

This **copy** is for personal, non-commercial use. To order presentation-ready copies for distribution you can: 1) Use the "**Reprint**" button found on the top and bottom of every article, 2) Visit reprints.theygsgroup.com/dailyherald.asp for samples and additional information or 3) **Order a reprint of this article now.**

Article updated: 2/23/2014 6:26 AM

Wheaton dad to run in hopes daughter can walk

By **Burt Constable**

With their daughter's fifth birthday just two weeks away, Bill and Jackie Babiarz allow themselves the fantasy of being able to give Cameron just one of the gifts she wants.

"We do play that game," says Jackie Corrado Babiarz, running through a litany of gifts that would be perfect for Cammy, the smiling little girl in her daddy's lap. The Wheaton parents, both 34, say their choice is unanimous and surprisingly easy to make.

"If she could have one thing, I'd say 'hands,'" Jackie says.

"Most people would think 'voice,'" Bill says. "But if she had control of her hands, she could feed herself and learn sign language."

To raise awareness and funds for the fight against Rett syndrome — the genetic, neurological disorder that robbed Cammy of the ability to talk, walk and control her hands — Bill is embarking on "The Run Across Illinois." A former marathoner who gave up running for a decade due to a bad back, Bill will begin his pilgrimage on March 12 in Fulton, an Illinois town along the Mississippi River.

He plans to run 27 miles that first Wednesday, 38 on day two, 32 on Friday and 20 on Saturday before the final 28 miles land him in front of Chicago's Buckingham Fountain on March 16.

"I have a good inspiration," he says, noting Cammy has motivated throngs to their cause through the Cammy Can campaign. After Cammy's diagnosis on Jan. 7, 2011, the Babiarz family wanted to make a positive statement in time for that year's International Rett Syndrome Foundation's spring Strollathon fundraiser. Working off a photograph of Cammy in pigtails, artist Jenn Kim, a friend of a friend, designed a "Cammy Can" logo featuring the girl as a young superhero.

"It's weird to say marketing, but it's true," Bill says of the Cammy Can campaign that expects to top \$200,000 in donations after his run and the third annual Cammy Can's Cinderella Story gathering with food and drink, from 5 to 10 p.m. on March 22 at Sidebar, 221 N. LaSalle St. in Chicago. Timing the event during the NCAA "March Madness" basketball tournament, Bill notes that "Cammy's Cinderella is the underdog story, not the princess."

Identified by Austrian physician Dr. Andreas Rett in a 1966 medical journal, Rett syndrome wasn't recognized fully by the medical community until a 1983 Swiss researcher wrote a second paper about the disorder. Caused by a spontaneous mutation on the X chromosome on a gene called MECP2, the incurable disorder strikes about one in 10,000 to 23,000 girls. Boys with the mutation rarely survive.

Some girls with Rett syndrome can walk and talk. Others can't even chew or swallow and require feeding tubes. Some suffer seizures, serious breathing and digestive issues. There are patients now in middle age, although some die earlier from related complications. Cammy's disorder is more severe than most, but she's a loving, happy girl, her parents say.

Jackie grew up in the Edgebrook neighborhood on the Northwest Side of Chicago, and Bill grew up in Addison. They met as students in the class of 2005 at the University of Illinois at Urbana-Champaign, started dating later, and married on 7/7/07.

Born March 10, 2009, Cammy appeared to be a healthy baby. She had learned to roll over by 16 weeks. Then she fell behind cousins around her age.

“At 6 months, I was concerned. The doctor said, 'Wait and see,'" Jackie remembers. “At 9 months, I was concerned. The doctor said, 'Wait and see.'”

They have the video of Cammy in the highchair at 10 months old, picking up food with her fingers to eat. But by her first birthday, Cammy had lost the ability to sit up.

“She's never crawled. She's never walked,” Jackie says.

When a doctor first mentioned Rett syndrome during an appointment two days before Thanksgiving in 2010, “It was horrifying,” says Jackie, who read an online list of worst-case symptoms.

“At first, we were in denial,” she says of her husband and herself. “I don't think we said it to each other, but we both knew it fit.”

She was eight months pregnant with their younger daughter, Ryan, when doctors confirmed Cammy's grim diagnosis, which involves stages of developmental setbacks.

“The regression, that was the worst of the worst,” Jackie says. Bill remembers their daughter saying Mama (for mom) and Baba (for bottle) and then going backward. From her first birthday to her second, Cammy lost everything. She would scream through the night, vomit and lost the ability to control her hands, often sticking them in her mouth or wringing them repeatedly in a classic sign of Rett syndrome. She's stronger now, generally sleeps well and has an uncanny ability to communicate without talking.

When they ask Cammy if she wants to eat more french fries and pasta (“The breakfast of champions,” her dad says) mashed with a fork so that she can swallow it, the girl's instant look away is her signal for “no.”

“Do you want dessert?” Jackie asks, offering strawberry shortcake.

Cammy's smile and flash of her eyes couldn't be a clearer “yes.”

The girl also communicates through a Tobii computer, which tracks Cammy's eye movement to let her select images programmed to talk for her. For Ryan's third birthday party on Monday, Cammy was able to wish her sister “Happy Birthday!” by looking at the corresponding image on the video screen.

That computer, provided by the state's early intervention program, costs about \$20,000. Essential items such as her \$13,000 wheelchair and \$4,000 orthotic implants for her shoes are provided by the health insurance Bill receives through his job as an options trader with IMC Financial, where he says he also enjoys a supportive, generous and understanding contingent of bosses and co-workers.

Cammy spends the bulk of her mornings as a student at Jefferson Early Childhood Center, a Community Unit School District 200 preschool for children ages 3 to 5, with or without disabilities. Ryan plans to join her sister there next year. Ryan often kisses her big sister and holds her hand as she walks next to Cammy's wheelchair.

“She has brought so much joy to Cammy and to us,” their mother says.

Cammy seems smart, makes it clear that yellow is her favorite color, loves to play a computerized horse-racing game and laughs in the right spots at her Elmo videos and children's books, her parents say.

“At school, she told them (through her computer) that her ears hurt,” her dad says of a recent example of how well Cammy communicates. “I took her to the doctor and she had a double ear infection.”

This cold and snowy winter has not been a good one to train for five consecutive days of marathon runs, but Cammy inspires people. Jackie ran the Chicago Marathon in 2012. Bill and Cammy joined her near the end so that Jackie could carry Cammy across the finish line.

“That was the vision I had the whole time I was training,” Jackie says. “You think about how hard she works every day just to take one step.”

Bill will be joined on his run by his 63-year-old father, Bill, and longtime friend Eric Santa, 33, who will ride bikes alongside the runner. Other friends plan to join him for parts of his course.

To donate and learn more about Cammy Can events, the run and Rett syndrome, visit the Cammy Can Facebook page, the Run Across Illinois Facebook page and rettsyndrome.org.

Encouraged by the discoveries science has made in recent years, Bill posted a medical story this week touting, “Cure for Rett syndrome is on the horizon.” The couple say they do sometimes allow themselves to imagine their daughters riding bikes together, walking hand in hand or saying, “I love you.”

“What her voice would sound like or what she'd look like walking,” Jackie says, her eyes growing moist. “I've had dreams of her talking, and I wake up crying.”

Unable to give Cammy the birthday gift they long to give, the couple focus on Bill's run, Cammy Can's Cinderella Story and the push to raise funds and awareness.

“That,” Jackie says, “is the only thing we have control over.”

Copyright © 2014 Paddock Publications, Inc. All rights reserved.