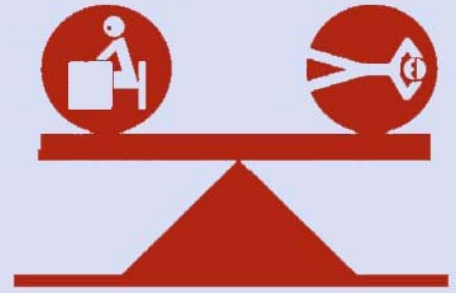


POST POLIO PACER

Conserving Strength and Energy through Pacing
April 2010 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985



Polio Survivors Ask...

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

Q: I need to lose weight. My longtime post-polio weakness limits my choices of exercise. How can I enjoy going the nutritional route?

A: Want some adventure in your nutritional life? Grab a wide-brimmed hat and head for the nearest farmers' market! Warm breeze nudging you from one canopied booth to the next, baskets of intriguing produce lighting up the gourmet corner of your brain, food so fresh you can almost smell the garden it came from mere hours earlier.

Talk with the vendors. Relish this one's description of the rather thin, tapered, dark green pod he holds, the perfectly-named Chinese rat tail—and imagine chopping this kooky radish into your next salad. Laugh with that one, as he explains in mock-exasperation that his 12-year-old nephew, dutifully spritzing the collard greens (not to mention the vendor in the next booth) is, well, just a kid and whacha gonna do. People! Fun!

Here's bright pink amaranth, which dazzles up a salad a bit more than the green variety, though they both have the same spinachy taste. And arugula—dark green here, a tender leaf with a peppery bite. And spigariello, long-leafed broccoli that comes with a dainty, yellow edible flower. All of these help make salads enticing.

Get an exciting assortment: Pleasantly bitter radicchio, its beautiful magenta leaves streaked with ivory; or frilly-edged kale, with its gray-green (and even purple) leaves and slight cabbage taste; or turnip greens and their mustardy touch of sweetness; or cabbage-flavored collards, flat and green; or baby bok choy, cupped deliciousness from the mustard cabbage family; and our old stand-by, spinach.

Make salads. Shred young, tender beets into them; embellish with fresh herbs like thyme or basil or dill or rosemary. All from the market. Add chickpeas or kidney beans or Craisins or slices of mangoes or pears. You won't need more than a touch of fat-free dressing. Steaming is good, too, quick and tasty, and will retain nutrients that otherwise might leach out if cooked in water.

This isn't merely a salad story. The best book I've seen about eating the right stuff in the right way is *Everyday Cooking* by Dean Ornish, M.D. Oh yes—it has scrumptious recipes, too. Who can resist Creamy Mushroom Stroganoff or Brandied Pear Bread Pudding or Braised Brussels Sprouts and Chestnuts!

Irma S. Rombauer's classic *The Joy of Cooking* is a wonderful source of veggie information, with outstanding drawings, overflowing with tips, explanations, and recipes.

Of course, the trip to the market merely whets the appetite for the eating changes we realize we must make if we want a different outcome. We all know losing weight requires taking in fewer calories than our bodies burn up. Here's the good news: This isn't about deprivation—it's about making healthier choices. Experiment. Try new stuff. Let curiosity get the better of you!

How about taking home a handful of delightful little Yukon Gold potatoes, so new the skin comes off when you barely rub them with your fingers? Steam them with some fresh green beans and a breath of basil. Heaven!

And don't forget to check out the kohlrabi, those alien-looking turnip-y globes with weirdly shaped appendages sticking out in all directions where leaves used to hang. Great for snacks or soups or stews.

What to drink? Remember the Brewster sisters in

the play *Arsenic and Old Lace*? Eccentric spinsters who treated their suitors to a sip or two of poison-laced elderberry wine? Here we have elderberry blossoms! You, too, can make your own wine. Or easier yet, brew up a pot of tea by steeping the blossoms in hot water. Or perhaps you'd prefer juicing a large, cool glass of antioxidant-packed aronia berries.

What a refreshing outing this has been!

A FEW TIPS

Food has wonderful flavor, all by itself. Everything doesn't have to taste like some form of fat and salt. Food already has fat and sodium in it—adding more may only mask the unique flavor of the food. Guidelines say our bodies actually require no more than 20-25 grams of fat a day. One tablespoon of ANY oil contains 14 grams of fat. One tablespoon of butter contains 14 grams of fat.

There's no good reason to fry food in butter or oil. Ever taste a fresh mushroom sautéed in its own juice? All that delicious liquid cooks right back up into the mushroom—divine! Invest in a Teflon skillet—that's all you need. If you know a food is absolutely going to stick to the pan, toss in a spoonful of the broth on pages 18-19 in Ornish's *Everyday Cooking* for spectacular added taste. Or very lightly spray the pan with Pam. Think you need to add fat in your recipes? Try substituting plain, unsweetened applesauce or plain yogurt instead of butter or oil. Use your inquiring mind. Alter recipes to fit your needs. Spend time investigating fat-free products.

Salt's another culprit. When 140 mg is the cutoff for low sodium, eating food containing five or ten times that amount simply makes no sense.

A smart choice of juices: Low-sodium, all vegetable V-8. No fat, 140 mg salt, nearly three times the potassium of a banana, 50 calories. Check that label out! And always use skim milk. Did you know you can whip it into "whipped cream?"

Here's a good exercise: Move away from FAT and SALT!

And sugar. Do we really have to say anything more about sugar? Here's a little nugget of chocolate candy barely over an inch long. Doesn't look as if much harm could be lurking there. How about 13 g of fat, 60 mg of sodium, 20 g of sugars, and 200 calories. What a bite! Think you can stop with one?

It's imperative to know the Nutritional Facts and Ingredients for everything we eat. Learn how to read these. For starters, they are on the back of every package of processed food. Pay attention to number of calories, amount of fat, sodium, sugar, and protein. Processed food can be riddled with things we don't even imagine. Don't ever buy any food without checking the labels to be certain you're within the nutritional parameters you've chosen for your eating style. To be clear: READ THE LABELS!

You can't beat this for canned tuna: StarKist's special Very Low Sodium Chunk White Albacore Tuna in Water—1 g fat, 30 mg sodium, 13 g protein, 60 calories. Compare that!

Eat Complex Carbohydrates—whole grains, breads, cereals, pastas, beans, which are absorbed slowly and can supply energy steadily, helping maintain an even blood sugar level. Limit Simple Carbohydrates—fruit juices, sugar, sugar products, jams, jellies, syrups, etc., which cause a quick rise in blood sugar, are easily converted into fat, and leave us feeling tired.

For times when cooking is out of the question, keep a well-stocked freezer. It's not much more difficult to make a quantity when cooking. Store individual servings in containers in your freezer to pop out for a yummy meal on those blah days.

Chestnuts may be the only nut that doesn't contain fat. Buy them peeled and vacuum packed with no liquid if you don't want to struggle peeling fresh ones. Mind you, we're not talking about water chestnuts here. Dream of all the ways you can use these nuts in your cooking.

Make this kind of cooking a hobby. What a sensational way to enjoy a day!

As always, seek your doctor's advice before making major changes in diet.

Want some delicious, healthful recipes? Please send a request to Nancy at <n.carter@cox.net>

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)

Addition to the Pacer Staff

Welcome Kathleen Blair,
Columnist for the Pacer.



Kathleen, the mother of seven, grandmother of fifteen and great-grandmother of 2, was widowed in 2002. Although she retired from her position as Vice President of Administration for PFS Corporation in 2005, she continues to author and publish their electronic newsletter. In her retirement she enjoys writing and serving as the family “memory keeper” of photos and home movies. Another project in progress is a book about disability and care giving based on her experiences of caring for her disabled, diabetic husband until his death.

Watch for Kathleen’s column in each issue of the Pacer.

How I Learned to be a Pacer

By Kathleen Blair, Columnist

“May I ask why you’re walking with a cane?” she asked.

“I had polio in 1955 and now I’ve been diagnosed with Post Polio Syndrome.”

“I thought so. My mother has Post Polio Syndrome so I recognized your symptoms. Do you know we have a Post Polio Support Group in Madison?”

“No, but I’m sure interested in learning about it.”

“Well, we meet at the Monona Garden Family Restaurant for lunch on a Saturday five times a year. Give me your email address and I’ll send you the schedule and a copy of our newsletter.” *This was too good to be true – a support group I needed with the meeting location only five miles from my home and at one of my favorite restaurants.*

This chat with Jennifer Klotzbach occurred during a break at a joint pastoral council meeting of our respective parishes in September 2008. Although I was eager to take in a meeting of the support group, family events or out-of-town trips pre-

vented me from attending until the following May. That’s when I realized how much I needed to learn more about my condition and how I needed to change my lifestyle.

The specialist who diagnosed my syndrome several years ago was not my primary care doctor. I don’t remember telling him I was still working and responsible for the care of my invalid husband 24/7. So, of course, I cannot blame him for not cautioning me about the importance of conserving my energy and avoiding fatigue.

I had made the appointment with a post polio specialist because I was having days where I felt weakness all over my body when every nerve ending seemed to be screaming. After some tests, he gave me a prescription and said I would need to take it for the rest of my life; I should start with one capsule a day and work up to as many as two or three. I don’t remember the name of the drug because I threw the bottle of capsules away after I had experienced too many “senior moments” in one week. I decided I’d live with the discomfort but I wasn’t going to give my brain away.

On receiving the Post Polio Pacer, I noticed the masthead carries the tagline “Conserving Strength and Energy through Pacing.” Wow! That’s the mind-set this Type A personality needed to adopt. And repeated often in the newsletter is the Golden Rule of Post Polio Syndrome: *“If something you do causes you fatigue, weakness or pain, you shouldn’t be doing it!”*

Yes, thanks to a chance meeting with the daughter of a fellow polio survivor my quality of life will be much improved through my change of attitude and change of lifestyle called PACING.

It’s a struggle, but I’m learning to stop pushing myself to the point of fatigue. I accept the weakness and low grade pain as my lot in life and make every effort to conserve my energy and strength. Instead of being my own worst enemy I like to think I am now my own best friend.

I’m learning how much fun it is to be lazy. With that statement I hope my parents who fostered a strong work ethic in their children aren’t turning over in their graves. Here are some of the things I do to pace myself:

1. I limit myself to only one load of laundry a day. And if it’s a bad day I leave the clothes in the dryer and fold and put them away the next day.

2. I change my bedding on days when I feel good. No need to force myself to do this when I'm tired.

3. Cleaning I leave to a young woman who comes regularly each month.

4. When I cook I try to have enough leftovers to freeze in single-serving containers so on my low energy days I can still enjoy healthy meals.

5. I've learned how easy it is to close my bedroom door instead of making my bed.

6. When I work on my computer and end up with a messy desk of little stacks of research notes and ideas or printouts, I close that door, too.

7. I only shop in stores where there are scooters all charged and ready to go near the door, and wide aisles to get around in. If I get in someone's way I say, "Excuse me, but I'm training for my next job as a semi driver." Humor is an important part of acceptance.

8. If I need to shop in a big box store I recruit one of my children to meet me there and we use the wheelchair that I keep in the trunk of my car. Often I find their advice very helpful when shopping for an electronic item. They're much better geeks that I am.

9. I take regular breaks during the day. My favorite break consists of heating my rice bag in the microwave, pouring a cup of decaf and sitting in a recliner with my feet up reading or watching TV for at least an hour. Sometimes I make myself sit there for a second hour. Remember, I said it's so much fun to be lazy.

10. I'm following an "energy diet." I use my daily energy doing only those things I really love to do. For example:

a. I volunteer at my grandson's early learning classes on Mondays and Thursdays from 12:30 to 1:00 p.m. where I get to supervise coloring, painting, cutting and pasting. Five-year-olds are so cute and one of them calls me "Blair Grandma." After 1 o'clock I come home and take a break in my recliner.

b. I rarely miss a grandchild's sporting or musical event. When there's a game or a concert that's my priority for the day or evening, and I rest before and after each event.

c. My friends and I go to the Fireside Dinner Theatre six times a year. (We have season's tick-

ets.) When we check in I go right to our table and relax while they shop.

Thanks to the Madison Area Post Polio Support Group and Jennifer Klotzbach for making me aware of the group, I've learned to enjoy the slower, smarter pace of life. Deeply grateful for the limited strength I still have, I accept the probability that the future may bring greater challenges. But keeping my spirit strong and trying to maintain a sense of humor will make it bearable.

Looking around the room during our support group meetings and observing polio survivors in power chairs and at various stages of disability, I see proof that spirits can stay strong even as our bodies falter. We are indeed a spirited group of polio survivors.

EXCITING NEWS!
With this issue, the on-line version of the Post Polio Pacer is in color. To take a look, e-mail <wghmch@chorus.net>
Please let us know if you would prefer to receive ONLY the on-line version.

Update on Injured Post Polio Pacer Reporter

Carole Ann Parsons, who suffered significant injuries in an equipment malfunction at her home in July '09, continues to have numerous infections which impede her recuperation. She enjoys receiving thinking of you cards sent to Village at Manor Park, 3023 S. 84th St., West Allis, WI 53227-3703. Please keep her in your prayers.



POST-POLIO SUPPORT GROUP MEETINGS

Madison Area Post Polio Support Group— the next meeting is Saturday, May 8. Theresa Fishler will share information about Community Alliance services.



The Madison Area Post Polio Support Group meets at Monona Garden Family Restaurant. Consider supporting this restaurant when you are dining out & tell them how much you appreciate their hosting our group.

The Post Polio Resource Group of Southeastern WI meetings are held at the Easter Seals Kindcare Recreation Center located in Holler Park at 5151 S. 6th St., midway between Grange & Layton Ave., Milwaukee (just north of the Airport Spur). Social time from 1:00 to 1:30 pm.; meeting from 1:30 to 3:30 pm in March, April, May, September, October and November. Check their website at www.pprg.org for dates and program.

On May 15 Harvey Padek and Beth Kowall, polio survivors, will discuss Living Well with Chronic Conditions.

The **Janesville Post Polio Support Group** meets from 1-3 p.m. at the Mercy Health Mall, 1010 N. Washington St., Janesville, WI on the first Friday of May, June, August, October and Nov. Contact Art Arnold at UncleBunks@aol.com if you want information on speakers.

The Western Wisconsin Post-Polio Resource Group will meet on April 10, 2010 from 12:30 to 3:30 at the Tri-County Memorial Hospital Education Room, Whitehall, WI. For more information call Betty Marsolek at 715-985-3801 or e-mail at bmarsolek@tcc.coop

FYI

Betty Leiser, who recently gave up her driver's license, has for sale her '03 Oldsmobile Silhouette GLS Extended Mini-van, 36,000 miles, with all the options and brand new tires. Presently set up and preferred sold as an accessible vehicle with a Bruno Scooter lift. A Sierra front wheel drive scooter included in the price, plus the remaining Quad seats (2), which can be easily installed when the lift is removed. Asking \$13,000.00, OBO. Call Betty at 608-222-8897, between 10-12 am or 6-8 pm if you are interested.



CORRECTION OF WEBSITE ADDRESS for American West Center's Polio Oral Project
 American West Center at University of Utah Looking for Polio Survivors This Oral History Project is Documenting Treatment, Outcomes, and Effects of Polio. If you are interested in sharing your oral history please contact: <http://www.amwest.utah.edu/?page1d=1771&news1d=1577>

New CPR Method from the Mayo Clinic
 A must see, new CPR method. No mouth to mouth and works better. Anyone can do this after seeing it once.
<http://www.youtube.com/watch?v=E5huVSebZp>

Cleaning for a Reason
 If you know a woman currently undergoing cancer treatment, please pass the word to her that there is a cleaning service that provides FREE house-cleaning - 1 time per month for 4 months while she is in treatment. All she has to do is sign up at <http://www.cleaningforareason.org> and have her doctor fax a note confirming the treatment. *Cleaning for a Reason* will have a participating maid service in her zip code area arrange for the service.

This organization serves the entire USA and currently has 547 partners to help these women. There are people out there that care.

Shelley Peterman Schwarz has exciting news about an accessible cruise

The following is for information only and is not endorsed by Easter Seals Wisconsin or the Madison Area Post Polio Support Group.

An exciting ACCESSIBLE cruise aboard the Royal Caribbean "Jewel of the Seas" ship is being offered



by Flying Wheels Travels to Scandinavia and St. Petersburg, Russia, July 6-18, 2010, for people living with disabilities, chronic illness, and/or age-related limitations as well as for anyone else who wants to join the cruise.

Flying Wheels Travel has 40 years of experience helping people with disabilities and age-related limitations travel the world. They handle all the details, including arranging for escorted, accessible shore excursions to sights of interest at each port. To further insure our safety and enjoyment, they will help locate a personal care attendant should you need one and, if requested, will help match you with a roommate. Should you need special equipment, they will make the arrangements to have that equipment available to you. (You'll be responsible for the cost.)

Handicapped cabins have been reserved and are available on a first come, first served basis. The "Jewel of the Seas" is a large ship so for groups traveling together, there are plenty of cabins for folks who don't need handicapped accommodations.

We fly to London, board the ship and sail to Copenhagen, Denmark; Stockholm, Sweden; and Helsinki, Finland before spending two days in St.

Petersburg, Russia. Then, we all sail to Tallinn, Estonia; Gothenburg, Sweden and back to England. Travelers may also extend their stay in Europe either before or after the cruise.

My husband Dave and I have been on several cruises and find it the easiest most relaxing way for us to travel. We love the fact that you unpack once and each morning you wake up in a new port. Even with my severe physical limitations, (I only have limited use of my left hand), it's a perfect way for me to travel because of all the conveniences - a fully accessible cabin, ever-present assistance from the ship's staff to open doors, carry buffet trays, cut my food in the kitchen (allowing me to be independent at mealtime) and even helping me into and out of the ship's pool.

Perhaps the best part for me, is that Dave gets a well-deserved opportunity to rest and relax knowing that I am safe and enjoying my independence.

I'm working with Flying Wheels Travel to make this a trip you'll never forget! Flying Wheels has asked me to be part of the cruise by offering some "Sailing with Shelley" informal, fun, interactive sessions. Passengers are under no obligation to attend..... and there will be no charges for these sessions..... just lots of good laughs and sharing.

So, if you know people who thought their traveling days were over, are worried about leaving the safety and comfort of their home, or are concerned about the stress of traveling, this is a chance for them to leave their worries behind and join us on a relaxing, fun, and entertaining trip of a lifetime to Scandinavia and St. Petersburg, Russia!

To learn more about the trip, go to <www.MeetingLivesChallenges.com> and click on Sailing with Shelley or the Flying Wheels Travel logo.

Golden Rule of Post Polio Syndrome

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

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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

**To get your Pacer on line, set your email
program to always accept messages from
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.

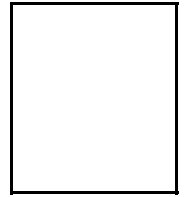
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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

LOCATION:

Monona Garden Family Restaurant
6501 Bridge Rd., Monona
Noon to 2:30

Saturday, May 8, 2010

**Theresa Fishler shares information about
Community Alliance services.**

Saturday, July 10, 2010
Program to be announced.

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