ONE LIFETIME LONG

The Heartwarming Memoir of a Pediatric Cardiologist

Dr. Carol Cottrill

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This is a nonfiction book about pediatric cardiology patients.

To respect the privacy of the patients and their families, the names of most people mentioned in this book have been changed.

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Chapter 1

Robert

I remember very clearly the first time I met Robert. It was on a Sunday morning, and I was on call for the university's cardiology service and had gone to Mass separately from my husband and children. They came in the van, and I took our second car, which happened to be a little red Volkswagen Bug. I had gone to the hospital and made rounds and then went to ten o'clock Mass at the Newman Center. During Mass, I got a page, which I promptly answered, and I was asked to come to Central Baptist Hospital to see a baby that had been born with what was suspected to be heart disease. Just after Mass, I sent my family home for brunch and in the bright autumn sunlight, made my way to Central Baptist Hospital. I came up to the neonatal intensive care unit to find Robert. I remember thinking that it was a strong name, and I realized later that he was going to need a strong name. When I first approached his crib, all I could see was flaming red hair. He had this very thick red hair, and then I looked beyond it to find a very dysmorphic baby. When pediatricians use "dysmorphic," they are talking about babies who often have unusual features. Robert had a constellation of things that we call Pierre-Robin Syndrome. He had a very small, posteriorly placed lower jaw and his tongue, which was normal in size, had no real place to go in his mouth except up to block the cleft that was in his palate or to fall back

and occlude his airway. Indeed, he was having a lot of trouble breathing. He also had some congenital contractures of his legs and was quite stiff all over. I noted from his chart that he had very low platelets in his blood and that was of concern. When I listened to him, he had a loud click, and I suspected that he had a bicuspid aortic valve. Because his color was good, and he had good pulses and a normal EKG, I did not think that he had very much aortic valve stenosis with it.

Before going to talk to the parents, I looked at the admission sheet and figured out some things. These were young parents, and this was their first baby. They had had 13 infertile years. This was the mom's very first pregnancy. I noted on the chart that they were Catholic and thought maybe the fact that we were of the same faith might stand me in good stead in talking to this family. I left the nursery and went into the mom's room where Mom and Dad were together. They didn't look very happy. I started talking about Robert's red hair, and I realized where it came from . . . Robert's mother had beautiful long red hair. I learned that she was an artist and that her husband was an engineer.

They reiterated the whole story about their infertility and recalled their joy at finally being able to conceive a child. I commended them for making the decision to give physical life to Robert, and I suggested that they maybe think about offering him eternal life through baptism. They were both taken aback by that, and Dad said, "Well, you know we thought that he was probably going to die and that if he is going to die, we should not get very emotionally attached to him, but let him go ahead and die. Then we will go on and decide what to do with the rest of our lives."

We talked a little bit about that, and I pointed out that no human really knows when any other human is going to die. We talked about how each life is one lifetime long, whether it is short or many, many years. There is a reason why each human being is on the earth, and it is sometimes a reason that we don't always understand.

As Thomas Aquinas said, "The pool of human intelligence is not meant to be contained in the sea of divine knowledge." That is a fancy way of saying, we don't really understand the Lord's ways, but we have to trust that they are good.

I told his parents that I didn't think his heart disease was threatening and told them to think about that baptism. I asked them if I could have one of the priests come and talk to them, and they said that was fine. I left the hospital and went back to the Newman Center where I found Father Cooper, fresh from two Masses that morning, enjoying a cup of coffee. I said, "You have to go to Central Baptist and talk to these parents. They have a baby that they think is going to die, and they are going to let him die without love or baptism, and you need to talk to them." I insisted that he go and crammed him into my little red Volkswagen and took him to Central Baptist. I let him go back to talk to the parents while I had a cup of coffee.

I don't know what he had said to them, but plans were made that they would baptize Robert and Mrs. Miller's aunt, who was a nun, would come from Indianapolis to be Robert's sponsor. That was all set up for the next afternoon, and we left the hospital. I deposited Father Cooper back at the Newman Center and went on home to recoup what I could of Sunday with my family.

Before going to work at the university the next day, I stopped at Central Baptist to find that a surgical consult had been obtained to try to do something about Robert's airway obstruction and it was decided that, to keep him from choking on his tongue, his tongue would be sutured to his lower jaw outside. That was accomplished just after his baptism that afternoon. For a day or two, his tongue did not obstruct his airway. He had a feeding tube, and his mom was beginning to pump breast milk to give him through the feeding tube. I saw him daily while he was in the hospital and a lot of things happened.

The tongue is a muscular structure and is always moving,

particularly in babies who have a very strong sucking instinct. The motion of Robert's tongue pulled the suture and tore his tongue and now he not only had a tongue that fell back and obstructed his airway, but he also had a forked tongue. It was felt that there wasn't much else that could be done, and he was placed in a position on his side where his tongue occluded only part of the time. Mom became very good at pumping breast milk, and Robert was solely on breast milk at the end of the first week of life. He was discharged after 10 days in the hospital; his mother had made her way to the hospital every day to deliver breast milk. Just after his discharge, he was seen in the clinic at the university.

At that time, we had a clinic on the fourth floor and hematology had clinic on the same day with cardiology and so both of us saw Robert. The hematologist looked at his platelet situation and although his platelets were low, they were holding. It was decided that he didn't need to be followed by the hematologist on a regular basis, but that a platelet count would need to be obtained once a week. We saw him in cardiology and an echo confirmed the fact that he had a bicuspid aortic valve with a dilated ascending aorta, but really not much aortic stenosis or insufficiency and his heart was working pretty well. I communicated this to the parents and noted that they were much more into his care than they had been earlier.

He went home to be seen back in a month and instead of coming to the cardiology clinic at the end of a month, he was admitted to the hospital with pneumonia. While he was in the hospital, we all noticed that his mother was the best nurse that he had, and I pointed out to his dad what a good job she did at passing his NG tube and at feeding him and really doing nursing-type care. The father commented that he did not expect that his wife, as an artist, would be a very good nurse, but indeed Robert's illness had brought out strength in his mother that no one had expected. He recovered from his pneumonia and went home.

I saw him once a month until Christmastime. He was not a vigorous baby. He did not fit into any other chromosomal syndrome, so no further workup was done after genetics saw him once. Mom continued to produce enough milk to be the sole nourishment for Robert. They called frequently for support and advice, and I tried to help them the best that I could with day-to-day matters, such as constipation, pneumonia, bellyaches, and crying.

Just before Christmas, Robert's mom called me with a big decision. They had stayed close to Lexington because Robert was not well, and they wanted to be close to doctors and hospitals in case something serious happened to him. The question his mom raised was whether or not he could go several hundred miles away to Western Kentucky to see family members on Christmas Eve. The entire family was planning to gather, including Robert's great-grandfather and there were plans made to take a photograph of four generations of the family. I pointed out to them that, although Robert was sick, he was stable and Western Kentucky was not the other side of the earth, so I felt they could certainly take Robert there. They had a good Christmas Eve and as they were driving back to Lexington on Christmas Day, they noticed that Robert was having increased problems with breathing and his color was not good. They called as soon as they got back into Lexington, and I told them to go right to the emergency room. At that time, I was on call for the ICU, so I went to the emergency room as well and met them there. Robert looked pretty poorly. His perfusion was bad. He had blue undertones. He had only gasping respirations. We supplied oxygen for him and had the big talk about whether we would intubate him and resuscitate him the entire way. The parents, who by now, loved Robert very much had a hard time deciding what to do. On the one hand, they really wanted to do everything to extend Robert's life, but on the other hand, they knew that he had had an awful lot of trouble breathing and a lot of trouble with pneumonia. They asked me what I would do, and I told them that it was an intensely personal call and that they had to make it. I said I would be happy to facilitate anything they wanted, but it had to be their decision.

We moved Robert to the ICU, and he was still not in very good condition. We had an IV in and gave him some broad-spectrum antibiotics, drew some cultures, got the basic things done, and just as he was getting settled in the ICU, he had an episode of bradycardia where his heart rate slowed into the 30s. I ask them what to do, and they asked to hold him. As they were holding Robert, his heart rate came back up again, and we had the big talk again about how much do we do for Robert. They decided to stay with him that night and that if his heart rate slowed or he had more trouble breathing, they would like to hold Robert. When Robert developed more episodes of apnea, that is when he frequently stopped breathing, they held him, they sang to him, and we prayed together.

About 3:30 in the morning on Christmas night, Robert died very peacefully in the arms of the two people who loved him most. After Robert died, the parents held him, and we talked for a long time. We talked about how I first met Robert and his parents and how I didn't really understand why God would give two beautiful people a child that wasn't perfect and then we talked about how each of the parents had recognized strengths in the other that only a child like Robert would have uncovered. Mr. Miller proudly pointed out that his wife had become a superior pediatric nurse. Mrs. Miller pointed out how good an assistant she had at home.

I asked if they would like to have a priest come, and they said yes. Then I was in trouble because Catholic priests tend to do all of their work on Christmas Eve and Christmas Day and sort of take off and go away for extended vacations starting on Christmas about noon. I finally located Father Davis at St. Paul's Church, who, at four in the morning, agreed to come over to the ICU and

talk with the parents. I can remember Father Davis looking rather disgruntled, unshaven, and sleepy. I ask him if he would like a cup of coffee and went off in search of one. I brought coffee for Father Davis and some more tissues for Robert's mom and in an effort to try to say something meaningful, Father Davis ask them what Robert's life had been like. They talked about how when Robert was born, they had wanted to maintain some distance between themselves and this child they knew they would lose. They said that at the time of his baptism, the family galvanized, and his baptism actually provided an opportunity to introduce this child to the family.

They were worried about how the family would accept the child who had unusual facial features. They smiled as they remembered that everyone seemed to comment about his wild red hair. They talked about coming occasionally to church on Sundays with Robert and how each time they did something new, it was a challenge, wondering how folks would accept Robert. Mrs. Miller at first had the feeling that everyone in the grocery store was looking at him but after she had been to the grocery a few times, she took it in stride. The first few times at church, they also were concerned that people would have their curiosity piqued and ask what was wrong with Robert. But that didn't happen.

People accepted Robert as much as they accepted his parents. Father Davis asked if there were any things that they looked to for strength and hope during this period of Robert's life. The father said, "There were times during Robert's short life when we didn't know where God left off and Dr. Cottrill started." I was very moved when I heard him say this. I'm sure that God was responsible for most of it and I, only for a little bit.

In the final analysis, these parents learned to accept and cherish a child that they really didn't want right after he was born. The child made them appreciate each other in a different. way. We were planning a funeral, and Father Davis, in his wisdom,

began to tell them about funerals and about what they could do and how this was their baby and not the rest of the family's baby. They could have a funeral anywhere or anyhow they wanted, and he would be happy to support their decisions and defend their feelings and desires about how this should be carried out. They finally decided to bury Robert in Western Kentucky in the family plot and the local priest would be in charge of the funeral. The music and the readings would be chosen by the parents. The nun who was his sponsor for baptism would do one of the readings and the grandmother and grandfather would do the other two readings.

After Father Davis's talk with the Millers, we got involved in some of the nuts and bolts of what you do when you are a nursing mother and your baby dies. Mrs. Miller had been accustomed to using a breast pump anyway, so she could relieve the breast engorgement that she had. We called her obstetrician who provided some medicine to help dry up her milk supply but, in the meanwhile, for relief, she continued to use her breast pump.

I didn't see the Millers again for a couple of months and during that time, another baby came in and died rather suddenly. This was also a breastfeeding mother, and the baby was the first child of young parents. The baby died on a weekend and the mother really didn't know where she could get a breast pump over the weekend. Thinking of Mrs. Miller and how kind and helpful a person she was, I called her and ask her if she would mind lending her breast pump to this other mother in a similar situation. The newly bereaved parents went over to the Millers' house to pick up the breast pump and they talked together. The families exchanged stories and supported each other in a way that I could never have done for either family.

A few weeks later, on a Sunday afternoon, I was walking in downtown Lexington and happened to see the two couples enjoying lunch out together. It really restored my feelings that

they should be together and sharing their grief and becoming good friends.

I didn't see Mrs. Miller again for quite some time. She called my office to make an appointment to do a cardiac assessment of a little boy that the Millers had adopted. He was born with a patent ductus arteriosus but was an otherwise healthy young man. They came to the clinic, and we talked a bit about Robert and about their decision to adopt and everything seemed to be well. I was pleased to inform them that their son's ductus had closed and that there were no cardiac issues for him at all.

They went home happy and I didn't see her again for about two years. I was in K-Mart one day pushing my cart when I saw flaming red hair and stopped to find Mrs. Miller with her two-year-old in the cart. I realized that she was very pregnant. I gave her my congratulations and said a quick prayer that everything would be okay with this baby.

I have never seen the Millers again. I don't know whether they have moved away. I suspect they did, as Lexington is not a terribly large place, and I feel that we would have run into each other at some point. I still remember Robert and remember all that he accomplished during his short life and all that he taught all of us about living, dying, and loving.

Chapter 2

Christopher

"Vivacious"—that is the only word you could use to describe Georgia. She was of average height but looked a little shorter. She was of average build but looked a bit heavier when I saw her the first time. She had sparkling black hair and dancing black eyes and just gave you the impression she was in charge of everything. I was about 40 years old at the time, and I think she was about 10 years younger. I was doing volunteer work for an organization that helps women with problem pregnancies.

When Georgia came to us, she was 36 weeks pregnant and had concealed her pregnancy from her family and her employer. Realizing that this couldn't go on very much longer, she arranged to take a six-week leave of absence from work and told her parents she was going on vacation and came to stay with my husband and our family. I went to work during the day and Tom had a lot on his plate at that time with working and taking children different places. So, the evenings were the only times we spent together.

During those evenings, Georgia confided in me about her situation. She was pregnant by a man who wasn't her husband. Her husband was in the service in Germany and didn't know anything about her pregnancy. Her plan was to have the baby, give it up for adoption, and resume life as if all of this had never happened. I was a bit skeptical but had no reason to doubt Georgia's words.

About the Author

Carol Cottrill was already the mother of four children when she started college at the University of Cincinnati. Motivated to learn about health sciences by the severe heart disease of her daughter, Carol graduated from medical school at the University of Cincinnati, where she was one of only three women students in her class.

Cottrill was the first pediatric cardiology fellow to complete training at the UK Medical Center. She later served as director of the Pediatric Intensive Care Unit for 16 years. She was a tenured professor, while at the same time maintaining a full-time pediatric practice and conducting clinics in remote areas of Eastern Kentucky.

This extraordinary physician cared for children with serious heart disease for more than 45 years. During that time, she and her husband, Tom Rolfes, fostered more than 20 children, many of them patients at the UK Medical Center. Suffering from rheumatoid arthritis in her later years, Carol made her rounds in a wheelchair, often singing as she pushed along the halls on her way from patient to patient. She died in 2017 at the age of 80.