never let go

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CHERIE DIEZ - Times

AT LAST: My baby was 2 weeks old when I first held her. She was so sick and small that moving her just a few feet was risky. I learned later that the doctors allowed it because they feared I wouldn't get another chance to hold her while she was still alive.

PART TWO

The zero zone

We were cast into a neverland of sick babies, where every moment is a fight for existence.

Bent double, I shuffled down a winding corridor, trying to find my baby.

Somewhere in this place my new daughter lay alone in a neonatal intensive care unit, struggling to breathe. I could feel the stabbing incision where they had cut her out of me two days before. That's how it felt - like there had been an assault, perhaps in an alley with a dull spoon. The doctors had been kind and correct, and they'd had no choice. But they might as well have taken my liver, or my heart.

The curving pastel hallways felt infinite. I'd visited her - a raw and tiny thing, born four months premature - but could not remember how to get back there, and I wasn't supposed to go alone.

I clutched a syringe containing a trace amount of milk. Since her birth, I'd spent nearly every hour in a hospital bed attached to an electric pump, a frustrating and painful exercise that only magnified the absurdity of the situation. My body did not seem to know what to do. It was April 2011 and the baby wasn't due until August, yet here she was. Everything was out of synch.

I had wrung out a few drops and collected them in this syringe, like you'd use to feed an orphaned squirrel. It was a pathetic amount, but the nurses insisted the baby needed every drop. Her underdeveloped gut was vulnerable to infection and rupture, calamities that killed many babies her size. My milk could coat her stomach lining with protective antibodies. The pressure to produce the stuff was immense. If one more nurse called it "liquid gold," I was going to spit.

The odds said she would die. I wondered how much time we had. I couldn't hold her or feed her. She couldn't see me. I didn't know if she was aware of me at all. I could do nothing to tip the odds, or even to assert myself as her mother, except deliver this milk.

My insides screamed. Vicodin had been prescribed, but I had skipped the dose because I wanted to keep drugs out of the milk. I came to the long window of what I thought of as the Fat Baby Nursery. This was the place for healthy newborns - goliaths who wailed petty complaints with robust lungs. "What's your problem, fatty?" I said to one. No 9-pounder had any right to complain.

I took a staff elevator up three floors. At a pair of locked double doors I picked up a phone. "I'm here to visit my daughter," I said. Daughter. The word was so unfamiliar it caught in my throat.

Inside a nurse guided me to her and took the milk from my hand.

"Is it enough?" I asked.

It was 1 mL, a thimbleful, but just enough for a baby so small. The nurse attached it to the tube snaking into the baby's mouth and down to her belly.

It was gone in a second.

I always knew I'd have a daughter. I pictured her with a puppy in her lap and dirt under her nails. She'd make me laugh and she'd refuse to wear shoes. I had carried and shaped the idea of her as long as I could remember.

When I started dating Tom French, I watched him load the dishwasher with his two boys - they did a sloppy job but they sang the whole time - and I knew he should be her dad. He was nearing 50 and wary of starting over. Convincing him took a breakup now referred to in our house as the Dark Era. I never questioned why I wanted a daughter so much. She was a real person to me. I would will her into existence.

Conceiving her took four years of fertility treatments - pills and vials, needles in my arms, needles in my stomach, needles in my butt, surgeries and so many wands and gloves shoved into my nether regions that it stopped seeming strange. After three failed in-vitro fertilizations, it took an egg donor, too. The donor was a friend of mine. A better friend, it turned out, than I even knew. We worked out the details over pomegranate margaritas, and when the test came back positive, she was the first person I called.

I didn't mourn the broken limb on my family tree. I was excited about the genes I'd chosen for my daughter, on both sides. I imagined that someday she'd thank me for the blue eyes and dark hair she was bound to inherit. She didn't have my DNA, but when she squirmed inside my belly, I knew she was mine.

Then she was snatched away at birth, and the umbilical cord connecting us was cut and replaced with lines connecting her to machines.

Tom and I had stretched the limits of science once already, to create her. To keep her, we'd have to do it again. The doctors said we could end up with a live

CRISIS: When she was 5 days old, Juniper's intestine ruptured. Air and stool spilled into her abdomen, flooding her with bacteria. The doctors suspected a terrifying condition called necrotizing enterocolitis, which is often fatal in babies so small. Dr. Joana Machry, a neonatologist, and certified physician's assistant Ryan Nachit examined her before a surgeon inserted a drain into her belly.

baby, a dead baby, or a wrecked baby. Before we'd know, we would explore the wonder and peril of man's ability to manipulate nature, and we'd surrender to the understanding that we control so little.

Would my baby and I find our way back to each other? Was I really a mother now? Was mother a noun or a verb, and what did it mean, in this strange place?

The neonatal intensive care unit at All Children's Hospital was a world out of science fiction. Before, there had been only my baby in my body. Now we found ourselves in a multimillion-dollar artificial womb. The work of my balking uterus was replicated by an army of specialists in a facility that looked like an alien hive.

There were rows of incubators covered with quilts to shut out light and sound. I couldn't see or approach the babies inside. I expected to hear crying, but babies didn't cry here. Their faces contorted in protest, but the tubes in their throats stopped the sound. The machines beeped and alarmed. The room swarmed with people in scrubs. Here and there sat bleary parents in various stages of boredom and shock. I did not know my place in this new world.

The NICU was a technological triumph. Science had made life possible at earlier and earlier stages of development, but inside those possibilities, terrible bargains were made. Science, ambition, compassion and common sense collided here, every day.

Another parent once called it the Zero Zone, and when I heard that, my mind flooded with context and understanding. It was a place that existed outside of time, apart from everything I used to know and from the person I used to be. It was as if I'd been jerked out of my own shoes, out of the life I recognized. Every second was an improbable gift and an agonizing eternity. Would my baby die today? Would she die before lunch? If I left for an hour, would she die while I was gone? There was no future, no past. There was only a desperate struggle to maintain.

The Zero Zone. The idea became hypnotic, took on multiple interpretations. Our baby was born at a unique window of time, at 23 weeks and six days' gestation. She was a thwarted miscarriage, not yet fully her own person with her own standing. Because the questions were so unanswerable, the decision to put her on life support and allow her a chance to live had belonged to Tom and me, not the doctors and not the state.

This place was a frontier. Between life and death, certainly, but also between right and wrong, and between who we used to be and who we were becoming.

There were 97 beds taking up an entire floor of All Children's Hospital. Ninety babies were admitted that April. About a quarter were drug babies - mostly oxycodone - and the rest were genetic disorders, birth defects and preemies. We became aware of babies with missing limbs, holes in their spines, shunts in their brains. Two babies were born that month at the edge of viability. I never saw the other one.

Parents were oddly scarce. The chairs by many of the incubators stayed empty. All Children's took babies from as far away as the Caribbean. Some parents couldn't make the trip. Some were in prison or rehab.

And some, faced with the fragility and complexity of life here, simply fled. Babies lingered alone until they were discharged to foster care. Volunteers held and fed them. Nurses rocked them while they did their charts.

We saw a mom who could not have been older than 18, sitting alone in a wheelchair, holding her gown closed in the back with her hand. I could see her baby's intestines piled in a bag atop his stomach. I desperately wanted to take her out for a milk shake. But we never spoke.

We saw a couple no older than 16, surrounded by family and balloons. The boy looked barely old enough to shave. We expected him to disappear, but he came back day after day in his white undershirt and too-big shorts. "Do you have any questions?" the doctors would ask. They'd just shake their heads.

One afternoon we watched someone pull a privacy screen around a family gathered at one of the incubators, and our nurse ushered us out. When we returned, the family was gone, and inside the incubator, underneath the blankets, was a shape, not moving. The blankets were perfectly tucked and smoothed. On the floor were an empty alcohol packet and two crumpled tissues. The dead baby stayed there for hours. The nurses did not speak of these things, did not look in the direction of the lump under the blanket, but their

THE NURSE: Tracy Hullett has had her heart broken by preemies before, and she wasn't ready to get attached to our critically sick daughter. When we asked her to be our nurse, she hesitated. She never explained why she changed her mind, but she became one of the most important people in our lives.

THE PREEMIE WHISPERER: Physical therapist Ana Maria Jara has an astonishing ability to relax a tiny baby with her hands and voice. She teaches nurses and parents how to touch and position babies without overstimulating them. Keeping the babies calm and comfortable helps them breathe and grow, and eases the transition from the womb to the world. Here, in a photo taken this fall, she works with another preemie.

mouths grew tight. In this place, death was not theoretical.

I would think about the dead baby every day. I would imagine when that day would come for me. The nurses would sit me down in the blue vinyl recliner.

They would turn to the baby and unhook the tubes and wires, one by one. They'd gently lift my daughter out of the incubator, wrap her in a blanket, and lay her in my arms. She'd be sedated, so she wouldn't struggle, but she'd gasp. My husband would want to hold her, but I'd cling to her as long as I could. I would be a mother for a moment. I would try to say something a dying baby would need her mother to say. "You are not alone. I love you more than the world." I would memorize her face. I would be terrified of forgetting. We would pass her back and forth until she grew cold and mottled and dark. It would take longer than you'd think. The stethoscope would leave an imprint on her chest.

We would walk away not knowing who we were.

Nurse practitioner Diane Loisel stopped by Bed 692, where we sat frozen and numb. She lifted the quilt and peered at the day-old baby inside.

We recognized her as the person who'd led us to the decision not to let our baby die. I felt solid ground for the first time in days.

Our baby was a tiny thing, Diane said, but wiggly.

That was a decent sign. Diane opened a porthole and used a stethoscope the size of a quarter to listen to the baby's lungs. They sounded clear on both sides.

She looked at the ventilator settings. The baby was receiving 21 percent oxygen - the same amount as in the air around us. Excellent.

Diane listened to her gut as she moved from baby to baby. Something about this baby encouraged her. The first week, though, was often called the honeymoon period. She warned us that things could turn in a flash.

We reminded her that we did not want to torture our baby with futile treatment.

Diane nodded. "She looks good for now," she said.

"But you'll let me know when to freak out, right?" I said.

"I will tell you when to freak out."

I'd slept maybe five hours in the first five days. I had vomit in my hair. The capillaries under my eyes were busted from crying. I wasn't allowed to drive. As if that wasn't enough, the people in charge of birth certificates were hounding me at all hours. They wanted a name and they by-God wanted it now. They left a baby name book in my hospital room. They stalked me wielding blank forms.

Tom and I had been in such collision over names we'd agreed to table the question until the third trimester. We finally stole a name a friend had given his daughter: Juniper. We called her Junebug.

Someone wrote her name on a card on the foot of her incubator with her birth weight: 570 grams. One pound 4 ounces. I've eaten burritos at Chipotle that were bigger than that.

She was so fragile that even the delicate handling after birth had left her bruised. All her fine details - hair, eyelids, fingernails - looked slightly blurry, like a partially developed Polaroid. Her head was smaller than a tennis ball. Her ears had no cartilage, so they crumpled. She had no nipples - they wouldn't form for a few more weeks. The ventilator made her belly heave with such force her chest dimpled under the ribs. Wires snaked from electrodes on her chest. A red sensor glowed on her foot. An IV ran into her hand. A wheeled pole next to her bed was stacked with three

HELLO: My stepson Nat French, 22, flew home from Southern Methodist University in Dallas to meet his baby sister when she was 3 days old. Like all big brothers, he got a sticker from the nurses.

levels of pumps dosing out caffeine, antibiotics, pain medication and sedatives. A hanging bag contained liquid intravenous nutrition, precisely calibrated each day. She was so obscured by tape and technology that I struggled to imagine her naked face.

The biggest fear was intraventricular hemorrhage: bleeding in the brain. Vessels could burst from the stress of delivery or a surge in blood pressure. Blood could clot, causing pressure to build. Brain tissue could die, destroying the capacity for movement, language, learning. A bad enough brain bleed would mean taking her off life support.

Her intestines were vulnerable to infection and rupture. In times of stress, the body diverts blood to the brain and heart first, the gut last. A lack of circulation could make her belly distend and turn black. Her intestines could die, poisoning her from the inside.

The ventilator kept her alive, but the pressure stretched her tiny air sacs, scarring her lungs. A surge in pressure - from aggressive resuscitation, for example - could burst the air sacs. Too much pressure in the blood vessels could fill the lungs with blood, drowning her.

Antibiotics to ward off infection could shut down the kidneys. Oxygen to keep her alive could make her blind. Narcotics to keep her comfortable could make her an addict.

Nurse Tracy Hullett warned us to keep our hopes in check.

"Never trust a preemie," she said.

I watched Nurse Tracy attach a tiny bow to Juniper's forehead using KY Jelly. I didn't know what to make of all the pumps and monitors, and I struggled to follow the medical babble, but I understood the meaning in that small gesture.

This is your daughter. Get to know her.

I used medical tape to attach a photo of Tom and me to her isolette, so when her eyes opened, she would know who her parents were. For the harder stuff, I was lost. How do you connect with a little girl who can't see or eat or cry? How do you parent a baby in a plastic box?

Tracy showed us how to tuck a thermometer under the baby's arm to take her temperature. It was shocking how strong she was and how hard she fought, swatting and kicking blindly with her chicken limbs.

Tracy showed us how to change the tiny diaper, which she trimmed with scissors so it fit just right. We had to hold it with just our fingertips, being careful to avoid the wires, and tuck a cotton ball inside to collect the pee.

She measured Juniper's belly and head to check for swelling that would indicate a bleed or a break. When she changed the leads on the baby's chest, she touched the sticky side with her fingers to weaken the glue so it wouldn't pull off skin. On good days, she let us lift the baby while she changed the blankets. She fit easily in our hands, but her arms and legs would flail, pulled by the weight of the IVs, and we'd have to be careful not to dislodge the ventilator tube in her throat. Tracy showed us how to touch the baby. Her skin was so new and the nerves so close to the surface that stroking rankled her. She liked firm, steady pressure that made her feel secure, like in the womb. We'd cup one hand around her head and the other around her feet. We could feel the huge soft spots throbbing in her unfused skull.

Tracy would gently turn her each time she tucked her in, so the baby's soft head wouldn't flatten on the sides. It was an effect common in preemies that the nurses called "toaster head." Once I learned about toaster heads I saw them everywhere. In the elevator.

In the grocery. Preemie! I'd think, proud of my new diagnostic abilities. I wanted my baby to be brilliant and have a nice round head like Charlie Brown, but mostly I wanted her to live. If she ended up with a head like a kitchen appliance, well, kids look so great in hats.

I shared every one of my rambling, crazed thoughts with Tracy, and she didn't appear to judge me.

Tracy moved quietly, in the background, and was hard to read. While the other nurses wore scrubs featuring teddy bears or Disney characters, Tracy's had cats from outer space. She was meticulous, but had a gift for improvisation. She hemmed her pants with staples.

She was 48. She didn't have kids of her own and didn't want them. She joked that she lost interest in babies once they cut teeth. That was fine with me. I wanted her to save our baby's life, not teach her to water-ski. She had a soft spot for wounded things. She had a houseful of rescued cats. She came to remind me of a cat. She was stealthy.

Tracy was undaunted by doctors. When one ordered a barrage of blood tests, she calmly picked up a phone to remind him that the baby had a little more than an ounce of blood in her whole body. "This baby doesn't have that much blood to give," Tracy said. "You're going to have to decide which tests you want the most." We'd been told that one important advantage we could give our baby was to convince a great nurse to take her on as a primary patient. I made Tom ask. I didn't think I could handle it if Tracy said no. I could see the conversation from across the room, and Tracy looked cornered. She was collected as always, but her step quickened when she walked away.

"She said she'd think about it," Tom said. "She's really busy."

The truth was, Tracy told me later, she did not want to get attached.

If she agreed, she'd spend every shift with us and Juniper, enduring all the terror in a much more personal way. She'd had many primaries over the years, and kept stacks of photos of them at home. She'd attended their birthday parties and pushed them on swings.

She'd seen their high school graduations. She'd seen them grow up with blindness, cerebral palsy, wheelchairs and adult diapers. She'd attended their funerals, with their tiny open caskets.

One baby's parents lived far away, so Tracy had taken home the blankets and laundry herself and washed them with her scrubs. That baby lived eight months in the NICU and then died. Another was discharged to medical foster care and died the next day. The family of one baby who had died still sent a Christmas card every year.

Juniper was going to be a lot of work. Tracy was not at all sure she was going to survive.

She liked the baby's spunk, though. She'd chuckle

when the tiny girl batted at her with her spindly arms.

"Listen, young lady," Tracy told her as we watched. "I have been wrestling preemies for a long time, and I am not afraid of you."

No one knew what kind of card to send. Were we celebrating or grieving? Even we didn't know.

"Congratulations!" people said, but that didn't seem quite right.

Friends and co-workers filled our freezer with Italian food from Mazzaro's. They held back the baby gifts they'd bought, not knowing if they would ever be used. Juniper had lots of visitors, but when they saw her they would step back and gasp. One family member was so unnerved he threw up.

Everyone, it seemed, knew somebody who knew somebody who was born at 1 pound and went on to have a remarkable life. My husband's co-worker's wife. A waitress' father. Without exception, it seemed, these babies were tucked into shoe boxes and kept warm by the oven.

"When can you take her home?" people asked, and it always stung.

Ours wasn't the world's smallest baby. Babies weighing just over 9 ounces have survived, and ours weighed more than twice that. But gestational age, not birth weight, is the key predictor of how a baby will do. Our baby was born so early some hospitals would have refused to save her. If she had come one week earlier, All Children's would have declined to try. In less developed countries, resuscitation would have been impossible. In the Netherlands, it would have been all but forbidden.

When she was 4 days old, I was discharged. Tom pushed me out in a wheelchair, no baby in my arms, no balloons. I cried on the curb.

"It's a miracle," people would say. I'd thank them and grind my teeth and think, *Ask me in a year if it's a miracle.*

At home on the fifth day, I felt uneasy in a way I couldn't explain. I asked Tom to call the NICU, because I was afraid to dial the phone myself. Jackie, the nurse that day, said Juniper was fine. She was wearing a pink hat and resting on a pink blanket. The feeling didn't go away. I asked Tom to call again that afternoon. She was still fine.

That evening a young nurse named Whitney Hoertz started her shift at 6. She looked at the monitors and the chart. All good. She looked at the results of that afternoon's chest X-ray. All good. She looked at the baby.

Juniper's belly looked a little dark, maybe, but it could be hard to tell in the light. Whitney got out a measuring tape and wrapped it under and around her. Her belly measured 18 cm - it had grown by 1.5 cm since that morning. She called a doctor, who called for an X-ray.

We were arriving at the hospital to see Juniper when we got the call. Her intestine had ruptured. Air and stool were spilling and collecting in her abdomen, flooding it with bacteria. The doctors suspected a terrifying and often fatal condition called necrotizing enterocolitis. It was the very problem I'd hoped to inoculate her against by pumping so much milk.

VULNERABLE: My husband, Tom French, held Juniper's hand just before a surgeon inserted a drain into her belly. Until this moment we had never seen her with her incubator open, and we had only touched her through the portholes. The access was thrilling but also terrifying, because we knew it signaled a serious problem. The rupture in Juniper's intestines could kill her.

Her body hadn't deteriorated to the point that the mon itors would register any trouble. Whitney's hunch had been the only warning.

We rushed upstairs to find a gathering at her bedside. The lid was off the incubator, and she lay there, distended and subdued. We each held her hands in our fingertips for a second. Then surgeons inserted a drain, like a soft drinking straw, to wick away the gunk in her belly. All we could do was wait to see if she healed, or if infection took her down, or if her intestines died off. It was a good thing she'd been getting breast milk, they said. Maybe it would help.

We struggled to find the right thing to say to the 28-year-old who had seen what the monitors could not.

"Whitney," Tom said. "Whitney ..."

"I know," she said. "I don't know what would've happened either."

Tracy was off that day, but Whitney was a reminder that an army of people watched over our baby - nurses, nurse practitioners, neonatologists, respiratory technicians, lactation consultants, specialists of all kinds.

The hospital cleaning lady prayed for Juniper while she swept.

We stayed there all that night.

"I just don't want her to be alone," Tom said.

We watched the numbers flash on the monitor - the green number for the heart rate. The white number for her breathing. The blue number for the oxygen saturation in her blood. Those numbers were mesmerizing. The monitor alarmed whenever something got out of whack - about every 15 minutes. I stared at it, not sleeping, as the floor grew quiet and the windows grew dark.

Tom, fighting tears, opened a book and rested it on the lid of the incubator and began to read. It was an act of faith, I suppose, that he did not choose Goodnight Moon or Go, Dog. Go! He started with Chapter One of book one of the Harry Potter series, a series that totaled more than 4,000 pages. I knew he intended to read the entire thing, all seven books, even if it took him seven years.

"Chapter One," he began. "The Boy Who Lived."

The book tells the story of a baby who survived an attack by the most powerful evil in the world. He survived because his mother stood by his crib and protected him with her life.

Before dawn. Tom slumped in the chair next to me. A technician rolled a portable ultrasound machine to Juniper's bedside. He raised the lid and delicately cradled her head in one hand. With the other hand he placed the ultrasound wand against the wide, pulsing fontanelle. My heart hit my throat and I nudged Tom awake.

This was the test that would show us whether she had suffered bleeding in her brain. I'd been too upset about her belly to remember that it was scheduled for today, her sixth day of life. If it showed a massive bleed, the prognosis could mean severe disabilities.

That, combined with the life-threatening rupture in her belly, would mean we would take her off life support, because how much insult can a 1-pound baby take?

I tried to divine some meaning from the image on the monitor. I saw the gray expanse of her brain and, inside it, two pools of black. I knew from the many ultrasounds during my pregnancy that black meant fluid.

They looked like oil spills.

Blood? The technician, I knew, would tell us nothing.

I whispered to Tom, "Is fluid black?"

"I don't know, sweetie," he said, taking in the machine, the tech, the monitor. "Let's not jump to conclusions."

There's a saying in neonatology - "waiting to declare." Doctors will say that they stabilize the babies at birth and then wait for them to declare themselves - their intentions and their will - either by improving or deteriorating.

We were done with the honeymoon period now. We were waiting for Juniper to declare.

Tom and I were still cramped and bleary in the chairs next to the incubator when we saw a small, slow-moving battalion rolling through the unit. Morning rounds.

At the center of the group, Dr. Fauzia Shakeel wore a look like a battle commander.

She knew some of the nurses called her Terror Doc, and she was okay with that, because what did that matter to a sick baby? Rounds was the one chance she had to evaluate each baby and make critical decisions for the sickest ones. She wouldn't tolerate anyone showing up unprepared.

Diane, the nurse practitioner, read from the chart.

"This is Juniper French, day of life six, she weighs 600 grams, up 40 from yesterday." She bristled under Dr. Shakeel's firm command. Even I sat up straighter in my chair.

Dr. Shakeel already knew what was in the chart. When she had a critical baby, she read it herself ahead of time.

Worsening blood gases ... metabolic acidosis ... penrose draining blood-tinged fluid...

Dr. Shakeel glanced at us, sitting so tense in our chairs. I chewed maniacally on a cuticle.

The computer showed a new report from radiology that morning. An ultrasound of the brain. It showed the two perfectly normal brain cavities that look like oil spills in the picture.

Dr. Shakeel looked up from the monitor, softened and smiled.

"Her head is fine," she said.

She continued to not die.

Some nights, she needed 90 percent oxygen to keep going. If the baby gets to 100 percent and keeps

THE DOCTOR: Dr. Fauzia Shakeel had to make an impossible decision: send Juniper to surgery that would likely kill her, or do nothing, knowing she'd probably die anyway. She talked to the surgeon, who insisted she did not want to operate on a baby so small. Then she looked at the baby, and found her answer. Here she examines another baby this fall.

deteriorating, there's not much more they can do. The ventilator was damaging her lungs, so they put her on a gentler oscillating machine that made her whole body vibrate. There was no rhythmic in-and-out, no visual cue that she was a living, breathing person. Just a bizarre, full-body shudder.

Her black eye faded into a dark crescent. Her eyelashes grew longer. Her skin became lighter and more opaque.

No one discussed it, and we weren't aware of it until much later, but when the brain scan came back clean we'd crossed a threshold. She still faced death or an array of handicaps. But the test suggested her brain could be okay. She could someday laugh, sing, call me Mom.

We began to feel we could communicate with her, a little. We spoke to her nonstop, and she never made a sound, though sometimes we could tell she was crying. We learned that very early babies are animal-like in how they perceive the energy in a room. The monitor would alarm when she was bothered by something - a loud voice or a tense conversation.

"If you have to cry," one of the nurses told me, "try not to do it by the isolette."

The measure of the oxygen saturation in her blood - the blue number on the monitor - was an easy, constant register of her overall state. I related it to the grading scale in college. If I saw 90s, she got an A. But anything below 85 was cause for intervention.

We knew she could crash any time. Sometimes Tracy turned the monitor around so I couldn't see it.

Tom finished Chapter Two of Harry Potter and then Chapter Three. I would listen to him read and stare at the saturation number. Juniper seemed to enjoy the book. 97 ... 98 ... But when he would act out the gruff voice of Hagrid the half-giant, her oxygen saturation would plummet and the alarms would sound. 78! 76! 74!!

I swatted Tom on the shoulder. "You're scaring the baby," I said. "Stop doing Hagrid."

"No way," Tom said. He kept reading.

Ding! Ding! Ding!

Thereafter, Tom read every paragraph in a sweet, singsong voice. The alarm stayed quiet. In this way we learned what music she liked - Bruce Springsteen's Waitin' on a Sunny Day became our theme song. She had never seen the sun.

We developed a routine. Tom, who had raised two fine boys, always told me that being a good parent starts with showing up. Every morning he left the house in the dark. He never complained, he simply sat beside our baby as the sun rose.

I stayed home and strapped on the breast pump, grumbling and spilling milk on myself in the dark. The machine's rhythmic croaking mocked and insulted me. You're pathetic, it said. You're pathetic. You're pathetic.

I was biologically unfit for motherhood. I had failed to conceive her, failed to carry her, and now struggled to make enough milk to feed her. If I were a farm animal, I'd be culled from the herd.

Tom learned the name of every person on the floor. He baked 12 dozen chocolate chip cookies. I would have resented his campaign for Father of the Year if I hadn't been so grateful for it.

"I thought if they got to know us, and got to know our baby, maybe they'd pay closer attention," he told me. Then his voice dropped to a whisper. "Maybe if something happened, they'd run a little faster."

Tracy was around more and more. She never announced it, but we got the idea that she'd decided to be our primary nurse after all.

The hospital wasn't so much a place we visited as a place we existed. It was our baby's home, so it became

THE SURGEON: Pediatric surgeon Dr. Beth Walford, center, thought operating on Juniper was a long shot at best. The baby was so premature, the doctor worried that once she cut into the paper-thin skin, she would not be able to get it closed. Here, she does an appendectomy on another patient this fall.

ours too. All of our flaws and insecurities were on display. I wore my pajamas there every day for weeks.

When I cried, though, I did it in the car.

"Do you want to hold her today?"

She was 2 weeks old. We had family arriving from out of town that day. Our nurse was one we hadn't met before. I wondered if she knew what she was doing, or had missed the memo about how sick our baby was. I glanced around for doctors, or security personnel, who might try to stop her.

Then I just settled into the blue vinyl recliner and watched as a physical therapist spent half an hour massaging and calming my baby to prepare her for the 3-foot journey to my chest.

The therapist explained what should have been obvious. Babies need their moms. In the early days of neonatology, parents didn't get to hold their sick babies. Now, doctors knew that even the most critical held their body temperature better, breathed better, digested food better and generally fared better if they spent time skin to skin with their parents.

All Children's had designed this NICU to put families at the center, with round-the-clock visitation and an elaborate support system for breastfeeding.

Therapists like Ana Maria Jara helped the smallest babies navigate the divide between the safe dark nest of the womb and the bright stark world of the hospital. We watched her massage Juniper with the tip of her finger. Juniper's face contorted into a silent cry, then relaxed. She melted into Ana Maria's hands.

"They don't listen to your words," Ana Maria explained. "They listen to your feelings." We called her the Preemie Whisperer.

Ana Maria showed us how to tuck Juniper's knees under her and move her hands to her face. She gathered all the tubes and wires so nothing would tug at the baby when she was moved. She spoke softly to her in English and in Spanish.

"Que pasa, la nina?"

Tom recorded it all on the iPhone. I just grinned, crazily. I didn't wonder why they were letting me hold her so soon. Much later I'd ask about it and learn what I would have seen if I hadn't been so deep in denial.

The nurse, the physical therapist and Dr. Shakeel had agreed that the baby was having a rare good day, and that this might be my only chance to hold her while she was still alive.

When all was ready, Ana Maria lifted Juniper. She moved her slowly, on a straight plane, careful not to jostle the ventilator tube even a few millimeters, because doing so could dislodge it. Finally she placed her on my chest and tucked her inside my shirt. Her feet kicked my ribs, and her head rested right under my chin. I put my hand on her back and watched the monitor as she began to breathe easier and easier. 97 ... 98 ... 99.

Just as she was settled, Tom's brother and sister arrived from the airport. Everyone gathered around wide-eyed, taking in how tiny she was, how wrinkled and dark, and how safe she looked. I don't know if she felt it, but she was part of a family then. They greeted her not as a mishap or as a possibility, but wholeheartedly, as one of a tribe.

Ana Maria told me to breathe deeply and calmly and the baby would copy me and we would fall into a rhythm together. I tried to project strength and comfort with every breath. I don't know if Juniper picked up on all that, or if she even knew where she was. But I like to believe she did.

She was so bony and so light. Like a baby bird, I thought. I breathed for both of us.

2:17 a.m. The phone jangled us awake.

ALL CHILDREN'S NICU

Tom answered. I could hear Dr. Aaron Germain's ultra-calm voice on the other end of the line.

"How far away do you live?" he said.

No one used the word, but she was dying.

Her intestine had ruptured a second time. The drains weren't working. She was breathing pure oxygen and it still wasn't enough. If she survived, so much oxygen could make her blind. She was swelling and retaining fluid, so they put in a catheter. Her blood pressure was faltering, so they pumped up her dopamine. Her organs weren't getting enough blood. Soon they would start to shut down.

Dr. Shakeel took over that morning. She told us that she had talked to the surgeon, who insisted she did not want to operate on a baby so small. The trip to the operating room could kill her, and they couldn't patch her intestine at the bedside. Once the surgeon cut her open, her skin was so papery she might not be able to get her closed.

Dr. Shakeel knew the surgery was a huge risk and a last resort, but what other option was there? Juniper was dying anyway. Later the doctor told me that she had debated it in her head for an hour. *I've adjusted the vent. I've bumped up the drips. What else can I do?*

These kinds of decisions were part of the job. She learned all she could, made the best decision she could, and then she never second-guessed herself. Her Muslim faith told her that God was in control. She let him guide her.

She knew numbers never told the whole story, and so, torn about what to do, she looked at the baby. Juniper's eyes were just starting to open after being fused shut for so long. Now she opened them wide and looked right at her.

The doctor saw a baby who was almost a month old and not yet 2 pounds, whose body was shutting down, who was sedated and groggy and in so much pain, but was fighting to engage with the world. Her eyes were opening and closing. Opening and closing. Dr. Shakeel felt her saying, *I'm here. I'm here.*

Juniper French was declaring herself.

She was going to surgery. I held her hand. She was looking at me. Right at me, in a way she never had before. Her eyes were dark pools, taking in everything. Taking in my face, and my voice.

"It won't always be like this, baby."

"There are some things you need to know about. Like ice cream. You won't believe the chocolate milk shake at Coney Island. And at home there's a goofy dog named Muppet who will lick you too much, and her breath stinks but you can tell her all your secrets and she'll never share. You have your own room, with

a big orange rug with a monkey on it. We'll take you to a Springsteen concert, if he can keep going long enough, and you can hear Waitin' on a Sunny Day and watch him slide across the stage. We'll take you to Fort De Soto and you can mush your toes in the sand. Someday you'll ride a horse bareback in the sun, and you'll go so fast your eyes will water. You'll dance in your jammies. You'll hold my hand and I'll take you to school, and when the bell rings, I'll be waiting for you."

They wheeled her away.

Dr. Beth Walford saw only the rectangle of dark flesh peeking through the surgical drape. The baby, smaller than a footlong sub, was shrouded in blue sheets. It was easier that way. A surgeon needed to focus.

She did not want to be in this position. Surgeons had a saying: "Never operate on a patient on the day of their death." If a kid was that sick, you probably weren't going to help. And if she died, it would be your failure too.

"Knife," she said. Out went her gloved hand, for the scalpel.

The X-ray showed air in the abdomen, which meant there was a hole somewhere in the intestine. She would have to find it. She'd rinse and clean the intestines, then cut out the holes and dead spots. She'd reroute part of the intestine so it emptied out the baby's side. That would give her lower intestines a rest. When the baby was bigger she'd put it all back together. She held the scalpel like an X-Acto knife and sliced horizontally, just above the belly button.

Cutting through the skin was easy. Eighties music was playing over the satellite radio. She peeled back the peritoneal wall, but what she saw made her freeze. In her head, the room got quiet. She couldn't hear the music anymore.

Everything inside was red and inflamed. The intestines were matted together, stuck to the peritoneal wall like old spaghetti would stick to a Tupperware lid. Dr. Walford picked up a pair of forceps and touched the tissue. It started to bleed. She was creating new holes, making things worse.

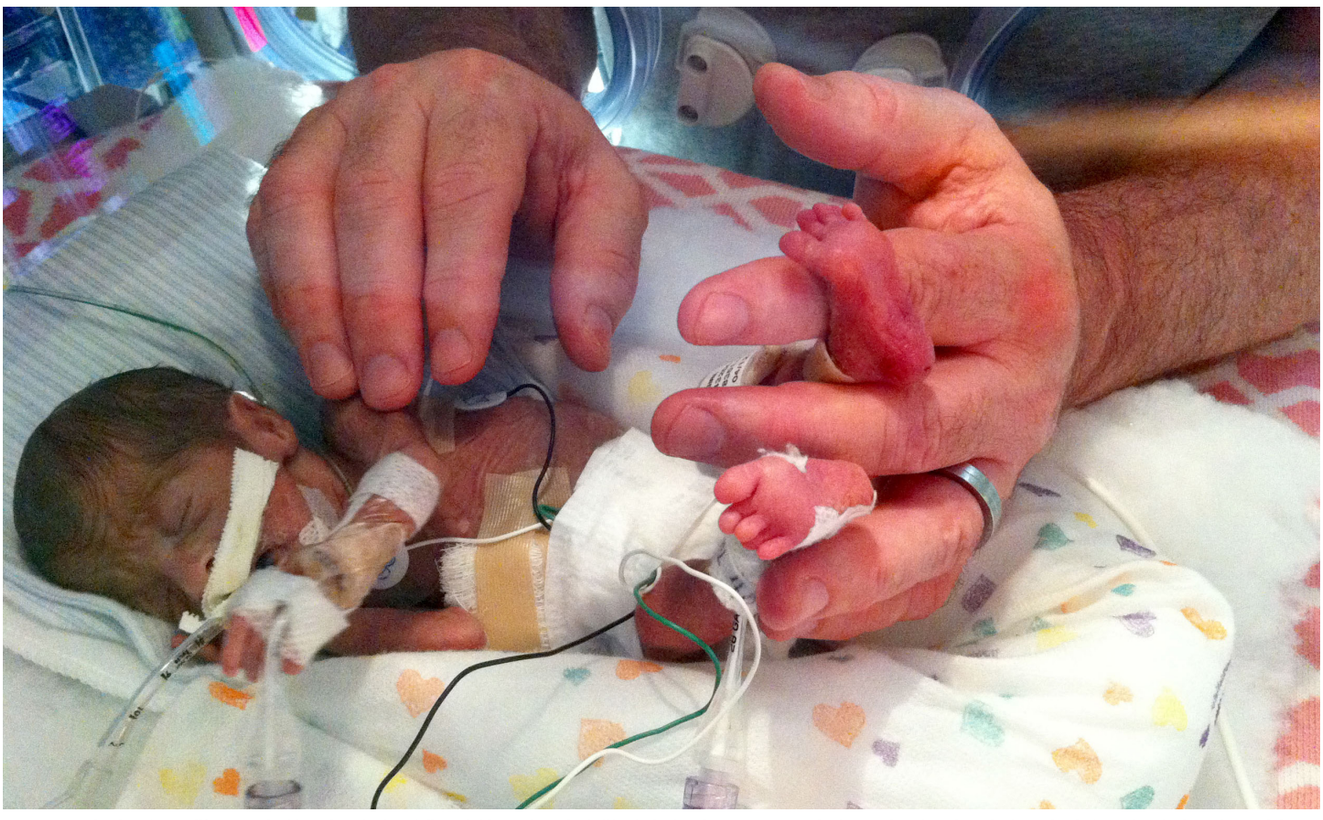
She became a surgeon because she wanted to fix people. But she couldn't fix this.

There are worse things than watching your baby die, I told myself.

Forgetting your baby in the back seat of a car on a hot day. That would be worse. But that happens to good people, all the time. Pulling a 2-year-old out of a swimming pool would be worse. Losing a child at any age greater than hers would be worse, because every day makes letting go so much harder. But these impossible goodbyes were happening right now, in this building. They happened here every day. They had been happening long before I had reason to pay attention.

My mind played a game as I walked the hospital's halls. I saw cute kids in the elevator or the cafeteria, and I tried to guess what was secretly wrong with them. I wondered if I would trade my problems for theirs. Big-eyed Hispanic kid in the lobby? Blood disease. Cute black kid in the parking garage? Heart trouble. Baby in the stroller in a full-body cast? Brittle bones.

I knew I would not trade. Even if she died, trying to save her had been the right decision. We'd gotten to know her. We'd let her hear our voice, and hear music, and feel our hands on her. Some of the greatest moments of my life had been tucked inside this misery. Memorizing her face. Holding her hand. Feeling her warm and weightless form on my chest. Reading her a



CAREFUL: My husband, Tom, lifts 2-week-old Juniper for her daily weighing. When she is lifted, the incubator zeroes out its internal scale. When she is set back down, it calculates her weight. Lifting her was terrifying and exhilarating. The nurses often told us the first measurement was off, and we had to weigh her again, so Tom and I each had a turn. Here she weighed 1 pound 7 ounces.

story. Writing "mom" on a consent form. Every act, no matter how mundane, affirmed that this child belonged to me. If those moments were not so precious, there would be no terror, no cruelty, in seeing them snatched away.

"She's my daughter," Tom said. "I wouldn't change any of it."

The prayer book in the hospital chapel told the story.

Every day, prayers were launched into the universe, to God, to Jehovah, and to Senor Jesucristo y mi Virgen Maria Guadalupe. Love and faith and grief bled through every page.

I am really scared. All I do is pray.

She doesn't know it, but she is my world.

Well, God. I've been praying every day, but sometimes the answer is not what we want. I trust you. Take care of her.

Thank you Lord for one more day.

I thought about all the people who'd told us they were praying for our baby. Churches we'd never set foot in. Our friend's mother had her Catholic church praying in New York. Some of Tom's friends had gotten word to a mosque in India, where 700 people gathered just to pray for Juniper. Some spiritual types in Atlanta were meditating on it. My friend Lucia had an altar set up on her fireplace mantel, with candles burning. The people at Preacher's Barbecue held hands and prayed for Juniper before they handed us our ribs. I began to think of all this prayer as a big cloud over us, sheltering us.

I didn't know it, but somewhere in the cloud of prayer rising up out of that hospital was the voice of Dr. Shakeel.

That afternoon, as we waited for word from the surgeon, Dr. Shakeel retreated to a small room near the NICU and kneeled on her prayer rug. She had exhausted her expertise, pushed technology to its limit. Now she surrendered.

She faced east toward Mecca. She spoke to the one who creates life and brings death, the one with the power to heal. She told God he was in control. She asked for his help. She touched her forehead to the ground.

KEEPING WATCH: Nurse Tracy Hullett took on an overtime shift the day after Juniper's surgery so she could help her through the most critical hours. If Juniper had died, Tracy wanted to make sure she'd done all she could. Here, she tends another micropreemie born this fall.

THE STORY ONLINE

Scan this code with your mobile device to see our online coverage at **tampabay.com/never-letgo.** You will find photo galleries, multimedia, resources, places to share reactions, personal experiences and more.

MEDICAL INFOGRAPHIC

Scan this code with your mobile device to view and share the graphic. You may also find and share this graphic at **tampabay.com/never-letgo.**

COMMON SEVERE COMPLICATIONS

Eighty-three percent of babies born at Juniper's size — less than a pound and a half — will have one or more serious complications while in the hospital. Here are some of the more common threats to babies weighing less than about 3 pounds:

93%

RESPIRATORY DISTRESS SYNDROME

RDS is the most common illness in the NICU. It mainly affects preemies who are too young to produce their own lung surfactant. Surfactant is a slippery substance that keeps the lungs from collapsing between breaths. RDS is treated with artificial surfactant and supplemental oxygen.

36%

SEPSIS

Preemies are susceptible to serious infection because their immune systems are immature. Skin that easily tears and numerous IVs create entry points for bacteria.

6%

SEVERE BLEEDING IN THE BRAIN

Intraventricular hemorrhage is most common in babies born before 30 weeks of pregnancy. Mild cases resolve on their own, but severe bleeds can cause pressure in the brain and brain damage.

5%

NECROTIZING ENTEROCOLITIS

NEC, the death of intestinal tissue, is thought to be related to bacteria or to decreased blood flow to the bowels. It causes feeding problems and can be fatal.

7%

SEVERE RETINOPATHY OF PREMATURITY

is an abnormal growth of blood vessels in the eye. Mild cases resolve on their own, but severe cases can require laser surgery to prevent vision loss. Supplemental oxygen is thought to be related to ROP, so nurses try to give no more than they have to.

46%

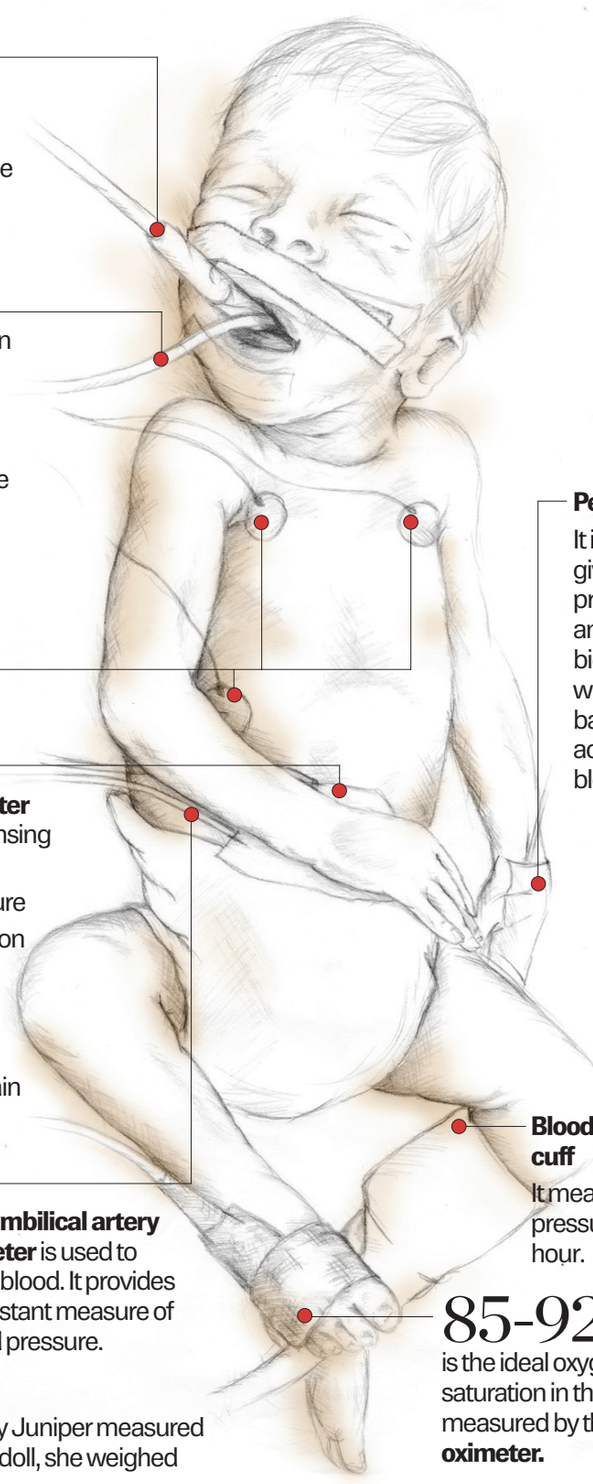
PATENT DUCTUS ARTERIOSUS

An unborn baby has an open blood vessel near the heart that normally closes on its own. When a baby comes too soon, sometimes doctors have to close the vessel. Left untreated, PDA can lead to heart failure.

Sources: Statistics for RDS, PDA and sepsis are from the Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network; other numbers are from Hobart et al. Mortality and Neonatal Morbidity Among Infants 501-1500 Grams from 2000 to 2009. Pediatrics, 2012. Other information is from the March of Dimes.

THE DELICATE SCIENCE OF KEEPING PREEMIES ALIVE

Caring for an extreme preemie in the first days of life means creating a technological womb. Caretakers must perform a balancing act, taking measurements, calculating odds and making difficult choices. The preemie's body, sometimes as small as a Barbie doll's, does not provide much access for the myriad tubes and sensors that monitor temperature, oxygen intake, nutrition and more.



21-100%
oxygen is provided as needed. The room air we breathe is 21%.

An **endotracheal tube** connects the baby to the ventilator until she can breathe on her own.

Replogle tube
provides continuous suction to vent stomach acid or air.

40-60 breaths per minute is the optimal respiration rate.

100-160 beats per minute is the optimal heart rate.

Chest leads
measure heart rate and respiration.

UVC
The **umbilical venous catheter** runs up near the heart, dispensing medicine and nutrition:

- Dopamine, for blood pressure
- TPN, Total Parenteral Nutrition
- Liquid fats
- Antibiotics
- Caffeine
- Fentanyl or morphine for pain

Peripheral IV
It is used to give blood products and sodium bicarbonate, which balances acidity in the blood.

Blood pressure cuff
It measures blood pressure every hour.

UAC
The **umbilical artery catheter** is used to draw blood. It provides a constant measure of blood pressure.

85-92%
is the ideal oxygen saturation in the blood, measured by the **pulse oximeter.**

11.4 in. was how long baby Juniper measured at birth. Roughly the size of a Barbie doll, she weighed **1 pound 4 ounces.**

Source: All Children's nurses Tracy Hullett and Scott Levengood.

LEE GLYNN I Times