

Dear Wind,

Nicole Walker

Dear Wind,

I inch toward you. I do not go with grace. I have been putting it off, which is not the right thing to do. You are just a baby but even when my baby Zoe, whose name means “life” in Greek, hovered in the hospital, I did not want to be hospital bound. I prefer to go. Tubes and traches and vents are the Twenty-first century chains in this broken world. Still, I should have come right away but I had just been to Tucson where the wind was blowing, where the girls ate forty-eight orange Cuties, staving off all scurvy and also whatever diseases everyone else came down with later that week, where Misty chopped the red bell peppers so tiny all the pesticides disappeared, where the re-routed Colorado sunk into the aquifer and we turned on the hose, brought up that water, made our own canal system in the gravel driveway, and then recycled it ourselves, letting it soak into the ground, back into aquifer from whence it came. I should have gone but I am not sure how much I can help. I do not blow much more than hot air and I don’t like to fly. I hate the I here. I should have gotten no a plane.

I would go to you girl, girl in California, girl, where the oranges we ate in Tucson came from, where the Colorado goes to, if I knew that my coming would catalyze your alveoli to do their chemical work. If there was something the smell of me could do, the slip of my sweat commingling with the abrasive soap that would make the CO₂ in your lungs convert out of your blood, to pull the oxygen in, if the dust mites on my eyelashes could make nanowork and puff air sacs open better than the ventilator could, if the microorganisms in my gut, keeping me as healthy as any orange Cutie, could bounce into your stomach and train your stomach to pull in the whole round of the world. It’s like you’ve got your soul stuck halfway in and halfway out and you’re choking on it, little girl. You’ve been womb-free for eight weeks girl and your eyes are open and looking at your mom whose eyes I won’t be able to look into when I tell you girl, it’s not the horror of death you see but the horror of little miracles that are just not getting off the ground. I would like to think that my impending arrival will bump those pneuma from concrete flats into the phenomena they are supposed to be, pneuma from the Greek, the vital spirit; the soul. Or in Theology, the Spirit of God; the Holy Ghost.

I will come anyway and sing a song about being forsaken. In between the lyrics of the song, I will chant words to you. An incantation that I pray will become an incarnation. In that song about flying on the wind I will sing also the word “pneuma” over and over again. From the Greek: *pneûma* literally breath, wind, akin to *pneîn* to blow, breathe. I will say to you, forget about pneumonia. I will incant to you the pneuma and, in my dreams, it will become your lungs and I will blow myself from here, so far away, to you.

But my song, like everyone who is singing to you, is made of very privileged air. Air goes in. Air goes back out. How reliable. But wind. Wind is what you need. Where does it come from? Where does it go? Wind is its own kind of miracle. Not even the Holy Ghost can blow it himself. Wind is a small miracle and what's going to save you has got to be a little thing. Smaller than you, tiny baby. The smallest thing in the world.

Dear Galaxy,

Nicole Walker

It was almost imperceptible the way time slipped from the normal, waiting until your baby is big enough to the waiting until your baby is well enough. It's a different kind of patience, maybe the real patience. The first is: hurry it up, goddamnit. The second is: you come in at 9:30. You leave at 5:30. This is your job. You may have it for a long time. You might have it forever.

When she was born, you could have sworn you heard her breathe deeply. But a breath taken in does not necessarily carbon dioxide exchange compute. The oxygen she 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 babies get over this quick, this pulmonary hypertension in newborns. Not your baby. Your baby's alveoli, sacs of lung, are not making that equal sign in those chemical equations you swore off studying so many high-school years ago. By the time of the imperceptible time change, you have studied up on your stoichiometry. You have calculated moles. You have memorized the upper half of the periodic table. You have learned to whisper alveoli as a talisman.

You are glad for your iPhone. You keep up with the doctors. The doctors didn't know you could spell so well. You didn't know you could type so fast in the middle of the night when the doctors call to say she was desatting and do you in fact wish for heroic measures. Wish? No one wishes for a hero. Who is the hero here? Obviously, the galaxy will be the hero—with its nebula and cosmic dust—when she pulls through. Obviously, the dark of space will be a gift one day when it stops ringing you awake. It was a strange dream you were having: two girls, your twins, the twins you were 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. Her eyes are ringing and there's the phone. There's the call you don't want. You would rather return to your dream where babies are metaphors and the only real thing is white sheets warmed by your body's burrowing in. Your chemical signature is inscribed in these sheets. You would like to stay there, with it. You go to the phone.

You already know 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. You 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. You Google tachypnea and cyanosis:

Tachypnea, rapid breathing. Oh, you think. Tachy. The nurses use that word all the time to describe your baby's breathing. Tachy up means breathing goes faster, harder, like a bird. A dying, fluttering bird.

Cyanosis. You're a painter. You've seen your baby. You know that she has been blue. Cyan Cyan Cyan. Cerulean blue.

This is what you don'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 twenty weeks gestation. What were you doing at twenty weeks, you wonder? You Google "normal lung regression period at twenty weeks gestation." You get, "during the canalicular phase (sixteenth–twenty-sixth 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. You already know your baby has a hard time making surfactant.

What you also don'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"

You don'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 your baby in the middle of the night. In the middle of the night, when you are sweating and your stomach turns and cramps and threatens to unleash itself upon those white sheets you just one minute ago thought of as comfort are now as diseased as your possible daughter. Maybe the dream meant something. Maybe this word you can now spell reads "twin." You wonder why *fetalis* and *fatalis* are so easily exchanged, chemically, in your head.

In the morning, when you've wiped all the fluids away from your body, when you make it to the hospital to wipe all the fluids off her body, 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 you say, 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, decreases surface tension, 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.

Your baby's lungs do not comply. You think, in the dark part of your brain, go ahead, rebel, little rebel. But you don't mean it. What you mean is, I have better words for it: elastic, flexible, effective. They have given your 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. You can't live, or rather, you 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 who died. 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 thirty-four-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) is a rare, likely congenital, disorder of the lungs (pulmonary system) 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 was two months old. Can you imagine, waiting in the hospital with the diagnosis of probable ACD hanging over your head, over the head of your 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 you can imagine. I suspect you know. I suspect that the wait to find out would be very, very hard. Almost as hard as doing no lung biopsy at all and just waiting to see. Two months old. She's already almost there. One more week and she will have been in the hospital for two months. Does that make her two months old? Does Wikipedia count from birth or from gestational due date? If she lives for two months does that rule out ACD? 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 her off the jet ventilator. But just before they do, they want to run one more test—one more baby CT scan to see if your baby has something called Interstitial Fibrosis in Newborns. You can type that one—that one you're sure has a cure. You know to always type "in newborns." Diseases of the newborns do not present like diseases of the awhile-ago born. You know the symptoms: tachynea, cyanosis, respiratory distress syndrome. Word for word in every diagnosis. This one has treatment: inhaled steroids. Steroids make you nervous. She already has an infection. They're giving her antibiotics. You

know to give an infection a steroid is like giving the infection a big bowl of Wheaties. You know infection can lead to pneumonia. You know pneumonia can lead to atelectasis. You know lungs collapse and the alveoli sacs can fall down into themselves and not lift back up. You know she 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 she has to think about and you can't do her thinking for her. All you can do is wait to see if this new diagnosis can be ruled in or ruled out. Interstitial is a word you like better than the others but is still not the word you want to hear which is breathe and home. You decide to wait and see. If she gets better, then, once again, what she has is not that.

Dr. Lou is angry at you for not agreeing to the CT scan. She doesn't care about the radiation. She doesn't care, when you voiced concern about the steroid dexamethasone, which has been suspected to cause severe neurological effects in children. She doesn't care because she still doesn't believe your baby is going home. She told you so to your face. She said, she is still a very sick baby and when she said baby you could not hear in her 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. She says the word atelectasis. She 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 her to you this week so you could see her now, at six years old, what you are waiting to have in the future but now I see that you may also see in my girl all that you 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 you to Google so you can spell your new found, hateful words, breathe, drive left, breathe, girl, breathe, drive right, breathe girl, that car in front of you had better not stop because you're breathing on behalf of a baby who is in the NICCU in California and traffic is not part of the patience, not part of the diagnosis. The only diagnosis today is sign into the hospital, wash your hands for two and a half minutes, up to the elbows, sign in again, talk to the nurse, sing to your baby, Google words you wish you never had learned to spell, be afraid all the time, wish you had a ventilator for yourself, 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 tell you, go get the car seat. You'll be as surprised as you were the day they said, let's take her off the vent. You'll be as surprised as the night you got the phone call saying, we were wrong, it's not ACD. You'll be as surprised as you were the evening she was born and you heard her inhale and the exhale tumbled right after it. As surprised as you were, two days after they extubated to see her smile and to hear yourself laugh as if you hadn't been waiting at all.