



# Sisters' Lifelong Bond Helps Them Through Premature Births, Babies with Special Needs

Story by Heidi Dahms Foster



Having a new baby is a stressful, albeit joyful, life change. But when health problems and special needs present themselves, heartbreak and confusion also can enter in, and life radically changes. That's what happened to two Prescott Valley sisters and their husbands in the past year and a half.

In Spring 2017, Rachael and Aaron Moore were expecting their first baby, a little girl. Rachael started her pregnancy with extreme morning sickness that lasted until 21 weeks. Then, she underwent an ultrasound.

"The tech was really focused on my daughter's face. I was oblivious, but my husband noticed and asked what was wrong. It was so frustrating hearing her say 'you'll have to wait until you see the doctor,'" Rachael said.

The doctor told the Moores that their daughter, Evie, had a cleft lip, and sent them to a specialist in Phoenix. There, doctors also found a cord abnormality, and also sent Rachael for an in-utero echocardiogram for the baby.

In March 2017 the Moores were at Yavapai Regional Medical Center East for a steroid shot to help develop Evie's lungs, when a nurse found Rachael's blood pressure was elevated. Doctors put her immediately on bedrest.

Pregnant for just under 28 weeks, Rachael was ill most of that weekend, and then on Sunday, she noticed some spotting. Her husband took her immediately to YRMC. Doctors found she was dilated to a three and prepared to fly her to Phoenix, where she could receive advanced treatment. It wasn't to be. Remembering a time of total trauma, Rachael can now express a bit of humor.

"Spaghetti saved my life," she said. Minutes before the helicopter was to pick her up, Rachael vomited her spaghetti dinner, and then lost a lot of blood. Nurses found her baby was coming immediately, and she was rushed into delivery. Shortly after, Evie, at just 1 lb. 11 oz., forcefully made her entrance into the world.

Evie was air evacuated to Phoenix St. Joseph's Hospital Neonatal Intensive Care Unit, and Rachael remained in Prescott Valley while



Rachael with Evie.

Photo courtesy of Amy Dangerfield.

doctors worked to get her blood pressure under control.

"On Wednesday, I was finally released and went to Phoenix to be with my husband and baby." Evie would remain at St. Joe's for three months before being transferred to Phoenix Children's Hospital for further care. She came home at 4 lbs. 3 ozs. and continues to progress. She has had surgery to repair her cleft lip and is a strong toddler with a distinctive personality.

Rachael feels grateful and fortunate that she and her baby survived, after doctors told her that if Evie had not come when she did, both mother and baby would have died.

"My little miracle Evie Marie Moore is a fighter. She has had



Moore family.

Photo courtesy of Moore family.

her lip repair surgery and a gastric tube placement at the same time. She still needs her alveolar plate (gum line) fixed and a possible heart surgery. We won't know until her next echocardiogram," Rachael said.

About the time Evie was born, Rachael's sister Andrea Sylvester and her husband Andre found they were expecting their first baby, also a girl. At her 20-week ultrasound, Andrea and Andre heard their baby also would have a cleft palate. While the news was a shock, Andrea said it was perhaps not as hard as her sister's experience.

"It wasn't as scary a diagnosis, because I had my niece to see it would be OK, and I had my sister's strength as a guide," Andrea said. Their real concern now was whether daughter Aria, like Evie, would be born prematurely. "Mom and all of us rejoiced and breathed easier with each week passing Aria's gestation time."

Though a premature birth didn't look imminent, Andrea faced other challenges. At about 27 weeks, she was diagnosed with Gestational Diabetes. This required a specialized diet and testing her blood sugar levels four times each day.

At 29 weeks, however, Andrea's cervix was shortening, and there was a concern that Aria also may be born early. Andrea was placed on restricted activity and eventually strict bedrest as doctors worked to delay delivery as long as possible.

At 32 weeks, Andrea was resting in bed one evening with her dog. "My dog was really restless and wouldn't settle down, which was out of character for our senior pup. We put him on the bed with me, and he continued to be agitated. It was then I realized I was having more contractions than normal. We started timing and contractions were consistently five minutes apart. It was at that point we knew it was time to go to the hospital."

The following morning, dilated to a four, Andrea was air evacuated to Phoenix Abrazo Arrowhead Hospital, where she stayed for two weeks. On October 11, 2017, Aria was born at 4 lb. 1 oz., and 33 weeks.

Andrea and Aria were transferred to Phoenix Children's Hospital, where the family received an immediate consultation to treat her bilateral cleft palate.

"We were able to consult with her surgeon the same day Evie had her lip repair," Andrea said. "The surgeon took the time out of her day to be sure we were seen and to talk about Aria's future. She made us feel so much better. The care for the parents as much as the children has been extraordinary. Aria was able to be off the feeding tube by the end of November, and she was only in the NICU for 22 days."

Aria had her lip repaired in March 2018, and her palate repair in August. Both girls still have a long road ahead.

"Cleft children can have surgeries up to 18-20 years of age depending on their growth and development," Andrea said. "They may need jaw surgery, more nose repairs, lip fillers, scar eliminating, palate spreading, palate repair if holes form, and so much more. Both girls have holes in their hearts that, if they don't close, will need to be closed with surgery at around three years of age."

Both mothers, along with their husbands, have understandably undergone a lot of emotions.

"It was terrifying finally going home with a baby on oxygen, a feeding tube, and a heart monitor. You literally have to go one moment at a time or go crazy with what if's," Rachael said. "It can be very overwhelming in the NICU. I cried the first two weeks every time I saw my daughter. I cried the day she got transferred to another hospital, and I cried when she came home so small. For almost a year I couldn't stop blaming myself for not keeping her in longer. God's love kept me going, even when I was standing in the darkness of my mind. Most of all, I'm happy my Evie Bear survived and so did I."

Both are grateful for the support of their husbands and their families.

"It's hard enough being a first-time parent and walking this unknown path," Andrea said, "but to have special needs on top of it all makes it that more daunting. It was rough at first for both Andre





Andrea with Aria.

Photo courtesy Amy Dangerfield.

and myself but that's just learning how to be a parent. I honestly can't imagine what I would have done without him, not only for my recovery emotionally and physically, but for everything he does for Aria. We as a pair have figured out what we need individually to get through all this. We know what the other needs to be able to move forward."

"I wouldn't have survived without my husband Aaron," Rachael said. "He actually graduated paramedic school during Evie's NICU stay, so he had more of an understanding of all the 'medical speak.'"

Andrea and Rachael both also credit their mother Lisa for her unfailing help through the births and surgeries of the girls. "She has sacrificed so much for both of us and our girls, from staying at Ronald McDonald house with us so we weren't alone, to driving us to Phoenix multiple times for all our appointments. She has been our biggest support, and she is incredibly giving. I don't know what we would do without her," Andrea said.

Lisa Haywood Gill entered a whole new world with her grandchildren's deliveries. "I never had any issues during my pregnancies or deliveries," she said. "When Rachael found out she was pregnant and started having complications, I gained a new understanding of what some women have to go through to have a child. The day we found out Evie had a cleft and other physical issues

came as quite a scary shock. I was with Rachael when Evie came totally unexpected 12 weeks early.

"The series of events leading up to Evie's birth were totally miraculous and seeing her tiny 12-inch body and hearing her tiny cry—what an amazing miracle this little baby is. Through the team at St. Joseph's hospital and the Barrows cleft team I have learned so much about babies born too early. They have been amazing and have helped all of us immensely. As I have watched Evie's journey for the last 21 months through all her ups and downs I constantly see what a miracle God has given us!

"When Andrea found out that Aria had a cleft the journey did not seem as daunting. I was with Andrea when Aria was born seven weeks early. What a difference five extra weeks in the womb makes. Aria too was another little miracle that God has given us. I am so proud of both of my daughters and the amazing strength that God has given them!"

Friends, other family members, and the medical community have all pitched in to help Evie and Aria get off to a good start after their tough first months. Their mothers say there are plenty of resources available to help, but you have to be able to ask.

"The best advice I can give is to ask questions. If you don't understand what the doctor says, ask more questions so you feel comfortable with the knowledge you have, and not so confused. And don't be afraid to cry," Rachael said.



Andrea, Lisa and Rachael.

Photo courtesy Amy Dangerfield.

"At first it felt silly to ask for help and to look things up," Andrea said. "I have called the nurse line so many times for what felt like a silly concern, and they made me feel heard and helped me feel less stressed about everything. If you have a concern or question do not hesitate to call your pediatrician or your surgical team. That is what they are there for. We have seen our pediatrician so much, and even if we walk out with nothing wrong it was peace of mind."

The sisters have received assistance from the beginning when they were able to stay for extended time at Ronald McDonald House in Phoenix while their babies were in NICU. Other programs offered them assistance with baby checks, extensive information early on, and therapies, including the High Risk Perinatal Program/Newborn Intensive Care Program (HRPP/ NICP), the The Arizona Early Intervention Program (AZEIP) and the Arizona Department of Economic Security (DES), Division of Developmental Disabilities (DDD).

When Andrea found her baby also would be born with a cleft, she clung to Rachael's courage and ability to move ahead. She's happy the sisters can continue raising their little girls together. "We not only have someone to talk to about frustrations, but we know as the girls get older, they'll have each other as support just like Rachael and I did. I honestly can't imagine how bad it would be not having my sister. I see how truly blessed I am that we haven't had to travel this journey alone."

As Aria progressed through her first surgeries and began to walk, Andre and Andrea received a big surprise. They were expecting again.

Their first son is due in March, and of course, the couples' first concern was whether he also would have a cleft. "At his 20-week scan they couldn't see a cleft, but they had us follow up at a perinatal clinic in Phoenix. They also didn't believe they saw a cleft lip or palate."

Andrea is still under care because of the risk of another prema-



Evie. Photo courtesy Moore family.

ture birth, but she's progressing well. "I joked with the doctor—how do you 'normal baby'?! It's all overwhelming but I'm so excited for everything! Aria still doesn't quite understand why my lap has disappeared, but she has reached the stage of Daddy's girl."

Today, Evie and Aria are active little girls with bright futures, thanks to a tight knit community of family, friends, health care professionals, and other parents who have walked their road before.

"When the doctor told my wife and I that our little girl would have multiple surgeries that spanned nearly 20 years," Andre said, "I was concerned for Aria's safety, but was never concerned about the clefts. She would be different from other kids, of course, but I knew that Andrea and I would love her the same way regardless."

"I've never seen my daughter's cleft as a problem or even a negative thing. I cannot say that my family is small anymore, because my wife and I have been supported by more than our blood relatives. From Nana taking Andrea and the baby to Phoenix on days when I was working to friends from church and school visiting the house and just talking, we have been blessed every day. I've never felt more loved, frustrated, happy, and terrified than I have since my daughter was born. God has blessed my family, and for that I am thankful."

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