

not your everyday miracle

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Third Place, Creative Non-Fiction

O THE NIGHT EMMA WAS BORN, I read an Anne Lamott story called "Barn Raising" about a family dealing with their daughter's illness. I read this excellent, heart-breaking story and then I said a prayer, "Thank you God for my family. Thank you for another healthy baby. Thank you for knowing there is no way I could handle an illness like cystic fibrosis. Amen!"

If my life was a movie, right then there would have been the kind of music that tells the audience that this is *foreshadowing*.

"Does she seem a little jaundiced?" I ask Phil and the nurses. No, not really they say. But the young nursing assistant who weighs her that night, says "yes" she does indeed seem a little jaundiced.

Love Your Liver—A Workbook for Children

I get this workbook with a smiling cartoon liver to help Jake understand what is wrong with his sister. It answers some of his questions:

Jake: "Why does Emma have a special tube for food?"

Workbook: "The liver helps your body digest food."

But not others:

Jake: "What does God's liver look like?"

Workbook: (nothing)

Jake: "Why did God make Emma sick?"

Workbook: (nothing)

I think of the workbook when I explain things to friends:

"So why does Emma have blood in her diaper?" asks curious friend.

I answer, "Well the liver has many functions," ("Over 500 jobs to do." page 6) "and one of them is to help with clotting." (The liver helps stop cuts from bleeding." page 9)

"So how are you doing?" asks curious friend (the workbook has nothing).

Welcome to California

The night Emma and I left Phoenix Children's Hospital to go to UCLA and wait for a new liver, our nurses, patient care tech's and favorite housekeepers all came in to chat and joke and say goodbye. In all the confusion, I still don't know which nurse was assigned to us that night. When we left with the transport guys, the staff lined up in the hall to wave goodbye.

A medical flight takes us to UCLA. We are taken to our room on the pediatric floor. It's midnight. A patient and mom are in the window bed, the good bed. The pretty but serious nurse comes in (I'll call her "Nurse"). The sleepy resident follows. Nurse does Emma's physical assessment and hands me the admitting form. She asks questions and when my answers don't meet her approval, she glances over at the yawning resident and arches an eyebrow or two. There may have been eye rolling. The resident finishes up and leaves.

"Do you have her TPN ready?" I ask.

TPN is IV nutrition, total parenteral nutrition. Emma's liver failure has progressed to the point that she only takes two ounces of horrible formula each day by mouth, and the rest of nutrients through a tube in her chest. My hospital faxed the orders over, twice.

"No, we'll just run fluids in the morning," says Nurse.

Nurse shows me the call button, the bathroom we are not allowed to use and the tiny closet for my things. There are no phone calls after 9 p.m. She shows me the chair bed, "But," she says, "there really isn't enough room in here for it."

At this point I say, "Hey, maybe you'd feel better if I just took off. I'll be on the next flight back to Phoenix. Take good care of my dying baby, ok?"

Actually I said nothing. She looks at me for a long time, and then sighs, "I guess we can put it in front of the bathroom, since you won't be using that anyway.."

The chair bed is positioned so that every time the door to the room opens, the bright light from the hallway assaults me. I can't turn in any direction to avoid it.

Emma starts to fuss. I ring for Nurse.

"Can I have one ounce of alimentum, warmed up a bit, please?" "The doctor has written NPO," she tells me.

NPO means nothing by mouth. I know when I am being tested. Sometimes a doctor or (usually) a nurse will use some medical acronym or polysyllabic term to see if I'll ask them to please, for the love of God, enlighten me with your wisdom and tell me what that means. I never blink. I know the lingo.

"Can you ask him again," I plead, "she needs it to get to sleep."

She leaves. I bring the now frantic Emma into the chair-bed with me. There are many problems with liver failure. Since she is 9 months old, she cannot tell me if she is having the headaches or body pain. Sleeping next to me sometimes soothes her. Nurse comes back, too quickly to have asked the resident.

"Sorry, it's hospital policy, she can't sleep with you. And the doctor says no formula."

"Well then, "I clench my jaw to keep my voice from breaking like it does when I'm angry, "she'll just scream herself to sleep."

"What about a pacifier?"

"She hates them, she sucks her thumb."

Nurse leaves and comes back with a pacifier. "It's vanilla flavored."

"She will spit it at you."

I wished I could spit at her too. Nurse leaves.

I lay Emma in her bed. She howls for 10 minutes. I leave and get a cup of ice water at the machine down the hall... Standing at her bedside, glancing furtively over my shoulder, I feed her tiny chips of ice. She sucks greedily at my fingers. Someone comes into the dark room, I stand still. Emma whimpers and smacks her lips for more. The person leaves, I resume the illicit feeding. Once she settles down, I lie on the chair-bed and cry and pray myself to sleep.

I am asleep for an hour when blinding hall light awakens me. Nurse shakes my shoulder, "Just so you know there are pay-phones down the hall."

I roll over, my face to the light in the hall, my back to Nurse. She leaves. This exchange wakes up Emma. I give her more of the secret ice chips. We fall asleep and I have one of those dreams that don't feel like dreams. The other moms on the floor come into my room.

"Can we talk to you?" they ask, "We hear you've had a problem with Nurse. You know she's really a lovely person, California nurse of the year. You've hurt her with your rudeness. Could you just *try* and be nice?"

I try to defend myself, "Everyone at our own hospital loved us, loved me. We were no trouble at all. They lined the halls to wish us well..."

The other moms smile sadly and shake their heads.

I wake up early. Someone is in the room. She whispers. Whispers! A great nurse is one who whispers when there are sleeping parties present. She is Maria. Emma stirs. Would I like her to hold Emma while I take a shower and get breakfast? The night is over, Nurse is gone.

Later that day the silent roommate is discharged and I get the window bed. We get a new roommate. Jade had her transplant four months before, she is here for a blip in her liver numbers. Her mother, Diana, is beautiful and funny. Our nurses are good, great even. Doctors, social workers, transplant coordinators visit our room. We laugh about everything.

A Picture's Worth

You should see the pictures from that day. The first one I would show you is just her sullen—swollen cheeks (jowl's one nurse called them), dull, yellow eyes and skin shiny and orange. Not just jaundiced but Tropicana orange. "Is something wrong with the camera?" you would ask. And I would give you the second picture. She is sitting on a nurse's lap, same baby, but now you would see the contrast. The pale blonde nurse and Emma. And you'd gasp. Maybe I'd point out the little blood marks all over her face where she scratched herself raw.

On Sunday morning Phil, Jake and I went to the Santa Monica Pier. There wasn't much to do in the ICU, especially for a 5-year-old. The guys were driving to Phoenix that afternoon. So we went to the beach.

I could show you those pictures too. Standing and smiling in front of the Pacific Ocean. Me smiling too much for Jake in the picture he takes of me at the end of the pier. Phil won Jake a big floppy yellow dog at the amusement park. "It's the color of your sister," we helplessly tease. We had gotten good at this kind of joke, calling Emma our "little golden girl". In these pictures it looks like we want to shout, "WE ARE A VERY HAPPY FAMILY!!"

There is no picture of Phil getting the ok from his boss to stay one more day. Likewise, there's no picture of the surprise on our faces when the resident asks us when we come up to the ICU, "if the surgeon had been to see us yet...maybe there's a liver for Emma."

If we had used our camera, we could fill a photo album with pictures of what happened next. Maybe video would be better. The flurry and hurry and waiting. Finding someone to keep Jake. The residents, fellows and attendings that come to tell us, maybe it is true, maybe there was a liver for Emma. Phil on the 405 after dropping off Jake with a friend. (Almost certainly best not to have evidence of the laws broken and tears shed just trying to get back to us on that stagnant freeway).

There are no pictures of Emma vomiting bright red blood all over me as we waited that afternoon. Probably better that way. Who needs to see it? The shock in my face as I pray this liver can't be a false alarm, please God I can't take this. Nurses and residents scurrying around. One puts his arm around my shoulders. And Emma vomits again. Yes, better that we have no pictures of that.

And nothing of a mourning donor family, spirits weary, who say "give" on this, their most awful day.

The next pictures would have been boring. Phone calls made, hugs shared, prayers said. People saying "congratulations" like we won the lottery. Dinner was good (Thai basil noodles) but hardly worth the film. The line of people across the street from the restaurant waiting to see "The Matrix". People walking around like it was just Sunday night.

You might smile politely at the next ones. Emma feeling suddenly good for no apparent reason as they take her to the Operating Room at (finally!) 3 a.m. Us sleeping fitfully on makeshift beds on chairs in the waiting room/lobby/entrance hall. The young Japanese in the chairs across from us. Their incessant happy patter giving me white noise to sleep by. Their heavily accented English calling our name as the lobby phone rings with news from the O.R. More nonexistent snapshots of:

- the first call—the old (dirty, scarred, cirrhotic) liver is out
- the second call—the new (pink, lovely) liver is in
- the third call—she is being sewn up, the surgeon will be out to see us shortly.

We surely do not have pictures of what came next. A pale (!!) yellow baby in a bed in the ICU. Tubes aplenty. Or a picture of what I saw that night. I'm leaving, it's late, I need to see Phil and Jake now. Emma is asleep, monitored, intubated. I lean in, her eye flashes open for one microsecond. I see *white*. I am floating above the ground, a magical picture. No, a trick of the camera you would say.

Those pictures I mentioned? The charge nurse took those in the ICU that morning, because it was Mother's Day. I'm not in the pictures because I'm at the beach. They are our favorite pictures now.