

CHAPTER 1

The Call That Changed My Life

“For happiness is anyone and anything at all that’s loved by you.”

—From the musical,
You’re a Good Man, Charlie Brown

Everything around me froze.

The voice on the other end of the phone sounded like a muffled, underwater siren handing me a death sentence. Cold. Removed. Terrifyingly robotic and sterile.

“The fetus has a 9/10 chance of having Trisomy 21.”

“What do you mean,” I said, “Like, Down syndrome?”

“Yes. I’m sorry.”

Just an hour before I had been driving home from an event. It was March 6, 2020, and although it was still very cold, I noticed that the black, bare trees whizzing past seemed to have a bit more life in them. Maybe even a few buds of spring? I could have been imagining it, of course, because I was wearing rose colored glasses at the time. I was pregnant with my second child and, aside from the pure exhaustion of the first trimester, I was feeling tremendously hope-filled. I was excited and grateful for this rainbow baby growing inside of me. Just a few months before, I’d experienced a miscarriage and the physical, emotional, and spiritual pain had been devastating.

But this time . . .

THIS pregnancy was destined to be different! I could feel it in every fiber of my being. I'd recently heard the heartbeat and surpassed the week where my other pregnancy abruptly halted. As I drove home, there was a brightness to the brisk, late winter day. I'll never forget that feeling of calm, cool contentment before the impending storm.

As soon as I got home, I threw off my winter boots, changed into my pajamas, and wriggled beneath the covers for a quick nap while my two-year-old son slept soundly in his crib. I began to drift off to dreamland when, out of nowhere, I bolted up and looked at my phone, which had been on silent mode. The letters "OB" flashed across my screen, and I immediately swiped to answer. This was it—the moment I would find out the sex of the baby! The prenatal testing I had done was for *this call*. So I could prepare and plan for the colors of the nursery.

In a flash my mind went from pink or blue to black and white. White noise. Stark silence in between awkward utterances of a doctor who apologized with every word, spoken and unspoken.

"Down syndrome" reverberated between my ears over and over again like an echo chamber. I somehow had the wherewithal to ask the sex of the baby.

"The fetus is a boy," she said in a low whisper.

I got up slowly from my bed and felt the weight of my legs. Every step down the stairs toward my husband took an extreme amount of effort and I felt like a blob of cells moving with no direction. I could still hear the doctor speaking but only in the form of fragmented sentences:

". . .Genetic counselor. . ."

". . .maybe they can get you in on Monday. . ."

". . .you have options. . ."

". . .Potential problems with the fetus. . ."

". . .again, I'm sorry. . ."

". . .questions. . ."

". . .concerns. . ."

". . .risks. . ."

Every word seemed more terrifying than the one before it. I felt like I couldn't breathe and I had the uncontrollable urge to run to some uncharted destination. Somewhere to escape. My body. My mind. The voice on the other end of the phone. I collapsed in a puddle of tears at the bottom of the stairs.

My husband, who was working from home that day, rushed over to me and sat with me on the bottom stair as I sobbed. After what felt like an eternity, I threw the phone down and gathered enough air to blurt out, "They think he has Down syndrome . . . I can't . . . How can we . . . what about my life . . . what about OUR life . . . what about Clay (our older son) . . . I can't do this!"

My husband, often the grounded one in times of heightened emotion, paused for a moment and said gently, "We CAN do this. He is our son and we will love him." With those simple, soft, and succinct words, I calmed down for a millisecond and knew he was right. I knew we already carried so much love in our hearts for this dear boy. But I could feel a dark cloud of fear creeping down over the horizon like lava flowing from an eruption. Slow. Hot. All encompassing.

I curled back into bed and didn't emerge for the entire weekend. The weight of my body was dense and heavy and my mind began to go numb to block out the millions of thoughts. The dissociation was perhaps a defense mechanism to protect me from all the information that had come down like a gavel in a courtroom. A life sentence for a crime I didn't commit.

A few hours after that call, in between crying spells, I saw a clearing from the fog in my mind and remembered a young girl I'd watched onstage, singing "Hello Dolly." Just one night before that fateful call, and two weeks before the entire world shut down from COVID-19, I'd gone to see a high school production with a friend. Midway through the show I noticed a girl who had different features than the other teenagers. Her almond-shaped eyes glistened as she sang and danced along with her fellow performers.

When we left the show that evening I exclaimed, "I'm so impressed the director chose to cast someone with Down syndrome! I've never seen that before! How cool!" I genuinely felt encouraged and filled with hope by the diversity and inclusion I saw reflected on that stage. In all my years of amateur and professional theater, I had not once

seen a person with Down syndrome onstage. The whole idea seemed revolutionary to me.

And yet, as I lay in bed the following day, completely paralyzed, mind, body, and soul by my baby's potential diagnosis, I pictured that girl onstage. Where was all that hope I'd felt about her? Why had that vision suddenly diminished? I realized that, in addition to fear, I was grappling with resentment, having already been through so many struggles in 38 years. I considered this another unexpected act in a play I called "My Life." Hadn't I been through enough? A steady stream of emotions filtered through my body 100 miles a minute until one crept in that I hadn't expected and couldn't explain away.

Shame.

Not guilt. Guilt comes from an action that someone does or does not take. I recognized in the early days that nothing I did caused this turn of events. But the shame I felt all throughout my body was all consuming. I wanted this baby. I prayed for this baby. My husband and I intended to have a second child. But the feelings stirring inside of me when the diagnosis was fresh did not align with all of that. I felt like I wanted to run away from my body . . . from this baby . . . from this life. And that made me feel shameful. How could I have gone, in a moment, from celebrating the baby I was carrying to wanting to escape because of the child's potential diagnosis? The darkness that consumed me with those feelings was something I had never experienced before and was more than I could even begin to process, at the time.

Come Monday morning, I finally managed to drag myself out of bed and get ready to meet with the genetic counselor. My husband and I dropped our two-year-old off with a friend and drove to our appointment. A list of questions and worries began to form in my brain as I watched the lifeless, leafless trees whiz past my window, now without a hint of spring budding on their branches.

What would I even ask this person when I met her?

- ◆ Did I want to hear what she had to say?
- ◆ Would I always feel this alone?
- ◆ Would my friends abandon me?
- ◆ Were my dreams crushed?
- ◆ Is a 9/10 chance as high of a probability as it seemed?
- ◆ Was there a loophole in this statistic?

I felt completely desperate and searching as we parked the car in the lot. I was on a relentless merry-go-round of rationalizations and explanations. A sort of “He loves me, he loves me not” dance I was doing in my mind, still desperately trying to make sense of the news we’d been given just two days before. Walking slowly into the building, I noticed a little girl in between her parents. Holding her hands on either side, they were swinging her up and down. I had a flashback to a moment like this with my parents at Disneyland. This is one of the oldest recollections in my memory bank and it gripped me with a sense of nostalgia and a desire for simpler times. As my husband and I passed them, I glanced briefly at the little girl’s face.

She had Down syndrome.

I smiled because I don’t believe in coincidences.

And then I cried because I don’t believe in coincidences.

The hallway leading up to the tiny office felt like an endless sea of white. It was cold and stark with no paintings on the walls. No frills. I felt a little faint as I walked into the room where the genetic counselor stood, welcoming us. Much to my surprise, the woman didn’t seem afraid or sorry to see us. She smiled warmly and invited us to sit down.

Without wasting a moment, she began to explain the basics of Down syndrome. It went something like this: “Down syndrome is a genetic condition that occurs when a person has an extra copy of chromosome 21.” She showed us a chart that demonstrated the information she was explaining (see Figure 1.1).

“This extra chromosome causes developmental delays and can sometimes make individuals more prone to health concerns. 50% of individuals born with Down syndrome have a heart defect.”

As I listened, I could feel the tears primed and ready to flow like Niagara Falls. But instead of continuing to list all the daunting and overwhelming statistics, she shifted gears unpredictably and said, “This occurs randomly at the moment of conception and NOTHING you did caused this or altered the pregnancy. Your baby had this extra chromosome from the very first moment of conception.”

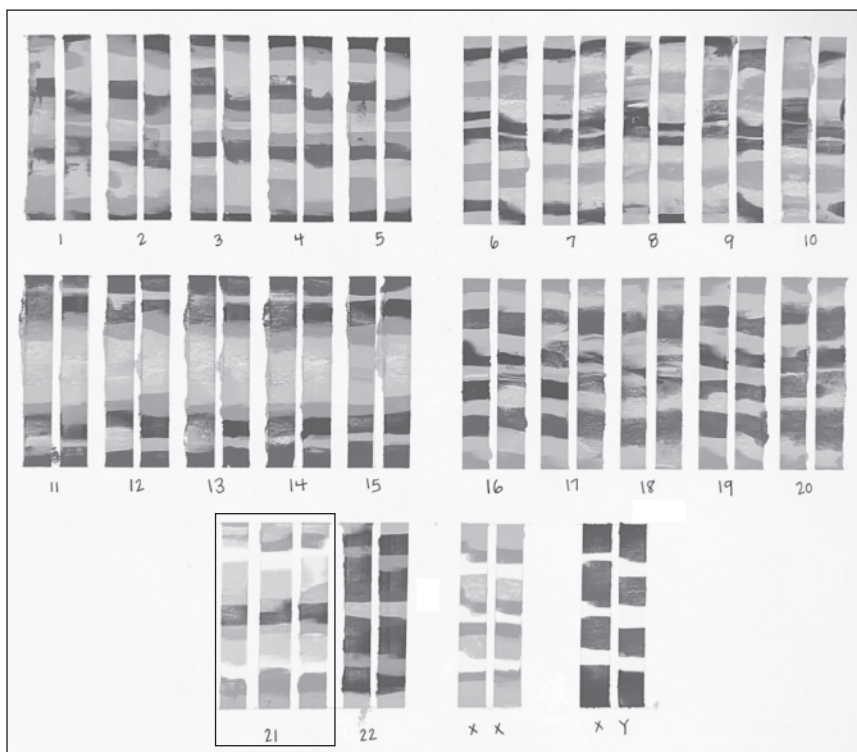


Figure 1.1 Karyotype: An organized profile of a person's chromosomes. This chart shows the extra 21st chromosome characteristic of Down syndrome. Courtesy of Tiffany Abbott Fuller

The genetic counselor handed me some resources (many of the same organizations you will see listed in a chapter in this book)—Jack's Basket, The Down Syndrome Diagnosis Network (DSDN), and a couple of local networks and online support groups to investigate. She shared some statistics about sibling relationships when she learned we had an older son (you'll read about those statistics in Chapter 7). She also shared some quotes from real people with Down syndrome and their love for life (in Chapter 14, you'll read some of their firsthand accounts about living a life with an extra chromosome). The statements she read aloud reflected a brighter view of life than most individuals I've encountered in my lifetime. All of this felt so foreign to me but I slowly began to feel a weight being lifted off my chest. I felt like I could take a baby step forward, into a foreign land.

I had no idea that this newly embarked territory would also include the country shutting down from a global pandemic just a few weeks later. Every doctor's appointment became more daunting and mysterious than the last. My husband couldn't accompany me to any appointments due to lockdown, and there never seemed to be enough masks or hand sanitizer to make me feel safe. I washed my groceries and cleaned boxes that came to the house with gloves on my hands. Nothing seemed steady or certain, and *everything* felt different and more difficult than the day before. The extraordinary magnitude of hardship I went through felt all-encompassing at the time and, reflecting back, I'm not even sure how I got through it. But one baby step at a time, I crept forward. I cried when I needed to cry, I laughed whenever I found something remotely funny, and I tried to hang on to hope. What hope, I didn't know.

About seven months into my pregnancy, my friends threw me a baby shower over Zoom. Twenty-five or thirty people came and we all gushed being together, since we'd been so deprived of human connection for months during the pandemic. I relished the laughter; I allowed the tears to fall slowly down my face as I honestly expressed my fears about this precious baby. Would he be ok? Would I be ok? Would our family be ok?

But in this call, I also found hope wrapping itself around my heart like a glove in a way it hadn't before. In the midst of the hope I was feeling, I had a sudden flashback to watching *FROZEN II* with my son, shortly after the call I'd received from the doctor. The character Anna found herself in uncharted waters and sang a song that described exactly how I felt. The final verse said:

With the dawn, what comes then

When it's clear that everything will never be the same again?

Then I'll make the choice

To hear that voice

And do the NEXT—RIGHT—THING.

The "next right thing" had indeed carried me through my pregnancy to the moment of my Zoom celebration and all the way up to Jedidiah's birth . . .

. . . but we'll get to that.

A Little Extra

As I write this, I'm picturing a woman who received word from her doctor about the child in her belly. I'm envisioning the mom and dad who are sitting in a dark hospital room with a birth diagnosis after a lot of whispering and side glances. I can see the single mom who has been juggling so many things already, and now she has to figure out how to balance and immerse herself in an all-encompassing land of early intervention and appointments with specialists. I wish I could hug every person who did *NOT* have the positive experience with their genetic counselor that my husband and I experienced.

In my correspondence with hundreds of families through my platform, Happiness Is Down Syndrome, I've heard about the terrible bedside manner that often accompanies a diagnosis. The fear and grief that can follow those moments are *REAL* and *SACRED* and not unusual. I traveled to Armenia with an organization called RODS Heroes (you'll hear more about them, later) and met with mothers who had lost their whole support system, including their husbands, simply because they chose to keep their baby with Down syndrome and not give the child up for adoption. I stood face-to-face with a mother from India and another from Ghana after giving a speech at the UN who told me about their unique challenges in their respective countries. No two journeys are the same, yet we can relate to one another in a powerful way when given the opportunities and proper tools to do so.