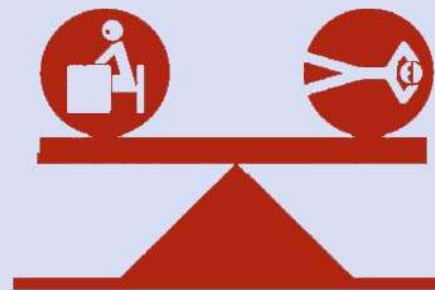


POST POLIO PACER

Conserving Strength and Energy through Pacing
October 2017 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 — This Is Our 32nd Year!



The Stoughton Live Coffee House was a Great Success!

By Marcia Holman

This was Dr. Richard Bruno's first "live" coffee house. Do you wonder how this happened?

In July Dr. Bruno contacted Easter Seals about the possibility of having a "Coffee House" in Madison on Sept. 9, 2017 and requested a contact person in the Madison Area Post Polio Support Group. Easter Seals emailed me and I quickly shared this responsibility with the Executive Committee.



Because the UW football team had a home game on that date, hotels were already full. Our usual meeting room at Monona Garden Family Restaurant was not large enough for groups over 50, so Gail Beckwith, the group's new lead person, contacted Skaalen Nursing and Rehabilitation in Stoughton. They offered their meeting room at no cost, and coffee, water and cookies at a modest price.

Easter Seals *Post Polio Pacer* bulk mailing list and the Support Group email list were utilized to spread the invitation to attend the "Coffee House" to as many people as possible. Twenty phone calls were made to people with no

street address and twenty regular mail flyers/ registration forms were sent with 3 positive responses from the effort. Dr. Bruno also posted information about the Stoughton event on the Facebook "Post-Polio Coffee House" site. If you are not familiar with this site, go to:

<https://www.facebook.com/groups/PostPolioCoffeeHouse/> to visit a safe place to "meet, learn and share" with other polio survivors.

Seventy-one people, mostly from Wisconsin, but also two each from Illinois, Iowa, and Minnesota, attended. The program started at 12:45 p.m. Dr. Bruno, a psychophysicologist, described his education, development of the Salk vaccine, the Sabin vaccine, polio treatment, and rehabilitation goals before answering questions which had been submitted with the registration forms. After about 1 1/2 hours of questions and answers we had a twenty minute refreshment/rest break, followed by more Q & A until 4 p.m.

Gail Beckwith's comments:

Our Live Coffee House with Dr. Bruno was a wonderful event. I want to thank all that were involved to help make it a success. Skaalen Nursing Home in Stoughton turned out to be a wonderful location. With all the activities going on in Madison that weekend this location allowed ease of parking and a lot less traffic. Skaalen Home allowed us to use the room without a charge. We only had to pay for the cookies and coffee provided.

Dr Bruno is most charming and personable. He started speaking at about 12:30 pm and

continued until about 4:15 pm, with only one short break. He initially referred to his book ***The Polio Paradox-- What You Need to Know***. The book was written in 2002. He said he recently re-read the book and there is nothing he would change. The information is all still correct and pertinent. I hate to admit I had not read this before. But I did go on Amazon to purchase this book and am almost done reading it.



He impressed on us that anyone with symptoms of increased fatigue and sleepiness during the day, needs to have a sleep study done. If currently one is using a C-Pap machine and not seeing improvement, he/she should discuss this with their doctor and maybe should change to a Bi-Pap or a volume ventilator. C-Pap provides continuous stream of air into the lungs, to keep them filled. A Bi-pap puts air into the lungs at one pressure and a lower pressure when we exhale.

He advises that we take at least 2 breaks a day for up to 15 minutes--one in the a.m. and one in the p.m.--to just rest quietly and not think about anything. Let the brain shut down.

Don't push your body to the point of over fatigue, this can cause the loss of motor neurons. Once they are lost they cannot be replaced and you will now have permanent muscle loss. When we had polio, neurons that produce dopamine were damaged or destroyed. Thus, we have increased fatigue as years go on. You may note the inability to find the right word when speaking. He again indicated that post-polio patients need half

the anesthesia and twice the pain medication for twice as long. We are twice as sensitive to pain than the average person. If you don't have this information, go to the web site <post-polio.org>. There is information there that you can print and give to your doctor. Keep a file with you in case you end up in a hospital and need urgent surgery, so doctors caring for you will be able to see it before you have surgery. Your family members, especially your POA for healthcare, need to have this information.



Again, it was an honor to meet Dr. Bruno. So much can be learned from him.

Sheryl Shaffer commented, "I think everyone really enjoyed the Coffee House. It was nice meeting the Dr. I've heard about for so long. I also enjoyed meeting all the other people that came to the meeting. It's interesting to hear how post-polio is affecting people in different and similar ways. I learned a lot from everyone's questions"

Editor's note: Share your reflections about the "Coffee House" at the November 11th luncheon meeting at Monona Garden Family Restaurant.

Golden Rule of Post Polio Syndrome
"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"

For those who are not familiar with *Post-Polio Health*, the quarterly newsletter of Post-Polio Health International, Joan L. Headley had been Executive Director and editor of *Post-Polio Health* for nearly 30 years and recently retired. Below is her message to all the readers of *PPH*.

I never wanted to be a red bird or a blue bird.

I am, like everyone else, defined by nature and nurture. I am retiring because I am 70 years old, in good health, and I have my list. My parents treated me as an equal to my brother and sister, although later in life they revealed they thought I was "babied." My sister had distressing bouts of asthma and my brother was the boy they wanted. I thought they were (babied) instead!



The memory most relevant to my 30-year-long distant relationship with you happened in 1953 in first grade. I vividly remember looking at the bulletin board from my front row seat and seeing our names listed under a cut-out of a red bird or blue bird. The teacher explained we would earn points and a winner would be declared. I don't recall which group I was in, but I knew I didn't want to be better (or worse) than my friends. I just wanted to be me. After all, I had stood in another room listening to my mother strongly instructing her brother never to call me Hopalong again. I interpreted that as "You are fine, as you are, even though different."

In my job at PHI, I soon learned that there were many polio survivors all defined by their own nature and nurture.

The challenge for me as executive director:

How do I meet the needs of all polio survivors? Our founder, Gini Laurie, had said in a presentation that polio survivors needed two things: accurate information and a connection to those with similar experiences. That has been the focus of the work—accurate information and access to those with similar experience and knowledgeable health professionals who have our best interest at heart.

The challenge for you as polio survivors: Determining what information pertains to you and your situation and applying it, so that you can be a polio survivor living the best you can "considering" and more. We have varied up-bringsings, opportunities and physical problems. Being honest with ourselves and then with our families and health professionals is important.

It seems to me (and maybe I am projecting) that the answers to the tough questions are not found ultimately on the "outside" but on the inside. Let me reassure you, I am not a great philosopher. Tom Sellick, who plays a small-town police officer, Jesse Stone, on TV, advises, "The information is out there. All you have to do is let it in." Every time I hear him say that, I think of us.

I know each of us has been affected by our experience of having had polio. While there are commonalities, we are each unique and that is a good thing. We are in control of what we "let in" and in how we act on it.

And, I have complete confidence that our acquired knowledge and experience translates into wisdom.

May we all be wise,

Joan L. Headley, Executive Director

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Easter Seals has a new logo!



Easter Seals Wisconsin has adopted the new logo and brand created by their national organization, Easter Seals, Inc. Their programs and services, of course, remain the same!

Life Changed in an Instant

by Gail Beckwith

I have been asked to write about the changes in our life after my husband, Don's, accident. Don retired from Oscar Mayer in 2006. Being only 55 years old, he tried to find the perfect job. Trust me, he had many jobs, and finally was hired as a bus driver for Head Start in Sun Prairie. He loved this job. He loves kids and had really found his niche.

On August 28, 2013 Don was on his way to a meeting to get his new route for the upcoming school year. He was in morning rush-hour traffic, on Highway 51 North at the intersection with Pflaum Road. He was in his Pontiac Vibe at a red light, the third car in line. He states that he looked into in the rear view mirror and saw a SUV bearing down on him. Seconds later he was rear ended. The impact forced Don's car into the car in front of him and that car into the lead car. Immediately after impact Don felt no sensation below the nipple area of his chest.

The result of the accident was a spinal cord injury at T2-4, a concussion and severe whiplash for Don. The driver, an 18 year old on her way to MATC, came up to Don's car. She was not injured. She told Don she was sorry

and had just looked away for a second. She gave him her cell phone to call me. He called and I thought he said he had been in a car accident and could not move his leg. Luckily for me, while driving to Madison, that is what I thought.

I told him with our insurance that he needed to go to Meriter Hospital. A few minutes later an EMT called and said, that with his injuries they would be taking him to UW Hospital. When I heard that, I knew things were more serious than I initially thought. As a nurse, I knew more serious injuries go to UW.

When I arrived at UWH ER I had to wait for a few minutes as he was being scanned. When I finally got back to see him in the ER, the doctor informed me of his injuries, that he was paralyzed from the upper chest down. I stood there in disbelief. How could this be? Was Don going to make it through all of this?

I immediately called our children. We have 2 sons, one in Stoughton and one in Albany. I tried to explain how serious this all was and clearly they did not want to believe this, or just could not comprehend. Our daughter lives in Colorado Springs, CO and at the time was an ICU nurse. I called her and with the early time of day she thought maybe something had happened to grandma, my mom. When I explained what had happened she said, "I will be home as soon as I can." The call was at 9 am and she was in Madison by 7 pm that night.

Don was transported to Neuro ICU. He had surgery that afternoon to stabilize his spine. In the ER we were told it looked like a complete spinal cord injury. By the time he went to surgery there were some changes with neuro testing that indicated maybe it was an incomplete injury, which could be an indicator of hopefully, some return of function for him.

Don made it through the surgery well. He had some bone spurs on his spinal column that were forced into the spinal cord with the impact of the collision. Those first days were touch and go to keep his vital signs in a normal range with the use of fluids and medica-

tion. He was in severe pain due to the whip-lash. I felt so helpless that I could not help him. He spent 6 days in ICU and then transferred to a regular room where therapists began to work with him. He needed people supporting him as they sat him up. He was like a “weeble wobble” and could not do anything for himself besides feed himself.

Eventually he was transferred to the 3N rehab unit at Meriter Hospital. Don initially had to be moved to/from bed or wheelchair via a Hoyer lift. When he arrived at 3N he could move only his left great toe. Every day more sensation and movement began to return. I don't remember how I did it but I would get up, spend the day with him, as I did not want to miss any progress, then go home and work. I worked at home as a triage nurse. Then I would get some sleep and a new day would start.

Medical complications gradually started. He had a few trips to ICU with heart issues. So, since he was unable to continue in daily rehab per his insurance he was discharged to Oakwood East, a rehab facility, to see if he could gain strength to be able to go home. That was the beginning of October. I cannot tell you how proud I am of Don. That man worked so hard every day. Eventually he was brought back to Meriter 3N the second week of December, and finally discharged home December 30, 2013. During his time in rehab, I was still working. But I had to make plans for discharge to a handicap accessible residence, Luckily a condo was opening in the condo village next to Skaalen Nursing home in Stoughton. As they got the one floor condo with 2 bedrooms ready for us to move in, the bathroom was remodeled with a roll in shower. It had a storage area where a half bath was put in.

I worked with Independence First, formerly called Wheelchair Recycling. Many items used for daily care are not covered by insurance. I purchased a wheelchair shower chair, a get-up-stand, and hospital bed with a trapeze. I had to hire care for him. Leaving the hospital, we hired an agency that came in twice a day,

a.m. and p.m. Eventually, when we got an insurance settlement, we set up our own staff which we continue with now.

It was such a relief to get Don home. The hard part has been that only some progress has been made. He can stand in the get-up-stand and bear some weight on his legs. But we now know he is paraplegic--he cannot walk, and he now has begun to accept this. In December 2016, Don got his driver's license to drive our ramp van with hand controls.

After we got Don's settlement, I retired April 2014 and then we were able to purchase a ramp van. With the number of medical appointments, to hire a van would have been very expensive.

My health issues have also been another wrench in our lives. Since retiring, I had to



have back surgery compression of a vertebra at L5. And then a fall caused a fracture of my left (bad) leg femur. I have also had cellulitis and lymphedema at times in both legs. So, living where we are now has been a necessity for both of us.

We utilize care givers to cook, clean, get groceries, assist Don with his shower, get him up and back into bed. Every day can be different in what he is able to do. Having the injury so high has really affected Don's body. He has had visits back to ICU with heart issues. Don has chronic back pain, that for the most part is fairly under control. But every so often he has a day of significant pain. So, we both

have had to learn to take each day as it comes. One thing that we have not been able to do is get back out to Colorado. Before his accident we would go there every summer. We are hoping at some point to get back out there.

Our church has been a support as well as some of our family. Don has done some activities with the Madison Spinal Cord injury group. We play cards three times a week in Stoughton, two of those days at the clubhouse with our condo group, and one day a week Don plays cards at the Senior Center here in Stoughton. We use equipment in the therapy department at Skaalen Nursing Home to maintain/improve our physical conditions.

So, I hope that this shows a little of what our life is like now.

Books donated by the disbanded Janesville PP Group’s library:

“In the Shadow of Polio—A Personal & Social History” by Kathryn Black copy right ©1996.

“Managing Post-Polio—A Guide to Living Well with Post-Polio Syndrome” by Lauro S. Halstead, M.D., Editor. ©1998.

“Handbook on The Late Effects of Poliomyelitis for Physicians and Survivors,” Edited by Frederick M. Maynard, M.D. and Jaon L. Healdey, M.S. ©1999.

“A Balanced Way of Living—Practical and Holistic Strategies for Coping with Post Polio Syndrome” by Vicki McKenna. ©1999.

“The Polio Paradox—Understanding and Treating ‘Post-Polio Syndrome and Chronic Fatigue’ by Richard L. Bruno, H.D., Ph.D. ©2002.

“Postpolio Syndrome” by Julie K. Silver, M.D. and Anne C. Gawne, M.D. ©2004.

“Splendid Solution—Jonas Salk and the Conquest of Polio” by Jeffrey Kluger. ©2004.

DVD: Post-Polio Resource Group, “Disability Rights,” by Attorney Shirin Cabraal, March 15, 2008.

DVD: Post-Polio Resource Group “Avoiding Falls”, by Dr. Waring and Team, Sept. 20, 2008.

Many thanks to:

Kathleen Blair for her thoughtful columns in the January, April & July 2017 *Pacers*.

Tim Duffy, Sandy Person, Theresa Post and Kathleen for helping fold & label the quarterly *Post-Polio Pacer*.

Gail Beckwith, Fayth Kail, Marilyn Klotzbach, and Sheryl Shaffer who helped make the “Stoughton Coffee House” with Dr. Bruno on Sept. 9th a great success.

Kathy Sue Schubring, who donated several books from the disbanded Janesville PP Group’s library to the Madison PP Support Group. Titles are to the left—check them out at the November luncheon meeting.

And with *great gratitude*, Easter Seals Wisconsin for printing and postage for the print edition of approximately 250 copies of the *Post- Polio Pacer* quarterly newsletter. In addition, they also pay for speakers’ luncheons. This group *would not* survive without their help.

We can help Easter Seals Wisconsin by shopping at *Savers* and donating used clothing, shoes, kitchen equipment/ utensils, household goods, furniture—and even vehicles in good working order including cars, trucks, boats or trailers. In Madison and other cities, Easter Seals will pick up your donation.

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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 mchwgh@gmail.com

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.

Time flies when you are having fun—especially if you pace your activities!



Happy Holidays
 Everyone!

From
 Kathleen Blair
 And
 Marcia Holman



Easter Seals Wisconsin
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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

2017 meeting dates:

Nov. 11

NO MEETING IN JANUARY

Printing and postage
 is provided by:

EASTER SEALS WISCONSIN

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<http://www.EasterSealsWisconsin.com>



LOCATION:

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

November 11, 2017

**Traci Miller, RPh, a pharmacist
 at a Racine hospital will
 talk about:**

**All You Need to Know
 About Medications...with time for
 Questions & Answers**

