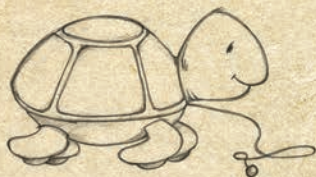


Don't Blink



*What the little boy
nobody expected to live
is teaching the world
about life*

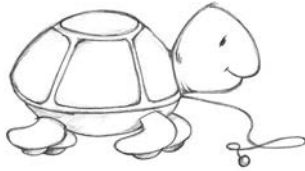


BRANDON & BRITTANY BUELL
parents of "Jaxon Strong"

with ANGELA HUNT

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Don't Blink: What the Little Boy Nobody Expected to Live Is Teaching the World about Life

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Introduction

MY WIFE, BRITTANY, AND I have a small problem. Ever since the birth of Jaxon, our baby boy, we've been deluged with Facebook messages, e-mails, and letters. We hear from people who watched our story on *Nightline*, read about us in the newspaper, or saw our posts and photographs online. Some of them want to give us a long-distance hug of encouragement, and a few want to give us a piece of their minds. Some want to cheer us on because they've been in similar situations, and others want to warn us about the challenges ahead. Some write out of a well of anger or disappointment, but far more write from an ocean of compassion.

I wish we had the time to sit down and respond to each message and answer every question, but meeting the needs of our unique son fills nearly every hour that isn't already required for sleeping, eating, or working.

DON'T BLINK

So we're writing this book to answer all the questions and comments we haven't been able to respond to . . . and perhaps a few that haven't been asked yet. We're writing so you can know why we made the decision to have Jaxon even though we knew he would face serious physical challenges. We're writing so you can know how we felt when he first came into the world and what we thought when medical experts told us he probably wouldn't live more than a few hours after birth. We're writing so you can understand why we're convinced that Jaxon is who he is—and he is not a mistake, because God does not make mistakes. Most of all, we're writing in the hope that our joy can splash from these pages into your life. We adore our son, and we celebrate him for being the marvel and inspiration he is.

We could fill this book with platitudes and some of the cute phrases you often find beneath pictures of wide-eyed kittens dangling from branches. Instead, we'd like to tell true stories about two ordinary people who welcomed an extraordinary child into their home and haven't regretted that decision for a single minute.

Through the tears and the challenges, beneath the struggles and the complications, we have learned a few things about living a life of joy in the midst of challenging circumstances. If any of these life lessons can help you bear

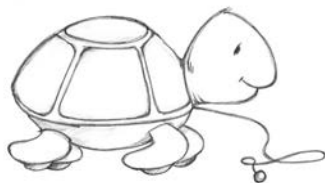
INTRODUCTION

your burdens with greater patience, look at your loved ones with new appreciation, or find hope in a desperate situation, then we will have accomplished our purpose.

Brandon and Brittany, for Jaxon Buell

LESSON I

Trust Your Gut



Brandon

You'll never be fully ready; just make the leap.

Perhaps I should start this story at the beginning, before I was married.

I'm one of those rare Florida natives, the son of two schoolteachers. I was pretty much heading nowhere special until I answered a message from a girl on Myspace .com. I'd been raised in a Christian home and my grandfather was a Methodist preacher, so I was never much of a hooligan. But nothing had inspired me to set the bar exceptionally high in the area of personal achievements.

Then in March 2010, I saw the message from a girl named Brittany. The message was about a week old, and I nearly missed it because I was in the process of moving my digital existence from Myspace to Facebook. But I clicked on Brittany's post, and there she was, all cute and blonde and blue eyed. Naturally, I thought it might be worth a shot to give her a call. After all, I wasn't dating anyone at the time. I was out of college, living on my own, and trying to get started in the banking business.

My gut told me to go for it.

Isn't that how it is? When you're not actively looking for something, that's often when you find it.

So I contacted Brittany, who was new in town and visiting a Baptist church in St. Augustine Beach. After a week or two of exchanging messages, I went to church with her, and some of my friends saw right away that this girl and I were never going to be "just friends." After we went out a few times, I could see that she was independent, big hearted, and strong enough not to need me—a quality I found extremely attractive. Even though she was three years younger than I was, she had a certain air of maturity about her.

No one had to hit me over the head—I realized pretty quickly that I'd found a treasure. I'd been praying for a woman who would keep me on my toes, and God had sent her to me via Myspace, proving that He has a great sense of humor.

Brittany and I hit it off, and six months later I asked her to become Mrs. Brandon Buell. We got married on May 1, 2011, and officially began our journey together. We were energetic, eager, and ready to begin building the future we had imagined for ourselves.

When I first met Brittany, I didn't really want children. I was envisioning myself as a successful banker, and kids weren't an integral part of that picture. I wouldn't have

mind them, but I was content with just the two of us. I liked being half of an independent couple who could do things and go places at the drop of a hat, and I knew that would change if we had kids.

We *did* make some changes at the drop of a hat shortly after we got married. In 2011, we moved across the state in search of better jobs and more opportunities for career advancement. After moving a couple of times, we finally settled in central Florida, close to where I was born and raised.

After a year or so, Brittany thought it might be nice to have kids, and I was swept along by her optimism. After a few months of trying, the doctor told us that we probably wouldn't have children, so we stopped focusing on getting pregnant. But after a few months, Brittany gave me surprising news: she was pregnant, for real.

Wow. It was an honest-to-goodness miracle. I sat, stunned, as a whirlwind of astonishment whipped through the room. I was happy, excited, and worried, all at the same time. Concerns started popping up in my head like critters in a Whac-A-Mole game. How were we going to take on the additional financial burden of having a child?

Since I worked at a bank, I was always dealing with numbers and bottom lines. My frantic thoughts centered

on our financial future—the house payment, insurance, and now the added expense of a child. Not to mention the looming specter of college tuition in only eighteen years . . .

“How are we going to do this?” The words slipped off my tongue before I even realized what I’d said.

“We’ll be fine.” Brittany squeezed my hand and gave me a confident smile. “Everything’s going to work out.”

Really?

The timing was crazy. We were getting ready to move into a new rental home, so we were busy packing and trying to organize our lives. As I looked at our list of regular expenses and added to it the miscellaneous costs of moving, I couldn’t help thinking about baby clothes, car seats, diapers, and wipes.

I fretted over our budget and analyzed it for a couple of weeks, but eventually I began to relax. It helped that Brittany was completely confident and happy. We moved into our rental house and started settling into a new routine. Life was good. Brittany was ready to enter dental hygienist school, and after that she’d be working full time.

Feeling relaxed and confident about the future, we held hands as we went to the doctor’s office for the first ultrasound. Watching that grainy image appear on the screen, I felt a shiver of pure excitement. This pregnancy

TRUST YOUR GUT

was actually happening. As the technician moved the scope over Brittany's lubricated belly, we saw little arms, legs, a torso, and a head. Then we heard the baby's steady heartbeat, and my own pulse quickened in response. That was a real, live, beating heart in there, and it was so strong.

Ready or not, we Buells were no longer two, but three.

Sometimes you have to dream it before it becomes a reality.

Until we learned Brittany was pregnant, I'd never dreamed of having a son. I know I would have loved a daughter just as much, but within a few minutes of hearing our baby's strong heartbeat, I began to hope our child was a boy. The more Brittany and I talked about it, the more the idea of having a boy appealed to me.

Maybe I felt that way because although I had an older sister, I was the only boy in my family. Growing up, I was an athletic, "all boy" kind of kid. I played sports, I liked cars, and I earned my share of scraped knees and bruised elbows from roughhousing with the kids down the street.

Sitting in that doctor's office, I began to dream about raising my boy—cheering from the bleachers during his Little League games, taking him fishing, teaching him how to throw a football and catch a baseball.

Brittany and I had already discussed our favorite names, and we were favoring Jaxon Emmett for a son.

Jaxon means “God has been gracious and shown devotion,” and Emmett means “hardworking.” Perfect!

I envisioned little marks on a doorframe in our house, where we'd record our son's latest growth spurt. Each year we'd stand Jaxon up against the doorframe, measure him, and record the date along with his height—gently, in pencil, so Brittany wouldn't mind.

I imagined Jaxon and me kicking back on the couch and watching a football or baseball game, roaring like lions each time our team scored and giving each other high fives as we did victory dances in the living room. The extended family would come over on weekends, and all the guys would talk sports, our Jaxon chiming in with his cousins as we rooted for the Jacksonville Jaguars, the Pittsburgh Steelers, the Florida State Seminoles, and the Atlanta Braves.

On his birthday, Brittany would decorate our son's cake with miniature baseball and football players. We'd gather around and urge him to make a wish before he blew out the candles. Brittany, of course, would know what he was wishing for, so we'd have the new basketball or bike or scooter in the garage, all ready for him. The neighborhood kids would come over and gaze admiringly at his birthday gift, but we would have taught Jaxon to be polite and share, so he'd graciously let all the other kids play with his gift too.

My thoughts halted abruptly. Who was I kidding? I was talking about a *boy!*

Whenever I got into trouble while I was growing up, my mom always said, “You just wait—one day you’re going to have a little you!” If my son was anything like me, he would be strong willed, determined, and curious. He’d probably spend a lot of time in the naughty chair while he was a toddler, and we would probably get called to the school at least a couple of times a year. Little boys are often determined to test the rules, and I was sure our son would do his part to try his teachers’ patience.

One thing was certain: if we had a boy, and if he was anything like me, Brittany and I would have our work cut out for us.



Brittany

Be ready to listen to divine promptings.

I had always envisioned myself as a working mom because I’d been working ever since I was a sophomore in high school. I was naturally drawn to the medical field, and over the years I’d worked as a medical assistant, a certified nursing assistant, and a physical therapy technician. I’d always loved science, and the medical field seemed like a natural offshoot of that.

DON'T BLINK

I was born in North Carolina, and I lived there with both my parents until they split up when I was fourteen. They would always drop me off at church, and one Sunday the preacher said, “If you haven’t accepted Jesus Christ as your Lord and Savior, feel free to come down front so we can pray with you.” I didn’t really know why, but I felt this irresistible urge to go to the front. That kind of thing was completely out of character for me. I was never one to voluntarily put myself in front of people, so this prompting to go forward meant something outside myself was responsible. I walked down front and prayed that prayer to accept Christ.

I made it through middle school and high school, with all their ups and downs. After graduation, I was working and living with my dad in North Carolina when one night I had the oddest feeling that God wanted me to move to Florida. Why? I had no idea, but I couldn’t shake the thought. Once again, it was like something or someone outside myself was calling me to take action.

I resisted. I told God that I didn’t want to move to Florida. My mom lived there, and I didn’t necessarily want to live with her. I loved her, but I was twenty-one and no longer a little girl.

The next morning I woke and sat up in bed, hoping that God had moved on to nudge someone else. I looked

at the calendar—March 4, 2010—and there it was again, that strong feeling that God was whispering in my ear. *Go to Florida.*

“Why? I don’t have a job there. I don’t have any friends there. I don’t have anywhere to live, except with Mom.”

Go to Florida.

Sigh.

What could I do? I had to either go to Florida or get used to waking up every morning with an insistent voice whispering in my ear.

So I quit my job and went to live with my mom in a small town near Daytona Beach. Once I’d unpacked, I spent the first couple of days doing research online. I was looking for friends, male or female, who could introduce me to a good church. I searched Myspace for people who lived in the area and found Brandon’s profile. He talked about God in his bio, a fact that impressed me, so I sent him a message.

We messaged online for a couple of weeks, and then we met in St. Augustine, about forty-five minutes north of where I was living. I was a little nervous as I walked up to the beach restaurant where we’d arranged to meet for the first time, but his relaxed manner and his smile immediately put me at ease. I wouldn’t have admitted it to Brandon at the time, but I knew this in my gut: God certainly had a plan for me here in Florida.

There are times you need to ignore the experts.

We started trying to have a baby after the first year and a half of our marriage. When I didn't get pregnant right away, I went to a doctor who told me that due to some problems with ovarian cysts and other complications, I wouldn't be able to have children without help. I went through a couple of rounds of hormone therapy to regulate my ovulation, and when that didn't work, we quit trying and just decided to focus on being active and healthy. I worked out a lot—so much that my doctor told me I'd need more fat on my body if I really wanted to have a baby. I cut back on my running, and in January 2014, I discovered I was pregnant.

I had my first ultrasound at eight weeks. Brandon and I were thrilled to see our baby and hear the heartbeat. The fact that I was pregnant seemed like an absolute miracle. We hadn't been able to create a pregnancy when we wanted to, but God had no problem using us to create a new life in His perfect timing.

From a human standpoint, the timing was a little rough, but that didn't do anything to dampen our enthusiasm. My life had become super busy in the last several months, as I was working during the day and going to dental hygienist school at night. I was confident we could make it work, however, especially since I planned to be

finished with my classes around the time the baby was born.

The day of the seventeen-week ultrasound arrived, and we couldn't wait to find out the gender of our baby. I climbed onto the table, and the technician squirted my belly with gel and applied the scope. Brandon and I were chattering away when the baby's image appeared on the screen. All at once, the technician got really quiet. A line appeared between her brows, and although she tried to hide her concern, I could tell something was bothering her. She told us we were having a boy, which was great news because we were both hoping for a son. When she was done, she told us she needed to check with the doctor before we left.

As she slipped out of the room, I looked at Brandon. "Something's wrong," I told him. "I feel it."

But then we got the all-clear to leave. We headed home, rejoicing over the news about our baby boy. I told myself that I'd misread the technician's expression and that nothing whatsoever was wrong.

The next day we got a call from the doctor's office. The baby's head was unusually small, the doctor told me, and the ultrasound seemed to indicate that our baby would be born with spina bifida. She would be transferring my file to a clinic for high-risk patients in Orlando, where they

had better ultrasound equipment. This would enable them to keep a close eye on my developing fetus.

My heart pounded as I hung up the phone and closed my eyes. I could hardly breathe. I felt as though someone had threatened my baby. What should I do? What did it all mean? I looked at the empty bedroom we'd been planning to use for a nursery. Had we been foolish to even hope for a child? Had we been too confident, or even presumptuous?

To make matters worse, we were studying genetics in my night classes. I went to class and listened to the teacher talk about chromosomes and genetics and birth defects while at the same time our counselor at the high-risk clinic was telling us that our baby might have a genetic disorder. I wondered what I had done—or what *we* had done—to cause a problem with our baby.

“What happened?” I asked my doctor. “Was this my fault? Are our genes defective? Did we do something to cause this?”

The doctor shook her head. “In most cases, no one knows what causes these kinds of problems,” she said. “It could be genetic, but it could also be due to a lack of blood flow or oxygen to the developing fetus.” In other words, we might never completely understand what had caused a problem with the growth of Jaxon's head.

TRUST YOUR GUT

After some long nights of talking through the possibilities and wrestling with our fears, Brandon and I eventually decided that the *why* didn't matter. Much more important was the fact that God had sent us a child, a unique child. Since God is sovereign, since He controls the planets and the stars and the weather and the hearts of kings, we could certainly trust Him. *We had* to trust Him.

As I went in for my twice-weekly ultrasounds, I trusted my gut and stopped listening to the doctors' warnings. They talked as if I was going to lose the baby at any time, but I didn't believe their dire predictions. After I got to the halfway point in my pregnancy, I told Brandon that our baby was going to be fine. "Yes, I believe something's wrong," I said. "I can see that he's behind in his growth. But I don't care. We're going to have him, and he's going to be fine."

From the seventeenth week through the twenty-third week of my pregnancy, we were given numerous diagnoses of Jaxon's condition—and none of them were right. At the same time, the doctors kept reminding me that I had until twenty-four weeks to terminate my pregnancy. After that, it would be too late under Florida law.

I'll be honest—Brandon and I did have a brief conversation about termination, but only in regard to three specific questions. First, we asked the doctors if this pregnancy

would threaten my life in any way. No, it would not, they said. Then we asked if our unborn baby was suffering or in any pain. Again, the answer was no. Finally we asked if his condition would cause him to suffer unavoidable pain after birth. They said no.

“Then we’re not terminating,” I told my doctor.

We simply couldn’t see any reason for ending the life of a baby who might be small but was still growing and developing—a baby who was even now being made in the image of God. His heartbeat was strong. How could we stop that beating heart?

We decided to leave our son in God’s hands. If He wanted to take our baby to heaven, it would be His decision, not ours.

Yet our resolution didn’t stop my doctor’s office from issuing reminders. Every day at work I got a phone call to this effect: “I just wanted to remind you that you have five days to terminate your pregnancy.”

“You have four days.”

“Only three days to terminate.”

They even set up an appointment for an abortion in case we changed our minds. We didn’t. We were determined to see this pregnancy through and to usher this child into the world. He was God’s gift to us.

Aside from the mysterious condition that was slowing

TRUST YOUR GUT

Jaxon's growth, I had the healthiest pregnancy imaginable. I didn't experience high blood pressure, morning sickness, or any of the usual unpleasant side effects. And because Jaxon was such a small baby, my belly didn't even get very big.

The doctors scheduled Jaxon's delivery for the thirty-seventh week of my pregnancy. To this day I regret letting them do that—I think it would have been better for Jaxon



if I'd gone to term and waited the full forty weeks. But they were assuming Jaxon wasn't going to survive. They didn't think he'd grow much during the final three weeks, so they scheduled my induction for August 25.

I should have listened to my instincts. I learned that day that when you hear a still, small voice telling you to do something different from what everyone else is saying, pay attention to it. It just may be that God is using your gut to speak the truth to you.

When I got to the hospital, they hooked me up to the IV drip that would induce labor. After two days and

several rounds of Cervidil and Pitocin, I tried to deliver my son. But as I pushed and strained to bring our baby into the world, Jaxon's respiration dipped to a dangerous level. The doctors determined that the umbilical cord had wrapped around his neck, so they told me to stop pushing. The medical team whisked me off to the operating room for an emergency cesarean.

They transferred me to an operating table, but I wasn't numb yet. I told the doctors that I could still feel my body and nearly scooted off the table to demonstrate, so they upped my meds until my arms and legs began to shake. I felt like I was suffocating, so I tried my best to focus on my breathing. Brandon had been left behind in the mad rush, and I missed having him by my side.

Though my love for science made me want to watch the surgery, the nurses put up a drape that blocked my view of my belly. Unable to do anything else, I stared at the ceiling and prayed that the baby would be okay. Brandon came in, wrapped in a yellow gown, his head covered in a blue cap. His face looked pale beneath the surgical mask. His eyes squinted in an attempt at a smile, but I couldn't focus on him. All I could think about was meeting my son.

I didn't see Jaxon when they lifted him out. Brandon stood to my left, and he didn't say anything at first. He turned to watch the medical team handle the baby, and

I didn't hear anything for a long, scary moment. Then, finally, I heard a tiny squawk.

Brandon turned back to me, and I could tell he was trying to prepare me. "Babe," he said, "his head is really small."

A nurse brought Jaxon over to me. He was tiny—long and skinny—and his head appeared practically flat. I saw a wide face, a pointed forehead, and a pair of squashed-



looking ears. Yes, his head *was* small. But the rest of his body looked absolutely perfect.

I kissed my little son hello as tears flowed onto my cheeks. "Jaxon," I whispered, still struggling to breathe. "Hello, baby."

"Four pounds even," I heard someone say. "Let's get him to the NICU."



Over the course of my life, I'd experienced a number of situations when I was sure God spoke to me through my gut: when I walked down to the front of a small church as a child, when I felt prompted to move to Florida, and when I sensed that Brandon was "the one." But the strongest

DON'T BLINK

instinct I've ever had is that Jaxon is someone special—that God has a plan for his life, even if it's one we never could have imagined ourselves.

Until we had Jaxon, we never realized how completely God controls life and conception. “I knew you before I formed you in your mother's womb,” God told the prophet Jeremiah. “Before you were born I set you apart and appointed you as my prophet to the nations” (Jeremiah 1:5). That's one of Brandon's favorite Scriptures, and now that we've seen it play out in our son's life, it's one of my favorites too.