## A Rare Child – Beau's Story A Collective Expertise Approach to Congenital Heart Conditions

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To look at him now, you would never guess 22-month-old Beau Kientzle was different than any other energetic and curious toddler. But flashback to June 1, 2019 – the day Beau was born – and it's a different story.

The first child of Trianna Stark and Brandon Kientzle of Morton, Illinois, Beau was born by cesarean section with no indication anything might be wrong. But just 12 hours after he was born a nurse heard a murmur in his heart. Beau was admitted to the Neonatal Intensive Care Unit at OSF HealthCare Children's Hospital of Illinois in Peoria where the search for answers – and solutions – began.

Tests revealed Beau was born with severe mitral regurgitation which means the valve on the left side of the heart was malformed and leaking badly. This was affecting the proper flow of the blood through the left side of his heart, causing heart failure. His doctors wanted to give Beau some time to get bigger and stronger before considering surgery to fix his failing heart.

"In most scenarios with this type of defect they can be managed medically, and surgery or intervention can be postponed until they're a little older and a little bigger. So it is unusual to have to operate this early in life for this particular problem," explains Mark Plunkett, MD., Pediatric Heart Surgeon at OSF HealthCare Children's Hospital of Illinois.

Turns out, Beau's condition was fairly rare, especially how severe it was. For his parents, it was a time of asking a lot of questions and processing information from a variety of sources, including people who thought Beau might be better served at a larger facility in a bigger city.

As they weighed their options, each question and concern was addressed by the congenital heart center team at OSF Children's Hospital, which was having its own conversations with other programs across the country. Turns out, it's a well-connected network which benefits children across the country.

"Not only do we have the input from these individuals that are here in Peoria but we also have easy access by a quick phone call to any of these other centers to run the case by them or see what they would do. So I think we have a collective expertise that is as good as you're going to find anywhere," says Dr. Plunkett.

"I think the most important thing for us was how comfortable they made us feel and how readily available everybody was. When we had a question, the cardiologist was there," according to Beau's father Brandon Kientzle.

Adds his mother Trianna Stark, "We are so grateful that was in our backyard, we don't even know what we would've done if we had to travel and be far away from home - it would've been a completely different experience. It was obviously terrible and hard to go through, but I can't imagine not being at home doing it."

Following a week of discussions and planning, and just 28 days after he was born, Dr. Plunkett repaired Beau's heart during a five hour surgery. After two-and-a-half months mending and getting stronger, Beau came home from the hospital. His parents say doctors continue to be impressed with his progress at his regular follow-up check-ups, and Beau's parents know that somewhere down the road he might need another surgery.

But for now, Trianna says they are enjoying what they consider to be a typical childhood.

"It's just been great to kind of just sit back and enjoy him, finally going to be able to act like a normal childhood. It's been great to just kind of hang out and play with him."

Learn more about the congenital heart program at OSF HealthCare Children's Hospital of Illinois.