

# Introduction

*I know I will survive, I'm a fighter.*

—SHIRLEY CHISHOLM

*Laura Posada:*

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The night before our son Jorge Luis's first surgery, while everyone was asleep, I locked myself in the bathroom and took a long, hot shower. There, in the heavy steam, my tired mind and body, unable to pretend any longer, finally gave in. I fell down on my knees and collapsed there to cry. I cried so much, my tears and the water pouring down on me, as I prayed for my son not to die. All I could do was replay the horrible string of words the doctors all used when talking about the surgery: *fronto-orbital advancement . . . cranial vault remodeling . . . three blood transfusions . . . must be type O negative . . . a complicated surgery that could last up to eleven hours . . . delicate . . . the skull needs to be*

*opened from ear to ear . . . there is the risk of brain damage . . . they have to reshape the bones, reinstall them, and then sew him back up.* All of this to my nine-month-old. How could I not imagine that he was going to die? It crossed my mind that this might be the last time I would ever get to put my son to sleep, and the thought of losing him became tangible, stinging me deeply in the center of my soul.

When we awoke the next day, it was scorching outside, the heat and steam relentlessly pressing down on New York the way they know how to in early August. It was only 6 A.M., and you could already feel how hot the day was going to be. The operation had been scheduled early in the morning, purposely to avoid Jorge having to sign autographs in the hospital or deal with any paparazzi, since he was so well known and recognized in New York.

When we arrived at the hospital, we sat in a little waiting room before they called us in, huddled all together but no one really saying anything, the weight of the future pushing us down into the earth. Jorge and I looked at each other and said no words—but in that silence communicated to each other that we had to do what we had to do.

We were told that one parent was allowed to accompany the baby into the operating room where they would prepare him, and Jorge and I had decided that I should be the one to do it. No task has ever daunted me more, but I agreed and watched my family (Jorge, his father, and my parents) shrink smaller and

smaller as my baby and I were escorted down an ugly, white-gray hospital corridor toward the OR. I was now alone in the world, alone with my son, who could not possibly understand any of it and who would likely one day turn to me for an explanation.

The operating room was set up for the surgery, and I was instructed to put on a full bunny suit with my head and feet fully covered to maintain sterility. There were photographs and X-rays around the room. A tray lined with a light blue paper cloth was equipped with all varieties of meticulously placed surgical tools, all of them looking to me like torture devices, gleaming ominously under the hot surgical lights. Surgeons and nurses shuffled about, whispering in unintelligible codes, their intent eyes looking serious through the tiny spaces in their masks. They put Jorge Luis on the operating table, but he wouldn't stop crying. I was actually the one who put him down on the table, and honestly I don't know how I was able to let go. A nurse gently placed a mask on his face until he slowly fell silent and then just lay there totally still. They escorted me out of the room, explaining that it would be at least twelve to thirteen hours before I would see him again. It would be the longest amount of time that I'd ever been separated from him since the moment of his birth, not to mention *where* I was leaving him, and under what circumstances. For the first time I would not be the one to address his needs and make him feel better. Against everything that felt normal and right to me, I was forced to relinquish my responsibility for my son to a team of doctors, forcing myself to

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believe that their expertise would eclipse the feelings of doubt that would bubble up for every single moment of those thirteen hours. Never mind the obvious trauma of having to see my firstborn son sedated on that cold steel operating table—but the thought of this moment being one of his first experiences in the world totally and utterly crushed me.

And so began my first real encounter with motherhood.

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For a new parent, one of the most glorious things in existence is the tiny spectacle of a beautiful newborn child looking up at you, his perfect little features fresh and soft, his infectious smile representing for you a brand new world of hope and possibilities. In that momentary flash, we come to understand the power of creation, our roles within it, and the divine magic built into the experience of such profound kinship. We inhale the sweet aromas of newness and innocence, realizing with each breath that moves into our center that our lives indeed have new meaning. Many would say that this moment is the quintessential peak of life, the first magical encounter with your very own blood, a unique and primal meeting that has the power to awaken your sense of purpose and fuel your ability to love.

But what would happen if the beautiful face was not perceived? What would happen if those early days that you had envisioned would radiate with the happy glow of sweet pastel pinks

and baby blues became instead cast with a dismal and mysterious gray that only seemed to darken with each day that passed? What would happen if you were to look down at your newborn and, rather than experience the long-awaited surge of bliss you'd always imagined, you instead encountered your own sense of dread bubbling up from within? *What happens when the illusion of perfection is shattered right from the start?*

These were some of the painful questions that haunted our world when our son, Jorge Luis, was diagnosed with a skull deformation at just ten days old, a shocking revelation that would radically alter the course of our lives. From one day to the next we abruptly went from being the joyful young couple, strong and successful, smiling proudly to throngs of adoring fans and waiting in bliss for the arrival of our firstborn son, to a couple of terrified, helpless parents with no concrete answers and only the looming prospect of a very sick baby to contend with. Talk about curveballs.

With the birth of our son came a dark and looming silence, a fear of the unknown, and what felt like a knife stab to the heart. Words like “craniotomy,” “facial deformities,” and “neurological problems” were thrown at us, and every moment became an exercise in emotional survival. Each year brought a new surgery and each surgery a new aftermath, laden with complications and even more questions. Our lives became defined by the grim new reality and subsequent progress of our precious son's health, and our collective mission became to understand and conquer his disease.

But because this took place almost a decade ago, way before the word “Google” was considered a verb, information was scarce and there was little we could do to learn much about this understudied illness. We felt alone in our suffering and terrified by our helplessness. So many aspects of our son’s condition seemed impossible to digest, starting with the multiple surgeries that would be involved in treating it. Our doctors and surgeons became saviors, entrusted with the deepest, most vulnerable parts of us every single time we let our child go under the knife.

We quickly had to come to terms with the fact that the mysterious illness would be an ever-shifting phenomenon, one that would elicit much anguish and little relief. On the one hand, we would never quite know how things were going to develop, but on the other hand, we had to be ready to respond, with courage, to pretty much anything that arose; and being that this very nebulous “anything” was occurring to an adorable, helpless infant—our first baby—the whole thing seemed both incredibly scary and ridiculously unfair.

We would lie awake at night trying to grasp how this could be happening to a creature so small; wondering what we had done wrong, what we could have possibly done to cause this, and worried ourselves crazy about how it was all going to work out. For years, we woke up to countless mornings of not knowing what the day ahead would hold. We felt the massive and intimidating doors of so many operating rooms swing open and closed behind us, with our tiny little man on the other side.

We shuffled along so many icy hospital corridors in agony and anticipation, praying for miracle after miracle, as our friends and families watched, praying with us.

Our son's well-being became our unspoken mission, fueled by what became our unshakable determination to stay positive. We decided to face the condition head-on, determined to go through each step of the process with grace and fortitude, and were at last able to find that strength deep in the sweet brown eyes of Jorge Luis, who would look up at us after every surgery, reminding us silently to show our resilience. Given the fact that he was just a baby, his health problem was not exactly something he could understand rationally; nonetheless, he would seem to boldly look the world dead in the eye, accept his circumstances and reality, always poised like a little adult—and after eight surgeries and countless doctor visits, exams, checkups, and tests, he *never once complained*. His innocent little smile became the symbol of our hope, and each day in his company would bring us a new and invaluable lesson in endurance, patience, perseverance, and countless other virtues that we would have to call upon and hold close. We realized that despite the challenges of such a disease, it would always be our duty to give our son the best life that we could—and we dedicated ourselves to the pursuit of his happiness. In this journey, we discovered a love so pure and real, a love that had nothing to do with our egos and everything to do with our family.

Just like that, our sense of “what matters” was turned on its head, an unexpected paradigm shift that ultimately brought

us endless transformation. After what seemed like an eternity spent in total despair, something finally clicked, and we realized that our burden could also be a blessing and that our experience could actually matter in the bigger picture of this disease. We looked far past the horizon of our own reality and found a way to change our suffering into initiative. Our role as awareness builders for this illness gave new meaning to our lives, and we began to see our own experience of sorrow as a tremendous opportunity—a chance not only to educate the medical community about this disease but also to help those afflicted with the condition in every possible way we could. And with that realization, our lives would change forever.

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This book is a testament of love, our personal account of the power of family unity when faced with uncertainty and pain. It is meant to inspire families dealing with any type of illness, reminding them that hope dies last and that the possibility of solutions and support will always exist.

Through our own narrative, along with the various insights, ideas, and comments of many of the close friends, doctors, and family members who were very much part of the experience, we have compiled our story, a story of hope, faith, and fierce positivity—one that we sincerely believe expresses the beauty in love. Because as we understand it now, true beauty lives deep in

the soul and can be properly appreciated only when you begin to truly love.

There is not a day that goes by that we do not thank the universe for the blessing of our son. He, along with our little daughter, is the absolute love and light of our lives—but he also represents the true meaning of valor, strength, and the power of family when the chips are down. In this way, Jorge Luis is more than just our son—he is also our total inspiration and a delicious little miracle. *The Beauty of Love* is the story of our family's greatest victory, and how, through much perseverance, we won it with our hearts.