

## *Chapter 32*

### The Miracle

Ana

. . . Isa is not doing so great and asks for your prayers and positive energy. Her shortness of breath has gotten progressively worse and she is very anxious, as are Andrew and I. One day at a time . . . one breath at a time. Easier said than done. My twin-gut-vibe tells me she'll be okay.

—Ana, post on a CF online chatboard, age thirty-two

She lay there, just trying to breathe. Her chest heaved up and down like an accordion; her closed eyes were obscured by the face mask of the BIPAP (bilateral positive airway pressure) machine, a preventilator device to help force air in and out of her damaged lungs. Cool air flowed into the room from the open window. I sat by her bed holding her hand. Through the rubber glove I wore I could feel the warmth of her skin. Beads of sweat clung to Isa's forehead as she worked so hard, as if she were running her last marathon, just to breathe. I shivered in the cold room.

I stared at her in the darkness. Was she awake, or was she finally asleep? The hissing of the BIPAP machine blowing pressurized air into the mask created a soothing background hum, interrupted by occasional explosive coughing fits. When she coughed, her chest vibrated, tightening in squeezing motions as copious blobs of foul mucus poured out of her lungs, making sounds like shoes stepping in deep mud.

"I'm coughing," she'd manage to say, signaling me to step away, and I would move back from the bed, giving her space to cough. There was no more muffling of the noise with cough towels, no modest covering of dirty tissues. It didn't matter anymore. All that mattered was expelling the peanut butter-like goo that was solidifying her lungs. It took everything she had to cough, exhausting her so that she was barely able to hold the paper cup to spit into.

She relaxed again. "Ana," she said, "just rub my chest. I'm so sore. It hurts."

I put my hands beneath her T-shirt and again absorbed the heat of her skin. I could feel the smoothness of her chest, the chest that I had pounded for so many years. The sinewy muscles were firm, the expanded rib cage hard. I put my hand firmly on her chest, repeating Mama's mantra, "*Yokunare, yokunare*" (Get better, get better).

"My stomach," Isa whispered. "Rub my stomach."

I slid my hands down to her belly, the smooth, flawless belly free of a scar. I felt the dimple created by her protruding belly button surrounded by her proud six-pack abs. The muscles were contracting heavily, as if she was doing sit-ups every second, her diaphragm pumping just to breathe.

*Just to breathe. All she wants to do is breathe.* Such a simple task had become so momentous in such a short time. A routine hospitalization for another tune-up last month had led to an unexpected, relentless, downhill decline.

"What happened? When did I become end-stage?" Isa kept asking. It was only a *Pseudomonas* infection, not a virulent new strain of bacteria or a virus that we had feared. So why weren't the five potent IV antibiotics working?

The signs were staring me in the face. The BIPAP machine. The panic attacks. The cessation of eating and sleeping. The commode. The Depends. The Gatorade. The darkness of the room. The plea to make the room colder because she was burning up. The way she was breathing, or not breathing. I had seen it with Bob Flanagan, with Karen, and with so many others. Was this really happening? Was it her turn in line? I stared at Isa in the darkness. No, this can't be happening to Isa. We were supposed to be at the end of the line—the dreaded line we were all standing in, just waiting for our turn to die from this fucking disease. We were supposed to write a book together. She had unfinished business. My denial kicked in, and I heard voices in my head. *She's strong. Those Stenzel-Arima genes will keep her going. She'll pull through. This is just a bad spell.* Rob had said Sonya was like this, and then she'd snap out of it and be okay for a while. I trusted Rob.

There was a knock on the door. It was the respiratory therapist. Time for another treatment. They came every two hours for an exhausting hour of aggressive chest percussion in a last-ditch effort to remove her lungs' putridity.

"Isabel, treatment time," remarked Tom, the tall, burly man that Isa had requested for his strong percussion skills. He towered over her bed, his large frame casting shadows on her body.

Isa opened her eyes. She turned to him, almost whispering, "Later, not now. I just want to sleep."

*This is the ultimate sign, I thought. She's refusing therapy. Oh my God. Maybe this is it.*

"You need your treatments," Tom replied. "I'll come back in half an hour. We have to get this crap out of you."

"Yeah," she whispered, "half hour. Just let me sleep."

A few moments later Isa awoke, her wide eyes staring at me as she shouted, "There's going to be a miracle!" Then, her body relaxed, and she closed her eyes again. I didn't know what she meant.

Later that night, Isa awoke again, this time shouting, "Praise God! Praise God!"

I watched her unusual religious proclamation and prayed that God was with her. Just a day before, Isa had told me, "I'm having a spiritual epiphany."

Sometime later, there was another knock on the door. It was Dr. Henig. Andrew, pale and unshaven, was at her side. I stepped into the hallway with them. The warmth, after the cold of Isa's room, soothed my chilled bones.

Dr. Henig spoke in a low voice, explaining how grave Isa's condition had become. "I believe," she said, "that your sister is at the end of her life. Without a transplant, we need to seriously discuss compassionate care."

I blocked out the words. My mind swam with a million reasons why Dr. Henig must be wrong, that the Stenzel twins were somehow an exception to the ultimate CF death sentence.

I was losing my twin. She lay there, just as Bob Flanagan had before he died, a contorted skeleton in a fetal position, destroyed by this disease. Her face was squeezed from the mask, her cheeks swollen from fluid retention.

"My family! Where's my family?" Isa shouted.

Andrew rushed in, his eyes watery and puffy. "We're here, sweetheart. We're here. We just stepped outside to talk to Dr. Henig so we wouldn't wake you. You need your sleep, baby."

Dr. Henig and I stood by Isa's bed.

Her eyes were closed. She mumbled weakly, "I don't want to be alone. I'm afraid. I want you to watch me."

"I'm so sorry, dear. I won't leave you again. I'm right here."

Isa opened her eyes and saw Dr. Henig standing at the foot of her bed. "Are you here to give bad news?"

Dr. Henig smiled. "No, but we need to talk."

She began a discussion about whether or not Isa wanted to be on a ventilator.

Isa perked up, salvaging the energy she had left to sit up in bed. She resisted, "I don't feel like I'm dying. I'm still strong. I'm still coughing tons of stuff up."

Dr. Henig explained that if Isa's lungs continued to fail, she would be taken to the intensive care unit to be put on a ventilator.

Isa protested, "I don't want to go to ICU. I don't want to be on a ventilator. Then I couldn't cough. I know what all that means."

"If you're on a ventilator, you'd be able to get more rest. I'm concerned that you're not sleeping, that you're exhausted, and that's not helping the situation." She sat down on Isa's bed and took her hand.

"I think there's going to be a miracle," Isa said.

"I hope so," Dr. Henig acquiesced. After a pause, she asked, "Why aren't you sleeping, Isa?"

"If I sleep I won't wake up."

"Are you afraid you'll stop breathing?"

Isa nodded.

"You need your sleep. We'll watch you. No one will let you stop breathing while you sleep."

"Okay." She was calmed by Dr. Henig's soothing, gentle tone. Isa reached out and held my hand.

"I'll watch you, Isa," I said. "I can see you breathing, strong and hard. I'll wake you, I promise, if you don't breathe."

A few minutes later, Ryuta arrived. He could see we had been crying. Isa woke briefly, holding out her hand to him. "Ryuta," she mumbled, "I'm sorry to put you through this. I'm sorry you have such sick sisters."

"No," Ryuta replied, his voice composed, "it's all right."

"I wish you had normal sisters."

"No, you're better than normal sisters." His face was blank.

She gripped his hand tightly. "I love you, Ryuta."

"Love you, too."

The night before, Ryuta had slept at her bedside so she wouldn't be alone. Worn out by recurrent panic attacks brought on by the torturous sense of suffocation and impending death, she had broken down and sobbed in front of Ryuta and the respiratory therapist. "I just can't breathe. Is this the end?"

Ryuta had stroked her back as she continued, "If I'm dying, take care of Andrew. Take care of the dog. Tell Mama and Dad I love them. I don't want to die yet." He fought back tears, trying to focus on the moment, trying to calm her. Each sob strained her breathing more as her chest heaved, wrenched, her muscles twisted in an effort to get air.

"Just breathe. Just concentrate on breathing. You'll be okay, you'll pull through. You gotta fight. You're strong."

"I want you to have my German gold coin, the one from Oma."

"Shh. Don't talk like that. Just keep fighting. You're gonna win."

Now, Dr. Henig and Ryuta stepped out, and Andrew and I were left alone with Isa. It had been over three days since she had slept. Just when it seemed like she had drifted off to sleep, Isa spoke: "Haven't we been here before? Haven't we done this before?" followed by an apologetic whisper, "I'm so confused. I'm delirious."

Andrew and I looked at each other in the darkness. Our red and swollen eyes exchanged glances of disbelief.

I couldn't imagine life without Isa. She was part of my everyday consciousness, my every move. "Isa, does this outfit match? Isa, what should I get Mama for Christmas? Isa, do you want me to make you dinner? Isa, what do you think about what I wrote?" Her guidance permeated every aspect of my life, and I envisioned a life without Isa as one filled with unfathomable emptiness.

I bowed my head and wept silently, holding her hand. My tears and runny nose soaked the masks covering my face—the masks that had separated me from Isa for over three years because of the risk of cross infection. Fuck cross infection. It wasn't going to keep me from spending these last days with her.

Isa turned to Andrew. "Babe, I want you to love again. I want you to marry again, to have a child, to be happy."

Andrew buried his head in his hands, shaking his head, sobbing, "No, only you . . . No . . . No, never . . ."

The pain of watching him lose his love gave me images of heart-wrenching agony, and even psych consults, Prozac, and suicide attempts.

For a moment, there was immense peace in the room. The night sky outside the window was dark. There was a soft drizzle of February rain tickling the leaves of the trees outside. A few stars peered through the clouds. A gentle breeze swayed the flowers in the garden outside the window, like the night itself was exhaling. It was quiet.

For what seemed to be hours, we sat there: Andrew, seated at one side of the bed, holding Isa's hand, and I at the other, our sniffles muffled by the humming of the BIPAP machine. The moment embraced us with dread and beauty.

Isa was dying. *Dying. Dying. No fucking way. I can't believe this. What happened?* There's so much left to do together. What about our aspirations to hike, travel, write a book together after our transplants? I had always envied her. Was it some cruel justice that I was meant to live with new lungs

and she wasn't? I felt sick at the thought of Isa dying without ever having experienced life without CF. Would God be so cruel?

Isa turned to her side and began to cough. I stepped away. After a few seconds the coughing became a shallow, wheezy, empty exhalation. Then silence. Andrew and I watched. More silence.

"Isa?" Andrew said in a loud voice. No response. He peered at her and noticed a small stream of blood oozing out of her mouth.

"Oh, my God, get the nurse."

He reached for the emergency call cord and yanked it from the wall. I ran to the door, flinging it open and shouting as loud as I could, "Help!"

Within minutes, the room was filled with a dozen medical personnel hovering over Isa's limp body. Bright lights were flicked on, a crash cart wheeled into the room, and alarms beeped, all while a voice repeated over the intercom, "Code blue. Ground floor. Room 41."

Andrew and I were escorted to the corner of the crowded room by a nurse. "You need to step aside."

"Isa!" I shouted over the commotion. "We're here! Hang in there!" Could she hear me?

She began to speak loudly with a fervor I hadn't heard for days. "It's okay," she called out. "I'm all right; this is not a big deal. I'm fine. I'm okay."

Then she became confused, "Am I having my transplant now?" The doctors worked over her, pulling out tubes, syringes, measuring this and that. I noticed her hands were a deep magenta.

"Twins! We're twins!" she continued. "We're writing a book!"

I shouted back. "Yes, we are twins. Hang in there. We're right here!" Tears streamed down my cheeks. My muscles trembled like I was seizing. Andrew and I held each other, terrified. He sobbed, "Oh my God, it's happening. No, no, no . . . please, God, no." I began to hyperventilate. I saw Isa's face turn a deep purple, her hands and legs began to writhe and flex. *She's dying right in front of me.*

A few seconds later, Isa's whole body began to contort like she was riding a wave; her legs flew back and forth wildly.

"Woowwwwww," she cried out. "This is ammaaaazzzing! This is beautiful!" She giggled. It was as if she were flying somewhere far away, admiring the view. "Ammaazzzing!!"

She was crossing over. Then she called out, "Bob Flanagan! Bob Flanagan!" as if she saw him and was greeting him.

She laughed, "Ooooh, it's sooooooo bright!"

A respiratory therapist working on her yelled, "Isabel, stay with us! Don't look at the light. Stay here, sweetie!"

I was trembling. Panic swept over my body like a torrential rain, and I felt faint.

"You need to step outside," the nurse said again.

I stepped away, dazed, as though moving through a fog. *This is it. I can't believe it.* From the hallway, I peered back into the room at the team of doctors and respiratory therapists working over Isa's body. I heard the suction machine, the hissing of oxygen, the shouting of a doctor, "We need a face shield."

A chaplain approached us and stood by my side. Suddenly, I felt more religious than ever before. I prayed. *I'm sorry I'm such a shitty Christian, God, but please, please, help Isa. Please bring her back. Please let this not be the end.*

In the flurry of people entering and exiting the room, I saw the faces of the respiratory therapists who had worked so hard for Isa in the days before, doing therapy on her until their arms burned, acquiescing to her demands for longer and harder therapy as she desperately fought to save herself. Looking into their faces, I could tell that they had watched this scene play out all too often. How did they do it day after day, code blue after code blue, CF patient after CF patient, always with the same result?

Later than night, Isa was put on a ventilator, the machine she had argued against just a few hours earlier in her last coherent conversation. She did not die. She was heavily sedated, so that she would not fight the tube in her throat. She was finally resting.

She had seven days. After seven days on a ventilator, Stanford deemed a patient too sick to survive the lung transplant surgery. Most people wait on the list for over one year and Isa had been listed only two weeks earlier. We were told there were 211 people waiting for lungs in the Bay Area. The odds were unbearably slim. I mentally wrestled with denial and hope: denial that she would die and that I would be left behind, and hope—visions of her telling me someday, "I don't know why everyone was so freaked out, I told you there'd be a miracle."

Mama and Dad arrived late that night, and we embraced. "I have been dreading this moment all of my life," Mama said, tears welling up in her eyes. "I thought I would be prepared, accepting. But I'm not ready to lose Isa-chan." The last time I had seen her cry was when Karen died.

The next day things were grim. Our family besieged the ICU, making the waiting room a base camp of hope and mourning. I watched Isa, my mind numb. I felt disoriented; I had lost all track of time. It didn't matter. Isa's pale, thin body lay motionless, her belabored breaths the only sign of life. She developed a fever, and Dr. Henig began to worry about her lung infection spreading to other organs, a condition called sepsis, which would really signify the end. Throughout the day, friends streamed in and out of the waiting room in a seemingly endless outpouring of support and love. Despite the somber mood, there was beautiful energy in the air, like love was talking and people were listening.



Later, I stood by Isa's bedside alone. Her eyes were half-open, and she stared at me. But her eyes were glassy, blank, and her pupils trembled like dancing beads. She was absent, but I spoke to her anyway.

"I love you. Hang on, Isa. You're strong. We're all praying for you." I looked at her jugular vein, which was bouncing like a pinball in her neck. "If you want to stay, hold on . . . stay strong, fight, give it everything you've got." She moved her arms. Could she hear me?

"But if you want to go, it's okay. I don't want you to suffer. I'm here with you either way." Tears soaked my mask again. "It's okay to let go if you need to."

I held her hand, watching her. Suddenly her chest vibrated and her face became red. She seemed to be coughing, her chest erupting into the closed ended tube of the ventilator. I looked at the monitor. Her oxygen saturation was 92. Then 88. Then 73.

I turned to the nurse. "She's de-satting. Can you check her?"

The number was now 62. *Oh my God. She's letting go. Now, it's really happening.* The nurse ran to the door and shouted out to the nurse's station, "We need some help in here."

I stepped aside as a flurry of medical personnel entered the room again. The nurse unhooked the ventilator tube and began pumping air into Isa's ventilator using a plastic bagging device. I left the room, panicked, scurrying toward the waiting room in tears.

"She's de-satting!" I blubbered to the audience of family and friends. "I was talking to her, and her sats began falling. I told her it was okay . . . that if she wanted to stay, she should fight . . . but if she wanted to go, that it was okay . . ." My voice trailed off.

Andrew stood up, his face darkening and tears streaming down his face. He yelled, "How could you say that?! You have to be positive. You have to give her encouragement. If you tell her she can go, you're killing her!!"

"Andrew, we have to give her permission. She'll decide. We're being selfish by wanting her to be here. She's suffering . . . do you want to prolong her suffering?" He didn't understand. He had never been around death before.

"No!" he screamed, "You shouldn't say such things. Not yet." He fell onto the sofa, cradling his head in his hands, his face beet-red and his hands shaking.

"Isa and I talked about it. I know what she wants. I can tell her anything." I turned to Rob. He knew; he'd been there. "Don't you think it's okay? It's okay, isn't it? People need to hear that it's okay to let go, or they'll keep hanging on for the sake of others." Rob nodded and put his arms around me.

The room was filled with statues, everyone frozen by the volatile exchange they had just witnessed. I looked around at the tearstained faces,



and then I looked back at Andrew. A knot of resentment swelled inside me. I hated Andrew, yet I loved him because we were in this together. I plopped down on the sofa, my back turned to him. My body was consumed by fatigue, and my head ached from dreadful emotions.

Death happens every day for so many reasons. I tried to find comfort in the idea that if others had gone through this then it would be easier, but I was not finding this to be true. I envisioned Isa's funeral, what we would do with all of her belongings, and wondered if I could even return to work, or my CF community involvement, without Isa as my sidekick? I just saw myself crawling into a big hole and not coming out for a very long time. Would my broken heart roll me into organ rejection, and would I die soon after her?

A while later Andrew, my parents, and I approached her room. She lay calmly now. The respiratory therapist explained that Isa had begun to cough, and that had moved mucus up into her main airways, and they had been able to suction out a large amount. Her oxygen saturations had improved. So it hadn't been something I had said. It had been Isa's deliberate attempt to keep fighting, to cough the poison out, to clear her lungs. I was relieved.

Dr. Henig approached the room, a tall man in a white coat at her side. Her eyes were sunken under her dark-rimmed glasses, her frizzy red hair hung above her brows. She looked exhausted. She spoke in a serious tone. "We need to examine Isabel. Can you excuse us?"

The four of us staggered back to the waiting room, dazed. It was close to six in the evening. I watched as nurses walked nonchalantly down the hall with their belongings, having finished another workday, going on with their lives.

Outside, the sun was setting behind cumulus clouds; the puffy white cotton balls floated in a fading blue, their edges silhouetted against the illuminated pink and purple streaks. The sun sets every evening, but it is funny how I remember this sunset in particular, the day Isa was dying. The first blossoms of spring were emerging, and gentle petals were beginning to cloak the barren brown branches of plum and pear trees in the hospital courtyard. It reminded me of Japan.

Later that evening, Dr. Henig entered the waiting area followed by the tall man in the white coat. Under his coat, he wore hospital scrubs, and he had a surgical cap on his head. On his name tag, I glimpsed the words *Cardiothoracic Surgery* next to his name.

Dr. Henig's eyes were tearful, her face reddened behind freckles. "We have lungs available for Isabel," she announced, her face coming to life with a smile.

I gasped in disbelief as my family and friends around me cheered as if the Stanford football team had just won the Big Game. The transplant team from Stanford was on its way to the donor's hospital to examine the lungs. For a moment, I mentally tiptoed around my exuberance since there was a small chance that the lungs were not suitable. But then I suppressed that slim "what-if" and grabbed onto faith: God would not put us through all of this for nothing.

In an instant, the ominous cloud of impending death was lifted, and the rainbow of hope shone through with radiant light. Our prayers were answered. The sunset outside turned brilliant.

Isa was taken into the operating room at 4:30 that morning. By two in the afternoon, the surgery was over and was a success. Dr. Reitz, who had also done my transplant, reported that Isa's carbon dioxide before surgery was 140, and he had never known anyone to survive with such a high level.

That evening, I peeked into the ICU. Isa was still on a ventilator, completely sedated, similar to how she had been the night before. But this time, there was no straining at each breath, no heaving chest moving up and down like a piston. Instead, her breathing was peaceful and calm, a gentle inspiration and expiration like the movement of a butterfly's wings. Her lips and nail beds were pink.

Back in the ICU waiting room, I held Mama's hand. "Congratulations," I said, "you are now guaranteed not to have your children die of cystic fibrosis lung disease."

She smiled back, squinting through the tears of relief and awe.

"Now aren't you glad you didn't have triplets?" We laughed.