

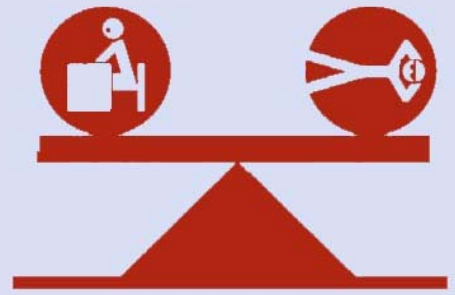
# POST POLIO PACER

*Conserving Strength and Energy through Pacing*

*April 2011 — Madison, Wisconsin*

*Madison Area Post Polio Support Group Newsletter*

*MAPPSG formed in 1985 — This Is Our 26th Year!*



## It's Our Turn Now

**By Kathleen Blair, Columnist**

During a recent telephone conversation with my sister, I described to her how I managed to get to most of my three grandsons' basketball games this past winter. Yes, that's three grandsons: Zach – 7th grade, Henri – 6th grade, and Caleb – 4th grade. Each winter week I would check my calendar to decide which games I could fit in beginning Friday evening and ending Sunday afternoon. Winter "flew" by with the hectic basketball schedule.



No, I wasn't trying to be "grandmother-of-the-year" nor did I feel duty-bound to be at the games. I just love watching my grandchildren's school activities, be it athletic events, concerts or plays. It helps me to relive the many years my late husband, LaVerne, and I attended our children's school events. It was fun then and it is fun now.

Knowing that I'm able to walk only short distances on dry surfaces with the aid of a cane, Margaret asked, "How do you manage to get into the games with all the snow and ice?"

"I carry a wheelchair in the trunk of my car."

It's the same wheelchair I pushed my dis-

abled husband around in for 12+ years. It's lightweight, has balloon tires, and handles easily. Since I pushed that wheelchair through snow and slush when I was the able-bodied one, I know the weather usually doesn't present a problem. If I can drive to the school where the game is being played, I can ride into the gym in the wheelchair – that is, if I can find someone to lift it out of the trunk and wheel me through the entrance door. Actually, that's the hardest and most humbling part – I'm not comfortable having to ask for help. It was much easier to be the helper.

When I arrive at the school, I pop my trunk and a family member is usually there to lift the wheelchair out and wheel me inside. If no one is in sight I use my cell phone to let a son or daughter-in-law know I'm there.

On those rare occasions when a family member isn't readily available, I sit in the car and watch for a familiar dad to appear. Then I beep my horn and signal for help.

"It's really hard asking for help," I lamented to Margaret, "but I would hate it more if I had to sit at home and miss watching the kids play, as long as I can figure out a way to get there."

"Those dads are always generous with their help," I said. "And I find myself hoping they feel good about helping me, remembering how much more fun it was to be the one giving the help than it is now to be on the receiving end."

"Well, just remember it's your turn now," Margaret told me. "Don't sit at home and risk

slipping into a depression. Get out as much as you can, and let others feel the joy of helping you. Give them the opportunity to feel good about themselves."

And then I went to our Madison Area Post Polio Support Group Meeting on Saturday, March 12th, where I enjoyed the camaraderie of fellow polio survivors. All of us had served others through the years; in our families, workplaces, churches and neighborhoods. Now as post-polio syndrome takes its toll, we are called to, not only accept help, but to request it when needed, and to give our families and others the opportunity to care for us. Remembering how much we used to enjoy being givers, it's our turn now to be receivers.

At the March 12th meeting, Fayth, Gail and Mary as well as others, expressed attitudes of gratitude. As Fayth put it, "Many of our friends have passed on. We thank God that we are still here just as we are."

As my big sister told me, "It's your turn now!" Let's remind each other, "It's our turn now!"

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## Post-Polio Thoughts

Nancy Baldwin Carter, B.A., M. Ed. Psych,  
Omaha, Nebraska, (n.carter@cox.net)

### Changes of Heart

"You just don't get it," she said.

My friend was accusing me of having "no idea what it's like to be handicapped." No milk of human kindness coursing through my veins, apparently. No empathy.

In a sense, she's right. Never mind that I spent a year in hospitals, fighting my way out of total paralysis when I was a kid. Haven't raised my right arm since. Haven't had a neck that could hold up my head. Never mind. And post-polio paralysis increasingly riddling my

body for the past four decades. Never mind. When the high school principal at my first teaching job, unaware that he was being politically incorrect, told me I was the most normal cripple he'd ever seen, I knew he meant to compliment me. Odd, I thought, that he would think of me as a cripple. I saw me as a teacher. A good one, too. And a daughter, a sibling. And a friend. But I never thought of myself as a cripple—or even a person with disabilities.

Of course I know I have physical limitations. Nobody with a body as erratically functional as mine could miss the fact that often it's not working well. So what? I always get the job done. One way or another.

The thing is, we don't all think alike. Certainly not my friend and I. My disability seems normal to me; it's simply the way I am—it's me. Not non-disabled, but me. So my arm doesn't work. How does that feel? Well, after sixty-two years of this, it feels normal. Does my disability seem normal to her? Probably not. Am I in denial merely because I don't think of me as she does? Hardly.

So what is it like to be handicapped? Our answers are shaped by our personal experiences, our philosophies—to her it's one thing, to me, another. Both valid. How I feel inside about disability does not necessarily have to reflect the condition of my body.

Years ago I had a doctor who berated me for suggesting that my pain and weakness could be polio-related. "Nonsense," he said. "I had polio when I was in medical school and nothing like that is happening to me." He wrote the name of a shrink on a prescription pad and said, "Here. This will help you." Adios, doc.

Some time later, he ran into my husband at the library. He was retiring, he said, stepping down because he was undergoing symptoms of post-polio syndrome. He apologized. He had seen the light. A bit of revised thinking when it became his dysfunction. Was he learning what it's like to be handicapped?

Obviously having had polio did not make this man a better “polio” doctor. But I cannot forget that the most amazingly knowledgeable and wonderfully understanding polio doctors in my life were not polio survivors. Did they know how it felt to be handicapped? Does it matter?

Here’s what matters to me: I want independence. I want to be the one to decide. I want to do what I can do. I want to accept me as I am and love the life I live. It’s an attitude. A state of mind.

Do I know what it’s like to be handicapped? Define handicapped.

Nancy Baldwin Carter, B.A., M. Ed. Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

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

**A MATTER OF WORDS**

Handicapped, crippled, disabled you say,  
Whatever term you use, I say, "No way!"

I do have limitations as one can plainly see,  
But that doesn't keep me from being me.

Chores take forever, and tears do come,  
But what a sense of accomplishment  
When the job's done.

My walk is slow, and I'm clumsy as a bear,  
If my friends don't notice why should I care?

If I sound like I'm preaching, maybe I am,  
It's not what I can't do, but rather what I can.

Nancy McElmurry

## Living in the Moment\*

### Practice Mindfulness to Reduce Stress

By Karen K. Ross, PhD., DMRF Vice President of Support



\*This article is reprinted with permission from “Dystonia Dialogue”, magazine of the Dystonia Medical Research Foundation, Winter 2010, Vol. 33, No.3.

*Editor’s note: Mary Parks provided this article with the following comment: “As a polio survivor and PPSer, I identified with the anxiety immediately, especially every time I transfer – from bed or toilet. I thought the article might prove helpful to others as well so received permission for reprint.”*

While stress does not cause dystonia, feelings of anxiety can certainly make symptoms worse. Taking a few moments each day to focus on relaxation can improve your overall well being and may help keep dystonia symptoms under control.

*Mindfulness* – the practice of living in the present moment. *Mindfulness meditation* is a practice that uses focusing on the breath as a way to calm the mind and body. The primary focus is your breathing. However, the primary goal is maintaining a calm, non-judging awareness, allowing thoughts and feelings to come and go without getting caught up in them.

Here are the basic steps of mindfulness meditation:

Sit or lie comfortably, with your eyes closed and, if possible, your spine reasonably straight.

Clear your mind and direct your attention to your breathing. Observe your natural breath without trying to change it.

When thoughts, emotions, physical feelings, or external sounds occur, simply acknowledge them and let them go without judging or getting involved with them.

When you notice that your attention has drifted off and your mind becomes engaged in thoughts or feelings, simply bring them back to your breathing and continue.

Start by trying to meditate for 3-5 minutes & gradually try to progress to 20-30 minutes.

It's natural for thoughts to arise and for your attention to follow them. No matter how many times this happens, keep bringing your attention back to your breathing.

For additional relaxation and meditation practices to combat feelings of stress and anxiety, visit <http://www.dystonia-foundation.org> under "Living with Dystonia."



### **F.Y.I.**

Most of us can't do the physical giving and aren't millionaires, so this is a simple way to help others.

Did you know there are several websites that allow you to help others with the only cost to you being the time you spend online? Some even provide games to keep you entertained while donating rice or water! Since our disabilities prevent a lot of physical help, this could be an alternative. Here are a few you might enjoy visiting:

[www.TheHungerSite.com](http://www.TheHungerSite.com)

[www.FreeRice.com](http://www.FreeRice.com) (word games)

[www.TheBreastCancerSite.com](http://www.TheBreastCancerSite.com)

[www.TheAnimalRescueSite.com](http://www.TheAnimalRescueSite.com)

[www.FreePoverty.com](http://www.FreePoverty.com) (geography)

[www.TheRainForestSite.com](http://www.TheRainForestSite.com)

There are some ads from sponsors as well as the opportunity to purchase goods that also help the organization; however, there is no cost to just click to donate. Thanks to Mary Parks for the above information.

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New information is available at Post-Polio Health International [www.post-polio.org](http://www.post-polio.org)

"Post-Polio Health Care Considerations for Families & Friends", page 2 of Winter 2011, is available on PHI's website [www.post-polio.org](http://www.post-polio.org) It can be downloaded as a booklet or can be viewed in sections choosing the most relevant topic by clicking "Let's Begin"

Polio Place, [www.polioplacel.org](http://www.polioplacel.org) a dynamic Internet repository for medical and practical information, historical records and artifacts went on line on January 30, the 120th anniversary of Franklin D. Roosevelt's birth. Polio survivors are encouraged to submit to the *Artifacts* area of the website essays on "Living with Polio", unique devices or ways of increasing your independence, and photographs, letters, or a newspaper article that tells your polio story.

## What Did You Miss on March 12?

Russell King, from Dane County Emergency Management, provided a lively and interesting discussion about "Emergency Preparedness for People with Disabilities". He indicated we must prepare ourselves, family, homes and community for disasters, and that much has been learned about problems after the Katrina hurricane and California fires.

He had several recommendations for preparedness for emergencies:

1. That people sign up for the reverse 911 at: <http://www.countyofdane.com/emergency/assistance/reverse911.aspx>
2. In an emergency, the best place for a person in a wheelchair, is in a room without windows, generally the bathroom.
3. If you have a power wheelchair or need ventilator assistance, have back-up batteries and/or a gas powered generator available in case the electricity goes off.
4. He suggested that if you would need special assistance in the case of an emergency, you should sign up with Dane County Emergency Management.

Dane County Disaster Assistance Voluntary Registration Forms were provided for those attending the luncheon meeting. He left extra copies to be distributed at the next meeting.

On July 9, Mr. King, who also is Director of WI Homecare Organization, will speak to us about changes in home health care. Come and learn about the changes in home health care and pick up a Dane County Disaster Assistance Voluntary Registration Form for yourself or a friend.

### Golden Rule of Post Polio Syndrome

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

## Polio Outbreaks in Central Africa and South Asia

by Dr. Richard L. Bruno

Last November, an unusual polio outbreak occurred in The Congo Republic. A "wild" (naturally-occurring) Type I poliovirus, imported from Angola, has paralyzed at least 409 and killed 170. What is unusual is that those affected are not children under five but adults 15 to 29 and that 41% have died, versus the norm of 15% in an epidemic. Historically, more deaths do occur when older individuals get polio, but not nearly half. This epidemic, in a country that had been polio free for 10 years, adds to the continued outbreaks in countries where polio remains endemic: Afghanistan, India, Nigeria and Pakistan.

There is an aspect of the Congo epidemic that is not unusual: There has been no mention of it in the American press. However, there was wide-spread attention given to a polio outbreak in May 2010. A wild Type I poliovirus imported from India triggered an epidemic in Tajikistan that spread to three other previously polio-free countries and all the way to Moscow, affecting 476. This outbreak was more typical; 86% of those initially infected were children and 6% died.

This European pandemic caused the American Academy of Pediatricians in July 2010 to warn that "Low immunization rates in parts of U.S. could pave the way for a polio outbreak, [showing] how precarious our control of the disease can be, when immunization rates fall below the target level of 90%. The polio immunization rate in Tajikistan is 87%." The article goes on to warn that "polio immunization rates are lower than 90% in many areas of the United States" because of parents having "no recent experience" with polio, "concerns about vaccine safety and religious objections to immunization. With increasing globalization, the United States could be just an asymptomatic traveler away from an outbreak." Remember, 70% of individuals infected with the poliovirus have no symptoms but can carry and spread the disease.

In 2007, the International Post-Polio Task Force began the National Immunization for Polio Prevention in Infants and Toddlers—or "NIPP-IT"—Campaign, when CDC reported drops in polio vaccination and that one million U.S. infants and toddlers were unvaccinated against polio. The NIPP-IT motto: "America's next polio epidemic could be just a plane ride away."

This theme was adopted by an August 2010 *Houston Chronicle* editorial: "Polio's return to Tajikistan has raised some unsettling questions. International medical activists had planned to snuff out the disease by 2000. What's going wrong? The ongoing problem seems to be a mix of factors. Some are political, such as Muslim leaders in Nigeria who originally branded the vaccine a western sterilization plot. Meanwhile, isolated tribes or subcultures can harbor the disease."

Not mentioned were the effects of war and corruption, lack of sanitation, basic public health and medical infrastructure and that the Sabin oral vaccine mutates and actually causes polio.

The editorial concludes: "Houston residents have reason to watch this battle and wish its warriors well. Even if polio is almost gone, the last cases will always be only a plane ride away from our own city." Indeed, Houstonians need worry. CDC found that Houston has the lowest polio vaccination rate of any reported U.S. city—87%—a drop of 5% from last year.

"Polio outbreaks highlight our global vulnerability to infectious disease," said Dr. Robert Scott, chair of Rotary's polio eradication effort. "It reinforces the fact that polio 'control' is not an option, and only successful eradication will stop the disease."

Unfortunately, eradication is not happening in spite of \$800 million spent on vaccination. In 2010, polio was at an all time high in Pakistan, primarily in the war-torn tribal areas bordering Afghanistan.

Perhaps it is time to admit that polio eradication is not possible given the political and social conditions in the Third World. Perhaps the millions being raised for polio eradication would be better spent, as the *Chronicle* proposed, "improving health care or hygiene more broadly," and, as Dr. Scott prescribed, a "fast, large-scale, high-quality immunization response" to any polio outbreaks, plus treatment for polio survivors and those with Post-Polio Sequelae.

The International Post-Polio Task Force has proclaimed 2011 "The Year of Getting Serious About Polio," serious about vaccinating America's children, about treating the world's 20 million polio survivors who have Post-Polio Sequelae and about containing—not eliminating—polio.

*Dr. Richard L. Bruno is Chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research. E-mail through PostPolioInfo.com.*

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### Easter Seals Camp Wawbeek Needs 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 May 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](http://www.EasterSealsWisconsin.com)>. Donations made at the meeting will be delivered to Easter Seals.

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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  
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program to always accept  
messages from  
wghmch@chorus.net

*Spring is here!*

*Spring is here!*



**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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**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, May 14, 2011**

**Randy Sproule will inform us about Rotary International's programs to eradicate polio in third world countries and their work with people with post-polio syndrome.**

**Saturday, July 9, 2011**

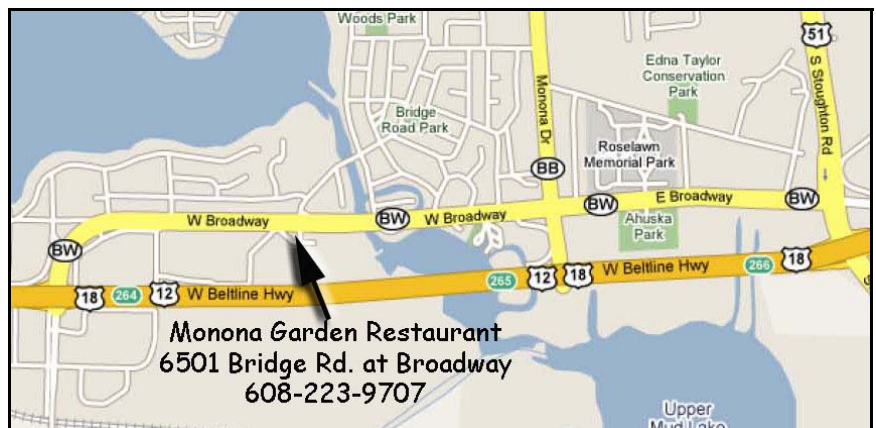
**Russell King, Exec. Dir. of Home Health Foundation, will discuss changes in home health care.**

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