

“Flawed”

by lauren t. klein

I searched for a hair-tie in the kitchen junk drawer. Even in our new fancy house, there was a junk drawer. My son, Matthew, age three, called it the “yunk” drawer. He thought it was a treasure trove. After two months, his hospitalized, ill, infant brother was supposed to come home. I was on the phone, the coiled white cord fully stretched across the kitchen counter.

“Yes, we’ll need 24-hour care, at least overnight care -- I can do about three hours a day, and I think my babysitter can do, maybe...two hours a day. I have a three-year-old as well, you know.”

“No, no. I really don’t have time to do in-person interviews.”

Matty runs in, yelling, “Mama! When are we going to visit baby Davey??”

“Sorry, just a minute, please.” I say into the phone, simultaneously trying to contain my errant hair with the tie.

“Honey. Soon—just let me finish this call.” Matty mopes a moment, then runs out.

“I’m sorry, what else did you say?” I’m back with the caregiver agency. “Yes, perfect -- just two phone interviews on Friday. I can handle that.”

“Thanks so much. Yes, same number, yes. Thanks again. Bye.”

I hang up and wonder where Matty’s gotten off to... We should really try to abide by the visiting hours. It’s thirty minutes or so to the Neo-Natal Intensive Care Unit. I hear him galloping upstairs. His hair is blonde and he has a lighter streak on the left side, as if a shock or fright lightened his hair. I don’t know when that might have been, but it’s been there for almost all of his three years. He’s a sensitive boy, and very loving. He’s a mama’s boy in the best of all ways. I hoped that his father didn’t mind that we were so attached. And Matty is perfect: green eyes, healthy body, active. As perfect as his baby brother is imperfect.

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I found out about the defects when I was seven months pregnant. My obstetrician questioned the amount of amniotic fluid around the fetus. “Too much,” she said. I trusted her – She was smart, warm, and clear. She’d delivered Matty when she was seven months pregnant with her own daughter. Another ultrasound. The results

were inconclusive, but very suspect. They sent me to the 'big guns' at UCSF*, to the world-renown experts in fetal ultrasonic surgery. For God's sake, I had no idea there was such a damn specialty. Enough alarms had sounded that my husband, Steve, met me at the hospital to accompany me through the next scan. They concluded that the fetus, my baby, had a hole in his heart, and other defects. Defects. Defects. And now my heart seemed to flood similarly: a defective condition perhaps...too many tears, too much fluid. Steve slowly walked me back down to the parking lot and guided me to my car. He asked if I was OK. I said yes.

"See you tonight then."

"Yes. Tonight we'll talk." I replied.

He kissed me, and I drove home. I'm sure I was a hazard on the road.

The daze and numbness stayed with me while I prepared dinner and corralled Matty. Then I began to feel dirty, monstrous, and wrong. My body had betrayed me. And it was betraying the family: Matty, Steven, my sisters, our folks. All of us. All of us who were so happy to be having a new baby.

After many conversations about using "extraordinary measures," the labor came suddenly. They did not know if the baby would live, and they felt certain his quality of life would be poor. Hard to understand what this meant for my life, and my family's life. But we did warn Matt that the new baby would be 'a little sick.' We headed to our regular hospital where I labored a couple hours before the docs decided to send me by ambulance to UCSF. I was mid-labor, mid-contractions. As they put the stretcher in the ambulance, Steve was screaming something about it not being necessary. Because the baby was so ill, we'd decided with the doctors that there would be no 'extraordinary measures' taken to save his life, and an ambulance transfer mid-labor did seem 'extraordinary.' But they had concluded that the UCSF neo-natal staff would better equipped to handle my case, and I was in no shape to contradict the medical team.

I'd already met the UCSF obstetrician at a consult. It seemed appropriate that her specialty was medical ethics. They hooked me up to Pitocin, to "hurry it along." They asked if I wanted more pain meds. Before I could answer, he was well on his way. David was born alive and small, all of 5 pounds. He had sweet brown eyes, and dark hair, and I loved him immediately. He was very flawed. He could not nurse since his plumbing was blocked. The nurses had me pump my milk and store it in case we could figure out a way to feed him. We did, but it became an ethical question, one of many in the first days of Davey's little life. They brought him back to me after an initial examination. He stared up at me, questioning his fate, and I stared back, holding him, hoping I could love him enough to cure him.

Three days after David's birth, they had a diagnosis. We sat down in a conference room. I have doctors in my family and had worked in hospitals, so I am used to

medical jargon, and have always considered myself good at 'medical-ese.' But at the meeting there were so many doctors around the table, physicians of all persuasions: pediatric cardiologist, urologist, geneticist, two obstetricians, and my regular pediatrician. The diagnosis was C.H.A.R.G.E Syndrome, a rare constellation of associated defects. The chance of something like this happening are one in 10,000.

The nice medical ethicist chimed, "This did not happen because of that extra glass of wine you had during pregnancy. This is a random and unfortunate event. Please do not feel responsible."

She was trying to make me feel better, since after telling us the diagnosis, they laid out the prognosis, which was bad. David was not likely to live very long. They could not tell us how long. A few days. A few months. His heart was very compromised. They suggested a feeding tube be inserted surgically for 'comfort care' right away. If he did survive, he would have trouble hearing, his sight was likely to be poor, and his development, both mental and physical would be severely delayed. At that meeting, we began the discussion of declaring David a DNR baby, 'Do Not Resuscitate'. That would mean, for example, that if he got an infection, antibiotics would be withheld. It would mean he was essentially on hospice care. That he would die, and that our responsibility was to see him through it as best we could, as comfortably as possible. Considering the dire prognosis, there seemed to be a consensus on this point, but on the feeding tube, there was not.

They say that people grieve differently, sometimes very differently, over the same loss. They say it breaks up relationships -- the statistics on that are clear. Steve and I were processing in entirely different ways. I had but one focus: to enjoy and comfort my baby as much as possible before he died. I knew the process would be emotionally painful, but I wanted to be there for him. Steve needed to detach as soon as possible. He said we should not allow the feeding tube surgery as it would just prolong the suffering. I felt David should be comfortable, and without the tube he would starve to death, which I considered a painful death. The medical team seemed to concur with me more than Steve, although there was a certain logic in Steve's reasoning. We went home to our other son, our perfect son. We told him that we did not think baby Davey would be able to come home. The decision needed to be made quickly, and Steve was out-numbered. Within a day, he relented and the surgery was performed.

Two months later, after daily visits, with and without Matty, they had started talking about sending David home for care. I loved my time with this sweet, small baby son of mine. His eyes looked up at me so calmly, so wisely. He perked up when Matty and I visited, eyes wide open, legs kicking. We brought him some of Matt's baby clothes and a little stuffed bear. Mostly the outfits were too big, but Matty enjoyed that his brother could wear his 'baseball' outfit. I found a couple onesies for premies, and he looked pretty dapper in them. Davey was not thriving, but he was surviving. Some moments were quite exquisite: his funny expressions, his reaching to me for holding. We had to be careful of his tubes, his frailty, but there was a

strength to David that seemed to will me to wake up, to live. If he could not live, then I must for him, in full.

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“Matty!! Time to go!!” I called.

I heard him scrambling down the stairs. He was always excited to go see Davey, and also to play in the children’s area at the hospital. The toys were different there, the huge red and blue tow truck, and even a bubble machine. We popped in the car and headed over the bridge to the hospital. Going up the elevator, I took a deep breath. What will this visit bring? What will he teach me this time, this baby of mine? We ran into my friend Sandy in the hall – she was a lactation specialist and had begun coming to visit Davey also. Some other friends had started coming in the last month, including Sandy’s husband. Davey loved being held.

Sandy: “He’s seems a little weaker today, Cynthia.”

“Oh, I wonder why.” I said.

“Not sure—got to run now, but I’ll come again Wednesday. Love you. Matty, give your baby brother a kiss for me, OK?”

“I will, Sandy!!” Matty was already rushing off to find him. By the time I got to his crib, Matty was already tickling him. I lifted him up so he could kiss Davey, and cuddle a bit more. He was ready for the play area, so I suggested he go. Sandy was right. David’s breathing was slow. I alerted the nurses. Dr. Piel was on duty. In his long cardigan sweaters he always reminded me of Mr. Rogers. He examined Davey.

“His heart seems weak today, and his breath is shallow. I’m not sure, Cynthia, what’s happening, but since he’s DNR, I can’t do too much, you know.” He said gently.

“Yes, yes, I know Dr. Piel. I’ll hold him.” I said, taking him in my arms.

“I’ll come back in a few minutes.” Dr. Piel left the room.

“What’s up today, my sweet boy?” I whispered. I kissed him and sat down. He smiled up at me in his little tie-die knit hat, and then his breath was gone. Five days later, Sandy’s husband conducted a short service at the mountain cemetery near our home. We had a small marble stone engraved as a marker. I wept in the sunshine and warm breeze. And then Matty, Steve and I went home.

*UCSF is University of California at San Francisco Medical Center.
[Names have been changed for privacy.]