

# March 2018 - Benjamin Banas

For any parent, the word “normal” can be a source of endless anxiety, fear and expectation. It’s a word that underscores doctors’ appointments, playdates and the formative years of a child’s life. It’s a concept that’s avoided and longed for all at once. It’s all that so many parents want for their kids: The normal opportunities, health and chances to develop into their unique, full selves.

When your son is born with half a heart, however, “normal” might just be the most coveted word of all.

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As Renee Banas walked into her 20-week ultrasound in late 2014, she and her husband Johnathan anxiously wondered if they’d be having a boy or a girl. Filled with the worries of any expecting parent, but accustomed to this process after having had two children already, they were excited to see how their third child was doing.

Much to the chagrin of their daughter Marley – who was hoping for a younger sister – the news came that they would be having a second boy. But as the ultrasound techs took longer and longer, Renee and her husband began to worry.

Shortly after, their doctor entered with a grim expression on her face. And by the time the family walked out, they had learned that their 20-week old son had been diagnosed with Hypoplastic Left Heart Syndrome. Benji would be born without the left side of his heart.



“It was devastating,” said Renee. “We just weren’t sure what would happen. We had no idea what our future looked like with him.”

Before 1980, a diagnosis with HLHS was uniformly fatal. At that time, only five percent of children made it through the first month of their lives. Since then, survival rates have climbed, but it’s still the congenital heart defect with the highest mortality rate – A condition that affects the lives of one in 4,300 children each year in the U.S.

As Renee put it, a diagnosis that severe cast a shadow over the second half of the pregnancy. The couple's weeks were soon filled with tests, ultrasounds and visits to specialists.

“So much was unknown,” said Lori Schoeck, Renee’s mother. “It was really scary – Scary for me as a mom because it was my daughter and she was upset. And also scary because we had never even heard of HLHS, and when you start researching it gets pretty scary. A lot of kids don’t make it.”



On February 24, 2015, Benji was born, but was quickly taken away to the Children’s Hospital of Atlanta for medical procedures to save his life. Six days later, he had his first open heart surgery. Seven months after that, he had his second. Surviving with the help of a feeding tube and additional oxygen, he struggled through a first year where his family had no idea how developmentally far behind he would be.

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Soon after the second surgery, the family began to see real improvement, as over the next year Benji went from struggling to breathe to scooting around on his backside. He went from having his vocal chords damaged by the feeding tubes to being an excitable young child, screaming and chatting away with the family.

“It was amazing,” said Renee. “Being a mom in general you learn all sorts of things. But our other two kids barely even got colds. So when you have this medically fragile child you have to almost re-learn how to parent and you get to watch as they grow and thrive. It just gives you a different perspective on what’s really important because you’re just happy he’s healthy.”

With that perspective, Renee and Johnathan focused on giving Benji as “normal” a childhood as they could. Yes, there were plenty of trips to doctors and there was a long scar running along his chest, but to the outside world he was no different than any other young kid. And Benji was committed to doing everything a typical two-year-old would do as well.

“He just wants to do everything his big brother and sister do,” said Lori.

In the Banas family, that includes running. Marley (seven) and Jeremiah (five) are active kids, playing sports and running in a number of Kilometer Kids Fun Runs. Johnathan and Marley have raced together, and she's looking forward to joining a running club at school next year. Naturally, Benji wanted to run too. And after his remarkable recovery, he was able to quickly pick up the active lifestyle of an energetic two-year-old and get used to running around the house.

For a lot of children with HLHS, however, that isn't possible. And the Banas know it. So much so that they've committed to raising awareness about this disease that almost took their son. On the Facebook group I Heart Benjamin, the family tells Benjamin's story and shares stories of other children affected by the condition.

"A lot of [kids with HLHS] can't run," said Renee. "A lot of them don't stay healthy because they can't do a lot. But looking at him you wouldn't know that he's sick. We did not expect he would be able to do as many normal things as he is doing."

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Two and a half years later, that boy who barely made it out of the hospital was making his way across the finish line of his first-ever race – A Kilometer Kids 50m Dash at Tribble Mill Park. Running in the three-and-under division, he swung his arms as fast as he could and teetered his way across the finish line. With his siblings, parents and grandmother cheering loudly, he finished the race and was embraced in their celebration.

"I went very fast," Benji said. "I had fun. It makes me feel happy and strong."

For the family, it was a remarkable moment showing just how far Benji had come.

"It's exciting for all of us," said Renee. "It's exciting that we can do all these things together and he doesn't have to just sit out and watch. It just goes to show how well he's doing and how healthy he is and the fact that he can do it just such a huge accomplishment. He's just our little miracle baby."

After the race, Benji was awarded his finisher's medal. Displaying it proudly for the world to see, he snacked on M & Ms, bragged about his speed and posed for pictures. It was just about as normal as can be



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