

Michelle Rose Ekis
April 1, 2003 - October 26, 2003

How can a life that was lived in 6 months and 25 days take so many words to describe? Although Michelle's life was never easy, it was filled with love and faith. I was 41 years old when we discovered I was pregnant with our fifth child. After the initial shock and with the steadfast support of my husband, I grew in excitement at the prospect of adding another child to our noisy and fun family. During a routine sonogram in my seventh month, my family doctor discovered excess amniotic fluid and some unusual things so I was sent to a specialist for a level II sonogram. There I was first told that there was a good chance that my baby would not be born alive. My heart almost stopped beating and I could barely hear anything he said after that as my mind shouted "No!" The doctor did mention Trisomy 18 but all I caught was Trisomy and it was never brought up again. When I did look up Trisomy a month later, I found T21 Down's Syndrome so I thought I knew what to expect. They encouraged an amniocentesis but I refused.



With many friends and family members praying for us, I woke up the next day with a sense of calm and strength. I knew that God would guide us through whatever lay ahead. The rest of the pregnancy was fairly normal, except that I was very uncomfortable because my belly was huge with all that excess amniotic fluid. We visited the perinatologist a few more times for more ultrasounds but no one ever mentioned T18 again. The baby was small so my very optimistic family doctor agreed with me that we wouldn't deliver her early and give the baby some extra time to develop so we scheduled to be induced at almost 42 weeks.

During the contractions, the baby started showing signs of distress, so an emergency C-Section was ordered. This wasn't unexpected but traumatic never the less. At 2 p.m. on April 1, 2003, Michelle Rose Ekis was born. She was 5 lbs. 9 oz. and 18 ¼ inches long. She needed a little assistance to get started breathing but she was alert within a few minutes. She was put in the NICU with some oxygen to get her levels up but by the next day, Michelle was only on forced air. Then the next day, she was breathing room air.

We received the devastating news that Michelle had T18, the next day while in the hospital. I was an emotional wreck at first and I could not hold or look at Michelle without bursting into tears. But slowly I realized that God had given me a beautiful child to love and take care of. Only He knew the length of her life and only He knew what Michelle could do. And I realized that this was true of all my children. It just took a child as special as Michelle to remind us that tomorrow is never guaranteed with anyone.

So after a three week stay in the NICU, we took Michelle home with us. We had learned to feed her with an NG tube since she couldn't learn to nurse and she tired easily while drinking a bottle. We were set up with home healthcare nurse, counselor, and volunteers from a pediatric hospice and occupational therapy from the local children's services. These women were my angels. Janet, the nurse, accompanied us to all of Michelle's doctor appointments. The volunteers gave me some needed breaks and loved all my children when they needed the extra love. They all comforted me when we found out that Michelle did have an 8 mm VSD in her heart and they gave us information as my husband and I made many decisions on Michelle's care.

Michelle grew and life became "normal". We were a family. We took Michelle to church, the kid's soccer games, trips to the park and events at school. We explained to our children that Michelle

had T18 and that was just the way she was born. We told them that although babies with T18 usually don't live long, we don't know what God has planned for Michelle. So we will just love her and enjoy her for however long she is with us.

We celebrated whenever we could and everyone loved to hold Michelle. Michelle would smile and giggle at the antics of her sisters and brothers. She loved to be talked to and was almost ready to roll over. Evenings were hard because she never wanted to fall asleep and during the day, she spent a lot of time being fed through her NG tube so she would not throw up. But at 6 months, we were beginning to think Michelle might be one of the children to make it past one year.

We threw a huge party for Michelle's 6 month birthday to celebrate our little daughter and to thank everyone who had helped us through so many prayers, dinners, transportation of children to events, childcare and all the other ways our friends, neighbors and church members helped us out. I am still touched by how many people were involved in Michelle's life and touched by our miracle. One week later, after a brief hospital stay for an infection, Michelle's heart and lungs gave out. She died quietly and peacefully in her sleep while I slept in the bed next to her. I woke up at 1:30a.m. and realized Michelle had gone to our eternal home and our Father's loving arms.

We miss her very much. We have faith that we will be reunited again in heaven. God gave us such a wonderful gift of 6 months and 25 days with Michelle. She has touched so many lives and changed our family in ways that we are still discovering. She was so beautiful. Her smile would light up her whole face and we were stopped where ever we went. She made so many people think about the gift of their children. She didn't "do" anything. She just loved and was loved.

"I know God will not give me anything I can't handle. I just wish that He didn't trust me so much."
Mother Teresa
