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Delivery room crisis could have been avoided by early testing

By Mary Ann Roser

When they saw their newborn son, denial washed over them, almost obliterating the warnings they'd gotten earlier.

Little Max was beautiful and looked perfect in every way. They wanted to believe their firstborn would be fine.

But doctors at St. David's Medical Center soon confirmed their suspicions to Aimee Rye and her husband, Billy Graham, of Austin. Their son would never know them. He would never sense their love. He would never be able to love them back.

"We were devastated, obviously," Graham said in a quiet voice.

He had been so optimistic just hours before, when the nurse snapped a picture of him grinning over the baby's crib in the neonatal intensive care unit, where the sickest babies go. Max had squeezed his daddy's finger. It was more than Graham had expected.

"I was just elated," he said.

Neither he nor Rye had any idea when they sped to St. David's on June 18 that Rye had developed a rare and highly dangerous condition called vasa previa.

In vasa previa, fetal blood vessels from the placenta or umbilical cord cross the entrance to the birth canal and lie beneath the fetus. When the cervix dilates at childbirth, the vessels tear and rupture. A hemorrhage follows, and the baby suffers catastrophic blood loss.

The outcome is often tragic. Brain damage can occur, and about two-thirds of the babies die, said Dr. Yinka Oyelese, a vasa previa expert and chief resident in obstetrics and gynecology at Georgetown University Hospital in Washington.

But if the condition is diagnosed by ultrasound after the 16th week of pregnancy, the chances of having a healthy baby by Caesarean section are better than 95 percent, Oyelese said.

Most doctors don't look for the condition, though.

Graham, 28, and Rye, 32, want to change that so other parents don't experience the heartache that still brings them tears.

Rye is using her own money to put together an informational guide for local obstetricians on vasa previa, which Oyelese said occurs about once in every 2,000 to 3,000 pregnancies.

Rye plans to deliver the books this spring and is organizing a walk in Austin on Aug. 24 to coincide with an international fund-raising walk for the Vasa Previa Foundation.

A woman in the Netherlands who lost her baby at childbirth founded the organization in 2001.

Those tragedies don't have to happen, said Rye, an administrative associate at the LBJ School of Public Affairs at the University of Texas.

Omens in red

At St. David's in June, Graham, who waits tables at Texicalli Grille, filled out paperwork while his wife went to labor and delivery.

When he stepped off the elevator to join her, "the whole floor was lit up with lights, doctors flowing out of rooms. They rushed Aimee on a gurney past me."

She needed an emergency Cesarean section. Graham sat on a stool outside the operating room and focused on the one thing that stood out: a red cabinet.

Red had been an ominous color during the pregnancy.

In the 14th week, Rye woke up and felt wetness. She was bleeding heavily and passed out.

Graham wrapped her in a towel and hurried to the hospital. She thought she had a miscarriage, but an ultrasound showed that the baby was OK.

The couple did not know it then, but bleeding during pregnancy is a warning sign of vasa previa. So is a low-lying placenta and a condition called placenta previa, when the placenta lies in front of the birth canal.

After the bleeding episode, Rye spotted a few more times but had no other major bleeding. Her doctor, who was out of town and could not be reached for comment for this story, did not diagnose the vasa previa.

While they were on the way to the hospital to have the baby, a red car in the fast lane on Interstate 35 kept braking in front of Graham, forcing him to slow down. And, now, petrified, Graham stared at the red cabinet, "the only way I could maintain my composure," he said.

He waited -- an hour, maybe?-- until the operating room doors swung open. Max was being whisked to neonatal intensive care.

"They wheeled him past me, and all I could say is, 'That's my son.' He was white as a ghost. . . . All I could do was pray."

The doctors told him Max had lost a lot of blood and they weren't sure how bad off he was. Graham worried about what he would tell his wife. But he also was in denial.

"I had a niece who was born with half a heart, and they built her half a heart," he said. "I was very optimistic."

Graham was bracing for a mentally retarded son. That was fine, he said. "I just kept saying, 'My son's coming home with me. He's coming home with me.' "

When he told Rye about Max, she couldn't absorb it.

"I remember them telling me the baby was in NICU and that he was beautiful and they already had pictures," she said. "I didn't really understand."

She went in to the neonatal intensive care unit in a wheelchair to see Max.

"I was able to talk to him and touch him, but you weren't able to hold him. That was really hard," she said. "I remember I was touching him, and he started to shiver, and they said I shouldn't touch him that much because his little nerves in his skin were very sensitive right now. That was hard, too, because I wanted to touch him."

Somehow, she thought he'd get better.

But less than two days after Max was born, a neurologist gave the couple the shattering news. A scan showed that the brain stem was functioning, but that was all. Doctors could keep Max alive on life support, or they could remove him and let nature take over. Max would die within hours or, perhaps, in a few days.

"I knew there was no choice," Graham said.

A life cut short

Keeping Max alive would be like keeping him in a prison, he said. The couple asked the nurses to dress Max in the outfit they had planned to take him home in. Graham went to the neonatal intensive care unit in the early hours of June 20. He would carry Max to his wife's room.

"I walked him down the hallway, and I just remember I reached the point where I was at the end of my strength, and I said a loud prayer," Graham said. "I called out to my ancestors, 'I need your help; hold me up.' And they did. I walked so strong down that hallway, and I carried my son into the room."

Graham, who had been awake for three days, kept himself going by reading children's books to Max. He had been reading the same books aloud during Rye's pregnancy so the baby "would know my voice."

"My body was giving out, I was so tired," he said. But "I didn't want to sleep. I didn't want to miss a wink of this boy's life, because I knew he was going to die.

"Basically, I tried to spend a lifetime with that boy for just a few hours."

Rye, still recovering from the surgery, slept a lot, escaping her physical and emotional misery with pain medication.

"I couldn't stand hearing him struggle to breathe," she said, wiping away tears.

The couple's families came in to comfort them and to hold Max that morning. About nine hours after he was disconnected from life support, at 9:41 a.m., Max took his last breath.

"We cried so hard we howled," Graham said. "I screamed at him, 'You go straight to God, and don't you look back.' I just kept telling him, 'Go to heaven; go to heaven; go to God. Don't worry about us.' "

They buried Max with a teddy bear next to Rye's brother, who had Down syndrome and died young, before Rye was born.

Striving for education

Max's death and that of thousands of babies every year could be prevented if all pregnant women, especially those at risk of vasa previa, were screened, Oyelese said.

Diagnosis is made with ultrasound, Oyelese said. Only in the past 15 years has the technology made it possible to make the diagnosis before birth, he said. The Vasa Previa Foundation recommends using color Doppler ultrasound.

Educating doctors, not giving pregnant women something new to worry about, is the solution, Oyelese said.

But because "doctors are not looking for it, unfortunately," said Victoria Goldstein, a spokeswoman for the foundation, "it's up to the pregnant woman to bring it to the attention of the doctor. . . . It's so fatal if you don't know."

Goldstein lost her full-term, healthy baby daughter in August 2001. "All of us share the same story if it's not diagnosed," said Goldstein, who lives in Boca Raton, Fla., and began the fund-raising walk to memorialize her daughter, Sophie.

The obstetricians whom the foundation has approached at conferences have not been receptive about changing their practice, unless they have a patient who has lost a baby, Goldstein said.

"Looking for vasa previa takes about 20 seconds" and can be done during the regular ultrasound, Goldstein said. "We're not calling for a special ultrasound."

Some doctors will do "reassurance" ultrasounds for a nominal fee of \$150, she said. An obstetrical ultrasound costs \$500 to \$1,000, she said, although one Austin clinic charges \$415.

Austin obstetrician Dr. Linda Litzinger said her practice group orders ultrasounds for all pregnant women at 18 to 20 weeks to assess the fetus and to check for abnormalities. But they do not ask for a check for vasa previa specifically because it's so rare, she said.

That is the norm nationally, Oyelese said.

That's what Rye wants to change with the books she is delivering. She and her husband hope that by spreading the word on vasa previa, something positive will come of Max's death. If sharing their story saves one baby's life, it's worth a tearful re-telling, they said.

Nine months after grief robbed them of their happiness, they are approaching the future with a mixture of hope and terror. They're expecting another baby in July.