

GREGORY MARTIN

## *Brittany's Choice*

**B**RITTANY WOOD WOULD NOT WAKE UP. Not at the sound of her name. Not at the curtains opening or the bright light of morning. She slept curled beneath her covers, dark hair wild on her pillow, her eyes closed, clear tubing snaking from her nasal cannula to the blue oxygen tank leaning against the wall. But it was summer vacation, and Brittany's parents, Dee Dee and Kevin, were content to let their daughter sleep in, even though this was unusual, even though she often woke *them* up, ramming her wheelchair into their bed frame and proclaiming in her thin voice, "Morning time!"

But afternoon came and Brittany would not wake when they rubbed her shoulder or brushed her hair from her forehead. She half-opened her eyes. She didn't speak. Her color was bad, a blueish gray.

They put Brittany in the tub under a cold shower. Nothing. They dressed her in shorts and a T-shirt and tried to sit her at the kitchen table. She nearly tumbled out of her wheelchair. Most families would have long ago called an ambulance or raced off at reckless speed to the ER. But the Woods were not strangers to ambulances and ERs. Brittany had undergone more surgeries, contracted more infections, seen more doctors and specialists in her ten years than most families encounter in generations.

Brittany has two brothers—Michael, sixteen, and Cody, eight—and they finally insisted that something was terribly wrong. "Call 911," they demanded.

It had been more than a year since Brittany's last major surgery. A good, happy year. Brittany had gone to school in the mornings and stayed out of the hospital. They had all just returned from a camping trip over the Fourth of July weekend, and so the last thing Dee Dee and Kevin could have imagined was that they would soon choose to defend their daughter's right to die.

BRITTANY WAS BORN WITH A RARE, congenital musculoskeletal disorder characterized by a limited range of motion in the body's joints. One in three thousand children are born with arthrogryposis, a spectrum diagnosis covering a wide range of medical defects. The most common presentations—hands turned inward, clubfeet, dislocated hips—are correctable with minor surgeries, casting, and splinting. Brittany's arthrogryposis, Type 5, is one of the rarest and most life-threatening. She has severe forms of both scoliosis, the sideways twisting of her spine, and kyphosis, the forward curvature of her spine.

Brittany is still growing, her spine is still twisting and curving, and her heart and lungs are ever-so-gradually being crushed.

Imagine a tiny, frail, hunchbacked elderly woman. Now take away the shawl and cane, the gray hair, wrinkles, and sagging skin, and replace them with light-up Bratz sneakers, a weathered Winnie the Pooh baseball cap, dark, uneven bangs, and an elfin grin, and you have Brittany.

BRITTANY WAS RUSHED THIRTY MILES by ambulance from her home in Las Lunas, New Mexico, to the Pediatric ER of the University of New Mexico Children's Hospital in Albuquerque. Brittany's case file there is several inches thick. She was quickly diagnosed with carbon dioxide narcosis—her bloodstream was like hallways filling with smoke. Most people's CO<sub>2</sub> levels range between thirty and forty millimeters of mercury, an arterial blood measurement. Due to a lifetime of compensating for respiratory insufficiency, Brittany's normal CO<sub>2</sub> range is in the seventies. On this day, her CO<sub>2</sub> was a hundred and eighteen—off the charts. Had her parents not brought Brittany to the ER, she would have sunk deeper into unconsciousness, suffered brain damage and cardiac arrest, and died.

Brittany was put on a bi-level positive air pressure (BIPAP) ventilator, a respiratory machine connected to tubing and a face mask that forces open air sacs in the lungs. Brittany slept with the mask on and, during her waking hours, was administered a regimen of four hours on, two hours off. Over the next several days, her CO<sub>2</sub> level gradually came down, and she became more alert.

Then she contracted a drug-resistant staph infection. Again. For the third time in as many years, she was put in isolation—doctors and nurses coming in and out in gloves and gowns—to prevent her from contaminating other children. She had terrible diarrhea. She took Zoloft for depression. She didn't understand why this kept happening to her. Or rather, she understood about arthrogryposis and its complications—as much as any ten-year-old could—but she did not think it was fair. Brittany wanted to go home.

"I'LL BE PERFECTLY HONEST," Lea Davies told me. "I tend to be blunt. I've had people write down what I've said verbatim and quote it back to me later as evidence. But the interests of my patients sometimes require plain speech." Davies is a pediatric pulmonologist at the University of New Mexico Hospital; she met Brittany for the first time while Brittany was recovering in isolation in the PICU. Davies is Australian. I visited her in December of 2008, in her sun-lit office on the third floor of the hospital.

Davies is a “trach and vent” expert, and earlier that summer she recommended that Brittany undergo a tracheostomy, a surgical incision into the trachea to form an opening that is connected to a tube and mechanical ventilator. Instead of breathing through her mouth and nose, Brittany would breathe through the tube. Davies explained to Brittany, Dee Dee, and Kevin that, once Brittany reached puberty and her bones stopped growing and began fusing, her spinal curvature would stop. If she survived beyond puberty, she might live a long time. But Brittany probably couldn’t get there without some kind of intervention.

So in the summer of 2008, Dee Dee and Kevin had a choice to make, a decision which, to Davies, seemed clear. A tracheostomy could dramatically improve Brittany’s quality of life. Because it was full-time, it ventilated carbon dioxide better than intermittent BIPAP. Brittany would have fewer headaches, think more clearly, sleep better. There would be less strain on her heart. No surgery was without risk, but compared to the surgeries that Brittany had undergone before, the risks of a tracheostomy were minimal.

But Dee Dee and Kevin didn’t see it this way. Each of Brittany’s surgeries in the past had failed. And Brittany had never once participated in the decision. “I have lots of regrets,” Dee Dee told me. “Last time, Brittany did not have a say. We didn’t ask her what *she* wanted. I was *not* going to make that mistake again.”

Informed consent is limited in pediatrics, because child patients, by law, may not make medical decisions until they reach the age of eighteen. While there are exceptions—for teen mothers and emancipated minors—no court in America will allow a ten-year-old to be the decision-maker regarding life-sustaining surgery. But the principle of *assent* is rooted in the belief that children are “intelligent, observant, capable, and responsible persons who deserve our utmost respect.” The Bioethics Committee of the American Academy of Pediatrics goes on to say that physicians and parents must give “great weight” to the clearly expressed wishes of the child patient.

Brittany was clear. She said no. She didn’t want another surgery. She wanted to go home.

DEE DEE AND KEVIN WENT HOME. For three weeks, while Brittany remained in isolation, they deliberated. Agonized. They went back to Davies with their decision. They would not put their daughter through surgery against her will. They wanted to continue with BIPAP at home.

The BIPAP was only temporary, Davies countered. On BIPAP, Brittany was bed-bound and could not eat or talk. The tightly sealed mask bruised her face.

Davies had one teenager in her clinic on trach and vent who drove himself to high school. (The ventilator is the size of a laptop.) Davies arranged for one of her patients, a wheelchair-dependant boy with a trach and vent, to visit Brittany in the hospital. Kevin and Dee Dee were told of this visit but did not attend. Davies offered to set up meetings with other parents of children with trachs and vents. She urged them to visit the clinic.

Kevin and Dee Dee refused.

Davies asked me, "Do you have kids?"

I told her I did. Two boys, eight and five.

"I've got an eight-year-old at home, too. Would you let your child make this decision?"

I didn't think so, but I didn't say anything.

Davies said, "It's the parents' job to make this decision. I know Brittany's smart, but I don't think any ten-year-old has the maturity to understand death. Can we truly say she can make a decision when her CO<sub>2</sub> is in the eighties? It was in the one-hundred-twenties when she was admitted. Can anyone who has such bad CO<sub>2</sub> levels make an informed decision? I can't make decisions at two in the morning anymore. How can we say Brittany can make an informed choice?"

"I'm under no delusions," Davies continued. "It's a real hardship. The care demands increase manifold. But they can do it. This is a loving extended family. But Brittany's parents had preconceived ideas I couldn't get beyond. They would say, 'I don't want my daughter attached to a machine for the rest of her life.' It happens. Usually, we educate the family, they talk to other families, other kids, and we wait for time to pass and for them to get used to the idea.

"Many specialists I consulted felt that child protective services should be involved. That I had to do something."

*Do something* means obtain a court order to have the New Mexico Children, Youth and Families Department take Brittany away from her parents, place her in foster care, and perform surgery against her will. In bioethics, the principle invoked to support such a decision is *professional integrity*, which demands that physicians be faithful to their own moral values and seek legal recourse when parental refusal places a child at substantial risk.

Davies called for a consult with the hospital ethics committee. In a conference room packed with lawyers, physicians, nurses, clergy, and social workers, Davies urged Kevin and Dee Dee to choose a tracheostomy. Brittany was there as well.

“We felt like we were being thrown to the wolves,” Dee Dee told me. “I lost it. I threw a wall-eyed fit. They said they loved Brittany. Don’t sit there and tell me how much you love *my* child. I was screaming.”

The ethics committee does not adjudicate. It tries to get people to listen to one another. It does not make decisions. But Kevin and Dee Dee didn’t understand this going in. They saw the ethics committee as a partisan institutional body with the power to enforce the doctor’s recommendations, the medical version of a military tribunal, a Gitmo court for rogue parents.

Davies told Kevin and Dee Dee that it was her duty as a physician to advocate for Brittany. Brittany was only ten; she had no understanding of the risk she was taking. Her refusal might prove fatal. The chair of the ethics committee made sure Brittany and Dee Dee and Kevin understood what Davies was telling them. Did they understand? They understood. They had met with the medical team from the Mariposa Program, UNM’s pediatric hospice; they wanted to place Brittany on hospice service. They wanted to take Brittany home.

“Everybody thought we were crazy,” Dee Dee told me.

Mary Ann Freedman, who has been Brittany’s pediatrician since she was four months old, confirmed this. “People thought they were out of their ever-loving minds.”

I VISITED BRITTANY the day before Halloween with Cynthia Baber, a nurse with the Mariposa Program. Baber has been a nurse for twenty years, and a hospice nurse for the past two. She has thick, short blond hair, and is voluble, warm, opinionated, and given to wry humor. She is also a bereaved parent. Her second son, Cameron, died in 2002 when he was eleven years old. So Baber can relate deeply to what parents with children on hospice are going through. “The loss of a child is the worst thing that can happen,” she told me. “After that, nothing compares.”

We drove south from Albuquerque thirty miles to Las Lunas, where Baber navigated from memory the twists and turns through a new development of ranch houses. The Woods’s home was decorated with cobwebs, a hanging skeleton, and bats. In the middle of the yard, a plastic tombstone read *R.I.P.* I pointed it out to Baber.

“That’s what you’re getting yourself into,” she said and laughed.

Dee Dee met us at the door, and she and Baber hugged. “Come on in,” she said in her Texas drawl. Dee Dee is from *Amarilluh* and is in her thirties, has dark hair, brown eyes, and a tiny, single-studded diamond nose ring. She led us into a carpeted living room where Brittany was waiting, a blue oxygen tank mounted to the back of her yellow wheelchair.

I said hello and Brittany reached out and we shook hands. Her fingers were thin and tapered—one of the many presentations of arthrogryposis. Brittany tilted her head up toward the ceiling, as if listening to something in the distance, and we made eye contact. Her eyelids were half-open; she lacks the muscle strength to hold them fully open.

“Nice to meet you,” she said.

Baber and I sat down on the couch and Brittany climbed down from her wheelchair and sat between us. She wore a pale blue polo shirt and khaki pants—her school uniform. She was so small. My kindergartner at home was in the eighth percentile for height and weight, and Brittany was five years older but much smaller. She whispered something to Baber, who had to remove the stethoscope from her ears; she had already begun listening to Brittany’s lungs.

“You’ll have to ask *him*,” Baber said and she rolled her eyes.

Without raising her head to make eye contact, Brittany said, “Do you know how to play spin the bottle?”

I laughed. I asked if she was trying to embarrass me.

“I’m just asking,” she said.

“It’s been a while,” I said. This seemed to satisfy her.

“Boy crazy,” Baber said.

“What did you bring me?” Brittany asked Baber.

Baber took a card game from her purse called States and Capitols.

“How do you play?”

“Read the directions.” Baber handed her the sheet of instructions.

“In a minute,” she said.

Brittany and I chatted for a while—about the elementary school she attended most mornings, about her plans for Halloween the next day; she was going to be a ninja, with nunchucks and twin swords. She showed me some recent artwork—a pastel of an orange and red sunset, another pastel of a row of candles rising like a strong broadband signal. She’d painted the pastels with Edie Logan, the Mariposa Program’s social worker, who came once a week. We moved on to the topic of recreational torture; one of her life goals was to give Cody a swirly—to hold his head down in the toilet and flush.

I said that I was a little brother once but had escaped that particular treatment.

“Cody won’t be so fortunate,” Brittany said.

Kevin came out from a room in the back of the house. A man of moderate height, with bright blue eyes and a neatly trimmed goatee, Kevin is the family expert at administering Brittany’s meds and ensuring her different machines work properly.

Dee Dee pulled up two chairs, and she and Kevin sat down. Baber and Brittany went to the kitchen table to play States and Capitols. There was an awkward silence, and I remembered why I had come. In late July of 2008, Brittany received a referral for pediatric hospice, and she went home to die.

WHEN I ASKED DAVIES why she decided not to call child protective services, she grimaced. "I just couldn't do that. Taking Brittany from her family would have been far worse than doing nothing. Her quality of life would have been horrible.

"We don't have a system for this kind of situation. We don't have a way to make sure that this child gets the surgery she needs *without* removing her from her family, which would just be cruel. That would be worse than death.

"Brittany will die, though, if she doesn't get better ventilation. I know people might say she looks great now. People can see acute changes. We're not good at seeing the slow progression."

Davies was quiet for a time. "I'm supposed to do what's right for Brittany. But what I keep thinking to myself, over and over, is this: Have we let this child down?"

RICK SCHWEND DID NOT WANT to let Brittany down. But he was waiting for her to get fatter. Schwend is a pediatric orthopedic surgeon, an expert in exactly the surgeries Brittany needed. He'd been Brittany's orthopedist since she was two, and for five years, he'd known that her kyphoscoliosis could kill her if it wasn't corrected. Back then, when Brittany was seven-years-old, she didn't yet weigh thirty pounds. She was skin and bones. Schwend had never operated on a child so thin and frail. But in the summer of 2006, Schwend decided he couldn't wait any longer.

The first surgery was the halo. A halo, in this context, is a steel ring screwed into the skull. Brittany's halo was connected by a spring-loaded wire and pulley to a kind of scaffold above her. "Maybe I shouldn't say this," Kevin told me, "but it looks just like the sketch you make playing a game of hangman." Brittany was in halo traction for three weeks, an hour on and a half hour off, all day. She *slept* in halo traction, six pounds of pressure instead of eight. The second surgery was an anterior spinal release. Schwend cut discs and ligaments in her rib cage to relax the stiffness in her spine. The third surgery was one of the most complicated orthopedic procedures performed on children. Schwend anchored two pre-shaped metal rods on either side of Brittany's spine with screws, hooks, and wires.

All three surgeries went well. Optimism reigned. Brittany recovered in the PICU and went home. Not long after, Schwend took a job at a hospital out of state. Talking to me on the phone from his home in Kansas City, Schwend said, “And then Brittany fell. The implants broke through her skin. Her bones were so soft, her skin so paper-thin...” His voice trailed off.

Then he said, “I feel terribly responsible that it didn’t work.”

“I have a picture of Brittany on my desk at my office,” he said, “of the two of us in the therapy pool. The chlorine kept the pins in her skull clean. Besides, it was fun. I think about Brittany all the time. I remember the ones that fail. Those kids are the ones that stay in my mind.”

He sighed. “When I was in medical school, we learned that you do everything you can. And there is something very valid about that training. You want the physician that will not give up. And yet, the rods didn’t work. Every major hospital in the nation has children like Brittany. Where you just don’t know what to do.”

**BRITTANY FELL.** The metal implants broke through her skin and became infected. They had to come out. Patrick Bosch, Brittany’s new orthopedic surgeon, thought he could save two-thirds of the implants, and so, during surgery, he took out only the hardware at the top of her spine. The infected opening in her back was the size of a baseball. A wound VAC (vacuum assisted closure) was embedded in a dressing to help close the wound. Brittany recovered in the hospital for three weeks. She had just gone home when the hardware broke through her skin again. Bosch operated a second time, cutting the rods and removing the hardware in the middle of the spine, but leaving the implants in her lower vertebrae, hoping to salvage some correction from the initial surgery. Brittany went home two days before Thanksgiving. She still had the staph infection, and so had a PICC line (peripherally inserted central venous catheter) delivering antibiotics through an IV. She was also losing weight—she didn’t have any weight to lose—and so had a G tube inserted in her abdomen, delivering two thousand calories a day.

In the spring of 2007, the remaining implants became infected. On March 11th, 2007, Brittany celebrated her ninth birthday at Chuck E. Cheese’s. The next day, Bosch removed the remaining implants. The day after that, in the PICU, while her breathing tube was being removed, Brittany coded.

“It was a nightmare,” Kevin said. “Twelve people standing around her bed, all shouting at once. The mechanical ventilator wasn’t getting her enough oxygen, even at the highest setting. So Dr. Crowley, the head of the PICU, climbed on the bed and started hand-pumping air into Brittany. He hand-



bagged her for what seemed like hours. He wouldn't let anyone else take a turn. He kept saying, 'I've got it. I'm in a rhythm.'"

"I felt like I was outside of my body," Dee Dee said. "It was like watching *ER* on TV. I kept thinking, 'This is my little girl. Please don't lose her.'"

"That was the worst day of my life," Kevin said.

Brittany finally stabilized. She was put in prolonged deep sedation, all her voluntary muscles chemically paralyzed. She was so tenuous that the slightest involuntary cough might send her back into respiratory failure. Four weeks later, when Brittany was finally extubated, the room was packed with specialists. But she didn't crash. She opened her eyes. She smiled. Everyone in the room who could do so breathed a long, deep sigh of relief.

But then Brittany contracted another staph infection and was placed in isolation. This time it was VRE, vancomycin-resistant enterococcus. I'm neither religious nor given to biblical analogy, but it's helpful for me, when I think of Brittany's story, to keep the Book of Job in mind. Because Brittany's story is about suffering and despair as much as it is about children's rights or parental authority or bioethics or end-of-life care. Like Job's story, Brittany's confirms the hard truth we were told kids: *No one said that life is fair.*

Three and a half months after she coded, Brittany went home. Dee Dee didn't know Brittany was being discharged. Kevin, Michael, Cody, and Brittany had kept it a secret. Dee Dee was in bed, asleep, when Brittany whispered in her ear. "Mom, it's time to wake up." Brittany smiled with satisfaction when she told me this story. She tilted her head up and looked at her mom. "You should have seen the look on your face. I thought you were going to pee your pants."

There followed a good year. School. No trips to the hospital. Camping. Then Brittany was rushed to the ER with narcosis, contracted another staph infection, spent four weeks in isolation, and she and her parents refused a tracheostomy, chose hospice, and people thought they were out of their ever-loving minds.

THE TABLE IN THE CENTER of the ethics committee conference room is big. Executive boardroom big. Imagine an episode of *This Is Your Life* filmed in the room, but instead of people coming in and telling stories about Brittany, they come in, set an object on the big table, and leave. Think of it as an exercise in the narrative power of objects: Yorick's skull turned over in Hamlet's hands. Willy Loman's briefcase.

So: an ultrasound tech no one remembers enters and sets on the table the black and white, grainy, skeletal print of Brittany in utero that first told Kevin

and Dee Dee something was wrong. Michael and Cody lug blue oxygen tank after blue oxygen tank, and heave them on the table. Rick Schwend sets down a shiny steel halo and the picture of him and Brittany in the therapy pool. Patrick Bosch sets down the metal rods he cut into all those pieces, along with the wound vac and G tube and PICC line and an IV full of antibiotics. Mark Crowley sets down the handbag and breathing tube. Dee Dee sets down the BIPAP machine. Kevin sets down Brittany's bottle of Zoloft. Michael and Cody are back with a pastel sunset, nunchucks, a neon skeleton, and the tombstone that reads R.I.P.

The trach and vent aren't on the table. The whole point here is to answer "the craziness question," to decide if Brittany and Kevin and Dee Dee's refusal of life-sustaining surgery is nuts, or if, perhaps, it might be not just understandable, but perhaps informed, ethical, good, right, wise.

Because, on the one hand, it is easy to be deeply sympathetic to the doctor who says, Wait. No. Don't give up. Just let me try. There are hundreds of neurologically devastated kids all over the country on mechanical ventilation whose parents *can't* let go. Why should we let go *now*? This is a bright kid. She could go to college. Don't you remember Terry Schiavo? All the national, impassioned, ethical fuss over her right to die? Terry Schiavo was brain dead. She did not have a biting wit and precocious comic timing.

But, on the other hand, as the objects accumulate on the table, Brittany's refusal seems more and more valid. The more objects that accrue, the more her refusal seems, paradoxically, like affirmation. The more it seems Brittany chose to go home and *live*. The more it seems she was saying, I can't live *that* way. In a hospital, filled with tubes, in isolation. In a coma. I've been operated upon many times and usually something awful happens. What if I'm not strong enough this time? If you operate on me again, I'm afraid I will die. I don't want to go to sleep and not wake up. I want to go home.

MAKE NO MISTAKE: most children who receive hospice service die. But Brittany did not die and Brittany did not get better. She stabilized. Her underlying condition, now, at this writing, more than two years after her refusal of life-sustaining surgery, remains the same—her kyphoscoliosis is still progressive, and her lungs are still slowly being crushed. The question of long-term mechanical ventilation is unresolved, an intervention which, though it may bridge the gap to puberty and beyond, is not a cure. Precise enough phrases, like *life-limiting illness* and *life-threatening condition*, serve as ballpark prognoses for four hundred thousand children in the U.S., and attempt to capture severity, pragmatism, and uncertainty, all at once. But such phrases refuse

translation to a life-expectancy calculation. In the most vexing cases, this is about as helpful as saying the child is sort-of-terminal, maybe.

I VISITED BRITTANY AGAIN on a sunny day in the middle of December. I drove out with Edie Logan, Mariposa's social worker. Logan is a tiny, thin woman in her fifties with short hair and a quiet manner. Art supplies packed the back of her Honda CRV. As we drove south past farmland along the Rio Grande, she told me that a boy who had been on hospice for several months had died that morning. This was the second child who had died on hospice since I'd visited Brittany six weeks earlier.

When we pulled up to the house, a festive wreath with candy canes decorated the front door. Brittany opened it for us, hooking her foot on the edge and reversing her wheelchair.

"Hi Eddie," Brittany called out.

"She always mispronounces my name," Logan said, in mock bafflement.

Logan and I brought in four boxes full of paints and wooden houses and masks. Brittany inspected each object, turning it over in her hands, then discarded it, handing it to me without a glance, the way a surgeon passes a scalpel to her assistant. "This is the one," she said and zoomed over to the kitchen table. Brittany got to work painting a house with Logan. Dee Dee, Kevin, and I stood around the kitchen island and drank coffee.

I asked how their meeting went with Lea Davies. Davies had visited the Woods's home two days earlier.

"We didn't think we'd have another Christmas with Brittany," Dee Dee said. "The last time Dr. Davies saw Brittany, she didn't think BIPAP would work. But she told us, 'You're doing a great job. Brittany is thriving.' In fact, Brittany's doing so well, she's going to graduate off hospice." Dee Dee shook her head in amazement.

"We have more time with her," Kevin said, "and that's all we want."

"She still has boys to meet," Dee Dee said.

"And butts to kick," Brittany added, without looking up from her painting.

I asked Dee Dee and Kevin if they felt better about the ethics committee. "Absolutely," Dee Dee said. "I can see their perspective. Now I can look back. If I were in their shoes, with their liability."

I remembered something Cynthia Baber had told me, when we were driving home from my last visit. "Do not judge a family in the hospital. They're too helpless. Too upset. Too confused. Too heartbroken. It's so different when they're home."

“Disagreements happen,” Kevin said. “Everyone’s emotions were high. Dr. Davies told us there might come a time when the BIPAP will not work anymore. We heard that this time.”

“But I will not make that decision for her,” Dee Dee said. “She’s the one who lives in that body.” She paused and looked at Brittany. Brittany was focused on the house she was painting, which was now brown with red trim and white eaves. Kevin brought Brittany a bowl of chocolate pudding and set it wordlessly beside her. He disconnected Brittany’s oxygen tank and replaced it with another one.

“Maybe, when the time actually comes, who knows,” Dee Dee said. “Maybe we won’t let her choose. Maybe we’re going to save her no matter what.”