



a parent's tale



Call Tucker Varns a miracle. Born without a left ventricle in his heart, he had his first open-heart surgery when he was 11 days old. The second son of Dixie and Terry Varns had been born on a Wednesday in Spearfish, South Dakota, an hour northwest of Rapid City.

Sonograms had failed to show the heart defect. The medical staff suspected something was wrong when Tucker was born purple and it took a long time to get him to breathe. But doctors told Dixie and Terry that once he was breathing, everything would be fine. Tucker was home by Friday, but on Saturday he stopped nursing.

The Spearfish ER diagnosed pneumonia and started treating him for that before transporting him to Rapid City Regional, a larger hospital. There the staff worked on him for three hours, but his kidneys and liver were failing. Finally they brought in a cardiologist who identified the heart defect.

“At 4 AM, we were all life-flighted to Omaha Children’s Hospital,” says Dixie. “There we were given three options: let him go; do a transplant; or do a three-stage procedure that required three surgeries to correct the hypoplastic left heart syndrome.”

Dixie and Terry chose the third option. “The day of his surgery was the first day I got to hold him since we’d taken him to the ER,” she says. “My emotions were pretty messed up. I was worried about Steven, our older son in South Dakota with his grandparents, and my new baby. It was hard for me to let anyone else hold him.

“I felt that I had done something wrong in pregnancy, and even though everyone assures me that I didn’t, I still wonder that. It’s always in the back of my mind.”

Tucker did well in surgery, but then there were complications. Finally, he was taken to a room his parents could enter. “They tried to prepare me for what I would see, but you can’t really prepare

“It’s overwhelming to listen to the mothers of these children with heart defects. Every story is different, but they are all saying the same thing.”

someone to see their child in that much distress with tubes everywhere,” says Dixie. “I just bawled the whole time. You don’t think of your baby being that sick.”

The Varns stayed in Omaha almost a month and made friends with other parents of sick children. Then a month after they’d returned home, right before Thanksgiving, Tucker went into congestive heart failure, which resulted in an unscheduled surgery in Omaha, and another month-long stay ten hours from home. It also meant another surgery to install a pacemaker — they finally got home right before Christmas.

In March the family returned to Omaha for the second of Tucker’s three scheduled open-heart surgeries. That was another month away from home, with yet another surgery to redo the leads on his pacemaker. He spent his first Easter in the hospital.

“When he was two,” says Dixie, “they did the last open-heart surgery. All surgeries are hard, but that one was hardest because he could say ‘Mama’ by then. He was saying that when they were taking him in. That surgery only took three hours, and he did awesome. He was breathing on his own the next morning.”

Today Tucker is a pretty healthy four-year-old boy. He likes to ski, though the elevation is a problem and he tires easily. “But just playing, he can go as long as his older brother,” says his mother. “Just looking at him, you’d never know anything was wrong. He continues to have all three therapies — speech, OT and PT. The main thing that holds him back is his speech, but that has come a long way in the last year.”

During the course of these surgeries, the Varns got to know other parents with children with congenital heart

defects. They were surprised to find two other families in Spearfish and four more in Rapid City. Four of the families started Thumper’s Support Group. “We wanted to get the word out that there was someone to talk to,” says Dixie. “Family’s great, but they don’t know what you’re going through day-to-day. Other parents understand that you have good moments and you have bad moments, and that could be within a half hour.”

The group got to know local Mended Hearts volunteers, who helped however they could. “Then Mended Hearts contacted us about Mended Little Hearts. Tita Hutchens, Mended Little Hearts Taskforce Chair, and Regina Dixon came up,” says Dixie. “They told us they didn’t want to take over but just help us get the word out because they wanted to start this program all over the U.S. We thought it was a miracle because they could train us how to talk to the parents, who are in such need.”

Today, western South Dakota has a thriving chapter of Mended Little Hearts involving 20 families. Mended Little Hearts chapters are not numbered but are referred to by name. The South



The Varns Family: Terry, Dixie, Tucker, Steven

Dakota group is Thumper’s Mended Little Hearts of Rapid City.

“It’s overwhelming to listen to the mothers of these children with heart defects,” says Tita Hutchens. “Regina and I both just sit and cry. Every story is different, but they are all saying the same thing. Mended Hearts is in a position to help these families, and it’s a really great thing. We need these different age groups in Mended Hearts. It’s really opening doors for us. The mothers are anxious to get us in these hospitals. We’ve worked on this for two years, and we’ve got everything in place. We’re ready to grow.” ❤️

The Facts

- 8 babies out of every 1,000 births will have some form of congenital heart disorder.
- Approximately 40,000 babies are born with a defect each year.
- About 1,000,000 Americans born with a congenital heart defect are alive today.
- Heart defects are among the most common birth defects.
- Between 1987 and 1997, the death rates from congenital heart defects dropped 23 percent.
- Though research is ongoing, at least 35 heart defects have now been identified.

A good resource for information on congenital heart problems is the Congenital Heart Information Network at www.tchin.org.