they predicted I would never walk. At middle age I believed I had escaped post-polio. Years later when I started getting symptoms, I blamed other causes, and a neurologist blamed depression.

And what appeared to be alarmingly worsened post-polio last summer turned out to be fatigue caused by a breathing mask defect, and a limp caused by hip arthritis that doctors and I had missed for four years.

An old medical adage advises: "When you hear hoof beats, think of horses, not zebras." In other words, in making a diagnosis first look for common illnesses, not exotic ones. By that metaphor, post-polio is exotic. And the maxim needs a corollary: "But if you have a zebra and hear new hoof beats – don't rule out horses."

What I have learned is to take nothing for granted, neither medical expertise nor my own guesses and assumptions. Keep an open mind, explore possibilities, question everything, get more tests and second and third opinions, keep searching and welcome serendipitous insights like my physical therapist's hunch. □

Bruce Lambert is a PHI member and retired New York Times reporter and union advocate in Hempstead, N.Y.

The Western Wisconsin Post Polio Resource Group will meet on April 11, 2015 in Whitehall at Gunderson Tri-County Memorial Hospital in the Education Room at 12:30 p.m.- 4:30 p.m.

For more information, please contact Betty Marsolek at 715-985-3801 or <bmarsolek@tcc.coop>.

What Did You Miss on March 14?

We were delighted to welcome two people from Beaver Dam, Don, who is experiencing new weakness in his left leg, and his wife Cheryl to our open discussion about coping with cold weather.

Of the 14 attendees, a few suggestions were: wearing layers over his lower body and over the brace which makes his affected leg feel warmer; wearing 3 layers—expedition weight long johns and 1 layer of fleece; wearing wool socks to keep feet warm; using an electric blanket to keep body and legs warm.

The discussion progressed to answering questions Don and Cheryl had about increasing fatigue, pain, etc. Alternating periods of activity with periods of rest and avoiding over working at times when "you feel good" were frequently mentioned.

Pacing, pacing, pacing should be our mantra!

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 May, July, September meetings.

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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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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.





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Saturday, May 9, 2015

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

•

Saturday, July 11, 2015

**We hope to have a representative from
Medicare. Watch your email for more
information.**

