

Chapter 25 Hiccups

Sunday, Dec 10, 2017

“As you know, Mrs. Whiting, Charlotte’s conjugated bilirubin numbers have not come down since birth. Basically what this tells us is the abdominal cyst is interfering with proper function of the biliary tree and liver,” explains a tall blonde man in a white coat with a name badge that says “Dr. Carter.” He looks like a man who on the weekends collects wine bottles for their interesting labels. He’s the fourth doctor who’s come by to speak with us today. Or, is he the fifth? I can’t remember. My head is spinning from all the conversations of this organ and that organ, this potential surgery and that potential intervention.

Today is reminiscent of those busy days in the office when I’d hop from one meeting to another, one phone call to another, one impromptu hallway discussion about XYZ project while I was on my way to the coffee pot for my fourth cup of the day. That feeling like I’m powering through full-speed ahead with little time to breath. Like I’ll probably crash soon but there is no time to think about it now. Except, here in the NICU we are addressing life and death topics and instead of bouncing from meeting to phone call, I’m bouncing from consultation to pump room.

After such a quiet and calm Saturday with Charlotte, apparently every specialist decided Sunday is the day to come talk to the Whiting family.

Dr. Carter seems like a new face. He doesn’t look familiar. But, that doesn’t mean much. I’ve seen so many faces parade by Charlotte’s bedspace and explain their involvement in her care that I could have met him three times by now and I still wouldn’t remember. Heck, some people seem to come by just to gawk at my daughter in amazement. I suppose maybe that’s the nature of a teaching hospital—you end up having a lot of spectators coming by in the name of learning.

I can’t help but feel like she’s an exhibit at a zoo sometimes. I often want to say, “She’s not a giraffe, now please, unless you have something critical to share for her care, move

along.” Of course, I never say a word. I don’t have the energy to worry about unnecessary confrontation. But Dr. Carter seems critical to her care, or so I’m learning.

I try to focus on what he’s saying, realizing he may be the most important person I talk to all day, or even all week. After all, he’s here to tell me we may be facing the operating room (OR) again sooner than later, and for life-threatening reasons. I wish Dan was here now to hear this news himself. He stepped away to get us some lunch, which is long overdue seeing as it’s already 2:00 p.m.

“We are going to wait until tomorrow and see what her bilirubin numbers do in the morning labs. That will indicate our course of action. We were hoping to make it a few more weeks before having to surgically intervene and remove the cyst, so she can heal from the last operation and so she can grow bigger and stronger. That just might not be an option at this time ...” He goes on with further explanations of what each lab number means and then offers to draw me a picture of the liver, biliary tree, and gastroenterology tract so I can understand what we are talking about.

“Yes, please do. Pictures always help,” I say, ripping out a piece of paper from my notebook the NICU social worker gave me. He pulls a pen from his chest pocket. As he begins to draw I notice a faint but familiar sound. I look over toward Charlotte who is comfortably snoring in her isolette and confirm the source of the noise. She’s hiccuping. I smile.

“So as you can see here, Mrs. Whiting,” Dr. Carter points to his freehand drawing.

I interrupt him, “You know what Dr. Carter, I’m so grateful for your time and your input and I really want to hear what you have to say. I love your drawing and your helping me understand what we are facing. But could you please step out for just a few minutes? My daughter is hiccuping and I want to sit with her and listen.”

He must think I’m crazy. Maybe I am. I am dismissing the Director of Fetal Surgery, a Pediatric General and Thoracic Surgeon, whose time and attention is very valuable, and he’s telling me we might be walking back into the OR this week.

But, my daughter is hiccupping. I want to listen.

He looks at me, bewildered. I can tell he's trying to understand what I just said.

"Just, like, ten minutes. Could you come back in ten minutes?" I ask.

He nods, "No problem, take your time. I'll go speak with the attending Neonatologist and then I'll come back." He graciously walks away, and I get the sense he truly does understand, as much as he possibly can anyway. I sit down next to Charlotte and open the little side doors to her isolette so I can better hear her hiccups, which are muffled inside her little clear plastic cocoon. I cup my hands around her head and feet like I've grown accustomed to doing, and I listen.

Charlotte's nurse watches me curiously. "Could you help me have just ten minutes with Charlotte? If anyone else comes to talk with me, can you ask them to wait and come back in ten minutes?" I ask the nurse.

She nods with a surprised smile on her face, "Absolutely."

I feel empowered. This is the first time I've ever dictated when I will speak with specialists, surgeons, or any other medical staff member for that matter. I feel emboldened. Like maybe I'm not just the puppet on a string like I've felt for so long, being pulled this way and that way according to the hospital's schedule and consultation times.

I get comfortable in my chair and watch as Charlotte's chest rhythmically pops up and down.

"Hiccup. Hiccup." She sounds like a little dog squeaker toy. This is so ... human. So visceral—this hiccupping.

When I was pregnant she hiccupped several times a day and almost always around 9:00 p.m. My rounded belly would bump up and down, reminding me she was very much alive in there, feisty, and full of life. Seeing her hiccup now is like an injection of hope, reminding me she is not just a litany of lab numbers. She is not just a portfolio of

parading specialists. She is not just a looming OR trip. She is not just facial tape and nasal hooks, tubes and wires, leads and lines, medications and TPN.

She is human. She is beautiful. She is strong. She is Charlotte.