

Caleb

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHO LOST A CHILD TO
TRIFUNCTIONAL PROTEIN DEFICIENCY (TFP)

My husband William was frantically driving me to the hospital at 4 a.m. He wasn't just nervous because he was about to be a father. He was trying to get us to the hospital in one piece. Caleb Patrick was born at 5:20 p.m. during a really horrible tropical storm. My son blasted into the world as the storm blasted by us. I will always remember September 14, 2001. That is the day I became a first time mother. It was the happiest day of my life. My son was finally here. He made it through all of my infections, severe preeclampsia (I am waiting to find out if it was FLOP or HELPP) and having the umbilical cord around his neck twice. I was the proudest mother ever.



I was only able to hold Caleb for a minute before he was taken to NICU. Caleb was placed in the NICU because he was born at 35 weeks and his blood sugar had to be monitored because I had Gestational Diabetes.

I was so afraid to hold him for the first time. I was afraid that if I touched him that he would get sick. So all I did was lift up his blue knitted hat to see if he had hair. I told him that "I love you and I will see you soon". I was on bed rest for the next two days so I wasn't able to visit Caleb in the nursery. The nurses did however sneak Caleb in for a thirty-minute visit. That was the only time I was really able to be Caleb's mommy. I didn't have any staff watching me or listening to what I was telling my son. During that visit I told Caleb all of my hopes for him. I looked at every inch of his body. And yes I counted his fingers and toes. They were all accounted for so I was happy and at peace.

Every day William would come and visit us. I would sometimes get jealous. William would come in and say hi to me and give me a kiss, then say, "well I gotta go see my boy".

Now, I am jealous because William had more time with our son. I am thankful that Caleb received so much love from his father. Caleb knows that his parents love him so much and will never stop loving him.

I was released on my fourth day. That's when I found out that Caleb wouldn't be coming home with us. I was then informed that he was being kept because he was a lazy p.o. feeder. I wasn't even informed of this by his doctor. I was informed of this when I went to the nursery to feed Caleb. I was always left in the dark by the first hospital.

That night William and I attended Caleb's 6 p.m. feeding. The nurse in charge of Caleb that night told us that Caleb was floppy earlier so she tested his sugar. It was at 20. She sent the blood to the lab and it was actually

under 20. She said Caleb received some sugar water in a bottle and that he perked right up. Both my husband and I asked if they are still monitoring his sugar. We were told that it was not necessary. It was just an episode for my having Gestational Diabetes. I went on to explain to the nurse that I have a family history of Diabetes. She still said that there was no need.

That night Caleb took 20cc of formula. Over the week William and I would make our daily visits to drop off breast milk and to feed our son. During these visits we were not allowed to hold him until it was time to feed him, then we would have to leave right when he was finished. Needless to say that we never really got to bond with our son. I will never forgive the hospital staff for that. I was allowed to change Caleb's diaper a few times. I loved it. I was actually allowed to take care of my child. During this time Caleb became a more lazy p.o. feeder according to the doctors. Caleb was put on an NG tube on his fifth day of life. Caleb would start off on a bottle for 20 minutes, then what formula was left would be given by NG.

On Caleb's 10th day of life everything was looking bright. We were present for his 9 p.m. feeding. Caleb took 29cc in 10 minutes. I made a comment to my husband "watch Caleb will be home this Friday or next Friday by the latest". I said this on a Tuesday night. The following afternoon at 1:30 I received a call from the NICU telling me to come to the hospital. I didn't hear any concern in the doctor's voice. I asked if Caleb was being released. I was told no that Caleb has gotten worse. Of course I said what? I was then informed that during Caleb's noon feeding he became floppy in the nurses arm's and that he was given oxygen. I said how is he right now? "He's still floppy, cold and pasty white". I called William home and we arrived an hour later. I have never seen a baby so white. We sat caressing our son until 6:30 p.m. That is when I ran out of the nursery while they were bagging Caleb. I came back after he was stable to tell him that I loved him and to fight for mommy. I wanted to wrap my baby in a blanket and just hold him. He was so cold. During this time I was informed that he was being transferred to a level three hospital.

Caleb was transferred at 9 p.m. We were informed that we would not be able to see Caleb till morning. I kissed Caleb good bye and told him that I loved him. The transport team went one way while we went another. As we were heading to the parking lot the transfer team were coming out a different door. A little boy was walking in front of us, he said to his parents "Awe look at that cute little baby". I broke down. Praying to God "Please don't let this be the last time that I see my son". William and I sat in our car until the ambulance pulled away. I cry whenever I hear sirens.

Caleb survived the transport. I called that night at midnight to see how he was doing. I was told that he is hanging in there. And that he was receiving a blood transfusion due to anemia. I could hear my baby crying. At this point whenever someone would touch Caleb he would cry. He knew that another needle was coming. I asked if he was going to make it through the night. I was told yes and that I can visit him tomorrow. I was up all night just starring at the clock waiting for it to turn to 9:30 a.m. We arrived at 10:30 to visit Caleb.

The doctor in-charge of Caleb that day spoke to us. We were informed that Caleb might have an inborn disorder that affects the heart. We were then told not to expect Caleb to survive the night. I kept praying that God would spare my son and if it was not meant to be to please let my mom make it in time from Michigan so that she can hold her grandson. William's parents flew in from Texas. They were able to welcome their first grandchild into the world and they were able to be present when he passed.

During our first visit Caleb opened his eyes three times. It was if he was telling me hey mom I am still here. That was the last time I saw Caleb's beautiful blue eyes. I also noticed that his umbilical cord came off. I made the nurse find it. William and I were waiting for the day that it would fall off. Will used it as an excuse for not changing his diaper. The excuse was now gone. The cord and a lock of my son's hair is the only physical reminders I have.

The second visit that we were allowed that day I just kept touching him. I kissed any part of him that didn't have an IV in it. Caleb had six total. And he was on a respirator. By the third visit the IV's all started failing on him. A central line was ordered but the surgeon never showed. At 8:30p.m. I had my son Baptized. It was something I felt I had to do. I wanted my son to be able to enter Heaven to be with my father. This way I knew he would be in good hands. Everyone in the NICU sang YES JESUS LOVES CALEB.

Visiting hours were over at 10:30. I was kicked out at 10:45. Caleb arrested at 11:00. They were able to revive him. I was told at 11:30 that this happened. I told the doctor that if it happens again that I want to be there. "I was there when he came into this world, I will be there when he leaves" I asked if I could visit with Caleb. I was told no because they were trying to stabilize him.

Around this time a nurse from the first hospital came to be with us. Caleb was known as their little Mr. Grabow. He touched so many in such a short time. We were talking when the doctor informed us that Caleb stop breathing. I ran in back. My son was already blue. I had them stop what they were doing. I said let my son go in peace. They unhooked the last two IV's and wrap him in a blanket and placed my baby in my arms. Caleb took his last two breaths in my arms at 12:45 a.m. It was on Caleb's 14th day of life. Afterwards I gave my son his first bath and the nurse from the first hospital combed his hair. She was the first one to do it and I wanted her to have the honor of being the last. I put my son in a diaper and dressed him for his next journey into God's hands.

The following day was Friday. The day I thought my son would be home by for sure. It was the day I had to plan my son's funeral. The day I had to pick out his urn. I finally brought Caleb home on October 9, 2001. No mother should have to put her child's urn in a crib. I kept telling Caleb I couldn't wait until he was home sleeping in his own bed. I will be crying for the rest of my life. I am just grateful that I was Caleb's mommy for fourteen days. Caleb we love you BIGGIE MUCH.

Love,

Mommy and Daddy

Jacksonville, Florida

Written August 2002 by Shelly Grabow

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Mom to Caleb (TFP) September 14, 2001 - September 27, 2001