Where the Tiny Things Are: Feathered Essays
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It was almost imperceptible the way time slipped from the normal, waiting until her baby is big enough to go home to the waiting until her baby is well enough to go home. It’s a different kind of patience, maybe the real patience. The first is: hurry it up, goddamnit. The second is: she comes in at 9:30. She leaves at 5:30. This is her job. My best friend the artist’s new job is to sit by the bed of her babies. She may have it for a long time. She might have it forever.

When the girls were born, she could have sworn she heard them both breathe deeply. But a breath taken in does not necessarily carbon dioxide exchange compute. The oxygen didn’t last for the first baby. The oxygen the second baby breathed did what it could to redden the blood vessels but the blue veins bringing back the carbon dioxide could not find a way to exhaust. Some newborns get over this quick, this pulmonary hypertension. Not this baby. Her baby’s alveoli, sacs of lung, are not making that equal sign in those chemical equations she swore off studying so many high school years ago. By the time of the imperceptible time change, she has studied up on her stoichiometry. She has calculated moles. She has memorized the upper half of the periodic table. She has learned to whisper alveoli as a talisman.
She is glad for her iPhone. She keeps up with the doctors. The doctors didn’t know she could spell so well. She didn’t know she could type so fast in the middle of the night when the doctors call to say the baby is desatting and does she in fact wish for heroic measures. Wish? No one wishes that one will need a hero. Who is the hero here? Obviously, the galaxy will be the hero—with its nebula and cosmic dust—when the baby pulls through. Obviously, the dark of space will be a gift one day when it stops ringing her awake. It was a strange dream she was having: two girls, her twins, the twins she was going to bring home, playing basketball. One girl blocking the other’s pass. The girl still manages to lift the ball into the air and toward the basket but it’s not the ball falling through the basket—it’s the image of the two suns, one collapsing into the blackhole of the basket, the other going supernova, waves of light burning out the basket, the ball, the blacktop, the mother’s own eyes. The baby’s eyes are ringing and there’s the phone. There’s the call she does not want. She would rather return to her dream where babies are metaphors and the only real thing is white sheets warmed by her body’s burrowing in. Her chemical signature is inscribed in these sheets. She would like to stay there, with it. She goes to the phone.

She already knows pulmonary. But spell this: Pulmonary lymphangiectasia also known as lymphangiectasis also known as lymphangiomatosis is the diagnosis this night. Here’s what the doctors
say: rare congenital disease. We’d like to rule it out. She would also like to rule it out. Here is what Google says: PL presents at birth with severe respiratory distress, tachypnea, and cyanosis, with a very high mortality rate at or within a few hours of birth. She Googles tachypnea and cyanosis:

Tachypnea, rapid breathing. Oh, she thinks. Tachy. The nurses use that word all the time to describe her baby’s breathing. Tachy up means breathing goes faster, harder, like a bird. A dying, fluttering bird.

Cyanosis. She’s a painter. She’s seen her baby. She knows that she has been blue. Cyan Cyan Cyan. Cerulean blue.

This is what she doesn’t know. How rare? How congenital? This is a rare congenital disease caused, maybe, no one really knows, by the lungs not going through their normal regression period at 20 weeks gestation. What was she doing at 20 weeks, she wonders? She Googles “normal lung regression period at 20 weeks gestation.” She gets, during the canalicular phase (16th–26th weeks), differentiation of the epithelial cells lining the alveolar ducts occurs, the first type II cells containing lamellar bodies appear, and capillary growth within the developing lung begins.” The capillaries in the lungs are not growing. The alveolar ducts are not venting. The type II cells containing lamellar bodies are what
make surfactant. She already knows her baby has a hard time making surfactant.

What she also doesn’t know is this: “Although the incidence of these conditions is not directly correlated to the possible incidence of PL, it may be useful to keep in mind that the incidence of hydrops fetalis in obstetric-neonatal referral centers may be as high as 1:800. Furthermore, this condition carries a poor prognosis with a mortality rate ranging from 50% to 98%, and the incidence of congenital chylothorax is about 1:10,000–15,000 pregnancies, with a male-female ratio of 2:1.”

She doesn’t need to know Latin to know what “hydrops fetalis” means. A water-filled baby. A baby with water where her lungs ought to be. This baby sounds a little too much like her body in the middle of the night. In the middle of the night, when she is sweating and her stomach turns and cramps and threatens to unleash itself upon those white sheets she just one minute ago thought of as comfort are now as diseased as one would-be daughter and the other hard-breathing baby. Maybe the dream meant something. Maybe this word she can now spell reads “twin.” She wonders why fetalis and fatalis are so easily exchanged, chemically, in her head.
In the morning, when she has wiped all the fluids away from her own body, when she made it to the hospital to wipe all the fluids off the body of her one daughter, her only daughter, her living twin, another doctor comes in and says, I don’t think it’s lymphangiectasia.

The doctor jokes, I don’t even know how to spell that.
And she says, I do.
But, the doctor says, we’ve tried three rounds of surfactant replacement therapy. It’s not working.

Surfactant decreases surface tension—the word refers to any kind of soapy liquid. Detergents. Surfactants are used to make the cogs turn. Grease the wheels. In humans, the grease is especially cleansing. It makes what would be tacky, sticky, stuck little balloons in the lungs slippery. On a micro-level, the surfactant slides between the stick and tack, and lets the balloons alight letting the alveoli do their clean-up work—bringing the carbon dioxide in to be released, sending oxygen out into the blood vessels. On a larger level, surfactant is necessary to make the lungs compliant—to comply means to expand just the right amount to bring the oxygen in and to let the CO₂ out.

Her baby’s lungs do not comply. She thinks, in the dark part of her brain, go ahead, rebel, little rebel. But she doesn’t mean it. What she means is, I have better words for it: elastic, flexible, effective. They have
given her daughter three doses of replacement surfactant—donated by
the kind dead lungs of a pig. There is a disease called surfactant syndrome
which means the first type II cells containing lamellar bodies cannot
make surfactant. One can’t live, or rather, one can’t breathe, without
surfactant. The lungs flatten like balloons at a birthday party no one is
going to.

The doctor says, we gave her one more dose. It’s not working
anymore. The pig died for nothing. No one is complying, except for
maybe the pig. Really, no one is complying at all.

The lymphangiectasia phone call was easier to type than the next
phone call: We believe your daughter might have ACD. We will have
to do a lung biopsy to confirm. To perform a lung biopsy on a 34-week
gestation preemie baby with chronic lung disease who suffers from
respiratory distress is a risk. A very, very big risk. But we should find out
if she has ACD.

Anyone can spell ACD. Not so many people can stand the
definition: Alveolar capillary dysplasia (ACD) which Wikipedia says is
a rare, likely congenital, disorder of the lungs and especially of the blood
system serving the lungs. It is a disorder of the newborn. The normal
diffusion process of oxygen from the air sacs to the blood in the lungs and,
thence, to the heart, fails to develop properly. The disorder is sometimes called misalignment of the pulmonary veins. Rather than misaligned, the pulmonary vein is malpositioned in a site somewhat different from its normal position.

Infants with the disorder present with the signs of lack of oxygen (hypoxemia) and severely increased pulmonary hypertension. Since treatment is seldom, if ever, effective, life expectancy of the infant is very, very, short.

Wikipedia says the longest living survivor of ACD was two months old. Can she imagine, waiting in the hospital with the diagnosis of probable ACD hanging over her head, over the head of her baby, with the threat of an unnecessary lung biopsy lurking with the question of why bother, we’ll know in two months whether it is ACD or not ACD?

I suspect that she can imagine. I suspect she knows. I suspect that the wait to find out would very, very hard. Almost as hard as doing no lung biopsy at all and just waiting to see. She’s already almost two months old. If she makes it past two months old, does that reverse the diagnosis? We would like some rules. Some clear, strict rules, like the rules for stoichiometry.
It is so rare, so rare, these diseases so rare. But she is getting better. They want to take the baby off the jet ventilator. But just before they do, they want to run one more test—one more baby CT scan to see if her baby has something called Interstitial Fibrosis in Newborns. She can type that one—that one she is sure has a cure. She knows to always type “in newborns.” Diseases of the newborns do not present like diseases of the awhile-ago born. She knows the symptoms: tachynea, cyanosis, respiratory distress syndrome. Word for word in every diagnosis. This one has treatment: inhaled steroids. Steroids make her nervous. The baby already has an infection. The doctors are already giving her antibiotics. She knows to give an infection a steroid is like giving the infection a big bowl of Wheaties. She knows infection can lead to pneumonia. She knows pneumonia can lead to atelectasis. She knows lungs collapse and the alveoli sacs can fall down into themselves and not lift back up. She knows the baby is tired from all this work and that she could use a big bowl of something herself, her own Wheaties, preferably not a steroid, to give her the energy to inflate those lungs, transfer oxygen to the blood vessels, remove carbon dioxide from the veins. Every single gas exchange is something the baby has to consider and her mom can’t do her thinking for her. All she can do is wait to see if this new diagnosis can be ruled in or ruled out. Interstitial is a word she likes better than the others but is still not the word she wants to hear which is breathe and home. She
decides to wait and see. No steroid. If the baby gets better, then, once again, what she has or had is not that.

Dr. Lou is angry at the artist-painter for not agreeing to the CT scan. Dr. Lou doesn’t care about the radiation. Dr. Lou doesn’t care when she voiced concern about the steroid dexamethasone, which has been suspected to cause severe neurological effects in children. Dr. Lou doesn’t care because she still doesn’t believe this baby is going home. She told her so, to her face. She said, she is still a very sick baby and when Dr. Lou said baby she could not hear in Dr. Lou’s voice that flip of a stomach that we all hear when we hear baby and think baby, I love babies, and the fact that the baby is still in the hospital is to her a given not a not given, not a not fair, not a not real. Dr. Lou says the word atelectasis. Dr. Lou doesn’t say collapsed lung because she doesn’t know what it’s like to collapse. I know the word atelectasis. My baby was collapsing alveoli all over the place. I brought my baby to her this week so she could see her now, at six years old, what she is waiting to have in the future, but now I see that she may also see in my girl all that she may not have, even for all this waiting, even for this new patience, this kind of patience that wakes up in the morning, thinks, breathe, steps into the shower, breathe, shampoo in hands, breathe, suds in hair breathe, no conditioner, no one cares, breathe, brush teeth, breathe, breathe on Dr. Lou, breathe, eat a bite of banana, breathe, eat another bite of banana breathe, quit eating banana
because it’s too tiring, breathe, look for car keys, breathe, look for iPhone because there is no other waiting friend better than the phone that will take her to Google so she can spell her newfound, hateful words, breathe, drive left, breathe, girl, breathe, drive right, breathe girl, that car in front of her had better not stop because she’s breathing on behalf of a baby who is in the NICU in California and traffic is not part of the patience, not part of the diagnosis. The only diagnosis today is sign in to the hospital, wash her hands for two-and-a-half minutes, up to the elbows, sign in again, talk to the nurse, sing to her baby, Google words she wishes she never had learned to spell, be afraid all the time, wish she had a ventilator for herself, be afraid and hopeful that one day all this waiting will change imperceptibly to that kind of waiting where it’s not waiting to heal, just waiting to grow.

One day, they will tell her, go get the car seat. She’ll be as surprised as she was the day they said, let’s take her off the vent. She’ll be as surprised as the night she got the phone call saying, we were wrong, it’s not ACD. She’ll be as surprised as she was the evening her babies were born and she heard them inhale and the exhale tumbled right after it. As surprised as she was that she could make at least one daughter reach two-months old. As surprised as she was, two days after they extubated that baby to see her breathe as if she hadn’t been waiting to catch her breath at all.