

# Four Pounds of Promise

*God works through the smallest of His creations*

## Chapter 1 – A New Baby Girl

I always wanted to have a large family; in fact, as a teen, I thought I would have seven children. I was the youngest of six and loved the dynamics of a large family. Early in our marriage, Tom and I were eager to start a family but needed to wait while I finished college and worked for a few years. Sadly, our first pregnancy ended in miscarriage, but after six and a half years, we were blessed with the birth of our oldest daughter, Elizabeth Ann, which means ‘consecrated to God, full of grace, mercy and peace.’

We then mourned two more children through miscarriages. I began to believe Elizabeth would be the only child we would be blessed to parent. But God knew the desires of our hearts and sent Lauren Marie to our family in 1986. We were thrilled and wondered if our family was now complete or if God had more planned for us.

In the 7<sup>th</sup> month of Lauren’s pregnancy, Tom began what would be three and a half years working in Chicago, three hours away. The recession of the 1980’s caused jobs to be cut with no hope of employment, including jobs in Davenport, Iowa, and surrounding school districts, where teachers had been laid off when enrollments dropped as families moved from the area. As a former teacher in the Chicago School District, Tom was easily rehired for what we hoped would be no more than a year of weekend commuting, ending with a move for all of us to Chicago. We didn’t expect to welcome another baby at this time.

To learn of a new pregnancy the summer of 1987 when Lauren was 15 months old was more than wonderful; it was surprising! But by February, I suspected something was wrong with our unborn child. I woke up every night at 2 am with a sense of foreboding. The fingers on my left hand were numb, and with each passing night, the pain traveled further and further up my left arm. By the time I was in labor, the excruciating pain was headed to my chest. I thought I was having a heart attack, which I managed to whisper to the nurses, who immediately covered my upper body with warm blankets. They hoped the heat would relax my body and reduce my anxiety. It worked and I was able to focus on my breathing, as I sought to stay above the pain of the contractions.

Within the hour, Caitlin was born on March 28, a day before her due date. She didn't make a sound. No one spoke. I had believed this baby would be a girl, but at that moment, I wondered if she was even alive. I prayed she was. I managed to say, "Is it a girl?" Immediately, the deathly quiet room came to life. As the doctor spanked our baby's bottom, she began to whimper, a faint cry. I thanked God she was alive! Immediately, a nurse whisked Caitlin away in an isolette before I could even see her or hold her. I knew something was terribly wrong, as I had expected.

Because Caitlin's birth weight was so low (4 lb, 5.5 oz), a pediatrician was brought in to examine her and assess her condition. When Dr. Barry came to talk to me, still in the delivery room, he said that my baby was going to be ok, that she only had a little Bell's palsy on her left cheek that would eventually go away. Plus, one of four floating ribs that attach to the sternum was missing. Otherwise, he said, she was fine. I couldn't believe him. I knew Caitlin had something terribly wrong with her, and I just thought he was hiding that fact from me. Maybe he was waiting until I had recovered from the delivery. Maybe he really didn't know.

On Wednesday, March 30, my doctor made the obligatory visit to my room to inform me that my insurance would not cover additional days in the hospital, and I would be discharged by noon. He offered no caring words—just an abrupt announcement that I needed to leave while Caitlin remained in the nursery. Thankfully, the nursery staff assured me I could stay by Caitlin's side at any time.

As her bilirubin count began to rise, Caitlin was placed under lights. She didn't have the strength for bottle-feeding, so a tube was inserted through her nose to provide nourishment. She hated it and tried, often successfully, to pull it out. She was losing weight, and no one could figure out what was wrong with her. Finally, five days after her birth, she was transferred to the University of Iowa Hospitals and Clinics in Iowa City, an hour away.

Before she left by ambulance, Caitlin was baptized by our pastor, who was able to arrive quickly from his office across the street. A good friend, Nurse Marilyn, stood in as a proxy sponsor.

Tom and I were told not to follow the ambulance to Iowa City. As we slowly walked with Nurse Doris to the exit, she stopped us and said, "If they can't do anything for Caitlin in Iowa City, bring her back here. We will take care of her." I knew what Doris was saying, that Caitlin might not survive. It was the first time anyone hinted at what I had believed for the past month.

Caitlin was admitted to the Iowa City hospital the Saturday before Easter. We were allowed to see her in an isolette in a room with eight other critically ill newborns. Their cries were normal infant cries, much louder than Caitlin's. I wondered why.

That evening, Tom returned to our home in Davenport to be with Elizabeth, age 8, and Lauren, age 2. He planned to bring them with him the next day, Easter Sunday, so they could see their baby sister.

At 3am that Sunday morning, the telephone rang in the patient room where I slept. A nurse advised me that Caitlin was undergoing a total blood transfusion, to hopefully eliminate the infection believed to be a result of what they termed her 'premature' condition.

Numerous medical personnel were crowded around the flat table where she lay in isolation--too many people for me to actually see what they were doing. I was told it would be a three-hour process, so I waited down the hall, reading the Easter story from the Bible and praying this procedure would really help her. I would return every 15 minutes to see if I could tell what progress was being made, only to again realize, I couldn't even see Caitlin, let alone the work that was being done.

At 6am, the transfusion was complete and declared to be a success by the resident doctor. I asked how they would know it was successful. "Caitlin is responding well, and we will have blood test results in a few days," she replied. "Then we will know how to treat her."

I doubted the news would be good, but on Monday and again on Tuesday, the resident assured me Caitlin would improve, and they would soon know what had caused her issues. It was hard for me to believe the doctor, which I didn't until Wednesday. That morning, when I went to see Caitlin, she appeared to have a healthier color and even had gained a bit of weight. I finally allowed myself to be hopeful.

That hope died when five physicians walked into the waiting room at 3pm. They asked if my husband was there; I said I expected him within the hour but that they could tell me the results of the blood work. One talked while the other four observed. The lead doctor said, "We have the test results, and it isn't good news. Your daughter has a condition called trisomy 18 or Edwards Syndrome."

"What is that?" I immediately asked. I had never heard of it.

“It’s when a person has an extra 18<sup>th</sup> chromosome,” the doctor replied. “Usually, extra is good but not in the case of chromosomes. It’s a terminal condition. There’s nothing we can do.” I asked if he had any literature on this condition—I am a visual person and need to read new information to fully understand. The doctor would have a nurse ‘look into their files’ but didn’t promise anything. This was before the internet or cell phones, so resources were limited.

The moment the doctors left, I raced to Caitlin’s room, where I discovered all monitors and any form of help that had been there earlier had been removed. She was naked, on the table, all alone. I immediately rushed to the nurses’ desk and told them that I wanted Caitlin released to me since they weren’t going to do anything for her. I was told they couldn’t do that—then remembered Nurse Doris’ words, “Bring her back to Davenport.”

I demanded that Caitlin be moved to Mercy Hospital. “We will have to look into it,” was the reply. Evidently, an ambulance needed to transport her back, and our insurance wouldn’t pay for the return trip.

As I waited for Tom to arrive at the hospital, I prayed about how to get Caitlin released back to our hospital. Were they just going to wait until she passed away? I knew I didn’t want my baby to spend whatever days she had in a hospital that had given up on her. The social worker had come in right after the doctors left to see if I wanted them to return when Tom arrived to repeat the news. I said no, I didn’t think that would be necessary.

At that moment, Tom did arrive, and the social worker explained Caitlin’s diagnosis. I don’t remember a lot of what she said except the one thing that shocked me at the time and still upsets me today: “You should know that most marriages don’t survive after the death of a child,” she declared. She was already at the point #1 where our daughter was dying, and #2 giving us no credit for surviving something like this as a couple. I really didn’t want to talk to her anymore; instead of offering help and support, she had planted a seed that our marriage would end. She didn’t know us and the strength we had as God’s children.

Needing to get away from the dark news shared at the hospital, Tom and I found a local restaurant where we could talk. Neither of us felt like eating. Tom brought baby cards that had arrived in the mail, congratulating us on Caitlin’s birth. I just thought, “What’s the point; we should throw them away because this was not a happy day.” We both were in shock and so very sad.

Tom wanted to stay, but he had to return to Chicago to work. I remained in Iowa City, grateful to my sister who had left her own family hours away to care for our two girls in Davenport.

Thankfully, God answered my prayer to return Caitlin to Davenport on Friday, April 8, and we didn't have to stay at the hospital any longer. Mercy Hospital stepped in and provided the ambulance to return Caitlin to them less than 48 hours after we learned she had trisomy 18.

\*\*\*\*\*

I have had many years to reflect on Caitlin's short time on earth. Some people would say, "What was the point of her life? She only weighed four pounds, never achieved any milestones and never did anything according to our world's standards." When people hear that Tom and I lost an infant daughter, they wonder, "What was it like when she died?" I reply, "Let me tell you how she lived." The following chapters are about the people whose lives God touched through our baby, Caitlin.

## **Chapter 2 – Softening Hearts**

With Caitlin back in Davenport, my sister Ruth was able to return to her own family, and I could be at home with Elizabeth and Lauren, who had turned two years old while I was in Iowa City. I felt terrible missing her birthday, but we celebrated at the end of the week, when Tom and I were both home.

At Mercy Hospital, Caitlin was placed in an isolette away from the other babies, in a room where newborns were brought to be weighed and measured. I saw many babies during those weeks, marveling at how healthy they all seemed to be. One baby weighed nearly 13 lbs!! Each one served as a reminder that my baby was not healthy. I just prayed she would be strong enough to go home.

At three weeks, Caitlin was moved to the nursery with the newborns, where I could finally hold and rock her. Because she couldn't nurse or take a bottle, I pumped my breastmilk, which was fed to her through a tube. She slowly added ounces to her weight, which had dropped below four pounds while she was in Iowa City.

Every day was cause for a celebration because I had learned that most babies with trisomy 18 don't survive the birth, and if they did, life expectancy was two weeks or less. When Caitlin reached her one-month marker on April 28, the nurses celebrated with balloons and a cake for me and the girls. It was a happy day! My sister Eunice, who is artistic, created a monthly birthday card for Caitlin. Each one became more special than the last, as it was a reminder of God's goodness and answer to my prayer that we would have Caitlin for as long as it would take for her to know she was loved.

I got to know each nurse very well, as shifts changed, and new ones returned from days off. I noticed one young nurse didn't provide care for Caitlin when we first returned from Iowa City. She would smile at me from a distance but seemed to have other duties for the first four or five days. I learned later that all the nurses were informed of Caitlin's diagnosis before she returned to Davenport and were given the option not to care for her if it would be too emotionally difficult for them. Only one had chosen this option. However, after watching how the older, experienced nurses provided loving care to Caitlin, the young nurse realized she, too, could do this. I never talked to her about her earlier decision, but she shared that it was a privilege to have Caitlin in the nursery and to get to know our family.

My mom had passed away four years before Caitlin's birth, and since we didn't have any relatives nearby, I relied on friends from church to help so I could spend time at the hospital. Mary and Casey,

Tom's parents, visited from Chicago three weeks after Caitlin's birth. I was anxious for them to meet their newest granddaughter, to hold her and bond with her. I wanted them to know her as their own.

When Casey and Mary arrived, I could tell they weren't comfortable. We had moved to a rental home when our house suddenly sold right before Caitlin's birth. We planned to move to Chicago at the end of the school year, renting a house until then.

When I mentioned going to the hospital before Elizabeth got home from school, my father-in-law, Casey, immediately declared, "It's all Rose's fault!"

"What's all Rose's fault?" I asked, suspecting where this conversation was headed.

"She put a curse on our family so we would have a baby like she did," Casey declared. "That's why this happened!" Rose's baby girl had been born with Down's Syndrome.

Instantly, my mother's instinct to defend my child erupted. "Don't you ever blame my daughter's health condition on a curse!" I shouted, much more loudly than I had ever talked to him before. "Caitlin was created by God, and we love her as she is. I am going to the hospital to see her now, and if you want to see your granddaughter, you will need to get in the car!"

I don't know who was more surprised by my outburst, my father-in-law, mother-in-law—or me! But we immediately went to the hospital where I was able to place Caitlin into Casey's arms, and he finally recognized this beautiful baby was a part of our family. What I didn't realize at the time was that, in a few months, Casey and I would share a special moment with Caitlin that no one else would. It would be another piece of God's plan to soften his heart.

### **Chapter 3 -- Mother's Instinct**

Dr. Barry, the pediatrician brought in to examine Caitlin right after her birth, checked her from head to toe and returned to the delivery room to say that she was fine. I remember wondering, "Why won't he tell me what's wrong with her?" Later I learned that he really didn't know and wasn't hiding anything. "Go to the nursery to see her," he urged. I hadn't yet held Caitlin and wasn't sure how I would find her in the nursery, where I probably wouldn't be allowed to hold her. I wasn't wheeled me in a wheelchair to the nursery. allowed to walk, so Tom

There, gazing into the isolette, I finally saw my Caitlin. She was just so tiny. A total of four pounds, five and a half ounces of life. I didn't know at the time, but that would be the most she ever weighed.

I soon learned that Dr. Barry had never treated a baby with trisomy 18, so he didn't even know to test her blood to identify her problem. Instead, as the days passed and her bilirubin count continued to rise, he decided to transfer her to the University of Iowa Hospitals and Clinics, an hour away in Iowa City. When she returned to Davenport six days later, Dr. Barry again was her doctor. His knowledge of trisomy 18 was limited, partly because it was still a relatively new medical condition identified just 15 years earlier by a Dr. Edwards. Dr. Barry learned that most babies with this genetic condition don't survive the pregnancy and very few survive beyond two weeks after birth. When Caitlin, just shy of turning two weeks old, returned to Davenport, he must have assumed that she would die at any moment. But she didn't. She passed the two-week milestone.

The nurses soon recognized what a special baby Caitlin was to have survived so many odds just to be alive. Their love was evident in the attention and gentle care they consistently gave to her.

Even the ophthalmologist who tested Caitlin's vision expressed great care in the gentle way he examined her. When Dr. Landers entered the nursery, Elizabeth was gently rocking Caitlin. "Is this your baby sister?" he asked. She shyly nodded 'yes'.

"Would it be ok if I bring her over to her bed so I can examine her?"

"Yes," Elizabeth whispered.

After examining Caitlin, Dr. Landers returned her to her sister, happy to once again cradle the smallest baby she had ever held.

“You have a very special little sister, and I can see you take good care of her,” Dr. Landers declared. Elizabeth smiled broadly as she tightened her hold on Caitlin. To me, Dr. Landers shared that babies with trisomy 18 have poor vision. “You will also want to protect her from bright sunlight,” he shared. I just hoped we would have the opportunity to take her outdoors.

As Caitlin’s hospitalization turned into three and then four weeks, my frustration grew. I didn’t know how long we would have her, and I just wanted her to be home for the days or even weeks that she would be with us. But Dr. Barry wouldn’t release her, insisting she needed to be there for all her required care, which only included receiving a very small amount of oxygen. A nurse shared that they provided oxygen as part of her care so that insurance would cover her stay.

Finally, on May 2, when Caitlin was five weeks old, a doctor from University Hospitals and Clinics visited Mercy Hospital to conduct a clinic on patients who had been treated at their Iowa City location, which included Caitlin. After listening to her heart and checking her appearance, he looked at me and asked, “Why is this baby here?” I replied, “I don’t know, but I want to take her home.” He looked at Dr. Barry and said, “Release this baby today!” Finally, we were able to take Caitlin home to be loved and cared for by her family!

Dr. Barry was protecting me by keeping Caitlin at the hospital. He knew Tom, working in Chicago four days a week, was not home to support me or take care of our other two girls. Plus, he was afraid that the stress of taking care of Caitlin, who required feedings every three hours for up to 45 minutes each, would be too much for me and that, in the end, she would die at home, leading me to feel very guilty. He didn’t know me that well then, but we got to know each other very well over the years as he became the doctor for our other girls.

After we moved to Missouri in 1993, I learned that Dr. Barry had also moved, to conduct research at the Mayo Clinic in Rochester, Minnesota. I don’t know if Caitlin was part of that decision, but I do know that his experience with her taught him to listen to mother’s intuition and appreciate the strength that we get from our Christian faith. He had shared those thoughts in a letter I was to take to the girls’ new doctor in Missouri.

In addition to having Caitlin at home, we also were finally able to take her to church with us. Many of the members there knew about her condition, and a few had even visited us in the hospital. Most were curious about her appearance and exclaimed over her small size: “She looks like a newborn!” “She looks perfect!”

One friend asked to hold her our first Sunday back. As she gazed into Caitlin's face, tears ran down her face as she shared, "My husband and I lost twins early in our marriage and I never got to hold them." As she handed Caitlin back to me, she said, "Thank you for letting me hold your angel." And so, God provided comfort to this mother's heart, who had ached for her twin boys for many years.

Other church members marveled at Caitlin's size and wondered what it was like to care for such a small infant. Some would look at her closely while others stared from a distance. There was much interest in our little girl, but I just wanted us to be viewed as a normal family. I wanted to go places and blend in, not attracting attention. I didn't want to hear one more person say, "Oh, you must have a newborn!" This experience was common for the first four months of Caitlin's life.

Throughout these months, God provided His love through many people, especially Nurse Marilyn, a church friend but also the nurse who had served as a proxy at Caitlin's emergency baptism; her presence at the hospital when we needed to transfer Caitlin to University Hospitals in Iowa City was a gift from God. Marilyn was there to comfort us and also to contact our pastor who came to perform the emergency baptism. She was also the one who held Caitlin less than a month before she passed away. When she gave her back to me, she said, "I don't think she'll be with us very long." Her words alerted me to the signs that Caitlin would soon be leaving us.

Marilyn was also the nurse on duty in the emergency room when Tom rushed Caitlin with me to the hospital after she had passed away at home. She always seemed to be present each time I needed her.

## **Chapter 4 -- Extra Isn't Always Good**

While at the University of Iowa Hospitals and Clinics in Iowa City, I had asked the doctor who revealed Caitlin's diagnosis for any information on trisomy 18. At that time, this condition had only been recognized by the medical field for 18 years. Described by Dr. John Hilton Edwards in 1960, trisomy 18 was also referred to as Edwards Syndrome.

A nurse gave me a magazine article listing the name of a support group for families with trisomy 18 or 13 babies. There was no contact information, other than the Bureau for Women and Children, which was a separate division of the federal government at that time. Directory assistance provided a number for that bureau, and the operator connected me to someone who was able to identify a contact for SOFT (Support Organization for Trisomy). However, the number I dialed was the number for the previous president, who then provided the current president's name and number. From her, I learned that current research being conducted on trisomy 18 would be shared at a conference in Philadelphia in July, a clinic where the top physicians in this field would also be available for clinic examination at no charge to participants.

Talking to the SOFT president, I was excited to learn that babies can be partially affected by trisomy 18, which means that just some of their cells have the extra 18th chromosome. Because four-month-old Caitlin seemed to be doing so well and had no issues that required special medical attention, I was hopeful that she was partially affected. She wasn't on oxygen or medication of any kind, and I was able to feed her using a soft bottle developed for babies with cleft palates. We needed to get Caitlin to that clinic where we hoped to learn more about her terminal condition.

We took our oldest daughter Elizabeth, along with Caitlin, to Philadelphia but left two-year-old Lauren with Tom's parents in Chicago. I was thankful that there would be sessions just for Elizabeth to be around other children who also had a sibling with trisomy 18. Counselors would also talk to her about her sister's condition.

Tom and I attended large group sessions, where we met other parents of children diagnosed with trisomy 18. We were surprised that some of the children were not just babies but were two, four, six years and older. One of our speakers, who was partially affected by the disorder, was 32 years old! We were encouraged to think that maybe our Caitlin was also partially affected by this condition and might live a long life.

Parents whose children had already passed away were drawn to our little girl. One mother from Canada exclaimed, “Your little girl looks so much like my Mary! She died last year. Can I hold your angel?” Of course, we agreed, not only then but throughout the conference. I realized she had traveled to Philadelphia for that very reason, to be close to other babies just like her own daughter. I recognized that this was part of her grief journey and wondered if my own would be similar.

One couple we met from southeastern Iowa had brought their ten-month-old son. He was a good-size boy, tube-fed since birth, which helped his body to grow. But he had a lot of issues that trisomy 18 brings, including a bad heart and other concerns that resulted in frequent hospitalizations. We were thankful to support each other through phone calls and letters.

While at the conference, Tom and I were asked to participate on a panel with two other couples blessed with a trisomy 18 baby. One of them had already lost their child, but the other couple, like us, still had our baby. Our discussion was video recorded for use and training purposes at John Hopkins. Some of the questions dealt with the impact on our marriage of having a special needs baby, as well as the impact on the rest of our family.

The moderator also asked what things were most helpful in supporting us and to provide details on that support.

“This has been a journey of accepting help from others,” I shared. “With Tom gone with his work, I have learned to let our church family and neighbors spend time with our older girls while Caitlin slept so I could also rest. I was used to taking food to others in need, but now I am accepting meals from others, including a weekly meal from our small group from church. I appreciate the home-cooked meals but especially their visits.”

“Also, one friend from our church picks up the two older girls every Wednesday this summer to take them either to the park, an ice cream shoppe, her house to bake cookies or other fun activities,” I shared. “This provides a break from the routine at our house, which was focused on taking care of Caitlin. I really appreciate that time, which gives me an opportunity to nap, take care of things around the house and just spend time with Caitlin.”

I also was blessed to connect with a retired nurse in the neighborhood who came to stay with the girls several mornings a week while I finished a book scheduled for publication that fall. My next-door neighbor was especially helpful because her daughter and Lauren were the same age. She

frequently invited Lauren over to her house for playtime when Elizabeth was at school during the first month that Caitlin was home. This time away from the constant care of her baby sister helped to provide some normalcy to Lauren's life, which was anything but normal for a two-year-old.

## **Chapter 5 -- The Angels' Visit**

While Tom worked in Chicago during the week, I planned activities outside our home with all three girls, especially that summer, when the weather was nice. One day, I packed a picnic lunch before heading to Vander Veer Park in central Davenport, where I knew there would be lots of space for the girls to run and play. I chose a spot where the ground sloped gently down to the pond where the swans peacefully swam. Loving the outdoors, I was so thankful for this day.

As I unpacked our lunch on the blanket, I gazed at my three beautiful daughters, thanking God for this moment, doing a normal activity that other families do. I only wished that Tom could be there. As Elizabeth and Lauren ate their sandwiches, I held Caitlin, thinking about her life and wondering how long we would have her. "What could be the purpose for a baby with a terminal condition?" I asked myself, as I gazed at her tiny face.

Soon I sensed someone nearby. I looked up to discover a man dressed in a white shirt and dark pants, with a boy by his side. The boy appeared to be eight or nine years old. I was immediately comforted by their presence, which surprised me because I normally was alarmed by strangers near me and my girls.

I realized that the man was staring at Caitlin with the same tender gaze that the boy showed to me. As the man turned his focus on me, he stated, "You have been blessed with a special baby." His words sent such a rush of warmth that enveloped my body, giving me a wonderful sense of peace that I knew must be a message from God. They didn't offer any small talk, just the simple sentence that Caitlin was a special baby.

I agreed with the man and as I looked down at Caitlin, I felt an overwhelming tenderness for her. Just mere seconds later, I looked back up to speak to the man, only to realize he and the boy were gone. The girls and I were in an open area, surrounded by grass 20 feet in all directions. If you were to get up to leave, you would have to walk for several minutes to reach a bush or tree. To be gone that quickly was not possible unless you were an angel. I glanced at the girls, but it didn't appear that they noticed the man and boy, and I wondered if I had imagined the encounter.

What a blessing the visit was to me, confirming my belief that our daughter was sent to us for a purpose. I had already seen how she had touched the lives of people who met her. They were drawn to her by her very small size, but when they learned how she had survived not just pregnancy and the early days of living outside the womb weighing less than five pounds, they realized that she was truly

a miracle baby. I had no idea what God had in mind for Caitlin, but I felt very privileged to be her mother and so thankful that God had loaned her to us.

The angel's message remains with me today. I was reminded of his words several months later when I was able to meet with a family who was blessed with their own special baby. I was so thankful for that encounter, for God's messengers and for that opportunity.

## Chapter 6 -- The Gift

Each summer, our family traveled to Chicago to visit Tom's parents and siblings. During our trip with Caitlin, we were sure to include the Brookfield Zoo, a tradition that Elizabeth enjoyed, and we knew little Lauren would also. We wanted Caitlin to experience the fun we always had at the zoo, but I guess it was more of us experiencing it with her since she wouldn't really understand what the zoo offered. Plus, I suspected we wouldn't have another summer with her, to visit the zoo again.

The light rain that morning didn't deter us from our plan. Tom gathered the older girls and headed out to our conversion van, which we had purchased specifically to transport Caitlin, whose eyes could not tolerate bright sunshine. The van's pleated shades could be pulled down to cover the windows, keeping out light. Plus, she received a pair of tiny sunglasses at the trisomy conference in Philadelphia to wear outside.

Tom's dad agreed to hold Caitlin while I finished getting ready. I was happy that he was more comfortable with her and didn't treat her as if she had any health issues. When I walked into the living room to take Caitlin from Casey, I was surprised to see he was holding her extended from his chest so that she was looking directly at his face, and he could talk to her. I wish I had taken a picture of that moment, but that was before cell phones, and my camera was already in the van. I didn't expect the special gift we were about to receive.

Trisomy 18 babies frequently lose all or part of their hearing, so at times I tested her ability to hear my voice. As I approached Caitlin from behind her, I said, "Caitlin, are you ready to go to the zoo?" To my amazement, not only did she move her head towards the sound of my voice, but she smiled!! I couldn't believe it!! At nearly five months old, she gave us her first smile! I was so excited, but Casey didn't respond, not realizing that this was a special moment.

"She's never smiled before," I excitedly told him. "Let me try that again." I wanted to be sure it wasn't an accident. He continued to hold her in the same position as I backed up, waited a moment, and again said her name and asked if she was ready to go to the zoo. To my joy, she again turned her head in my direction and smiled!

I couldn't wait to tell Tom, so I quickly gathered up my baby, told Casey goodbye and headed to the van. As I climbed in and settled Caitlin in her special car bed, I said, "Tom, you are not going to believe what just happened! Caitlin smiles, not just once but twice, while your dad was holding her!"

“I hope I get to see her smile—maybe she will be doing that more often,” he excitedly replied.

We both believed this was the beginning of other smiles and new milestones. However, those were the only two smiles we ever received from her. I believed part of God's plan was that her smile would melt her grandpa's heart; he was a tough guy who had been hurt by the church in his youth as well as by disappointments that life throws at all of us. He protected himself from further pain by not showing emotion. I sensed he told himself, “Don't get close, don't express love, don't get hurt.”

I found out many years later that the local parish where his mother attended had denied his baptism. Learning of this rejection as an older child fueled his negative relationship with organized religion. However, he was baptized, but at another parish. That rejection led to bitterness that festered throughout the decades of his life and contributed to anger that seemed to simmer beneath every conversation.

I learned of his early experience with the church when he phoned after reading a story in *Guideposts Magazine*, a subscription that Tom and I ordered for him each year. “That's my story,” he shouted when I answered his call.

“What is your story?” I asked.

He excitedly related that the author of a story in the latest issue of *Guideposts* had turned against the church because of a rejection she experienced. She shared that she later learned that God had not rejected her, that she was loved by Him. What a blessing for me to know that Casey now knew that God also loved him and would never reject him! I thanked God that He continued to share this truth with Casey as He gave this moment of love to him through Caitlin's smiles.

But smiles weren't the only blessing we were to receive that day.

As we headed to the zoo, I was thankful that it was a cloudy day. We wouldn't have to worry about the sunshine bothering Caitlin's eyes. Plus, she would wear her tiny sunglasses.

At the zoo, we always rode the train, a fun activity we could do together. On this trip, we were fortunate to find seats in the front row of the first car. The girls could see the engineer in front of us and have a better view all around. I was seated in the middle of our bench, holding Caitlin, when a lady behind us leaned forward and said, “You have been blessed with a special baby. I know by looking at her that she is a gift from God.”

I thought to myself, "That's the second time someone has said that to me!" The first time was spoken by the angel in the park. This lady was with her husband and adult daughter. I don't believe she was an angel, but I believe her words came from God. I was comforted by them as she reinforced what I knew in my heart.

Caitlin's tiny size brought frequent stares from strangers. She never weighed more than her birth weight of four pounds, five and a half ounces, even though her body had started to stretch out before we visited in Chicago. As a result, she lost her once plump cheeks and bright eyes. Her heart just couldn't keep up with any physical growth. So, the words from the lady on the train reminded us that, not only were we blessed to be the parents of a special baby, but that she was still with us, longer than the majority of trisomy babies.

During our time in Chicago, all of Tom's family met Caitlin; she was able to be loved on as a part of our family. Elizabeth and Lauren were also able to spend time with their cousins, while Tom and I experienced the support and love of family.

## **Chapter 7 -- God's Perfect Timing**

As parents, Tom and I worked to create meaningful family times, not only for us to spend with Caitlin, but especially to spend with our other two daughters, whose lives had been changed with the birth of a sister with a genetic disorder. Socializing with people other than family didn't happen very often due to Tom's work away from home and just the daily schedule of caring for Caitlin.

However, we were friends with a couple we had met when Tom attended a chiropractic college in Davenport. Already the parents of three boys, Gary and Coleen were expecting their fourth child within the month. Coleen was very anxious about the pregnancy and really wanted to have a daughter.

That Labor Day in 1988, we invited Gary, Coleen and their sons over for a cookout. It was a beautiful end-of-summer day, closing out a four-day weekend with Tom, who would head back to Chicago that evening.

The day began at 3am when Caitlin woke me up with a feeble cry typical for trisomy 18 babies. I tried to console her by walking around, patting her back as she rested against my shoulder. This time she just couldn't be consoled. Instead, her body began to convulse as she tried to vomit, much like someone having dry heaves.

Just two days earlier, on Saturday morning, her body had experienced this same trauma for nearly 10 minutes. Recalling the lady from the conference who had been so smitten with Caitlin because she reminded her of her own daughter, I decided to call her at her home in Canada, praying she would answer. She did. She was very concerned when I told her about the convulsions because her daughter had that same experience multiple times before she passed away. Her doctor had prescribed a medication that brought relief to her daughter, but she wasn't sure if it had been approved in the United States. I wondered why it wouldn't be approved if it could help a child with a terminal condition.

I called Caitlin's doctor's office that Saturday and was connected to the on-call doctor. He was not my favorite person, because he had shown no care or concern when he visited Caitlin in the hospital. Of course, I was disappointed when I heard his voice. I told him what had been happening and the name of the prescription my friend in Canada had shared.

He laughed, then bluntly said, “You need to accept that your baby is going to die; I cannot prescribe a medication that has not been approved by our government. And don’t bring her to the hospital-- there's nothing we can do for her.”

I was so mad at him and hurt by his callous attitude that I just hung up before I could say something I would regret. I wished that my daughter's real doctor had been available.

With no solution offered by the doctor, we just comforted Caitlin as best we could until the seizures stopped. Thankfully, Sunday was uneventful, and we were able to spend time together with all the girls—just like a ‘normal’ family, I thought. But privately, I realized Caitlin was sleeping more and wondered if she was declining.

That Monday morning when Caitlin woke me up at 3am, I felt like this might be the day that she would leave us, or that it soon would be. God was preparing my heart. As I held Caitlin over the bathroom sink, she did manage to bring up a little bit of her food. She hadn't eaten very much, so I was surprised her vomiting was productive at all.

As I held her, I cried out to God, “Please help me; help me to know what to do for my baby.”

A very small voice in my head said, “Just rock her; rock her.” So I carried her to the rocking chair in the living room. After a few minutes, the seizures stopped, and she fell asleep. I gently laid her in her little bed, the same bed we used in the car. In the house it was attached to a frame that would rock her.

Then I went outside to see the sunrise; it was 6am. Standing in the driveway, I reflected on all that Caitlin had endured, wanting to keep her but not wanting her to suffer.

“God,” I said, “if this is how her life is going to be, that she will continue to suffer with seizures, then I am ready for her to go to heaven. I know there she will be a perfectly healthy little girl.”

I realize now that God was waiting for me to release Caitlin back to Him. He doesn’t want any of His children to suffer; I know He felt that way about Caitlin but also about me.

At one point after Caitlin was born, I had a dream about her in heaven. She appeared to be around 13 years old, with long blonde hair and a healthy body. That's what I pictured as I asked God to take her from this life. A wonderful sense of peace came over me as I knew she would be ok.

About that time, my neighbor, whose Allison was the same age as my Lauren, came out of her house to get the tricycle from the garage for her daughter. When she saw me, she walked over to see why I was outside at such an early hour.

“Caitlin will be going to heaven today or very soon,” I said. “I don't think we'll have her much longer.” Debbie, of course, was very surprised by my declaration and tried to reassure me that we would have her longer, but I knew in my heart that our time with her was ending soon.

When our friends arrived around 4pm for the cookout, Coleen and I visited in the living room while the kids played outdoors, and the men fired up the grill.

Caitlin wanted me to hold her any time she was awake that day, but when Coleen asked to hold her, I gently handed her to my friend. Immediately, Caitlin started crying; nothing Coleen did to console her worked. I knew Caitlin just wanted me to hold her. Maybe she sensed something was changing, and she would be leaving. So I held her, but when I realized I needed to finish preparing the food and take the burgers and hot dogs outside to the men, I put her in her bed and turned the crank to start the swing. She soon fell asleep.

After dinner, the kids returned outdoors, so Coleen and I decided to watch them play as we sat at the picnic table. The men remained indoors; I asked Tom to keep an eye on Caitlin. When she woke up, which I expected would be soon, she would want to eat, and he would let me know. I enjoyed the beautiful day, talking with my friend, watching the kids play--just surrounded by some normalcy.

The time with Coleen seemed to give her peace about her unborn baby. We discussed how much time until she delivered and how God had her situation under control. As we talked, her 7-year-old son told me that he had checked on Caitlin while getting a drink of water in the kitchen and saw that she was not moving. I assured him that she didn't move around a lot while she slept, but I thought that it was interesting that he might notice.

Dane returned to play with the other children but soon went back indoors. Within minutes, he burst back outside, excitedly telling me that he had touched Caitlin, stating, “I don't think she's alive.”

“Oh, no,” I shouted, as my heart dropped, and I ran into the house.

The men still sat near Caitlin, but they hadn't heard any cries or noticed anything different about her. I quickly picked her up and instantly knew she was gone.

"I'm going to call for an ambulance," Tom declared. "The EMT's can work on her."

"No," I said, knowing that she was gone and the fire truck that was sure to accompany the ambulance would frighten the other children. "There is nothing we can do."

Coleen and the other children had followed me into the house; just as quickly, she ushered them into the backyard, away from the baby whose spirit had left us.

"Let me drive you to the hospital," Gary offered.

"No, I will drive Caitlin and Nancy," Tom declared.

The three of us headed to the hospital where Caitlin had been born exactly 23 weeks earlier. It was 6:30pm on Sept. 5.

Tom wanted to help Caitlin, not accepting that she was gone, and insisted I perform CPR as we raced to the hospital. I did, as tears ran down my face, knowing it was too late. Her still body was cool to the touch.

Tom dropped me off at the emergency room entrance while he parked the car. Alone, I carried my tiny baby, wondering what I should say. How do I walk in and announce, 'My baby died.' I couldn't do it. Instead, I walked up to the desk and simply said, "My baby quit breathing." Which she had.

Looking back, I should not have even said that. I should have said, "I think my baby is dead." Then they might not have tried to revive her poor little body, which had fought so hard to live for five months. She had defied the odds of living past birth. And now her body was being subjected to life-saving procedures which I knew were not going to do any good. They didn't hurt her body, but I felt like I put the hospital people through a lot and gave false hope to Tom, who had joined me in the waiting room.

As always, God provided for the support we needed that day, as we said good-bye to our Caitlin. First to appear was Nurse Marilyn, scheduled to work in the Emergency Room to support families of loved ones who needed care. She immediately contacted our pastors, two of whom were able to join us in the room she found for us to receive Caitlin's body.

In the meantime, Marilyn contacted other friends who came to be with us. One of the friends volunteered to go to our house to get Elizabeth, while the friends who had been visiting at our house

stayed with Lauren. I knew it was important for Elizabeth to be with us as we shared our last hours with Caitlin and experienced the support of caring friends.

When they brought Caitlin's body to the room and placed her in my arms, my first thought was, "Do people think this is strange that I'm holding a dead baby?" I don't know why I was so concerned about what people thought or maybe it was just a part of my brain that suggested that, trying to avoid the pain that she was gone.

Eventually, everyone in the room held Caitlin's little body, wrapped in a sweet pink blanket, including Elizabeth, who was able to say goodbye to her sister. It was a very healing process led by our pastors who spoke prayers and shared meaningful Scripture, all very comforting. I will never forget the love that was in that room and the presence of the Holy Spirit as Tom and I were ministered to by our Christian family of believers. We were forever grateful.

Giving up Caitlin's body to the funeral home was difficult, but God had that worked out as well. As we walked to the ER waiting room, I was relieved to see that the man who came for Caitlin was our next-door neighbor, a fellow Christian with a kind and gentle spirit. We had chosen his family's funeral home to care for Caitlin. I knew she would be safe in his arms.

## Chapter 8 -- Family, Friends and an Angel

Caitlin's Celebration of Life service was held at our church, Trinity Lutheran, in Davenport IA.

Elizabeth attended third grade in the church's school, where she received much love and support from the staff and her classmates, who blessed us by singing at the service. Their young voices floated from the choir loft, sending a comforting blanket over the worshippers below. All three pastors asked to participate in the service, with many friends and church members in attendance.

The support of my sister Ruth and her family and my dad, who traveled from Jefferson, IA, as well as Tom's family from Chicago, provided great comfort as we celebrated our little girl's life.

At the end of the service, as the pall bearers took our daughter's all-white casket out through the side door to the hearse, I remember thinking, "It's so small!" She was not even 5 lbs **ever** in her life, and yet, it took two people to carry her casket out to the hearse!

At Pine Hill Cemetery where Caitlin's body was buried, Tom and I were able to pick a plot located in an area designated for children two years old and younger. The day of her service was beautiful--sunny sky, warm, but not too warm--for a September morning. As we proceeded with the burial service, a couple we were our close friends, attempted to sing a song that was special to our family, *Somewhere Out There*, from *An American Tail*. Afterward, I realized what a terrible thing that was to ask parents to sing at an infant's burial. It's just such a sad time, but at the same time, we knew she wasn't there, that Caitlin had already gone to be with our Savior.

A number of mourners traveled with us to the cemetery, including several nurses who had cared for Caitlin during her stay at Mercy Hospital. One of the nurses asked me to wait while she went back to her car to retrieve a gift. The six-inch statue of the hand of Jesus holding a small child in His palm has always been a special remembrance not only of our daughter but of all those people in the hospital who cared for her. She touched each one of their hearts as they recognized that she defied great odds by living for five months when statistically 80% of babies born with trisomy 18 don't survive the labor and delivery. Of that number, another 80% die within two weeks. Our Caitlin was a little fighter who taught the nurses so much as they cared for her.

The infant cemetery held a variety of headstones, many of them flat in the ground. Some older monuments rose 24 inches high. One of these was a young angel at the far end of the small cemetery. I didn't pay attention to that angel at the time, but later, 2 1/2-year-old Lauren said she saw

an angel at the cemetery; I believed she was thinking of the statue of the young angel which had caught her attention and comforted her.

As Lauren's vocabulary increased over the years, she shared more about the angel. "The angel at the cemetery made me feel better about Caitlin going to heaven," four-year-old Lauren told me.

"How did she do that?" I asked.

"Well, I was afraid that Caitlin wouldn't find her way to heaven, but as we let go of the pink balloons," she shared, "the angel went up into heaven with them. I knew she would go with my sister, that Caitlin would be ok."

The angel provided great comfort to our young daughter, which we didn't even realize at the time. God sends His angels throughout our lives, to comfort and guide us. I was so thankful that God showed His angel in the cemetery to Lauren.

## Chapter 9 -- The Miracle

After Caitlin went to heaven, I told the nurses at Mercy Hospital that I would be available for any parents of a baby born with a terminally ill condition. I wanted to provide whatever support I could, and when Tom was home, he would be available as well. Just three months after Caitlin passed, I received a call on the first Wednesday in December. Tom was in Chicago, and I was home with Elizabeth and Lauren.

“We have a baby here who was born without a brain,” the nurse explained. “We told them about you and they would like to talk to you. Can you come to the hospital this evening?” I had never seen a baby born without a brain, so I wasn't sure what to expect, what the baby might look like. I thought there would be an obvious deformity, but I really didn't know.

“Yes,” I agreed, despite my concerns, “I can come, but first I need to find a place for my girls to stay.” I had planned to attend the Advent service at church and remembered that they offered nursery care during the service. So, I stopped by the church, just across the street from the hospital, to leave the girls in the care of the nursery volunteers. Feeling very guilty that I wasn't staying for worship, I told the workers where I would be and that I would be back by the time the service was over. They promised to take good care of the girls, for which I was very grateful, and I headed across the street to the hospital.

On the elevator ride to the nursery floor, I wondered, “What do I say to this young couple, knowing this is their first baby?” As the elevator doors opened, a nurse met me to share that the parents had decided not to feed their newborn girl. I asked, “Why? What would lead these parents to make that decision?” Silently, I asked myself, why would any parent NOT feed their baby, regardless of their condition?

The nurse explained that an advisory group at the hospital had told the parents that withholding feeding was an option because of the terminal diagnosis. I assumed this option was considered to be a benefit to the parents, who would not have to wait long for their baby to die. I learned later that the advisory group included one of my own pastors! I knew that I would want to talk to him to learn why he had supported that decision. As the pastor of a church who supports life at any age and stage of development, he should have recommended feeding the baby.

However, the nurse explained, the advisory group recommended this option because feeding her would only prolong her life, which was destined to end soon. “How can a decision to surely end a life be considered as a loving act,” I wondered.

I had to stop to collect my thoughts as anger boiled up inside to think that parents wouldn't feed their own baby girl. I just couldn't understand that at all. I understood not wanting to see her die, but then they wouldn't get to see her live either, which is so important when you have a baby with a terminal condition. Every moment with that child is a precious gift, a chance to know them as their own and for them to experience the love of their parents.

As I considered what I could say to these parents that could possibly be helpful, I asked God why He had sent me when this decision to withhold feeding had already been made, a decision that I could not support. How could I even talk to this couple without expressing my anger?

As I followed the nurse down the hall to the mother's room, I silently talked to God, asking Him, “What do you want me to say? Lord, I don't know what to say. This is such a scary situation. I'm angry and I don't want to be angry. Please, Lord, take the anger from me and give me Your words. Tell me what to say.” All I heard was this simple direction: “Tell them about Caitlin... tell them about Caitlin... tell them about Caitlin.”

As we approached the mother's room. I noticed an elderly couple sitting in the hallway. The nurse introduced me to the parents of the baby's father, whom the young couple were visiting when the baby was born a month early. The grandmother said their son and his wife were from Fontenelle, Iowa, which was just five miles from Greenfield, where I had graduated from high school. I was happy to have that connection.

Then the grandmother angrily declared, “This never should have happened! Her doctor should have known and taken care of it.” I knew what she left unsaid: the baby should have been aborted. I wanted to help this woman to see this baby as her granddaughter, knowing that the grieving process would be delayed if she couldn't acknowledge the baby as one of her family and not see her as a mistake.

So I asked, “Is this your first granddaughter? Do you have other grandchildren?” Her angry comments stopped as she stared at me in surprise. I knew something had clicked to cause her to think in terms of this baby who initially was a mistake, but now, she recognized, was her granddaughter.

“Yes, she is,” the women slowly replied.

I opened the door and walked into the room to find the mother sitting up in bed with the dad standing next to her. I was surprised to see that he, rather than the mom, was holding the baby. Angry, she immediately blurted out, “This never should have happened! My doctor should have known about this condition and taken care of it!” Just like her mother-in-law, she believed her doctor should have terminated the pregnancy.

The father quickly explained, “We want to talk to you about your daughter who died. Our daughter is going to die, too.” He seemed to genuinely care for this baby, as he gently held her close to his chest. Wrapped in a soft blanket, only the baby’s beautiful face was visible. I guess I expected to see some abnormality as a hint of her terminal condition, but she looked like any other normal newborn. Her pink complexion was that of a healthy newborn.

Before sharing about Caitlin, I wanted the parents to know who I was, what we had in common in addition to our daughters. I guess I thought this would give me more credibility for what I was to share.

So I said, “I understand you’re from Fontanelle; that’s about 5 miles from Greenfield where I graduated from high school.” He seemed to relax a bit as he replied, “We know your baby died from a genetic disorder. Can you tell us how she died--what was that like?” I knew at that moment what I was to share.

“Rather than tell you about how she died, I would like to tell you how she lived. First, my Caitlin beat the odds for a baby with trisomy 18, not only by surviving birth when 80% of these babies die **before** birth, but she survived **beyond** the first two weeks of her life, when 80% of those infants who survive birth die. So, the probability that a baby with trisomy 18 survives more than two weeks after birth is very, very small. Our Caitlin was one of those survivors. We knew we had a special baby with each new day she was with us, for exactly 23 weeks.”

“We also realized she was a special baby when we witnessed the many lives she touched, including our own family members as well as strangers,” I continued. “We saw how God worked in her life to heal the hearts of parents who had lost their own infants before they could even hold them.”

“We met many other parents of terminally ill children when we attended a national conference in Philadelphia for trisomy 18 and 13 families. What a blessing that experience was for my husband and me, as well as our oldest daughter, who was able to participate in siblings’ workshops.”

“Tom and I were amazed at how Caitlin didn’t require any kind of extra treatment normally required for a baby with her condition, including oxygen. She also didn’t need any special feeding techniques. A nurse here at Mercy Hospital suggested we try a bottle used by babies with a cleft palate. I learned to squeeze the sides of the bottle in a rhythm that matched Caitlin’s swallowing, so she came home without any special equipment.”

“I’m not familiar with your baby’s condition, and I don’t know how long your baby’s going to live. But I do know you have been blessed with a special baby, just as Tom and I were blessed with Caitlin. I don’t know *how* she is going to bless you and others in her life, but I do know that God will be working for His purpose. I will keep you in my prayers.” Then, as I turned to leave, I said, “I am so glad I got to meet you and your little girl.”

My heart was heavy, knowing their decision not to feed their daughter would shorten the time they had with her. I wasn’t sure how long it would take for a baby to starve to death, so I prayed not only that this little girl would be given the days that she needed to experience the love of her family, but also for her parents and grandparents to know her as their own, to be able to mourn her when she was gone. If we don’t acknowledge the life and the importance of that life to us, then we cannot truly grieve that loss. We might become stuck in a stage of grief, especially anger.

So many people I have met over the years have denied the grieving process because it scared them to know it can’t be controlled; it’s not something anybody wants to experience, but it’s something we all need to process when a loved one dies. We need to grieve. That was my concern for those parents--they needed to love this baby so they could grieve for her when she was gone.

As the days passed, I prayed for the parents and grandparents, that they would be given enough time with their special baby. Then, on Saturday, just three days after I met the family, I called the hospital to see when the baby had died, assuming a baby wouldn’t survive without food beyond three days.

The nurse who answered the phone was surprised by my question. She said, “Oh, didn’t anybody tell you? The parents decided to feed the baby and took her home yesterday!” I was shocked because I believed what the parents had been told--that their baby had a terminal condition and would die from that condition, a process that would happen more quickly when they withheld feeding. But they had

changed their minds and decided to feed her, enabling them to take her home. They were gifted more time! I thanked and praised God because I knew He had intervened. God is the God of miracles, and whatever He was doing for that family was a huge miracle. I continued to pray for them every day; I just couldn't get that precious baby out of my mind.

Several months passed. In March of 1989, I met for lunch with one of the nurses who had befriended me at Mercy Hospital. I asked her, "Doris, did you ever hear when the baby from Fontanelle died? Did they ever let you know?" With surprise, she exclaimed, "Oh, didn't anybody ever tell you?"

"Tell me what?" I asked.

"Well, you know they fed the baby and took her home. A month later, early in January, the parents went to the University of Iowa Hospitals and Clinics for genetic testing and counseling and took their daughter with them."

"She was still alive when she was a month old?" I asked in disbelief.

"Not only was she alive," Doris said, "but they had her tested. Turned out, she does have a brain! There was fluid on it, so they drained the fluid, and at this point, she is as healthy and normal as any other three-month-old infant!"

I was so excited and thrilled! I wanted to shout for joy because God had performed this miracle. Doris agreed that this child was a miracle. We will never know if God healed her or if her condition was misdiagnosed, but I do know and thank God that the parents listened to His voice to feed their daughter.

I think about that girl yet today and know that she is a living tribute to my own daughter. They would be the same age, just eight months apart. I pray for her still, that God is using her for His purpose, that she knows His voice. I thank God that her parents chose to feed her, to give her the nourishment that she needed to live and risked any extra pain they might feel by extending her life.

Our God is such a God of miracles! I've seen it many times in other circumstances, and I see it all around me every day. We don't live in a world that just happened to evolve. We live in a world created by the God of the universe, who cares about each of us so very much.

## **Chapter 10 -- My Life-Changing Baby**

Caitlin changed my life while she was here and continues to impact how I live and who I am today. As one of my bookend babies, she was born as I was finishing the edits on a book that was published in 1988 by Bethany Publishing House.

Having Caitlin was one of my greatest blessings in life. She taught me so much—to treasure the life we are given and to recognize each day as a gift from God. Without her, I would not have met all the people whose lives were touched for the better by her own little life. I would not have seen how God used her to heal the hearts of those who were grieving for their own lost infants, for those who had never held a child who had died at birth or even for the parents who had never even seen their stillborn baby, whisked away immediately after birth. So much sadness and so much loss, yet God used Caitlin to comfort the parents and to give them hope that they too would see their child when they went to heaven. I witnessed this healing step many times.

I didn't always want to tell Caitlin's story, why she was so small. I didn't want to answer their question, "Is she ok now?" Some days I simply wanted to be out in public like every other 'normal' family. But then I remembered that our baby was not like others, and God was using her for His purposes. I couldn't deny Him the opportunity to use Caitlin to witness of His love for her—and them!

I often asked God for discernment to know when I should share the full story of Caitlin's condition and when I should not. If I identified her medical condition as trisomy 18, I would be met with confused, blank stares. Even if I said Edwards Syndrome, named after the doctor who identified the genetic disorder, they still would have no idea what I was talking about, unless I gave more details. So I said she was born with a genetic disorder that makes her small. Often, they wanted assurance that she would grow and live a normal life. I knew what they wanted to hear, but I couldn't admit the truth. Instead, I said that God knows how long her life is going to be, but for now, we are just loving every day that we have with her, that she has blessed our family in so many ways.

Some people accepted that explanation, while others pursued the full truth. If they honestly wanted to know why she appeared to be so small at her age, then I knew they were open to the full story. I explained that she had a terminal condition without a definite end date. I told them that each day with her was a gift from God. I also shared about the love of God and how Tom and I, as her parents, knew that we would see her again in heaven. Her leaving would not be a permanent separation. God answered our prayer to let Caitlin be with us, to give us enough time with her so she would know she was our daughter and a part of our family and that we would know her as our baby girl.

I have happy memories of how our older daughters interacted with their sister, wanting to play 'house' and 'church'. At the time, few preemie clothes were available, so I frequently bought Cabbage Patch doll clothes, which fit her just right. Often, my other daughters' nightgowns came with a small one for a doll, perfect for Caitlin. The girls loved modeling their matching gowns.

Through Caitlin, I learned how personal God's care really is. He knew my every need and never allowed things to happen that would add to my stress. Instead, He provided people at just the right time to help me, and through them, I learned to accept His care. I couldn't do everything myself, and Caitlin showed me that it's okay to let others help. I grew up as a very independent girl who became an independent wife and mother. When people wanted to help, my first thought was, "No, no, I can do this myself; I don't need any help." I soon learned that I did need help, and it was a blessing to *be* helped.

I was so thankful when someone from my small group brought home-cooked food every week, so I didn't have to take time from the girls to prepare food for one and possibly two meals. One lady from my church picked up the two older girls each week during the summer months, taking them to her house to make cookies, play and have lunch. Or she treated them to McDonald's and spent time at the park. While I wanted to be able to do those things with my girls, I knew they needed time when they could receive the full attention of an adult who wasn't focused on a baby sister.

I also learned that God blesses the person providing the blessing. Art, an older man from our former neighborhood, stopped by one day with a meal. His wife had passed shortly after we moved next door to him. During his visit, he shared about the children he and Virginia might have raised, but who had been lost through miscarriage. Because losing those children had been so hard, they decided they weren't meant to be parents. They had other relatives but not children of their own, so he always appreciated watching our daughters play in the yard and taking time to talk to him.

Art reminded me that I would see Caitlin someday in heaven. His words meant a lot to me because he was a private man who typically did not share personal feelings or experiences. I was so thankful that he explained how seeing Caitlin comforted him as he thought about his own unborn babies.

Other people, including strangers, encouraged me with their words when they likely knew in their hearts that something was very wrong with our daughter but didn't ask questions about her condition. They simply commented on her pretty face as she seemed to connect with them through her gaze.

God was very present in my life in many ways--in the visit from the adult male and young boy angels who talked to me at the park, and when He spoke reassuring words through friends and strangers alike. And I saw God's love whenever I looked at Caitlin's bright blue eyes.

Parents of trisomy 18 children whom we met at the conference in Philadelphia shared how their child had been such a blessing to their family. Some even believed they would welcome another such child—that it would be a privilege to parent a second special baby. At first, I considered that thought to be unusual and a bit crazy, that to have a baby who would die would be too painful. But after witnessing Caitlin's sweet personality, her comfort to other parents, her strength and her determination to live on her terms (no oxygen, no feeding tubes, no special needs), I knew that another special baby would indeed be a gift from God.

Caitlin's determination has encouraged me throughout my life as I have faced other challenges with family members, including my husband's last years fighting diabetes. I have learned that not only is each new life a gift from God but also each day on this earth is a gift. Each of us is God's unique creation, and He loves us more than we can imagine. While He has a purpose for us during our time on this earth, He has also prepared a place for us to be with Him in heaven for eternity. He made that possible through the birth, the life, the death and the resurrection of His own son Jesus Christ, our Savior. Thank you, God!

Two years after our months with Caitlin, Tom and I were blessed with a fourth daughter, Natalie Elise. People have asked if we were afraid to have another baby, knowing a new child might also have a genetic disorder. And because I conceived at the age of 35, I was classified as having a geriatric pregnancy. I was offered various tests to determine ahead of time if this fourth baby had any condition that we should be aware of, and if needed, decide whether to continue with the pregnancy.

We never considered that Natalie would have any health issues, but we knew if she did that God would be with us, to love and support us. All children, no matter their condition at birth, have a purpose, so no test results would lead us to terminate a pregnancy. We did not need to be in control because we knew that God always is.

We also believed that God sent Natalie to our family to take away the sadness of losing Caitlin. The name Natalie means, birthday of the Lord. While this is a name frequently given to baby girls born near Christmas, for us, it was a reminder of the gift that Jesus, whose birthday we celebrate at Christmas, is to our world. Her middle name, Elise, is the shortened French form of Elizabeth and

originates from a Hebrew name meaning, "My God is abundance." He truly has abundantly blessed my family and directs my days as I look to Him for guidance. How can I dare to go to Him? He provides a way through Jesus, who lived on this earth for 33 years and experienced life in human form. Jesus desires to have a personal relationship with each of us. Personal relationships don't just happen; they take time to develop. When we commit to building that relationship, we realize that He is always there for us, and we never have to face anything in life without Him.

Jesus cares about us and wants to be included in our daily lives. He doesn't want to be an afterthought, someone we think about just when we go to church. When we relinquish control of our lives and let Him take charge, we are amazed at what He does. Trusting in Him and not in this world makes all the difference. This is the life-changing lesson He taught me through Caitlin.