

never let go

BY KELLEY BENHAM • TIMES STAFF WRITER



CHERIE DIEZ | Times

TOGETHER: For long months, I could hold my daughter only rarely. I tried to memorize those moments. When she grew stable enough for me to lift her on my own, I spent every hour I could rocking her, studying her face. When she was 4 months old, I marveled that although she still depended on machines and monitors, she had grown into a real baby. She recognized me.

PART THREE

baby's breath

As our daughter lay in the NICU, we wondered: What does a miracle look like?

The surgeon sewed our baby shut. The neonatologist rose from her prayer rug. Then a nurse returned our tiny daughter to the quiet of her incubator, and we made our bargains with God.

The surgeon wouldn't say it, but she was certain our baby would be dead by morning.

That night, Dr. Fauzia Shakeel had trouble sleeping and logged into the All Children's Hospital network to check on Juniper. Nurse Tracy Hullett picked up an overtime shift so that if our daughter died, she'd know she'd done all she could. Tom and I arrived at the hospital early, walked past the kids climbing the pelican sculpture, past the painted hot air balloons. I wondered

if, by the time we left that night, I'd no longer be a mom.

Dr. Shakeel stopped by Juniper's incubator that afternoon, where I sat curled, pale and fetal, in the chair.

"Babies are very, very resilient," she said. I had my chin on my hand and was rocking like a mental patient. Dr. Shakeel wrapped her arm around me.

"Where there's life," she told me, "there's hope."

Juniper didn't die that day and she didn't die the next.

She didn't die all that week. I was terrified that she'd die on Mother's Day, but she didn't.

Maybe the simple act of cutting her open had re-

lieved pressure in her abdomen, allowing her kidneys and lungs to function. Maybe one of the four soda-straw-sized drains the surgeon had inserted in desperation had made a difference.

“She’s being a smart girl,” Nurse Tracy told us. “Enjoy the moment.”

She didn’t die, but in a way she disappeared. She bloated until she became unrecognizable. Her head grew misshapen, waterlogged. She couldn’t move.

She couldn’t open her eyes. She was awful to look at. I didn’t tell anyone this, but I’d delivered a stillborn puppy once who looked like her. The sight of it had scared me so much I’d wrapped it in a dish towel and stuffed it in a plastic bag. Now I had to find a way to reach my daughter, wherever she had gone.

Sitting stoop-shouldered on the swivel chair by her incubator, occupying the same few square feet of space that had been our continent for the past month, I tried to build a world for my baby out of pieces that didn’t fit. I couldn’t hold her, couldn’t feed her, and I didn’t even know the right songs. My husband, Tom, had raised two sons and knew all the words to all the songs in Mary Poppins and The Wizard of Oz. I sang Johnny Cash.

When I was just a baby

My mama told me son

Always be a good boy, don’t ever play with guns

But I shot a man in Reno, just to watch him die

I dredged my brain. Old country songs, TV jingles I hadn’t heard since I was 10, half-remembered hymns. Bits and pieces of my own childhood dislodged from my subconscious and surfaced at my sick baby’s bedside.

I talked to her about everything. She never reacted. I was aware of the sound of my own voice, of its rhythms and tone. I watched the monitor, but the clues were not there. I talked to God, too, but I did that in my head. I asked that Juniper have just one good day.

She had lived more than a month, and each day had been measured in needle sticks, isolation and pain.

She’d been held only once. I didn’t know if my touching her brought her comfort or aggravation. I thought if she had one good day she would want one more, and another and another. Without that, what did she have to live for? Why would she fight?

Eventually I ran out of words. I picked up Harry Potter and turned to the folded-over page where Tom had left off. I hoped that something in my voice, or in the cadence of the language, would comfort her.

Tom, like me, is a writer. Stories for him are a source of meaning. The stories we chose carried messages of love and faith and friendship, and the shared experience of generations.

“A story is a promise,” he said. “It’s a promise that the end is worth waiting for.”

That’s what I wanted for her - to know that life was worth the fight. I read to her about the great green room with the telephone and the red balloon. As parents and children have done for decades, we invented new endings. “Good night Dr. Shakeel. Good night IV pole. Good night ventilator.”

I read all of Winnie the Pooh and The House at Pooh Corner, and cried when Piglet sidled up to Pooh and took his hand and said, “I just wanted to be sure of you.”

Nurse practitioner Diane Loisel folded back the quilt covering our baby’s incubator and opened the portholes.

“Oh, little girl,” she said, “little girl, little girl.”

It was mid May, about a week and a half after the failed surgery to repair Juniper’s intestines. Under the gauze on her stomach the incision was a jagged gray gash. The drains placed by the surgeon had come out and the holes had scabbed over, but we wouldn’t know for a few weeks whether her intestines had healed.

Probably there would be scarring and blockages, and in the worst case, whole dead sections.

Diane probed Juniper’s brown, distended belly, checking for firmness that would indicate pressure inside. It was soft: That was good. She wiped the scab on the right side where one of the drains had been and saw strange green goop on her gauze. This was bizarre. She wiped again. More goop.

It was poop. Coming from a place where poop should not be.

“Little one, little one, little one,” Diane said.

A horrifying breach had opened in our baby’s plumbing. But Diane, as always, was outwardly calm. It could even be a good thing, she told us. Had the surgery been successful, the surgeon would have created an escape hatch just like this in order to give Juniper’s lower intestines a rest. The surgery had essentially failed, but Juniper’s body had rerouted itself. It was sending poop out the most convenient exit. They would attach a little bag to the hole under her ribs to catch the poop, and add it to the list of things to fix later.

Diane noticed that Juniper had grown. She was almost 2 pounds, but so much of that was fluid from the swelling it was hard to guess her real weight. Diane brushed back the baby’s hair with her fingertips, so gently, and touched what she could of her face, between the tubing and all the tape.

Tom asked the question he had asked before. “Have we pushed her too far?”

It was impossible not to wonder if we were torturing our baby. I could not imagine another area in medicine where the ethical questions were as immediate as here in the neonatal intensive care unit. All around us were sick infants unable to voice an opinion about their care or their quality of life. In front of us was one who couldn’t tell us how much pain was too much.



HEALER: At one of the most terrifying moments of my life, while my daughter fought her way back from surgery, Dr. Fauzia Shakeel took time to sit and talk with me. She spoke of resilience, faith and miracles. "Where there's life," she said, "there's hope."

Where does medical progress blur into hubris?

Diane shook her head. No, we hadn't yet pushed her too far. "Not even close. But I'll tell you if we reach that point."

She didn't tell us that some of her colleagues had wondered the same thing. *Do the parents still want everything done?*

It was unsettling to think about what all this care was costing. Those thoughts led to uncomfortable questions about what Juniper's life, or anyone's life, is worth.

A day or two after Juniper was born, we'd met with a financial specialist at All Children's Hospital. When we sat down at her desk, I was gripping Tom's hand and nearly hyperventilating. I knew that medical disasters like this cost people their homes, their careers, their retirements, their marriages. I was paralyzed by the fear that if Juniper lived, she'd come home to a ruin of the family that had created her.

"You can't think about that right now," the financial specialist said. Babies born this young almost always exceeded \$1 million in medical expenses, and if they had private insurance, they frequently hit their plans' lifetime caps. Most ended up on Medicaid. I was halfway to a panic attack when she said, "Well, this is amazing news." She swiveled toward us in her chair.

"It's only going to cost you \$400."

Four hundred what?

That was the copay for our baby's hospitalization. Everything that happened to Juniper until she was discharged would be covered by Blue Cross Blue Shield. We had one of the best private insurance plans she'd

seen in a long time. There would be plenty of expenses later, but all I heard from that point forward was blah blah blah.

I was relieved, but also stung by the guilt that comes with privilege and luck. My husband had changed jobs a year earlier and was commuting every week from St. Petersburg to Bloomington, Ind., where he taught at Indiana University. Our health plan came with no deductible or lifetime cap.

Still, Juniper's situation raised broader questions that are impossible to consider when a newborn baby is gasping for breath. How does one long-shot baby justify so much expense, when so many people go without health care?

One day, a friend asked me a difficult question, trusting that I knew she meant no harm.

"Don't take this the wrong way," she said, "but wouldn't it be better to vaccinate a million kids in Africa?"

I was sure a lot of people wondered the same thing. Health care was not strictly a personal issue. One way or another, society shared the costs.

I could have argued with her for an hour. Who are we to know when an investment in a child's life will pay off? If we don't cut off care to the very old, why would we deny it to the newly born?

I wanted to know more, though. So I dug into the research.

Babies born earlier than 28 weeks' gestation require an average of about \$200,000 in medical care by age 7, said Dr. Norman J. Waitzman, an economist at the University of Utah. Waitzman worked on a major study in 2006 that put the cost of preterm birth in the



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A LITTLE MAGIC: For Father's Day, nurse Tracy Hullett surprised Tom by dressing Juniper as Harry Potter, with doll-sized tennis shoes, a handmade wizard robe and a taped-on lightning-bolt scar. Tom read to Juniper every day from the 4,000-page Harry Potter series. He insisted that Dobby the house elf was her favorite character. They did share a certain resemblance.

United States at more than \$26 billion per year.

The statements that arrived almost daily from our insurance company told another part of the story. It appeared that the neonatologist cost about \$1,900 a day. A month in the NICU - presumably room, board and nursing care - was billed at between \$200,000 and \$450,000. Then there were the costs for surgeries, lab work and specialists. All together, Juniper's care cost more than \$6,000 a day. The statements would add up to \$2.4 million, of which the hospital collected from the insurance company a negotiated rate of \$1.2 million.

Waitzman said Juniper's bill sounded typical for a baby born at 23 weeks. But because so few babies are born that early, their bills, however staggering, barely register in the big picture.

A study by bioethicist John Lantos and colleagues showed that 90 cents of each dollar spent in the NICU goes toward the care of kids who survive. This is true even for the tiniest babies. By contrast, most of the dollars spent on the elderly go to patients who die without ever leaving the hospital. The NICU, Lantos argues, is a bargain compared with adult intensive care, because dollars spent there buy many more years of life.

Neonatal intensive care for the sickest babies has become the most expensive intervention in pediatrics, Lantos has written. Because Medicaid and insurance companies are willing to pay, NICUs are profit centers for many hospitals. Premies often require further treatment in other departments - cardiology, neurology, pulmonology - so the tiniest babies run up total lifetime medical bills about double their NICU costs.

So, would it be better to spend the money on a million kids in Africa?

Standing there with my friend, I didn't wade into the complexities. I just answered honestly and reflexively, with the perspective of a desperate new mom. "Better for who?"

One night in May, Juniper opened a swollen eye and peeked out.

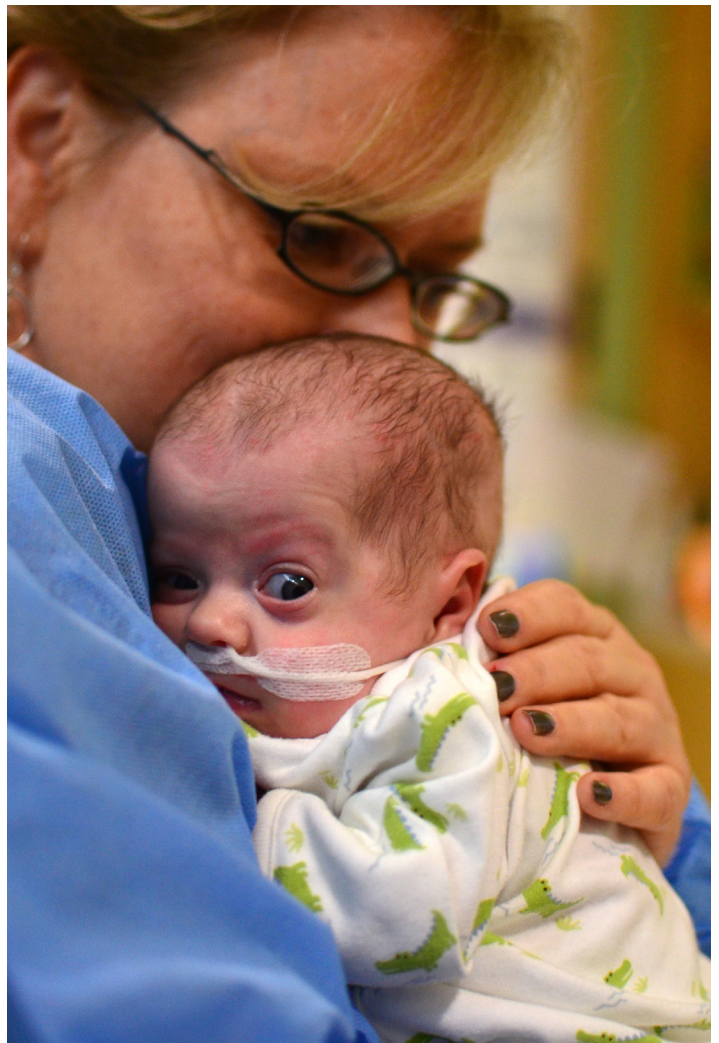
The swelling subsided, then came back. We watched helplessly as one system in her body after another faltered and recovered.

By June, when she was 2 months old, we were hugging Dr. Shakeel goodbye and greeting a new doctor, our third. They rotated every three weeks because the most critical cases were hard on them too. Everyone was coming and going except us. We had been moved to our own room, 670, with a sliding glass door with Juniper's name on it. Best of all, it had a cabinet where we could stash our baby blankets, mouthwash and smuggled granola bars.

Dr. Rajan Wadhawan was our new neonatologist. He was calm and assertive, quick to smile, like the Dog Whisperer on TV. He asked us to sit down with him to review Juniper's progress. It felt like our first parent-teacher conference. When a baby was very sick, the doctors and nurses would say it was not behaving. I'd had a bad baby for a long time.

We sat on swivel chairs as Dr. Raj, as everyone called him, methodically reviewed the obstacles Juniper faced, in order of urgency.

A blood clot had been discovered that morning



SAFE: By late August, Juniper was 4 1/2 months old and had spent as much time with Nurse Tracy as she had with me. When Juniper would fuss, Tracy would say, "I thought we were friends." When Tracy stuck Juniper with needles, we imagined that Juniper was saying the same thing.

in her heart. It was about 6 mm, which seems small, but her heart was the size of a chicken's. Relatively speaking, it was a boulder. Blood clots either dissolve or dislodge. If this one broke loose, it would slalom through her vessels until it reached her lung or her brain and killed her.

Fluid was leaking from a breach in her lymphatic system and pooling in her chest, crowding her lungs. Tubes had been placed in each side of her chest to drain the fluid so she could breathe. Four to 8 ounces poured out every day. The tubes hurt, so we couldn't hold her. The condition, called chylothorax, was a puzzle, not a typical premie thing at all. It meant she couldn't be fed the breast milk I was still torturing myself to produce, because the fats in the milk exacerbated the problem. They stashed my milk in a hospital freezer and fed her through an IV. In a day or so they'd start giving her a foul concoction through a tube, testing her healing intestines.

Next came the scarring in her lungs from the ventilator, her mind-of-their-own intestines and the constant threat of infection. She was getting too few calories, growing too slowly. Her bones were brittle and her liver was stressed.

Death remained a real possibility. But I still clung to an image of a little girl holding my hand on the way to kindergarten. I couldn't help it. The longer she held on, the more I wanted my daydreams back.

"Just one more question," I said. "Could she still be a normal kid?"

Dr. Raj rattled off some research, but in a field that changed so fast, it added up to maybe.

I held a sleeping baby in my arms.

It wasn't my baby. This was a baby from down

the hall, Jack Cole, who'd been born with Down syndrome. We'd met his parents when they were still shaken by the news that he needed surgery to save his life. Their faces had been clouded with exhaustion and fear, but something else, too. Joy.

"We just can't wait to take him home and love him," his dad said.

When I told his mom, Danielle, that we couldn't hold Juniper, she'd plopped Jack in my arms, just like that. I looked at him, all soft cheeks and soft breath and soft hair.

They said it would not have mattered if they had known he had Down syndrome. I envied them for that.

Jack was beautiful, but in his extra chromosome I saw a parallel to our worst fears.

Doctors had told us Juniper would probably die or be disabled. We'd considered letting her die rather than face the odds. Why did we struggle so much when Jack's parents seemed so content?

Society seems fairly comfortable with Down babies. But in 1982, not so long ago, the parents of a Bloomington, Ind., baby with Down syndrome declined an esophageal surgery that would have saved his life. The case got national attention, and surgeon general C. Everett Koop argued that it was child abuse to withhold treatment to a baby because of a mental handicap. The Baby Doe case forced doctors, hospitals, and parents to confront how they make decisions about withholding treatment in disabled newborns, and how they weigh quality of life.

Thirty years later, parents still struggled with a diagnosis of Down syndrome, and many aborted their babies after prenatal testing. But once a child was born with the condition, there was more of a consensus in the medical community to provide treatment. Kids with Down syndrome were in Target ads. There was even one on Glee.

There was no such consensus when it came to the earliest preemies like Juniper. Maybe the issues were still too new. Maybe it was easier to confront a well-defined disability like Down syndrome than a buffet of probabilities.

Looking at Jack, I knew that whatever became of Juniper, I'd love and defend her. But I wished for a little of the certainty and joy I saw in Jack's parents. I wished for a little of the clarity the doctors could offer them about his future. I hoped that whatever happened, I'd be as accepting of Juniper as they were of Jack.

I made a promise to myself, and to her, that I would be.

She sounded, at first, like a kitten.

On the 59th day, her breathing tube came out. For a quick second, I saw her unobstructed mouth and chin. I saw her breathe on her own.

She graduated to a pressurized mask, and later to prongs in her nose, which made her look even more like an old man on oxygen. She could close her mouth. She could suck her pacifier, which was smaller than a pencil eraser. And she could cry.

At first, her voice was tiny and hoarse. She mewled. It quickly strengthened, to a squeak like a rusty door hinge. During her weekly eye exams, when a doctor pried open her eyelids with metal clamps, she

screamed. She screamed so loudly I had to step out into the hall and lean against the wall.

After two months of watching her writhe mute-ly, her cries were staggering. They were a testament not only to her will, but to the technology that had propped open her flimsy lungs until they could function.

Nearly 50 years ago, when John F. Kennedy's son was born at 34 weeks, there were no ventilators for preemies. The baby was placed in a high-pressure oxygen chamber - the newest technology - but lived just two days. If he were born today his odds of survival would be nearly 100 percent.

The death of baby Patrick Kennedy spurred innovation in neonatology. Early mechanical ventilation was tested on babies who had just died. Some sputtered briefly back to life.

In the late 1980s, artificial lung surfactant moved the limit of viability ahead several weeks. Babies like Juniper suddenly had a chance.

Juniper's lungs were scarred, maybe permanently. But her scratchy cry was a marvel. It was a triumph. It was an announcement.

People clash over the question of when life begins and when a fetus becomes a human being with its own standing and stake in the world. Some say it happens at conception. Some say it happens when the brain forms. I never saw my incomplete daughter as pre-human. Even on her first perilous day, four months before she was supposed to be born, I witnessed her individuality and her will. But there was something magical about watching her take shape in the incubator as she would have in my womb. When the ventilator came out, I saw that from under so much hardware, a little girl had emerged.

If she'd been born that day, in June, she would still have been two months premature. But she looked like a baby now, only smaller. She looked like one of those itty-bitty baby dolls toddlers drag around by the leg.

She had opinions. She felt pain, irritation, discontent, outrage.

For the first time, she had a voice.

Father's Day was approaching, and Tracy and I were plotting.

During slow periods at work, when Juniper was sleeping, Tracy took a piece of dark felt from her bag and cut it into two pieces shaped like a T. She hand-stitched it up both sides, and put a slit in the front for the wires. She was careful to hide the tiny robe when anyone was around, so she wouldn't ruin the surprise.

The other nurses were used to Tracy's stunts. She'd once dressed a baby in a blue top hat, bow tie, cummerbund and cuffs and tucked a tiny dollar bill into his diaper. A Chippen-preemie. There'd been a UPS driver, a nurse, and Rudolph the Red-nosed Reindeer. She'd wrapped one in gauze like a mummy in a haunted incubator, crawling with plastic spiders. The preemies always cooperated.

For the June telethon - "Pimpin' the preemies," Tracy called it - she'd decked out Juniper in her first real outfit. It was a black and white dress with a hot pink tutu and matching headband.

Where'd you find a dress that small? everyone asked. Tracy laughed. She got it in the pet aisle. It was

made for a chihuahua.

Even in a place like this, it helped to maintain a sense of humor. But it was more than that. Tracy was starting to see Juniper react to things that could not be measured, prescribed or ordered on rounds.

She breathed better when we were at her side. She responded to our stories and songs. Tracy was not sentimental. But she was starting to believe the risk she'd taken by letting herself get attached had been worth it.

When I watched Tracy lean close to Juniper and whisper, or stroke her head with a fingertip, or dress her up like a chihuahua at a dinner party, I knew she didn't just take care of my baby. She loved her.

Together one afternoon, Tracy and I broke the sticks from cotton swabs to make a tiny broomstick. Tracy had a superstition against dressing babies in eyeglasses, eye patches, fake casts, peg legs or anything that might portend a future disability. But this costume demanded round eyeglasses and a lightning bolt scar.

She cut out the glasses from a black hospital mask and drew the scar on a piece of clear tape. When the time came, just before Tom visited that afternoon, she stuck the scar on Juniper's forehead.

Harry Potter.

Like breathing, we say, as a metaphor for something effortless.

Now that the ventilator was out, it was all up to Juniper. It seemed so simple. In and out. In and out. Sometimes she forgot.

One morning, very early before rounds, Juniper was blinking, looking around, holding Tom's finger. Then she was gray, limp, slumped. First her oxygen saturation started to drop, triggering one alarm. Then her heart rate dropped, and a more urgent alarm sounded. 150, 120, 80, 60, 40 . . .

Tom rubbed her back and stared at the monitor, then her face, the monitor, her face. "Come on baby."

Tracy hurried into the room. An alarm outside Juniper's door flashed red and a team swarmed in behind her. Juniper's lips were blue. Someone grabbed the green oxygen bag and held it to her face. Come on, Junebug, they were saying. Come on.

Long minutes passed before those numbers climbed again, the nurses stepped back, and Juniper glanced anxiously around the room, perhaps wondering where she had been.

This began happening up to a half dozen times a day. We saw numbers fall into single digits. Each time, I felt the room spin and my blood swoosh. There was nothing to do but retreat to a corner and try to stay on my feet.

Breathe, I would pray, plead, scream inside my head. *Breathe*.

This was common in very early babies, with their immature nervous systems. We saw it happen around us all the time. Sometimes it took just a pat on the back to bring Juniper back. Sometimes it took a team. It happened so often, the alarm light outside her door burned out.

Our night nurse, Kim Jay, began every evening with a quick prayer.

Please don't let her die on my shift.



SKINNY DIP: My husband, Tom, holds 5-month-old Juniper before a bath. She was as slippery and wiggly as any new baby, and we were more than a little afraid of dropping her.

I made a poster and stuck it on the wall of Juniper's room.

To Do:

- ✓ Survive birth
- Breathe (ongoing)
- ✓ Heal tummy
- ✓ Win over Tracy
- ✓ 1000 grams
- 2000 grams
- ✓ Off the ventilator
- Off oxygen
- Lose chest tube
- Dissolve blood clot
- Learn to eat
- Acquire pony

Tom added: Conquer space and time

I also posted a Freakout Level Indicator, color-coded. Most days were yellow - caution. Some days, like when she forgot to breathe, were orange. To get to green, she had to stop setting off the alarms. They said this would happen gradually, as she got older.

People still asked when she was coming home, and we had no answer. She had been in the hospital more than 100 days.

At home, I sat in the room that had once been the bedroom of Sam, my stepson. Now it was halfway to becoming a baby girl's nursery. The boy grease had been scrubbed from the baseboards. The paint had been touched up and the nail holes patched. I'd hung a Matisse print and put in a new dresser.

My husband said it was bad luck to keep decorating the nursery. I had to think about how it would feel to come home to this room if our baby died in the hospital. I decided that we were worthy parents, and one way or another, we would bring a baby into this house

and into this room. Juniper deserved all the faith we could muster. If anything happened to her, we would try again, or adopt. We'd poke fate in the eye until fate gave in.

In one week that summer, two babies on our hall died. One was right next door. We saw the family tumble out of the room, shuddering and sobbing.

I walked past the room and peeked through the blinds. I saw the incubator in the dark, the baby under the sheet. The monitor was disconnected. A red light blinked on and off.

Every day our baby grew. Every day she was revealed to us. Every day we weighed our gratitude against the stubborn reality of a place where it is bad luck to look even one day ahead.

When Juniper was 3 months old and about 3 pounds, we got word that the blood clot in her heart had finally dissolved. The fluid in her chest had slowed to a dribble, then stopped. The chest tubes would soon be removed. She was beginning to outgrow the terrifying lapses in her breathing. The hole in her side had closed on its own, and she had started to poop into her diaper. It wasn't a guarantee that her intestines were healed and she would not need surgery later, but it was a great sign.

She could wear preemie clothes with the sleeves rolled up. She'd been moved out of the incubator into a real crib. We'd rushed to Target to buy a baby mobile. We could hold her almost as much as we wanted. When we spoke to her, she smiled. Not an insincere, half-hearted gassy smile. She beamed.

"You might want to buy a car seat," Diane said one afternoon. "She doesn't have too much left to accomplish here."

I'd waited months - no, years - for a reason to buy a car seat. Now, as Juniper's due date approached, Diane offered the first suggestion that she might leave the hospital.

All the rest of that day, Tom and I were a gloomy mess. Shaking and sometimes crying. Descending into silences.

"What is wrong with me?" Tom asked.

We took that night off from the NICU. We grabbed the dog, Muppet, and her beloved tennis ball, and headed to her favorite spot on earth, Fort De Soto beach.

It was a weeknight in July. We had the dog beach nearly to ourselves. The wind was strong and the waves were wrestling and racing each other to the shore. Muppet was all ears and tail and dancing feet.

Watching Muppet race down the beach, I realized why we'd come undone. For months, our coping mechanism had been to measure time in minutes and hours. We never looked ahead. We never had to deal with the colossal risk of expectation.

Now the sand was shifting. The hopes we had strangled for so long overwhelmed us.

The dog ran down the beach and back. Tom wrapped his arms around me and cried.

Aug. 3 arrived. My due date.

The date had been seared into my cortex, and reaching it felt like a milestone. But instead of a newborn I



SENDOFF: Patient care assistant Katherine Glazer, left, and nurses Gwen Newton and Tracy Hullett say goodbye to Juniper, who is going home after more than six months in the hospital. Gwen stabilized Juniper in the delivery room, and Tracy became her most constant caretaker. Juniper had been in the NICU longer than any of the other babies. We learned that, as much as we depended on the doctors and nurses, it was not a place for babies to grow up.

had a sick 4-month-old. I didn't know how to feel.

From now forward, my baby would have two ages: a real age and an adjusted age. Her birthday was 113 days ago, but developmentally she was at Day 1.

Our nurse that day, Carol Tiffany, could see the mix of emotions on my face. She sent a patient care assistant named Brooke to labor and delivery to fetch a bassinet. Then Brooke and I stripped Juniper to her birthday suit and wrapped her in one of those footprint blankets you see in every Facebook photo of a new baby. We put a newborn hat on her head, and this time it fit. We weighed her - 4 pounds 10 ounces. We took handprints and footprints. Diane signed a ceremonial fake birth certificate and Brooke put a sign on Juniper's crib: Happy Due Date to Me!

Brooke and I stood over my baby. Juniper had none of the doughy features of a newborn. She was lean and wise. She could easily push herself up on her forearms. She scanned the room and smiled.

I told Brooke about all the times I'd worried she would die.

Brooke nodded. Part of her job, it turned out, was helping parents who have lost a baby. She would make handprints and footprints for those parents too, and present them a hand-painted box.

"There were a few times they told me to get a box ready for Juniper, just in case."

When the blood drained out of my face, I tried not to let Brooke see me sway.

A few days later Juniper hit 5 pounds. I photographed her next to a sack of sugar. Dr. Aaron Germain pronounced her "officially almost boring." She had a setback after that, when fluid started building in her chest again. It would keep her in the hospital a couple more months, but everyone seemed to think that sooner or later she was headed home. She was transferred to the less critical side of the NICU, for "feeders and growers." Some nurses called it "slurpin' and burpin'." "

Here, Juniper had to learn to drink from a bottle. After being on a ventilator so long, she wanted nothing in her mouth. Tracy warned us she would proba-

bly go home on a feeding tube - lots of preemies did. I couldn't stand the thought of one more hole in her body. Her belly was gouged and pocked with scars.

Tom and I would hold her for hours, watching the turbulence flash across her face, then subside. We melted, like all new parents, at the sucking motions she made in her sleep. We passed on life advice that we'd handed down to her brothers.

Never hit a cop. Don't piss off Bob Dylan, because he will write a song about you.

We told her she did not need a man to take care of her. She was not a princess.

"You can be a warrior princess," Tom told her.

Eventually, with weeks of guidance and therapy, Juniper drank a few swallows from the bottle, then a few more. Kim, the night nurse, showed us how to support her chin with a finger and to twist the bottle when she slowed down, to remind her not to stop. Juniper projectile-vomited on Tom. We started having real baby moments, just like other people.

By then it was late August, and Juniper had been in the NICU longer than any of the other babies. Kim, who always made time to calm my nerves or listen to me fret, sat with me one night and reminded me that this place was supposed to be temporary. It was not a place for babies to grow up.

"You won't believe how she'll take off when you get her home," Kim said.

I could not imagine leaving this place, leaving behind the reassurances of the doctors, the nurses, the monitors. Who would take care of this baby? Who would take care of me?

"Will you come too?" I asked.

One night, after dark, Juniper started to gnaw on my shirt. Her meaning was clear. Everyone had said breast-feeding was probably out of the question, after all this time. She grew frantic, trying to eat the buttons off.

I would have given her anything. But my boob? I looked around like we were about to break a law, and then unbuttoned my shirt. She latched on. I heard her swallow.

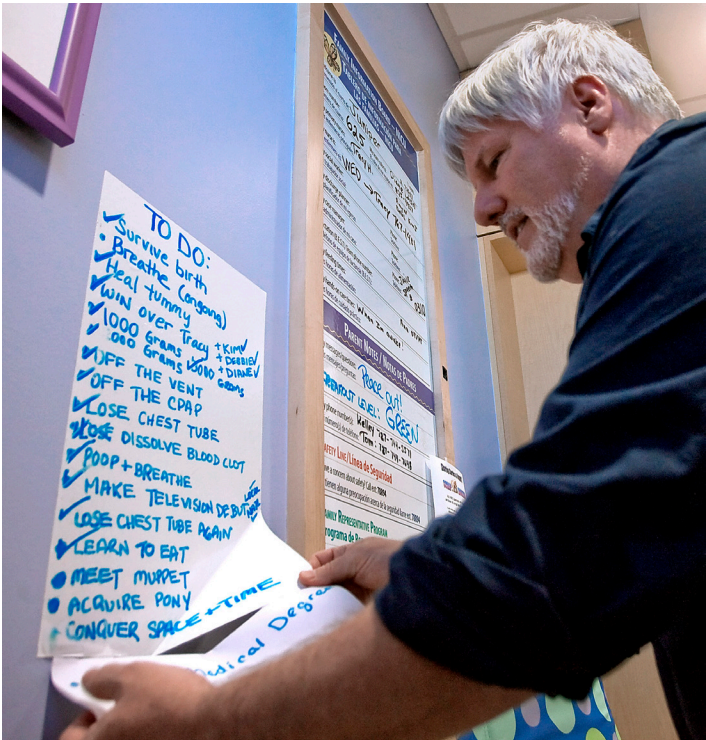
It was exactly as weird as I'd imagined it would be. "Kim!" I wailed. "What the hell?"

Kim smiled so big, she looked like she might cry.

When she was 5 months old, the prongs came out



FRIENDS: A few days after coming home from the hospital, 6-month-old Juniper gets to know our dog, Muppet. Juniper had been lying next to me on the couch and rolled toward the dog to investigate. Muppet greeted our new family member with a casual curiosity and stinky breath.



DONE AND DONE: Tom takes down Juniper's list of goals before checking her out of the NICU. She had survived one crisis after another, grown into doll clothes and then newborn clothes, and made dozens of friends. All that remained were normal childhood moments. We'll talk about the pony later.

of Juniper's nose. We saw her face - her whole, bare face - with its big eyes, soft cheeks, red mouth, and startled look, like, why are you people crying?

The nurse told Juniper breathing was like riding a bike without training wheels. Tom told her the key was to keep her eyes on the road ahead, and feel the wind in her hair.

She kept going, going, going.

Not long after that, Nurse Carol helped me get Juniper ready for a bath. She whipped off her diaper, disconnected all the wires and handed me a naked baby.

"What are you doing?" I asked Carol. "She's off the monitors."

She was untethered for the first time in her life. What if I dropped her? Or she stopped breathing?

Nurse Carol had been doing this a long time.

"Are you watching your baby?" she said. "Just watch your baby."

She walked out.

In September, Nurse Kim started unhooking Juniper's monitor long enough for me to put her in a baby sling and walk the halls. We'd say hi to all the babies as we passed their rooms. Jersey, Dontrell, I'mya, Freddy. There were always Miracles and Nevaehs - heaven spelled backward.

Juniper was outgrowing her room. She was outgrowing the hospital. She liked it when I walked fast.

Eventually I was allowed to carry her as far as the big window by the sixth-floor elevator. I held her up to it and let her look out at the lights and the moon and, in the distance, Tampa Bay.

"There's a big world out there," I told her. "I'm going to take you there."

I saw our reflection in the glass.

The doctor had tears in his eyes. He knew discharge day was near, so he'd approached us one afternoon as we were signing in at the front desk.

"I've worked here a long time, okay," Dr. Tony Napolitano said, "and there's such a thing as a miracle.

And your baby is one.”

Miracle. We had been hearing that word since the day of her birth. In those early awful days, I’d cringed. It was an overused, Hallmark cliché of a word, one that I’d banned from my writing, and, in general, my life. It was a word people used when the truth was so much more complicated.

Now, as our baby got ready to leave the hospital, I didn’t mind the word. The people who said it spoke from experience and insight I didn’t have.

On matters of faith, Tom and I have little clarity. But we were forced to consider the idea of a miracle.

I’ve spent months now with research and experts, and I know some things I wish I’d known when Juniper was born.

The odds we were given were correct: She had an 80 percent chance of death or significant disability. But there was another way of slicing the numbers that I had not considered. If she lived - as big an if as it was - her odds of being reasonably okay were about half.

And that first day when I was searching the statistics for loopholes, hoping to find an exemption for good parents, I would have been comforted to know that studies do show that babies with involved families have a huge advantage.

I’m not dismissing the possibility of miracles. Certainly Juniper defied medical expectation and astonished doctors who aren’t easily moved. But it makes me uncomfortable to imagine it’s as simple as God laying his lightning-bolt finger on our baby’s head, passing over some other baby along the way. Passing over all those babies we saw lying under the sheets.

I only know that back in April, a young, inexperienced nurse looked at our baby at a critical moment and saw what machines had not seen. I know that one of the best nurses in the hospital risked her heart and went against her own judgment when she agreed to take Juniper on. I know a doctor facing an impossible decision looked into our baby’s eyes and told God he was in control before ordering a risky surgery. I know



PRICELESS: Juniper spent 196 days in the neonatal intensive care unit at All Children's Hospital, at a cost of \$1.2 million. She had 20 blood transfusions and was diagnosed, at various times, with 40 different conditions. She left the hospital under the supervision of 14 specialists and therapists. Today she weighs 18 pounds. She has 11 scars. She takes no medications, is diagnosed with no delays and has, as far as we can tell, no clear memory of the NICU that saved her life.

the surgeon thought our baby was beyond repair, but somehow fixed her anyway. I know a 1-pound baby found the will to keep going day after day, until finally some version of the world that awaited her came into focus.

Maybe the miracle was all around us, in little pieces. The science that created her inside a petri dish from another woman’s egg. The obstetricians who stalled my labor. The machine that breathed for her.

Tracy, with her attention to the smallest details. Diane, with her unwavering optimism. My husband, with his faithful reading from a 4,000-page story, and his belief that the ending was worth waiting for, and we’d all get there together.

Kim and all the other nurses who came running when I wailed. Who taught me to scrunch the diaper so it fit better, to pat her bottom to settle her for sleep. I had wondered, once, how to be a mother to a sci-fi baby in an artificial world. All those people taught me how. Juniper taught me how.

So if you want to say there’s a miracle in any of that,



TAKING OFF: People often ask if Juniper is doing okay. I can say that she's developmentally on track for her adjusted age, which is 16 months, and even ahead in her speech and problem solving. I can acknowledge the statistics that say problems may still emerge. I can cite studies and quote her doctors. But the best answer is probably, "Just look at her."

I will say that feels true to me.

Tracy came to the hospital in the middle of her vacation. Kim came in with tears on her face. Dr. Shakeel lifted Juniper in her arms. Ana Maria, the Preemie Whisperer, gave her one last shoulder rub. Nurses, social workers, lactation consultants, respiratory therapists, patient care assistants and a trainee from gastroenterology all converged on our room in 6 North. Tom read from Chapter Seven of Book Seven of the Harry Potter series. Diane reminded us that she'd never doubted this day would come.

It was Oct. 25, 2011. Day 196.

Juniper wore a red tutu and a onesie that said, "Chico's Bail Bonds: Let Freedom Ring." Then she pooped all over that outfit, and Tracy orchestrated an emergency bath and produced from her big bag a home-made Harry Potter onesie. That was Tracy, pulling the answer out of her magic bag one more time. Finally Kim and Tracy disconnected the last of the wires and monitors.

We buckled Juniper into her car seat and carried her out. No wheelchair and no balloons, but that was okay. Tom and I walked side by side, Tracy beside us.

"She won't know which of us is her mom until we get to the car," I said to Tracy, not kidding.

In the elevator we negotiated who got to carry her out. (Him as far as the door, then me.) A couple in the elevator laughed at us. I wondered whether they were long-timers, like us. I wondered about the child they were tending to. My brain still played the game. Cystic fibrosis? Leaky heart? I remembered nights when I'd approach the building and look up at all the lighted windows, and wonder about the terrible things happening inside. Worlds ending. Holes in the universe, opening.

Now I knew something I hadn't known then. Tremendous things happened here every day too. They had been happening all this time, long before I had any reason to pay attention. This was our moment, but ours was not the only improbable child. The car seat went bump bump bump against my knee.

Juniper wore sunglasses, but I can't imagine what she must have made of it when those doors slid apart and everything opened up in front of her.

So much sun.

All that sky.

Epilogue

I still see the baby under the sheet.

If Tom wants to take Juniper with him to the grocery, I try to talk him out of it.

"Unnecessary risk," I say.

Until they return, images flash in my head. Ambulance lights. A crunched door panel. Shattered safety glass in the car seat.

Death breathed cold on her neck for months. Where

did it go? Is it coming back? It always comes back.

It comes back.

She's 20 months old. But when people ask, I say she's 16 months old, because that's how old she would be if she'd been born on time. "So tiny!" they say. She weighs 18 pounds. Can't they see she's huge?

People ask if she's fine. I hesitate. The superstitions of the hospital have become part of me. I have learned how fast things go from fine to not fine. From fine to everything flying apart, everything unrecognizable, everything lost. Is she fine now? She's here. She's ours. She's magnificent.

She walks and runs. She does not need glasses. She feeds herself. Our ceiling is stained with blueberry yogurt. She sat up, crawled, took her first step, scrawled with crayon, all on schedule. The other day, I heard her laughing, spun around, and saw her standing naked on the coffee table, waving her diaper in the air.

She speaks in phrases: "I want that." "I did it." "I go there." About 500 times per day, she points at something and says "IZZAT!"

What's that! It's not a question.

She picks at her scars. Someday I will tell her how she earned each one. I can't guess how so many procedures and interventions might stunt her in the years ahead. Her brain was deprived of the proper fats for months; her body got too few calories. Time after time her oxygen levels plummeted. Did her brain suffer? Did her nerves get jangled? Does she remember pain? She is scrutinized by therapists and specialists. More than a year after leaving the hospital, she still has three to five appointments every week. Statistics say she's at risk for learning trouble, sensory issues, fine motor delays.

Statistics.

It's so quiet in her room. After I read her and rock her and nurse her and feel her drift off in my arms, I hold her too long. I whisper to her the names of all the people who love her. Mommy, Daddy, Nat, Sam, Tracy, Diane, Dr. Shakeel, Kim, Ana Maria. . . . There are 30 or 40 names some nights. The doctors and nurses come before a lot of the family.

I kiss her, lower her into her crib, and forget to exhale.

I lay my hand on her back, feeling its rise and fall. Standing by her crib like that, it's so easy to imagine that she's back in that incubator. That I'm standing guard. That Tom is beside me in the blue chair. I note the ventilator settings. I hear the alarms. I watch her heart rate slow ever so gradually as she falls asleep. I stand there, just stand there.

I have to remind myself to come back to the present. To take in the crib, the dark room, the turning fan, the picture of Tracy on the bookshelf, the moonlight peeking through the blinds. No alarms, no wires, no machines. Just me and my daughter. My hand on her back. The soft steady whisper of a baby, breathing.

ABOUT THE JOURNALISTS

Kelley Benham French, 38, has been a writer and editor at the *Times* since 2003. She has won a number of national awards for her writing, including the Ernie Pyle Award for Human Interest Writing and the National Headliner Award. She edited two series that were finalists for the Pulitzer Prize: “Winter’s Tale” in 2009 and “For Their Own Good” in 2010.

Cherie Diez has worked at the *Times* for more than 20 years. Many of her stories have won national and international awards, including top honors in the Pictures of the Year and National Press Photographers Association competitions. In 1997 she worked with Thomas French to produce “Angels and Demons,” the Pulitzer Prize-winning series on the murder of an Ohio mother and her two daughters in Tampa Bay.

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You can see the entire story, photo galleries, graphics, resources, and a video of Juniper today at **tampabay.com/neverletgo**. Scan this code with your mobile device to go there now.



TALK WITH KELLEY

Kelley Benham will hold a live chat at 12:30 p.m. on Wednesday to discuss the series. Join her at **tampabay.com**.

ABOUT THIS STORY

All of my recollections in this story have been verified with the people involved, and with photos and video taken at the time, and with 7,000 pages of medical records. I also relied on my own journal entries and on notes taken by my husband, Thomas French, a journalist and author. To supplement my understanding of extreme prematurity, I interviewed doctors, bioethicists and epidemiologists, talked to other parents of micropreemies, and read dozens of journal articles and books. Dr. John Lantos, director of the Children's Mercy Bioethics Center in Kansas City, Mo., was essential in helping me shape the ideas in this story. Scenes for which I was not present were described to me by the people who were involved and verified by medical records. *Times* photographer Cherie Diez photographed Juniper at the hospital as a friend of the family. Only much later did she and I return to All Children's Hospital as journalists.