Remembering the Extraordinary Life of Mimi Wallerstein

As the wind gently blows through Mimi’s Garden at Bon Secours St. Mary’s Family Center, chimes sing sweetly to the children playing nearby, and all are reminded of the constant and unconditional love that surrounded their friend Mimi Wallerstein.

Mimi’s family credits her longer than expected life to the care she received at the Bon Secours Family Center, which pursued special licensing and permission to ensure Mimi could stay with them nearly every day of her 28 years of life.

Love was a constant in Mimi’s extraordinary life.

Mimi lived filled with unconditional love for others, including her parents Ricky Wallerstein and Leah Darron, her younger sister, Adair, and her caregivers at the Bon Secours St. Mary’s Family Center.

Although Mimi courageously faced the challenges of being non-verbal and non-mobile due to Wolf-Hirschhorn syndrome, she demonstrated love through her peaceful existence and comforting presence.

During her 27 years as a student, Mimi quietly served as a calm and constant reassurance to thousands of children who attended the Family Center with her.

“She was like the Energizer Bunny, because she lived longer than we ever anticipated,” said her father. “She was happy, healthy and comfortable at the Family Center. I’d carry Mimi into the Family Center most mornings around 7 a.m., and my wife, Leah, enjoyed picking her up around 5 p.m.”

In 1994, students depicted Mimi’s treehouse with special tile art on a mural in the Family Center.
The loving care she received at the Family Center was why Mimi lived so long,” he said. “She spent more waking time during her life as a student in the Family Center than she did at home. They totally embraced her from day one in February 1989 when we were one of the first families in the new center until her final days in July 2016. Their love and support were such comforts to our family.”

Donna Shifflett helped to care for Mimi at the Family Center for almost three decades.

“She had a glow,” said Shifflett, who now is the center’s director. “She always helped me put things in perspective. She lived such an incredible, selfless life.”

As the Family Center’s babies quickly grew into toddlers and preschoolers exploring their worlds, Mimi was there to mark the milestones.

One of the first words many of the Family Center’s children learned was “Mimi,” and they always loved stopping by her classroom to say “hello.” Mimi was there when the Family Center staff would send new kindergartners off to school and welcome summer students and volunteers with her distinct laugh and gentle smile. Mimi was a constant.

Mimi loved the activity and noisy bustle of the Family Center. “When the babies would cry, Mimi would laugh,” said her father. She cherished her music days and her musical octopus. “We had an octopus at home and one at school,” her dad said. “When we’d hear Mimi’s octopus, we knew that she was OK. It was comforting. She would coo and laugh.”

Mimi also adored her special treehouse in her classroom at the Family Center. With a raised platform for Mimi and built-in tunnels underneath for her curious classmates to explore, the treehouse served as a safe place for children to interact with her.

“She taught the children and our staff how to truly experience happiness, joy and love,” said Samara Musselman, who served as one of Mimi’s teachers and now serves at the director of the Bon Secours St. Francis Family Center in Midlothian. “Mimi’s life is a testament to how a nurturing and loving environment makes a difference.”

About Mimi’s condition

Wolf-Hirschhorn syndrome or 4p- is caused by a deletion of genetic material near the end of the short (p) arm of chromosome 4.

“Mimi was an infant in all respects, functioning at about the level of a four- to six-month-old at about 30 pounds and 36 inches long,” said Ricky. “Sometimes she would roll over, but have trouble rolling back over.”

Some individuals affected by 4p- are mobile and can talk and assist in their daily care. However, others are non-verbal and require constant care, such as Mimi.

Some patients diagnosed with 4p- are near normal height and weight, while others at ages 20-30 weigh only 35-50 pounds and are only 45-55 inches tall, according to the 4p- Support Group, a nonprofit for families and guardians of children with 4p-.

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Mimi’s early years

Mimi’s incredible story began when she was born four weeks early in 1988 at the Medical College of Virginia Hospitals at Virginia Commonwealth University (now VCU Health) in Richmond, Va. Her parents eagerly awaited the birth of their first child. The young couple quickly learned their precious Mimi or Miriam, which means “wished for child,” weighed a little over 3 pounds. As a preemie, Mimi required special care at MCV’s Neonatal Intensive Care Unit.

Shortly after her birth, Mimi’s parents moved her to St. Mary’s Hospital where she could continue her care near the family’s home. Initially, doctors weren’t sure about Mimi’s medical condition. The official diagnosis of Wolf-Hirschhorn syndrome, or 4p- syndrome, came when Mimi was 2 years old. When Mimi started at the Family Center in February 1989, she had a soft cleft palate, but as time progressed, Mimi lost her ability to suck or drink from a bottle.

As Mimi grew over time, so did her needs and care, but her love remained a constant, according to Donna Shifflett, who helped to coordinate with the Family Center’s licensing agency, as well as educational services provided by Henrico County, where Mimi’s family lived.

“She grew bigger and longer over time,” said Donna, who in recent years enjoyed having Mimi join her in her open office in the afternoon while her classmates played outside. “As our teachers changed some over the years, I’d always tell them, ‘Mimi is long and lanky. Don’t be scared of Mimi. She will teach you so many lessons.’ She taught me so much.”

Donna Trivette, administrative director of Work & Family Programs at Bon Secours Virginia, said, “Our ministry provided Mimi with nearly three decades of exceptional care that included her occupational and physical therapy. We coordinated with our licensing agency and the Virginia Department of Social Services to ensure we could continue to care for Mimi.

“Being part of a community Catholic health system, our Family Center team cared for Mimi longer than any individual in the health system’s history. It truly was remarkable. Helping to provide a loving place for Mimi has been one of the highlights of my career. Mimi’s pediatrician believed her extended life for her condition was due to the constant love and support she received at our Family Center.

“I’m comforted when I reflect back on my career knowing that when others might have said no to Mimi’s family, we were always able to say yes,” Dawn added. “The care we provided Mimi and support for her family define who we are at Bon Secours. It makes me incredibly proud to work here.”

Caring for the entire family

The caring staff at the Bon Secours Family Center made a difference in Mimi’s life.

“We provided a loving, safe environment, so her parents could have peace of mind as they worked,” said Donna. “I know God brought us Mimi.”

Ricky added, “It wasn’t just Mimi. They took care of our entire family. I remember well when Mimi’s sister Adair, now 24, began coming to the Family Center as an infant in 1992.”

“I’d have Mimi on one arm and Adair on the other. Those were wonderful times. As Adair grew, she became more protective of Mimi, but she also shared her older sister, Adair eventually went on to elementary, middle and high school, and then college. Mimi didn’t. She remained at the Family Center.”

The toddlers in the Family Center especially gravitated to Mimi, according to Donna. “We’d have to tell the little ones, ‘gentle hands with Mimi.’ They included Mimi in their greeting song every morning.” she said. “One of our younger students, Vivian, who wasn’t even 2, earlier this year declared that Mimi was her best friend. Friendships like these make our center so special.”

Ricky and Leah appreciated how the Family Center’s team always worked to accommodate Mimi. Her parents also cared for the Family Center’s caregivers with kindness, generosity and a little humor. Mimi’s parents routinely brought in breakfast for the staff and remembered their birthdays.

Donna said, “They really made the staff feel appreciated and special. I remember when Ricky would pick up Mimi in the afternoon he would sometimes joke, ‘If Mimi could talk, I can only imagine what she’d say about us.’”

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About Mimi’s Garden

To celebrate and honor Mimi’s extraordinary life, the Bon Secours St. Mary’s Family Center and the Bon Secours Richmond Health Care Foundation created a memory garden off Maple Avenue outside of Mimi’s classroom.

“The garden is a lasting memorial to Mimi’s life,” said Ricky. “Our family is so touched by this outpouring of generosity and love for Mimi.”

Dozens of families donated the funds for the garden that features an outdoor learning area and potting area. Bon Secours employees also donated unused paid time off to help fund the garden designed and installed by Stone, Earth & Water Inc., a landscaping firm in the Richmond area.

Reflecting Mimi’s love of music, the garden also features musical chimes and 28 different seasonal flowers to honor Mimi’s 28 years of life. A special plaque at kids’ eye level will ensure that future students and their families will forever remember sweet Mimi.

“A firm foundation

Over the years, the Bon Secours ministry continued to grow as did the St. Mary’s campus. The one-level, brick Family Center and cheerful playground along Maple and Monument Avenues remained a secure and solid foundation for the Wallerstein family.

Amid a stream of visits with doctors, therapists and specialists, Mimi remained relatively healthy during her life, except for a few hospital stays, including a lengthy visit in the Pediatric Intensive Care Unit at St. Mary’s, where she received exceptional care, when she was 2.

“Mimi’s incredible family will forever be part of our Bon Secours family,” said Dawn. “Mimi’s life is a testament to how Bon Secours fulfills its mission of providing good help to those in need. We will always remember Mimi.”

Ricky added, “Our daughter was so special. I am touched by the way she was able to love and be loved by so many.”

Hundreds remember Mimi

Mimi died peacefully at home on July 5, 2016, from respiratory complications due to her genetic disorder.

During a celebration of Mimi’s life, hundreds shared how she personally inspired them.

As one family wrote in a tribute to the Wallerstein family, “Mimi touched the lives of those around her in profound ways. She touched mine as well, mostly through the way she captivated the hearts of everyone in the room as she brought out smiles and love from everyone that met and interacted with her.

Through their love for Mimi, Rick and Leah showed me what real parenting was. As they balanced two very successful and demanding careers with their parenting commitment, it never seemed difficult because of their obvious love for Mimi.”

Mimi’s Garden

Dedication October 28, 2016
In memory of Miriam “Mimi” Kirksay Wallerstein
Loved and tenderly cared for by the Staff of Bon Secours Family Center at St. Mary’s Hospital 1988-2016

Donna Shifflett, the Bon Secours St. Mary’s Family Center director, stands besides Mimi’s treehouse. Mimi spent time on the top while her young classmates crawled through the tunnel below.
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