

SGT RYAN CHASSE

TINA CHASSE

HEATH CHASSE

CRIMSON CHASSE

full hearts

AFTER WATCHING A DAUGHTER BATTLE A RARE DISEASE AS BRAVELY AS ANY WARRIOR, A TENNESSEE SERGEANT AND HIS FAMILY HAVE DEDICATED THEMSELVES TO HELPING OTHERS IN HER NAME.



BY MSGT ROBIN OLSEN

IN 2005, AT A SMALL RURAL HOSPITAL IN CARTHAGE, TN,

Sergeant Ryan Chasse returned from a deployment in Iraq so that he could witness the birth of his first daughter. But what started out as a leave from one fight turned into the beginning of another.

His wife, Tina, was induced on May 17 at 7 a.m. Four and a half hours later, **Haley** arrived, coming much faster than her dad expected. "Ryan walked out of the room briefly to call his mom to come in and missed Haley being born," Tina says. "He was shocked when he walked right back in the room and she was already here."

But joy quickly turned into alarm for Tina and Ryan, a training NCO for the Tennessee Army National Guard's Joint Force Headquarters in Nashville. The couple learned their newborn might not live.

Haley was transported by helicopter to Nashville's Monroe Carell Jr. Children's Hospital at Vanderbilt. Ryan went with her and didn't return until 1 a.m., when he broke the news to Tina. Haley had been born with a rare heart condition known as Ebstein's anomaly, a defect that occurs early in fetal life when the right chamber and valve do not form correctly, and blood is not properly pumping to the lungs. She would need to have open-heart surgery.

"I was in total shock," Ryan recalls. "How could they possibly perform heart surgery on such a little heart?"

Instead of being snuggled by her parents, Haley was attached to several wires, monitors and an IV, 50 miles away from her mother. "I was scared because I didn't know if she would make it through the night," Tina says.

Dr. David Parra, Haley's cardiologist at Children's Hospital, says that some cases of the disease can go unnoticed into adulthood, but that Haley's case of Ebstein's anomaly "was extremely rare." She was born looking blue because of her low oxygen levels, he says.

With the new baby facing immediate surgery, the Chasse family was even more on edge, because Ryan was home on leave only for Haley's birth. He would soon have to go back overseas.

"Tina and I were a young, newly married couple with one child and now a newborn with a heart condition. Adding Haley's situation on top of all the normal stressors [of deployment and family life] was extremely difficult," Ryan says. "I was approved extended leave, giving me another two weeks stateside. Fortunately, Haley was able to come home the day before I had to leave. When it came time for me to actually leave, the Soldier inside of me was ready to return to finish the mission I was trained to do, but the heart and mind inside the uniform couldn't stop thinking about the family [I] left behind."

SASSY CHASSE

Over the next five years, Haley endured multiple trips to the hospital for various operations and cardiac catheterizations to record pressure in the heart and vessels and to perform necessary interventions, like balloon dilations or stent placements, to improve overall heart conditions, says Parra. Even through all of this, you couldn't keep her spirit down, he says.

"If you ever met Haley, you loved her. There was no way not to," says Suzanne Gaffney, a friend of the Chasse family. "She was very spunky and demanding, but always very loving and thankful for everything."

Haley's nickname at preschool was Sassy Chasse. "She was so much fun: outgoing, full of life and so thankful for everything she had or was given," Tina says. Haley loved to go to preschool and hang out with her friends; go to her nanny's house; and eat macaroni and cheese, chicken and dumplings, and "big chicken,"



Above: SGT Ryan Chasse holds a picture of his daughter Haley, who passed away in 2010 from complications caused by a congenital heart defect. **Left:** Five years after Haley's passing, the Chasse family is united in honoring her memory.



the Pediatric Heart Institute at Children's Hospital each year, and it provides other support to families in the form of gas cards, medical equipment, rent and utilities, and more. Often, the foundation supplies social workers with gift cards to hand out to families in need, so Ryan and Tina do not always get to know the people they help.

The foundation provides support in other ways as well. "They even purchased a headstone when the family could not afford it," says Gaffney.

To make all this possible, Haley's Hearts Foundation holds two fundraisers each year, a **Chili Supper and Winter Carnival**, most recently held on Feb. 28 at the Trousdale County High School in Hartsville, TN, and a **Forever 5K Run/Walk**, also held in Trousdale County, every October.

Of all the families Ryan and Tina have been able to help, the first child was Silas Smith. He had received a heart transplant in November 2010 and was in the hospital for four months. "In March 2011, he was able to go home to the apartment our foundation obtained for his mom," Tina says.

However, one of the biggest ways Haley's Hearts helps families has nothing to do with donations. "Who knows what it feels like to go through all of these things better than someone who has been through them?" Gaffney says. "Tina and Ryan are huge emotional supporters, as well."

For the Chasse family, Haley's battle for life was the most difficult time in their lives. "Losing a child is something you never get over," Tina says. "You just learn to cope with it."

Having gone through the experience themselves, one of the ways they cope is by comforting other ailing families.

"When we go visit with a family to sit down and talk, or help with whatever their needs may be, seeing the look of relief on their face is a humbling experience," Ryan says. "It is a true



"WE HAD TALKED ABOUT STARTING A FOUNDATION BEFORE HALEY PASSED, AND THEN WHEN IT HAPPENED, WE KNEW IMMEDIATELY IT WAS SOMETHING WE WANTED TO DO." — Tina Chasse

her name for KFC. She loved to play babies, and play with her cousin and best friend Mike.

Parra says that Haley would pretend to be upset with him during her frequent doctor's office visits, but that eventually she'd smile and give him a hug or a high-five.

As much joy as Haley experienced and offered others, her young life was also full of challenges. Her parents credit the huge support system they had, which helped them get through the toughest times.

"We are from Trousdale County, a small-town community. Everybody knows everybody," Tina says. "During our [hospital] stays [with Haley], or any procedure, our community—church, family, friends, co-workers and strangers—prayed for us, brought food to the hospital and helped us pay bills."

In June 2010, Haley had surgery to replace her internal pacemaker that had become damaged. "Two days after the pacemaker surgery, they found a huge life-threatening blood clot in her abdominal aorta," says Tina. "She spent the next three weeks on extracorporeal membrane oxygenation (ECMO) going through several surgeries."

A machine that temporarily works as a patient's heart and lungs, ECMO allows the actual heart and lungs to rest, giving them time to heal, says Parra. "Blood from the patient is directed into the machine, which oxygenates the blood and pumps it back into the body," he adds. "It is very invasive."

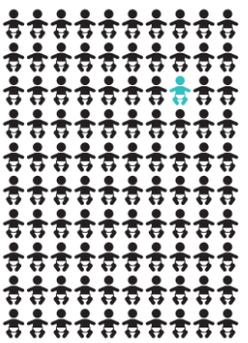
During this stay, the couple realized their family wasn't the only one with a very sick child.

"When you stay in a hospital, you often see the parents of other children as you pass by their room, in the halls or on the elevator," says Tina. "You talk about your children and bond with the other families. There was one parent in particular in the room next door. She was a single mother from Alabama who was there alone most of the time. Her son, Jaxon, also had a heart defect, multiple surgeries and had been on ECMO a couple times. He was admitted a few days before [Haley], and we became friends."

The two families were grateful for the mutual support. "Ryan and I would always ask if she needed any-

1
in 100

That's how many babies are born with a congenital heart defect each year.



200+

Number of families Haley's Hearts Foundation has helped financially. To learn more or donate to Haley's Hearts Foundation, go to HaleysHearts.org

thing," Tina says. "We realized how we were blessed to have each other, people to call, text, visit, bring food and pray for us."

Ryan says that he and Tina spent a total of 174 days in the hospital. During Haley's last hospital stay, friends created imprinted wrist-bands that said, "Praying for Haley," and sold them at \$5 each to raise money for the family's many hospital bills.

"Haley had many procedures: operations, catheterization, long periods in the ICU and hospitalization with chest tubes and IVs," says Parra. "Seeing her in her last days was truly difficult for the family and the team of doctors and nurses who took care of her. She and her family endured all of these moments with great courage and dignity."

Then Ryan and Tina had to make a decision no parent should ever have to make.

"We had to decide to leave her on the ECMO machine [life support] or take her off," Ryan says. "We decided to take her off and leave it in God's hands, so that he would do what was best for her."

Haley, age 5, passed away on Aug. 2, 2010.

"Holding her hand, watching her take her last breath and realizing that this was it—my baby girl wouldn't be going home with us—was the most difficult moment for us," Tina says.

"It was so difficult to know that her little heart beat for the last time," Ryan adds. "But there was also peace knowing that she wouldn't suffer anymore."

After losing Haley, Ryan and Tina had to relay the sad news to Haley's older brother, Heath, who was just as devastated by the loss.

HALEY'S LEGACY

Despite the Chasse family's heartache, they had found comfort in the support of others. They soon realized that one way to heal and to honor Haley's memory would be to pay it forward.

In 2010, Ryan and Tina founded Haley's Hearts Foundation, a nonprofit that raises money for families of children born with congenital heart defects. "We had talked about starting a foundation before Haley passed, and then when it happened, we knew immediately it was something we wanted to do," Tina says.

"So many [people] helped us in our time of need; it was time to do our part and help others in need," Ryan adds.

The foundation has raised over \$150,000 and helped more than 200 families financially. It donates money to

blessing to know that we can help that family focus on their child and to know that even though Haley is no longer physically here, she continues to bless lives."

Remembering Haley also offers the Chasse family comfort. Ryan says one of his most memorable times with Haley was a trip to Disneyland provided by the Make-A-Wish Foundation. "Being able to take Haley so that she would experience that was amazing," he recalls.

One year after her death, to honor what would have been Haley's sixth birthday, Ryan says family and friends gathered together at the cemetery and released 100 balloons where she was laid to rest. They continue to honor her legacy through the foundation.

"[Having watched] my own little girl and the other children endure all they go through and how mentally and physically tough a person can be, I try to be as resilient and positive as they are every day, whether at home or at work," says Ryan.

In 2013, Tina gave birth to another little girl, named Crimson, who is now almost 2. Her big brother, Heath, is now 12. No matter how old they get, they can always look to their sister as an example of how they should live.

"Haley was the bravest and toughest little girl I have ever known," Tina says. "She taught me what life is truly about." **GX**



Left and opposite page: Despite their loss, the Chasse family has endured through the love and support of family and friends. **Above:** Ryan and Heath run with Crimson during the Haley's Hearts 5K last October.