

A MOTHER'S DEDICATION



Tim Bath | Kokomo Tribune

Monica Bush, of Kokomo, is a mother who has become an advocate since her son was born with a cleft lip.

Kokomo woman a 'warrior' for cleft families

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KOKOMO TRIBUNE

Kokomo mother Monica Bush went into her doctor's appointment at 19 weeks pregnant like any other mother would — excited to see what gender her and her husband's baby was.

That excitement, though, soon turned to worry as the ultrasound was taking longer than it should have.

"My husband was like 'There's something wrong,'" Bush said.

Later that afternoon, Bush got a call from her physician telling her that her baby had a cleft lip and presumably a cleft palate as well.

"I remember shutting my phone off and just slumping to the floor because it was like a bomb just dropped," Bush said.

At the time, Bush and her husband, Jason, had little idea what a cleft lip and palate was. No one in their immediate family had ever been diagnosed with it.

As many people would, she turned

to Google, though, as it almost always is, that was a bad idea.

"So many families do that because between getting the call and diagnosis, they don't know where to turn, they don't have anybody," Bush said. "In the beginning, I just remember feeling very isolated because things got very serious very quickly."

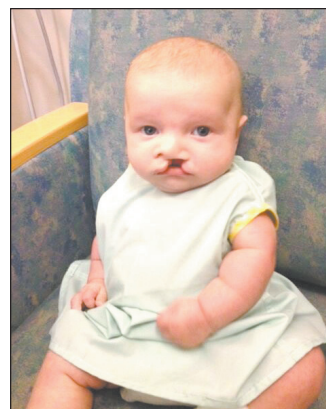
Regardless of how much the couple read about the condition, nothing could have prepared them for the many hours in doctor's appointments, surgeries and struggles they and their new son would have to endure.

WHAT IT IS

During a pregnancy, the lip of the baby forms between the fourth and seventh week.

Ideally, during development, the body tissue and cells of the face grow toward the center of the face and join together to make the lips and mouth of the baby.

When that tissue and cell don't join together is when a cleft lip



Provided photo

Henry Bush, shown here as a newborn, was born with a unilateral complete cleft lip and cleft palate.

occurs. The opening can be small, or it can go through the lip into the nose.

The roof of the mouth, also known as the palate, develops around the same time as the lip,

between the sixth and ninth week of pregnancy. Similar to a cleft lip, a cleft palate occurs when the tissue that makes up the palate doesn't join together completely. Some babies can have a partial or full cleft palate.



Henry Bush

According to Centers for Disease Control and Prevention, about 1 in 1,050 babies is born with cleft lip with/without cleft palate and about 1 in 1,600 babies is born with cleft palate alone in the U.S.

The causes of most cases of cleft lip and cleft palate is not known exactly but is thought to be caused by a combination of genetic and environmental factors.

Thanks to advancements in treatment, the malformation is less lethal than it used to be.

In 1990, about 14,600 of those

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born globally with cleft lip and cleft palate died. In 2017, that number dropped to about 3,800, according to the medical journal *The Lancet*.

While cleft lip and cleft palate may be seen to the general public as merely a condition that affects one's physical appearance, it is much, much more.

Those born with a cleft lip and/or cleft palate are subject to numerous complications, including chronic ear infections and hearing loss due to the eustachian tube not being able to drain fluid as well, dental problems, speech difficulties and potentially low self-esteem and stress as they potentially face some stigma from peers over looking "different" than others.

"I think most people, unless you have a personal connection, don't understand how complex the condition is and that it's truly a lifelong jour-

ney," Adina Lescher, vice president of community development at the nonprofit Smile Train.

Smile Train is the world's largest cleft-focused organization. It provides free cleft surgery in nearly 100 countries, trains doctors and provides hospital funding for the procedures.

SURGERIES AND MORE SURGERIES

Bush's son, Henry, was born in 2012 with a unilateral complete cleft lip and cleft palate. He essentially didn't have a left nostril.

At just 12 weeks old, he had his first surgery to correct the cleft lip. It was surprisingly a bittersweet moment for Bush.

"I really fell in love with that smile, and you can't even imagine (as a mother) changing it," she said. "I did not expect the flood of grief I felt ... He's never ever going to look like the baby I delivered. So I took a ton of pictures and cried about it."

Later came surgery to repair the cleft palate. Those first two surgeries, though, were just the

beginning.

In total, Henry, now almost 12-years-old, has undergone surgery 13 times, including multiple orthodontic type surgeries, and that number is likely to grow as Henry matures and his body continues to change throughout puberty.

"How do you get over the fact that your child's surgery count is higher than his age for the longest time?" Bush said.

Because of the need for multiple surgeries, Henry's development during childhood was far from normal.

He learned to walk before crawling because he needed arm stabilizers after his cleft surgeries so that his infant self would not pick at his face.

At 10 months old, all Henry could say was "mamma." Bush and her husband resorted to teaching him sign language to communicate.

At two and half to three years old, Henry was still not sucking through a straw.

After an extensive surgery that reconstructed his entire palate, Henry, around the age

of four or five, was able to say "puppy" correctly. Soon after, Henry began having full conversations, something that had never happened before. He spent three years in preschool before moving on to kindergarten.

"Along the way, you realize you have to celebrate every small victory we have because he is behind, and it never feels good to have somebody come in and say 'He's delayed,' because we're doing all we can," Bush said.

Throughout it all, Henry has, for the most part, remained upbeat about his condition and has gone from being shy about his cleft to, one year in grade school, choosing his "cleft smile" as the best part about himself.

"He's enjoyable to be around," Bush said about her son. "He's also a more empathetic and caring person because of what he's gone through and had to endure.... Everyone's a friend."

BURDEN TO BENEFIT

Throughout the entirety of

Bush's experience with her son Henry's cleft lip and palate, one thing became abundantly clear: there needed to be more peer support for "cleft parents."

Bush founded her own nonprofit, *Legendary Smiles*, in 2020 with the aim to strengthen and support "cleft families" in the state of Indiana, whether that's simply listening and having conversations to pointing them to needed resources, such as financial help, doctors and therapists.

Since then, the nonprofit has more than 300 families in its support group. In addition, Bush is also a parent advisor in the Craniofacial Anomalies program at Riley Hospital for Children in Indianapolis, where Henry receives his care.

Bush's efforts were recognized a few years ago by Smile Train.

Every year, the nonprofit puts on Cleft Con, a one-day event that aims to "share stories, exchange knowledge and foster connections to enhance empowerment and education

in the cleft space."

Bush attended the first ever Cleft Con in 2020. Her dedication and passion for helping other cleft-affected families stood out to Lescher and others at Smile Train.

"Monica is such a fierce warrior when it comes to her family but also the larger cleft community," Lescher said. "She has a deep emotional attachment when it comes to fighting for her child, and she really feels that same sense of obligation to the larger cleft community."

Bush was invited to this year's convention in Houston, held on July 20, to tell her story to attendees.

"I want to be that person who people can reach out to," she said. "You never know how you're going to impact someone just by sharing your story."

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