

CHAPTER 1

A PARALYZED LIFE

Dark are the days when all of our hopes inexplicably dissolve, followed by events that complicate life in unimaginable ways

"*Your son is in a coma!*" It was two weeks after the birth of my second son, Artur, when his doctor pierced my soul with this statement. Now, when I think about that day in January 2002, I realize that my life had forever changed. Time seemed to pass in slow motion and I was living in an eternity of doubts, exams, inaccurate diagnoses, hospitals, and needles.

Yes, my two-week old son was in a coma, living like a vegetable. He couldn't open his eyes. The veins in his arms were about to collapse from all the blood tests. Sometimes, nurses even had to take samples from his head. The doctors were bewildered. They had no idea what was affecting our baby or what to do to help him. Only my wife, Soraya, and I had permission to enter into the ICU. Our cell phones never stopped ringing. Relatives and friends were calling every minute, but we had no news for them. Our callers only knew that our anxiety level was high.

Thirty days later we finally had a diagnosis, Leukodystrophy. When I hung up a phone call from my mother-in-law, I left my parents' house almost to the point of weeping. I felt like the world was crumbling around me. Why was this happening to me? Why is this happening to my son? What had I done wrong to be punished in such way? My wife must have been horrified. To me, she had already suffered enough! I felt like the most insignificant person in the world. To me, it seemed to be the end, and in my desperation, I proposed a pact to God: "*Lord, why are you doing this to me? If it's Your will, take my life for the happiness of my wife and my children. From now on, You do what You want with me, but please protect my family.*"

Throughout the day, doctors were throwing around names of diseases that fall into the category of Leukodystrophy, like Phenylketonuria, Urea Cycle disorder and MSUD. And one of them caught my attention: MSUD, that is, Maple Syrup Urine Disease. I had been doing some online

research when it hit me. The symptoms of this disease were very similar to the way Artur was right after he was born.

Could this possibly be my son's mystery disease?

That night, I was with Artur in the ICU while my wife was praying in a small hospital chapel. Knowing her, she would be asking for our son and for our family's happiness. I looked at him in his incubator, imagining that we needed a true miracle to save him.

Then, the unexpected happened. My little boy moved his left arm. Were our prayers being answered? I turned around to see if anyone else had seen this, but God, his many angels and I were the only ones there. This time, I knew it from the bottom of my heart that it was not a fantasy that I had created out of despair. Seeing Artur as a fighter that would never give up, I declared to myself that he was not only my boy, but my little king, like the legendary King Arthur.

With Artur coming out of his coma, our hope grew, and my desire to fight gave me a new persona. From that day on, I would be a knight for my King Artur. In his stead, I would fight all battles to find the Grail that would save his life. Like the Arthurian legends, only the Grail would return peace to the kingdom. Only Artur's cure, my Grail, would give us peace. Beside me, I had my lady, Soraya, and my fellow knave, Vinicius. Without them, I would have succumbed to the pain of the journey and given in.

At this moment, all of us had merged into a cross-cultural life of struggle, unfulfilled promises, pain and happiness, mazes, faith and hope. A new life so different from the one that we had known or planned had just begun.