MOM TERRI

Terri was 22 weeks pregnant when she found out that something was wrong. A routine ultrasound had revealed her baby had a heart defect. She was devastated as she nervously waited for more information.

Tests revealed the baby had a chromosome 8 deletion, a rare genetic condition that can result in growth deficiencies, skull and facial malformations, heart abnormalities, mental impacts and other defects.

"The doctor told me the worst of the worst possible outcomes," Terri said. "All I could think was 'What did I do?' 'What went wrong?' "

Fortunately, she had nurse Karen.

Terri met Karen when she enrolled in Nurse-Family Partnership® (NFP) at McLeod Health in Florence, S.C.

"We met at a Dunkin' Donuts after her classes and I knew right away it was going to be a good relationship," said Karen. "With certain people, you click almost immediately."



Throughout her journey as a new mom, Terri (shown left) has leaned on nurse Karen for emotional support to help her care for her daughter's health challenges.

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Karen had worked as a pediatric intensive care nurse before she came to NFP, so she could help Terri understand what the doctors were saying and prepare her for what to expect.

"When I expressed my fears and my worries, she gave me great information and resources that made me feel better," Terri said.

Labor was induced when Terri was about 36 weeks along and Aubrielle was 6 pounds, 3 ounces when she was born on Aug. 17.

The doctors handed her to Terri in the delivery room. "They let me hold her for probably two seconds," she said. "Then they took her away from me and I didn't hold her again until maybe a week later."

One chamber of Aubrielle's heart was much smaller than it should have been, and her heart beat too rapidly, so the baby was placed in neonatal intensive care immediately where she was treated aggressively to manage the situation.

"I worked to prepare Terri for what to expect, seeing her baby hooked up to a lot of things with lines everywhere," Karen said. "I knew that if I didn't have a nursing background, that would be anxiety-producing for me as a mom, so I gave her a head-to-toe assessment of what she might see. It's important to prepare moms for these things."





Terri worked with her nurse Karen to encourage her daughter's development.

Aubrielle stayed in the NICU for more than a month and Terri lived in the Ronald McDonald House nearby so she could see her every day and reach through the ports of her incubator to touch her.

One of the toughest problems at first was Aubrielle's inability to grasp the concept of sucking, which affected both breastfeeding and bottle-feeding, Terri said.

"Eventually she got it, but it was a big problem."

Aubrielle had heart surgery at 9 months of age and has responded well.

"The doctors told me she's the biggest baby they've ever seen with a heart defect," Terri said. "She wants to eat all day. It did make a difference that she's always had a bigger appetite."

Now, with her second birthday coming in August, Aubrielle is an active, healthy, busy toddler.

"She's playful and cheerful, and I'm surprised she's learning everything so quickly," Terri said. "She's not delayed at all. It's not what I expected." Nurse Karen helped Terri encourage Aubrielle's development.

"We discussed reading to Aubrielle even when she was in utero," Karen said. "After she was born, we continued with books throughout her infancy, starting with black and white contrast books and progressing to books that prepare a child for school."

Terri followed Karen's advice as the months elapsed, spending tummy time on the floor with Aubrielle to encourage motor control and handeye coordination, singing and talking to her constantly to support language development and dancing with her to encourage balance and other skills.

At one point, Terri told Karen she was worried about Aubrielle's language development.

Karen arranged for a screening, which determined that her communication skills were a little low, so she recommended an intervention program for Aubrielle. But before she could enroll, Terri said Aubrielle's language skills had clicked and she no longer needed it.

"I just want her to be the very best she can be," Terri said.



Aubrielle (shown in her mother's arms) is now a happy, healthy and active toddler.





Nurse Karen says that Terri is an awesome mom.

Terri is attending Florence-Darlington Technical College in Florence to prepare for nursing school, and also works at McLeod Health.

"I'm so proud of her," said Karen. "Sometimes I forget she's only 22 years old. She's mature beyond her years. It's been amazing to see her grow."

Terri said she's naturally a shy person, but it was easy to talk to nurse Karen about anything.

"She's always happy and bubbly, and she made the relationship really comfortable for me," she said. "Her energy was incredible, and she helped me understand everything."

Karen said that Aubrielle is "growing into a vibrant young lady. She speaks her mind even if sometimes you don't know exactly what she's saying."

Despite the early worries about Aubrielle, the future seems limitless for the young family.

"Aubrielle is so active it would be easy to get overwhelmed, but Terri doesn't give into everything," Karen said. "She sets boundaries and wants to raise her child right. She has a good work ethic and wants her child to develop that, too.

"All those things make me so proud of her. Terri is just an awesome mom."

In addition to finishing nursing school and caring for Aubrielle, Terri dreams of venturing out of the comfortable environment where she has lived all her life. She and Aubrielle's dad talk about someday moving far from home.

"We've been here all our lives," she said. "Our families and our friends are all here. But someday we'd like to go to a place where everything and everybody is new, with new opportunities. It might be Georgia, or we've thought about Charlotte.

"It will be exciting and scary," she said. "It will take courage to say, 'Let's move.' But it's OK to get scared sometimes.

"I know whatever happens, it will be OK."



Terri is studying to become a nurse. Nurse Karen says that she is mature beyond her years.

Terri was enrolled in NFP as part of the <u>SC Pay</u> <u>for Success project</u>.

