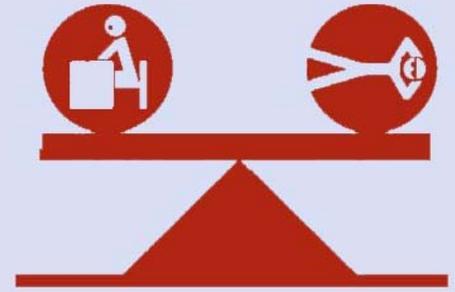


# POST POLIO PACER

*Conserving Strength and Energy through Pacing  
July 2012— Madison, Wisconsin  
Madison Area Post Polio Support Group Newsletter  
MAPPSG formed in 1985 — This Is Our 27th Year!*



## Re-connecting with My Kidself

**William Stothers, San Diego, California**  
([wstothers@cox.net](mailto:wstothers@cox.net))

When I was 8 years old, my family moved from a big city to a tiny town (pop. 600). We lived in a rented house, complete with an outhouse. I loved it.



There were farms nearby, and I got up-close to a different world, helping to herd and milk cows, “assisting” in the fields, and “riding” farm horses.

There was a small creek down the hill from our house. I wandered along the mostly ankle-deep creek, looking for fish or turtles. About a half-mile from home, a little railway bridge went over the creek; at times, my buddies and I would try to catch fish there, and while we did, we would build a little fire to heat up a can of pork and beans.

Riding my bike around country roads, exploring the woods, climbing trees, getting caught in the rain, jumping into puddles and off a bridge and swimming in a deep pool said to be filled with old tires and other discarded trash, consumed summers.

I loved it all. There is something about getting dirty, touching and feeling the real natural world that thrills and energizes me at some level.

Two years later, when I was 10, polio came calling, and for the next three years I worked (“worked” is the right word isn’t it?) my way through rehab institutions away from home.

Then I returned to our newly built house in town. No more outhouse – thank heaven, since that old one was not accessible!

And there were many other “no mores.” No more wandering along the little creek, no more fishing from the bridge, no more exploring the woods, no more riding my bike.

Now when I went out, someone pushed me in my wheelchair. My feet stayed put, about six inches off the grass, the sidewalk, the gravel roads.

The natural world seemed to slip away, vibrancy fading out of touch. After a while I didn’t notice, caught up with just getting used to doing as much as I could on wheels.

Fast forward several years, and I was back in a big city, working at a newspaper and living on my own (praise be to power chairs!) in a downtown high-rise apartment building. It was there in that ninth-floor apartment that I began to feel a certain anxiety.

I finally realized that I was going back and forth to work and leading a busy life, but that I was going for long periods of time without seeing anything green and growing. No grass. No trees.

I tried growing corn on my balcony. No corn either.

After three years, I was able to buy a house, with a backyard and elm trees. It was wonderful.

I took up photography and found myself spending lots of time in local parks, getting close to and making pictures of flowers, plants and outdoor life. That anxious feeling ebbed.

Nature is becoming more accessible. Due to the efforts of people with disabilities, national, state and local parks are providing accessible trails and features that make it possible to get closer to flowers, trees and even animals – without paving paradise.

In the many years since then, I have kept up my picture making (see [www.flickr.com/photos/40637835@N02/](http://www.flickr.com/photos/40637835@N02/)), and it helps me connect with the real world around me.

My feet continue to skim six inches above the grass. Still, I can stick my nose closer to the roses in my front yard and take in the perfume. I can rub my hands over the bark on the big tree in my back yard. And even though the techs tell me not to, I can't stop powering through puddles, splashing and grinning. Life is good.

*Bill Stothers is a long time editor and consultant on media and disability policy. He edited Mainstream, a national advocacy and lifestyle magazine for people with disabilities and major newspapers in Toronto and San Diego. He is a member of the Board of Directors of Post-Polio Health International and currently serves as its Chair.*

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

### Golden Rule of Post Polio Syndrome

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

### F.Y.I.

Jane Clay, a retired nurse many of you may know from the U.W. Hospital Post Polio Clinic in the 80s and 90s, has moved to Pullman, WA. She has donated to the Madison Area Post Polio Support Group the following 2 books.

**Research and Clinical Aspects of the Late Effects of Poliomyelitis**, editors, Lauro S. Halstead, MD and David O. Wiechers, MD. Copyright 1987 by March of Dimes Birth Defects Foundation.

**Comprehensive Rehabilitation Nursing**, edited by Nancy Martin, RN, MA, Nancy B. Holt, RN, MS, Dorothy Hicks, RN, MN. Copyright 1981 by McGraw-Hill, Inc.

Also available are:

**The Polio Paradox—What You Need to Know**, Richard L. Bruno, HD, PhD. Copyright 2002 by Dr. Richard L. Bruno. Warner Books, Inc.

**Postpolio Syndrome**, Julie K. Silver, MD and Anne C. Gawne, MD. Copyright 2004 by Hanley & Belfus.

The books will be available at the regularly scheduled meetings and are to be returned by the next meeting.

## Guard Those Happy Thoughts

### By Kathleen Blair, Columnist

Several weeks ago I had the opportunity to chat with a small group of disabled women. Most of us were elderly and many had suffered varying degrees of disability and serious pain for a long time. My heart went out to them. Everyone except me was confined to a



wheelchair; and everyone, including me, took a turn at complaining about the difficulties we experience. Once an individual's problems were aired, everyone in the room got on the same wave-length. We unloaded.

Since I was the only one who could walk, I felt guilty when I stood up with my cane and slowly trudged out to my car later that afternoon.

That evening clouds of negative thoughts and images swirled around me; I couldn't get the unhappy tone of those conversations out of my mind. I understood the need to vent frustrations with pain, the unfairness of life, shortage of money, poor services, adequate living arrangements, transportation difficulties, occasional poor health care, thoughtless individuals, and the list went on. But it was a sad, sad discussion. Unhappiness overwhelmed me.

That night I awoke from a nightmare – someone was mistreating me and I didn't like it. I believe the strange dream was the result of too much sad, negative information.

Something had to change. I had to get back to a positive attitude in order to feel any peace or happiness. I had to make a conscious effort to be grateful for those things I do have and forget about anything I may be missing. In order to be grateful and not slip back into self-pity, I made a list:

I can see. I'm blessed with good eyesight so I can enjoy seeing friends and family members, beauty outdoors, reading, writing at my computer, my grandchildren's musical and sporting events, and so many more things.

My mind still works – most of the time, I think – so I can enjoy my hobby of writing and preserving memories in order to leave a legacy for my children and grandchildren, perhaps even great-grandchildren.

I can hear, although not always clearly. But with the help of a remote I can turn up the volume when watching TV. Other times I can



I'm grateful to have been at my granddaughter's college graduation in Bethlehem, PA on May 12, 2012. We enjoyed an art fair the following day. Thanks to: Tricia, Miranda, Becky and Monica.

politely say, "I didn't hear you, would you repeat that a little louder, please?"

I can still drive my car even though I have to limit my trips to places I can get into without having to walk too far.

Walkers, wheelchairs, and electric scooters are improving all the time. Do you remember what Franklin D. Roosevelt's wheelchair looked like? Even the White House wouldn't be a good place in which to be shut in.

So far this summer I've been able to park where I can watch my youngest grandson learn to play baseball without having to have someone push me across the field in the wheelchair I carry in my trunk. I just need to arrive early enough to get that parking spot.

Last week I enjoyed a wonderful dinner and show at The Fireside with three dear friends. One of them pushed me in a wheelchair. And we talked about how lucky and grateful we are to have each other plus many more good friends.

We have radios and CD players in our homes and cars so we can listen to our favorite talk shows or music – again, turning up the vol-

ume so we can hear comfortably.

My sense of taste isn't all that great, but many things taste delicious to me. I'm impatiently waiting for home-grown corn on the cob, cucumbers, vine-ripened tomatoes, cantaloupe and raspberries to appear on street corners and farmers' markets.

We can enjoy sunrises, sunsets, the song of birds, sunshine, cool breezes, the moon, stars, rain and all things nature affords us at different times.

I'm grateful for neighbors who shovel snow from my driveway in the winter, and take out my garbage cans and bring them in.

I'm grateful for the many kindnesses shown me by people I don't even know, such as opening doors and offering to help me before I admit I need help.

Many of us can enjoy remembering the accomplishments of our lives; mine are few, but I enjoy remembering them.

I'm most grateful for my family and friends and the many happy memories we share.

And I am grateful for faith, hope and love in my life.

I could go on and on but just writing this list makes me more aware of how good my life really is.

By keeping a positive attitude I can ignore the loneliness of widowhood, the intense fatigue that comes all too easily when I want to keep on going, the dread of perhaps someday having to move out of my house that I love so much, and the fear of losing the rest of my ability to walk.

I need to fill my mind and heart with happy thoughts, happy memories and, most of all, gratitude to God for my life just as it is.

## The Book Shelf

### The Polio Journals- *Lessons from My Mother*

By Anne K. Gross, Ph.D.

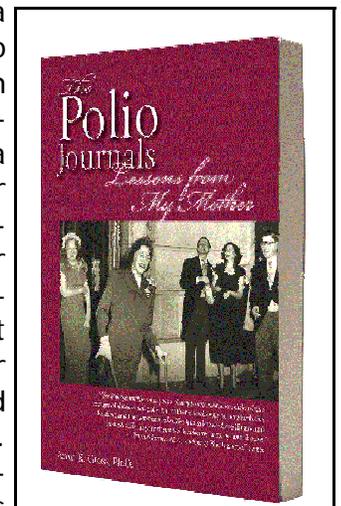
Reviewer: Mary Parks

Part biography, part history of polio – *The Polio Journals, Lessons from My Mother* forces the reader to re-live/re-experience if a polio survivor, or to gain a better understanding of what life was like for those whose life was forever altered by the virus.

Anne Gross has done a great job delving into family dynamics when one member has a disability by contracting a disease such as polio or suffers from an emotional illness. Her mother, Carol Rosentiel, contracted polio at age two, leaving her permanently paralyzed from the waist down. Although born to a family of means, Carol's parents, in particular her mother (Anne's grandmother) felt shame at having a child who was less than perfect and among other things refused to look at her legs or help her with the braces. Shame was brought on by the family, feeling non-acceptance by family and friends.

Carol went on to college and became an accomplished harpsichordist until post polio syndrome, particularly in her shoulders, forced her to give it up. Consequently she then studied to be a clinical psychologist to work with families with disabled members.

The shame expressed by her mother never left her. Carol did go to Warm Springs on a couple of occasions as a child, staying in a cottage next to Franklin Delano Roosevelt the



first time. She made a good impression on him and he invited her to his inauguration; however her father would not take her since he was a Republican. She kept the invitation and letter from him for the rest of her life.

Anne touches on the importance of using support groups such as our Madison Area Post Polio Group to share feelings and experiences – a place where there is no need to feel shame since all participants theoretically also have similar challenges. Unfortunately, Carol Rosenstiel did not have and was not encouraged to interact with others with disabilities and she was forever living in the world as if polio was not a factor in what she could or could not do, instead pretending that everything was normal and no effort required to accomplish everyday tasks.

This book captured my interest from page one to the end – first by the history of polio and then reflecting on challenges my parents faced when I had polio and the challenges faced by my husband and children because of the polio.

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## The Miracle of the Singing Bunny

### Sunny Roller (elsol@umich.edu)

Her bright blue-eyed pre-kindergarten daughter lies flaccid in a hospital bed, almost completely paralyzed from polio. Now 60 years ago, that horrifying summer polio epidemic had swooped this young family into its vile clutches, never to fully let go during their generation. Devastated, Marj, her husband, Art, and their toddling one-year old son, Scotty somehow got a ride back and forth to the urban acute care hospital every day to see Sunny. It was 1952 and the couple didn't even own their first car yet.

*Throughout their frightening earliest bedside visits, they knew death loomed all around. Children with polio were dying in the beds nearby. Would their firstborn little girl live or would she die with the others?*

*After what seemed an eternity of days, an attentive young nurse approached them smiling, "I have good news. We're out of the woods! Sunny will be okay. We don't know how much strength she will regain though. The doctors say she will need about nine months of rehabilitation now, likely followed by several orthopedic surgeries and years of physical therapy. But she has survived!"*

So now it began—this young family's search for the strength to stay endlessly hard working, encouraged and optimistic. Marj lovingly asked Sunny that afternoon, "What would you like me to bring you tomorrow, Sunny? What would make you feel better?" Sunny searched her imagination. "A singing bunny," she softly whispered.

*"Yes," Marj thought. "Perfect. A cuddly and cheerful bed-friend with a music box inside to hold close and sing to her in this humorless hospital." "Okay Honey. I will bring you a singing bunny..."*

Do you believe in miracles? I do. I recently read that nearly 80% of Americans do too. I have seen miracles, felt the presence of encouraging and comforting angels and have encountered many spiritual inspirations. They are often what helped me get through my tough lifelong encounters with polio. With this in mind, let's get back to the story about a miracle that happened to my mother long ago in 1952 ...

*Marj left the hospital that afternoon determined to make Sunny a singing bunny. She found a stuffed toy rabbit at home in a box of playthings. She figured out that she could snip a slit in the fabric, dig out a little filling, and then find a small music box to sew into the bunny. But in searching through all the toys, she found no music box anywhere in the house. So, determined to get to the shops before they closed, she swooped Scotty up, lowered him into his baby stroller and hustled half a mile downtown to buy a music box. Sunny must have a singing bunny! But after searching the shelves and inquiring in every promising shop downtown, she was left be-*

*reft. Every single merchant told her, "Sorry, we have none."*

*What could she do now? A musical stuffed animal was her fragile little girl's lone request. And this mama knew that right now, a singing bunny could be the one special buddy Sunny needed to keep her company through the grueling months of stinky hot packs, painstaking physical therapy and learning to walk all over again with orthopedic braces and crutches.*

*Bewildered, Marj plodded along the sidewalk toward home, mindlessly steering her son straight ahead in the baby stroller. Suddenly a sparkle in the grass caught her glimpse. As her eyes focused downward to the shiny object, she couldn't believe what she saw. It was a little music box that someone must have been dropped or thrown away. Amazed and delighted, she snatched it up and wound it up. Dingling a tune, it worked! Racing home, Marj washed the newfound treasure off and carefully stitched it into the awaiting stuffed rabbit. Together Marj and Art delivered the new singing bunny to Sunny the next day. And that bunny stayed close and served its purpose as part of the family for years to come. Actually he's still around somewhere.*

I'm so thankful that Mom shared this story with me before she died. She taught me that there are unexplainable events in our lives that help us get through. And just as Mom shared her account with me, I believe that we may very seriously want to consider sharing our life experiences with the children and grandchildren in our lives. Who we are and what we have experienced in life can offer young people a sense of their genetic heritage: describing where they came from; endorsing what they can still become.

Recording our life experiences might be a wonderful project to do in our support groups. Together we can begin to encourage one another to document our personal stories either in writing, on audiotape or DVD. Each person might write a comprehensive memoir or just

one or two short stories. The support group could invite a guest professor from a local college to help members learn about how to write effective memoirs or successfully record oral histories. The group also might want to engage a local media specialist to help certain members create quality DVD recordings.

Support group members could choose to compose short autobiographical stories that teach life lessons or illustrate personal values. We could document individual experiences about overcoming the odds or taking risks that either paid off or failed. We could tell about the role of people we encountered throughout life that either helped us succeed or who were desperately difficult and discouraging. We could write at home, and then bring the stories to group meetings to share--even engaging each other to constructively critique the writings for diction and syntax. Another option might be to find a child, grandchild or student who needs "service-learning project" credit to record our life stories. We might even find a budding journalist like the lead character in this year's movie, *The Help*, to listen and write it all down for us. Whatever works!

As polio survivors, we have a rich legacy to leave. We have experienced life from a unique and important perspective. Believe it or not, the "kids" in our lives want to hear from us directly now more than ever. And frankly, we'd better do it fast.

*Sunny Roller, a polio survivor, has written a variety of published professional articles, personal essays, and book chapters; edited an instructor's manual for a holistic wellness program for people who had polio; and presented at national and international post-polio conferences. In 1997, the Regents of Central Michigan University awarded Ms. Roller an honorary M.D. degree for her pioneering work in the field of post-polio disability and wellness. She currently serves on PHI's Board of Directors.*

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

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

**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, July 14, 2012**

**Linda Lane, CEO, Independent Living, Inc.**  
will talk about their programs.

**Saturday, September 8, 2012**

**Honoring Caregivers**  
After viewing excerpts from the DVD  
“And Thou Shalt Honor”,  
open discussion will follow.

