

# Rare disease draws out rare courage in couple

Gary Beyer's challenge with sIBM brings out best of friends and faith

By Dan Roherty  
OSHKOSH HERALD

Gary Beyer's daily challenges with sporadic inclusion body myositis (sIBM), a progressively debilitating muscle disease, don't allow him and wife Julie to easily leave town, or the house, on short notice.

The Beyers' decade-long journey of acceptance and advocacy, in concert with doctors, researchers and their "golden friends," has inspired them to push through the physical limitations when they believe their work and message needs to be advanced.

An opportunity for Gary to speak before state legislators on Rare Disease Day, marked annually on the last day of February, was one of those occasions that would have spurred Gary and Julie down to Madison but didn't materialize when the Legislature closed its session last week. He had been working with Assembly Minority Leader Gordon Hintz of Oshkosh on that appearance and may get another chance if a similar Senate Joint Resolution can be advanced in a future session.

Beyer lives by the theme, "Inspiring hope in the face of life-altering circumstances" whether giving presentations to groups and organizations around the state or through the three books he has authored on living with a so-far incurable disease. He calls "You Must Answer This," "I Promise I'll Pay Attention" and "When the Time is Right" as story-based, issues-based and message-based, respectively, all trying in different ways to explain something that doesn't get high-profile awareness.

Usually characterized by progressive weakness and atrophy of the muscles, especially those of the arms and legs, sIBM can lead to severe disability. The exact cause is unknown, most likely a combination of genetic, immunological and environmental factors.

Beyer said more is being learned about sIBM and related IBM disorders because of focused research and the ongoing dedication of others in the medical community. He also credits the flow of social media communication among sIBM sufferers and devoted caregivers in helping accumulate helpful information and important friendships.

"What's made it clear in my divinely inspired journey is that it is bigger than me," he said.

Rare Disease Day marks its 10th anniversary this year, coinciding with Beyer being formally diagnosed with the disease a decade ago by Dr. Barend Lotz of UW



Julie and Gary Beyer are shown on the cover of Gary's book, 'When the Time is Right.'

Health Neurology. Beyer expects sIBM was starting its slow but invasive entry into his body some years before that.

From that life-changing point in time, the Beyers have been continually adjusting and sharing the ups and downs of daily life tasks that most take for granted. Basic efforts like climbing stairs, getting up from chairs and toilet seats, and swallowing have become more difficult for Beyer over time.

Julie, a retired English language arts teacher, tries to keep pace with the progressive adjustments as tasks get tougher. She also credits their dedicated medical staff and said she is "getting very accustomed to calling the 911 dispatcher."

Gary had a bad fall in the shower last week that required an emergency call, and Julie said it takes two paramedics to get Gary upright again because of the lack of muscle tone in his legs. Julie has nothing but praise for the Oshkosh Fire Department rescue squad and paramedics.

"They are so kind, caring and compassionate, and have been helping us out of some very difficult binds," she said.

While Julie has the steadfast role of primary caregiver, Gary said, "I'm blessed to have what I call golden friends" who help in other specific care needs, most recently a friend who created a hooked dowel to help him shut the SUV door behind him securely.

Standard equipment that allows Beyer to get through the average day includes a hydraulic lift chair for sitting and sleeping, an EZ-Step cane unit, chairs and toilets at the necessary elevated heights, various grabber devices, modified entryways and a multitude of adaptors to public accommo-

dations.

Paul Steger of Neenah, who has known Beyer since junior high school, counts as one of those special friends in making himself available at their home for general assistance or modifications. Steger knows he's appreciated.

"He's one of the most sincere individuals, one of the most thoughtful individuals that you'll meet," Steger said.

Beyer stays current with research progress on sIBM and related muscle diseases, leading to connections and friendships with some of those researchers. Todd Cohen, assistant professor in the Department of Neurology at the University of North Carolina, has been conducting work there on manufactured proteins that change the nature of cells and bring on conditions that lead to IBM, Lou Gehrig's disease (ALS), Alzheimer's and related diseases.

The binding protein TDP-43 can escape from neurons into cytoplasm and clump or "misfold" muscle cells, making those muscles a dumping ground for the protein. Cohen's lab has reported recent progress with enzyme treatment that shows some breakdown of the TDP-43 protein clumps as well as generating some muscle growth. (Cohen talks about his work in a podcast at [www.buzzsprout.com/49109](http://www.buzzsprout.com/49109), and a GoFundMe effort is underway to help support his research).

Beyer's rheumatologist, Dr. Eric Gowling at Affinity Medical Group, had offered some cautious hope that a trial study given "breakthrough therapy status" by the FDA in 2013 would offer a viable treatment for sIBM sometime in 2016, only to be removed from the therapy pipeline due to inadequate results. Related clinical trials are continuing.

The most recent clinical development

came in November when Danish biotech company Orphazyme A/S, working in the "orphan drug pipeline," gained U.S. FDA drug designation to arimoclomol for the treatment of IBM.

As with most research, progress is often slowed by setbacks that can't help but disappoint IBM sufferers around the country who may not have enough time to benefit from a cure.

"Resiliency and perseverance is what will keep us focused in the right direction," Beyer writes in 'When the Time is Right.' "My state of mind will remain hopeful and I will continue to be genuinely encouraged."

Beyer also credits Nicki Jansma, a certified holistic health care practitioner who operates Remedies, LLC in Oshkosh, as a steady positive force in his life from the time he first went to her in February 2008 soon after the sIBM diagnosis. Jansma specializes in patients with difficult medical conditions.

"Numerous other people around the country come to see her regularly and, like myself, they strongly swear by her level of expertise, professionalism and focused input," Beyer said. "I consider her a highly valued friend."

Beyer's relationship with Rep. Hintz goes back two and a half years when Beyer spoke at an Oshkosh Rotary Club meeting that Hintz attended, which sparked the idea of Beyer addressing the Legislature on rare disease awareness. In the meantime, before the Beyers get an opportunity to prepare for that trip to Madison, Gary vows to stay positive for family, friends and those who share the IBM challenge.

"That's the message I'm trying to get over to other people: Don't give up," Beyer said. "You have to find and utilize what brings you joy."



## Bringing Local News Home

Direct Mailed to 26,500 homes and businesses in Oshkosh  
Found online at [www.oshkoshherald.com](http://www.oshkoshherald.com), and available free of charge at the following locations:

BP Air	1585 W. 20th Avenue	Pilora's Cafe	910 N. Main Street
BP Service Oil Company	2531 Omro Road	Planet Perk at City Center	100 City Center
First Weber Realty	601 Oregon Street, Suite B	Planet Perk in The Grind	240 Algoma Blvd. Suite 101B
Fish Tales Bait and Tackle	4050 County Hwy A	Quent's Service Center	2167 State Road 44
FVTC Riverside Campus	150 N. Campbell Road	RE/MAX on the Water	814 Knapp Street
Hergert Sport Center	1232 N. Sawyer Street	Reimer Jewelers	11 Waugoo Avenue
Jackson Street Mobil	5171 Jackson Street	Richards Insurance	48 N. Oakwood Road
Kwik Trip	1725 W. 9th Avenue	Saint Vincent De Paul	2551 Jackson Street
Mark & Susie's Piggly Wiggly	525 E. Murdock Avenue	Ultimart - BP Party Mart	1424 S. Main Street
Mike's Place Family Restaurant	2402 Jackson Street	Ultimart - BP Lakeside Superette	4733 Hwy 45 S
NDC Natural Market	2018 Witzel Ave	Ultimart - BP Eastside Superette	811 Merritt Avenue
New Moon Cafe	401 N. Main Street	United Coop - Pickett	6646 W. Highway 44
Oshkosh Herald	923 S. Main Street	UW Oshkosh -	
Oshkosh Public Library	106 Washington Avenue	Gruenhagen Conference Center	208 Osceola Street
Oshkosh Seniors Center	200 N. Campbell Road	ZaRonis	2407 Jackson Street
Parnell's Place	2932 Fond du Lac Road		

If you are outside of our delivery area subscriptions are available for just \*\$35 every 6 months.

Complete the coupon below with payment or call 920-508-9000 to subscribe.

Check  Credit Card

Credit Card \_\_\_\_\_

Name on Card \_\_\_\_\_ Exp \_\_\_/\_\_\_/\_\_\_ CSV \_\_\_\_\_

Mailing address \_\_\_\_\_

Mail to: Oshkosh Herald, 923 S Main St. #C, Oshkosh WI 54902

\*Our goal is to increase our delivery to all 35,000 homes in the OASD as advertising support increases. Refunds will not be issued as new carrier routes are added in to our distribution. Thank you for your understanding and support.

HAPPY HOUR SPECIALS

## THE MAPLE PUB

AT MENOMINEE NATION ARENA

920.309.8343

HAPPY HOUR Tues-Fri 4p-7p | Sat 11a-5p  
OPEN TUES THROUGH SAT 11a-close

**TUESDAY**  
TEQUILA TUESDAY  
\$3 Tequila | Complimentary taco bar

**WEDNESDAY**  
WINE WEDNESDAY  
\$3 Wine with 1/2 price Wisconsin aged cheese and meat tray, or cheese fondue

**THURSDAY**  
PINTS AND PRETZELS  
\$2 pints | \$2 Bavarian pretzel

**FRIDAY**  
FABULOUS FRIDAY  
1/2 price rail, draft, house wine  
1/2 price appetizers

**SATURDAY**  
BLOODY MARY EXTREME  
\$5 multiple choice Bloody Mary's | Seafood special