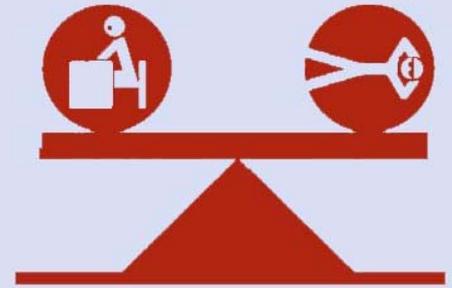


# POST POLIO PACER

*Conserving Strength and Energy through Pacing*  
*January 2013— Madison, Wisconsin*  
*Madison Area Post Polio Support Group Newsletter*  
*MAPPSG formed in 1985 — This Is Our 28th Year!*



## A Legacy of Life

*By Kathleen Blair, Columnist*

Early the morning of October 9, 2012, a bizarre accident dealt our family a crushing blow. Our lives were changed forever. Three days later two other families' lives were also changed to lives of renewed hope and second chances.



**Rebecca Karlen**  
4/5/60—10/12/12

My daughter, Becky, was driving to work – from Marathon to Wausau – on Highway N when an oncoming car hit a deer that flew up crashing through Becky's windshield landing on her back seat. Doctors told us later they were amazed that she was still breathing on her own when she arrived in ER.

A nurse on duty recognized her and immediately called a priest; Becky was anointed by Father Dan and given a final blessing.

In the following hours our entire family rushed to Wausau from as far away as Philadelphia, keeping a round-the-clock vigil at her bedside as her body was kept alive on life supports.

I went into denial, crying, praying and expecting a miracle – the last one to accept the sad truth that my loving, generous daughter was leaving us and beginning her new life in heaven.

After more than 24 hours when all tests showed no brain activity—no hope—the donor emblem on Becky's driver's license was acknowledged. Sitting in my wheelchair outside the hospital room, I heard my granddaughter, April, say, "Dad, I think we should do it. You know Mom always gave her all. I think she would want us to do this."

\* \* \* \* \*

Two weeks later Becky's husband, Pat, received a letter of thanks from the UW Organ Procurement Organization telling him they were impressed that he would consider others even when suffering such a deep personal sorrow. It stated in part: ***"Your decision illustrates how helping another person is one of the most important gifts in life."***

Our family found comfort in learning that Becky's final gift of her organs gave two people a second chance at life: a patient in Minnesota who suffered from end-stage renal failure received one of her kidneys. Another in Illinois who suffered from end-stage renal and liver failure, and had been on the waiting list since December 2001, received her other kidney and liver. *Please join us in praying for them and their families, that their lives will be healthy, happy and fruitful.*

A Certificate of Recognition from the State of Wisconsin "in Memory of Rebecca Karlen" came with the letter. It stated: ***"Although she will be missed greatly by her family, friends and neighbors, they can take comfort in knowing that through her compassion and concern she will hold forever a special place in the hearts of other individuals and their families and***

*friends.*" I sincerely hope and pray that someday we may have contact with these individuals in which Becky's legacy of life lives on.

**How am I doing today?** Losing a child is the worst thing that can happen to a parent; for me it's worse than accepting polio and its consequences. But my faith has shown me that God has a plan for all of us, and I won't have the final answer until I catch up with Becky in heaven. In the meantime, I believe that the miracle I prayed for and expected was granted in the two lives and the lives of the families that received a second chance through Becky's final gifts. Yes, I am looking forward to meeting them someday. In the meantime, I am keeping them in my prayers.

\* \* \* \* \*

*Visit*

[www.YesIWillWisconsin.org](http://www.YesIWillWisconsin.org)

*or*

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

*...to learn more about organ donation, and to join the many Wisconsinites who are already listed as registered organ donors. Currently there are more than 1,800 people on a waiting list in Wisconsin alone, and a grand total of more than 112,000 people waiting for a life-saving transplant.*

*Yes, you can, if you just say, "Yes, I will."*

Kathleen Blair will bring copies of her book "Earthen Vessels" to the March meeting. The book is a memoir of her caregiving experiences with her husband.

There will be a modest purchase price to cover her expenses.

## "The Sessions" – Polio and Sex on the Big Silver Screen

**William Stothers,  
San Diego,  
California**

(wstothers@cox.net)



Hollywood has a history of portraying people with disabilities as objects of pity, inspirational "supercrips" or embittered villains. So going to see a film about a man with a disability seeking to lose his virginity sets alarm bells clanging. "The Sessions" puts those expectant fears to rest.

Beyond "disability correctness," however, for polio survivors this film stirs deep memories of our own growing up experience.

Based on the writings and life of Mark O'Brien, a poet and writer who had polio and spent most of his time in an iron lung, the R-rated film is an engaging, often lighthearted, portrayal of a 38-year-old severely disabled man who lives independently in an apartment in Berkeley, California. Mark manages his personal care attendants, gets out into the community on a gurney, and writes poetry in addition to essays and articles for several publications.

He's no wallflower or shut-in, but, like all of us, he has his self-doubts and struggles. He yearns for love and intimacy. He falls for Amanda, one of his personal assistants. Finally, he screws up his nerve to tell her he loves her. Pause. For while Amanda cares a lot for Mark, "love" and all that that means frightens her off. Mark is left feeling his old sense of low self-worth and shame.

I'm sure many of us with disabilities have felt the sting of hearing "I really like you, but... only as a friend," or words to that effect. I can relate.

Deeply distressed, Mark, who is a devout Catholic, consults his priest about his desire

to experience sex. He wants permission to follow his therapist's urging to hire a sex surrogate. After some dramatic reflection, the priest says he thinks God will give him a pass on having sex outside of marriage. "Go for it," he says.

The film follows Mark's halting journey with sex surrogate Cheryl. Sensitively played by actor John Hawkes, Mark stumbles and is awkward in his first encounters with Cheryl, who has her own learning curve but is very matter-of-fact and professional.

In their first session, Cheryl asks Mark: "Do you have any area of unusual sensitivity? Any parts of your body you don't want me to touch?"

Mark responds, "I have normal sensitivity all over. It's just that my muscles don't work. You can touch me anywhere."

That's polio for you.

You've got to see "The Sessions" for yourself to see how it plays out. But the context of the film is pretty realistic in showing that a polio survivor with a significant disability can live a remarkably normal life and experience mature feelings of real intimacy and love.

Kathi Wolfe, a writer and poet herself who has a disability, writes: "... it was with Mark as it has been and will continue to be for so many of us: joy, pain, hurt, pleasure, humor, shyness and chutzpah are indelibly intertwined in life. Keats spoke of what he called 'negative capability' – of the poet being capable of being 'in uncertainties, mysteries, (and) doubts....'"

In reviewing the film, long-time disability advocate and scholar Anthony Tusler said, "O'Brien was one of those polios [sic] that used his intellect and sense of humor to connect with the wider world. We've known many of them, and most are now gone. I'm not sure what it is about polios. One theory of mine is they gained confidence in who they were in the open wards and the polio camps

of the 50s. They found their disabled brothers and sisters early on, and they changed the world.... They refused to believe it was okay to exclude their disabled brothers and sisters, their community, from life, liberty, and the pursuit of happiness."

The reaction among people with disabilities has been overwhelmingly positive. People embrace the honesty and matter-of-factness of how disability, especially polio, is portrayed.

The credit goes to Ben Lewin, the screenwriter and director who is a polio survivor. He has said that he wanted Mark to be depicted as a human being who could, like all of us, be at times, "a jerk." The cast, Hawkes as Mark, Helen Hunt as Cheryl and William H. Macy as the priest, is spectacular, and bring the great script to vibrant life.

"The Sessions" is now in theaters across the country and in Canada. Go see it. I would be surprised if it doesn't unlock some memories, both good and uncomfortable. It did for me.

*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))

*Editor's Note: The above review appeared in the November 12, 2012 issue of PHI, but you may still find the film in theaters.*

### Golden Rule of Post Polio Syndrome

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

## What Did You Miss on November10?

Although only 13 people attended, there was lively discussion about "Caring for Caregivers." Jessica Hanson, sociology instructor at Madison College, formerly a social worker at Elder Care, and Kathleen Blair, caregiver for her late husband, presented their perspectives about caregiving.



Jessica Hanson shared a number of "pearls":

"Taking time for me"—how important it is to ask for help—priceless! All of us need to take advice and help from others.

We need to identify limits...remember you are not a superhero.

Worry: a spasm of concern. To alleviate worry, 1<sup>st</sup> define the problem; 2<sup>nd</sup> collect information about the worry; 3<sup>rd</sup> make a plan; 4<sup>th</sup> execute and evaluate the plan.

Journaling is good for the writer.

Criers should do so to relieve sadness.

When you can joke about a tough situation, you are in control.

Meditation, exercise, getting outside, reminiscing, laughter and tears all relieve stress.

One of life's greatest values is caring for each other.

Ideas were shared among the group, many of whom are or were caregivers. Kathleen Blair has nearly completed a book about caregiving and shared some of her experiences as a caregiver.

## In Memoriam

Betty Mielke, 82, of Fond du Lac, a long time member of the Madison Area PP Support Group, died Saturday, December 8, 2012, at home.

Many of the members of the PP Group will remember her husband, Niles, who died in 2007. They used to come to every meeting. After Niles' passing, Betty enjoyed her annual visit to the Group when her daughter and son-in-law from Virginia provided transportation.

Her daughter, Susan Midland, commented in an e-mail, "My mom was apparently trying to close her curtains when she fell and hit her head. She most likely was knocked unconscious because she did not activate her life line."

Betty was an indomitable spirit. Despite her handicap as a result of polio, she never gave into self-pity. She found unconventional ways for accomplishing everyday tasks making the most of her abilities. After Niles' death, she lived alone in their home with the assistance of wonderful neighbors and caregivers. She is now with her loving husband, Niles.



She is survived by two children, Susan (Phil) Midland of Earlysville, Virginia; and Rick (Carol) Mielke of Fond du Lac; four grandchildren, Brett Mielke, Daniel Mielke, Julia Midland, and Douglas Midland; a sister-in-law, Rita Rohde; and two brothers-in-law, Gerald (Rita) Mielke, and Florian Zimdars. She is further survived by many beloved nieces and nephews, other relatives and friends. Our condolences to her family.

*Some of the information above was excerpted, with the family's permission, from the December 12, 2012 Fond du Lac Reporter.*

## In Memoriam Anthony H. Guernsey, Janesville

Art Arnold, of Janesville, alerted us to the passing of Tony with this remembrance.

"Tony and I were classmates at Milton Union High School. We were members of the football team, I played right guard, and he was the left guard. I remember riding up to Madison on a hot September afternoon. We sat together on the bus going up and coming back home. Four days later Tony was in the hospital with polio; a few days later I followed. We were roommates in Mercy Hospital overnight but I had to leave because of respiratory complications as Mercy Hospital had no respiratory equipment. I went to the University hospital in Madison and spent the next seven months in an iron lung. Tony went back to high school, graduated from Milton High and U.W.--Whitewater, obtained a great job at Barber Coleman in Rockford and spent a lot of his retirement years in New Mexico."

Excerpts from the obituary the Janesville Gazette, January 17, 2013: Anthony Harley Guernsey, age 76, of Janesville, died on Friday, Jan. 4, 2013, at HospiceCare, Inc., Fitchburg. Tony married Rita Ford in Janesville on Aug. 17, 1963. He was employed for his working years in Rockford, IL, retiring to Janesville in 2004.

Tony is survived by his wife, Rita Guernsey; his three children and four grandchildren.

Our condolences to his family.

## Many Thanks To:

Everyone who contributed to the Monona Garden Family Restaurant gift card presented to Bill and me at the November luncheon meeting. It is surely much appreciated by Nick and the Monona Garden staff as well.

All the contributors to the *Pacer*, especially Kathleen Blair for her columns, and Mary Parks for short items and articles. Kathleen B. and Gail K. who help fold and put address labels on the 200+ *Post Polio Pacers* that are bulk mailed each quarter.

Our planning committee, Gail Kempfer for keeping us organized, and the faithful attendees who keep this group going—you know who you are.

Easter Seals for printing and postage for the *Post Polio Pacer* and meals for our speakers. Without their help this group would not be able to do the things we do.

This group is a labor of love for all involved.

*Marcia Holman*

## F.Y.I.

From WAL Publishing LLC: A video titled *Moving the Post-Polio Conversation Forward* is now available for all to view free of charge at [www.TravelingWithoutASpare.com](http://www.TravelingWithoutASpare.com). The video is an interview with Wenzel A. Leff, MD, author of *Traveling Without A Spare: A Survivor's Guide to Navigating the Post-Polio Journey*.

*Traveling Without A Spare: A Survivor's Guide to Navigating the Post-Polio Journey*, by physician and polio survivor Wenzel A. Leff, MD is available at [www.TravelingWithoutASpare.com](http://www.TravelingWithoutASpare.com). Regular book price is \$15. Volume discounts: 10% off on purchases of 5 to 9 books; 20% off on purchases of 10 or more.

The book (but not volume discounts) is also available at [amazon.com/Traveling-Without-Spare](http://amazon.com/Traveling-Without-Spare) for \$15.

If you are interested in buying this book, a volume purchase will be made if at least 5 people contact Marcia Holman by e-mail [wghmch@chorus.net](mailto:wghmch@chorus.net) or phone 608-249-2233.

## HELP WANTED

No experience or resume needed, other than being a polio survivor. Share your "polio story" with the readers of *Post Polio Pacer*. Each story is unique, yet shares some aspects with other survivors.

Perhaps writing answers to these questions will help you get started:

I contracted polio in (month and year) at age\_\_\_\_. Did you have bulbar polio? How did it affect you?

Where were you hospitalized (name of hospital, city, state) and for how long? What are your recollections about this time period?

Did either of your parents, siblings, friends or neighbors contract polio at the same time?

At the beginning of your rehabilitation, what kinds of assistive devices did you use? What devices did you use on discharge? What devices do you use now?

If you had any surgeries, what kind did you have? What types of therapy?

How did being a polio survivor affect your schooling (grade, high school, college) and work? Was the school accommodating to any new needs you had as a result of having polio or did you not return to your home school? If you were able to be employed, was your employer helpful in making needed changes for you? What types of work are you doing now or retired from?

If you have had symptoms of post polio syndrome, describe them and how they affect your daily life.

What unique methods of accomplishing every day tasks have you developed?

How does your family, children and/or friends/neighbors assist you? Do you employ people to assist? If so, what advice do you have for others who might need it?

How has polio affected your family's life?

What are some positive things that have happened to you as a result of polio (i.e., the opportunity to meet stars)? What are some negatives or challenges (i.e., could no longer play football)?

Share some funny moments such as, "I knocked over a ready-made piecrust display when the wheelchair caught the display while rounding a corner." This comment comes from Mary Parks who helped with the questions above.

We're not looking for an autobiography. Consider sharing a "short story" about a specific time span after you contracted polio, not only with the readers of *Post Polio Pacer*, but make copies for your family members to help them understand what you went through and accomplished as a polio survivor.

Information in addition to that from the questions above is encouraged. E-mail submissions are easiest for the editor to "cut and paste" into the *Pacer*, but hand written stories are also welcome.

Send your story to:

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or e-mail <wghmch@chorus.net>

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 Do you have a need for customized clothing? "Adaptations by Adrian" provides customized clothing including wheelchair jeans, capes and accessories.  
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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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Happy Valentine's Day

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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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**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, March 9, 2013**

**Open Discussion**

**“My hobbies & how they help me”**

**Saturday, May 11, 2013**

**Jason Glozier, Disability Rights Specialist and Randy Black, Physical Disabilities Commission, will discuss their Programs.**

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