Trusting parent learns too late: the tragic consequences of instant cord clamping

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The false safety of a hospital or health care setting

Life, as I had known it, changed for me on November 27, 2002. That day my daughter Kaitlyn entered this world. Before that day, I label myself naïve. I thought as many women do—that when you are in a hospital or health care setting cared for by nurses and doctors, that you and your baby are safe. I will tell my story, my daughter's story, my family's and friend's story. I want the world to know that you are never safe leaving the well-being of your child in my friend Kelly's words, "in strangers hands." I wish to educate everyone I can.

On Tuesday, November 26, I stayed at my parents home. I was two weeks overdue with my first child. I was set to be induced the following week if nothing had changed with my pregnancy. A few days earlier, I had been at the hospital thinking I was in labor… I was not and was promptly sent home. As I visited with my parents, I started having contractions. I was in pain—worse pain than I had ever felt in my life. My pain continued, so following dinner I returned to my apartment. I lied on the couch in pain as Charlie asked me continuously if I wanted him to take me to the hospital. "No," I responded as I believed they would only send me home again. I used the bathroom and there was a watery discharge. As I was unsure of what that meant, I placed a call to the OB/GYN floor at the local hospital. They told me that it was best if I would come in to be examined. We got everything ready for the trip to the hospital and made all necessary calls. This time I would not be sent home.

Much of what transpired overnight and into the following day is unclear to me. I remember family and friends visiting. I remember trying to focus on the clock to distract myself from the pain of the contractions. I figured the baby inside me was never going to make her exit.

At the hospital, drugs were given for pain management

In the early evening, I was given an Intrathecal injection to manage the pain I was experiencing. Shortly thereafter, the monitor lost track of the baby's heartbeat. I was told to turn on my side. I could sense panic in the room, but I was very drugged and did what I was told. I was not worried. The heart beat was picked up. The nurses and doctor then had me in a variety of positions. I was told to turn left, turn right, and my favorite—to get up onto a huge inflated ball. I could not feel anything below my waste due to the injection, so in this condition it was a very odd sensation to try to balance on a ball.

Two hours of pushing

My mom was at my side. I can recall my mom asking the doctor if I was dilated to 9 and she was told that I was ready to have the baby. My mom exited the room, racing to retrieve Charlie. Not long after, the room was full of familiar faces. An OB nurse, my doctor, Charlie, my mom, my sister Sarah, my sister Katie, my Aunts Sandy and Patty were all there to witness the birth of my first child. And still my baby did not want to make her entrance into the world and exit the womb. I was told to push; I pushed. I kept pushing and no baby. I was told to stand up and hold onto a bar, then to squat… I did so, no baby. After two hours of pushing, those in the room spotted the baby's head. I was joyous to think that my baby was going to be born. I did not realize until later that at that point an episiotomy had been performed. Still no baby.

Finally, delivery and instant cord clamping

Pushed again and felt a release. I heard Charlie say, "It's a girl" and I was thrilled—Charlie had two little boys from a previous relationship and we had wished for a girl. I took notice of the doctor immediately cutting the cord and not long after realized our baby girl wasn't crying. I asked my mom why the baby wasn't crying: she said sometimes baby's don't cry. I knew that was a lie, I knew healthy babies cried.

Transport to another hospital

Medical professionals rushed into the room as my family was ushered out from it. My mom stood strong at my bedside as Charlie's mom came in and comforted him. Our baby girl was taken to the warming bed where people worked to help her. I asked my mom what was wrong with my baby and my mom told me that she didn't know. As she answered, she was now crying. It wasn't until much later that I was told that the pediatrician had come to talk with me about the events taking place. I knew someone had come to me in my room after I had been stitched up and spoke to me. I was told that Kaitlyn (my baby girl) had been knocked out in the birth canal and was not breathing at birth. He informed me that the hospital was not equipped to handle the situation and Life Flight had been called to transport Kaitlyn down to Saint Mary's Medical Center about 90 miles away. I was helped into a wheelchair and brought down to the nursery to see my daughter. I held her little hand and looked out the window to see the waiting area full of family and friends. It was a scene that would be repeated numerous times in the coming years. I signed paperwork allowing the transport team to take Kaitlyn and returned to my hospital

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room. Kaitlyn was brought down to my room in an isolette to allow me to say good-bye before they lifted off. I could hear the helicopter from my room—my family and friends watched as it lifted off into the chilly November sky. That night we stayed at Saint Mary's hospital. The following day was Thanksgiving 2002. I had gotten word from the nurses overnight that Kaitlyn was breathing on her own. I spoke with my mom by phone and she told me that Kaitlyn looked like her daddy. We waited anxiously for my doctor to come in for my examination and to give the okay for me to be released. She did so and as we waited for the paperwork to be done.

We left the hospital without our daughter, but left with hope that once we were reunited we could return home as a family. Charlie and I went to our apartment where I packed up everything I could conceivably need. My dad and sister Katie picked us up and we made the trip to Duluth.

When I laid eyes on Kaitlyn, I was in awe that the beautiful little girl in the crib was my own daughter. I longed to pick her up and hold her, but due to the IVs and everything, I was not allowed.

Tests were performed

Charlie and I were allowed to stay in a room located down the hall from Kaitlyn who was placed in the Neonatal Intensive Care Unit. This would become our home for the next three weeks—during which time a battery of tests were run to determine the reason why Kaitlyn was not responding as a expected of a normal baby. Blood tests, EEGs, CAT scans, and an MRI were all performed. We spoke to neonatologists daily and were in contact with a neurologist as Kaitlyn had been deprived of oxygen at birth. Dr. Kanoff, the neurologist, told us that there could be minor delays in her development or, worst case scenario, she could have Cerebral Palsy. I and others, immediately researched all we could on Cerebral Palsy. Cerebral Palsy was something I felt I could deal with my daughter having. The following is an excerpt from my online journal from December 11, 2002:

> I have been as open as I could be while writing these messages. I don't know how to write what I am now faced with writing. My heart feels shattered. Charlie and I talked with Dr. Kanoff earlier. The third EEG was better than the previous two, but there are still long pauses between the waves. This would be fine if she were sleeping, but these appeared while she was awake. The hard news came when he discussed the findings of the MRI. Kaitlyn suffered severe brain damage. The part of the brain that does the thinking was what had been damaged. The opening of her eyes, yawning, eating, and such are more automatic. That part of her brain wasn't as badly damaged. He said she is not comatose or vegetative—but close to vegetative. Which means, she would blink or laugh but inappropriately... not meaning to and not necessarily in response to the situation. It is very unlikely that she would ever walk or speak.
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> I don't understand. I don't. I will never hear my little princess tell me she loves me. Kaitlyn won't be able to experience everything I always took for granted. How unfair is that? I feel Why Me? Why Kaitlyn? Why Charlie?
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> I saw two babies leave the NICU today and Kaitlyn will leave but what kind of life will she have? Somewhere deep inside of me I know that I should have hope but I am so angry. Where has hope gotten me? I let a little in when I was told that she could come home and that she was bottling so well. Now it is as if I am punished for allowing myself to feel happy, to smile. Kaitlyn is such a beautiful baby. She deserves to live a better life than what Dr. Kanoff laid out for her. I asked if she would always be in the vegetative state and Dr. Kanoff said he couldn't say for sure right now. That is something we would have to watch in the coming weeks and months. I knew that there would be work to be done, but I never imagined the news coming back would be this negative. I just glanced at the clock and I forgot to be in there at 8:02 for her birthday. Two weeks today... that in and of itself is a blessing. I don't know what else to write at the moment. We have a meeting Friday with the doctors. I will write again soon.

Kaitlyn suffered Hypoxic Ischemic Encephalopathy

Two days after receiving this life changing news, Kaitlyn was released home. The next four months of her life were spent trying to motivate Kaitlyn to react to her surroundings. She would sleep most of the day. We met with various doctors and were introduced to therapists. We started our journey into a world that was spent caring for our disabled child. I was fortunate early on in our journey to find an online support group through Yahoo that was intended for parents of children who had suffered Hypoxic Ischemic Encephalopathy as Kaitlyn had. The HIESC group was and is my saving grace.

As the years went by, the list of doctors that Kaitlyn had grew. The list of medications she needed increased. The diagnosis given to my beautiful little girl added up. Kaitlyn had Hypoxic Ischemic Encephalopathy, Microcephaly, Dysphasia, Spastic Quadriplegic Cerebral Palsy, Cortical Visual Impairment, Neuromuscular Scoliosis, Reactive Airway Disease, Immune Thrombocytopenic Purpura, and Chronic Lung Disease. She would battle eating issues which resulted in a feeding tube being placed for her nutrition. She would be seen by physiatrists, ENTs, intensivists, neurologists, pulmonologists, gastroenterologists, endocrinologists, hematologists and several other specialty doctors. Along this journey, I learned it was less important what Kaitlyn could do and to cherish who she was. Kaitlyn was full of feistiness, a strong and determined little girl who changed the lives of all those who knew her.

I am fast approaching the age of 30-years-old. I can sum up my huge life events but to try to "sum up" Kaitlyn's life is difficult. I will have pictures to accompany my words and they will speak vol-

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umes.

The first two years of Kaitlyn's life were focused on therapies. She was rarely ever ill. We worked with various equipment—a stander, creepster crawler, tumble forms tadpole system, etc. (The picture shows Jessica in a pediatric stroller.)

We would take her to appointments and be told that she was not at an age appropriate level as if we weren't aware of this.

The second pregnancy and birth would be different

In February 2004, we learned that I was expecting. I worked hard with Kaitlyn while battling the ins and outs of pregnancy. I was excited for our new baby to make his arrival, but worried because I now had knowledge I hadn't with Kaitlyn. I had made many friends through my online support group, one of which was Kelly Moscarello. Kelly opened my eyes to the travesty of premature cord clamping. When medical professionals prematurely clamp a baby's cord, they cut off the lifeline between mother and child. There is no medical reason for this to take place. I made it clear to my OB that I did not want the cord clamped. I discussed my fear of being induced as that is what had caused the problems with Kaitlyn's delivery. Although I was reassured that the medication would be properly administered and I would be watched for problems, I refused to be induced. I told the doctor that I would have to be taken for a C-section should the need arise.

My son, like Kaitlyn, decided he was going to stay put two weeks past my due date. The morning of October 16, 2004 I was admitted to the Virginia Regional Medical Center in labor. My labor did not progress as anyone had hoped and I was prepared to have a C-section. Logan John Walker entered this world at 1:31 p.m., big and healthy and screaming his lungs off. October of 2004 would be a month that would foreshadow blessings and curses to follow.

Kaitlyn's ongoing medical problems

Kaitlyn was bottlefed in October of 2004. My mom and sister Sarah had let me know that she wasn't bottling well for them. Although concerned, I thought it was due to my not feeding her—my little girl was partial to her mommy with feedings. The morning of the 19th, I received a call in my hospital room from my mom telling me that Kaitlyn had vomited that morning and was running a fever. The decision had been made to bring her to her doctor. I prayed for my sweet girl as I prepared myself to be discharged home with my new son. I welcomed my first shower since my c-section, put on a dress and did my make up. I changed Logan's diaper and talked with him. I was calm and ready for our new path, I did not know the change my path would take. My mom would call to tell me that Kaitlyn was being admitted to the hospital, they believed she had pneumonia. For years I had feared that word, I knew pneumonia took the lives of children such as Kaitlyn. I called Charlie at work and told him what was taking place. We had to bring our new son to our home, leave him with family to be with Kaitlyn who was very sick. Kaitlyn would be taken by ambulance to Saint Mary's in Duluth. She would spend the next three weeks there as the doctors worked to determine what was causing her illness. Charlie and I, along with our family and friends, would jump from being with Kaitlyn, to being with Logan. It was a scene that would play out frequently the next two years.

Kaitlyn, it turns out, did not have pneumonia in October of 2004. However, Kaitlyn battled pneumonia nine times in the following two years. As if my little girl struggling with chronic lung issues wasn't taxing enough, we found in August of 2005 that Kaitlyn had pancreatitis. Both her respiratory problems as well as her issues regarding pancreatitis would bring us into 2006.

2006 had a rough start. Kaitlyn hadn't been feeling herself and daily she was being administered albuterol nebulizers in addition to the Pulmicort and Atrovent. I spoke with Kaitlyn's pediatrician by phone and had gotten the okay to treat Kaitlyn with Prednisolone. We knew that if the situation did not improve, we would need to bring Kaitlyn in. Kaitlyn did not improve and we brought her to the emergency room. They determined that she again had pneumonia. Because of her trouble breathing, she required 5 liters of oxygen to keep her saturation level up. Kaitlyn fought hard but her condition grew worse; the call was made for her to be taken via ambulance to Saint Mary's. After a few weeks, Kaitlyn made a recovery and was allowed home. She was sent home on IV antibiotics and TPN feedings. We were home a week when we learned that Kaitlyn's central line had grown a yeast infection and again returned to Saint Mary's. A week later we returned home knowing we had the weekend before we would be traveling to the cities for Kaitlyn to have her gall bladder removed and the Nissen Fundoplication performed.

February 15th Kaitlyn had her surgeries performed. It was a long day for everyone. The night before Logan had gotten sick. He was vomiting the entire night and once morning arrived, I joined his illness. Not long after, my mom also became ill. I could not kiss my sweet girl before surgery. The surgeon let us know that the surgery had gone well, that there was minimal blood loss, and he was pleased at the outcome. It took Kaitlyn a while to be weaned from the vent. We were happy when the nurse finally allowed us back to view our precious girl. It hurt me to not be able to kiss Kaitlyn due to being sick, but my heart was full as I viewed her looking around with her big blues. She was very alert and happy. Two days later, exhausted we returned home. The weekend was uneventful and was spent having time as a family.

It had been a typical night in our home preceding February 20, 2006. I awoke a few times to use the bathroom and check in on both Kaitlyn and Logan. When I looked in on Kaitlyn, there she was with those big blues looking back at me. She looked calm and content. I checked and changed her diaper, covered her up with her blankets, and showered her with love. I kissed her chubby cheeks and told her how happy I was to have her back home. I let her know, as I often did, that we would always be connected in our hearts. I returned to bed. Logan woke early as he often did. I lifted him from his crib and looked in on Kaitlyn in hers, she remained asleep. I took Logan down to the kitchen where I got him cereal and milk for breakfast. I started going about getting Kaitlyn's morning medications ready for her.

As Logan played, I went up the steps to give Kaitlyn her morning medications and to get her up for the day. As I approached the crib, the sight of her stopped me. I set the medications down. My darling girl was pale and barely opening her eyes… something was wrong. I talked to her as I administered

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her medications. I then called for Charlie who was in our bed asleep. He responded and I asked him if he would please take a look at Kaitlyn as she didn't seem right to me. He got up and came to my side at Kaitlyn's crib. He talked to Kaitlyn and did not get the response he had hoped for. He too was worried. I told him that we would need to make the familiar trip to the emergency room. I went back downstairs to be with Logan and call my parents home to ask if someone could care for Logan as we brought Kaitlyn in.

The phone at my parent's home was answered by my dad. I explained that Kaitlyn didn't seem herself and had diarrhea, that both Charlie and I felt we needed to have her looked at. He told me that he would talk to my mom and return my call. He called back saying that my mom wasn't sure what the hospital could do for Kaitlyn as she very well might have the flu. I told Charlie to get the car ready and that I would stay behind with Logan knowing Kaitlyn wasn't okay. As Charlie went out to start the car, I returned upstairs to Kaitlyn. At that time, she had now started dropping her bottom lip in a gasping motion and looked to be more pale than earlier. My thought was that she was dying. I ran down to get Charlie and told him that we needed to call 911. He went up and saw Kaitlyn—he agreed that the call needed to be placed. For the first time in Kaitlyn's life, I called 911. I told the operator that Kaitlyn didn't seem right and that she could possibly be seizing. I did not know what was happening but felt it was not good. The 911 operator told me that I needed to calm down at which time Charlie took the phone from me to speak with her. The ambulance would be on its way.

As I waited for the ambulance, I talked with Kaitlyn. I cried. I changed her diaper. I cried. I arranged her blankets in her crib. I continued to cry. I could see the ambulance pull in front of our home from my children's bedroom window. Charlie and the paramedics ascended the stairs a short time later. Questions were asked and answered to the best of our ability. The woman told us that she hated to ask but did we have a DNR/DNI in place for Kaitlyn. I told her that no we did not and that Kaitlyn was full resuscitation. No sooner did those words escape my lips than Kaitlyn's own lips stopped moving and went blue. I said the obvious, "Oh my god, she's stopped breathing!"

The two paramedics and Charlie worked with Kaitlyn. They used her BiPap machine which had oxygen flowing from the concentrator—the woman paramedic told the guy to call Hibbing and tell them that they didn't have time, they needed to come straight to the house. They moved Kaitlyn from her crib to the floor and continued working on her, paramedics from Hibbing arrived. They determined that the bedroom was not allowing them enough space and moved her downstairs.

They shoved an IV into Kaitlyn's leg and hung the bag off a nail from which a mask had hung on our living room wall. They intubated Kaitlyn and prepared for transport. I needed to make arrangements for Logan's care and told Charlie to follow the ambulance.

I grabbed the phone and placed the call to my parent's home. My mom answered. I said, "Mom, Kaitlyn stopped breathing and the ambulance took her… I need someone to watch Logan." My mom was in shock but let me know that she would be over. I cleaned up the mess left behind from the paramedics to enable Logan to play. My mom arrived soon after. I couldn't focus on what I needed to do to get Logan ready. I couldn't think of what needed to be packed in his diaper bag. Charlie called and told me that he had spoken with the doctor. Kaitlyn had not started to breathe again. My sister Sarah arrived not long after and told us to go. I told my mom on the ride to the hospital that this time Kaitlyn was not going to be okay.

A mom knows. Before Kaitlyn was born, I did not know the connection I would have with her. I could not understand the love parents have for their child. After Kaitlyn exited my womb, she still was with me. I told my little girl often that we were connected in our hearts. A mom knows. My mom and I ran into the hospital and through the emergency room doors. There were people seated in the waiting room and a woman asked if I was, Mrs. Torgerson. My mom asked if Kaitlyn had died. She said we would need to speak with the doctor and directed us through doors that led from the waiting area to the emergency room.

As we entered the emergency room area, Charlie exited a room in front of us. My mom asked, "Didn't she make it?" Charlie was crying and shook his head no. I hugged and held Charlie. I may have cried. I am not sure. My mom had gone in to see Kaitlyn. I followed. A mom knows.

The time that followed was spent alternating between time with our sweet girl and informing family and friends on what had taken place. Friends and family gathered with us at the hospital. I felt empty. We were informed that Kaitlyn would need to be moved to a room since they needed the space in the emergency area. It was at this time I was alone with my princess, it was then I cried. I cried and cried and cried. I didn't want her to be gone. I know now that she will never be gone, she is with me as we are connected. A mom knows.

I remember thinking that the worst moment in my life would be hearing Dr. Kanoff say that it was very unlikely that Kaitlyn would ever walk, talk, see, or hear. How wrong I was. The worst was leaving the hospital on February 20th without Kaitlyn for the second and final time. I did the best for what was expected of me the week that followed. I went with Charlie the day Kaitlyn died and we found a dress for her to be buried in. Within a day or two, Sarah and I would choose shoes to match. I talked minimally on the phone. I talked minimally at all. I slept. I did what I could for my little boy. I slept a lot.

Physicians must be told not to prematurely clamp the cord

Kaitlyn was a presence, her beauty unsurpassed in my mind's eye. Her pink dress with matching tights and perfect shoes were what they should've been in a fitting casket—what wasn't right was the casket held my three-year-old daughter. Free now from her struggles in life, but taken from a life that I worked tirelessly at making the best for her.

Why? Why couldn't her cord have been allowed to finish pulsating? I am sure that question will go unanswered. I know that—because no other answer makes sense. There is no logical reason not to let that cord finish pulsating and provide that oxygenated blood that every baby needs—much less a baby who has been deprived of oxygen. I write and share this story to work towards change. To inform doctors of the negative consequence of instant or early cord clamping. Had her cord been left alone, it is highly likely that Kaitlyn would be getting ready to celebrate her fourth birthday end of November. Instead, I along with my friends and family are left with a hole in our lives.