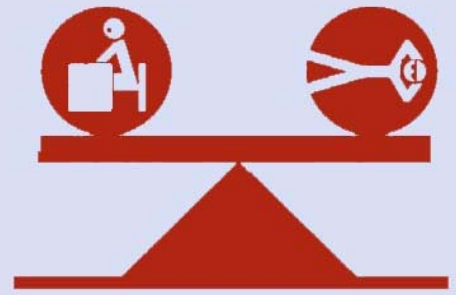


POST POLIO PACER

Conserving Strength and Energy through Pacing
July 2011 — Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 — This Is Our 26th Year!



TRAVEL BY AIR, RAIL, BUS & SHIP

By Ruth Diehl

Last fall, I shared some travel experiences with the Post Polio Support Group, and was asked to put together an article for the newsletter. I can't include all the details but will give an overview.



I've been traveling for about 40 years and things have changed a lot. Accessibility improves every year. My abilities are changing too – I have switched from a manual wheelchair to a motorized chair, which makes using public transportation more challenging but greatly improves my mobility when I get to a destination.

In the early years, I traveled more by airplane because buses and trains just weren't accessible. I was traveling to Europe, Asia and Africa, so planes were really the only option. I was using a manual wheelchair then, and the airlines can handle that reasonably well. Now that I've switched to a motorized chair and transfers are more difficult as I get older, I prefer my own car, trains, buses or cruise ships, because I can stay in my wheelchair. Airlines will transport a motorized chair but I'm always concerned about the potential for damage. So I've cut back on airline travel in recent years to try out some of the other options.

I took the Amtrak train to New York City a couple of years ago. The train has accessible seating and an accessible bathroom in a few cars on each train. The seating is near the entrance door and you can stay in your wheelchair or transfer to the train seat. The nearby bathroom has a wide door and adequate space inside. Entrance to the train varies by station. Some are level and you can roll

right in. Other stations provide a lift to raise you in your wheelchair up to train level. The entrance was just wide enough and required a sharp turn, so if your chair is extra wide or long, you may need to check the dimensions in advance. You can only get to your seat and the bathroom. The rest of the aisles are too narrow to pass. Train staff will bring you food from the dining car.

Accessible seats must be reserved advance by calling Amtrak and you will receive a 15% discount. They have accessible sleeper cabins as well, but I have not been in one.

I have used both Badger Bus (for trips to New York City and Branson) and Coach USA/Van Galder (for trips to O'Hare and the train station). These buses have a lift on the side near the back of the bus which lifted me in my wheelchair up into the bus, where there was space for me to travel in my chair. Tie downs are provided. The Badger Bus trips were tours and included overnight stays. I worked with Badger Tours staff in advance to assure I would have accessible hotel rooms. They were very helpful. Both bus companies require advance notice so they can assure accessibility.

I have been on cruises to the Caribbean, Alaska, Norway, and the Panama Canal. I have found Royal Caribbean to be the most accessible and the



most helpful. Accessible cabins on the ship have wide doors, level entrances, accessible bathrooms, and extra space. Trips ashore vary in accessibility. A few shore excursions are accessible but many are not, so I often just roam around the port towns to soak up the local atmosphere. Royal Caribbean has accessible tenders (boats that take you ashore) in case you are at a port that does not have a dock for the ship. One great advantage of cruises is that you only unpack once and yet see many great locations.

Car travel is nice because you have your own transportation when you get to your destination. We just returned from a 3 month car trip to Texas (including a cruise out of Galveston). With the Internet, it is fairly easy to reserve accessible ho-



tels and get lots of information about sites along the way. Of course, each hotel interprets accessibility a little differently. I have found hotel chains like Comfort Inn are pretty consistent across the nation. So once you find one you like, you can get fairly good accommodations wherever you go.

Travel can present challenges to those of us with disabilities but with a little persistence and a sense of humor, you will have a wonderful time.

Easter Seals Camp Wawbeek Continues to Need Our Support

One way to help is to make a gift to the Campership Fund. Make checks payable to Easter Seals Wisconsin & send to Easter Seals Wisconsin, 101 Nob Hill Rd.,



Suite 301, Madison, WI 53713.

Another is to bring to the July luncheon meeting, items that are always needed at Camp Wawbeek & Respite Camp. They are: wet wipes, bug spray, sunscreen #30 or 45, non latex powderless gloves—all sizes, construction paper, markers & other craft supplies, white T-shirts, & masking/duct tape.

For a more comprehensive list, please visit <www.EasterSealsWisconsin.com>. Donations made at the meeting will be delivered to Easter Seals.

Many thanks to those who have already made monetary and/or supply donations to Camp Wawbeek this year.

Learn About Chair Yoga on Sept. 10

Mindy Wiseman, OTR and Chair Yoga Instructor will demonstrate and talk about chair yoga at the Sept. 10 PP luncheon meeting.

She's been working as a registered Occupational Therapist since 1985 and currently works at Care Wisconsin.

Mindy completed her chair yoga teacher training in 2009 and is certified in Lakshmi Voelker Chair Yoga. She completed the 200 hour yoga teacher training in Alignment Yoga in March 2011, and is registered with the Yoga Teacher Alliance.

F.Y.I.
Precautions re: Mammograms and Dental X-Rays/ A Useful Warning

Dr. Oz had a show on the fastest growing cancer in women, thyroid cancer. It was a very interesting program and he mentioned that the increase could possibly be related to the use of dental x-rays and mammograms. He demonstrated that on the apron the dentist puts on you for your dental x-rays there is a little flap that can be lifted up and wrapped around your neck. Many dentists don't bother to use it. Also, there is something called a "thyroid guard" for use during mammograms which is seldom used unless you ask for it. **So the next time you have a mammogram or dental x-ray, be sure to ask for the guard for the neck.**

In Memorium

During the past few months information has been provided about the following people who have passed away.

Don Minter's wife Nancy of Portage, WI provided this tribute.

Don Minter was born September 8, 1948. The polio came when he was just 3 years old and robbed the strength from his legs but not his spirit. He was a man who never complained about anything and he overcame obstacles most of his life, a man who would do anything for anyone. He had recently retired from American Family Insurance where he had worked for 40 years. He was an avid fisherman, hunter, and outdoorsman. He was also a skilled craftsman and enjoyed wood-working. He had a wealth of knowledge that he would share with anyone who was interested. He is greatly missed and was a best friend to many. He went to heaven July 20, 2010, due to complications from asthma.

Curtis Konopacky shared this information about his mother.

Marjorie Cammack Konopacky was born on October 28, 1916 in Buffalo, SD. She contracted polio when she was 10 years old and was hospitalized in Madison, WI. She was 93 years old when she died on September 8, 2010. Richard, her husband and 3 children, myself, and my two younger sisters, Lyn Konopacky and Peggy (Kurt) Slowinski, all are still alive.

Mom was employed at the Medford Star News and Stevens Point Journal as a printer and linotype operator for many years.

She was a Stevens Point alderwoman from 1967 to 1975 and served on numerous committees for the entire time she was in political office.

In 1973 she received Samoset Council's (Boy Scouts) highest award for women volunteers, The Silver Fawn Award. She also held the Den Mother Training Award and the National Instructor's Training Award.

She also was a member of St. Stephen's Prayer and Study Group.

Mother dedicated much of her life to volunteer ,

work and community service along with raising the three children she was told she could never risk delivering.

There was nothing that my mother could not do or would not attempt. She could paint, draw, sew, and do any kind of craft work that existed. The polio didn't slow her down until the last few years.

Our condolences to each of these families.

Caring – Our Gift to Each Other

By Kathleen Blair

June 21-28—seven days that rank high on my list of happy days in 2011. Thanks to my son, daughters, daughter-in-law and grandchildren, I was able to enjoy the Inaugural State Wars Soccer Tournament at Uihlein Soccer Park in Milwaukee. It was a delightful family event.

A family member was always willing to drive me to and from Milwaukee from my home in McFarland, Wisconsin, squeeze my wheelchair into their vehicle, and wheel me into the arena when we arrived. Zach (WI 1997 Team) and Caleb (WI 2000 Team)



played in their respective age group tournaments. Sitting right up front beside the bleachers at one end of the indoor soccer field, I watched sixteen games during those seven days and didn't miss a play. What a great release! Since I was off my feet, my back was pain-free most of the time, and my mind engaged in so much excitement I didn't feel handicapped. I experienced all this fun thanks to my caring family who pushed me in the same

wheelchair in which we pushed their dad several years ago.

Having previously supported and cared for my disabled husband, I understand the sacrifices made by caregivers, but I also know the greater satisfaction of giving to a loved one. Frequently, we take a deep breath, smile inwardly and say, "Thank you, God, for helping us through this."

However, my sacrifices were minimal compared to our PPS friend, Mary Parks, who cared for her husband, Tom, for 34 years, and she did it from a wheelchair while working full time to support her family!

"Disability certainly changes the dynamics in a family," Mary told me. "Our two daughters were forced to grow up fast because they had two disabled parents." My heart swells in admiration of the two Parks daughters; they learned to help their mom and dad at a very early age.

"One of the most important things in caregiving," Mary said, "is to let the disabled person have as much control over his or her life as possible even when it might appear to be easier to do it yourself. It is as much of a joy to the caregiver as to the person receiving care when that individual is able to accomplish personal cares. Self control and dignity are important." Thank you, Mary for sharing those very important insights.

Bob Kail who has "been there" for Fayth all of their married life says he doesn't feel that he's doing all the caregiving.

"Fayth is a wonderful woman," Bob said. "She makes both of our lives wonderful because of her attitude. She worked for many years until we retired, is independent and takes care of herself even in her wheelchair." They are definitely a couple to be admired.

Ruth Diehl has enjoyed traveling in the United States plus numerous countries around the world, thanks to her husband, Bob, who serves as capable caregiver and travel companion.

Earlier this year Bill Holman stepped in as a super caregiver when Marcia suffered a broken hip. As Marcia wrote in the January 2011 Pacer, "after three days of PT she was discharged to go home with Bill as her caregiver, and she couldn't have had a better one." Actually, I was impressed with the daily emails from Bill keeping us apprised of

Marcia's progress.

Marcia said, "Bill was able to keep us fed, have clean clothes, have a reasonably clean home and get me to my many PT and doctor appointments. Without his help I would have had to go to a rehabilitation center for a few weeks."

"Now it is my turn to be Bill's caregiver. He had an accident in April with his new Harley Davidson trike which resulted in three broken ribs on his left side and serious fractures of his right wrist. Coming home after eight days in the hospital, my assistance was needed for fastening buttons, belt buckles, tying shoes, cutting up food and carrying anything that required two hands."

Marcia's OT skills are valuable now as she helps Bill with his therapy, and massages his injured hand and forearm to help him regain use of his right hand.

"And the saga goes on," Marcia said, "Sometime in the future I will have my left total hip replacement when Bill's right hand is more functional and he can be caregiver again. Together we make a great team and our love grows."

Reflecting on my own experiences and after talking with my PPS friends, I've affirmed my conviction that caring goes both ways and attitude is everything. We return the love and care given by our families and friends in the best way we can, and our ties remain strong.

What gifts we are to each other!

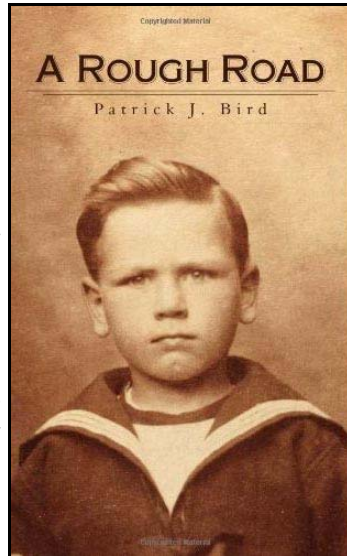
Golden Rule of Post Polio Syndrome

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

The Book Shelf

A ROUGH ROAD By Patrick J. Bird

This recently published book, *A Rough Road*, is a novel based upon the author's nineteen month confinement in a "reconstruction home" after contracting polio in 1940. The story may resonate with many polio victims and also appeal to anyone who had experienced long-term separation from home and family as a child, for whatever reason. In addition, it provides a glimpse into the treatment of polio victims prior to the innovations of Sister Kenny and the rehabilitation knowledge gained treating soldiers injured during World War II.



It is available from Amazon.com, Kindle eBooks, as well as through book stores and other outlets. ISBN-13: 9781452892955 \$10.45 Trade Paperback

The following is a summary of the book.

After contracting polio at age four in 1940, Paddy spends nineteen months in a "reconstruction home" far from his family. This is his story of that time, presented mainly from the child's point of view.

Enduring aching sadness and loneliness along with the pain and disappointments of rehabilitation, Paddy learns to prevail physically and emotionally through his interactions with a colorful cast of hospital staff—from a friendly giant orderly and a light hearted nurse to a no-nonsense physical therapist and an evangelical swimming instructor as well as an imposing and frightening physician and his unsympathetic nurse.

Perhaps most important to his "reconstruction," however, is the arrival of roommate Joey. An older, adventure loving youngster with spina bifida, Joey introduces Paddy to the joys and tomfoolery of boyhood and inspires him with his physical and mental toughness. Then there are the infrequent—but significant—visits of Paddy's

mom, who is sure the Blessed Virgin will cure him, and his pop, who fears in his heart that he will have a *cripple* for a son.

Also woven gently into the fabric of this deeply personal story are relevant aspects of the polio experience during the early 1940's including the painful immobilization in casts, the dreaded iron lung, the often unwise corrective surgery, and the stigma (feeble and likely retarded as well) associated with survivors—even President Roosevelt, for instance, stricken with polio in 1921, went to great lengths to hide his atrophied legs from the public.

A Rough Road is a testament to the capability of children to overcome the most difficult of times. It is a walk down memory lane for some, a lesson in history for others, and a moving experience for all.

T'N'T for POLIO SURVIVORS

By Dr. Richard L. Bruno

No polio survivor-no one with breathing problems—should take Vesicare

Jane Smith went to her gynecologist with a common complaint: The Ditropan she was taking no longer was controlling her overactive bladder. So, her doctor prescribed a new medication, Vesicare, which Jane started on November 18. Four days later Jane was too exhausted to leave the house. The next day, all she did was sleep. By Wednesday, Jane was unable to stay awake. When she was awakened she stared into space, unable to understand or respond appropriately to questions. Even more frightening, Jane's ability to breathe was compromised. While asleep, her oxygen dropped to 78% (normal 90%). When she was awakened, her oxygen was in the low 90s (normal 95%) and carbon dioxide rose to 55% (normal 45%). Jane was placed on a ventilator with a face mask.

Vesicare was stopped on November 24th. The next day, Thanksgiving, Jane was still unable to stay awake on her own but, when prompted, did try to eat. She discovered that her stomach and intestines had shut down, a side-effect of medications like Vesicare that are anti-cholinergic, that stop you from peeing, that cause a dry mouth and, especially in polio survivors, can turn off your

gut. Jane was placed on a liquid diet and given domperidone, a drug available through Canada, which activates the stomach and intestines without entering the brain, as does Reglan, the medication typically used to treat gastroparesis.

Unfortunately, Vesicare has an extremely long half-life. It would take Jane's body anywhere from 10 to 14 days for the Vesicare to clear out. During those days, although Jane mostly slept, she became progressively more aware and mentally sharp when awakened, but she could only eat very small amounts.

On the 15th day after Vesicare care was stopped, Jane awoke like Sleeping Beauty. She was able to stay awake on her own and was her usual intelligent and funny self, albeit easily tired. Although her intestines were functioning thanks to domperidone, Jane could still only eat small portions. She was given Erythromycin, an antibiotic that also stimulates stomach emptying. After three days, Jane was eating normally. Today, one month after waking from her Vesicare-induced stupor, Jane is back on the Ditropan, which is again controlling her bladder. Unfortunately, Jane still requires the ventilator at night and at times throughout the day when her diaphragm is unable to push enough carbon dioxide out of her lungs. Jane will need the ventilator for the rest of her life.

What are the morals of this frightening story? First, no polio survivor – no one with breathing problems – should take Vesicare. When I called the drug's maker, Astellas, about Jane's condition, the physician director of "adverse reactions" was aware that Vesicare not only turns off the bladder, but also turns off the stomach and intestines and enters the brain. Vesicare is known to block activity in brain areas damaged by the original polio infection, the brain activating system. In fact, the doctor told me that Astellas had just been required by the FDA to add "somnia" to Vesicare's list of side effects. Somnia? How about coma? To date, Astellas has not notified physicians that "somnia" is one of Vesicare's side effects.

I also discovered that Vesicare is also known to block brain diaphragm stimulating neurons. So, Vesicare did to Jane what the poliovirus had not done 60 years earlier: put Jane on a ventilator and, in effect, gave her the symptoms of "bulbar" polio.

I told Astellas' doctor that I was concerned Vesicare

would very likely have the same effect in other polio survivors, especially those who originally had bulbar polio or any polio survivors who had breathing problems, such as central sleep apnea. What's more, I told him I was worried that individuals who had both difficulty breathing and bladder problems and might be prescribed Vesicare – those with muscular dystrophy, multiple sclerosis and traumatic brain injury – might have a reaction like Jane's. The doctor told me that people at Astellas were "discussing the issue."

The second moral is that polio survivors can have difficulty blowing off carbon dioxide and should not be given oxygen without having their carbon dioxide monitored, since oxygen levels can be normal while carbon dioxide can become dangerously high.

The final moral is that a polio survivor should never take a drug that is **anti-cholinergic** or that enters the brain without your doctor researching the side effects. The coma you prevent will be your own.

Dr. Richard Bruno is Chairperson of the International Post-Polio Task Force & PPS Institute. He may be reached for consultation at <postpolioinfo@aol.com>

Reprinted from United Spinal Journal: Action March-April 2011

Do you have friends (polio survivors or not) or family who would like to receive the quarterly Post Polio Pacer in color on-line?

Encourage them to send their e-mail address to wghmch@chorus.net with instructions "I wish to receive the on-line Post Polio Pacer". Set your email program to always accept messages from wghmch@chorus.net

If a print copy is preferable, send your/their name and address to Marcia Holman, 3629 Alpine Rd., Madison, WI 53704-2201 indicating "Please add my name to the Easter Seals Post Polio mailing list."

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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: 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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**Russell King, Exec. Dir. of Home Health Founda-
tion, will discuss changes in home health care.**

September 10, 2011

**Mindy Wiseman, OTR and Chair Yoga
Instructor demonstrates and talks
about chair yoga.**

