

Xavia's heart

As the small jet carrying 10-year-old Xavia Pirozzi's new heart approached Philadelphia International Airport the evening of Jan. 5, there was a 20 percent chance the aircraft would not be able to land in the dense fog.

Inside the Children's Hospital of Philadelphia, Xavia's parents, Nicolle Borys-Pirozzi and Ralph Pirozzi, waited anxiously, knowing the fog was just one of many challenges their daughter has weathered in her short lifetime.

Xavia's damaged heart

The parishioners of St. Joseph, Fullerton, first learned about Xavia's damaged heart after she developed a case of pneumonia and an X-ray revealed an enlarged area of the heart.

Because the family has no history of heart disease, the Pirozzis were baffled when doctors diagnosed restrictive cardio myopathy - a rare degenerative disease, especially in children, which causes the heart to stiffen over time.

"Cardiomyopathies, in general, are the diagnosis in about half of all the children (birth to 18 years) who require cardiac transplantation," said Dr. Maryanne R.K. Chrisant, CHOP's medical director.

The Pirozzis faced the reality that their daughter, a fifth-grader at St. Joseph School, would need a heart transplant.

"You wanted to shake yourself and say, 'Is this really happening? How can it be?'" said Mrs. Pirozzi, who cried with the doctor and her husband.

Surprisingly, the word transplant wasn't foreign to Xavia. At age 3 or 4 she told her mother she had a "feeling" and "had a vision of some kind which told her her heart would be bad," Mrs. Pirozzi remembered.

Dr. Chrisant said a transplant was necessary because Xavia "was showing signs of compromise from her restrictive heart," and without the transplant the child would not have a normal lifespan.

Because Xavia required continuous medication by catheter to keep her heart from worsening, she was a priority on the United Network of Organ Sharing (UNOS) list.

Waiting, hoping, praying

Xavia, of Fallston, stayed in CHOP, one of the leading pediatric facilities, for 10 months, with her mother and grandmother, Joanna Borys, alternating week-long stays, before a heart was found.

Mrs. Pirozzi, an Associate Administrator in Anatomic Pathology at the University of Maryland, Baltimore, said she never wanted her daughter to be alone in the hospital.

Mr. Pirozzi, a dentist, visited on weekends with Xavia's siblings, including second-grade triplets (also students of St. Joseph) and a 3-year-old girl.

Except for brief trips outside for a breath of fresh air, Xavia did not leave the hospital.

On the evening she learned a potential heart had been located, Xavia strolled toward the operating room with her anesthesiologist, not knowing if she would awaken from her sedation with a new heart or her original diseased one.

Fellow hospital friends lined up in front of their rooms to offer encouragement and hugs as Xavia and her doctor walked past. Nightshift nurses cried silently nearby at their station.

As doctors prepared Xavia for surgery, in another state, a heart was removed from its donor, an anonymous child.

The life-giving organ could only endure a mere four hours between removal and transplant.

As the Pirozzi family waited for the plane carrying their daughter's new heart, carefully and sterilely packed in iced saline, emotions ran the gamut.

The family had experienced a false alarm around Easter of 2006 when doctors called off surgery because a potential heart proved an incompatible match.

While the family was grateful for another heart, Mrs. Pirozzi's first thought was for

“the poor donor family” whom she thanked to herself, understanding that they were grieving while the Pirozzi family was rejoicing.

Mr. Pirozzi’s first thought was of elation, ‘It’s finally here!’ and disbelief, ‘Can it really be happening after all this time?’

It’s difficult to describe, said Mrs. Pirozzi, how much they wished for this moment.

“We gave Xavia big hugs and prayers outside of the OR,” she said. “That was the longest walk. It amazed me she was able to walk that distance without shaking like a leaf. She is such a brave and strong girl. It takes a lot of courage to face what she had to face.”

A new heart

At 12:15 a.m. Jan. 6, the Pirozzi family received the news that the plane landed safely and their daughter’s new heart was on its way to CHOP.

“Thank you, God!” was their reaction.

Two hours later, the successfully transplanted heart began to beat in its new owner’s body.

“It’s a beautiful heart. It was made for her,” the doctor told Xavia’s family.

Once the transplant was complete, Xavia moved to a nearby Ronald McDonald house while treatment and tests continued and the new heart acclimated itself.

On Feb. 19, the child finally returned home, greeted by dozens of red heart decorations sprinkled across her front lawn. There have been no signs of rejection during routine heart biopsies, the family reported.

Medical costs

While Xavia’s new heart is priceless, her medical bills have topped \$3.5 million. After insurance coverage, the Pirozzis estimate their portion will be \$600,000. The drug to be administered to Xavia for the remainder of her life costs \$1,500 a month.

“I worry about her health first,” said her father. “That is my main concern. On a

financial basis, I'll deal with that later."

Fellow St. Joseph parents are helping the couple deal with it now. They formed a committee, The Heart of St. Joseph, to raise funds; other schools and parishes are assisting as well (see related story).

"The outpouring of prayer support from family, friends and patients was tremendous," said Mr. Pirozzi. "It came from Catholics and non-Catholics alike. It was a needed shoulder to lean on."

Finances are not the end of the worries, however. A heart transplant is not everlasting.

"We say that the 'half life' of a transplanted heart in a child (birth to 18 years) is about 13 years," said Dr. Chrisant. "This means that at 13 years (age of heart), half the children are still alive with their heart grafts and half have either died (from various causes) or have required repeat heart transplantation."

Mrs. Pirozzi, who actually held her daughter's diseased heart in her hands, said she can't even think of that now; she has to live for today.

The couple knows they are buying time, said Mr. Pirozzi.

"I look at it as a continual process, buying time until the next transplant is necessary, better anti-rejection meds are created or artificial devices become more practical," he said.

Their faith has been challenged at times over the last year.

"At low points I'd say, 'God, where's the heart and why is it taking so long?'" confessed Mrs. Pirozzi. "There were down days and up days and days you'd want to run screaming from the building. You go day to day or you'd go crazy. There was so much to handle."

Change of heart

Xavia's literal change of heart has left the girl with a new perspective.

"The child has matured in so many ways," said Mrs. Borys. "It was a hard 10

months.”

Xavia’s mom said her daughter is a totally different person than before she came in.

“She’s been great,” she said. “She has had ups and downs. Sometimes she felt sad and wanted to go home. She made friends here – they understand each other.”

The 10-year-old is curious about where the heart under her blue and pink butterfly shirt came from, and what happened to the donor. But unless the donor family wishes to be revealed, the Pirozzis won’t find out. The family plans to write to them through UNOS to express their infinite gratitude and hope to receive a response.

“It’s very important to donate organs and share the gift of life with others,” said Xavia.

During her tribulation, Xavia said she prayed for herself, as did so many others. She knows the prayers helped, she said, “because we were able to do this for 10 months straight!”

St. Joseph School principal, Phyllis Karko, has prayed for the second time for someone to receive a heart. Two years ago one of her teachers underwent a transplant. The principal constantly encouraged the students to pray for Xavia.

“You know how it is with prayer,” she said, “If you believe it, it’s going to happen.”