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By BY ANDREA K. WALKER and THE BALTIMORE SUN
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Jenny Mohler lay on an examining bed holding her pregnant belly at Sinai Hospital in Northwest Baltimore. Sonogram pictures hung from a machine in the right corner of the room. She was nervous, unable to block a feeling of uneasiness as she waited for a specialist to come in and decipher the images.

Just two days earlier, the Catonsville resident had received a call while sitting at her desk at a Catholic Charities health clinic in Baltimore, where she worked as a school counselor. There were developmental concerns about the baby, Dr. Mary Ann Sorra told her. The baby's head was misshapen and its limbs short. Don't worry, Sorra told Mohler, but more tests were needed as soon as possible.

Mohler, who was 19 weeks into her pregnancy, began a frantic Internet search, typing "developmental disorders" and "short limbs" into her office computer. Could it be Down syndrome? Or maybe dwarfism?

As she and husband John, now 33, waited at Sinai that September day last year, he tried to assure her that nothing major was wrong. She wanted to stay positive, but it was difficult.

A perinatologist who deals in high-risk pregnancies came into the room to deliver the diagnosis: Your baby has thanatophoric dysplasia, they remember him saying.

The Mohlers' unborn child was suffering from a rare disorder — whose name meant "death-bearing malformation" in Greek — that would prevent the rib cage from growing, smothering the heart and lungs. The baby would likely be stillborn. Or it would die shortly after birth, unable to breathe on its own.

The baby, whose gender they didn't even know yet, had just been given a death sentence.

Mother, baby at risk

Two months later, across town at Johns Hopkins Hospital, Kimberly Queen lay in a

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ran from her arm, trying to nourish a body of shutting down.

Queen's health was deteriorating from hyperemesis gravidarum, a condition that causes severe nausea and vomiting, making it hard for expectant mothers to keep enough nutrients in their bodies. The Elkridge resident had cycled in and out of the hospital her entire pregnancy, and just days before Thanksgiving was admitted to Howard County General Hospital. Her symptoms were so severe that doctors transferred her by ambulance to Hopkins for more specialized care.

A small group of doctors in scrubs entered her room to give Queen and her fiance, Keith Brown, now 34, some news about her fourth child. Brown held her hand while two doctors sat in chairs near the bed. One did most of the talking.

An ultrasound, the doctor said, showed blood and fluid around the brain of the baby Queen had already named Kirsten. The baby's weight was below normal, and she probably wouldn't survive the pregnancy. If she did, her quality of life would not be good. She might not be able to breathe on her own, the doctors said, urging Queen to consider terminating the pregnancy.

Queen, a certified nurse technician at Johns Hopkins Bayview Medical Center, took the news as if she were on the job. She felt the doctors were talking about some other patient, someone other than her. She found herself explaining to her fiance what the doctors were saying, but not fully absorbing the news herself. She said little to them.

But in the middle of the night, her maternal instinct kicked in. She woke up and could only think of one thing: Her baby might die.

Source of comfort

Queen and Mohler discovered themselves in a spot they would never have predicted: grieving instead of celebrating new life and growing families

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Their predicaments would become the most trying they had ever confronted. Doctors encouraged Queen and Mohler to connect with a hospice program to handle the myriad of emotions.

Both women turned to Gilchrist Kids, a division of Towson-based Gilchrist Hospice Care, one of a handful of hospices in the area with a perinatal component. Through the program they were connected with social worker Briana Shirey who became lifeline and source of comfort through their pregnancies.

Queen, now 33, said her doctors focused on the possibility of terminating the pregnancy, and pushed palliative care for the baby to prepare her for death after she was born. But Queen did not want to think about that; she even ignored advice to contact Gilchrist.

"I was feeling my baby moving around in me," she recalled. "I had already seen the sonogram with her features. She had the nose of my son, the mouth of my daughter. In order for me to accept the possibility that my child wasn't going to be here anymore, I had to know I did everything I could to make sure the doctors did what they could to save her."

Still, Queen and her family were having a hard time with all that was happening.

Her fiance Keith had become withdrawn since the diagnosis. Extended family members didn't understand why Queen sometimes chose not to discuss what she was experiencing. They wanted to throw her a baby shower, but Queen didn't want one.

"If [Kirsten] didn't make it, I didn't want to be in a house with a bunch of baby clothes and baby furniture," she said.

And Queen suffered constant anguish thinking about the daughter she might never get to hold alive.

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The social worker asked some simple questions: How are you feeling? Is there anything bothering you? For Queen, talking about what was going on brought clarity to her situation and a sense of relief.

"She made it easier to concentrate," Queen said. "She made me realize that whatever happened, I could deal with it."

Shirey visited once a week, assuring Queen that it wasn't selfish to shut out relatives sometimes. Shirey said it was normal to want to be alone, to feel anxious and out of control. She also helped Queen's fiance open up so the couple could support each other.

As they met, Shirey got Queen to understand that she had to accept that her baby might not survive. She coaxed Queen into picking a funeral home — such details would be harder to deal with once the baby was born, Shirey said.

Most importantly, she helped Queen think through a birth plan — a key part of the grief process. Such plans outline how a mother envisions labor and delivery, and list what care the baby should receive after birth.

Queen's plan called for doctors to do "whatever was necessary" to keep Kirsten alive. She also wanted to bathe, dress and hold the baby right away — she knew Kirsten's life might be measured in minutes.

'That is your time'

As the months of pregnancy passed, Shirey also worked with the Mohlers, encouraging them to bond with their child. Talk to the baby, she said. Rub Jenny's belly and interact with him anyway you can, she urged husband John.

"Your time is limited, so during pregnancy, that is your time," Mohler said. "That is your time to love the baby, to bond with the baby and parent while the baby is in the

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Jenny, now 32, had no illusions about the chances of their baby's survival — the condition occurs in 1 in 20,000 to 50,000 newborns, and few survive. It was the first case Sorra had seen since she began practicing medicine in 1997. The Mohlers had to accept that they wouldn't have long with their baby.

The couple felt unconditional love for their unborn child, and drew strength from their Catholic faith during the pregnancy.

After finding out about their baby's illness, the Mohlers had taken the afternoon off from work and made the 15-minute drive to the Church of the Immaculate Conception in Towson. There they joined others in the adoration chapel, a small building connected to the main church where parishioners go throughout the day to pray.

They sought comfort from God in the modest room with a few rows of simple wood en chairs and stained-glass windows, praying for their unborn child and their family. Then they went to a park near their Catonsville home where they sat quietly, sometimes holding hands, sometimes crying. They worked through a range of emotions — fear, shock, sadness, grief — as they mustered the strength to break the news to their families.

"It was then that we most mourned the loss of our dreams for our son, it was then that it hit me," Jenny Mohler recalls.

Those moments were the hardest the couple, married since 2009 and together five years prior to that, had ever faced together.

The Mohlers hadn't planned on finding out the gender of the baby until it was born. After the diagnosis, they wanted to know. They named him Joseph Angelo Mohler — Angelo because Jenny felt she was carrying an angel in her womb.

They took him to concerts — the Allman Brothers at [Merriweather Post](#)

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"It was hard to explain to her because she was so young," Jenny said. "We just told her that this was her little brother and he would soon be an angel."

'It's not about me'

Creating these memories helps families better prepare for the death of a baby, says Shirey, who lives in Towson. When it actually happens, it does not come as a shock and they are less overwhelmed.

Shirey has been drawn to helping families cope with life's big moments ever since she was an undergraduate studying mental health, social work and psychology. People have always found her easy to talk to and trust, which has helped her in her career.

She has counseled children from abusive families and helped spouses navigate divorces. She thought the hospice job would be a new challenge as advances in prenatal testing put more parents in the position of grieving during pregnancy.

Dealing with death day after day is not an easy job, Shirey acknowledges. She tries not to think about her own family, including her two children. Instead, she focuses on how she can help someone else's family.

But she usually forms bonds with her patients, something that is almost inevitable when people let you into their lives at such a vulnerable time.

"I am not going to say that I don't cry and I don't get sad," she said. "But it's not about me. I can't be there for them if I am emotionally distraught."

Sometimes after a session, she'll sit in her car for a moment and simply take a deep breath.

Precious hour

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baby would die in the womb, putting the sonograms throughout the pregnancy to monitor the baby's development.

Within seconds of delivery, Jenny and her husband were greeted by a sound they weren't sure they would ever hear from Joseph. He cried. Their son was alive.

Dr. Sorra felt a sense of relief. She went into the waiting room to deliver the news to the Mohlers' parents.

"Congratulations," she said. "Everything went well. You have a grandson."

John, the father, swaddled Joseph and nuzzled him. He held him up so Jenny could see her son as doctors sutured the incision from her C-section. He then brought him over for Jenny to kiss on the cheek. The parents remember their baby gazing at them almost knowingly.

The Mohlers took their son to another room, where their parents, young Abby, Shirey and other relatives and friends waited. Photos were taken as everyone in the room bonded with the baby. They made molds of his tiny feet and hands.

Their actions stirred the emotions of the medical staff, Sorra said.

"It was extremely moving," Sorra said. "There was so much joy and tragedy at the same time."

Soon, the baby's breaths became further and further apart. He became still, as if he was sleeping. A doctor came in to say Joseph had died.

Joseph lived one precious hour, which the Mohlers say they will remember forever.

"It was very peaceful," Jenny Mohler said. "We didn't even realize he had passed."

Joseph was buried Dec. 22 in a baptism gown made from a recycled wedding dress

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The Mohlers say that while they grieved for their son, they had accepted his death. The hospice program helped prepare them for what was to come and create good memories.

"I know most people would expect us to say the most difficult day was the day of his death, but to be honest, it wasn't at all," Jenny Mohler said. "December 13th was an amazingly grace-filled and peaceful day full of love. Because we had good care and we were prepared, the hour we spent with our son was truly one of the most beautiful and meaningful of my life."

'Best sound ever'

As Queen's pregnancy progressed, her baby began to defy the doctor's dire diagnosis. The bleeding in Kirsten's brain stopped and the swelling went down.

She went into labor at 37 weeks on Jan. 13. Doctors at Hopkins were prepared for the worst, stationing equipment nearby to help resuscitate Kirsten if that were needed.

"None of us knew if the baby was going to breathe at birth," recalls Dr. Renee Boss, a neonatologist. "None of us knew if the baby would have a normal heart rate. We were prepared to do whatever we needed to do for the baby if it came to that."

After three days of labor Queen delivered Kirsten, who weighed 5 pounds 9 ounces and had a healthy heartbeat. She looked like her father but had Queen's nose.

"She's breathing," fiance Keith bellowed upon hearing his baby girl's cries. "She's breathing."

Queen felt an overwhelming sense of happiness and relief.

"She came out crying," she recalls. "It was the best sound ever."

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was very much alive.

Kirsten stayed for five days in the neonatal intensive care unit for monitoring, but an ultrasound and MRI confirmed that the bleeding in her brain had stopped. The outcome looked promising.

Now 6 months old, Kirsten is home, where her two sisters and brother dote on her. Queen is glad she gave Kirsten the chance to live.

"She beat all odds," said Queen, who also has recovered. "She is showing them wrong every day."

Kirsten is still at risk for developmental problems. The bleeding was in the part of the brain that controls physical development, Queen said. She is one month behind most children her age. But therapy has helped her learn to sit up and react to sounds, such as the shake of a rattle. Therapists are also helping her learn to crawl.

Her parents said no physical disability would stop them from loving their child.

Queen's son Khalil Brown, 5, climbs into his parents' lap as they gaze down at Kirsten.

With a big grin, he said, "Happy family ending."

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