



# never let go

BY KELLEY BENHAM • TIMES STAFF WRITER



CHERIE DIEZ | Times

**DAY ONE:** The doctors did what they could to delay my baby's birth, but she arrived four months too soon. At 23 weeks' gestation, she was so early our doctors would not insist on trying to save her. It might be kinder, we were told, to let her die. She weighed 1 pound, 4 ounces. We didn't know if she would live even an hour. The footprints at the top of this page are actual size.

## PART ONE

# lost and found

When a baby is born at the edge of viability, which is the greater act of love: to save her, or to say goodbye?

Our baby by came swirling into view in black and white, week after week, in the grainy wedge on the ultrasound monitor. First a dark featureless pool, then a tiny orb, then budding arms and legs and finally long fingers and a recognizable profile. Precisely on schedule, I felt her squirm and thump.

After years of grueling and unnatural fertility treatments, the promise of her unfolded easily.

We learned her gender in week 16, cataloged her anatomy in week 20. I scrubbed the baseboards in the spare bedroom and stopped buttoning my jeans. I

tried to imagine her as a real child, in my hands and in my life. I drew, in ballpoint pen, her cartoon outline on my skin - with big eyes, a sprout of hair, and an umbilical tether to my navel that made her look like a startled space walker. That was the extent to which I understood her: only in outline, the details waiting to be filled in.

Suddenly there was blood. Blood on my hands. Blood on a thin cotton hospital gown. Blood in red rivulets and blood in dark clumps. Bright beads of blood on the doctor's blue latex gloves. Blood in such





startling quantity we could only imagine there was no life, no baby, not anymore.

My obstetrician looked stricken that day in March 2011 when he rushed into a triage room at Bayfront Medical Center. I clenched and vomited as he explained that our baby had no chance of surviving outside the womb - if she wasn't already gone. A tech tried for long minutes to summon a heartbeat on the monitor, searching every quadrant of my abdomen.

I don't remember if we held our breath or gasped or spoke or sobbed. I remember only the frozen shock when a heartbeat flooded the room, a sound like a galloping horse.

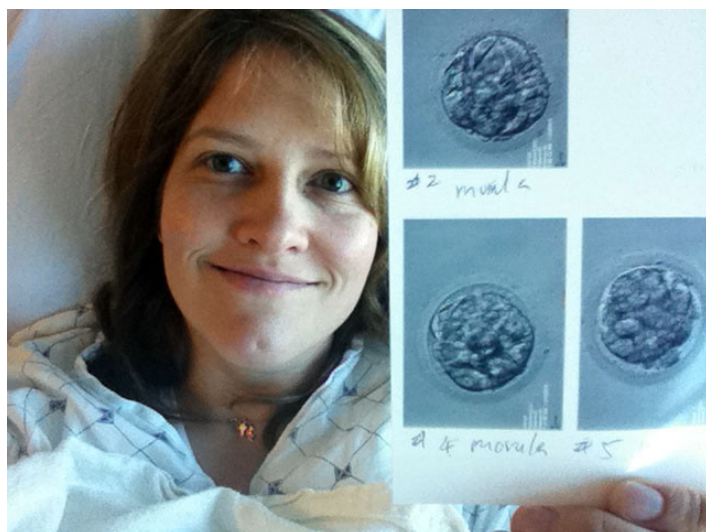
In just a few hours, our baby had been lost and then found. On the monitor, she bobbed and floated in a pixelated haze. But next to her loomed a mysterious shape that had not been there two days before: a clot of blood the size of a fist, created as the placenta had begun to tear loose from my body. A nurse pumped drugs into an IV to stall the labor, and gradually they took a tenuous hold. But it was clear to everyone that the reprieve was temporary. My baby and I were coming apart.

A normal pregnancy lasts 40 weeks. I was only halfway there.

If the doctors had not intervened, my baby would have been a miscarriage. But the odds for her had not improved by much.

Early arrival kills more newborns than anything else, and complications from prematurity kill more babies in the first year than anything else.

Some babies are born so early they are beyond rescue. If a baby is born at or before the 22nd week, it is usually considered a miscarriage or a stillbirth. Almost



**BABY PICTURES:** One of the 5-day-old embryos I'm holding became my daughter. Reproductive endocrinologists at the University of South Florida created these embryos in a petri dish from my husband's sperm and the egg of a donor. We knew we were manipulating nature in our determination to have a child. Later, when things went wrong, we'd wonder if we pushed too hard.

no doctor will intervene, because there is nothing he or she can do.

Other babies ripen in the womb into the third trimester but arrive a little early. If a baby is born later than about 25 weeks, studies show that almost all doctors feel morally and legally obligated to try to save its life.

Some preemies have serious medical problems, but most spend a few days or weeks in the hospital learning to breathe and eat and then they go home.

In between those scenarios is a zone between life and death, between viability and futility. If a baby is born after the 22nd week of pregnancy but before the 25th, not even the smartest doctors in the world can say what will happen to it. New technologies can sometimes keep these micropreemies alive, but many end up disabled, some catastrophically so. Whether to provide care to these infants is one of the fundamental controversies in neonatology.

Babies born at the edge of viability force us to debate the most difficult questions in medicine and in life. Who deserves to live, and at what cost? Who decides whether a life is worth saving, or worth living?

When does a fetus become a human being, with its



**FRONTIER:** The Neonatal Intensive Care Unit admissions pod is the first landing spot for most premature babies at All Children's Hospital. It's a place where caregivers balance science and compassion. Even as machines keep the babies alive, families are encouraged to touch and hold them as soon as they are stable enough. Incubators are kept covered when possible to protect preemies' developing nervous systems from an assault of light and sound. Most babies eventually move to private rooms within the unit.





own rights? When does life begin?

About one in 750 babies arrives in that awful window of time, suspended between what is medically possible and what is morally right.

One of them was born on April 12, 2011, at Bayfront Medical Center. My daughter.

This summer I returned, not as a parent, but as a journalist, to the hospital where my daughter was born. I interviewed the people who took care of her about the scientific and ethical challenges of trying to save babies born so soon. I pored over her medical chart and read dozens of journal articles on extreme prematurity. I learned the things the doctors had been too kind to tell us, and the things I'd been too dazed to comprehend.

When the doctors stalled my labor, they gave us a slim measure of hope, but no assurances. Our baby could die quickly, could die slowly, could suffer needlessly, could live vegetatively. She could be broken in any pocket of her body or mind.

She would come squawking into the world unfinished and vulnerable. Conceived artificially, she would have to grow in an artificial womb. She would reveal to us the wonders of medicine and science, and the limits of those things. She would show us the ferocity of our most primal instincts.

A sci-fi baby in an engineered world, she'd teach me, against all possible odds, what it means to be a mom.

The Baby Place at Bayfront Medical Center is designed for celebrations. The rooms are private, with sleeping couches and flat screen TVs. Sliding panels obscure all evidence of the mess and peril of birth.

Mothers are wheeled out holding fat drowsy newborns, dutiful dads follow with the balloons. Every time a baby is born, the loudspeaker carries the tinkling of a lullaby.

It's easy to pretend, in that cozy place, that all babies come wailing into the world pink and robust, and are bundled and hatted and handed to teary mothers and proud dads. But sometimes it doesn't go that way at all. That's why behind the sliding panels there are devices for oxygen, suction and epinephrine. That's why there's a morgue on the ground floor. That's why Bayfront's labor and delivery unit is actually housed across the street, inside All Children's Hospital. When a baby is born in trouble, as mine was bound to be, it is already in the place that cares for some of the sickest and most fragile children in the state.

After the day I almost lost the baby, the doctors made it clear that for now I had one purpose in life: Stay pregnant. In their calmest and firmest bedside voices the doctors said I had to make it another month to 24 weeks, loosely considered the limit of human viability outside the womb. Deliver earlier than that, and I would watch my baby struggle and die.

I lay still in bed and watched the calendar as my baby survived to 21 weeks, then 22. I checked in and out of the hospital twice, and then back in. I Googled images of half-formed babies. I bled and cramped. One tactless doctor made the situation plain when he



**THE STORK TEAM:** When our baby was born, a special team was waiting in the delivery room to stabilize her. Stork nurse Gwen Newton, along with a neonatologist, a nurse practitioner and a respiratory therapist, took the baby from the delivery nurse. They warmed her, put her on a ventilator, took her vital signs and whisked her to the NICU in a mobile incubator. In this photo, taken this fall, Gwen delivers another new baby to the NICU.

tried to discharge me. "Your baby is not viable," he said, "so you might as well deliver at home."

By the 23rd week, I was taunted by that incessant lullaby on the hospital loudspeaker, a reminder of how natural this process was supposed to be. Nothing about it had been natural for me. To get this far had taken four years, \$40,000, four in-vitro procedures, an egg donor, lawyers, counselors and contracts. Now my body was trying to spit out the baby we'd made. It felt like biological mutiny.

I stayed anchored to the hospital bed by a strap around my belly that charted the volcanic activity within on a computer monitor. The contractions came and went, and when they got bad enough, the doctors stalled the labor by elevating my feet above my head and flooding me with magnesium sulfate, which made me feel like my blood and skin were on fire. That's how I was - inverted, scalding - when doctors conceded the baby was coming soon, and a neonatologist visited to advise my husband and me of what lay ahead. Dr. Aaron Germain was thin and kind, with a look of constant worry. I viewed him as an ambassador from the Land of Sick Babies, a place I could not imagine.

He told us he knew how badly we wanted our child, and an army of specialists with the most advanced technology was ready upstairs to try to save her life.

But we needed to decide whether saving her was what we really wanted. The effort would require months of aggressive intervention, and could leave us with a child who was alive, but very damaged.

Few doctors would insist on intervening. The choice was ours to make.

He went through the list of possible calamities, each with its own initials. IVH, PVL, RDS, CLD, ROP, CP. The magnesium sulfate burned through me, sucking the will from every cell. *Blood in the brain. Hole in the heart. Respiratory distress. Chronic lung disease. Ventilator. Wheelchair. Blind. Deaf. Developmental delays. Autism. Seizures. Cerebral palsy.*

Every part of her was underdeveloped, fragile and weak. Every treatment would exact a toll. She might live, but she would likely have, to use the medical term, profound morbidities.



Odds she would die, no matter how hard they tried: better than half.

Odds she would die or be profoundly disabled: 68 percent.

Odds she would die or be at least moderately disabled: 80 percent.

There was a 20 percent chance she could live and be reasonably okay. I pictured her in the slow class at school, battling asthma or peering through thick glasses. We would buy her pink sparkly ones and tell her they were cool.

I contemplated that figure: 20 percent. It didn't seem hopeless. Then again, imagine a revolver with five chambers. Now put four bullets in it and play Russian roulette. Would we bet on a 20 percent chance if losing might mean losing everything we cared about? Would we torture our baby with aggressive treatment just so she could live out her life in a nursing home or on a ventilator? Would we lose our house? Would our marriage fall apart?

Dr. Germain gamely counseled us as we searched for loopholes in the statistics. Girls do better than boys, he said, but white babies like ours fare worse than black babies. Our daughter would be delivered by C-section so her body didn't get mangled in the birth canal, and I would be injected with steroids before she was born to strengthen her lungs. But the figures the doctor had given us already accounted for those advantages.

But what were the odds, we wanted to know, for a middle-class girl baby with good parents, who sing songs and read stories? With two big brothers and aunts and uncles and a friendly, big-eared dog? The baby who slumbered inside me, her heartbeat galloping along over the speakers, reminding us that she was perfectly fine in there, and safe, and how wrong it was that soon she would be wrenched into the bright, cold air, and made to breathe?

Dr. Germain spoke softly and didn't rush. I wanted to shake him and his probabilities, to make him yelp and tell us what to do.

He just couldn't say. The answers we wanted weren't in the data.

"The statistics don't matter," he said, "until they happen to you."

What echoed in my head was something Dr. Ger-

main never said: Saving her might be the most selfish act in the world.

After the doctor left, my husband sat on the edge of the bed and held my hand as we tried to work our way toward a decision. I started with shedding my expectations. We were a family of high achievers. My husband, Tom French, was a Pulitzer Prize-winning writer. His two sons, Nat and Sam, were salutatorian and valedictorian, respectively, at Gibbs High. Now they were off at college. We had envisioned a similar path for our daughter - horseback riding, piano lessons and the dean's list. All that was gone now, and we grappled with the fundamentals. Would we try to keep her alive? If she lived, would she walk or talk? Would she one day give us a look that said, Why did you put me through this?

People always ask me if I prayed. I prayed the way people in foxholes are said to pray. I prayed with every thought and every breath. And I prayed with the certainty that I had no business praying, that I hadn't earned the right. I'd never been religious. Worse, I knew we had defied the natural order in our determination to have a child. Through so many in-vitro procedures, with so many tests and needles and vials of drugs, we'd created life in a petri dish. To be given a child just long enough to watch her die felt like punishment for our hubris.

I was crying when I asked Tom, "Did we want her too much?"

I don't remember sleeping that night. As dawn crept closer, we both swallowed the thing we couldn't say. I knew once I said it our baby would be gone, and we'd be the parents who'd turned our backs. Tom climbed in next to me on the skinny bed and wrapped his arms around me and all of the wires as best he could. "I don't know how to do this," he said.

Our baby's heart kept beating. I held out my iPhone and used its voice recorder to capture the sound, in case it was the only evidence of my daughter I would ever have.

I'm here, it seemed to be telling us. I'm still here.

Google was of no use. The research was confusing and out of date. The blogs and news sites trumpeted miracle babies but offered little nuance or detail. Noth-

**THE ODDSMAKER AND THE OPTIMIST:** Dr. Aaron Germain, left, visited my husband and me in the hospital before our daughter was born to prepare us for the long odds she faced. The next day, nurse practitioner Diane Loisel, above, counseled us about the medical challenges ahead, then helped us find a way forward. Here, in photos taken this fall, they work with other babies and families at All Children's Hospital. Thirteen percent of babies born in Florida in 2011 were premature.





ing we read reflected the agony and complexity of the situation we faced.

The next day, a second counselor arrived from the neonatal intensive care unit. Nurse practitioner Diane Loisel found us still choking on indecision and grief.

Diane had a relaxed, no-makeup look, a contrast to the crisp, professional bearing of the neonatologist. Given the stakes, I thought, could we get another doctor in here? As soon as she started to talk, I felt foolish. She was so straightforward and so patient, it was clear that her only priority was our baby.

Diane told us she had worked with small and sick babies for 30 years. When she started, 23 weekers never made it out of the delivery room. Any baby born weighing less than 1,000 grams - about 2 pounds - was considered not viable and allowed to die. But now science had advanced, raising new questions for everybody.

Some parents insisted the doctors do everything possible, and then insisted on the impossible too. Diane told us it sometimes made her angry to see tiny babies subjected to futile intervention, to see them go into nursing homes or to families ill equipped to care for them. The more educated parents asked more questions, considered quality of life. Diane often wondered if asking parents to make such life-and-death decisions was cruel.

When it came to babies born at 23 weeks, research showed, there was little consensus from one hospital to the next or even among doctors working the same shift in the same unit.

Some were born limp and blue, and some came out pink and crying. In those first hours and days, much could be revealed. And there was a window of time, while the baby was on a ventilator and still very fragile, when doctors and families could reverse course and withdraw life support.

"You don't have to decide right now," she said. "It's a process."

She seemed to be offering an escape from the torment we had suffered all night. Enough of the unbearable coin toss. We could let them intervene and see how it went. If our baby was born too weak, we could decide later to let her go.

"We don't want her to suffer," Tom said. "But we want our baby to have a chance."

As Diane headed back to the NICU, she told me later, she knew she had changed everything. She also knew that once a mother had seen her baby for the first time, there often was no turning back. She hoped we wouldn't blame her for the rest of our lives.

Another day went by. I imagined my baby gathering a few more air sacs in her budding lungs, a few more ripples in her developing brain. Every hour was crucial, but how many would be enough?

Tom and I discovered it was impossible to stay miserable around the clock. We amused ourselves by speculating about the romantic lives of the doctors and nurses. One doctor looked like a lost Kennedy. Another one - I called him Dimples - kept the nurses laughing. We could hear them out in the hall. Our favorite was a glossy-haired nurse we called Cupcake who wore Grey's Anatomy label scrubs. I imagined all of them screwing in supply closets and gossiping at the

nurses' station. One of the doctors, while sketching a diagram of the untenable situation in my uterus, asked if I had any questions.

"Just one," I said. "Is it me or are the people on this floor unusually hot?"

"Yes," he said, "and thank God for it."

All of these people had been between my legs, and I was too wrecked to care. The absurdity of it made me laugh, even though laughter was discouraged while on bed rest.

That afternoon we watched DVDs and allowed ourselves to hope the doctors were wrong and we would make it another week. As soon as the sky darkened outside the window, I tried to sleep, to make the day end before anything could ruin it.

Still tethered like Gulliver by IVs and wires, I shifted left, then back to the right. Adjusted the bed up and back down. Stole my husband's pillow and asked the nurse for extra blankets. A vague sense of unease settled in and I shut my eyes and willed it away. The monitor registered no unusual activity.

When the nurse came in for yet another blood pressure, I told her I felt strange.

Constipation, she said.

At first it was uncomfortable. Then it started to hurt.

The monitor mocked me with its refusal to acknowledge what I was feeling. I kept moving the straps around, trying to pick up the signal, then gave up and tossed them all off. I paced the floor, clutching an IV pole, setting off alarms at the nurse's desk.

I had a prescription for morphine, but the nurse stuck to her constipation theory and refused to give me any pain relief at all. I cramped for hours until she sent my husband on a 2 a.m. trek through St. Petersburg in search of prune juice. By the time Tom returned with a 64-ounce bottle, I was screaming on the bathroom floor.

The pain was sharp and low and I could feel the baby kicking with both feet like a mule trying to take down a barn door. "Please," I told the baby. "Be still."

The nurse appeared in the doorway. "What would it feel like if there were feet coming out of me?" I asked her. "Because that's what this feels like."

"No, honey," she assured me. "That's not what's happening."

A doctor finally checked just before dawn. I was sobbing and gulping air. I asked him if he could put me in a coma, and make it all stop, and wake me up in a couple of months when the baby was bigger. Or maybe he could sew me shut. Or hang me upside down. He pulled on his gloves and told me to be still and to breathe.

"Please be careful please be careful please be careful." I couldn't get my breath. "Please be careful." He reached in and felt the baby's feet, just where I knew he would find them.

A second doctor confirmed it. "We have to go now," she said.

We'd made it 23 weeks and six days.

I watched the ceiling roll by as nurses whisked me on my hospital bed to Operating Room 4. Doctors debated whether there was time for anesthesia, then someone rolled me over and put a needle in my spine and the pain washed away.





If I'd been able to sit up and look around, I would have seen a group from the NICU, called the Stork Team, preparing to stabilize the baby in a room next to the O.R.

Gwen Newton was the Stork Team nurse that day. She described it all for me later. She said most mornings, she needs a good jolt of coffee to get going. But today, all it took was a look at her assignment sheet: 23 weeker.

When she was pregnant with her son, she said, she had nightmares that he was born at 23 weeks.

She readied a mobile incubator that would keep the baby warm and monitored on the short ride to the NICU. She made a nest of blankets and spread a pillowcase over it to catch the blood.

The baby's arm would be so small she'd use a rubber band for a tourniquet. She got out a No. 1 blood pressure cuff, small enough to fit around her finger. She set the warmer to 37 degrees Celsius, laid out catheters for IVs and wires for monitors. She drew a mixture of sugar and dextrose in a 60 mL syringe - a snack to get the baby started. And she drew 1.4 mL of an artificial lung surfactant - a milky mix of fats and proteins that would help prevent the baby's sticky lungs from collapsing.

A respiratory technician was prepping the ventilator and a neonatologist and a nurse practitioner were studying the chart. When Gwen had everything ready, she stepped to the doorway to watch the C-section.

Some of what happened next would be out of her control. Some babies came out fighting and some did not. You never know what's coming out of that belly, she thought.



**FLYWEIGHT:** Our baby was bruised by the delivery and emerged looking like a wasted prize-fighter. Extremely preterm babies like her are vulnerable in every system of their bodies. Her immature brain, lungs and intestines were all at risk of bleeding and scarring. Her eyes were fused shut; a mask protected them from the lights correcting her jaundice. Her skin, thin like papyrus, easily tore. The doctors said some babies fight and some do not. Ours came out angry, squawking and kicking.

I felt a sickening tug. I knew that we were two separate people now.

"She's kicking," Tom said. He was peering over the surgical drape at the gaping red meat of my abdomen, and at the creature that had just emerged from it.

Someone said she cried, but I didn't hear it. I tasted prune vomit in my mouth.

Pretty soon someone slipped a piece of paper in front of me, and an ink pad, and asked for a fingerprint. On the paper were two still-wet footprints, each an inch and a half long. Startling evidence that she was here.

"My baby," I kept saying, "my baby, my baby." Gwen took the tiny blood-spotted bundle from the delivery nurse. She unwrapped her, laid her on heat packs, and slipped her into a plastic bag up to her neck to help prevent heat and fluid loss. Gwen rubbed and dried her like a mother cat roughs up a kitten, but more gently, so as not to tear her skin. The baby was dusky blue, then dark red. Gwen pinched the tiny greenish umbilical cord between her thumb and forefinger and felt it throb. She counted 17 beats in six



**VIGIL:** I saw my daughter for the first time when she was about seven hours old, when my husband, Tom, wheeled me to her bedside. She was dwarfed by technology. I knew the doctors had had no choice but to deliver her, and that they were doing all they could to save her, but I kept thinking how wrong it was that she'd been cut from my body before she was ready. I wanted to put her back inside, to keep her safe.



seconds.

“Heart rate is 170,” she called out. It was strong, a good sign.

The baby was trying to breathe but her lungs were not ready and her muscles were weak. Through the stethoscope her breathing sounded squeaky and coarse. A respiratory technician threaded a tube the size of thick spaghetti through her mouth and into her chest. Into the tube she placed the milky fluid that would coat the baby’s lungs. She connected her to a small portable ventilator that delivered oxygen at a constant pressure, and tapped her finger over a hole in the tube to pace the breaths. The baby’s chest heaved mechanically.

She weighed 570 grams - 1 pound, 4 ounces. She was 11.4 inches long - the length of a Barbie doll. I saw Gwen roll the incubator past. Inside was a raw dark creature, a blur in a too-big hat. My husband looked at me and looked at the baby.

“Go with her,” I said. “Please go.”

A baby at 23 weeks’ gestation has just begun to hear, but can’t yet see. It may recognize its mother’s voice. It has a dawning awareness of whether it is right side up or upside down. The surface of its brain is smooth, just beginning to develop the hills and valleys that become wrinkles and folds. It responds to pain, but has no capacity for memory or for complex thought.

Its lungs look like scrawny saplings compared to the full, bushy trees of normal lungs. Its bones are soft.

It swallows. Its hair and eyelashes are just starting to grow and its fingernails and fingerprints are just forming. Its body is covered with a soft protective down. It is recognizably human, but barely.

I was still in recovery when Tom returned from the NICU, crying.

“She’s so perfect,” he said. His voice was a squeak. “She’s so beautiful.”

I just stared at him. My sweet, emotional husband, in the grip of something terrifying and overwhelming. He’d been to a place I couldn’t fathom.

“That’s my baby girl up there,” he kept saying. “That’s my daughter.”

I used to imagine what I would say to her when I first saw her. She’d be wrapped in a blanket and wearing a hat, and she’d feel solid in my arms, like a puppy. She might open one eye and peek up at me, perplexed but curious. She would know my voice and my smell, know I was her mother, and because she knew that, she would not be afraid. I’d be hit with a force that would unmake me and remake me, right there.

Instead I waited in recovery while she fought for her life somewhere beyond my reach. After seven hours Tom took me up to the NICU in a wheelchair, still in my cotton surgical gown, lugging an IV pole.

Tom pushed my wheelchair up to the deep sink so I could scrub my hands. There were posted instructions and a disposable scrub brush and I felt determined to do it properly, for the full 30 seconds, in the hottest possible water, as if precise compliance with the rules might tip the odds.

I saw her plastic box halfway across the room. I didn’t see anything else, just this tunnel of space and time and of everything changing that marked the

distance between us. Here I was one person and there I would become someone else. The soap was hard to rinse, and I let the water run for a long time.

Tom wheeled me to her portholed plastic box. The nurse introduced herself as Gwen, but I barely heard her. There, through the clear plastic, was my daughter. She was red and angular, angry like a fresh wound.

She had a black eye and bruises on her body. Tubes snaked out of her mouth, her belly button, her hand. Wires moored her to monitors. Tape obscured her face. Her chin was long and narrow, her mouth agape because of the tubes. Dried blood crusted the corner of her mouth and the top of her diaper. The diaper was smaller than a playing card, and it swallowed her. She had no body fat, so she resembled a shrunken old man, missing his teeth. Her skin was nearly translucent, and through her chest I could see her flickering heart.

She kicked and jerked. She stretched her arms wide, palms open, as if in welcome or surrender.

I recognized her. I knew the shape of her head and the curve of her butt. I knew the strength of her kick. I knew how she had fit inside me, and felt an acute sensation that she had been cut out, and of how wrong that was.

I had crazy thoughts. Should we prepare a birth announcement? What would we name her? If she died, would we get a birth certificate? Would there be a funeral? Would we get a box of ashes, and if so, what size box? Was she aware of us? Did she recognize me like I recognized her? Was she afraid? Did she wonder where I had gone? If she ever got out of this box, would she know I was her mother?

She was alien and familiar. She was terrifying and beautiful. She was complete and interrupted. I felt the icy hush that comes with looking at a secret you are not meant to see. I was peeking into God’s pocket.

“You can touch her,” Gwen said.

I reached in through the porthole. I saw how white and swollen my hand was. I let it hover over her for a second, then pulled away, as if from a fire. Finally I placed the tip of my pinky into her tiny palm.

She grabbed on.



ABOUT THIS STORY

All of my recollections in this story have been verified with the people involved, with photos and video taken at the time, and with thousands of pages of medical records. I also relied on my own journal entries and notes taken by my husband, Thomas French, a journalist and author. To supplement my understanding of extreme prematurity, I interviewed doctors, bioethicists and epidemiologists, I talked to other parents of micropreemies, and I read dozens of journal articles and books. Scenes for which I was not present, such as Gwen Newton's resuscitation of our baby, were described to me by the people who were present and verified by medical records. The statistic in the top of the story about the number of babies born at the edge of viability comes from the National Center for Health Statistics' U.S. birth certificate data from 2006, supplied by Harvard epidemiologist Tyler J. VanderWeele . The statistics cited by Dr. Aaron Germain are from the Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network. Times researcher Natalie Watson contributed to this report. Times photographer Cherie Diez was at the hospital on the day our baby was born as a friend of the family. Only much later did she and I return to the hospital as journalists. For more detailed information about sources and research, go to [tampabay.com/neverletgo](http://tampabay.com/neverletgo).

ABOUT THE JOURNALISTS

**Kelley Benham French**, 38, has been a writer and editor at the Times since 2003. She is the winner of 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 international awards, including top honors in both Pictures of the Year and National Press Photographers competitions. In 1997 she collaborated with Thomas French to produce "Angels and Demons," the Pulitzer Prize-winning series on the murder of an Ohio mother and her two teen daughters in Tampa Bay.

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