

# **Small Miracle: However long they have him, family cherishes its youngest**

A play train table sits prominently in the living room of the home Brandie and Dan D'Orazio make in Baltimore's Federal Hill.

Christmas stockings embroidered with their names and those of their four children line the staircase, the last for their youngest, Leo.

Leo was born Jan. 5, 2017. Four days later, he was diagnosed with a life-threatening genetic disorder that limits his brain development. The D'Orazios, who worship at St. Ignatius in Baltimore, remain strong in their faith despite the knowledge that any day could be their infant son's last.

"Your relationship with each other and your relationship with God goes one of two ways," Dan said. "It either weakens, or it gets stronger."

"These tears you see from us, they're a combination," Brandie said. "They're happy tears, they're sad tears. They're life tears, they're faith tears. We love him so much and he's given us so much."

## **Great love**

Brandie grew up a parishioner of Holy Family in Randallstown, and earned a degree from the Notre Dame of Maryland University. She met Dan, a New Jersey native who attended Georgetown University, when both were on the staff of the Choice Program in Baltimore, which helps at-risk youth.

On their first visit to Jesuit-led St. Ignatius, they heard mentions of Mother Teresa, Rev. Dr. Martin Luther King Jr. and Ghandi. Married in 2006, their pew at 10:30 a.m. Mass filled in, with Stella, 8, Anna, 4, and Luca, 2.

Leo's pregnancy was relatively normal, but after giving birth at Greater Baltimore

Medical Center, Brandie noticed that his breathing was rapid, and that his muscle tone and cry were weak.

Dan attributes that attention to detail to her “mother’s instinct,” but her medical background helps. Brandie holds a nursing degree from Coppin State University, and worked in the University of Maryland Shock Trauma Unit.

Her advocacy led to a preliminary diagnosis of pontocerebellar hypoplasia (PCH) at just four days – much earlier than most children with similar disorders.

PCH affects the development of the hind brain, where the pons transmits signals to and from the cerebellum, which coordinates movement. A PCH prognosis includes severe cognitive and physical limitations, and a short life. (Full genetic testing traced the disorder to a spontaneous mutation in Leo’s CASK gene, which creates a protein that aids in the development and function of the hind brain.)

Intubated to assist with his breathing, Leo was transferred to Johns Hopkins Hospital, which is equipped to handle unique cases. Doctors told the D’Orazios that if Leo were removed from the ventilator, he would die within minutes.

Wearing the baptismal gown worn by his father, Leo was baptized at Hopkins by Deacon Paul Weber, amid family and friends who assumed it would be the first and only time they would meet the baby.

The D’Orazios said they did not want to be “selfish” and seek extraordinary measures to keep Leo alive for themselves.

On Jan. 18, doctors removed 13-day-old Leo from the ventilator.

## **The Gift of Leo**

He lived more than a few minutes. Hours turned into days. At three weeks, Leo was brought home on hospice care.

The D’Orazios had packed away his baby items in their basement. Prepared to grieve, they continue to rest on the presence and prayers of friends, family, their parish community and strangers.

Dan, the CEO of a marketing consulting firm, said that one of the family's greatest blessings is Brandie, who logged 11 years as a critical care nurse. Dan describes his wife, Leo's primary caregiver, as the baby's "travelling hospital."

"I couldn't ask for a stronger or more caring soul to be my partner," Dan said.

Leo's lack of hearing and vision make tactile contact his best form of connection, as his parents said that he loves being held. Brandie takes her baby to a number of therapies and treatments, all designed to comfort him.

"When we have a tough day," Dan said, "we look at each other and say, 'Our family is all together.'"

Brandie, Dan and Leo's three siblings treasure his presence. They say he makes them appreciate what others might take for granted, and has encouraged them to continue to help others, what they call "The Gift of Leo."

Even the name they gave him embodies his spirit.

"I looked at him and said, 'He's going to be a Leo,'" Brandie said. "Leo the lion. Strong; a fighter."

They do not question God's plan.

"Why not us?" Dan said. "We're no different than anyone else."

"For them, it's not extraordinary," said Jesuit Father James Casciotti, pastor of St. Ignatius.

They have helped lead their parish's annual pre-Cana retreat, school supply drives and its Advent support of the Angel Tree project. The D'Orazios' newest cause is the Child Life Department at Johns Hopkins Bayview Hospital. Its counterpart at the main Hopkins hospital helped Leo's siblings understand his diagnosis.

"Miracles don't have to be big," Brandie said. "They can be small, but you've got to be open to them."

*Editor's note: Dan D'Orazio and his company, Sage, have done contractual work for*

*the Archdiocese of Baltimore.*